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“A Wild and Inaccessible Place”: The Lived Experiences of Autistic Pregnancy and Birth

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Abstract

Background: Pregnancy is associated with a multitude of physiological and emotional changes that can be challenging for physical and mental health. Emerging pregnancy research suggests additional challenges for autistic women exist, including heightened sensory sensitivity, barriers to communication and overwhelming birth experiences.

Methods: This study provides an in-depth investigation of autistic women's experiences of pregnancy and birth using Interpretative Phenomenological Analysis. Eight autistic cisgender women, seven of whom received their autism diagnosis after birthing, participated in semi-structured interviews.

Results: Three group experiential themes were identified: 1. *Reinterpretation of perinatal experiences after diagnosis (Disconnection from reality during birth; Grief for expected journey; Battle with sensory experiences),* 2. *The ups and downs of connecting to their maternal identity (Feelings of instant affection and love; Sense of not belonging)* 3. *Seeking support: need versus reality (Feeling uncared for, unsupported and powerless; Containing, consistent, warm support).*

Conclusion: Autistic people have similar pregnancy experiences to non-autistic people but experience additional challenges. Most participants experienced disconnection from reality during birth, leading to confusion and distress. Societal stigma and perceived judgement negatively impacted maternal identities. Heightened sensory sensitivity was common and could interfere with daily life. Consistent support was valued but rarely experienced, all participants struggled to communicate their needs to professionals and felt uncared for and misunderstood.

Keywords: Autism; Pregnancy; Interpretative Phenomenological Analysis; Qualitative Research

Introduction

Autistic women have traditionally been underdiagnosed and misdiagnosed in comparison to their male counterparts[1]. There is a need to understand the experience of autistic women, as this under-representation has led to delayed access to appropriate support[2]. Autistic women generally struggle to access services and these services tend to be ill-equipped to recognise their needs[3].

Many women, neurotypical and neurodivergent, experience profound physiological changes that can impact physical and mental health, during specific milestones such as puberty, pregnancy, and menopause[4],[5]. The nausea, pain, insomnia, and fatigue associated with pregnancy can limit women's daily functioning[5]. This can contribute to stress in pregnancy which has been linked to increased risk of mental health difficulties[6]. Autistic parents reported experiencing elevated stress, anxiety, and depression within the third trimester of pregnancy[7],[8].

There have been several qualitative studies using interpretative phenomenological analysis (IPA) to understand experiences of pregnant women, which have provided valuable insight into this complex life event[9],[10],[11]. Research found when interviewing four women, that pregnancy acts as psychological preparation for motherhood[10]. Varying perceptions of pregnancy were reported, with some women reporting a profound sense of maternal responsibility and apprehension[9].

Research in this field has been expanding over recent years. When compared to non-autistic women in a survey, autistic women reported decreased overall satisfaction with their prenatal healthcare, feeling less likely to trust healthcare professionals or feel comfortable disclosing their diagnosis [12]. Similarly in a survey post-natal, autistic women were more likely to feel they were not listened to during birth and identified the need for communication adjustments for autistic people such as information in varying formats to feel more informed [13].

Qualitative research has also been increasing. Autistic women have consistently reported their experience of heightened sensory sensitivity impacted their wellbeing, resulting in overwhelming negative experiences, sometimes described as ‘meltdowns’[7],[12],[13],[14],[15],[18]. Autistic women also felt they had a lack of control over their own bodies and their environment during birth[14]. This is important to highlight for maternal care, considering autistic adults report feeling emotionally and physically unsafe during ‘meltdowns’, experiencing them as intently distressing and painful[17],[14].

Autistic women encountered stigmatising experiences during pregnancy, and they internalised this as inadequacy. This consequently impacted their identities as mothers[11]. Autistic women also experience regular barriers to communication and felt they should be offered additional support[13],[14],[15]. Research[16],[17] found healthcare services were unable to meet autistic women’s needs. Autistic mothers reported difficulties communicating their pain and needs, as well as feeling birth was not explained clearly[18],[19]. This led to feeling misunderstood, judged, and apprehensive about what to share[14],[15]. There is a dearth of research that investigates what professionals know about how to support autistic patients, with many professionals reporting they lack sufficient training[7],[18],[19] .

Autistic mothers described their sensory experiences in pregnancy as muti-faceted and pervasive, noting particular sensitivities with auditory and tactile senses, requiring regular downtime to manage the impact [7],[19]. There was also concern regarding effective communication during birth and participants were reluctant to disclose diagnoses to professionals, feeling they lacked appropriate knowledge.

Although the body of literature is growing, qualitative literature is currently limited to case studies and thematic analysis exploration of pregnancy in autistic women[7],[11],[12],[13]. Research investigating pregnancy in autistic women is not currently very extensive. ʼInterpretative Phenomenological Analysis (IPA) is a valuable method for understanding the lived experiences of autistic people[20]. IPA’s idiographic nature gives a voice to individuals, while aiming to make sense of how individuals within specific contexts make sense of their situation[21]. IPA is considered an appropriate and useful approach for understanding the lived experiences of autistic individuals, serving as co-productive and insightful into understanding distinctive experiences of autistic individuals[21]. Research has suggested providing this equality of voice in IPA is advantageous in understanding how autism is experienced individually[22]. There is currently no existing literature using IPA to explore autistic women’s experiences of pregnancy and birth.

Aims

This study aims to gain a deeper understanding of autistic women’s lived experience of pregnancy and birth.

Method

Design

The study used IPA, chosen for its focus on understanding of individual experiences in particular contexts[22].

Ethics

Ethical approval was obtained and granted by the University of Sheffield, Department of Psychology ethics sub-committee.

Participants

Eight autistic cisgender women participated in the study. Participants were included if they were over 18 years old, had received a formal diagnosis of autism and had experienced pregnancy within the last 16 years. We opted not to include those who self-diagnosed as we judged that experiences and interpretations of experiences may differ between those who are formally diagnosed and those who are self-diagnosed. A pregnancy cut-off was employed to limit extensive variability in memory recall. The limit of 16 years was selected as research suggested that many autistic women are diagnosed at the same time their children are in school[23] and hence was chosen so that those with school-age children could be included. Participants were excluded if they lacked capacity to consent or were not fluent in English.

Demographic information was collected (Table 1). Participants were between the ages of 33years and 52years (*M*= 39.6). All participants identified as White and there was a lack of representation from individuals from Black, Asian and other minority ethnic groups. One participant was diagnosed with “Autism Spectrum Condition (ASC)” (participant’s terminology) pre-pregnancy and was pregnant during the interview. The remaining participants received their diagnoses post-pregnancy. The remaining participants received their diagnoses post-pregnancy. These participants were the only individuals who expressed interest in completing the study within the recruitment timeframe. Seven participants had additional diagnoses including attention deficit hyperactivity disorder, anxiety, and depression. Four participants chose to discuss their multiple pregnancies. Children’s ages ranged from two to 15 years old. All names are pseudonyms for confidentiality.

INSERT TABLE 1.

Community Involvement Statement

Two autistic cisgender women were contacted by the lead researcher (CG) via the Sheffield Autism Research Lab database. The Sheffield Autism Research Lab database has details of autistic adults who consent to being contacted regarding research. They provided feedback on the interview schedule and information sheet and consent form. No changes to interview question content were recommended. Grammatical and spelling changes were made based on this feedback.

Materials

Semi-structured one-to-one interviews are the recommended data collection method, based on IPAs aims of understanding an individual's story[24]. A semi-structured interview schedule was developed considering the studies aims and Smith's[25] guidelines.

Procedure

This study recruited by emailing from the Sheffield Autism Research Lab database (*n*=1), a recruitment poster advertised via X (formerly Twitter) (*n*=6), and Instagram (*n*=1). All interviews were conducted over university approved video technology between May and August 2022.

Video interviews were recorded, converted into an audio file and stored securely. Interviews lasted between 46 minutes and one hour 43 minutes. The first two interviews and the last interview were transcribed by the first author. The remaining interviews were transcribed by an approved transcriber.

Data Analysis

Reflexivity statement

Literature acknowledges that qualitative research is a reflexive process, reflexivity is the influence of the researcher and the field reciprocally[25]. The researcher engages in self-reflection to raise awareness of their values, and beliefs for potential influence on the research process[25]. To continually reflect upon the influences within the research, a reflexive journal was maintained throughout. This detailed personal influences and reflections on the interviews, themes, and interpretation, which was then discussed with the co-authors. The lead researcher is a White British cisgender woman who is not autistic. The co-authors are not autistic. In this case there were not any personal experiences of the lead researcher that were used to inform the analysis. The lead researcher works with autistic individuals in their clinical work, however, has no personal experiences.

Coding and Analysis

After interviews were transcribed, the data was analysed using IPA in accordance with the approach as described by Larkin and Thompson[22] and Smith[25]. This involved six stages, with the first two stages focused on coding, where the primary researcher immersed themselves fully in the data. The second stage, initial noting involved examining language on an intricate level[26]. The third stage was the development of experiential statements, individual data was then arranged into conceptual maps and narrative summaries. The fourth stage was searching for connections across experiential statements, which led to the fifth stage of naming personal experiential themes (PETs). These commonalities mapped to contribute to the final stage; looking for general experiential themes (GETs) across cases.

Results

Group Experiential Themes and Subthemes

Data analysis produced three Group Experiential Themes (GETs) with eight GET Subthemes (Table 2). Each theme is discussed below alongside illustrative quotes. The themes are not an exhaustive account of participant experiences, rather a demonstration of the narrative of several accounts**.**

INSERT TABLE 2.

Reinterpretation of perinatal experiences after diagnosis

This GET explored participants' feelings that their diagnosis retrospectively contextualised their experiences, in terms of making sense of their internal worlds, communication, and the challenges they encountered perinatally: "Now you know you're autistic because, so many things that made sense now" (Emily).

Participants also described a sense that their diagnosis added another layer of difficulty to some of their pregnancy experiences:

> Like it's hard for any woman, don't get me wrong but why maybe it's hard, hard in a different way because they don't realise, they are autistic (Penny).

Nearly all participants felt if they had their diagnosis during pregnancy, they would have had a deeper understanding of themselves:

> If I had known that I was autistic at the time, I think I could have advocated so much better for myself" (Emily).

Conversely, for the participant who was diagnosed pre-pregnancy, she said pregnancy allowed her to be: "a lot more accepting about being autistic… this is part of me" (Olivia).

Disconnect from reality during birth

Nearly all participants referred to being out of contact with reality: "somewhere else completely" or "not in my body" (Penny) during birth. Participants struggled to make sense of what was happening during this time, feeling “oblivious” to their surroundings and like they “shutdown” (Nora).

I keep looking back at that experience and thinking. Why was I so oblivious to everything? Because I remember in labour that I felt like I was out of contact with the world and with myself (Nora).

This disconnect meant many participants felt they were unable to “process” (Ameillia) the information professionals were giving them. Participants described being given “vague” (Penny) information.

I didn't I didn't really understand what was going on, erm, I think probably people might have explained it to me, but I don't recall them explaining (Nora).

This meant participants struggled to make sense of their internal world but also externally during birth. Participants were unable to clarify or communicate their needs, feeling they became “really passive” (Nora).

Grief for expected journey

Some participants described a sense of grief for the loss of their expected birthing journey: “It took me a really, really long time to be ok with what happened, because it was different, and it wasn’t what I’d expected” (Clara). This was exacerbated by struggling to understand and connect with reality during birth: “I had planned for fully natural… I sort of feel like I missed his entry into the world” (Nora).

Nearly all participants felt they were unprepared and about what may happen during birth. This left participants with residual feelings:

Subsequently left me feeling a bit negative about the experience, but actually if I had been prepared differently and if it had been presented differently, as in, you know this is what is expected, this is the right thing to do. I was given an awful lot of decisions and biased advice (Grace).

Furthermore, these feelings extended beyond birth: “it really affected him and I for probably that first year of his life” (Penny).

Battle with sensory experiences

All participants reported noticing significant changes in their senses and “sensory issues” (Emily) that were overwhelming and confusing: “I didn’t know what was wrong with me but those sort of being oversensitive to everything” (Penny).

Nearly all participants identified smell as being the most prominent sensory change they noticed during pregnancy: “My sense of smell was phenomenal. It was outrageous” (Julia). For some participants, senses were “all-consuming” (Penny), and they were unable to carry out daily activities:

“I felt like I was being hit by a wave of just this intense disgusting smell… it would make my whole-body tense…and I just wanted to get away from it, it made going anywhere really, really difficult… it made me feel so sick, sick isn’t the word… all-consuming” (Penny).

Participants found they had associations with certain objects or clothing items, even years later post birth.

“All the clothes that I had from… the ones from the early phase of pregnancy I couldn’t wear. Because the association of nausea was so strong” (Grace).

Participants also described struggling with strong taste: “if anything has got an overwhelming taste to it, I’ll get heartburn instantly, even now” (Ameillia). As well as seeking certain textures: “my cravings have been totally sensory focused” (Olivia). Two participants connected childhood sensory experiences with diagnosis: “Well, I’m craving a bath sponge now, what do you want me to do... and I remembered that’s something I used to do when I was younger” (Ameillia).

Some participants had positive memories of connecting pregnancy and senses:

“I enjoyed it the same way that I enjoy some other sensory seeking kind of stuff “(Clara). As well as making associations between birthing experiences: “I struggled more with breastfeeding because its sensory” (Emily).

Another participant described how her birthing experience was accommodating for her sensory needs: “I was really lucky in that, their techniques really, really suited my sensory needs and, and what I didn’t get when I did transfer to the hospital”. Sensory overwhelm was a similar concern for Olivia, feeling “excessive stimuli” during her pending birth would lead to a “meltdown”.

The ups and downs of connecting to their maternal identity

This GET reflected the processes that participants went through as they developed their identity as a mother, which came with unique positives and challenges. For some participants, this process was associated with a sense of difference they had always felt to others pre-diagnosis. For others, this was closely linked with the developing bond they nurtured with their baby, as well as internalised and externalised pressure to be a “better mother” (Grace).

Feelings of instant affection and love

Most participants described feeling “very attached” (Clara) with their baby. As well as a definitive, unquestionable sense of knowing: “[I knew] that I wanted this baby and to be a mum” (Olivia, Emily). This sense of connection was personalised for each participant, some nicknamed their babies: “I really bonded with him, I called him [ ]” (Clara), and some connected through movement:

> “I can remember the first time I felt her kick, we had been for a Chinese meal in XXX and then we had gone to see the Ramba in the [ ] … and I felt the first kick and that was really exciting. Erm I love dance so I kind of thought that was really cool” (Grace).

Participants described feeling their baby was present in their daily life: “I’d just tell him about things” (Nora), or they included them by talking about “anything really, just chit chat” (Julia). Participants also spoke about wondering about their baby’s personality: “My baby is gonna be such a little character and I just thought it was great, like oh my god this is gonna be so cool, like oh she’s or he’s going to be a dancer” (Grace).

However, two participants found they needed to: “focus on the pregnancy rather than the baby” (Ameillia) due to pregnancy difficulties. Whether this was due to ill-health “I didn’t feel anything but ill” (Ameillia) or feeling overwhelmed. There were also some concerns about “connecting in the same way” (Penny) depending on the sex of the baby: “I always got on better with boys” (Julia). Despite these challenges, participants connected with their babies meaningfully in their own way: “I just kept distracting myself with telling […] to talk to her sister” (Ameillia). Alternatively, they had a moment where they felt their bond fell into place instantly: “Oh, he’s doing yoga… it kind of was a switch that flicked, and it was like oh we are the same” (Penny). Many participants retrospectively reflected how their bond strengthened on recognition that they and their child were both autistic, as their own “diagnosis came out of [him]” (Penny).

Sense of not belonging

For some participants they described an innate sense of “feeling different” and “not fitting in” but struggling to identify why: “I had a sense life was harder for me somehow” (Grace). This had implications for how they felt about becoming a parent. This led to a self-blaming narrative, with participants believing they were “just a bit crazy” (Clara) or a “freak” (Ameillia).

“I had a very low opinion of myself, and I suppose they were just more sort of evidence that there was something wrong with me. I didn’t know what was wrong with me but those sort of being oversensitive to everything, and other people's reaction to that of me being fussy" (Penny).

Participants also reflected on messages from society or family that told them there was "something wrong with me" and that they "should be trying harder" (Grace). This further internalised the sense of difference and feeling they had "something missing my entire life" (Ameillia).

For some participants these feelings led to questioning their ability to "raise a child that's not like me" or believing they were "not the kind of person that should raise a child" (Ameillia) not wanting to "pass my genes on". Some also reflected they "didn't want this baby to be like me" but had a "strong" determination that they:

"Wanted their life to be very different to how mine had been, I had always been autistic but I had never known I was autistic, so I just felt different, felt different, like I didn't fit in" (Grace).

Pressure and expectation

Participants described a journey of "processing" (Grace) and "acceptance" (Clara) of their pregnancy, which was an integral point of identifying as a mother. Within this, participants reflected on intense internalised pressure and apprehension that they "wouldn't be a good parent" (Julia).

For some participants, this journey included questioning if it was "fair for me to have a kid" (Ameillia) or recognising initially they "didn't want to have kids" (Julia) but that changing. For others, they reflected on the pressure that they felt they "should be doing something differently" and "be a better mother" (Grace).

Seven participants reflected how this internalised pressure was compounded by external stereotypes: "being a new mum, you are made to feel like 'crack on'" (Grace). Many participants reflected on feeling professionals were "expecting" that they were "not going to cope" (Julia) or "do the wrong thing" (Penny) feeling judged, based on previous mental health diagnoses. There was concern that being honest would be "held against me" (Clara). The "pressure" from professionals led to internalised beliefs such as: "You're going to be a bad mother… because you've got an eating disorder, you're not going to look after your baby" (Penny). Amelia reflected on feelings of "guilt" during pregnancy: "They said it was my fault my baby wasn't growing" (Ameillia).

Participants also described feeling like they needed to maintain a persona during pregnancy to protect from judgement:

"Just on a minute-to-minute basis hard to cope with, and at the same time maintain a erm persona of … you're happy about your pregnancy and you're looking after your baby and everything's fine and everything's great" (Penny).

Participants also described a "maternal instinct" arising and feeling a need to "protect" (Olivia) their children from danger. Olivia described feeling "vulnerable" being "autistic and a parent" worried autism would be "held against them" based on the stigma they had faced previously.

Seeking support: Need versus reality

The final GET theme explored participants experience of support throughout the perinatal period. Participants reported feeling "neglected" (Ameillia) and "dismissed" (Emily) with support being "unhelpful", "awful" (Julia) and "impersonal" (Grace),

> "It all felt a bit, not like I would, you know I felt like a very small cog in a very big machine that really wasn't very interested, and I did feel like that all the way through" (Grace).

Feeling uncared for, unsupported and powerless

Seven participants reflected on the inconsistent professional care they received, which consequently left them feeling unprepared for birth: “I’d see a different consultant every time, and they would just say different things every time” (Julia),

> “It was so impersonal, and each member of staff seemed to be off doing their own thing, it wasn’t co-ordinated. I had no sense of seeing the same person twice and no sense that they were even singing from the same hymn sheet” (Grace).

Some participants reported needing to be “guarded” (Olivia) with what they chose to share with professionals, through fear of judgement even if they were struggling. Nearly half of participants reported residual feelings about the care, they received: “I am still angry” (Ameillia, Penny),

> “But it was judging what things to mention when, because I knew that some things probably weren’t normal, so there were things that, I probably needed to keep to myself” (Penny).
>
> “I would be worried to speak out about certain things that I might have struggled with in case people said, “oh well, if you’re struggling now what are you gonna be like when the baby’s here”” (Olivia).

Participants described a sense of powerlessness: “I was so scared to say the wrong thing” (Penny) feeling unable to verbalise their distress or needs: “I would have said no but I didn’t feel I could” (Penny). As well as feeling uncared for: “Oh, they were listening, they just didn’t care” (Ameillia). Some participants described feeling the support they did receive was biased, which gave them unrealistic expectations of birth: “Unhelpful was the sense of avoid medical intervention, you know until the last hour. So, I think it would have been helpful to have a more balanced view” (Grace).

That also led to feelings of guilt and inadequacy if their birth did not go to plan: “I had convinced myself it was my life’s work” (Grace). Some participants felt like they were "being a problem" if they did disclose distress and were ultimately left feeling dismissed and misunderstood. Experiences were genrealised as stereotypical pregnancy experiences "oh that happens to everyone" (Emily),

> "Like over emotional or whatever, so I don't feel like they really took it seriously until basically I had that meltdown, and then they realised how much I actually was really struggling" (Emily).

Furthermore, when information was provided to professionals about autistic needs, it was "acknowledged" but: "I think they want me to feel like its normalised as well like; oh, it's okay, it's no different to whatever identities people can have, you know, it's no different to being asthmatic" (Olivia).

All participants reported needing clear communication from professionals that they felt, in hindsight would have prevented miscommunications they experienced during birth. Reflecting the language used was "ambiguous" and needing it to be "clearer",

> "Obviously If they'd have known about my diagnosis that would have made a massive difference to how everyone there had treated me… I didn't feel like anyone explained anything clearly to me, everything, I was just expected to know" (Penny).

Containing, consistent, warm support

Despite the difficulties all participants reflected on some "excellent" support from "really lovely people" (Nora). Participants also described what good support could look like. All participants recalled personal examples of "human connection" (Emily) and "warm support" (Nora) they shared with specific midwives, healthcare workers or consultants which they felt impacted their experience for the better: "He was just really funny. He just made me feel positive because I was laughing" (Emily).

One participant described her "personal", "consistent" (Clara) support to homebirth and how professionals considered her sensory needs. This support aligned with what other participants felt ideal support should be. It was important for support to have "more consistency" (Julia) and "continuity of care" (Penny).

The majority of participants felt "personalised" support was important and gave examples of how this could be achieved. Particularly feeling specific understanding of autistic individuals would be priceless: "it would be good to have a midwife who specialises in Autism" (Grace). Penny spoke of the value of the 'after thoughts service'

"…went to, they offer a service called After Birth Thoughts, where you can go back and you can see a Midwife… I came away from it feeling better thinking actually it wasn't my fault, I didn't, it was just how it happened" (Penny).

> "I don't know how many autistic health care professionals there are around… being able to be supported by someone who understands some of the challenges around autism would be, priceless…" (Nora).

Participants also reflected on how helpful it would have been to tell professionals they were autistic, had they known, in order to get the right support: "Erm, if you know that you're autistic, I think it's a really good idea to say something about it" (Nora).

> "I think I'd have been able to communicate better if I'd have known because I'd have had a more, a better understanding of who I am and how I communicate, so I could have made alterations, like I have" (Ameillia).

Indeed, Olivia spoke about how she was preparing to give professionals information about her needs that she felt they valued: "I've started putting together a birth plan and the, the National Autistic Society have a Self-Advocacy Booklet" (Olivia).

Discussion

The aim of this study was to understand the lived experience of pregnancy in autistic women. When interpreting the findings, it is important to consider that seven of the eight participants in this study did not have their autism diagnosis during pregnancy and this will have shaped their experiences particularly in relation to their own understanding of their experiences, how they advocated for their needs and have influenced how they were treated by healthcare professionals. It was clear that participants reflected on their pregnancy experiences differently following receipt of their autism diagnosis and they felt that had they received their diagnosis pre-pregnancy, this would have facilitated their ability to self-advocate and it would also have facilitated self-compassion at the time. Experiencing being totally overwhelmed and disconnected from reality during birthing was strikingly prominent in the narratives, and this contributed to feelings of grief the expected journey. Heightened sensory sensitivity and narratives of overwhelming experiences were also very prominent. While all of such feelings are not uncommonly reported in non-autistic people, the frequency and extreme nature of the experiences were striking. We suggest that these are likely of a categorically different nature to the common experiences of non-autistic people and being diagnosed at the time may have helped participants to deal with these things. For all, there was a transition into maternal identity with the ups and downs of this experience being clearly articulated. Most described instant feelings of affection and connection though for a minority the pregnancy experience was so overwhelming that these individuals found it difficult to focus on anything other than surviving the physical symptoms. Many felt that they were having a qualitatively different pregnancy journey to others but struggled to understand why, which left them feeling inadequate. The pressure and expectations exerted by others was felt acutely. The vast majority experienced significant internalised pressure that was exacerbated by feeling they were not meeting others' expectations. Many participants felt neglected and dismissed by perinatal services. This was particularly exacerbated by inconsistent continuity of care. Most participants felt judged and that they needed to hide their distress. All felt that communication from healthcare professionals could have been clearer and experiencing miscommunication was common. However, there were some common reports of good practice from specific individuals. A common narrative was that participants felt it would have been helpful to have known they were autistic when they were pregnant as this would have helped with self-advocacy. In the following paragraphs we discuss some of the particularly striking aspects of lived experience that emerged and we consider where these are / are not aligned with finding in the broader literature that focuses on non-pregnancy autistic lived experiences and non-autistic pregnancy experiences.

Knowing I'm autistic would have helped

The finding that participants felt their experiences would have been better had they known sooner that they were autistic is consistent with previous findings[2],[27] whereby participants reported an increased sense of self-acceptance and compassion towards themselves post-diagnosis when reflecting on previous experiences. Participants reported that diagnosis provided a new lens that facilitated understanding of difficult past experiences. These new understandings of past experiences transformed personal narratives to be less self-critical and more compassionate.

Extreme disconnect from reality during birthing

Most participants described a sense of extreme disconnect from reality during birth, where they shut down and felt oblivious to their surroundings and needs of themselves or their baby. This is similar to the previously reported childbirth experiences of autistic women in acute care settings[18]. This response to the bodily sensations experienced as overwhelming during birth appears to be somewhat similar to non-autistic women who experience intense fear and negative birthing experiences [5,10]. However, for the autistic women in the current study there seemed to be a loss of connection to all aspects of the birth experience, including sensing needs or danger which resulted in distressing, confusing experiences.

Extreme sensory experiences

Smell was identified as the most prominent sensory experience during pregnancy. This experience is not uncommon in pregnancy of non-autistic women with both smell and taste in terms of sensitivity, aversion and nauseating responses reported[28]. However, consistent with several recent studies[7],[15],[19] heightened sensory sensitivity was experienced as "all-consuming" and had a detrimental impact on quality of life. Increased and emerging sensory sensitivities were reported that led to avoidance of environments due to noise, smell, and physical sensations. Associations in some cases were still strong years post pregnancy, to the extent that certain foods or clothing were still avoided due to the intense physiological response. The above suggests sensory sensitivity is a common experience in pregnancy, but for autistic women this can be so intense it interferes with coping with daily life.

Struggling with internal and external pressure to conform

Participants in this study grappled with internal and external pressures in relation to their maternal identities. In his IPA study, Smith[11] identified that pregnancy facilitated a process of changing self-perception, where all women discovered their role as a mother. Although participants described their feelings about motherhood, most felt judged about their ability to cope relating to co-occurring or misdiagnosed mental health conditions. This, in turn, led to self-doubt about their competency and worth as a mother. Further, some participants described feeling innately different to others and internalised the message from society they should be trying harder to conform. Autistic women have been found to have internalised beliefs that they were flawed in comparison to others[2]. They tend to feel the burden to conform to expectations of being more neurotypical, which is likely to take them further from their authentic selves[28]. Participants described needing to hide their true selves and executed caution disclosing to professionals through fear of judgement, much like camouflaging to reduce social stigma[29],[14],[15]. These findings seem relevant to social constructionism theory whereby individual knowledge of self and the world is developed culturally [30]. In this case, the socially constructed narratives of needing to be a *good* and *present* mother and conform to this ideal, influenced participants internal representation they had of themselves[31]. Although autistic women clearly experience a process of developing their maternal identity, this is heavily influenced by societal expectation and stigma. This stigma can create feelings of inadequacy, as well as a need to compare or conform to societies norms. Social constructionist theory principles can also contextualise the varying experiences participants had in relation to their developing bond with their child. Some participants reported concerns about connecting with their child, holding the belief to be a good mother is to develop such connections, which only strengthened pre-existing self-criticism. These findings support the literature on the dominant co-constructed narrative of motherhood, that expects mothers to have immediate, positive connection to their child[35].

Feeling powerless in seeking support

In relation to seeking support, autistic women have reported feeling disempowered and suppressed when communicating needs with professionals[20]. Power imbalances between healthcare professionals and patients have been found to impede shared decision making[32]. Participants described feeling scared through fear of judgement that meant they needed to be guarded when sharing information. Similarly, Leedham[2] and Pohl[17] found autistic women felt misunderstood leading to intense self-doubt when sharing with professionals. Hampton[7] also found autistic mothers were less likely to disclose their diagnosis to professionals, fearing lack of knowledge. In another study participants also described feeling unprepared by professionals for birth or being given biased advice wanting more of a balanced view[15.] Existing literature acknowledges that neurotypical and neurodivergent women can be socialised into certain models of childbirth, that are co-constructed intersubjectively by the media, society, and culture[33]. Therefore, professionals should consider what birthing narratives are communicated and how this may contribute to expectant mothers understanding and beliefs. Particularly considering the experiences of suppression and disempowerment of autistic women, that may hinder shared decision-making during birth.

Continuity of care could have facilitated communication

Participants felt clearer communication and continuity of care would prevent feeling unheard and unsupported. Indeed, positive experiences within healthcare for autistic mothers has been correlated to a consistent, collaborative approach[18]. Turner[34] has made recommendations to consider using clear, explicit information and visual aids with autistic women during birth. Participants described limited information and ambiguous language led to misunderstandings about the health of themselves and their baby. Autistic women in research reported communication difficulties with healthcare professionals that negatively impacted birth[13]. Pohl[17] suggested that anxieties about needing to converse with professionals impeded communication, which was echoed in this study with fear of judgement by professionals. Similarly, literature exploring autistic adults experience of accessing healthcare noted a significant barrier was fear of being misunderstood[35]. However previous literature highlights many professionals report they lack sufficient training to support autistic individuals[20],[12],[19]. This suggests that autistic women may struggle to communicate pain, distress, and sensory needs during birth, but professionals also lack the training to empower them to do so.

Strengths, Limitations and Future Directions

As far as the authors are aware, this is the first IPA study exploring in-depth experiences of pregnancy and birth in autistic women. The multiple recruitment strategies allowed for wide reach of the study, which is a strength reflected in the various countries represented. Additionally, utilising auditing methods with independent reviewers increased the transparency of the findings.

IPA was selected as the chosen methodology because it allows for a deep exploration of the lived experiences of autistic women, which was suggested as important by previous literature [2],[10]. There was however variability between participants, seven had not received a diagnosis prior to pregnancy, while one had received a diagnosis and was pregnant during the interview. Additionally, time since pregnancy varied considerably, between one and 15 years ago. This may have resulted in less clear accounts of experiences from many years in the past. Nevertheless, given the salience of pregnancy for women it was deemed important to be inclusive with the criteria[36]. The findings sought to keep the idiographic nature of each participant, nevertheless the lack of homogeneity may have limited this. Although transferability is not the aim of qualitative research, it is worth considering how these factors impacted reported experiences.

The participants also varied in terms of their cultural backgrounds, with one participant being Australian, one Dutch and six British. This is advantageous as various cultural perspectives could be captured. However, all participants identified as White, and their experiences may differ from autistic women from other ethnicities which is an acknowledged limitation. This is a problem in research in general, and is recognised at a national level [37]. Future qualitative studies are needed that include participants from the global majority. Further, future studies should also include participants with a known diagnosis.

Clinical Implications

This study raised several implications for consideration in clinical practice. Participants highlighted the limited provisions available in maternity healthcare services for autistic women, which has also been identified as an area of concern by the Care Quality Commission[38] in their state of healthcare report. Firstly, participants reported inconsistent care with biased communication from professionals, that left them feeling unsupported. However, participants generally felt that if they'd had their autism diagnoses at the time, this would have facilitated their ability to self-advocate. Participants suggested the value of specialist autism trained midwives and experts by experience in maternity healthcare roles, which could encourage co-production of service development. On a service level, specific training could be delivered on effective communication and use of language with autistic individuals. Secondly, findings from this study and previous literature highlighted how some autistic women experience a disconnect from reality during birth,[18],[39]. Psychoeducation regarding this experience, alongside training for triggers, warning signs and strategies to support autistic women through this, would be beneficial for midwives. An easily accessible advocacy service for autistic women during birth would be valuable, to give power and a voice to communicate needs if they feel unable to in the moment.

Conclusion

This study identified that autistic women have similar pregnancy experiences to non-autistic women but some aspects of experience appear more intense for most. Also, autistic individuals who are pregnant experience additional barriers to accessing adequate support compared to non-autistic individuals. Participants described extreme heightened sensory sensitivities, specifically smell that led to aversion and avoidance. Feeling entirely disconnected during birth was very common, resulting in miscommunication of needs and lasting emotional impact. Concerns were exacerbated by pre-existing stigma which significantly impacted their maternal identities. Consistency and compassion in care was deemed important yet experienced minimally, with participants feeling powerless and unheard. These findings have important implications and considerations for autistic perinatal needs in healthcare.

Authorship Confirmation Statement

C.G. conceptualised this work and led the data collection, transcription of data, data analysis, and drafting of the study. A.R.T and M.F supervised C.G. and supported the study's conceptualisation, design, and interpretation of the results. All authors revised the article and approved of the final version for publication. The article has been submitted solely to this journal and is not published, in press, or submitted elsewhere.

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References

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[1] Mandy W, Lai MC. Towards sex- and gender-informed autism research. *Autism*. 2017;21(6):643-645. doi:10.1177/1362361317706904

[2] Leedham A, Thompson AR, Smith R, Freeth M. 'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism*. 2020;24(1):135-146. doi:10.1177/1362361319853442

[3] Yau N, Anderson S, Smith IC. How is psychological wellbeing experienced by autistic women? Challenges and protective factors: A meta-synthesis. *Res Autism Spectr Disord*. 2023;102(102101):102101. doi:10.1016/j.rasd.2022.102101

[4] Koch MK, Mendle J. In their own words: Finding meaning in girls' experiences of puberty. *Child Dev*. 2022;93(6). doi:10.1111/cdev.13836

[5] Soltani F, Maleki A, Shobeiri F, Shamsaei F, Ahmadi F, Roshanaei G. The limbo of motherhood: Women's experiences of major challenges to cope with the first pregnancy. *Midwifery*. 2017;55:38-44. doi:10.1016/j.midw.2017.08.009

[6] Herbell K, Bloom T. A qualitative metasynthesis of mothers' adverse childhood experiences and parenting practices. *J Pediatr Health Care*. 2020;34(5):409-417. doi:10.1016/j.pedhc.2020.03.003

[7] Hampton S, Man J, Allison C, Aydin E, Baron-Cohen S, Holt, R. A qualitative exploration of autistic mothers' experiences I: Pregnancy experiences. *Autism*, 2023;*27*(5), 1271-1282.

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[8] Hampton S, Man J, Allison C, Aydin E, Baron-Cohen S, Holt R. A qualitative exploration of autistic mothers' experiences II: Childbirth and postnatal experiences. *Autism*. 2021. 10.1038/pr.2015.222.

[9] Birtwell B, Hammond L, Puckering C. 'Me and my Bump': An interpretative phenomenological analysis of the experiences of pregnancy for vulnerable women. *Clin Child Psychol Psychiatry*. 2015;20(2):218-238. doi:10.1177/1359104513506427

[10] Gagnon, R. A longitudinal study of women's representations and experiences of pregnancy and childbirth. *Midwifery*. 2021.10.1016/j.midw.2021.103101.

[11] Smith JA. Identity development during the transition to motherhood: An interpretative phenomenological analysis. *J Reprod Infant Psychol*. 1999;17(3):281-299. doi:10.1080/02646839908404595

[12] Hampton S, Allison C, Aydin E, Baron-Cohen S, Holt R. Autistic mothers' perinatal well-being and parenting styles. *Autism*. 2022;26(7):1805-1820. doi:10.1177/13623613211065544

[13] Hampton, S., Allison, C., Baron-Cohen, S., & Holt, R. (2023). Autistic people's perinatal experiences II: A survey of childbirth and postnatal experiences. *Journal of Autism and Developmental Disorders*, *53*(7), 2749-2763.

[14] Lewis LF, Stevens K. The lived experience of meltdowns for autistic adults. *Autism*. 2023;27(6):1817-1825. doi:10.1177/13623613221145783

---

[15] Dugdale AS, Thompson AR, Leedham A, Beail N, Freeth M. Intense connection and love: The experiences of autistic mothers. *Autism*. 2021;25(7):1973-1984. doi:10.1177/13623613211005987

[16] Lum M, Garnett M, O'Connor E. Health communication: A pilot study comparing perceptions of women with and without high functioning autism spectrum disorder. *Res Autism Spectr Disord*. 2014;8(12):1713-1721. doi:10.1016/j.rasd.2014.09.009.

[17] Pohl AL, Crockford SK, Blakemore M, Allison C, Baron-Cohen S. A comparative study of autistic and non-autistic women's experience of motherhood. *Mol Autism*. 2020;11(1). doi:10.1186/s13229-019-0304-2.

[18] Donovan J. Childbirth experiences of women with autism spectrum disorder in an acute care setting. *Nurs Womens Health*. 2020;24(3):165-174. doi:10.1016/j.nwh.2020.04.001
24(3),165–174. https://doi.org/10.1016/j.nwh.2020.04.001.

[19] Talcer MC, Duffy O, Pedlow K. A qualitative exploration into the sensory experiences of autistic mothers. *J Autism Dev Disord*. 2023;53(2):834-849. doi:10.1007/s10803-021-05188-1.

[20] MacLeod A. Interpretative Phenomenological Analysis (IPA) as a tool for participatory research within Critical Autism Studies: A systematic review. *Res Autism Spectr Disord*. 2019;64:49-62. doi:10.1016/j.rasd.2019.04.005

---

[21] Larkin M, Thompson AR, eds. Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners. Published online 8 July 2011. doi:10.1002/9781119973249

[22] Howard K, Katsos N, Gibson J. Using interpretative phenomenological analysis in autism research. *Autism*. 2019;23(7):1871-1876. doi:10.1177/1362361318823902

[23] Kanfiszer L, Davies F, Collins S. ‘I was just so different’: The experiences of women diagnosed with an autism spectrum disorder in adulthood in relation to gender and social relationships. *Autism*. 2017;21(6):661-669. doi:10.1177/1362361316687987

[24] Smith JA, Flower P, Larkin M. Interpretative Phenomenological Analysis: Theory, Method and Research. *Sage.* 2021. http://digital.casalini.it/978152978076.

[25] Darawsheh, W. (2014). Reflexivity in research: Promoting rigour, reliability and validity in qualitative research. *International journal of therapy and rehabilitation*, *21*(12), 560-568.

[26] Smith JA, Flower P, Larkin M. Interpretative Phenomenological Analysis: Theory, Method and Research. *Sage.*1999. http://digital.casalini.it/978152978079

[27] Wilson RB, Thompson AR, Rowse G, Smith R, Dugdale AS, Freeth M. Autistic women’s experiences of self-compassion after receiving their diagnosis in adulthood. *Autism*. 2023;27(5):1336-1347. doi:10.1177/13623613221136752

[28] Cameron EL. Pregnancy and olfaction: a review. *Front Psychol*. 2014;5. doi:10.3389/fpsyg.2014.00067

---

[29] Hull L, Lai MC, Baron-Cohen S, et al. Gender differences in self-reported camouflaging in autistic and non-autistic adults. *Autism*. 2020;24(2):352-363. doi:10.1177/1362361319864804

[30] Burr V, Dick P. Social constructionism. In: *The Palgrave Handbook of Critical Social Psychology*. Palgrave Macmillan UK; 2017:59-80.

[31] Kerrick MR, Henry RL. Totally in love": Evidence of a master narrative for how new mothers should feel about their babies. *Sex Roles*. 2017;76:1-16. doi:10.1007/s11199-016-0666-2.

[32] Joseph-Williams, N., Elwyn, G., & Edwards, A. (2014). Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Education and Counselling*, *94*(3), 291-309. 10.1016/j.pec.2013.10.031.

[33] Luce A, Cash M, Hundley V, Cheyne H, van Teijlingen E, Angell C. "Is it realistic?" the portrayal of pregnancy and childbirth in the media. *BMC Pregnancy Childbirth*. 2016;16(1). doi:10.1186/s12884-016-0827-x

[34] Turner L. Supporting women with autism during pregnancy, birth and beyond. *Am Nurse*. 2017;27(4):462-466.

[35] Doherty M, Neilson S, O'Sullivan J, Carravallah L, Johnson M, Cullen W, Shaw, SC. Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study. *BMJ open*, 2022;*12*(2), e056904.

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[36] Watkins EE, Zimmermann ZJ, Poling A. The gender of participants in published research involving people with autism spectrum disorders. *Res Autism Spectr Disord*. 2014;8(2):143-146. doi:10.1016/j.rasd.2013.10.010

[37] The challenges for families affected by autism from black, Asian and minority ethnic communities. The National Autistic Society.

[38] Comissioners NHS. Perinatal Service Provision: The role of Perinatal Clinical Psychology. NHS.

[39] Steward R, Crane L, Mairi Roy E, Remington A, Pellicano E. “life is much more difficult to manage during periods”: Autistic experiences of menstruation. *J Autism Dev Disord*. 2018;48(12):4287-4292. doi:10.1007/s10803-018-3664-0

Table 1. Demographic Information of Participants.

Participant pseudonym	Ethnicity	Age at Diagnosis	Additional Diagnoses	Number of Children
Nora	White	51	Yes	3
Grace	White British	45	Yes	1
Ameillia	White British	34	Yes	3
Olivia	White British	4	Yes	1
Clara	White Australian	34	Yes	3
Julia	White British	38	Yes	1
Penny	White British	38	Yes	2
Emily	White British	35	No	1

Table 2. Group Experiential Themes and Group-Level Subthemes.

Superordinate	Subthemes
1. Reinterpretation of perinatal experiences after diagnosis	1.1 Disconnect from reality during birth 1.2 Grief for expected journey 1.3 Battle with sensory experiences
2. The ups and downs of connecting to their maternal identity	2.1 Feelings of instant affection and love 2.2 Sense of not belonging 2.3 Expectation and pressure
3. Seeking support: Need versus reality	3.1 Feeling uncared for, unsupported and powerless 3.2 Containing, consistent, warm support