

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

A Conversation with Rosanna DeMarco
Associate Professor, Community Health,
Boston College

INTERVIEW BY SUZANNE HEVELONE
BOISI CENTER FOR RELIGION AND AMERICAN PUBLIC LIFE
BOSTON COLLEGE, CHESTNUT HILL, MASSACHUSETTS
FEBRUARY 26, 2009

SUZANNE HEVELONE: Today we're speaking about ways of knowing the Catholic Intellectual Traditions in relation to women living with HIV/AIDS in the U.S., and I want to start by asking you how you see your work with women with HIV and AIDS as illuminating both the ways of knowing and also the Catholic Intellectual Traditions. Where do you see the connection?

ROSANNA DEMARCO: There's a huge connection. When I first started getting involved about a year ago with the Catholic Intellectual Traditions, the Provost initiative, lots of folks who responded to the concept of CIT said, "I'm not Catholic, so that has nothing to do with me." I was concerned about those kinds of comments, so I started seeking out writings that specifically targeted the notion of Catholic Intellectual Traditions and thinking about what it really meant.

In essence, part of the meaning of CIT is the sustained effort of reflection on something from which we want to draw meaning from. For me, I'm a nurse and am proud to say that I am. For years I've been a public health community nurse, and so my interest has never been in the area of acute care, where patients really do need care at particular points in their lives. I've been more interested in the sustained level of work people do to keep healthy and promote their health within a community setting. That means when you go home from the hospital after finding out you have diabetes, it's trying to figure out how you eat the right things when the tray isn't coming to you in the hospital. I've been very intrigued by that.

The notion of sustained reflection and meaning for women living with HIV – it has to do with how I, as a white woman from an academic setting, go into a black community that's been disproportionately affected by HIV and AIDS. How I try to figure out what helps and supports them in the promotion of their own health after they've been diagnosed, or before they've been diagnosed, or even before they get into situations of high risk.

I decided as a scientist that I needed to develop a method that would help me have this sustained reflection. The way I actually approached this was looking at a method called community-based participatory research. That method is very much like ethnography in that you need to be engaged with the community of persons of interest as an equal really, not as a scientist, as the professor, the person with the Ph.D. This involved talking to them and listening about what they need, what they

experience, what they struggle with, and so I did that for a five-year period of time through a prevention program.

I was working with two other nurses in a nurse-led, peer-driven prevention education program called Healing our Community Collaborative. After every time we gave our monthly program, we would evaluate the program, formally. We would sit with the women and say, what do we do next? What troubles you with what you're dealing with? Most of the women were either at high risk for HIV or were living with the virus. All of them, with a few exceptions of Latino women, were black. They were African-Americans living in Boston, in Roxbury, in Mattapan, in Dorchester.

One day I gave a talk that turned out to be significant. It was oriented to gender studies. The talk was about silencing the self, and it came out of literature from psychology, sociology and gender studies. It's about a theory says why it is that women choose to not talk directly to others about what they need and feel. This is a very significant issue, not just for black women but all women.

Four women came up at the end of the session and said to me, we're tired of talking. We don't want to listen to one more lecture. We've had it. This is after five years of presentations. I asked, what do you want to do? We want to do something. We want to use our voice. You're right. We silence ourselves. We want to use our voice to help younger people in our community not get this virus and to help women who have the virus stay well and not keep transferring the virus to others or be exposed to other things.

All four of them were living HIV. All four of them were African-American women. They said they wanted to make a film. I was thinking, well great – it's not a skill set I have. I went back to BC and was thinking again about the Catholic Intellectual Traditions.

We're not all Catholic – practicing or not, Catholic or not, Christian or not. It's that there's a tradition of being reflective people here, and I'm convinced that the more reflective we are as educators, the more we help our students be reflective and think about what's the meaning behind this data.

We started a journey of volunteer time with support from the School of Nursing. In particular with support from my colleague, Dr. Anne Norris, who is no longer here, and Chad Minnick, who is here. He was the filmmaker, and we made the film *Women's Voices, Women's Lives*. That film was a participatory action research project. It's concrete and it's resolute in the sense that it's now in a Vietnamese version and a Spanish version. We have a Creole version that might be happening, but I don't know yet.

The women and their participation in this were phenomenal. They helped with the editing and they named the film. Anne and I wanted to name the film *Older Women*

Speak Out, and they said, hell no. That's not the right title for us. We created curricula to match the film. There are three versions – teen, women and provider. It's been a big journey. This is at the international scene now. One of the Jesuits who was here (Juilo Guillietti) was very committed to work in Vietnam, and he asked that I take on two nurses from Vietnam and mentor them for a couple years. I did, and we ended up having a Vietnamese version. We have a Spanish version now. It's been very exciting. It's at the international scene. It's at the local scene. The film is really across the country.

SH: Where is it shown?

RD: It's shown all over the country. We made VHS tapes and we established a system of getting the film and curricula out gratis. Initially, we thought we would make money to help the women do what they needed to do, to continue this vision of prevention work, but it just really wasn't a financial boon. We started gratis getting it out. And one of the women told me somebody was at a conference in San Francisco and they saw her. I told her, we had a poster hanging up for you and for your work. It's out there. Now many of those same women have created a project called *Sistah Powah*, which they named, and we're using the film as part of an intervention to affect change in adherence, sexual safety, stigma, among other things.

SH: What does adherence mean in this context?

RD: Adherence is a term that means making a commitment to abide by whatever your medical care plan is. If it includes medications, primary care clinic appointments, taking good care of yourself – whatever you ought to do. Many people think of it as just medications. It's really much more than that.

This is where we are right now. We have an intervention running. It's peer led. The women who run the groups use the film. They use meditation and they use a writing exercise to gain levels of meaning from the film so they can talk through the experiences they've had. What we're trying to do is figure out what's the best combination as an intervention to help sustain these women in taking care of themselves. It's that adherence piece – decreasing stigma, being self-advocating and not silencing themselves. This is the project that I'm working on currently and seeking out major national funding to try to support it and keep it going. I'm trying to find out what is the gender sensitive, culturally relevant way to intervene and help these women stay well.

SH: When you were saying the film is on an international level, I was wondering how those international communities, including the male community, accept or reject this piece of film because of the fact that it's focused on black American women.

RD: It's a very good question. One of the publications that Anne Norris and I put out a couple years ago is about this very issue. When we were pre-testing the film and

there was a lot of editing going on. We showed the film to a lot of groups of people. We were always concerned about this thing. As researchers, the whole notion of a valid piece of work and the validity component in terms of science, especially if you were using this in an intervention, was very important to us. We always asked if there was anybody in the group who disconnected or didn't feel the film applied to them.

In the work we did with just men, the men said that they got an image of what women go through on the other side of sexual relationships in having safe sex and negotiating safe sex that they didn't have before. We asked in our survey what it would propel them to do, and many of them said to get HIV tested right away. That's a very important intervention or an outcome from an intervention, but also it made them more sensitive to being a partner that negotiated with women in a sexual relationship.

When we asked women in the audience who were Cape Verdean, who were Haitian, who were Latina, if in any way they didn't feel it applied to them, all of them, without exception said that the message in this film was universal to women. The exact quote was that after the first 60 to 120 seconds of the film, they didn't see African-American women. They saw poor women living in the community that they could identify with, with the same kinds of struggles they had.

The women spoke at a level that had to do with issues of women, a very gender sensitive way to talk about this. The fact that we got a request to have it dubbed in Vietnamese is a testimony that there's some universal message there for women. Why would Vietnamese women look at black faces dubbed in Vietnamese and still get meaning from the film? It could be critiqued as a highly insensitive, culturally insensitive thing to do, but there's something in the film that's pretty universal, and I would say with great bias, that as a white woman thinking about what the women say in the film, much of what they say resonates for me also.

SH: That's great. I wonder if we could just talk for another moment about class and poverty because that seems to be such a key component of the HIV/AIDS struggle. Why do you think HIV/AIDS afflicts that segment of our population, or how does poverty factor in?

RD: It's good that you asked. I'm actually writing the literature review for an NIH grant, National Institutes of Health grant, right now, and a lot of this is fresh in my head. I just came from Philadelphia, where the National Association of African-American Women with AIDS Conference occurred, and I spoke there. There's a tremendous level of complexity in the lives of these women. Unfortunately, from a research perspective, we make choices philosophically to either study them empirically, that is deductively, or inductively. I've chosen to study these women from what I have understood from the meaning that they've given me in talking to them through this CBPR approach.

And what I've concluded is that one has to really ask two different questions, inductive questions and deductive questions. I've approached this from a mixed methods perspective. If you heard what I said earlier, the intervention that I'm working on is looking for the effect on stigma, on adherence, so there are measures that we are actually looking at. But I'm also analyzing what the women write and what they say when they share their writing in a group format, so there's a qualitative inductive approach.

In listening to these women, what they talk about are five key things. They talk about multiple traumatization or victimization – very big words that simply mean that at an early age, many of them talk about child sexual abuse or something that happened that was inappropriate. They talk about IPV, intimate partner violence. When they finally connect with someone, something happens. There's either rape from a legal perspective or there's violent sex of some sort or violence that is connected with the sexual relationship. They talk about addiction. Many of them are addicted or had been addicted to alcohol, crack cocaine, IV heroin, either before they became HIV positive or during the time after they got diagnosed.

They talk about this addiction recovery traumatization, this post-traumatic experience, and then they talk about being poor, being homeless, trading sex for food, trading sex for money, trading sex for housing, and it's this complexity that starts to rise when you listen to what they're talking about. As scientists, we go in and we take a slice of that to try to study. An ecological model is needed to think about all of these things. They are connected, that social influences, who people are, their mental health issues. I failed to mention the fifth issue, which is chronic mental health problems. All of these things are related.

It is those that are poor, who live in neighborhoods where there are not resources, what we call in a very sophisticated way now health disparities, they are left steaming in this multi-complex situation. The health disparities piece is a very significant one. I wanted to mention it only because it's used all the time as a rationale for why we need to attend to poor people who have these issues, across class, across ethnicity and across race. This happens at two levels. There's the level that someplace like Massachusetts General Hospital will talk about in terms of the process of care – the notion of equity, fairness, who gets the best care, the quality at that level. There's another level, and that level is at the personal level or the individual level of the patient. If you're poor, you're a black woman in Boston, who has had a history of child sexual abuse, intimate partner violence, drug addiction, and mental health issues, there's a real insurmountable barrier for you to have the courage to have a voice to say, I need this care and I need it now.

That's why this idea of silencing the self rings a chord that's very true and is very, very clear through a long history of oppression. It is very key. It's not only key for women living with HIV, it's key for all women actually, but when you have five or six antes up on you around this issue, it's very formidable.