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A Case Series on Disordered Eating Among Transgender Youth With Autism Spectrum Disorder



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A B S T R A C T

Transgender youth with autism spectrum disorder (ASD) may experience complex relationships with eating because of cognitive rigidity, including inflexible thoughts and behaviors around food and/or their body. Yet, there is no research that provides guidance to clinicians providing care for youth with the unique triad of gender dysphoria, ASD, and disordered eating. This case series discusses trends in presentation and management of three cases from a multidisciplinary gender care clinic. All three individuals endorsed rigid thoughts around food and/or body appearance, which affected nutritional intake; however, their presenting eating disorder behaviors, described etiology for disordered thoughts, diagnosis, and level of engagement in a multidisciplinary treatment model varied. Based on these cases we hypothesize several strategies including early engagement with ASD specialists, proactive screening and discussions around eating with all transgender youth with suspected/confirmed ASD, continued discussions throughout care, as disordered eating behaviors may change after the initiation of gender-affirming medications, dietician visits early in treatment regardless of endorsed thoughts and behaviors, tailored management to the unique needs of each individual and their eating thoughts/behaviors, and consistent multidisciplinary collaboration.

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IMPLICATIONS AND CONTRIBUTION

Both young people with autism spectrum disorder and young people with gender dysphoria are at heightened risk for disordered eating. Young people with all three conditions present complex cases that require care tailored to each patient.

Youth with autism spectrum disorder (ASD) and youth with gender dysphoria are at higher risk of disordered eating compared with general population youth [1–10]. These two populations overlap epidemiologically, with literature

suggesting an overrepresentation of ASD in adolescents with gender dysphoria and vice versa [11–15]. Prior studies have explored relationships between gender dysphoria and ASD, disordered eating and gender dysphoria, and disordered eating and ASD in adolescents [1–14]. To our knowledge, no extant studies describe presentations of youth with disordered eating, gender dysphoria, and ASD. The aim of this case series is to better elucidate trends in the presentation of youth with this triad to inform care for this unique group.

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Table 1
Details of cases

Case	1	3	3
Age at initial visit	14	17	15
Assigned sex at birth	Female	Male	Male
Gender identity (pronouns)	Transmasculine (he/him)	Transfeminine (she/her)	Transfeminine (she/her)
Gender-affirming hormones	Testosterone started shortly after first gender appointment	Estradiol started shortly after first gender appointment	Estradiol started shortly after first gender appointment
Gender-affirming surgeries	None	None	None
Mental health diagnoses and concerns at initial appointment	History of anxiety, depression, OCD. Endorsed self-harm, passive suicidal ideations, and passive homicidal ideations.	History of anxiety, depression, and ADD. Endorsed passive suicidal ideations.	History of anxiety and depression.
Initial disordered eating behaviors	Restrictive eating to attain specific body appearance/shape	Restrictive eating associated with lack of self-care and motivation	Restrictive eating associated with rigid food preferences
Initial eating disorder diagnosis	Other specified feeding or eating disorder	Unspecified eating disorder	Avoidant restrictive food intake disorder
Changes in disordered eating after establishing care	Increase in appetite and intake with testosterone and eventual binge eating	Improvement in intake and eventual return to restrictive eating to attain specific body appearance/shape	None
Endorsed desire to lose weight associated with gender goals during course of treatment	Yes	Yes	No
Initial visit BMI z-score ^a (percentile) and percent estimated treatment goal weight (eTGW) ^b	BMI: +.5 (69.0) % eTGW: 94.5	BMI: −2.4 (.8) % eTGW: 84.2	BMI: +.6 (71.9) % eTGW: 94.7
General BMI and % eTGW trend after establishing care	Gradual increase in BMI to a maximum z-score of +1.84 and 128.2% eTGW after starting testosterone and endorsing binge eating	Gradual decrease in BMI to a minimum z-score of −2.76 and 81.2% eTGW then gradual increase in BMI to a maximum z-score of −.56 and 103.8% eTGW after family care conference, assistance of dietician, and initiation of olanzapine. Later decrease in BMI to −1.53 and 95.7% eTGW after return of restricting behavior to acquire more feminine appearance	Gradual decrease in BMI to a minimum z-score of −.43 and 89.1% eTGW after parent limited "junk food" intake and then increase to BMI z-score of +.02 and 94.9% eTGW with assistance of dietician
Dietician involvement	Established care with a dietician shortly after first gender appointment, but declined services after initial visit until he became concerned with binge eating and weight gain approximately 1.5 years later	Established care with a dietician soon after first gender appointment with follow-up as frequently as every 2 weeks	Initially declined nutrition services until BMI declined and then saw a dietician approximately every 2 months
DEXA results	Not done	Low BMD. Total BMD z-score −3.6. Total body fat 32.4% of total body weight.	Low BMD. Total BMD z-score −2.7. Total body fat 50.5% of total body weight.
Autism involvement	Referral placed at first gender appointment because of concerns from therapist. First appointment in Autism Center 7 months later.	Referral placed at first gender appointment because of concerns from therapist. First appointment in Autism Center 1 year and 9 months later.	Diagnosed with ASD before first gender appointment. Referral placed at first gender appointment at request of parent to gain further insight and resources. First appointment in Autism Center less than 1 month later.
Autism spectrum disorder (ASD) diagnosis	ASD without intellectual disability and impairments include: Deficits in social–emotional reciprocity Deficits in nonverbal communicative behaviors used for social interactions Deficits in developing, maintaining, and understanding relationships Stereotyped or repetitive motor movements, use of objects, or speech Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior	ASD without intellectual disability and impairments include: Deficits in social–emotional reciprocity Deficits in nonverbal communicative behaviors used for social interactions Deficits in developing, maintaining, and understanding relationships Stereotyped or repetitive motor movements, use of objects, or speech Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior	ASD without intellectual disability and impairments include: Deficits in social–emotional reciprocity Deficits in nonverbal communicative behaviors used for social interaction Deficits in developing, maintaining, and understanding relationships Stereotyped or repetitive motor movements, use of objects, or speech Insistence on sameness, inflexible adherence to routines or ritualized patterns of verbal or nonverbal behavior

Table 1
Continued

Case	1	3	3
	Highly restricted, fixated interests that are abnormal in intensity or focus	Highly restricted, fixated interests that are abnormal in intensity or focus	Highly restricted, fixated interests that are abnormal in intensity or focus
	Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment	Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment	Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment such as textures
ASD severity specifiers	Social communication impairment: level 1; mild	Social communication impairment: level 2; moderate	Social communication impairment: level 2; moderate
	Restricted or repetitive patterns: level 1; mild	Restricted or repetitive patterns: level 1; mild	Restricted or repetitive patterns: level 2; moderate
Social Responsiveness Score ^c	Total T score 59; within normal range	Total T score 58; within normal range	Total T score 77; severe range of impairment
Autism Center Recommendations	Since patient responded well to dialectical behavioral therapy (DBT) with community therapist and over time developed a range of strategies to manage social discomfort and improve social skills, recommended continued therapy with someone who has experience in gender dysphoria and ASD and provided resources and referrals for ASD groups and individual Autism Center cognitive behavioral therapy (CBT) sessions addressing social cues, understanding of setting events, and executive functioning skills.	Recommended interventions aimed at improving ASD symptoms such as social skills training and CBT to reduce symptoms of depression and anxiety while improving social engagement and skills. Provided a list of recommendations and resources such as learning strategies and referrals for ASD groups.	Recommended individual psychotherapy with help navigating situations related to gender and social interactions while also addressing symptoms of anxiety and depression. Recommended CBT to help with promoting executive functioning skills and adaptive skills that allow for emerging independence as an adolescent. Provided referrals for ASD groups and recommended individual therapy in the Autism Center to target challenges with impulsivity, social communication, and mood regulation

BMD = bone mineral density.

^a Body mass index (BMI) z-score is a standard deviation score widely used in anthropometry to quantify a measurement's distance from the mean for a child's age and sex assigned at birth.

^b Estimated treatment goal weight (eTGW) is determined by an individual's previous growth curve trends in weight and BMI.

^c This table does not include all diagnostic scores because the ASD assessment and workup is tailored to each individual person.

Methods

A team of gender-affirming medical providers, a psychologist with ASD specialization, a dietician, and social workers completed a retrospective medical records review of three patients with gender dysphoria, ASD, and disordered eating who established care between January 2018 and January 2019 at Seattle Children's Gender Clinic (SCGC). SCGC is a multidisciplinary clinic that provides collaborative care with Seattle Children's Autism Center (SCAC). Seattle Children's Hospital institutional review board approved this study.

Results

Table 1 contains case presentation and treatment course details.

Case 1

Fourteen-year-old, transmasculine. On intake at SCGC, the patient endorsed a history of depression, self-harm, suicidal ideations, and obsessive-compulsive disorder. Before SCGC care, the patient participated in dialectical behavioral therapy (DBT) with a community therapist who recommended an ASD evaluation [16]. A referral to SCAC was placed at the first SCGC appointment. Seven months later, the patient was diagnosed with ASD and received resources and recommendations. Wait time for assessment of ASD in the

greater Seattle area is typically 12–16 months. Seven months later, he returned to SCAC for one cognitive behavioral therapy session to address social pragmatic and executive functioning skills [17].

At his first SCGC appointment, the patient endorsed calorie counting, restriction of intake to one meal a day, and elimination of high-fat and high-sugar foods to lose weight and minimize body curves. He saw a dietician for one appointment then declined follow-up because he felt his DBT skills were sufficient to address disordered eating. After starting testosterone, the patient noted a common effect of testosterone not addressed in many consent or medication guides: an increase in appetite. Initially, he experienced guilt around his intake, but these feelings improved with DBT skills and learning that increased appetite was expected with testosterone.

The patient was seen at SCGC every 3 months and his body mass index progressively increased over time. One year after starting testosterone, body mass index had increased from the 69th to the 96th percentile. At this time, the patient's mental health had improved with decrease in suicidal ideations, but he now described mood-related binge eating. His SCGC medical provider recommended re-establishing care with a dietician and discussed binge eating with the patient's therapist. Patient again declined seeing a dietician. The patient subsequently endorsed a decrease in frequency of binge eating with the help of therapy. In the last visit included in this chart review, because of the patient's concerns with persistent weight gain, he reestablished care with a dietician.

Case 2

Seventeen-year-old, transfeminine. On intake, patient endorsed a history of anxiety, depression, and passive suicidal ideations. Her community therapist recommended an ASD evaluation and a referral was placed at the first SCGC appointment. The patient attended a single visit in SCAC approximately 21 months later where she received a diagnosis of ASD as well as resources and recommendations. By the time of completion of chart review for this patient, she had not attended any follow-up visits at SCAC.

At her initial SCGC appointment, patient endorsed “picky eating” beginning in childhood with aversions to certain tastes and textures. The family was told by multiple physicians that she was low weighted. The patient was eating one meal a day and identified the main barrier to eating as being “lazy.” Family described her lack of nutrition as being associated with worsening self-care and noted infrequent showering as another example. Initially, she denied concerns with her weight/body shape. The SCGC medical provider discussed optimization of estrogen effects with adequate nutritional intake and the patient established care with a dietician. The family struggled to implement structure with administering meals and patient endorsed low motivation to autonomously increase intake. Patient continued to lose weight to a level of severe malnutrition. A care conference was held with the patient’s parents, medical provider, dietician, and community therapist to provide consistent messaging regarding concerns with the patient’s level of malnutrition. After the care conference, the patient established care with an eating disorder therapist and a psychiatrist who started the patient on olanzapine and later, fluoxetine. Eventually, the patient showed persistent weight gain with improvement in family support around meals and additional mental health and eating disorder care. Approximately one and a half years after the start of gender-affirming medical care, in the last visit included in this chart review, weight had begun to down trend. The patient endorsed wanting to be thin to pass as a female.

Case 3

Fifteen-year-old, transfeminine. On intake at SCGC, the patient endorsed a history of anxiety and depression and a prior ASD diagnosis. The patient had a community therapist with ASD expertise. The parent requested a referral to SCAC for resources for an emerging adult with ASD. Approximately 1 month after her first SCGC appointment, SCAC reconfirmed an ASD diagnosis and provided a list of resources and recommendations. She attended one session at SCAC to receive psychoeducation on increasing independent living skills.

At her first SCGC appointment, patient endorsed a longstanding history of limited food variety, eating a preferred food until fatigued and then eliminating it from her diet. Although patient denied, her parent endorsed aversions to certain textures and smells. Throughout care, patient denied concerns with weight/body shape. The family initially declined seeing a dietician, but at her follow-up SCGC appointment, she had lost 3 kg over 3 months. The family attributed the weight loss to parent-driven restriction of “junk food.” The parent’s intent was to eliminate these foods to be healthier, but this decreased overall intake because of limited food preferences. The family saw a dietician who recommended increasing nutritional intake with preferred foods to prioritize meeting baseline energy needs to

promote weight stabilization and decrease prioritization of achieving balanced meals. During the course of follow-up, patient was able to increase nutritional intake once parent and patient learned that all foods are good for a person’s health. After the patient achieved weight stabilization, the dietician recommended food exposures to increase diet variety.

Discussion

These cases highlight a spectrum of care needs for youth with gender dysphoria, ASD, and disordered eating. Although each youth presented differently, in all three cases, beliefs around food and/or body shape affected nutritional intake and treatment. Cases 1 and 2, despite different gender identities, described complex patterns of disordered thoughts related to mental health and body dysmorphia. Case 1 initially endorsed restrictive eating as a strategy to make his body more masculine and had an improvement in self-harm and nutritional restriction after starting testosterone. Once his nutritional intake improved, he struggled with binge eating to regulate his mood. Case 2 presented with restrictive eating secondary to depression but eventually endorsed restriction to change her body to match societal expectations of a female. Case 3 did not endorse rigid food preferences that were apparently associated with mental health concerns or body dysmorphia. Similar to Case 1, nutritional support was delayed because they declined seeing a dietician until behaviors led to concerning weight changes. The three cases differed in the timing of their ASD diagnosis, and all had minimal engagement with SCAC after their initial visit.

We hypothesize potential strategies to improve care outcomes for these youth. First, integration of early and consistent involvement of autism assessment and services in gender-affirming care may be beneficial for transgender youth with disordered eating and suspected/confirmed ASD. Integration of an ASD specialist in this patient population could improve uptake of eating disorder interventions. For the two cases with suspected ASD, there was a long delay before an official diagnosis of ASD was established. Delay in establishing care with SCAC could have been related to long wait times or other factors such as symptom presentation differing from cisgender peers, stigma associated with an ASD diagnosis, a history of mistrust of medical/mental health providers among transgender individuals, and/or other psychosocial factors associated with barriers to care among transgender individuals with ASD. Consistent with recommendations of Strang et al., gender-affirming medical providers should provide discussions and support around suspected ASD diagnosis to improve timely access to ASD-specific care and providers treating individuals with ASD should consider expanding services tailored to the needs of this population [15].

Second, gender-affirming care providers should consider proactive communication with transgender youth with suspected/confirmed ASD about the intersections of disordered eating, ASD, and gender dysphoria and provide concrete anticipatory guidance on changes in appetite and body shape with gender-affirming hormones. Early conversations could allow youth to build rapport with their providers when discussing eating habits and allow the care team to provide education and dispel myths around eating. Because an individual’s relationship with eating can change throughout their medical affirmation, these conversations should continue throughout care. Where possible, clinics could also consider early and routine inclusion of a dietician for transgender youth with ASD with disordered

eating regardless of weight and current status of eating behaviors. Framing of dietician visits as supportive and preventive rather than involving them only when disordered eating and weight become a concern could increase engagement, decrease shame around disordered eating, and help to address rigidity around nutrition and/or body appearance.

Third, because presentation and root causes of disordered eating appear to vary across persons as well as over time among youth with this triad, providers should explore causes of disordered eating rather than presuming the etiology. If the etiology is untreated depression or anxiety, the provider can discuss therapy and medication options. If thoughts are associated with body dysphoria and gender goals, providers can discuss realistic expectations of gender-affirming medications, society's influence on standards of beauty and gender, and body diversity/neutrality [18]. If disordered eating is related to rigidity of thoughts, consistent involvement of a mental health provider with experience in behavioral ASD treatment may be the most effective way to address disordered eating.

Finally, we posit that treatment of disordered eating should be multidisciplinary and collaborative and not interfere with gender-affirming medical care. From our experience at a multidisciplinary gender care clinic, optimal care for transgender youth with ASD and disordered eating occurs when there is consistent communication and collaboration among the ASD specialist, gender-affirming medical provider, dietician, and community mental health therapist. In all three cases, eating disorder treatment occurred in parallel with gender-affirming medical care and, even when malnutrition was a concern, did not prevent the initiation of gender-affirming hormones. Because a multidisciplinary approach for ASD, eating disorder, and gender-affirming medical care entails multiple providers, it may be helpful to provide patient support such as a list of team members, appointments, and treatment recommendations as well as case management involvement of a social worker and/or the primary care provider.

There are limitations to this case series study. It is important to note that not all youth/families will have access to the supports we hypothesize will be effective in reducing disordered eating symptoms and optimizing gender-affirming and ASD care. If these strategies are found to be effective in future work, advocacy to provide more widespread access to these supports will be critical. In addition, although authors include a psychologist with ASD expertise, we do not include perspectives of community mental health providers. Finally, the timeline and details included in the case descriptions are limited to the information found in the medical records.

The three cases demonstrate a heterogeneity in presentations of mental health, disordered eating, and engagement in a multidisciplinary model. Transgender youth with ASD may experience diverse features of disordered eating that may or may not be uniquely related to gender dysphoria or ASD and may change with gender-affirming medical care. Although disordered eating may appear to present similarly to neurotypical and/or cisgender youth, youth with both gender dysphoria and ASD may be at higher risk of negative clinical outcomes because of the additive effects of gender dysphoria and ASD. One study described this additive effect and found that individuals with

ASD and gender dysphoria had significantly worsened mental health in comparison to individuals with ASD without gender dysphoria [19]. In addition, it is unclear if evidence-based eating disorder treatment modalities designed largely based on data in non-ASD, cisgender females would be effective for transgender youth with ASD [20,21]. Taken together, future research should be conducted to better understand whether youth with gender dysphoria and ASD experience different clinical sequelae and/or require different treatment strategies for disordered eating in comparison to cisgender, neurotypical youth.

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