IMPROVING CARE FOR TRANSGENDER INDIVIDUALS WITH EATING DISORDERS

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At least 30 million people of all ages and genders suffer from eating disorders in the United States. They are complex mental illnesses that affect thinking, mood & behavior, often leading to dangerous medical complications.

An Eating Disorder is an Illness, Not a Choice.

Eating Disorder Prevalence

Eating disorders are often shown in the media to effect heterosexual, affluent, cisgender, thin, young, able-bodied, white females.

Let’s get real...
- Eating disorders are common across gender, sex, age, race/ethnicity, socioeconomic status, and body shapes and sizes
- Female to Male ED ratio: AN ~3:1, BN ~3:1, BED ~5:4
- Boys of color > White boys
- Lesbian, Gay, Bisexual youth > Heterosexual youth
- Transgender youth > Cisgender youth

(Swanson et al., 2017)
Eating Disorders Do Not Discriminate

Inaccurate stereotypes decrease the likelihood that those who are male, homosexual, poor, people of color, larger-boded, or transgender will be diagnosed and receive adequate treatment.

Urgent Attention is Needed

Transgender individuals are an understudied and under-recognized group that experience eating disorders and disordered eating at very high rates. Until about 5 years ago, we knew almost nothing about eating disorders in the transgender community.

LGBTQ studies have had to cover a very diverse group and often lack statistical power to investigate gender dysphoric patients specifically.

Among gender minority people, lived experiences and health needs differ substantially across the continuum of non-binary and binary gender identities, as well as based on AFAB versus AMAB.

Eating disorder research is already underfunded, which also contributes to an even greater disparity in research about trans people with eating disorders.

(Gaudiani, 2018; Muhlheim, 2019)
A 2018 survey conducted by Trevor Project and NEDA consisted of > 1,000 LGBTQ youth ages 13-24

54% reported an ED diagnosis
- An additional 21% (75% total) suspected that they had an ED

71% of transgender individuals who identified as straight reported having an ED disorder
- Anorexia nervosa was the highest reported diagnosis

58% of respondents diagnosed with an ED had also considered suicide

(Eating Disorders & Suicidality Among LGBTQ Youth)

Overview of Eating Disorders in the DSM-5

- Anorexia Nervosa
- Bulimia Nervosa
- Binge Eating Disorder
- Avoidant Restrictive Food Intake Disorder
- Other Specified Feeding and Eating Disorder

(Overview of Eating Disorders in the DSM-5)
Anorexia Nervosa

Restriction of energy intake leading to a significantly low body weight
- Restrictive F50.01 or Binge/Purge Type F50.02

Intense fear of weight gain or becoming fat despite low weight

Body image disturbance – either in how their body is experienced or how much influence body shape/weight has on self-esteem
- Constant comparison of self to others
- Refers to self disparagingly – “fat”, “gross”, “soft”, “ugly”, “thick”
- Consistently over-estimates their own body size and seeks constant reassurance from others that their looks are acceptable

(APA, 2013)

Anorexia Nervosa

Malnourished state/weight represents self-worth, self-control and accomplishment
Persistent lack of recognition of the seriousness of the current low body weight
Menses may stop, but not mandatory for diagnosis

Mild BMI $\geq$ 17, Moderate BMI 16-16.99, Severe BMI 15-15.99, Extreme BMI $< 15$

$\sim 50-60\%$ recover; $\sim 30\%$ improve; $\sim 7-15\%$ chronic

SMR for AN = 5.86 (about 20% due to suicide). Highest of any psychiatric disorder.

(APA, 2013)
**Bulimia Nervosa**

Recurrent episodes of binge eating

- Eating in a discrete period of time (~2hrs) an amount of food that is definitely larger than most people would eat during a similar period of time and circumstance.
- A sense of lack of control over eating during the episode

Recurrent episodes of inappropriate compensatory behavior to prevent weight gain

- Shame and disgust associated with binge eating leads to “undoing”
- Vomiting, laxatives, enemas, diet pills, diuretics, fat burners, excessive exercise...
- May underreport frequency

_Bulimia Nervosa does not always have a visible impact on weight._

Very critical self evaluation unduly influenced by body shape and weight

Binges and compensatory behavior occur on average of at least once a week for 3 months

Mild 1-3, Moderate 4-7, Severe 8-13, Extreme 14 or more episodes/week

Short-term success of treatment: 50-70%; High relapse rates: 30-85% at 6 mo to 6 years

SMR for BN = 1.9 (~20% due to suicide)
Binge Eating Disorder

Recurrent eating of large amount of food within a 2 hour period of a large amount of food with sense of loss of control

Binge eating episodes are associated with 3 or more:
- Eating with extreme guilt, self disgust
- Eating past fullness, uncomfortably full
- Eating large amounts when not hungry
- Eating alone due to embarrassment, rapidly
- Food is used as a mood altering substance
- Eating much more rapidly than normal

Marked distress regarding binges

(APA, 2013)

Binge Eating Disorder

Occurs, on average, at least 1 time a week over 3 months
Not associated with compensatory behavior

Mild 1-3, Moderate 4-7, Severe 8-13, Extreme 14 or more episodes/week

Course of illness among patients with BED is often chronic
Degree of weight suppression predicts binge eating
Adolescent onset is associated with later bulimia

(APA, 2013)
Avoidant/Restrictive Food Intake Disorder

Feeding/eating disturbance and failure to meet appropriate nutritional/energy needs with:
- Significant weight loss
- Significant nutritional deficiency
- Dependence on enteral feeding or oral supplements
- Marked interference with psychological function

Not explained by lack of available food – sensory food aversion, allergies, trauma, or picky eating may precede illness

No evidence of a disturbance in the way in which one’s body weight or shape is experienced

Not explained by concurrent medical or psychological condition

Not occurring solely in course of AN or BN

(APA, 2013)

Other Specified Feeding or Eating Disorder

DSM-IV EDNOS -> DSM-5 OSFED
- Atypical Anorexia Nervosa: Despite significant weight loss, the individual’s weight is within or above normal range
- Binge Eating Disorder or Bulimia Nervosa of low frequency and/or limited duration
- Purging disorder: Recurrent purging behavior to influence weight or shape in the absence of binge eating
- Night Eating Syndrome: Recurrent episodes of night eating. Eating after awakening from sleep, or by excessive food consumption after the evening meal.

(APA, 2013)
What Causes Eating Disorders?

Factors which Increase Risk

- Dieting
- Early body dissatisfaction
- Trauma
- Bullying
- Intensive sport training
- Participation in activities that emphasize ideal body size/shape or need to make weight
  - dance, gymnastics, modelling, wrestling, crew
- LGBTQ

Psychological
Biological
Genetic
Environmental
Social Factors

ACHA Study of ~ 300,000 US College Students

Comparison group: Cisgender heterosexual women
- 1% diagnosed with ED in past year
- 3% vomited or used laxatives and 3.5% used diet pills in last month

Trans students were 2-4x more likely to report ED dx and behaviors

Trans students who were unsure of sexual orientation were significantly more likely to report ED diagnoses and behaviors

Cisgender heterosexual men were 1/3 as likely to use ED behaviors

Gay men were 1.5x more likely to have formal ED diagnoses

Lesbian women had similar rates

(Diemer et al, 2015; Gaudiani, 2018)
ED Prevalence by Gender Identity

In study of 452 transgender adults in Massachusetts
- 31% AFAB and gender non-conforming/non-binary
- 31% Trans men
- 9% AMAB and gender non-conforming/non-binary
- 28% Trans women

Those who were AFAB and gender non-binary had highest lifetime rate of self-reported and formally diagnosed EDs (7.4%).
Non-binary individuals were 3x more likely to have had an ED compared with trans binary
Lowest level of ED was in trans women

(Diemer et al, 2018; Gaudiani, 2018)

Why are Trans and Non-binary Individuals at Increased Risk for having an Eating Disorder?
Body Dissatisfaction

Body dissatisfaction, negative evaluation of one’s appearance, has consistently been associated with eating disorders. Transgender people are particularly vulnerable due to the distress and incongruence they experience with their gender and body. Desire to achieve body image “ideal”/“beauty”, LGBTQ cultural contexts. Desire to stop menses, puberty and development.

- Trans men seeking less feminine body shape (stop breast and hip development)
- Trans women seeking ideal thin and to accentuate femininity
- Non binary may restrict to appear as thin, androgynous

However, not all trans and cisgender people with eating disorders report a connection between body image and eating disorder. (Diemer et al, 2018; Jones et al, 2018)

Minority Stress

Stress experienced by individuals in stigmatized social categories. Fear and/or experiences of adverse consequences or rejection, violence, discrimination, bullying, loneliness, internalized stigma, and pressure by family, school, religious, and social communities to conceal one’s identity all have a major impact on mental health. Those with lower visual conformity, those who defy a quick verbal label of male or female, may be more vulnerable to societal mistreatment. The eating disorder can serve as a way to cope with these difficult situations, emotions and stress.

(Diemer et al, 2018; Jones et al, 2018; Gaudiani, 2018)
Importance of Protective Factors

Canadian online survey of 923 transgender youth (aged 14-25)

Enacted stigma (higher rates of harassment and discrimination experienced by sexual minority youth) was linked to higher odds of reported past year binge eating, fasting or vomiting to lose weight.

Youth with the highest levels of harassment and discrimination and no protective factors had high probabilities of past year ED behaviors.

Protective factors, including family connectedness, school connectedness, caring friends, and social support, were linked to lower odds of past year disordered eating behaviors.

(Watson et al, 2016)

Lack of Access to Gender Affirming Care

Lack of needed gender affirming health care can increase body dissatisfaction and increases eating disorder risk.

Related obstacles:
• Lack of coverage of gender affirming care by their health insurance.
• Perceptions of care providers.
• Harassment in healthcare settings.
• Systemic oppression – forms, bathrooms, etc...
• Fears around coming out to health care provider.

(Gordon, 2018; James et al, 2016; NEDA, 2016)
ED Treatment Barriers for Trans Folk

Lack of culturally-competent treatment and crossover competency
- Lack of availability of culturally-competent treatment addressing gender identity issues.
- Insufficient eating disorder education among providers who are in a position to detect and intervene.
- Insufficient transgender education among among eating disorder treatment providers.
- Insufficient research of intersectional identities

Intensive eating disorder treatment (RTC, PHP, and IOP) has been historically binary—but this is improving.
No specific treatments exist for transgender individuals with eating disorders.

(Gordon, 2018; James et al, 2016; NEDA, 2016)

Medical Complications, Psychiatric Co-morbidity and Suicide
Medical Complications in Eating Disorders

Cardiovascular: low BP, low pulse, postural tachycardia, arrhythmias, electrolyte abnormalities
Gastrointestinal: constipation, reflux, bloating, dysmotility, regurgitation, IBS like symptoms, gas, pain
Bone/endocrine: amenorrhea, osteoporosis, osteopenia
Hematologic: anemia, low white count
Metabolic: hypoglycemia, hyperlipidemia, high cholesterol
Psychiatric: MDD, GAD, Social anxiety, Panic, OCD, PTSD, ADHD, Substance use/abuse; self-harm, suicidal ideation/attempts

Work Up: CMP, Magnesium, Phosphorus, Amylase, TSH, CBC, postural VS, Height, Weight, Urinalysis, EKG, DEXA

(Holland et al, 2007)
High Suicide Risk—Eating Disorders

Eating disorders have increased suicide risk and mortality

- AN has highest rate of mortality of any mental health condition due to suicide and medical complications
- Research shows similar mortality rates with OSFED
- Adolescents have an increased risk of suicidal behaviors and completed suicides across all eating disorder diagnoses

Rates of death by suicide in those with EDs are elevated compared to other mental health disorders (depression, bipolar, schizophrenia)

Those with AN are 31X and BN are 7.5X more likely to die by suicide than the general population

(Arcelus, 2011; Dancyger, 2005; Crow, 2009; Smith, 2017; Chesney, 2014; Pretti, 2011)

High Comorbidity and Suicide Risk—Transgender

Trans and non-binary people have an increased psychiatric diagnoses compared with the general population.

- High prevalence of depression (44.1%) and anxiety (33.2%)
- 10% reported lifetime substance use treatment

Transgender individuals risk of attempted suicide is 5-10x higher than general population.

- The 2015 U.S. Transgender Survey documented a 40% lifetime prevalence of suicide attempts among trans and non-binary people compared with 4.6% in the general population.

A 2017 systematic review of studies found prevalences of suicidal ideation ranging from 37% to 83%.

(Beckwith 2019; Bockting, 2013; Keuroghlian, 2015; McNeil, 2017; James, 2016)
Gender minority individuals should be assessed on an ongoing basis for eating disorder symptoms, medical complications, mental health concerns and suicide.

Trans individuals are best served by a multidisciplinary team specialized in eating disorders as well as gender-affirming care.

**Physician(s):** ongoing assessment and treatment of medical complications, psychiatric comorbidities and provision of gender-affirming care

**Dietitian:** nutritional assessment, weight goals, meal plan

**Therapist:** individual, group and/or family therapy

**Others:** family/loved ones, sport family, school nurse or counselor
Weight Goals in Trans Eating Disorder Patients

Most likely you will need to individualize

Possible helpful tools
- Growth charts from birth assigned sex and asserted gender
- Find IBW for both sex’s and go from there
- You cannot rely on hormone levels if on hormone therapy
- Monitor vitals, labs and mindset

Consider weight suppression

Fears of resuming menses
- Patient may lose menses due to malnutrition
- If on continuous OCP – don’t stop just to access energy balance
- Consider IUD

(Haldon et al, 2018; Gaudiani, 2018)

Hormone Therapy and Body Dissatisfaction

A recent study found trans people who were not on hormones reported more ED symptoms than trans people on hormones.

N = 563 (AFAB 211, AMAB 352) : 139 HRT, 416 no HRT

Findings suggested hormone therapy may be able to alleviate ED symptoms through increasing body satisfaction which reduces perfectionism and anxiety and increases self-esteem.

Clinicians working at eating disorder services should assess gender identity issues and refer patients with such issues to transgender health services so that they can be evaluated for hormone therapy.

(Jones et al, 2018)
Surgery and Body Dissatisfaction

154 TFS, 288 TMS individuals completed the Trans Health Survey.

Findings suggested that GCMIIs reduce experiences of non-affirmation, which increases body satisfaction and decreases ED symptoms.

- GCMIIs – genital surgery, chest surgery, HRT, hysterectomy, and hair removal

Among TFS, the relationship between chest surgery and lower ED symptoms was most strongly mediated by body satisfaction, suggesting that body satisfaction alone may result in lower ED symptoms—even if affirmation from the external world is unchanged.

More research is needed to better assess whether particular GCMIIs have a preventative or ameliorative role in ED symptoms and whether a particular level of ED recovery is advisable before initiating GCMIIs.

(Testa et al, 2017)

“‘Life-saving’ for someone with anorexia can be changing their perspective instead of changing their body. But ‘life-saving’ for a trans person could be changing their body rather than trying to change their perspective. And for trans folks who are recovering from eating disorders... sometimes it’s about both changing your perspective and changing your body”

(Sam Dylan Finch, 2016)
Therapeutic Pearls for ED and Trans Folk

Create a safe space
- Ask for and use preferred pronouns and name
- Be aware of the unique stressors often be experienced by trans people

Reduce blame, shame and stigma
- Help them understand they are not to blame for gender dysphoria or ED
- Work with them on identifying the difference between external oppression that has been internalized versus their own values and beliefs
- Distinguish between the ED voice and their own unique thoughts and feelings

Provide ongoing care, compassion and support
- Explore the intersection of gender identity and eating disorder behaviors
- Educate about and explore the appropriateness of hormone therapy/surgery

(Lang, 2018)

Transgender and Eating Disorder Resources

AED Eating Disorders: Critical Points for Early Recognition and Medical Risk Management in the Care of Individuals with Eating Disorders

NEDA: the largest nonprofit organization which supports individuals and families affected by eating disorders, and serves as a catalyst for prevention, cures and access to quality care.
- (NEDA Toolkits: parent, educator and coach versions)
  - http://www.nationaleatingdisorders.org/

Trans Folx Fighting Eating Disorders (T-Ffed): collective of trans/gender diverse people and allies who believe eating disorders in marginalized communities are social justice issues.
- https://www.transfolxfightingeds.org/
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Image from T-FFED Visibility Project http://www.transfoxfightingeds.org/untitled