

A PROGRAM OF THE FENWAY INSTITUTE

Mental Health among Transgender and Gender-diverse Communities Living with HIV

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Continuing Medical Education Disclosure

- <u>Program Faculty</u>: Alex S. Keuroghlian, MD, MPH;
- <u>Current Position</u>: Director of the Division of Education and Training at the Fenway Institute; Associate Professor of Psychiatry, Harvard Medical School/Massachusetts General Hospital
- <u>Disclosure</u>: Editor of forthcoming McGraw-Hill Education textbook, will receive future royalties.



Our Roots

Fenway Health

- Independent 501(c)(3) FQHC
- Founded 1971
- Mission: To enhance the wellbeing of the LGBTQIA+ community as well as people in our neighborhoods and beyond through access to the highest quality health care, education, research, and advocacy
- Integrated primary care model, including HIV and transgender health services

The Fenway Institute

Research, Education, Policy

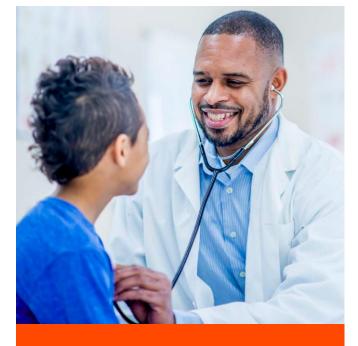




LGBTQIA+ Education and Training

The National LGBTQIA+ Health Education Center offers educational programs, resources, and consultation to health care organizations with the goal of providing affirmative, high quality, cost-effective health care for lesbian, gay, bisexual, transgender, queer, intersex and asexual, and all sexual and gender minority (LGBTQIA+) people.

- Training and Technical Assistance
- Grand Rounds
- ECHO Programs
- Online Learning
 - Webinars and Learning Modules
 - CE, and HEI Credit
- Resources and Publications
- www.lgbtgiahealtheducation.org



Creating a Transgender Health Program at Your Health Center: From Planning to Implementation SEPTEMBER 2018



Learning Objectives

- At the end of this session, participants will be able to:
 - 1. Explain the context for mental health inequities across diagnostic categories within a gender minority stress framework
 - 2. Describe culturally responsive tailoring of evidence-based clinical practices for transgender and gender-diverse (TGD) people
 - 3. Apply strategies for building inclusive, affirming, and trauma-informed environments within health centers to optimize mental health outcomes for TGD people.



Training in Sexual and Gender Minority Health — Expanding Education to Reach All Clinicians

Kevin L. Ard, M.D., and Alex S. Keuroghlian, M.D.

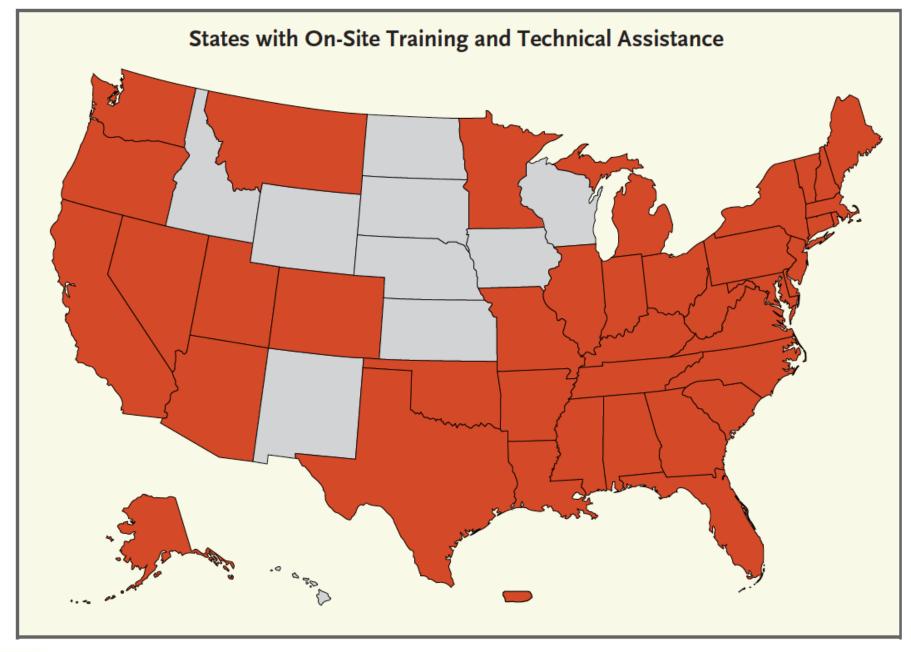
"If a man says he is a woman, does that mean he is mentally ill?" The staff member asking this question was attending a mandatory training session on health care for sexual and gender minority (SGM) patients at an urban hospital. She spoke timidly and seemed genuinely curious. We explained that incongruence between the sex assigned at birth and gender identity — denoted by the term "transgender" — is not a mental illness, and that transgender people's mental health often improves with care that affirms their gender identity. She thanked us for the explanation, and we moved to the next topic, but her question lingered in our minds. We were surprised that concepts we took for granted were unknown to this clinician, who practiced in a large, diverse medical center. And yet questions such as hers are becoming more common as continuing medical education on SGM health expands.

The National Institutes of Health (NIH) defines SGM peo-

N ENGL J MED 379;25 NEJM.ORG DECEMBER 20, 2018



Ard *et al.*, 2018



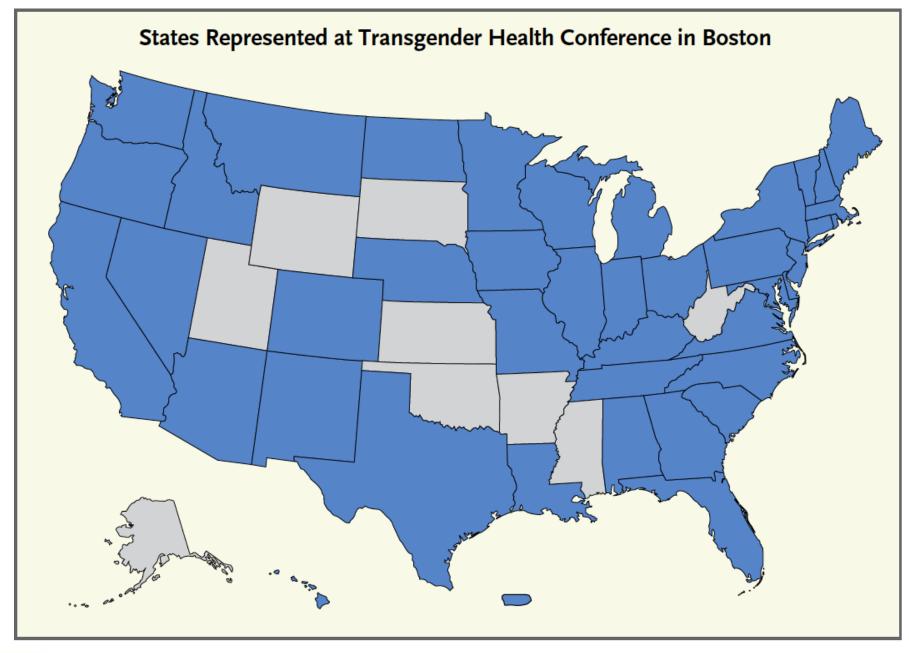


Ard *et al.*, 2018





Ard *et al.*, 2018





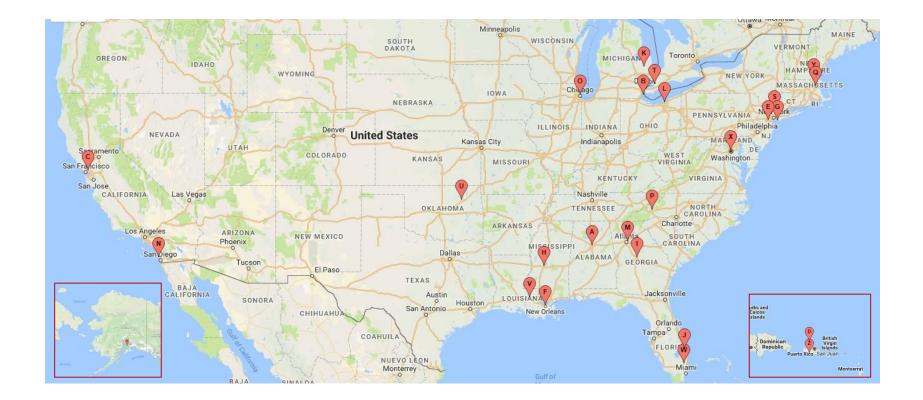
Ard *et al.*, 2018

Evidence-informed Interventions Coordinating Center for Technical Assistance (HIV/AIDS Bureau)

- Using Evidence-informed Interventions to Improve Health Outcomes among People with HIV (E2i) is an initiative to facilitate the implementation of evidence-informed interventions to reduce HIV health disparities and improve HIVrelated health outcomes in four focus areas:
 - Improving HIV health outcomes for transgender women with HIV
 - Improving HIV health outcomes for Black men who have sex with men (MSM) with HIV
 - Integrating behavioral health with primary medical care for people with HIV
 - Identifying and addressing trauma among people with HIV



E2i Intervention Sites



EIII NATIONAL LGBTQIA+ HEALTH EDUCATION CENTER

Federal Ending the HIV Epidemic Priority Jurisdictions and E2i

Intervention Sites



Intervention site; = the 48 counties, Washington, D.C., and San Juan, Puerto Rico where more than 50% of new HIV diagnoses occurred in 2016-2017. States shaded in blue represent states with a substantial rural burden. Adapted from: U.S. Department of Health & Human Services. Federal response: Ending the HIV epidemic. <u>https://www.hiv.gov/federal-</u>response/ending-the-hiv-epidemic/overview



E2i Intervention Sites

Transgender Women

Healthy Divas

- CAL-PEP (CA)
- Rutgers New Jersey Medical School (NJ)
- Birmingham AIDS Outreach Inc. (AL)

Transgender Women Engagement and Entry to Care Project (T.W.E.E.T.)

- CrescentCare (LA)
- Henry Ford Health System (MI)
- Centro Ararat (PR)

Black MSM

Client-Oriented New Patient Navigation to Encourage Connection and Treatment (CONNECT)

AIDS Taskforce of Greater Cleveland (OH)

Tailored Motivational Interviewing (Tailored MI)

- HOPE Center (GA)
- Broward House, Inc. (FL)
- University of Mississippi Medical Center (MS)

Text Messaging Intervention to Improve Antiretroviral Adherence Among HIV Positive Youth (TXTXT)

- UNIFIED-HIV Health & Beyond (MI)
- SUNY HEAT Program (NY)

Trauma Informed Care

Trauma-Informed Approach & Coordinated HIV Assistance and Navigation for Growth and Empowerment (TIA/CHANGE)

- Alaska Native Tribal Health Consortium (AK)
- Chicago Women's AIDS Project (IL)

Cognitive Processing Therapy

- Western North Carolina Community Health (NC)
- Positive Impact Health Centers (GA)

Seeking Safety

- Multicultural AIDS Coalition (MA)
- The Regents of the Univ. of Calif., U.C. San Diego (CA)

Behavioral Health Integration

Buprenorphine

- Consejo de Salud de Puerto Rico Inc. dba Med Centro (PR)
- Greater Lawrence Family Health Center (MA)

Collaborative Care Management (CoCM)

- La Clinica del Pueblo, Inc (DC)
- Oklahoma State University Center Health Sciences (OK)
- Health Emergency Lifeline Programs (MI)
- Our Lady of the Lake Hospital, Inc. (LA)

Screening, Brief Intervention and Referral to Treatment (S.B.I.R.T.)

- The Poverello Center Inc. (FL)
- North Jersey Community Research Initiative (NJ)



Global Health Initiatives

- Uganda: Clinical Skills Sharing Project with Ministry of Health (PEPFAR/HRSA)
- Jamaica: Clinical Skills Sharing Project with Ministry of Health & Wellness (PEPFAR/HRSA)
- India: Transgender Care Training with National AIDS Control Organization (USAID)



WWW.LGBTHEALTHEDUCATION.ORG

Gender Minority Stress Framework

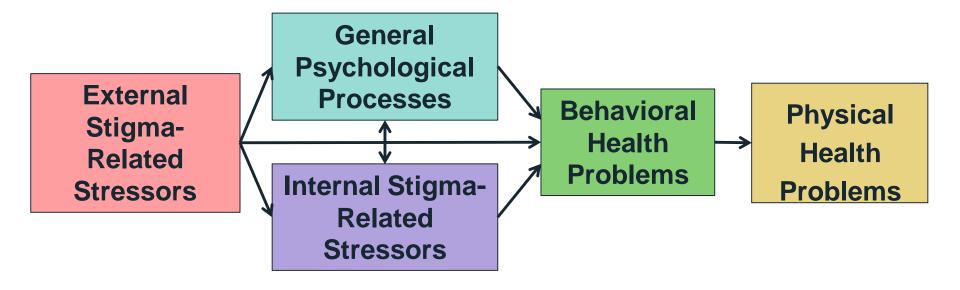


Fig. 1: Adapted from Hatzenbuehler (2009)



DSM-5 Gender Dysphoria (F64._)

- A. A marked incongruence between one's experienced/expressed gender and assigned gender, <u>of at</u> <u>least 6 months duration</u> ...
- B. The condition is associated with <u>clinically significant distress</u> or <u>impairment</u> in social, occupational, or other important areas of functioning, or with a <u>significantly increased risk of</u> <u>suffering</u>, such as distress or disability

.1 adolescence & adulthood .8 other gender identity disorders .9 unspecified

APA (2013)



Gender Minority Stress Treatment Principles for Clinicians

- Normalize adverse impact of gender minority stress
- Facilitate emotional awareness, regulation, and acceptance
- Empower assertive communication
- Restructure minority stress cognitions
- Validate unique strengths of transgender and gender-diverse (TGD) people
- Foster supportive relationships and community
- Affirm healthy, rewarding expressions of gender

Adapted from Pachankis (2015)



Perspective

Strategies to Mitigate Clinician Implicit Bias Against Sexual and Gender Minority Patients

Michal J. McDowell, M.D., M.P.H., Hilary Goldhammer, S.M., Jennifer E. Potter, M.D., Alex S. Keuroghlian, M.D., M.P.H.

Background: Implicit bias is an ingrained, unconscious cultural stereotype that can negatively affect a person's interactions with members of stigmatized groups, including sexual and gender minorities. Clinician implicit biases may negatively impact the quality of patient care. **Methods:** This article uses 4 case scenarios to illustrate how implicit bias among psychiatrists and other clinicians can affect patient-clinician communication and diminish the quality of health care provided to sexual and gender minority people. We offer strategies for clinicians to recognize, challenge, and address implicit bias. **Discussion:** Through continuing education, self-reflection, and practice, psychiatrists and other clinicians can improve communication and foster more affirming care experiences for their sexual and gender minority patients, with the goal of addressing and ultimately eliminating sexual and gender minority health disparities. (Psychosomatics 2020; **_:_**-

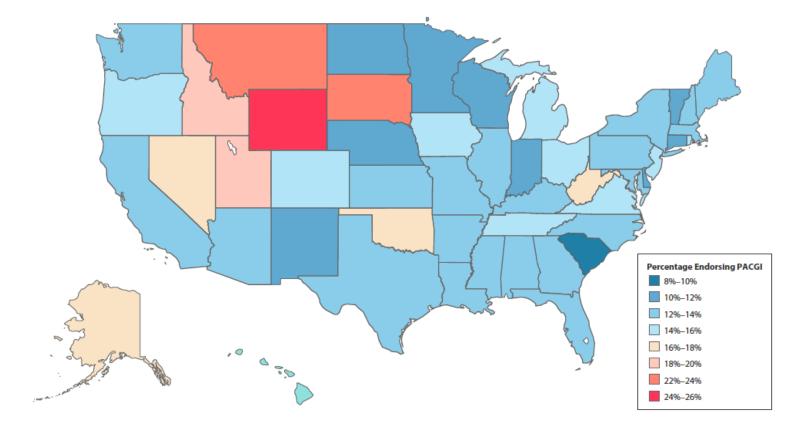
Key words: sexual minority, gender minority, implicit bias, unconscious bias, LGBT, communication.

Psychological Attempts to Change a Person's Gender Identity From Transgender to Cisgender: Estimated Prevalence Across US States, 2015

Jack L. Turban, MD, MHS, Dana King, ALM, Sari L. Reisner, ScD, and Alex S. Keuroghlian, MD, MPH



Gender Identity Conversion Efforts Across U.S. States



Note. Heat map depicts the percentage of respondents from the 2015 US Transgender Survey reporting lifetime exposure to PACGI.

FIGURE 1—Estimated Proportion of Transgender People Exposed to Psychological Attempts to Change a Person's Gender Identity From Transgender to Cisgender (PACGI): United States, 2015

Turban et al., (2019)



Health Disparities (2015 U.S. Transgender Survey)

- 39% of respondents experienced serious psychological distress in the month prior (compared to 5% of the U.S. population)
- 40% had lifetime suicide attempt (compared to 4.6% of US population)

James et al. (2016)



Suicidality: Gender and Sexual Minority Adults

- Lifetime prevalence of suicide attempts in the United States:
 - General adult population: 4%
 - Sexual minority adults: 11-20%
 - Gender minority adults: 41%



Kann et al. (2011); Perou and Bitsko (2013)



Suicidality (2015 U.S. Transgender Survey)

In the preceding 12 months:

- 48% had seriously thought about suicide
- 24% made a plan to kill themselves
- 7% had attempted suicide
- 40% had attempted suicide at one point in their lives
- 34% had first attempt by age 13
- 92% had first attempt by age 25

James et al. (2016)



JAMA Psychiatry | Original Investigation

Association Between Recalled Exposure to Gender Identity Conversion Efforts and Psychological Distress and Suicide Attempts Among Transgender Adults

Jack L. Turban, MD, MHS; Noor Beckwith, MD; Sari L. Reisner, ScD, MA; Alex S. Keuroghlian, MD, MPH



Adverse Impact of Exposure to Conversion Efforts

- 27,715 transgender adult respondents to 2015 U.S. Transgender Survey
- 14% reported gender identity conversion efforts
- Lifetime exposure associated with:
 - lifetime suicidal attempt (aOR 2.27; 95% CI 1.09 to 2.24; P<.001)</p>
- Exposure before age 10 associated with:
 - lifetime suicide attempt (aOR 4.15; 95% CI, 2.44-7.69; P<0.001)</p>
- No difference in outcomes between conversion efforts by religious advisor versus secular-type professionals

Turban *et al*. (2019)



Pubertal Suppression for Transgender Youth and Risk of Suicidal Ideation

Jack L. Turban, MD, MHS,^a Dana King, ALM,^b Jeremi M. Carswell, MD,^c Alex S. Keuroghlian, MD, MPH^{ab}

BACKGROUND AND OBJECTIVES: Gonadotropin-releasing hormone analogues are commonly prescribed abstract to suppress endogenous puberty for transgender adolescents. There are limited data regarding the mental health benefits of this treatment. Our objective for this study was to examine associations between access to pubertal suppression during adolescence and adult mental health outcomes.

METHODS: Using a cross-sectional survey of 20 619 transgender adults aged 18 to 36 years, we examined self-reported history of pubertal suppression during adolescence. Using multivariable logistic regression, we examined associations between access to pubertal suppression and adult mental health outcomes, including multiple measures of suicidality.

RESULTS: Of the sample, 16.9% reported that they ever wanted pubertal suppression as part of their gender-related care. Their mean age was 23.4 years, and 45.2% were assigned male sex at birth. Of them, 2.5% received pubertal suppression. After adjustment for demographic variables and level of family support for gender identity, those who received treatment with pubertal suppression, when compared with those who wanted pubertal suppression but did not receive it, had lower odds of lifetime suicidal ideation (adjusted odds ratio = 0.3; 95% confidence interval = 0.2-0.6).

CONCLUSIONS: This is the first study in which associations between access to pubertal suppression and suicidality are examined. There is a significant inverse association between treatment with pubertal suppression during adolescence and lifetime suicidal ideation among transgender adults who ever wanted this treatment. These results align with past literature, suggesting that pubertal suppression for transgender adolescents who want this treatment is associated with favorable mental health outcomes.



Turban et al. (2020)

Pubertal Suppression and Risk for Suicidal Ideation

- 2.5% of respondents who desired pubertal suppression had ever received it
- Recipients of pubertal suppression, compared to those who desired it but did not receive it, had lower odds of lifetime suicidal ideation
 - aOR = 0.3; 95% CI = 0.2-0.6; P = 0.001



Turban et al. (2020)

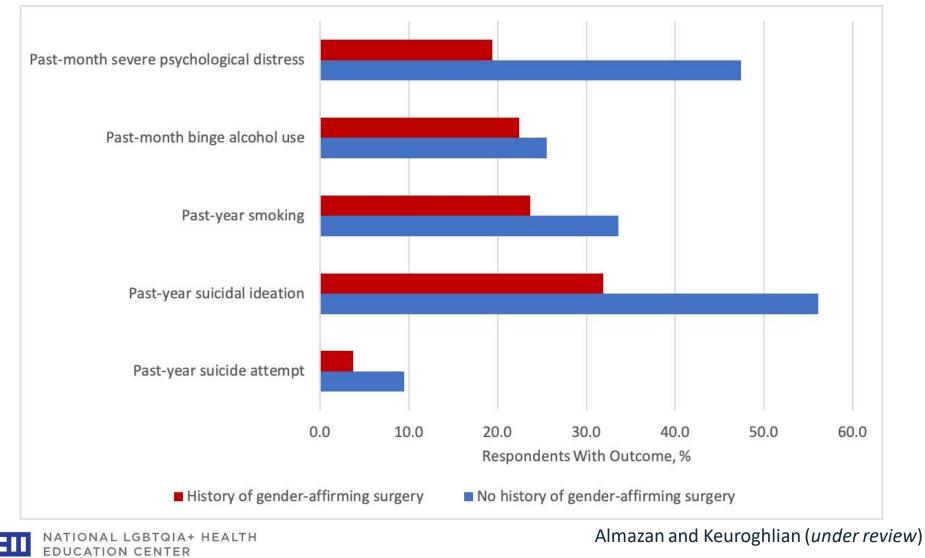
Association between Genderaffirming Surgeries and Improved Mental Health Outcomes

- Of the 27,715 respondents to 2105 U.S. Transgender Survey, 4,974 (17.9%) had undergone one or more types of genderaffirming surgery at least two years prior to submitting survey responses
- Compared to respondents who desired gender-affirming surgeries but did not undergo any, undergoing gender-affirming surgery was associated with:
 - Improved past-month psychological distress (aOR, 0.57; 95% CI, 0.50-0.66; P<0.001)
 - Improved past-month binge alcohol use (aOR, 0.80; 95% CI, 0.70-0.92; P=0.002)
 - Improved past-year smoking (aOR, 0.64; 95% CI, 0.56-0.73; P<0.001)</p>
 - Improved past-year suicidal ideation (aOR, 0.61; 95% CI, 0.54-0.69;



Almazan and Keuroghlian (*under review*)

Outcomes among Respondents Who Did and Did not Undergo Genderaffirming Surgery



Factors Associated with Higher PTSD Severity in Transgender Adults

- Higher everyday discrimination
- Greater number of attributed reasons for discrimination
- More visually genderexpansive expression
- Unstable housing



Reisner *et al*. (2016)



Factors Associated with Lower PTSD Severity in Transgender Adults

- Younger age
- Trans masculine gender identity
- Medical gender affirmation



Reisner *et al*. (2016)



Cognitive Processing Therapy for PTSD

- Adapting selected components of cognitive processing therapy for PTSD by Resick
- Focus:
 - Education about posttraumatic stress;
 - Writing an Impact Statement to help understand how trauma influences beliefs;
 - Identifying maladaptive thoughts about trauma linked to emotional distress;
 - Decreasing avoidance and increasing resilient coping.



Cognitive Processing Therapy for Minority Stress

- Possible tailoring for TGD people:
 - Focus on how gender identity-specific stigma causes posttraumatic stress (e.g., avoidance, mistrust, hypervigilence, low self-esteem);
 - Attributing challenges to minority stress rather than personal failings;
 - Impact Statement on how discrimination and victimization affect beliefs (e.g. expecting rejection, concealment needs, internalized transphobia);
 - Decreasing avoidance (e.g., isolation from TGD community or medical care);
 - Impact of minority stress on health behaviors and goals.

Girouard et al. (2019)



Minority Stress Impact on Antiretroviral Adherence

- Transgender women and men who have sex with men are the two subpopulations with the greatest HIV incidence and prevalence in the U.S.³⁹⁻⁴¹
- Antiretroviral medications for HIV treatment and pre-exposure prophylaxis require adequate adherence for effectiveness.⁴²⁻⁴⁴



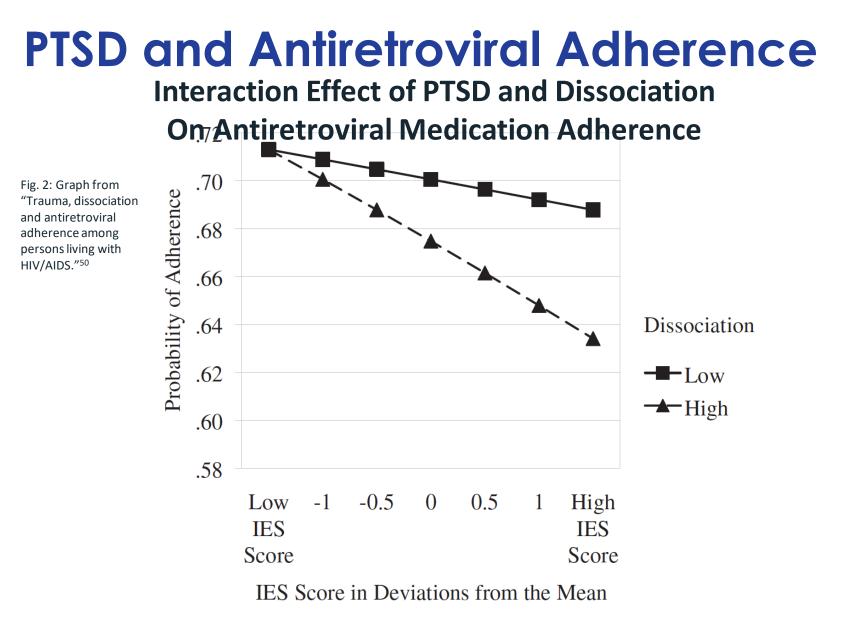
References available upon request

Minority Stress Impact on Antiretroviral Adherence

- Studies of antiretroviral adherence emphasize population-specific contextual barriers.
- Sexual and gender minority stress (e.g. discrimination, victimization) both adversely impact HIV self-care.⁴⁵⁻⁴⁹



References available upon request



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PTSD

Keuroghlian et al., 2011

PTSD and Antiretroviral Adherence

- Importance of psychosocial interventions that target posttraumatic stress symptoms to maximize antiretroviral adherence in community populations.^{51,52}
- Integration of trauma-focused treatment services into antiretroviral medication management may effectively improve adherence.



Bio-behavioral HIV Care

- Tailored behavioral interventions exist for antiretroviral adherence (e.g. Life-Steps).⁵³
- Combined biomedical and behavioral HIV treatment and prevention strategies are optimal.
- Behavioral health treatments that restructure minority stress cognitions can improve self-care and physical health outcomes.⁵⁴



Addictions among TGD People

- Substance use disorders (SUDs) among TGD people have historically been understudied
- Reporting of gender identity data in SUD-related research is limited
- In several studies, TGD people have elevated prevalence of alcohol and drug use disorders compared with the general population



Gender Minority Stress and Substance Use among TGD People

- 35% of transgender people who experienced school-related verbal harassment, physical assault, sexual assault, or expulsion reported using substances to cope with mistreatment related to gender identity or expression
- Psychological stress of health care access disparities faced by transgender people is believed to contribute to worse mental health, including disproportionate substance use as a coping strategy





Contents lists available at ScienceDirect

Drug and Alcohol Dependence

journal homepage: www.elsevier.com/locate/drugalcdep

Full length article

Substance use and treatment of substance use disorders in a community sample of transgender adults

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Substance Use Disorders among TGD Adults

- Among 452 TGD adults, increased odds of SUD treatment history plus recent substance use were associated with:
 - intimate partner violence
 - PTSD
 - public accommodations discrimination
 - unstable housing
 - sex work
- Higher SUD prevalence increasingly viewed as downstream effects of chronic gender minority stress



Drug and Alcohol Dependence 186 (2018) 138-146



Contents lists available at ScienceDirect

Drug and Alcohol Dependence

journal homepage: www.elsevier.com/locate/drugalcdep

Review

Alcohol research with transgender populations: A systematic review and recommendations to strengthen future studies



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Alcohol Research with TGD Populations

- Recommendations:
 - Being explicit as to whether and how sex assigned at birth, current sexbased physiology, and/or social gender are operationalized and relevant for research questions
 - Expanding repertoire of alcohol measures to include those not contingent on sex or gender
 - Testing psychometric performance of established screening instruments (e.g., AUDIT) with TGD populations
 - Shifting beyond cross-sectional study designs
 - Shared decision-making in counseling regard healthy alcohol use



Screening, Counseling, and Shared Decision Making for Alcohol Use with Transgender and Gender-Diverse Populations

Jacob Arellano-Anderson, BS¹ and Alex S. Keuroghlian, MD, MPH¹⁻³

Abstract

At-risk alcohol use occurs among transgender and gender-diverse (TGD) populations, yet current alcohol use screening tools and guidelines do not distinguish between sex- and gender-related characteristics, having been developed without accounting for natal sex-based physiology, effects of gender-affirming medical care, and gendered drinking behavior among TGD people. More research on how sex- and gender-related factors independently influence alcohol use can help validate gender-inclusive screening protocols and develop evidence-based guidelines meaningful for people of all genders. In the interim, clinicians must be mindful of gender diversity and engage in transparent, collaborative discussions when screening for and counseling about alcohol use.

Keywords: alcohol, counseling, gender identity, nonbinary, screening, transgender



Gendered Guidelines for Unhealthy Alcohol Use

Term	Society	Definition	Limitations for TGD Populations		
Gendered					
Moderate drinking	CDC	1 drink per day for women and up to 2 drinks per day for men.	may vary for TGD people who have accessed gender-		
Heavy drinking	CDC	Alcohol consumption that exceeds an established threshold of 15 weekly drinks for men and 7 weekly drinks for women OR 5 drinks per episode for men and 4 drinks per episode for women.			
Binge drinking	NIAAA/CDC	A pattern of drinking that brings blood alcohol concentration (BAC) levels to 0.08 g/dL, specified as typically occurring after 4 drinks for women and 5 drinks for men—in about 2 hours.			

Columns 1 through 3 are adapted from Connor EA et al.24



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SUBSTANCE ABUSE https://doi.org/10.1080/08897077.2018.1544963

COMMENTARY





Understanding and treating opioid use disorders in lesbian, gay, bisexual, transgender, and queer populations

Michael P. Girouard, BA^a, Hilary Goldhammer, SM^b, and Alex S. Keuroghlian, MD, MPH^{a,b,c}

^aDepartment of Psychiatry, Harvard Medical School, Massachusetts, USA; ^bNational LGBT Health Education Center, The Fenway Institute, Fenway Health, Boston, Massachusetts, USA; ^cDepartment of Psychiatry, Massachusetts General Hospital, Boston, Massachusetts, USA

ABSTRACT

Although little is known about the specific burden of the opioid epidemic on lesbian, gay, bisexual, transgender, and queer (LGBTQ) populations, there is evidence to suggest that opioid use disorders are disproportionately prevalent in the LGBTQ community. In this commentary, we present an overview of the current state of evidence on opioid use and misuse among LGBTQ-identified people in the United States and suggest ways to adapt behavioral health interventions to the specific needs of this population. Programs that integrate behavioral health with primary care, address minority stress, and use a trauma-informed approach have the most potential to produce effective, long-term benefits for LGBTQ-identified people with opioid use disorders.

KEYWORDS

Cognitive-behavioral therapy; gay; opioid-related disorders; opioids; prescription drug misuse; sexual and gender minorities; substance use disorders



Opioid Use Disorders among TGD People

- Transgender middle school and high school students more than twice as likely to report recent prescription pain medication use compared to other students
- Transgender adults on Medicare have increased prevalence of chronic pain compared to cisgender (non-transgender) adults.
- Transgender patients may be at increased risk post-operatively of developing an opioid use disorder.

De Pedro *et al.* (2017); Dragon *et al.* (2017)



Cognitive-behavioral Therapy for Substance Use Disorders

- Adapting selected topics and practice exercises from the manual by Carroll
- Focus:
 - Coping With Craving (triggers, managing cues, craving control)
 - Shoring Up Motivation and Commitment (clarifying and prioritizing goals, addressing ambivalence)
 - Refusal Skills and Assertiveness (substance refusal skills, passive/aggressive/assertive responding)
 - All-Purpose Coping Plan (anticipating high-risk situations, personal coping plan)
 - HIV Risk Reduction



Cognitive-behavioral Therapy for Substance Use Disorders

- Possible tailoring for TGD people:
 - Minority stress-specific triggers for cravings (e.g., gender identity-related discrimination and victimization, expectations of rejection, identity concealment, and internalized transphobia)
 - SUDs as barriers to personalized health goals
 - Assertive substance refusal with sex partners; HIV risk from hormone and silicone self-injections; SUDs as barriers to personalized goal of successful gender affirmation

Girouard et al. (2019)



Opioid Agonists and Genderaffirming hormone therapy

- Co-prescription of opioid agonists (e.g., methadone and buprenorphine) and gender-affirming hormone therapy
 - safe and feasible with appropriate monitoring and follow-up.

Kerridge et al. (2017); Dragon et al. (2017)



Affirming Gender Identity of Patients With Serious Mental Illness

William B. Smith, M.D., Hilary Goldhammer, S.M., Alex S. Keuroghlian, M.D., M.P.H.

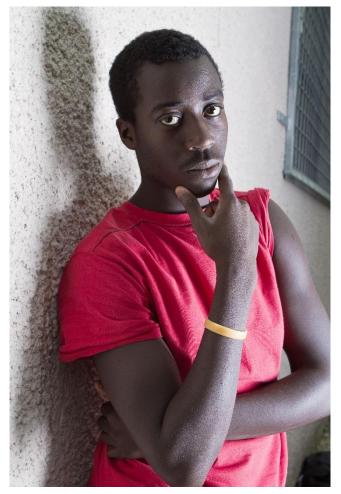
Transgender people who experience serious mental illness represent a uniquely vulnerable population. Because of limited research, however, recommendations for treating this population are scarce. In this article, the authors describe the challenge of recognizing gender dysphoria in people with serious mental illness. They then discuss why existing evidence and clinical experience support provision of gender-affirming medical and surgical treatments for transgender people who have serious mental illness and also demonstrate capacity to make informed medical decisions. More research is needed to develop evidence-based treatments and programs for transgender people with serious mental illness.

Psychiatric Services 2018; 0:1–3; doi: 10.1176/appi.ps.201800232



Gender Identity and Psychiatric Disorders

- Often impede gender identity exploration and alleviation of distress
- Need to stabilize psychiatric symptoms for facilitation of gender identity discovery and affirmation
- World Professional Association for Transgender Health guidelines for reasonable control of physical and mental health problems



Smith et al. (2018)



Role of Clinicians in Gender Affirmation Process

- Fostering gender identity exploration, discovery and affirmation
- Presenting appropriate non-medical and medical strategies for gender affirmation
- Assistance in making fully informed decisions regarding personalized gender affirmation process:
 - relevant options
 - risks/benefits
 - evaluate capacity for medical decision making/informed consent
 - arranging suitable referrals to care



Focus Areas in Gender-affirming Care

- Explore gender identity, expression, and role
- Focus on reducing internalized transphobia
- Help improve body image
- Facilitate adjustment through affirmation process (physical, psychological, social, sexual, reproductive, economic, and legal challenges)



Required Sexual Orientation and Gender Identity Reporting by US Health Centers: First-Year Data

Chris Grasso, MPH, Hilary Goldhammer, SM, Danielle Funk, MA, Dana King, ALM, Sari L. Reisner, ScD, Kenneth H. Mayer, MD, and Alex S. Keuroghlian, MD, MPH

Objectives. To assess the performance of US health centers during the first year of required sexual orientation and gender identity (SOGI) data reporting and to estimate the baseline proportion of lesbian, gay, bisexual, and transgender patients accessing health centers.

Methods. We conducted a secondary analysis of SOGI data from 2016. These data were reported by 1367 US health centers caring for 25 860 296 patients in the United States and territories.

Results. SOGI data were missing for 77.1% and 62.8% of patients, respectively. Among patients with data, 3.7% identified as lesbian, gay, bisexual, or something else; 0.4% identified as transgender male or female; 27.5% did not disclose their sexual orientation; and 9.3% did not disclose their gender identity.

Conclusions. Although health centers had a high percentage of missing SOGI data in the first year of reporting, among those with data, the percentages of lesbian, gay, bisexual, and transgender people were similar to national estimates, and disclosure was more than 70%. Future data collection efforts would benefit from increased training for health centers and improved messaging on the clinical benefits of SOGI data collection and reporting. (*Am J Public Health.* 2019;109:1111–1118. doi:10.2105/AJPH.2019.305130)

challenges are diminishing. Studies have revealed that most patients, regardless of their SOGI, understand the health benefits of disclosure and feel comfortable doing so.¹⁰ Since January 1, 2018, all EHR systems certified under the federal Meaningful Use Stage 3 Incentive Program are required to have the capacity to record SOGI data.⁹ In addition, there are now several training resources and guidelines available that help equip organizations to collect these data and that educate clinicians in understanding sexual orientation and gender identity as distinct yet interconnected concepts.^{3,6,11}

Recognizing the value and urgency of SOGI data collection for population health management and equity, the US Bureau of Primary Health Care, Health Resources and Services Administration (HRSA) began requiring their Health Center Program grantees (HCs) to collect and report SOGI data in

NATIONAL LGBTQIA+ HEALTH

Planning and implementing sexual orientation and gender identity data collection in electronic health records

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 Table 1. Sample timeline for implementing sexual orientation and gender identity (SO/GI) data collection in healthcare settings

Months 1 to 3	Identify a team of internal change champions Collect and read resources on SO/GI	Staff	Role in Data Quality Assurance and Control
Months 4 to 6	Engage leadership Plan implementation timeline Begin continuous quality improvement process Determine data collection systems Modify electronic health record	Registration	Cross-check paper registration forms with electronic health records Provide feedback on challenges (eg, lan- guage barriers)
Months 6 to 8 Month 7	Train staff Make changes to policies and physical environment Pilot SO/GI in 1 department/provider panel	Data Analysis/Programming	Run monthly reports of SO/GI data to identify problem areas, such as missing data and misclassification errors
Months 8 to 11	Expand to more departments and monitor progress through data feedback reports		Look at trends over time (eg, every 6 months) to identify unexpected pat- terns and statistical outliers
Ongoing M Tr Ga	Conduct first data summary report Monitor data quality Train new staff and re-train existing staff Gather feedback from staff and make changes as paeded	Quality Improvement	Incorporate SO/GI quality control and monitoring into existing workgroups Help develop changes in workflow to fix problem areas
	needed	Health Information Technology Clinical Care	Create checklists and confirm all compo- nents are installed after upgrades Provide feedback on challenges in

 Table 2. Staff roles for quality assurance and control of sexual orientation and gender identity (SO/GI) data



Grasso et al. (2018)

accessing SO/GI data from the EHR

Sexual and Gender Minority Health in the COVID-19 Pandemic: Why Data Collection and Combatting Discrimination Matter Now More Than Ever

more likely to smoke cigarettes⁵ and vape than are heterosexual, cisgender people. These disparities intersect with racial/ethnic health disparities. All of these conditions and risk behaviors could increase the vulnerability of SGM people to complications if they develop COVID-19.

See also the AJPH COVID-19 section, pp. 1344–1375.

The COVID-19 pandemic has exposed striking racial and ethnic disparities in the United States, with hospitalization and death rates highest for Black and Latinx Americans on a per capita basis and Native Americans and Pacific Islanders also experiencing greater disparities compared with White and Asian Americans.¹ This is attributable to multiple syndemic factors, including higher rates of underlydisparities, the risks of COVID-19 for sexual and gender minority (SGM) people have received little to no attention. Most SGM people are a hidden population that exists in all racial/ethnic groups. Until recently they were invisible in the health care system. In recent years, the need for training in culturally responsive care and sexual orientation and gender identity (SOGI) data collection has been embraced by (LGBT) people work in restaurants and food services (15.0% of all LGBT adults), 1 million work in hospitals (7.5%), and half a million work in retail (4.0%). Additionally, SGM people are more likely to live in dense, urban areas, where physical distancing measures are much harder to maintain and have emerged as early COVID-19 infection hotspots. Many, especially bisexuals and transgender people and

THE NEED FOR DATA COLLECTION

It is not known whether SGM people are more likely to become infected with SARS-CoV-2, nor is it known whether they are more likely to develop complications from COVID-19 or to die as a result of infection. The role of intersectionality (i.e., whether Black, Latinx, and indigenous SGM people have worse outcomes from COVID-19 than their demographically similar non-SGM



City-level Structural Stigma and Patient Sexual Orientation and Gender Identity Data Collection

- In 489 U.S. cities across 49 states:
 - Sexual orientation non-discrimination laws significantly associated with sexual orientation data completeness at health centers (OR 1.32, 95% CI 1.09-1.60).
 - Gender identity non-discrimination laws significantly associated with gender identity data completeness at health centers (OR 1.44, 95% CI 1.18–1.76)

Almazan et al. (in

preparation)









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The Education Center is part of The Fenway Institute, the research, training, and health policy division of Fenway Health, a Federally Qualified Health Center, and one of the world's largest LGBTQIA+ focused health centers.



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