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2019

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citation for published version (APA)

Waltz, M., & Syurina, E. (2019). *Women with autism: Exploring healthcare and health outcomes disparities*. Poster session presented at Autisme Europe conference 2019, Nice, France.

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Women with autism: Exploring healthcare and health outcomes disparities

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Introduction

People on the autism spectrum are disproportionately affected by health and healthcare disparities, including in areas of health unrelated to autism, such as gynecological care. These can have a lifelong negative impact, including contributing to premature death.

There are also disparities between males and females with autism in relation to diagnosis and to access, duration and success of therapies. However, research is still lacking on the extent to which sex, gender, and dynamics regarding the development of gender identity of individuals with ASD have a determinant impact on these disparities, and how these variables may intersect with other dynamics, such as age.

Research methods

This project began with a scoping study using data from the National Autism Registry (NAR), followed by focus groups, interviews and questionnaires. This data will be used to map pathways to care for males and females with autism, and to identify possible barriers and enablers that are specific to women.

Research question:

How do natal sex and gender identity impact diagnosis, treatment and health outcomes for natal female individuals with autism across the lifespan in the Netherlands?

Sub-questions:

- Is there a different diagnostic pathway for male and female clients with autism?
- What needs do women with autism express in relation to diagnosis and treatment of autism and co-morbid conditions, and are they satisfied with how these needs are met?
- Can sex-related barriers and facilitators and gendered norms be located within the diagnostic process, and if so, what are they?
- How do sex-related barriers and facilitators and gendered norms impact on structure, quality and success rates of therapeutic procedures for autism and co-morbid conditions in relation to women with autism?
- What additional information is generated when the diagnostic and treatment experiences of natal females with autism are re-analysed with regards to intersectionality with self-reported gender identity or (older) age?
- How can this knowledge be used to improve the pathway to and through care for women with autism in the Netherlands?

First results

- Gender makes a difference in the form of autism diagnosis received, and in increased diagnostic delay.
- Women (not parents/teachers) are more likely than men to start the diagnostic process themselves.
- Women are more likely to have another psychiatric diagnosis before ASD diagnosis—sometimes incorrectly.
- Women are more likely to have comorbid diagnosis of depression, bipolar disorder, suicidality, dysthemic disorder, eating disorders, PTSD, trauma and combined tics/OCD/anxiety conditions. We did *not* find a higher prevalence of borderline personality disorder in female database sample.
- Women with autism are more likely to take psychiatric medication than men.
- Significantly more women than men reported having allergies, stomach and bowel disorders, headaches, tiredness and sleep problems—but less likely to have sleep disorder diagnosis.
- Significantly more women reported using alternative medications/supplements than men (but not homeopathy or special diets).
- Women are slightly less satisfied with their lives overall than men.

We are currently exploring these results through focus group discussions with women who are on the autism spectrum, in collaboration with autistic research partners.