Providing Effective and Specialized Care to Autistic Women During Breastfeeding and Lactation
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Background
Over the last decade, there has been an increased awareness and diagnosis of Autism Spectrum Conditions (ASC) in both children and adults. However, the diagnosis among females of all ages is disproportionately low compared to males. There is minimal data on the experiences of autistic women during the reproductive years, specifically during breastfeeding and lactation. Lactation clinicians are not adequately equipped with research to provide effective and specialized care for the breastfeeding autistic woman.

Methods
- A review of the literature was completed utilizing PubMed, Cochrane Review, and Google Scholar platforms.
- The author consulted with a family practice medical provider and doctor of psychology student to design two online surveys.
- Lactation Sensory Survey was designed to collect comparative data on sensory experiences during breastfeeding and lactation. There were 94 respondents, 10 participants identified as autistic and 84 identified as non-autistic.
- Lactation Spectrum Survey was designed with a focus on the autistic woman’s breastfeeding and lactation experience. There were 18 respondents, 14 participants identified as autistic and 4 identified as non-autistic.

Data
- 80% of the autistic women surveyed did not share their autistic identity with their providers.
- 75% of participants would prefer their HCP inquire about their autism on a form or during a face to face interaction.
- 68% of autistic women surveyed experienced an increased intensity in their preferences and/or aversions during breastfeeding.
- *17,900:3 Ratio of literature on “breastfeeding experiences of women” to “breastfeeding experiences of autistic women”
- 100% All respondents agreed that an abbreviated questionnaire pertaining to neurodiversity and sensory preferences/aversions would be helpful to a new mom.

Results
- “The touch of skin on skin was almost intolerable.”
- “The smell of my own milk was overwhelming.”
- “Making eye contact with my baby or anything that required me to respond non-instinctually was difficult.”
- “The sound of my infant crying was intolerable.”

50% of autistic women surveyed sought support via social media and 44% found no support at all.
Undiagnosed women may be excluded from medical, social, and financial services.
“Difficulties are frequently mislabeled or missed entirely” (Lai and Baron-Cohen, 2015).

Providers are left to rely on anecdotal and peripheral research.
There are no guidelines or recommendations for autistic women who are breastfeeding.

Conclusions
The breastfeeding challenges among both autistic and non-autistic women surveyed were similar. However, the autistic woman must also navigate the overwhelming sensory experiences, healthcare interactions, and lack of credible support resources.

Preliminary considerations for the lactation clinician include awareness and assessment of sensory involvement. Near term advancement of research and collaboration is critical to the long term success of supporting the autistic woman during breastfeeding and lactation.

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*Approximate number of lit search results for the 2010-2020 time frame as of May 10, 2020.

All information conforms to the International Code of Marketing of Breastmilk Substitutes and WHA/WHO Resolutions.
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