

Identifying Training Needs of Health-Care Providers Related to Treatment and Care of Transgendered Patients: A Qualitative Needs Assessment Conducted in New England

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SUMMARY. The Transgender Training Project of the New England AIDS Education and Training Center has been providing training on transgender-related issues to health-care providers in the New England region since 1999, having trained nearly 600 providers in that time. The Transgender Training Project embarked on a study during the 2001-2002 grant year to interview providers of HIV-related care and advocacy on their knowledge and experience with working with transgendered people and to assess training needs to increase their effectiveness with transgendered clients.

The methodology consisted of face-to-face interviews with 13 providers of HIV treatment and care who are affiliated with the New England AIDS Education and Training Center network to discuss clinical challenges in working with transgendered people.

In this exploratory study, we found that providers had:

1. Desire to treat transgendered patients respectfully but admitted discomfort and lack of tools for specific interviewing/assessments.
2. Experience with a range of transgendered patients, but lack of information on distinctions among transgendered experiences.

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3. Restrictions based on time constraints that create an overarching barrier in building trusting relationships with clients, and trusting relationships are integral to quality care.
4. Concern and frustration with lack of information, studies and research.
5. Concern and frustration with lack of treatment guidelines, (or ability to access them), referral contacts and ways to advocate for transgender clients.
6. Belief that training by transgendered people themselves was an essential teaching element.

These results point to the need for the development and dissemination of specific training materials and resources for health-care providers serving transgendered people living with or at risk for HIV. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2005 by The Haworth Press, Inc. All rights reserved.]

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INTRODUCTION

With studies spanning back a decade, HIV prevention and treatment providers have been seeing alarming signs of the impact of HIV on transgendered people. Prevalence studies have shown strikingly high rates of HIV among transgendered populations. Studies of transgendered sex workers have found 68% in a study in Atlanta (Elifson, 1994) and a 1998 study in San Francisco—the largest scale study to date—some of the starkest evidence was gathered: 35% of the group was HIV positive and 63% of African-American male-to-female subgroup were found to be HIV positive (Clements-Nolle et al., 2001). Of this, many learned of their status by being tested as part of the study itself.

A number of findings have been consistent and telling as members of the transgendered community have been surveyed in community-based needs assessments. Highly marginalized lives mix with other issues such as poverty, racism, violence, lack of housing and employment options and damaging or discouraging experiences with medical providers put transgendered people at high risk for HIV and make it difficult for transgendered people to obtain respectful, quality care.

A primary finding of these needs assessments is that health care providers lack basic knowledge and need to be trained on working with transgendered people. Participants in focus groups and interviews have reported experiences of being refused care, mistreated, harassed and ridiculed by providers (Clements,

1998; Elifson, 1993; Bockting, 1998; McGowan, 1999; Kammerer, 1995; Xavier, 2000; GLBT Health Access, 2000; Kenagy, 2002). Transgendered people have said that negative experiences with providers, including HIV test counselors, prevent them from seeking HIV testing (GLBT Health Access, 2000).

In related studies, HIV-positive participants have stated that they receive confusing messages from medical providers and that they need more information about hormone therapy and gender reassignment surgery to make informed decisions (Bockting, 1998; Clements-Nolle, 1999). Indeed, very little information is readily available for providers to assist patients in making informed decisions and much of the knowledge is developing in practices with high numbers of HIV-positive transgendered people. Even providers in those settings have little or no training and are experiencing a steep learning curve as they work with patients for whom there is little clinical research to guide the way.

The word “transgender” is generally used as an umbrella term for a wide range of people who do not fit neatly into traditional societal views of male and female, man and woman. One way of looking at how society constructs language and concepts around gender is to refer to our dominant cultural paradigm as “bi-gendered,” that is, only two genders are commonly recognized. Transgender experience encompasses a range of people who experience their own identity, or express that identity to the outside world, in ways that broaden the boundaries of a two-gender system. Some transgendered people, however, believe perfectly well in the

two-gender system, and feel they were simply assigned the wrong gender at birth. “Transsexual” is generally used to distinguish those who desire to live full-time in the gender role different than the one assigned at birth, and who take or plan to take hormonal and/or surgical interventions to have their bodies better fit that role. (Further, transsexual spelled with one ‘s’ is the preferred community spelling; whereas two s’s, transsexual, is the more common medical community spelling. The former spelling connotes community and identity whereas the latter focuses more on a medical model based on a bi-gender construct) (Bockting, 1997).

Male-to-female (MTF) is the common term for those born biologically male who express or feel their gender in more feminine ways; and female-to-male (FTM) is used for those born biologically female who express or experience their gender in more masculine ways. Both constitute spectrums, or continuums, with a range of experience, expressions and desires along that continuum. Further, an individual’s place on that continuum can and does change throughout their lives. “Trans” is also accepted as an umbrella term and is becoming more popular, especially since there is a history of some tension between those identifying as transsexual versus transgendered (Koyama, 2001). In this article, trans and transgendered are used interchangeably, and both serve as umbrella terms describing a range of gender variant or gender non-conforming experiences, identities or expressions.

The Transgender Training Project of The New England AIDS Education and Training Center has been providing training on transgender-related issues to health-care providers in the New England region since 1999. The project has delivered 31 presentations to providers in the New England region, reaching over 600 people in workshop and conference settings. Additionally, the project has trained over 3,000 providers in other regions of the country.

The Transgender Training Project embarked on a study during the 2001-2002 grant year to interview providers of HIV-related care and advocacy on their knowledge and experience with working with transgendered people and to assess training needs to increase their effectiveness with transgendered clients. Below we will report on the study’s findings.

METHODS

Participants

Participants were health-care providers involved in HIV-specific care who are affiliated with the New England AIDS Education and Training Center network and who have had some experience working with transgendered clients. Providers were recruited at the New England AIDS Education Center’s annual meeting and through other contact information available through this agency. In some cases, the initial provider contacted referred another provider in their agency or practice who was then interviewed.

Thirteen interviews were conducted with clinicians (1 physician, 2 nurses, and 3 nurse practitioners), case managers (n = 4), and pharmacists (2 pharmacists and 1 pharmacy technician). Interviewees worked in Connecticut, Maine, Massachusetts, New Hampshire, and Vermont. Providers worked in urban, small city and rural settings. Worksites included community health centers, community-based clinics, community-based pharmacies, and HIV clinics in hospital settings.

Instruments

Interview questions were designed to discover information about:

1. knowledge and experience on transgender issues;
2. comfort with transgendered patients and provider-patient relationship;
3. challenges with provision of health care and referral;
4. HIV-related experience including Highly Active Anti-retroviral Therapy with HIV-positive transgendered patients, sexual history-taking, and risk reduction counseling;
5. agency-related barriers;
6. preferences for methods of training and learning.

The interview questions were pilot-tested with several providers as well as reviewed by a physician involved in transgender health care. In the pilot sessions, providers indicated that they and their colleagues would “feel uncom-

fortable being asked questions they didn't know the answers to." As a result, questions were reframed to be more open-ended and allow for more free-flowing responses. For example, instead of asking "How would you explain 'pre-op' and 'post op'?" the final question was "How does the medical community define 'Transgendered'?" Another example was to go from the specific "Are you familiar with the Harry Benjamin Standards of Care? What is your understanding of them?" to the more broad "What do you think are some challenges for providers in working with Transgendered people?" and "What are some specific things you would like to know more about?" (For a complete list of interview questions, please contact the author directly.)

Since many of the providers interviewed had no or little exposure to transgender medicine, and were not familiar with community definitions or language or the Harry Benjamin International Gender Dysphoria Association's Standards of Care (HBI-GDA is the professional organization dedicated to treatment of transgender conditions), the final framing of the questions honored their areas of expertise while allowing them to identify gaps in training and information.

Procedure

Key informants were interviewed individually in their office setting. Interviews lasted from 45 minutes to an hour. Participants reviewed and signed an information and consent form and were given a choice of books on transgender health care for their personal libraries as a small token of appreciation for their contribution to the project. The interviews were audiotaped, transcribed and coded to determine themes.

RESULTS

Knowledge of Transgender Experience

All of the providers interviewed had had some experience with a transgendered patient or client, but many said that they were not necessarily familiar with terminology or distinctions within different communities. A number of providers explained understanding "transgender" to mean "medical intervention to move

from one gender to another gender" "as opposed to transvestites." Some explained "someone who is gender ambiguous but not having gone through a gender process." "Gender process" in this context referred to traditional gender reassignment, involving psychotherapy, hormone therapy and genital surgery.

But there was a range of thinking and an awareness that a broader view of gender non-conformity might not be common in the medical community. One experienced participant explained:

Currently, the transgendered population is all over the map in terms of stages of reassignment they are going through. That's what I'm seeing. Have people intent on having complete gender reassignment and working towards that process. And have other patients who have no plans at all of ever going through that. And I have other patients who want to do certain components of it, may go through some. They might for instance, go through breast augmentation, but not genital surgery. But my colleagues are not with that definition. Providers with my mindset are few. . . . For the most part, the old way of looking at it, client says they are gender dysphoric, in the ways they can say it, usually psychologically, and then [providers] say how can we move this person along to full transition, from whatever, MTF or FTM. That is the standard.

Using a medical model to define a transgendered patient was more common among the clinical providers. One of the non-clinical providers offered an opposing definition that he thought was more common among his colleagues at an urban community-based clinic. His belief was that people were more likely to think of people who cross dress, who don't "pass," as transgendered.

I know the definition of TG because I used to work with them. But I think that the people that I work with here? I think they define transgenders as cross dressers. If they are a man who dresses in women's clothing or a woman who dresses in men's clothing, they would consider

them transgendered. They call them drag queens. I think they mostly think about the male to female more than the female to male. I know that the term transgendered is more broader than that. The word “transgender” is an umbrella term and encompasses much more than that. Could be drag queens and drag kings, cross dressers, pre-ops, it can encompass a lot more than that. It is not necessarily the dress up piece but also the mental piece.

One important factor in providers’ knowledge was the degree of their experience and exposure to transgendered people and the cultural norms that exist in different trans communities. When providers only have exposure in rare instances, they are not able to develop comfort and expertise.

I don’t have repeated exposures to develop enough expertise. And that’s one of the problems when you don’t run into something a lot. I know that experience helps. I know where I was 15 years ago dealing with gay men.

Mental health providers might be very experienced around HIV, substance abuse, depression, but really don’t have as much experience dealing with psychosocial challenges of someone who is transgendered.

The lack of experience influences a sense of discomfort on the part of providers, and this can then lead to unhelpful or even hostile treatment of the trans client. This can be based on lack of knowledge and discomfort.

When a person comes to [the provider’s] site, there’s no algorithm or context or training that they can rely on and I think what happens in that case is that people rely on what they do know, which may be neutral or may be negative, depending on their other life experiences.

Patients can also have extremely negative experiences, which might be due to lack of training and guidance, but also due to discrimination and bias against transgendered people.

One of the case managers described a hostile scene at a community health center.

The transgendered person was at central registration and the worker clearly laughed in their face. They just laughed at the person. And they kept demanding the person’s birth name. And the person was identifying themselves by their transgender name. [The worker] laughed at the person and clearly made the person feel like they were not welcome. And that was in a “community” health center. They tried to get me involved in the “haha” joke, and when they saw that I didn’t find it funny they were wondering what was wrong with me.

Providers Play a Role in Teaching Patients

Sometimes the provider has language or exposure that the client does not have. Even within the transgendered community, there is a range of awareness and of language. Not all self-describe as transgendered, some may have a bias against the word or simply not be aware of its meaning, and providers sometimes play a role in educating them and introducing them to the transgender community in a new way.

I’ve learned in working in this field to meet people where they’re at. If they ID as male, and I clearly know them as female. I will ID them as male. But I’ll let them know that there is another word for that, that it is transgender, I’ll try to educate them around that. You know, “you may want to consider yourself to be transgendered.”

Information is often needed to dispel myths and lack of information on the part of patients and their perceived risks. An example:

One patient, this was my most surprising situation. I had a FTM patient who had hypertrophy of the clitoris because of long-term use of testosterone and also he had bought a device that helped to enlarge the clitoris where it looked like a small penis, and he was in a relationship with a woman where he believed that he

could impregnate her. And I had to go through—first of all my surprise, that you could think that—and then go and explain that the genitalia could change but that [capacity to impregnate] doesn't happen.

Dealing with Difference and Complexity

Working in the field of HIV, providers feel they are already situated in marginalized communities and more equipped to handle issues of difference and non-conformity in areas of sexuality, sexual expression and gender identity. HIV providers expressed that complexity of individuals' life and psychosocial challenges are built in to the relationship around issues of HIV prevention, risk assessment, and treatment.

You expect, you're an HIV clinic, people in HIV work, expect to have folks of all sorts of stripes, quote "out of the norm." We deal with a wide variety of individuals marginalized in different ways. People come here who move in and out of society for many reasons.

There was a recognition that issues faced by transgendered people are many layered and that tools for cultural competency would be useful in training providers on how to work with this population.

A challenge we have as providers is that we want to do targeted work, but someone who comes who is transgendered is not coming as one targeted thing. There are a lot of aspects, besides transgendered identity, that define that person's identity. You have to be able to understand that, part of it is to focus on the individual and part of it is to focus on the community and what its needs are.

The problems that arise for transgendered people are multi-factorial. You have to look at them from all perspectives in order to provide comprehensive care.

Distinctions from Gay and Lesbian Services

Several of those interviewed self-identified as gay or lesbian or worked in gay, lesbian, bi-

sexual, and transgender (GLBT) agencies. Often, transgender lives and experiences are conflated with gay and lesbian experience. While there is overlap, for instance, effeminate men and masculine women have a strong presence in gay and lesbian communities, sexual orientation and gender identity are different things. Transgender people may identify as gay, lesbian, bisexual, heterosexual, pan-sexual, or asexual. Their sexual orientation may be based on their identity, not their anatomy. Thus, a male-to-female transwoman might identify as a straight woman in her relationships with men. A female-to-male transman might identify as a gay man if he is sexually attracted to or has sexual experiences with biologically male gay men.

It is not unusual for providers to miss the distinctions. For instance, one gay-identified provider said, "I think of people who are drag queens. I don't label them as transgendered. If they engage in sex with other men, I consider them as gay men."

Interviewees expressed reluctance on the part of their organizations to embrace transgendered people:

People that work in this agency, they're all in a different place in terms of understanding. Some of us are like, we just have to do it [add transgender to our mission and focus]. But others resist. And I think the resistance is fear-based.

We know that not including Transgender [in our agency name] we're doing a disservice. The B and the T are there, they're just not in our name. . . . To do it right, takes time. If you can't provide the services, you shouldn't add the letters. Need to know, what are the services we need to provide in order to add that to our name.

Building Trust for Effective Provider-Patient Relationships

Providers were uniformly well-intentioned and discussed how being able to focus on the client and build trust are necessary to create sufficient comfort for patients to open up, discuss and disclose risks, work through risk assessment and risk reduction plans, etc. Both

medical providers and case managers who provide counseling said being accepting as a clinic and non-judgmental as a provider, letting clients know “anything you say in this exam room is fine,” were key elements to building trust.

How people get and receive care from a provider does depend on how comfortable that person feels with the provider. Many transgendered people have enough self work to do and enough self stuff going on that the last thing they want to do is train someone on their needs or the needs of the transgender community, so it becomes the provider’s responsibility to have that information.

Obviously, there are limitations to the degree of trust, openness and success any counselor or provider can have with a client. Interviewees also recognized that the power imbalance inherent in provider/patient relationships plays a big role in the ultimate extent of that relationship, especially pertaining to such issues as gender non-conformity, drug use, sexual behavior and other activities that might be illegal or judged harshly by providers.

Another thing we know is that people lie. And part of that is we don’t want to expose ourselves to a person who may have a lot of power over our lives as a medical provider. If my experience in life is that you are going to withhold something [e.g., access to hormone therapy] from me, I’m going to lie. It’s hard enough to tell these things to people who I know and trust. If I tell you, it could be a bad thing.

Understanding that there is a power relationship, but also wanting to build rapport, asking questions in an affirming way and not assuming to know what a client wants or needs were also seen as essential to effective interviewing.

The point becomes how do we ask the question that’s affirming, how do we value that person and get the information that we need.

One of the barriers is, not having an understanding of the person who is across from you, who is the patient. The second barrier that is related to that is treating them as if you know what their needs are. In a sense that you put them into a box. For instance, if they are biologically female and you’re treating them as female, but they don’t view themselves as female, that’s going to create real barriers in the rapport that you have with that client and ultimately may turn them away from receiving services.

Providers need to ask open-ended questions that are general in scope. So patients can answer as is appropriate to them. Can’t ask “do you have anal sex” [and they believe it is vaginal sex] because you’re not gonna get the right answer. I think that’s part of the problem. As soon as one of those questions is asked, everything stops. You can’t go any further with that person.

Lack of Time

While providers recognize key elements to successful interviewing, there are institutional barriers that stand in the way, regardless of a provider’s personal intentions. Simply put, building trust takes time. Case managers and counselors have a little more time than the clinical providers, some can take as long as a client needs to get to the root of tough issues, but in general, providers have only a short period of time to meet with a client and must cover a range of medical concerns in that time.

Physicians are really overwhelmed. Managed care has really changed things. The way we arrange medical care as a society, you’re lucky if you get 10 or 15 minutes with a person. If you have 1 or 2 minutes, what can you really ask? We’re saying “add this to what you’re already doing, and we want you to do it well.” It is a burden.

Also, [building trust] takes a lot of talking. Here we have the luxury of half hour

visits. Cut that down to 15 minute visits, and if the person has medical problems, don't have time to do it. It's like if you're gonna open a door . . . If you're HIV positive, we have case managers to talk, but if HIV negative, we don't have that luxury.

Provider Discomfort

One of the largest single issues found in this study was discomfort with asking questions—“fear of saying the wrong thing”—and wanting skills on how to ask questions of a transgendered client. Providers expressed that “ignorance is a barrier. People [providers] are generally uncomfortable, just like society at large.” Providers stated that they understood the importance of connecting with a client but expressed awkwardness and discomfort with the actual interview process.

People don't know how to ask. Particularly if you don't know where someone is physically. How do you ask the questions? “Are you sexually active” is hard enough, to actually go into details is harder. Most people don't go further and ask “what kinds of activities do you do?” . . . How do you ask without seeming voyeuristic or prying.

As noted earlier, professionals working in HIV are typically more experienced asking difficult or awkward questions and working with clients who have experiences outside of the providers' comfort level. This experience is directly applicable to working with trans clients. There are commonalities in the skills that are developed in this work, and the ways in which providers feel frustrated with being unsuccessful in connecting with clients.

Part of me thinks it isn't any different than asking any other awkward questions. Same basics of dealing with stuff you don't know about. Trying to set some comfort level. You just don't want to put people on the spot. You don't want to sound like you don't know what you're talking about. You don't want to make anybody uncomfortable. And frequently,

the easiest way to do that is to avoid everything. Or just be very ambiguous. These are ways of being really useless. You can avoid the awkwardness by saying “you always use condoms don't you?” Which isn't helpful.

Interviewing Skills and Limitations

Another issue related to discomfort had to do with a sense that providers would not necessarily know what to do next if a client disclosed their gender identity or gender issues and then would need services or assistance related to trans issues. Limitations in terms of time, skills, referral networks, and medical information all contribute to this concern. While interviewees stated that they might not know what to do with the information, they also said they wanted to know how to begin to ask the questions that would lead them there, so that the interaction could be useful, helpful and effective. There is a tension between wanting to help clients feel comfortable and being afraid of getting too much information and not knowing what to do with it.

What do you do next if someone discloses? How do you ask the first question. If there's somebody you sense there's something going on around gender identity, how do you ask the first question?

I think my biggest need is to get some skills on how to get conversations going. And then what to do with them. Balancing invasiveness with what I need to know to help this person figure out what they need.

There's a limit in terms of how much I'm going to be able to go into a person's life. But how to make someone comfortable and ask questions that probably a lot of people haven't been asked before because we all sort of run around avoiding it. Then I start thinking, well, who are you to bring this up. But I would like to be able to do that.

Lack of Guidelines and Protocols for Hormone Therapy

How and why people access medical care is important to consider, particularly for populations that are resistant to or have had bad experiences with institutionalized care. For transgendered people, one primary motivation to access health is to obtain hormones. Hormones aid in masculinization and feminization for trans people, and play an essential part in their ability to live in their chosen gender role, both physically and emotionally. Providers acknowledged that they weren't very familiar with guidelines for prescribing and monitoring hormones, especially for clients who were also HIV positive.

Interviewees stated that the lack of standard guidelines for hormone therapy and other standard screening guidelines were a significant barrier in providing care. Additionally, lack of medical literature on effects of hormone therapy, particularly with other medications or conditions, made providers concerned about their ability to serve their clients and meet their health care needs.

To effectively work with them, I think we don't offer the services that they necessarily want. If they come in for HIV counseling and testing, we can address that, if they come in for hepatitis vaccinations or STDs, we can address that, or women's clinic, we can address that. But if they come in for hormone therapy, we're not equipped to handle that. That is an area where we've been approached by people in the transgender community and we don't have the resources to provide that.

Hormones, Highly Active Anti-Retroviral Therapy (HAART) and HIV

Many comments were made about physicians' lack of knowledge about the effects and potential risks of hormone therapy and sex reassignment surgery for those living with HIV. There were two main areas of need and concern among the providers when it comes to the transgender-specific health needs of their HIV-positive patients. One was to recognize the im-

portance of hormone therapy for transgendered people's general health and well-being, and the other was a frustration about the dearth of literature and expertise about combining hormone therapy and HIV medication regimens.

What I have found is that a transgendered person is more likely, if they have to choose, which medication to let go of, hormones are first to hold on to. They would let go of HAART therapy or medications for other chronic diseases, but letting go of hormones is very difficult to negotiate. The gender reassignment seems to be the predominate drive. And a provider has to be sensitive to that, and respect that.

Sometimes the person has to give up the hormones to take the meds and that's very traumatic for them. Because they are taking the hormones so they could be who they want to be. When they stop taking the hormones, their physical appearance changes, and I've seen them deal with that, it's very traumatic, and not a lot of people understand. [One client] died not long after they took her off the hormones. I just remember her being very depressed about it. She was very caught up on her looks. That was very important for her. When she knew she was dying, she requested a closed coffin, because she thought she wasn't beautiful.

In addition to a patient's emotional well-being being affected by hormone therapy, there are many specific questions about side effects, dosaging, long-term effects, co-infection with hepatitis and the like. Providers had many more questions than answers in this area and expressed frustration with lack of some of the most basic information.

The whole issue of medications period. Since medications are processed in the liver. And when we're talking about a transgendered person, particularly MTF, dosages of hormones are very, very high, and then you're talking about combining that with HAART therapy, which is a

three drug regimen—all of which are processed in the liver . . .

We need to know: What are the medical implications, in terms of something as simple as what do you write on the referral, what are the medications people are using. Hormones and implications around interactions. I found out things theoretically, extrapolated. We know that some of the protease inhibitors will drop estrogen levels . . .

Particularly with HIV, we know that a lot of medications alter hormone levels. Oral contraceptive pills, thyroid medications, all those things need to be changed, how to actually manage somebody who is on hormone therapy who is also on protease inhibitors.

Lack of Expertise and Relevant Studies in the Literature

As in other evolving areas of medicine, expertise develops by providers who see a lot of patients and then somehow disseminate that information. But adequate, helpful professional consultation is also a need.

The person who takes care of a hundred people is gonna become the expert. What guidelines are they using? Who are the three or four experts in the U.S., get them to come up with basic guidelines.

It's very difficult to get information. I had my first [transgendered] patient, I didn't have a clue about hormones. Tried to reach people. Couldn't just get medical advice, "this is what you screen for, this is what you look for." A resource, like Hopkins has the AIDS Line, something like that, you could just click on for people taking care of transgendered patients, I think would be very helpful.

One provider who had extensive experience working with transgendered patients was very clear that the lack of literature and standards feels dangerous and irresponsible.

The literature that exists at this point is scanty at best. With transgender care, we don't know—Are we doing harm or not? There's no standard. I'm very concerned about long-term hormone use. Are we potentially doing harm? If we know that we can negotiate with our patients? I'm really into informed consent. This is part of our responsibility as providers.

Along with the lack of visible, well-known experts in the field, there is also a dearth of published literature that informs treatment decisions and informed consent.

Literature is not very broad compared to other areas of medicine where we have more than we can read at times. With transgender care and medicine, there are big gaps in information base. We don't really know the long-term effects of hormone therapy that we give, the doses that are given we have no idea as to the potential risk . . .

Because we don't have any long-term studies, don't know other potential risks or contraindications to use of high doses of hormones that we're not even fully aware of. We don't have the expertise in terms of endocrinology to assist us in this process.

Screening Guidelines

Another area of training need is the provision and dissemination of guidelines for providers in screening patients for transgender-specific care. The most widely used guidelines for gender reassignment are the Standards of Care for the Treatment of Gender Identity Disorders of the Harry Benjamin International Gender Dysphoria Association (available online at: <http://www.hbigda.org/socv6.html>), and these guidelines help providers establish some consistency in care and a potential consultation network. However, the guidelines focus on evaluation for hormone therapy and gender reassignment surgery, not on general screenings for primary health care maintenance. Providers offering maintenance and primary care have many questions:

If you have a standard set of screening guidelines for males and females, how do you figure out which ones you use for transgender patients? What do you do about osteoporosis, for example. How does that change?

The most concrete need is simply basic medical issues. Issues of screening, breast implants' potential risks, utilization of hormonal treatment, persistence of screening for prostate cancer for male-to-females.

Providing Referrals

Both case managers and clinical providers act as advocates and mediators for their clients and in both cases, interviewees felt obligated to be able to provide quality, appropriate referrals. For transgendered clients, however, interviewees stated that they don't have a good professional network and often send clients to a provider without knowing if they can trust the reception or care that awaits the client.

An interviewee at a community-based GLBT clinic explained that he thought access to care in general for transgender patients is very limited:

I think that it is difficult because the transgendered people that we see here, when you talk to them about health care, they're not going anywhere. So that says to me that they're not going because they can't find providers who understand what the transgendered experience is all about. . . . As far as general health, we just send them off to people on our list, hoping that their needs get met.

Providers expressed struggles with what is normally a simple part of a referral—describing the patient and problem. But with trans clients, it gets complicated quickly. “What are the medical implications in terms of something as simple as what you write on a referral? How do you describe that person on a radiology request form when you refer for an MRI? I'll write down ‘43-year-old woman’ and they put her under MRI machine and she's a pre-surgical transgender person.”

Emergency Rooms and Hospitals

There was a sense that patients are better off within interviewees practice than outside of it. Stories of emergency room visits and hospital stays confirmed this impression.

An issue is: how to alert the emergency room. If they got admitted to the hospital, what amount of detail to explain to the nurses, how much detail did they want us to go into. One of them was initially very difficult for the nurses—they had no idea about how to deal with it, how to discuss it. It was a big issue about what room to put the person in. Had to negotiate it and when she was admitted, got put into a private room.

One patient who was in the hospital, once she got over her anger at how she was being treated, was pretty good about educating [the nursing staff]. We tried to have her always be on the same floor and with the same nurses, so that the nurses knew and became more sensitive around it.

Access to Substance Use Treatment Programs

One case manager related a particularly painful story about trying to access a drug treatment referral for a transgendered client. Substance use is well documented among transgendered people and being able to access appropriate drug treatment is a huge community need (Lombardi, 2000). In turn, providers need to know where to send someone for substance abuse treatment. The case manager described trying to help a trans woman who was getting out of prison and asked for his help in getting into a drug treatment program upon her release:

She knew she was getting out and if she spent any time on the streets she would pick up her habit again and I was trying to do something before she got out and I was unsuccessful. She wanted to go into a female residential treatment facility and the director said she wasn't a female. I was trying to explain she wasn't a threat to the other women. [The director] wasn't

hearing it. The person had implants and had her testicles removed, but she had a penis. She started working the streets again and picked up her habit. Essentially I was pissed. I was really, really pissed. As far as I know, there's no transgender treatment center out there. If there is, I would love to know about it. There's not even one that is even sensitive to these issues. Putting an MTF in a male facility, that would be cruel.

Indeed, most substance use treatment programs are structured along binary gender lines, with patients often being placed according to their birth gender, obviously severely limiting their options regarding treatment.

Agency Issues

Above, under "Provider Discomfort," we addressed individual responsibilities of providers for building an effective relationship with their transgendered clients. But change must be system-wide as well. The climate of an agency, its policies, training, and location in the community all influence how transgendered people can access care.

The interviewees described significant issues that are institutionally based. Providers felt: (1) that agencies have a responsibility to be inclusive and to have policies in place for culturally competent treatment of trans people; (2) that making an agency welcoming should not be up to any one individual; (3) that individuals who want change within their agencies may not be empowered to create that change; (4) that there is transphobia and resistance among staff; and (5) that training and awareness must be across all levels of staff, including front desk staff.

Intake Forms, Frontline Staff and Insurance

Patients who come in to a clinic or agency have to interact with the receptionist, security staff and other people long before seeing a treatment provider. Regardless of the training or sensitivity level of the providers they will see later, that initial interaction is crucial to making a person feel welcome and safe. It is at the front

desk where issues of in-take forms, legal name versus preferred name, and insurance issues must be handled.

I know working here the [sensitivity] training would even have to start at the front door. The frontline people that meet them at the door before I would even consider bringing a transgendered person in here and consider they could get care here.

Do they train receptionists here? They should but they don't.

Some providers interviewed also felt that questions about past surgery or medications would capture a person's transgender status. It depends on how the questions are asked and how a provider reads and interprets the form.

You first have to have in-take forms that offer T as one of the options. Or "other" and let them fill it in. I've actually had patients who leave it blank, and then I say "Why did you leave this blank." And that's another way to get at that information.

Insurance policies are often restrictive for transgendered people, with many insurance companies denying coverage for hormones or treatment related to gender reassignment. Providers in the study attested to these difficulties, starting at the level of listing gender and pronouns.

Insurance forms [as they exist] are gender specific. A prescription is rejected if medication that is normally used for men or women is prescribed differently and they might reject it. It is absolutely a big potential problem.

There's no deviation with insurance companies. We need another pronoun. I have a client who is intersexed. It's a slap in the face when genetically you aren't M or F.

Tension in Agencies About Trans Inclusion

Providers had stories of tension within their agencies over trans inclusion, including resis-

tance, fear and outright discrimination. One interviewee who had worked for many years in a lesbian-oriented women's health clinic, an agency she had helped guide through many different changes, told this story:

The issue came up on whether or not the organization would provide services to transgendered people. We struggled for many months. Many people did not want to do it. Since we were only seeing women, had to decide how we would draw the line. Said okay, we will see female-to-males pre-surgery and male-to-females post surgery. Surgery was the deciding factor. We had to do a lot of work, a lot of training, to come to the decision that "if you present yourself as a woman, then you are a woman and we will view you as a woman." So the whole discussion/argument/fight about pre- or post-surgery versus psychological identification. And we finally, though a lot of work, a lot of training, came to the decision that "if you present yourself as a woman, then you are a woman and we will view you as a woman." That it doesn't matter whether you have male genitalia or not. . . .

Another interviewee with a GLBT community health clinic acknowledged tension within the staff about actively pursuing and accepting transgendered clients.

People that work in this agency, they're all in a different place in terms of understanding. Some of us are like, we just have to do it. But others resist. And I think the resistance is fear-based.

Training

An important domain of the interviews regarded methods for teaching and learning among health care professionals, and exploration of successes and failures on transgender topics specifically. This information could likely lead to more effective trans awareness programming, as well as help in planning for other methods of disseminating treatment information and research.

The following training needs and suggestions were identified in the interviews with the providers:

1. Staff at all levels should attend awareness training.
2. Have transgendered people as trainers.
3. Offer appropriate language to use in interviews, including role plays of specific interviewing skills.
4. Because of the potential challenge to get providers to attend a transgender-specific training, transgender issues may be better incorporated into broader trainings on diversity or other topics.
5. Utilize ways of training that are already institutionalized, such as journals, web pages, telephone "warm" lines, in-services, Grand Rounds, conferences.
6. Incorporate training in curriculum for medical students.

Sensitivity versus Knowledge

Among the providers who have had some exposure to transgender training, a distinction was made between gaining an understanding of the issues involved versus having the knowledge and skills to provide adequate care, treatment and counseling.

When I think of the trainings I have done, they've been kind of similar, and not taken me farther, but it feels fresh each time that I do it. I feel like I'm sensitized, but not knowledgeable. I don't know how to take it to the next level.

Clinicians don't even know that there are transgendered people. It's important to get them to take that seriously. After you did that, you could engage them in conversations about actual care.

Training Barriers

Providers cited difficulty in attracting people to trainings on transgender issues because of the many competing training needs that providers have, a lack of time, and sense that this issue isn't a priority. A suggestion was to incorporate trans issues into a training on a broader

topic, such “Taking a Sexual History,” or on prevention issues.

If you did something solely on Transgenders, nobody would go. Because they have too much to do already. You have people who still need to get diabetes training, which they are seeing a lot of. Incorporate [trans information] into training that has to do with interviewing, or even around sexual history taking. Roll it into something they want to learn about. Make it part of half-day training on prevention.

Role Playing to Learn Interviewing Skills

Because providers were clear about needing actual interviewing skills, role plays were identified as an effective method for learning. Experiential learning, within a reasonable time-frame, is beneficial and effective for busy providers who need to learn a lot quickly. Interviewees expressed a desire for interview tools, such as a script with questions.

Give them words to use, or the first questions, and you can use those and then come up with the words and style that works for you. I went to a lecture on sexual history taking and I was like, I wouldn't say it that way, but I've been doing this for a long time. If I hadn't then it is good to have the actual words to use. Tell me just three sentences as intro sentences, and I'll try those.

I don't have repeated exposures to develop enough of an expertise. And that's one of the problems when you don't run into something a lot. But if there were something, probably role playing is the way to do it, watching someone and then doing it. Video, vignette, actually hear words and get to hear how they sound to you. Then maybe you can use those words for the first time.

Importance of Transgendered People as Trainers

Interviewees felt very strongly that transgendered people needed to be involved in the design and delivery of trainings for providers. They stated that hearing personal experiences

and being able to see the provider-patient relationships through the transgendered person's eyes would have a strong impact on the quality of care. Additionally, it was noted that the trans person doing the training would need to have training skills and come across as empowered, charismatic and knowledgeable.

Inviting a transgendered person here. Someone who is very comfortable in their skin. And who is comfortable talking about transgendered issues. Who possibly even works in the field. Who knows all the idiotic and stupid questions that people probably would ask, who would subject themselves to having case managers and health educators ask them any kind of questions . . . Sort of open themselves up to questions.

You have to have members of the population present to talk about their own experiences to get the full spectrum of what gender reassignment means. Again, the multidisciplinary approach is really essential.

It would be helpful for someone to guide us through what it feels like to be on the other end of the exam table. To help us think about how we talk to our patients—having someone who is transgendered come and talk to us.

One provider stated “I've been extensively trained by my patients. They teach me things all the time.” On the other hand, providers recognized that it can be a burden for patients to educate their health care providers and that providers may have to go elsewhere to seek out information about transgendered people and their lives. Further, it was recognized that one patient cannot educate a provider about all trans people.

I also could learn a lot by sitting down with a patient. Although I think there are a lot of people who are sick of having to educate their providers, the same way people with HIV are sick of having to teach their providers this and that. So I don't know specifically about transgendered people, but I think people expect more of their providers than having to educate them, even though a lot of people take that role on pretty nicely.

DISCUSSION

Transgendered people are emerging as a visible group that is at high risk for HIV, and clearly there are many information and training needs for HIV providers who are, (or will be), working with members of this population. The lack of studies and difficulty accessing information will continue to impact how well providers can offer care. At the same time, as providers in this study noted, their comfort level will naturally improve as they grapple with increased experience and exposure to transgendered patients. This small study is a beginning step in identifying the many areas in which research, training and information are needed, and identifies some effective ways to deliver that information.

In summary, we found that providers had:

1. Desire to treat transgendered patients respectfully, but admitted discomfort and lack of tools for specific interviewing/assessments.
2. Experience with a range of transgendered patients, but lacked information on distinctions among transgendered experiences.
3. Restrictions based on time constraints that create an overarching barrier in building trusting relationships with clients, and trusting relationships are integral to quality care.
4. Concern and frustration with lack of information, studies and research.
5. Concern and frustration with lack of treatment guidelines, (or ability to access them), referral contacts and ways to advocate for transgender clients.
6. Belief that training by transgendered people themselves was an essential teaching element.

Limitations

This was a small qualitative study, based on only 13 interviews. The providers interviewed here all volunteered their time and were interviewed face-to-face, indicating their commitment and interest to this issue. They are best perceived as representative of providers who work in HIV and want to improve their capacity

for providing compassionate care to this marginalized group. While transgendered people have identified bias and discrimination as barriers to care, in this group, the greatest barriers were lack of experience and access to information. Their honest assessment of barriers and limitations provide useful evidence for the development of training curricula and strategies. Further data gathering from this group will continue to justify and inform training programs.

Research Is Needed

The need for research is abundantly clear. Any medical database search will turn up amazingly little on transgendered people and health care, even less on the effects of HIV or HIV medications with transgendered patients. Providers acknowledged that this lack of information—on dosages, risks, complications, drug interactions and co-morbidities—prevent them from being able to partner with their patients on decision-making and informed consent.

Pharmaceutical companies also have an obligation to include transgendered people in studies. As remarkable as it may seem, the use of hormone therapy for gender reassignment is off-label. No studies have been conducted by pharmaceutical companies on use of hormones in gender transition, again, leaving providers and patients virtually in the dark about long-term concerns and reinforcing the invisibility and disregard of transgendered lives in traditional areas of medicine.

There are a number of barriers related to this lack of research. Lack of funding, and indifference to the topic by researchers are among them. But where transgendered lives are considered, there is still a great deal of misunderstanding. For example, the federal Centers for Disease Control, which controls HIV-prevention funding and thus the direction of most prevention efforts, categorizes all transgendered people in the risk category of men who have sex with men, or MSM. This fails to recognize that many male-to-female transgendered people who have male sex partners consider themselves to be women in heterosexual relationships. Their partners also see the relationship as heterosexual. Categorizing these men and women as MSM fails to recognize the identity and experi-

ence of the population and cannot result in useful risk assessment or the development of effective programs (Xavier, 2000; Kenagy, 2002; Kammerer, 1996 and Clements-Nolle, 1999).

This example also shows a lack of distinction between gender identity and sexual orientation. It is common for community agencies and health centers who have historically served gays and lesbians to now use the initials “GLBT,” or gay, lesbian, bisexual and transgendered, to define their target population. People who identify as transgendered may, in fact, identify as straight, gay, bisexual or even something else to categorize their sexual orientation. The letters “GLBT” are often used to express inclusion of sexual and gender minorities within the same movement or organizational mission. The differences are important for agencies and providers to recognize, and it is also important to recognize that some transgender people have specific negative experiences within the gay and lesbian communities (Clements-Nolle, 1999 and McGowan, 1999). Yet, there remains an urge to conflate sexual orientation, particularly homosexuality, with transgender identity.

In 1999, the American Public Health Association issued a policy resolution addressing this tendency. “The Need for Acknowledging Transgendered Individuals within Research and Clinical Practice” concluded “that transgendered individuals are not receiving adequate health care, information or inclusion within research studies because of discrimination by and/or lack of training of health care providers and researchers, urges the National Institutes of Health and the Centers for Disease Control (as well as individual researchers and health care workers) to categorize MTF and FTM transgendered individuals as such and not conflate them with gay men or lesbians (unless appropriate to an individual’s sexual orientation in their preferred gender) as well as acknowledging the variation that exists among transgendered individuals” (Lombardi, 1999).

Recognizing the variation among transgendered people can also lead to broader research areas. For instance female-to-male transgendered people, or trans men, are ignored altogether in the CDC categorizations, yet this is a subpopulation becoming more widely visible. Some data gathering is starting to ask questions about FTM lives and sexual risk behaviors, but

it is largely an ignored category, leaving HIV-positive FTMs, or FTMs with HIV-positive partners with little information on treatment or secondary prevention.

With such a longstanding history of tension from and mistrust of the medical system, it is also a challenge to recruit transgendered people as participants in studies. Having transgendered people involved in designing research projects can help build trust and create a climate where participants of a minority group are tapped and acknowledged for their contributions to developing areas of health care. Building this culture of partnership between researchers, providers and patients will result in studies that will begin to fill the gaps in information and enlighten standards and options for care.

Once the research is done, it needs to be disseminated quickly. In an area with such little research and information, studies should be released widely using various methods of distribution, including web sites such as the AIDS Education and Training Center’s National Resource Center and the National HIV/AIDS Clinician Consultation Center.

Treatment Protocols and Standards of Care

The Harry Benjamin International Gender Dysphoria Association, or HBGDA, Standards of Care are the best known guidelines, but they are geared towards assessing eligibility and readiness for hormone therapy and sex reassignment surgery and are not guidelines for ongoing medical care. The HBGDA is an international professional association for a range of providers (surgeons, psychologists, endocrinologists, sociologists, etc.) and has an active and committed membership that includes many transgendered people.

The “Benjamin Standards,” or SOC, as they are known, have been criticized for limiting patient’s autonomy and creating a “gatekeeper” relationship whereby patients need a provider’s, usually a psychotherapist, approval for hormones. “The real lives of transgendered people might be more complex or divergent from the guidelines and patients may not feel they can be honest with their physicians if termination of hormonal therapy is a possibility” (Karasic, 2000). However, this criticism seems to have been directly addressed with the development

of more recent versions of the SOC that allow for much more flexibility (Standards of Care for Gender Identity Disorders, Sixth Version). It might be most useful to see the SOC as a companion to other documents that give screening and treatment guidance to physicians.

One of these documents is “Medical Care of Transgendered Patients” (Oriol, 2000), which is founded in the Benjamin Standards and also offers clinical guidelines for practitioners. “Transsexual patients often have difficulty finding care because many physicians are not comfortable prescribing appropriate hormone regimens. Management of hormones for transsexual patients is not difficult and these medications are safer than many therapies routinely prescribed by the primary care physicians. . . . This review is intended to teach primary care providers how to initiate and maintain hormone regimens for transsexual patients and describe medical issues unique to transsexual patients.”

Several clinics are establishing their own protocols. Guidelines established by the Tom Waddell Health Center in San Francisco (Protocols for Hormonal Reassignment of Gender from the Tom Waddell Health Center, 2001) are available on the Web and are being used by clinics working with low-income, high-risk transgendered patients who seek access to hormone therapy. The Michael Callen-Audre Lorde Community Health Center in New York City (Callen-Lorde Protocols for the Provision of Hormone Therapy, 2001) has developed extremely detailed protocols for providers, outlining specific instructions for numerous visits with different categories of patients, samples of consent forms, and tables of contraindications and side effects. These guidelines can help increase the numbers of providers able to confidently treat transgendered patients and increase the number of clinics willing to provide hormone therapy as part of primary care with patients. Both agencies allow other clinics access to their documents to create their own protocols.

Providing hormones as part of primary care attracts transgendered patients and also allows them to have access to HIV prevention or treatment information. Providing this access directly addresses HIV risk by eliminating the alternative means of accessing hormones—using street market hormones, sharing needles and vials, and having no ongoing monitoring regarding dosaging, complications or risks. A

successful program in New York entitled “The HIV Hormone Bridge” (Grimaldi et al., 1996, 1998) drew impoverished HIV-positive sex workers to HIV care by offering hormone therapy as part of a broader treatment contract and community program. The program was successful in creating community for participants through support groups and building self-esteem; and in helping transgender patients develop trust for their providers, dramatically decreasing risk-taking activities such as use of street hormones and increasing medical compliance and receptivity to HIV medication.

Access to sex reassignment surgery, or SRS, is also an important need for many transgendered people, and the presence of HIV complicates this surgery, as it does all major surgeries. Some research and guidelines for SRS and HIV-positive patients have been developed, including two appearing in the *International Journal of Transgenderism* (Kirk, S., 2001, Wilson, N. A., 2001).

Final Recommendations

The findings from this study fall under three main areas. All three areas need to be addressed in providing training for providers, including skills related to relational and systems issues, encouraging advocacy and policy change, and facilitating linkages to informational resources. The three areas are:

1. *relational*, relationship between provider and patient; provider and transgender community; provider and his or her referral network;
2. *informational*, related to research, scientific literature, guidelines and expertise available for review and consultation; and
3. *systems*, how institutions (agencies, insurance companies, hospitals, and society at large) incorporate policy and procedure and attitudes related to transgendered patients.

Based on the findings of this study, recommendations in the three areas are:

Relational

- Training should be provided by transgendered people.

- Trainings must be easily accessible with concrete take-home messages given in a short period of time.
- Awareness training should be provided for all levels of staff.
- Skills for increasing comfort and competence in interviewing, especially sexual history taking and risk assessment should be stressed.
- Transgender awareness should be included in curriculum of broader topics, such as sexual history taking or prevention.
- Transgender Health subcommittees should be established in HIV/AIDS health care associations such as the Association of Nurses in AIDS Care.
- Have agency policies and guidelines in place, including disciplinary procedures for mistreatment of transgendered clients.
- Create resources such as sample policy and procedures, forms, checklists and planning strategies for agencies wanting to become trans inclusive.
- Normalization of transgendered people in institutional settings, and information on appropriate care for transgendered patients in hospitals, emergency rooms, insurance companies, etc.
- Work to destigmatize gender non-conformity and gender variance to increase safety for transgendered people to disclose their status.

Informational

- Research and dissemination of findings on long-term health risks of hormone therapy and sex reassignment surgery.
- Research and dissemination of findings on hormone treatment for HIV-positive transgendered people.
- Establishment of transgender categories in HIV risk assessment and transmission categories in all data collection efforts.
- Establishment and dissemination of guidelines for medical care for transgendered people and for transgendered people living with HIV.
- Availability of Continuing Medical Education on Transgender Health issues.
- Utilization of information systems such as the AIDS Education and Training Center's National Resource Center's website for central location of information for providers.

Systems

- Utilize existing training mechanisms—inservices, quarterly meetings, Grand Rounds, professional conferences—to present information.
- Incorporate transgender health information as part of regular curriculum in professional schools (medical school, nursing school, social work school, etc.).
- Advocate for and create changes in intake forms to include expanded gender choices and options for chosen versus legal name.

CONCLUSION

This study showed enormous gaps in knowledge, literature, professional expertise and skills around addressing the needs of transgendered patients living with or at risk for HIV. But this study also showed a sincere concern and desire on the part of providers to serve trans clients effectively. The challenge in designing and delivering trainings will be to strike a balance between providers' many demands for their time, institutional limitations related to policy and staff turnover, and the evolving visibility of trans communities demanding access to quality care.

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