

Autism Spectrum Disorders in Gender Dysphoric Children and Adolescents

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Abstract Only case reports have described the co-occurrence of gender identity disorder (GID) and autism spectrum disorders (ASD). This study examined this co-occurrence using a systematic approach. Children and adolescents (115 boys and 89 girls, mean age 10.8, SD = 3.58) referred to a gender identity clinic received a standardized assessment during which a GID diagnosis was made and ASD suspected cases were identified. The Dutch version of the Diagnostic Interview for Social and Communication Disorders (10th rev., DISCO-10) was administered to ascertain ASD classifications. The incidence of ASD in this sample of children and adolescents was 7.8% ($n = 16$). Clinicians should be aware of co-occurring ASD and GID and the challenges it generates in clinical management.

Keywords Autism spectrum disorder · Gender identity disorder · Co-occurrence · Incidence

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Gender dysphoria is the distress resulting from an incongruence between assigned and experienced gender. The official DSM-IV-TR diagnosis of gender identity disorder (GID) is characterized by a strong and persistent cross-gender identification as well as a persistent discomfort with one's biological sex and a sense of inappropriateness in the gender role of that sex (American Psychiatric Association 2000). Estimates of GID in adults range from 1:10,000 to 1:20,000 in men and 1:30,000 to 1:50,000 in women (for a review, see Zucker and Lawrence 2009). Prevalence rates of autism spectrum disorder (ASD) in various recent studies are generally in the range of 60 per 10,000 (for a review, see Fombonne 2005) although some studies report a prevalence above 1% (e.g. Baird et al. 2006). With the reported prevalence rates of ASD and GID, the random co-occurrence of both would be extremely rare. However, gender identity clinics are now reporting an overrepresentation of individuals with ASD in their referrals (Robinow and Knudson 2005). The putative co-occurrence is not only relevant for diagnostic and clinical management reasons, but it also raises important theoretical questions if, indeed, there would be evidence for co-occurrence.

To date, however, studies using systematic measures on this co-occurrence have not been published. The literature on the co-occurrence of ASD and gender dysphoria consists of seven papers describing nine case histories of individuals with ASD and concomitant gender identity problems, mostly children (Gallucci et al. 2005; Kraemer et al. 2005; Landen and Rasmussen 1997; Mukaddes 2002; Perera et al. 2003; Tateno et al. 2008; Williams et al. 1996). Authors show various perspectives in how to understand the co-occurrence of ASD and gender dysphoria. Some of them state that gender dysphoria and autism can be truly co-occurring disorders (Mukaddes 2002; Tateno et al. 2008). Others assume that cross gender

behavior results from the inherent predisposition toward unusual interests characteristic of ASD (Williams et al. 1996). It is also suggested that gender dysphoria in individuals with ASD may be considered an obsessive compulsive disorder, separate from both ASD and GID (Landen and Rasmussen 1997; Perera et al. 2003).

In sum, the co-occurrence of gender dysphoria and ASD is of current clinical interest. This study was conducted to establish the incidence of ASD in gender dysphoric children and adolescents, and to describe the specific clinical characteristics of individuals with both gender dysphoria and ASD.

Method

Participants

Participants were 231 children and adolescents who had been referred to the Gender Identity Clinic of the VU University Medical Centre in Amsterdam between April 2004 and October 2007. This is the only clinic in the Netherlands with a multidisciplinary team examining gender dysphoric children and adolescents. Nineteen children and eight adolescents were excluded from the study because they were not able to complete the assessment procedure. Reasons were cessation of the gender identity problems at the time of assessment (in some cases due to the waiting list), or serious other psychopathology making a referral to a local mental health clinics necessary and completing the assessment not possible. This resulted in a study group consisting of 108 children (mean age 8.06, SD = 1.82) and 96 adolescents (mean age 13.92, SD = 2.29) consecutively assessed of whom 11 ASD suspected children and 15 ASD suspected adolescents were identified.

Procedure

All 204 individuals received a standardized clinical assessment, according to the Standards of Care of the World Professional Association for Transgender Health (Meyer et al. 2001). A separate protocol is followed for children under the age of 12 and adolescents between age 12 and 18, respectively. It includes psycho-diagnostic interviews with the child or the adolescent, interviews with the parents about topical functioning as well as the developmental history of the child or adolescent, psychological testing by a trained psychometrist and collection of school information (for a detailed description of the clinical procedure and used instruments, see Cohen-Kettenis 2006).

Persistence of the gender dysphoria of the children and adolescents with ASD was evaluated in 2008 or 2009,

which was at least 1 year and in some cases 4 years after the initial assessment. The clinical files were evaluated for those individuals who still attended the gender identity clinic. If no recent information was available, the parents were called.

The study was approved by the Ethical committee of the VU University Medical Centre. Informed consent was obtained from the parents as well as the adolescents age 12 and older.

Measures

Intelligence

IQ was assessed by use of the Dutch versions of the Wechsler Intelligence Scale for Children or the Wechsler Adult Intelligence Scale depending on the participant's age (Wechsler 1997; Wechsler et al. 2002).

Autism Spectrum Disorders

ASD suspected children and adolescents were identified by discussing potential characteristics of ASD of all new referrals in weekly team meetings. Further diagnostic assessment for ASD was considered when either earlier reports suggested an ASD or the examining psychologist or psychiatrist (first author AV) suspected an ASD. Parents or caregivers of ASD suspected individuals were then invited for a diagnostic ASD interview. ASD diagnoses were confirmed using the Dutch version of the Diagnostic Interview for Social and Communication Disorders-10th revision (DISCO-10 Wing 1999; Dutch version Van Berckelaer-Onnes et al. 2003). The DISCO-10 was chosen for its particular effectiveness for diagnosing disorders within the broader autism spectrum. The DISCO is a semi-structured 2–4 h interview. Its algorithms enable to investigate whether the necessary criteria of different diagnostic systems for ASD are met. During the interview, answers to over 300 questions are coded for computer entry. Inter-rater reliability for the items in the DISCO interview were high, with a kappa coefficient or intra-class correlation at .75 or higher achieved for over 80% of the interview items (Wing et al. 2002). The DISCO-10 was administered by two of the authors (IvBO or IN), who were formally trained in the use of the DISCO-10. The diagnostic algorithms that were used in the current study reflect DSM-IV-TR and ICD-10 criteria for Pervasive Developmental Disorders (American Psychiatric Association 2000; World Health Organization 1993). From the DISCO-10, one obtains an 'ever' diagnosis, which is retrospective, as well as a 'current' diagnosis, with 'ever' including 'current'. In the current paper, only 'ever' diagnoses are reported.

Gender Dysphoria

Based on the DSM-IV-TR criteria, children and adolescents were classified as GID, the subthreshold GID not otherwise specified (GID-NOS) or no GID (APA 2000). Additionally, the list of Dimensional Diagnostic Criteria of the GID (DDC-GID) was used. This list was constructed by one of the authors (PCK) and describes DSM-IV-TR sub-criteria of the GID A and B criteria (cross-gender identification and discomfort with his or her sex, respectively). Each sub-criterion can be rated dimensionally with regard to strength, persistence, and duration. Whether criterion A and B are fulfilled remains a clinical decision. Criterion C is an exclusion criterion (no intersex condition). Criterion D (the behavior should reveal clinically significant distress or impairment) may range from no distress, mild distress to strong distress (or unclear) in social, occupational, family or other areas of functioning. GID diagnostic criteria of the individuals who had received a DISCO interview were specified (e.g. sexual orientation, history of childhood GID) by making use of the DDC-GID. Clinical consensus was met for each case by the first author (AV) and one of the other members of the gender identity clinic team for children and adolescents.

Analyses

Incidence of ASD in the referred children and adolescents was calculated by the percentage of DISCO-confirmed ASD diagnoses in the total number of referrals of children and adolescents separately as well as in the combined sample. Fisher exact tests were used to analyze differences in incidence of individuals with ASD in individuals with GID compared to individuals with GID-NOS.

Independent *t*-tests were used to ascertain differences in age and IQ between all referred children and adolescents with and without an ASD.

Specific clinical characteristics and follow-up reports of the gender dysphoria were collected from the clinical files and described with regard to GID classification, ASD classification, age of onset of GID, the persistence of a GID diagnosis at follow-up, and, for the adolescents, sexual orientation.

Results

Children

According to the DISCO algorithms, seven (six boys, one girl) of the 11 ASD suspected children had ASD. The incidence of ASD in all 108 assessed children (70 boys, 38 girls) was 6.4% ($n = 7$). The incidence of ASD in the 52 children

with a GID diagnosis was 1.9% ($n = 1$), which was significantly lower than the incidence of 13% ($n = 6$) of ASD in the 45 children with a GID-NOS (gender identity disorder not otherwise specified) diagnosis ($p < .05$). In the 11 children with no GID diagnosis, none had ASD.

The mean age of children with ASD ($M = 9.1$, $SE = 0.47$) was not significantly different from the children without ASD ($M = 8.0$, $SE = 0.18$, $t = -1.63$, $df = 106$, $p = 0.11$). The mean IQ ($M = 82.00$, $SE = 3.74$) of the children with ASD was significantly lower compared to the mean IQ of the children without ASD ($M = 103.92$, $SE = 1.18$, $t = 4.88$, $df = 101$, $p < .001$).

Table 1 presents the specific clinical characteristics of children with co-occurring GID and ASD. Most remarkable results were that six of the seven children with GID and ASD were male, all seven children fulfilled the strict criteria of autistic disorder, and in six of the seven children the gender dysphoria had alleviated when outcome was evaluated at least 1 year after the initial assessment.

Adolescents

According to the DISCO algorithms, nine (six boys, three girls) of the 15 ASD suspected adolescents had ASD. The incidence of ASD in all 96 assessed adolescents (45 boys, 51 girls) was 9.4% ($n = 9$). The incidence of ASD in the 77 adolescents with a GID diagnosis was 6.5% ($n = 5$), which was significantly lower than the incidence of 37.5% ($n = 3$) of ASD in the eight adolescents with a GID-NOS diagnosis ($p < .05$). In the 11 adolescents with no GID diagnosis, one suffered from ASD and transvestic fetishism but no gender dysphoria.

The mean age of the adolescents with ASD ($M = 15.41$, $SE = 0.65$) was significantly higher than the adolescents without ASD ($M = 13.77$, $SE = 0.24$, $t = -2.09$, $df = 94$, $p < .05$). The mean IQ of adolescents with an ASD ($M = 89.88$, $SE = 5.52$) was not significantly different from the mean IQ of the adolescents without ASD ($M = 96.67$, $SE = 1.72$, $t = 1.20$, $df = 85$, $p = .23$).

Table 2 presents the specific clinical characteristics of the adolescents with co-occurring GID and ASD. Most remarkable results were that six of the nine adolescents fulfilled the strict criteria of autistic disorder (the other three Asperger's disorder), four adolescents were eligible for sex reassignment, of whom two were female, but none of them as yet had their sex reassignment surgery. Two adolescents dropped out of care, of whom one was reported to have sex reassignment surgery abroad.

Children and Adolescents Combined

The incidence of ASD in the combined sample of children and adolescents was 7.8% (204 individuals, 115 boys and

Table 1 Demographic and clinical characteristics of children diagnosed with both GID and ASD

No	Sex	Age	IQ	ASD classification	GID classification	GID symptoms: history	At time of assessment	Follow-up
1	Boy	7	88	Autism ^a	GID-NOS ^b	From toddler age on, fascinated by jewelry, girls' toys, female bodies (mother)	Seems to get sexually aroused by touching women's breasts and dressing up	No GID ^c ; at age 10, no female preferences anymore, still attracted to female bodies with some sexual arousal
2	Boy	8	108	Autism	GID-NOS	Obsessive dressing up as a girl, wearing high heels, interested in make-up	No further interests in girls' toys, no wish to be a girl	No GID; at age 10, obsessive dressing up reduced by behavioral program, still wearing high heels
3	Boy	9	69	Autism	GID-NOS	From toddler age on, playing with dolls, dressing-up in robes, high heels, make-up	Likes cars as well, but rather wants to be a girl	No GID; at age 12 happy being a boy, but still female behavior resulting in difficulties with peers
4	Boy	9	75	Autism	GID-NOS	From toddler age on fascinated by mermaids, fairy tales, dolls, ballet, dressing-up, did not like his penis	No interest in dolls and dressing up any more, now fascinated by nature and culture, still liking ballet and theatre	No GID; at age 10, no explicit wish to be a girl
5	Boy	10	95	Autism	GID	From toddler age on interested in dolls, dressing up, pink, wishes to be a girl	Wearing girl's clothes restricted, but looks and behaves like a girl with long hair and bright colored clothes	Persisting GID; at age 12, explicit wish to be a girl
6	Boy	10	72	Autism	GID-NOS	From toddler age on, fascinated by music, dancing, dressing up, glitter, long hair, girls' clothes	Still interested in music and girls' clothes, but does not want to be a girl	No GID; at age 12, no female preferences, likes music, happy being a boy
7	Girl	10	81	Autism	GID-NOS	From toddler age on, only wearing trousers, short hair, playing with boys' toys	Hates being a girl, but being called a boy irritates her, anxiety about any medical intervention	No GID; at age 13, happy being a 'tomboy' girl

^a *Autism* autistic disorder

^b *GID-NOS* gender identity disorder not otherwise specified

^c *GID* gender identity disorder

89, mean age 10.8, SD = 3.58). The incidence of ASD in the combined sample of 129 individuals with a GID diagnosis was 4.7% ($n = 6$), which is significantly lower compared to the incidence of 17.0% ($n = 9$) of ASD in 53 individuals with a GID-NOS diagnosis ($p < .05$).

Discussion

The incidence of 7.8% ASD in gender identity clinic referred children and adolescents is ten times higher than the prevalence of 0.6–1% of ASD in the general population (Baird et al. 2006; Fombonne 2005). This important finding confirms the clinical impression that ASD occurs more frequently in gender dysphoric individuals than expected by chance.

Most remarkable in the clinical presentation of individuals with co-occurring GID and ASD in this study was

the considerable diversity concerning: sex (both male and female), GID classification (GID, GID-NOS, transvestic fetishism), ASD classification (autistic disorder, Asperger's disorder), age of onset of GID (before or after puberty), and the persistence of cross-sex behavior (ceasing or persisting).

The overrepresentation of males in our study is in accordance with the epidemiology of both ASD and GID (Fombonne 2005; Zucker and Lawrence 2009). Studies in girls with congenital adrenal hyperplasia, who are prenatally exposed to high levels of testosterone, showed that they had more traits of ASD than controls and some developed gender identity problems (Dessens et al. 2005; Knickmeyer et al. 2006). However, the idea that prenatal testosterone may be involved in the vulnerability to both ASD and gender dysphoria, seems not applicable in our sample. In that case, especially girls with ASD would have been susceptible to develop gender dysphoria. In addition,

Table 2 Demographic and clinical characteristics of adolescents diagnosed with both GID and ASD

No	Sex	Age	IQ	ASD classification	GID classification	GID symptoms: history	At time of assessment	Follow-up
1	Girl	12	82	Asperger's ^a	GID-NOS ^b	Childhood GID	Sexually attracted to males	Not eligible for SR ^c ; happy being a 'tomboy' after counseling
2	Boy	13	92	Autism ^d	GID ^e	Childhood GID	Sexually attracted to neither boys nor girls, no sexual arousal while cross-dressing	Eligible for SR; delayed start puberty suppression, waiting to start cross-sex hormones
3	Boy	14	106	Asperger's	GID	Childhood GID	Sexually attracted to boys, no sexual arousal while cross-dressing	Eligible for SR; delayed start puberty suppression, now on cross-sex hormones
4	Boy	15	62	Autism	TF ^f	No childhood GID	Sexually attracted to both girls and boys, sexual arousal while cross-dressing	Not eligible for SR; referred for cognitive behavioral therapy around disturbing sexual arousal
5	Boy	16	NA ^g	Autism	GID-NOS	Childhood GID-NOS	Sexually attracted to homosexual boys, no sexual arousal while cross-dressing	Dropped out of care
6	Boy	16	104	Autism	GID-NOS	No childhood GID	Sexually attracted to girls, sometimes sexual arousal but no sexual motivation while cross-dressing	Not eligible for SR; referred for autism treatment, still strong wish for SR
7	Girl	17	110	Asperger's	GID	Childhood GID	Sexually attracted to girls, no sexual arousal while cross-dressing	Eligible for SR; delayed start cross sex hormones, waiting for mastectomy
8	Boy	17	81	Autism	GID	Childhood GID	Sexually attracted to girls, no sexual arousal while cross-dressing	Dropped out of care; unwilling to assent to treatment plan, got himself a SR surgery abroad
9	Girl	18	86	Autism	GID	Childhood GID	Sexually attracted to girls, no sexual arousal while cross-dressing	Eligible for SR, delayed start cross sex hormones, waiting for mastectomy

^a *Asperger's* Asperger's disorder

^b *GID-NOS* gender identity disorder not otherwise specified

^c *SR* sex reassignment

^d *Autism* autistic disorder

^e *GID* gender identity disorder

^f *TF* transvestic fetishism

^g *NA* not available

why gender dysphoria and ASD co-occur in males is unexplained by prenatal androgen exposure. This finding adds to the lack of experimental evidence for a link between low testosterone and GID in males.

Symptoms of GID displayed by individuals with ASD varied substantially. Individuals with an ASD frequently received a GID-NOS diagnosis. GID-NOS appeared to be given when the cross gender behavior and interests were merely subthreshold (mostly in children), or atypical or unrealistic. For example, an adolescent with ASD, who always had the feeling of being different from his peers in childhood, but had no history of childhood cross-gender behavior, became convinced that this feeling of alienation was explained by gender dysphoria. He had the hope that his communication problems would alleviate by taking estrogens. In another adolescent, the cross-gender behavior indicated transvestic fetishism rather than gender dysphoria.

This corresponds with the findings of frequent non-normative sexual interests and behaviors in adolescents and adults with ASD (Hellemans et al. 2007). Feminine interests of many gender dysphoric young boys with ASD concerned soft tissues, glitter, and long hair and could be understood as a preference for specific sensory input typical for ASD.

While almost all adolescents with GID are sexually attracted to individuals of their birth sex (Smith et al. 2005; Wallien and Cohen-Kettenis 2008), the majority of the gender dysphoric adolescents with ASD was sexually attracted to partners of the other sex. This may be clinically relevant since adult transsexuals not sexually attracted to their natal sex show in some studies less satisfactory postoperative functioning compared with birth-sex attracted transsexuals (Smith et al. 2005).

Most individuals with co-occurring gender dysphoria and ASD fulfilled the strict criteria of autistic disorder. For

several youth with ASD, their ASD-specific rigidity made enduring gender variant feelings extremely difficult to handle. After all, in our society a considerable amount of flexibility is needed to deal with gender variant feelings. Normally developing young children (age 3–5) display more rigidity in gender-related beliefs than older children; this rigidity decreases after the age of five (Ruble et al. 2007). Individuals with ASD may not reach this level of flexibility in their gender development.

In most gender dysphoric children, gender dysphoria will cease when they reach puberty, whereas adolescents with a GID will likely pursue their wish for sex reassignment into adulthood (Cohen-Kettenis and Pfäfflin 2003; Wallien and Cohen-Kettenis 2008; Zucker and Bradley 1995). Likewise, in children under age 12 with co-occurring ASD the gender dysphoria alleviated and in adolescents between age 12 and 18 their GID persisted.

The present findings should be considered in the light of limitations in sampling and assessment. First of all, it is apt to realize that the actual incidence of ASD in gender clinic referred children and adolescents is probably higher than the reported percentage. One of the reasons to assume an underestimation is that some children and adolescents with ASD (as diagnosed elsewhere) were unable to fulfill the assessment procedure due to serious impairment. In other cases, features of ASD were observed, but parents tended to underreport the ASD symptoms in the DISCO-10 interview, as that was not the primary concern about their child. Finally, it was not feasible to administer a DISCO-10 interview to all participants. Clinicians of the gender identity clinic identified suspected cases. Based on the epidemiology of ASD, the majority was expected to fall into the broader spectrum, whereas in this study no pervasive developmental disorder not otherwise specified was classified. This may reflect that our clinicians had a high threshold for suspecting ASD, as their primary focus was gender dysphoria.

Second, the individuals who investigated whether criteria for ASD were met, were aware that the reason for referral was a possible GID. This study was performed at a specialized gender identity clinic, and therefore blinding was not feasible.

Third, we studied a gender identity clinic referred population. Whether the same high incidence of co-occurring ASD and gender dysphoria will also be found in individuals with ASD as primary concern remains unknown and should be of interest for further studies. One might expect milder or more atypical types of gender dysphoria as part of other non-normative sexual behaviors and interests, as was found in a study of males with ASD (Hellemans et al. 2007).

Third, the categorical DSM-IV-TR classification approach is not appropriate to study more subtle expressions of both ASD and GID. Future studies should focus on

dimensional measures and specific cognitive or neuropsychological profiles of individuals with co-occurring gender dysphoria and ASD. For example, the observed rigidity in gender related beliefs in young children may make children with ASD more prone to develop gender dysphoria (Ruble et al. 2007). Furthermore, it seems important to address the broader autism phenotype (clinical traits that are milder but qualitatively similar to the characteristics of autism (Losh et al. 2009) in upcoming studies in a gender identity clinic referred population. It may be that these traits occur more often in gender dysphoric individuals than a full-blown ASD as was found in, for example, children with mood and anxiety disorders and ADHD (Nijmeijer et al. 2009; Pine et al. 2008).

For clinical management, our findings on clinical characteristics of individuals with co-occurring gender dysphoria and ASD have consequences. In all cases described, the diagnostic procedure was extended to disentangle whether the gender dysphoria evolved from a general feeling of being ‘different’ or a ‘core’ cross-gender identity. Most helpful seemed an individual approach that took into consideration that rigid and concrete thinking around gender roles and difficulty developing aspects of personal identity may play a part. Concerning sex reassignment, ASD does not have to be a strict exclusion criterion. Only one case study described a woman with an Asperger’s disorder who received sex reassignment (Kraemer et al. 2005), although we know of more cases in clinical practice. In our sample, almost half of the adolescents with both ASD and GID started with gender reassignment. Worrisome are the adolescents that dropped out of care, probably finding their own ways to sex reassignment, without psychiatric treatment or medical attention. It remains a challenge to provide individuals with co-occurring gender dysphoria and ASD with proper care.

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