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A PEER-REVIEWED ARTICLE

Challenges associated with HIV in transgendered patients

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Male-to-female transgender persons are individuals who experience discomfort with their biological male gender and identify instead as women. The term “transgender” is an umbrella term that includes persons whose gender identity, expression, or behavior does not conform to societal gender norms associated with sex at birth. Transgender persons experience a gender identity that differs from their anatomical sex; they may seek to alter their physical appearance by undergoing cosmetic procedures, using hormones, or having sex reassignment surgery. Others may not choose a physical transition but rather express their gender identity through varied presentations and behaviors. These persons are also described as “gender-variant” and terms used to describe them include male-to-female, transsexual, transvestite, cross-dressers, drag queens/kings, gender-queer, and others.

Male-to-female transgender persons have high rates of HIV infection, ranging in some cohorts as high as 35%. The estimated incidence of new infections among this group, in one study in Atlanta in the early 1990s, reported rates of 3.4-7.8/100 person years; these rates were higher than among men who have sex with men (MSMs) at the height of their epidemic in the 1980s. More recently a growing body of literature has shown that African-American transgender clients had a substantially higher rate of HIV diagnosis (28.6%) than all other racial or ethnic groups (California Department of Health Services 2006). The four factors associated with risk of HIV infection among this group include being of African American race, being an intravenous drug user (IDU), having multiple sexual partners, and being at a low educational level.

Feminization of a male fetus due to inadvertent exposure to progesterone-containing contraceptive agents *in utero* or masculinization of a female fetus due to inadvertent testosterone exposure during pregnancy may lead to features at birth that present as hemaphroditism or “intersex” and may in later life be interpreted as “transgender.” It is possible that such exposures may also occur with plant-based sources of estrogenic and androgenic substances used as foods or as medicinal plants in native cultures. This may help explain why many native and aboriginal cultures such as the ancient Romans, present-day Samoans, and Native Americans recognize and sometimes revere this phenomenon. Recent policy changes may begin to more adequately meet the social, emotional and medical needs of this highly marginalized population, especially when they are infected by HIV/AIDS.

This article will explore some of the numerous issues associated with transgenderism in the setting of HIV/AIDS, including among other concerns the use of hormones along with antiretroviral agents and medications for treatment of opportunistic infections (Ogbuokiri and Davis 2009) and a best practice model recommended to increase awareness among HIV providers and to improve cultural competency, sensitivity, and clinical capacity among all levels of HIV care providers.

Components of best practice model

The following recommendations comprise the best practice model for managing transgender HIV-infected clients: (1) Awareness, cultural competency, clinical capacity building, and traineeships for medical, social and mental healthcare providers serving transgender minority populations; (2) Provision of transgender-friendly HIV testing sites with referral capabilities for treatment facilities; (3) Establishment of transgender-friendly primary-care and ambulatory care HIV clinics; (4) Referral or connection to care that recognizes the need for hormonal replacement therapy alongside highly active antiretroviral therapy and respectful use of personal pronouns and preferred names of clients; (5) Education of patients and providers on the need for close clinical monitoring for both hormonal and antiretroviral side effects, key drug interactions, short- and long-term adverse events, especially in patients who continue to smoke; and (6) Establishment of a list of priority topics that must be addressed with each patient at every visit.

The proposed strategies are best applied at the clinic or hospital level, at AIDS service organizations, community-based organizations, and also at correctional settings including prisons and jails.

It is important that HIV providers at all levels of primary, secondary, tertiary, or referral care receive the needed cultural competency and clinical capacity building to improve care for this marginalized population. Other individuals who can benefit from this training are front-end staff and all other personnel offering HIV services at HIV/STDs early intervention clinics, HIV/AIDS ambulatory care programs, ASOs/CBOs, hospitals, correctional facilities, associations of nurses in AIDS care, and minority-serving organizations such as the National Medical Association, National Pharmaceutical Association, and National Black Nurses Association.

Purpose of best practice

The implementation of the best practice model should increase awareness of HIV providers and improve cultural competency, sensitivity, and clinical capacity to care for this population among all levels of HIV care providers, as well as promote health and decrease HIV infection rates through increased screenings for sexually transmitted infections (STIs) at transgender-friendly facilities based on the Center for Disease Control and Prevention HIV testing recommendations.

Numerous problems can be addressed by implementing the best practice model. Some situations that may be favorably impacted are these:

- High incidence and prevalence of HIV/AIDS, sexually transmitted infections and HIV-associated opportunistic infections
- High prevalence of smoking, drug and substance abuse
- High rates of commercial sex work
- Poverty and lack of adequate education, lack of jobs and insurance; high levels of marginalization and lack of job skills
- Current lack of visibility within the national healthcare and other public systems
- No national census figures thus no organized provision for health or other care

Recommended steps

1) All providers and all staff serving this population need cultural competency training in order to identify personal and institutional biases that may negatively impact the care offered to these persons.

2) Health education and support for care seeking behaviors, including overall engagement and retention in care, provision of hormonal replacement and HAART, and linkages to transgender-friendly ancillary services and specialist care.❖

BIBLIOGRAPHY

Clements-Nolle K, Marx R, Guzman R, Katz M. HIV prevalence, risk behaviors, health care use, and mental health status of transgender persons: implications for public health intervention. *Am J Public Health 2001; 91:915-21.*

Simon PA, Reback CJ, Bemis CC. HIV prevalence and incidence among male-to-female transsexuals receiving HIV prevention services in Los Angeles County. *AIDS 2000;14:2953-5.*

Kellogg TA, Clements-Nolle K, Dilley J, Katz MH, McFarland W. Incidence of human immunodeficiency virus among male-to-female transgendered persons in San Francisco. *J Acquir Immune Defic Syndr 2001;28:380-4.*

Hessol NA, Elifson AR, O'Malley PM, Doll LS, Jaffe HW, Rutherford GW. Prevalence, incidence, and progression of human immunodeficiency virus infection in homosexual and bisexual men in hepatitis B vaccine trials, 1978-1988. *Am J Epidemiol 1989;130:1167-75.*

Nemoto T, Luke D, Mamo L, Ching A, Patria J. HIV risk behaviours among male-to-female transgenders in comparison with homosexual or bisexual males and heterosexual females. *AIDS Care 1999;11:297-312.*

Nemoto T, Operario D, Keatley J, Villegas D. Social context of HIV risk behaviours among male-to-female transgenders of colour. *AIDS Care 2004;16:724-35.*

Selvaggi G, Ceulemans P, De Cuypere G, *et al.* Gender identity disorder: general overview and surgical treatment for vaginoplasty in male-to-female transsexuals. *Plast Reconstr Surg. 2005; 116(6):135e-145e.*

American Psychiatric Association. Diagnostic and Statistic Manual of Mental Disorders. 4th Edition. Washington, DC; 2000.

Lurie S. Identifying training needs of health-care providers related to treatment and care of transgendered patients: A qualitative needs assessment conducted in New England. *Intern J Transgenderism 2000; 8:93-112.*

Simon, PA, Reback CJ, Bemis CC *et al.* Prevalence and incidence among male to female transsexuals receiving HIV prevention services in Los Angeles County. *AIDS 2000; 14:2953-2955.*

Kellog TA, Clements-Nolle K, Dilley J *et al.* Incidence of human immunodeficiency virus among male-to-female transgender persons in San Francisco. *J Acquired Immunodeficiency Syndromes, 2001; 28: 380-384.*

Nemoto T, Operario D, Keatley J *et al.* Social context of HIV risk behaviours among male-to-female transgenders of color. *AIDS Care 2004b; 16: 724-735.*

Nemoto T, Luke D, Mamo L. *et al.* HIV risk behaviors among male-to-female transgenders in comparison with homosexual or bisexual males and heterosexual females. *AIDS Care 1999; 11: 297-312.*

Clements-Nolle, K, Wilkinson W, Kitano K *et al.* (2001b). HIV prevention and health service needs of the transgender community in San Francisco. In W. Bockting, & S. Kirk (Eds.) Transgender and HIV: Risks, prevention and care (pp. 69-89). Binghampton, NY: Haworth Press, Inc.

Garofalo R, Deleon J, Osmer E, Doll M, Harper GW. Overlooked, misunderstood and at-risk: exploring the lives and HIV risk of ethnic minority male-to-female transgender youth. *J Adolesc Health 2006; 38:230-6.*

Herbst JH, Jacobs ED, Finlayson TJ, McKleroy VS, Neumann MS, Crepaz N. Estimating HIV prevalence and risk behaviors of transgender persons in the United States: a systematic review. *AIDS Behav 2008; 12:1-17.*

17. Ogbuokiri JE, Ebigbo PO, Anidi AI. Hemaphroditism or Intersex?: A Report of Two Cases. Abstract #231C presented to the African Society for Pharmacology, Cairo-Egypt, September 2-5th, 1992.

18. Cobos DG and Jones J. Moving forward: Transgender persons as change agents in health care access and human rights. *JANAC 20(5): 342-347. September-October 2009.*

19. Rovner J (2009). Obama to overturn Bush "conscience" rules. Retrieved May 14 2009 from **http://www.npr.org/templates/story/story.php.story** id 101241248.

20. The Yokarta Principles. Principles on the application of international human rights law in relation to sexual orientation and gender identity (2006). Retrieved May 14 2009 from **http://www.yokartaprinciples.org/principles-en.htm**

21. National Center for Transgender Equality (2009). Newly released "provider conscience" regulations and their effects on transgender people. Retrieved May 14 2009 from **http://blog.genderology.com/topic/national**-center-for-transgender-equality.

22. Herbst JH, Jacobs ED, Finlayson TJ *et al.* HIV prevalence and risk behaviors of transgender persons in the United States.www.medscape.com/view article/571708. Accessed June 7th 2010.

23.Ogbuokiri, JE and Davis IJ. Challenges associated with estrogen replacement therapy in male-to-female HIV-infected transgender minority patients: experience from two busy inner-city ambulatory care clinics. Abstract presented to The Infectious Diseases Society of America Meeting, New Orleans, LA., December 8th 2009.

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For more information about the BESAFE model

developed by the National Minority AIDS Education and Training Center, contact NMAETC at Xavier University of Louisiana College of Pharmacy, 504-520-7430, or National Minority AIDS Education and Training Center, Howard University College of Medicine, Washington, DC, 202-865-8146.

See next page for summary

of BESAFE model

for transgendered patients.

Summary of BESAFE model for transgendered patients

Barriers to Care

- Factors associated with risk of HIV infection: African American race, intravenous drug use (IDU), multiple sexual partners, and low educational level
- Social stigma that limits employment opportunities, deepening poverty that forces many male-to-female transgender persons into commercial sex work, substance use as a coping strategy for dealing with an oppressed environment
- Psychosocial stress that manifests as feelings of isolation, depression, as well as transphobia, exacerbating HIV risk-taking behaviors leading to adverse health outcomes
- Resource constraints that limit exposure for provider acquisition of needed cultural competency and clinical skills relevant to this population
- Negligence by government and social agencies, lack of census data, lack of insurance and other assistance with health and other care such as housing, drug and substance abuse services, harm reduction, and mental health counseling.

Ethics

Ethics refers to issues of morality and its impact on the belief system of individuals, their values and behavior. Following the belief among most transgender male-to-female HIV-infected persons that they are "trapped" in the wrong bodies, many have low self-esteem, remain pre-occupied with acquisition of the desired sexual characteristics and orientations, and often remain in abusive relationships to "affirm" their desired sexual orientation. Providers for this population need to remain aware of the high rates of suicidal ideation, drug and substance abuse, violence, and emotional/physical abuse to which such persons may be subjected.

Sensitivity of the Provider

Certain organizations have been in the forefront of the effort to raise the issues associated with HIV-infected transgender persons and to increase the overall comfort and sensitivity of providers. Since many HIV-infected male-to-female transgender persons are unable to find meaningful work, and so engage mostly in commercial sex work, they have been stereotyped as drug-seeking and sexually promiscuous. It is important that, through sensitivity training, providers increase their understanding of the need for survival through sex work, develop an appreciation for the emotional burden in this population, and manage to get past any biases that impede delivery of optimal care to this marginalized population.

Assessment

Because of time constraints and perhaps lack of knowledge on the part of the provider, assessment of the HIV-infected male-to-female transgender person presents the greatest challenge. Many providers lack exposure to the subject of transgenderism in their medical curriculum and often experience discomfort in assessing these patients. Any information that could potentially impact the care provided to a patient should be elicited as relevant: mental health status, domestic or intimate partner violence, street violence, homelessness, substance use, street hormones, risks of suicide, joblessness. Providers assessing these patients may need to prepare, ahead of time, a listing of the most important 10-20 questions or issues that must be addressed with each patient.

Facts

The undefined and sometimes evolving reproductive pathology that can exist with transgender HIV-infected male-to-female patients places them at greater risk for acquisition of other sexually transmitted infections; this is especially relevant if they exchange sex for drugs or hormones or subject themselves to multiple sex partners during commercial sex work. Being African-American, a group with the highest rates of gonorrhea, syphilis and chlamydia, further places this group at higher risk for both HIV seroconversion and transmission to sexual and drug-using partners. As a result of extreme poverty, commercial sex work among this population may be carried out without condoms and with engagement in other high risk behaviors such as anal and vaginal sex. During patient interviews, it is crucial that the nature of sexual encounters be questioned by providers in order to offer necessary counseling and harm reduction strategies for each individual patient.

Encounters

At each encounter, providers must conduct a detailed cultural assessment of the patient regarding lifestyle, beliefs about their HIV disease, co-morbidities (relationship to HIV or other treatment, use of hormonal replacement therapy), thoughts and plans for sex reassignment surgery if any, attitudes and behaviors relative to sexuality and sex work, mental health issues, violence and physical/emotional abuse. Cultural competency and acquisition of the necessary clinical skills are encouraged to optimize care for this population.

Challenges

- Scarcity of providers and both front- and back-end staff with training, empathy, medical and cultural competencies needed to optimally serve this population
- Scarcity of transgender-friendly clinics at ambulatory care clinics, hospitals, and correctional facilities
- Fear of rejection by society at large and health clinics in particular
- Lack of adequate family and social support
- Addressing patients with the wrong or offensive pronouns
- Rushing patients through visits and creating a sense that they are not welcome at that site
- Failure to maintain patient confidentiality
- Institutional barriers such as lack of referrals for needed services including smoking cessation, hormonal replacement, substance use treatment and counseling, gender reassignment surgery, lack of medical insurance, screening for cancer-related diseases, and other co-morbidities common in this population.

Need for Comprehensive and Transgender-Friendly Services

- The scarcity of providers interested in taking care of the transgender population in rural settings forces many such persons to migrate to larger, urban cities, where such providers may still be in scarce supply.
- Sensitization of medical providers toward the needs of this population should start with inclusion of this topic in the training curriculum for physicians, nurses, and other health care providers.
- Lack of knowledge on the part of providers continues to be a major barrier.
- For the few providers with the relevant knowledge, skills and empathy, time constraints may make it mandatory that they treat more patients in less time, a factor that makes improved care through relationship-building difficult.

Impact and Expected Outcomes

- Reduced number of infections among male-to-female transgender persons and, by extension, the general population with whom they interact
- Increased access to transgender-friendly programs and providers with increased access to both antiretroviral and hormonal therapies
- Enhanced clinical capacity and cultural competency among HIV providers serving male-to-female transgender persons of color
- Male-to-female transgender HIV-infected persons experiencing and reporting greater satisfaction and better quality of HIV and other care
- Recognition of the problem of transgenderism and the creation of programs to serve the unmet needs of this highly marginalized population starting with their recognition through census and other data collection processes by government. This is long overdue and is a human rights issue. [20, 21]

Critical Issues and Lessons Learned

Cultural competency, sensitization, and increased awareness by providers of the problems associated with this population will create a cadre of providers who can identify better with these patients and so improve engagement and retention in care. Patient empowerment through health education, self-esteem support, and training for life and job skills will foster enhanced quality of life

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