Ways of Knowing and CIT: Women Living with HIV/AIDS in the US

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Well, welcome everybody. I didn't want anybody to feel like they were on a blind date, so we had this illustrious introduction, but I wanted to say fundamentally, I wanted to start off with thinking about the title a little bit, *Catholic Intellectual Traditions and Ways of Knowing*, and just sort of set up what I'm about to talk to you about from that perspective.

When I started to get involved with the Catholic Intellectual Traditions group, which was an initiative from the Provost as you probably know, I was talking to some of my colleagues and I told them about it, and they said, I'm not Catholic, so it has nothing to do with me. I remember trying to get a handle on that to understand what that actually meant to me as we were developing as a group.

One of the things I think it meant as I did more and more reading and as I tried to describe this to my colleagues was that it had nothing to do with being Catholic, active or not, or Christian, active or not, or Muslim or not, or Buddhist or not. It had more to do with the ethic of being a part of the Catholic university and being a reflective group of people. That really has been the center of what I am about to talk to you about, a journey about working with women living with HIV here locally, who are consistently African-American or black. Statistically, that's where they show up.

The point is that I think from a methodologic perspective and even from a philosophical perspective, I learned a long time ago, even though I was trained as a researcher, as a scientist, the truth is that we get information from all different ways of knowing. I've always been what I would call a mixed-methods researcher, meaning that I think there are things we can deduce. We can measure empirically, but I think there are things we just need to listen to, stories that need to be told, and somehow, those two things really give us information.

It's difficult to do both. It's a lot of work. It's a lot of time. In reality, it's a lot of money. But in my way of knowing or how to know, it's the only way to really get an accurate view of what's going on. So this idea of reflectivity or being reflective as from a Catholic Intellectual Tradition perspective for me, it's been sustained reflection. That's really helped me understand what women who are living with HIV need and want and feel.

I have a handout that I gave you, and I'm going to be talking about points. The first piece of information I need to share, and I think it's fairly obvious, is that women of color are really attacked unfairly in some ways; they more than any group of women in this country and in the world are affected by HIV. Statistically, we see a very grim picture. We see either unchanging statistics about incidence or prevalence, or we see rising incidence.

One of the things I have on your handout is that is that there was sort of a confession of sorts at the end of last summer. The CDC JAMA reported this also and said they made a mistake, and they underestimated what was going on with HIV. The numbers are really higher than they ever believed them to be in the United States, and again with this group of African-American or blacks – statistically black is how it

comes up, which means African-Americans and other individuals that would identify as black. They have an unequal share of this particular virus, having the virus, living with the virus and actually dying from AIDS. It's a formidable problem.

Then we hear in the health care community this notion of health disparities. It's become a very popular and sobering thing. When I think about health disparities, I think about two things, and it's important to talk about it because I am a public health community health nurse. My interests have not been so much in the acute care areas of hospitals, just to set that forth in terms of nursing and health, although I've needed hospitals when I was acutely ill and we need them there, but I've been more interested in how people sustain themselves in terms of wellness and health promotion in their neighborhoods. My interest has been not so much how the diabetic gets her tray in the hospital, but how the diabetic makes choices when the tray isn't forthcoming in the real world.

We see a lot of issues at hand in the community setting that are really stunning, and I was interested in trying to figure out what was going on for women living with HIV, specifically African-American women. I started a five-year journey on the sustained reflection, this Catholic Intellectual Tradition that I think really lives here and breathes here at Boston College, and also this way of knowing what's going on. This tradition from a research perspective is called community-based, participatory research and what I did for five years was on a monthly basis, we did a prevention program.

We went out, two nurses and myself, and we did topical conversations with women who would come. We served lunch. We're pretty sure they just came for the lunch, but they got whatever else we talked about. The truth is that we talked about a lot of things, but unlike the usual thing that we do when having an evaluation at the end, we talked to the women in groups and said, what should we talk about next? What are you struggling with? What would you like to talk about? What do you want to address? And we would go with the flow.

In the fifth year, I gave a talk because they wanted to talk about the fact as women, they felt that they were struggling with not being able to tell people in the health community what they needed and felt that they needed or just what they felt. Health disparities really started getting translated to me as it's not just equity in terms of fairness, in terms of what one gets, it's also how we help people to be able to have a voice to be able to get what they need. We're not digging out in the community asking people to come in. They must have some levels of advocacy, too, and disparities occur at both ends of that spectrum.

One day I gave a talk about this theory, *Silencing the Self*, which I had been very interested in. It was very gender-oriented, based in psychology, talking about why it is that women choose silence many times. This is not a sexist idea, because men silence themselves also for different reasons perhaps, at least theoretically we say that. At the end of the talk, it was like the white professor from Boston College would come down to Dorchester to speak. It was the answer to a dream in that I was participating with them as an equal in this conversation. I wasn't trying to tell them what to do.

Four women came up to me, were all living with HIV, all African-American, and said we're tired of listening to you and all the other nurses – we didn't take this personally – and we want to do something. We want to use our voice, and we want to do something for other women in our community. We want to speak to youth, and we want to speak to women who are living with HIV to help them in their process.

I said what would you like to do? They said they would like to make a film. I started internally hemorrhaging, thinking how would I ever do that – because that's not my skill set. But BC was my skill set. I had just arrived here at Boston College, and Chad Minnick, who was at the School of Nursing, an experienced filmmaker, became the filmmaker. Dr. Ann Norris, a colleague interested in HIV also teamed up together, and we made the film *Women's Voices, Women's Lives*.

The film is a way of knowing. It's a way for women to reflect on what it is like to live with HIV. The clip we're going to show you is the clip where they're talking about what it's like to feel stigma, where everything changes in your life after you've been diagnosed. Just think about this. This is very important. These women did the most courageous thing they could possibly do, on their own, and this is the process of reflecting with them and staying with them with the topic at hand. They disclosed their HIV status publicly to help a lot of other people. When we're done with the clip, I'll tell you where the film's gone. It's amazing how it's affected these women and how we've come to know more about HIV through this film.

Film Segment

Woman 1: When I was diagnosed, I was totally devastated, and for about a year or two, I totally went into denial. It's like, look at me, I'm fine. Nothing's going to happen to me, and what scared me most was that I was so ashamed that I couldn't even tell my family. I was afraid that people around me would know. I would listen to people talk about people with HIV, not knowing that I was in their circle and I had HIV. I became homeless. I used to sleep in the Boston Commons. I slept on the rotunda in the Boston Commons, and my penthouse was the fan room inside the Park Street station. These are places that, in my life in normal times, I would never have been, but because of the fear and the running that I was doing because of HIV, that's where it took me. It took me to homeless shelters. It took me to clothing banks to get a pair of clothes just for the day. It took me into constantly unsafe predicaments.

Woman 2: I felt that I was damaged. I felt that I was damaged. I felt like I was one of those dented cans on the shelf. I felt that I was never going to have a relationship again, nobody was ever going love me. I just didn't think that I was going to be able to deal with HIV. I felt very, very, very suicidal. I was very scared. I was hurt, and I just felt like my life was ending. I had AIDS. I had AIDS and I was going to die.

Woman 3: My biggest worry was because I found out when I was pregnant. So I wanted to think of how to have a healthy baby. How could I do this? Would my baby be infected? What kind of things would I have to deal with an infected child? Dealing with the fact that I was having unprotected sex, and that these are the things that I did to myself.

Woman 2: Living with HIV has totally changed my life. It has totally changed the way I think, the way I see things, how I act. My life is totally different now. I don't feel like a normal person. I feel bad. I have something inside me that's slowly but surely killing me, and there is nothing I can do about it. I can't do anything about it. I can't poke a hole and let it squish out. I can't do that.

Woman 3: I was pregnant and to bury a baby at six months old and basically, for a long time I had to live with the guilt that this is something that I did to myself, that because I didn't take precautions, I got pregnant and had a baby that was infected with HIV and had to deal with it.

Woman 1: I'm trying to deal with being HIV and even then, since then up until now, my life has totally changed. You'll find out that the people that you thought were your friends, some of them are not really going to be there for you. You're going to be disappointed in the way that people react to you sometimes. Sometimes, you're going to be overjoyed, but sometimes, you're going to be really hurt by the negative attitudes that you get from people around you.

Woman 4: They look at us like we're dirt. We're tramps to begin with. They think they're meeting a sexual pervert or a low-life dope-fiend and God is punishing you. You can't go to everybody, even in your own family, you can't go to people and say, I don't feel good, and I'd like a hug and some sympathy in return – no, because half of them will say, well, shouldn't been with him like that. You shouldn't have done that. You know you shouldn't have had sex with that boy. Come on, girl, let me tell you something taking two pills does not make it alright. Not at all. It's horrible.

Woman 1: It hurts to know that with all of the education that is there that people still are so cruel sometimes, making fun of us and stuff like that.

We see in this sort of clip from the film, this reflection around a couple of things. First of all, the women are older women. I have to be careful when I say that, I mean they're over 40, and they've been living with the virus for a long period of time.

This sector of African-American women that are living with HIV are heterosexual women, so we're talking about women in heterosexual relationships. How can a film of African-American women in Boston speak to a woman in Vietnam or in Africa or a white woman or a woman from Cape Verde? How could it be? We showed the film to many audiences that were very mixed, and both Ann Norris and I were concerned that somebody would say, "That has to do with Dorchester and black women. That's not me. It's just not me. That's not my life. That's not who I am." And we asked the question over and over again. We asked it of Cape Verdean women, white women and Haitian women. We actually asked it of men. All of them said that after the first 60 seconds, they don't see African-American women. They see women who are struggling, who are poor, who are in relationships with men and are trying to deal with the realities of having children who have HIV, having continued intimate relationships with men, how to protect themselves, how to protect others, how to take care of themselves.

The film is now in a new generation of movement in helping others. One of the women in the film, the one with the blond hair, Katherine, and another woman living with HIV and I teamed up because they wanted to use the film with me as an intervention of some sort. In other words, they wanted to try to affect change. It wasn't enough to just have this film. We actually have curricula that go with the film. We have three versions – a teen version, a women's version, a provider version – because we never wanted the film to be just shown with popcorn and then say good-bye and good luck, but there needed to be conversation and skill building along with it.

We now are using the film in a project called *Sistah Powah*. The women, again, named the project. *Sistah Powah*, said with a Bostonian accent. And what we're doing is we're using meditation, a clip of the film and narrative writing that shared in a group format, and the women share their writing with the group. You can see the qualitative research component. I'm analyzing what the women say, and we're recording that information and we're also analyzing what they write, but we're also looking to see if that intervention affects change on a variety of parameters, which is the quantitative methodology or research component. We're looking at adherence. If you're not familiar with that word, it refers to not just taking the medications that you need to but going to see your physician, nurse practitioner, your health care facility. It's getting adult checkups. It's having pap smears, doing all the good things that you need to do. It's also quitting smoking, taking good care of yourself and safe sex practices for these women.

We also look at stigma. We look at self-advocacy, which gets at that "silencing the self" piece. These are all measures that are actually quantitatively calculated. We just finished an 18-month study that was funded by the Hardner Foundation, as well as the Massachusetts Department of Health, and we're seeing effect in the intervention group. We had a control group, so it was a randomized control trial from a scientific perspective – 74 women were involved in this – and we see affect between time one, before we started the intervention, at six weeks, when the intervention ends, and at six months. And we've had 100% retention, which is really a big thing. In research, as you probably know, that many people fall out for a variety of reasons, and everybody's stayed with it. Must be the lunch, again that we offer, or dinner in this case. We're continuing to try to find meaning in what's going on in these women's lives and how we can affect their voice to really, ultimately affect health disparities at that level.

I'm going to stop there. I promised I would. There's so much more I want to say. You can read between the lines on this handout, but I wanted to just talk to you about questions you might have about this idea of ways of knowing, working with these clients, my own perspectives on that, and the Catholic intellectual traditions as I see it.