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

PROF MEGAN FREETH

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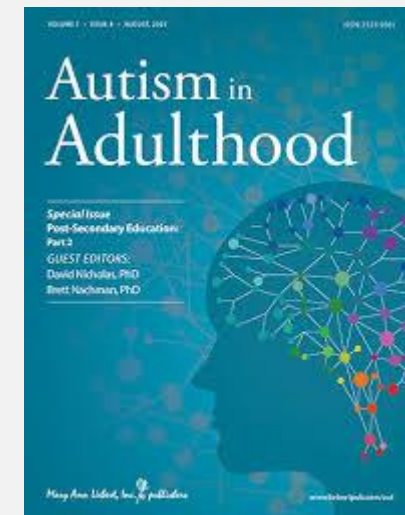
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Background

- Autistic women have traditionally been underdiagnosed and misdiagnosed compared to men (Mandy & Lai, 2017)
- Autistic women generally struggle to access services, and these services tend to be ill equipped to recognise their needs (Leedham et al. 2019; Yau et al. 2023)
- Several qualitative studies using interpretative phenomenological analysis (IPA) to understand experiences of pregnant women, which have provided valuable insight into this complex life event (Birtwell et al. 2015; Gagnon, 2021; Smith, 1999)
- Autistic women reported decreased overall satisfaction with their prenatal healthcare, feeling less likely to trust healthcare professionals or feel comfortable disclosing their diagnosis (Hampton et al. 2022)
- **Aim: To gain a deeper understanding of autistic women's lived experience of pregnancy and birth**

Method

Participants

- 8 cisgender women interviewed
 - 7 received their autism diagnosis after birthing
- Inclusion criteria
 - 18 years or older
 - Formal diagnosis of autism
 - Experienced pregnancy in the last 16 years
- Exclusion criteria
 - lacked capacity to consent
 - unable to speak English
 - no official autism diagnosis
- Ethical approval granted by University of Sheffield
- One-to-one semi-structured interview analysed using IPA



Method

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

Interpretative Phenomenological Analysis (IPA)

- No preconceptions of what themes will emerge
- The researcher engaged in a 'double hermeneutic' process, making sense of how individuals make sense of their world

Reading the transcripts repeatedly to immerse oneself in the data

Noting down initial ideas and themes regarding content, context, language, process and initial interpretations

Developing tentative emerging themes from the data

Grouping themes based on characteristics and labelling them (PET then GET)

Developing a final list of themes and subthemes to report and interpret alongside theory and literature

Why IPA?

- Helps to understand the lived experience
- Better informed services and professionals
- Validating
- The first IPA study exploring in-depth experiences of pregnancy and birth in autistic women

Results

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

Reinterpretation of perinatal experiences after diagnosis

"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)

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

"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).

"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)

"My sense of smell was phenomenal. It was outrageous" (Julia)

"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)

"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).

The ups and downs of connecting to maternal identity

*"[I knew] that I wanted this baby and to be a mum"
(Olivia, Emily)*

"I really bonded with him, I called him []" (Clara)

*"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)*

"I didn't feel anything but ill" (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).*

*"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)*

Seeking support, need vs. reality

"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).

"It was so impersonal, and each member of staff seemed to be off doing their own thing, it wasn't co-ordinated." (Grace)

"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).

"Oh, they were listening, they just didn't care" (Ameillia).

"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)

"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).

"I've started putting together a birth plan and the, the National Autistic Society have a Self-Advocacy Booklet" (Olivia)

Conclusions

Autistic women have similar pregnancy experiences to non-autistic women ***BUT*** these are more intense for most

Autistic women who are pregnant experience additional barriers to accessing adequate support compared to non-autistic women

Extreme heightened sensory sensitivities, particularly smell

Feeling entirely disconnected from birth was common

Miscommunication relating to needs

Feelings of powerlessness

Lasting emotional impact

Clinical implications

Limited provision in maternity healthcare for autistic women

Improved consistency of care required

Experts by experience in maternity healthcare roles

Psychoeducation in relation to expectations

Specify wellbeing plan in advance

Thank you!

Any questions?