Eating behaviors of Women with an Eating Disorder and Autism Spectrum Disorder

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The goal of this study is to gain insight into the eating behaviors of women with an eating disorder (ED) and comorbid autism spectrum disorder (ASD). By comparing this group to two other groups (women with an ED but without ASD and women with an...

Ethical review	Approved WMO
Status	Completed
Health condition type	Other condition
Study type	Observational non invasive

Summary

ID

NL-OMON49878

Source
ToetsingOnline

Brief title
Eating behaviours of women with ED and ASD

Condition

- Other condition
- Eating disorders and disturbances

Synonym
Autism spectrum disorder, eating disorder

Health condition

Autismespectrumstoornissen

Research involving
Human

Sponsors and support

Primary sponsor: Universiteit Utrecht
Source(s) of monetary or material Support: Ministerie van OC&W

Intervention

Keyword: Autism spectrum disorder, Eating behaviors, Eating disorders, Psychiatric complaints

Outcome measures

Primary outcome

Cross-sectional investigation with one time measurement of disturbed eating behaviors such as disordered eating (EDE-Q - Eating Disorder Examination Questionnaire), picky eating behavior (APEQ - Adult Picky Eating Questionnaire), eating disturbances found in avoidant restrictive food intake disorder (ARFID) (NIAS - Nine Item ARFID Screen) and ASD specific eating disturbances (SWEAA - Swedish Eating Assessment for Autism Spectrum Disorders).

Secondary outcome

Eating behaviors (as mentioned under primary study parameters) in relation to general psychiatric complaints (BSI - Brief Symptom Inventory), neurocognitive functioning (D'Flex - Detail and Flexibility Questionnaire) and quality of life (MHQoL - Mental Health Quality of Life).

Other parameters that are taken into account in the analyses are age, illness duration, age of onset, BMI, educational level and other comorbidities.

Study description

Background summary

Eating disorders (ED) are serious and often fatal illnesses that are associated with severe disturbances to a person's eating behavior and related thoughts and emotions, accompanied by a preoccupation with food, body weight and shape (American Psychiatric Association, 2013). While EDs do not discriminate between gender, age and ethnicities (Marques et al., 2011), most sufferers are women (Keski-Rahkonen & Mustelin, 2016). Reports of lifetime prevalence rates of EDs range between 1 and 8.4% (Galmiche et al., 2019; Keski-Rahkonen & Mustelin, 2016), with anorexia nervosa (AN) being associated with the highest mortality rate among all mental disorders (Smink, van Hoeken & Hoek, 2012).
Among other personal and behavioral issues, a substantial amount of people with EDs display difficulties with rigidity (Danner et al., 2012; Dingemans et al., 2015; Aloi et al., 2015) and social impairments (Mandy & Tchanturia, 2015). These issues often go hand in hand with other psychiatric comorbidities that are thought to hamper treatment and subsequently impede recovery (Keshishian et al., 2019; Franko et al., 2018; Welch et al., 2016; Keski-Rahkonen & Mustelin, 2016). One of these comorbidities is autism spectrum disorder (ASD). Based on the apparent symptomatic overlap between these disorders that has been found on neurocognitive, behavioural and personal levels, a large body of literature has recently focused on the role and clinical implications of ASD and ASD traits that are repeatedly found in ED samples (Dell*Osso et al., 2018; Huke et al., 2013; Karjalainen et al., 2019; Nickel et al., 2019; Westwood & Tchanturia, 2017). Problems with communication (Treasure, 2013), cognitive rigidity (Danner et al., 2012; Aloi et al., 2015), restrictive and repetitive behaviours (Treasure, 2012) and perfectionism (Treasure, 2013) been reported as commonalities, as well as social impairments such loneliness, isolation and shyness (Krug et al., 2013; Fairburn, Cooper, Doll & Welch, 1999).
Reported prevalence rates of ASD and ASD traits in ED samples vary between 4% and 52.5% (Nickel et al., 2019; Dell*Osso et al., 2018; Westwood & Tchanturia, 2017; Huke et al., 2013), suggesting an overrepresentation of ASD and ASD traits in ED samples. This broad range of reported ASD and ASD traits can be attributed partly to the use of various diagnostic measures that handle diverse criteria and thresholds: With ASD officially being a pervasive neurodevelopmental disorder, one of its criteria is the onset of ASD traits to be during the early developmental period (American Psychiatric Association, 2013). Studies using parental reports to determine the presence of these traits during that time, often report much lower rates (Westwood, Mandy, Simic & Tchanturia, 2018; Rhind, Bonfioli, Hibbs, Goddard & Macdondald, 2014; Pooni, Ninteman, Bryant, Nicholls & Mandy, 2012). On the other hand, studies that used self-report measures like the Autism Spectrum Quotient (Baron-Cohen et al., 2001) or semi-structured assessments like the Autism Diagnostic Observation Schedule (Lord et al., 2012) to observe characteristics associated with ASD, do not handle this criterium and often report higher rates of ASD traits. Another issue in the investigation of ASD and ASD traits in ED populations is that ASD often presents itself often differently in women compared to men on various cognitive-behavioural domains (Hull et al., 2017; Lai et al., 2015; Lai & Baron-Cohen, 2015): Women with autism are thought to have a stronger use of strategies to compensate for and mask autistic characteristics during social

interaction called camouflaging (Hull et al., 2019), less restrictive and repetitive behaviors (Lai et al., 2015; Supekar & Menon, 2015) and different special interests (Halladay, Bishop & Constantino, 2015). In the past, diagnostic assessments such the DSM-5 criteria or the ADOS-2 have been validated with males ((Westwood & Tchanturia, 2017), not taking gender differences into account. This oftentimes resulted in females being not at all or diagnosed much later than men (Rynkiewicz et al., 2016). This difficulty has recently led to the investigation of the female ASD phenotype and subsequently to the development of diagnostic instruments that specifically take characteristics of the female autism phenotype into account (e.g. M-ASD; Bezemer & Blijd-Hoogewys, 2016). With ED populations reporting a much bigger female to male ratio compared to gender ratios in ASD where there are 3,5 males for every female (Loomes et al., 2017), assessing ASD and ASD traits in ED populations therefore poses an extra difficult task. In light of these obstacles regarding the assessment of ASD traits in ED populations, the discussion remains whether these found traits were already premorbidly present to the start of the ED, possibly even playing a role in the development of the ED (Gillberg, 1985; Tchanturia et al., 2004), or whether they are a consequence of the EDs themselves, for example through starvation effects in anorexia nervosa (Keys et al., 1950; Oldershaw et al., 2011).

But regardless of whether these traits are epiphenomena of the ED itself or are indications of an ASD existing next to the ED, the presence of them has serious clinical implications for patients. Although there is still a lack of research in this area, elevated ASD traits have been associated with a more severe presentation of the ED and subsequently with poorer treatment outcome (Kinnaird et al., 2017, 2019; Nielsen et al., 2015), often requiring an augmentation of standard treatments (Stewart et al., 2017; Tchanturia et al., 2016). A qualitative study by Kinnard et al. (2019) suggests that women with an ED and elevated ASD traits might have unique needs that relate to their autistic traits and require an adaptation to treatment. It is possible that the rigidity and inflexibility associated with their ASD contributes to the development of their ED, where the need for control, rigid thought patterns and sensory difficulties play a greater role than body image issues and a desire to lose weight (Kinnaird et al., 2019). When treatments are thus aimed at changing apparent ED behaviours that are in fact related to their autism, recovery can stagnate (Kinnaird et al., 2019). A way to tackle this is to gain more knowledge on how the eating patterns and behaviours of women with an ED and comorbid ASD actually look like and how they compare to women with an ED without ASD. Little to no research has yet looked into the specific eating behaviours of ED patients with comorbid ASD. When approaching from a different angle, there has been some documentation on eating behaviours of children with ASD, who appear to be five times more likely to have feeding related problems compared to age-matched controls (Sharp et al., 2013). Their eating behaviours vary from food selectivity to refusal, food neophobia, sensory sensitivity with regard to certain foods and problems around meal time behaviours (Postorino et al., 2015; Sharp et al., 2013), resembling behaviours and attitudes with regard to food often found in people with avoidant restrictive food intake disorder

(ARFID) (Hay et al., 2017). Regarding eating behaviours of adults with ASD however, documentation is scarce, as most studies have either focused on children or on people with intellectual impairment. Spek and colleagues (2019) recently investigated eating behaviours of men and women with ASD and compared these to age-matched controls. Their results indicated that men and especially women with ASD experience significantly more eating problems than controls, such as having eating rituals, sensory sensitivities, experiencing difficulty to eat among other people, problems with mealtime surroundings and adapting their eating behaviour to their social environment. Here, women with ASD also reported significantly more charac

Study objective

The goal of this study is to gain insight into the eating behaviors of women with an eating disorder (ED) and comorbid autism spectrum disorder (ASD). By comparing this group to two other groups (women with an ED but without ASD and women with an ASD but without an ED), it will also be investigated if and how their eating behaviors are differed compared to women with an ED but without ASD and compared to women with an ASD but without an ED. In addition to that, we will investigate whether the eating behaviors of women with an ED and comorbid ASD relate to other general psychiatric complaints and how they relate to problems with regard to daily and neurocognitive functioning and quality of life.

Study design

Observational cross-sectional study that will involve at least 80 female participants, 18 years or older: 30 with an ASD, 30 with an ED and at least 20 with an ED and ASD, as this group will be harder to collect, that will be recruited with the help of clinicians on two different study locations (Altrecht Eating disorders Rintveld and the Autism Expert Centrum). Participants will be asked to take part in a one time online assessment containing various questionnaires about picky eating behavior, ARFID related eating behaviors, disturbed eating behaviors, ASD specific eating behaviors and other general psychiatric complaints, problems with daily and neurocognitive functioning and quality of life.

Study burden and risks

Participants are asked to take part in a one-time only interview and to fill in some questionnaires, which will take max. 65 minutes. The burden can therefore considered to be low and no risks are associated with participation. It is thus our opinion that benefits of this study outweigh the risks.

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Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age
Adults (18-64 years)
Elderly (65 years and older)

Inclusion criteria

In order to be eligible to participate in this study, participants must meet all of the following criteria: participants will be included if they are female and 18 years of age or older. We will collect three groups of participants: participants with a sole diagnosis of ASD (ASD group), participants with a sole diagnosis of ED (ED group) and participants with an ASD and ED diagnosis (ED and ASD group). For the ED and ASD group, participants need to have a diagnosis of either anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED) or other specified feeding- or eating disorder (OSFED) and a comorbid ASD diagnosis. For the ED group, participants need to have one of the above mentioned ED diagnoses. For the ASD group, participants need to have an ASD diagnosis. Diagnosis are determined according to DSM-5 criteria by an

experienced clinical professional (psychiatrist or clinical psychologist).

Exclusion criteria

Potential participants who meets any of the following criteria will be excluded from participation in this study: For all groups, we exclude participants with level of education below basic primary education (NL: basisonderwijs), with mental retardation and insufficient knowledge of the Dutch language. Additionally, participants of the ASD group are not allowed to have (a history of) of one of the above mentioned eating disorders, unspecified feeding or eating disorder (UFED), Pica or avoidant restrictive food intake disorder (ARFID) and participants of the ED group are not allowed to have ASD or traits thereof. This will be assessed before the actual participation in the study.

Study design

Design

Study type: Observational non invasive

Masking:	Open (masking not used)
Control:	Uncontrolled
Primary purpose:	Diagnostic

Recruitment

NL

Recruitment status:	Completed
Start date (anticipated):	12-11-2020
Enrollment:	80
Type:	Actual

Ethics review

Approved WMO

Date:	11-11-2020
Application type:	First submission
Review commission:	METC NedMec

Study registrations

Followed up by the following (possibly more current) registration

No registrations found.

Other (possibly less up-to-date) registrations in this register

ID: 20463
Source: Nationaal Trial Register
Title:

In other registers

Register	ID
CCMO	NL74635.041.20