

HIV Specialist

Transgender Health

Excellence in
the Care of
Trans Patients

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Hormone
Therapy

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A TIP FROM A
**FORMER
SMOKER**

**HIV alone
didn't cause the
clogged artery
in my neck.
Smoking with
HIV did.**

Brian, age 45, California

Brian had his HIV under control with medication. But smoking with HIV caused him to have serious health problems, including a stroke, a blood clot in his lungs and surgery on an artery in his neck. Smoking makes living with HIV much worse. You can quit.

CALL 1-800-QUIT-NOW.



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BY JAMES M. FRIEDMAN, MHA
EXECUTIVE DIRECTOR, AAHIVM

The Academy will greatly miss Ken's leadership, insight and passion for advancing the care and treatment of HIV patients.

Making a Change for Good

MET KEN SOUTH on my first day as executive director of the Academy in September, 2007. When I joined AAHIVM, Ken had been with the organization for only six weeks as director of membership. Ken did an excellent job building and managing the AAHIVM membership until he transitioned over as head of credentialing following the untimely passing of Director Peter Fox in 2012.

Under Ken's leadership, the Credentialing Program doubled in size, the credential for HIV Pharmacists (AAHIVP) was introduced, and the credentials were extended to three years. The Academy will greatly miss Ken's leadership, insight and passion for advancing the care and treatment of HIV patients.

But on a personal level, it will be me who will miss him the most. He was the only one on staff that I could talk to about black and white TV, the Studebaker, the Kingston Trio, or Vice President Nixon. Thankfully, he will be staying on for one day per week to direct and manage our HIV and Aging project—which he developed.

We have been fortunate to find and hire Dan Ebeling, who held a management position at the Registry of Interpreters for the Deaf (RID), where he was responsible for the management and growth of their credentialing program. The RID program is both larger and more complicated than our credentialing program in that it included over 1,800 individual exams per year, including management of a network of over 40 remote test sites. Dan will provide a fresh perspective and new insight into strategically growing our credentialing program. I have no doubt he is the right person to accept the baton from Ken as we continue to run the race to end this epidemic.

Besides providing a forum for me to thank Ken and welcome Dan, this is an important *HIV Specialist* because it explores a topic many of our providers have asked us to cover, transgender health.

While the transgender community has been in the news as a topic of societal debate, one fact is not debatable: the provider community wants and needs to learn more about the unique health challenges facing transgender individuals.

As it relates to HIV, studies reveal high HIV prevalence rates among transgender women in the United States, with African-American transgender women being more likely to have HIV than transgender women

of other races/ethnicities. We know that many social and structural factors pose challenges to preventing HIV among transgender people. This edition explores many of those issues, along with clinical insight into treatment and prevention.

I would like to extend my sincerest gratitude to Dr. Asa Radix and Dr. Peter Meacher of Callen-Lorde Community Health Center in New York, NY, for serving as our guest editors for this issue. The pages that follow provide the valuable insight into transgender health that our providers requested, thanks to their contribution and their collaboration with top experts in the field.

HIV



James M. Friedman

James M. Friedman

HIV Workforce Crisis

THANK YOU for writing that important piece in the March *HIV Specialist* about the HIV workforce crisis.

I wanted to let you know that there is another FM-based HIV fellowship, now in its second year, that I started at UMass in July of 2014, in response to the need you outline in your article and the NHAS.

Here is a link to our homepage: <http://www.umassmed.edu/fmch/fellowships/hiv/>, which is listed on both the AAHIVM and HIVMA websites.

I was the lead author on the most recent AAFP HIV/AIDS Curriculum Guideline you mentioned, and Jeff Kirchner was a contributing editor.

Later this month the *FP Essentials Monograph Care of the HIV Patient* will be published, written by myself and three of my colleagues at UMass/Worcester. <http://www.aafp.org/cme/subscriptions/fp-essentials/editions/443-ed.html>, and here is the link to the AAFP Curriculum Guideline: http://www.aafp.org/dam/AAFP/documents/medical_education_residency_program_directors/Reprint273_HIV.pdf

Along with Chris Bositis, of Lawrence, MA, I am also the STFM HIV Working Group Co-Chair. Chris runs an HIV AOC in Lawrence, and we are both committed to addressing the HIV workforce shortage.

I thought that I should put Chris's and my name on your radar given our similar professional passions in this area.

Thank you,

Phil Bolduc

HIV Program and Fellowship Director

Assistant Professor of Family Medicine and Community Health

University of Massachusetts Medical School

Family Health Center of Worcester

THE ISSUE of primary care physician shortages is very concerning for the healthcare delivery in our nation. I was pleased to read that one solution to this shortage is to engage more nurse practitioners into providing HIV care in the article titled "One solution to looming physician shortage" in the March 2016 issue of *HIV Specialist*.

It is a fact that as of March 2016, only 21 states and the District of Columbia, allow nurse practitioners full scope authority/practice; however, the three states mentioned as having the highest prevalence of HIV (New York, California, and Florida) ALL have restricted scope of practice. The article

states California has full scope authority/practice, which it does not.

Thank you for your time and for addressing that nurse practitioners are an integral solution to the overall transformation of healthcare delivery.

Sincerely,

Aimee Castellon-Maestri,

RN, BSN, DNP student **HIV**





Dan Ebeling Joins AAHIVM as Credentialing Director

AAHIVM WELCOMES DAN EBELING as our new Credentialing Program director. Ebeling was chosen from over 100 applicants to replace the retiring Ken South as director.

South's last day at the Academy was June 30, marking the ninth anniversary of what he describes as the pinnacle of his impressive 45 year-long career.

"I absolutely feel that the Academy has been the perfect fit for me because I have been able to apply my knowledge of my life experiences with the epidemic with the autonomy and creativity I crave," said South. "Best of all, are the countless fond memories of the relationships with AAHIVM staff, board and members. My life has truly been enriched because I was lucky enough to be a part of the team!"

South joined AAHIVM nine years ago as the membership director, then transitioned to head the credentialing department. Following his retirement, South will consult for AAHIVM, continuing to oversee the organization's HIV and Aging Consensus Project, developed to assess how the presence of both HIV and common age-associated diseases alter the optimal treatment of HIV as well as other co-morbidities.

After earning his Masters of Divinity degree in 1972, South founded the GLBT Coalition of the Connecticut Conference of the United Church of Christ and was co-founder of the Hartford Gay & Lesbian Health Collective. He began his HIV career at the height of the epidemic with AID Atlanta and has worked with the AIDS National Interfaith Network, AIDS Action, the AIDS Institute of KOB Associates, and the President's Commission on the AIDS Epidemic.

"There is no doubt that Ken has made a significant contribution to the fight against HIV and AIDS throughout his career," said AAHIVM Executive Director James Friedman. "Just as the HIV community has benefited from Ken's passion for the cause, so too has the Academy. I consider it an honor to have worked with him and wish Ken all the best in this next chapter of his life."

New Credentialing Director Dan Ebeling most recently held the Certification Management position at the Registry of Interpreters for the Deaf (RID), where he was responsible for the management and growth of their credentialing program. Ebeling oversaw the administration of over 1,800 individual exams per year including management of a network of over 40 remote test sites. He excels in working directly with subject matter experts, volunteer committees and association leadership.

"We are confident that Dan will be an asset to our organization because of his extensive experience in leading a successful certification program," added Friedman. "I welcome his new perspective, fresh ideas and passion for strategically growing the AAHIVM credentialing program."

The AAHIVM three-year professional certifications are the first and only credentials offered to physicians, nurse practitioners, physician assistants and pharmacist specializing in advanced level HIV care. The HIV Specialist (AAHIVS) credential is available to practicing frontline care clinical providers, while the HIV Expert (AAHIVE) designation can be earned by non-practicing practitioners. The HIV Pharmacist (AAHIVP) certification is available to HIV-specialized pharmacists.

"AAHIVM has an established credential that promotes a high quality standard of care for HIV patients, and I'm excited to be joining a team that is focused on such an important mission," said Ebeling. "I'm looking forward to continuing the growth of a reliable and relevant credentialing system to ensure that HIV patients receive the best of care."

Ebeling began this new chapter with the Academy on June 1 in order to have the opportunity to work in conjunction with South prior to his retirement.



In the **NEWS**

CDC Offers New Materials Featuring Transgender Women Living with HIV

THE U.S. CENTERS for Disease Control and Prevention (CDC) is expanding its Act Against AIDS portfolio to bring more visibility to transgender women. The most recent addition brings three new digital story videos, posters, web banners, and palm cards to the HIV Treatment Works campaign, which encourages people living with HIV to stay in care.

CDC and its partners are pursuing a high-impact prevention approach to achieve the goals of the *National HIV/AIDS Strategy: Updated to 2020*, which includes goals and recommendations specific to transgender persons. Activities associated with these endeavors include funding and supporting community-based organizations in their efforts to improve services for transgender persons with a particular focus on transgender women of color, on the HIV care continuum.

Although many transgender people have difficulty finding health care providers who understand their unique challenges, there are positive stories that demonstrate excellent patient/provider relationships. One of these stories comes from Jamie, who describes her HIV care provider in her own digital story. “I can’t say anything negative about [my doctor]. She’s very positive and she has a lot of resources. She’s been helpful in getting me to feel comfortable with this process and not feel like I’m completely lost.”

To view Jamie’s and other digital stories like hers, or share them with your patients, visit www.cdc.gov/hivtreatmentworks. In addition to *HIV Treatment Works*, transgender women are also featured in the *Doing It* and *Let’s Stop HIV Together* campaigns. Other materials regarding HIV prevention and treatment in the transgender community, as well as resources for HIV care providers who are working to address transgender needs, will be added in the future. All of these materials are available at no cost and can be ordered directly from CDC-INFO at www.cdc.gov/cdc-info.

“HIV, you have no power here. And if it's between you and me, I guarantee I'll win.”

Jamie – Atlanta, GA
Living with HIV since 2015.

HIV TREATMENT WORKS

When I was first diagnosed with HIV, I felt like I would never have a strong quality of life again. But life does not end with an HIV diagnosis. I formed a strong, honest relationship with my medical provider and together we created a plan to keep me healthy. I want to encourage other transwomen living with HIV to take care of themselves by taking their medication, and taking time to do what makes them happy. There is light at the end of the tunnel, and you can live a full and amazing life as long as you stay in care and prioritize your health.

Get in care. Stay in care. Live well.
cdc.gov/HIVTreatmentWorks

‘DO ASK, DO TELL’ TOOLKIT Provides Pathway to LGBT Data Collection for Providers

THE FENWAY INSTITUTE and the CENTER FOR AMERICAN PROGRESS have launched a project to help health care providers and other health system stakeholders collect sexual orientation and gender identity (SOGI) information in clinical settings. The project’s goal is to promote better understanding of the specific health issues facing lesbian, gay, bisexual, and transgender (LGBT) individuals and improve health outcomes for this population.

At the heart of the campaign is the “Do Ask, Do Tell” toolkit (www.doaskdotell.org), which provides tested sexual orientation and gender identity questions that are recommended by national LGBT organizations and which have been shown to work with diverse patient populations served by community health centers in the U.S. The toolkit focuses particularly on electronic health records (EHRs), which are at the heart of the multi-year federal “Meaningful Use” initiative that promotes a transition from paper to electronic records in clinical settings. In fall 2015, the federal Department of Health and Human Services released a final rule for the third and final stage of the Meaningful Use program that requires certified EHR systems to have the capacity to collect structured data on sexual orientation and gender identity.

The toolkit describes how to collect SOGI data in EHRs, how to use these data to support clinical processes such as ensuring that transgender individuals receive anatomically appropriate screenings and care, and how to train clinical staff to interact with LGBT patients in ways that are affirming and welcoming. As part of a partnership with the National LGBT Health Education Center (www.lgbthealtheducation.org), the toolkit also highlights other resources that health care providers can use to offer culturally and clinically competent care reflective of their LGBT patients’ unique needs.

In the NEWS

Biomarker Tracks Accelerated HIV-Associated Aging

BY MEASURING A MOLECULAR SIGNATURE OF AGING, researchers have found that HIV infection accelerates aging, adding an average of five years to an individual's biological age.

The more rapid aging is occurring in people receiving antiretroviral treatment, so that even though treatment enables them to live for many decades, they remain at higher risk of aging-related chronic disease.

The National Institute of Mental Health, in an AIDS.gov blog, said that studies of people with HIV infection have noted a higher risk of diseases associated with aging, such as liver and kidney failure, cancer, and heart disease.

While the observations have suggested that HIV infection causes accelerated aging, there hasn't been a biologically based marker of aging with which scientists could clarify and quantify the impact of HIV on aging.

In search of such a marker, scientists at the University of Nebraska Medical Center, led by Howard Fox, M.D., Ph.D., in collaboration with scientists at the University of California, San Diego School of Medicine, led by Trey Ideker, Ph.D., turned to epigenetics, a term for changes to DNA that affect its function without altering the sequence of bases that make up DNA. Through epigenetic processes, experience can alter the genome, silencing or activating genes.

Building on information from previous research on methylation and aging, the team found that methylation tracked well with chronological age in those without HIV. In HIV-positive individuals, however, the changes in methylation were accelerated, adding an average of five years to "epigenetic" age. This fast forward occurred even in those who had had HIV for short duration, less than five years. Previous models found that aging-related changes in methylation parallel increases in mortality; the changes found here in HIV positive patients suggest a 19% increase in mortality.

The team also found that one region of the genome was particularly rich in HIV-associated changes in methylation: this region, the human leukocyte antigen locus, encompasses genes that encode molecules that are central to immune responses. The authors suggest that epigenetic processes may contribute to the changes in regulation of this region of the genome and thus the progression, or control, of HIV.

The work provides an objective method of assessing the impact in individuals of HIV on biological age. It provides insight into the mechanisms behind the accelerated aging, and may offer a means of identifying individuals vulnerable to aging-related chronic disease, and who may benefit from more careful attention to monitoring and preventive treatments. Given epigenetic changes observed in the HLA region, it may provide clues to future approaches to controlling infection.

To read the complete blog, please visit <https://blog.aids.gov/2016/04/biomarker-tracks-accelerated-hiv-associated-aging.html>



President Obama Reflects on 35th Anniversary of HIV/AIDS in America

NOTING THAT FIVE YEARS AGO HE SAID that an AIDS-free generation was within reach, President Obama recounted advances that have been made and said "the global community" is committed to ending the epidemic by 2030.

"This will take American leadership, smart investments, and a commitment to ensure that all communities are heard and included as we move forward," the President said.

Over these 35 years, he said, "We've learned that stigma and silence don't just fuel ignorance, they foster transmission and give life to a plague." But, he added, "We've seen that testing, treatment, education, and acceptance can not only save and extend lives, but fight the discrimination that halted progress for too long."

"We've invested in research and evidence-based practices that have given us revolutionary tools like treatment as prevention and pre-exposure prophylaxis," Obama said. "We've made critical investments to help eliminate waiting lists for the AIDS Drug Assistance Program. We've continued efforts to support the promise of a vaccine. And the Affordable Care Act has resulted in millions of individuals gaining affordable, high-quality health coverage—all without denial for pre-existing conditions like HIV."

There is more work to do, said the President. "The economically disadvantaged; gay and bisexual men, especially those who are young and Black; women of color; and transgender women all continue to face huge disparities—I'm confident that if we build upon the steps we've taken, we can finish the job," he said.

Johns Hopkins Performs First Transplants Between HIV+ Donors and Recipients

IN MARCH, Johns Hopkins Medicine in Baltimore, MD performed the first liver and kidney transplants from an HIV-positive donor to recipients who are also HIV-positive.

The transplants were made possible by the bipartisan HIV Organ Policy Equity (HOPE)

Act passed by Congress and signed by President Obama in 2013. In February, Hopkins became the first U.S. hospital to be approved for the transplants from the United Network for Organ Sharing, which had banned transplantation of organs from HIV+ patients since 1984.

In the surgeries, one donor provided a liver to one recipient and a kidney to another.

The new law was drafted with the help of Dorry L. Segev, MD, a Johns Hopkins associate professor of surgery, who had watched organs from HIV-positive donors being wasted while HIV-positive patients awaiting transplants died. Dr. Segev led the team that performed the transplants.

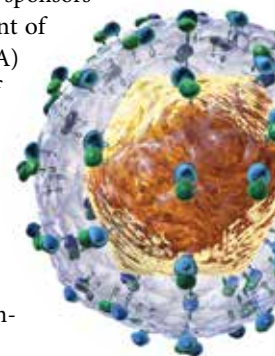


Dr. Dorry Segev (right), of Johns Hopkins Medicine, led the team of doctors who transplanted organs from an HIV+ patient into two different HIV+ patients in March.

Chronic Hep C Virus Infection: Developing Direct-Acting Antiviral Drugs *Industry Guidance*

The Food and Drug Administration (FDA) has issued guidance to assist sponsors in the clinical development of direct-acting antiviral (DAA) drugs for the treatment of chronic hepatitis C. The guidance is intended to serve as a focus for continued discussions among the Division of Antiviral Products pharmaceutical sponsors, the academic community, and the public.

The guidance is available at http://www.fda.gov/downloads/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/UCM225333.pdf?source=govdelivery&utm_medium=email&utm_source=govdelivery



Pentagon to End Transgender Troops Ban

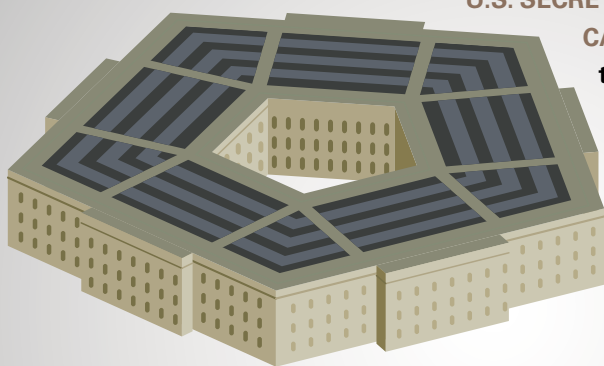
U.S. SECRETARY OF DEFENSE ASHTON B.

CARTER ANNOUNCED JUNE 30 that the armed services' ban on transgender members is being repealed.

The decision comes as the military has undergone major changes in the role of women and the inclusion of gays, lesbians and bisexual service members.

Defense Secretary Ashton B. Carter said last July he was establishing a working group to research transgender military service and set a six month deadline for completion of its work. However, the process has taken nearly a year.

Under the Pentagon's previous policy, transgender people could be discharged, although last year that policy was modified to move the discharge authority to higher levels in the military, making it harder to force out transgender troops. But the lack of a new, clear policy created complications for transgender soldiers as well as their commanders, including questions about gender-specific uniforms, grooming requirements and bathroom usage.



Feds Launch HIV Health Improvement Group for Medicaid Programs

The Centers for Medicaid Services (CMS), the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) announced June 24 the launch of new joint initiative, the HIV Health Improvement Affinity Group.

The new entity will bring together state public health and Medicaid and Children's Health Insurance Program CHIP agencies to collaboratively improve health outcomes for enrollees living with HIV by identifying opportunities to strengthen the HIV care continuum among those populations.

An AIDS.gov blog said participating state public health and Medicaid/CHIP programs can learn about, and share, best and promising approaches with their state peers to improve viral load suppression among people living with HIV who are enrolled in Medicaid and CHIP.

Read more at <https://blog.aids.gov/wp-content/uploads/HIV-Health-Improvement-Affinity-Group.pdf>.

HIV

FROM THE MARGINS TO THE

Challenges Remain for Transgender Health, Best Practices Needed for Proper Care

ASA RADIX, MD, MPH, AAHIVS and PETER MEACHER, MD, AAHIVS

OVER THE LAST FEW YEARS transgender individuals have gained greater visibility in the mainstream media, appearing on the cover of *Time* magazine and *Vanity Fair* and prominently featured on both the small and big screen. What is missing however are transgender narratives that accurately portray day-to-day life experiences faced by the majority of transgender people.

Transgender individuals, especially transwomen of color, encounter extremely high rates of stigma and discrimination, including social rejection, verbal, physical and sexual assault, exclusion from employment opportunities and housing, and yes, even access to public restrooms^{1,2}. It is no surprise that transgender persons experience higher rates of psychological distress, including anxiety, depression and suicidality^{3,4}.

Although research in this population is limited, it has been evident for some time that transgender women have disproportionately high rates of HIV infection, with estimates that about one in five transwomen are HIV-positive^{5,6}. HIV risk factors include higher rates of sex work⁷, lower rates of condom use⁸, sexually transmitted infections^{9,10}, co-occurring mental health issues and substance use^{4,11,12}. Studies have shown that transgender people avoid necessary medical care due to healthcare discrimination, including denial of care, facing harassment and abuse, and encountering providers who are uninformed about their health

care needs¹³. This avoidance of health services leads to poorer health outcomes, including lower rates of viral suppression for those who are HIV-infected^{14,15}.

This issue of *HIV Specialist* highlights both unmet needs and best practices for the care of transgender individuals. This is extremely timely considering the recent statements from experts in the field that “the majority of health-care needs can be delivered by a primary care practitioner.”¹⁶

Dr. Steven R. Klemow (Influence of Integrated Transgender Healthcare on ART Adherence and Outcomes) provides a first-hand perspective from his decades’ long experience working with transgender persons, including an overview of HIV care continuum and the importance of integrating gender affirming care in a medical practice.

Linda Wesp and colleagues (Excellence in the Care of Trans Patients; expanding the base of gender affirming healthcare professionals) discuss

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MAINSTREAM

gaps in medical education that result in many health professionals lacking knowledge to care for sexual and gender minorities. The authors provide concrete recommendations to improve curricula and institutional culture to enhance the delivery of culturally competent and appropriate care to transgender clients. This article also provides links to clinical practice guidelines and online educational resources in transgender health.

What does it mean to provide gender affirming services in your practice setting? Andrew Goodman (Culturally Sensitive In-Office Care for the TGNC Patient) gives a step-by-step guide to creating a safe environment, and best practice tips for history taking and physical examination.

Some transgender clients may opt to initiate hormone therapy. Dr. Meera Shah (Transgender Hormone Therapy; Practical guidelines for the HIV care provider) provides an overview of the feminizing and masculinizing hormone protocols as well as recommendations about laboratory monitoring.

Finally, Elena Cyrus, et al, discuss the current status of PrEP use and the need to scale up prevention services to transgender women. She outlines some of the barriers to PrEP use and provides an agenda to address educational, research and funding gaps.

This issue provides a unique look at some of the HIV-related health concerns affecting transgender people, predominantly transgender women. Many issues are not fully addressed here, such as the health needs of transgender men and those of non-binary people, who have largely been excluded from HIV-related research. Although greater visibility has been achieved for transgender people, there is still much more to do to ensure health equity for this population. **HIV**

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EXCELLENCE IN THE **Care** OF TRANS PATIENTS

Expanding the Base of Gender-Affirming Healthcare Professionals

BY LINDA WESP, RN, MSN, NP-C, AAHIVS, OSCAR E. DIMANT, MD CANDIDATE and TIFFANY E. COOK, BGS

THE WORD “TRANSGENDER” IS AN UMBRELLA TERM used to describe individuals who have a gender identity different than the sex they were assigned at birth. Transgender people face health disparities that research suggests are linked to societal stigma, discrimination, and denial of civil and human rights^{1,2}.

According to the National Transgender Discrimination Survey³, over 19% of transgender respondents were refused medical care and 28% postponed medical care when sick or injured due to discrimination or inability to pay.

When presenting for care, 50% of transgender people reported having to teach their medical providers about transgender-related healthcare needs. Of the patients who had a health care provider deny them care, 60% attempted suicide, in stark comparison to the 4.6% rate of the general U.S. population who report a lifetime suicide attempt.

It is imperative and urgent that we address these health disparities. This article reviews some background and gaps in practice and education, and advances a recommendation for a three-pronged approach to improve the healthcare climate for transgender patients: improved education, community-based action, and commit to ongoing assessment and sharing knowledge.

Background

Healthcare professionals currently do not receive consistent or comprehensive training regarding transgender patients. In a 2011 survey of allopathic and osteopathic medical school deans in the United States and Canada, the median number of hours spent on sexual and gender minority populations in medical school education was approximately five⁴.

The authors also found that although 97% of schools reported education about sexual orientation to include questions about a history of sex with “men, women, or both,” only 30.3% taught about gender transitioning. A survey of nursing faculty in baccalaureate nursing programs found that the median time devoted to sexual and gender minority health was about two hours, and that the knowledge, experience, and readiness for teaching LGBT health topics was limited among baccalaureate faculty⁵.

Faculty members and healthcare professionals can choose to seek out continuing

education to improve knowledge and competence in caring for transgender populations; numerous educational opportunities exist and are outlined in the online resources box below. However, evaluation of the impact of continuing education on patient care outcomes has been limited.

Knowledge cannot be assumed to lead to behavior change, improved quality of care, or improved patient outcomes. Therefore, assessing learning regarding clinical behavior changes through knowledge-based questions alone is considered insufficient.

Recommendations

To transform the healthcare experiences of transgender patients, we suggest a three-pronged approach: improved institutions, education, and climate; community-based action; and a commitment to ongoing assessment and information sharing.

These are iterative, rather than sequential steps that are core aspects of expanding our capability to care for transgender communities. All three are necessary and serve to support each other.

Key components for developing gender-affirming providers include openness to learning, honesty about what is not known, and self-reflexivity when mistakes are made.

Understanding the difference between cultural humility and cultural competence is also crucial.

At the center of this recommendation is the concept of cultural humility. Cultural humility is defined as openness, self-awareness, egolessness, supportive interactions, and self-reflection/critique⁶. Entrenched norms of gender binary, lack of exposure to transgender identities, and/or biased cultural narratives about transgender people contribute to a situation in which the majority of healthcare providers, educators, and support staff within healthcare institutions are not ready to care for transgender patients.

Key components for developing gender-affirming providers include openness to learning, honesty about what is not known, and self-reflexivity when mistakes are made. Understanding the difference between cultural humility and cultural competence is also crucial, with the latter being a “detached mastery of a theoretically finite body of knowledge”⁷.

Therefore, all efforts should continually seek to encourage a lifelong commitment to self-evaluation in order to redress power imbalances, as opposed to solely memorizing information. With this foundation, healthcare providers will be well on their way to becoming professionals the transgender community can trust and collaborate with.

Improve Institutions, Education, and Climate: A crucial step in expanding the base of gender-affirming healthcare professionals is to prepare future graduates to care for transgender patients and to ally themselves with the community. Learning

objectives in mandatory curriculum for health professions students should cover information about emergency and routine healthcare needs that may be the same or different for cisgender and transgender patients. It should also include information about social determinants of health and disparities. Resources for health professions faculty regarding education and collaboration can be found in the online resources box.

Students should be encouraged to participate in skill-building opportunities to learn appropriate clinical interactions with transgender patients in situations both related and unrelated to gender transition. One recommended modality is simulation and the use of transgender standardized patients or teaching associates⁸. In addition to assisting students in developing new skills and achieving authentic interactions, standardized patient employment opportunities for transgender individuals, an oft underemployed population, provide compensation and shift the power dynamic between the cisgender professional and the transgender patient. In addition to focusing on student trainees, training the current healthcare workforce is crucial. Several new studies explore large-scale educational interventions. One training covered basic terminology, transgender identity, common stressors, health disparities, transitioning (social, medical, and surgical), allyship, primary care and transition related care, intake/registration concerns, and billing concerns in two-hour training sessions for 35 administrators and providers across four months⁹.

Embedded within these topics are important sub-topics, including barriers to care, HIV prevention, gathering sexual orientation and gender identity data formally and regularly, caring for partners and families, gathering a sensitive and comprehensive sexual health history, and making appropriate referrals to social work and mental health providers.

Findings included improved post-training scores on attitudes towards transgender individuals, increased awareness of transphobic practices, and increased readiness to serve transgender populations. Another training covering similar content provided a six-week modular health education curriculum focused on health care for LGBT elders to over 800 nurses over a three-year period. They found post-test knowledge gains across all modules, but were unable to measure long-term outcomes¹⁰.

A theory-based strategic plan for implementing institutional and educational change can enhance didactic trainings. Often underutilized in bio-medicine, paradigm and theoretical approaches are intrinsic to the development of effective curricula.

We recommend utilizing a transformative paradigm that helps learners identify their own assumptions about gender and reframe them through interactive discourse¹¹. When seeking to train the local current workforce, a needs-assessment (discussed further below in *Community-based action*) can establish goals.

Within the strategic plan, structural needs (policies, procedures, etc.) along with professional development needs are

considered for every student, staff member, and volunteer who comes in contact with patients. When there is sufficient momentum to move forward with training, delivery methods and content should be considered.

Identify potential educators and internal champions for both trainee- and professional-level education. A committee that is dedicated to the longitudinal outcomes of transgender experience within the institution should be developed and provided with the tools to move forward. Consider that some learners benefit more from a problem-based learning environment in which they are challenged to solve a problem without guidance from an instructor, while others learn best in web-based courses which allow time to critically reflect and work through definitions and information without group process.

Community-based action: When seeking to develop change within a system, it is critical that we do not postpone immediate action while working towards development of the best possible care system.

Healthcare providers who are interested and able to provide care for transgender people can begin to do so immediately, following established practice guidelines provided in Online Resources for Healthcare Professionals sidebar. While this may increase capacity in the short-term, further steps must be taken to establish partnerships with the local community to assess needs and plan longer-term actions.

Transgender people may be of any age, race, ethnicity, ability, or socioeconomic status, and they present with a wide variety of healthcare needs. Lack of training for healthcare providers leads to provider ambivalence and uncertainty during the healthcare encounter and anticipation by transgender people that their needs will not be met¹².

This process cannot be ignored, especially considering that many patients have already had negative personal or communal experiences with healthcare professionals, as documented in the National Transgender Discrimination Survey³. Given this, it is essential to build trust and genuine collaboration between the healthcare system and the transgender community that is grounded in community-based action.

Establishing partnerships can occur through identifying initial leaders within the local community and reaching out to them. Community Advisory Boards or Community Participatory Action Research are powerful ways for institutions to receive feedback, engage in critical reflection, and enable community members to fully participate in their care.

These strategies will help provide the data necessary for a thorough needs-assessment that is necessary to train the workforce and create systems appropriate for the local communities. James et. al documents one formation of a Community Participatory Action Board, tracking its development into a rich resource that was effective in reaching their goals and building trust with the community¹³, and this is consistent with previous research suggesting that



GLOSSARY

The following terms may be used throughout the article and are important concepts in gender-affirming healthcare.

GENDER IDENTITY: One's sense of self as female, male, a blend of both, a third gender, or no gender.

GENDER EXPRESSION: How one presents one's gender to the world; may include expression through behavior, clothing, haircut or voice.

TRANSGENDER: An umbrella term used to describe individuals who have a gender identity different than the sex they were assigned at birth. May include individuals who identify as genderqueer, gender fluid, transsexual, gender nonconforming, or agender.

GENDER NON-CONFORMING: A term describing people who do not conform to societal expectations of how they should express their gender; may also include people who have a gender outside of the gender binary.

GENDER BINARY: A gender system that classifies sex and gender into two distinct and opposite categories of male/female and masculine/feminine.

GENDER-AFFIRMING: Positive attitudes, language, and behaviors that are consistent with someone's authentic gender identity. For example, using greetings, names, and pronouns that validate authentic identified gender as opposed to ignoring or negating it.

GENDER TRANSITION: The individualized process of modifying social gender expression and/or physical secondary sex characteristics to align with authentic gender. May include some, all, or none of the following: change in hairstyle, clothing, name, pronouns; masculinizing or feminizing hormone therapy; gender confirming surgeries.

CULTURAL HUMILITY: When someone is open, self-aware, egoless, supportive, and engaged in ongoing self-critique when dealing with others who are culturally different from themselves.



participatory research is a valuable tool with great potential to address health disparities¹⁴.

Commitment to ongoing re-assessment and sharing knowledge: Finally, building the capacity to care for transgender patients includes continually assessing progress and sharing knowledge to support future directions. As the scientific, political, economic, and cultural climates change along with the needs of the communities, it is essential that professionals be flexible in order to provide the best possible care to our patients.

To accomplish this, we must have systems in place to assure safety and quality improvement, track patient outcomes utilizing both quantitative and qualitative data, and share our data with other professionals and across disciplines.

One way to formally share data is to develop a shared data agreement and database with other practices. Another is to publish results in journals: the advantages to publishing include reaching more providers and having the opportunity to elucidate the framework/theory of our work, which is important in understanding work in the context of multiple viewpoints and

choices. When publishing results, it is again critical to partner with, and give recognition to, community members and leaders.

Recognizing the people in the community who have been invaluable to the work is an important aspect of remaining accountable to, and demonstrating genuine collaboration and respect for, the community.

Through this triad of professional education improvements, community-based action, and ongoing assessment and research base development, we can radically expand the base of gender-affirming healthcare professionals, establish healthier relationships with the transgender community, and achieve widespread excellence in the care of trans patients.

Conclusion

Expanding the base of gender-affirming healthcare providers in the United States must begin with the adoption of cultural humility on the part of providers and educators as the foundational component to providing patient-centered care and building trust within transgender communities.

Each organization or institution may be at a different point in the process; therefore, include ongoing critical and honest assessment of your own needs as you implement structural and curricular change internally, take short-term and long-term community-based action, and commit to ongoing reassessment.

Doing this will ensure a program has taken the essential first steps in transforming transgender healthcare and together we will continue to build institutional and organizational capacity to meet the needs of our transgender patients. **HIV**

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Online Resources for Healthcare Professionals

Practice Guidelines:

- Center of Excellence for Transgender Health Primary Care Protocols
- WPATH Standards of Care Version 7
- Transgender HIV/AIDS Health Services Best Practices Document

Educational Opportunities:

- World Professional Association for Transgender Health (WPATH) Global Education Initiative
- National LGBT Health Education Center Webinars
- Services and Advocacy for GLBT Elders (SAGE) Publications
- AETC National Resource Center
- Callen-Lorde Community Health Center
- Health Professional Advancing LGBT Equality (GLMA) Publications
- National Resource Center on LGBT Aging

Support and Collaboration:

- Transgender Medical Consultation Service (TransLine)
- AAMC MedPORTAL LGBT and DSD Patient Care Collection

Fellow at the University of Wisconsin-Milwaukee College of Nursing PhD program, where she is conducting her dissertation research on access to care for trans youth.



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give feedback.”

inclusive signage
discrimination

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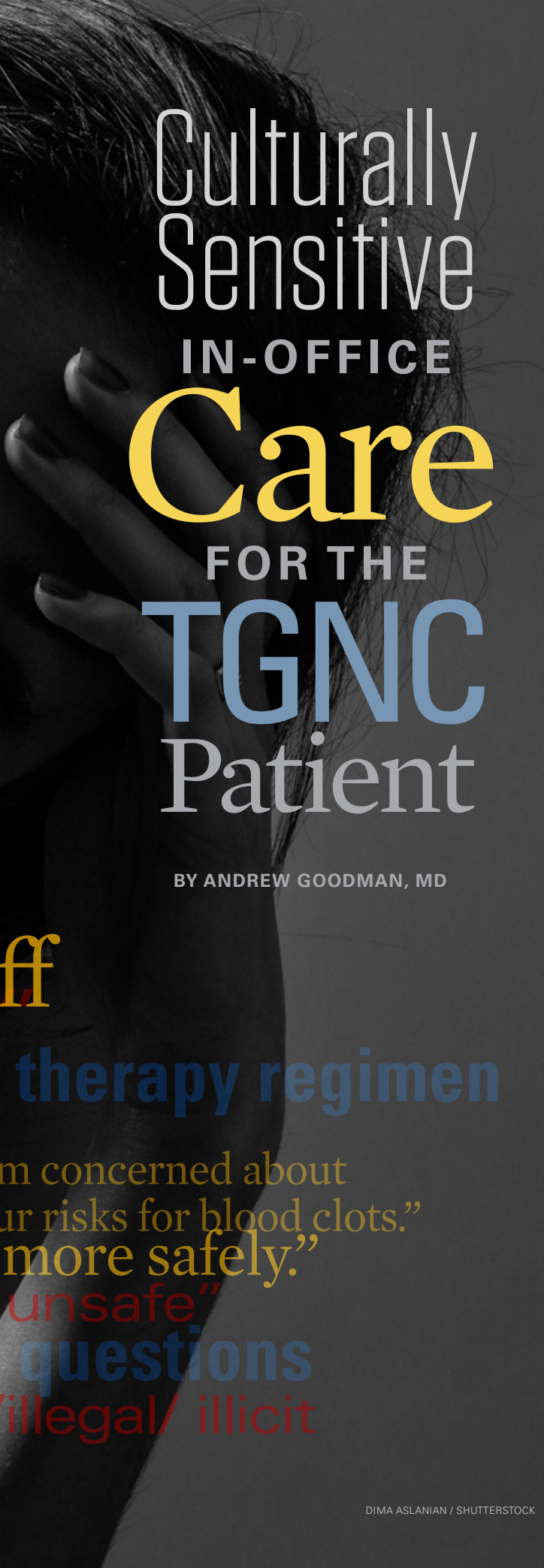
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“I’d like to continue your hormones

“what you’re doing is really

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Culturally Sensitive IN-OFFICE Care FOR THE TGNC Patient

BY ANDREW GOODMAN, MD

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TRANSGENDER AND GENDER NON-CONFORMING (TGNC) people face a unique challenge when accessing medical care. For many, basic expression of identity necessitates accessing feminizing or masculinizing hormone therapy, or surgical care from a system that is untrained and unprepared to offer these services in a sensitive and supportive manner.

A recent survey of a sample of endocrinologists showed that over one-third refused to provide transgender patients hormone care and two-thirds reported no formal training in transgender care¹. TGNC patient care is not part of the curriculum in most U.S. medical schools². Many insurance payors still carry specific exclusions for coverage of hormone therapy or gender-affirming surgeries and fail to cover necessary screenings based on gender (pap testing in transgender men, for instance.)³

Many transgender patients also experience discrimination in health care. A 2010 survey of LGBT people found that 70% of TGNC patients reported experiencing health care professionals refusing to touch them or using excessive precautions, using harsh or abusive language, being physically rough or abusive; blaming them for their health status or refusing needed health care. In almost every category in this survey, TGNC respondents reported experiencing the highest rates of discrimination and barriers to care. Caring for TGNC patients may seem intimidating to providers who are inexperienced. Although most primary care and HIV providers do not currently prescribe hormone therapy or perform gender affirming procedures, integrating sensitive and knowledgeable history and physical exam skills is very important in fostering rapport, facilitating trust, and improving patient health outcomes.

History-taking Skills

In obtaining a medical history providers must understand that TGNC patients may *anticipate* discrimination based on prior experiences accessing health care. Providers should communicate in a sensitive and nonjudgmental way, understanding that, although grouped under the same umbrella of TGNC, each patient is unique.

Patients should be given the opportunity to describe their own identity and experiences, rather than providers making assumptions⁵. While many aspects of taking medical history for TGNC patients may be no different than for non-TGNC patients, providers should keep a few areas in mind.

Fostering Rapport

Building rapport with TGNC patients starts well before the patient is in the exam room. Inclusive signage and brochures in the waiting areas, respectful and sensitive staff, and intake forms that include a broad range of sexual orientations and gender identities are all clues that patients may look for to judge a practice's sensitivity.

Additionally, TGNC patients should be invited to identify their preferred name and pronoun when registering. There

are many pronouns that patients may identify with, including masculine, feminine, and gender neutral pronouns. Practices should have systems and training in place so these patients' preferences are documented and used consistently with all staff. Titles, such as Ms., Mrs., or Mr., should be avoided⁵.

Some providers express concern that changing procedures to ask all patients about pronouns and gender identity may offend some cis-gender patients. Staff can be trained to teach patients about why this question is asked: "We ask every patient about their preferred name and pronoun, instead of assuming, to make sure our practice is welcoming and accepting of everyone."

Asking About Hormone Therapy

While many providers may not be directly managing a patient's hormone therapy, it is still important to know details about a patient's regimen to provide comprehensive care. Questions about medications, dosaging, and route of administration, as with any other medication a patient may be taking, are appropriate. There are many guidelines for hormone therapy, dosing and monitoring, that are freely accessible online, including Callen-Lorde's own guidelines⁶.

For many TGNC patients, due to lack of providers or insurance coverage, obtaining hormone therapy from licensed providers who are following accepted care guidelines is not always possible, so obtaining hormones from friends, unlicensed providers, or internet pharmacies may be their only options to the medication they need.

This can result in unnecessary harms for patients from poor quality pharmaceuticals, inappropriate dosages, and unsafe injection techniques⁷. Patients may not readily disclose this due to concerns about stigma. Providers should avoid stigmatizing words, such as "street", "illegal", or "illicit" hormone therapy and ask instead about "non-prescribed" hormone therapy. Patients can be invited to describe their injection technique so the provider can assess for safety.

When assessing progress through hormone therapy, providers should use the patient's own individual treatment goals and appropriate lab monitoring as guides. It is inappropriate for providers to comment on a patient's physical appearance, masculinity or femininity, or body changes. If patients ask providers to comment on their physical appearance, providers should politely redirect the conversation back to the patient's individual treatment goals.

When concerns about a patient's hormone therapy regimen arise, it is important to provide counseling in a sensitive manner. Feedback should be based on medical science or expert opinion, and discussion of risk should recognize that many TGNC patients experience tremendous benefit from hormone therapy.

Statements like "you are going to give yourself a blood clot" or "what you're doing is really unsafe", are inappropriate. "I am concerned about your risks for blood clots" or "I'd like to help you continue your hormones more safely" are much

better phrases to begin conversations with patients. I prefer to ask for permission to give feedback, in order to increase the patient's openness to discussing risk.

Sexual Health History-Taking

As is the case with all patients, taking a sexual health history from TGNC patients is crucial to gaining a comprehensive picture of their health. This may feel intimidating to providers who are unfamiliar with TGNC care.

Gender identity (one's own internal sense of maleness or femaleness) is often confused with sexual orientation (one's identity as it relates to the genders one feels attracted to.) Providers may mistakenly make assumptions about their TGNC patient's sexual orientations, rather than asking. TGNC people include a broad range of sexual orientations, including gay, straight, bisexual, queer, or pansexual (attracted to a broad range of genders.) Some TGNC patients experience difficulty in deciding on a sexual orientation. Although patients should be invited to identify with a sexual orientation that feels most correct, sexual orientation should generally be based on the affirmed, rather than natal, gender of the patient⁵.

When discussing specific body parts, especially genital or chest/breast, many TGNC patients may feel uncomfortable using traditional anatomy words that feel gendered. Many providers have learned to adopt more gender neutral language or to ask patients which words they are comfortable with using. Gender neutral language is also useful when discussing screenings, such as pap testing⁸.

Providers may also mistakenly assume that TGNC patients are not at risk for sexually transmitted infections or pregnancy. As with all patients, providers should collect information on sexual health and offer appropriate supportive counseling, screenings, and treatment in a non-judgmental manner. Providers should use open-ended questions to start a conversation, such as "What questions do you have about your sexual health?" or "What do you think about your risk for STI's (or pregnancy)?"

Asking About Surgeries

Medically necessary gender affirming surgeries are pursued by many, but not all TGNC patients. Sometimes this is due to financial or insurance barriers. TGNC patients experience varying degrees of dysphoria with their bodies, and some do not desire surgery or only certain surgeries. Providers should approach asking patients about surgery without assuming a patient's desire to undergo surgery.

Due to these financial and insurance barriers, many patients choose to pursue medically necessary surgeries from unlicensed or inexperienced providers. Trans-feminine patients may have had silicone injections, for instance, from friends or other unlicensed providers, using unsafe injection practices or non-medical silicone⁹. Patients may not know what anatomic structures were removed during surgery⁸,



may not have been appropriately counseled on post-operative care, and may experience poor surgical outcomes. Providers should recognize that TGNC patients sometimes accept or are uninformed of increased risk in pursuing medically necessary procedures, and discuss this with patients sensitively and supportively.

“Top surgery” is the most common gender affirming surgery, and may include removal of breast tissue, chest reconstruction, or breast augmentation. “Lower surgery” may include hysterectomy and or oophorectomy, orchiectomy, or various genital reconstructive surgeries. As genital reconstructive surgeries involve complex surgeries with specific cosmetic, urologic, and sexual health outcomes, these procedures should only be performed by experienced surgeons^{8,10}.

Sensitivity During Physical Examination

Due to traumatic and stigmatizing experiences that many TGNC patients have had with medical providers, many may have boundaries with physical examination. This may be especially true with chest/breast, anal, and genital examinations. In general, providers should only examine these areas when absolutely necessary and assess a patient’s comfort with doing so before proceeding. If patients indicate discomfort with examination, providers should respect those boundaries and not withhold medical necessary treatment as a consequence. Providers should maximize opportunities for patients to maintain control, especially during sensitive examinations⁸.

Although use of medical staff as chaperones during sensitive exams may be a standard practice, many TGNC patients may not be comfortable with chaperones, experiencing this as voyeuristic. TGNC patients may wish to have friends or other support people present during sensitive exams. Some patients may also have specific requests during their exam, such as undressing only from the waist below. Providers should respect these requests as much as possible. Similar to history-taking, providers should also avoid the use of gendered language during examination or when describing physical exam findings to a patient⁸.

While office visits with a TGNC patient may become focused on support and care needs for a patient’s gender identity, providers should consider the patient’s general health needs. Providers should monitor their patient’s psychosocial well-being, perform routine health screenings, and manage

chronic conditions that may emerge¹¹. Although office visits and examinations can be intimidating for TGNC patients, skilled providers providing sensitive and appropriate care can help to restore patient trust in medical care and improve patient health outcomes. **HIV**

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Influence of Integrated Transgender Healthcare on ART Adherence and Outcomes

BE A HEALER [not simply a clinician]

BY STEVEN R. KLEMOW, MD

THE BURDEN OF HIV INFECTION in the transgender population is significant, particularly among transgender women. The most recent 2015 World Health Organization (WHO) Technical Brief on Transgender People and HIV reported an estimated prevalence of 19%, based on meta-analyses accrued from pooled data of transgender women in 15 countries with laboratory-confirmed data.

The accuracy of these estimates is of course confounded by many factors, including potential reluctance of transgender individuals to seek testing and treatment, lack of identification documents and EMR systems that account for non-binary or patient-reported gender definitions, and the mercurial nature of how individuals self-report in matters pertaining to gender identity in healthcare settings. Isolated populations who have historically been excluded from traditional societal definitions are elusive targets for study.

The factors driving this crisis are equally complex, but seem to share a similar theme of isolation, lack of access to resources, and a struggle for acceptance or validation. Employment discrimination, lack of legal protections, exclusion from healthcare resources and gender-affirming care, homelessness, substance abuse, subsistence sex work and subsequent incarceration all contribute to increased risk of high-risk behavior.

Many transgender women who have sex with men have high risk partners, or may eschew condom use in an effort to achieve validation of their gender identity, or to avoid rejection. In the United States, we still offer few sanctuaries where transgender individuals can feel safe, and many healthcare settings unfortunately

remain particularly daunting to this population. Given the crucial link between adherence and outcomes in the HIV positive population, what measures can we take as providers to encourage transgender persons living with HIV to engage and remain in care?

Encouraging adherence

Several studies have demonstrated that transgender women living with HIV are less likely to adhere to antiretroviral therapy, compared to their cisgender counterparts (Mizuno, Frazier, Huang, & Skarbinski, 2015; Sevelius, Carrico, & Johnson, 2010).

The reasons postulated for this are multifactorial and complex, and in many ways mirror those obstacles identified for all people living with HIV. These include low levels of social support, younger age, depression, financial obstacles, perceived medication side effects, substance use, and low adherence self-efficacy. However, for transgender individuals, adherence may be complicated by additional factors, such as poor provider engagement and trust, previous negative experiences in healthcare settings, and the lack of integration of their transgender health into their primary care.



Previous population-based surveys have suggested that transgender individuals may prioritize hormonal therapy and other transition-related interventions over other aspects of their health, including HIV care and pharmacotherapy (Kammerer, Mason, Conners & Durkee, 2001).

This priority is understandable in the context of self-reported improvements in quality of life, psychological well-being, and self-confidence when transgender individuals achieve gender congruency and integrity, often via hormonal therapy (Murad, 2010). Although prescription hormonal therapy is not costly (for transgender women, standard regimens such

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as estradiol, spironolactone, and finasteride are available via \$4 generic programs at commercial pharmacies), lack of access to providers willing to provide transgender care often forces these individuals to obtain agents at considerable cost via street markets without medical supervision or guidance.

A 2010 study of 314 transwomen in San Francisco found that 49.1% reported taking hormones not prescribed by a clinician (de Haan, Santos, Arayasirikul, and Raymond 2015). As a consequence, this relatively routine and safe intervention often becomes an emotionally-consuming ordeal, fraught with potential complications, both medical and psychosocial. Since there is consensus agreement that patients living with HIV are well-served by receiving both HIV and primary care from an integrated resource, it is logical to surmise that transgender health should be integrated into HIV management as well, since non-surgical transgender management is a primary care issue.

The New York State Department of Health AIDS Institute Guidelines for the Care of the HIV-Infected Transgender Patient recommend that clinicians providing services to HIV-infected transgender patients should integrate transgender treatment recommendations and standards of care into their practice. This recommendation is in part informed by evidence that ART adherence has been found to correlate with positive gender affirmation and adherence to hormones (Sevelius, Saberi, & Johnson, 2014). Additionally, informed consent models for transgender health are well-established, and have greatly simplified the process of managing hormonal therapy on practical and medicolegal terms.

Although cultural incompetence has been ascribed to the historical reluctance of many HIV clinicians to adopt transgender management into their practice, some have hesitated to pursue hormonal therapy due to concerns of inadequate expertise or time. However, the management of hormonal therapy in transgender individuals living with HIV is neither time-consuming nor complex, particularly with the advent of published algorithms.

Also, the emergence of newer antiretroviral regimens that portend significantly less drug interactions with feminizing agents has greatly ameliorated concerns of polypharmacy. For transgender men, androgen-based therapies are exceptionally straightforward and have no meaningful ART interactions at all.

Although previous studies have suggested that compared to cisgender women living with HIV, transwomen are less likely to receive ART (Melendez, 2005), and are less likely to be adherent (Sevelius, 2010), there is some evidence that these disparities may be improving.

In a ten-year retrospective analysis conducted in 2013 by the University of Pennsylvania, which evaluated 37,000 patients being treated for HIV among 13 clinics participating in the HIV Research Network, the percentages of transwomen who were retained in care, received ART, and achieved virological suppression were roughly equal to men (80 percent, 76 percent, and 68 percent vs. 81 percent, 77 percent and 69 percent respectively) (Yehia, 2013).

Provider affirmation essential

Some progress may be explainable by general advances in HIV therapy and management, and an increased focus on overall LGBT health over the last decade. However, it is reasonable to postulate that heightened transgender activism and a paradigm shift in emphasis on cultural competency may be having a positive effect. Based on focus groups and surveys of transwomen conducted by the Tom Waddell Health Center and the Center for AIDS Prevention Studies Department of Medicine at UCSF, it is clear that transgender persons clearly associate gender affirmation from their healthcare resources with their likelihood of engaging and remaining in care. (Sevelius 2014).

As providers of HIV care, we are in a position to set an example for transgender-inclusive care, and changes must occur at all stages of patient engagement and interaction. In a population who has experienced such trauma and rejection, rapport and trust may be thwarted at the earliest steps in intervention.

In my experience working for many years at a large Ryan White-funded HIV clinic, I observed many patients identifying themselves as cis-gender during intake interviews, only to report otherwise once they had assessed their sense of safety during their encounters with providers. Many transgender women (we saw few transgender men) presented for their initial

If we are to identify ourselves as healers, not simply clinicians, it is incumbent on us to provide one place where these human beings will unequivocally be safe, respected, and heard.

encounters dressed in masculine attire, and remained closeted about their gender identity for several visits. Admittedly, this was at a county hospital setting, where patients were mainly underinsured and seeking subsidized healthcare—but it was clearly an LGBTQ-friendly environment, completely devoted to HIV care, and there was still a palpable fear of rejection.

There also remains a tendency to apply our own definitions of cultural competency. Gender-affirming care must account for individuals who don't conform to traditional binary definitions, and generalizations cannot be made regarding what "community" with whom these individuals align.

Among at least 50 transgender individuals for whom I provided combined HIV and transgender primary care over a decade, the majority had few to no transgender friends, and many reported minimal participation in LGBTQ circles. Even with the implementation of transgender-inclusive protocols, many members of staff still deferred to the LGBTQ community as a preferred haven for these women, despite sexual orientation and gender identity being distinct entities, united predominantly in activist terms, sequestered together as demographic groups perhaps only due to shared ostracism.

For some of these women, affiliation with the LGBTQ community came at the cost of discretion, and many I encountered were in pursuit of a means to be, and to live life as, women—not as transgender women. Some preferred not to identify with any gender at all. Every assumption I made afforded a new lesson in stereotypes and humility, and it quickly became apparent that the appropriate strategy was to eschew all definitions and simply mirror the language they used to describe themselves.

Arguably, the unifying factor leading to the elusiveness of this community to healthcare providers and advocates is a misconception that they are in fact a community, as opposed to a population of discrete individuals, with unique identities, who in the absence of gender-affirming treatment or care often live in isolation—driven by fear of being singled out, shunned, abused, or abandoned.

If we are to identify ourselves as healers, not simply clinicians, it is incumbent on us to provide one place where these human beings will unequivocally be safe, respected, and heard. And if we can relieve our patients from the chaotic ordeal of trying to manage their transgender health on their own, we may make room for them to focus on their HIV care, which we know is essential for survival.

I posed this question to Nell Gaither of the Transpride Initiative in Dallas, who has been a leader in obtaining healthcare resources for trans persons in our community, and she perhaps summarized what we can accomplish most eloquently:


"I think part of the phenomenon of better HIV medication adherence once transgender patients are relieved of the chaos of managing their own hormonal therapy is, that maybe for the first time in their lives, their identity is being respected. When someone else values them and validates their lives, they begin valuing their own lives as well. For so many trans persons, all we ever hear is that our most core sense of identity, our most fundamental concept about who we are, is illegitimate, is a fabrication, is a lie. Often that comes, directly or indirectly, just from standard cis-normative assumptions and interactions, from healthcare professionals basing identity on biology. So when a person who historically represents the most likely source of undermining our identity instead validates and even celebrates our identity, it's powerful. It changes lives. Or maybe you could say in a way it gives new life." **HIV**

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**PrEP as a
viable option
for HIV
incidence
reduction
among
transgender
women**

Transgender Women **& PrEP**

BY ELENA CYRUS and ASA RADIX, MD

TRANSGENDER WOMEN continue to be at the forefront of the HIV epidemic in the U.S. and globally. Pre exposure prophylaxis therapy (PrEP) is a biomedical treatment that can curtail the spread of HIV in at-risk populations. However, PrEP awareness and uptake have not reached levels needed to impact the concentrated epidemic among transgender women. This article briefly overviews PrEP for transgender women, examining potential barriers and providing recommendations for future research and programmatic efforts.

Transgender women who have sex with men are at increased risk for HIV transmission, surpassing odds of seroconversion among cis-gender, high-risk heterosexuals, and other sexual and gender minorities (e.g., men who have sex with men, transgender men, or transgender women who have sex with women).¹⁻³

Pre exposure prophylaxis (PrEP), a biomedical therapy that combines the antiretroviral medications emtricitabine and tenofovir (Truvada®) received approval by the U.S. Food and Drug Administration (FDA) in 2012 for HIV prevention among high-risk heterosexual individuals and men who have sex with men (MSM). Despite the known efficacy of PrEP and potential impact on HIV incidence reduction, there has not been wide-spread acceptance as expected⁴.

A recent study demonstrated MSM and transgender women were willing to engage in PrEP therapy once they became aware of the drug as an option, suggesting that low PrEP uptake may be associated with low knowledge and self-efficacy.

In the extension phase of the landmark iPrEX efficacy study for Truvada®, researchers found no significant difference between MSM and transgender women in opting to initiate PrEP therapy once they were aware of that option. Thus, it's natural to ask why aren't more high-risk transgender women in our communities using PrEP?

Epidemiology

There is limited surveillance data on HIV among transgender women. Data for transgender women often are conflated with data for cis-gender men who have sex with men, and existing studies have been conducted with populations outside of the U.S. or non-ethnic or racial minorities⁵. The studies that do focus on transgender women have consistently demonstrated that HIV prevalence is higher for transgender women, and by extension the risk of acquisition also is greater.

There is no reliable denominator to accurately estimate the prevalence of HIV among transgender women in the U.S. While estimates of the transgender population (men and women) in the U.S. range between .3%–1%^{6,7}, reliable population level statistics for transgender women are not readily available.

Reasons for the lack of data are multifaceted, including non-self-identification as transgender for fear of harassment or discrimination, inappropriate methodology to capture changing gender status of individuals in census data, un-standardized research instruments and methodology for the transgender population, and limited funding for studies focusing specifically on transgender populations^{5,8}.

Policy differences across the states can also influence transgender women's risks, as some states prohibit discrimination

and provide more legal protection for transgender populations than others⁹.

For example, in states where the Medicaid extension under the Affordable Care Act (ACA) has not been accepted, transgender women with an SES between the cut offs for Medicaid and ACA may fall into the insurance gap, rendering them ineligible for either type of insurance coverage¹⁰.

Policies of this type enforce institutionalized discrimination against transgender women and other underserved populations, increasing their vulnerability. One sequelae of this social isolation, discrimination, and prejudice is the engagement of transgender women in commercial sex work for economic survival. Commercial sex work alone is high-risk, but has compounded risk as it is also linked with more substance use, multiple sexual partners, and unprotected sexual acts¹¹⁻²².

PrEP efficacy among transgender women

PrEP therapy has the potential to curtail the concentrated epidemic of HIV in high-risk populations, but certain conditions must be satisfied to ensure efficacy.

For example, routine HIV testing is integral to achieving lower incidence in at-risk populations. High-risk individuals who are routinely screened and are aware of their HIV status diminish the risk of transmission to uninfected people, and, help inform medical providers on appropriate courses of treatment.

In 2013, the largest percentage of new HIV infections was among transgender women²³. Meta-analysis studies estimated HIV prevalence among transgender women to be between 22%–28%, but in one study, only 12% of transgender women self-reported their positive HIV status, suggesting that 10%–16% were unaware of their status²³.

Transgender women face exacerbated experiences of discrimination, social isolation, and stigma, which may manifest into acute negative mental health outcomes such as depression and anxiety.

Adherence to PrEP is essential to reduce the odds of HIV seroconversion. Without adherence to the drug regimen, effective drug concentration will not be achieved and the protective effect against HIV transmission will not occur. Adherence has been shown to be higher in those who are older and, among those with a self-perception of being high-risk. However, this does not hold for transgender women, who were found, overall, to be more non-adherent than MSM in the iPrEX study, regardless of demographic factors or social context.

Depression, other mental health co-morbidities, and substance use have been examined as mechanisms for non-adherence among transgender women and MSM. Substance use can be used as a coping mechanism for the social stress transgender women constantly experience^{2,5,7,11,12,15,19,21,24-50}, but

investigations on additional specific risk factors for non-adherence among transgender women are lacking.

Compared to MSM, transgender women face exacerbated experiences of discrimination, social isolation, and stigma, which may manifest into acute negative mental health outcomes such as depression and anxiety. Results from the open label extension of the iPrEX study showed depressive symptoms were linked to non-adherence, but compared to MSM with mild to moderate depressive symptoms, transgender women with mild to moderate depressive symptoms had higher odds of non-adherence³⁰, further highlighting the difference in risk factors for these two groups and the need for them to be investigated separately.

Barriers to PrEP

There are social and structural barriers transgender women encounter that can reduce their likelihood of electing to use PrEP. These barriers, which limit access to primary care, PrEP or, other medical services, include transgender women's distrust of the medical community, perceived discrimination from the medical community, lack of financial resources, prioritization of hormone therapy, being un-insured, and lack of trans-competent providers.⁵¹⁻⁵⁷

For a population already struggling to access basic medical services, PrEP may not be a priority. In the past seven years since the drugs for PrEP have been on the market, the cost has increased from \$700–\$800 to \$1300–\$1500 per month^{58,59}. When deliberating whether to use PrEP within their limited financial resources, transgender women may consider seeking basic care or gender affirming services that can boost confidence and improve perceptions of self-efficacy to be more important⁵⁴.

Integrated medical services may be one cost-effective option to alleviate the struggle of competing medical services for transgender women^{60,61}. By providing integrated services whereby psychosocial, preventive care, and gender specific services are offered in one clinical setting, transgender women may be better equipped to receive all or more of the services they need to improve their personal agency, and reduce their risk. Additionally, initiating PrEP may be an opportunity to engage and retain transgender women in routine care⁶².

Medical providers should, at a minimum, ensure that transgender patients are cared for in a way that respects their gender identity and expression as well as addresses privacy and confidentiality concerns. For example, providers can make an effort to adhere to the convention of medical consultations being conducted in private spaces, allowing transgender women to speak freely about their sexual history without fear of confidentiality being compromised. This may encourage transgender women to seek care, an integral initial step in the PrEP continuum.

Marketing of PrEP across the U.S. has not been adequately transgender inclusive, and alternative bio-medical strategies



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such as use of antiretrovirals for post-exposure prophylaxis (PEP) are more accepted⁶³.

Transgender women may be aware of PrEP as an option for risk reduction, but they have not necessarily accepted the therapy as a viable option for them, nor are they receiving all of the information they need to help make that decision.

Concerns transgender women may have include possible or unknown long-term side effects of PrEP and negative interactions of PrEP with concurrent medications. Trans-specific side effects have not been determined, but to date, no negative interactions with hormone therapy has been observed, although the body of evidence on this subject is scant³⁴.

If PrEP is to become more widely accepted and used, promotion of PrEP among transgender women must be based

on scientific evidence conducted in their population¹⁴ and the information should be publicly accessible.

Conclusion

Advances made with PrEP are encouraging, but at this juncture, rigorous research and action items are necessary to address current gaps in knowledge that may prevent transgender women from using the promising preventive therapy. Some recommendations to address these gaps are:

- More funding and research dedicated to the investigation of efficacy, effectiveness, and acceptability of PrEP among more representative samples of ethnic and racial minority transgender women;
- Validation of transgender specific evidence based interventions that can facilitate more wide-spread dissemination and implementation of PrEP;
- Further investigation on reasons for non-adherence, interactions with concurrent therapy, and side effects (short and long term);
- Education and public health programs to aid in reducing social stigma and discrimination within communities, and among medical providers;
- Collaboration with researchers, providers and community members to implement cost-effective but impactful transgender clinical and behavioral programs.

The concentrated HIV epidemic among transgender women may seem unrelated to the general population, but implications may be more far reaching than what is apparent. Data reflect an increase, over time, of individuals in the U.S. who identify as having some type of gender dysphoria⁶, and the overlapping social and sexual networks among cis-gender and transgender individuals⁶⁴ indicate a public health issue important for transgender women and their communities.

HIV

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TRANSGENDER Hormone Therapy

Practical
guidelines for
the HIV care
provider

BY MEERA SHAH, MD, MS
and ASA RADIX, MD, MPH

A COMMON CLINICAL SCENARIO: a 25 year-old HIV positive trans-female, virally suppressed on dolutegravir/abacavir/lamivudine, presents to establish care and desires hormone therapy. How would you approach this patient?

It has becoming increasingly more known that transgender people, particularly transgender women, are among the groups most affected by HIV and it is for this reason that HIV care providers should integrate transgender care into their scope of practice.

There are several reasons why trans-identifying patients are at higher risk for HIV and while this is a complicated issue that stems from discrimination and stigma, these reasons include:

- Exchanging sex for money, high-risk sex (condomless sex, anal sex)¹
- Sharing needles to inject hormones and silicone²
- Gender-based violence³.

It is important for HIV care providers to understand these risk factors in order to improve screening for HIV and to prevent transmission of HIV.

Unfortunately, many HIV positive transgender women do not seek care out of fear

of being shamed for their gender identity or because of cost and therefore obtain hormones and procedures through oftentimes unsafe methods. It is important for clinicians to understand that HIV may not be the transgender patient's priority, so addressing their psychosocial and transgender-specific health needs can often times improve linkage and retention to care.⁴

Transgender hormone therapy is the process of administering masculinizing or feminizing hormones for individuals who

The first step in addressing this 25 year-old patient's needs is determining her past use of hormones and surgical history and what she is hoping for in her transition.

desire a transition or change from their sex assigned at birth.

The first step in addressing this 25 year-old patient's needs is determining her past use of hormones and surgical history and what she is hoping for in her transition. While some individuals desire maximum feminization or masculinization from hormone therapy, others want to relieve or minimize some of their secondary characteristics in order to achieve a more androgynous presentation.

The next step would be to take a thorough medical and social history and physical exam. Certain medical conditions, such as breast cancer and active venous thromboembolism can be contraindications to hormone use or may require that the patient use a lower dose or alternate route of hormone. Hormone therapy can be administered safely in the setting of antiretroviral therapy for HIV positive trans-women with little concern for adverse outcomes due to drug-drug interactions.⁵

Smoking is common among the transgender population, with some data showing up to 30%, so evaluation for tobacco use as well as smoking cessation counseling should be incorporated into the patient's visits given the risks associated with hormone use.⁶

The initiation or maintenance of hormones should always include a risk/benefit discussion with the patient. Many protocols require a consent form to be reviewed and signed between the provider and patient.

While guidelines and protocols exist to help guide hormone management, a patient's specific preferences and goals must be taken into consideration. For example, our patient might desire the feminizing effects of estrogen, but want to maintain erectile function and therefore not want to take an androgen blocker. Also, if she has undergone orchiectomy, she will not need androgen blockade and may require lower doses of estrogen.

A discussion about fertility should be held early on with this patient. While sperm-banking is best to do prior to initiating hormones, many transgender women have had

successful sperm-banking and sperm-washing once hormones have been discontinued.^{7,8} Expectations of changes to one's body should be addressed and managed early on and patients should be reassured that the transition process is slow—up to two years and sometimes longer. Some of these changes are not fully reversible, others are and it is difficult to predict the reversibility.

Initiating hormone therapy

There are several organizations that have outlined recommendations for hormone therapy for transgender or gender non-confirming individuals. The Endocrine Society and The World Professional Association for Transgender Health have protocols for hormone management that are widely used,^{7,9} however many individual organizations also have created their own protocols. Also, practices for hormone therapy vary from provider to provider and are tailored based on a patient's individual need.

Estrogen

Estrogen can be given in several forms: estradiol tablets, patches or injections. Estradiol patches may be preferred in certain circumstances such as age over 45, history of venous thromboembolic disease or cardiovascular risk/disease based on evidence from postmenopausal non-transgender women.^{10,11}

Estrogens are metabolized by cytochrome P450 enzymes in the liver¹² as are protease inhibitors and non-nucleotide reductase inhibitors. Ritonavir and cobicistat are used in combination with some antiretroviral agents as "boosters" to increase their efficacy. Both are potent inhibitors of cytochrome P450 enzymes and can have interactions with estrogen.

Boosted protease inhibitors tend to reduce estradiol levels and dose adjustments may need to be made when co-administered with estrogens. Non-nucleoside reverse transcriptase inhibitors may also affect estradiol levels. In both instances the medical provider should obtain estradiol levels to allow for appropriate titration of estrogen dose. Nucleoside reductase inhibitors do not affect cytochrome P450 enzymes, and are therefore unlikely to have a drug interaction with estrogen.^{13,14} For this reason, pre-exposure prophylaxis, or emtricitabine-tenofovir disoproxil is safe to use with estrogen. Integrase inhibitors and entry inhibitors have no known significant drug-drug interactions with estrogen.

Anti-androgen

Oral anti-androgens can come in the form of an androgen blocker (spironolactone) or dihydrotestosterone (finasteride) blockers. They are used in conjunction with estrogen as part of the feminizing regimen for transgender women. There are no significant interactions between spironolactone or finasteride and antiretroviral medications.

Effects of feminizing hormones

| Effect | Onset (months) |
|--|----------------|
| fewer erections, difficulty having and maintaining an erection | 1-3 |
| decreased ability to make sperm or ejaculatory fluid | Unknown |
| slower growth of facial hair | 3-6 |
| nipple and breast growth | 3-6 |
| softening of skin | 3-6 |
| decrease in muscle mass and increase in body fat | 3-6 |
| decreased testicular size | 3-6 |

Adverse effects/risks of feminizing hormones

| |
|---|
| increased risk of venous thromboembolism |
| increase risk of stroke |
| increase risk of heart disease |
| liver toxicity |
| increase risk of gallstones |
| increase blood pressure (can be offset by the addition of spironolactone, which is also an antihypertensive) |
| breast cancer is rare in transgender females, but patients should be evaluated for risk of estrogen-dependent cancers |
| elevated potassium if on spironolactone |
| increase in prolactin and/or prolactin-secreting tumor |

Monitoring and titrating hormone therapy

Our patient has no other medical or surgical history besides HIV and is virally suppressed on dolutegravir/abacavir/lamivudine. She was initiated on biweekly delestrogen injections and low dose spironolactone for androgen-blockade. Follow up visits include monitoring of liver and kidney function, prolactin levels, serum potassium, and blood pressure.

It is important to periodically monitor the patient for satisfaction with her transition and evaluate for adverse side effects. Mid-cycle estradiol levels can be checked if there is concern for toxicity or non-therapeutic dose. A testosterone level can be checked in order to titrate dosage of spironolactone (with close attention to blood pressure and potassium level) until testosterone is suppressed. If she desires orchiectomy or vaginoplasty, androgen-blockade should be discontinued and low-dose estrogen started after the surgery.

HIV

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Benefits of Ongoing Small Talks About Partner Services in HIV Care

OVER 30 YEARS INTO THE EPIDEMIC, HIV stigma remains very prevalent. Fearing stigma and discrimination, people living with HIV may be reluctant to notify their partners of their possible exposure to HIV or other sexually transmitted infections (STI).

As HIV care providers, we often see HIV-infected patients uncomfortable revealing their status despite understanding the importance. Whether immediately after diagnosis or years later, our assistance in helping patients to learn techniques to disclose their status is essential and should be tailored to meet the needs of each patient; some will choose to do this on their own, while others may use Partner Services.

Partner Services is a valuable resource through which health department staff can contact reported sexual or drug-injection partners of potential exposures in a confidential, anonymous manner; offer on-site testing and counseling; and provide linkage to care and treatment and other services at a location convenient to the potentially exposed person. Following are two instances in which I discussed Partner Services with some of my patients and how they benefitted my patients and their partners.

Assisting a patient who develops an STI

Mario is a bisexual African-American man in his mid-20s who has been diagnosed with HIV infection for about five years. For the first two years after his diagnosis, Mario did not inform anyone of his HIV status and refused to share any names with the Disease Intervention Specialist from the state-run Partner Services when he was contacted for partner tracing. Mario is excellent about his adherence to his single-tablet antiretroviral therapy (ART) regimen and has had an undetectable viral load for at least three years. He has been in a relationship for about two years with another man who was HIV-negative and they are “mostly monogamous.”

One day I received a call from Mario that he had developed a few non-painful sores on his penis, and he was concerned. When he showed up, we began a discussion about his recent sexual activities. I routinely inquire with all patients about the number of sexual partners for “any activity beyond kissing” since their last visit. Previously Mario stated that he was only with this partner for male-to-male activity, but occasionally would have protected vaginal sex with a few female friends. At this visit, he stated that he had gone to a bar in New Orleans about two to three weeks prior and allowed a man to give

him oral sex in the bathroom. He denied any fever, dysuria, penile discharge, joint aches, or rashes that he had noticed.

Upon examination, I found Mario had multiple abnormalities: three annular lesions on his tongue mucosa, three painless ulcerations on his penile shaft about 1 cm across with raised borders, and two verrucous small masses in his perirectal region. He also had a few hyper-pigmented lesions on his palms, but no lesions on his soles. No discharge was elicited during examination of his penis.

I explained to Mario that it appeared that he likely had simultaneous primary and secondary syphilis. He had a negative rapid plasma regain (RPR) test about five months prior to this visit (with screening done annually). I explained that occasionally in HIV-infected patients, primary syphilis—as evidenced by the penile ulcerations—and secondary syphilis—as evidenced by the palmar and tongue lesions and the condyloma lata near his anus—can occur simultaneously.

I also informed him that primary syphilis can present with multiple chancres in HIV-infected patients. Mario said he only had protected vaginal sex with women outside his relationship and that his partner was always the insertive partner in anal sex, thus they don’t always use condoms. I explained to Mario that syphilis can also be transmitted via oral sex, either from his brief encounter with the man from the bar, any of his female partners, or possibly from his male partner, if any of them were infected.

We discussed the importance of partner notification when a suspected or confirmed STD is diagnosed. We talked about the very high incidence of gonorrhea, chlamydia, and syphilis in our state and the association of HIV transmission with the presence of another STI.

Since Mario was uneasy about telling his partner himself, we discussed two other options: (1) using Partner Services to anonymously inform his partner about a possible syphilis exposure and provider testing or (2) enlisting my assistance to help Mario inform his partner in a controlled environment, such as our medical clinic. Mario said he felt comfortable with us working together to inform his partner of his recent syphilis diagnosis and to allow his partner to then ask questions.

I gave Mario a single dose of Bicillin L-A for his syphilis, sent off an RPR. I also tested Mario for gonorrhea of the throat, urethra, and rectum. I told Mario that I would like to see him again in one week to assess response to therapy and invited him to bring his partner along to his appointment, offering to assist Mario with informing his partner of his syphilis diagnosis at that visit.

I urged Mario to use condoms for any sexual activity until we had a chance to inform his partner and treat his partner for syphilis exposure. I encouraged Mario to inform any of his casual sexual partners of his diagnosis if he had their contact information and reminded Mario about Partner Services, available through the state's health department, if he felt uncomfortable revealing the information himself to his casual partners. Mario said he would talk with Partner Services when they contacted him this time.

Mario and his partner returned one week later. All the skin and perianal lesions had resolved. I informed Mario with his partner present of the positive RPR titer of 1:256 and negative screening for gonorrhea and chlamydial infection. I offered to test the partner for syphilis and HIV at this visit and gave him a single dose of Bicillin L-A while awaiting his test results.

Mario's partner wanted to know where the infection came from, and we discussed the ways syphilis can be transmitted. This also opened up a discussion about the low, but present, risk of HIV transmission when having unprotected insertive anal sex with someone with a fully suppressed viral load. We also discussed the increased risk of HIV transmission when another STI is present.

Although a tense situation, this occurrence of an STI created a perfect opportunity to open a dialogue between the couple about boundaries and allowed me to have a more detailed discussion about safer sex with my patient and his partner. It also created a provider relationship with the partner and brought him into care. We discussed the possibility of PrEP, but Mario's partner wanted to consider this more before starting. Mario appeared to come away from the experience with a better understanding of what constitutes safer sex and the levels of risk of different behaviors.

Partner Services especially useful with new HIV diagnosis

Jennifer is an 18 year-old Caucasian woman who presented to the clinic with complaints of a thick vaginal discharge. She reported that she was sexually active in a monogamous relationship with her boyfriend of the past two months and that they don't use condoms. She had been in five monogamous relationships sequentially over the preceding two years since she had become sexually active. Jennifer noted that she had been in good health except for a "flu" she had about four months previously.

On exam, Jennifer was noted to have a vaginal yeast infection. Since she was sexually active, Jennifer was offered both rapid HIV testing and syphilis testing. Her syphilis test was negative, but her rapid HIV test was positive. Another rapid HIV test, of a different brand than the first, was also positive, and the patient was informed of the results.

Jennifer began crying, stating repeatedly, "I can't have AIDS." I explained to Jennifer that the tests done so far only indicated that she was infected

Benefits of Using Partner Services for HIV Care Providers:

- Helps relieve your workload by offering a free resource to help your patients notify their sex and drug-injection partners of their possible exposure to an infectious disease.
- Presents an opportunity for you to identify unsafe transmission behaviors and discuss how to reduce those behaviors with your patients
- Leverages your relationship with patients and maximizes that trust to help stop the spread of HIV and STIs.

Benefits of Using Partner Services for Your Patients and their Partners:

- Informs your patient's sexual partner(s) of their exposure to HIV or STIs, while protecting confidentiality and removing the burden of disclosure from your patient.
- Ensures that adequate time is spent coaching your patient on how to inform his or her partners about their exposure, if the patient chooses to self-disclose.
- Helps partners get tested quickly and links exposed partners to care and treatment
- Provides a free resource for your patient and partners and access education and counseling about how to live successfully with HIV.

Partner Services and other Resources:

- To locate a comprehensive risk counseling service program in your area, find your local health department at: <http://www.healthfinder.gov>Organizations>State Agencies>
- For CDC Partner Services Recommendations and Guidelines go to: <http://www.cdc.gov/hiv/prevention/programs/pwp/partnerservices.html>
- Order CDC's New CDC *Prevention IS Care* Resource Kit—This recently updated suite of materials was developed to assist providers with integrating prevention into care for their patients with HIV, including provider and patient brochures on Partner Services and a handy provider referral reference tool. To obtain free kits for your practice, go to: <http://www.cdc.gov/actagainstaids/campaigns/pic/materials/index.html>

with HIV and that, since she had only been sexually active for two years, it was very unlikely that she had progressed to having AIDS. We discussed that with the quality and simplicity of the current HIV therapies, Jennifer would likely be able to live a normal life span, but it was very important that she stay in care and take care of herself. Jennifer appeared to be feeling better about the diagnosis by the end of the visit.

Our Agency has funding for a Patient Navigator, who is able to meet with newly HIV-diagnosed patients and assist with their navigation of our health care system to improve their retention in care. Intake labs were obtained, and Jennifer was able to meet up with our Patient Navigator.

When Jennifer returned one week later to review her lab results, she was more composed. She had met twice with the Patient Navigator to get some "HIV 101" teaching and seemed to accept her diagnosis. The Patient Navigator, during one visit, brought up the importance of notifying Jennifer's previous sexual partners of their potential exposure to HIV and the need for the person who infected her to know of his status. Jennifer had not yet told anyone of her diagnosis, including her current boyfriend or any family members. I discussed with Jennifer the ways in which HIV is transmitted and the concern that the man who infected her may be unaware of his diagnosis and may be infecting other women in the community.

Jennifer was very leery about telling her sexual partners about her HIV diagnosis. We discussed the various options for disclosure for future partners and for previous contacts. Jennifer decided she wanted to inform her current boyfriend herself, but was very interested in the use of Partner Services to notify previous sexual partners. Her main concern was that disclosure of her own status would lead to the information getting out to her community.

I informed Jennifer that Partner Services requests contact information for previous and current sexual partners, but

never discloses the identity of the person who gave their name. I stressed to her that the Partner Services personnel contact the partners listed, inform them that they have been reported as having a possible HIV exposure at some time in their past, and offer on-the-spot rapid testing if the contact is interested. No details are ever given about the person who provides their name nor how they were exposed. Jennifer expressed concern that it may be obvious to some of her partners who reported their names, because they had only one or two other sexual partners of which she was aware.

Jennifer agreed to wait a half-hour to meet with Partner Services personnel, who came to our office to meet with her. During their visit, the Partner Services worker was very comforting and gentle with Jennifer, assuring her that all efforts would be made to not disclose her name or identity to any of the contacts she reported to them. She was tearful again during the session, but was willing to provide contact information for three men with whom she had been sexually involved in the past, but she chose to inform her current boyfriend herself, not giving his name or contact information to the Partner Services worker.

I did not learn the test results of Jennifer's reported contacts, but I suspect the "flu-like" illness she had a few months ago may have been her initial infection. She had a high CD4 count and a reasonable viral load of < 50,000 copies/ml. Unfortunately, her boyfriend did not take the new diagnosis well and broke off contact with Jennifer.

We were able to get her scheduled with a behavioral health therapist, and Jennifer is now on anti-retrovirals, doing very well with no significant side effects. She reports that she has not heard any rumors about her status in her community and feels comfortable that the Partner Services worker was able to contact her previous partners for testing without revealing her identity.

The Partner Services personnel were very helpful in assisting this patient through a difficult time with her new diagnosis and were able to get the information they required in a sensitive, caring manner. We are currently working with Jennifer on skills to disclose her diagnosis to any family members she thinks should know as well as future sexual partners. **HIV**

*Centers for Disease Control and Prevention. Recommendations for Partner Services Programs for HIV Infection, Syphilis, Gonorrhea, and Chlamydia Infection. MMWR (2008); 57(No.RR-9). Available at www.cdc.gov/mmwr/preview/mmwrhtml/rr5709a1.htm.



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Training Opportunities in HIV Medicine for Residents and Medical Students

IN THE LAST ISSUE OF *HIV Specialist*, a feature article by Bob Gatty, editor of the magazine, discussed the future of the HIV workforce in the United States, noting a growing concern regarding a future shortage of HIV-care providers.

As noted in the article, some training programs exist as focus areas within primary care residencies (Family Medicine and Internal Medicine) as well as post-graduate HIV Fellowships. Encouraging feedback and additional information was received by many academic programs throughout the country.

In addition, at the recent national meeting (May, 2016) of the Society of Teachers of Family Medicine, in Minneapolis, MN, a working group of Family Medicine Teachers/HIV Specialists shared data, information about their Residency programs and other aspects of their respective HIV curricula as they endeavor to train the next generation of HIV physicians. The list below includes current post-graduate training sites for HIV/AIDS medicine.

The Residency HIV "Clinical Tracks" or "Areas of Concentration" are most relevant to medical students seeking a Residency Program where they can get more HIV training than what is offered in a typical Residency Program and depending on the program may be prepared to care for HIV patients independently or in collaboration with an HIV Specialist. The post-graduate fellowships are one to two years in length and provide more intensive training in HIV/AIDS upon completion of a Residency in Primary Care, which could be Family Medicine, Internal Medicine, or Pediatrics.

Residency Training Track or Area of Concentration (AOC)

1. Family Medicine Residency of Idaho, Boise, ID
<http://www.fmridaho.org/residency/fellowship/hiv-primary-care>
2. Family Medicine Residency – Lancaster General Hospital, Lancaster, PA (AOC)
<http://www.lancasterfamilymed.org/Home.aspx>
3. Family Medicine Residency – Lawrence, MA
http://lawrencefmr.org/site/?page_id=1393
4. Family Medicine Residency – Montefiore Medical Center, Bronx NY
<http://www.einstein.yu.edu/departments/family-social-medicine>
5. Family Medicine Residency – McKeesport - University of Pittsburgh, Pittsburgh, PA
<http://mckeesport.familymedicine.pitt.edu/content.asp?id=2458>
6. Family Medicine Residency – Southern New Mexico, Las Cruces, NM
http://www.nmfamilymedicine.com/article/hiv_hepc_services
7. The Northwestern McGaw Family Medicine Residency, Humboldt Park, Chicago IL
<http://www.familymedicine.northwestern.edu/education/residency-programs/humboldt-park/index.html>

8. Family Medicine Residency Training Program at Family Health Centers of San Diego (FHCSO)
<http://www.fhcsd.org/fmresidency/>
9. Family Medicine Residency – University of California, San Francisco. San Francisco, CA.
<http://fcm.ucsf.edu/education/sfghfcm-residency-program>
10. Family Medicine Residency – University of Texas South Western, Austin TX
<http://www.utsouthwestern.edu/education/medical-school/departments/family-community-medicine/faculty.html>

HIV Fellowship Programs (1 to 2 years in length)

1. Family Medicine Residency at University of Idaho
<http://www.fmridaho.org/residency/fellowship/hiv-primary-care/>
2. University of Massachusetts – Worcester, MA
<http://www.umassmed.edu/fmch/fellowships/hiv/background/>
3. University of Southern California – Keck School of Medicine, Alhambra, CA
<http://www.keck.usc.edu/family-medicine/training-education/HIV-fellowship/>
4. University of Texas - Houston (TX) Medical Center
http://www.hivma.org/HIVMA/Site_Map/Careers_Training/HIV_Training_Programs/Texas/University_of_Texas_Houston_Medical_Center_Fellowship_in_HIV_Medicine.aspx
5. The ViiV Healthcare/LA DHS HIV Public Health Fellowship Program
<https://dhs.lacounty.gov/wps/portal/dhs>
6. HIVMA Clinical Fellowships (Variable clinical locations)
http://www.hivma.org/HIVMA/Career_Training/Minority_Clinical_Fellowship_Apply_Online/

HIV



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U.S. Study Looks at Long-Term Durability of Hepatitis C Cure, Risk of Relapse and Liver Cancer

RESearchers in several countries—including France, New Zealand, the U.K. and the U.S.—reviewed the records of several thousand people who had been cured of HCV using direct-acting antivirals (DAAs) and found very high rates of cure that were sustained up to three years after cessation of therapy. That is, once cured, the vast majority of participants stayed cured. Rates of relapse, reinfection and liver cancer were very low after cure was achieved.

Study Details

Participants in Gilead Sciences' sponsored studies were encouraged to enroll in an observational study that monitored them for up to three years after cure was achieved. As part of this observational study, participants regularly visited study clinics where their blood was drawn for analysis.

There were 5,433 participants enrolled and their average profile upon entering the study was as follows:

- age—54 years
- 63% men, 37% women
- 20% had severe liver injury (cirrhosis)
- most (99%) had been infected with genotypes 1, 2, 3 or 4

Results—Keeping Track of HCV

Researchers found the following:

- 99.7% of participants maintained their cure status.
- 0.1% of participants had evidence of late relapse.
- Participants who relapsed tended to have HCV genotype 1a or 3. Historically these genotypes have tended to respond poorly to treatment.
- 0.2% of participants had evidence of HCV re-infection.
- Reinfections began to occur as early as eight months after cure was achieved.

Results—Monitoring Liver Cancer

Cases of liver cancer were detected after treatment cessation but were low. This is likely due to the smaller proportion of people with cirrhosis in this study compared to the previously reported French study (where more than 60% of participants had cirrhosis).

Most cases of liver cancer were distributed among people with pre-existing cirrhosis and occurred within the first year after treatment cessation.

Liver cancer diagnosed upon study entry

- among people with cirrhosis—5 cases
- among people without cirrhosis—3 cases

Liver cancer diagnosed 24 weeks after study entry

- among people with cirrhosis—5 cases
- among people without cirrhosis—1 case

Liver cancer diagnosed 48 weeks after study entry

- among people with cirrhosis—6 cases
- among people without cirrhosis—0 cases

Liver cancer diagnosed 72 weeks after study entry

- among people with cirrhosis—3 cases
- among people without cirrhosis—0 cases

After week 72, there were no further cases of liver cancer.

Other Liver-Related Issues

A similar trend (a decrease over time) was seen with the relatively small proportion of cases of liver-related complications that were detected after treatment cessation. Complications included the following:

- build-up of fluid in the abdomen (ascites)
- internal bleeding
- brain-related issues
- yellowing of the skin and whites of the eyes (jaundice)

Over time there were fewer cases of these and by the third year of the study, there were no reports of these complications.

There was also a similar trend with analyses of blood tests with a trend to normalization over time.

Overall, the findings from this review are reassuring and show that the vast majority of people who are cured with DAAs remain cured. Rates of complications, including liver cancer, were lower than those found in another study from France (reported in this issue of *TreatmentUpdate*). The lower rate of liver cancer seen in the present study likely arose because most participants were treated relatively early in the course of liver disease, before the onset of cirrhosis. **HIV**

Reference

Lawitz E, Ruane P, Stedman C, et al. Long-term follow-up of patients with chronic HCV infection following treatment with direct-acting antiviral regimens: maintenance of SVR, persistence of resistance mutations and clinical outcomes. *The International Liver Congress*, 13–17 April 2016, Barcelona. Abstract 166.

**Please note that this article is a reprint originally appearing on TheBodyPro.com. The article was provided to TheBodyPro.com by Canadian AIDS Treatment Information Exchange. It is a part of the publication *TreatmentUpdate*.

High Prevalence of Geriatric Conditions Among HIV+ People Over Age 50 in San Francisco

OLDER HIV-POSITIVE PEOPLE have a high prevalence of multiple age-related problems, investigators reported in the March 29 online edition of the *Journal of Acquired Immune Deficiency Syndromes*. The research involved people aged 50 years and older receiving outpatient care in San Francisco. Overall, 40% reported difficulties with daily activities, most reported loneliness, many had mild cognitive impairment, and 30% had only poor to fair quality of life.

“This is one of the first studies to have evaluated a wide range of geriatric assessments among HIV-infected individuals in an outpatient clinical setting and provides a comprehensive overview of the health needs faced by the aging HIV-positive population,” wrote the authors. “We observed a high burden of clinically-concerning deficits in older HIV-infected adults across multiple domains, including functional impairment, falls, depression, and social isolation.”

The investigators believe their findings have implications for patient care, commenting, “our results highlight the importance of systematically providing functional, social, and mental health support for the aging HIV-infected population.”

Improvements in treatment and care mean that many people with HIV are now living well into old age. Over half of HIV-positive adults in the U.S. are now age 50 years and over. Previous research has shown that these individuals frequently have multiple health problems and develop conditions associated with old age earlier than the traditional cut-off for old age—65 years.

The Veterans Aging Cohort Study (VACS) Index, a prognostic tool based on markers associated with HIV and other health conditions, can be used to identify older HIV-positive people with a high risk of illness and death. The VACS Index score has also been associated with risk of fragility fractures, cognitive impairment, and reduced exercise capacity. However, less is known about its association with geriatric conditions, such as functional status.

Investigators therefore designed a cross-sectional observational study assessing the physical, cognitive, social, and behavioral health of a large sample of older HIV-positive adults receiving outpatient care at 2 clinics in San Francisco. A combination of geriatric and other assessments were used to assess psychosocial issues observed in older patients with HIV. The investigators

hypothesized that both age and VACS Index score would be associated with the geriatric conditions identified in the assessments.

Recruitment occurred between December 2012 and December 2014 and English-speaking patients aged 50 years and older were eligible to participate.

Assessments included questions on physical, social, mental, and cognitive health. The investigators used a combination of assessments that addressed traditional geriatric conditions and also specific issues faced by older HIV-positive people.

The researchers assessed 4 broad areas of health:

- Physical health and functioning, falls, and walking speed (Activities of Daily Living and Instrumental Activities of Daily Living);
 - Social support, including physical and perceived support and loneliness;
 - Mental health, including depression, anxiety, and post-traumatic stress disorder (PTSD);
- Behavioral and general health, including adherence to HIV therapy and overall quality of life.

A total of 359 patients were assessed. Most (85%) identified as men, two-thirds were in the men who have sex with men (MSM) risk category, and approximately 60% were white. Approximately three-quarters had attended college. Half were receiving disability benefits and the majority had an annual income below \$20,000. Most (85%) had been living with diagnosed HIV infection for 10 years or more. As regards HIV-related markers, 82% had an undetectable viral load and over half had a CD4 cell count above 500 cells/mm³.

The median age was 56 years and two-thirds of patients were in their fifties. Patients aged 60 years and older were more likely to be white, college educated, and to have a higher annual income when compared to younger participants.

The patients had a high burden of conditions associated with older age, with 41% reporting a

fall in the previous year, almost 60% reporting loneliness, half reporting low levels of social support, and over a third met the criteria for mild cognitive impairment.

Patients aged 60 and older were more likely to report problems with balance than patients in their fifties (47% vs 33%). Prevalence of problems with physical health and functioning was similar in the 2 age groups (12%), but people in their sixties had slower walking speed.

However, the older patients reported less anxiety and had higher levels of adherence to their HIV treatment. Although older patients were more likely to rate their health-related quality of life as “good,” fewer reported that it was “very good” or “excellent” compared to people in their fifties.

A higher VACS Index score—indicative of higher mortality risk—was associated with greater levels of dependence and Instrumental Activities of Daily Living scores, i.e., falls and slower gait speed.

“Our data add to the growing body of evidence that older HIV-infected adults are facing increasing medical, psychiatric, and social complexity and help to provide insight into how this complexity varies in different age groups in older adults,” concluded the authors. “Our findings highlight the importance of taking a comprehensive approach to identify health issues facing older HIV-positive patients and the critical need to develop interventions to improve the quality of life and address the multifaceted needs of older HIV-infected patients.” **HIV**

Reference

M John, M Greene, NA Hessel, et al. Geriatric Assessments and Association with VACS Index Among HIV-Infected Older Adults in San Francisco. *Journal of Acquired Immune Deficiency Syndromes*. March 29, 2016

**Please note that this article is a reprint originally appearing on HIVandHepatitis.com, written by Michael Carter published on May 8, 2016.

Are Your Patients Pregnant and HIV-Positive?

We are seeking your professional consideration in the referral of patients for a study to assess the pharmacokinetics of darunavir and cobicistat, in HIV-1 Infected pregnant women.

The program is open to HIV-positive pregnant women who:*

- Are at least 18 years, and in their first six months of pregnancy
- Are already taking darunavir and cobicistat
- Have a normal physical exam and ultrasound
- Are receiving care for their pregnancy and HIV from an obstetrician and/or a primary HIV provider, and agree to continue doing so during the study
- Are willing to continue taking their darunavir and cobicistat—as well as their other medicines—during the study

* This is not a complete list of the inclusion/exclusion criteria



For more information please contact Keith Dunn at Janssen Scientific Affairs at kdunn1@its.jnj.com or visit www.clinicaltrials.gov (ClinicalTrials.gov Identifier: NCT00855335)

Open sites are recruiting patients in the following cities:

- | | | | |
|----------------|-----------------------|---------------------|----------------|
| • Syracuse, NY | • West Palm Beach, FL | • Daytona Beach, FL | • New York, NY |
| • Savannah, GA | • Philadelphia, PA | • Miami, FL | • Houston, TX |
| • Chicago, IL | • Greensboro, NC | • San Juan, PR | |

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