

Supporting Gender Diverse Youth with Medical Conditions: The Mental Health Provider's Perspective

Chris Brady, PhD
Gender Spectrum
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About Our Clinic

- Established in 2016 we are a multidisciplinary team consisting of MDs, NPs, RNs, SW, and Psych
- Referrals can be made within our system to various specialties including GYN, Urology, Plastics, Dermatology and Speech Pathology
- Families can self-refer or be referred by outside providers
- We have served over 600 families



Objectives

- Define complex medical conditions and describe rates
- Discuss relevant theories relating medical conditions to gender identity
- Identify pertinent clinical consideration to improve care

Medical Conditions in Youth

- Complex or chronic medical conditions - Chronic health conditions (both chronic illnesses and chronic physical disabilities) are generally defined as those conditions that last > 12 months and are severe enough to create some limitations in usual activity
 - Occur in an estimated 10-30% of youth (400% increase in the last 50 years)
 - Complicated by inclusion of mental health diagnoses (ADHD, ASD, depression)
 - 20-30% children and adolescents with chronic pain
- Common examples include asthma, cystic fibrosis, diabetes, cancer, hearing or vision impairment, and cerebral palsy
- Growing research and awareness of autoimmune disorders and other chronic pain and fatiguing conditions
 - POTS - Postural Orthostatic Tachycardia Syndrome (6.8%)
 - FND – Functional Neurological Disorder (5-6%)
 - CFS – Chronic Fatigue Syndrome (1.1%/.5%)
 - Chronic headaches (2%)
- Often more complex due to lack of effective treatment and loss of daily functioning

Medical Conditions and Gender Diversity

Extrapolating from adult data (Dragon, Guerino, Ewald, & Laffan, 2017)

- One study comparing cis gender to transgender Medicare beneficiaries
 - Trans beneficiaries had more chronic conditions
 - Higher rates of asthma, ASD, COPD, depression, hepatitis, HIV, schizophrenia and substance use

New studies examining youth (Valentine et al.)

- Children's Hospital Colorado
 - 1.8x abnormal cholesterol
 - 1.4x liver dysfunction
 - 1.3x high blood pressure
 - 1.5x overweight
 - 1.9x PCOS

Rates may differ by gender identity (Cicero, Reisner, Merwin, Humphreys, & Silva, 2020)

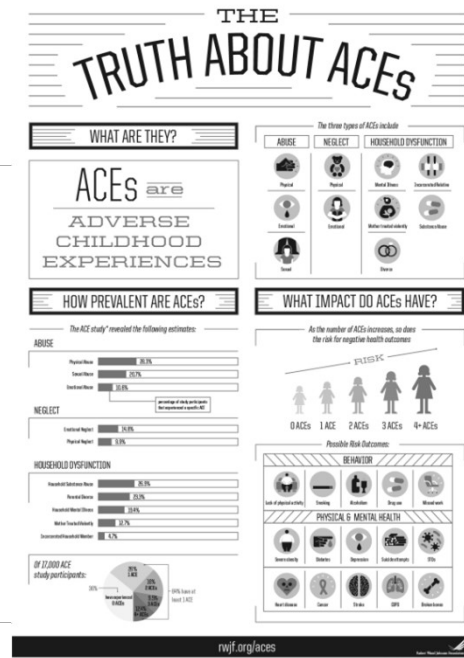
- Self rated health (non-binary < transmen < transwomen)
- Mental unhealthy day (transmen < non-binary and transwomen)
- Transmen more likely to be uninsured

Focus on Symptoms

- Diverse nature of medical conditions and differing rates across studies
 - Focus on symptoms such as pain, fatigue or confusion
 - Impacting of those symptoms on functioning and identity development
 - Considerations for readiness assessments and clinical work with families
- Clinically we see a good number of patients who are working with other specialties to manage their conditions and symptoms
 - Conversations with providers across the country are observing similar
 - Obtaining rates and percentages to examine possible overrepresentation

ACEs

- Austin et al. (2016) LGB
 - 73.2% 1 ACE
 - 69.5% 4 or more
 - Partially accounts for health discrepancies
- Schnarrs et al. (2019)
 - Compared cisgender LGB to transgender
 - More emotional abuse and neglect and physical neglect endorsed
 - 91.2% 1 ACE
 - 50.8% 4 or more



Minority Stress Model

- Many conditions involving chronic fatigue and pain are stress sensitive

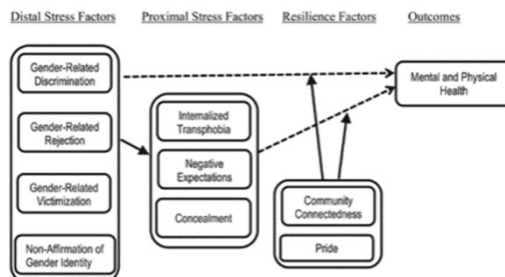
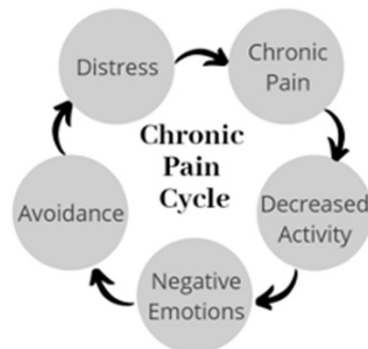


Figure 1. Gender Minority Stress Model: Hendricks and Testa, 2012



Impacting on Functioning

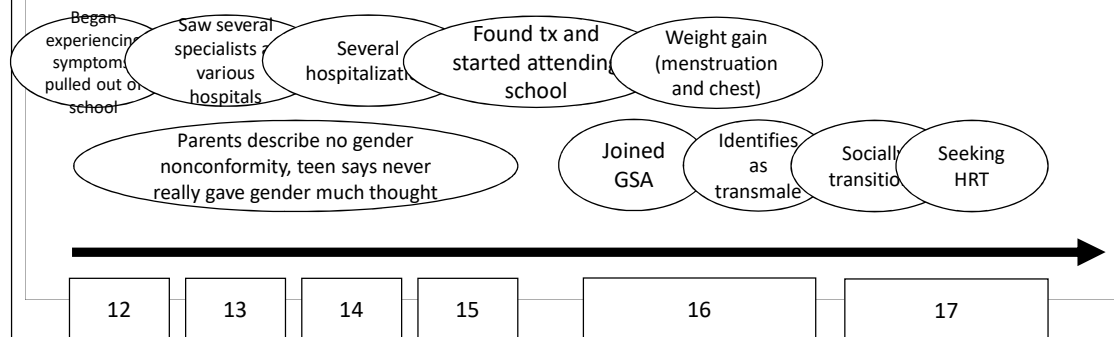
- Vary by condition
 - CNS disorders – physical mobility and cognitive functioning
 - Chronic fatigue – energy and time spent accomplishing daily tasks
 - Cancer – cognitive impairment and social skills
- Many struggle to attend school, have jobs, maintain friendships and engage in physical activity

Impacting on Identity Development

- Due to impairments in functioning identity development may also be delayed
 - Inability to socialize may limit exposure to diverse individuals
 - Reliance on caregivers for basic needs may impede growth and independence
- May be consumed by medical identity

Consideration for Assessment

- Important to obtain both gender and medical history to fully conceptualize a patient/client



Addressing Parental Concerns

- “They haven’t experienced enough to really know who they are”
- “I want their medical issues to be well managed before adding anything else in”
- “They are overly focused on medications to fix their problems”
- “I’m worried the treatment may make symptoms worse”

Ensuring Appropriate Expectations

- A 16-year-old assigned male, non-binary identifying youth presents with complex medical history including symptoms of chronic headache, back pain and fatigue. Expresses interest in estrogen therapy to help with weight loss and hip shape. Believes estrogen will also greatly improve functioning.
 - Education around estrogen and timeline of changes
 - How estrogen may worsen, improve or not impact symptoms
 - Offer alternative treatments to meet goals

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Tandy Aye, MD
Gender Spectrum
July 15, 2021

Objectives.

- To help define the role of the medical gender provider
- To explain the importance of advocacy during care conferences
- To share some best practices in supporting medically complex patients during their gender journey

Role of the Medical Gender Provider

- Identify all team members and their roles
 - Pictures are key
 - Family roles are important as well
 - Lines of communication
- Release of Information
- Primary Care Provider (PCP)
- Mental Health Provider(s)

Minimize Side Effects

- Wound healing and infections
 - Ex: Type 1 Diabetes and Blood Glucose control
 - Hygiene
- Coagulopathy (issues with blood clots)
 - Role of estrogen for AMAB patients (complete history)
 - Use of OCPs for AFAB patients (forms and formulations)
- Nausea from chemo (take into account treatment that may add to nausea; examples: Aygestin, OCPs, progesterone, estrogen)
- History of migraines (try sublingual or patch estrogen; consider adding in other forms of tx ; meditation; acupuncture; etc)

Encourage primary/preventative care

- Well checks
- Immunizations
- Urgent care visits
- Important for the young person to know how to tell medical history especially when entering the adult world
- Be in communication with the PCP who should coordinate all subspecialty care
- Transition of care to adult providers is important

What is a medical care conference?

- In the inpatient setting when all subspecialties meet to discuss the care plan of a medically complex patient
- The primary team is the ultimate decision maker with all subspecialties providing input and keeping the PCP informed
- Each subspecialty meets and write the medical goals
- Inpatient Social Worker helps family understand medical goals
- Ask to be a part of this care conference

What is a medical care conference? To advocate

- Maximize respect for the gender identity: name, pronouns, signage
- Is there a way to reduce dysphoria from patient identification
- Always think of trying to be gender neutral (bandages, clothing, positioning for procedures, etc.)
- Work with the subspecialties that may interfere with gender therapy
- Help set realistic goals
 - NOT “when mental health is no longer an issue”
 - NOT “when chronic condition XX is no longer an issue”

Support the patient

- Often time hospitalization is scary and can provoke anxiety
- Gender provider maybe the only connection to the non-acute medical situation and provides continuity and a familiar face
- Separate gender and gender affirming therapy from the other medical issues, if possible

Remember:

- We know our patients
- We can advocate for gender care
- We can educate
- We can be flexible and creative to affirm our patients during the acute medical event
- We need to form partnerships with other providers and be a team

Questions and Discussion

