

Plenary session on Measuring progress in gender issues

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Gender issues in HIV/AIDS research

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Over the past decade, social science research has identified the role that gender plays in determining individual risk and vulnerability in the HIV/AIDS epidemic. We have learned that socio-cultural norms about masculinity and femininity, and the unequal balance of power between men and women that arise from those norms, restrict women's access to productive resources (such as land, income, education, and credit), and increase men's sexual freedom, and thereby conspire with biological and physiological factors to compound individuals' risk of infection, resulting in epidemics of significant size and proportion in different parts of the world.

Through social science research we also know that gender is a factor in determining the level and quality of care, treatment, and support that HIV-positive women and men receive, the ways in which women and men cope with an AIDS related illness or the death of a loved one, the burden of care shouldered by women and men for family members who are sick, and the degree of negative economic and social consequences of AIDS. In brief, gender is a central determinant of an individual's experience in the HIV/AIDS epidemic.

The purpose of my talk today is to:

- ◆ First, provide a brief historical review of how research led to the HIV/AIDS field discovering the importance of gender;
- ◆ Second, create a case for the value of integrating gender in HIV/AIDS research by highlighting the different ways in which we gain because of such research;
- ◆ And finally, highlighting some of the key gaps in research and the challenges that lie ahead in integrating gender into future HIV/AIDS research projects.

Historical Review of the Emergence of Gender as a Determinant

In providing you a summary of the history of how gender emerged as a determinant in the HIV/AIDS epidemic, I begin with two disclaimers: first, my telling of the history is colored by my personal perspective, and therefore, is restricted to the sexual transmission of HIV which has been the focus of my work over the past decade. Second, because of the restrictions of time, I am going to simplify the complex iterative twists and turns that history typically takes by presenting developments in a more linear form.

In the early years of the epidemic, the mid-1980s, research focused only on female sex workers and men who engaged in high risk behaviors, and most of the program interventions were directed entirely toward one single behavioral act: that of putting on a condom. Gradually, as

researchers began to evaluate the impact of such programs on these target populations they found that they were not making much headway in bringing about behavior change because individual behavior was greatly influenced by the sociocultural, economic, and political contexts within which it took place. Bringing about behavior change it was concluded required the identification of ways to influence and alter those more complex contextual factors. Simultaneously, in the early 90s, epidemiological research began to report the rising rates of infection among women who were in long term relationships, even among women who staunchly maintained that they had no more than one sexual partner. Thus, two kinds of research – evidence from program evaluations and epidemiological data – led to some resources being directed in the early 90s toward social science research to investigate the factors that contribute to women’s risk and vulnerability to HIV infection.

The Women and AIDS Research Program, funded by USAID, and implemented by ICRW, the organization that I lead, was perhaps the largest such effort at that time. Over a period of seven years, from 1990 to 1997, it sponsored 25 different studies in 15 different countries worldwide and generated many insights on the gender-related economic and sociocultural factors that contribute to women and girls’ vulnerability to HIV. At a time when most other agencies were involved in quantitative KAP surveys, this program supported the use of a combination of qualitative and quantitative methodologies. The intent was not just to get a better understanding of knowledge, attitudes and practices but to also get an insight into the dynamics of sexual interactions and sexual experiences – what motivated these interactions, who controlled the outcomes, how did women acquire information about prevention and how did they act upon that information.

The findings from that research, undertaken by skilled local research teams in each site, and many other similar studies conducted at that time, noticeably shifted discourse and practice in the world of HIV/AIDS. More people began to recognize that women bore a disadvantage because of their gender and that if we were to help protect women we needed to empower them by increasing their access to information and productive resources, as well by guaranteeing them their reproductive and sexual rights. As I repeated this recommendation in countless forums, I watched eyes glaze over. How could HIV/AIDS programs and policy experts do anything about those other things that fell in other sectors? Empowerment was a long-term goal and what did it mean anyway?

So, much to my disappointment, and the disappointment of many others, very soon the message of the need to empower women to protect themselves in the epidemic, led to new attempts to convince men to change their behavior, based on the rationalization that if men had the power, all prevention messages should be directed to them. And so for a while we went back to the usual – condom promotion for men.

However, the epidemiological data kept pouring in – women, particularly young women, were the new face of the epidemic. The gender gap between women and men in sub-Saharan Africa and other regions was falling as more and more women got infected. Gender differences in the use of new program interventions such as voluntary counseling and testing services were being noted. Data on the prevalence of sexual violence and other forms of gender based violence erupted forcefully in southern Africa and India and violence was identified as a key variable in

the epidemic. And, perhaps most importantly, a small group of researchers in Brazil, Peru, South Africa, the U.K. the U.S. and other places began to listen as boys and men who have sex with men talked about the pressures on them to be heterosexual, to have multiple partners, to be sexually adventurous and assertive, knowledgeable about sex, and to be self-reliant and never ask for help. It was only then that we began to uncover that just as gender norms restrict women's sexual autonomy, they exaggerate men's sexual freedom, thereby putting both women and men at risk of infection. In 2000, when in a plenary presentation on gender and AIDS at the Durban International AIDS Conference, I pointed out that gender norms and structures negatively affect both women and men and increase the vulnerability of both, you could almost hear an audible sigh of relief from the men in the large hall – finally someone had acknowledged that they experienced societal pressure too – finally someone acknowledged that gender is not the same as women, and it is not about men doing bad things to women. It is instead about the ways in which women and men relate to each other, about both women and men reinforcing traditional gendered structures and enforcing sanctions against those who do not comply, and about men and women following prey to gender norms of sexual behavior that in this epidemic are harmful for all. Such an understanding of gender, even while acknowledging that gender inequality puts women at a significant disadvantage in society, requires both women and men to change their behavior. Calling for the empowerment of women and a transformation of the definition of masculinity and femininity within such a gender framework was acceptable to all.

Since then, there has been an ever-increasing amount of data on gender-specific needs, constraints, and outcomes within the world of HIV/AIDS research literature. This includes data that highlight women's and men's differential responses to the use of VCT services and their patterns of disclosure of test results; data on the differences in perception of risk; on the costs to households and women of the burden of care that is borne entirely by women; analysis of the role and motivations of young women and older men in what are now being called cross-generational transactional sexual relationships; documentation of the damage caused by stigma; data on the way in which fear of violence, almost as much as the actual experience of violence, regulates women's behavior and restricts their ability to protect themselves against infection, and data on the gender differences in the use of care and treatment services, including the use of antiretroviral therapies. These data, emerging at a fast pace from studies all over the world, highlight the important ways in which gender as a construct influences the experience of individuals in the epidemic and determines the effectiveness, or lack thereof, of program interventions. Looking back, we can see that three types of research – epidemiological analysis, evaluations of programs, and in-depth qualitative and quantitative research on women, men and adolescents, contributed to the evolution of knowledge of the role that gender plays in the epidemic.

Value of Integrating Gender Variables and Analysis into HIV/AIDS Research

Knowing as we do that gender plays a key role in the experience of individuals in the epidemic, it is obvious that sex-disaggregated data and an inclusion of gender variables and analysis must be central to all research on HIV/AIDS. Overall, gender analysis is useful for identifying and understanding differences in health risk, outcomes and use of services by sex, and allows for an analysis of the ways in which gender norms and responsibilities influence those differences. Let

me summarize the specific ways in which gender analysis is of value in containing the HIV/AIDS epidemic.

First, gender analysis improves understanding of the particular factors that contribute to the vulnerability of women and men, boys and girls, to HIV infection and thereby can improve the effectiveness of prevention interventions. Research on gender-related determinants of risk and vulnerability to date forms the majority of research on gender and HIV/AIDS.

Second, gender analysis improves understanding of the epidemiology of HIV infection and other related illnesses -- it provides the answer to the question “why” when looking at particular epidemiological patterns. For example, the high rate of new infections among girls between the ages of 15 to 24 can be explained through gender analysis that identifies the particular vulnerabilities and behaviors of young women and their sexual partners.

Third, gender analysis improves the relevance of biomedical technologies and other interventions, because, as we have learned, biomedical interventions are not gender-neutral. Gender analysis, for example, suggests that young women are likely to have gender-specific constraints to accessing the use of an AIDS vaccine once it is available. The voluntary use of an AIDS vaccine by any individual, like the use of any other prevention intervention, will constitute a public acknowledgment of risk and unsafe sexual activity. As a result, agreeing to be vaccinated against AIDS could expose an individual to the same potential stigmatizing consequences as using other interventions. We can also hypothesize that the consequences of this stigma and the resulting discrimination will be more costly for women because of their unequal economic and social status. The stigma is likely to be much greater if the vaccine has to be administered to adolescent girls prior to the initiation of sexual activity because it is likely to be perceived by parents and communities as signifying a license for their children to engage in sexual activity. Knowing this provides us advance warning of the type of community based research, education, and mobilization that are required today, even while clinical trials on the AIDS vaccine are being conducted.

Fourth, gender analysis has the potential for increasing access to and use of HIV/AIDS services by all. By highlighting the gender specific constraints of users, services can be modified to expand access and use. Let me share one example with you. Remember how excited we were when a low-cost version of an antiretroviral regimen was found to be effective in preventing the transmission of infection from infected mothers to their infants? It finally provided the one low-cost way to stem the tide of the epidemic on at least one front. The world responded by making this intervention available in several countries in prenatal clinic sites and then the bad news arrived – there were very few takers. Data from several studies began to document the low rates of uptake in several settings. We then began to do what we should have done all along – we talked to the experts, the ones who would know best why this was happening – the women for whom this service was designed and their families and communities. We learned that women are hesitant to be tested when they are pregnant, at a time when they are most vulnerable. We learned that they fear that if they are found to be positive, their men will blame them for being the first to bring the infection home. Men, we learned, are resentful of such prevention services because it is offered in sites that are primarily used by women. Women, we learned, find it stigmatizing to walk out of maternal health clinics carrying their babies and cans of breast milk

supplements for all to see. They told us that in order to help them cope with this stigma, their men and elders needed to be educated about this intervention, that community advisory boards needed to be set up to help service providers modify the delivery of services to suit the particular needs of families. And most of all we were told that it would be useful if we offered mothers something, too – not just antiretrovirals to protect their babies. Our response to such research has greatly increased the use and effectiveness of services to prevent the transmission of HIV infection from mothers to their babies.

Thus, research that uses gender analysis adds value and increases the effectiveness and efficiency of programs and policies. Conversely, as the booklet on gender in health research that is in our conference bags so clearly point out, researchers who ignore gender run the risk of doing bad science. Worse still, practice based on incomplete information can lead to avoidable mortality or morbidity and can perpetuate or exacerbate existing gender inequalities.

Key Gaps and Challenges in Integrating Gender into HIV/AIDS Research

Finally, let me attempt to identify some of the key gaps in gender research on HIV/AIDS and the challenges in integrating gender into HIV/AIDS research.

Although there are a host of descriptive research questions that are valuable to pursue, the highest priority, in my opinion, is the need for greater operations research and evaluation studies to respond to the “how” – how to translate what we know about gender-specific constraints and needs into program models that are effective. In part there is an urgent need to interpret existing data to create guidelines and recommendations for policy makers and program managers, while also encouraging gender-differentiated evaluations of different programs and services.

In order to do such operations or evaluation research we need to develop the right indicators and measures for concepts that are central to our goal of promoting gender equality and the empowerment of women. We need to operationalize the concept of power in relationships, the construct of empowerment and individual agency, and most importantly, develop and standardize the tools to measure these variables. In recent years, we have made a great deal of progress in this area and over the next few years we should see a burgeoning of tools and instruments that can be used to measure the impact of interventions on these aspects of women’s and men’s experience.

Another gap in operations research is in the area of multisectoral programming. We have repeatedly called for multisectoral responses in order to address gender inequalities yet we know very little about how to implement such programs. We are also often asked for the data to prove the effectiveness of interventions in another sector, such as economic interventions, on HIV/AIDS related variables. Conducting such research is complicated because the pathways of causality are multiple and relationships are often bi-directional. One could argue that we do not need research to prove these relationships. In an epidemic that is furiously rushing on, it may be wise to just provide communities and individuals with what they most need without having to prove the wisdom of such action.

In the ultimate analysis, containing the HIV/AIDS epidemic requires normative change. We need to test different models of community mobilization and education to know how for example, to end the culture of silence and shame that surrounds sex in most societies which cripples our efforts to bring about changes in sexual behavior, to reach the goal of zero tolerance for violence against women, to end homophobia and stigma, and to increase the value of gender equitable heterosexual relationships. There are few models currently being tested in Ethiopia, Zambia, Vietnam, India, and the U.S. to bring about such types of normative change but we need data on their impact before we can begin replicating them in other sites.

And, last but not the least, in a world in which political will is being cited as the single most important factor to get countries to respond effectively to the AIDS epidemic, we need to test the effectiveness of different models of advocacy and policy education in creating a gender-responsive and appropriate political response to the epidemic.

Let me conclude by listing two of the key challenges that we continue to face in integrating gender analysis into HIV/AIDS research and in finding the resources to conduct more gender-focused research. The first challenge continues to be the need to convince researchers and donors of the value of such analysis to achieve the very outcomes that they are seeking. The second is the need to build capacity to conduct such research and translate its findings into useable recommendations for action. Sessions such as this plenary and the sessions that will follow go a long way toward meeting both these challenges.

Because the sexual transmission of HIV continues to be the primary mode of transmission, gender is much more accepted as a key variable in HIV/AIDS research than in other infectious diseases. In fact, research on gender in the epidemic has created a new impetus for more resources for research on broader issues of gender and development in order to meet the goal that is set forth in the Millennium Development Goals : to achieve gender equality and the empowerment of women. The AIDS epidemic has proved what our research has been telling us for a while -- gender inequality is expensive, very expensive. In fact, in the context of the HIV/AIDS epidemic, gender inequality is now fatal. That, if nothing else, should create a strong case for integrating gender into all research on HIV/AIDS. Thank you.