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Intense connection and love: The experiences of autistic mothers

Amber-Sophie Dugdale¹, Andrew R Thompson^{1,2} ,
Alexandra Leedham³ , Nigel Beail¹ and Megan Freeth¹ 

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Abstract

Knowledge of how parenthood is experienced by autistic women is currently poor. Nine autistic mothers to children aged 5–15 years completed semi-structured interviews, analysed using Interpretative Phenomenological Analysis. All mothers considered at least one of their children to also be autistic. Four superordinate themes emerged: 1. *Autism fundamentally impacts parenting*; 2. *Battle for the right support*; 3. *Development and acceptance*; and 4. *The ups and downs of parenting*. The themes demonstrate that while motherhood is largely a joyful experience for autistic mothers (Themes 1 and 4), it is associated with specific issues unlikely to be found in neurotypical motherhood (Theme 1), including negotiating misunderstandings from others (Theme 2). The need for self-care and self-acceptance was expressed (Theme 3) with parenting resulting in personal growth and adaptation (Theme 3). Feelings of intense connection and closeness were experienced (Theme 4), though managing children's needs had a profound personal impact (Themes 2 and 4). The findings demonstrate that service-providers would benefit from training, ideally led by autistic individuals, on how autism presents in adulthood, masking, the potential for mismatching between emotional experience and facial expression, sensory needs (especially in pregnancy), and the double empathy problem (Theme 2). This study represents the first systematic in-depth analysis of the experiences of autistic mothers presented from their own perspectives.

Lay abstract

For many women, adulthood involves becoming a mother. Knowledge of how motherhood is experienced by autistic women is currently poor. Poor knowledge has a range of negative consequences and can lead to inappropriate support. In this study, nine autistic women were interviewed about their experiences of motherhood. Seven of the nine mothers had an officially diagnosed autistic child, the final two mothers also suspected at least one of their children to be autistic. Systematic in-depth analysis of interview transcripts identified a range of common themes. Participants largely experienced motherhood as joyful, rewarding, and enjoyable, though managing children's needs had a profound personal impact. Participants reflected on the need for self-care and self-acceptance, resulting in personal growth and adaptation. Participants also spoke of strong bonds, feelings of intense connection, and a range of shared experiences with their children. It was also clear that autistic motherhood is associated with a series of challenges unlikely to be experienced by non-autistic mothers, including the necessity of negotiating misunderstandings from others. The findings demonstrate that, generally, professionals need to be better educated on how autism presents in adulthood, including the fact that autistic women often engage in behaviour to mask their true self. Professionals need to know that there is potential for mismatching between emotional experience and facial expression, that autistic women have sensory needs (especially in pregnancy). Professionals frequently struggle to effectively take the needs and perspectives of autistic mothers into account, resulting in profoundly negative consequences for the mother.

Keywords

autistic mother, interpretative phenomenological analysis, lived experience, parenting

¹University of Sheffield, UK

²Cardiff and Vale University Health Board & Cardiff University, UK

³Chesterfield Royal Hospital NHS Foundation Trust, UK

Corresponding author:

Megan Freeth, Sheffield Autism Research Lab, Psychology Department, University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield S1 2LT, UK.

Email: m.freeth@sheffield.ac.uk

Introduction

For many women adulthood involves becoming a mother. Across many different cultures, it has been shown that having a child brings mixed experiences; both positive, such as joy, warmth, and connection to another, as well as negative, such as increased stress (Louie et al., 2017). Autistic adults appear to have different experiences of various life events compared to those who are not autistic (Bargiela et al., 2016; Gillespie-Lynch et al., 2017; Morgan, 2020; Rumball et al., 2020; Sala et al., 2020). It is therefore possible that the experience of motherhood is somewhat different for autistic women than for non-autistic women. Autistic people display a range of traits and values, such as high standards of performance via increased attention to detail and strong work values (Lorenz et al., 2016), that may bring increased resilience and dedication to the challenge of motherhood. However, autistic women also tend to experience a broad range of life challenges (Bargiela et al., 2016; Leedham et al., 2020) and co-occurring mental health difficulties are prevalent (Buck et al., 2014; Croen et al., 2015; Gillott & Standen, 2007; Hofvander et al., 2009; Joshi et al., 2013; Lever & Geurts, 2016; Maddox & White, 2015). As motherhood can often trigger depression, even in those who have never previously experienced it (Shorey et al., 2018), it is important to investigate how autistic women experience motherhood, considering the increased challenges that can occur while parenting and to begin to acquire knowledge on what may help autistic women prepare for motherhood.

To date, there have been few empirical investigations relating to autistic parenting and none that ask autistic mothers themselves to consider and explain their own experience. Most published research in this area has used questionnaires aimed to quantify various aspects of parenting. Lau and Peterson (2011) investigated parenthood satisfaction finding that being diagnosed autistic did not significantly diminish the satisfactions and pleasures that respondents derived from their parenting roles. Van Steijn et al. (2013) investigated the impact of parental autistic traits on parenting styles in a non-clinical sample. Higher maternal autistic traits were linked to a permissive parenting style (responsive, but less boundaried) towards their typically developing children, but not to their autistic children. Lau et al. (2016) found autistic fathers had lower parenting efficacy compared to autistic mothers and neurotypical parents. Dissanayake et al. (2020) found higher autistic traits were associated with increased parenting difficulties when parenting their typically developing child. Finally, Pohl et al. (2020) found that autistic mothers were more likely to experience mental ill-health and greater parenting difficulties (such as feeling misunderstood by professionals, struggling with domestic responsibility) compared to non-autistic mothers. While all of this cross-sectional survey research is useful, it does

not provide a detailed account of the lived experience of autistic parenting or motherhood.

To our knowledge, only two studies to date have utilised qualitative approaches to investigate the lived experience of autistic parenting. Prince (2010) explored the researcher's own experience as an autistic parent using narrative ethnography, and Bertilsdotter Rosqvist and Lövgren (2013) completed discourse analysis on magazine articles written by autistic adults. Both highlighted some similarities of experience in autistic parenting to neurotypical parenting, such as bonding and trying to achieve 'good enough' parenting. However, they also implied there are extra stresses for autistic parents, describing 'complex challenges' (Prince, 2010) and the necessity of navigating stereotypical perceptions of autism (Bertilsdotter Rosqvist & Lövgren, 2013). Although these studies provide useful insights, ethnographic design is not a phenomenological approach that enables detailed individual case analysis leading to the emergence of nuanced themes that capture experience. Furthermore, Bertilsdotter Rosqvist and Lövgren's (2013) discourse analysis included views from autistic adults generally, rather than specifically from autistic parents. Hence there is scope for improving the understanding of autistic parent experiences with the application of a rigorous, systematic phenomenological research approach.

In summary, the current literature on the experience of autistic parenting is sparse and has not yet included a qualitative approach that sets out to gain a systematic in-depth understanding of the lived experience of autistic parents. Biggerstaff and Thompson (2008) highlight that Interpretative Phenomenological Analysis (IPA: Larkin et al., 2006; Smith, 2004) is a robust method for understanding experiences due to going beyond simply giving a voice to the participants, by additionally providing an approach for drawing out meaning that may be of use in understanding processes relevant to well-being. Indeed, Howard et al. (2019) and MacLeod (2019) argue that IPA provides a close and considered approach to understanding autistic experience. The aim of this study was, therefore, to better understand and identify themes relating to experiences of motherhood by autistic women.

Method

Methodological approach

This study employed a qualitative design, using a participatory research approach. Such an approach facilitates the potential for gaps between research and practice to be bridged (Cargo & Mercer, 2008) and has been found to be valuable in disability research (Bailey et al., 2015). Crafting mechanisms of participation into autism research has been argued to be highly valuable and has the potential to reduce power imbalances (Pellicano & Stears, 2011). With regards to this study, a semi-structured interview

Table 1. Demographic Information Regarding Participant's Children.

Participant pseudonym	No. of children in total	No. of children aged 5–15 years ^a	Are diagnosed autistic?	Method of becoming a parent	Live with children full time?
Olivia	3	3	Yes, for all	Birth	Yes
Ava	2	2	Yes, for all	Birth	Yes
Sophie	1	1	Yes	Birth	Yes
Lucy	5	3	One undergoing assessment; one parent feels they have and may undergo assessment.	Birth	Yes
Emily	2	1	Yes	Birth	Yes
Grace	1	1	Assessed previously: parent disagreed with lack of diagnosis, diagnosed with attachment disorder.	Adopted	Yes
Zoe	3	2	Yes, for all	Birth	Yes
Alice	1	1	Yes	Birth	Yes
Leah	2	2	Yes, for one One has global developmental delay and developmental trauma	Adopted, Birth	Yes

^aExact ages and genders of children are not displayed to protect confidentiality.

schedule was developed in collaboration with two autistic parents who did not participate in the study.

Interview transcripts were analysed using IPA. This involved an in-depth iterative process where the researcher engaged in a 'double hermeneutic' process. This analytic technique encourages reflective engagement with individual participant's account prior to bringing these accounts together to form cross-cutting themes. The double hermeneutic process occurs throughout the study and is used to refer to the joint venture of both the participant making sense of their experience, and the researcher further making sense or interpreting the accounts provided within the context to which they occurred. As such the analytic process both gives a voice to individual accounts of experience within a specific context while also bringing a reflexive and hence interpretative lens to the analytic process (Larkin & Thompson, 2012; Larkin et al., 2006; Smith et al., 2009).

Ethical approval for this study was obtained from the University of Sheffield ethical review board.

Participants

Nine autistic mothers were recruited via purposive sampling involving our own research laboratory database, social media, and local charities. Participants self-identified regarding whether they met eligibility criteria following discussion with the lead researcher. Inclusion criteria were: over 18 years of age; formal diagnosis on the autism spectrum, including variants such as Asperger's syndrome, or high functioning autism, or self-identifying as autistic and awaiting assessment for a formal diagnosis; currently a parent to child between 5 and 15 years of age.

Participants were excluded if they had a co-occurring learning disability or were not fluent in English. Of the

nine participants, eight had a formal diagnosis of autism, the final participant had been referred for a formal assessment for diagnosis and self-identified as autistic. All diagnosed participants were relatively recently diagnosed with time since diagnosis being between 0 and 6 years prior to the study (Mean = 2.6 years). All participants were female, married and aged between 27 and 44 years (Mean age = 39.5 years). Seven participants identified as White British, one participant as White Welsh, and one as Mixed race. All participants had further education qualifications with minimum qualification level being National Vocational Qualification (NVQ) Level 2. Five participants had completed Bachelor's degrees and one a Master's degree. Four participants were self-employed, three were employed, and two were full-time carers or parents. Six participants had additional neurodevelopmental, mental health or physical health diagnoses, of which three felt these previous diagnoses were incorrect and that difficulties experienced were related to being autistic.

All participants, except one, co-parented with their married partner who was also the birth or adoptive father for all children. One participant had split from their first child's birth father and co-parented with the biological father and their new married partner. See Table 1 for additional information regarding the participants' children. All names are pseudonyms to protect confidentiality.

Procedure

A participatory research design was utilised which involved developing a semi-structured interview schedule in collaboration with two autistic parents who did not participate in the study. The content of the interview schedule was based on the study's aims and Smith et al.'s (2009) guidance on IPA format (see Table 2). During the interviews, the

Table 2. Interview schedule.

Question number	Question wording
1.	When did you first find out you were going to be a parent with X (or first child under 5–15 years)? Can you talk me through this?
2.	What was it like for you when you first started being a parent, that is, when X was a baby? How well did you manage being a new parent?
3.	Can you tell me about your initial relationship with your child/children?
4.	How has your relationship with X been as s/he has got older?
5.	What are/were the ups and downs of being a parent to child X? How did you manage these ups and downs?
6.	How have your family been with you in relation to parenting X? Have any support services been involved? If so, how have they been in relation to parenting X? How have other people been towards you, this could be others not spoken about in the above, such as friends or people you know?
7.	Is there anything else that you have not had the chance to tell me about today that you feel would be important for me to know about your experience of being a parent?

schedule was adapted or deviated from where appropriate to aid the participant in sharing their lived experience. Prompts were utilised if the participant required clarity or more information, or if the participant had not covered aspects of a question. Interviews lasted between 51 and 97 min (mean interview time: 74 minutes). The interview was recorded using an encrypted digital audio recorder. Participants were debriefed at the end of each interview. This involved thanking the participant for their contribution to the research, checking whether the participant had any questions or topics they would like to discuss further, and sharing information about the planned outcomes of the research. The interviewer (the first author) operated under supervision and used her clinical psychology training skills to ensure that any matters that had arisen during the interview or the debriefs were appropriately addressed.

Analysis

Analysis was conducted utilising principles outlined by Larkin and Thompson (2012) and Smith et al. (2009). All interviews were transcribed verbatim. Transcripts were initially read through alongside the audio recordings and the researcher engaged in ‘free coding’ (responses, thoughts, ideas on patterns and observation of important descriptions were noted down). Following this, transcripts were read through again with a more structured and organised approach. Notes on concepts, descriptions and linguistics were made ‘line by line’ on the right-hand side of the transcripts. Parallel to this, the researcher started to engage in ‘interpretative coding’ by noting down possible interpretations and meaning on the left-hand side of the transcripts. Following this, individual data were organised and summarised into patterns and themes, creating conceptual maps. Data were then analysed by identifying overlapping patterns and themes, as well as consideration of exceptions and differences in the data. Following this, superordinate and subthemes were extracted. An audit of each stage of the analytic process was carried out on three of the transcripts by the last author to ensure

transparency and rigour of analysis. A reflexivity log was used by the lead researcher throughout the data collection and analysis process in order to note the influence of any personal experiences, theoretical knowledge and preconceptions throughout the study (Biggerstaff & Thompson, 2008). Field notes were utilised during each stage, including analysis, to ensure transparency, reduce bias, and to make use of personal and professional knowledge.

Community involvement statement

Gaining a better understanding of autistic parenting was identified as a priority for research via a range of personal discussions between the authors and members of the autistic community. The semi-structured interview schedule used in this study was developed in collaboration with two autistic parents who did not participate in the study. The outcomes of the study have been disseminated to and, where possible, discussed with the autistic mothers who participated in the study. The outcomes of the study have also been presented to, and discussed with, local autism diagnostic service and paediatric health professionals.

Results

Data analysis gave rise to four superordinate themes, each comprising several subthemes, as shown in Table 3. Each theme is discussed alongside illustrative participant quotes. Missing data are represented by the use of ‘. . .’ and additional explanations of points are included within ‘[]’. The themes are not an exhaustive account of participants’ experiences, instead they are an interpretative narrative of several accounts.

Theme 1 – autism fundamentally impacts parenting

This superordinate theme reflects participants descriptions of how being autistic is a fundamental difference, giving rise to specific strengths and difficulties when parenting.

Table 3. Emergent superordinate themes and subthemes.

Superordinate themes	Subthemes
1. Autism fundamentally impacts parenting	Shared diagnoses and similarities An intrinsic part of myself for better or worse
2. Battle for the right support	Misunderstood, judged and dismissed Understanding autism within the family unit
3. Development and acceptance	Diagnosis, self-care and self-acceptance Parenting as growth and adaptations
4. The ups and downs of parenting	Intense connection, enjoyment and rewards Managing children's autism/other needs and impact on self

Shared diagnosis and similarities. The majority of participants' children also had a diagnosis on the autism spectrum or were undergoing an assessment. Shared diagnoses helped participants feel closer and more connected to their children, such as a sharing a 'special bond' (Olivia) or 'world' (Leah), having 'natural relationship' (Alice), 'common ground . . . to bond with and talk about' (Lucy) or being 'peas in a pod' (Emily). Even in the case where there was not a shared autism spectrum diagnosis, participants still noticed similarities between themselves and their children's needs which were positive. Grace reflected that both she and her son were quieter and 'avoider[s]', which they were both 'quite happy' with.

Participants reflected that shared diagnoses meant they had a more in depth or 'instinctive' (Alice) understanding of their children's needs compared with others; 'I'm the one who can get through to him' (Leah). This helped participants meet their children's needs:

We're the same . . . I can usually figure out what they want or need when they can't always verbalise it and help them in ways that other family members can't. (Zoe)

Despite these positives, increased understanding compared to others meant participants were typically the main carers had to explain or 'translate' (Alice) difficulties to others, or 'mediate' (Alice) conflicts. Participants reflected how their shared diagnosis led to challenges, such as balancing conflicting autistic needs and negative impact on self-care:

. . . he drives me nuts with his sensory needs, he likes being on top of me and all over me and climbing on me and I'm directly the opposite. (Emily).

Many spoke of feeling guilty or blaming themselves for the experiences their children had, as they felt they 'passed on something possibly genetic', (Olivia). Often, this linked to having experienced similar struggles to their children and a wish to protect them:

I feel bad that she feels so anxious a lot of the time [Crying] and I feel bad because I used to feel like that . . . I don't want her to feel the way that I did. (Sophie).

An intrinsic part of myself for better or worse. All participants reflected on how being autistic was a part of them and how their strengths and weaknesses in relation to parenting were, therefore, inherently related to being autistic. Consequently, many highlighted the impossible task of 'teas[ing] out the autisticky bits from the non-autisticky bits' (Leah). All participants reflected that being autistic resulted in both strengths and weaknesses for parenting. Some felt being autistic resulted in a 'normal' (Leah), but more 'amplified' (Alice) emotional experience of parenting which could be positive at times and overwhelming at others:

We have lots and lots of empathy, but if it's too much to deal with you have to just shut it off because it's so overwhelming. (Grace).

Several participants reflected on their analytical thinking, in-depth 'research' (Ava, Alice), and planning of 'practical matters' (Lucy) as positive and linking with their 'autism trait[s]' (Ava). For example, participants linked such behaviour to a 'special interest' (Alice), 'a desire for certainty' (Zoe), or to a 'black and white thinking' (Lucy) style resulting in a desire to be 'all in' (Lucy) or to be 'the best parent I [they] could'. (Alice). However, some acknowledged this planning could negatively impact other areas of life, such as social or work.

Many participants spoke of a need for routine which 'help[ed]' (Emily) their children by giving 'consistency' (Grace) and 'safety . . . security in our [the] relationship'. (Lucy). For others, this routine was hard to achieve as there were 'demands being put on you all the time' (Ava). Similarly, others struggled with the constant nature of demands, which Leah termed 'demand overload' and some linked to being autistic and 'demand avoidant' (Ava).

Participants also reflected on their social and communication differences, such as struggling to 'socialise with [other] parents' (Zoe) due to difficulties with 'conversation that's not like answering questions or specific' (Olivia), feeling different, or sensory needs. Managing sensory sensitivities while parenting, especially in pregnancy, was another common difficulty:

I had to stop work at six weeks because my body was just in sensory overload. (Sophie)

Theme 2 – battle for the right support

This superordinate theme relates to participants' shared experience that trying to make use of support was often a difficult process. Participants also reflected on what good support was, or could be like, and its benefits.

Misunderstood, judged and dismissed. All participants spoke of feeling misunderstood, judged or dismissed, leading to difficulties in receiving support for themselves or their child. Participants reflected on how being misunderstood was typically linked to their autistic traits. Sometimes, judgement was positive, such as participants being seen as 'good at parenting' (Olivia) or 'coping very well' (Emily). Often this related to participant's in-depth research, caring experience, or 'masking' (Zoe). Unfortunately, this positive judgement led others to assume participants did not need support, as 'they [professionals] didn't understand why we were asking for it' (Alice). Sometimes support was denied even when requests were very clear. For example, Lucy reflected that while in labour she felt 'vulnerable . . . the mask was up'; meaning she did not appear as distressed as she was, nonetheless, she communicated her needs clearly, but to no avail:

' . . . they [professionals] don't believe you if you just say it, they want you to perform it'. (Lucy).

Similarly, participants often reflected how their feelings or needs and outward expression of these were 'two very different things' (Emily), leading to multiple misunderstandings. This mismatch led to difficulties with professionals as they assumed participants were 'aggressive' (Grace) or experiencing 'anxiety' (Olivia, Zoe) when they were 'upset' (Grace) or had a need for 'certainty' (Alice). This often resulted in dismissals or not being 'taken seriously' (Olivia).

When professionals were not aware of participants diagnosis this sometimes led to a 'pressure' (Lucy) to conform to 'unwritten social hierarchy' (Alice). However, disclosing their diagnosis sometimes created further misinterpretations or negative judgements, such as professionals negatively judging participants ability to 'cope' (Ava) or parent and viewing them as 'cold' (Lucy). This then resulted in participants feeling patronised or exposed to stigma and intolerance of their difference:

' . . . when he [GP] realised I was Autistic he wanted me to write down all of the times and dosages for (NAME-son)'s medicine (LAUGH), I was sat there going, no it's fine. (Emily)

Sadly, for many, this stigma led to an internalised belief of not being a 'good enough parent' (Olivia) and to a fear of disclosure. The judgement participants were exposed to

not only related to their own diagnosis on the autism spectrum, but often inter-linked with their children's autism diagnosis or additional needs. Participants often felt 'parent-blamed' (Sophie) for their child's difficulties or 'treated as a problem parent' (Leah) when advocating for their child's needs. Many experienced significant dismissals of their concerns about their children's needs; for some this felt like being constantly 'pushed away' (Sophie) by professionals and for others it was experienced as not being believed accused of 'making stuff up' (Zoe).

Sometimes participant's own autism spectrum diagnosis led to a reversal from this 'disregarded' position in relation to understanding their child's support needs, to being taken 'seriously' (Emily); linked to professionals viewing this as legitimate expertise. Nonetheless, these judgements, misunderstanding and dismissals resulted in 'undue stress' (Lucy), 'anxiety' (Sophie) and a persistent feeling that accessing the right support was a 'fight' (Olivia, Ava, Leah), 'battle' (Emily), 'mission' (Grace), or a constant 'pushing' (Alice); which some felt they were 'losing' (Olivia) leading to 'withdraw[al]' (Olivia) from support services.

Understanding autism within the family unit. Many reflected good support systems required listening and an understanding of autism:

People really need to listen to Autistic parents . . . were not thick, we see things from a different perspective. (Olivia)

Participants felt more respected and 'accepted as the experts' (Alice) in their or their children's needs by professionals that understood autism. Others recalled feeling 'validate[d]' (Leah) or reminded 'it's just a different way and it's not necessarily the wrong way' (Grace). Understanding of autism also led to increased trust that support requests would be acted upon, rather than dismissed:

I can just phone them [husband's parent] up and say 'I need your help, I'm really struggling'. And that's it, like, they'll help me. (Zoe)

Participants often wanted help with practical aspects of parenting which aided their self-care:

I have an Au Pair so I just get more of the quality time with her . . . I'm not stressed all the time . . . that make a huge difference the fact that I get enough down time. (Ava)

Shared experiences (being autistic or parenting autistic children or additional needs) often improved understanding in social support networks, leading participants to feel as though they had an 'ally' (Grace) or supportive other:

I have got some friends who have children who are very diversities themselves and therefore they get it far more than most. (Emily)

Participants also found support from their neurotypical partners who helped to accommodate for aspects of parenting that participants found difficult:

(NAME-husband) was able to do the make-believe stuff that, I, I couldn't do. (Olivia)

Participants often commented on the importance of general healthcare professionals (such as 'midwives', health visitors and general practitioners (GPs)) and schools having training in 'how autism presents' (Lucy) to improve support (for them or their child). Some felt this training needed a recognition that autistic adults may also be undiagnosed; especially if their children were autistic. Some felt strongly that services should be more explicit in considering if the parent is autistic:

They [children's autism service] just ask if you've got any diagnosis . . . And if the parent says no, that's just the end of it, but it could be that they have got something there, but they've just not got a diagnosis, but they just don't ask that. (Zoe)

Similarly, several participants felt very strongly that, at minimum, if there were diagnoses, services needed to consider both child and parent's autism:

[Professionals need a] consciousness that a two-for, like an autistic parent with an autistic child is its own thing, that is different from either being a parent of an autistic child, or an autistic parent of a neuro-typical child. I think there's just zero recognition of that being a dynamic, and it's, for us, the defining dynamic that colours literally everything . . . and having to sort of separate those things out, is – is kind of absurd and unhelpful. (Leah)

Olivia highlighted the importance of this as she felt her own autism difficulties got in the way of meeting her children's autistic needs at times:

I've got needs myself, I can't do it and my kids are entitled to this support but I'm going to have to say that they can't have it because I can't do the accounts. (Olivia)

Theme 3 – development and acceptance

This superordinate theme reflects how participants described parenting as a process of adjustment, self-development, and self-acceptance.

Diagnosis, self-care and self-acceptance. All of the participants received a diagnosis on the autism spectrum (or self-identified in Sophie's case) after already becoming a parent. Prior to being diagnosed, some participants spoke of feeling 'guilty' (Ava, Alice) for their difficulties and their impact on their children. Others recalled being diagnosed with other physical or mental health conditions, such as 'postnatal depression diagnosis and anxiety'

(Sophie), but feeling like these did not fit and their experience was linked to autism. Receiving a diagnosis led to a 're-process[ing]' (Sophie) of participants' experiences in a positive way. For many, this reduced feeling guilty, increased self-acceptance, and gave an explanation that was felt to fit with their identity:

I'm a girl and I'm different and I've been misdiagnosed my entire life and it just made sense to me, my life just fell into place and I now love being Autistic, I love being allowed to be Autistic and not anxious. (Olivia)

This increased understanding helped participants 'accept' (Alice) being 'different' as not 'wrong' (Grace) and in turn gave participants permission, or the relevant 'understanding about [themselves]' (Emily), to self-care, accept support, or access more appropriate support. There was a strong sense that such understanding and self-care resulted in them being 'better parent[s]' (Alice), although, many felt this increased understanding and practising self-care was an on-going process; *'I'm still trying to work it out'*. (Alice).

Growth and Adaptations. Many participants reflected on how parenting their children led to self-growth and acceptance:

It's taught me so much patience . . . it's taught me to find joy in the little things, it's taught me to live in the moment for me . . . to communicate on my terms, it's taught me that there's nothing wrong with how I communicate erm because these small people are understanding me and these small people have no life experience, no knowledge of communication, can understand exactly what I'm saying. (Lucy)

Some reflected on how growth and 'managing [the] change' (Alice) felt apart of parenting, such as observing growth and loss of some developmental stages as well as experiencing excitement for new ones. For many parents, changes and development within parenting were linked to making adaptations or changes to support their autistic children's or their additional needs. Many reflected that although change or flexibility was something they could struggle with (as linked to their autism) parenting helped them become more accepting of this:

Autistic people aren't famous for coping well with change, but you know, it is what it is and you just have to kind of adjust as you go and just learn as you go. (Alice)

Sometimes making adaptations for their children needs felt a clash with participants' own autistic related needs. Nonetheless, although initially difficult, many still adapted:

I'm not a very touchy-feely person, but . . . I had to get used to not minding . . . if my son's like climbing all over me . . . at first it got to me . . . but once I'd got used to it, you know, I just get on with it. (Zoe)

For some, adapting themselves to meet their children's needs was a positive experience resulting in them feeling 'proud of [themselves]' (Olivia) or it being easier than expected:

I was more laid back than I thought I would be, I was always a stickler for having rules in place more (LAUGH) . . . (Emily)

Theme 4 – the ups and downs of parenting

This superordinate theme describes both the positive experiences and challenges that participants felt were directly linked to parenting.

Intense connection, enjoyment and rewards. All participants reflected on their 'connection' (Zoe, Emily, Grace, Leah, Sophie), 'bond' (Lucy) or 'love' (Alice, Ava, Olivia) for their children. Many reflected on the intensity and strength of this connection describing it as 'overwhelming' (Olivia), 'complete adoration' (Leah) and 'strong' (Zoe). Several commented their relationship was 'close' (Lucy) or involved a sense of warmth and being 'always together' (Emily). Ava recalled fearing that her love was so immense for her first child it might not be as strong for her second but was pleasantly surprised:

I was worried I wouldn't love her as much, I just couldn't see how anyone could be as good as (NAME-son) (LAUGH) and how could you have enough love for two babies, but . . . it just wasn't the case at all so you do get more love. (Ava)

Participants reflected on the development of their connection. For some this felt like it 'just happened' (Emily) and was 'absolute bonding straight away' (Lucy); including before the birth or adoption of their child:

You sort of fall in love with this child in your head before you've even met them. (Alice)

The first time I saw her it was like the most amazing feeling . . . and I looked in her eyes and it was like I'd know her forever . . . I can't even ex, it was beautiful. (Sophie)

For others the connection felt 'initially . . . awkward' (Grace) or took time to develop. This was typically linked to other difficulties; for Grace this was around the adoption process being 'awful'. For others, it was related to concern for other children, pregnancy issues, or post-natal depression. Participants also reflected on the changing nature of their connection, noticing it develop as their child developed. For most, this connection was similar in strength, but just '*different*' (Sophie, Alice, Lucy). For some, this connection was 'more' (Zoe) or 'better' (Grace) over time.

Participants noticed how children reciprocated their affection physically or verbally:

Really often she will say 'you're the best mum in the world' and gives lots of kisses, she is very huggie and kissie. (Ava)

They also expressed that their child's love and reciprocated connection felt linked to children trusting their parent:

Well, they both come to me when they're upset about something, they both take comfort from me and if we go into a new situation they like to be close to me and they use me as a safe base. (Alice)

Many parents reflected on how they 'enjoyed' (Zoe) parenting or found it 'fun' (Leah). For some, this was linked to their strong connection, and for others, it was enjoyment of teaching their children and watching them grow. Many reflected on how rewarding the process of seeing their child develop was and how 'proud' (Leah) they were:

Seeing his progression and celebrating the wins and the small things that other parents would take for granted . . . for us is a huge celebration. (Emily)

Managing children's autism/other needs and impact to self. For many, managing their children's autism or other additional needs was the 'hardest thing' (Ava) when parenting. For some, this was related to their child being 'different' (Sophie) and feeling they did not fit in 'the normal mum's club' (Sophie). For others, it was related to the 'extra difficulties that other parents don't have'. (Zoe). Many described struggling with the impact on themselves from parenting, such as lack of sleep and exhaustion, especially with new-born babies and the demands (emotional and physical) of 'breastfeeding' (Olivia):

I didn't have two thoughts to rub together, and that was almost panic inducing. Like, it was like I felt like I was just being taken to pieces. And there was nothing left of me. (Leah)

Similar to Leah above, several of the participants spoke of the emotional impact of parenting. For some, this began when trying to start a family:

The last six years have been hell doing IVF the whole time and I was just exhausted. (Ava)

For others this started, or continued, when they had new-born babies or difficulties arose in providing care:

He [son] started disclosing some significant abuse [from when he was adopted] which . . . I just didn't have the capacity to deal with . . . my emotions around it. (Alice)

Often the emotional impact was linked to feeling not good enough, a 'failure' (Zoe, Olivia), or an 'imposter'

(Grace) as a parent. This led to high anxiety, guilt, or fear that participants were ‘doing everything wrong’ (Sophie). Often this emotional impact was linked to children’s autism or additional needs. For some, these feelings felt ‘classic’ (Leah) parenting experiences that were not ‘anything special to Autistic people’ (Lucy). For others it felt linked to their autism, as well as their child’s.

Discussion

This is the first study to investigate in detail the experience of motherhood in autistic women. The first superordinate theme within our findings, ‘Autism fundamentally impacts parenting’, reflected a narrative that autism is intrinsic to the experience of parenting, giving rise to specific strengths and difficulties. The second superordinate theme, ‘Battle for the right support’, reflected difficulties participants experienced in accessing appropriate support for themselves and their child. This involved being subjected to judgement, stigma and misunderstandings. The third superordinate theme, ‘Development and acceptance’, highlighted the importance of receiving an autism diagnosis, as this supported self-understanding and self-care, which in turn was described as improving parenting. The fourth superordinate theme, ‘The ups and downs of parenting’, demonstrated the intertwined joys and stresses of parenting. Each theme is discussed below, considering how these findings relate to and extend existing knowledge.

The first superordinate theme ‘Autism fundamentally impacts parenting’ aligns with Robertson’s (2010) work in suggesting that rather than a narrative of deficit, a narrative of neurodiversity is more appropriate with autism giving rise to specific strengths and difficulties. Autistic adults are often noted to have strengths in their love of learning (Kirchner et al., 2016) and this has been linked to engagement with special interests (Teti et al., 2016). These strengths were noted in this study, in that participants often described parenting and caring for others as a special interest which lead to them thoroughly researching around this. For some parents, this researching, and their parenting style generally, may be linked to having good attention to detail and focus, as commonly reported in autistic people (Baron-Cohen et al., 2009). Participants described needing to be ‘all in’ and fully committed to being as good a parent as possible. These traits resulted in family and friends commenting on participants’ good parenting or seeking advice from them.

In terms of specific difficulties, this study indicated that changes and sensory issues associated with parenting were of particular difficulty, consistent with the diagnostic criteria for autism (American Psychiatric Association, 2013). This appeared most prevalent and hardest during pregnancy. Despite these difficulties, participants reported adapting to change in order to meet the needs of their children thus demonstrating their dedication and resilience in

the face of challenges. This is consistent with the findings of Pohl et al. (2020), who reported that autistic mothers had increased parental difficulties compared to non-autistic mothers, but nonetheless overcame these in order to put their child’s needs first. Another consistently reported phenomenon in this study was that of intensified feelings and empathy for their children, which was described as being overwhelming at times. This is in line with research suggesting although autistic individuals may have some difficulty with cognitive empathy (perspective taking), they appear to have heightened emotional empathy (directly feeling the emotions another is feeling) which can be overwhelming (Smith, 2009).

In this study, seven of the nine participants’ children also had a diagnosis on the autism spectrum, with the final two participants also considering that they had an autistic child, albeit currently undiagnosed. This was described by participants as giving an instinctive understanding and ability to meet their children’s needs. Some participants described that this resulted in them being the main carer due to having a deep bond with their child and their child also seeking them out for support. Attachment theory research (Bowlby, 1958; Mikulincer et al., 2003) provides a possible explanation for this as it suggests that through atonement and meeting of children’s needs secure attachment, trust, and bonds are formed. Interestingly, there was a lack of emerging themes around co-parenting experiences, which may be due to participants typically reporting being the primary caregiver. Partners (all male) tended to provide a more supportive role, such as providing aspects of care that the participant reported struggling with due to autism, or in supporting the participant with the impact of parenting. Participants in the study also found support from others with similar experiences, in particular, other autistic adults. This aligns with research that suggests relationships between autistic adults involve a sense of acceptance and belonging (Sinclair, 2010) and peer support from other autistic adults can be highly valuable (Bertilsson Rosqvist, 2019; Sosnowy et al., 2019).

The second superordinate theme, ‘Battle for the right support’ reflects difficulties participants experience in accessing appropriate support for themselves and their child, such as being subjected to judgement and stigma, consistent with previous literature suggesting that such experiences are common (Holton et al., 2014) with judgements often made quickly (Sasson et al., 2017). This is likely linked to a lack of understanding and negative stereotyping around autism (Harnum et al., 2007; Treweek et al., 2019; Wood & Freeth, 2016). The source of misunderstandings, dismissals and negative judgement were generally reported to be from neurotypical individuals. This is consistent with previous research (Holton et al., 2014) and supports Milton’s (2012) ‘double empathy problem’ theory that neurotypicals and autistic individuals equally struggle to empathise and understand one another,

rather than autistic individuals being the source of the empathy deficit. The double empathy problem and existence of negative stereotypes may account for why many individuals and professionals were reported to struggle to understand or meet the needs of participants. Similarly, a lack of awareness of masking (Hull et al., 2017), the assumption from some professionals that autistic people struggle with parenting, and differential display of emotional affect, were noted in the study and may contribute to professionals doubting the stated word of individuals.

Negative judgement, misunderstanding and dismissals were not only related to participants' autism diagnosis but also linked to their child's autism diagnosis. This is consistent with research that shows parents struggle to access support for their autistic child and it often feels like a 'battle' (Vassallo, 2016). Potentially exacerbating this, Pohl et al. (2020) found autistic parents experienced increased misunderstanding and difficulties with professionals compared to nonautistic parents when both groups were parenting an autistic child. It appears, therefore, that there may be particular difficulties for autistic parents with an autistic child. Linked to this, services were reported to lack consideration for both child and parent's autism diagnosis simultaneously. This issue is potentially compounded where there are clear splits between adult and child services in the United Kingdom. Consideration of the family unit as a whole and the dual impact of parent and child being diagnosed autistic is, therefore, needed within services.

The third superordinate theme of 'Development and acceptance' particularly highlighted the importance of receiving an autism spectrum diagnosis, as this supported self-understanding and self-care, consistent with previous findings (Hearst, 2014; Leedham et al., 2020), which in turn was described as improving parenting. The fourth superordinate theme of 'The ups and downs of parenting' particularly highlighted that many parenting difficulties were considered to relate to their child's autism spectrum diagnosis or additional needs. This reflects prior research which suggests having an autistic child or child with other difficulties can result in increased difficulties and parental stress (Anderson et al., 2020; Dabrowska & Pisula, 2010). Some of the challenges expressed by mothers in this study, such as the intensity of the experience and the need to be an advocate for their child have been echoed by mothers of children with other complex care needs (Woodgate et al., 2015). Findings from these themes also demonstrated aspects of autistic parenting that were similar to general parenting experiences, involving joy and connection but also leading to increased stress (Louie et al., 2017) as well as concerns around being a 'good enough' parent (Pedersen, 2016).

Future directions

While this study provides some important insights into the experience of autistic parenting, there are current gaps in knowledge that future research in this area could contribute

to addressing. All autistic mothers in this study had at least one child who they considered to also be on the autistic spectrum. However, experiences may be different for autistic mothers whose children are non-autistic. Furthermore, there is currently minimal knowledge on how autistic men experience fatherhood. These gaps in knowledge should be addressed by future research. Another important area that clearly needs to be better understood is the experience of pregnancy for autistic mothers. The sensory experience and interaction with service-providers emerged as important issues in this study, and these should be investigated further, in a more systematic way to ensure that autistic mothers are appropriately supported through their pregnancy. It is clear that the autistic mothers interviewed for this study also experienced misunderstandings from professionals post-natally and, on occasion, there was a perceived disparity between what appeared to be perceived by professionals and the reality of what was happening in an individual's life. It will be important to explore the exact nature of these conflicts and misunderstandings in future work in order that more appropriate training can be put in place to ensure that autistic mothers do not continue to experience such difficulties.

Conclusion

Overall, this study highlights the need for improved standards of education, training and understanding of autism within general healthcare services, with a particular need for this in antenatal services and perinatal mental health services. Specific areas requiring improvement are knowledge of how autism presents in adulthood, masking, mismatching of emotional experience and facial expression, sensory needs (especially in pregnancy) and the double empathy problem. Improvements in these areas will likely result in enhanced health by promoting a preventive, proactive approach. It will be important for autistic individuals themselves to be involved in co-producing the development and delivery of such training for healthcare service professionals and the value of having access to peer support should be considered. We suggest that within parenting services a narrative of difference, rather than deficit, in relation to autism should be adopted, though the specific difficulties relating to autism that exist need to be acknowledged and supported. A drive to counter use of stereotypes and over-simplifications is required. Implementing these recommendations could reduce misunderstanding and stigma, as well as reducing the internalised guilt described by participants in this study. Despite the challenges of motherhood, the shared experience between mothers and their children in this study highlighted a narrative of enduring connection and love.

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ORCID iDs

Andrew R Thompson  <https://orcid.org/0000-0001-6788-7222>

Alexandra Leedham  <https://orcid.org/0000-0002-4739-4241>

Megan Freeth  <https://orcid.org/0000-0003-0534-9095>

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