

They Just Don't Get Me: A Qualitative Analysis of Transgender Women's Health Care Experiences and Clinician Interactions

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Abstract

Transgender individuals face many barriers when accessing health care, including having to teach clinicians how to care for them to receive appropriate care. We conducted a secondary analysis of qualitative data collected via semistructured interviews with 18 transgender women ranging in age from 21 to 60 years and living with HIV. Data were analyzed using conventional content analysis. Participants encountered two clinician types: *Those who get me* and *Those who don't get me*. *Clinicians who get me* provided gender-affirming care, fostered patient engagement, performed appropriate health screenings, and were willing to learn about transgender health. *Clinicians who don't get me* were aloof, uninterested, and unwilling to provide care. *Clinicians who don't get me* and system-level factors such as fragmented care, lack of insurance, and a low volume of transgender-competent clinicians contributed to transgender women's unmet health and education needs. Recommendations for improving transgender health care are provided.

Key words: HIV, minority health, nursing education, transgender health, transgender women, vulnerable populations

Transgender individuals face many barriers when accessing formal health care including being verbally harassed, refused treatment, physically assaulted, and having to teach clinicians how to care for them to get appropriate care (Bauer et al., 2009; James et al., 2016). Research has shown that the quality of care afforded to transgender patients is often determined by where they seek care (Bauer et al., 2009; Safer et al., 2016; Sanchez, Sanchez, & Danoff, 2009). The lack of transgender-specific education and training offered in medical (Obedin-Maliver et al., 2011) and nursing schools reinforces these structural barriers.

Of 132 North American medical schools surveyed, an average of 5 hours was devoted to lesbian, gay, bisexual, transgender-related medical school curriculum (Sawning et al., 2017). In nursing schools, the average was even lower at 2.12 hours (Lim, Johnson, & Eliason, 2015). A

critical component of providing inclusive care to transgender people is the integration of transgender-specific education and training in medical and nursing school curricula and continuing education requirements for licensed health care professionals. However, to our knowledge, only one state (California) and the District of Columbia have legislation requiring licensed health care professionals to receive lesbian, gay, bisexual, transgender-related continuing education (California Legislative Information, 2014; Council of the District of Columbia, 2016).

Studies have reported that knowledge among nurses, physicians, and other health care providers is inadequate to manage the complex health care needs of transgender patients (Ogbuokiri & Davis, 2010; Sanchez et al., 2009; Unger, 2015). Further evidence presented in a 2016 survey of transgender care by endocrinologists in the United States revealed that 74% of endocrinologists were *not at all to a little competent* in providing transgender care, and only 20% felt *very comfortable* discussing gender and/or sexual identity (Irwig, 2016). Lack of access to culturally tailored and competent care contribute to health disparities in this population, including higher rates of HIV infection, greater psychological distress and suicidal ideation, and higher rates of substance abuse (James et al., 2016).

The way in which clinicians are trained to care for transgender people will be a key factor in reducing health disparities in, and improving the quality and comprehensiveness of care for, transgender patients (Giffort & Underman, 2016; Sanchez, Snelgrove, Jasudavicius, Rowe,

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Head, & Bauer, 2012; Strong & Folse, 2014). We explored the health care experiences of transgender women (TW) living with HIV, described their encounters with clinicians, and made recommendations for creating transgender-friendly environments of care.

Methods

Study Design and Oversight

This was a secondary analysis of qualitative data collected as part of a grounded theory study conducted by the primary author. The parent study examined factors that influenced TW's coping strategies following a new HIV diagnosis. Findings from the parent study indicated that interactions with health care providers influenced how TW progressed through the coping stages. We wanted to reexamine the data to explore how interactions with health care providers affected TW's general health care experiences.

The parent study was approved by the Institutional Review Board (IRB) at Indiana University, and approval for our study was granted by the IRB at The George Washington University. A waiver of signed consent was obtained from the IRB at Indiana University to protect the identities of the study participants. Verbal informed consent was obtained from each participant before data collection. No identifying information was collected, and aliases were used in lieu of actual names. Participants were informed that portions of their transcripts might appear in publications.

Setting and Participants

The parent study was conducted in Indiana (Hines, Draucker, & Habermann, 2017). Indiana has ranked 18th among the 50 states in the number of HIV diagnoses (Centers for Disease Control and Prevention, 2015) and 23rd in the nation for percentage of adults who identified as transgender (Flores, Herman, Gates, & Brown, 2016). A total of 18 TW, ranging in age from 21 to 60 years, were included in the parent study, and data from all participants were used in the secondary data analysis. Participant characteristics, inclusion criteria, recruitment procedures, and research protocols have been reported (Hines et al., 2017).

Data Collection

The first author collected data for the primary study via face-to-face interviews. Questions broadly explored participant experiences accessing care and interactions with primary care clinicians and nurses (Table 1). Interviews

lasted approximately 90 minutes and were digitally recorded and professionally transcribed. Recordings were compared against transcripts for accuracy.

Data Analysis

Transcripts were de-identified before being analyzed via conventional content analysis. Two independent coders read the transcripts multiple times to obtain an understanding of the participants' overall experiences. All text units (e.g., relevant words or phrases) related to health care experiences and clinician encounters were highlighted. Text units were then coded deductively using preset codes informed by the Network Episode Model, which asserts that relationships and interactions with clinicians influence health outcomes and care seeking behaviors (Table 2). Inductive (data driven) coding was also used and the codebook was updated to reflect newly emerging codes and themes (Creswell, 2013). Codes were organized into data display tables that were used to organize similar codes into categories and to display emerging categories for further discussion and refinement (Creswell, 2013). The coders met regularly to discuss emerging findings and to resolve any coding discrepancies.

Results

Participant narratives contained detailed and rich information about their health care experiences and interactions with clinicians. They addressed four main themes: (a) clinician types, (b) unmet health and education needs, (c) system-level barriers to health care access and engagement, and (d) recommendations for improving the quality of health care experiences.

Theme 1: Clinician Types

Participants encountered two clinician types: (a) *clinicians who get me* and (b) *clinicians who don't get me*. The clinician type influenced the quality of the health care interaction and the care experience.

Clinicians who get me. Participants described *clinicians who get me* as clinicians who provided gender-affirming care, were willing to learn about transgender health, and/or who shared social identities (e.g., identified as gay or as a person living with HIV). Participants indicated that these clinicians were well known in the "gay community," understood that being transgender was "not just a phase," made participants "feel comfortable," and took time to answer their questions. One participant described, "When I became a transsexual, my nurse practitioner (NP) was the only person who saw me. I hadn't seen

Table 1. Interview Questions

| Category | Related Questions |
|----------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Quality of the health care encounter | Can you tell me about an experience with your health care provider that was the most meaningful to you? |
| | What does treating you with respect look like when it comes to interacting with your health care provider? |
| | Is there anything that you would change about any of your care experiences? |
| | How can nurses or physicians motivate transwomen to enter care? How can they gain trust? |
| | What can health care providers do to improve transgender women's care? |
| | Do you find it difficult to find a health care provider who is experienced with primary, preventive care? |
| | Have your family doctors been good about ordering your other female screening examinations (e.g., breast examinations)? |
| | When you have had health care encounters, in the hospital or the clinic, and you identify yourself to the health care team as a transgender woman, what is the reaction that you get? |
| | Can you talk about your experiences in seeking other care? Like primary care with other doctors? |
| | Does your doctor talk to you about other general health screenings? Do they examine the male parts of your body? |
| Quality of other health and social service encounters | You talked about having to go to a shelter. What was it like going into a shelter as a transgender woman? |
| | What does your psychiatrist do that you like really well and that you would like to see other health care providers do? |
| | What are your interactions like with the endocrinologist? |
| | What are your conversations like when you're talking to your care providers about hormones? |
| Educating nurses and physicians about transgender care and transgender women | What are some things that you feel like nurses and doctors need to be educated about as it relates to transgender care? |
| | Do you feel that there are any areas that health care providers need to be educated on? Or re-educated about as it relates to providing care of any sort to transwomen? |
| | How would you describe your health care provider's knowledge about transgender women? |
| | Have there been times when you've had to provide education of any kind to your provider? Can you tell me a story about one of those situations? |
| | What type of education or training do you feel health care providers need to be able to relate to you from a provider level? |
| Educating other members of the health care team about transgender care and transgender women | What about your general (non-HIV related) health care as a transwoman? Do you feel like there is anything that doctors or nurses need to do differently in terms of the health care setting? |
| | What advice would you give to people who are providing care to transwomen? |
| | Have there been any defining moments that stick out in your mind about your experiences with interacting with your case manager or health care provider? |

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Table 1. (continued)

| Category | Related Questions |
|----------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Creating transgender-friendly environments of care | In thinking about the encounters that you've had with the staff and health care professionals, were there things that you liked and did not like? |
| | What do you like about your health care provider or the place where you are receiving care? |
| | What are some ways that the health care team can treat you as a transgender woman with respect? |
| | How can we create a care environment that is transgender friendly? |
| | If we want to create an environment of care that is supportive to transwomen who are living with HIV, what are the things that health care providers need to focus on? |
| | What suggestions would you give to nurses, doctors, or other health care professionals on ways that we could make the health care experience even better for transgender women? |
| | What do you think are some things that health care clinics, or other settings, and health care providers can do to be more transgender friendly? |
| | Are there things about your clinic itself that you really like or feel that they really do well to cater to you as a transgender woman? |

my doctor in forever, but she was very accepting" (60 years old, White). Another participant explained how the NP made her feel comfortable.

Unlike the interns who always seemed to have too much on their caseload and didn't give me the attention that I needed, the NP was, she was always there for me. If I had a question, concern, or anything she was there. (31 years old, Black)

Gender-affirming care made participants, "feel accepted as complete women." This meant receiving hormones and the same health screenings (e.g., breast cancer), education, and medical treatment as cis women. A participant, who had completed gender confirmation surgery (GCS), explained, "My doctor would do the pelvic exam... and it just made me feel accepted as a woman" (58 years old, White). Another participant described the way in which her clinician addressed her breast health needs. She said, "My doctor showed me how to do a breast exam. She showed me how to lift them and how to look for certain things round the breasts. Then she set me up for a mammogram" (35 years old, Black).

Participants described *clinicians who get me* as "willing to learn" and "educate other health care professionals" (e.g., "nurses") and they listened to participant health concerns. One participant said, "I inherited a doctor who was a god-send. He knew nothing about me or transgender women, but took it upon himself to learn" (58 years old, White). Another participant said, "I was one of my doctor's first transgender patients. She told me that she was not going to turn me away. She was on board. So we worked together" (31 years old, Black).

Shared social identities were another hallmark characteristic that participants used to describe *clinicians who get me*. For instance, some participants expressed greater affinity toward clinicians who were female, gay, or living with HIV infection. One participant stated, "Men don't really listen as much as women and my doctor [he] was not listening to me... Fortunately all of my doctors are women now and they listen" (36 years old, Black). Statements about serostatus suggested that a few other participants felt best understood by clinicians who personally knew the challenges of living with HIV: "My doctor was HIV positive, and through our relationship, convinced me to share that I was positive. It helped me understand my purpose and power as an individual" (43 years old, Black).

Clinicians who don't get me. Participants perceived *clinicians who don't get me* to be aloof, uninterested, uncomfortable with transgender identities, or unwilling to provide care. These clinicians misgendered participants (used the incorrect pronoun, e.g., he rather than she) and did not address, or take seriously, their health concerns. Encounters with these clinicians were uninformative, meaning that they were given either no information or misinformation about their health concerns or not asked pertinent questions about their health.

Participants observed *clinicians who don't get me*, to be uncomfortable interacting with them or conducting their physical examinations, or at times refusing to care for them.

Table 2. Code Book

| Code (Definition) | Subcodes | Subcode Definition |
|------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Treatment network structure | | |
| The push or influence of the treatment network structure either toward or away from the formal health care system | Density | Degree to which something is filled, crowded, or occupied; also used to describe compactness. In terms of treatment network structure, we associate density with factors such as wait times, proximity, or closeness of related treatment services, and number of patients at a particular care site. |
| | Duration | Length of treatment (e.g., treatment duration or amount of time in care). |
| | Reciprocity | Mutual exchange of information between the patient and health care provider. Also refers to a mutually beneficial relationship. |
| | Strength of tie | Closeness and level of connection between the patient and health care provider. Strong ties are characterized by greater communication and emotional/social support. |
| | Multiplexity | Degree to which network relationships overlap or are multidimensional. For example, a health care provider who shares commonalities with patients (e.g., identifies as a sexual minority or has an HIV diagnosis). |
| Treatment network content | | |
| Ways in which culture and climate within treatment organizations shape treatment options, bonds between providers and patients, and health outcomes. | Treatment efficacy | Whether treatment is effective. |
| | Diagnostic capacity and technology | Ability to make a diagnosis. Technology refers to tools that are used to treat a diagnosis. |
| | Modalities (treatment) | Methods of treatment or the ways in which a health care provider goes about treating a health care condition. Treatment modalities include multiple treatment methods. |
| | Staff attitudes and culture toward health, clients, community, and treatment organizations | Messaging or messages directed toward patients. Refers to whether or not the treatment setting creates/provides a climate of care. |
| Treatment network functions | | |
| Information, advice, regulation, expressive or emotional support, and material or practical support provided within treatment systems. | Information | Knowledge that is communicated or received about a particular factor or circumstance. Also refers to the act of informing. |
| | Advice | Opinion or recommendation offered as a guide to action. |
| | Regulation | Law, rule, or other order prescribed by an authority. The act of regulating or being regulated. For example, regulations regarding treatment access or treatment protocol. |
| | Expressive or emotional support | Psychological or emotional encouragement. |
| | Material or practical support | Help with ordinary activities or affairs. Can take on many forms such as food and clothing, assistance with finances, housing, and other basic necessities. |

The doctor walked in and then walked right back out the room. I heard him say, "Where is such-and-such?" And they [clinic staff] said, "That's her." The door was open [and I heard] a lady [tell him] and he responded, "Oh!" He came in and said, "I'm so sorry." He did everything [check-up], but not like a doctor would usually do it. You know how the doctor puts the thing [stethoscope] on you and listens? He wouldn't touch here [indicating chest] and it was really weird (26 years old, Black).

As another example:

I went to the emergency room because I fell and broke my toe. That had nothing to do with this up here [breasts], but I was immediately categorized as a transgender. I was in so much pain. The doctor on call didn't want anything to do with me. So they had to call another doctor in to fix my toe. (58 years old, White)

These awkward encounters occurred in clinical and psychosocial care environments. One participant, who was referred to a psychiatrist for support in coping with her new HIV diagnosis, described being refused care because of the psychiatrist's inexperience in caring for transgender people. She said,

I had a psychiatrist tell me, "I don't know how to deal with this." He said, "I've never dealt with anybody like this before." I looked at him and said, "Is there any paperwork that I need to sign for you to release your duties or something?" He said, "No, but I will put you back in the system so that you can find a new doctor." (31 years old, Black)

Instances of misgendering were distressing, embarrassing, and discouraged participants from returning for future care.

The whole thing of being called "mister" in waiting rooms... Until I got my driver's license changed they wouldn't use my preferred name. I used my initials instead and they wouldn't put that on my chart. They [front office staff] don't look at you. They just look at a chart and start calling you sir. Sometimes I got pretty heated. It should be obvious when you look at me. So why would anybody say sir, him, or mister? (60 years old, White)

One participant described how the clinician misgendered her during an encounter: The nurse practitioner told her student nurse that even though I had [GCS] surgery I was still male. I thought, "Oh my god, I've done all this and I'm still a man?" ... I could have gone and killed myself, or something like that. That could have been the adverse effect. Afterwards I walked away and never went back. (58 years old, White)

Some providers avoided discussing sensitive health topics and deferred examining some body areas despite health concerns voiced by participants. One participant said,

I was itching down there (indicating rectal area) and had never experienced that problem before. I told the doctor that I was itching and asked him if it was because I have HIV. He was like, "No-just put some powder down there and it will be ok." He

never looked down there or anything. It still itches and I want to know where the itch is coming from. But my doctors haven't checked it or anything. (26 years old, Black)

Theme 2: Unmet Health and Education Needs

Participants attributed their unmet health and education needs to clinician inexperience with transgender patients. This lack of knowledge disrupted access to feminizing hormones and inhibited genitourinary and breast health care.

The new doctor wouldn't accept my medical records from the previous doctor because they were handwritten... and would not resume my hormones. So I ordered them online and did them myself... Later I lactated for about 10 months. My boobs hurt so bad and were swollen. The doctor advised me to take a warm shower and massage my breast. This made the leaking worse. So I bought a breast pump and pumped myself out 3, 4 times a day. On top of the estrogen I was taking Depo-Provera for the Progesterone every 3 to 4 weeks... it had my body believing that I was pregnant. I went off the progesterone for a year and haven't gone back on it. (50 years old, White)

Although GCS was uncommon among our participants ($n = 2$), there was an obvious need for ongoing postprocedure education. One participant, who completed GCS 13 years before the study, had gynecological and genitourinary problems that her clinician was unable to manage:

Right now I'm with Doctor Jones (alias), and even though he's a wonderful doctor, I just don't think he gets me. I have a problem with my bladder. It's dropped and is pushing in on the side of my vaginal canal. I asked him about it and he suggested I ask my surgeon who is in Arizona. I told him that I didn't have the money to go to Arizona and that I was trying to find somebody locally. (58 years old, White)

Participants who were on feminizing hormones, and those with a history of silicone injections in their breasts, had unmet concerns about breast development (e.g., breast bud development, lumps, tenderness) and breast cancer.

I am knowledgeable about HIV. But I'm confused about the female part. I'm not asked those questions so I just let it go... I'm always afraid that I'm going to miss something. If I start thinking about it too much it makes me crazy. I had four treatments of silicone in 1993, so I know where those are. We have breasts and a lot of people think that we're not going to get breast cancer. Well, men get breast cancer-men, women, and whoever. So I feel my breast and do my self-breast exams. (58 years old, White)

Although many participants were aware of their risk of developing breast cancer and one participant had been diagnosed with breast cancer, several were unaware of the risk and indicated that their clinicians

never discussed breast health with them. When asked if a physician or nurse had ever talked to her about examining her breast, one participant replied, “Can we get breast cancer too? I didn’t know that” (21 years old, Black). When asked a similar question, another participant shared that her doctors never talked to her about breast health or cancer screenings. She said, “No, it never comes up... Can we get breast cancer too?” (34 years old, Black).

Theme 3: System-Level Barriers to Health Care Access and Engagement

The quality of the health care encounter was negatively affected by the lack of knowledgeable primary care clinicians, fragmented health services, and lack of insurance coverage for services.

Lack of knowledgeable clinicians. Participants expressed difficulties finding clinicians who were experienced in transgender health: “Indiana lacks health care clinicians who are knowledgeable about caring for transgender women.” Knowledgeable clinicians often had long appointment wait times and were “usually very booked up.” By comparison, clinicians who rarely “treated the trans community” had shorter wait times.

My doctor really isn’t booked up, but I don’t think she provides a lot of transgender care. I don’t know how many other girls go to her. I’ve been seeing her for a year and a half and I’ve never seen another transsexual woman in her office. (50 years old, White)

Fragmented health services. Having several primary care clinicians, traveling great distances for health care appointments, and a lack of clinicians who provided total care (primary, HIV, hormones, and post-GCS issues) also disrupted care.

I’ve always had one doctor for my HIV and hormones. When my last doctor quit his practice all of his patients spread throughout Indiana and I ended up with two doctors. It was easier to see one doctor for both things. (58 years old, White)

Further complicating care access, was frequent changes in primary care clinicians.

I saw my doctor regularly, but they [insurance company] kept changing my doctors. I’ve had three or four doctors in less than 5 months. So it’s hard. At first I was going to my doctors’ appointments regularly and they were all in one place. Then they moved them. Now I’ve got a whole different doctor that I’ve got to go see today that I have never met. I don’t know why I keep getting new doctors. (26 years old, Black)

Participants preferred receiving “all of their care” from one clinician over “venturing” out to other clinicians. However, insurance regulations often required participants to have multiple clinicians.

I don’t have a primary care doctor. I use my HIV doctor for everything. This new insurance tells me I have to get a primary care doctor, but I don’t like change. My infectious disease doctor takes care of everything... my allergies and hormones. I don’t see a reason to go anywhere else. But the insurance companies want them [doctors] to be separate. That’s not comfortable for me. I just like having one person who knows everything about me. (49 years old, Black)

Continuity of care with the same clinician was especially important for participants in our study. As one participant stated, “Change is [the] hardest thing for me... new people... new doctors” (51 years old, Black). Constant changes to clinicians and clinic sites also made participants feel unwelcomed. As one participant said, “I get used to one doctor and start expressing myself to the doctor and then I get a new doctor. It makes me think, ‘Is it me? Or what is it?’” (26 years old, Black). One participant explained the importance of staying with the same clinician,

I have been with my doctor for a long time. I can be honest and upfront with her because she is the one person who can help me with whatever I need medically... I can also be honest with her and not be penalized. (31 years old, Black)

Lack of insurance coverage. Most participants in our study were on Medicaid or received care through the Ryan White HIV/AIDS program, which provides comprehensive primary medical and support services for people living with HIV. Feminizing procedures that are gender affirming, such as breast implants and hormone therapy, are not covered under this program. The majority of participants had a history of silicone injections and implants (breast, buttocks, and facial); however, silicone was rarely addressed during the health care encounter. This was likely because silicone injections were not covered by insurance and were accessed from non-medical sources. Consequently, participants rarely disclosed this part of their medical history and had lingering concerns about its health impact.

Insurance doesn’t pay for cosmetic procedures and there are girls who will help you feminize your body. Is it safe? Absolutely not! These girls are self-taught in administering silicone. One girl teaches another girl and so girls watch while the procedures are being done on them, and they learn how to do it. Most of the girls are very sterile in their process. They use gloves, alcohol, and clean everything, but it’s not very safe. If insurance companies paid for it, or offered it at a cheaper price, then going to a doctor to get these injections would be more feasible. (43 years old, Black)

Lack of insurance coverage for feminizing procedures caused several participants to seek care from places outside of the United States. These services were sometimes performed in medical facilities that were unregulated. One participant explained,

I went to Mexico to [have] breast implants, liposuction, and facial surgery done. There you paid the doctor and stayed in the hospital. When I woke up I didn't feel right. I almost died. It felt amazing to have boobs, but I got real sick. I ended up with a staph infection so they had to give me antibiotics and stuff. (32 years old, White)

Although the majority of participants received hormones from both medical and nonmedical sources in the United States, at least one participant purchased her hormones from Mexico. She said, "Prior to moving back to Indiana I didn't even see a doctor for my hormone therapy. I have breast implants and I was taking hormones from Mexico. I would go there for my hormones because they were the strongest" (34 years old, Black).

Theme 4: Recommendations for Improving Care

Participants were asked what advice they would give to physicians and nurses about their care and for making care environments more transgender friendly. In response, participants offered recommendations they felt would help TW feel safer and more comfortable accessing health care, minimize transgender stigma and discrimination, help clinicians establish trust with their TW patients, and minimize awkward clinical encounters. Recommendations covered seven key areas: (a) education and training for clinicians; (b) tailored services for TW; (c) modified medical forms; (d) interpersonal communication, understanding, and empathy; (e) employing transgender peers or staff; (f) normalizing care experiences; and (g) gender affirmation. Recommendations are organized into key topics according to the context in which the participant described the particular phenomenon.

Recommendation 1: Education and Training for Clinicians

Narratives from participants in our study suggest that feminizing hormones (prescribing and managing); genitourinary care, including special considerations for caring for TW patients with a history of GCS; monitoring breast health; monitoring and managing silicone for feminizing appearances, and strategies for conducting a history and physical examination that is non-gender specific (Deutsch et al., 2013), should be included in preservice curriculum for clinicians. The need for clinician education and training in transgender health is demonstrated in the following quotes.

In regard to genitourinary and breast care, one participant with a history of silicone injections stated, "Every now and again the doctor checks my hormone

levels to make sure they're okay. But as far as asking me if everything is okay down there (pelvic area), or up here (breasts), I don't think he knows to" (58 years old, White).

Similarly, a participant who had recently initiated feminizing hormone therapy and had questions about breast development explained,

A clinic doctor gave me hormones. [Afterwards] I started getting these lumps in my breasts... They were really tender and they hurt... I asked him [doctor], "Should I hurt this bad?" He said, "I don't know, go ask somebody who knows." And I thought, "Why is he giving me something that he doesn't know about?" (21 years old, Black)

Non-gender-specific histories and physical examinations were problematic for some of the participants.

I went for a prostate exam... I was listed under my male name. The doctor comes in and thinks that he's in the wrong room. He turns around and walks out, realizes that he was in the right room, and comes back 2 minutes later. He looks confused and says... "I thought you were a real woman" (35 years old, Black).

Sexual/reproductive health was also of concern. "Health care workers don't understand that most transsexuals do not function as a male sexually. Some think that because we have a penis that we use it, and we don't" (60 years old, White).

Recommendation 2: Transgender-tailored Services

Participants expressed a desire to have services that were tailored to their needs as TW. Sentiments such as "Don't lump us under the LGB umbrella... We're different and we have different needs" were common. As one participant stated, "I don't identify with gays, lesbians, bisexuals, cross-dressers, she-males, or any of that. None of them address gender identity, they *all* address sexuality" (50 years old, White). For one participant, the history of the gay community's rejection of TW provided the social context for the importance of tailoring services to TW and for distinguishing TW from gay men. As one participant explained,

I was diagnosed with HIV in the 1990s and, at that time, it was okay to be drag in the gay community. But it wasn't okay to, "quote, unquote," have your stuff cut off. So I just hid my feelings and went on with the show aspect of it. (58 years old, White)

The theme of tailored services also emerged with respect to HIV care with comments such as "Most HIV-related services are geared toward the gay community" and in the context of psychosocial support groups, "As

far as meetings, groups, and stuff like that, there's really nothing for actual transgender women..."

The need for transgender-tailored services was not limited to the health care setting. As one participant shared, "We need housing where transgender women can live a comfortable lifestyle. I've seen many homeless women who are put in a men's shelter" (22 years old, Multiracial). Because participants in our study were also living with HIV, the need for housing that was tailored to TW was critical to their well-being. This need was especially realized for TW who were dealing with a dual diagnosis of HIV and substance abuse disorder. As one participant described,

I just wish there were places where girls could go to get their lives together while they are going through this stuff, [a place] where we could go and stay until we get on our feet. That way the girls don't have to be out here prostituting, and living the wrong life. (32 years old, White)

Recommendation 3: Modifying Medical Forms

Participants felt strongly that medical forms should be modified to reflect more diverse gender expressions and expressed frustration about the absence of transgender as a gender identity on medical forms. As one participant expressed, "I don't understand why hospitals cannot just have something that indicates [patient] identifies as female. How hard would that be?" (60 years old, White). Participants also felt that modifying medical forms would facilitate appropriate care and improve communication between TW patients and clinicians.

Having boxes ahead of time will help the doctor out. If you have transgender on it the doctor can ask ahead of time if you are post- or pre-op. This way they can make sure they know before they say anything that's going to embarrass you. Having these three boxes [male, female, transgender] eliminates the awkwardness. It eliminates the conversation because some girls don't want to talk about it... Some girls don't want you to know what's down there [indicating pelvic area]. So that's where the box eliminates it and if the box is checked for transgender then they [clinicians] will understand what is completely going on. (30 years old, Hispanic/Latina)

Recommendation 4: Interpersonal Communication, Empathy, and Understanding

The quality of TW health care encounters was largely determined by the clinician's communication style and capacity to understand TW life experiences. Participants expressed a shared desire for their clinicians to "understand the struggle of a trans patient talking to them about everything... and the feeling of being in places

where we do not always feel welcomed." Comments such as "Being transsexual is hard... we get discouraged and sometimes... we need places where we can go and feel comfortable" illustrate the importance that empathy and understanding play in TW health care encounters with clinicians.

Recommendation 5: Employing Transgender Peers and Staff

A major recommendation to create affirming environments of care for participants in our study was the adoption of "peer-led models." Comments such as "I don't think they [clinicians] can relate to me like another transgender person can" were common. As one participant explained, "There should be more TW who actually work in the [health care] field because we need them" (29 years old, Multiracial). Peers also played an important role in helping some participants remain engaged in care. As one participant described, "Having a friend, a sister out there who helps me keep track of my appointments helps me. I can't say that I would be able to do [manage HIV care] without her" (21 years old, Native Hawaiian/Pacific Islander). Participants also acknowledged the potential role of peers as peer educators for clinicians, "I have always favored the model of peers helping peers navigate. It would be comforting to walk into the doctor's office and see a transwoman working there... they could [help] educate the staff members" (43 years old, Black).

Recommendation 6: Normalizing the Care Experience

For participants in our study, normalizing the care experience or being "treated just like any other patient" was an essential component of improving the care experience. As one participant said, "Just see me for what I'm there for, don't make a big spectacle by coming in the room and running out to tell everybody there's a transpatient here," (43 years old, Black). Normalizing the care experience was also discussed within the context of living with HIV. As one participant described, "They knew about my HIV, but didn't come in all gloved up and making me feel alienated. They treated me just like the next person, gave me my injection, and checked my blood pressure" (49 years old, Black).

Recommendation 7: Gender Affirmation

Gender affirmation, "the process by which an individual is affirmed in their gender identity" (Sevelius, 2013,

p. 675), emerged as another recommendation for creating inclusive environments. For participants in our study, gender affirmation meant receiving care and health education that was typically provided only to cisgender women. As one participant explained,

Treat [us] like women and talk to [us] about women's health care. I have breasts and am subject to breast cancer. That's not a conversation most doctors have with men, but it is a conversation that they have with women. Talk about the different things that might affect a woman. (43 years old, Black)

Gender affirmation was also viewed as a determinant of entry and engagement in care, two critical steps along the continuum of care for TW, and all persons, who are living with HIV. "There's a big population of transgender people in Indiana, but they don't go to these places [health care settings] because they're thrown into a male category. They (health care providers) don't know how to treat these women" (30 years old, Hispanic/Latina).

Discussion

We explored the health care experiences and clinician interactions of TW living with HIV in Indiana. Findings revealed two clinician types that TW encountered during their health care interactions: *clinicians who get me* and *clinicians who don't get me*. To our knowledge, our study is one of the first to present a typology of clinicians encountered by TW in the health care setting. Our findings also revealed a variety of clinician- and system-level factors that influenced the level of unmet health and education needs of the TW in our study.

In our study, participants who encountered *clinicians who get me* felt that their clinicians were capable of meeting their health and education needs. Other studies have also identified factors that facilitate timely and sustained health care utilization and transgender patient satisfaction with their clinicians. Because TW in our study felt more understood by clinicians who provided gender-affirming care, a study of barriers and facilitators to engagement and retention in care for TW living with HIV revealed that when TW's gender affirmation needs were met, they were more likely to trust their clinicians and engage in collaborative discussions and planning about their health and positive self-care behaviors (Sevelius, Patouhas, Keatley, & Johnson, 2013). Similar to our findings that TW felt best cared for by clinicians who were willing to learn about transgender health, a qualitative study of sexual and gender minority perspectives on provider behaviors indicated that sexual and gender minority patients were appreciative of providers who did

their homework or took time to review their charts before seeing them (Rounds, Mcgrath, & Walsh, 2013). Our findings also mirrored those of Street, O'Malley, Cooper, and Haidet (2008), who reported that clinician-patient relationships were strengthened when patients perceived similarities to their clinicians' personal beliefs, values, and communication. Our participants felt most connected to and understood by clinicians who identified as gay, were female, or living with HIV. Shared social identities facilitate mutual understanding between clinicians and patients, provide a common social context for improved communication, and improve patient perceptions of quality care (Bertakis, Franks, & Epstein, 2009; Thornton, Powe, Roter, & Cooper, 2011).

Participants in our study also expressed greater connectivity to peers and favored peer-led models of care. Peer support can improve patient outcomes and motivate patients to take ownership of their treatment. In addition, peers can relate to patients in ways that many clinicians cannot. For transgender patients in particular, the presence of peers in health care settings can help cultivate cultural competency, may minimize instances of transgender discrimination in health care spaces, and encourage transgender patients to seek medical care (Broadus, Hanna, Schumann, & Meier, 2015; National LGBT Health Education Center, 2016; Sanchez et al., 2009; Seelman, Colón-Díaz, LeCroix, Xavier-Brier, & Kattari, 2017). Use of classic peer navigation models can help transgender patients navigate the ins and outs of the health care system and facilitate optimal care experiences for transgender patients.

Alternatively, participants who encountered *clinicians who don't get me*, clinicians who participants felt were unwilling or uncomfortable caring for transgender patients, or who misgendered participants during their encounters attributed their unmet health and education needs to clinicians' lack of knowledge. Our findings build on the exploratory work of studies examining the negative health care experiences of transgender patients (Kosenko, Rintamaki, Raney, & Maness, 2013). For example, Kosenka et al. (2013) reported that transgender patients experienced an array of negative experiences such as gender insensitivity, displays of discomfort, denial of services, subpar care, and verbal abuse during encounters with physicians, nurses, and emergency department technicians (Kosenko et al., 2013). Our findings were similar to another study that examined health care barriers among transgender people and found that transgender people are often burdened with the task of having to educate their clinicians on how to care for them (Bauer et al., 2009).

Our results further emphasized findings reported in a study that examined physician perceptions of barriers to providing care for transgender patients and revealed that clinical management of transgender patients was impeded by inexperience or lack of preparedness and lack of comfort and knowledge in caring for transgender patients (Snelgrove et al., 2012; White et al., 2015). Encounters with clinicians who “don’t get me” hamper the development of patient–provider trust, hinder open communication about health care concerns, and constrain TW’s access to appropriate health care. The way in which clinicians and auxiliary staff interact with transgender patients also affects patient satisfaction, a criteria used to calculate Medicare reimbursement (Centers for Medicare & Medicaid Services, 2017), the overall quality of the health care encounter, and can determine whether a transgender patient adheres to medical recommendations, returns for future visits, or remains engaged in care. Previous work has underscored the detrimental health outcomes that transgender people endure because of mistreatment, abuse, and refusal of health care because of their gender identity (James et al., 2016).

Normalizing the care experience for TW may help minimize the stigma and psychological stress that goes along with being a gender and/or sexual minority and may help increase levels of comfort and trust in clinicians. However, transgender patients often endure embarrassing and humiliating experiences when accessing care (Beagan, Fredericks, & Bryson, 2015; Cicero & Black, 2016; Kosenko et al., 2013). One way in which clinicians can normalize transgender patient experiences would be to validate their experiences, show empathy, and acknowledge that their feelings are real and justified (Valin-Bloom, 2017). Although there are currently no standardized approaches for teaching empathy to medical or nursing students, research has shown that education interventions can foster empathy in clinicians in training (Batt-Rawden, Chisolm, Anton, & Flickinger, 2013; Kelley & Kelley, 2013; Riess, Kelley, Bailey, Dunn, & Phillips, 2012; Riess & Kraft-Todd, 2014; Webster, 2010). Communication techniques such as active listening, use of gender-affirming language, adapting case studies and simulations to include accurate representation of transgender patients, and providing clinical rotations to meet transgender patients in clinical settings can help cultivate clinician empathy toward this population of patients. Sensitivity training can also help promote a culture of caring and acceptance toward transgender patients (Batt-Rawden et al., 2013; Cicero & Black, 2016; Riess et al., 2012; Strong & Folse, 2014).

Our participants’ recommendation to tailor health care services to be specific to the needs of TW patients and to distinguish TW from gay men reflected the history of TW being subsumed into the category of men who have sex with men. Including TW in the same category of men who have sex with men ignores TW’s true gender identities, minimizes the role of gender identity and transgender stigma and discrimination in influencing health, particularly the sexual health of TW, and reinforces stereotypes that TW’s health needs are essentially the same as those of men (Kaplan, Sevelius, & Ribeiro, 2016; Sevelius, Keatley, Calma, & Arnold, 2016). Previous work has particularly underscored the importance of tailoring services for HIV prevention and treatment services to TW rather than applying prevention and treatment services that were designed to target gay men (Bauer et al., 2009; Kaplan et al., 2016; Logie, James, Tharao, & Loutfy, 2012; Sevelius et al., 2016).

Our participants’ recommendation to modify medical forms to include transgender as a gender identity underscored the role that gender plays in determining an individual’s health care needs and deciding how those needs are managed within the treatment system. As participants in our study mentioned, some transgender individuals “cannot afford to get their name changed;” therefore, collecting data on gender assigned at birth, current gender identity, and sexual orientation can facilitate clearer communication and planning for care (Cahill, Baker, Deutsch, Keatley, & Makadon, 2016). One way in which clinical settings can standardize data collection about sexual orientation and gender identity would be to adopt the two-step method of collecting current gender identity and sex assigned at birth (Cahill et al., 2016). Education and training for medical and nursing students and practicing clinicians should address best approaches for asking questions about sexual orientation, gender identity, and gender pronouns (Cahill et al., 2016) during the history and physical examination. Evidence-based learning modules, such as those provided by the National LGBT Health Education Center (2016) and the Gay and Lesbian Medical Association (2006), provide a clearinghouse of education resources for licensed clinicians and for clinicians in training.

Our findings that fragmented care, lack of insurance, and a low volume of transgender-competent clinicians impede access to care resonate with report findings from the 2015 U.S. Transgender Survey, which reported lack of insurance coverage, health provider inexperience treating transgender people, and distances required to travel for gender-affirming care as barriers to quality and affordable health care (James et al., 2016).

Limitations

Our study had several limitations. First, because of our sample size, we may not have identified all possible clinician types that TW encounter in health care settings. In addition, because our participants were living with HIV, clinician types and quality health care encounters may have been irrelevant to TW not living with HIV. Because our participants were TW living with HIV, it is possible that they encountered greater levels of stigma during their encounters with clinicians than TW not living with HIV would have experienced. Third, our study did not capture the experiences of clinical and nonclinical staff who might have differing perceptions about their transgender-related knowledge and the quality of care provided to TW. Clinicians who fit within the typology of those “who don’t get me” could use the recommendations outlined by participants in our study to increase competency and comfort in caring for transgender patients.

Conclusions

Efficacious and tailored care relies on clinicians having the necessary knowledge and information to diagnose,

treat, and manage the care of an individual patient. Moreover, inclusive care relies heavily on the quality and nature of patient and provider interactions. Incorporating transgender-specific topics into medical and nursing school curricula and continuing education requirements for practicing clinicians could improve health quality and outcomes for TW. Clinicians managing a low volume of transgender patients but interested in learning more about transgender health could benefit from connecting to a network of transgender-competent clinicians who can serve as mentors. Websites that connect clinicians to transgender-specific resources and specialists in their areas may also help facilitate timely patient referrals to specialty services and improve the quality and comprehensiveness of health care for TW. Topics identified in our study can be used to enhance transgender-related curricula in medical and nursing schools, to advance transgender-related knowledge in practicing clinicians, and to improve overall health care experiences for transgender patients.

Disclosures

The authors report no real or perceived vested interests related to this article that could be construed as a conflict of interest.

Key Considerations

- Clinician education and training can play a key role in reducing health disparities for transgender women.
- Tailoring health care services to the needs of transgender clients can improve their care experiences.
- Modifying medical forms to capture diverse gender identities is a practical way to identify transgender clients and can facilitate more inclusive health care screenings and examinations.
- Clinician willingness to learn about transgender health creates a more welcoming space for transgender clients.
- Clinicians can normalize the care experience of transgender clients by treating them as they would any other patient.
- Clinicians can deliver gender-affirming care by providing education and health screenings that acknowledge and affirm the transgender client’s true gender identity.
- Hiring transgender staff or integrating transgender peers into the clinical setting can foster supportive care environments for transgender women.

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