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Barriers to Care for Transgender People: A Conversation With Dana Hines, PhD, MSN, RN

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A public health nurse talks about her career trajectory, her entry into nursing research, and her research career in transgender health. Transgender people encounter many health and social disparities, yet medical and nursing professionals are often ill-prepared to care for this population of individuals. The nursing profession is well known for its contributions to population health and for developing nursing-led interventions to improve the health outcomes of marginalized populations. Hines urges nursing to take a more active stance in transgender health and is leading this effort by example.

Keywords: transgender; structural barriers; health care access; public health nursing

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Donna Biederman: Dana, I know you've recently transitioned into a research career. Tell us a bit about yourself—your clinical practice and your trajectory into research and academia.

Dana Hines: I have been a nurse for 17 years. During the earlier part of my career, I worked as a staff nurse on a cardiac care unit, as a clinical educator, and spent a short time working as a drug safety coordinator for a large pharmaceutical company. But the majority of my career has been devoted to public health nursing. In fact, it was through my entry into public health that my passion for working with populations disproportionately impacted by HIV blossomed. It was also during this time that I decided to pursue a PhD in nursing because I came to recognize the potential impact that my research could have on improving systems of care for patients with HIV. My trajectory to academia started when I was a hospital-based clinical educator for a large hospital network. Through my role as a clinical educator, I was given the opportunity to serve as an adjunct clinical faculty member for a large, state-funded school in the Midwest.

Biederman: Tell us about your work with populations disproportionately affected by HIV.

Hines: Over the past 7 years, I have had the opportunity to lead several major public health projects aimed at minimizing health disparities and barriers to care

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among minority populations living with HIV. I spearheaded the development of a partnership between the county jail and the Ryan White HIV/AIDS Services program to reduce the number of HIV-positive inmates who were being released from prison without adequate resources to link them to HIV care. As a result of this partnership, inmates in several prisons are now receiving pre-release case management and are connected to an HIV care provider before leaving prison.

I also conducted a county-wide case review of all infants born to women infected with HIV between 2000 and 2008 and found that the majority of these infants were born to African American women who had inconsistent prenatal and HIV care. So I started an informal perinatal transmission workgroup to further evaluate these cases and to identify areas of improvement in HIV testing and treatment of pregnant women in a large Midwestern city.

Later, I was part of an interdisciplinary team that used the model for improvement as a framework to test various patient- and nurse-identified strategies for improving cervical cancer screening rates among HIV-positive women; this project resulted in increased cervical cancer screening rates among women receiving care through Ryan White–funded agencies. The model for improvement was designed by Associates in Process Improvement to accelerate improvements in organizations; it uses the Plan-Do-Study-Act process to test changes on a small scale (Institute for Healthcare Improvement, 2016). And in 2011, I spearheaded a quality improvement project that resulted in the expansion of case management services to people living with HIV who were previously not able to access services.

Frontline staff members such as receptionists and medical assistants are often the first to greet any person at a medical visit, and can play a key role in creating an affirming and welcoming environment for a transgender patient.

Biederman: Wow, you've done some amazing work in the community! What led you to a research focus with transgender people?

Hines: I first became interested in conducting health research with transgender people through my work with the Ryan White HIV/AIDS Services Planning Council, the governing body for the Ryan White Part A HIV/AIDS Services program. The Council is composed of people living with HIV, lay community members, and HIV service providers, and is responsible for allocating resources and setting priorities for all core medical and supportive services funded by Ryan White Part A dollars. At one time, we had a fairly active and vocal group of transgender council members who were challenging us to present, and consider independently, data that were specific to the transgender population, and to stop including transgender women in the population of men who have sex with men [MSM], a long-standing epidemiological approach to capturing and presenting HIV-related data. I will never forget "M," a transgender woman who has been living with HIV for over 20 years, saying, "Each month, you all [referring to the Grantee staff] present data on MSM, Black men and women, White men and women, Hispanic/Latino men and women, but never on the transgender population! It's like we don't exist and don't matter." Her words resonated with me, and I could feel the passion that she and other transgender members felt about their health needs.

I began developing a relationship with M and other members of the community in an effort to better understand their health needs and concerns. At the same time, I began examining the state of the science on transgender health. I quickly learned that there were gaps in knowledge about transgender health. I was also deeply affected by the injustices, stigma, discrimination, and health disparities that this population encountered and felt compelled to help alleviate these issues on a larger scale. As a result, I decided to focus my dissertation research on this topic. Initially, I met with some resistance from my dissertation committee and research

training faculty and was discouraged from pursuing transgender health as a research topic. Fortunately, around this same time, the Institute of Medicine's [IOM, 2001] report, *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*, was released and provided the leverage I needed to convince my dissertation committee that a study focusing specifically on transgender health was fundable and that a program of research focusing on transgender health issues was sustainable.

Biederman: From your experience, it sounds like there are structural barriers even to doing research with transgender people. What are some of the biggest issues in access to care for this population?

Hines: For transgender people, accessing health care is generally problematic due to exclusion by the treatment system. Social and institutional stigmatization of the transgender population has created systematic avoidance. There are several reasons for this. One is that transgender health care is not a routine component of many medical and nursing school curricula, so physicians and nurses are not prepared to provide competent care to transgender patients. This lack of preparation threatens the quality of patient–provider communication and reinforces a treatment system that is intrinsically designed to be unresponsive to the health needs of the transgender population. Also, because of their gender status, transgender people may have two different health care providers: one to help manage their hormones for gender transition and another to help manage their general health care. This is not to say that all transgender people take hormones. According to the National Center for Transgender Equality's survey with 6,456 transgender individuals, about 62% of study respondents reporting having received hormone therapy, and 23% expressed a desire to have hormone therapy in the future [Grant et al., 2011]. In this same study, transgender women reported using hormones at higher rates [80%] than transgender men [69%]. It is also important to note that not all transgender people who are taking hormones undergo gender reassignment surgery but take them to facilitate the development of secondary sex characteristics and to achieve transitioning *without* surgery. Insensitive and insulting comments and lack of trans-friendly health care environments can pose additional barriers to care.

Biederman: What would a trans-friendly health care environment look like? What resources can help clinicians better understand the structural barriers to care for transgender persons?

Hines: *Injustice at Every Turn*, a report of the National Transgender Discrimination Survey, highlighted a number of structural barriers impacting transgender people in health care settings [Grant et al., 2011]. This survey was one of the largest in the U.S. conducted with transgender people.

Transgender women are disproportionately impacted by HIV, and are a bridge to new infection among other populations.

Key reasons why transgender respondents reported postponing medically necessary care included stigmatization and discrimination, inability to afford care, and fear of being [or having previously been] refused care because of their gender status. Other reasons may come as a surprise to many health care providers because these reasons are reprehensible: Transgender people are often verbally harassed and physically threatened in medical settings. Imagine going to an emergency room for treatment and being physically assaulted or verbally attacked because of your gender identity. We are socialized to trust health care professionals with our lives and our health, yet those health care professionals are the same ones

whom some transgender people fear. This is unacceptable, and undermines the core ethical principles of medicine and nursing: respect for persons, justice, nonmaleficence, and beneficence.

Providers' lack of knowledge, which I alluded to earlier, also functions as a structural barrier to care for transgender people. For example, because transgender people often encounter health care professionals who are not knowledgeable about transgender health, they often have to teach their care providers how to care for them. As a health care professional, I feel very confident having discussions with my health care provider about my health needs and concerns; however, I still expect my health care provider to be knowledgeable enough about me to provide or recommend appropriate health screenings and treatment. I do not expect, nor would most people, to need to teach my health care provider how to take care of me each time I seek care. That is not how the patient–provider relationship is expected to function. Now, consider a transgender person who is already socially marginalized and oppressed, living with the chronic stress associated with being a member of a gender or sexual minority, grappling with other social and health disparities, and needing medical attention. Is this the profile of someone who should be expected to teach health care providers how to provide care? Who would trust a health care provider enough to even seek care? But these are the conditions that transgender people are facing when they seek care and, as a result, they often receive subpar care and mistrust everything associated with the health care system. These structural factors cause transgender people to withhold pertinent information about their sexual orientation, illness, and health behaviors, which then hinders effective treatment and care discussions as well as informed decision making. When we start to unpack these layers, it is easy to see why transgender people experience poorer health and social outcomes than cisgender people.

The experiences of women as both transgender and HIV-positive are often intertwined; health care and coping are impeded when the women encounter health care providers who are intolerant, insensitive, and uneducated about transgender identities.

Biederman: I've heard that the misuse of personal pronouns makes transgender persons feel uncomfortable and unwelcome. Do you have any advice about what pronouns to use in the clinical setting?

Hines: My advice to clinicians and other staff is that if they are unsure of which pronoun to use, ask. Misuse of personal pronouns is offensive and embarrassing and can cause transgender people to avoid seeking health care. Using a transgender person's preferred pronoun is gender affirming because it shows respect and acceptance of their preferred identity. Gender affirmation is the process through which transgender people's gender identities and expressions are affirmed through social interactions. Gender affirming social interactions such as using the appropriate pronoun [or asking, if unsure] send a message that "we accept you for who you are." Frontline staff members such as receptionists and medical assistants are often the first to greet any person at a medical visit, and can play a key role in creating an affirming and welcoming environment for a transgender patient, because a welcoming environment starts when a person enters the facility or care setting for the first time. Far too often, it is at this point that the quality of the care-seeking experience for transgender people is first compromised.

"J," a transgender woman who participated in my dissertation study, shared her front office/waiting room experience.

> In the waiting room, the staff wouldn't call me by my name until I got my driver's license and everything changed, and they wouldn't put my preferred name on my chart. I had to remind them, because a lot of people didn't look up or look at me.

> They just looked at my chart and called me Sir or Mister. I wouldn't answer when they said, "Mr. X." I would go up to the registration window after they looked around, and tell them who I was.

I believe that these practices can be changed by educating health care providers and frontline staff on how to be culturally sensitive and how to interact with transgender patients in the clinical setting.

In addition to asking individuals which pronoun they prefer, modifying paperwork to include transgender identities [e.g., transgender woman or transgender man] as a gender option would also help minimize those uncomfortable moments. If staff members are unsure of which pronoun to use, using the individual's last name in the waiting room and then establishing the preferred pronoun in the exam room is also an option.

Gender-neutral pronouns to consider are:

- They, them, theirs
- Ze [pronounced like "zee"] which can be used in place of she/he/they
- Hir [pronounced like "here"] to replace her/hers/him/his/they/theirs

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In addition to misuse of pronouns, transgender patients often experience other moments of awkwardness when interacting with health care providers who are not familiar with or comfortable treating transgender patients. For example, one transgender woman from my dissertation study discussed how uncomfortable she felt and how uncomfortable she perceived her doctor to be during her clinic visit.

> The doctor did everything, but not like usually a doctor would do. You know how the doctor will put the stethoscope thing on you and listen? He wouldn't touch right here [indicating her breast/chest area]. It was really weird. I never went to see that doctor again. I got a new doctor.

Biederman: Are there specific models of care for the transgendered population that are exemplars to be replicated?

Hines: The National LGBT Health Education Center, a program of the Fenway Institute, has published best practices for frontline health care staff [National LGBT Health Education Center, 2013]. These best practices focus on gender affirmation. The Center of Excellence for Transgender Health at the University of California, San Francisco, has also published protocols on primary care for transgender patients [Center of Excellence for Transgender Health, 2011]. The protocols offer guidance on everything from assessing readiness for hormones to gender-specific preventive care and health screenings, to aging issues.

Biederman: Tell us about your research. What are some of your findings?

Hines: My research focuses on health disparities and health services utilization among gender and sexual minorities. I have a particular interest in HIV-related health disparities. To date, my research has focused on transgender women living with HIV. Transgender women are disproportionately impacted by HIV and are a bridge to new infection among other populations [e.g., men who have sex with men, and heterosexual men]. Worldwide, transgender women are 49 times more likely to be HIV-infected than other populations. Therefore, they play a significant role in HIV transmission both domestically and globally. The aim of my dissertation study was to describe the illness trajectory of HIV-positive transgender women.

The illness trajectory refers to all the attempts that an individual uses to cope with an illness episode and the steps [timing, sequencing, and actions] they use throughout the process.

Results confirmed that health care settings and health care encounters, regardless of stage, influenced the women's experience with HIV and their patterns and pathways of care utilization. Similarly, findings confirmed that relationships with important others such as family, friends, and romantic partners strongly influenced the women's ability to manage and cope with their illness. The final product of this study was a four-stage theoretical model, *Having the World Change*, that described the psychosocial process through which transgender women progressed following their initial HIV diagnosis. By determining a transgender woman's current stage in the model, a care coordinator, mental health professional, and/or clinician would be alerted to the types of help and support that might facilitate entry into and retention in care. Findings also indicated that the experiences of the women as both transgender and HIV-positive were often intertwined. As a result, health care and coping were impeded when the women encountered health care providers who were intolerant, insensitive, and uneducated about transgender identities.

Biederman: Dana, thank you for sharing your expertise about structural barriers to health and health care for transgender persons. Is there anything else you would like to add?

Hines: Research on lesbian, gay, bisexual, and transgender [LGBT] issues has drastically increased over the last 20 years among most health disciplines, but the nursing profession has been criticized for its lack of involvement in research focusing specifically on LGBT health. More recently, during the 2013 annual policy conference of the American Academy of Nursing, Bobbie Berkowtiz, dean of the Columbia University School of Nursing and president of the American Academy of Nursing, issued a call to action, urging nurses to take a more active role in LGBT health. Specifically, she urged nursing to lead the charge for change by examining LGBT health issues across the life span, investigating the social factors that impact well-being of LGBT populations, and exploring social and health challenges within various subpopulations of the LGBT community.

The nursing profession is known for its compassion, humility, and willingness to care for vulnerable and marginalized populations. These qualities, coupled with our discipline's track record of developing evidence-based, sustainable nursing interventions that significantly improve health outcomes, minimize health disparities, reduce suffering, improve self-efficacy, and increase patient and provider education, suggest that we are more than capable of leading the charge in LGBT research and of contributing to the overall quality of health and health care for this population of individuals. For these reasons, I am really excited to see that *Creative Nursing* was interested in this interview in furthering the discourse on transgender health. It is a good first step toward increasing nursing's visibility in this important area of research and reducing health disparities in the transgender population through nursing-led research.

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