# Breastfeeding and ASD: A spectrum of challenges

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#### **ABSTRACT**

As their children are diagnosed with autism, many mothers are discovering their own neurodivergence. With the long-overdue acknowledgment of mothers' position on the spectrum, pregnancy, parenting and breastfeeding issues of autistic women should become a priority for the scientific and healthcare community. Beyond the protective benefits of breastfeeding for reducing autism risk, the breastfeeding experience of autistic women also deserves a much closer look.

Key Words: autism, breastfeeding, protective properties of breastmilk in autism, autistic mothers breastfeeding, atypical sensory experience.

#### Introduction

More than 20 years ago the Centers for Disease Control (CDC) started tracking the number and characteristics of eight-year-old children with autism through the Autism and Developmental Disabilities Monitoring Network (ADDM).¹ Behind those early prevalence statistics were children diagnosed with autism spectrum disorder (ASD), children who are now adults. Neurodivergent adults dealing with many of life's milestone events like securing and improving employment prospects, getting married, conceiving, and for some new mothers, breastfeeding.

Would a mother on the spectrum, diagnosed or not, be any more or less likely to breastfeed? Would an infant, especially those with an elevated genetic risk of developing autism, obtain greater benefits from being breastfed exclusively for a prolonged period?

Research does highlight the benefits of breast milk for mothers and infants, more specifically, the potential protective effect of exclusive breastfeeding against ASD.<sup>2</sup> While such studies suggest lower autism rates linked to higher levels of breastfeeding, other autism risk factors are difficult to exclude.

The protective potential of breast milk against autism is only part of the puzzle; unfortunately, the topic of autistic women breastfeeding their neurodivergent, or even neurotypical infants, is a discussion that receives far less attention from the scientific community.

This article will focus on breastfeeding not only in terms of the effect and association of breast milk on ASD, but also the breastfeeding experience of autistic women.

#### Autism and breastfeeding

ASD is a highly heritable condition, therefore parents diagnosed with autism, parents who believe they may be

on the spectrum, and those who already have an autistic child may be especially interested in the protective and beneficial properties of breast milk in ASD.

Many studies support breastfeeding for a mother and infant's physical and emotional health; popular media campaigns proclaim: "Breastfeeding saves lives," and "Breast is best." Breastfeeding as it pertains specifically to autism is a less mainstream topic, but more research is slowly trickling in. In fact, a recent retrospective survey study found decreased prevalence of autism in Fragile X Syndrome in response to long-term or exclusive breastfeeding in comparison to formula feeding.<sup>3</sup>

More encouraging results emerged from a meta-analysis examining the association of breastfeeding status with the risk of autism.<sup>4</sup> The authors shared the following:

- According to their dose-response meta-analysis, breastfeeding a baby for 6 months was linked to a 54% reduction in risk
- In the conventional meta-analysis, the greatest reduction in the risk of autism spectrum condition was associated with prolonged breastfeeding of young children, between 12 to 24 months

The conclusion of the authors highlights the importance of breastfeeding to reduce the risk of autism. This may be a sound conclusion, reached after a meticulous meta-analysis, but for many women it may feel like a scientific reprimand. This recommendation comes from authors in ivory labs where poor, painful latching is a myth, where tactile sensitivities do not cause feelings of rage and agitation and where mothers are not feeling isolated and unworthy of their title. Such advice is of little support to mothers on the autistic spectrum who may be dealing with all of the aforementioned challenges.

# Neurodivergence and breastfeeding

High breastfeeding initiation rates reveal most mothers want to breastfeed.<sup>5</sup> Many have firm plans to feed their infant an exclusive diet of breast milk, but the physical and emotional health of the mother, insufficient milk supply, and support struggles may get in the way.<sup>6</sup> For neurotypical women postpartum depression, other children, work, health conditions like mastitis and even the way the baby feeds may interfere with breastfeeding.

For autistic women these challenges are often present but may be overshadowed by struggles caused by the very characteristics of their neurodivergence. Breastfeeding advice is usually tailored to the neurotypical mother; many lactation consultants may be unaware that almost all autistic individuals have atypical sensory experiences.<sup>7</sup>

In fact, research suggests tactile and auditory hypersensitivity may predict an ASD diagnosis.<sup>8</sup> While such sensory abnormalities are increasingly investigated in the pediatric population, the sensory experience of a breastfeeding mother on the spectrum remains a mystery mainly whispered about on blogs and online forums.

A crying child, latching on incorrectly causing pain for the mother, and frustration for the infant, is often part of the initial breastfeeding challenge. This ordinary scenario seems more disconcerting when happening to a mother with auditory and tactile sensitivities. Especially when many in the autism community mention sensory overload as a meltdown trigger.

In the above situation a new neurotypical mother may seek guidance from family, friends and professionals. For the new autistic mother, an attempt to seek guidance or even participate in commiseration with other mothers may be as daunting as breastfeeding. A study examining the experience of motherhood from autistic women's perspective found the women battled to find appropriate support.<sup>10</sup>

The women interviewed spoke of feeling "misunderstood, judged and dismissed." It impacted their ability to receive support for themselves and their children. In stark contrast, when healthcare professionals understood autism, the women interviewed felt acceptance and respect.<sup>10</sup>

Another review found autistic adults experience challenges and dissatisfaction communicating with health care providers throughout pregnancy and birth.<sup>11</sup> Other results from this systematic review include:

• Autistic mothers are more likely to experience depression during and after pregnancy.<sup>11</sup> (It is interesting to note that breastfeeding struggles have been linked to

postnatal depression, while breastfeeding itself could be associated with a lower risk of postnatal depression; conflicting results have been reported in literature.)<sup>12</sup>

• Autistic mothers may experience more pregnancy complications.<sup>11</sup> (Research indicates such complications may hinder breastfeeding.)<sup>13</sup>

With autism prevalence rates rising, it behooves professionals in all spheres of medicine to become more well versed in treating individuals with autism. The aforementioned studies highlight the negative consequences of autistic individuals seeking support, only to be met with stigma, negative judgments or ignorance. To gain insight about the lived experience of such situations—from women on the spectrum—we need to give these women a judgment-free platform to educate us.

For a long time, nursing mothers have criticized literature and research penned by out-of-touch male academics; for women with atypical sensory experiences and significant social-communication differences, current breastfeeding literature and advice may seem even less relevant.<sup>14</sup>

# Underdiagnosed, overwhelmed

Women may camouflage or mask certain symptoms of autism for social acceptance. Autism is probably underdiagnosed in females, with research suggesting some autistic females may be missed by the current diagnostic procedures. <sup>15</sup> Should these undiagnosed autistic women have children, such children will have a higher risk of ASD and protective properties of breast milk may be especially relevant.

This leads to speculation—as little research is available—about the probability of women with autistic traits breastfeeding their infants, and the implications of protection for infants with a potentially elevated risk.

From the (scarce) research delving into the autistic woman's breastfeeding experience, it seems as though common themes include: powerful sensory perception with feelings of "over-touch and overstimulation," "focused determination," and the unique experience of each individual where "one size does not fit all." <sup>16</sup>

It's dangerous and unfair to generalize about neurodivergent women's attitude to breastfeeding, especially because the autism spectrum is so broad. Research does seem to suggest, however, that autistic mothers who decide to breastfeed may be intensely driven. <sup>10</sup> Particularly as some autistic mothers view their children (respectfully) as their "special interest." They focus every ounce of energy on their newborn. Their knowledge of the benefits of breast milk means they breastfeed, even when it is a daily struggle.

The author interviewed a neurodivergent mother who was still breastfeeding her 15-month old daughter every two hours, every single night. She was exhausted, worryingly underweight, but her black and white outlook meant prolonged breastfeeding was non-negotiable.

During a recent interview for the Autism Parenting Summit (April 2022), Dr. Natasha Campbell-McBride, the creator of the GAPS diet, recommended breastfeeding a child for at least three years. Her own child was diagnosed with autism, and her breastfeeding recommendations were firm.

This kind of advice may seem non-negotiable to an autistic woman who wants to reduce the risk for her infant. The reality of breastfeeding for three years while dealing with intense sensory issues, with little appropriate support, seems extreme.

This may be the reason some mothers on the spectrum cease to breastfeed after their first overwhelming attempt. The first few weeks after giving birth, when babies feed on demand, may be especially tough for autistic mothers, as autism is often characterized by insistence on sameness and a love of routine and structure.

Even highly sensitive neurotypical mothers reveal the overwhelm of breastfeeding. They whisper, in fear of judgment, about the respite of handing the baby to dad for bottle feeding. This may be an important coping mechanism for new moms; even more so for mothers with postnatal depression, where a break for self-care may be vital. Healthcare, CAM (complementary and alternative medicine), and family support in addition to self-care is especially relevant for mothers on the spectrum, as research tell us more than 20% may also have a comorbid anxiety disorder (in children with ASD almost 40% have concomitant anxiety disorders).<sup>17</sup>

The idea of a perfect mother, a beatific smile on her face, breastfeeding her quiet baby in her freshly cleaned lounge is the reason so many women–neurotypical and neurodivergent–struggle in silence through the first few months.

Autistic women face an additional challenge. When they reveal their diagnosis, to appeal for support and accommodations, they may face the stigma of not being a good enough parent due to their neurodivergence. Conversely, they may hide their diagnosis from healthcare professionals, to avoid such stigma. This may, however, expose them to a different type of judgment. Lack of eye contact and social communication struggles are often unfairly judged as "cold" behavior, as it contrasts to preconceived notions of what a mother should look like.

## Against the odds

Despite the stigma, despite the challenge of breastfeeding with an overwhelmed sensory system, many autistic mothers breastfeed successfully. It is left to speculation (rather than having solid statistics) until studies provide any estimate of success or failure. What can be reasonably conjectured is that most of these women need better support.

Support (accepting of the unique parenting style of autistic mothers) could mean more babies are breastfed for prolonged periods of time. When one considers autism with its challenging symptoms and concomitant medical conditions (like gastrointestinal disorders occurring in up to 84% of children on the spectrum) it makes sense to encourage breastfeeding for infants who may have an elevated genetic ASD risk. 18

# The missing ingredient in breast milk

When dealing with mothers who want to breastfeed, particularly neurodivergent mothers, healthcare professionals and lactation consultants should aim for an empathetic, holistic approach. This may be challenging for those who are not familiar with neurodivergent conditions like autism–especially the different ways it presents in women. Camouflaging to avoid ASD stigma, girls and women are often missed or misdiagnosed by doctors.<sup>19</sup>

When healthcare professionals are knowledgeable, and accepting of neurodivergence, their support may be especially beneficial for the unique needs of this population. As a practical example, an autistic mother who plans to breastfeed should be made aware of the importance of vitamin D and the consequences of deficiencies of this important vitamin in breastfeeding.

Vitamin D, the so-called sunshine vitamin, has an alarming deficiency prevalence. Breastfeeding women are at a higher risk of vitamin D deficiency in comparison to non-breastfeeding women.<sup>20</sup>

The fetus (and newborn baby) will be affected by maternal vitamin D concentrations; a mother who is deficient will be breastfeeding from a depleted level and without supplementation the baby will also be deficient in this vital vitamin.

This may be especially concerning for parents of autistic children, or mothers with a higher genetic risk of having a baby with autism. Results from a recent study seemed to confirm an increasing body of evidence suggesting early childhood concentrations of vitamin D may be involved in an increased risk of neurodevelopmental conditions like autism spectrum disorder.<sup>21</sup>

Research details the incredible results from an open trial study where about 80% of children showed improvement in core autism symptoms with high dose vitamin D.<sup>22</sup> The connection between vitamin D deficiency and autism will need further investigation and more research, but mothers should be made aware of the risks and vulnerable groups may need to be advised about supplementation.

## The complicated benefits of breast milk

The protective benefits of breast milk with respect to ASD seem clear. There are even suggestions of protection against gastrointestinal problems which most children on the spectrum experience—and gastrointestinal issues are thought to increase the severity of autism symptoms.

For women's health, breastfeeding offers protection against breast cancer, and it might also protect against ovarian cancer and type 2 diabetes.<sup>22</sup> But breastfeeding is complicated, and such benefits may matter little when core autism symptoms interfere with any attempt by the mother.

## Healthcare: accommodating neurodivergence

For autistic adults in general, and autistic mothers in particular, the barriers to accessing healthcare can be substantial. Healthcare providers, including those in the mental health field, may be unfamiliar with the needs and challenges specific to autistic patients.

Most autistic individuals are highly averse to making phone calls; a health care provider's reliance on phone calls and other traditional methods of communicating may create barriers to access.<sup>23</sup> This is but one simplistic example demonstrating how healthcare providers' ignorance of neurodivergence can be disabling for autistic individuals.

Improving access to care and improving the quality of care for a neurodivergent population requires sensitivity training for the health care practitioner. Broadening these skills should include but not be limited to:

- Providing sensory considerate care (communicating what an exam involves before touching the patient and understanding that their "pain threshold" may differ substantially from that of the neurotypical patient).
- Cultivating a wider spectrum of communication skills including: asking clear, concrete questions; allowing for atypical processing times when asking such questions; and an understanding of the differing response methods nonspeaking individuals on the spectrum may employ, ranging from sign language to communication programs on devices like an iPad.
- It may be helpful to provide alternative, accessible forms of communication when appropriate (longer appointments, text-based communication or visual aids, for example).<sup>24</sup>

#### Conclusion

Most autistic women want more judgment-free information about breastfeeding, they need more support tailored to their neurodivergent needs and acceptance of decisions made in the best interest of their babies.<sup>25</sup>

For the autistic adults, part of the initial CDC prevalence statistics, parenting challenges may be significantly less when stigma is removed and support is increased, especially amongst the healthcare providers that serve this population. Autistic women should receive care that takes their unique support needs into consideration. Such support should be extended to autistic fathers too, another group whose experience and needs warrant more attention.

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