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Chapter 6

Acceptance: Living With HIV/AIDS: An Interview with Video Producer Paul van der Veur

Jean Young

Cornell University

Ithaca, New York, September 2007

“HIV is in our blood, it’s not in the mind.”

“We want people living with the virus to go to the schools to teach the kids.”

“You have to have a healthy life, please.”

The voices of three Namibian women, *Acceptance: Living With HIV/AIDS*

<http://web.cortland.edu/acceptance/>

Paul van der Veur is the executive producer/editor of the four part video series, *Acceptance: Living With HIV/AIDS*. As a former Peace Corp volunteer, Paul is involved in many facets of international programs. Paul recently returned from a 5-month trip to Namibia where he interviewed women living with HIV/AIDS in a four-part series production, *Acceptance: Living With HIV/AIDS*. The series was produced with funding by a Fulbright scholarship, a grant from the President’s Emergency Plan for AIDS Relief (PEPFAR) for the U.S. Department of State, Windhoek, Namibia in 2006, and a \$250,000 grant from Bristol-Myers Squibb for AIDS education and prevention for Swaziland. *Acceptance: Living With HIV/AIDS* was screened during the 2006 AIDS Day program in the Namibian capital of Windhoek and entered in the 2007 *Wild Cinema* Film Festival in the same city. The series was screened nationally by the Namibian Broadcasting Corporation. *Acceptance: Living With HIV/AIDS* is also being distributed on DVD.

Paul van der Veur currently serves as chair of the Communication Studies Department and as Program Coordinator of the Bachelor of Arts program in New Communication Media at Cortland College, which is part of the State University of New York. After arriving at Cortland in 2002, he has been the recipient of over \$50,000 in grants to develop the new media program.

In this interview, conducted in Ithaca, New York, September 2007, I spoke with Paul, focusing on the off-screen or behind the scene story of the video series, *Acceptance: Living With HIV/AIDS*.

Jean Young (JY): Paul, please tell us about your background in broadcast journalism and video production. What attracted you to the

documentary form? What unique perspective does your combination of production background, academic background and/or social activist background give you in terms of research and representation of the HIV/AIDS crisis in Africa?

Paul van der Veur (PV): My foundational background is in fine arts. I have a Bachelor of Arts from MTS Vakschool Schoonoven in the Netherlands and a Master of Fine Arts from Ohio University. I also have a PhD from Ohio University in the United States. I have tried to incorporate aspects from these experiences into my work since that time. I have been shooting, editing and producing video for about 15 years. I worked in the communication for development arena for several years in Lesotho before my doctoral research in Southern Africa.

My documentary work began in Montana (U.S.) where I created a variety of multimedia productions centered on environmental issues of the region. During that time, I produced works for both the Montana Department of Justice and the Arco Corporation among others. My work is strongly influenced by my background in the fine arts, my life in Africa, and my involvement in development, human rights and environmentalism. I think my research into the colonial legacies of mass communication on the continent has also strongly influenced my work.

JY: How do you, as a scholar and as a broadcast journalist, utilize the digital medium for maximum benefit? What are some of the advantages of this type of reporting over print journalism or traditional academic writing?

PV: Video allows a higher level of interaction with the subject matter than either print journalism or traditional academic writing. Documentary videos are potentially more participatory. They allow individuals to retain more authority over their own stories than either of the above forms.

JY: Please talk about the instances that fueled your interest and subsequently lead you to produce the video series, *Acceptance: Living With HIV/AIDS*. Specifically, what events led you to take an interest in HIV/AIDS in Africa? Paul, what part of Africa do you focus on and why?

PV: My interest grew out of a love for the continent and its people. I lived for 5 years in Southern Africa, and it became a part of who I am. I saw the devastation wrought by the disease (HIV/AIDS). From this experience I gained an opportunity to work on developing a grant proposal to develop a parish nursing program in Swaziland, specifically centered on the provision of hospice care to AIDS patients. I have had the opportunity to return on a number of occasions.

JY: Each woman that you interview in your documentary receives some type of treatment for HIV/AIDS. Paul, what is your general sense of HIV/AIDS in Africa as it impacts women, particularly women in the countryside? Are more women being reached and treated today—are you hopeful that more is being done to mitigate [the] HIV/AIDS problem among African women or are the efforts not reaching the vast population of HIV/AIDS infected women?

PV: I cannot speak to the continent as a whole. However, my sense is that progress is being made—especially in more urban areas, to address treatment issues. My understanding is that Botswana, for example, is making headway in addressing the issue. Getting information and medication out to rural populations remains problematic primarily because of two things: the lack of infrastructure and the lack of labor in these areas. My experience is that women are a primary focus in rural areas.

Recent findings, however, suggest that male circumcision is a crucial factor in lowering AIDS transmission rates. How that finding will change the implementation of HIV/AIDS campaigns has yet to be seen. However, my fear is that resources will be diverted from other worthwhile areas rather than addressing this new finding. Fortunately, for now, NGOs and the government are all making significant progress in getting basic information out to women.

JY: What is HIV/AIDS education like in Southern Africa today, Paul? What needs to happen in order to facilitate preventative dissemination of information around HIV/AIDS? What is HIV/AIDS education like, specifically for women?

PV: What really needs to happen now is to have the discussion opened up so that people feel more confident to talk openly about HIV/AIDS, the stigma associated with it, and some of the socio-cultural factors that continue to make women susceptible to contracting the disease, even within marriage. I believe that by creating and airing these videos nationally we have taken a good step along the road to creating this dialogue. My sense is that we have moved beyond providing basic information about HIV transmission. For example, research in Namibia suggests that the population is aware of what AIDS is, how it is actually transmitted, and how to protect one's self against becoming infected. Some of the important issues are now finally being addressed, as is the lack of behavioral change.

JY: Are there uniquely gendered aspects of the HIV/AIDS epidemic in Africa? How is the transmission of HIV/AIDS in Southern Africa affected by the status of women in these countries?

PV: There is tremendous variation in the social, cultural, political and historical structures that govern a persons' concept of self. Complicating the

matter is the fact that within many Southern African societies, women's legal status is equivalent to that of a child. Rules governing property ownership as well as inheritance laws can often increase women's dependence on men. In addition, there are often few moral strictures placed on men in terms of fidelity.

JY: Going back to your video series, what was your primary inspiration or motivation for producing *Acceptance: Living With HIV/AIDS*?

PV: As I noted in my Fulbright application, some related production work had already been done in Tanzania. This, coupled with UNAIDS recommendations that involvement of HIV positive individuals could be pivotal in combating the disease, grounded this work. I synthesized readings with my own experiences. We needed a vehicle that could move the discussion beyond the provision of information.

Video documentaries such as *Acceptance: Living With HIV/AIDS* allow people the opportunity to tell their own stories. This in turn highlighted related social issues that contribute to the transmission of HIV and more generally to the position of women in the country.

JY: Paul, it seems to me that the four women that you choose as your focus represent various faces of HIV/AIDS in Southern Africa. In Part I of the series, there is Kaalina, a married 40-year old mother of four who was diagnosed with HIV/AIDS in 1994 and who struggles with a husband in denial and an entire family that eventually tested positive for HIV/AIDS. Part II relays the story of Elizabeth, a young single woman who continues to suffer harassment from a man she dated and who knowingly infected her. She receives help from a supportive young female counselor who encourages women to accept their status and to seek the knowledge and education that will allow them to survive. Part III is about a teenager and student named Herlyn who contracted HIV/AIDS after hitchhiking a ride with a truck driver to Johannesburg and subsequently being convinced that she should "pay" for her ride with sex. Part IV focuses on young mother, Olivia, with two pre-school children who discovered her HIV/AIDS status after her three year-old son was diagnosed with the disease.

All the women portrayed in the documentary not only valiantly cope with the devastating physical effects of the disease, but also the stigma of having HIV/AIDS while facing ostracism from their respective families and communities. They are additionally challenged with the responsibility of providing for themselves and their children while living in rural communities that have limited resources. The women, who are remarkably unafraid to share their stories, speak directly into the camera while relaying their difficulties and triumphs. The four women whose lives are profiled in the series have managed to cope with their status and to go on to lead productive lives. Support comes in part from their families, but importantly from other women of the community

who volunteer as counselors and mentors. All women rely on spirituality to help them through their day-to-day challenges.

Talk about the reasons for selecting these four women in particular. Do they represent the face of AIDS in Southern Africa? Alternatively, is the problem much more complex, and if so, why? Which women do we NOT hear from in the video?

PV: In many respects, these women selected themselves. After arriving in Namibia, I was given the opportunity to speak with a group of about 50 representatives of governmental and non-governmental organizations (NGOs). I asked them for assistance in identifying individuals who would be willing to come forward and tell their stories. The consensus of that group was that while some people might be willing to talk to the international media, they saw little hope that anyone would willingly show their face on national television. Therefore, we were forced to bypass these more formal channels and employ more grassroots methods of identifying women to interview, and because of the prevalence of the disease it seemed that everyone knew, or was related to someone with HIV. We were therefore, in an amazingly short period, able to identify women who were willing to talk about their stories for us on camera.

The story of AIDS in Africa is as complex as it is large. I believe that every story is unique and profound in its own way and that to grapple with all the intertwining threads that surround its transmission, we need to tell as many stories as possible. That being said, I think we did a nice job with the limited resources we had. We were able to humanize the story and put faces to the statistics. Those women who are not visible in these stories are those at both ends of the socio-political spectrum, for example, the rural poor, simply because they were not accessible to us. Also not visible are the social elites within Namibian society. Although statistics seem to suggest that rates of infection are high among affluent, well educated women, we were not able to identify any willing to come forward within the time that we had.

JY: The general attitude of AIDS among the population is one of shame and avoidance, as examined in the videos. Does your research methodology and presentation propose an intervention in this overall attitude? If so, how?

PV: There continues to be a profound stigma associated with HIV infection in almost all societies in Southern Africa. I believe that the videos themselves are a mechanism for addressing this issue. Our goal was to tell the stories of people *living* with HIV...not *dying* of AIDS. As more and more faces are associated with the disease, and as more and more stories are told, it is my belief that people will begin to change their perceptions of what it means to be infected.

JY: Paul, do you see this broadcast video production helping to empower women with HIV? If so, how?

PV: My hope is that having these films air on national television will begin to open up space for discussion of the social, political, and economic forces that impact peoples' lives. In a sense, their HIV status becomes less important as other elements intrude. Open dialogue is, I believe, a strong catalyst for change.

JY: What other types of video productions would you like to see made around this difficult topic?

PV: I would just like to see more productions focusing on people's abilities to live, grow and to succeed. When we were trying to communicate the dangers of the disease and when treatment options were non-existent, there was a tendency to employ scare tactics in an effort to change behavior. An unintended consequence of those campaigns was that a sense of inevitability set in which made behavior change less likely. Now I think we need to balance that by showing how people are continuing to live in spite of their status.

JY: Are people in Southern Africa getting the message about AIDS or have things changed only a very little?

PV: My reading of the latest statistics in Namibia is that people are generally aware of what HIV is, how it is transmitted and how it can be prevented. Unfortunately, many people have not changed their behaviors.

JY: According to your research, how does the African woman's socio-economic position make her more vulnerable to HIV?

PV: This is an extremely complex question. In Namibia, the factors that force women to remain dependent on men work along with poor income distribution, ironically making affluent women more susceptible than other groups.

JY: Expand a little about the attitude of the government, the community, and the family when it comes to persons with HIV. Have attitudes changed over the years?

PV: I believe that there has been limited change in attitudes toward HIV positive individuals. However, I am not sure that this is not just a result of the sheer numbers of people infected. The discrimination against HIV positive people is obvious in the films.

JY: Expand on your discussion of the support systems available for women with HIV in the community that you focused on in your video series. One such support system is the women's discussion group. Are these systems making a significant impact?

PV: Many of the support groups highlighted in the films are assisted with interventions by donors and non-governmental organizations. These support groups are important on a number of fronts. First, they provide emotional and often spiritual support to those with the disease. In addition, they link these women into a support network that makes it more likely that they will receive financial and medical support. And finally, these groups are important vehicles for community activism.

JY: In your view, Paul, what can be done to help mitigate the HIV epidemic? Are governments moving in these directions, or is the problem still beleaguered with obstacles such as denial, under funding, and those socio-cultural or political barriers?

PV: Often infection rates can be influenced by strong stances of individuals with social capital. Here, I am thinking of King Mswati of Swaziland on the one hand, and former president Nelson Mandela on the other. Most leaders, however, seem reluctant to openly guide their countries in this area. In countries like Namibia, money is spent in attempts to address the disease. Botswana, in particular, has made significant strides in reducing the infection rates.

JY: Finally, what role did HIV infected women play in the planning, preproduction, production, and post-production of the video?

PV: A team of 15 Namibian filmmakers was involved in creating these videos. None of these individuals was openly HIV positive, although statistics would suggest that it was certainly possible that a number of the team were infected. Women got involved throughout the production process, with one of the films being shot and edited by an all woman crew.

JY: Where will your HIV/AIDS activism and scholarship take you from here?

PV: In the future, I hope to continue this work because I feel that we have an effective model here that could be replicated on a more sustained basis. This would add new perspectives and would continue to enrich the discussion.