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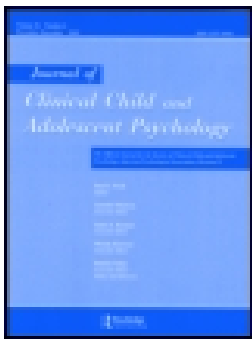
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Initial Clinical Guidelines for Co-Occurring Autism Spectrum Disorder and Gender Dysphoria or Incongruence in Adolescents

John F. Strang, Haley Meagher, Lauren Kenworthy, Annelou L. C. de Vries, Edgardo Menvielle, Scott Leibowitz, Aron Janssen, Peggy Cohen-Kettenis, Daniel E. Shumer, Laura Edwards-Leeper, Richard R. Pleak, Norman Spack, Dan H. Karasic, Herbert Schreier, Anouk Balleur, Amy Tishelman, Diane Ehrensaft, Leslie Rodnan, Emily S. Kushner, Francie Mandel, Antonia Caretto, Hal C. Lewis & Laura G. Anthony

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Kenworthy, Annelou L. C. de Vries, Edgardo



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Initial Clinical Guidelines for Co-Occurring Autism Spectrum Disorder and Gender Dysphoria or Incongruence in Adolescents

John F. Strang¹, Haley Meagher¹, Lauren Kenworthy¹, Annelou L. C. de Vries², Edgardo Menvielle³, Scott Leibowitz⁴, Aron Janssen⁵, Peggy Cohen-Kettenis⁶, Daniel E. Shumer⁷, Laura Edwards-Leeper⁸, Richard R. Pleak⁹, Norman Spack¹⁰, Dan H. Karasic¹¹, Herbert Schreier¹², Anouk Balleur⁶, Amy Tishelman¹³, Diane Ehrensaft¹⁴, Leslie Rodnan¹⁵, Emily S. Kushner¹⁶, Francie Mandel¹⁷, Antonia Caretto¹⁸, Hal C. Lewis¹⁹, and Laura G. Anthony²⁰

¹*Division of Pediatric Neuropsychology, Children's National Health System*

²*Department of Child and Adolescent Psychiatry, VU University Medical Center*

³*Division of Psychiatry and Behavioral Sciences, Children's National Health System*

⁴*Department of Psychiatry and Behavioral Sciences, Northwestern University, Feinberg School of Medicine*

⁵*Department of Child and Adolescent Psychiatry, New York University School of Medicine*

⁶*Department of Medical Psychology, VU University Medical Center*

⁷*Division of Pediatric Endocrinology, University of Michigan Health System*

⁸*School of Professional Psychology, Pacific University*

⁹*Division of Child & Adolescent Psychiatry, Hofstra Northwell School of Medicine*

¹⁰*Division of Endocrinology, Boston Children's Hospital*

¹¹*Department of Psychiatry, University of California San Francisco School of Medicine*

¹²*Department of Psychiatry, University of California San Francisco-Benioff-Children's Hospital Oakland*

¹³*Departments of Psychiatry, Endocrinology and Urology, Boston Children's Hospital and Harvard Medical School*

¹⁴*Child and Adolescent Gender Center, Department of Pediatrics, University of California San Francisco Benioff Children's Hospital*

¹⁵*Division of Psychiatry and Behavioral Sciences, Children's National Health System*

¹⁶*Department of Radiology and Center for Autism Research, The Children's Hospital of Philadelphia*

¹⁷*Divisions of Endocrinology and Social Work, Boston Children's Hospital*

¹⁸*Private Practice, Farmington Hills, MI*

¹⁹*Division of Psychiatry and Pediatrics, University of Colorado*

²⁰*Division of Pediatric Neuropsychology, Children's National Health System*

Evidence indicates an overrepresentation of youth with co-occurring autism spectrum disorders (ASD) and gender dysphoria (GD). The clinical assessment and treatment of

Correspondence should be addressed to John F. Strang, Division of Pediatric Neuropsychology, Children's National Health System, 15245 Shady Grove Road, Suite 350, Rockville, MD 20850. E-mail: jstrang@childrensnational.org

© John F. Strang, Haley Meagher, Lauren Kenworthy, Annelou L. C. de Vries, Edgardo Menvielle, Scott Leibowitz, Aron Janssen, Peggy Cohen-Kettenis, Daniel E. Shumer, Laura Edwards-Leeper, Richard R. Pleak, Norman Spack, Dan H. Karasic, Herbert Schreier, Anouk Balleur, Amy Tishelman, Diane Ehrensaft, Leslie Rodnan, Emily S. Kushner, Francie Mandel, Antonia Caretto, Hal C. Lewis, Laura G. Anthony

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adolescents with this co-occurrence is often complex, related to the developmental aspects of ASD. There are no guidelines for clinical care when ASD and GD co-occur; however, there are clinicians and researchers experienced in this co-occurrence. This study develops initial clinical consensus guidelines for the assessment and care of adolescents with co-occurring ASD and GD, from the best clinical practices of current experts in the field. Expert participants were identified through a comprehensive international search process and invited to participate in a two-stage Delphi procedure to form clinical consensus statements. The Delphi Method is a well-studied research methodology for obtaining consensus among experts to define appropriate clinical care. Of 30 potential experts identified, 22 met criteria as expert in co-occurring ASD and GD youth and participated. Textual data divided into the following data nodes: guidelines for assessment; guidelines for treatment; six primary clinical/psychosocial challenges: social functioning, medical treatments and medical safety, risk of victimization/safety, school, and transition to adulthood issues (i.e., employment and romantic relationships). With a cutoff of 75% consensus for inclusion, identified experts produced a set of initial guidelines for clinical care. Primary themes include the importance of assessment for GD in ASD, and vice versa, as well as an extended diagnostic period, often with overlap/ blurring of treatment and assessment.

Gender dysphoria (GD; formerly described as gender identity disorder; American Psychiatric Association, 2000), currently referred to as transsexualism in the International Statistical Classification of Disease and Related Health Problems, 10th Revision (ICD-10; World Health Organization, 2010) and likely to be referred to as gender incongruence in ICD-11 (ICD-11 Beta Draft; World Health Organization, 2014), is the condition of incongruence, with or without distress, related to a discrepancy between an individual's assigned gender at birth and their experienced gender (American Psychiatric Association, 2013). Gender nonconformity (GNC; also known as "gender variance") is a broader term that encompasses GD and describes the situation in which an individual's gender identity or expression shows variation from the cultural norms prescribed for a particular sex. Standards of clinical care for GNC and GD youth include those outlined in the World Professional Association for Transgender Health "Standards of Care for the Health of Transsexual, Transgender, and Gender-Nonconforming People" document (Coleman et al., 2012) and the practice parameter on gay, lesbian, or bisexual sexual orientation, gender nonconformity, and gender discordance in children and adolescents (Adelson & American Academy of Child and Adolescent Psychiatry Committee on Quality Issues, 2012). These guidelines include providing psychoeducational and social support for GNC young people and their parents and careful psychological evaluation for GD. For those youth (as young as early puberty) who meet criteria for GD, who are determined to be appropriate for physical interventions to promote healthy psychological adjustment, the following treatments are available: puberty suppression beginning in early puberty, cross-sex hormones in later adolescence, and gender-affirming surgical procedures (many different types of procedures, some of which are also referred to as sex reassignment surgery; generally available when a young person reaches the legal age of majority to give consent).

Several studies have suggested that autism spectrum disorder (ASD) and GNC/GD co-occur more often than by chance in adolescents (de Vries, Noens, Cohen-Kettenis, van Berckelaer-Onnes, & Doreleijers, 2010), and this co-occurrence presents significant clinical challenges (Menvielle, 2012). Ten independent case studies of co-occurring ASD and GNC/GD appear in the research literature, representing a range of nationalities and ages (four prepubescent children, three adolescents, six adults, and a 10-year-old whose pubertal status was not reported; Gallucci, Hackerman, & Schmidt, 2005; Jacobs, Rachlin, Erickson-Schroth, & Janssen, 2014; Kraemer, Delsignore, Gundelfinger, Schnyder, & Hepp, 2005; Landén & Rasmussen, 1997; Lemaire, Thomazeau, & Bonnet-Brilhault, 2014; Mukaddes, 2002; Parkinson, 2014; Perera, Gadambanathan, & Weerasiri, 2003; Tateno, Tateno, & Saito, 2008; Williams, Allard, & Sears, 1996). Several studies have found an overrepresentation of ASD or ASD symptoms among child/adolescent referrals for GD (de Vries et al., 2010; Shumer, Tishelman, Reisner, & Edwards-Leeper, 2015; Skagerberg, Di Ceglie, & Carmichael, 2015; VanderLaan, Leef, Wood, Hughes, & Zucker, 2015). Three studies have found an overrepresentation of the "wish to be the other gender" among children and adolescents with ASD (Janssen, Huang, & Duncan, 2016; Miesen, Hurley, Bal, & de Vries, 2015; Strang et al., 2014). Shumer and colleagues examined relationships between Social Responsiveness Scale (SRS) scores (used as a proxy for ASD symptoms) and GNC, finding that elevations on child SRS scores (as rated by the parent) and maternal SRS scores (as rated by the other parent or a close relative) independently predicted greater GNC in the child (Shumer, Roberts, Reisner, Lyall, & Austin, 2015).

ASD is often a debilitating disorder, with studies reporting generally poor long-term (adult) outcomes in terms of independence and meaningful employment (Howlin, Goode, Hutton, & Rutter, 2004). Even for individuals with

average or above intelligence, estimates indicate that only 9% reach full adult functional independence (Farley et al., 2009). Deficits in social skills and communication, and the presence of repetitive behaviors/overfocused interests characterize the diagnosis. Children and adolescents with ASD often show profoundly underdeveloped adaptive/independence skills, which are related to problems with executive function skills (Gilotty, Kenworthy, Sirian, Black, & Wagner, 2002; Pugliese et al., 2015). Typical ASD executive function profiles include problems with cognitive and behavioral flexibility, as well as with organization and planning (e.g., setting and completing goals; Kenworthy, Yerys, Anthony, & Wallace, 2008).

The co-occurrence of ASD and GNC/GD in adolescents presents significant diagnostic and treatment challenges given the social, adaptive, self-awareness, communication, and executive function complexities of youth with ASD. However, many adolescents with this co-occurrence are found clinically appropriate for GD-related treatment (de Vries et al., 2010). A primary challenge is how to clinically assess and support them (Kraemer et al., 2005). Individual clinics have through experience developed rich clinical knowledge for supporting adolescents with the co-occurrence; however, there are currently no guidelines published. In response to this need, this current study aimed to develop initial clinical guidelines for the care of adolescents with co-occurring ASD and GNC/GD through use of the Delphi procedure, which allows collaborative participation of experts in the field. These guidelines address the clinical care of adolescents (defined as the time of onset of puberty through age 19) but do not address the clinical care of prepubertal children, as prepubertal children do not receive gender-related medical interventions and therefore their care needs are somewhat different. Further, many youth with ASD first present with gender issues in adolescence, with no significant signs of either gender exploration or gender dysphoria in young childhood. We strongly endorse future workgroups developing specific clinical recommendations addressing the needs of prepubertal children with co-occurring ASD and GNC/GD.

METHODS

To obtain clinical consensus statements, as well as to identify areas in which current experts differ, this study employed a two-stage Delphi procedure. The Delphi procedure is a well-studied multistep survey method for obtaining consensus among experts to define appropriate clinical care (Keeney, McKenna, & Hasson, 2011; Linstone & Turoff, 1975), such as with self-injury (Kelly, Jorm, Kitchener, & Langlands, 2008), postdisaster care (Bisson et al., 2010), palliative care (Morita, Bito, Kurihara, & Uchitomi, 2005), stroke care (Philp et al., 2013), and so forth. The method presents structured pertinent questions in a field to experts,

who then anonymously offer responses. The data are combined and returned to the expert participants, with no names tied to statements, and each expert indicates his or her level of agreement with each item. The method helps circumvent the problems of a group process including rigidity in defending proposed ideas, conforming to more senior members, and rejection of novel ideas. Various formats have been used for the Delphi method, including in-person work sessions and online survey formats (Hsu & Sandford, 2007). For this study, we employed an online survey method, which allowed for experts to participate from geographically distant regions (Keeney et al., 2011; Linstone & Turoff, 1975). The Delphi procedure is a robust method for fields in which there are a small number of experts (Akins, Tolson, & Cole, 2005), such as with adolescents with co-occurring ASD and GNC/GD.

Participant recruitment followed Delphi method standards for recruiting experts in a field (Keeney et al., 2011; Linstone & Turoff, 1975). Potential participants were identified first through a comprehensive search of the research literature using the terms “autism spectrum disorder,” “autism,” or “Asperger’s” combined with the following: “gender identity,” “gender variance,” “gender nonconformity,” “transgender,” or “gender dysphoria.” Authors were identified from the resulting research literature. In addition, a comprehensive search of pediatric outpatient gender clinics was conducted, including the names of the directors and clinical staff experienced in co-occurring GNC/GD and ASD in adolescents. We then used a snowball sampling technique to allow this group of experts to identify other potential experts who were missed in our initial search (Biernacki & Waldorf, 1981). This was accomplished by asking the participants to forward the invitation e-mail themselves to other researcher or clinician experts in the field of co-occurring ASD and GNC/GD youth. In total, 30 potential participants were invited, and 27 expressed interest in participating.

The 27 potential participants were then screened both for level of training/experience in the fields of ASD and GNC/GD independently and for their experience with adolescents with the co-occurrence. In total, 22 individuals met criteria for the study in terms of expertise and then participated. Expertise, and resulting invitation to complete the Delphi surveys, was defined as at least 2 years of experience working with adolescents with the ASD and GNC/GD co-occurrence clinically and/or in research settings, as well as a clinical and/or research specialization in GNC/GD, ASD, or GNC/GD and ASD. As was expected, a majority of participants were experts in GNC/GD (91%), as the co-occurrence with ASD has been primarily reported on from gender clinics/specialists in past reports. Forty-one percent reported being experts in ASD, and 36% reported being experts in both GNC/GD and ASD independently. Although not all were experts in ASD, 68% reported specialization in the co-occurrence of GNC/GD and ASD. The participants represented a broad range of specialties: clinical

TABLE 1
Participant Experience With GD and ASD

Diagnosis	Years Experience M (SD)	Expert With Population Total (%)	Published in Population Total (%)	No. of Individuals Participant Has Seen Clinically Total (%)		
				1–10	11–20	21+
GD	17.2 (10.7)	21 (95%)	18 (82%)	1 (4.5%)	1 (4.5%)	20 (91%)
ASD	14.2 (10.2)	9 (43%)	7 (32%)	—	6 (27%)	16 (73%)
GD + ASD	11.9 (10.0)	16 (73%)	7 (32%)	9 (43%)	5 (24%)	7 (33%)

Note: Data were missing for one participant's self-assessment of expertise with ASD and in the reported number of individuals one participant had seen clinically. GD = gender dysphoria; ASD = autism spectrum disorders; Years Experience = years experience working with this population; Expert with Population = participant has a primary clinical specialty and advanced training with this population; Published in Population = participant has published at least one peer-reviewed article in an area related to this population.

psychology (45.5%), psychiatry (31.8%), endocrinology (9.1%), pediatrics (4.5%), social work (4.5%), and counseling (4.5%). A majority of participants reported participation in peer-reviewed academic research, with 32% published in the field of ASD, 77% in GNC/GD, and 32% in co-occurring GNC/GD and ASD. Twenty-one of the 22 participants were child/adolescent specialists, and one participant was an adult specialist with significant experience working with children/adolescents. Three of the participants reside and work in Europe (the Netherlands), and the others work in the United States. A majority of participants were affiliated with academic medical center clinical and/or research programs at the time of this study (20 of the 22 participants). See Table 1 for a summary of participant training, specialization, and experience.

Informed consent was obtained from all individual participants included in the study. For the first round of the Delphi interviews, participants were asked to complete online surveys, responding to 12 areas of clinical care. Questions focused on diagnosis/evaluation, treatment, and significant issues that affect people with the co-occurrence. Nineteen participants completed this first round. The data were compiled and coded using NVivo qualitative data analysis computer software (NVivo 10, 2012). The data were first divided between the main categories of diagnostics and intervention, with considerable overlap between the two. Because terminology in the data was extremely diverse for clinical and gender issues, the NVivo search mechanism would have resulted in a significant loss of data. Therefore we used the manual coding functions of NVivo, which resulted in the following principle thematic areas: approach to assessment, differential diagnosis, and treatment. Subcategories within these thematic areas included diagnosing GD in youth diagnosed with ASD, diagnosing ASD in youth with GD, assessment protocols, appropriate clinical specialists/team, challenges working with other providers, parent/family involvement, protocols for treatment, treatment targets, treatment approaches, issues of safety, and coping/socialization.

Next, two readers worked to synthesize the data into summary statements, working independently and then together to achieve consensus for how best to express the ideas clearly and concisely while maintaining the integrity of the participants' intents. This process included removing repetitious data, as well as generating a structure for organizing the statements. The resulting statements were presented to the participants for their review (Round 2 of the Delphi procedure), without any indication linking authors/ names to statements. Participants were asked whether they agreed or disagreed with each statement, and if they disagreed, what changes would need to be effected in the statement for them to agree. Twenty people participated in the second round: 17 of the original 19 participants and three participants who chose not to participate in the first round of the Delphi procedure. The "new" participants were allowed to respond to the second questionnaire even though they did not give any input into the original questionnaire, because their input provided more perspectives, which is critical in a field in which there are few experts. This inclusive method has been used in previous studies using the Delphi procedure (Keeney et al., 2011).

Statements were evaluated for consensus, with 75% consensus required for a statement to be included in the expert guidelines (see Results section). If participant recommendations for editing a statement could be made without changing the essence of the statement, these slight edits were made. These edits were often clarifications, or more inclusive language to describe variations in gender. Finally, all expert participants were invited to identify themselves and serve as coauthors of this resulting article. A majority of the participants (> 90%) consented to identify themselves as coauthors. Additional informed consent was obtained from all identified participants. This group then participated in the editing of the resulting article, with the exception of the Results section, which was produced through the Delphi procedure and is presented in its original form based on that process. The first three authors were primary architects of the study, and the final author made significant

contributions to the statistical methods. All of the other authors were from the expert participant panel, listed as Authors 4–22. The author order, excluding the first three authors and the last author, was determined by a random procedure.

RESULTS

The following is the document that was developed through the Delphi procedure, with an average of 89.6% agreement for all items. These guidelines were created to accompany and support existing best practice GD/GNC treatment guidelines for adolescents (e.g., Adelson & American Academy of Child and Adolescent Psychiatry Committee on Quality Issues, 2012; Coleman et al., 2012). Minor clarifications to the guidelines were made following masked review, all of which were considered and approved by the author team. Contentious items that need further consideration and research are reviewed in the discussion.

Assessment

When assessing for co-occurring ASD and GD, gender specialists and autism specialists should collaborate to be part of the assessment when there is no available clinician skilled in both specialties. Due to the complexity of diagnosis in many of these cases, there may be a more extended diagnostic period and clinical decisions may proceed more slowly. Given the high incidence of ASD among adolescents with GNC/GD, gender referrals should be screened for ASD. If ASD is suspected and the screening clinician is not an ASD specialist, the patient should be referred to an ASD specialist for ASD diagnostics. ASD-related evaluation can provide important information about the capacities of the

adolescent, including cognitive level, executive function/future thinking-skills, communication abilities, social awareness, and self-awareness. Understanding this profile of skills will help inform the clinical approaches to best match the patient’s profile/strengths. Given the increased incidence of gender issues among people diagnosed with ASD, youth with ASD should also be screened for gender issues. Screening may be accomplished by including a few questions about gender identity on an intake form and/or by including some content about gender issues in the clinical interview. If gender concerns are noted, a referral should be made to an appropriate gender specialist for assessment and supports. See Figure 1 for a clinical assessment protocol.

The diagnosis of ASD should not exclude an adolescent from also receiving a GD diagnosis and, when indicated, appropriate GD-related treatment. However, clinicians and parents sometimes dismiss GD as a trait of ASD (e.g., as an overfocused or unusual interest). Although in some cases GD symptoms appear to stem from ASD symptoms, many adolescents have persistent GD independent of their ASD. Similarly, an undiagnosed ASD can be missed if a clinician and/or parents view an adolescent’s social difficulties as stemming from GD-related challenges alone. Parents and/or clinicians may resist further assessments after receiving one diagnosis, whether it be ASD or GD, if they view all symptoms through the lens of the initial diagnosis.

Diagnosing ASD can be complex in gender nonconforming youth. A young person might appear socially awkward or withdrawn related to their history of GNC, such as when there has been insufficient opportunity to develop a sense of social belonging and acceptance. Diagnosing GD can be complex in adolescents with ASD due to ASD-related weaknesses in communication, self-awareness, and executive function. For example, ASD communication deficits can result in unclear, tangential communication, which can

- **Emergency intakes:** If the adolescent presents in a state of emergency, as some gender dysphoria (GD) referrals do, then as in any assessment, the **first priority is risk reduction/safety**. Hospitalization may be necessary in extreme cases to prevent self-harm/mutilation, though psychiatric hospital units are often not equipped to work with gender dysphoric adolescents with autism spectrum disorders (ASD), and so outside consultation to the unit may be necessary. Ultimately, engaging a therapist with training (or consultation support) in both ASD and gender nonconformity/GD may be a critical step; helping a patient understand that relief is coming and that their gender-needs will be addressed may reduce safety risks, and support further assessment.
- **ASD assessment:** When an ASD diagnosis is suspected, it is important for an autism specialist to confirm the diagnosis, if a diagnosis has not been established. Whenever possible, a neuropsychological/autism evaluation should be conducted to **evaluate the impact of ASD on an adolescent’s ability to understand and report GD symptoms as well as engage in therapy/treatments**. Evaluations should include assessment of general cognitive skills, executive function skills (impulse control, flexibility, planning, future thinking), communication skills, emotional functioning, self-awareness/social cognition, and capacity for self-advocacy. Knowledge of the young person’s capacities will inform the GD diagnosis process (i.e., how to best obtain clinical/diagnostic information and understand that information), as well as deciding on clinical treatment options (i.e., the ability to understand treatments, comply with treatments, consider a range of gender possibilities vs. concrete/black-and-white thinking).
- **Gender-related assessment:** When gender issues are reported/suspected in an adolescent with ASD, a structured interview should be used to assess for gender dysphoria, including dysphoria over time, intensity of dysphoria, and its pervasiveness. Whenever possible, it is important to **obtain additional report from other sources (e.g., parents), as communication, self-awareness, and self-advocacy skills may be vulnerable in adolescents with ASD**. It is difficult to separate the assessment and treatment of many of these individuals, because assessment continues throughout the treatment process as the person may develop increased understanding of themselves and increased ability to express their wants and needs. Therefore, gender-related diagnostics may take more time. For some individuals, however, GD diagnosis is immediately clear, such as when the dysphoria has been present for an extended period, the young person is already presenting as a different gender, or when the level of urgency about gender transition is extreme.

FIGURE 1 Assessment protocol.

make it difficult to know how an adolescent truly feels about their gender. ASD-related executive function deficits may result in concrete thinking and struggle with ambiguity and future thinking, which can make assessing an adolescent's understanding of the long-term implications of gender transition/treatment challenging. In addition, ASD-related flexibility difficulties can limit a young person's ability to embrace the concept of a gender spectrum or that gender can be fluid; adolescents with ASD may present with more "black-and-white" thinking about gender.

Adolescents with ASD may have limited self-awareness and may struggle to recognize or understand their gender concerns until later in development. There are some young people with ASD who do not embody a binary transgender presentation (e.g., they may not work to present as a different gender, they may not dress as a different gender, they may not be concerned with their name, etc.) These variations from more common GD presentations may raise issues of credibility for parents, medical/psychological professionals, and so on. However, many such youth appear to have persistent gender signs, feelings, or experiences of another gender and should not be excluded from consideration of GD diagnosis and appropriate related treatments, tailored to their individual needs.

ASD-related symptoms can sometimes create or intensify an identification with GD. Rigid, overly concrete thinking (i.e., black-and-white thinking) in adolescents with ASD and milder gender concerns may lead some children/adolescents to assume that their gender nonconforming interests/traits imply full GD and a need for transition. These young

people may struggle to see or consider an "in-between" solution, such as being a feminine male or "gender queer." Gay or bisexual adolescents with ASD may concretely assume that their sexual attraction to the same gender means that they must be a different gender. Important to note, although some adolescents express gender concerns clearly related to (or due to) their ASD symptoms as just described, based on our long-term clinical experience with this population, we have observed that many have enduring GD and are over time found appropriate for GD supports/treatment (see also de Vries et al., 2010).

Treatment

Assessment and treatment of gender-related issues in adolescents with the co-occurrence often overlap and blur because insight, flexible thinking, communication, and other skills develop over time in ASD treatment. Assessment may continue over time as the young person, through treatment, develops increased capacity for thinking and communicating about their gender. Treatments often must address both diagnoses (GD and ASD) concurrently and evaluate the gender-related needs as therapy progresses and patients have a better understanding of their needs and challenges, the possible solutions that might meet their needs, and their consequences. See Figure 2 for a treatment checklist. Adolescents and their parents often require psychoeducation about the nature of the co-occurrence of ASD and GNC/GD (e.g., that this is a common co-occurrence, that there are a range of options/outcomes), with a focus on

- Establish appropriate clinical team**, ideally a clinician trained in both autism spectrum disorders (ASD) and gender nonconformity/gender dysphoria (GNC/GD), or clinicians collaborating from each specialty.
- Address and assess intensity of gender feelings/urgency throughout the treatment process**, as assessment often continues during treatment, informing and shaping the goals of the treatment. Key clinical questions:
 - a. Is the GD clear, urgent, pervasive, and persistent over time (i.e., meeting full diagnostic criteria for GD)? If yes, consultation with medical transition services may be indicated (see "If medical transition is indicated" below).
 - b. Does the GD increase or decrease with intervention (e.g., as adolescent develops increased social/self-awareness, executive function flexibility and big picture thinking skills, communication/self-advocacy skills)?
- Provide psycho-education about and explore the possibility of a range of gender outcomes** (e.g., gender spectrum, incorporating aspects of a different gender without full gender transition, etc.) This may require specific approaches targeting ASD related deficits in cognitive flexibility (i.e., reducing all or nothing/black and white thinking).
- Provide structure, as necessary, for gender exploration**, supporting the adolescent's ability to explore gender transition, including clothing, name, pronouns, etc. Parents may need to assume a central role in helping facilitate an individual's exploration of their gender when ASD-related weaknesses in daily living skills, planning and self-advocacy interfere with that exploration. Such family support may include reminding a young person of their gender exploration therapy goals during the week, helping a young person to obtain appropriate clothing to try on, and so forth.
- Over the course of treatment, assess for signs that the adolescent's experience of GNC/GD is caused by comorbidities or symptoms of ASD** (e.g., ASD preoccupations, misinterpreting sexual orientation for gender, etc.) If it becomes clear that a wish to transition is caused by a comorbidity or symptoms of ASD, explore alternative solutions to gender transition.
- If medical transition is indicated during the process, ensure that a pediatric endocrinologist (or similar medical specialist) trained in GD is engaged in the treatment to discuss risks/benefits of pubertal blockade and/or cross sex hormones**. The endocrinologist/medical specialist and other treatment providers (e.g., autism specialist) should collaborate around diagnostics and treatments. If medical treatments begin, provide concrete psycho-education about treatment side effects, risks and benefits and ensure that these issues are understood by the adolescent with concurrent GD and ASD.
- Consider the accessibility and appropriateness of adjunct gender and/or ASD-related supports/services**. Provide support, coaching, and vetting as needed. For example, an LGBT youth group leader may require some coaching in how to welcome and engage a person with ASD, and an autism skills group provider may require support in how to work with a GD/gender nonconforming adolescent.

FIGURE 2 **Treatment checklist (psychosocial and medical).**

how GD presentation may be different in individuals with ASD than those without ASD (e.g., differences in presentation and age of onset) and how the assessment/treatment process will unfold. To the extent possible, the assessment/intervention sequence should be outlined in a straightforward and visual manner for the adolescent with ASD (e.g., a checklist or flowchart), using clear language to reduce overload and increase participation in treatment. To reduce the conceptual complexity and vagueness of gender-related concepts, the concepts should be presented as simply and concretely as possible.

Some adolescents with the co-occurrence struggle with treatment compliance. They may not see the purpose, or may not have sufficient organizational skills to attend regular appointments (e.g., psychotherapy or medical) without supports. Given the importance of ongoing monitoring and counseling, it is critical to develop a plan to maximize a patient's motivation and ability to participate consistently in the treatment process. Parent/caregiver involvement is often necessary to support treatment compliance, help move the therapy goals along, and help clarify key information such as intensity of symptoms/gender dysphoria, gender expression/behaviors outside of treatment, and so on. An adolescent with ASD may not know how to present as a different gender, such as choosing/obtaining appropriate clothing. Parent/caregiver involvement may be necessary to guide the gender exploration process. Young people with ASD who are transitioning may require family organizational supports for transition to manage hormone treatments, medical appointments, remembering aspects of dress/presentation, and so forth.

Adolescents who are clearly in an exploratory phase of gender (e.g., with unclear or inconsistent signs of GD) should be encouraged to explore their gender identity over time before being considered for any potentially irreversible gender-related medical treatments. Clinical work may help adolescents explore whether they might be more comfortable with their body than they originally assert and/or whether they might feel comfortable identifying somewhere outside of the gender binary (i.e., "gender spectrum"). A focus on comorbid symptoms may be helpful during this phase, such as treatments targeting executive function (e.g., flexibility/big picture thinking), communication, social cognition, and so on. By providing concrete psychoeducation about how gender for some people can be fluid, not just binary and physical, and concurrent intervention targeting flexible thinking and self-awareness, some individuals with less urgent gender presentations may realize that full gender transition does not fit them. These young people may become more comfortable with a less binary solution, such as maintaining a female body while expressing some male-typical interests/behaviors.

For those adolescents who ultimately engage in some level of transition or cross-gender presentation/identification, intervention may be required to help them navigate

the inherent complexities of GNC/GD and transition. Specific challenges often arise in the areas discussed next.

Social

For some young people with this co-occurrence, it may be difficult/anxiety provoking to express their gender publicly, such as at school or at work. Others are surprisingly resilient and unconcerned (or perhaps unaware) with how others experience them, related to their apparent disconnect from social expectations/bias. Our experience is that the co-occurrence can often lead to increased social isolation, as both ASD and GD can in themselves be isolating, and together the impact is exacerbated. These individuals may struggle to fit in with ASD treatment/social groups due to their GD, and teen gender support groups may struggle to welcome them due to their ASD-related social differences, which may be off-putting to non-ASD peers. Sometimes the primary social contact that these adolescents have is through Internet-based transgender-related blogs/groups, and this may be where they are first introduced to the concept of GD/transgenderism.

Medical Treatments

An ASD diagnosis should not exclude the potential for medical GD treatments, including puberty suppression and cross-sex hormone intervention. Of these treatments, puberty suppression is considered to have generally reversible effects if discontinued, though further research is required (Schagen, Cohen-Kettenis, Delemarre-van de Waal, & Hannema, 2016). Cross-sex hormones may have more permanent effects, even if discontinued (Seal, 2016). More caution may need to be taken in this population when deciding on medical treatments that may have irreversible effects given the presence of ASD-related deficits in future thinking and planning. Because it is often harder for an adolescent with ASD to comprehend the long-term risks and implications of gender-related medical interventions, consenting for treatment may be more complex in this population. It is important for the clinician to develop a specialized consenting plan for an adolescent with ASD and GD, with the benefits and risks presented in a concrete manner, appropriate for the young person's cognitive and communication abilities. If hormone treatment is initiated, it may be helpful in some adolescents to start with lower doses and increase more gradually. Attention should be given to how ASD-related sensory issues and problems with changes in routine may impact medical treatments (e.g., pill taking, injections). The Delphi group could not achieve consensus on exact criteria for commencing medical treatments in this population, but several of the key considerations offered by the Delphi team are reviewed in the Discussion section (paras. 3–4).

Medical Safety

Adolescents with ASD and GD may pose a higher risk for medical compliance and medical safety. Young people with this co-occurrence may have difficulty following a specific medical protocol. For example, it may be more challenging for some adolescents with this co-occurrence to remember to take medications, maintain regular medical checkups, and refill prescriptions. Some may struggle with making safe decisions, such as taking the appropriate (prescribed) dose of hormones/medications or obtaining hormones/medications through a doctor, rather than illegally and/or from abroad. Adolescents with this co-occurrence often have unrealistic expectations from treatment and medical interventions, including the belief that hormones alone will result in a perfect/complete transition. Unrealistic thinking about the transformational possibilities of medical interventions may be followed by disappointment/hopelessness, when a young person's expectations for their body (or others' perceptions of them) fall short of reality. Medical safety issues may be even more complex when an adolescent with ASD has lower cognitive skills and/or significantly impaired communication skills.

Risk of Victimization/Safety

These youth are at high risk for being bullied and exploited and for being victims of violence. Some struggle with gender transition, making them less likely to "pass" as their affirmed gender, which may increase their risk for victimization. ASD-related deficits can make it difficult for them to consider the safety demands of social and romantic interactions, such as the implications of nondisclosure of transgender status in romantic encounters and meeting/being in potentially unsafe locations. They may be less aware of the relative safety level of different settings/situations (e.g., when in a group of supportive friends in locations that are transgender friendly vs. walking alone at night in an unfamiliar setting). In addition, societal prejudice/victimization, combined with poor coping strategies, detail-oriented and rigid thinking, and social difficulties/isolation may contribute to suicidal ideation.

Young Adulthood

Because transition to adulthood is a particular challenge for adolescents with ASD and because skills necessary for young adult life must be practiced during the school-age years (Howlin & Moss, 2012; Parsi & Elster, 2015), the Delphi team offered some commentary on topics bridging into young adulthood (employment and romantic relationships). These areas are included so that clinicians may provide targeted psychoeducation and therapeutic supports aimed at helping the young person navigate these challenges in their transition to adulthood.

School and Employment

Youth with ASD or GNC/GD may have more difficulties at school or in the workplace due to related challenges and/or stigma; a co-occurring diagnosis of ASD and GNC/GD often compounds these difficulties. Young people with the co-occurrence may have more problems navigating their gender presentation at work or in school and may be less aware of the potential safety risks and how others are perceiving them. Finding and maintaining a job and developing a career is challenging for many people with ASD, and with additional GNC/GD-related issues of stigma/bias (i.e., hiring/firing practices), they may have even fewer job opportunities.

Romantic Relationships

It can be difficult for a young person with co-occurring ASD and GD to understand why potential romantic partners might feel and respond differently to a transgender person regarding issues of dating and sexual attraction. GD youth without ASD more easily comprehend the social nuances of being transgender and dating, whereas a young person with GD and ASD may struggle to understand why a potential partner does not just accept them as their transitioned/intended gender. It can be challenging to help people with this co-occurrence understand that their medical and dating/romantic decisions affect the life of their romantic partner as well. They may struggle to understand the implications of failing to disclose their transgender status to a romantic partner and that gender transition mid-relationship might be hard for the other person to accept. These young people may have increased difficulty finding an understanding partner who can accept both ASD and GD. Although the dating pool may be narrowed for these individuals, there may be some structure for finding a partner within specific groups, such as a group of people with ASD, who themselves may be less concerned with GD in a potential dating partner.

DISCUSSION

This study found that a group of international clinicians and researchers, highly experienced in working with adolescents with co-occurring GD and ASD, were able to achieve consensus around a broad set of initial clinical guidelines for working with this population. Study participation rates reflect the importance of this clinical inquiry, as the overall participation rate of clinicians/researchers who met "expert criteria" was 85%, and 73% of the consensus panel participated in both rounds of the Delphi procedure. Several primary themes emerged in the consensus guidelines. Participants emphasized the importance of screening for ASD among gender referrals and the importance of screening for gender issues among ASD referrals. There was

acknowledgment that the assessment and intervention aspects of care must often overlap, as ASD-related treatment supports the ability for adolescents to consider different gender-related options/outcomes, contemplate future implications, and self-advocate for what they need regarding gender. The panel noted a more extended diagnostic process for many adolescents with the co-occurrence while they agreed that many adolescents with the co-occurrence are ultimately over time found appropriate for gender transition services.

The Delphi group did not reach consensus on several key clinical issues. Although prior literature has reported that in *some* adolescents, apparent overfocused interest in gender-related imagery/concepts appears to have driven the report of GD (de Vries et al., 2010), only 64% of the panel had experienced this clinical phenomenon, and so it was not included in the guidelines. A majority of participants noted that in some cases gay or lesbian adolescents with ASD may concretely assume that their sexual attraction to the same gender implies that they are a different gender. However, several Delphi participants reported never experiencing this clinically. Most participants emphasized the particular challenges that ASD adds to GD, though some described potential protective effects related to ASD profiles, noting that adolescents with ASD may be less aware of social bias or social expectations and may therefore be less worried about how others may react to their transition or gender presentation. This concept has been previously discussed in the literature, related to the finding that children and adolescents with ASD and GD symptoms had less parent-reported anxiety than children with GD and other neurodevelopmental disorders (Strang et al., 2014). Although most participants noted that adolescents with this co-occurrence may pose higher risk for medical safety and treatment compliance, some participants noted that some young people on the autism spectrum may have increased treatment adherence related to their strength in following routines exactly.

A key area of divergence between Delphi participants was around the question of specific criteria for commencing medical interventions. Some participants endorsed the importance of adolescents experiencing their affirmed gender in daily life (i.e., living as their affirmed gender) in at least some settings (e.g., at home, in gender group therapy, etc.) prior to commencing medical treatment. These participants felt that the experience adolescents with ASD gain by living as their affirmed gender in at least some settings helps them to assess whether gender transition (and medical treatments) are the best fit, and therefore allows them to more confidently consent for treatment. However, other Delphi participants were concerned that requiring adolescents to “live as” their affirmed gender prior to beginning medical treatments is an inappropriate barrier. Of those who advocated a more flexible approach around commencing treatment, some noted that some adolescents with ASD struggle

significantly to get started with gender affirmation/transition until they feel that their medical needs have begun to be addressed. Some Delphi participants noted that the executive function and adaptive challenges of many teens with ASD often interfere with their ability to move forward with outward expressions of gender affirmation/transition and that commencing requested medical treatments may be appropriate if the teen’s experience of GD and gender-related needs are clear, even when there are few (or slowly progressing) outward signs of gender transition/affirmation.

Some Delphi participants emphasized the importance of considering the broad range of gender-related experiences/expression that are present in many individuals with GD and ASD when considering medical treatments, and carefully avoiding expectations/biases, such as that gender must be binary (e.g., gender is male or female) or that outward gender expression and inner experience of gender must be clearly parallel. From this perspective, some Delphi participants encouraged more flexible approaches to medical treatments to address an individual’s specific, and sometimes nonbinary, needs; for example, an individual who feels the need to suppress male-typical characteristics but who does not wish to increase female-typical characteristics could be considered for antiandrogen medication without estrogen. Given the complexity of the many treatment factors highlighted by Delphi participants, the Delphi method did not produce simple consensus statements around when and how to provide medical treatment in this population. Future work should aim to synthesize the different, and in some cases seemingly competing, treatment considerations and emphasize longitudinal treatment outcome studies in this population to better inform treatment decision-making approaches.

This study has several limitations. First, although we employed an intensive procedure to locate clinical and research expert participants internationally, a majority of participants were from the United States, and the remaining participants were from the Netherlands. In addition, although a diverse group of professionals are represented (e.g., psychologist, psychiatrist, etc.), a majority of our participants were affiliated with academic medical centers, and we did not include key stakeholders such as adolescents with the co-occurrence and their families. Second, the study focused on a restricted age range (puberty age through age 19). Although many of the recommendations may also be useful for adults with GD and ASD, additional guidelines must be developed to address adult-specific issues such as decision making around surgical procedures, which generally do not occur until the age of majority. Development of clinical care guidelines for prepubertal children is also clearly an important future direction. Finally, because these guidelines generally rely on some level of verbal communication with the adolescent, they are appropriate for individuals without severe intellectual disability or severe language disorders; cognitive and language impairments

that make communication about gender needs, the nature of medical treatments, and the future implications of treatment more challenging (or impossible) were not addressed in this current work. This limitation was highlighted in the Delphi procedure, as participants expressed frustration with the lack of appropriate assessment approaches for supporting the needs of individuals with more severe cognitive/language impairments.

Several additional directions for research are recommended. The appropriateness and utility of current gender assessment tools should be evaluated in individuals with ASD, and as necessary, modifications should be made to existing assessment instruments, or new instruments created to accommodate the communication and thinking styles of people with ASD. There is also a need for ASD-specific gender-related intervention materials, which would translate more abstract gender concepts into more concrete language/imagery. Finally, given executive function and social cognition weaknesses in ASD, as well as cognitive and communication deficits in some individuals, there is a need for developing ASD-specific methods for obtaining and assessing consent for medical-related gender treatments.

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