Children and Adolescents With Gender Identity Disorder Referred to a Pediatric Medical Center

abstract

OBJECTIVES: To describe the patients with gender identity disorder referred to a pediatric medical center. We identify changes in patients after creation of the multidisciplinary Gender Management Service by expanding the Disorders of Sex Development clinic to include transgender patients.

METHODS: Data gathered on 97 consecutive patients <21 years, with initial visits between January 1998 and February 2010, who fulfilled the following criteria: long-standing cross-gender behaviors, provided letters from current mental health professional, and parental support. Main descriptive measures included gender, age, Tanner stage, history of gender identity development, and psychiatric comorbidity.

RESULTS: Genotypic male:female ratio was 43.54 (0.8:1); there was a slight preponderance of female patients but not significant from 1:1. Age of presentation was 14.8 ± 3.4 years (mean ± SD) without sex difference (P = .11). Tanner stage at presentation was 4.1 ± 1.4 for genotypic female patients and 3.6 ± 1.5 for genotypic male patients (P = .02). Age at start of medical treatment was 15.8 ± 2.8 years. Forty-three patients (44.3%) presented with significant psychiatric history, including 20 reporting self-mutilation (20.6%) and suicide attempts (9.3%).

CONCLUSIONS: After establishment of a multidisciplinary gender clinic, the gender identity disorder population increased fourfold. Complex clinical presentations required additional mental health support as the patient population grew. Mean age and Tanner Stage were too advanced for pubertal suppressive therapy to be an affordable option for most patients. Two-thirds of patients were started on cross-sex hormone therapy. Greater awareness of the benefit of early medical intervention is needed. Psychological and physical effects of pubertal suppression and/or cross-sex hormones in our patients require further investigation. Pediatrics 2012;129:418–425

WHAT'S KNOWN ON THIS SUBJECT: Studies in the Netherlands show that pubertal blockade at Tanner 2/3 prevents unwanted sex characteristics and improves psychological functioning. Endocrine Society guidelines (2009) recommend pubertal suppression for adolescents with gender identity disorder until approximately age 16.

WHAT THIS STUDY ADDS: This is the first study of a US cohort of children and adolescents with gender identity disorder. Patients were referred for medical treatment to a pediatric center that supports a multidisciplinary Gender Management Service.
The diagnosis of gender identity disorder (GID), including both childhood and adolescent/young adult subtypes, is listed in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition. Adolescents with GID must display strong and persistent cross-gender identifications, discomfort with his or her sex, and exhibit significant distress from gender dysphoria. Younger children may report gender dysphoria, yet most of these children will ultimately not meet criteria for GID once they become pubertal.

Many of these gender-variant children will ultimately develop a nonheterosexual orientation in adolescence; however, gender dysphoria in children that intensifies with onset of puberty rarely subsides. Individuals with GID have no proven genetic, anatomic, or hormonal abnormalities, but present with psychological symptoms, including anxiety, depression, or suicidal ideation; a significant number engage in self-harm behaviors.

In 1979, the World Professional Association for Transgender Health established standards of care for the treatment of GID, which included partially irreversible cross-sex hormone therapy treatments (androgens for genotypic female individuals and estrogens for male individuals) for patients who had completed or nearly completed puberty, and fully irreversible gender reassignment surgery thereafter. Although cross-sex hormones and genital reconstructive surgery promote cross-gender physical features, they often fail to achieve the appearance of the affirmed gender. Cross-sex hormones cannot undo breasts, body contour, and limited height in genotypic females or male-pattern facial/scalp hair distribution, skeletal changes, voice pitch, and “Adam’s apple” in genotypic male individuals. These cause emotional distress and can be altered only with expensive out-of-pocket treatments, often with unrewarding results.

In September 2009, the Endocrine Society published guidelines for the treatment of adolescents with GID that recommended suppression of puberty by using reversible gonadotropin-releasing hormone (GnRH) analogs at Tanner stage 2/3 for adolescents who fulfill strict readiness criteria. The World Professional Association for Transgender Health has just released its latest standards of care (7th edition), which echo the Endocrine Society in its recommendation to offer reversible pubertal suppression in young adolescents. All guidelines require close collaboration with mental health providers.

Pubertal suppression with gonadotropin-releasing analogs has been used since the 1980s for central precocious puberty. In 2000, the Amsterdam Clinic for Children and Adolescents initiated a protocol for the use of a GnRH analog with adolescents with GID who were at least age 12 and had reached Tanner stage 2 or 3, in doses comparable with treatment of central precocious puberty. Some teenagers were older and more developed. This fully reversible treatment allowed patients time until age 16 to decide, in consultation with health professionals and their families, whether to begin hormone treatment that would allow them to transition physically. The first 70 Dutch candidates treated with GnRH analogs between 2000 and 2008 showed improved psychological functioning. None opted to discontinue pubertal suppression and all eventually began cross-sex hormone treatment. More recently, the Amsterdam group found that adolescents with GID who underwent pubertal suppression had improved behavioral, emotional, and depressive symptoms with psychometric testing.

The 2009 publication of the Endocrine Society guidelines placed hormonal care of patients with GID into pediatric hands. Many academic centers treat adults with GID, but few pediatric centers provide treatment of adolescents with GID. Since 1998, the Endocrine Division at Children’s Hospital Boston has been evaluating and treating youths with GID. In 2007, the hospital created the first multidisciplinary gender-identity clinic in North America, the Gender Management Service (GeMS), to provide medical treatment of disorders of sex development to youths with GID. The team initially included a pediatric endocrinologist, urologist, and psychologist. Ongoing counseling was provided by outside mental health professionals (MHPs) who referred patients for medical treatment.

Patients underwent a psychological testing protocol that was adapted from that used by the Dutch team to assess eligibility to be treated medically, as evidenced by persistent clinical symptoms that interfered with psychosocial functioning and posed serious risk for self-harm. As the clinic population evolved, complex comorbid psychiatric presentations required the addition of a social worker and psychiatrist. This article provides characteristics and clinical data about the patients who presented for treatment from 1998 to 2010.

METHODS

Setting and Subjects

From 1998 through 2006, before the start of the GeMS clinic, the Endocrine Division at Children’s Hospital Boston accepted for evaluation patients with GID who provided a letter of referral from an MHP familiar with gender issues; 65 (67%) patients were Tanner stage 4 or 5. Cross-sex hormone treatment was offered when appropriate. All patients had entered puberty, were participating in ongoing psychotherapy, and had parental support. Upon the establishment of GeMS in January 2007, we began to see, but not medically treat, prepubertal children (Fig 1).
Appropriately screened patients with GID who were at Tanner stage 2 or 3 were offered pubertal suppression with GnRH analogs if they could obtain it. We did not limit our candidates to a minimal age of 12, as the Amsterdam group did. Postponing treatment until age 12 would result in many natal female patients being late Tanner 3 to Tanner 4, postmenarche, decelerating in growth velocity to a female final height, and with sufficient breast development to require a disfiguring mammoplasty. Because few medical centers for gender identity treatment of adolescents existed, the patient population grew and staffing was enhanced.

Beginning in 2009, individuals seeking care were triaged via telephone by the social worker, who obtained information about basic demographics, psychosocial functioning, and existing mental health supports. A letter sent to each referring therapist asked for information about their background, philosophy, and experience with GID; their patient’s history and supports; and mental health concerns.

In the course of the enhanced intake process, of 229 consecutive inquiries, most from the general public, 90 were deemed ineligible (Table 1). Patients with GID were accepted for testing by the GeMS psychologist only when they (1) had a triage history indicating persistent cross-gender behaviors and identification, (2) were concerned about or had commenced puberty, (3) were in mental health counseling, (4) had supportive parents, and (5) had a letter of referral from an outside MHP.

Patients considered eligible for medical intervention (GnRH analogs and/or cross-sex hormones), first met with a psychologist, along with their parents, for a gender-identity–focused, structured, comprehensive clinical interview and psychometric testing (Table 2). The psychological protocol was adapted from the Adolescent Gender Identity Research network to assess the degree of gender dysphoria, coexisting psychiatric conditions, and psychosocial stability.11 They next saw the pediatric endocrinologist, who took a full history, performed a physical exam, and ordered relevant blood tests and bone age films.

Since January 2007, appropriate patients with GID who are at Tanner stage 2 or 3 have been offered pubertal suppression with GnRH analogs. In 2009, the GeMS program expanded its original staff composition to include social work and psychiatric services.

As of 2009, patients who did not meet eligibility criteria for medical interventions were referred for treatment to MHPs, including our psychiatrist. The choice of medical treatment of eligible adolescents with GID depended on their stage of pubertal development and psychological/cognitive/developmental readiness. Parents of prepubertal children were instructed to watch for the first pubertal signs, counseled about future evaluations and therapeutic options, and instructed to remain in counseling with an MHP.

Of the patients included in this article, 14 patients needed to wait for pubertal signs. The age range was 4 to 12 years (3 at or younger than age 8, 2 at age 9, 8 at age 10, 1 at age 12). Seven were natal female individuals and 7 were natal male individuals. Those in early or midpuberty, Tanner stage 2 to 3, were candidates for pubertal suppression.

New patients who presented nearly or fully developed (Tanner 4 to 5), and existing 14- to 16-year-old patients being treated with GnRH suppression, were eligible to receive cross-sex hormones. All patients were required to

TABLE 1 Consecutive Inquiries by Intake Social Worker

<table>
<thead>
<tr>
<th>Reason</th>
<th>Number (% of the 90 Inquiries Deemed Ineligible)</th>
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<tbody>
<tr>
<td>Too young</td>
<td>34 (37.8)</td>
</tr>
<tr>
<td>Too old</td>
<td>18 (20.0)</td>
</tr>
<tr>
<td>Insurance denied coverage at hospital</td>
<td>9 (10.0)</td>
</tr>
<tr>
<td>Self-identified “queer” or “questioning”</td>
<td>12 (13.3)</td>
</tr>
<tr>
<td>In stable treatment elsewhere</td>
<td>6 (6.7)</td>
</tr>
<tr>
<td>Too distant to travel</td>
<td>11 (12.2)</td>
</tr>
</tbody>
</table>
TABLE 2 Psychological Testing Performed

<table>
<thead>
<tr>
<th>Psychological Testing</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Piers-Harris Children’s Self Concept Scale</td>
<td>Piers EV, Harris DB, Herzberg DS. Piers-Harris Self Concept Scale Los Angeles, CA: Western Psychological Services; 2001</td>
</tr>
</tbody>
</table>

Parent

| Asperger Syndrome Diagnostic Scale (ASDS)         | Myles BS, Jones-Bock S, Simpson RL. Asperger Syndrome Diagnostic Scale. Austin, TX: PRO-ED; 2001 |


meet psychological readiness criteria as described previously. Predicted heights were ascertained by personal growth records, calculated mid-parental target height, and skeletal age. If predicted height was excessively tall or short for the affirmed gender, initiation of cross-sex steroids could be adjusted to hasten or delay epiphyseal closure. All patients attended follow-up every 3 to 6 months to assess medical and psychosocial functioning. Members of the GeMS team met weekly.

Data Collection

The demographic data described here were derived from a chart review from consecutive initial visits of patients with GID seen at Children’s Hospital Boston from 1998 to 2009. “Pre-GeMS” is before 2007. Demographic information, individual history of gender development, and psychiatric history and current functioning were obtained from endocrinology notes for patients seen before 2007 (Table 3). For those seen in 2007 and beyond, the psychology and social work notes were reviewed as well. Prepubertal patients were included, even if they never received medical treatment, because we wished to include every patient who presented consecutively. Parameters based on the patient’s history of gender dysphoria included age of declaring gender dysphoria, age of expressing identification with cross-gender role, and age of living full-time in the affirmed gender role. Information was based on patient or parent recall and supplemented by information in the referral letters from mental health professionals. Psychiatric history included psychiatric diagnoses, number of psychotropic medications, self-mutilating behaviors, suicidal ideation, suicidal attempts, and number of psychiatric hospitalizations.

Statistical Analyses

Statistical analyses were performed by using SPSS 15 (SPSS Inc., Chicago, IL). For measured variables, statistical comparisons (biological female versus biological male; pre-GeMS versus post-GeMS) (Tables 4 and 5) were performed by the nonparametric Mann-Whitney test because the data were not normally distributed. The Fisher Exact Test was applied for proportions.

RESULTS

A significant proportion of patients presented with a history of psychiatric diagnoses and mental health issues (Table 6). Forty-three patients (44.3%) presented with a significant psychiatric history (see Table 6), with 20 patients (20.6%) reporting self-mutilation at least
once and 9 patients (9.3%) attempting suicide at least once.

Most patients (56, 57.7%) were started on a medical intervention within a week of their initial GeMS visit and psychological evaluation. Of those, 39 (69.6%) were started on cross-sex hormone therapy at Tanner 4/5, whereas 11 (19.6%) were treated with GnRH analog for pubertal suppression at Tanner 2/3. Medical intervention was initiated at a mean age of 15.6 ± 2.8 years. For those who did not immediately start medical therapy, the time to treatment was 9.0 ± 6.7 months, either because they were not yet Tanner 2, were too pubertally advanced for pubertal suppression but deemed too young (<14) for irreversible cross-hormone treatment, or were pre-Tanner 2 and waiting to obtain GnRH analog.

Data were obtained on the sexual orientation of 55 of the patients. Sexual orientation data were not regularly recorded at first (Table 7). Data were obtained on parents’ marital status for 66 of the 97 patients. Thirty-five (53.0%) of the parents were married, and 31 (47.0%) were divorced or separated. Eight patients of the total 97 (8.2%) were adopted.

**DISCUSSION**

This study is the first to provide demographic and clinical data on adolescents with GID treated at a pediatric center in the United States. Following the creation of a formal gender clinic offering treatment of transgender patients, our population increased fourfold. Families, clinicians, and MHPs became aware of the new clinic after the hospital promoted GeMS services and word spread through national conferences and in the public and social media. The increase in the number of patients and the distances traveled to receive treatment reflected a pent-up demand for medical intervention not available in any program in the United States. The number of youths entering GID clinics worldwide has been rising.

The sex ratio of our cohort was 1:1, comparable with the ratio in the Dutch program for adolescents with GID. These data indicate that the demographic male/female composition of the adolescent population presenting for treatment differs from that of the adult population. The literature on adult transsexuals suggests a ratio up to 3:1 of genotypic male individuals to genotypic female individuals.

One of the most striking characteristics of our population is the prevalence of psychiatric diagnoses and history of self-harming behaviors, which corroborates previous findings. Comorbid psychiatric conditions may hinder the diagnostic evaluation or treatment of gender dysphoria. Comprehensive interdisciplinary treatment services were, therefore, created emphasizing the mental health component. Gender-dysphoric children who do not receive counseling have a higher risk of behavioral and emotional problems and psychiatric diagnoses. Transgender youths are also at higher risk of substance abuse, suicidal ideation, and suicidal attempts. Of our patient population, 44.3% had a prior history of psychiatric diagnoses, 37.1% were taking psychotropic medications, and 21.6% had a history of self-injurious behavior.

Our observations reflect the Dutch finding that psychological functioning improves with medical intervention and suggests that the patients’ psychiatric symptoms might be secondary to a medical incongruence between mind
TABLE 6 Gender and Psychiatric History  

<table>
<thead>
<tr>
<th>Gender history</th>
<th>n (%) or Mean ± SD</th>
</tr>
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<tbody>
<tr>
<td>Living in full-time gender role at presentationa</td>
<td>89 (91.8)</td>
</tr>
<tr>
<td>Demonstrated cross-gender behavior before age 5b</td>
<td>44 (45.4)</td>
</tr>
<tr>
<td>Age living in full-time gender role, y</td>
<td>13.6 ± 3.8</td>
</tr>
<tr>
<td>Age of medical intervention, y</td>
<td>15.6 ± 2.8</td>
</tr>
<tr>
<td>Started medical intervention immediately (&lt;1 wk) after first CHB evaluation</td>
<td>56 (57.7)</td>
</tr>
<tr>
<td>If not started immediately, time to medical treatment, mo</td>
<td>9.0 ± 6.7</td>
</tr>
</tbody>
</table>

Psychiatric history

- With psychiatric diagnosis before CHB evaluationc: 43 (44.3)
- On psychiatric medications: 35 (36.1)
- With prior psychiatric hospitalizations: 9 (9.3)
- History of self-mutilation: 20 (20.8)
- History of suicide attempts: 9 (9.3)

Psychiatric diagnosesd

- Depression: 25 (58.1)
- General anxiety disorder: 7 (16.3)
- Bipolar disorder: 7 (16.3)
- Pervasive developmental disorder (nonautism): 4 (9.3)
- Eating disorder: 3 (7.0)
- Attention-deficit/hyperactivity disorder or attention-deficit disorder: 2 (4.7)
- Autism: 1 (2.3)
- Panic disorder: 1 (2.3)
- Posttraumatic stress disorder: 1 (2.3)

TABLE 7 Sexual Orientation of Patientsa

<table>
<thead>
<tr>
<th>Sexual Orientation</th>
<th>Affirmed Males (Natal Females)</th>
<th>Affirmed Females (Natal Males)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attracted to same natal sex</td>
<td>22 (62.9)</td>
<td>11 (55.0)</td>
<td>33 (60.0)</td>
</tr>
<tr>
<td>Attracted to opposite natal sex</td>
<td>6 (17.1)</td>
<td>4 (20.0)</td>
<td>10 (18.2)</td>
</tr>
<tr>
<td>Attracted to both male and female individuals</td>
<td>3 (8.6)</td>
<td>2 (10.0)</td>
<td>5 (9.1)</td>
</tr>
<tr>
<td>Unsure</td>
<td>4 (11.4)</td>
<td>3 (15.0)</td>
<td>7 (12.7)</td>
</tr>
<tr>
<td>Total recorded</td>
<td>35</td>
<td>20</td>
<td>55</td>
</tr>
<tr>
<td>Unrecorded</td>
<td>19</td>
<td>23</td>
<td>42</td>
</tr>
<tr>
<td>Total</td>
<td>54</td>
<td>43</td>
<td>97</td>
</tr>
</tbody>
</table>

* n (%). Unrecorded orientation not included in calculation of percentages. Distribution of sexual orientation did not differ significantly between natal male patients and natal female patients, P = .81 by Fisher exact test.

and body, not primarily psychiatric. Future research is needed to understand how adolescent patients change psychologically when they attain a physical appearance similar to or indistinguishable from their affirmed gender peers after being treated with early pubertal suppression followed by cross-sex hormone therapy.

The mean Tanner stage at initial visit in our program did not significantly change even after we expanded services and outreach via the formal GeMS clinic. Of our patients or their parents, 44.3% described gender dysphoria or cross-gender identifications and behaviors during the child’s preschool years, yet our patients did not present for medical treatment until mean Tanner stages of 3.6 ± 1.6 for genotypic male individuals and 4.1 ± 1.6 for female individuals. The Dutch program reports delayed presentation for medical treatment as well, with genotypic female individuals presenting at a later mean age and Tanner stage than genotypic male individuals. Unfortunately, at these mid to late Tanner stages, pubertal suppression provides lesser benefits. The $500 to $1000 per month out-of-pocket cost of GnRH analog at Tanner 4 to 5 renders cross-sex steroids as the only affordable medication to treat symptoms and hormonal levels. When covered by insurance, as in the Netherlands, analog combined with cross-sex steroids can be used until gonadectomy, necessitating much lower doses of estrogen in Male-to-Females and with greater effect than with steroid alone.

For genotypic male individuals who identify as female, virilization of hair follicles, lowering of vocal pitch, and Adam’s apple prominence are irreversible. For genotypic female individuals who identify as male, preventing the endogenous estrogen-driven epiphyseal plate closure is crucial to achieve male height. Preventing endogenous secondary sexual characteristics from fully developing not only relieves distress but enables the individual with GID to live in the phenotype of the affirmed gender. To minimize acute distress from endogenous pubertal development and maximize appropriate “gender attribution” (society’s perception of one’s gender), the Endocrine Society guidelines recommend pubertal suppression at an early Tanner stage for appropriate candidates of both sexes.

There are numerous reasons for late presentation. Parents of genotypic female individuals may believe their daughters with GID are going through a temporary phase because Western society accepts androgyny in female individuals. Genotypic male individuals often wait to seek medical care until the most obvious changes occur in voice, skeletal growth, genitals, and facial/body hair (Tanner 3/4). In addition, the
Many of our adolescent patients report that it was their pediatrician who first asked if they were experiencing gender-related issues, which became the springboard to counseling and further medical evaluation. Even if patients are too young to receive medical treatment, they and their families can benefit from counseling to cope with the difficulties of being or raising a gender-variant child.

Patients with GID should be provided with care that helps prevent self-injurious behavior and suicidal ideation and attempts, among other psychiatric difficulties. We are not proposing medical treatment of prepubertal children. We do advocate for early evaluation of these children by experienced professionals. Clues indicating GID in genotypic male children include preference for female clothing and underwear, always sitting to void, exclusive play with female toys when given a choice, and desire for long hair. Clues indicating GID in genotypic female children include preference for male underwear, breast binding, refusal to wear female swimsuits, and psychiatric decompensation at the onset of menstruation. Persistence or intensification of gender dysphoria into full Tanner 2 indicates that patients should be considered for medical treatment. Referrals can be made to specialists who treat adolescents with GID. With consultation and supervision from an interdisciplinary team familiar with GID treatment protocols, pediatricians may continue to provide observation of their patients and remain key players in their care team.

ACKNOWLEDGMENTS

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REFERENCES

7. Standards of Care for the Health of Transsexual, Transgender, and Gender Nonconforming People. 7th ed. Minneapolis, MN: World Professional Associations for Transgender Health; 2011
NAMING CHILDREN: When we first started having children many years ago, picking out a name for each child involved reviewing family names, buying a book of names, and making lists of names that were at least acceptable to both of us and those that were definitely off limits to at least one of us. Even when we were asked “Do you really like that name?” (still one of my favorite questions), we shrugged it off and named our third son Samuel anyway. Now, it seems that naming a child has gotten more complicated. According to an article in The New York Times (Fashion: November 25, 2011), naming a baby now frequently involves a Google search. In one small online poll conducted by a parenting site, 64% of respondents reported performing a Google search on the prospective name of their child. Evidently many parents are looking for less common names. They are seeking exclusive but not necessarily bizarre names that could lead to problems at school. One reason for the search is to be able to create a relatively unique online persona for the child. Twenty years ago, most parents simply mailed friends and family members a card with the name of the child and some vital statistics like the weight and length. Now, some parents register their child’s name as a domain name and claim the name on Twitter and G-mail accounts even before the child is born. By the age of two in the U.S., 92% of children already have some type of online presence. Some parents are looking for a creative name, but others are simply making sure that the name is not associated with a serial killer or an ugly oath in another language. If parents are still unable to decide between two names, they can always download an inexpensive iPhone application. After downloading, parents hold the phone against the mother’s abdomen. The program rotates between the two names but freezes on a name as soon as the baby kicks. If the parents don’t have an iPhone, they can always do what my wife and I did for child number two: a best of 13 coin toss.

Noted by WVR, MD
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The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://pediatrics.aappublications.org/content/129/3/418.full.html