

Original Research

## "They Don't See Our Feelings." The Health Care Experiences of HIV-Positive Transgendered Persons

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**Objective:** To support longer survival, it is necessary to reach an understanding of the knowledge and experience of the HIV-positive transgendered population of current HIV antiretroviral therapies and mainstream health care. **Methods:** This qualitative study utilized a grounded theory analysis with data collection occurring through two peer-facilitated focus groups. The study participants were 10 male-to-female HIV+ transgendered persons who were street-involved injection drug users or recovering addicts. A short questionnaire was used to complete a demographic profile of the group. Focus group sessions elicited information on participants' experiences with (a) health care delivery and (b) primary care services. Audiotapes from the sessions were transcribed verbatim. Major themes were generated and subthemes explored via hierarchical branching schema. **Results:** Primary care providers emerged in the text as dominant figures on which the participants were completely dependent for a variety of care needs. Text data revealed many barriers to the mainstream health care system. Specifically, poor coordination and/or lack of services prevented transgendered persons from accessing HIV care. Findings illustrated a failure in professional skill, poor practice, and a lack of cultural competence in existing health care agencies. **Conclusions:** Health providers must coordinate care with sensitivity and skill with respect to issues of gender, addiction, and HIV for transgendered persons. Adherence to antiretroviral therapy is more effective when addiction is addressed with methadone and/or recovery programs at the same time. The need for hormone therapy creates an important entry point to care, and represents a pragmatic reference point to which to affix HIV prevention and care programs effectively.

**KEY WORDS:** HIV; health care; gender; addiction; doctor-patient relationship; hormones; adherence; antiretroviral; social identity; sexual identity; transgendered; women; female; male.

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### INTRODUCTION

The mainstream health sector is viewed by the transgendered as a patriarchy which has previously ignored or wounded them. This perspective may be due to the fact that, like any marginalized group in our society, the transgendered community has great difficulty expressing their legitimate health needs (1, 2). The common use of street drugs and the participation in the sex trade further exacerbate this fragile relationship (3, 4). The absence of a healthy dialogue has meant that health care professionals have had great difficulty in identifying the needs of this com-

munity (5, 2) and responding adequately (6, 2). This is especially evident in the absence of adequate drug treatment and recovery programs (2, 6-8).

The health status of the transgendered community has not been well documented in the past, but the health status of this community is assessed to be much worse than that of gay or bisexual men (9). HIV infection rates among transgendered sex trade workers have been reported as being as high as 74% in Italy and 68% in the United States (10, 11). The health problems of transgendered communities are likely to be exacerbated by their marginalization in poor inner city areas where the environmental and social degradation (12, 13) is compounded by injection drug use and involvement in the sex trade (10, 11, 14). The relationship between social and behavioral determinants of health and social policy has not been explored for this community (2, 15, 16). What does exist is limited to sexual problems (17) without any appreciation of other basic health concerns. While there is a well-developed literature on penectomy and vaginoplasty concerned with sexuality and gender constructs (18), it has ignored the mental, social and other concerns of this community.

The purpose of this study is to characterize the relationship between social identity and health care experience (19) and the use of HIV therapies within the transgendered community. The ultimate goal is to improve access to care, especially antiretroviral therapy, by giving physicians and other health care practitioners an insight into the health experience and beliefs of this community.

## METHODS

### Sample and Data Collection

This study was undertaken by the British Columbia Centre for Excellence in HIV/AIDS in partnership with the High Risk Project Society, a community-based transgendered organization. Two peer-facilitated focus groups were used to document the health and lived experiences of a select group of HIV-positive transgendered persons who identify as women. The grounded qualitative theory approach was used to reveal the experiences and important themes and concepts from the transcripts of these focus groups (20).

Both focus groups occurred at mid-day and lasted for about 3 hours. Each participant was provided with an honorarium of \$40 and lunch. At the

beginning of each session, participants were read an introductory statement outlining the intent of the study and the measures taken to protect the confidentiality of their responses. All sessions were taped, but any reference to a participant's real name was excluded. Focus group sessions elicited information on participants' experiences with (a) health care delivery and (b) primary care services. Exploration of care was focused on antiretroviral therapies and adherence to them, addiction programs, and gender care. Finally, participants were asked to complete a short nonnominal questionnaire eliciting information about their current living conditions and socioeconomic status.

The study took place in Vancouver, Canada. Advertising occurred in several community and health care settings where transgendered individuals usually congregate. Word of mouth and social networks also facilitated recruitment. Interested participants were contacted by the study facilitator, who is also a leader in the transgendered community. Two facilitated focus groups were organized to attract transgendered persons who were HIV-positive, street-involved, and self-identified as women. The focus groups were conducted at two sites. The first site was a transgendered community-based organization located in a sector of downtown where the sex trade and injection drug use are common, and predictably drew more attendees. This first site is regarded as the poorest neighborhood in Canada, in addition to having the highest rates of HIV infection in the developed world (12, 13). The second site used was a community-based AIDS organization located in a high-density residential area in downtown Vancouver.

### Data Analysis

Audiotapes for the two focus group sessions were transcribed. Textual documents were then audited by the principal investigator and coinvestigator to ensure the accuracy of the transcriptions against the tapes. QSR NUD\*IST (nonnumerical unstructured data indexing searching theorizing) software was used in the analysis of the data. Using the grounded theory method, all textual data were given meaning with coding. The interpretive process moved coding into categories and then into theories (21). Major themes were generated and subthemes explored via NUD\*IST's hierarchical branching schema. Grounded theory assumes that a group with similar experiences shares basic social psychological

issues and will process them similarly. The objective of this analysis is not to focus on the similarities that could be developed into generalizations, but to reveal specific issues that will provide a contextual understanding of care and identity (22, 23).

Many quotes from our textual data have been used to illustrate emergent themes. Quotes of the participants and identity are lettered alphabetically within study and bear no relationship to an individual's identity. The credibility of this research is supported by voices and lived experiences of the transgendered participants. In addition to peer debriefings with participants, coinvestigators, and faculty colleagues, the reliability of our findings was supported by further investigations within the community context.

## RESULTS

Ten HIV-positive transgendered persons participated in this study. All participants were born in Canada. Six participants were white and 4 were Aboriginal [First Nations or Metis (French and Aboriginal)]. The median age was 32 years (range 23–43). All had been known to be infected with HIV for at least 10 years. Six had acquired HIV through sex with a man, 3 through injection drug use, 1 through a sexual assault, and 1 through exposure to infected blood products.

Participants generally lived in unstable rental housing and had low incomes. Six participants lived in apartments, 2 in hotels, and 2 in shared accommodations. Four subjects reported incomes below \$10,000 per annum (range \$10,000–70,000). Nine participants received income from social assistance, and 8 from income derived from the sex trade. Inevitably those with high incomes were active in the sex trade. On the average, participants had 11 years of schooling.

### Health Care Delivery

Transgendered persons generally felt they experienced discrimination in their interactions with the health care system in Vancouver. The following quotes highlight this important theme in the transcripts.

"I would think that the health care professions—they don't see our feelings. People say oh wow, if

they don't like us and they think we're fucking sickos, and freaks and everything else, that's their problem. But after a while it does hurt, you know. Sure it's their problem, but it becomes your problem too because it does hurt. Everybody wants to be accepted... and it's just a shame that we're not accepted. Because we're not hurting anybody—who are we hurting? Everyone wants to be loved." [C]

"I don't think they [health care professionals] see the years of isolation and struggle. I think probably isolation is the biggest one that I would think probably most transsexuals go through. [Because] as people who have identified as opposite genders,—if you identify [with] female where you have been categorized male... that isolation just becomes an overpowering thing. And I honestly don't think that most health care workers are aware—number one, this isn't an extension of the drag personality. This isn't a sexual fetish. This isn't something you decided you were going to do [for fun], you know. This is something that you've reached a point, usually where there is no choice. It is either you can explore this transformational gender issue, or kill yourself. Simply that. And I don't think they understand that. So I think that's probably something they do not see when they look at me." [I]

Many did not fully disclose all their health care issues or concealed their social identity from health providers for fear of rejection. Some of the subjects would go to the doctor dressed in "drag" (i.e., as a man) to avoid discrimination. As a result of discrimination many participants delayed contact with the health care system until illnesses such as endocarditis, abscesses, septicemia, pneumonias, sexually transmitted infections, or liver disease forced them to obtain care.

"But now when I get sick I just go right to the emergency at St. Paul's [Hospital] I don't bother with the doctor or anything, I just go straight to emergency. Because when I get sick it's usually very serious. So I just don't bother with anyone and just go straight to the hospital." [G]

Maintaining the appearance of "passing" as a woman remained a central issue in care. This is the definition of self and the affirmation of self-concept by others. Participants desired to live and maintain the physical appearance of women during the course of HIV disease.

"When you're in drag—and it is a lot of work to be able to go out and be passable—that gets to you too—like if you go out and you're not passing. People are still reading, figuring out that you're a man—and they look at you even worse." [B]

The problems of female self-perception (the protection of one's gender selection) during hospitalization remained paramount to the transgendered. However, all participants described the health care experience as a challenge to their self-concept in which health care professionals used the transgendered as an opportunity to affirm their own concept of sexual and social identity. In these circumstances, only the care provider received self-affirmation of personal self-concept; the patient was alienated and objectified, resulting in a complete compromise of care.

"[The] Health care system towards me I find is just ... very cold... very stereotyping. You go into a health care unit and they ask for your PIN number [medical insurance number] and it has 'M' or 'F' [male or female] on it. They look at you and see female, but on that it says male, so they go by male. And they call you 'he, him' and you're nothing but a sexual number to look at. That's it. No feelings, no nothing." [F]

"She and that. And then a doctor will come in and look at the form and see male—look at me and go 'he.' Even though it's like she he sees .... I feel like Dr. Zeus." [C]

In the focus group discussion many psychological issues surfaced without probing. Depression and suicidal ideation were strong themes and appeared to stem from both marginalization and HIV infection. It is important to note that statements reflecting suicidal ideation were made by 4 out of the 10 individuals.

"I go through periods of very deep, deep depression and there's times when I just want to jump off a fucking bridge and say 'why—why do this to myself?'" [A]

### Primary Care

The "doctor" was seen as the most influential health figure to emerge within primary care delivery. The word "doctor" appeared more often than any other word. A full range of relationships was associated with doctors, from good to bad, depending on the age and the experience of the participant with the health care system. Participants who were addicted and not in recovery were more likely not to state their legitimate health needs and be more concerned with their physician's needs. The following statement was made by an emaciated person with visible abscesses and a productive cough.

"My Doctor's excellent. I haven't had any major health issues so she's very happy with me so that makes me very happy with her as long—as she's happy with me, I'm happy, so I haven't had any trouble." [F]

Complexity of the health needs of this population surfaced quickly from the textual references, which suggested a knowledge and skill base for primary care providers specializing in transgendered care. Others had negotiated satisfactory doctor-patient relationships built on many years of experience.

"My doctor's good with both hormones and HIV treatment and he's very well educated for dealing with transsexual issues [hormone therapy]. I'm going to stick with him. He has a heart—he actually cares, and he shows it." [D]

Dual primary care specialization was observed such as gender care with addiction care, or gender care with HIV primary care. Only one primary care doctor was conversant in all three areas. In this sample, transgendered people were involved in the sex trade and were also addicted to drugs, mostly heroin and cocaine. It was observed that those who were receiving care from a physician who also prescribed methadone were more likely to adhere to antiretroviral therapy.

"He's got me on all the AZT, 3TCs and all of those. He's also got me on methadone so I'm not on the street looking for heroin. He's good." [E]

The study group depended heavily on the HIV knowledge and recommendations of their physicians in assessing therapies. Participants exhibited limited knowledge of and fluency with HIV or contemporary therapies. Gender care, addiction care, and HIV care appear to comprise a minimum set of professional skills required by physicians treating this population. Incidences of poor coordination with HIV specialists, addiction specialists, and the local gender clinic surfaced in the data. Themes suggested that a key subset of physician education would include cultural competence, mental health, and human sexuality.

### Antiretroviral Therapies

In this group, an ability to integrate complex therapeutic dosing regimens required by antiretroviral therapy into daily life often was impossible when attempting to continue working in the sex trade. There were also predictable fears of disclosing HIV status by the mere presence of the drugs. Side effects

of the current HIV therapies emerged as a dominant underlying issue impeding adherence. There was great concern by the participants over side effects and ability to tolerate therapeutic drugs. Another important collateral concern emerged. Combined effects of hormones and HIV therapies on the liver were not addressed, as both physician and patient had no definitive knowledge of known interactions or side effects. Interestingly, another relevant theme that surfaced in the text was an overwhelming hostility to AZT and refusal to use it.

"I do not like AZT. Well my personal opinion why I don't want to take it, is because of the side effects—I'm on 4,000 pills a year, or 5,000 pills a year. If I have to take a protease inhibitors three times a day, that's 1000 pills a year. I can't tolerate alcohol because my liver is just fighting to keep up...to all the pills I'm ingesting. That's a lot of pills to take. I have a hard time keeping track—a lot of my friends don't take them because they have to carry them around. If I want to go out tonight I know I might not make it ... home till tomorrow...so I have to carry an extra 15 pills for the morning." [J]

### Addiction Care

All but one [the youngest] of the participants in this study had previous experience with injection drug use, or were on methadone therapy.

"I'm on AZT and 3TC and methadone. The methadone is to curb my heroin addiction and the AZT and 3TC obviously is to fight the HIV disease. Since then, I've put on 26 pounds, so obviously something's working. I moved out of the skid row area, because it's just like a magnet.... I'm trying to make my life as normal as it's ever going to be." [C]

Addiction therapy was often isolated from HIV primary care. Study participants who were linked to a methadone or recovery program indicated a greater adherence to HIV therapeutic regimens. Follow-up investigation assessed the capacity and ability of recovery services. The local detox center appeared conversant with managing gender issues by assigning participants to rooms on the women's side. However, there appeared to be a lack of a structured continuum for recovery and support. Follow-up interviews with two of the subjects on the street indicated that one had entered a suburban recovery facility for heroin addiction for 1 month. Another person indicated that access to such facilities had been impossible to obtain.

### Gender Clinic

The gender clinic cited in the textual data is located in another hospital which has a focus on broader human sexuality issues. This clinic was located in a hospital that the participants in this study did not utilize and viewed as distant. Textual data suggested that the facility was HIV unaware, and not coordinating services with addiction care, primary care, and HIV care. One text unit referenced an electrolysis technician working at the clinic refusing to treat an HIV-positive patient. There were also complaints about the lack of counseling services and follow-up of past corrective surgery. Many participants were also unable to cope with therapeutic protocols used within the clinic to prescribe hormones. As a result, many participants purchased these hormones on the street, especially if they were younger. In caring for this population a strategic point of *opportunity for intervention* is hormone therapy, especially for youth.

"My doctor—he didn't know much about it, so he said to refer me to the gender clinic and I've never been there but the stories that I've heard—it sounds to me like a bunch of bullshit. So I just buy them on the street." [F]

Some transgendered were reported to take excessive hormone treatment, and this was often done without the knowledge of their physicians. Hormones emerge as a common denominator that appeared linkable to future care and prevention services. There was also little acknowledgment within the gender clinic of the participant's active involvement in the sex trade:

"As far as HIV—well, you know, most of the transsexual women that I know have worked at some point in the sex trade because there is no education, there is no acceptance... because of society's and the medical industry's head in the sand approach to things." [I]

The use of illicit drugs, such as heroin, was not dealt with by the gender clinic staff. There appeared to be a void in considering the issues of addiction and HIV care. Availability of feminization therapy and gender reassignment surgery to persons with HIV disease was a major concern, as individuals said that if they could find a surgeon to do it, they had to underwrite the cost themselves. If HIV were not an issue, costs of surgery might be covered under the public medical system, but the expense of feminization therapy also needed to be secured. These basic

surgical costs alone can exceed \$20,000, which usually can only be covered by work in the sex trade.

### Hospital Care

To some participants the hospital was a sanctuary (care in a hospital ward) and a respite even if they are sick at the time.

"For some reason, a hospital is the most comfortable surrounding for me—I can sleep—there's always somebody around who cares, and if anything goes wrong I'm in the right place." [J]

Fear of isolation and abandonment was a sub-theme appearing throughout the data. Issues arise when segregation occurs within facilities between female and male patients in shared rooms.

"I've been in with women the first night... but they isolated me to my own room the next night." [H]

Invisible barriers such as designated bathrooms also impede access for the transgendered; this is easily resolved by nondesignation, as in any home. St. Paul's Hospital, large HIV tertiary care center in Vancouver, was generally recognized as being sensitive to transgendered issues. There was a clear delineation between St. Paul's and other large teaching hospitals in the city, which were viewed as incompetent in dealing with transgendered issues. Despite their tertiary care hospital providing care that was generally safe to the transgendered, it did not go far enough to insure their social comfort.

"If you're in the hospital ... the thing makes you feel better if you have your big, pink fluffy slippers and your pink frock, you can't do that in a hospital... If that makes you feel better, well then sure—that's good—you can feel comfortable being who you are—if you're with a queeny old girlfriend, or whatever, you can be like that—not to worry." [B]

Street-entrenched transgendered persons live within a vortex of abuse, and even a moderately invalidating environment can be a sanctuary for a time. A new hospice and day care center was well regarded by the participants as an environment in which they felt comfortable and safe, and as a place to participate in their own care and that of others. Although this center is independent of the HIV tertiary hospital, it was assumed to be the same provider because it is housed within the same complex of buildings. Unfortunately, different results and findings ap-

peared for emergency room care at this AIDS hospital:

#### *Judgment:*

"I went into [hospital emergency] with an abscess on my neck—it was like the size of a golf ball, from intravenous drugs. And I got this doctor—he didn't put no freezing in my neck or nothing—nothing and he put that cloth—you know with the hole—and he's pressing to get all the garbage out of me and I was screaming 'it hurt.' And you know what he told me?—'you weren't screaming when you stuck the needle in your neck for drugs, so just take it.' That's exactly what he said. No freezing, no nothing. I couldn't believe it. I haven't gone back there since." [C]

#### *Assault:*

"I'm in emergency, I get a new intern. He sticks his the stethoscope in my shirt to listen to my chest and then he comes across something... and pauses and rubbing my nipples for a few minutes... And I start looking at him like... what the hell are you doing? [breathes and sighs] He asked me some questions and then he clues in, and he just leaves, and sends a nurse in to finish up the rest. I was quite angry." [J]

#### *Violation:*

"My recent experience [in emergency at the] Hospital for stomach problems. They knew of my transgendered experience and I'm on a gurney... and he lifted the blanket—the doctor had come and lifted it up—and he says 'oh, yes, you did have sex reassignment surgery' [all participants gasped in horror]." [K]

Emergency room staff need to be sensitized to the best practice relating to sexual identity and social identity issues. There was a clear distinction in the data between care that was provided in the emergency room and within other sectors of this hospital. Some of the specialized care providers within the hospital were also seen as insensitive to cultural issues around sexual identity. The behavior of some physicians was prurient and sexist, with assumptions that the transgendered women need not be handled with the same protocols as "genetic" women in situations of examination.

"A dermatologist says... to take all my clothes off—I took all my clothes off—he took one look at me ... kind of opened up his eyes and said 'OK, get on the table and go on your hands and knees.' I thought...AAAAHH. I never went back [gasps of disgust from other participants]." [J]

Without an explanation by the physician, this Aboriginal person, who had a history of abuse and of the sex trade, assumed she was being asked to take

a submissive sexual position. To her, this request was abusive and humiliating.

## DISCUSSION

Our findings offer important insights into themes relating to the access of care by the transgendered community. Most notably, we have shown that transgendered persons are not always served well by health providers and within the services available to them (16). The relationship between health care practitioners and the transgendered is strained because of systemic poor practice resulting in avoidance, hostility, and indifference. We attribute this factor to lack of training in cultural competence with the transgendered community (24, 25), especially in issues dealing with human sexuality (26, 27). Overall we find considerable room for improvement in health care delivery to this community, especially in the coordination of antiretroviral, addiction, and gender care.

This study uncovered the importance of doctor-patient relationships in accessing care. We believe this relationship needs to be sensitized to the transgendered (2). The fragile identity of transgendered persons makes them vulnerable in care-giving settings, especially since they often are unable to state their needs to a doctor. Our results demonstrate that the transgendered often succumb to power imbalances, as they do not feel they have a choice because of persistent social and institutional reinforcement of their low social status (2, 3). Relationships with physicians further reinforce this power imbalance by failing to deal with the transgendered sexual identity. Ample time to counsel, careful negotiation, and communication are necessary to achieve a balanced, trusting therapeutic relationship (28).

This study highlights the need to improve access to primary and antiretroviral care for this community. This emergent issue presents us with a series of complex social and professional challenges (29). Other considerations also factor into the doctor-patient relationship, for which cultural competence remains an important issue for training. Access to and development of treatment strategies for this marginalized patient population must also be devised to ensure that they can be integrated into HIV drug access based on their lived reality (30). To be ethically responsive within their practices, health care professionals need to address issues of marginalization and discrimination (25). Failure to respond adequately may impede

access to life-prolonging drugs, which implies ethical liabilities.

The side effects and interactions of these drugs and the complex dosing regimens also present enormous obstacles (31-33). The concomitant presence of liver disease suggests that protocols that reduce the adverse side effects of combination regimens are needed. Antiretroviral therapy should be also considered for those with chronic liver disease (34). The drug interactions between antiretroviral drugs and hormone therapy need to be investigated (35). Consumer treatment information needs to be readily accessible and provided at the community level in plain language spoken by the community, to support the process of self-empowerment.

Key health services have not adequately dealt with concerns raised by this study group. Gender care has been remote and isolated from the community and remains inaccessible with little integration of addiction or HIV practice into its programs. It stands to reason that those who are actively engaged in drug use and the sex trade will be unlikely to adhere to current medical regimens. Primary care providers require training and coordination to fully address the major health challenges inherent in this community (11, 36, 37). Injection drug use and concomitant care for related needs (38, 39) has to be improved for this group. For adults and adolescents priority programs should provide drug and alcohol education and needle exchange with street outreach (40-43). Recovery and methadone care is a pre-determining factor for successful adherence to HIV therapeutic treatment protocols (8, 37, 39) and this is only possible when primary care providers are competent in providing gender, addiction (44) and HIV care simultaneously.

Adolescents, especially if they are transgendered, are at high risk for HIV, but have limited access to relevant and appropriate prevention education (4, 45) and early intervention services in health care (9, 11, 46, 47). The prevalence of histories of sexual abuse in childhood should be factored into all health care considerations for this community (48). Older transgendered persons also require specific treatment and diagnostic protocols to address the cumulative impact of marginality on health (49). Health care and support services should offer peer support and substance abuse counseling simultaneously with primary health care, access and referral to HIV care, and hormone therapy (2, 37). Depression and suicide consistently remain a risk for this population, and practitioners

should be quick to investigate and intervene (50, 51). Successful strategies of harm reduction should be integrated into a social context and be merged within a care and prevention paradigm similar to that developed from lessons learned from other minority groups (52, 53).

## CONCLUSION

In conclusion, this small study highlights a number of important health needs in this group of marginalized transgendered persons. We believe that any interventions for the transgendered should occur at the point of primary care—the entry point—and should address issues of HIV, addiction, and gender care. Hormone therapy remains a universal point of request for care to initiate other types of health care. Overall, in the face of the HIV epidemic currently occurring in Vancouver, health services must be reconfigured to ensure adequate access to care for the HIV-positive transgendered community, and to prevent further infections in adolescent transgendered persons.

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