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LITERATURE REVIEW

Autistic Women's Maternal Health: A Review of the Literature on Prenatal, Birth, and Postpartum Experiences for Autistic Mothers

Micah J. Hopkins

Prior autism research has noted a particular death in knowledge related to autistic mothers and their experiences with maternal care. This literature review synthesizes existing research on autistic mothers and their maternal experiences, focusing on the perinatal, birth, postpartum, and early childhood period. This search resulted in a final analysis of 17 articles. This review highlights major disparities between non-autistic women and autistic women across all phases of maternity. In particular, autistic women faced significant stigma and poor understanding of autism from medical providers, did not receive information in accessible forms, experienced distress and sensory overload due to the hospital environment, and had higher rates of postpartum anxiety and depression. Most autistic women still found motherhood to be a rewarding experience, showed resilience in advocating for proper care, and shared intense feelings of love, connection, and empathy for their children. The literature points to the need for leadership from autistic mothers and experts, who can use their lived experience to set priorities and change systems such that autistic women can reach reproductive justice.

Keywords

Autism • Maternal Health

Introduction

Autism Spectrum Disorder is a neurodevelopmental condition (Thapar et al., 2017) that affects sensory processing and communication; autism manifests in a spectrum, with each individual having unique traits and impairments (American Psychiatric Association, 2022). The past decade of autism research has highlighted gender disparities in autism presentation and diagnosis (Lai

University of Michigan, emihop@umich.edu

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et al., 2015), due to a combination of historical exclusion from research (Green et al., 2019; Lai & Szatmari, 2020; Lovelace et al., 2022) and gendered socialization starting from an early age (Begeer et al., 2013). However, there has been little research into how autism and sex discrimination impact autistic women through common milestones of adulthood, such as having children (McDonnell & DeLucia, 2021). This is particularly crucial as autistic women face an uphill battle to receive support and diagnosis in adulthood (Lockwood Estrin et al., 2021); for example, gender bias may lead a clinician to misdiagnose an autistic woman with Borderline Personality Disorder, leading to inadequate psychoeducation and misunderstanding from future care providers (Watts, 2023). As such, this literature review synthesizes the existing research on autistic mothers and their experiences with maternal care, closing with recommendations for maternal care providers to improve the well-being of autistic women and their children.

Autistic Women – A Brief Overview

Research on the sex ratio of autism diagnosis suggests an approximate 3-to-1 ratio of males and females (Loomes et al., 2017). Diagnostic markers of autism spectrum disorder, such as delayed speech, first present in early childhood (American Psychiatric Association, 2022), with diagnosis typically occurring between the ages of three to six years old (van 't Hof et al., 2021). However, girls receive a diagnosis, on average, one year later than boys (Petrou et al., 2018). This delay is often attributed to a female 'phenotype' (Hull et al., 2020), which presents with less externalizing symptoms (i.e., aggression), more 'internalizing symptoms' (i.e., anxiety) (McGillivray & Evert, 2018), and gender-stereotypical special interests (e.g., an interest in animals instead of math) (Lai et al., 2015). Notably, autistic girls may 'mask' their autism (Wood-Downie et al., 2021) by observing the behaviors of others and reflecting them to blend in with non-autistic peers; this is often described by autistic girls as a necessary way to socialize despite distress or disinterest in peers, causing significant strain due to the mental effort required for masking (Tierney et al., 2016).

Invisibility and a lack of support has implications for autistic women in adulthood. Autistic women face a high burden of mental health issues, with one study finding that 36–40% of autistic women are 'severely' or 'extremely severely' depressed, anxious, or stressed (McGillivray & Evert, 2018). When seeking support, autistic women report that services were often inaccessible due to cost, inappropriate tailoring for adults, lack of transportation, stigma from providers, and difficulties navigating medical systems (Tint & Weiss, 2018). Studies on autistic women diagnosed in adulthood reveal experiences such as: being punished for a 'hidden condition' (Leedham et al., 2020); being 'passive' to navigate social rules (Bargiela et al., 2016); disbelief from others after diagnosis; learning to advocate for oneself as an autistic person and a woman (Seers & Hogg, 2021); struggles relating to neurotypical women; disidentification with gender and autistic stereotypes (Kanfiszer et al., 2017); and experiencing autism not only as a condition, but as an identity (Seers & Hogg, 2023).

Autistic Mothers and Maternal Health

The transition to motherhood includes a shift in self-identity as parents re-negotiate daily life and social expectations (Hennekam et al., 2019; Laney et al., 2015). This time period also brings women into frequent contact with the medical system for prenatal care appointments, birth, and follow-up care for themselves and their infants. Prior research suggests that both autistic and non-autistic women attend the vast majority of their pregnancy related care appointments (Hampton et al., 2024), but autistic women have the unique pressure of negotiating diagnostic disclosure. In general, autistic women often face disbelief when they disclose that they are autistic, as others may minimize their struggles or claim that they seem neurotypical. (Seers & Hogg, 2021). This may particularly impact autistic mothers, who do not fit stereotypes for autistic people—after all, most people do not envision mothers as masculine, lacking in emotion, and disinterested in others.

Additionally, autistic mothers may experience poorer physical wellness in pregnancy when compared to non-autistic women due to sensorimotor differences and higher rates of other comorbid physical and mental disorders (Al-Beltagi, 2021). For example, many neurotypical women experience sensory processing changes in pregnancy, particularly smell (Cameron, 2014); autistic women experience the same changes, but they may be at a different intensity, and autistic women may already have coping strategies, having grown up with sensory sensitivities. Furthermore, physically disabled women are known to have higher rates of maternal mortality and worse overall outcomes compared to their nondisabled peers (Signore et al., 2021). Given that autistic women have higher rates of physical disabilities (Al-Beltagi, 2021), they navigate an even higher burden of inequality when attempting to access maternal care. Therefore, research into autistic women's maternal health experiences is necessary to provide practitioners with guidance on experiences that their autistic patients are more likely to face.

How autistic women navigate medical systems and interactions with practitioners within the context of provider knowledge gaps (Morris et al., 2019) and lack of adherence to stereotypes (Kanfiszer et al., 2017) warrants additional research. Stigmatizing encounters produces insufficient care, which may create distrust and worse overall outcomes for autistic mothers. The inequality in care that results from these barriers is a reproductive injustice—without an autistic patient-centered support system, autistic mothers are invisibly pushed away from having children and raising them in a supportive environment.

Literature Review

This section presents a review of the current literature on autistic women's experiences of early motherhood. This review is organized by theme; within the themes, results are presented in chronological order (i.e, findings are explained across the prenatal, birth, postpartum periods). To date, this will be the first comprehensive review of autistic maternal health literature.

Criteria and Methods

I used PubMed to conduct the search; terms are summarized below in a table. For inclusion, the population must be autistic women, either diagnosed or self-determined, who have been pregnant and/or given birth, and must be about autistic mother's feelings and perspectives on experiences related to the prenatal, birth, and postpartum period of motherhood. Papers were excluded if: the population included autistic mothers, but only discussed infant outcomes; population did not include autistic mothers; the study separated participants by autistic traits, not diagnosis or self-determination. Papers were also excluded if they were literature reviews; studies of singular autistic participants; and commentaries. Two fields were used to exclude animal studies, as the built-in search filter on PubMed did not prove sufficient on its own.

Table 1. Search terms, each field joined by AND.

Field	Keywords
MeSH	Peripartum period OR postpartum period OR pregnancy* OR parturition OR labor*
MeSH	Autism spectrum disorder
Any Field	Human NOT Animal
Filters	Humans and English

Results

Results are summarized in Figure 2. This search yielded 1,494 results; after removing duplicates and retractions, 1,490 articles remained. The most common reasons for exclusion papers: studies investigating maternal factors that impact child risk of autism; studies that focused on autistic children and not mothers; papers that pertained to other neurodevelopmental or genetic conditions; and commentary or response papers. 27 articles were pulled for further review based on their abstracts. Four additional papers were found via two systematic review papers, and an additional paper was published during the review process. After checking all 32 articles, 17 met the criteria for the final literature review.

Study Characteristics

Ten of the articles came from institutions in the United Kingdom; five came from institutions in the United States; and one article came from Australia and Ireland each. The majority of participants came from the United Kingdom, the United States, and Australia. Only one study disclosed that at least one author is autistic (Grant et al., 2024); twelve articles sought out community advisory boards or online feedback from the autistic community. The remaining articles did not disclose community involvement. One author noted that they were the parent of an autistic child and sought feedback from a midwife who works with autistic people, but no direct autistic community advice. A diverse range of methods were used across the articles; twelve articles employed qualitative methods, and eight articles included data from both autistic and non-autistic participants.

Six major themes emerged from the literature. 'Negative experiences with staff' includes stigma, a lack of feeling understood by practitioners, and unwanted touching. Theme two, 'inaccessibility', addresses barriers to positive pregnancy, birth, and postpartum experiences, such as examination rooms that triggered sensory overload, a lack of information, and unwelcoming peer groups. 'Sensorimotor impacts' includes changes in sensory processing and sensory experiences with motherhood. Theme four, 'need for support', details areas in which autistic mothers struggle, such as postpartum depression, executive functioning, and dismissive treatment when seeking help. 'Coping strategies' includes tactics that autistic women use to cope with struggles, like relying on fellow neurodivergent parents. Finally, 'being an autistic mother' reflects the strengths and challenges of being an autistic mother and what that identity means.

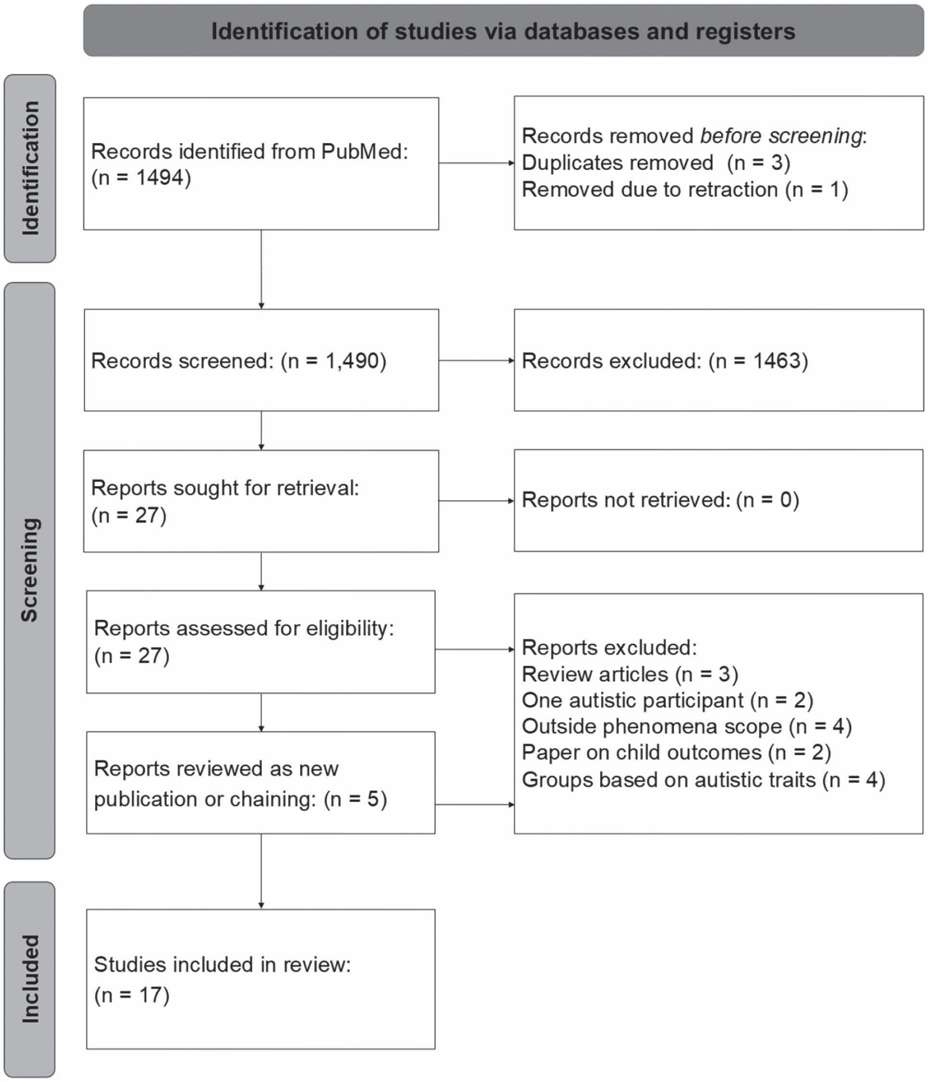

Figure 1. PRISMA diagram showing the inclusion/exclusion process of the literature review.

Table 3. Summary of themes found across papers.

First Author	Negative experiences with staff	Inaccess-ibility	Sensorimotor and physical health impacts	Need for support	Coping strategies	Being an autistic mother
Burton (2016)	X	X	X		X	X
Donovan (2020)	X	X		X	X	
Donovan et al. (2023)	X	X			X	X
Dugdale et al. (2021)	X		X	X	X	X
Gardner et al. (2016)	X	X	X	X	X	X

(*Continued*)

Table 3. (Continued)

First Author	Negative experiences with staff	Inaccess-ibility	Sensorimotor and physical health impacts	Need for support	Coping strategies	Being an autistic mother
Grant et al. (2023)	X	X	X	X	X	X
Hampton et al. (2023a)	X	X		X	X	X
Hampton et al. (2022a)				X		
Hampton et al. (2024)	X	X	X	X		
Hampton et al. (2022b)	X	X	X	X	X	X
Hampton et al. (2023b)	X	X	X	X		X
Lewis et al. (2021)	X			X	X	
Lum et al. (2014)	X	X		X		
Moore et al. (2024)	X	X		X	X	
Pohl et al. (2020)	X	X		X	X	X
Talcer et al. (2023)	X	X	X	X	X	X
Wilson et al. (2022)			X		X	X

Negative Experiences with Staff

Across all three periods of birth—pregnancy, birth itself, and the postpartum period—negative interactions with staff were common, creating a lack of trust between patients and practitioners. In one study, out of the participants who disclosed that they were autistic (n = 59), most did not agree that the practitioner who helped them understood how autism impacted them. Most participants chose not to disclose at all (n = 355), as they feared negative bias or felt the disclosure would be unhelpful (Hampton et al., 2024). Further research shows that this pattern of disclosure avoidance often continues after birth as well (Hampton, Allison, et al., 2023; Lum et al., 2014). Social interactions with health practitioners were sometimes adversarial; one interviewee mentioned situations where midwives asked how she could be a mother if she was autistic (Hampton, Man, et al., 2023), another recalling how a doctor assumed she was incapable of managing medications (Dugdale et al., 2021).

Many participants cited poor treatment from staff as a stressor during birth (Burton, 2016; Donovan, 2020; Dugdale et al., 2021; Gardner et al., 2016; Hampton, Man, et al., 2022; Hampton, Allison, et al., 2023; Lewis et al., 2021). Inappropriate treatment included unwanted interventions during birth (Burton, 2016; Moore et al., 2024), hostility when bringing accommodations, like a blanket (Gardner et al., 2016), or being labeled as mentally unstable when stimming (self-stimulatory behavior) (Donovan, 2020). Several participants recalled miscommunication while giving birth, leading to heightened distress (Donovan, 2020; Gardner et al., 2016; Hampton, Man, et al., 2022; Hampton, Allison, et al., 2023; Lewis et al., 2021; Lum et al., 2014; Moore et al., 2024). This led to some patients feeling powerless (Lewis et al., 2021) or having meltdowns (Hampton, Man, et al., 2022). Autistic patients were dismissed when they spoke up about their pain, particularly if they appeared calm (Donovan, 2020; Dugdale et al., 2021; Lewis et al., 2021; Lum et al., 2014). Practitioners may not be educated on how sensory processing and communication is impacted by autism, particularly how someone may seem calm while being in pain. This often resulted in mistrust (Lewis et al., 2021) and masking during labor (Dugdale et al., 2021; Moore et al., 2024), further impairing communication. Compared to non-autistic women, they were significantly more likely to agree that they had problems with communicating about pain during birth (Lum et al., 2014), and autistic women were less likely to agree that the staff understood how they physically felt (40% vs. 72%). Stigma and a lack of knowledge results in practitioners not understanding their patients and giving insufficient care.

Inaccessibility

Various aspects of maternal care were noted to be inaccessible for autistic mothers. Compared to 14% of non-autistic women, 76% of autistic women found the environment of their prenatal appointments overwhelming (Hampton et al., 2024). Specific aspects included physical contact without consent (Burton, 2016; Moore et al., 2024), fluorescent lights, and the gel used in fetal heart checks (Gardner et al., 2016); one participant found the hospital so overwhelming that she experienced a shutdown (Hampton, Man, et al., 2023). Participants who disclosed that they were autistic were rarely offered accommodations, such as home visits, different waiting rooms, or longer appointments (Hampton et al., 2024). During birth, sensory stressors included bright lights (Burton, 2016; Donovan, 2020; Donovan et al., 2023; Gardner et al., 2016; Hampton, Man, et al., 2022; Lewis et al., 2021; Talcer et al., 2023) and noise from other women, staff, and babies (Gardner et al., 2016; Hampton, Man, et al., 2022; Lewis et al., 2021; Talcer et al., 2023).

Across the maternal period, poor accessibility of information was prevalent. Compared to non-autistic women, autistic mothers were less satisfied with the amount of information they received (56% vs. 80%); less satisfied with how information was presented (61% vs. 85%); and less likely to agree that they knew when to seek help related to pregnancy (67% vs. 89%) (Hampton et al., 2024). One study found that 34% of autistic women did not have the process of birth adequately explained to them, compared to 17% of non-autistic women (Pohl et al., 2020). Compared to non-autistic mothers, autistic women were less likely to agree that breastfeeding resources were appropriately suited to them (Lum et al., 2014), less likely to agree that resources were accessible, and less likely to be satisfied when they did receive support (Hampton, Allison, et al., 2023). Socialization also presented a barrier; 87% of autistic women felt that there was too much pressure to socialize at prenatal classes, 72% found the classes too large, and 64% found the classes too loud (Hampton et al., 2024). For another example, autistic mothers were recommended to peer breastfeeding groups (Grant et al., 2024; Hampton, Man, et al., 2022) and general parental support groups (Hampton, Man, et al., 2022), but often had issues with how information was delivered and with social interaction (Grant et al., 2024).

Sensorimotor impacts

Several studies found that autistic women experienced heightened sensory sensitivities, such as heightened sense of taste, sound, and touch during pregnancy (Burton, 2016; Gardner et al., 2016;

Hampton et al., 2024; Hampton, Man, et al., 2023; Talcer et al., 2023). Further, while sensory processing changes for both autistic and non-autistic mothers (Hampton et al., 2024), autistic women reported changes at a higher frequency, impact to more senses, and found these changes more debilitating; for some, routine tasks, like shopping, went from difficult to unbearable (Hampton, Man, et al., 2023). In an earlier study, women reported that mundane sensations, like the smell of chicken or noises from the radio, were magnified, causing them to avoid busy environments (Gardner et al., 2016). In addition to increased sensitivity, autistic participants experienced more frequent meltdowns, worsening of pelvic girdle pain, and higher rates of severe or persistent nausea (Hampton et al., 2024; Talcer et al., 2023).

After birth, child crying and meltdowns (Burton, 2016; Hampton, Man, et al., 2022; Talcer et al., 2023), as well as the baby's physical contact and attachment (Dugdale et al., 2021; Talcer et al., 2023) were mentioned as particularly stressful. Breastfeeding was often challenging. In two studies about autistic mothers and breastfeeding, overstimulation from the baby or from pumps was a frequent barrier to comfortably breastfeeding (Grant et al., 2024; Hampton, Man, et al., 2022; Wilson & Andrassy, 2022). While a survey found that autistic women were highly motivated to breastfeed (87.2%), many mothers (46.6%) found the 'intensity' difficult the majority of the time, and 27.1% experienced pain 'all or most of the time' (Grant et al., 2024). As such, while both non-autistic and autistic women experience changes in sensory processing, physical health, and difficulties with breastfeeding, autistic mother's experiences were more frequent and magnified.

Need for support

Autistic women often did not have enough support across maternal care. For example, though autistic women strongly preferred seeing the same midwife at each appointment, they often saw different midwives without being informed ahead of time (Hampton et al., 2024; Moore et al., 2024). In another study, 82 participants shared negative experiences with receiving breastfeeding support, compared to just 23 participants who shared positive experiences (Grant et al., 2024). Those receiving support through at-home visits found it difficult to function if they were unsure when the visit would happen, as surprise visits can cause social stress and routine disruptions (Hampton, Man, et al., 2022). Stigma causes stress; autistic mothers are more likely to feel isolated, judged, and unable to ask for help in comparison to non-autistic mothers (Pohl et al. 2020). The majority of autistic mothers felt that autistic-specific support groups would have been beneficial (Hampton, Allison, et al., 2023). For example, new social demands related to having children, such as forming 'play groups' and creating a support network with other mothers was challenging (Burton, 2016; Hampton, Man, et al., 2022; Talcer et al., 2023), a challenge that may be eased by the existence of support groups for autistic mothers.

In general, autistic people often experience increased stress to their executive functioning capabilities after having children, as infant care requires large changes in routine, new skills, and accepting some amount of chaos. While the changes in routine are difficult for any new parent, autistic people often experience more distress in response to routine changes than non-autistic women (Grant et al., 2024; Hampton, Man, et al., 2022). Compared to non-autistic women, autistic mothers felt less capable of coping with multitasking (51% vs. 94%), were less likely to agree that they were organized (56% vs. 79%) and were overall less likely to feel that they were coping with the responsibilities of parenting (47% vs. 85%) (Pohl et al., 2020). For example, one mother mentioned that keeping track of and cleaning formula bottles was overwhelming (Grant et al., 2024). Additionally, over half (53%) of those surveyed had difficulties with the unpredictability of breastfeeding (Grant et al., 2024), with some women being overwhelmed with stress and anxiety around the practice (Wilson & Andrassy, 2022).

Autistic women consistently reported poor mental health. In comparison to non-autistic mothers, autistic mothers were more likely to report postpartum depression, anxiety, higher stress, and low feelings of life satisfaction (Hampton, Allison, et al., 2022). Many autistic mothers mentioned exhaustion and difficulties with coping with the demands of motherhood (Donovan et al., 2023; Dugdale et al., 2021; Grant et al., 2024; Hampton, Man, et al., 2022; Pohl et al., 2020; Talcer et al., 2023). While postpartum anxiety and depression certainly causes some of this exhaustion, the impact of internalized and externalized stigma, as well as feelings of inadequacy, has yet to be fully explored. Given that autistic women are more likely than non-autistic women to have concurrent mental health diagnosis (Hampton, Allison, et al., 2023), the stigma and lack of satisfactory support is especially hurtful.

Coping strategies

To manage anxieties related to sensory overwhelm and unpredictability, many autistic women sought ways to prepare themselves and their environment before labor (Gardner et al., 2016). Some autistic women who give birth in hospitals tour the room ahead of time to mentally prepare for labor, as an unfamiliar environment can be particularly stressful for autistic people (Gardner et al., 2016). Many women also have additional advocates with them, such as a doula, family member, or midwife (Hampton, Allison, et al., 2023), which is particularly crucial when verbal communication becomes difficult during birth. Additionally, choosing to have a c-section (Talcer et al., 2023) or an at-home birth (Burton, 2016) made some women more comfortable, as they could plan around a specific procedure or have control of their environment. Some nurses offered blindfolds or dimmer lights to reduce sensory stress (Hampton, Man, et al., 2022). Participants stressed the importance of a trusting relationship with a medical professional (Burton, 2016), as lacking a trusting relationship can lead to mothers hiding their struggles, such as postpartum depression (Donovan, 2020).

Autistic mothers relied on their own knowledge of their bodies and the support they had to adapt to the challenges of motherhood. While autistic women were less likely than non-autistic women to feel sufficiently supported (Hampton, Allison, et al., 2023; Pohl et al., 2020), many still shared their experiences with reaching out to family (Burton, 2016; Gardner et al., 2016), or relying on their partners for help (Dugdale et al., 2021; Grant et al., 2024). Autistic women often sought out support from other neurodivergent friends who had children (Dugdale et al., 2021) or used online support groups to exchange information and seek support from other autistic mothers (Talcer et al., 2023). Additionally, to cope with specific sensory stressors, autistic women sought time for themselves to rest (Hampton, Man, et al., 2022; Talcer et al., 2023) and distracted themselves while breastfeeding (Grant et al., 2024; Wilson & Andrassy, 2022).

Being an autistic mother

Pregnancy creates unique social interactions, as pregnant people attend prenatal appointments where they interact with practitioners, prenatal classes with other mothers, ask for help within their families, and even questions from strangers. These situations may be particularly taxing for autistic women. While some autistic pregnant women found conversations with strangers pleasant, since they were often specific questions (i.e., "when is the baby due?), others found the unsolicited attention tiring (Hampton, Man, et al., 2023). Other social experiences were also experienced differently. While many women felt an instant connection with their infant, some women had less immediate bonding experiences (Donovan et al., 2023; Gardner et al., 2016). For example, one mother noted that 'pretend play' was not something she felt capable of doing with her child due in part to being autistic (Dugdale et al., 2021). Notably, some women felt that breastfeeding improved their ability to bond with their child and read their cues (Gardner et al., 2016; Grant et al., 2024).

Several autistic mothers discussed their intense bond with their child (Burton, 2016; Donovan et al., 2023; Dugdale et al., 2021; Grant et al., 2024; Hampton, Man, et al., 2022). Despite the stereotype that autistic people are lacking in empathy and disinterested in others, some mothers felt that they had intense empathy for their baby (Burton, 2016), with one mother feeling protective when her baby anxiously cried, as she didn't "want her to feel [anxious] the way that I did" (Dugdale et al., 2021). Mothers found various aspects of parenting rewarding, such as watching their child's developmental progress (Dugdale et al., 2021) and thinking about teaching them (Hampton, Man, et al., 2022). Additionally, mothers mentioned positive aspects related to their own personal growth, such as becoming more flexible with routine changes (Dugdale et al., 2021) and being able to handle environments that previously caused sensory overload (Hampton, Man, et al., 2022). While autistic mothers do face greater struggles and barriers than non-autistic women, the majority of autistic mothers (86%) still agree that motherhood has been a rewarding experience (Pohl et al., 2020).

Conclusion and Recommendations

The research here demonstrates significant disparities in how autistic women receive and experience maternal care: they are significantly more likely to have stigmatizing encounters with staff, less likely to have adequate support, and have to find unique coping strategies on their own. As an increasing number of people are diagnosed with Autism Spectrum Disorder each year (Dietz et al., 2020), it is critical for healthcare systems to adapt to support the growing population of adults with autism. Structural barriers, such as neurotypical-centered support groups, stigma towards disability and reproductive freedom, and power dynamics between practitioners and patients prevent autistic mothers from having adequate maternal health experiences. To begin to address these issues, healthcare practitioners may consider collaborating with autistic experts, researchers, and patients, so they can apply their knowledge, experiences, and priorities to lead projects to improve access for autistic mothers. Within the framework of reproductive justice, this presents a barrier to autistic women in pursuing the right to have children, and the right to raise them in a supportive environment. This research presents how autistic mothers face an uphill battle in advocating for themselves—it is time for the healthcare system to advocate back.

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Appendix A: All Tables

Table 1. Search terms, each field joined by AND.

Field	Keywords
MeSH	Peripartum period OR postpartum period OR pregnancy* OR parturition OR labor*
MeSH	Autism spectrum disorder
Any Field	Human NOT Animal
Filters	Humans and English

Table 2. Summary of study information

First Author	Institution Country	Method	Sample Size	Stages of maternity		
				Pre.	Birth	Post.
Burton (2016)	UK	Qualitative	7	x	x	x
Donovan (2020)	US	Qualitative	24[a]		x	
Donovan et al. (2023)	US	Qualitative	24[a]		x	x
Dugdale et al. (2021)	UK	Qualitative	9		x	x
Gardner et al. (2016)	US	Qualitative	8	x	x	x
Grant et al. (2023)	UK	Mixed	152			x
Hampton et al. (2023a)	UK	Quantitative	382 (ASD) 492 (Non-ASD)		x	x
Hampton et al. (2022a)	UK	Quantitative	22–27 (ASD)[b][***] 25–29 (Non-ASD)	x		x
Hampton et al. (2024)	UK	Quantitative	417 (ASD) 524 (Non-ASD)	x		
Hampton et al. (2022b)	UK	Qualitative	21 (ASD)[b] 25 (Non-ASD)		x	x
Hampton et al. (2023b)	UK	Qualitative	24 (ASD)[b] 21 (Non-ASD)	x		
Lewis et al. (2021)	US	Qualitative	16[*]		x	
Lum et al. (2014)	Australia	Quantitative	32 (ASD) 26 (Non-ASD)		x	x
Moore et al. (2024)	Ireland	Qualitative	4[**]	x	x	x
Pohl et al. (2020)	UK	Quantitative	355 (ASD) 132 (Non-ASD)	x	x	x

(*Continued*)

Table 2. (Continued)

First Author	Institution Country	Method	Sample Size	Stages of maternity		
				Pre.	Birth	Post.
Talcer et al. (2023)	UK	Qualitative	7	x	x	x
Wilson et al. (2022)	US	Qualitative	23			x

* 16 women participated; some had given birth more than once, thus 19 stories were analyzed.
** This study included four autistic mothers, two autistic midwives, and two non-autistic midwives.
*** Some participants dropped out or joined between the three survey time periods.
a-b Denotes studies that used some or all of the same participants.

Table 3. Summary of themes found across papers.

First Author	Negative experiences with staff	Inaccess-ibility	Sensorimotor and physical health impacts	Need for support	Coping strategies	Being an autistic mother
Burton (2016)	X	X	X		X	X
Donovan (2020)	X	X		X	X	
Donovan et al. (2023)	X	X			X	X
Dugdale et al. (2021)	X		X	X	X	X
Gardner et al. (2016)	X	X	X	X	X	X
Grant et al. (2023)	X	X	X	X	X	X
Hampton et al. (2023a)	X	X		X	X	X
Hampton et al. (2022a)				X		
Hampton et al. (2024)	X	X	X	X		
Hampton et al. (2022b)	X	X	X	X	X	X
Hampton et al. (2023b)	X	X	X	X		X
Lewis et al. (2021)	X			X	X	
Lum et al. (2014)	X	X		X		
Moore et al. (2024)	X	X		X	X	
Pohl et al. (2020)	X	X		X	X	X
Talcer et al. (2023)	X	X	X	X	X	X
Wilson et al. (2022)			X		X	X

Appendix B: Figures

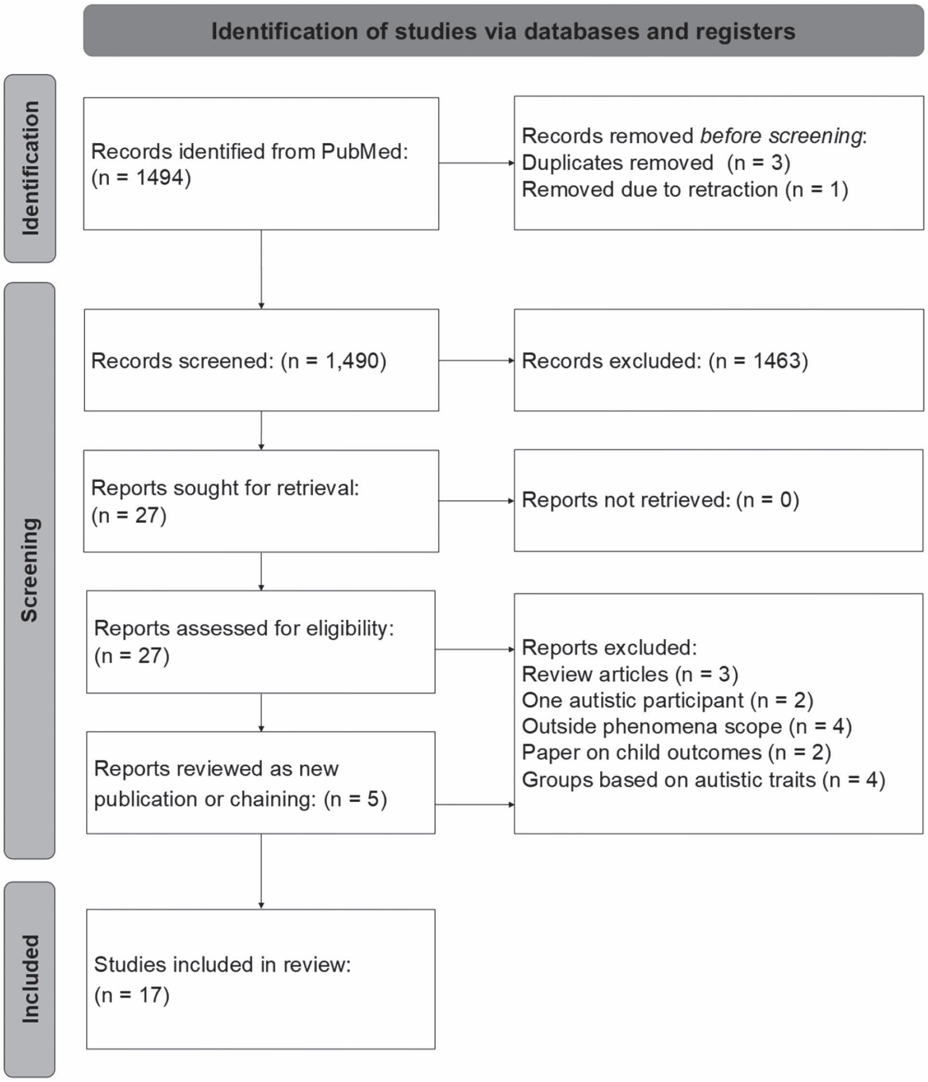

Figure 1. PRISMA diagram showing the inclusion/exclusion process of the literature review.

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LITERATURE REVIEW

Neurodegenerative Diseases and Socioeconomic Disparities: Analyzing Healthcare Access, Disease Outcomes, and Regulatory Measures

Anirudh Praveen

This paper reviews the current research on neurodegenerative diseases and explores how socioeconomic disparities influence the recognition and management of these conditions. Using data on healthcare access, disease outcomes, environmental factors, and economic influences, the paper advocates for policy reforms to enhance healthcare access and equity for underserved populations in light of rising life expectancies. The paper emphasizes the challenges faced by individuals of lower socioeconomic status (SES) towards timely diagnoses and/or treatments for neurodegenerative diseases, highlighting the broader goal of addressing healthcare disparities.

Keywords

Neurodegenerative Disease (NDDs) • Neuroinflammation • Socioeconomic Status (SES) • Parkinson's Disease (PD) • Multiple Sclerosis (MS)

Background

Neurodegenerative diseases (NDDs) are defined as disorders that lead to the progressive degeneration of central nervous system cells, resulting in a diminished ability to engage in activities of daily living (ADLs) (National Cancer Institute, n.d.). The term 'degenerative' distinguishes these diseases from others, as they are chronic and progressive, with few effective treatments available (National Cancer Institute, n.d.). Furthermore, the US population of those over 65 years old is projected to increase from 48 million to 88 million by 2050 (National Institutes of Health, n.d.). Current treatments for NDDs are focused on symptom management, requiring a long-term doctor-patient relationship. For instance, in 2017, approximately one million individuals were diagnosed with Parkinson's Disease,

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University of Nevada - Reno, apraveen@unr.edu

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resulting in a personal economic burden estimated at around $52 billion across the United States (Yang et al., 2020). Fortunately, most of the individuals in that study were eligible for Medicare, reducing their economic burden (Gao & Hong, 2008). Medicare eligibility is typically determined by factors such as being 65 or older, having worked in Medicare-covered employment for at least 10 years, and maintaining U.S. citizenship or legal residency for at least five years (California Health Advocates, n.d.). However, for those who fall outside of these criteria, such as individuals in the uninsured population—access to necessary healthcare, including treatments for neurodegenerative diseases, becomes a significant challenge. The uninsured population consists of individuals who lack health insurance, a characteristic often tied to socioeconomic status (SES) (United States Census Bureau, n.d.). Socioeconomic statistical data suggest that the prognosis for uninsured patients with NDDs is unfavorable, likely due to delayed healthcare access associated with lower socioeconomic status (Yang et al., 2020). Due to the projected increase in the U.S. 65-or-older population and economic burdens regarding NDDs, NDDs in the uninsured population could become a leading killer (Seifi et al., 2021). Ensuring that healthcare access via low/no cost healthcare clinics is expanded to provide basic plus advanced treatment, maintaining disease prognosis and medication accessibility, and controlling environmental factors could increase the life expectancy for the millions of uninsured.

Healthcare Access: Low/No Cost Healthcare Facilities

Healthcare access in the U.S. shouldn't be one-sided, where those with expendable income or adequate insurance receive the treatment they need, while those without these resources miss out on the care they deserve. SES is a way to describe an individual based on their job, income, or education (National Cancer Institution, n.d.). Unfortunately, lower SES tends to factor from discrimination and length of schooling (National Academies of Sciences, Engineering, and Medicine, 2017). Fortunately, data from around 775 low/no cost health care clinics show that 5.8 million patients benefit from their basic services (Thompson, 2023). These healthcare clinics offer essential services such as lab work, physical check-ups, and prescriptions, similar to those available at primary care facilities, often at no or very low cost to patients. What if these clinics gained the capability to offer more specialized services like Magnetic Resonance Imaging (MRI), Electroencephalograms (EEG), or even a team of neurologists to help these patients understand what they might be dealing with? The Medical University of South Carolina wanted to tackle this problem by establishing the Dream Center Neurology Clinic which has provided free routine neurologic care to over 250 patients since its inauguration (Taylor et al., 2015). Services offered by this type of clinic should be expanded to include current low/no-cost healthcare facilities. This is because approximately 1 in 3 people suffer from a neurological disorder (World Health Organization, n.d.), and uninsured or underprivileged individuals are not exempt from these conditions. With this in mind, a key question that arises is funding, which would require increased federal or state funding towards these low/no cost clinics since the benefits from them are extremely valuable. Increasing funding should increase access to healthcare for a wider variety of individuals since neurological treatment tends to be extensive and expensive (Callaghan et al., 2019).

Disease Outcomes: Diseases Prognosis and Medication Accessibility

Once a disease has been discovered in a person, a strict regimen consisting of medications, therapy, and/or consistent doctor visits will help dictate the course of that disease. Unfortunately, older individuals who classify as lower SES may discover their disease in the emergency room and tend to experience a heavier disease burden (Seifi et al., 2021). This could be from the lack of pursuing preventative care or routine screenings when compared to an individual from a higher SES (McMaughan et al., 2020). In numerous lower SES aging adults, cost tends to be the primary reason for reduced access to healthcare (McMaughan et al., 2020). Furthermore, disease prognosis isn't highly maintained in lower SES individuals in underserved populations due to the high volume of patients in low/no cost clinics or financial burdens. For example, multiple sclerosis (MS), is a neurodegenerative disease in which the immune system attacks the protective covering (myelin) of neurons (Mayo Foundation for Medical Education and Research, 2022). This disease could have symptoms such as vision loss, fatigue, muscle spasms, weakness, or even paralysis if not treated. MS impacts more than 2.8 million people globally and stands as a major cause of disability among adults (Mey et al., 2023). Neurologists may utilize an MRI, lumbar puncture (to analyze atypical immune responses), or a neurological exam to diagnose patients with MS. Once a diagnosis of MS is presented, treatment consists of strong medications and/or lifestyle changes (Mayo Foundation for Medical Education and Research, 2022). These medications can cost upwards of $60,000 per year without insurance (Hartung et al., 2015). Individuals who are uninsured or have lower SES may experience MS symptoms without receiving a diagnosis or treatment plan, potentially shortening their life expectancy.

Additionally, is pursuing a diagnosis worthwhile if the treatment is unaffordable? Broadly speaking, half of medicine tends to fall toward diagnosis while the other half tends to fall toward treatment. The 2.8 million individuals affected by MS might not fully represent the extent of the disease, as many people with lower socioeconomic status may lack access to a neurologist for diagnosis or may not have the financial means to afford diagnostic testing. Overall, enhancing access to neurodegenerative medications to foster competition among pharmaceutical companies could drive down drug prices. Along with competition, expanding neurological care for individuals with lower socioeconomic status or those uninsured could significantly improve life expectancy and ensure better access to necessary treatments.

Environmental Factors: Potential Prevention Before Detection?

As research on neurodegenerative diseases advances, neuroinflammation is increasingly correlated to the eventual detection of degenerative neurological disorders (Zhang et al., 2023). Neuroinflammation can arise from brain injury, infections, toxicity, or autoimmunity. Brain injury, infections, and autoimmunity tend to be determined by lifestyle choices or genetics (McKee et al., 2016). On the other hand, toxicity from an individual's environment is a preventable cause of neuroinflammation because the air we breathe, food we eat, or water we drink can contain numerous chemicals/bacteria if poorly maintained. U.S. Census data showcases that individuals from lower SES groups often reside in clustered communities (Benson, 2023), which are frequently located in areas with higher exposure to environmental pollutants (Hajat et al., 2021). For example, chemicals like paraquat (herbicide) or manganese (trace mineral) at higher concentrations could cause neurological impairment in a developing brain (Landrigan et al., 2005). Exposure to pollutants during childhood could lead to increased inflammation potentially triggering neuroinflammatory diseases later in life (Landrigan et al., 2005).

On the other hand, another article from the U.S. Census estimates that around 3.9 million children do not have health insurance (Mykyta et al., 2023) further limiting their doctor's visits for annual workups (lab work, physical exams, etc.). These children could have greater potential to develop neurodegenerative diseases than their fellow peers (Landrigan et al., 2005). This could be from being born into a lower socioeconomic status continuing the cycle of halting educational completion leading to income and health inequality (National Academies of Sciences, Engineering, and Medicine, 2017.). Another factor that plays into the environmental influences of neuroinflammation on neurodegeneration is ongoing research between the gut-brain axis (Ashique et al., 2024). The gut-brain axis refers to the bidirectional communication between the enteric system (gut) and central nervous system (brain and spinal cord) through signaling from various gut bacteria (Carabotti et al., 2015). This provides further evidence that the food we eat can influence our brain, as gut bacteria, which are highly sensitive to our diets, play a significant role in our overall health (Bourdea-Julien et al., 2023). Individuals of lower SES who are uninsured tend to live in impoverished communities facing food insecurity and/or food deserts (low access to healthy foods alters the gut bacteria composition (Zhang, 2022). Preventing neuroinflammation can be possible by reducing poverty, and ensuring that a healthy diet is accessible to all, regardless of socioeconomic status. Additionally, maintaining and consistently updating the Federal Drug Administration (FDA) regulations on chemicals used in food production is crucial as new discoveries emerge.

Conclusion

Ultimately, securing equitable access to healthcare is crucial for individuals to receive regular checkups and treatment for diagnosed conditions, regardless of their socioeconomic status. As life expectancy increases, neurodegeneration becomes a growing challenge (Morris, 2013). As neurodegenerative diseases represent a relatively new area of medical research, treatment costs remain high, potentially limiting access to preventive and protective care for individuals with lower socioeconomic status or without insurance. Fortunately, this doesn't have to be the case. Healthcare access via low/no cost healthcare clinics has already helped millions in the U.S. (Thompson, 2023), and expanding them to provide neurology-related treatment would only be a valuable investment. Additionally, raising public awareness about the importance of a healthy diet could play a crucial role in preventing or delaying the onset of neurodegenerative diseases. Ensuring timely prognosis and accessible medications not only benefits the uninsured but also drives competition and demand, ultimately reducing overall medication costs. This would make neurodegenerative treatments more affordable to everyone. Creating environments that nurture neurological development, irrespective of socioeconomic status, could significantly alleviate the burden of neurodegenerative diseases on the uninsured population.

Notes

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