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Abstract

Background

There have been numerous calls for an increase in autism research that explores the lifespan experiences of autistic people. Notable research neglect exists in the area of autistic adults' experiences of being a parent. This study aims to explore the experiences of autistic adults as parents and to investigate meaningful ways in which to support them.

Methods

Nine autistic parents took part in remote semi-structured interviews. The interviews utilised different modalities – as chosen by participants - to ensure maximum accessibility. Data analysis was carried out using Iterative Phenomenological Analysis (IPA) principles.

Results

We identified three superordinate themes: Identity and Purpose; Looking Through a Lens of Trauma; Protect, Defend, Advocate, Repeat. Our participants expressed intimate connections with their children, who were sources of love and joy. Participants' childhood trauma influenced their experiences of being a parent. This was born out in extreme empathy, perfectionism, and a drive to protect their children from experiencing the same things. Participants were continuously advocating and fighting for the right support for their children, and interactions with professionals were a significant source of stress.

Conclusions

This study draws attention to the influence of childhood trauma on the parenting experience of autistic adults. It thereby reveals an unexplored long-term consequence of the traumatising effect of lack of support and othering of autistic children. Professionals interacting with autistic parents and families should be aware that they may be parenting through a lens of historical trauma and should be adequately trained in trauma-informed approaches to support. Further research is needed to investigate this phenomenon and how this knowledge can be used to inform practice. Equally important is investigation and training on the broader systemic and societal issues that impact the parenting experiences of autistic adults.

Community Brief

Why is this an important issue?

Only a handful of research studies explore the individual experiences of autistic parents. Autistic parents are often assumed to be bad parents. This can be due to some people's negative beliefs about what being autistic means. We must investigate the truth about how autistic adults experience the role of parenting.

What was the purpose of this study?

We wanted to find out what being an autistic parent is like. We also wanted to know how to help autistic parents in ways that make their lives easier and more enjoyable.

What did the researchers do?

We spoke to 9 autistic parents (the participants) and asked them about their experiences. We recorded these conversations and wrote them down word for word. We looked at the conversations closely to discover if any of their experiences were similar.

What were the results of the study?

Participants had very close relationships with their children. Their children made them happy. Our participants could easily understand what their autistic children needed. Contacts with schools and health professionals were very stressful for our participants. They felt that professionals and schools did not understand autism or how to help them.

Our participants were affected by negative childhood experiences that caused lasting effects on their lives (childhood trauma). They were determined to protect their children from similar negative childhood experiences.

What do these findings add to what was already known?

We already know that childhood trauma can affect how a parent thinks about their parenting role, but this is the first time we have explored this with autistic parents. This is a long-term result of the lack of support and acceptance that autistic children can experience, which we did not know before. It also shows that professionals need to consider this childhood trauma when helping autistic parents with mental health difficulties.

Our findings increase the evidence that autistic parents are loving and dedicated and work hard to ensure the best for their children. Autistic parents can be afraid to tell others that they are autistic because they feel that they would be judged as bad parents and treated poorly.

What are the potential weaknesses in the study?

Most of our participants were female and white, so we cannot say that these results apply to all autistic people. All participants were diagnosed after becoming parents. Experiences may have been different for autistic parents who were diagnosed as children.

How will these findings help autistic adults now or in the future?

Our findings are important to professionals that support autistic parents and their children. Professionals can provide the right kind of support to help autistic parents thrive if they know how childhood trauma influences autistic parents' experiences.

Our findings also show schools and professionals that autistic parents have a lot of parenting strengths that should be recognised and valued.

Background

Autism is a lifelong neurodevelopmental difference.^{1,2} It is behaviourally diagnosed by a triad of difficulties in social communication, social interaction, and social imagination³. The worldwide prevalence of autism is estimated at 1-2%.⁴

There have been numerous calls for an increase in autism research that explores the lifespan experiences of autistic people⁵⁻⁸. This reflects the desire of the autistic community for research that moves away from the deficit-based medical model.^{9,10} Research neglect exists in the area of autistic adults' experiences of being a parent.

Being a parent can have a range of impacts on well-being, from happiness and joy to parental burnout.^{11,12} Research on the mental health of parents of autistic children reports high levels of stress, clinical depression, and anxiety¹³⁻¹⁸ linked to parental struggles for the right support for their children. Autistic people are at a higher risk of experiencing mental health conditions such as anxiety and depression.^{19,20} Therefore, autistic parents, who are also very likely to have autistic children²¹⁻²⁴, would be expected to be at increased risk for poor mental health outcomes. However, Adams et al.²⁵ found no significant difference in parental stress levels or family outcomes between autistic and non-autistic parents.

A survey including over 7 million school-aged children in England found that 1.76% of children were diagnosed autistic.²⁶ Heritability of autism is estimated at 50-96%²⁷⁻²⁹, which implies that significant numbers of parents of autistic children could also be autistic themselves. There are no current estimates of the number of autistic parents in the UK. Many of these parents only discover their autism when they already have children.³⁰

Autistic parents may experience parenthood differently. Characteristic traits of autism may bring unique challenges and strengths to the role. The paragraphs below explore this further in terms of Sensory sensitivities, Attention to detail; Differences in social communication and interaction; Empathy; and Alexithymia.

Autistic people may have sensory hypersensitivity, which can lead to avoidance of sudden, loud, or discordant sounds; strong smells; bright lights; tactile demands; etc..³¹ In the context of a busy family home, this could lead to sensory overload and distress. Rogers et al.³² and Hampton et al.³³ found that this is a prevalent feature for autistic mothers during childbirth and the perinatal period. Talcer et al.³⁴ found that sensory sensitivities had extreme and pervasive impacts on all aspects of autistic mothers' experiences. However, Pohl et al.²² found that autistic mothers could effectively manage these sensory challenges while caring for their children's needs.

Autistic people are known to be detail-oriented.^{35,36} This can be a strength when researching how to engage with a complicated Special Education Needs (SEN) system.^{37,38} It can also mean that trivial matters like planning family outings can become unnecessarily cumbersome.

Parenthood necessitates new and varied social connections that can be difficult and stressful for autistic people to navigate.^{3,39} Several studies have found that autistic parents experience difficulties regarding effective communication with professionals (while advocating for their children), and in healthcare settings.^{22,32,33,40-42}

Autistic people are stereotypically believed to lack empathy, mainly due to Theory of Mind research.⁴³ More recently, researchers have shown that while autistic people may have some difficulty with cognitive empathy or mentalising (understanding someone else's perspective), they have no differences in affective empathy (feelings of love, compassion, concern, and warmth towards others).⁴⁴

Another stereotypical belief is that autistic people are emotionless. Research has shown that this trait is more likely caused by co-occurring Alexithymia, which is not a lack of emotions, but difficulty recognising which emotion you are feeling and subsequently having difficulties naming emotions in others.⁴⁵

Studies examining parenting style, satisfaction, and efficacy found no significant difference in outcomes between autistic parents and non-autistic parents. However,

they saw an increase in perceived parenting difficulty in parents high in autistic traits.^{25,46-48} These difficulties included emotion control, sensory issues, spontaneity, and modelling behaviours.

The majority of current studies about autistic parents applied quantitative data analysis methods. These studies focus on outcome measures such as parental efficacy, parental satisfaction, and pregnancy and childbirth outcomes, and do little to explore the individual lived experiences of autistic parents. Qualitative methodology is much better suited to exploring these experiences in depth.^{49,50} Qualitative studies about autistic parents found that they experienced great joy and intense connections with their children, who were motivators for change and personal growth^{21,23,40,51}. In agreement with quantitative studies on this subject^{22,33,41,42}, difficulties around communication, judgement and acceptance from professionals were also commonly found.

However, qualitative data on the experiences of autistic parents are limited to a handful of studies with a total of 33 participants. Considering the prevalence and heritability of autism, we have merely scratched the surface of what it is like to be an autistic parent. Which factors determine the quality of that experience? How does this influence parent and family life and wellbeing? We need to keep asking this question of more autistic parents to gain a balanced view. This project aimed to delve deeper into the experiences of autistic adults as parents to investigate these issues further.

Research objectives were:

- To describe the factors that impact the experiences of autistic parents;
- To investigate meaningful ways to improve the wellbeing of autistic parents.
- To add to the growing pool of qualitative literature about the experiences of autistic parents.

Methodology

Ethics

We obtained ethical approval from the Manchester Metropolitan University (MMU) Department of Psychology Research Ethics Committee.

We made sure that we obtained properly informed consent. We provided participants with an easy-to-read Participant Information Sheet and Consent Form via email. We encouraged them to share these with their support networks and local autism charities to ensure that they understood what was required of them and what their rights were.

Participants initially gave consent via email. We also recorded consent verbally before the interviews took place. Before interview commencement, we reminded participants

of their right to withdraw or stop the interview process at any time. We debriefed participants after the interview and gave them information on helplines for local mental health organisations such as Mind and Shout to contact if they needed further support.

Recruitment

Inclusion criteria were: Parent or carer of at least one child under 18; Diagnosed (or self-diagnosed) as autistic; Resident in the UK; and a good understanding of written and/or spoken English. We excluded people who were not able to give informed consent, i.e. people who would need a guardian's consent. This was a requirement of the MMU ethics panel. Participants were asked directly about their ability to provide informed consent.

We placed recruitment advertisements in Facebook groups catering for parents of autistic children, and groups for autistic parents. We also placed an advertisement on the National Autistic Society forum and Twitter. Lastly, we placed an advertisement in the MMU student participant research pool.

Initially, 10 participants were signed up, but one dropped out (due to prior commitments) before data collection commenced.

Participants

There were 9 participants in this study (Table 1). We recruited 8 participants from Facebook and one via word of mouth. IPA methodology does not prescribe data analysis to saturation. The ideography of IPA dictates in-depth and iterative analysis of each case to produce a rich account of individual experiences. This number of participants provided a sufficient pool for meaningful research while remaining small enough to be manageable in a qualitative study.⁵²⁻⁵⁴

8 Participants were white British, and 1 was mixed race, of Irish and Asian origin. Eight participants were female, and 1 participant was male. All participants had children who were either autistic or referred onto the pathway for assessment. Five participants were formally diagnosed, and 4 participants were self-diagnosed. All participants were late-diagnosed after becoming parents. Age at diagnosis ranged from 34 to 50, with a median age of 37. 1 participant disclosed co-occurring disabilities.

Data Collection Method

Participants contacted the principal researcher (SS) via email to express interest in participation. SS then emailed participants with an online link to the Participation Information Sheet and an electronic copy of the Consent Form. Participants gave initial consent via email, and SS emailed them a link to the online Qualtrics

demographics questionnaire and arranged a suitable time and format for an interview. The email also included a short introductory video from SS and an invitation to an optional introductory meeting. We aimed to set participants at ease and eliminate as many uncertainties around the research process as possible. SS asked participants about their communication preferences to make adjustments to allow for accessibility.

SS invited participants to a semi-structured interview. She allowed participants freedom of choice for the modality of the interview to best suit their communication needs and comfort. SS sent participants a copy of the interview questions once an interview was scheduled to allow time to process the information and prepare. SS designed an initial interview schedule of 11 questions (Table 2). SS adapted this schedule as required to encourage participants to share rich details of their lived experiences. She also used prompts during the interview to provide more clarity and information.

SS carried out the interviews via Zoom (with or without video) or Whatsapp chat messages. (In-person interviews could not occur due to the Covid-19 pandemic and associated legal restrictions.) SS recorded consent verbally before the start of the interview. Zoom interviews lasted 45-76 minutes, with a median duration of 62 minutes. Whatsapp interviews lasted approximately 2-3 days due to participants requesting breaks or being interrupted by childcare responsibilities. However, we conducted Whatsapp interviews using the same interview schedule and adaptations as with all other participants and generated a similar amount of data in terms of transcript length.

SS encouraged participants to use images/memes/photos or other media to supplement their answers to questions to allow more accessibility, alleviating some of the possible communication difficulties inherent in autism such as Alexithymia⁵⁵ and concept processing.⁵⁶ 2 participants utilised this option during their interviews and SS analysed their media and elicitation responses as part of their transcripts.

Data Analyses Method

SS employed a qualitative approach to data analysis, exploring the individual experience in depth through IPA.⁵⁷ The iterative and cyclical nature of IPA makes it ideally suited to produce rich, in-depth accounts of participants' experiences.⁵³

IPA is centred around phenomenology, ideography and hermeneutics.⁵⁴ Meaning is co-constructed by both the participant's interpretation of their personal experience and the researcher's subjective interpretation.

The ideography of IPA dictates that every case is fully explored before producing any generalised interpretations. Analysis is iterative and cyclical. This makes the

epistemological approach of IPA particularly suited to the aims of focusing on individual experience in depth. This is confirmed by an evaluation of IPA studies within the field of autism research by Howard et al.⁵⁸, which reports that IPA offers a valuable framework for exploring autistic participants' experiences.

SS transcribed interviews verbatim, and transcripts were analysed in accordance with the principles of IPA.^{50,59} She closely followed guidance from Smith et al.⁵³ on how to conduct IPA studies through an ideographic case study approach. SS read through the first transcript multiple times to immerse herself in the participant's experience and meaning-making. As she was doing this, she recorded her initial thoughts, interpretations and keywords in the right margin of the transcript. She then read through the transcript again, along with the notes in the right margin, and analysed this data to capture the emerging themes. She recorded these themes in the left margin of the transcript as she progressed (Table 3).

SS then wrote these emerging themes down separately from the transcript and analysed them for apparent clusters. She matched these back to the transcript by attaching quotes to each theme. Next, she formulated these theme clusters into superordinate and sub-ordinate themes in a master theme table.

SS then analysed the following participant transcript just as the first one, keeping the master theme table in mind. Where new themes arose from the following transcript, she re-analysed the first transcript to compare with the new themes in a cyclical and iterative process. This process was repeated for every participant. In line with guidance on IPA methodology, once the analysis of all transcripts was completed, SS selected themes to use based on the richness of data and how they interact to illuminate participants' interpretations of their experiences.

SS then used diagrams to explore the patterns and relationships between themes.⁵³ Lastly, she translated the themes into a narrative account.

Rigour

An integral part of IPA is reflexivity on the part of the researcher due to the double-hermeneutics of the methodology and the influence of the researcher's viewpoint on their interpretation of the data.⁶⁰ SS's insider researcher status as an autistic parent has an added effect on her interpretation of the data.⁶¹

During data collection, it was also at times challenging to step out of the role of an autistic parent into an observer role. She was conscious of not asking leading questions and giving too many prompts to avoid subjectively influencing the discussion's direction. All participants were aware of the insider status of SS, as this was disclosed during the initial recruitment email that all participants received.

SS has maintained a reflexivity log throughout the analysis process to take note of and guard against undue influence on interpretation and analysis by pre-existing preconceptions and biases.^{57,62} As there was only one person analysing data, it was also crucial that all subordinate themes were evidenced by example quotations from participant transcripts.

Results

SS identified three superordinate themes that described the experiences of autistic parents: 1. Identity and Purpose; 2. Looking Through a Lens of Trauma; and 3. Protect, Defend, Advocate, Repeat. Three subordinate themes support each superordinate theme (see Table 4 for a list of superordinate and subordinate themes).

Participants shared complex experiences where themes influence each other bidirectionally. There are times when this is an inverse relationship. For example: Where a parent has experienced success while advocating for their child (theme 3), their perfectionism and related self-critical thoughts are mitigated (theme 2). Similarly, this can be a direct relationship: The experience of successful advocacy (theme 3) positively influences the parent's identity and purpose (theme 1).

Identity and Purpose

Three subordinate themes support this superordinate theme. They are Love and Joy, Personal Growth, and Close Connections. These subordinate themes describe the relationship qualities between participants and their children and how those relationships have informed the participants' identity as a parent.

Love and Joy

Participants all expressed incredible feelings of love for their children. Their children were sources of joy and unconditional love. Tara reflected that becoming a parent had awakened her emotions.

“Since having them, I have had a lot more emotions than I had before if that makes sense. A complete love for them which has made me appreciate them and enjoy being alive/aware. I felt like I was a bit 2 dimensional before I had them, ... (Tara)“

The joy that Maggie gets from her children is more complex, as it is counterbalanced by significant anxieties for their future wellbeing:

“I enjoy the feeling of pride as I watch them grow and learn. I enjoy knowing that I leave a legacy. I enjoy having an anchor. I enjoy their unconditional love. Sadly all these have a counterpoint to them, involving fear, anxiety and overwhelm! (Maggie)”

Personal Growth

Becoming a parent brought a shift in identity and acknowledgement of the loss of the person that came before, along with a sense of personal growth. Before having children, Judith experienced low self-esteem and self-recrimination. Now she sees herself through her children’s eyes:

“And because I didn’t realise I was autistic until I had children, I’ve done a lot of self-blaming. So like, it’s probably a positive, actually. Uhm. Since having children, I’m starting to see myself through their eyes and they see me as like, as worthy. You know? Like there’s that sense of worth coming from external sources. But it’s made me re-evaluate why I’m looking for it from external sources. (Judith)”

For Andrea, there was a sense of loss and grieving for the person she was before motherhood that she needed to process.

“I wasn’t prepared for the loss of my own identity. Um, that I was... forever more I was going to be Sam’s mum. I had stopped having this kind of existence where I was me and kind of recognised as a separate entity. And that individual before motherhood was something that was the, the, the most important thing in my life. (Andrea)”

Andrea’s personal growth through motherhood has led to a much more positive perception of herself:

“I think I’m a much better person for having to care for another human being, that he was completely dependent on me. I’ve I’ve lost a lot of, I’ve lost a lot of my selfishness. (Andrea)”

Close Connections

Many participants were surprised by the natural connection and intimacy that they experienced in their relationships with their children. Parents also shared an ability to intuitively understand and meet the needs of their autistic children through their shared paradigm.

While sharing a photo of himself on a day trip with his three children, Rick expressed connection and solidarity with them in a way that also hints at his intense need to protect them:

“I’ll send you... there’s a photo of me and the three kids together. And it’s the joke I always make is, uh, when they say that one person in a hundred is autistic, and we go out en-masse to mess with the statistics. Because you do feel like you’re a clan. You can take one of us on, you gonna take all of us on. (laughs) Just go for it! (Rick)”

Denise shared the comfort that she feels through the reciprocal nature of understanding between her and her son:

“... there’s that thing about when you feel that somebody else, they may not totally get your profile, but they, but there’s that real fundamental respect and understanding of the nature of the profile and the nature of the difficulties? ... And because I understand that I can be with him and, um, and really, really accept it. ... there’s a sort of radical acceptance that you have to sort of head into because we have a shared experience of that (Denise)”

Looking Through a Lens of Trauma

This superordinate theme is underpinned by three subordinate themes. They are Extreme Empathy, Changing the Narrative, and Perfectionism. Participants all shared experiences of historical trauma woven into their narrative. This thread of trauma is pervasive in the levels of empathy they feel for their children and in the high standards they set for themselves as protectors of their children. They experience a lot of self-doubts and often strive for perfection due to anxiety about the impact that they may have on their child’s development. They were very driven by their past experiences to change the narrative for their children.

Extreme Empathy

Our participants spoke about taking on their children’s emotions as if they were their own. At times, participants could not separate the child’s emotions from their own. As Sasha talked about her children’s anxieties and lack of support at school, she considered her extreme empathy. She related this response to her school-related trauma:

“It’s the empathy is so extreme that I feel like, I feel I take on all of their anxiety about school and their concerns about friendships or, you know, things. And I think. I think you empathise even more if you’ve been in

that situation. So, I really struggled with school and didn't get any support and was treated quite badly by a lot of the teachers. So I think I can be quite extreme in my empathy to the girls that, you know ... I think because of my past experience and that, that need to empathise and to show that you can empathise, I tend to be quite extreme with it. (Sasha)"

For Carol, this extreme empathy can make it hard to know whose feelings she is feeling:

"Uhm, and sometimes I feel him so deeply. So like when he's got his worries and fears and pain, uhm, I feel like I feel what he feels and I have to kind of remind myself that we're separate and they're his feelings and uhm, which is quite difficult to do, you know. (Carol)".

Changing the narrative

Our participants were driven to provide their children with a life where they were supported, accepted, and valued. This drive was motivated by participants' own childhood trauma experiences and their need to protect their children from going through the same things.

For Judith, changing the narrative of her historical trauma was the most important part of parenting:

"But the biggest thing for parenthood, parenting, for me, it was just that questioning everything. Because I don't want my kids to think like I did. That I was the problem. When I was young, if people treated me badly, I assumed it was my fault. (Judith)"

Andrea experienced being bullied as a child. She explained how she helped her son navigate this aspect of his life:

"I'm trying to explain to my son, okay. Uhm, there are going to be people like that in life and the way to deal with them, especially if they try and sort of create a reaction in you is to not give them a reaction ... Uhm, whereas growing up, I never had anybody to kind of teach me that. There was nobody there to kind of give me advice or support me. And, so a lot of the time I was completely lost. (Andrea)"

Perfectionism

Our participants were acutely aware of their own perceived inadequacies. They consistently questioned their abilities to carry out the task of protecting their children from adverse experiences that may affect their future wellbeing.

Sasha reflected on her personal growth in this area:

“And that’s, you know, that’s just not something you can be as a parent. That, you know, there is no perfect parent and all children need parenting in different ways. But I think for a long time I just constantly felt like I was failing as a parent. Because you couldn’t get everything right all of the time ...That’s just not the case with being a parent. Um, which. And I think that’s taken me a long time to realise that. I’m sure neurotypical parents probably realise that six weeks in but it’s taken me nearly 16 years to realise! (Sasha)”

However, for Carol, as for others, the need to be perfect had a persistent impact on her wellbeing: “The perfectionist trait is there strong and true ... There’s the constant worry and overthinking of: Am I doing it right? or Am I doing my best for him? (Carol)”

Protect, Defend, Advocate, Repeat

This superordinate theme is supported by three subordinate themes: Education Professionals, Other Professionals and Accessing Support. These subordinate themes are linked by the significant impact that these interactions can have on the wellbeing of autistic parents. The direction of this impact – either positive or negative – depends on the levels of awareness, acceptance and understanding of autism experienced.

Acceptance brings a positive impact:

“The speech and language therapist was fantastic when I mentioned that I was autistic as well. She’d noticed that I have an issue with word retrieval sometimes and she rang me up to give me some tips. (Judith)”.

In contrast to this, pervasive autism stereotypes led the same participant to experience high levels of stress in a hospital Accident and Emergency (A&E) department :

“I couldn’t do anything about it because they were talking to me like they were CBeebies* presenters. Outside the curtains they kept talking about me being “someone with autism”. (Judith)”.

(*CBeebies is a children's television channel in the UK)

Because of this kind of treatment, participants have shared fear of disclosing their diagnosis even when formally diagnosed. From her visit to A&E, Judith learned that "I'm not comfortable sharing I'm autistic, because of the treatment, like the way things change (Judith)".

Education Professionals

Necessary by the nature of being a parent, and very frequent and ongoing by nature of parenting children with SEN, interaction with the education system had mostly negative impacts on the wellbeing of participants. Even when her son's school is being very supportive regarding his SEN needs, Carol felt that "... there's a real pressure to get it right (Carol)". The drive to change the narrative for her child heavily influenced this feeling of pressure.

Rick had abundant amounts of parental satisfaction, but there is one parenting experience that he vehemently dislikes: "... you'll get really, really awful teachers. And you wouldn't have to deal with them if you weren't a parent."

When teachers have true empathy and understanding of autism, it is a very positive experience:

"Like the teacher that Grace had last year uhm was really good with her. And he was really good with me and I felt supported and, and kind of felt like he was on my side when it came to Grace (Sasha)".

Other Professionals

Participants lamented the lack of appropriate and accessible mental health services for autistic people. Denise had not been able to find support through the National Health Service (NHS). Fortunately, she can pay for private counselling:

"I'm paying for my own counselling now. I'm on a waiting list for, um, secondary services without our borough, uh, secondary psychological services within our borough has said they don't have the expertise, because they've got nobody who's got experience with autism. Um, so the waiting list, ... for the national offer is 30 months for, uh. So, I mean I'm going to be a totally different person by then. So, I'm paying for my own counselling from an autistic counsellor, which is fab and is exactly what I needed right now. (Denise)"

Accessing Support

When asked what meaningful support would look like, Maggie said that she wants: "... supportive relationships that accept my diagnosis (Maggie)". This would relieve the stress she experienced from constantly defending her autistic identity.

Other participants expressed frustration with professionals' perceived ignorance of the fact that autistic children may have autistic parents:

"That's the one thing that I wish for all services. That when they're dealing with the parents of autistic kids or any neurodiversity, that there is likely to be an element of neurodiversity in one or both of the parents. Then to me, that's obvious. (Sasha)".

There was also frustration among participants with "... the complete lack of awareness of what autism is (Andrea)" amongst professionals and services. Denise summed this up when she said: "Psychological support through the NHS with people who actually know something about autism, that would help! (Denise)".

Ultimately, participants wanted "... people to be the things that we get accused of lacking: like empathy, compassion, caring. Okay then rest of the world, show us how it's done! (Rick)"

Discussion

Summary of findings

Our participants all described positive personal growth, heightened emotions, joy and deep feelings of love for their children. This correlates with previous findings that autistic parents form intense connections with their children^{23,40,63} and refutes stereotypical beliefs that a lack of empathy would impair bonding between autistic parents and their children.²¹

We found that the shared paradigm of being autistic facilitates an extreme closeness and bond and enabled autistic parents to intuitively understand and meet their autistic children's needs. Marriott et al.⁶³ also found that autistic parents can instinctively understand the needs of their children in a way that non-autistic parents are unable to.

Interactions with professionals and support services were a persistent source of stress in the lives of our participants. They felt that stereotypes and a lack of awareness influenced professionals' perceptions. This frustration with professionals has also

been mentioned in previous research^{25,26,45,69}, which recommended furthering professionals' understanding and awareness through autistic-led training.

Participants highlighted that mental health services are either wholly inappropriate for autistic people or have untenable waiting lists due to a lack of resources. Camm-Crosbie et al.²⁰ similarly found that autistic adults feel effectively excluded from access to mental health services through the lack of adequately resourced services to address their needs. In light of these difficulties, our participants expressed the need for peer support from other autistic parents. Recent research⁶⁴⁻⁶⁶ has shown that peer support is an effective form of support. Supportive interaction with other autistic people also protects against the effects of minority stress and provides a sense of belonging⁶⁷.

Our research has revealed the conscious and sub-conscious ways that childhood trauma and adverse experiences impacted our participants' parenting experiences. This historic trauma most often relates to experiences of being unsupported and othered as an (unidentified) autistic child⁶⁸⁻⁷⁰.

How the findings advance the literature

We presented the possible impact of childhood trauma and adverse experiences on the parenting experiences of autistic parents. Our findings correlate with research in the general population that shows that childhood trauma can significantly affect how a parent views their parental role⁷¹. It can influence how parents respond to challenges and has a negative impact on mental health.

This may be an unexplored long-term consequence of missed identification of autistic children and the lack of support and othering that autistic children experience in schools and broader society. Research has shown that these experiences can result in trauma responses in autistic children, who may experience a broader range of events as threatening when compared to their non-autistic peers^{69,72}. This finding stresses the importance of creating environments where autistic children are identified early and provided with support that adds to their quality of life with true acceptance of their differences^{73,74}.

This study adds to the growing body of evidence that autistic parents are affectionate, loving, dedicated, and empathic^{21,25,40,51}. This is important because professionals often perceive being an autistic parent as a red flag for child safeguarding. Griffiths et al.⁷⁵ found that autistic parents were four times more likely to have their parenting ability questioned by professionals. They also reported that 1 in 7 autistic parents have been investigated by social services and that 4% of autistic parents had lost custody of their children. This is despite no statistical evidence that autistic parents would be more likely to interact with social services for parenting issues than the non-

autistic control group⁷⁵. A preliminary study by Adams et al.²⁵ also found no significant differences in family outcomes between autistic and non-autistic mothers.

Strengths and limitations

We were able to successfully create an inclusive and accessible research environment by offering a choice of different modalities for data collection and providing access to interview materials in advance, based on research guidelines formulated by Nicolaides et al.⁷⁶. This aided the collection of rich, descriptive data from participants. “Nothing about us without us”⁷⁷, the motto of disability rights activists, is also applicable to disability research.^{9,10} The case for participatory research has been made with growing interest.^{78,79} Although the principal researcher is an autistic adult, time constraints and ethical considerations meant that this study was not able to use participatory research design methods^{78,79}. Future studies would benefit from a participatory design and meaningful co-production where autistic communities are empowered to influence the knowledge produced about them.^{80,81}

Including self-diagnosed individuals in this study has opened participation up to a wider population of autistic adults who identify as autistic but have as yet been unable to access diagnostic services. Many research studies have discussed the significant barriers to diagnosis for adults.^{82,83} Pohl et al.²² found that self-diagnosed mothers in their study all had AQ-10^{84,85} scores above the cut-off and that including this group avoided wrongly excluding anyone’s experiences of autism. In this study, we found that the experiences of self-diagnosed participants related closely to those of formally diagnosed individuals and including them did not change our findings. However, this study would have benefitted from using the AQ-10 screener.

Participant demographics were not representative of the autistic population. The experiences of parents of other demographic groups may be different. In addition, participants in our study are limited to those that access social media and sections of the participant population who do not engage with social media may have very different experiences.

All the parents in our study have autistic children or possibly-autistic children. It is possible that autistic parents may have only non-autistic children. These parents’ experiences may be different from our participants’.

Implications for professionals and services

Our findings have several implications that should be considered by all professionals who interact with autistic children and their parents:

- Professionals should have an understanding of the hereditary nature of autism and consider that parents of autistic children may also be autistic themselves. They should adjust their interactions accordingly.
- Better training is needed – designed and ideally delivered by autistic adults such as autistic teachers, autistic psychologists, autistic social workers, etc. This will increase meaningful understanding of the challenges and strengths of autistic parents, with a particular point of view of how it applies to the services delivered by that profession.
- When children receive an autism diagnosis, it would be helpful for professionals to inform parents of the hereditary nature of autism and the possibility that they may be autistic or have autistic traits that may benefit from environmental adjustments or diagnosis. This is already standard practice for other medical conditions with a significant genetic component. Providing contact information for autistic peer support groups and referral to counselling to explore this would also be beneficial, as the mental health impacts of undiagnosed autism are well documented.^{83,86,87}
- Services and professionals should be aware of the possibility that autistic parents are more likely to be parenting through a lens of historical trauma. A trauma-informed approach providing safe and collaborative environments - where trust can be built - will result in better outcomes and successful partnerships.

However, for any of the above recommendations to be effectively realised, we must address and eliminate the stigma and stereotypes linked to being an autistic parent. Previous research has shown the impact of negative cultural assumptions and stereotypes of autism on autistic people’s well-being and interaction with professionals.⁸⁸ Assumptions can include: Autistic people have no empathy; They are cold and emotionless; They never show affection; they are unable to communicate with their children. This negatively influences the likelihood of disclosure and access to reasonable adjustments and other protections^{79,80}, resulting in a constructive denial of the support that can help them and their families thrive.

Implications for research

The experience of autistic parents within broader family research contexts is very under-researched. Research in this area is urgently recommended in light of the findings of the shared paradigm between autistic parent-and-child dyads and how this dynamic can serve to augment good outcomes.

Based on our findings, we certainly agree with Griffiths et al.⁷⁵ that: “... further research must look at why the parenting of autistic adults is being questioned and how autistic parents can be supported without feeling judged.” Equally important is investigating the broader systemic and societal issues that can impact the parenting experiences of

autistic adults. An essential facet of this research should be an extensive survey to determine the prevalence of autistic parents.

Collaborative, co-designed research focussed on the phenomenon of how a lens of trauma informs the quality of parenting experiences of autistic adults is essential. Avenues for investigation may include: Which factors influence the extent to which trauma informs the quality of parenting experiences? Does age at diagnosis impact this phenomenon? How may trauma-informed practices be adjusted to meet the specific needs and trauma experiences of autistic parents? How are these experiences different for autistic parents compared to non-autistic parents with historical trauma experiences?

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Authorship confirmation statement

S.S. created the research design, Qualtrics demographics questionnaire, and interview schedule. J.H. contributed to the final research design, Qualtrics questionnaire and interview schedule in the role of a supervisor. S.S. recruited participants and carried out all data collection and data analysis activities. S.S. wrote the draft article, and J.H. provided input on revisions. Both S.S. and J. H. reviewed and approved this article before submission. This article has not been submitted to any other journal and is not published anywhere else or in press.

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Supplementary Material

Supplementary Table A

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