Understanding Gender Nonconformity in Childhood and Adolescence

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Disclosures

• No financial conflicts of interest to disclose

• All medical treatments discussed in this presentation are off-label for use

• Treatment recommendations are based on best available evidence
Objectives

- Learn about developmental trajectories of gender-nonconformity and transgenderism in children and adolescents
- Learn about approaches to assessment and care of gender-nonconforming and transgender youth, specifically, the interface between behavioral health and medicine
- Understand the basic concepts of medical treatment for gender nonconforming youth
Lurie Children’s

Gender and Sex Development Program

Gender Development Clinic
Director: Rob Garofalo, MD, MPH

- Children/adolescents who are:
  - Gender nonconforming
  - Transgender
  - Gender questioning
  - Gender-fluid

Sex Development Clinic
Director: Earl Cheng, MD

- Infants/children/adolescents with Disorders of Sex Development:
  - Conditions marked by abnormal chromosomal, gonadal or anatomic development
Gender Nonconformity in Media

- Washington Post
- New York Times
- New York Magazine
- Huffington Post
- People Magazine
- ABC’s Nightline
- NBC’s Dateline
- CBS’s Sunday Morning
- 20/20
- PBS
- Orange is The New Black
- Transparent
Gender Nonconforming Youth

- Increasing numbers of gender non-conforming youth are being referred for care

- Presenting for care younger

- Many referred by primary care specialists
### Terminology

#### SEX
- Attributes that characterize biological maleness and femaleness:
  - Sex-determining genes
  - Chromosomes
  - Hormones
  - Anatomy

#### GENDER
- Attitudes, feelings, and behaviors that a given culture associates with a person’s biological sex (APA, 2011):
  - Gender expression
  - Gender roles/behaviors
  - Gender identity
- Varies by place, time period

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**Biological construct**

**Social construct**
Gender Expression
- How gender identity is communicated to others
  - e.g., one’s name, gender pronoun, style of dress, interests, etc.

Gender Role
- Behaviors, attitudes, and personality traits that a society in a given historical period designates as “masculine” or “feminine”
  - e.g., men: aggressive, strong, dominant, emotionally reserved; women: nurturing, dependent, passive

Gender Identity
- An individual’s personal sense of self as male, female, or an alternate gender
Terminology

**Gender dysphoria**
- Internal distress experienced due to the discordance between gender identity and biological sex

**Transitioning**
- Process by which an individual begins living in their affirmed gender role
- May or may not include hormonal and/or surgical treatment
Shifting Perspectives

**Gender Identity Disorder (GID)**
- Psychiatric diagnosis in the DSM-IV-TR
- Principle criteria: Persistent cross-gender identification resulting in clinically significant distress

**Gender Dysphoria (GD)**
- Replaced GID in the DSM-V
- Principle criteria: Clinically significant distress resulting from incongruence between one’s assigned and asserted gender

Gender Identity is NOT Pathological
Gender Dysphoria in Children

Gender Dysphoria in Children

A marked incongruence between one’s experienced/expressed gender and assigned gender, of at least 6 months’ duration, as manifested by at least six of the following (one of which must be Criterion A1):

- A strong desire to be of the other gender or an insistence that one is the other gender (or some alternative gender different from one’s assigned gender).
- In boys (assigned gender), a strong preference for cross-dressing or simulating female attire; or in girls (assigned gender), a strong preference for wearing only typical masculine clothing and a strong resistance to the wearing of typical feminine clothing.
- A strong preference for cross-gender roles in make-believe play or fantasy play.
- A strong preference for the toys, games, or activities stereotypically used or engaged in by the other gender.
- A strong preference for playmates of the other gender.
- In boys (assigned gender), a strong rejection of typically masculine toys, games, and activities and a strong avoidance of rough-and-tumble play; or in girls (assigned gender), a strong rejection of typically feminine toys, games, and activities.
- A strong dislike of one’s sexual anatomy.
- A strong desire for the primary and/or secondary sex characteristics that match one’s experienced gender.
- The condition is associated with clinically significant distress or impairment in social, school, or other areas of functioning.
Prevalence of Gender Dysphoria

Older estimates:
- van Kesteren et al.
  - Data from the Netherlands collected from 1975-1992
  - 1:11,900 natal males (MtF)
  - 1:30,400 natal females (FtM)

More recent estimates:
- Conron et al.
  - “Population based” household probability sample, n=28,176 adults
  - Telephone health survey
  - Do you consider yourself to be transgender? n=131
    - 0.5% answered affirmatively

van Kesteren and Gooren et al. An epidemiological and demographic study of transsexuals in the Netherlands. *Arch Sex Behav*, 1996

Gender Development
Gender Development

• By 18-24 mo, children develop the ability to label gender

• Between 2-4 years, most children recognize gender differences, use gendered pronouns

• By age 5 to 6 years, most children declare a gender identity of male or female

• For most children, this identity is consistent with their birth-assigned sex and remains constant across the lifespan

Gender Development

• Many children experiment with gender expression and roles
  – Cross-gender play (toys, games)
  – Cross-gender dress

• Exploring gender is a very normal part of development

• Some children exhibit persistent, insistent nonconforming behaviors and expression
Natural History of Gender Dysphoria

• For the majority of pre-pubertal children, GD does not “persist” into adolescence

• In a minority (~15%)*, GD does “persist”

• In contrast to GD in childhood, GD that persists into adolescence is unlikely to subside
  – For many children, GD intensifies with pubertal changes

• Most adolescents and adults with GD recall having gender nonconforming behavior and identity as children

Drescher & Byne. Gender dysphoric/gender variant (GD/GV) children and adolescents: Summarizing what we know and what we have yet to learn. *Journal of Homosexuality*, 2012

Gender Dysphoria

Can We Predict Persistence of GD?

• Impossible to always predict with certainty but...

• Study examining factors associated with persistence of childhood GD in a clinic-referred sample of youth in the Netherlands (n=127) suggests that the likelihood of transgender identity in adolescence/adulthood may be predicted by:

  1) High intensity of childhood GD
  2) Tendency to assert their gender cognitively versus affectively:
      * “I am a boy” versus “I feel like a boy”

Vignettes
Vignette 1
“Andrew” 6 yo natal male

- Mom reports from his earliest years Andrew preferred dresses, playing with make-up and dolls
- At 3yo Andrew asked his parents to buy him feminine clothing, a wig
- On a number of occasions, he tells his parents “I’m a girl”
- At 4yo he tells his mother “I can’t wait to get to heaven to be a girl” –
- Visited their pediatrician – “it’s just a phase”
- A year ago, parents allow him to wear dresses/skirts inside the home (they note that he’s so much happier during these times)
- Mom, tearfully explains “He’s so insistent - it’s beginning to feel oppressive - not allowing him to be who he is”
- Notice he’s becoming more withdrawn, starting to avoid school
Pre-Pubertal Children

- Presentation varies widely, often depending on environment
- Without pressure to conform, children may not be dysphoric
- May become angry, upset, sad, or withdrawn when parents or others attempt to redirect their behavior
Reversible: Social Transitioning

• The way a person presents themselves to the world:
  • Physical appearance
  • Names
  • Pronouns
  • Other changes in social role or living situation: Bathrooms, dorms

• Social transitioning for pre-pubertal children remains controversial
  • Lack of outcomes data in children who have completed early social transition
3 Behavioral Health Approaches

1. Corrective
2. Supportive/Wait and See
3. Affirming
Corrective Approach

Goal: Align gender identity and expression with natal sex

– Tenets:
  • To prevent transgenderism is to prevent psychosocial adversity
  • Identity as pathology (GID) or root of pathology
  • Internal gender identity is malleable through behavioral techniques

– Strategies
  • Discourage gender nonconformity
  • Encourage gender normative play and preferences
  • Allow social and/or medical transition for those ages 16 and up
Supportive Approach

Goal: “Wait and See” how gender identity unfolds

– Tenets
  • Gender variations are not disorders
  • Gender identity in gender-nonconforming youth cannot be determined early on

– Strategies
  • Neither discourage nor encourage gender-related behavior or expression
  • Unlikely to encourage social transition or medical intervention prior to puberty
Affirming Approach

Goal: Help child and family decipher subjective gender experience and differentiate those with persistent transgender identity from those exploring gender non-conforming expression

- Tenets
  - Gender variations are not disorders
  - Gender may be fluid and not always binary
  - Some transgender youth can be distinguished from non-transgender youth prior to puberty

- Strategies
  - Assist youth and families in learning about and engaging in gender transitioning, such as social and medical interventions
Why do we believe in Affirming approach?

- Affirming does not mean encouraging or pushing gender transition

- Children rejected and not supported are at increased risk of the following during adolescence:
  - Depressive symptoms, low life satisfaction, self-harm, isolation, posttraumatic stress, incarceration, homelessness, and suicidality

- Family acceptance and support during adolescence is tied to the following in young adults:
  - Positive self-esteem, high social support, positive mental health, less depressive symptoms, greater self-esteem, greater life satisfaction (compared with youth whose families were non-supportive)

Why do we believe in Affirming approach?

• For those whose gender dysphoria persists, affirming gender non-conformity is affirming the child’s core gender identity...

• We think that early treatment will lead to a better physical and psychosocial outcome.
Vignette 2
“Jack” 9.5 yo natal female, affirmed male

- Parents report preference for stereotypically masculine clothing, toys and play since his earliest years
- Reports knowing he was “really a boy” since age 5, when he remembers insisting on typical-male clothing and cutting his hair short
- Social transitioned at age 5
- Parents report some resentment/aggression toward younger brother
- Concerned about Jack’s increased anxiety, seems withdrawn and depressed, trying to avoid school
- Strong concern he will grow breasts and develop pubic hair: “I don’t want this to happen because I’m a boy...and boys don’t have those”
- Exam: Breasts SMR 2, Pubic hair SMR 1
Puberty

• Female puberty
  – Breast development
  – Growth spurt
  – Change in body shape
  – Increase fat deposition in hips, thighs, buttocks
  – Body hair growth
  – Menarche

• Male puberty
  – Increase in testicular volume
  – Enlargement of penis
  – Increase muscle mass
  – Deepening of voice
  – Adam’s apple
  – Body and facial hair growth
  – Body shape (broadening of shoulders)
  – Skull and bone structure
  – Increased secretions of oil/sweat glands
  – Growth spurt
For gender non-conforming adolescents, these physical changes can be **unbearable**.

Gender dysphoria often **intensifies** or emerges around puberty.

Early intervention with GnRH analogs may **alleviate** psychological harm.

GnRH agonists (leuprolide, histrelin) effectively suppress the production of sex hormones at the pituitary level.
GnRH Agonists

- **POTENTIAL BENEFITS**
  - Completely reversible
  - “Buys time”
  - Allows exploration while distress is alleviated
  - Prevents the physical changes of an undesired puberty, some which are irreversible
  - May prevent future medical interventions/surgeries
  - Considered safe – although long-term f/u studies meager
Potential Risks

Limited long-term studies of GnRH analogs used to suppress puberty in gender nonconforming children:

1. Bone density
   - Delemarre-van de Waal, 2006
   - 21 patients treated with GnRH analogs for 2 years or longer
   - During treatment, bone density remained the same range (lower than age-matched peers) – caught up with addition of sex hormone

2. Height
   - Decreased growth velocity

3. Impact on brain development

Practice Guidelines

• The Endocrine Society, 2009

  - Recommend that adolescents who fulfill eligibility and readiness criteria undergo treatment to suppress pubertal development

  - Suppression of puberty should start after the first signs of puberty, no earlier than Tanner 2-3

Vignette 3
“Jack” 15 yo natal female, affirmed male

- As a toddler Jack would only play with trains, cars, action figures
- Jack recalls feeling happy when male peers accepted him
- At age 4 yr he firmly asked for “boys clothes only” and requested a haircut “like a boy’s”
- At age 6 yrs, Jack told his mother “God made a mistake”
- In elementary school, Jack was always considered a “tomboy”
- In 3rd grade, he tried “to be feminine and fit in” but this felt miserable
- In 5th grade, puberty started and Jack became increasingly distressed - began wearing a bra to cover slight breast development. By 6th grade he routinely wore 2-3 bras to conceal his chest
- Jack initially disclosed to his parents in 7th grade – Mom tearfully explains she told him “it will go away”
- They didn’t discuss it again until this year, when Mom noticed increasing discomfort with his body
Partially reversible: Cross-sex hormones

• Indicated for adolescents with consistent, persistent and insistent gender identity

• Goals
  1) Reduce endogenous, undesired sex hormones
  2) Replace endogenous hormone levels with those of one’s asserted gender, thereby inducing desired secondary sexual characteristics
Partially reversible: Cross-sex hormones

- **The Endocrine Society, 2009**
  - For those meeting eligibility and readiness criteria, start cross-sex hormones no earlier than 16 years old

- **Lurie Children’s**
  - Individualized management needed for each adolescent – initiating prior to 16 years may have psychosocial benefit

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Treatment of Youth with GD

• Requires psychosocial support
• Require parental consent (under age 18)
• Letter of readiness from a mental health provider documenting:
  – Psychosocial assessment - evaluating support, identifying anything that may make transitioning difficult
  – Understanding and reasonable expectations of medications
  – Exclusion of any condition that may confound the diagnosis of GD
Testosterone therapy

- **IRREVERSIBLE EFFECTS**
  - Lower voice pitch
  - Increased hair growth (arms, legs, chest, ab)
  - Mustache/beard growth
  - Male pattern hair loss (temples, crown) and possibly baldness
  - Genital changes (clitoral growth and vaginal dryness/fragility)
  - Fertility?

- **REVERSIBLE EFFECTS**
  - Acne
  - Fat redistribution (pear→apple)
  - Increase muscle mass and upper body strength
  - Increased libido
  - Menstrual cessation
  - Increased RBCs
# Masculinizing effects

<table>
<thead>
<tr>
<th>EFFECT</th>
<th>ONSET (Months)</th>
<th>MAX (Years)</th>
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<tbody>
<tr>
<td>Acne</td>
<td>1-6</td>
<td>1-2</td>
</tr>
<tr>
<td>Facial/body hair growth</td>
<td>6-12</td>
<td>4-5</td>
</tr>
<tr>
<td>Scalp hair loss</td>
<td>6-12</td>
<td></td>
</tr>
<tr>
<td>Increased muscle mass</td>
<td>6-12</td>
<td>2-5</td>
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<tr>
<td>Fat redistribution</td>
<td>1-6</td>
<td>2-5</td>
</tr>
<tr>
<td>Cessation of menses</td>
<td>2-6</td>
<td></td>
</tr>
<tr>
<td>Clitoral enlargement</td>
<td>3-6</td>
<td>1-2</td>
</tr>
<tr>
<td>Vaginal atrophy</td>
<td>3-6</td>
<td>1-2</td>
</tr>
<tr>
<td>Deepening of voice</td>
<td>6-12</td>
<td>1-2</td>
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</tbody>
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Side effects/Risks: Testosterone

- Unknown effects on fertility
- Increased cardiovascular risk
  - Increased weight
  - Decreased HDL, Increased Triglycerides
  - Increased BP
- Increased insulin resistance
- Hepatotoxicity
- Mood changes: irritability, aggression
- Headaches
- Acne
- Polycythemia
- Theoretical risk: breast/endometrial cancer

RECOMMEND

- Egg preservation
- Weight loss
- Smoking cessation
- Pap screening
- Self-breast exams
- Mammograms
Feminizing therapy

• Estrogen
  – Most important for feminization

• Androgen antagonists
  – Blocks testosterone at the receptor level
  – Inhibits testosterone secretion
Feminizing therapy (MtF)

- **IRREVERSIBLE EFFECTS**
  - Breast tissue growth
  - Testicles may decrease in size
  - Body hair growth may slow (but will not stop)
  - Male-pattern baldness may slow but may not stop
  - Unknown effects on fertility

- **REVERSIBLE EFFECTS**
  - Skin softening
  - Reduced muscle mass/upper body strength
  - Fat redistribution (apple→pear)
  - Libido may decrease
  - Erections may decrease
  - Mood changes
Feminizing therapy: What it won’t do

1. Cause voice pitch to rise
2. Decrease size of laryngeal prominence (Adam’s apple)
3. Dramatically affect facial hair
Feminizing effects

<table>
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<tr>
<th>EFFECT</th>
<th>ONSET (months)</th>
<th>MAX (years)</th>
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<tbody>
<tr>
<td>Redistribution of body fat</td>
<td>3-6</td>
<td>2-3</td>
</tr>
<tr>
<td>Decrease in muscle mass</td>
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<tr>
<td>Skin softening</td>
<td>3-6</td>
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<tr>
<td>Decreased libido</td>
<td>1-3</td>
<td>3-6</td>
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<tr>
<td>Decreased erections</td>
<td>1-3</td>
<td>3-6</td>
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<tr>
<td>Male sexual dysfunction</td>
<td>Variable</td>
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<tr>
<td>Breast growth</td>
<td>3-6</td>
<td>2-3</td>
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<tr>
<td>Decreased testicular volume</td>
<td>3-6</td>
<td>2-3</td>
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<tr>
<td>Decreased sperm production</td>
<td>?</td>
<td>?</td>
</tr>
<tr>
<td>Decreased hair growth</td>
<td>6-12</td>
<td>&gt;3</td>
</tr>
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</table>
Side effects/Risks: Estrogen

- Not fully known
- Fertility effects are unknown
- Thrombosis
- Hepatotoxicity
- Increased cardiovascular risk
  - Weight gain
  - Increase LDL/Trig, decreased HDL
  - Fat deposition
- Diabetes
- Gallstones
- Headaches
- Nausea, vomiting
- Emotional changes
- Prolactinoma
- Breast cancer

**RECOMMEND**

- Sperm Banking
- Thrombophilia screen for those with personal/family hx DVT
  - Smoking cessation
- Weight loss, exercise
- Self-breast exams
Barriers to care

- **Cost**
  - Lupron $800-1500/month
  - Histrelin $15,000 for device + implantation
  - Testosterone $60 for 10-month supply
  - Estradiol $10 for 90 pills

- **Insurance exclusions**

- **Lack of medical providers with expertise**

- **Lack of mental health clinicians with expertise**

- **Negative past experience with health care**
A Word about Clinic Environment

- Sensitivity to all aspects of “affirmed” gender
- Chosen name “How do you like to be called?”
- Preferred pronoun for individual and group settings
  - “I’m Rob and I prefer he and him pronouns. What gender pronouns do you prefer?”
  - “Please share your name, your preferred gender pronoun, your grade in school, etc.”
When to Refer?

- If medical providers feel uncomfortable
- Any identified youth or family member struggling with gender nonconformity
- Any identified youth or family member seeking more education about gender identity
- Any identified youth expressing interest in gender-specific medical or mental healthcare
- Psychosocial concerns that may be related to gender
Thank You