Volume 2, Number 4, 2015

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DOI: 10.1089/lgbt.2014.0073

The Time Is Now: Attention Increases to Transgender Health in the United States but Scientific Knowledge Gaps Remain

Sarah MacCarthy, ScD,¹ Sari L. Reisner, ScD,² Amy Nunn, ScD,³ Amaya Perez-Brumer, MSc,⁴ and Don Operario, PhD³

Abstract

Attention to transgender health has dramatically increased in the U.S. Scientific knowledge gaps in empirical research, however, remain and act as barriers to achieving transgender-related health equity. We conducted a search using PubMed and PsycINFO to identify gaps in empirical, peer-reviewed publications related to adult transgender health in the U.S. between 1981 and 2013. We synthesized these findings and commented on opportunities for improving health research. Reducing health disparities and advancing transgender-related health equity requires greater investment in research that addresses current gaps to more comprehensively respond to the diverse health needs of transgender people.

Key words: gender minority health, peer-reviewed empirical research, research gaps, transgender.

Introduction

RANSGENDER PEOPLE HAVE an assigned sex at birth that ▲ differs from their current gender identity or expression. Attention to transgender health has dramatically increased in the U.S. In 2014, the Department of Education released guidelines stating that transgender students are protected under Title IX, a regulation passed in 1972 to eliminate discrimination based on sex in federally funded educational programs and institutes. The 2013 Employment Non-Discrimination Act banned workplace discrimination based on gender identity and sexual orientation. The American Psychiatric Association moved to decrease the stigmatization of transgender people by renaming "gender identity disorder" as "gender dysphoria," though not without pushback from many who feel the change in title did not address the implication that being transgender is a mental disorder. The arts, not surprisingly, can be credited with helping to promote greater transgender visibility across the U.S., including substantial attention turning to several transgender actors and activists. Contemporary social and cultural events have also brought transgender individuals and bodies to greater public awareness, especially in popular media (e.g., the television show "Orange is the New Black") and fashion

(e.g., a photography essay of 17 diverse transgender models in a stunning black-and-white campaign called "Brothers, Sisters, Sons & Daughters" by luxury retailer Barneys New York). Across various fields and multidisciplinary domains, transgender people are receiving unprecedented levels of attention.

With respect to health, in 2011 the U.S. Institute of Medicine's (IOM) ground-breaking report on lesbian, gay, bisexual, and transgender (LGBT) health noted that little research has examined the health needs of transgender individuals.² Subsequently, the empirical body of research has grown steadily, documenting substantial disparities in HIV,^{3,4} substance use and abuse,^{5,6} and various negative mental health outcomes in transgender people.⁷ Additionally, advocacy organizations have been critical in drawing attention to a range of health concerns faced by transgender individuals.^{8,9} While important progress is being made, scientific knowledge gaps remain. In this report, we aim to build on the previous base of knowledge by commenting on opportunities for improving transgender health research in the U.S.

We searched PubMed and PsycINFO using key terms (e.g., transgender, transsexual, gender dysphoria, gender identity disorder, gender nonconformity) to identify peer-reviewed articles in English that used quantitative methods to study adult

¹RAND Corporation, Santa Monica, California.

²The Fenway Institute, Fenway Health and Department of Epidemiology, Harvard School of Public Health, Boston, Massachusetts.

School of Public Health, Brown University, Providence, Rhode Island.

⁴Department of Sociomedical Sciences, Mailman School of Public Health, Columbia University, New York, New York.

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transgender health. Although this commentary does not report on a systematic review per se, we engaged in a structured search for all published records, beginning January 1981 (coinciding with the Diagnostic and Statistical Manual of Mental Disorders, Third Edition [DSM-III] publication referencing "transsexualism") through 2013. 10 Articles were excluded when transgender-specific information was not disaggregated, only intersex populations were addressed, qualitative methods or mixed-methods were used, results from a single case report were included, or samples focused on youth (age <18 years). All abstracts retrieved in this search (647 total) were collaboratively reviewed for population and methodological applicability (i.e., quantitative) by two members of the study team. Using a consensus-based and iterative approach, abstracts were then coded focusing on three types of output: taxonomy, themes, and theory. This also included categorization of the abstract based on the article's primary outcome of interest. Our goal was to identify and organize the breadth of published literature. In so doing, salient gaps in public health research with transgender populations emerged. We summarize the gaps and opportunities in the field, and we comment on how they present critical opportunities to advance research in U.S. transgender health.

Gaps and Opportunities

The empirical body of research on the health of transgender individuals has grown steadily and has continued to document multiple health challenges facing transgender people. Early studies tended to focus on psychiatric diagnoses and outcomes associated with gender confirmation procedures (i.e., genital reassignment surgeries) but as the AIDS epidemic gained emergence in public health literature, studies increasingly focused on prevalence of and behavioral risks for HIV and other sexually transmitted infections (STIs) in transgender populations, particularly in transgender women. HIV and STIs continue to be the most documented health issues in studies of transgender people.^{3,4} Prevalence estimates of HIV and STIs in transgender women are particularly high, 3,12 although few HIV/STI incidence data are available. The focus on HIV in many ways overshadows other critical health concerns, such as cancer and cardiovascular disease, which continue to be understudied despite concerns regarding their potential association with long-term hormone use and/or high rates of cigarette smoking. 13, 14 Various gender affirmation procedures (e.g., cross-sex hormones and gender reassignment surgery) have been studied and evaluated.¹⁵ Mental health problems represent a serious health concern for transgender people. Studies have found higher prevalence of suicide ideation and attempts in transgender people compared to non-transgender people, 16 in addition to high burden of substance use and abuse. 5,6 Several studies have noted the importance of social and familial networks on the health of transgender people. 17,18 With respect to HIV services and primary care services, studies have reported negative experiences with providers and healthcare systems, including being denied medical care. 19,20 Finally, studies have reported extensive transgender-related prejudice, including stigma, discrimination, and transphobia.²¹ Despite increasing attention to transgender health, the following scientific knowledge gaps emerged.

The understanding of resilience and health-promoting processes is inadequate

Researchers are beginning to shift away from a disease-based model (transgender as disorder) to an identity-based model (transgender as identity). Further research is needed to identify mechanisms through which transgender individuals cope with stress and overcome difficult life conditions influencing their health and wellbeing. Strengthsbased interventions emphasizing coping, social support, and transgender identity and community empowerment may assist in reducing health inequities commonly observed in this population.

Studies are rarely grounded in sensitive theoretical frameworks

Theories regarding the roles of sex (as a biological construct) and gender (as a social construct), as determinants of health are surprisingly absent from transgender research literature. Incorporation of social stress frameworks into research, including the sexual minority stress model and syndemic theory, ^{25,26} may improve understanding of transgender health, though additional work is necessary to ensure they address intersecting minority statuses. Some scholars have begun to apply more gender sensitive frameworks, ^{6,27} though much work is still required.

Recognition of population complexity and heterogeneity remains minimal

The diversity of the transgender population challenges any simple characterization. ^{28–30} Differences in gender expressions, gender affirmation procedures, self-presentation, sexual identities and behaviors, and distinctions of race/ethnicity, geography, and culture exist. Moreover, even the language around transgender health continues to evolve from "transsexual" or "transvestite" in its earliest appearances in the biomedical literature to "trans*" in more contemporary writing in an effort to create more inclusive terminology, such as gender non-conforming individuals. Language not only evolves but also depends on regional differences across and within countries. For example, in India biological males who reject their masculine identity and identify with a range of other categories are called kinnar in Maharashtra, thirunangi in Tamil Nadu, or shiv-shakthis in Andhra Pradesh.³¹ Further, transgender individuals may choose not to identify themselves openly according to their gender status and instead may wish to blend into society (i.e., live stealth). The transgender population complexity highlights the need for an intersectional perspective across public health efforts,³² recognizing multiple identity parameters that simultaneously influence health outcomes for transgender people. Research must continue efforts to accurately measure different identities while simultaneously acknowledging their fluidity and diversity.

Attention to female-to-male health is lacking

There is minimal attention to female-to-male (FTM) health needs in the empirical, peer-reviewed literature. This includes lacking FTM data on HIV, STIs, and behaviors known to increase risk of HIV and STI transmission. Thus, many of the biological risks experienced by FTMs who

engage in unprotected anal or vaginal sex, particularly with non-transgender men who have sex with men, are often ignored. Further, other health issues such as breast, cervical, and uterine cancer are rarely investigated, though some attention has recently been drawn to the disparity in receipt of gynecological services between FTM and non-FTM patients. ³³ Future research should focus on FTM and trans masculine identified people to raise their visibility. ³⁴

Studies are often limited to small clinical or community-based convenience samples

We note a primary reliance on convenience samples in the scientific literature. Greater efforts should be made to implement sampling approaches representative of transgender populations. This includes studies recruiting transgender people via multiple sampling methods. New technological approaches also warrant integration and consideration in sampling, in order to better reach transgender people who live outside of major metropolitan areas and who do not frequent mapped venues where transgender people have been shown to congregate. For example, in studying HIV risk, Internet-based hook-ups available via different apps should be considered. Also needed are studies with non-transgender comparison groups to document and understand health inequities by gender identity and to identify targets to achieve transgender-related health equity. Targets

Non-standardized measures of gender and health indicators are frequently employed

There is a lack of methodological attention to measurement in health research on transgender people, including a lack of inclusion of standardized and validated sex and gender measures to identify transgender respondents in population-level surveys. ³⁹⁻⁴¹ A two-step method has been proposed to elucidate sex/gender differences across health outcomes. ^{39,40,42,43} Further, many studies do not use health or psychosocial measures validated for use with transgender populations making comparisons across studies difficult. ²¹ There are some exemplary studies; ⁴⁴ but to conduct research that evaluates health trends over time and measures differences across groups allowing for comparisons, standardized and psychometrically validated measures must be more consistently employed.

Conclusion

Recognition of complex, overlapping relationships among different risk factors within a larger context of vulnerability has broadened the analysis of transgender health beyond studies of HIV and STIs and psychiatric diagnoses. Moreover, acknowledging that health is interrelated and interdependent on socio-structural factors such as housing, education, and employment, in addition to larger legal and policy contexts is critical. Many gaps highlighted here have been addressed comprehensively in qualitative work, especially from social science disciplines, further emphasizing the potential for multidisciplinary research to inform how programs and policies can address the health and wellbeing of transgender people. Continued work is needed to consider not only how qualitative research can compliment quantitative work, but also to employ (and publish) studies that en-

gage both methodologies in an integrated manner to better understand the contexts in which these poor health outcomes are occurring.

Thus, to build on the current base of knowledge there are key action points to inform how research can better address the health needs of transgender communities. For example, research must improve our understanding of resilience processes and be conducted with theoretically grounded frameworks sensitive to transgender health. Improved recognition of population complexity and heterogeneity, and increased research on FTM and trans masculine health, will prove critical to conducting work comparable across contexts. Sampling methods must be improved, and measures capable of identifying transgender respondents in surveillance and epidemiologic surveys are key to understanding gender-related population health. Transgender people may face specific health and social/structural issues that warrant attention. For example, transformative actions that can prioritize transgender health include the allocation of specific research funding for the study of transgender health issues, improving medical education training for transgender clinical care, and inclusion of transgender individuals in public health policy and decision-making entities. This will not be accomplished without challenges—there is often well-founded distrust within transgender communities regarding how best to engage in respectful and mutually beneficial research collaborations. Indeed, substantial work must be done—for public health researchers, policymakers, programmers, and advocates alike-to ensure the reduction and elimination of inequities that challenge the health and wellbeing of transgender communities.

Acknowledgments

This publication resulted from research supported by the training grant entitled "HIV and Other Infectious Consequences of Substance Abuse" (T32DA13911-12) and 1R25 DA035692. In addition, this publication was made possible with help from the Lifespan/Tufts/Brown Center for AIDS Research (P30AI042853) from the National Institute of Allergy and Infectious Diseases, from NIH grants U24-AA0022000 and R34-MH093232, as well as the T32 NRSA grant (T32 HD049339) and R25MH0836.

Author Disclosure Statement

No competing financial interests exist.

References

- American Psychiatric Association: Gender Dysphoria. Diagnostic and Statistical Manual of Mental Disorders (DSM-5), 2013. Available at http://www.dsm5.org/documents/gender% 20dysphoria%20fact%20sheet.pdf Accessed November 6, 2014.
- 2. Institute of Medicine: *The Health of Lesbian, Gay, Bisexual, and Trangender People: Building a Foundation for Better Understanding.* Washington, D.C: The National Academies Press, 2011.
- 3. Baral SD, Poteat T, Stombahl S, et al.: Worldwide burden of HIV in transgender women: A systematic review and meta-analysis. Lancet Infect Dis 2013;13:214–222.
- 4. Herbst JH, Jacobs ED, Finlayson TJ, et al.: Estimating HIV prevalence and risk behaviors of transgender persons in the

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United States: A systematic review. AIDS Behav 2008;12: 1–17.

- Operario D, Nemoto T: Sexual risk behavior and substance use among a sample of Asian Pacific Islander transgendered women. AIDS Educ Prev 2005;17:430–443.
- Reisner SL, Gamarel KE, Nemoto T, et al.: Dyadic effects of gender minority stressors in substance use behaviors among transgender women and their non-transgender male partners. Psychol Sex Orientat Gend Divers 2014;1: 63–71.
- 7. Reisner SL, White JM, Bradford JB, et al.: Transgender health disparities: Comparing full cohort and nested matched-pair study designs in a community health center. LGBT Health 2014;1:117–184.
- 8. Lambda Legal: When Health Care Isn't Caring: Lambda Legal's Survey on Discrimination Against LGBT people and people living with HIV. New York: Lambda Legal, 2010.
- Grant JM, Mottet LA, Tanis J, et al.: Injustice at every turn:
 A report of the national transgender discrimination survey.
 Washington, D.C.: National Center for Transgender Equality and the National Gay and Lesbian Task Force, 2011
- Drescher J: Queer diagnoses: Parallels and contrasts in the history of homosexuality, gender variance, and the diagnostic and statistical manual. Arch Sex Behav 2009;39: 427–460.
- 11. Bradley EH, Curry LA, Devers KJ: Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. Health Serv Res 2007;42:1758–1772.
- 12. Poteat T, Reisner SL, Radix A: HIV epidemics among transgender women. Curr Opin HIV AIDS 2014;9:168–173.
- Sattari M: Breast cancer in male-to-female transgender patients: A case for caution. Clin Breast Cancer 2015;15: e57–69.
- 14. Wierckx K, Elaut E, Declercq E, et al.: Prevalence of cardiovascular disease and cancer during cross-sex hormone therapy in a large cohort of trans persons: A case-control study. Eur J Endocrin 2013;169:471–478.
- 15. Murad MH, Elamin MB, Garcia MZ, et al.: Hormonal therapy and sex reassignment: A systematic review and meta-analysis of quality of life and psychosocial outcomes. Clin Endocrinol (Oxf) 2010;72:214–231.
- Mathy RM: Transgender identity and suicidality in a nonclinical sample: Sexual orientation, psychiatric history, and compulsive behaviors. J Psychol Human Sex 2002;14: 47–65.
- Golub SA, Walker JJ, Longmire-Avital B, et al.: The role of religiosity, social support, and stress-related growth in protecting against HIV risk among transgender women. J Health Psychol 2010;15:1135–1144.
- Erich S, Tittsworth J, Dykes J, et al.: Family relationships and their correlations with transsexual well-being. J GLBT Fam Stud 2008;4:419

 –432.
- Kenagy GP: Transgender health: Findings from two needs assessment studies in Philadelphia. Health Soc Work 2005; 30:19–26.
- Sevelius JM, Carrico A, Johnson MO: Antiretroviral therapy adherence among transgender women living with HIV. J Assoc Nurses AIDS Care 2010;21:256–264.
- Bradford J, Reisner SL, Honnold JA, et al.: Experiences of transgender-related discrimination and implications for health: Results from the Virginia Transgender Health Initiative Study. Am J Public Health 2013;103:1820–1829.

 Bockting WO: Transforming the paradigm of transgender health: A field in transition. Sex Relationship Therapy 2009;24:103–107.

- Erich S, Tittsworth J, Kersten A: An examination and comparison of transsexuals of color and their white counterparts regarding personal well-being and support networks. J GLBT Fam Stud 2010;6:294–324.
- Gonzalez CA, Bockting WO, Beckman LJ, et al.: Agentic and communal personality traits: Their associations with depression and resilience among transgender women. Sex Roles 2012;67:528–543.
- 25. Meyer IH: Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: Conceptual issues and research evidence. Psychol Bull 2003;129:674–697.
- Operario D, Yang MF, Reisner SL, et al.: Stigma and the syndemic of HIV-related health risk behaviors in a diverse sample of transgender women. J Community Psychol 2014; 42:544–557.
- Hendricks ML, Testa RJ: A conceptual framework for clinical work with transgender and gender nonconforming clients: An adaptation of the Minority Stress Model. Professional Psychology: Research and Practice 2012;43: 460–467
- Kuper LE, Nussbaum R, Mustanski B: Exploring the diversity of gender and sexual orientation identities in an online sample of transgender individuals. J Sex Res 2012;49:244
 254
- Bockting WO: Psychotherapy and the real-life experience: From gender dichotomy to gender diversity. Sexologies 2008;7:211–224.
- 30. Meier SC, Labuski CM: The Demographics of the Transgender Population. International Handbook on the Demographic of Sexuality. New York: Springer, 2013.
- 31. Johari A: Hijra, kothi, aravani: A quick guide to transgender terminology. Available at http://scroll.in/article/662023/Hijra,-kothi,-aravani:-a-quick-guide-to-transgender-terminology Accessed November 6, 2014.
- 32. Bowleg L: The problem with the phrase women and minorities: Intersectionality an important theoretical framework for public health. Am J Public Health 2012;102: 1267–1273.
- 33. Peitzmeier SM, Khullar K, Reisner SL, et al.: Pap test use is lower among female-to-male patients than non-transgender women. Am J Prev Med 2014;47:808–812.
- Reisner SL, Gamarel KE, Dunham E, et al.: Female-to-male transmasculine adult health: A mixed-methods communitybased needs assessment. J Am Psychiatr Nurses Assoc 2013;19:293–303.
- 35. Reisner SL, Conron K, Scout N, et al.: Comparing in-person and online survey respondents in the U.S. National Transgender Discrimination Survey: Implications for transgender health research. LGBT Health 2014;1:98–106.
- 36. Kirby T, Thornber-Dunwell M: Phone apps could help promote sexual health in MSM. Lancet 2014;384:1415.
- Conron KJ, Landers SJ, Reisner SL, et al.: Sex and gender in the US health surveillance system: A call to action. Am J Public Health. 2014;104:970–976.
- Reisner SL, Biello K, Rosenberger JG, et al.: Using a twostep method to measure transgender identity in Latin America/the Caribbean, Portugal, and Spain. Arch Sex Behav 2014;43:1503–1514.
- Conron K, Lombardi E, Reisner SL: Identifying transgender and other gender minority respondents on population-based surveys: Approaches. In: Best Practices for Asking

- Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys. J.L. Herman (Ed.). Los Angeles, CA: The Williams Institute, 2014.
- 40. Reisner SL, Badgett L, Landers S, et al.: Identifying transgender and other gender minority respondents on population-based surveys: How and where to ask. In: Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys. J.L. Herman (Ed.). Los Angeles, CA: The Williams Institute, 2014.
- 41. Reisner SL, Conron KJ, Tardiff LA, et al.: Monitoring the health of transgender and other gender minority populations: Validity of natal sex and gender identity survey items in a U.S. national cohort of young adults. BMC Public Health. 2014;14:1224.
- 42. Sausa LA, Sevelius J, Keatley J, et al.: Policy Recommendations for Inclusive Data Collection of Trans People in HIV

- *Prevention, Care & Services.* San Francisco: Center of Excellence for Transgender HIV Prevention: University of California, San Francisco, 2009.
- 43. Tate CC, Ledbetter JN, Youssef CP: A two-question method for assessing gender categories in the social and medical sciences. J Sex Res 2013;50:767–776.
- 44. Conron KJ, Scott G, Stowell GS, et al.: Transgender health in Massachusetts: Results from a household probability sample of adults. Am J Public Health 2012;102:118–122.

Address correspondence to: Sarah MacCarthy, ScD RAND Corporation 1776 Main Street Santa Monica, CA 90407

E-mail: sarahm@rand.org