Exploring the Birth Stories of Women on the Autism Spectrum

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Precis	Birth stories of autistic women were characterized by an uncaring approach by clinicians and sensory overload, which often led to discomfort and trauma.

Abstract

Objective: To explore birth stories of autistic women to understand how they make sense of the experience of childbirth.

Design: Narrative analysis.

Setting: Online interviews.

Participants: Sixteen women on the autism spectrum shared 19 birth stories.

Methods: Women were recruited from online autism forums and were invited to share their birth stories via online asynchronous interviews. Using Burke's approach to narrative analysis, we identified five elements within each story, including Scene (when/where), Agents (who), Act (what), Agency (how), and Purpose (why). We explored parts of the narratives where two or more elements were out of balance with each other.

Results: Tension most often occurred when actions taken by the health care team (Act) were out of balance with their approach to care (Agency), which left participants feeling that their concerns were minimized, their wishes were ignored, and they were left out of critical communication and education. Participants also struggled when their own autistic traits (Agent), such as sensory sensitivities, were out of balance with the birth environment (Scene), which impaired their ability to communicate with providers and participate in the birth.

Conclusion: Poor communication, untreated pain, and sensory overload dominated the birth narratives of participants. Nurses should trust women's reports of pain and anxiety because autistic women may appear calm even when in severe distress. Environmental adjustments, such as dimming the lights, can help minimize sensory overload. Nurses need to provide thorough and nonjudgmental education about the birth process to ensure that autistic women feel safe and in control and do not withdraw from care.

Keywords

autism spectrum disorder; childbirth; birth, obstetric; narrative analysis; parturition; pregnancy; qualitative research

Precis

Birth stories of autistic women were characterized by an uncaring approach by clinicians and sensory overload, which often led to discomfort and trauma.

Callouts

1. Results of previous studies indicate that autistic women frequently experience adverse outcomes in maternity care, but little is known about how they construct their birth stories.
2. Participants' birth stories were characterized by an uncaring approach and an overwhelming environment that left them feeling dismissed, overwhelmed, and traumatized.
3. Nurses need to create a nonjudgmental space where autistic women feel believed and safe during childbirth.

With increasing calls to address systemic inequities in health care (Trego, 2020), nurses must recognize the need to support the unique needs of neurologically diverse individuals as an important aspect of promoting equity and inclusion among those experiencing childbirth. Autism is a developmental condition that affects one in 54 individuals (Maenner, 2020) and affects social interaction, communication, and behavior (American Psychiatric Association, 2013). A lifelong condition, autism occurs on a spectrum and attributes are diverse in expression. For example, autistic individuals may be nonverbal, have intellectual disabilities, or require assistance in activities of daily living, while others may not. Many autistic individuals maintain employment, live independently, and engage in intimate relationships (Howlin, 2021). In this article, we use identity-first language (autistic person) instead of person-first language (person with autism) based on preferences expressed by some autistic individuals (Botha et al., 2021). We refer to autism as a difference rather than as a disorder because these individuals often benefit from intervention and support but also have inherent strengths related to autism that should not be ignored.

Autism is more common in men than women, but growing evidence indicates that women are frequently under-diagnosed, and an increasing number of women are discovering autism identities in adulthood (Hull et al., 2020). Little is known about how these women experience childbirth, which can be complicated by autistic traits. For example, autistic individuals often experience differences in executive functioning, such as difficulty making decisions, taking time to process thoughts, or experiencing stress when faced with unexpected changes in routine (Autistic Self Advocacy Network [ASAN], n.d.). Autistic individuals are often hypersensitive to sensory stimuli, may be uncomfortable with physical contact, and may experience and express pain differently from others. They may also have difficulty interpreting behaviors of others.

Further, many autistic individuals cope with stress by using scripted communication, and others may become nonverbal or lose control of their bodies in response to stress (ASAN, n.d.).

Autistic individuals experience many barriers that limit access to adequate health care, which increases the risk for physical and mental health conditions and premature mortality. For example, in a systematic review, Mason et al. (2019) identified significant barriers to accessing physical healthcare services for autistic individuals, including communication challenges between patients and providers, sensory overload from the health care environment, and issues related to understanding information such as memory and processing speed during appointments. In a systematic review of barriers to accessing mental health care services, Adams and Young (2020) further identified challenges related to lack of provider knowledge about autism and inflexible practices not tailored to meet the needs of autistic individuals. As a result of these challenges, autistic individuals are significantly more likely than non-autistic individuals to have unmet health care needs, lower health care self-efficacy (Nicolaidis, 2013), and increased anxiety while accessing health care services (Lum, 2014).

Studies indicate that autistic individuals experience similar challenges in the maternity care setting. For example, in a nationwide population-based cohort study in Sweden, autistic women were at increased risk of adverse pregnancy outcomes, including medically indicated preterm birth, elective cesarean, preeclampsia, low Apgar score, large for gestational age newborn, gestational diabetes, and stillbirth compared to those who were not diagnosed with autism (Sundelin et al., 2018). Pohl et al. (2020) conducted an online survey study of 487 both autistic and non-autistic mothers of autistic children and found that compared to non-autistic women, autistic women were more likely to self-report experiencing pre- and postpartum depression. In another online survey of 58 adult autistic women, respondents reported that

information and support services during pregnancy were less likely to meet their needs, and communication of pain during childbirth was more likely to be a problem when compared to non-autistic women (Lum et al., 2014).

Given these negative outcomes, further exploration into how autistic women perceive their childbirth experiences is warranted, and only three such qualitative studies exist. Gardner et al. (2016) conducted a secondary thematic analysis on the experiences of eight autistic women during pregnancy, childbirth, and the postpartum period. Participants reported difficulties processing sensations and heightened sensory sensitivities across all periods. Participants shared concerns related to bothersome lights, sounds, and smells during birth. They also described a lack of control that led to disorientation and trauma. As new parents, participants described "walking in the dark" as they struggled to understand their newborns' needs and connect with them emotionally. They also felt judged by friends and health care providers as they attempted to navigate new motherhood.

Rogers et al. (2017) conducted a case study on one autistic woman's experiences during pregnancy through early parenthood in Australia. She described communication challenges with health care workers and often felt that her needs were ignored. She described feeling like she was treated as an inanimate object and as a joke. She also struggled with sensory stress, including hallucinations and extreme sensitivity to touch during pregnancy and birth. In the postpartum period, she described feeling judged and being treated as an incompetent parent by health care workers because of her autism.

Donovan (2020) interviewed 24 women from the United States, United Kingdom, and Australia who gave birth to full-term neonates in acute care settings without complications. Participants in this study reported difficulty communicating how they felt and what they needed,

and they particularly struggled to communicate their pain, which often led to under treatment. Some reported that they relied on scripted phrases they learned from watching television, and others "shutdown" and became unable to speak. Many felt that they were ignored and that their concerns were disregarded or misinterpreted. Participants also shared difficulty understanding information during birth and reported that they did not have enough time to process what was said.

Across these three studies, sensory and communication challenges were pervasive. Existing research results indicate a high incidence of postpartum depression among autistic women (Pohl, 2020), and these women reported concerns about bonding with newborns, emotionally adjusting to parenthood, and understanding their child's emotions (Gardner, 2016). Given that these experiences mirror the known lasting effects of births that are perceived as traumatic, such as detachment from infants, cognitive changes, and intense negative emotions (Beck & Watson, 2019; Fenech & Thompson, 2014), it is critical for nurses to understand how autistic women construct their birth narratives. Therefore, the purpose of our study was to explore birth stories of autistic women to understand how they make sense of the experience of childbirth.

Methods

Design

Narrative analysis is an approach to analyzing stories or narratives. A narrative of personal experience refers to the story of an experience that has earned its place as part of the life story of the speaker and that carries some emotional connection for the speaker beyond a simple recounting of an observation (Labov, 1997). In this method, researchers collect personal narratives from participants, often through interviews or in writing, that are used as data. These

narratives are representations of a constructed reality because they are inherently influenced by factors including the speaker's culture, imagination, history, and identity. Thus, the purpose of narrative analysis "is to see how respondents in interviews impose order on the flow of experience to make sense of events and actions in their lives" (Reissman, 1993, p. 1-2). We aim to understand not only the story itself, but also why the story was told in this particular way. In this study, we used a narrative method to understand the constructed meanings of autistic women's birth stories. A university institutional review board approved this study.

Setting & Participants

We recruited a convenience sample via online groups related to autism, such as groups on Facebook and Reddit. Data were collected via asynchronous online interviews using LimeSurvey, a secure survey platform. We opted to conduct interviews in writing via online surveys rather than video or telephone interviews based on the reported communication preferences of autistic individuals (Gillespie-Lynch et al., 2014). This approach allowed participants to take their time in responding to questions without the added social pressures of real-time communication, which can decrease anxiety, increase feelings of control over communication, and increase comprehension among autistic individuals.

Women were eligible to participate if they were 18 years or older, self-identified as autistic, and experienced childbirth. We opted to include women who were self-diagnosed as autistic because evidence shows that women are frequently under-diagnosed in childhood, and formal diagnosis can be difficult to obtain in adulthood (Hull et al., 2020; Lewis, 2017). We did not set parameters on the length of time since the birth occurred because of noted issues with recruitment in previous studies (Donovan, 2020; Rogers et al., 2017). We continued recruiting new participants until we reached data saturation, i.e., when stories became repetitive and no new

ratio imbalances emerged in our analysis.

Procedures

The first author (L.F.F.) obtained permission from group moderators and posted recruitment notices, and women who were interested in participating were directed to the study website. This website included an information sheet, two screening questions to self-report that inclusion criteria were met, and initial interview questions. Participants were notified that they could stop participation at any time and were encouraged to stop participation and seek support if they became distressed. We provided a list of support organizations at the start and end of the survey.

In initial interview questions, we asked participants to share their birth stories. After reading initial responses, we created individualized surveys for each participant containing clarifying and probing questions and emailed these unique survey links to each participant for follow-up. We repeated this process until we felt confident that we captured the meaning of the story for the speaker. Table 1 includes examples of interview questions. Data collection lasted 9 months.

Data Analysis

We used Burke's (1945) narrative method for data analysis. Burke (1945) identified five elements of a story (act, scene, agent, agency, and purpose), called the dramatistic pentad, defined in Table 2. By looking at the interactions and relationships between these elements, we can use the pentad to identify "what people are doing and why they are doing it" (Burke, 1945, p. x).

In Burke's framework, we look at pairs of elements of the dramatistic pentad together as ratios, such as Agent:Purpose or Scene:Agency. Each ratio, of which Burke offers at least 10

combinations, creates a different lens for the story. Burke (1966) contends that, by nature of telling a story, a speaker filters the story through their own lens as they select the aspects of reality they wish to reflect and deflect:

> We must use terministic screens, since we can't say anything without the use of terms; whatever terms we use, they necessarily constitute a corresponding kind of screen; and any such screen necessarily directs the attention to one field rather than another. (p. 50)

By applying the pentadic ratios as alternative terministic screens to viewing the same story, we can reveal the messy nature human interactions and identify areas where ambiguity arises.

Burke focuses particularly on areas where elements of the pentadic ratio are out of balance with each other, which can be used to uncover tension and drama within the narrative. Bruner (2004) added the concept of "Trouble" to Burke's framework to further highlight these imbalances. Rather than a sixth component to the pentad, "Trouble is what drives the drama, and it is generated by a mismatch between two or more of the five constituents of Burke's pentad" (Bruner, 2004, p. 697). In other words, Trouble is tension between elements of the story based on what is culturally and situationally appropriate. For example, while it is typical to wear shorts and a t-shirt (Act) on a summer day (Scene), wearing the same outfit in the snow could lead to tension in the story due to an imbalance in the Act:Scene ratio. Likewise, it is acceptable for infants (Agent) to cry when they are hungry (Act), but this same reaction in an adult could lead to tension due to an Agent:Act ratio imbalance.

In our analysis, we read each narrative as a whole, then divided each into scenes within the story, similar to acts in a theatrical play. For each scene, we identified the five components of the dramatistic pentad, then examined those elements for areas of Trouble in which any two elements were misaligned, which created tension within the story. Figure 1 illustrates examples

of our analysis. In Rosalyn's story, the driving tension occurred because a participant with heightened sensory sensitivities (Agent) was in an overstimulating environment (Scene). This tension may have been resolved if the environment was modified to meet Rosalyn's needs. In Claire's story, the tension was driven by the approach that the nurse used (Agency) while performing a presumably necessary cervical exam (Act). Had the nurse explained the importance of this procedure or if Claire perceived that she was being treated with dignity and respect, she may have constructed this scene differently and the tension may have been avoided.

Trustworthiness

We used Lincoln and Guba's (1985) criteria, including credibility, transferability, dependability, and confirmability to establish trustworthiness. To enhance credibility, we shared our interpretations of each story with the speaker and invited her feedback. Four participants responded, and all indicated that our findings captured the meanings of their stories well and did not recommend any changes. We also paid careful attention to scenes that lacked tension, when the elements of the birth story appeared to be in balance, to illuminate how these scenes differed from those with Trouble and to capture the breadth of experiences rather than focusing only on negative outcomes. To establish transferability, we used thick description of findings by sharing rich examples of participants' quotes from diverse perspectives. Our participants came from five countries and were various ages. They had cesarean and vaginal births, hospital and home births, and various support systems at the time of birth.

A nurse-midwife and a doctorally-prepared registered nurse with extensive experience in maternity care reviewed an audit trail of raw data and findings to establish dependability. These content experts shared that many of our findings were consistent with the birth stories of non-autistic women, which helped us highlight those that were unique to our population of interest.

Their feedback also informed our discussion of clinical implications. To establish confirmability, two authors (H.S. & H.S.) analyzed each narrative independently and then discussed their findings with all authors to consider multiple ways of viewing data and illuminating blind spots. We also maintained reflexive journals throughout the research process to identify the influence of personal thoughts and feelings on our interpretations of data.

Results

Sample

Sixteen self-identified autistic women participated in this study, and two participants shared multiple birth stories, which resulted in a total of 19 birth narratives. Participants ranged in age from 21 to 57 years at time of participation (M = 37.6), and age at time of birth ranged from 19 to 41 years (M = 27.1). Length of time since the birth occurred ranged from 6 months to 26 years (M = 11.0). All participants identified as women and most were White (87.5%). Most participants were from the United States (37.5%), United Kingdom (37.5%), and New Zealand (12.5%). Five participants were aware that they were autistic at time of the birth, and of those, two did not disclose this fact to their health care teams. The remaining 11 participants became aware that they were autistic sometime after giving birth. Most participants described their first birth experiences (73.7%) and most were vaginal births (73.7%).

Through the 19 birth narratives, the participants described 50 scenes. Of these 50 scenes, 31 included an imbalance in the Act:Agency ratio and 15 included an imbalance in the Scene:Agent ratio. Ratio imbalances are illustrated with evidence from representative narrative accounts below using pseudonyms to protect participant privacy.

Act:Agency Imbalances

The most frequent cause of Trouble was an imbalance between an action that was taken

by nurses or other health care providers (Act) and the way that action was carried out (Agency). The actions, comments, and tone of the members of the health care team were commonly perceived as uncaring and left participants feeling that their experiences were minimized, their wishes were ignored, and that they were deprived of critical education and communication by those involved in their care.

Several participants felt that they were in labor and needed to be admitted to the hospital or that labor had progressed, and they needed to be examined. However, they shared that their concerns were dismissed by the members of the health care team, which left them feeling invalidated:

> They seemed to think I was making a fuss over nothing… I felt like they did not believe me about how I was feeling, but I couldn't express it in any other way…I felt that they thought I was being over dramatic as a first time mother, even though I was not outwardly expressing that. In hindsight, I was also appearing fairly calm on the surface in an attempt to remain focused. This is something that often happens when I am in pain.

Others also shared that their complaints of pain were minimized or ignored by the members of the health care team. During Hallie's third birth, she reported that her anesthesia wore off moments after her newborn was born via cesarean:

> No-one but [my partner] believed me because I didn't scream and cry. I did keep explaining to the surgeon and anesthetist exactly what I could feel happening but they kept insisting that it was all in my imagination and if I could really feel it I wouldn't be able to lay there talking to them I would be screaming, they kept insisting that until my blood pressure started to go through the roof. I passed out from the pain and when I came to they were panicking and had a mask over my face giving me a general anesthetic.

Hallie eventually reported that she left the hospital against medical advice: “As soon as I could walk I booked myself out because I didn’t feel safe since no one listened to me.”

Many participants felt their wishes for their plans of care were ignored. Some described enduring procedures that they did not want without their consent, such as cervical exams, membrane sweeping, rupture of membranes, or cord cutting. Others reported being touched in uncomfortable ways that evoked negative emotions without warning. For example, Lucinda explained that early in her labor, clinicians ignored her requests to be examined and minimized her reports of pain, which led to a mistrust in her health care team that affected her comfort with touch during the birth. When it became medically necessary to rupture her membranes, she said:

> I did not want these people who clearly were not taking me seriously to touch me and violate my space because I did not trust them at this point to listen to me if I became uncomfortable…I just felt extremely powerless and as though my wishes had been ignored, and my emotions and feelings belittled.

Lucinda’s negative experience had a lasting effect and created ongoing challenges with sexual intimacy and standard women’s health care: “I cannot tolerate the idea of somebody being near me in that way. It does have to be said that this fear is much more prominent around medical staff since my labor experience.” Others described feeling “violated” and “powerless.”

Most participants felt there was significant miscommunication during labor and often reported that they did not understand why certain actions were taken. For instance, Rebekah shared that she felt left out of communication regarding the birth:

> Everyone was just coming up and doing things to me and talking around and over me and I truly think it would have been terrifying and overwhelming if my mother (who is also a nurse) had not been there and sort of took over…I really feel that autistic women need

> extra care and additional supports when in the hospital or when accessing health care. Too often providers are rushed, talking quickly, and it can be overwhelming and we can lose the ability to speak up and self-advocate or share really important clinical information.

Some participants also shared that members of their health care teams made jokes that they found to be hurtful, offensive, or in poor judgment. Claire shared that "the nurses made fun of [her]" when she asked for anxiety medications, and others described nurses "laughing" during times that they perceived as serious or frightening. This left participants feeling "unsupported" and had lasting effects. For example, as Claire concluded her birth story, she wrote:

> For the better part of the last 2 years I've had a lot of anxiety and pent up feelings about my birth experience but have recently started to work through them. I can now drive past the hospital I delivered at without feeling angry and anxious and that's huge for me.

Scene:Agent Imbalances

The second most common cause of Trouble was an imbalance between the environment where the birth occurred (Scene) and the characteristics of the individual giving birth (Agent); this Trouble was often related to autistic traits. Participants reported that sensory experiences related to birth, such as sights, sounds, smells, pressure, and temperature, exacerbated existing sensory hypersensitivities and led to discomfort, dissociation, and trauma.

Several participants described experiencing such intense sensory stimulation that they dissociated during the birth, which significantly affected their ability to communicate with health care team members and to participate in labor:

> It was a complete sensory overload situation from the noise and lights to the pressure. I became non-verbal under the stress…I found myself so overwhelmed that I could not

speak to tell anyone how much pain I was in or to ask for help.

Rosalyn also shared that she felt "overstimulated." As a result, she struggled to communicate with her care providers and stated, "I made up answers to the questions because I had no idea. I said the right things at the wrong time, following the script." Rosalyn refers to a common coping mechanism in autism (ASAN, n.d.) in which she relied on common phrases that she learned and rehearsed rather than sharing her own thoughts with her health care team.

The effect of the sensory stimuli on the birth experience is perhaps best illustrated in Roseann's story. Roseann had an emergency cesarean and described her birth as "traumatizing" and an experience she will "always remember with great clarity":

> If you can imagine the most frightening, dreadful, and absolutely helpless feeling of being pinned to a small, cold table while you watch a group of people you've never met before assist your doctor in cutting open your flesh and watching them peel back your muscle and fat and continue to cut further past the uterine lining. I watched the whole procedure like a movie in the large, mirrored light that hung from the ceiling above my head. I couldn't look away. I was frigid, freezing and slipping in and out of consciousness. I remember holding a nurse's hand on my right and my boyfriend's on my left. I remember aggressively forcing back the vomit and I tried, and failed, to form words and ask for a barf pail. I think the perception and lived experience of my son's birth was definitely made worse by [autism], specifically sensory processing difficulties. The cut of the scalpel, the touch of the doctor's cold hands, the noises I kept hearing…In short, it was like a no good, worst case version of what every day is like living on the [autism] spectrum with ridiculous sensory sensitivities.

This event had lasting effects on her memory of the birth and initial bonding with her son:

> When I think back to the memories of his birth, it almost rips my heart out because after I had been stitched up and sent out the recovery area, I distinctly remember not wanting to touch, hold, or even look at my baby. Not because I didn't love him or want to hold him, but I was so disgusted at the events that had just played out in the room.

Maintaining Balance

Some participants shared that members of their health care teams were helpful in adjusting the environment to meet their sensory needs in ways that enhanced their birth experiences and outcomes. For example, two participants shared that using a bath helped them manage sensory sensitivities and pain. Priscilla shared, “I spent a lot of time in the heated birthing bath as it was very warm and I’m sensitive to cold.” Others appreciated limiting social stimuli by being “left alone” during labor, and two shared that they benefited from giving birth at home, which limited unfamiliar smells, sounds, and “social pressure.”

Discussion

Throughout the personal narratives collected in this study, participants indicated that the way they were treated by health care team members (Agency) as well as the social and sensory stimuli in the birthing environment (Scene) were most influential in shaping their birth stories. Participants felt minimized and ignored by nurses, which is consistent with the findings from previous qualitative studies on birth experiences of autistic women (Donovan, 2020; Rogers et al., 2017). Our findings also supported previous studies that showed that sensory overload during labor led to dissociation and becoming nonverbal (Donovan, 2020; Gardner et al., 2016; Rogers et al., 2017). Our results added to previous literature by connecting these pieces and highlighting that autistic women often struggled to explain what they were thinking and feeling (e.g., unable to explain a different way, becoming nonverbal, relying on scripted communication) because of

sensory overload, which contributed to their concerns being dismissed.

Our participants also shared that they often felt they were not believed because their demeanors were calm and subtle even when they were in distress. This finding sheds light on previous studies in which pain was often poorly communicated and undertreated among autistic women during birth (Donovan, 2020; Gardner et al., 2016; Lum et al., 2014). Our results emphasize the importance of listening to and validating these women to ensure safety because participants who felt invalidated shared that they lost trust in the health care team, refused medically necessary procedures, and left the hospital against medical advice.

Our participants in our study also reported that they frequently did not understand why certain actions were taken during the birth. This finding confirmed previous findings that autistic individuals often struggle with information processing during health appointments (Mason et al., 2019) and feel under informed about childbirth (Donovan, 2020; Pohl et al., 2020). Our participants benefitted from slow and repeated communication in which small amounts of information were presented at a time; this allowed them time to process and respond.

Our findings were consistent with those of previous researchers who reported that autistic women struggled to bond with their newborns (Gardner et al., 2016). However, in our study, participants associated this delayed bonding with birth experiences they described as "traumatic" rather than with their autistic traits. Thus, we need to consider whether these early parenting outcomes are a direct result of autism or whether they reflect an increased prevalence of birth trauma among autistic women. This differentiation should be explored in future research as well as ways to reduce birth trauma among autistic women as a potential means to improve bonding and mental health among autistic women after childbirth.

Implications for Practice

Several modifications to practice are indicated for maternity care providers who work with autistic women. First, it is notable that two of the five participants who were aware of their autism at the time they gave birth did not disclose their diagnoses to their health care teams. Thompson-Hodgetts et al. (2020) reported that autistic individuals frequently do not disclose their diagnoses because they fear stigma and discrimination. Autistic women in particular may fear they will be seen as unfit parents (Gardner et al., 2016; Rogers et al., 2017). The use of a universal screening tool, not only for autism but also for sensory sensitivity and other mental health conditions, is warranted as a standard component of antepartum care. Nurses may encourage disclosure by using a nonjudgmental tone and assuring women that they will be safe in sharing diagnoses or suspected diagnoses of autism.

Participants in our study shared overwhelming feelings of anxiety, fear, and pain that were frequently dismissed by nurses. Nurses need to be aware that autistic individuals may express pain atypically and often remain silent without a change in facial expression (ASAN, n.d.). Autistic women also tend to internalize their emotions, especially as they attempt to mirror the behaviors of those around them, which often leads to physical and emotional exhaustion (Hull et al., 2020). Nurses need to recognize that subtle cues of anxiety and pain in this population may be indicative of more severe distress and should be mindful to trust the woman's report of pain, regardless of nonverbal cues.

Detailed education related to birth plans may also help autistic women prepare for labor. Pohl et al. (2020) found that autistic women were less likely than non-autistic women to feel that birth was adequately explained to them even those who attended antenatal birth classes. Given the communication challenges identified in our study, future research should explore the effect of antepartum childbirth classes tailored to autistic individuals to provide realistic education about

what to expect. Providers should also recognize that autistic individuals may struggle to anticipate or respond to unexpected changes (ASAN, n.d.) and should assess common coping mechanisms that these individuals use in times of stress and consider ways to incorporate those strategies into the birth plan. Utilizing a tool such as the My Health Passport, developed by the National Autistic Society (2020), may help in planning for optimal communication, environmental modifications, and pain management during labor.

Nurses also need to be mindful to limit sensory and social stressors when working with this population. Participants shared that turning down lights, using warm baths, being asked for permission to be touched, limiting the number of people in the room, minimizing unnecessary social contact during labor, and giving birth at home were helpful techniques to improve the birth environment. Several participants shared that it was helpful to have a designated support person during labor, particularly if they became nonverbal. Partners or specialized support persons, such as doulas who are trained in autism, may serve as protectors. Protectors might advocate by reminding nurses of the woman's needs, such as, "Please ask before touching her," or "Please communicate what you need to do and why in simple terms," or by reinforcing the woman's preferences for birth, such as, "She would like to give birth in this position. It is important to her. Is it the time to get into that position now?"

Nurses should also be mindful that dry humor and sarcasm are often taken literally by individuals on the autism spectrum and may be perceived as offensive or cruel (ASAN, n.d.; Donovan, 2020). When working with this population, nurses should avoid humor and remain straight forward with a clear intent to support and encourage the woman during labor.

Finally, it is notable that most of our participants were not aware that they were autistic until after they gave birth, and they described experiences that may be considered traumatic even

outside of autism. Maternity care providers should recognize the immediate hours after birth as a critical window in which the woman constructs her birth narrative. For all women, team members involved in the birth should prioritize discussing the birth with the woman to help her reconstruct her birth story by answering questions, clarifying concerns, and filling in gaps. This might help women understand what actions were taken and why and allow them to manage feelings of lost control and uncaring that dominated these birth stories.

Limitations

This study had several limitations. Since participation occurred online, this sample was limited to those with the financial, physical, and cognitive resources to use a computer. We were also unable to perceive non-verbal communication such as body language, silence, and tone since stories were submitted in writing. Participants were predominantly White women, which limits transferability to non-White and non-cis-gendered individuals. We did not explore trends related to differences in culture or health care systems across the countries of participation or about differences in providers (e.g., midwives vs. physicians, provider gender). In addition, we did not evaluate or confirm that participants met criteria for an autism diagnosis beyond self-report, and five participants were self-diagnosed only. Participant narratives may also be affected by recall, particularly as two participants shared stories that occurred more than 20 years ago. However, this indicates the lasting effect of these experiences on participants, which is also consistent with previous literature on birth trauma (Beck & Watson, 2019).

Conclusion

Autistic women experience unique challenges during childbirth that may contribute to the perception of traumatic birth. Participants often felt belittled, ignored, and uninformed about care they received, which was complicated by autistic traits that affected their ability to express

themselves and process information under the stress of childbirth. They also commonly struggled with poor pain management and sensory overload that inhibited their ability to communicate and to be mentally present during birth and the early postpartum period. Modifications to the approach (Agency) and environment (Scene) within clinical practice are indicated, including detailed antepartum education that addresses potential uncertainties in care, recognizing and managing subtle signs of anxiety and pain, and reducing sensory stimuli in the care environment. Such interventions may be effective in restoring balance and allowing these women to find positive meaning in their birth stories.

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Table 1

Examples of Interview Questions

Initial Interview Question

- Please tell us your story of labor and childbirth from beginning to end. You can start and end this story wherever it makes most sense for you. Please share any thoughts, feelings, words, and emotions that come to mind in as much detail as possible. We are interested in any aspects of your story that are most important to you.

Examples of Individualized Follow-Up Questions

- In your previous response, you shared that your labor was "very long and difficult." Can you tell us more about this? How were you *feeling* during this time? What was this like for you?
- In your previous response, you mentioned that you "didn't like" one of the midwives on your team. Can you tell us more about this? What influenced your experience with this midwife?
- In your previous response, you mentioned how the nurse "was certain [you were] making a fuss over nothing" when you first arrived to the hospital. Can you tell us more about this and what made you feel that way?

Table 2

Burke's Dramatistic Pentad

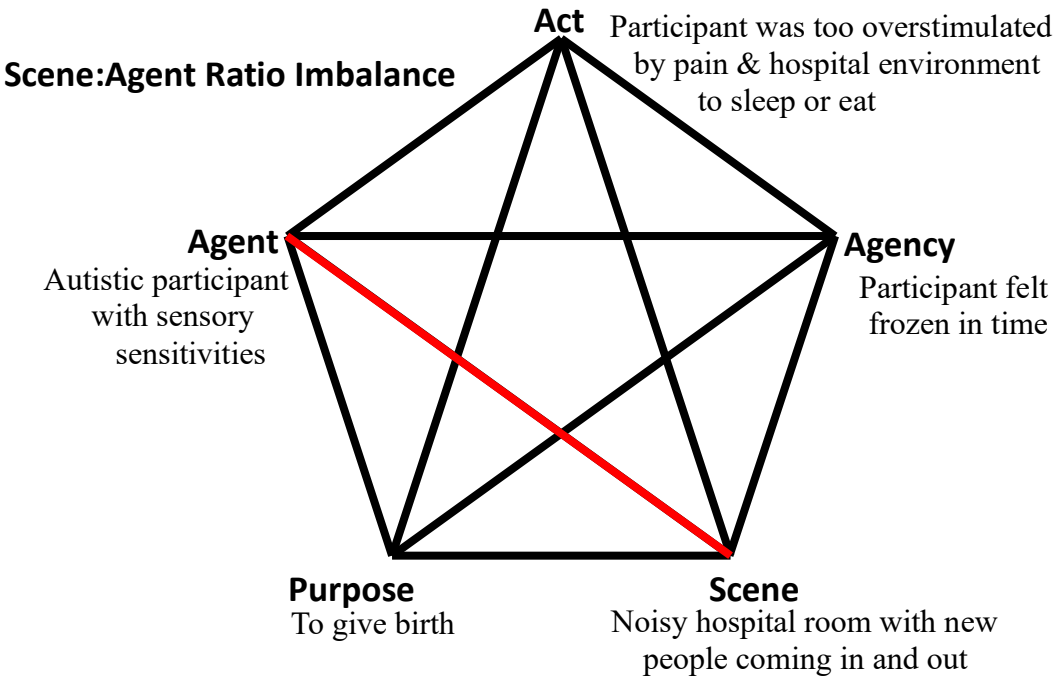
Element of the Story	Definition
Act	What happened, in thought or deed
Scene	The background or situation in which the act occurred
Agent	Who is performing the act
Agency	The means or approach to performing the act
Purpose	Why the act occurred

Figure 1

Examples of Narrative Analysis

Example 1: Rosalyn's Birth Story, Scene 2

"I had pethidine that night to help me sleep, but I couldn't sleep at all in the hospital. I was so over stimulated. … The next day by evening I was exhausted and a wreck. There were so many new people coming in and out of my room. I had an epidural placed. I had taken a day and a half just to get to 3 cm dilated and have my water broken. I was continually told my cervix was very hard to reach and very stubborn. I didn't sleep that night either. I also didn't eat anything from the first evening. It was too noisy and I felt frozen in time."



Example 2: Claire's Birth Story, Scene 3

"I remember the nurse checking my cervix at one point and leaving her fingers in for a full minute to feel a contraction even though I told her to please not do that. It was incredibly humiliating. I was told to get into certain positions to help speed up labor even if they were incredibly uncomfortable for me and I was made to feel like a child frequently. I was only 19 and I feel like I was judged for that. I asked for anxiety medication when they were going to place the epidural because the thought of it going into my spine freaked me out so bad and the nurse made fun of me."