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“I felt belittled and ridiculed for being in pain”: An online survey of Autistic people’s experience of care for pregnancy loss (perinatal loss) in the United Kingdom[☆]

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ABSTRACT

Background: Around 3 % of people are Autistic; women may be under-diagnosed. Autistic people report lack of staff understanding, stigma and environmental barriers to using midwifery services. It is not known if these issues are present in perinatal loss services.
Aim: To understand Autistic people’s experiences of care for perinatal loss.
Methods: An online survey for Autistic adults in the United Kingdom who had been pregnant, using closed and open questions. Data were analysed descriptively, using Kruskal-Wallis tests and thematically.
Results: The majority of losses appeared to be early in pregnancy. Among 67 participants, over half (58.2 %, $n = 39$) always sought healthcare during a perinatal loss, but 28.4 % ($n = 19$) never accessed care. Of those who received healthcare ($n = 48$; 71.6 %), over half ($n = 27$; 56.3 %) did not know they were Autistic at the time, and just one person told health professionals that they were Autistic. Four participants identified instances where staff were supportive or kind, but the majority of experiences were negative, with reported issues focused on communication, the way support was provided, inadequate pain relief and the hospital environment. We generated one overarching theme: “trauma”.
Conclusion: Autistic people from the UK identified significant Disability-related access issues with perinatal loss care in addition to issues reported by a general population. UK Perinatal loss services need urgent investment to be able to provide person-centred care to all. Staff supporting perinatal loss should receive neurodiversity-affirming Autism training and be aware that many Autistic people experiencing perinatal loss may not have or share a diagnosis.

Introduction

Statement of significance

Problem or issue	Around 3 % of people are Autistic, with limited gender variation. There has not yet been research to understand Autistic experiences of perinatal loss.
What is already known	Perinatal loss is known to have mental health impacts on those in a general population. Research has identified that perinatal loss services do not always meet parents needs.
What this paper adds	This study examines Autistic perinatal loss experiences for the first time, using an online survey comprising open and closed questions. We identified that perinatal loss healthcare in the UK may not meet the needs of Autistic people, particularly in relation to communication and adequate pain relief.

Recent estimates suggest that around 3 % of people are Autistic (Centers for Disease Control and Prevention 2023). Autistic people experience differences in communication and sensory processing when

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compared to non-Autistic people. These communication differences often include misunderstanding of indirect communication (Beardon, 2021), and finding telephone calls challenging (Howard and Sedgewick, 2021). Some Autistic people are non-speaking (they never speak), minimally speaking (they can only say a small number of words), or semi-speaking (they can speak sometimes, but not always); few are truly non-verbal (making no noise ever). Moreover, sensory processing differences can mean finding many elements of the environment painful, such as touch, visual and/or audio content (Tavassoli et al., 2014). Autistic people can also find it difficult to interpret and describe their internal bodily sensations (interoception), emotions (alexithymia) and pain (Morgan et al., 2024). When combined with an inaccessible environment, these differences can lead to anxiety and feelings of dysregulation, meltdowns, shutdowns and burnout (Hwang et al., 2020).

Autism is a lifelong neurotype, although research and services still tend to be directed towards Autistic children and their parents (Nicolaidis et al., 2019). Furthermore, those Assigned Female At Birth (AFAB)* have historically been less likely to be diagnosed than their peers who were Assigned Male At Birth (AMAB) (Lai et al., 2015). This difference has been attributed to Autistic women being more likely to ‘mask’ or ‘camouflage’ their Autism, by behaving in ways that are more socially accepted, due to gendered socialisation practices, rather than a true difference (Pearson and Rose, 2021). However, this does not mean that these Autistic AFAB people have not experienced the same challenges with communication and the sensory environment as their AMAB counterparts, and some will go on to seek diagnosis in adulthood (Leedham et al., 2020). Diagnostic pathways for adult women can be inaccessible to many Autistic people, and challenging to navigate for those who are most determined to persevere (Harmens et al., 2022), which may further result in lower rates of diagnosis for adult Autistic AFAB people. There are a broad range of barriers to Autistic people being able to access effective healthcare, based on inflexible systems which often do not understand or accommodate Autistic needs (Mason et al., 2019). To date, few interventions have been trialled to make healthcare more accessible to Autistic adults; those that have tend to focus on ‘health passports’, and the evidence suggests that a passport alone cannot remove these healthcare barriers (Ellis et al., 2023).

Analysis of the Secure Anonymised Information Linkage (SAIL) database has identified that 0.79 % of births in Wales, UK, during 2020 were to those with a diagnosis of Autism recorded within health or education data (personal correspondence: Professor Sinead Brophy). The previously mentioned difficulties in securing an Autism diagnosis, alongside stigma and social work intervention directed towards Autistic birthing parents (Benson, 2023), could lead to parents choosing not to share their diagnosis or status as a self-identifying Autistic person within maternity care. As such, this figure is likely a significant underestimate. Being Autistic is relevant to maternity as a nationwide cohort study in Sweden, spanning almost a decade, identified that births to those diagnosed as Autistic were associated with an increased risk of preterm birth, preeclampsia, increased induction of birth and elective caesarean sections (Sundelin et al., 2018). Systematic reviews focused on the experiences of Autistic birthing parents have identified issues leading to inequitable care, including staff having poor understanding of Autism, services not being tailored to Autistic needs (Grant et al., 2022), and a challenging sensory environment within hospitals (Samuel et al., 2021). Furthermore, when compared with non-Autistic peers in cross-sectional research, Autistic people were more likely to report feeling misunderstood by maternity staff (Pohl et al., 2020) and lower rates of satisfaction with care (Hampton et al., 2023).

Perinatal loss (including miscarriage, ectopic pregnancy, stillbirth and neonatal death) is common, with an estimated 15 %-20 % of pregnancies ending in miscarriage alone (Alijotas-Reig and Garrido-Gimenez, 2013). Swanson’s care theory, as applied to miscarriage recommends that those providing care should: support parents’ to have faith in being able to get through the loss; provide understanding; be emotionally present; treat parents as they would wish to be treated; and enable parents to navigate the (likely unfamiliar) transition of loss (Swanson, 1999). Research on the experiences of a general population who have experienced early pregnancy loss have highlighted that it can be distressing, including long waits in hospital, pain, and bleeding that continues after treatment (Petrou and Mcintosh, 2009). Women have noted being turned away from services when miscarrying (Lahman, 2013) and have experienced a stressful wait between appointments to confirm viability in expectant management (Meaney et al., 2017) Staff communication around pregnancy loss has been identified as unclear and disrespectful (Helps et al., 2020), in contradiction to Swanson’s theory (Swanson, 1999). Diagnostic scanning, however, was viewed as helpful in facilitating emotional detachment from the pregnancy (Spillane et al., 2018). Negative experiences during in-hospital care for early pregnancy loss included being placed on wards with women who were not experiencing pregnancy loss, a lack of sensitivity among staff, and failure by staff to adequately recognise the loss of life (Meaney et al., 2017). A lack of follow-up, unmet needs relating to information and answers, and accompanying misunderstandings and guilt have been identified by women as problematic in the post-miscarriage period (Wong et al., 2003).

Within stillbirth care, parents have described the impact of systems which can be distressing, and interpersonal aspects of care provided by staff, with a mixture of positive reports and areas for improvement (Ellis et al., 2016). Psychological stress has been identified in those with a history of perinatal loss, with more severe distress associated with recurrent losses (Luo et al., 2023), and this can impact on future pregnancies, due to ongoing mental ill-health and the fear of another loss (Donegan et al., 2023). As well as the support of perinatal loss staff and existing support networks, a “miscarriage circle of care” provided by online peer supporters has been recommended (Alqassim et al., 2022). Moreover, a graded model of screening and maternity care for those experiencing recurrent loss has been proposed in recognition of this emotional toll (Coomarasamy et al., 2021).

To date, there has not been a detailed exploration of Autistic people’s perinatal loss experiences in the peer-reviewed literature. We found only one autoethnographic account of care for an ectopic pregnancy by an Autistic researcher, which identified challenges in the sensory environment and in staff communication (Grant, 2023; Grant, in press).

Methods

The research reported in this paper is part of a wider national cross sectional mixed method (quantitative and qualitative questions) online survey of Autistic people’s experiences of the maternity period, also including pregnancy, birth and infant feeding (Grant et al., 2023). This specific paper reports Autistic people’s experiences of healthcare for perinatal loss. A mixed method online survey was the most appropriate method for this study, since little research currently exists on this topic. A mixed method approach therefore allowed the identification of exact frequencies of participants behaviours and experiences using the quantitative data, with the qualitative data providing a more detailed and richer account of participants thoughts, feelings and behaviours (Greene and Caracelli, 1997).

Autistic community participation and researcher positionality

We received feedback on our planned research design from Autistic people with experience of pregnancy via a social media consultation ($n = 27$). Furthermore, two of the researchers **(AG and KW)** are Autistic, and two additional Autistic doctoral researchers (Rebecca Ellis and Hayley Morgan) reviewed the survey instrument for clarity. The two non-Autistic researchers were a health psychologist (CG) and a professor of child public health (AB**).**

Survey design

The anonymous cross sectional online survey was hosted on Qualtrics. Questions were divided into four parts: demographics (see Table 1); health care access challenges (see Table 2), use of aids to communicate needs related to Autism with healthcare providers (reported separately, see Grant et al., 2024), and maternity experiences. This fourth part was subdivided into chronological sections, with the first of these focused on perinatal loss. Survey participants were given the opportunity to opt out of seeing the questions related to perinatal loss, in recognition that the subject was sensitive. In the survey, we used the term "pregnancy loss", which we did not define. A mixture of open and closed questions were used. We adopted this approach to be able to understand participants' challenges in accessing healthcare and use of perinatal loss services in a quantifiable way, whilst also providing space to hear first-hand accounts as occurs in qualitative surveys. Open-text questions related to perinatal loss were:

- Please tell us about the factors that influenced your decision to contact a healthcare professional (during pregnancy loss).
- Would you like to add anything else about your experiences of pregnancy loss and healthcare for pregnancy loss?
- Do you have any recommendations for how healthcare services for pregnancy loss could be made better for Autistic people?

The closed questions can be seen in Table 2, alongside some additional questions reported throughout the results. A five-point Likert scale with a sixth option of "prefer not to say" was used for most of the closed questions, with scales ranging from "always" to "never" and "strongly agree" to "strongly disagree". Participants were told that they did not have to answer any questions that they did not want to.

Table 1
Demographic profile of perinatal loss participants.

Demographic	Sub-categories	Number – total $n = 67$ (%)*
Autism Diagnosis status at time of data collection	Diagnosed	32 (47.8 %)
	Undergoing diagnosis	17 (25.4 %)
	Self-identifying	18 (26.9 %)
Communication preference	Speaking	57 (85.1 %)
	Sign language	–
	Alternative and Augmentative Communication	1 (1.5 %)
	Other	8 (11.9 %)
	Prefer not to say	–
Age (years)	Mean (SD)	36.21 (8.76)
	Range	24 - 50
Gender identity	Cis woman	57 (85.1 %)
	Intersex	1 (1.5 %)
	Trans man	–
	Non-binary	5 (7.5 %)
	Other	2 (3.0 %)
	Prefer not to say	2 (3.0 %)
Ethnicity	White	61 (91.0 %)
	Mixed or multiple	3 (4.5 %)
	Asian or Asian British	1 (1.5 %)
	Black, African, Caribbean, or Black British	–
	Other	2 (3.0 %)
	Prefer not to say	–
Disability other than being Autistic	Yes	50 (74.6 %)
	No	16 (23.9 %)
	Prefer not to say	1 (1.5 %)
Disability impact	A lot	14 (20.9 %)
	A little	43 (64.2 %)
	Not at all	8 (11.9 %)
	Prefer not to say	2 (3.0 %)
Highest qualification	None	–
	General Certificate of Secondary Education (GCSE)	5 (7.5 %)
	A Levels	8 (11.9 %)
	National Vocational Qualification (NVQ)	13 (19.4 %)
	Undergraduate	21 (31.3 %)
	Masters	11 (16.4 %)
	PhD	7 (10.4 %)
	Other	2 (3.0 %)
	Prefer not to say	–
Location	England	47 (70.1 %)
	Scotland	5 (7.5 %)
	Wales	10 (14.9 %)
	Northern Ireland	5 (7.5 %)
	UK other	–

[*] percentages may not equal 100 % due to small amounts of "prefer not to say" and unanswered questions.

Participants and ethics

The survey was open from 10th February to 31st March 2022. Eligible participants were: Autistic, including those diagnosed, undergoing diagnosis, and those who self-identified as Autistic, over the age of 18 years, lived in the UK, and were or had previously been pregnant. The survey was advertised through the social media networks of the researchers, including Autistic UK, the Autistic-led organisation that KW represents, and through two Facebook groups focused on Autistic people who (i) breastfeed and (ii) are planning to become pregnant, pregnant, and parents. When the survey closed, ten participants who provided their contact details were randomly selected to receive a £20 Amazon gift voucher; personal information was removed prior to analysis. Participants were required to read a detailed information sheet before committing to complete the survey. All participants gave freely informed consent. The study received ethical approval from The School of Health and Social Care, Swansea University Research Ethics Committee (approval number: 280,122, 10th February 2022).

Data analysis

Participants who completed any questions related to pregnancy loss were included in the analysis.

Quantitative analysis

Descriptive statistics were generated in SPSS (version number: 28.0.1.1) by CG, with the aim of providing frequencies and percentages in relation to participants experiences reported in the closed questions. Kruskal-Wallis tests were also conducted on the quantitative questions to identify if there was any significant effect of participants being in different demographic groups (i.e. age groups, education level, ethnicity, and Autism diagnosis status) on the experience of perinatal loss. These questions were answered on a Likert scale which is ordinal data. Kruskal-Wallis tests are most appropriate when analysing the differences between groups of ordinal level data and therefore this analysis was selected. (Calver and Fletcher, 2020) The statistical analysis was overseen by AB.

Qualitative analysis

Questions with open text responses were subjected to a hybrid inductive/deductive thematic analysis (Fereday and Muir-Cochrane, 2006) by AG facilitated by NVivo vR, based around the themes of seeking care and experiences of care, with positive and negative inductive sub-codes developed under each of these deductive themes. In addition to this we generated inductive themes where they cut across deductive themes (Fereday and Muir-Cochrane, 2006). Whilst hybrid deductive/inductive analysis can involve double coding (typically in stage 2), we preferred to undertake regular team discussion between AG, KW and AB to:

Table 2
Healthcare accessibility.

	Always	Most of the time	About half of the time	Sometimes	Never	Prefer not to say/ unanswered
Masking Autistic behaviour (general; not exclusive to healthcare)	11 (16.4 %)	30 (44.8 %)	16 (23.9 %)	10 (14.9 %)	–	–
Awareness of pain/injury/discomfort	19 (28.4 %)	26 (38.8 %)	12 (17.9 %)	10 (14.9 %)	–	–
Delaying seeking treatment for recurrent issue	36 (53.7 %)	17 (25.4 %)	8 (11.9 %)	6 (9.0 %)	–	–
Feel anxious when telephone healthcare services	54 (80.6 %)	4 (6.0 %)	3 (4.5 %)	5 (7.5 %)	1 (1.5 %)	–
Delay making telephone calls to book healthcare appointments	33 (50.0 %)	20 (30.3 %)	4 (6.1 %)	7 (10.6 %)	2 (10.6 %)	–
Sensory environment of healthcare waiting rooms make me anxious	30 (44.9 %)	14 (20.9 %)	8 (11.9 %)	10 (14.9 %)	5 (7.5 %)	–
Other patients in healthcare waiting rooms make me anxious	27 (40.3 %)	19 (28.4 %)	6 (9.0 %)	9 (13.4 %)	6 (9.0 %)	–
Experience frustration or misunderstandings when communicating with healthcare professionals	13 (19.4 %)	19 (28.4 %)	13 (19.4 %)	19 (28.4 %)	2 (3.0 %)	1 (1.5 %)
Anxious about healthcare appointments	35 (53.0 %)	20 (30.3 %)	4 (6.1 %)	7 (10.6 %)	–	–
Mask Autistic communication style/behaviour in healthcare appointments	33 (49.3 %)	28 (41.8 %)	3 (4.5 %)	3 (4.5 %)	–	–
Difficulty describing pain	18 (26.9 %)	25 (37.3 %)	7 (10.4 %)	14 (20.9 %)	3 (4.5 %)	–
Difficulty understanding healthcare professionals (lengthy question/ instructions)	19 (28.4 %)	13 (19.4 %)	11 (16.4 %)	18 (26.9 %)	6 (9.0 %)	–
Communication skills reduced when emotional/distressed in healthcare appointment	40 (59.7 %)	16 (23.9 %)	6 (9.0 %)	5 (7.5 %)	–	
Sensory experiences within healthcare appointments are difficult	20 (29.9 %)	17 (25.4 %)	13 (19.4 %)	14 (20.9 %)	3 (4.5 %)	–
Confident describing physical symptoms	1 (1.5 %)	11 (16.4 %)	11 (16.4 %)	25 (37.3 %)	19 (28.4 %)	–
Lengthy instructions, e.g.: follow up appointments, are easy to understand	5 (7.5 %)	9 (13.4 %)	11 (16.4 %)	27 (40.3 %)	15 (22.4 %)	–
Manage to follow post-appointment instructions exactly	6 (9.0 %)	22 (32.8 %)	12 (17.9 %)	20 (29.9 %)	7 (10.4 %)	–

- discuss the development of the coding framework (stage 1),
- test the appropriateness of the coding (stage 2),
- summarise the data and identify initial themes (stage 3),
- apply the coding framework (undertaken by AG, stage 4),
- connect the codes and identify themes (stage 5), and
- validate the themes against the initial coding (stage 6).

The purpose of this analysis was to understand Autistic lived experiences of perinatal care.

Results

Below we present participant demographics and general healthcare access challenges using data from closed questions. We then report on seeking care and receiving care using data from closed and open questions together, from our deductive analysis. We then present a single inductive theme of trauma. Finally, we present participants' recommendations to improve care, which were generated from the deductive analysis. We have taken the decision to quantify the open text responses (eg: $n = 6$), in order to show how common that particular finding was in our relatively modest sample, which we believe may be valuable to those reading this article with a plan to undertake service improvement (Maxwell, 2010). Following each quotation, we provide demographic information to provide context. This includes age, which is presented in age ranges (eg: "aged 21–30″) to reduce recognisability. In relation to communication preferences, we use terms such as 'preferring to speak', referring to using verbal communication the majority of the time, and the use of Alternative and Augmentative Communication (AAC), which can include the use of Applications on mobile phones or tablets, or 'low tech' options like using cards with writing or images on, or writing in a notebook.

Demographics

Of the 193 survey participants, 30 said they would prefer to skip the questions on pregnancy loss. Over one-third of all survey respondents ($n = 67$, 34.7 %) reported that they had experienced a pregnancy loss. Almost three-quarters of participants were already diagnosed as Autistic (47.8 %) or currently undergoing diagnoses (25.4 %) (see Table 1). In general, our sample was privileged in relation to communication, gender, ethnicity, and education, with 58.1 % of participants being educated to undergraduate degree or above. However, three-quarters of participants reported that they were Disabled in relation to a condition not related to being Autistic, and this impacted on many of their lives.

A series of Kruskal-Wallis tests were conducted to identify whether responses to the demographic questions (age groups, education level, ethnicity, and autism diagnosis status) had any significant effect on the quantitative perinatal loss questions related to seeking care and experiences of that care. No significant results were identified, with all p values (which ranged from $p = 0.06 – 0.74$) being non-significant ($p > 0.05$). These results indicate that participants' age, education level, ethnicity or autism diagnosis status did not significantly affect their experiences of perinatal loss, and the seeking and experiencing of related care.

Participants were asked about their experiences of barriers to inclusion, with most participants ($n = 57$; 85.1 %) "masking" their Autistic communication or behaviour at least half of the time in all settings. We then asked a series of questions about participants' healthcare access challenges, specifically within healthcare settings. Table 2 shows that the majority of participants routinely struggled to access healthcare, felt anxious when trying to access healthcare, and struggled to effectively communicate with healthcare professionals during consultations. Most participants also noted routinely having reduced communication skills when emotional or distressed in appointments. Accessing healthcare by telephone was a particular source of anxiety, with over three-quarters always feeling anxious during these encounters, compared to just over half generally feeling anxious about healthcare appointments.

Seeking care for perinatal loss

Of the 67 participants reporting that they experienced perinatal loss, over half ($n = 39$; 58.2 %) sought support from a health care provider every time they experienced a pregnancy loss, with 9 (13.4 %) sometimes seeking support and almost a third ($n = 19$; 28.4 %) never seeking support. Decisions regarding whether to seek advice were discussed by 32 participants in the open text questions, which were divided into subthemes: three relating to why care was sought and four focused on why care wasn't sought.

First, a group of participants ($n = 6$) reported that their pregnancy loss was identified at a routine appointment, so the decision to seek help was not actively made. At this time, scans – including repeated scans for three participants – were often used to identify the absence of a foetus or foetal heartbeat. However, none of these participants reported that the care received was positive, including one participant who noted: "[I was] told it was probably a miscarriage like it was nothing. Things weren't really explained then [I was] told go home and it'll pass as I was so early." (Formally diagnosed, white woman, aged 31–40, with a BTEC level 3, primarily speaking but writes using email or WhatsApp when struggling). A second participant who had a missed miscarriage described how they felt the need to disengage with treatment, despite continuing to experience complications for six months:

"I had already been in contact with midwives to get booked in when I found out I was pregnant. I had several scans as they were not sure if the baby was growing even though a heartbeat couldn't be found. I suffered a missed miscarriage. I was advised by a midwife if I had a negative pregnancy test I wouldn't need surgery to remove the foetus. I pretended to have a negative test in order to avoid further medical appointment and continued to suffer the miscarriage alone over a period of 6 months ." (Formally diagnosed, white woman, aged 31–40 with an NVQ, who is primarily speaking but has her partner speak for her when stressed).

The second group of three participants felt that their symptoms were so severe that it was essential to seek care, including a "late loss at 23 weeks"; such severe blood loss that "I had actually thought I was going to bleed to death"; and passing a second placenta for a twin that had died in early pregnancy following birth. The third group of seven participants reported their experience of seeking help outside of a medical emergency context. Bleeding ($n = 4$), pain ($n = 1$) and a feeling that something "wasn't right" ($n = 1$), or that they may have miscarried ($n = 1$), led these participants to seek help. Three of the participants who reported bleeding noted that they had been told previously or by the NHS 111 helpline to urgently seek help because of bleeding, which influenced their decision.

Finally, the largest group of participants ($n = 10$) described that they did not seek help when they thought they were experiencing perinatal loss. Five of the participants described that it was "early" in their pregnancy. Two participants noted that they didn't think there would be any support available for perinatal loss, with one noting that their loss was early in pregnancy but that it was still "incredibly painful" and traumatic.

Three participants reported that they did not feel that the support available would be suitable for them, specifically due to clinicians' misunderstandings of Autistic communication. This included finding clinicians "hard to understand", a belief that they would be misunderstood, and a previous negative experience that put the participant off seeking support:

> "I felt belittled and ridiculed for being in pain. The miscarriage I had after [the one in which I had sought help] I had at home, [I] will never involve them unless [it's an] emergency." (Undergoing diagnosis at time of data collection, white woman aged 21–30, with an NVQ, who is primarily speaking).

The final participant who did not seek help was aware of reduced foetal movements and had been feeling increasingly unwell, but did not seek help immediately, instead waiting for around a week for their routine scan appointment:

> "Baby was discovered dead at 20 wk scan after lack of movement and growing anxiety that something was wrong and feeling physically more ill each day for a week." (Self-identifying white person who preferred not to provide a gender identity, aged 41–50 with an undergraduate degree, who is primarily speaking).

Receiving care for perinatal loss

Of the 48 participants who had sought support for perinatal loss on at least one occasion, only one person (2.1 %) had sometimes told health professionals that they were Autistic, with a further 20 people (41.7 %) never disclosing to staff that they were Autistic. Over half of participants who had sought healthcare support did not know they were Autistic at the time of seeking care for their perinatal loss ($n = 27$; 56.3 %). Of those who knew they were Autistic, only two (10 %) participants said that they had "sometimes" tried to communicate their needs around being Autistic at this time, with a further 18 (90.0 %) noting that they had never tried to communicate needs around being Autistic.

Four participants reported examples of good care by at least one person during treatment for perinatal loss, including receiving continuity of care, staff who "were very kind", "one doctor who was honest and pragmatic", as well as a midwife who allowed the participant to take a break during a painful procedure after the participant had "screamed" due to severe pain but was unable to speak to communicate her needs. All other participant comments about care during perinatal loss were negative.

These can be divided into communication with staff, the way support was provided, and the hospital environment. The way in which staff communicated with them or understood Autistic communication was described negatively by 18 participants. A frequent issue was not being given enough information and staff not understanding that it was important for Autistic people to understand what was happening and why. A lack of information or explanation was experienced by twelve participants, which was distressing, especially when the care was generally experienced as unsupportive. For example:

> "Not enough explained (especially about the difference between 1st and 2nd trimester loss), not made aware that my milk would come in after 2nd trimester loss, no extra pads and pain meds provided when requested, babies treated with indignity, no home comforts, no emotional support at all." (Undergoing diagnosis at the time of data collection, white woman, aged 31–40, with GCSEs who primarily communicates in writing).

Five participants noted that they had explicitly asked for more information but had not been provided with it; for example, one participant noted: "No one would answer my continuous questions." By contrast, during a scan to confirm perinatal loss, one participant felt that too much detail was described, which "triggered a meltdown".

Vague communication was reported by three participants, which may have been intended to be comforting but was confusing and upsetting, including leading to significant ongoing trauma and mental ill-health for one participant who was led to believe that her miscarriage was her fault:

> "I was 19 years old and afterwards my doctor told me it was probably a good thing that happened because I wasn't ready yet and my body knew I wasn't ready to raise a child. It took me 3 years to realise she was trying to comfort me. All I took from it was that my body wasn't physically capable and I shouldn't be a mother. I wasn't good enough

> to be a mother or emotionally stable enough. To start with I believed my body had killed my baby and I became suicidal and depressed believing that I was a murderer." (Formally diagnosed, white female, aged 21–30, with an undergraduate degree, who is primarily speaking).

A second example of vague communication leading to significant distress was in relation to not clearly telling the person that their baby had died and three weeks later mocking the Autistic person for the misunderstanding:

> "When I was examined and they said there was no heartbeat they were so subtle that I didn't quite get the message…. I was left in a room alone for 4 hours with no support…. I went home and spent 3 weeks until a follow up appointment praying my baby would be OK…. It wasn't explained to me that there was no chance of this in a way I understood…. When I went back for the second appointment they practically giggled at me for hoping my baby was OK….." (Formally diagnosed, white non-binary person, aged 41–50 with an undergraduate degree, who is primarily speaking).

In addition to communication style, staff attempts to provide comfort to Autistic people undergoing perinatal loss were sometimes experienced as inappropriate, including during an early pregnancy loss, focusing on the foetus as a "baby" or suggesting that the foetus was "in heaven". At other times, care was experienced as lacking in empathy:

> "I felt at the EPU (Early Pregnancy Unit) they could be quite cold. As in emotionless, as opposed to the staff on the maternity bit. They are quite matter of fact when they tell you and not overly compassionate." (Self-identifying, white woman aged 31–40 with A' Levels, who is primarily speaking).

Participants also described staff as treating them with "disdain and disrespect", providing "cold and clinical" care that was "scary and intense" with "no emotional support at all", and being "completely lacking in compassion", including not believing them and being "short with me… [finding] my questions a hassle". One specific example of poor care also included a lack of privacy:

> "My case was discussed by doctors in front of me and other patients in a corridor. It was cold and clinical and I was treated like an incubator not a person." (Formally diagnosed white agender person, aged 31–40 with an undergraduate degree who is primarily speaking).

In this context, participants' experiences of care for perinatal loss left them feeling "dismissed", "belittled and ridiculous", "invalidated, "a fraud, unimportant and heartbroken", "abandoned and alone", "traumatised", "confused and terrified" and "distressed". Six participants noted that they experienced a meltdown or shutdown. Being unable to speak while receiving healthcare for perinatal loss was reported by three participants:

"I received minimal care during my pregnancy losses. I did not receive any information about what was happening or why, I was not signposted to any support services. I was unable to speak or ask questions and because I didn't have the power inside to do this [...] I was not offered anything." (Undergoing diagnosis at the time of data collection, white woman, aged 41–50 with an NVQ, who is primarily speaking).

In addition to this, for seven participants, staff appeared to misunderstand Autistic pain presentations or not know how to respond to them:

> "I felt my pain was dismissed by the doctor who removed the remains of my baby from my womb, he was cold and distant and un empathetic…" (Formally diagnosed, white woman, aged 31–40 with A' Levels, who is primarily speaking).

Two particularly worrying issues were reported. First, a participant described how their ectopic pregnancy was initially dismissed:

"I had an ectopic pregnancy and found that the midwife I initially saw was very dismissive, didn't seem to believe that I was in pain, and the pain scale is something that I find quite difficult, but changed her attitude when they scanned me and realised I was bleeding internally." (Formally diagnosed, white woman, aged 31–40, with A' Levels who is primarily speaking).

Second, another participant, who was so overwhelmed that they struggled to speak when giving birth to their stillborn child, reported that medical decisions were made for them and that they were not believed when they had given birth due to a lack of pain cues that the clinicians understood:

> "My daughter was stillborn, I was so overwhelmed that situational mutism would take over and a lot of my decisions were made for me, because they were rushing. At one point, when I gave birth they didn't believe I had delivered due to the lack of pain I was exhibiting, till I shouted at them to look and moved the sheets off of me, it was a horrifying time." (Formally diagnosed, white woman, aged 21–30, with an undergraduate degree, who is primarily speaking).

In addition to this, one participant who had a private scan when they suspected that there may be something wrong with their baby was refused a second scan prior to surgery and did not have confidence that she was definitely miscarrying:

> "I wasn't offered a second scan by the NHS after referral for the missed miscarriage. I specifically asked for this as I hadn't seen it for myself and before proceeding with the surgical procedure I wanted to be sure [I was definitely miscarrying] but was told the private scanner was to be trusted and not second guessed." (Self-identifying, white woman, aged 41–50, with an undergraduate degree, who is primarily speaking).

In addition to challenges with staff and the care provided, four participants described challenges with the hospital environment. Three of these focused around sensory challenges, with one participant noting that: "staying in hospital can only be described as sensory hell… [causing] inevitable meltdowns", with another two participants commenting on the brightness of the lights in the hospital: "being sat in a painfully bright room for hours", with "bright lights especially if any is flickering". Another issue described by one participant was being "placed in a room with a lady celebrating her scan news, when I had just taken medication to trigger a miscarriage."

Trauma

The only inductive theme generated was that of perinatal loss, and in particular healthcare for perinatal loss, as traumatic. This was assigned to eighteen of the 67 participants, many of whom have had their experiences described as part of the deductive analysis above. One participant reported becoming suicidal following poor care for perinatal loss, in addition to the seven who reported experiencing meltdowns or shutdowns during care. A further participant noted that they would not seek healthcare for perinatal loss in the future, unless it was a medical emergency, to avoid further trauma.

Recommendations for improving care

Participants were asked an open question about their recommendations for improving care for perinatal loss for Autistic people. Participants recommendations were in line with the issues reported with the care they had experienced. Participants suggested: the use of clear and direct communication ($n = 8$); increased compassion ($n = 7$); better understanding of the needs of Autistic people ($n = 6$) and meeting those needs ($n = 6$), for example in relation to providing individualised care; always allowing a partner or supporter to attend appointments ($n = 2$); answering all questions ($n = 2$); improving the sensory environment ($n = 1$); and providing continuity of care ($n = 1$).

Discussion

Our paper reported on the perinatal loss experiences of 67 Autistic people from the UK. This topic had not previously been addressed in detail. Our study found that almost one-third of participants reported that they had never sought healthcare in relation to a perinatal loss, a phenomenon also seen among Autistic people in relation to primary healthcare (Doherty et al., 2022). This quantitative finding was explained in part by our qualitative findings: some participants did not seek care because of the perception that it was too early for any healthcare support or because they felt they would be treated badly because of being Autistic. This highlights that the stigma associated with perinatal loss (Boynton, 2019) may be compounded by the routine stigmatisation of Autistic people by health professionals (Corden et al., 2021), potentially contributing to increased health inequalities (Bishop-Fitzpatrick and Kind, 2017). Those who received care mostly did so because the loss was identified in a routine appointment or because they felt it was a medical emergency, showing that most participants did not actively choose to seek support. Untreated potentially life-threatening conditions, due to treatment barriers, have been identified outside of a maternity context for Autistic people (Doherty et al., 2022), as such, our findings are somewhat anticipated.

Most participants routinely found all healthcare inaccessible due to being Autistic, as has been identified in a recent systematic review (Mason et al., 2019), including finding their communication skills decreased when emotional or distressed, which is common in a general population during prenatal loss (Boynton, 2019). Most participants in our survey did not know that they were Autistic at the time of their perinatal loss, although of the 21 participants who knew they were Autistic only one person felt comfortable enough to share this with some – not all – health professionals, and only two people asked for accommodations. Reluctance to share an Autism diagnosis is rooted in, often well-founded, fears of being stigmatised according to the general Autism literature (Leedham et al., 2020), and we found this in our open text responses. Subsequently, it is unsurprising that care for perinatal loss appeared to be inaccessible and did not meet Autistic needs, with only four participants reporting some positive aspects of their care.

Participants frequently reported that staff communication did not meet their needs, as is well established in a general population receiving prenatal loss care (Petrou and Mcintosh, 2009; Helps et al., 2020). Staff were generally viewed as having negative views of the Autistic person, as has been found in a systematic review (Corden et al., 2021), and struggling to effectively communicate with Autistic people, as has been found in another systematic review (Mason et al., 2019). Our participants reported that staff communicated with them as though they were a problem, including failing to obtain consent from Autistic parents who had become non-speaking because of a “shutdown”. Shared decision making tools have been recommended for Autistic adults using mental health services to ensure that consent has been obtained (McVey et al., 2023), and these may also be of value in perinatal loss services. Further examples of unmet communication needs included refusing to answer questions and being unclear, with one instance leading the participant to incorrectly believe that their pregnancy was potentially still viable for an additional three weeks. Clear and direct communication are recommended to ensure Autistic adults can make informed decisions in a general healthcare context (Doherty et al., 2023). Unmet communication needs were attributed to a wide range of negative feelings among participants leading to the only overarching theme of “trauma” as has been found in a general population undergoing perinatal loss (Wong et al., 2003). Unsurprisingly in this context, some participants reported a reluctance to use perinatal loss services in the future, showing psychological distress which, again, has been found in a general population (Luo et al., 2023).

A finding not commonly reported in a general population is participants’ reports of pain being misunderstood by staff, leading to greater risk of them receiving inadequate analgesia. For seven participants, their pain was either misinterpreted or ignored by health professionals, adding to feelings of trauma, which has also been identified for Autistic people during birth (Morgan et al., 2024). Whilst other research on Autistic experiences, including pregnancy and birth care, has identified the sensory environment as a significant barrier to care (Sundelin et al., 2018) this was not frequently reported in our research. We believe that this is because most participants’ experience of the interpersonal aspects of healthcare was so negative that it was therefore the focus of open text responses. We would still advocate aiming to make healthcare spaces accessible to Autistic people in relation to sensory needs.

Implications for perinatal loss services

Some of our participants noted struggling to access care, or withdrawing from services that did not meet their needs, despite continuing to be symptomatic. This lack of accessibility could increase the risk of adverse (perinatal) outcomes, which have been associated with barriers to healthcare access in research on a general population of Autistic adults (Doherty et al., 2022). If an Autistic person suspects they are having a perinatal loss or that their baby’s pattern of movements has changed, they may not be able to describe their symptoms or answer questions as you might expect from a non-Autistic parent (Mason et al., 2019). Due to the known communication differences, we recommend they are offered appropriate testing at the earliest opportunity. The MBRAACE surveillance reports in the UK correlate both stillbirth and neonatal death with deprivation regardless of ethnicity, and thus Autistic people from lower income backgrounds may particularly be at increased risk (MBRRACE-UK 2024), and in need of appropriate testing.

Swanson’s theory of care, when applied to miscarriage care, provides a framework that we believe can usefully inform perinatal loss care for all, including Autistic parents. It notes that staff should provide understanding of events (Swanson, 1999). Our participants’ reports suggests that this wasn’t always present; in the most extreme example, the basic standard of ensuring that an Autistic person understood they were having a perinatal loss was not met. The use of a calm sensory environment during discussions about loss, alongside clear and direct language accompanied by written information can increase the likelihood of effective communication (Doherty et al., 2023). Furthermore, answering all questions asked will enhance understanding. This approach is also recommended in clinical guidelines for early pregnancy loss, such as NICE guidance in the UK (NICE 2019) and those in other high-income countries which specify the importance of clear communication (facilitating informed consent), support, and dignity when telling people their pregnancy is not viable.

Swanson’s care theory, as applied to miscarriage, goes further than these clinical guidelines in recommending staff be emotionally present, facilitate faith in being able to get through the loss and treat people experiencing loss as they would wish to be treated. Responses to our open text questions highlighted that most participants had not received this sort of care, with only one participant noting the staff supporting them were “very kind”, and the vast majority reporting negative experiences of care. Autistic people are not a homogeneous group, and those using perinatal loss services may have different preferences in relation to how much emotion they would prefer in their care. They may also be used to “masking” (hiding) their discomfort as standard, and thus may not tell you if they are in discomfort or pain (Pearson and Rose, 2021). As such, we recommend asking for parent preferences by using open questions, for example “is there anything I can do to make this easier for you?” Autistic people can also appear outwardly calm whilst in severe pain, and may struggle to use linear pain scales (Moore, 2015), so requests from Autistic people for additional pain relief during perinatal loss should be treated in this light.

Our study provided limited data from four participants in relation to stillbirth and no reports of neonatal death. Accordingly, the data did not allow us to compare these findings to general experiences, which emphasise the importance of staff communication and care practices

(Ellis et al., 2016). However, we believe that an open approach that asks Autistic people about their needs and preferences will ensure that care around stillbirth can be optimised. During any birth, Autistic people may go into "shutdown" where they are less able to communicate than they have been at other times (Quinn, 2021). Furthermore, a lack of support and pain relief during birth is known to result in Autistic people experiencing distress and trauma (Lewis et al., 2023). As such, health professionals providing support during a known stillbirth may wish to discuss pain and communication in the early stages of labour, to provide tailored support during active labour. We understand that there are likely to be service level barriers to providing this level of care in general, and that this may be exacerbated when caring for Autistic people who may need accommodations. (Ellis et al., 2023) Accordingly, perinatal loss services urgently need improvements, to be able to better provide this person-centred support.

More generally, we know that health professionals may lack understanding of Autism and hold dehumanising views of Autistic people (Corden et al., 2021). Providing neurodiversity affirming training to staff in perinatal loss services is likely to be of value if it can help staff better understand Autistic communication, expressions of pain, and sensory needs, improving their ability to empathise with Autistic people (Wong et al., 2003). Likewise, many Autistic people are drawn to caring professions (Shaw et al., 2023), and there may be Autistic nurses, midwives, doctors and students within your teams. Promoting a neurodiversity-affirming and inclusive environment will benefit those colleagues and may allow them to feel comfortable to share their neurotype (whether diagnosed or self-identifying).

Online peer support for those experiencing miscarriage has been recommended, to ensure a "circle of care" in addition to formal healthcare (Alqassim et al., 2022). Autistic people make extensive use of online spaces to network with each other, including proposing theories and solutions to issues faced by the community (Botha et al., 2024). As such, we agree that Autistic perinatal loss peer support may be of use. At the time of writing, there were a number of community-led closed Facebook groups providing maternity-related support for Autistic parents, and Autistic women groups may also offer less focused peer support. Models of parenting peer support for Autistic people have not yet been evaluated, but there is some evidence that Autistic adults may value well-supported models of peer support (Crompton et al., 2022).

Strengths and limitations

This paper is the first to specifically focus on Autistic experiences of perinatal loss. Moreover, this research was led by an Autistic researcher, had other Autistic input in the research team including via Autistic UK, an Autistic-led advocacy organisation, and was based on a consultation with the Autistic community. Furthermore, our study adopted a neurodiversity-affirming lens which aims to make society more accepting of neurodivergence. Our research involved an online survey where 67 participants reported on their experiences of perinatal loss. Through the use of open questions, we received detailed accounts of participants' experiences, but the online survey approach meant that we were unable to ask follow-up questions to gather more information. Moreover, we did not ask about when participants experienced perinatal loss, the gestation at which the baby died, and if they had experienced multiple losses or had a live birth since. Our sample were, in general, relatively privileged, with a very high proportion of participants being of white ethnicity, *cis* gender, and highly educated, except for a very high proportion of participants being Disabled by something in addition to being Autistic. The experiences of Autistic people who are more marginalised, including those with a lower education level and those who are non-speaking warrant further research. Furthermore, our sample size was relatively small, potentially contributing to our identifying no significant findings between demographics and perinatal loss experiences. Further research, using both qualitative and quantitative methods, should be undertaken to better understand this phenomenon.

Conclusion

Our research highlighted that Autistic people experienced many of the same negative experiences of care for perinatal loss as a general population of women. However, in addition to this, Autistic differences in communication, pain presentations, and to a lesser extent the sensory environment appeared to be misunderstood by health professionals. This led to additional barriers to receiving care, including adequate analgesia, and staff appearing to be unempathetic and using communication styles that did not meet Autistic needs. There is a need for neurodiversity-affirming Autism training to be provided to staff providing care for perinatal loss. To allow for a cultural change in perinatal loss care, however, the environment in which it is provided needs improvement, including ensuring adequate funding for perinatal loss staff and services within Early Pregnancy Units and maternity care, reducing variations in care regionally, and providing psychological support.

End notes

*We undertook a community consultation prior to undertaking this research and received a very strong and clear report that gender neutral language was preferred. As such, we use this language in our reporting of this article.

CRediT authorship contribution statement

Aimee Grant: Writing – review & editing, Writing – original draft, Project administration, Methodology, Funding acquisition, Formal analysis, Conceptualization. **Catrin Griffiths:** Writing – review & editing, Formal analysis. **Kathryn Williams:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Amy E. Brown:** Writing – review & editing, Supervision, Methodology, Funding acquisition, Conceptualization.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Aimee Grant is a non-executive director for Disability Wales. Kathryn Williams is a non-executive director for Autistic UK.

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