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Autism in females and males

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Document Version

Publisher's PDF, also known as Version of record

Publication date:

2019

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Henning, D., Piening, S., Groen, Y., Greaves-Lord, K., Stapert, A. F., Euser, A. M., Davids, R. C. D., Castelein, S., & Balkom, van, I. (2019). *Autism in females and males: similarities and differences*. Poster session presented at 19e Nationaal Autisme Congres, Rotterdam, Netherlands.

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Elucidating Female Autism Study (EmFASiS): Preliminary results of a qualitative study.

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Aim

To understand the female autism phenotype.



Background

Recent research in Autism Spectrum Disorders (ASDs) shows females are more often affected than previously assumed. Compared to males, females seem to show and experience a different symptom-profile. Late recognition of autism in females often leads to increased and/or prolonged individual distress, decreased societal participation, and emergence of comorbidity.

Methods

- A qualitative study design using face-to-face semi-structured interviews.
- An interview guide was developed with service-users, clinicians, and researchers, which
- It covers three key themes: experiences with (1) diagnostic process and treatment (2) ASD symptom presentation (3) social roles.
- Audio-recorded and verbatim-transcribed.
- Inclusion criteria: ≥ 18 years, formal ASD diagnosis.
- Aim: $n = 30$ adults with autism, data collection is ongoing.

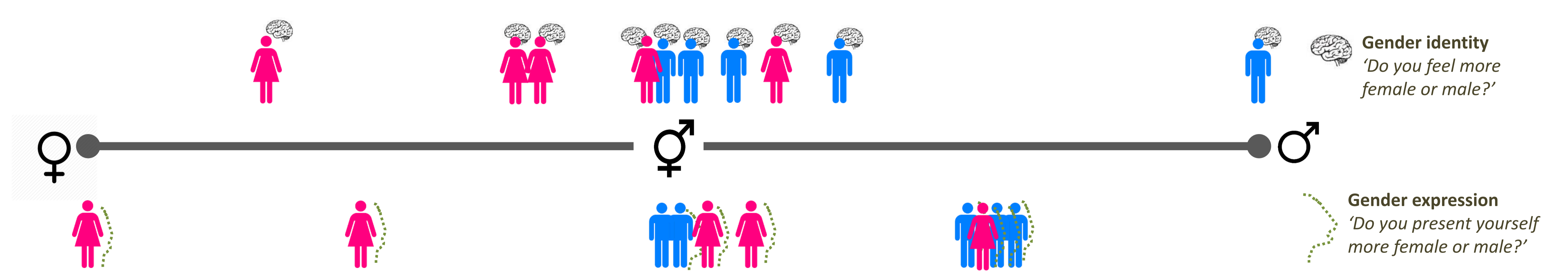
Preliminary results

Demographics

Current sample size is $N=10$ ($n=5$ females; $n=5$ males).

Mean age was 39.8 years (range 27-60; SD 10.4) and mean age at first diagnosis was 34.6 years (range 26-57; SD 11.1).

	Experiences with Diagnostics	Experiences with Symptoms	Experiences with Social roles
<p><i>"The diagnosis was a relief. I was finally able to continue and build up my life, instead of being depressed about why everything did not work out."</i></p> <p><i>"People know the stereotypical image of autism, and this seems to be very dominantly present in the thinking of humans and society. But this image isn't me."</i></p> <p><i>"For me autism means having a different life with certain limitations, but also with unpre-cedented opportunity if you have high functioning autism."</i></p>	<p>Females and males reported histories of varied comorbid diagnoses such as mood and anxiety disorders, PTSD, personality & eating disorders.</p> <p>Participants considered the time before first diagnosis as most stressful, as their symptoms could not be readily understood. Some felt stigmatized by erroneous earlier diagnoses.</p> <p>Females and males experienced mixed emotions at first diagnosis. Most felt relief and identification, some perceived resistance or neutrality.</p>	<p>Females and males reported feeling different early in life and experiencing various undefined symptoms.</p> <p>Reasons for seeking help were: 1) psychological complaints such as emotion regulation problems, work/study related problems; 2) unexplained physical complaints such as fibromyalgia, chronic fatigue.</p> <p>Females and males perceived their autism as positive (11%), negative (0%), neutral (45%) or both (44%).</p>	<p>Females and males reported small social networks. Significant others were: first-degree family members, a partner (if applicable) & friend(s).</p> <p>Participants reported that certain roles changed over time. Generally, the roles of employee or caregiver were most challenging. One participant described the parental role as most demanding.</p> <p>Some participants did not find the concept of social roles important, and perceived themselves as being themselves.</p>
<p><i>"I had a lot of physical pain...I could hardly sit on a chair, all my joints hurt, I had no strength in my hands and arms...but the doctors told me they could not find anything, so I could not have rheumatism..."</i></p> <p><i>"As an employee I want to do my work well...I have had positive and negative experiences...but I felt little respected and appreciated."</i></p> <p><i>"What I wanted to be and what I was is too dissimilar. A role has to be precise and needs to make sense."</i></p>			



Preliminary conclusion

- Females and males generally reported similar symptoms but of varying severity. Both females and males had a history of erroneous previous diagnoses and were all diagnosed with ASD in (early) adulthood. Some participants had suspected for a long time that their symptoms might be related to autism, whereas others had not and were surprised by the diagnosis.
- Most participants reported fairly neutral gender identities, while gender expression was more varied.
- Females reported more societal and intrinsic pressure regarding social skills. Males' attitudes towards societal expectations were more autonomous.

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