SUMMARY. The purpose of this research project was to examine female to male transsexuals' (FTMs) experiences of accessing health care. This was accomplished by documenting and recording the experiences of five FTMs through the use of photography and interviews. It was hoped that such an inquiry would provide a starting point for future research about the health care needs of the transgender community, and document some of the health care needs of the FTM community that would lead to recommendations for policy changes and educating providers.

Wendy Hussey received her MPH from San Jose State University in 2001. She is currently Project Director at UCSF's Center for AIDS Prevention Studies. She has an extensive background in grassroots community organizing and is passionate about using participant-driven methods like Photovoice and storytelling in qualitative research (E-mail: whussey@psg.ucsf.edu).


Available online at http://www.haworthpress.com/web/JH
© 2006 by The Haworth Press, Inc. All rights reserved.
doi:10.1300/J082v51n01_07
INTRODUCTION

Seeking health care can be a challenging and alienating experience for many people. Several factors contribute to the vast disparities in health care access. The most widely documented disparities are related to the key variables of race, ethnicity, socioeconomic status, and geography (HHS News, January 25, 2000). Disparities also exist for people of varying sexual orientations, and physical and mental abilities.

Female to male transsexuals (FTMs) have remained absent from mainstream discussions of health disparities for many reasons. An article published for FTMs on the Internet cites providers’ lack of knowledge and understanding, as well as insensitivity to FTMs and their health care needs, as the main factors preventing FTMs from seeking health care (Morton, Hans & Lewis, 1997). The lack of understanding about FTMs and their specific health care needs may also be placing FTMs at greater morbidity risk (Morton, Lewis & Hans, 1997).

Gynecological health care is one specific health need that is seldom addressed for FTMs. FTMs who are taking testosterone carry an increased risk for endometrial hyperplasia, and subsequent endometrial carcinoma (Lee, 2000). Furthermore, FTMs who use hormones but decide not to undergo a hysterectomy continue to be at risk for endometrial cancer, just as male to female transsexuals (MTFs) taking estrogen remain at risk for prostate cancer (Lee, 2000). The need for sex specific (biological sex at birth) health care does not change with one’s gender identity.

Another serious gynecological health risk to FTMs is ovarian cancer. Ovarian cancer is the fifth most common cause of cancer-related death, and the most common fatal gynecologic malignancy (Hage, Dekker, Karim, Verheijen & Bloemena, 2000). Hage et al. suggested that long term exposure to increased levels of androgens (male hormones) pose an increased risk of ovarian cancer to FTMs. Among women in general, an ovarian cancer diagnosis is often delayed due to the lack of an effective screening test. For FTMs, this delay in diagnosis may be exacerbated due to their reluctance to seek regular gynecological check-ups (Hage et al., 2000).

Little in the way of scholarly research addresses the health care needs of the FTM community. The prevalence of transsexuality in the US, as estimated by the American Psychological Association’s Diagnostic and
Statistical Manual IV, is 1/30,000 (born) males and 1/100,000 (born) females (1994, pp. 536-537). Most studies about FTMs have been conducted outside of the US in places such as the Netherlands, the Czech Republic, Germany and Canada, where the standards and quality of care for transsexuals are more complete. These studies examined specific health risks, such as long-term exposure to cross sex hormones, and the links with ovarian cancer (Hage et al., 2000). Much of the current literature links testosterone use with ovarian and endometrial cancer for FTMs who retained their ovaries and uterus (Hage et al., 2000). While these studies provided some insight into the specific health care issues of transsexuals, none addressed the issue of health care access.

One of the first transgender health studies was conducted in 1997 by the San Francisco Department of Public Health. The Transgender Community Health Project (TCHP) was a quantitative study designed to assess HIV risk among male to female transsexuals (MTFs) and female to male transsexuals (FTMs) in San Francisco (Clements, Katz, Marx, 1999). The study, which included 392 MTFs and 123 FTMs, consisted of an anonymous survey and HIV test. The study also included a confidential standardized face to face interview that addressed the following: (1) socio-demographics, (2) medical history and health status, (3) HIV prevention service access, (4) sexual behaviors, (5) drug use behaviors, and (6) psychosocial factors. The findings of the study suggested an urgent need for effective HIV prevention interventions that targeted MTFs, as 35% of the MTF participants were infected with HIV. The FTM participants' HIV prevalence was low, less than 2%, and their HIV-related risk behaviors were infrequent, yet a history of unprotected receptive anal intercourse was reported in 28% of the FTM sample. Among those who reported a history of injection drug use (18% of the sample), 91% of that group had shared syringes. Based on the results of this study, it was recommended that HIV prevention interventions be provided specifically targeting FTMs who have sex with men, and those that inject street drugs (Clements et al., 1999).

The Transgender Community Health Project also indicated that FTMs might be at risk for other Sexually Transmitted Diseases (STDs), such as Human Papilloma Virus (HPV), a precursor to cervical cancer. Thirty-one percent of the sample of FTMs had been diagnosed with an STD at some point in their life, 64% had engaged in receptive vaginal intercourse without a condom, and 59% had experiences of forced sex or rape (Clements et al., 1999).

A series of focus groups were also conducted as a part of the study, which yielded qualitative data about other aspects of transgender lives and
illuminated some of their experiences of accessing health care. The results of these focus groups indicated that transgender people have a difficult time accessing competent and respectful health care. This finding suggests a need for further inquiry into the experiences of transgender access to health care, and transsexuals’ overall experience of health (Clements et al., 1999). Much of the information gained from the San Francisco focus groups (Clements et al., 1999) mirrored the results of four focus groups that were conducted in Boston in July 2000 (JSI Research and Training Institute, 2000). The results of the Boston groups suggested that transgender people often encounter providers who will deny them treatment or provide sub-standard care as a result of lack of knowledge about transgender specific health concerns. The focus groups found that insensitivity, ignorance and discrimination are the norm for this community when its members try to seek health care (JSI Research and Training Institute, 2000).

Transgender individuals are often likely to experience some form of discrimination or violence in their lifetimes (Lombardi, 2001). The fear of discrimination and stigma often keeps transgender people from seeking health care for themselves, and when they do, this fear keeps them from disclosing relevant personal information to the provider with whom they are receiving care (Clark, Landers, Linde, & Sperber, 2001). Often times a transgender person is reluctant to access care due to the insensitivity of the provider (Lombardi, 2001). Furthermore, this lack of sensitivity by providers may keep transgender people from returning for follow-up treatment if it is needed (Lombardi, 2001). Transgender individuals’ access to health care is affected by the lack of provider knowledge about transgender people and their specific health care needs (JSI Research and Training Institute, 2000). The results of a series of focus groups conducted with transgender adults and youth in Massachusetts suggested that many providers lack the knowledge to treat routine health care issues having to do with transgender people. These health care issues included hormone use and monitoring, HIV prevention, and preventive gynecological care (JSI Research and Training Institute, 2000). The lack of understanding of transgender patients points to the need for health professionals to be educated and made aware of the lives and health care issues of their transgender patients (Bockting, Robinson, and Rosser, 1998).

**METHODOLOGY**

The conceptual framework used to guide this project came from Freirian Popular Education. Paulo Freire’s problem-posing education is
based on the understanding that education starts with the issues that are central to people's lives, the things they see. By examining the themes that emerge from everyday life, people can begin to question and start talking about the things that challenge them in their environment, and look at the forces that keep those challenging conditions in place (Freire, 1970).

Participants

The participants in this project were five self-identified female-to-male transgender individuals in the San Francisco Bay Area who were born with and still had at least one of the following female sexual organs: breasts, clitoris, cervix, vagina, ovaries and/or uterus. The participants were 18 years of age and older. In order to participate in the project, individuals must have had experiences of gaining access to, or trying to access health care as an FTM. The five men varied in age from 33 to 52 years of age. Four of the men self-identified as Caucasian, one self-identified as Latino. Two of the participants identified their sexual orientation as straight, and the other three participants identified their sexual orientation as queer. Three of the participants (60%) had private medical insurance. Of the two (40%) that were uninsured, one received regular health care from a city clinic and the other rarely accessed healthcare.

Participants were recruited by distributing flyers and discussing the study within the FTM community in the San Francisco Bay Area. Three of the participants were recruited from an FTM support and advocacy group called FTM International. The other two participants heard about the project from colleagues or peers and contacted the facilitator to enroll in the study.

Photovoice

This research project used a data gathering method called Photovoice. Photovoice is a process by which people can identify, represent and enhance their community through photographs, and their related dialogue. Dr. Caroline Wang from the University of Michigan developed the Photovoice technique, which provides people with cameras to photograph their perceived health and work realities. The meanings of the photographs are then discussed and analyzed with the people who took them in an effort to provide insight into their lived experiences (Wang & Cash, 2000). Through Photovoice, participants act as recorders and potential catalysts for change. Photovoice uses the photographs taken by
participants to create an opportunity for sharing the experiences and expertise of the community members (Wang & Burris, 1997). Photovoice has three main goals: (1) to enable people to record and reflect their community’s strengths and concerns, (2) to promote critical dialogue and knowledge about important issues through large and small group discussion of photographs, and (3) to reach policy makers (Wang & Burris, 1997).

**Data Collection**

Each participant in this study was given a point-and-shoot camera, four rolls of color film, and one practice roll. This allowed each participant to take up to 120 pictures. Participants were asked to tell the story of their experiences of gaining access to health care by taking pictures. The assignment was kept broad so that the participants could decide what kind of story they wished to tell through the photos. The participants had seven weeks to collect their photographs.

The participants were asked to select the ten photos that best illustrated their story. The project facilitator then met with each participant to hear the stories behind their photos. Freirian problem-posing questioning was used to debrief the stories. This debriefing technique used pointed questions to elicit information about the content of each photograph. Participants were asked each question associated with each letter in the PHOTO acronym for each of their ten selected photographs.

- Describe your picture.
- What is happening in your picture?
- Why did you take a picture of this?
- What does this picture tell us about your life?
- How can this picture provide opportunities for us to improve life with regard to healthcare? (phrase in italics added by project facilitator to adapt specifically to this project.)

This questioning technique provided a way to focus on the specific experiences and stories portrayed in the photographs. After discussing each photo in this way, they were asked if they would like to say anything else about the photograph that might not have been captured by the five questions. The sessions were audio-recorded and the interviews were then transcribed for analysis. The photos and transcripts were examined for common themes. Participants were invited to be advisors
during the analysis of the project, to ensure that the identified themes represented their experiences accurately and respectfully.

**RESULTS**

Six themes emerged consistently from the data: (1) The Health Care System, ("The System") (2) Provider Competence, (3) Vulnerability, (4) Invisibility, (5) Perseverance, and (6) Activism. These themes represent common topics discussed by all or a majority of participants when telling their stories.

"The System"

This is a hallway in a hospital, and it is leading straight down into a black hole. And here on the side is a gurney, and it’s all ready there with a nice white sheet and it’s just lonely. It’s scary to me. It is not comforting or reassuring at all. {What’s happening in this picture?} It’s the system sitting out there waiting, and heaven forbid you end up on that gurney wheeled down into that black hole, because it is lonely and scary.

FIGURE 1. Gurney in Hospital
"The System" was the phrase most often used by participants to describe the medical industry, the health care industry, or the public health system where they went for care. Some of the words used by participants to describe how they felt about accessing and navigating "The System" were: "humiliating," "daunting," "imposing," "lonesome," "dark, a black hole," "prejudiced," "ignorant," "scary," and "cold and inhuman." Most participants described numerous experiences of inhumane treatment when attempting to access the Health Care System. One participant described the inhumanity of the system in a broad sense with this image of the entrance to a hospital:

FIGURE 2. Hospital Entrance
The health care system is so imposing and it is so daunting. It is not me looking in someone’s eyes and having them understand that I have a problem that they have the expertise to help me, but it is in fact me out here off to the side terrified that the first person that I see is going to do something to shame me or embarrass me or cause me to be ridiculed in front of other people.

"The System" included the insurance companies, to which each participant made numerous references. All of the participants’ told stories about dealing with, or the fear of dealing with insurance regardless of whether or not they had health insurance. One participant took a photograph depicting what he termed his "house of cards":

My little house of cards is what I call it. I got these five cards in the space of three months from the same insurance company. First, they said that I didn’t have insurance, then they said that I did have insurance but it was with this primary care physician. Then they said ‘no it’s a different primary care physician and you have a
different subscriber number, we can no longer use your social se-
curity number because that is someone else’s social security num-
ber.’ I tried to explain to them, ‘it is still mine, I’m not changing it,
and I am just changing my name and gender on all of my document-
tation.’ So they decided to give me a new number altogether, but
they didn’t bother to tell me or anyone else that. So when I would
go to seek services I would be denied because they would say ‘who
are you? You’re not this person. This is not the right social security
number from this name . . .’ etc. We went back and forth on this. I
finally got documentation from them stating that I did indeed have
insurance, and then three days later got a bill from [the hospital]
saying ‘you don’t have insurance; you have to pay this bill.’

Another participant chose to avoid health insurance altogether, stat-
ing that the fear of navigating the health insurance system was too
overwhelming:

I don’t even consider insurance when I think about accessing the
health care system, particularly for gynecological care and things
like that. I would pay out of pocket before I would try to get an in-
surance company to cover me. It is just too overwhelming enough
to think of trying to access a gynecological clinic when I am an
FTM; to try to involve an HMO in the process . . . I just won’t do it.

Several of the participants shared stories of being treated poorly
when they tried to access the health care system. These experiences var-
ied in range from fear that service providers would be rude, to actual
poor treatment as a result of the participant’s gender identity. One par-
ticipant shared a story about poor treatment that he received at a
city-funded public pharmacy. To illustrate his story he used the image
of the outpatient registration offices at a hospital where he was required
to go before getting his testosterone prescriptions filled. In this story, he
had just returned to the pharmacy with his paperwork completed from
outpatient registration:

While [the pharmacists] were handling our stuff they were smirk-
ing at each other and laughing and elbowing each other because
they knew what we were there for, and they thought it was hilari-
ous—and they were not even hiding it. They were one inch away
from us, and they were acting like we were not even there . . . Any-
way when they hand us our vials of testosterone and bags of sy-
ringes, my friend wanted to know how he was supposed to store it. ‘Do I keep it refrigerated or do anything special to it?’ Because no-
body tells us anything; they just hand you stuff and expect us to
know what to do with it. They laughed at him. They openly
mocked him for asking a question like that. My friend just stood
there and endured it so that he could get the information.

As participants discussed their experiences of inhumane treatment and of navigating the insurance maze within the health care system, they also began to reveal stories about their experiences with individual providers. Provider competence emerged as its own theme.

**Provider Competence**

This theme reflected the ways participants described the ability of their individual health care practitioners to provide adequate medical care and to address their specific health care needs as transgender pa-
tients. Participants reported on both interpersonal relationships with providers, and the providers’ willingness and ability to address partici-
pants’ transgender-specific health care needs.
Three participants identified language as a powerful marker of provider competence. For example, they described their reactions to providers’ use of gender pronouns when referring to them. Participants stated that they noticed and appreciated when providers used the proper (i.e., male) pronoun. One participant spoke of the positive impact of providers’ awareness and proper pronoun use when referring to him:

The thing that I really appreciate about the clinic is that they are very aware of the little things that make a transgender person’s experience at the doctors go smoother—like they always use the right pronouns. They use language that lets me know that they don’t think of me as a freak or an oddity.

Some of the participants expressed frustration and feelings of identity invalidation when providers did not use the proper pronoun:

I had two hours of being Ms. X even to my continual objection... and because the technician had said ‘Ms. X’ the doctor started saying ‘Ms. X’ even when she looked at the file and recognized that it said ‘Mr. X’. ... I don’t want someone to come up and say I thought you said you were... or not even give me that much... just go away and come back and change pronouns, change their demeanor toward me, as if a woman should be treated differently than a man when seeking health care.

Another aspect of provider competence was their ability or willingness to treat transsexual patients with respect, dignity, and compassion. One participant talked about how providers could be more compassionate to their patients in the following statement:

[It is important] to have doctors that have the ability to look past you as a patient and ask what is it that you really need... to see what are your trigger points that are going to make you hurt more emotionally or physically, and how they can not hit those spots.

Another participant expressed the need for medical professionals to behave respectfully when treating transgender people:

When a transsexual person comes into a doctor’s office and is requiring care, that medical professional needs to be professional. They absolutely need to be medical, but they also need to be pro-
fessional. They need to not ask questions that are irrelevant. They need to not ask questions that if asked of them, would put them on edge. They need to remember that they have got someone’s life in their hands.

Participants also photographed and/or shared stories of receiving good health care. All of the participants who had a primary care provider reported receiving good health care from that provider. One participant photographed himself receiving good health care and described his experiences at the Tom Waddell clinic:

FIGURE 5. Receiving Good Health Care
I wanted to have an image of a nice experience of health care . . . The staff [at the clinic] are really sweet and very caring and very professional. Even though they are overworked and always in a rush, they are always warm and caring, even my doctor . . .

**Vulnerability**

All the participants discussed feeling vulnerable at some point in their contact with health care providers or the health care system. Participants’ expressed vulnerability when they had to remove their clothing, or “come out” (the process of telling their health care providers that they were transgender). Participants’ vulnerability occurred in three distinct social contexts: (1) when accessing emergency or specialty care, (2) when putting on “the gown,” or having to disrobe for a physical examination, and (3) when in “the waiting room,” the experience of waiting amongst the general public for specific types of health care, such as gynecological care.

While all the participants with a primary care provider reported receiving good care from that provider (as described above), they all expressed fear when they required emergency or specialist care from a new provider. Each visit to the emergency room or to a specialist required “coming out,” telling the providers that they were transsexual. Participants explained their vulnerability as the fear of exposure to unknown providers and potentially negative reactions from those providers—reactions that could affect the provision of adequate medical response. One participant’s image of the emergency room entrance was described with this comment:

The emergency thing is so traumatic for so many of us, and having had a number of experiences with emergency rooms myself, both accompanying other people and being the patient myself, I just know how important that little portal is . . . I want to talk about how important and how frightening the emergency room is. It’s important for everyone. It’s absolutely terrifying for transsexuals.

Many of the participants talked about feeling vulnerable when they had to disrobe for a physical examination, stating that disrobing made them extremely vulnerable because they were unable to hide that their sex organs were incongruent with their gender appearance. Participants stated that they feared being ridiculed or having their gender identity questioned, denied or ignored by health care providers, despite their re-
quests to the contrary. One participant photographed the gown itself and shared the following:

I don’t know what they are actually called: the dressing gown that you have to wear when you are getting tests done in the hospital. I wanted to represent that this is what I have to wear when I am going to have testing done, and it makes me very uncomfortable. I am very vulnerable . . . I was in this gown with nothing else on which is the first thing that puts a transsexual at a great disadvantage, and feeling very uneasy . . . So again, I can be who I am as long as I don’t have to take my clothes off, and I don’t have to be examined.

Participants expressed feeling vulnerable when sitting in waiting rooms prior to seeing their health care provider. The type of waiting room that caused the most anxiety was the gynecologist’s waiting room. One participant stated that his waiting room anxiety and feeling of vulnerability were so intense that it kept him from seeking gynecological
health care. He depicted his feelings through a series of photographs taken in a hospital waiting room:

The thing that came to my mind was that I need to take a picture of myself in the waiting room, because that is where I would feel the most anxiety... This is actually where it would be the hardest, sitting here knowing that these women probably think that I am here waiting for my wife or girlfriend who’s in there having an exam, and that she is going to come out and we are going to leave. What’s going to happen when the receptionist calls out my name and I stand up and go in to the room?

*Invisibility*

This is my collection of transgender health information... this is all that I had to work with when I was making my decision about whether to take hormones or not... that is not a lot of information...
and all of it has disclaimers in the front... [This picture says] that transgender health information is sparse and a lot of it is conflicting... This picture tells you that I have to make my health care decisions based on folklore information from people I talk to who are not experts... I would like to get more information from people who have more training but I don’t know where they are.

Participants described feeling invisible on many levels, from not having their gender identity acknowledged by individual providers, to the absence of transgender-specific health information. Participants noted that it was particularly difficult to find accurate or relevant information about transgender health care, and stated that this limited the ability to understand their own health care needs. This was expressed by one participants’ photograph of gynecological information taken from the Internet:

This is a conclusion people could come to about gynecological health care and FTMs. It is a very dangerous conclusion, because
FIGURE 9. Collection of Transgender Health Information

If it's on the web, it MUST be true....

Gynecology is health care for women.

Staying healthy is important. Whether you're young or old, married or single, sexually active or not, or whether you're lesbian, straight, bisexual — good gynecological care is the key.
biologically I am still female and I haven’t had a hysterectomy, I haven’t had any lower surgery whatsoever. So from that point of view I very much need gynecological health care, particularly in light of the fact that I do take testosterone and I believe, see I don’t even know myself, I believe from what I have heard that puts me at higher risk for cervical cancer. I don’t even know that for sure. It is something that I have heard from other FTMs, but not all of them have said the same things. We don’t know that much about our own health care needs, which is another component of being invisible.

According to all of the participants, providers lacked knowledge regarding transgender health and often relied upon patients to educate them about their relevant health care needs.

I can’t get answers because I have to educate them about transgender stuff . . . I think training needs to be in medical school. They need to know about us; they need to know how to deal with us.

Perseverance

All participants framed their path through the world as a “struggle,” and discussed feeling alone. Each described ways in which they had persevered against all odds, finding ways to cope with the difficulties they faced. Participants described ways in which they had learned to take care of themselves within a health care system that they perceived was ill equipped to handle their needs. They explained how a sense of optimism helped them to cope with the painful experiences of living as a transgender person in the world. They all spoke of trying to maintain a positive attitude, and believing that “things would get better” if they persevered. One participant related how optimism helped to counter painful feelings about his gender expression:

Luckily, I have this eternal optimism. I can distract myself about pain I am feeling. I figured eventually I will figure this out, but there is nothing that I can do about it right now . . .

Some participants shared stories about reaching a point of crisis, where they no longer felt they could cope with the obstacles before them. One described such a crisis as a juncture, at which point he faced a choice between persevering or giving up on himself (and on his life).
This is exemplified by a photo in which he is holding a gun to his head. (Note: the participant was not in distress when this photograph was taken; he staged the photograph to illustrate that previous time in his life.) According to several of the participants, suicidal feelings are not uncommon for transgender individuals. When asked how they persevered through these crisis points, participants responded that they made a decision to choose life:

This is literally a place I came from of making the decision to choose life [or death], and fortunately for me I chose life. This [suicide] became a very viable option for me at one time before my transition.

Participants emphasized the importance of transgender visibility, the visible presence of self-identified transgender people in the media and within health care environments, as a factor in their perseverance. For example, one participant created a montage of images of transgender people in the media, explaining how seeing those images validated his experience and allowed him to see himself mirrored in the world.

FIGURE 11. Montage of Images
Participants also described community as a key to their ability to persevere. One participant found community through a group called FTMI International, as pictured in his photograph:

This is actually the meeting space for FTMI which is Female to Male International. It's a very sweet home place for me. I went there for my first meeting and cried the entire time. 'Oh my god, I found where I am supposed to be.'

Activism

Like perseverance, activism was a strategy used by all the participants in the face of adversity. Participants' stories each revealed some form of

FIGURE 12. FTMI Meeting Room
leadership or participation in activities that increased transgender visibility or awareness. Some accomplished this through volunteering for transgender organizations; others were leaders in national and international efforts to increase transgender awareness. Each described his activism as an effective, positive, and in some cases necessary means of moving through the world and through the health care system as a transgender individual.

Activism was described by participants as not only a means for coping with the “system” and lack of provider competence, but also as a path to creating change through their interactions with the system and with providers. One participant saw it as giving back some of what had been given to him:

Right now I facilitate the support group meeting there [at FTMI]. So the room not only has meaning of that to me, it’s also a way of me giving back for what I have received . . . It is a space of me giving back chunks of me . . .

Another participant described himself as a “pioneer”:

I do have a vision for a future where it won’t always be as hard as it is now. I feel like a pioneer—very much so, like I am on the frontier.

Thus, participants described how their “pioneer” and activist efforts were “giving back” to people who had come before them, and “paving the way” for other FTMs who would come along in the future.

Participants told stories of acting as educators, advocates and supporters within and outside the FTM community and with their health care providers. Participants stated that they often needed to educate their own provider about transgender health issues. Some saw this as an opportunity to improve the quality of health care for all transgender people, one provider at a time. One participant shared a story of such a teachable moment with a medical student who was working with his gynecologist:

[My provider asked] ‘If it’s O.K. with you I’d like for you to come sit in the chair and I’d like to do an exam. We have a student here today who has never worked with Trans-people and I’d like her to be able to talk with you. You can say no.’ I said, ‘I think it’s important for students to get to know us, to get comfortable with us and what our medical needs are.’ So this woman came into the room
and helped to examine me. The doctor was explaining what to expect because of testosterone. The student was asking me about other surgeries, my health care, and was just generally concerned, asking me ‘If I want to find out more about transgender people, where do I go? How do I talk to them?’ We had a conversation about it. It made me feel a little bit more comfortable about the fact that I had to sit in that chair. It was good to know that at least a little bit of what I was doing was providing someone with some education so that when they see a transgender person later on, that person is going to get treated with respect. They’re going to get treated with the medical care that they really need to be. They’re not going to get asked inappropriate questions.

Participants shared about being educators in their own community. One participant talked about teaching other transgender men to inject hormones properly, and how to dispose of needles properly. Another
explained how transgender people disseminate health information to each other via the Internet or at meetings:

Transgender people are taking this task of providing information into their own hands. We do it ourselves. We collect information and share it with people in the only ways we know how. We spend our money photocopying stuff and handing flyers and brochures out at meetings. The Internet has also been an amazing help... We are taking things into our own hands. If the government and health care industry are not going to do it for us, then we are going to do it until they catch on and start doing it with us.

**DISCUSSION AND RECOMMENDATIONS**

The participants' photographs and stories confirmed that the FTM community is challenged to find competent and culturally respectful health care. The study also showed that FTM individuals are hesitant to seek regular preventive healthcare. This may be due to the fear and anxiety surrounding gynecological care for this population, as well as the lack of provider knowledge regarding gynecological needs of FTMs, and provider insensitivity towards FTMs when they do access preventive gynecological care.

**Emerging Themes**

The themes identified from the data illustrated that many of the causes of the current lack of competent health care services for transgender people are directly linked to one another. Thus, working to improve the quality of one aspect begins the process of change in other areas. An example of this can be seen with the connections between the themes of vulnerability and invisibility. These themes emerged separately, but are related to and influenced by one another. Participant stories reflected that the vulnerability they feel when seeing a specialist, getting emergency care, disrobing for an exam, or sitting in the waiting room is related to the invisibility they feel as transgender people (particularly FTMs) in society. In this study, invisibility was described as (1) inaccurate information, or complete lack of information about transgender-specific health care, (2) a general lack of understanding or acknowledgement about the existence of transgender people, and (3) the disbelief, shock, and other negative reactions on the part of practitioners—
including incorrect female pronoun use, despite the patient’s insistence upon his male identity. In those moments of invisibility, participants also described feeling vulnerable. Because of their experience of being made to feel invisible by providers, and their ensuing sense of vulnerability, the FTMs in this study often felt reluctant to seek care. Those two themes of invisibility and vulnerability thus interact to create a barrier to gaining access to health care.

Coping Mechanisms

Perseverance and activism emerged as both themes and coping mechanisms for participants to overcome barriers to competent care. In addition, these coping mechanisms helped them to reduce invisibility and vulnerability, and served to create improvements in provider competence and in the health care system overall.

Participants attributed their perseverance to a variety of support systems (community, positive media images) as well as to the necessity of survival (the choice of persevering in order to survive, or “chose life”). In one story a participant explained how he first heard the words “female to male transsexual” and discovered the possibility of an FTM identity through a documentary film. This is an example of how media visibility can support an individual transsexual’s identity. Seeing this film enabled him to attach a label to his identity, and begin making sense of his inner gender confusion:

I was sitting there watching this movie with my girlfriend and crying ’cause . . . I had always thought, I feel like a guy, but I am not, so I’ll deal with that, but I saw all these guys and they were telling their story, and it was my story, and I had never heard anyone tell my story before . . . and I thought oh my god I never had a word for it they are female to male transsexuals! FTM, that’s what I am. I never had a word for it before.

In this example, the presence of visible transgender people was key to the participant’s ability to persevere, giving him hope and lessening his feelings of isolation. The need for community was also discussed by several participants as a means of coping with invisibility and lack of competent health care. The search for community encompassed finding a place where participants did not feel judged, where they did not have to define or defend who they were. Within their communities, participants could let down their guard, be themselves, and feel respected.
The theme of activism emerged as a means for participants to overcome some of the barriers to health care, and thus was related to the themes of invisibility, vulnerability, and provider competence. Participants described their willingness to be visible in society and to act as agents of change (activists), particularly within the health care environment, as helping to remedy the invisibility perpetuated by the health care system. For example, the participant who allowed the medical student to take part in his gynecological examination stated that he was willing to be an educator in that instance in order to improve that provider’s future ability to work with transgender patients. The participant also described his decision to educate his providers as a coping mechanism in the moment, helping alleviate some of the stress he felt during gynecological visits. The participant’s response thus linked the theme of activism to other themes by reducing vulnerability and invisibility while increasing perseverance and provider competence.

Improving Provider Competence Through Perseverance and Activism

Provider competence, which includes direct contact and the administering of care to a patient, can thus be impacted by individual transgender people who are bold enough to act as agents of change (activism). Provider competence can be improved by informing providers about current transgender health trends and concerns, increasing transgender visibility, openly discussing life experiences that affect transgender health, and holding providers accountable for the quality of treatment that they are administering to their transgender patients.

The participant story about transgender people disseminating health information amongst themselves is another illustration of the advocacy component of activism, as the participant described how transgender people are “taking this task of providing information into their own hands” and thus advocating for themselves. This statement reflects the perseverance demonstrated by many transgender individuals, and the importance of FTMs educating one another about navigating the health care world as a transsexual. The education, advocacy and support roles in which the participants all found themselves reinforced their roles as pioneers and activists and as men who envisioned a better world for all people.

Thus, participants drew a connection between their own health care interactions and working towards a vision of equitable health care for all. Participants each saw their own lack of adequate health care treat-
ment as a product of greater problems of a system in which transgender invisibility was only one aspect. Each in his own words described greater injustices in the “system” that impact underrepresented communities. Participants perceived that these systemic injustices played a role in some of the improper or disrespectful treatment they received as transsexuals. Likewise, participants with positive experiences of receiving care felt hopeful of greater possibilities for improving the health care system for many other marginalized populations.

Participants all extrapolated from their own experiences to envision greater possibilities for improving the health care system for many other marginalized populations. Their ideas included improved education and training, adequate compensation and optimal working conditions for people who work in health care, and broad-based solutions such as a national health care system. One participant’s comment exemplifies a vision of a world in which all people could get their health needs met:

We all deserve to have our health, and if there is anything that you can do as somebody who provides that or has the power to provide it, then do it! What is stopping you? There are people dying and being sick and leading miserable lives that don’t have to. Why not make it a world where people can get what they need and deserve, instead of suffering? I don’t see the point really. That’s not the kind of world I want to live in.

Recommendations

Participants indicated that with provider training and a clearer understanding of transgender people, the level of vulnerability and invisibility that an FTM experiences trying to access health care may begin to diminish. As illustrated in this study, change begins to occur when (a) transgender people insist on their own visibility and act as agents of change (activists), advocating on their own behalf, and when (b) the health care system takes responsibility for educating its providers and practitioners to treat transgender patients with compassion, dignity and respect.

Furthermore, participants noted that they felt invisible when research studies and basic health care information did not include specific references to transgender health care. They felt the lack of transgender-inclusive research perpetuates the dearth of relevant and necessary transgender health information.
Therefore, recommendations for practice, as derived from participant comments, are summarized into three categories: training, service provision, and research. Training recommendations are those made for professional development among health care professionals, medical office staff, and emergency response workers. Service provision recommendations refer to guidelines for the delivery of health care to transgender patients. Research recommendations refer to further study needed in order to provide information on health risks, concerns, and needs of the FTM population.

Training. Increasing the knowledge of health care providers and health care staff is a crucial step in improving transgender access to care. Training that specifically addresses all aspects of working with transgender people in a health care setting is recommended: (1) at the provider level (including doctors, nurses, physician assistants, and nurse practitioners); (2) at the frontline staff level (including the office staff and receptionists who are the often the first to encounter a patient in an office setting); and (3) at the emergency and crisis intervention level (including, emergency medical technicians (EMTs), paramedics, police, and firefighters who may deal with transgender people in emergency situations). The training should be specific to the level of care that is being provided, and should be designed in consultation with transgender individuals.

Service provision. The results of this project made clear the need to create health education and health support systems that are specifically designed for, and inclusive of, transgender people. For example, transgender people would benefit greatly from gynecological services designed specifically for them. Such transgender specific programs would make these services more accessible and would increase the likelihood of transgender people seeking health care. Additionally, transgender focused support services would allow individuals seeking services to focus on their actual health care needs rather than spending their time combating others’ discomfort, pushing for their own visibility, and educating their own health care providers about transgender identity.

Another area of focus for service provision to transgender people would be the creation of specific health support for people who are in the process of gender transition. FTMs who are transitioning may have questions and need vital information about basic health maintenance as their bodies go through tremendous chemical and physical change. Major concerns regarding testosterone injection might include dosage; self-administered injection; interaction of hormones with tobacco, alcohol, and other substances; long-term health risks of testosterone; side
effects of and physical reactions to hormone injection; emotional and physical changes resulting from testosterone; and development of male secondary sex characteristics. Other relevant concerns might include sex reassignment surgery options and their health effects; interaction with the health care system for non transgender-related health concerns, and necessary elements of gynecological health maintenance during and after transition to male identity.

Finally, participants recommended clear guidelines for health care providers, medical office staff and emergency personnel on providing sensitive, quality care to transgender individuals.

Research. Overall, the lack of information about transgender specific health care issues inhibits providers’ ability to deliver competent care. More research is needed to assess the health risks, preventive health needs, and health care needs of transgender individuals. Dissemination of such research results within the medical community has the potential to improve health care delivery to transgender individuals. Results of these studies should also be shared with the transgender community, so that FTM individuals can be educated about their own health care needs and can seek appropriate care.

CONCLUSION

This project used Photovoice as a way to gather information about a segment of the transgender population (female to male transsexuals) that has rarely been studied. While the small sample size of this project prohibits making generalizations about the experiences of all FTMs, the insights and information gathered from these men and their stories may to inform health care providers and researchers about the need for more inquiry into this segment of the transgender population.

This project started an important dialogue with FTMs about the issues of health care access, and provided insight into needed areas of future research inquiry related to the transgender community. Transgender people are the experts on their community; therefore, they should be included at the table when policymakers and practitioners are discussing research, training curricula, and standards of care related to transgender people and their communities.

The project participants were paving the way for others, their stories revealing individual and collective struggles navigating the health care system. From a system that disregards and discriminates against them, to providers who are unable to treat them adequately, participants each
illustrated a great deal of hope and courage to persevere through all of these challenges. These men have not only persevered and overcome barriers to health care access, but have thrived and helped others like them to do so as well. The themes that emerged from the participants’ stories provided a dynamic picture of individuals who have taken great risk in their lives in order to live in a way that is most true to their identity. Although the group of men came from many different walks of life, the themes that emerged from their stories reflect a commonality in their experiences of accessing health care.

REFERENCES


