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Characteristics of Referrals for Gender Dysphoria Over a 13-Year Period

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Abstract

Purpose—Our Pediatric Endocrinology Clinic has seen a sharp increase in referrals for gender dysphoria (GD) during recent years. However, the frequency and characteristics of referrals have not been objectively examined.

Methods—A retrospective chart review of referrals for GD during the past 13 years was performed. Variables analyzed included numbers of referrals per year, patient characteristics, comorbid conditions, and hormonal therapy. Timing of referral and eligibility for treatment were measured against established recommendations.

Results—Of 38 patients, 74% were referred during the last 3 years. Most patients presented late in puberty before a GD-specific psychological evaluation and few were eligible for hormonal treatment at baseline. Over half had psychiatric and/or developmental comorbidities.

Conclusions—A dramatic increase in referrals for GD since 2002 was confirmed. Enhanced provider education and outreach regarding care of patients with GD are needed.

Keywords

Transgender; Referrals; Gender dysphoria

Gender dysphoria (GD) is characterized by cross-gender identification and distress associated with a patient's natal gender [1]. For those choosing medical intervention, treatment involves gradual physical and social transition to the identified gender. This requires collaboration between medical professionals and mental health providers (MHP). Guidelines for treatment and monitoring are available through the Endocrine Society and World Professional Association for Transgender Health and encompass criteria for children and youth [2,3]. Although referral to specialized gender clinics is ideal, this may not be feasible for many families due to financial and travel constraints.

Criteria for hormonal treatment of GD include confirmation of the diagnosis and recommendation for treatment by a qualified MHP. A real-life experience (RLE) of living

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full-time in the identified gender is also considered necessary before cross-sex hormone therapy. Puberty suppression is reversible and may be prescribed as early as Tanner stage II, whereas cross-sex hormones bring about partially irreversible physical changes. Although traditionally considered at age 16 years, there is a growing trend toward beginning this step as early as age 14 years [3].

There has been a perceived escalation in the frequency of referrals for GD to our Pediatric Endocrinology clinic in recent years. However, whether this has actually been the case has not been systematically examined. We also sought to characterize our referrals with respect to patient readiness for hormonal treatment at the time of presentation to our clinic.

Methods

After institutional review board approval, a retrospective review was performed to identify all patients seen in our Pediatric Endocrine clinic between January 1, 2002 and April 1, 2015 for “GD,” “gender identity disorder,” or “gender identity.” Variables analyzed included age and pubertal status at presentation, documentation of a psychological evaluation for GD, history of RLE, concurrent diagnoses, type and timing of puberty suppression, and cross-sex hormones. Population frequencies were compared using a chi-square test with a two-tailed *p* value, where applicable. All other population frequencies are expressed as a percentage.

Results

A total of 38 patients (81.6% Caucasian) aged 14.4 ± 3.2 years were identified, consisting of 16 natal males and 22 natal females ($p = .33$), with 73.6% presenting since January 1, 2013. Thirty-one (81.6%) were Tanner stage IV or V at baseline whereas six (15.8%) were prepubertal and one (2.6%) was in early puberty. Of natal females, 86% were postmenarchal.

At presentation, 29% of patients had received a GD-specific psychological evaluation and recommendation for treatment. Anecdotally, several families mentioned difficulty in finding an MHP, particularly in rural areas. In contrast, 57.9% of patients had pursued an RLE.

Fifteen patients received puberty suppression at 15.5 ± 2.1 years. Nine were approved for first-line treatment in the form of gonadotropin-releasing hormone analogs (GnRHa), whereas six were denied necessitating second-line alternatives. These consisted of progestins in natal females and an androgen receptor blocker in natal males. Of patients receiving puberty suppression, eight were treated with cross-sex hormones at 16.2 ± 1.4 years.

Of the entire cohort, 24 (63.1%) had concurrent psychiatric and/or developmental diagnoses. These consisted of depression in 31.6%, attention deficit/hyperactivity disorder in 15.8% and autism spectrum disorder in 13.1%. Five patients (13.1%) had a history of suicidality and/or self-harm. Patient characteristics and treatment course are outlined in the Table 1.

Discussion

Referrals for GD have reportedly surged at many centers [4]. The remarkable increase in the number of new patients seen in our clinic over the last 3 years has occurred even though our referral base is unchanged, and our clinic has not specifically advertised its care for transgender patients. Previous reports are usually from established multidisciplinary gender clinics. That our general endocrinology clinic has also seen a marked rise in referrals highlights the rising demand for services.

The reason for the increase in referrals is unknown. With greater media attention to lesbian/gay/bisexual/transgender/queer issues and gender-nonconforming celebrities, patients may find it easier to access information regarding transition. Greater visibility and social acceptance of being transgendered may also facilitate patients' ability to express their gender identity to friends and family. Publication of the 2009 Endocrine Society treatment guidelines and several high-profile lawsuits may have increased provider awareness.

Despite the availability of practice guidelines [2,3], most of our patients are referred before a GD-specific psychological evaluation. This likely represents a knowledge deficit regarding criteria for hormonal treatment on the part of referring providers. A shortage of MHP qualified to address this specialized issue is also a contributing factor for our patients and has been reported as a common barrier to transgender care elsewhere [5]. Even within our large tertiary care children's hospital, psychological services for GD are woefully lacking. Similarly, nearly half of our patients had not yet pursued an RLE at the time of their first clinic visit. Finally, most arrive in late puberty despite guidelines allowing for puberty suppression as early as Tanner stage II. This negatively impacts physical outcomes due to lost opportunity to modulate final adult height and the development of secondary sexual characteristics including breast development in natal females and low voice, Adam's apple development, and masculine facial features in natal males [4,6,7].

Our clinic encountered several patients with autism spectrum disorders and a high rate of psychological comorbidity, consistent with previous reports [4,8]. Although not all conditions are likely a consequence of GD, this nevertheless underscores the need for psychological services for this population, regardless of the stage of gender transition. It should be noted that 40% of our patients who met criteria for pubertal suppression were denied insurance approval for GnRHa, possibly related to off-label use. This represents a lack of awareness on the part of insurers regarding the serious nature of GD and high risk of depression and suicidality in affected children and adolescents who are denied psychological support and treatment [8–10].

In conclusion, our results confirm a drastic increase in the incidence of referrals for GD and the high rate of psychiatric and developmental issues in this population. Despite their advanced pubertal stage, only a minority of our patients met criteria for hormonal treatment at presentation. Thus, our findings also highlight the need for targeted education of referring providers and greater availability of psychological services. If the observed amplification in the diagnosis of GD continues, routine training of pediatric providers in standards of care for the management of gender nonconforming-children will be essential.

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IMPLICATIONS AND CONTRIBUTION

There has been a dramatic increase in referrals for gender dysphoria, even outside of specialized centers. Most patients arrive late in puberty without having fulfilled necessary criteria to begin hormonal treatment, resulting in a delay in care. The population has a high rate of psychiatric and developmental comorbidities.

Table 1

Referral characteristics and treatment

All patients, n = 38			
Affirmed gender, n		<i>p</i> = .33	
MTF	16		
FTM	22 (1 Gender fluid)		
Pubertal status, n (%)			
Postmenarchal	19 (86.4%)		
Tanner IV or V	31 (81.6%)		
Tanner II or III	1 (2.6%)		
Pre-pubertal	6 (15.8%)		
BMI SDS	Overall: .77 ± 1.11		
MTF	.56 +/- 1.35		
FTM	.93 +/- .90		
Ethnicity			
Caucasian	30 (78.9%)		
Asian	2 (5.3%)		
African American	2 (5.3%)		
Biracial	2 (5.3%)		
Other/unknown	2 (5.3%)		
Psychological evaluation at baseline, n (%)			
No	27 (71%)		
Yes ^a	11 (28.9%)		
RLE, n (%)			
No	16 (42.1%)		
Yes	22 (57.9%)		
Concurrent diagnoses at baseline, n (%)			
Autism spectrum	5 (13.1%)		
ADD/ADHD	6 (15.8%)		
Psychiatric diagnoses	18 (47.4%)		
Depression	12 (31.6%)		
History of self-harm/suicide attempt	5 (13.1%)		
Psychotropic medications	14 (36.8%)		
Treated patients, n = 15	MTF (n = 5)	FTM (n = 10)	Age (mean ± SD)
Pubertal suppression			15.5 ± 2.1 year
GnRHa	2	7	

All patients, n = 38		
Progestins	0	3
Androgen receptor blocker	3	0
Cross-gender therapy		16.2 ± 1.4 year
	4	4

ADD/ADHD = attention deficit/hyperactivity disorder; BMI = body mass index;

FTM = female-to-male; GnRHa = gonadotropin-releasing hormone analogs;

MTF = male-to-female; RLE = real-life experience; SD = standard deviation;

SDS = standard deviation score.

^aOne received an evaluation from a social worker, and the remainder received an evaluation from a clinical psychologist.