Improving Quality and Access to Gender-affirming HIV Prevention Care for Transgender Youth

Statement of Problem

As many as 1% of individuals in the U.S. identify as transgender or gender expansive, and among adolescents and young adults, estimates are as high as 2.7%. Transgender children and adolescents often lack access to appropriate care, including affirming identity through appropriate use of preferred names and pronouns, puberty blockers, hormones, and other recommended medical and surgical treatments. In fact, in a large national survey, nearly half of transgender individuals reported delaying or forgoing medical care due to concerns of being treated poorly.

Transgender youth also experience significant challenges to their physical and mental well-being, including alarming rates of HIV infection. While new HIV infections in the U.S. are decreasing, the rates of infection among young transgender women are likely stable or increasing. Compared to the average individual globally, transgender women are 49 times more likely to become infected with HIV. There are a multitude of factors that contribute to HIV infection vulnerability among young transgender women, but lack of gender-affirming medical care and lack of provider respect and supportive care environments are cited as two major barriers against young transgender women seeking care. While awareness of Pre-Exposure Prophylaxis (PrEP), a daily pill that prevents HIV infection recommended for people at high risk for contracting HIV, varies among young transgender women, many perceive that they cannot afford this treatment.

Description

Given the health disparities faced by transgender youth in accessing quality care, Dr. Dowshen, a Stoneleigh Foundation Fellow, and her team will develop and test a youth-driven method to evaluate experiences getting care and use what they learn to impact policy, improve practice and provide information to transgender youth to help them make decisions when accessing care. Specific aims for this project include:

- Adapting and validating an existing quality assurance checklist to assess aspects of HIV prevention services for use with young transgender women populations, and creating additional quality measurement methods that will be best suited to the unique health care needs of this population.
- Recruiting young trans women in Philadelphia to evaluate the quality of HIV/STI testing and counseling, as well as PrEP-related and gender-affirming care referrals made to young transgender women within local HIV/sexually transmitted infection (STI) testing sites. Our youth-led quality evaluation process will involve mystery shopping visits and other new methodologies we develop. Feedback reports will be provided to clinical sites and youth care evaluators will offer training and technical assistance when areas for improvement are identified.
- Exploring the impact on self-efficacy and health care knowledge of trans youth quality evaluators.

Additionally, the team will partner with local leaders in the Philadelphia area to apply similar methods and learnings to improve the ability of local systems and policies to support the health and well-being of transgender

youth. Beyond embedding and sustaining the intervention locally, partnering with other policymakers outside of HIV care, who are responsible for the health and well-being of transgender youth, will allow for broader impact.

Next Steps

As of summer 2022, Dr. Dowshen and her team have completed the first aim as well as recruitment of youth quality evaluators, who are currently conducting mystery shopping visits and facility audits at local HIV testing sites. After data collection, the research team will create the site-specific feedback reports and work with the youth quality evaluators to identify general improvements in gender-affirming HIV testing and prevention. Their hope is that the findings from this study will lead to the development of a framework for future research on the quality of care for young transgender women.

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Related Tools & Publications

Barriers to Care for Gender Non-conforming Youth: Perspectives of Experienced Care Providers, Transgender Youth and Their Parents
Article
Feb 2018

Intersectionality and Health Inequities for Gender Minority Blacks in the U.S.
Article
Aug 2020

Promoting Health Equality and Nondiscrimination for Transgender and Gender-diverse Youth
Article
Jun 2020

Sexual and Reproductive Health Considerations Among Transgender and Gender-expansive Youth
Article
Sep 2019

Using Chart-stimulated Recall to Identify Barriers and Facilitators to Routine HIV Testing Among Pediatric Primary Care Providers
Article
Jun 2019

“I Think That I Have a Good Understanding of How to Protect Myself:" A Qualitative Study About HIV Risk Perceptions Among Men and Gender Diverse Individuals Who Have Sex With Men
Article
Feb 2022
Related Projects

Development of Mobile Health Interventions to Improve Adherence to Medication and Reduce Sexual Risk Behavior among HIV+ Youth
Adolescent Health & Well-Being

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Adolescent Health & Well-Being