



Women's Experiences with HIV Serodisclosure in Africa:
Implications for VCT and PMTCT

Report of a USAID Technical Meeting
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The decision to host a technical meeting on *Women's Experiences with HIV Serodisclosure in Africa: Implications for VCT and PMTCT* was the culmination of a series of technical discussions between Charlene Brown, MD, MPH, Technical Advisor/VCT; Amanda J. Gibbons, PhD, MPH, Technical Advisor/MTCT; and Diana Prieto, MPP, Technical Advisor/ Gender and Policy, within the Office of HIV/AIDS at USAID. These three advisors wished to further explore the relationships between perceived outcomes and actual outcomes for women who learn and share their HIV serostatus, with attention to the implications for programs and policy. In an effort to dispatch the lessons learned through programs and research to the policy arena, this team brought together three outstanding leaders to present to an audience of more than 90 technical personnel. The efforts of the technical team, including the three presenters—Suzanne Maman, PhD Johns Hopkins University Bloomberg School of Public Health, Naomi Rutenberg, PhD Horizons/Population Council, and Gloria Sangiwa, MD, Family Health International—facilitated the production of this report.

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Abbreviations

AIDS	Acquired immune deficiency syndrome
ANC	Antenatal care
HAART	Highly active antiretroviral therapy
HIV	Human immunodeficiency virus
MTCT	Mother-to-child transmission (of HIV infection)
PLWHA	Person living with HIV or AIDS
PMTCT	Prevention of mother-to-child transmission (of HIV infection)
SAT	The Southern African AIDS Training Programme
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
VCT	Voluntary counseling and testing (for HIV infection)
WHO	World Health Organization

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Introduction

On April 2, 2003, the US Agency for International Development (USAID) hosted a meeting in Washington, DC to consider gender issues regarding the disclosure of HIV serostatus in sub-Saharan Africa. More than 90 technical personnel who work on HIV/AIDS, gender, and reproductive health issues participated in the meeting, including staff from USAID, various implementing agencies, private voluntary organizations, and research institutions.

David Stanton, the Chief of HIV/AIDS Technical Leadership and Research Division at USAID, was invited to open the session on behalf of Drs. Brown, Gibbons and Ms. Prieto, the technical planning team. Mr. Stanton stressed the importance of meetings of this kind in reviewing research and field programs in order to inform policy and future programming, as well as to set the agenda for further research.

Within the larger global context of increasing access to HIV prevention, care, support and treatment, more and more women will learn their HIV serostatus through various means, including Voluntary Counseling & Testing (VCT) and Prevention of Mother to Child Transmission of HIV (PMTCT) programs. This meeting should be viewed as the continuation of technical discussions on the intersection of three very important pieces of USAID's response to HIV/AIDS: 1) the scale up of the PMTCT programs, 2) the scale up of voluntary counseling and testing (VCT) services, and 3) the vulnerability of women to HIV and violence. There is research evidence indicating that women are at greater risk of gender violence during pregnancy, and evidence from the United States of increased mortality from violent causes extending through the first year after childbirth.

This meeting featured presentations from three individuals with considerable field and research experience. The focus of the meeting was on outcomes associated with serostatus disclosure. The meeting did not focus on the pros and cons of HIV testing and counseling. The discussion centered around "what next," on how to respond to the issues surrounding disclosure, but not on USAID policy formation. There are currently numerous efforts that will increase the proportion of women who learn and share their HIV serostatus, including The President's Emergency Plan for AIDS relief, including the Initiative on Prevention of HIV in Mothers and Children, and additional funding through the World Bank and The Global Fund for Fighting Tuberculosis, Malaria and HIV/AIDS. As more women participate in VCT, it is important to understand the range of impacts of such efforts in order to maximize positive effects and minimize negative effects.

This is a report of the meeting's presentations and discussion.

The first speaker, Dr Suzanne Maman, is on the faculty of Johns Hopkins University Bloomberg School of Public Health, Department of International Health. Dr. Maman has conducted research for a World Health Organization policy document, drawing on 22 studies in the United States and a further 19 from developing countries, of which 17 were in sub-Saharan Africa and 2 in Southeast Asia. Her primary data for her presentation is from her own continuing post-doctoral research (undertaken in collaboration with colleagues from Muhimbili University) on HIV disclosure and violence in Tanzania.

This effort included qualitative interviews of 17 men, 15 women, and 15 couples who had been through HIV testing, and prospective follow-up and interview of 245 women 3 months after HIV testing.

Dr Naomi Rutenberg, the second speaker, has a PhD in sociology and demography from Princeton University and has worked in the field of operations research for more than 15 years. For the past 5 years she has been the Director of Research for the Population Council's Horizons Program, involved in identifying best practices in a wide range of HIV/AIDS-related programming. Dr Rutenberg's presentation is based on operations research experience with VCT in antenatal clinics offering prevention of mother-to-child transmission services where the feasibility, acceptability and impact of PMTCT services are being studied based on service statistics, the experience of a cohort of clinic users, and observation of services. The data presented here are from 484 and 324 interviews, respectively, with women 6 weeks after delivery who attended the clinics with the PMTCT services in Karatina and Homa Bay, Kenya, and 422 women accepting HIV testing during antenatal care interviewed 1 week post-partum in Lusaka, Zambia. A comparison group was provided by women attending antenatal care prior to the introduction of PMTCT services.

The third speaker, Dr Gloria Sangiwa, is a physician from the University of Dar es Salaam, who took postgraduate training in psychiatry in Ireland, and is currently Associate Director for VCT and MTCT at Family Health International. Dr Sangiwa has more than 13 years experience in HIV/AIDS programming, including being the technical adviser to a very successful VCT program in Zimbabwe. Dr Sangiwa's presentation, building on her experience in developing VCT/PMTCT programs in Africa, focused on how the research data from the first two presentations can be applied to develop best practices in field settings.

“To Disclose or Not to Disclose: An overview of women’s HIV serostatus disclosure experiences globally,” Dr. Suzanne Maman, Johns Hopkins University Bloomberg School of Public Health, Department of International Health

This presentation, on the experience of women around the world in disclosing their HIV serostatus, sets the scene for the two presentations that follow on the experience of women in Africa. Disclosure has a number of important public health benefits, such as increasing social support for people who are seropositive, increasing untested partners’ awareness of the risk of HIV infection, and increasing the opportunities for risk reduction. The literature indicates that the change in risk behavior is particularly great for couples who know their HIV serostatus and who are able to make informed reproductive health choices. Disclosure can also improve access to care and support programs for infected individuals. Some people, however, are concerned about promoting HIV VCT and serodisclosure because of reports of negative social outcomes, including physical violence to and abandonment of women in many settings.

Rates of HIV serostatus disclosure among women

The literature indicates that the rate of disclosure of their HIV serostatus is higher among women in U.S.-based studies than among women in developing country studies, with rates of 42-100 percent in the U.S. compared with 16-86 percent in developing countries (Simoni, 2000; Armistead, 1999; Sowell, 1997; Lester, 1995; Rothenberg, 1995; Simoni, 1995; Maman et al., forthcoming; Kilewo, 2001; Nebie, 2001; Antelman, 2001; Issiaka, 2001; Pool, 2001; Farquhar, 2000; Gaillard, 2000; Sigxaxhe, 2000; Bennetts, 1999; Rakwar, 1999; Ladner, 1996; Van der Straten, 1996). Caution should be exercised, however, in comparing results across these studies, as there were differences in how rates of disclosure were measured and in the timeframes. Some studies looked at disclosure two weeks after testing, and others were almost four years after testing. Although direct comparison is therefore difficult, it is possible to identify trends. The lowest rates of disclosure in all the studies are among pregnant women tested during antenatal care (ANC) in sub-Saharan Africa (16.7 – 32%) (Kilewo, 2001; Nebie, 2001; Antelman, 2001; Gaillard, 2000). Many of the women tested in antenatal care were part of clinical trials of antiretroviral therapy for PMTCT. Disclosure and counseling were not the focus of these trials and it is likely that the counseling the women received was different from what they would have received in VCT services in other settings. It is also likely that some women tested in antenatal care settings may not have had the opportunity to psychologically prepare themselves or their partners for the consequences of testing and knowing their serostatus, as those who independently seek VCT. In most settings, there is a core group of women who choose not to disclose their serostatus to anyone: 3-10 percent in the U.S. and 10-78 percent in developing countries (Kilewo, 2001; Nebie, 2001; Antelman, 2001; Gaillard, 2000).

The studies also indicate that women often disclose to multiple categories of people: some disclose to partners and family members, others disclose to female confidants, and others disclose in their social network (Gielen, 2000; Armistead, 2000; Simoni, 2000; Hays, 1993). It is also clear that disclosure rates increase over time. The findings further suggest that the intention to disclose does not correlate well with actual disclosure; when

asked at testing, a higher proportion of women say they intend to disclose than the much smaller proportion of women at follow-up who say they have actually disclosed their serostatus (Ladner, 1996; Heyward, 1993; Rakwar, 1999).

Barriers to HIV serostatus disclosure

Across the different settings in the studies, the barrier to disclosure most often mentioned by women was the fear of abandonment, which was closely tied to the fear of losing the economic support of their partner (Kilewo, 2001; Antelman, 2001; Issiaka, 2001; Pool, 2001; Farquhar, 2000; Rakwar, 1999; Ladner, 1996; Heyward, 1993). The fear of rejection and discrimination, of violence, of upsetting family members, and of being accused of infidelity were the other most frequently cited barriers (Kilewo, 2001; Nebie, 2001; Antelman, 2001; Issiaka, 2001; Pool, 2001; Gaillard, 2000; Sigxaxhe, 2000; Bennetts, 1999; Rakwar, 1999; Ladner, 1996; Keogh, 1994; Heyard, 1993).

When women attending a VCT clinic in Tanzania were interviewed three months after testing, the fear of their partner's reaction was the barrier most often cited. Fifty-two percent of women who did not disclose gave this reason, and the reaction they most feared was the loss of economic support. These women's fears were grounded in actual experiences they had had with their partner before testing (Maman, 2001).

Fear of Partner's Reaction was barrier cited most often by women in Tanzania

52% of women reported reason for non-disclosure as fear of partner's reaction. Reaction women feared most was loss of economic support.

"He didn't know I came to test. [Why didn't he know?] I don't live with him. I feared annoying him because he is very brutal. If I tell him he may become brutal. He will decide to leave me and stick to his wife."

(HIV+ female, 23 years, not married)

Women attending a Tanzania VCT clinic had often fought hard to be tested or were tested without their partner's consent. One 41-year-old HIV-positive woman had tried to discuss testing with her partner, and he had reacted very badly. She said at the follow-up after testing, "Oh, we argued for nearly three or four months. I told him I am going to test and he said, 'What are you sick from?' So I went and told him 'I have already gone and the card is there. After two weeks I am going to take the results.' He yelled, 'Didn't I tell you don't go there... If it is to die, then just let me die.... When you return if you are sick, I am going to leave you.'" This woman's experience of trying to raise the issue of testing and disclosure beforehand presents a barrier to sharing her results with her partner.

Outcomes of HIV serostatus disclosure to sexual partners

In 90 percent of the studies of the outcome of disclosing to partners, the majority of women reported positive outcomes (Beevor, 1993; Comer, 2000; Gielen, 1997; Gielen, 2000; Mason, 1997; Kilmarx, 1998; Lester, 1995; Serovich, 1998; Simoni, 1995; Bennetts, 1999; Chin, 1999; Gaillard, 2000; Grinstead, 2001; Keogh, 1994). Disclosure was often associated with less anxiety, fewer symptoms of depression, and increased social support among women. Negative outcomes were less common but included blame, abandonment, violence, anger, stigma, and depression. Because of anecdotal

reports of the risk of violence as a consequence of disclosure, the incidence of such violence was analyzed across the studies. In the U.S. studies, disclosure-related violence ranged from 0.4-4 percent (Koenig, 2000), while the rates of violence in sub-Saharan African studies were higher, ranging from 3.5-14.6 percent (Kilewo, 2001; Issiaka, 2000; Gaillard, 2000; Matthews, 1999). The highest rates of disclosure-related violence were reported among women in antenatal care settings (Kilewo, 2001; Gaillard, 2000).

Once again, caution must be exercised in directly comparing rates of violence across different settings. Since most studies did not report base rates for violence, it is difficult to know if there is actually an increase in violence after disclosure. Moreover, most studies did not define violence in their setting and measured a range of violence in terms of severity. The study by Maman et al. in Tanzania, however, did ask women who came back three months after testing how their partner had reacted to disclosure, and the majority of HIV-negative women (82 percent) and a large percentage of the HIV-positive women (49 percent) reported that their partner was supportive and understanding of their disclosure. But there were some HIV-positive women who said that their partner blamed them (16 percent), abandoned them (6.1 percent), or physically assaulted them (4.3 percent).

While the proportion of women who experienced a negative outcome of serostatus disclosure in this study was small, some of the negative outcomes these women face can be quite severe, as indicated by statements made by women in the Tanzania study. “It took two weeks to tell him,” one 29-year-old woman said. “He had decided we get separated but I think it is because of the disease. He wants us to leave each other and me to go away and die.” A 38-year-old woman said, “When I informed him of the results, there was endless violence in the house.”

In summary, these studies reveal that the majority of HIV-negative women and a large proportion of HIV-seropositive women experience positive outcomes after disclosure. Although the major barrier to disclosure is the fear of negative outcomes, women are in the best position to know when it is safe to disclose. While a relatively small proportion of women report negative outcomes, this may represent a large absolute number of women as more women learn that they are HIV positive and disclose their status to others. Thus it is important to find approaches to the scale up of VCT and PMTCT as critical prevention and care intervention strategies that also enable women to capitalize on the beneficial outcomes and minimize the harmful aspects of sharing their HIV serostatus with others.

In December 2003, Dr. Maman’s recent work on outcomes of HIV serostatus disclosure in Tanzania was published. For more information, please refer to:

Maman S, Mbwambo JK, Hogan NM, Weiss E, Kilonzo GP, Sweat M, (2003) High Rates and Positive Outcomes of HIV-Serostatus Disclosure to Sexual Partners: Reasons for Cautious Optimism from a Voluntary Counseling and Testing Clinic in Dar es Salaam, Tanzania. *AIDS and Behavior* 7(4): 373-82.

“HIV Testing and Disclosure: Experience from prevention of mother-to-child transmission programs in Kenya and Zambia,” Dr. Naomi Rutenberg, Director of Research for the Population Council’s Horizons Program

Many women access VCT services through PMTCT programs. For example, in the PMTCT sites supported by UNICEF and the Elizabeth Glaser Pediatric AIDS Foundation, more than 450,000 women received HIV counseling and testing in several hundred antenatal sites in the first 18-24 months of services. The Population Council’s Horizons Program has assisted with operations research and in-depth evaluation of the PMTCT pilot program experience in selected countries. The research described in this presentation is a major source of information on VCT and PMTCT; lessons learned through these pilots can inform the scale-up of VCT and PMTCT.

Data and sample characteristics

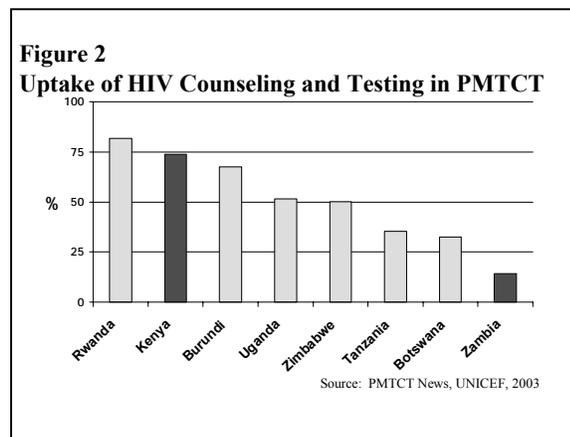
In Kenya (the Homa Bay and Karatina data) the study cohort consisted of all the women attending the antenatal care sites during the study period. The women were interviewed multiple times during antenatal care and after the delivery of their babies. A cross-section of clinic users was surveyed, including (1) women who elected to be tested and those who did not, (2) HIV-positive and HIV-negative women, and (3) women who accepted PMTCT services and women who did not. The data for this presentation are based on interviews conducted approximately 6 weeks after delivery.

A comparable cohort study was conducted in Zambia; however, the cohort was restricted to those women who elected to be tested for HIV during antenatal care in Lusaka. The Zambian data were collected from interviews conducted approximately one week after delivery.

Additionally, there was a separate set of interviews with women in the clinics in Homa Bay and Karatina, Kenya and Lusaka, Zambia prior to establishing the VCT and PMTCT services. These data provide baseline information on the experiences of women in these communities for comparison after the introduction of VCT and PMTCT services.

As can be seen in Figure 2, compared with other UNICEF supported PMTCT pilot sites in Africa, the Kenya site had a higher proportion of women accepting counseling and testing, with a nearly 75 percent acceptance rate. By contrast, Zambia was at the lower end with less than 20 percent accepting testing.

In Lusaka, 95 percent of the study group returned for the test results in contrast with service statistics that indicated that 51 percent of women who are tested



typically return for their results. The women in the study group in Kenya had similar rates of collecting their HIV results as the general clinic population (89% of the study group versus 79% of all clinic attendees returned for results in Karatina; in Homa Bay, the comparable figures are 83% and 82%). The service statistics for Karatina show that HIV-negative women are more likely than HIV-positive women to return for results, however, in the Karatina study group, a greater percentage of HIV-positive study cohort women returned for their results than HIV-negative women. In the Homa Bay study group, HIV-negative women were more likely to return for results.

Thus there may have been sample bias since women in the study were more likely to accept HIV testing and receive their results than pregnant women who did not participate in the operations research. In addition, within the study’s structural and clinical context, one person often conducted both the study interview and post-test counseling. This could have introduced further bias since women in the studies probably received more support from the PMTCT provider than most women seeking PMTCT services. Thus the study might be indicative of a “best case scenario.”

Disclosure

In the study cohorts, very few of the women had been tested for HIV prior to their pregnancy. Most of the study participants were tested during their pregnancy and thus the interview occurred three to four months after testing.

Figure 3
Disclosure of HIV Test Results
(measured between 2 weeks and 5 months posttest)

	Disclosed to Current Partner	Disclosed to Anyone
Lusaka	72%	81%
Karatina	58%	74%
Homa Bay	64%	69%

As shown in Figure 3, the rate of partner disclosure of HIV status amongst study participants ranged from 58 percent in Karatina to 72 percent in Lusaka. The proportion of women in the Lusaka cohort who shared their HIV status with anyone was even higher at 81%. Disclosure varied with HIV status, with HIV-positive women less likely to disclose than HIV-negative women. The proportion of women disclosing their HIV status to partners and others within

these cohorts are notably higher than described in literature on PMTCT in sub-Saharan Africa. It may be that women in routine PMTCT services receive more support for disclosure during their counseling sessions than women participating in trials focusing on the efficacy of preventative antiretroviral therapies.

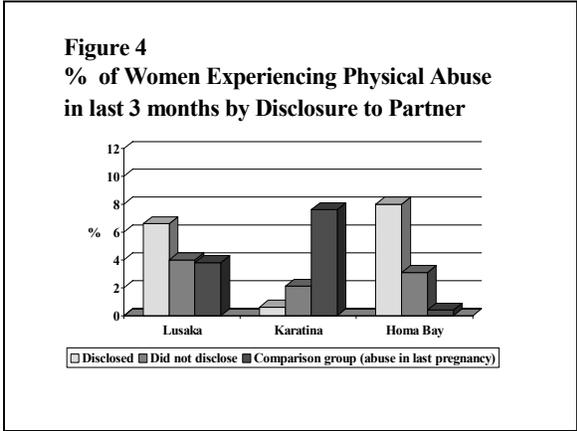
Outcomes of disclosure

Three outcomes of disclosure were investigated: physical abuse, the breakup of the marriage, and strengthening the relationship with the partner. These outcomes reflect reports by study participants for the three month period before the interview, which approximately corresponds to the time since antenatal HIV testing. For each outcome,

the results were stratified by HIV serostatus and by whether women disclosed or did not disclose.

Study results show that less than 10 percent of women, regardless of HIV status, across all of the sites experienced physical abuse in the preceding three months, with the lowest percentage in Karatina. There were no statistically significant differences in the outcomes of disclosure between HIV positive and HIV negative women within each site.

Figure 4 shows the proportion of women who disclosed their HIV status to their partner and experienced physical abuse in the last three months compared to the proportion of women who did not disclose their HIV status, but did experience physical abuse. Both groups are compared to a control group of women that reported physical abuse in their last pregnancy, which served as a proxy measure for the underlying levels of physical abuse in pregnancy across the three sites. The findings were not consistent across the three sites. There was no statistically significant effect of disclosure on physical abuse in Lusaka. Study participants at the Karatina site were less likely than the comparison group to have experienced physical violence in the preceding three months, regardless of



partner disclosure. In contrast, in Homa Bay, women who disclosed their serostatus were more likely to experience physical abuse in the preceding three months compared to women who did not disclose their HIV status and compared to the baseline group. The differences in Karatina and Homa Bay are statistically significant.

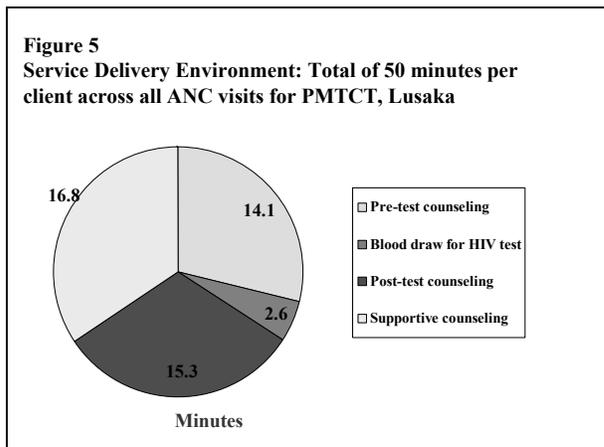
During the three months preceding the interview, marriage breakup occurred in less than 5% of marriages for women in the study across the sites, regardless of HIV status. None of the intra-site differences were statistically significant. Surprisingly, women who did not disclose their serostatus were much more likely to have experienced a breakup of their marriage in the last three months. Without further study, it is not possible to determine the direction of causality for the breakup of these marriages among women who did not disclose their HIV status. The marriages of these women may have ended for reasons, independent of their participation in PMTCT, leaving them without a spouse to whom to disclose.

Fifty percent of study participants at the Lusaka site and ninety percent of those at the Karatina site reported stronger relationships with their partners in the preceding three months. In contrast, twenty-five percent of women participating at the Homa Bay site experienced a stronger relationship with their partners during this time period. Although there was limited intra-site variation in this outcome when stratified by HIV status, a much higher proportion of women in Lusaka, who disclosed their HIV status, reported a

stronger relationship with their partner than those women in Lusaka who did not disclose. This finding remained consistent for the other sites, although to a lesser degree.

Qualitative data from the studies indicates that women at these PMTCT sites accept HIV testing to benefit their babies. Generally, they do not perceive the test as an HIV risk-reduction tool or as a mechanism for preventing the spread of HIV. In addition, they do not perceive PMTCT programs as an entry point into care for themselves and are dissatisfied with the level of services available for them.

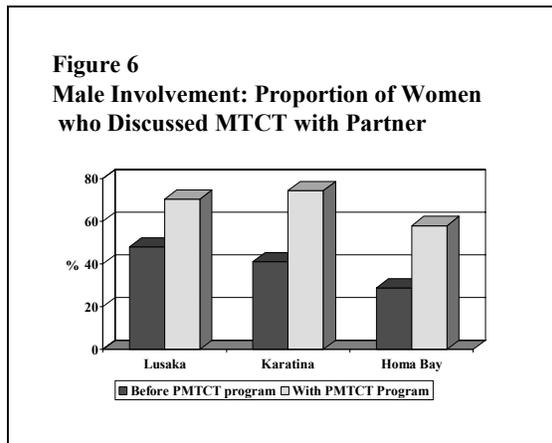
The studies provide data on the service delivery environment, including the amount of counseling and testing time for each client encounter (Figure 5). In Lusaka, across all ANC visits for PMTCT, participants receive a total of only 50 minutes of care consisting of 14.1 minutes of pretest counseling, 2.6 minutes for phlebotomy, 15.3 minutes of posttest counseling, and 16.8 minutes of supportive counseling.



As previously noted, this research context may have created an environment in which the duration of counseling sessions were longer than PMTCT sites outside of this study. Any efforts to expand the duration of counseling within the ANC

setting to assess clients' exposure to violence or support disclosure will need to consider the limitations on provider-client time.

An additional positive outcome of the PMTCT programs was increased involvement of the male partners of the study participants. During the interviews, women were asked if they had discussed mother-to-child transmission of HIV with their partner. Figure 6 shows that among the cohort who received PMTCT services, there were consistent and statistically significant increases in the proportions of women at all sites who discussed MTCT with their partner. There were also significant increases in HIV testing among the male partners of the women in the study cohort. For the most part, partner testing was conducted outside of the PMTCT programs. This may be associated with women's participation in PMTCT programs, coupled with the expansion of VCT within communities, which may prompt men to seek VCT from other sources.



In summary:

- (1) the majority of women in these studies experienced positive outcomes associated with disclosure of their HIV status;
- (2) a relatively small proportion of women reported adverse events with partners;
- (3) there was no consistent relationship between HIV status and adverse events;
- (4) there was no consistent relationship between disclosure and adverse events;
- (5) HIV negative women were more likely to disclose than HIV positive women;
- (6) PMTCT programs were associated with increased male involvement in VCT.

These findings reinforce those presented by the first speaker: women are likely to choose to participate in VCT when they perceive that it is safe for them, based on their knowledge of their partner. The women who disclose their status to their partner may have assessed that disclosure was safe.

The findings also suggest that there may be additional benefits to devoting counseling time to addressing the potential means and outcomes of disclosure in antenatal care service sites. The women in the study cohorts, who received slightly more counseling time, seemed to have much higher rates of disclosure than those external to the cohort.

The findings also suggest the need to further examine the baseline levels of gender based violence to better isolate the impact of pregnancy, HIV status, disclosure, and other variables on outcomes for women undergoing PMTCT, VCT and other forms of HIV counseling and testing. This knowledge can inform program design to increase positive outcomes for women.

“Disclosing HIV Serostatus: Programmatic implications for clients, policymakers, and service providers”, Dr. Gloria Sangiwa, Associate Director for VCT and MTCT at Family Health International Institute for HIV/AIDS

Disclosure in the context of HIV/AIDS occurs when a person’s HIV test result is revealed to another person. There are different levels of disclosure regarding to whom a woman discloses her serostatus and for what reasons. For instance, women may disclose to health care workers for care and support; to families, friends, coworkers, employers, and communities for emotional and social support; to partners for support and prevention of HIV transmission; or to the general public to “put a human face” on the epidemic, to reduce stigma, or to educate others. Regardless, disclosure should occur only with the individual’s consent.

The issue of serostatus disclosure is sensitive; high stigma in many countries creates a disincentive for people to share their HIV positive status with others. In order to access care and support for HIV infection, however, it is usually necessary to disclose one’s status to health care providers and one’s family. The degree of sensitivity around disclosure varies across settings, and consensus has not been reached on standards or procedures regarding when, how and to whom disclosure should occur. In addition, there are not adequate support mechanisms for clients and providers to facilitate disclosure.

Challenges in addressing disclosure

There are a variety of challenges for clients, policymakers, service providers, partners, families, and communities involved in addressing disclosure. Barriers to disclosure at the client level include both fear of a negative partner reaction and fear of stigma and discrimination, which may be grounded in the experience of witnessing others being mistreated because they are infected with HIV. Clients may fear adverse consequences for their children and/or that health care workers will disclose their HIV status to others without their consent. The negative consequences of disclosure may be harsher for women than for men, in part because women are more economically and socially vulnerable, often dependent on their partners economic status and because there is less societal tolerance for women perceived to have multiple sexual partners than for men.

Challenges for Clients

Many clients disclose because they expect some benefit, but the expected benefits do not always occur. Most women report positive outcomes from disclosing. In some instances, however, women may disclose to their partner expecting support, but find themselves abandoned. Some women encounter rejection and discrimination and may be accused of infidelity. These challenges may be even more pronounced for marginalized women who often experience discrimination, stigma, and rejection because their sexual behavior may fall outside of what is traditionally accepted for women. They may be viewed as criminals or outcasts, and their HIV-positive status only further marginalizes them. Despite health education messages about HIV/AIDS, family members may develop avoidant behavior with their HIV positive family members. For these reasons, the risk of

disclosure of a HIV positive test result is significant, and many women resist disclosing their results to anyone.

There are also contextual challenges to disclosure, including the issue of confidentiality. Many women who wish to know their status have voiced their concerns about professional confidentiality among health care workers, and some have cited it as one of the factors that prevent them from disclosing their results. This is illustrated in the adjacent quotation.

I was told unknowingly...my results were disclosed in the ward, where everybody heard. I was humiliated, and when I went home I told my husband expecting support, but he abandoned me. The miraculous thing came when I got my first counseling. It was like I started living again...I stopped mourning
(30 year old mother of 3, Nigeria)

Although the principles of confidentiality and informed consent that underpin VCT services were developed in western socio-cultural contexts, it is increasingly evident that professional confidentiality is becoming of paramount importance to HIV/AIDS in the context of sub-Saharan Africa. Lie et al (1994) findings in Tanzania suggested that confidentiality, interpreted as a “control” measure, is an important tool PLWHA have in managing the negative responses of family members to their HIV status. In this study, the authors found that that the concept of confidentiality, often considered “western” and individualistic, actually has strong roots in many ethnic tribes. It is “associated with normative regulation as to what kind of information can be shared among whom... and found to be an essential quality for the HIV/AIDS counselor.” The authors interpret confidentiality in the context of “control” rather than in the context of privacy, individualism, and secrecy. Using the “control” interpretation, the authors note that confidentiality and secrecy mean that the potential HIV infected individual or diagnosed patient can control some of the negative social impact of the diseases. The critical issue is therefore “who should be informed and how, in order to minimize the risk of rejection and maximize the mobilization of social support and the existing coping mechanisms.”

Furthermore, findings from a multi center VCT efficacy study in Kenya, Tanzania and Trinidad (The Voluntary HIV-1 Counseling and Testing Efficacy Study Group 2000) indicate that assurance of confidentiality and trust in the counselor facilitate disclosure of risk behavior. Hence the issue of confidentiality is the one that service providers will need to re-work and re-think in the context of VCT and PMTCT. These principles protect clients from unwanted disclosure of HIV status, thereby allowing a woman to decide when and whether to disclose based, in part, on her individual perception of outcomes. Some argue, however, that these principles may also contribute to the denial and stigma surrounding HIV/AIDS within many communities.

Challenges for Service Providers

Service providers face a number of practical and professional challenges in addressing disclosure, including the lack of clear policies, guidelines, and tools on disclosure. They have limited time and skills and may be grappling with the silence around HIV within their profession, place of work, and social network. Providers face an ethical challenge:

how to address the issue of negative consequences following disclosure, while, at the same time, promoting disclosure, given that most women report positive outcomes.

Providers often lack the interpersonal communication skills to effectively counsel and support clients to disclose, especially women who are within marginalized and vulnerable groups. Providers often do not have the capacity to establish or refer for follow-up and support services following disclosure. Many providers consider it unethical to facilitate disclosure without the availability of ongoing counseling and support services, and they do not know how to help their clients with conflict resolution after disclosure of positive serostatus.

Challenges for Policymakers

Policymakers face the challenge of balancing confidentiality protections with public health concerns. They must now consider whether legislation should allow breaks in confidentiality for HIV positive clients; whether there should be mandatory partner notification; whether there should be named HIV case reporting for public health reasons; and whether to allow prosecution of individuals for the failure or inability to disclose their HIV positive status.

Interventions and programmatic implications

Intermediate term interventions

Lessons learned through research and programmatic experiences provide possible solutions for the challenges described above. Providers can explore the clients' comfort level with disclosure of her HIV status to significant persons in her life, such as partners, family members or friends. Providers are advised to encourage clients to disclose only when the client feels it is safe to disclose. Providers can assist clients to strengthen their interpersonal communication skills and can encourage couple counseling and testing as a way to facilitate increased communication and disclosure between couple members.

In the context of PMTCT, disclosure can be facilitated through couple counseling, increased male involvement in the process, and the assurance of ongoing psychosocial support to meet the needs of women who choose to disclose. Innovative programs can include interventions to strengthen and empower women economically and socially, thereby reducing their economic dependency on male partners. Some programs can explore how gender norms can be modified to promote greater equity for women. Other programs can explore how to promote women's support groups that will ensure ongoing psycho-social support and reinforce the principles of 'positive living' (for example through formation of mother-to-mother peer support groups.)

Providers can consider developing and adapting domestic violence screening and referral services to identify women at risk of negative outcomes and ensure they have access to appropriate care and support. Many communities, however, do not have adequate support systems for women who are victims of emotional or physical violence. Providers should help their clients assess the consequences of disclosure in their own lives and how they might access social support to address possible positive or negative outcomes. Providers can prepare clients to share their test results through the use of role plays,

planned disclosure situations, or mediated disclosure, according to the client's needs identified through screening and self-assessment.

PMTCT and VCT program planners and managers can establish mechanisms for safe record keeping so that clients trust that their HIV information is confidential. Increased confidence in the service might help clients feel safer disclosing to health care providers. Counselors should be trained to understand the intersections of confidentiality, disclosure, and negative outcomes. Providers at all levels should be oriented to identify and prioritize clients who will benefit from or be harmed by disclosure. This can be achieved by recognizing that women generally know when it is or is not safe to disclose. They should provide ongoing supportive counseling services and ensure that providers have the necessary knowledge and can articulate the benefits of VCT and PMTCT services, including referral to necessary care and support to their clients.

Policymakers and community leaders should work together to formulate policy on disclosure, to facilitate community ownership of interventions, and to promote disclosure as a social norm. Policies must address fundamental human rights. Guidelines for promoting 'shared confidentiality' between partners and between clients and health care providers should be explored, where appropriate. Culturally-specific partner notification mechanisms—such as client referral, provider referral, dual referral, and contact referral—may need to be developed, and informed consent policies and forms may need to be revised to include options for partner notification. In addition, professional standards for counseling should be established and lawmakers should consider legal protection for people living with HIV or AIDS.

At the community level, interventions should foster community awareness of HIV, VCT and PMTCT and promote the establishment of self-help groups and post-test support groups. Broader community-based initiatives should be fostered to address gender inequity and power differences, as well as gender-based violence. Programs should work with young men and boys to promote improvement in gender relations, changes in sexual norms, and conflict resolution. Lessons learned through research need to be translated into action, with community ownership, and future research is necessary to address the gaps in understanding.

Intermediate and long-term interventions

VCT and PMTCT service providers should be equipped to recognize and address the consequences of disclosure. There should be an emphasis on changing gender norms and attitudes in society, including among young men and boys, such that gender-based violence and inequity becomes unacceptable. Community-based programs should focus on addressing and reducing stigma associated with HIV-positive women. Operations or intervention-linked research must be conducted to increase knowledge of the direct effects and outcomes of interventions.

In Summary

In sum, disclosure is beneficial for most women. However, there is more to learn about (a) the complexities of disclosure, (b) how to identify the small proportion of women who experience negative consequences of disclosure, and (c) understanding how women can be supported to disclose without negative consequences.

Questions that need further research include how to:

- Identify those women who most need assistance with disclosure and target scarce counseling resources so that they are supported.
- Establish and scale up effective PMTCT and VCT programs in a manner that protects women;
- Reduce further stigmatization of women through these services;
- Create community environments in which there are minimal negative effects of disclosure for women who are HIV positive.

Discussion Summary

On the whole, meeting participants were relieved to learn that for the majority of women in the studies, disclosure of their HIV serostatus was a positive experience eliciting benefits for the woman, such as increased psychosocial support. It was acknowledged that many women are able to judge for themselves when it is safe to disclose based on their experience and knowledge of their partner.

Meeting participants were curious as to why there was such a large difference in the proportion of clients accepting counseling and testing across the UNICEF pilot sites mentioned in the second presentation (figure 2, page 7). Dr. Rutenberg explained that the sites were in diverse settings—with variation within countries and across countries—with different resources, protocols, and implementing organizations, and widely different levels of service. In Rwanda, for example, a faith-based organization, with many extra resources, provided services, and the Homa Bay site in Kenya offered referral to a Médecins Sans Frontières clinic for HAART for the HIV-positive mothers. But in the Zambian sites, meanwhile, the study interviewers themselves became the counselors because there were not enough counselors on the service delivery side, possibly contributing to a barrier to uptake. Not enough is currently known to be able to identify with any certainty what the factors are that encourage the uptake of VCT and PMTCT in the pilot study sites.

Disclosure and its consequences

There was considerable discussion about the possible negative consequences of disclosure and the implications for the scaling-up of testing and counseling programs. Even though the proportions of women in the studies who experience negative consequences were relatively small, with rapid scale up of VCT and PMTCT services larger absolute numbers of women would be at risk of experiencing abuse and even violence. In the studies presented, the women who did disclose were self-selected, and it is hypothesized that only those who felt safe to disclose actually did so. There may be many women who do not disclose because of fears of the consequences. This raises the question of whether or not scaling up access to HIV testing and disclosure will result in increasing numbers of women who disclose. More women may disclose their status and while it is unclear if the proportion of women who experience negative outcomes will decrease, increase, or remain the same, it will be important to establish support mechanisms for the women who experience negative outcomes.

In this context, some participants were concerned that we do not seem to know why the different sites should vary so much in the incidence of physical abuse. Different cultures and communities may experience different levels of baseline domestic and gender-based violence. It was also noted that in many cases a woman's fear of abandonment is greater than her fear of violence, and that if she is abandoned then her children are also abandoned. In any event, participants also felt it was important not to actively promote disclosure without simultaneously putting in place mechanisms for identifying and supporting those women who are likely to experience negative outcomes. On that subject,

many participants concurred that communities must be mobilized to normalize the notion of disclosing one's HIV serostatus and to provide ongoing psychosocial support. In high prevalence communities, it should become the norm to be tested and disclose one's status in order to access care and support and to provide peer support for others. It must also become the norm for communities to both oppose violence and criticize perpetrators of gender violence and abuse. One participant suggested, from experience, that health workers and program managers working in VCT and PMTCT, should understand that sociocultural behaviors can change when there is a groundswell of popular support for change. They, together with policy makers and community leaders, should receive training to address change with clients and in the service delivery setting. The Southern African AIDS Training Programme (SAT) based in Zimbabwe is known to have been working in this area. SAT has published counseling guides¹ on "Basic AIDS Counselling," "Disclosure of HIV Serostatus," and "Domestic Violence."

Dr. Maman mentioned that, in Tanzania, young HIV-positive women reported considerable violence in their partnerships across their lifetime, compelling an examination of what could be done to help these young women. This effort resulted in an initiative to work with young men at the community level, similar to the "Men as Partners Program"² using "Stepping Stones,"³ that try to change norms in the environment to enable women and men to take preventive action and start talking about disclosure. Several people noted that gender norms can be changed with short-term interventions that engage men in addressing violence and gender imbalances, mentioning that they were aware of such programs in South Africa and elsewhere.

Male involvement

As the preceding suggests, male involvement must be a key element in addressing and eliminating potential negative consequences of serostatus disclosure. Men dominate decision-making in many relationships, and while many women would accept testing, they can return for the result, in many cases, only after discussion with their partner. It was suggested that women should be enabled to negotiate disclosure of their partner's serostatus along with disclosure of their own and that they are left at a serious disadvantage disclosing their own serostatus without knowing their partner's. One participant had observed that HIV-negative women found it harder to negotiate safer sex with their partners after disclosing their negative status. Another unknown mentioned in the discussion concerned the influence of the serostatus of the male partner on his response to serodisclosure by his pregnant partner.

In many societies there is already a tendency to blame women for bad fortune, and encouraging women to disclose seropositive status can reinforce this gender inequity.

¹ Southern African AIDS Training Programme training guides and other publications may be downloaded from <http://www.satregional.org/publications.asp>

² For information on "Men as Partners" contact: Engender Health 440 Ninth Avenue, New York, NY 10001, Telephone: 212-561-8000. Fax: 212-561-8067. e-mail: info@engenderhealth.org

³ Welbourne, A. (1995). *Stepping Stones: A package for facilitators to help you run workshops within communities on HIV/AIDS, communication and relationship skills.* London: ActionAid.

Mechanisms should be developed for reducing the inequities between partners. Couple counseling and testing would help in this respect, but facilitating couple counseling is not easy in some cultures. Many clinical settings, especially antenatal care settings, are not welcoming to men, and men may actually be ridiculed in some African cultures for attending these clinics with their partners. Since men are generally more comfortable attending VCT services outside clinical settings, mechanisms need to be found for making PMTCT settings more conducive for testing couples, perhaps by having the room for counseling located away from the antenatal care clinic or co-located with the laboratory.

Some participants noted that while couple counseling and testing might improve the rates of disclosure, facilitate communication, increase positive outcomes, and reduce negative outcomes, it may also create the potential for serodiscordant couples to become aware of their discordant status during pregnancy, a situation that might pose risks for a positive woman with a negative partner. Furthermore, in polygamous societies, the implications of including all the co-wives, along with the husband, within VCT and PMTCT services are not well understood.

Male involvement is also important for increasing the number of women seeking antenatal care and returning for further visits. Even in settings where rapid testing techniques are used, some PMTCT program managers are reluctant to provide same day results. In some cases, it has been difficult for women who have come to the health facility seeking ANC to be burdened with accepting testing and learning their result on the same day, without having had time to consider the wider implications of knowing their serostatus. A participant suggested that in many communities in Africa, only 35 percent of women have any ANC, and this may be in part due to the high cost of travel to the health facility both in the need for cash and the opportunity costs of their time away from their usual occupation. Men often control the resources that are needed to attend ANC clinics. Encouraging male involvement necessitates talking with political and traditional leaders in the community to establish the importance of antenatal care and preventing mother-to-child transmission. Getting male involvement can be difficult in places where there is high unemployment and alcohol abuse that affect male self-esteem, decision-making, and risk-taking.

Implications for counselors

There was discussion of the implications of the various gender issues for the training of counselors. Training is currently based on an adaptation of the western counseling model that assumes individual autonomy and personal choice. In many cultures around the world, however, women have limited autonomy and fewer choices than their male counterparts. The western counseling model, for example, trains counselors to help women disclose their diagnosis to their partner and family members and uses role plays and other techniques to help the client practice disclosure. Another point that was raised is that the western model doesn't always emphasize couple counseling. Dr Sangiwa mentioned that the training courses that she has been involved in give specific time to teaching about couple counseling and also follow up on couple counseling during in-

service training. She pointed out that for women attending PMTCT services, videos can orient women to the concept of testing and the basics of PMTCT, allowing more time for the counselor to discuss the advantages and disadvantages of couple testing and counseling.

Disclosing to whom?

Participants also expressed interest in the persons to whom a woman should disclose her serostatus and the different consequences of disclosing to various individuals. While disclosing to male partners may lead to psychosocial support, and some cases, abuse or violence, disclosing to a sister, aunt, or a friend is believed to have even fewer occasions in which the outcomes are negative. The point was made that while we need to focus on partner disclosure for reducing risky sexual behaviors, we also need to look at how women can be supported to disclose to other people who can also offer care and support. Dr. Sangiwa noted that in her experience a woman's partner is often the last person the client mentions as a significant person for disclosure.

Differences between male and female disclosure practices were discussed. It was observed that in general disclosure appeared to be more difficult for women than for men. Women were believed to be more likely to disclose to another woman before disclosing to their partner. Pregnant women attending PMTCT services often disclose to access treatment to prevent transmission of HIV to their infant. Yet for sexual risk reduction, there must also be disclosure to sexual partners. Men often disclose to obtain care and support, and thus disclose to their brothers or sisters. Men more easily disclosed negative HIV status to their partner as evidence that they were faithful and more easily disclosed positive serostatus to elicit care and support.

There was also some discussion of whether the norms for testing and counseling would change—and what the impacts of such changes would be—as services are scaled up and the notion of universal testing gains momentum. Participants noted that as approaches to HIV counseling and testing expand beyond the traditional VCT model, more counseling and support may be left to the communities. Are communities ready for this? What can be done to prepare them? How will this shape the impact on women who disclose their HIV status?

The Way Forward: What we know and what we still need to learn about disclosure

The presentations and the ensuing discussion highlighted key issues related to disclosure of HIV serostatus for women in sub-Saharan Africa:

What we know

In settings in sub-Saharan Africa:

- most women experience positive outcomes from serodisclosure
- most women choose whether or not to disclose, when to disclose, and to whom to disclose
- wide variations exist in the provision of counseling and testing.
- health care providers have limited time for the traditional VCT counseling model in many ANC clinics.

Furthermore,

- there is policy momentum toward a ‘public health’ approach to testing and counseling, making HIV serotesting more routine in the ANC setting, as long as pretest information and posttest counseling are provided
- gender inequity within many communities in sub-Saharan Africa is at the root of many of the negative outcomes of disclosure
- male involvement is important to maximizing positive outcomes and minimizing negative outcomes of disclosure.

What we still need to learn

- Why there are variations in the uptake of HIV testing and counseling services across different settings in sub-Saharan Africa.
- What factors affect, negatively and positively, the uptake of such services by both men and women.
- How to increase access to and utilization of VCT while at the same time minimizing negative outcomes.
- How to prioritize the time available for HIV counseling and testing in antenatal care settings and to determine the proportions of counseling time that should be used to address couple testing and counseling, disclosure, etc.
- How to target scarce resources, such as counseling, for maximum effectiveness.
- What types of services, including community-based services, should be in place to support women who test HIV-positive.
- How best to provide and link VCT and PMTCT to such services.
- What the impact of scaling up VCT and PMTCT programs is on positive and/or negative outcomes for women. Could more programs help to reduce stigma, thereby reducing negative outcomes? Or vice versa?
- What the background levels of violence against women are in communities within sub-Saharan Africa and elsewhere.
- How to identify the women who are most at risk for negative outcomes

- How pregnancy, HIV status, disclosure of HIV status, and violence interact.
- What the relationship and/or causality is between violence towards women and risk for HIV.
- What outcomes are associated with disclosure of HIV status for women in other regions, including Asia and the Near East, Latin America, and the Caribbean.

Descriptive studies in different operational settings both in Africa and in other regions can be used to better understand the dynamics of VCT and PMTCT on women and the positive and negative impact of services, including gender-based violence and abuse.

In summary

The meeting accomplished the key goals of bringing the issues around disclosure into sharper focus and beginning the important work of supplementing the largely anecdotal information on women's experiences with disclosure of their HIV status with research data.

The data presented at the meeting demonstrate that the majority of HIV-positive women surveyed reported positive outcomes with disclosure of their HIV status, including less anxiety, fewer symptoms of depression, increased social support and, in many cases, a strengthening of the relationship with their partners. This finding suggests that the considerable scaling up of counseling and testing programs now underway may pose a lower risk of negative outcomes of disclosure for HIV positive women-and suggest that there will be greater support for women-than expected, even by the women themselves. That said, the major barrier to disclosure for women usually is the fear of negative outcomes. Women who currently disclose do so selectively, choosing to whom they disclose and when they disclose, likely based on how they anticipate that their partner will react. While a relatively small proportion of women report negative outcomes, this may represent a large absolute number of women as more women learn that they are HIV positive and disclose their status to others. Thus, it is important to find strategies for the scale up of VCT and PMTCT programs that will allow women to maximize on the beneficial outcomes and minimize the harmful aspects of disclosing their HIV serostatus. A further result of the meeting was the identification of key knowledge gaps in this area. Included among these gaps are the factors that help to prevent or mitigate the worst outcomes, such as abandonment and abuse; and how to involve the community in general and men in particular in the care and support of women who disclose.

Disclosure of both HIV positive and negative status, along with its attendant issues, is fundamental to both preventing the spread of the disease and enabling persons to access treatment, care and support. It is crucial to increase the ease, safety, and acceptability of disclosure of HIV status for women as we expand global access to VCT and PMTCT. As understanding of disclosure and its implications increases through discussions such as this, donors, program designers, program managers, and community members become better placed to support this important work.

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Appendix I. Meeting Agenda

**Women's Experiences with HIV Serodisclosure in Africa:
Implications for VCT and PMTCT**

April 2, The Press Club, First Amendment Room
529 14th Street, NW
Washington, DC 20045

- 12:30pm – 12:35pm: Welcome — David Stanton, USAID Division Chief Technical Leadership and Research
- 12:35pm – 12:55pm: “To disclose or not to disclose: An overview of women’s HIV serostatus experiences globally” – Suzanne Maman, JHU
- 12:55pm – 1:15pm: “HIV testing, disclosure and partnership dynamics: Experience from PMTCT programs in Kenya and Zambia” – Naomi Rutenberg, HORIZONS/Population Council
- 1:15pm – 1:35pm: “Disclosing HIV serostatus: Programmatic implications for clients, service providers and policy makers” – Gloria Sangiwa, FHI
- 1:35pm – 2:30pm: Discussion

Appendix II. To Disclose or Not to Disclose: handout

To disclose or not to disclose: An overview of women's HIV serostatus disclosure experiences globally

Suzanne Maman, PhD
Johns Hopkins University
Bloomberg School of Public Health
Department of International Health

Why is disclosure an important public health goal?

- Disclosure can:
 - Reduce anxiety and increase social support
 - Expand awareness of risk to untested partners
 - Increase opportunities for risk reduction
 - Enable couples to make informed repro choices
 - Improve access to care and support programs

Why are people concerned about promoting HIV VCT and serostatus disclosure?

- Negative social outcomes including physical violence and abandonment have been reported by women in many settings

Data Sources for presentation

- Secondary Data: WHO policy document
 - Database & hand searches of journals, conf. abstracts and contact with selected authors
 - 22 studies from the U.S.
 - 19 studies from developing countries (17 SSA, 2 SE Asia)
- Primary Data: study on HIV & violence in Tanzania
 - 17 men, 15 women and 15 couples who had been through testing experienced interviewed qualitatively
 - 245 women followed prospectively and interviewed 3-months after testing

Rates of HIV Serostatus Disclosure among Women

Rates of HIV Serostatus Disclosure across all settings

- Disclosure rates to sexual partners higher among women in the U.S.
 - U.S. rates: (42-100%)
 - SSA/SEA rates: (16-86%)
- Lowest rates among pregnant women tested in ANC in sub-Saharan Africa
 - (16.7%-32%)
- Core group of women who choose not to disclose to anyone
 - U.S.: 3-10%
 - SSA/SEA: 10-78%

Limitations to Directly Comparing Disclosure Rates

- Disclosure rates reported in these studies are difficult to compare across studies
 - Studies differ in how rates of disclosure were measured
 - Time frame given for disclosure varied across studies (2 wks vs. almost 4 yrs)

Patterns of Disclosure

- Women often disclosed to multiple categories of people (partners, confidants, family members, others)
- Disclosure rates increase over time since testing
- Intention to disclose does not correlate well with actual disclosure

Barriers to HIV Serostatus Disclosure

Barriers to HIV Serostatus Disclosure across different settings

- Fear of abandonment
 - Closely tied to fear of loss of economic support from partner
- Fear of rejection/discrimination
- Fear of violence
- Fear of upsetting family members
- Fear of accusations of infidelity

Fear of Partner's Reaction was barrier cited most often by women in Tanzania

52% of women reported reason for non-disclosure as fear of partner's reaction. Reaction women feared most was loss of economic support.

"He didn't know I came to test. [Why didn't he know?] I don't live with him. I feared annoying him because he is very brutal. If I tell him he may become brutal. He will decide to leave me and stick to his wife." (*HIV+ female, 23 years, not married*)

Women in Tanzania VCT clinic fought hard to test or tested without consent of a partner

"Oh, we argued for nearly 3 or 4 months. I told him I am going to test and he said, 'What are you sick from?' So I went and told him 'I have already gone and the card is there. After two weeks I am going to take the results.' He yelled, 'Didn't I tell you don't go there... If it is to die, then just let me die... When you return if you are sick I am going to leave you.'" (41 year old, HIV+ woman)

Outcomes of HIV Serostatus Disclosure to Sexual Partners

Outcomes of HIV Serostatus Disclosure across all studies

- In 90% of the studies the majority of women reported positive outcomes
- Disclosure was often associated with less anxiety, fewer symptoms of depression and increased social support
- Negative outcomes were less common and included blame, abandonment, violence, anger, stigma, and depression

Violence as an outcome of disclosure

- Disclosure-related violence ranged from:
 - 0.4%-4% in U.S.
 - 3.5%-14.6% in SSA
- Highest rates of disclosure-related violence reported among women in ANC
- Rates of violence difficult to compare:
 - No base rates of violence reported
 - Most studies did not define violence
 - Severity of violence not described

How did partners of women in DSM VCT clinic react to disclosure?

	HIV+ (n=73)	HIV- (n=172)
Support	49%	82%
Felt sad	51%	1.4%
Panicked	45%	4.3%
Blamed woman	16%	1.4%
Abandoned	6.1%	<1%
Physical assault	4.3%	<1%

Negative reactions were a reality for some women in Tanzania

"It took two weeks to tell him. He had decided we get separated but I think it is because of the disease. He wants us to leave each other and me to go away and die." (29 year old, HIV+ female)

"When I informed him of the results there was endless violence in the house." (38 year old, HIV+ female)

Discussion

Let's not lose sight of the big picture

- Majority of HIV- women & large proportion of HIV+ women experience positive outcomes as a result of disclosure
- We should continue to find ways to promote VCT
- And continue to find ways to minimize negative outcomes for women

Are women at risk for negative outcomes as a result of HIV testing and disclosure?

- Relatively small proportion of women report negative outcomes
- When we think of scaling up VCT and testing large numbers of women, this "small proportion" adds up
- The major barrier to disclosure is fear of negative outcomes
- Women know when it is/is not safe to disclose to partners

Acknowledgements

- WHO collaboration: S. McGill, C. Garcia-Moreno (WHO) and A. Medley (JHU)
 - Funding: WHO Departments of Gender and Women's Health and HIV/AIDS
- Tanzania collaboration: J. Mbwambo, N. Hogan and GP Kilonzo, field research staff and the research participants (Muhimbili), M. Sweat (JHU) and E. Weiss (Horizons)
 - Funding: Population Council/Horizons Project, Fogarty International Center and USIS Fulbright Program

Appendix III. HIV Testing and Disclosure: handout

**HIV Testing and Disclosure:
Experience from PMTCT
programs in Kenya and Zambia**

Naomi Rutenberg
 Horizons/Population Council
 April 2, 2003

Collaborators

- Margaret Siwale and Chipepo Kankasa, MTCT-Secretariat, Zambia
- Ruth Nduati, Dorothy Mbori-Ngacha, and Jennifer Oyieke, NARESA, Kenya
- Sam Kalibala and Scott Geibel, Horizons/Population Council, Kenya

Data and Sample Characteristics

Horizons Operations Research Studies

- Women attending antenatal clinic offering PMTCT services interviewed 6 weeks post-partum in Karatina (N= 484) and Homa Bay, Kenya (n=324)
- Women accepting HIV testing during antenatal care and interviewed 1 week post-partum in Lusaka, Zambia (N = 422)
- Comparison group of women attending services prior to introduction of PMTCT

Socio-Demographic Characteristics

	Lusaka	Homa Bay	Karatina
HIV+	17%	32%	9%
Mean age in years	24.3	23.7	24.9
Completed primary school	56%	51%	84%
Married	92%	91%	84%
No cash income	61%	61%	37%
Mean number of children	3	--	--

Uptake of HIV Counseling and Testing in PMTCT

Source: PMTCT News, UNICEF, 2003

% of Women who Received Results of HIV Test during ANC: Service Statistics vs Cohort

	Based on Services Stats	Among cohort
Lusaka	51%	95%
Karatina	79%	89%
Homa Bay	82%	83%

% of Women who Received Results of HIV Test by HIV Status: Service Statistics vs Cohort

	HIV+	HIV-
Karatina: Service Stats	60%	81%
Cohort	98%	90%
Homa Bay: Service Stats	82%	82%
Cohort	73%	87%

Sample Bias: Best Case Scenario?

- Somewhat more likely to accept HIV testing and receive results than “average” PMTCT women.
- Post-test counseling and interviewing sometimes done by same person—women in study probably received more support from PMTCT provider than “average” PMTCT women.

Disclosure

Disclosure of HIV Test Results (measured between 2 weeks and 5 months posttest)

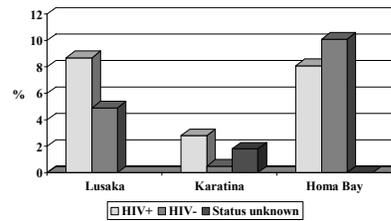
	Disclosed to Current Partner	Disclosed to Anyone
Lusaka	72%	81%
Karatina	58%	74%
Homa Bay	64%	69%

Disclosure of HIV Test Results to Partner by HIV Status

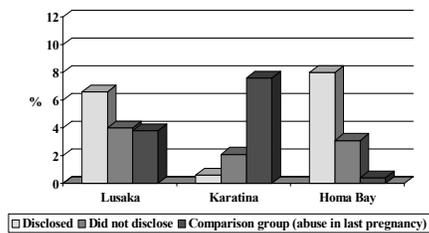
	HIV+	HIV-
Lusaka	49%	86%
Karatina	53%	70%
Homa Bay	35%	83%

Outcome of Disclosure

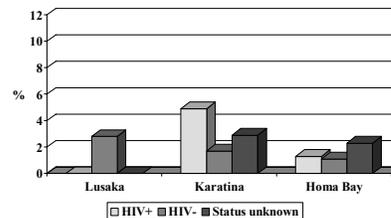
% of Women Experiencing Physical Abuse in last 3 Months by HIV Status



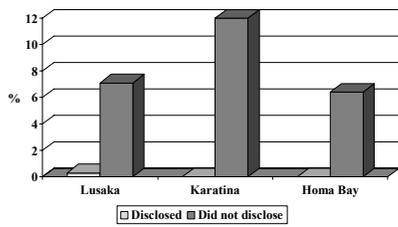
% of Women Experiencing Physical Abuse in last 3 months by Disclosure to Partner



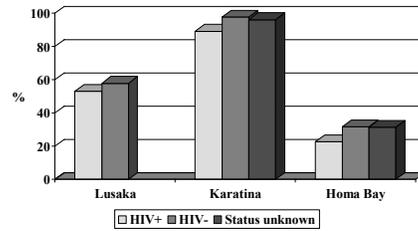
% of Women Experiencing Break-up of Marriage in last 3 Months by HIV Status



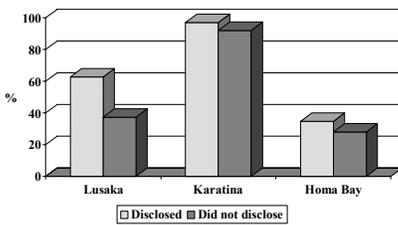
% of Women Experiencing Break-up of Marriage in last 3 months by Disclosure to Partner



% of Women Experiencing Stronger Relationship in last 3 Months by HIV Status



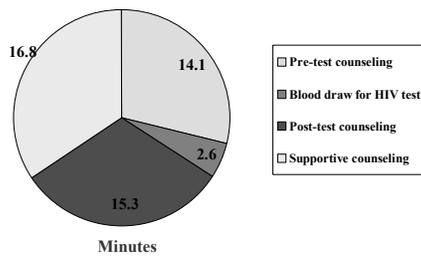
% of Women Experiencing Stronger Relationship in last 3 months by Disclosure to Partner



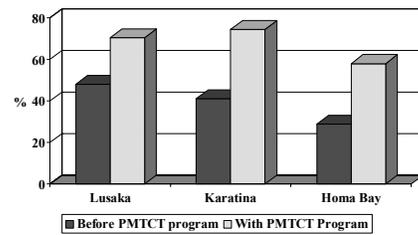
Qualitative data: Why test?

- Good for baby
- Not prevention or care for mother

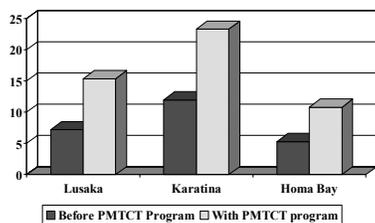
Service delivery environment: Total of 50 minutes per client across all ANC visits for PMTCT, Lusaka



Male involvement: % of Women who Discussed MTCT with Partner



Male involvement: % of Women who Report Partner had an HIV Test



Discussion

Conclusions

- Among the PMTCT clients who participated in the study, a small proportion of women report adverse events with partners.
- HIV- more likely to disclose... but no systematic relationship between HIV status or disclosure and adverse events.
- PMTCT program is associated with increased male involvement in HIV prevention.

Implications

- Reinforces
 - women likely self-select for “safe VCT”
 - benefit of small amount of counseling inputs
- Suggests need for research on the relative contribution of pregnancy, HIV, and other factors, to domestic violence and changes in relationships—good and bad--among PMTCT/VCT clients?
- Pregnancy is a vulnerable time for women but also opportunity for strengthening relationships and male involvement in HIV prevention and care.

Disclosing HIV serostatus: programmatic implications for clients, service providers, and policy makers

Dr. Gloria Sangiwa
Family Health International

Acknowledgements

- FHI Team
- Suzanne Maman: Johns Hopkins University
- Naomi Rutenberg: Horizons/Population Council
- Panel organizers: Charlene Brown, Diana Prieto, Amanda Gibbons, and USAID

Overview of presentation

- Background about disclosure
- Principles of confidentiality and informed consent
- Challenges of disclosure
- Interventions/programmatic implications

What is disclosure in the context of HIV/AIDS?

- Disclosure refers to informing others of one's HIV positive status
 - Partial or full
 - With or without consent
- Disclosure is very context specific
- There are no agreed upon standards or procedures for disclosure
- Levels of disclosure (whom does a woman disclose to and for what motivations?)
 - To health care workers for care and support
 - To families, friends, co-workers, employers, and communities for emotional support
 - To partners to prevent onward transmission
 - To general public for "putting a human face" on the epidemic (education, advocacy, money)

Challenges in addressing disclosure issues

- Client
- Contextual
- Professional
- Practical

Barriers to disclosure at the client level

- The expected benefits of disclosure may not happen
 - *"I was told unknowingly...my results were disclosed in the ward, where everybody heard. I was humiliated, and when I went home I told my husband expecting support, but he abandoned me. The miraculous thing came when I got my first counseling. It was like I started living again, I stopped mourning"* (30 year old mother of 3, Nigeria)
- Some women encounter rejection and discrimination and are accused of infidelity
 - *"When my blood was tested, I was found to be positive; the doctors advised my husband to test his blood but he refused. Everyone started blaming me, calling me names, that I was a woman of loose morals, bad character and that their son was good. I had brought on bad luck to their son and the entire family. My mother in law stopped accepting water from my hand... my husband also shunned me... later they threw me out of the house."* (MTCT user in Ghana)

Barriers to disclosure at the client level

- Fear of stigma & discrimination
 - *"If you see someone being mistreated because they are HIV infected, it is obvious the same will happen to you when it is known you are HIV+ so you keep quiet unless you are ill"* (female PLHA, Ethiopia)
- Fear of adverse consequences to one's children
- Fear that HCW will disclose to others
- Negative consequences of disclosure are more harsh for women than for men
 - Low socio-economic status of women
 - Less tolerance for women perceived to have multiple partners

Challenges associated with marginalized women

- These women experience discrimination, stigma and rejection because of their behavior
- Viewed as criminals and outcasts
- HIV positive diagnosis further marginalizes them
- Disclosure is mandatory in many drug rehabilitation programs
- Barriers to disclosure among these marginalized women:
 - Fear of further discrimination
 - Lack of treatment for HIV-related illnesses
 - Fears about how to disclose to partners and family
 - Fears about the future

Contextual challenges

- The principles of confidentiality and informed consent
 - Beneficence (Loyalty to the client)
 - Non-maleficence (Protecting clients & others from harm)
 - Respect for autonomy (Allowing clients to decide for themselves)
 - Privacy (Maintaining confidentiality)

Sometimes these principles conflict with one another
- Current concerns are that the principles:
 - Allow a person (especially women with a number of fears) to keep their results secret
 - Hinder efforts to prevent new HIV infections
 - Contribute to denial of HIV/AIDS within communities

Contextual challenges

- Should policy makers allow legislation and practices that would balance confidentiality with public health concerns:
 - Breaches in confidentiality?
 - Mandatory partner notification?
 - Named HIV case-reporting for public health reasons?
 - Prosecution of individuals for failure/inability to disclose or refuse sex?
- Women specific issues:
 - Gender power imbalance in the context of varying socio-cultural norms
 - Economic dependency on their partners
 - Lack of social confidence and negotiation skills necessary to convince sexual partners to reduce HIV risk

Professional challenges

- Lack of clear policy, guidelines, and tools on disclosure
- Limited provider's time and skills
- Conspiracy of silence
- How do we balance:
 1. The need to address negative consequences following disclosure (minority), and
 2. the call to promote the positive outcomes of disclosure (majority)
- Facilitating disclosure among marginalized and vulnerable groups
- Inadequate research
- Limited leadership from government and civil society

Practical challenges

- Lack of communication skills (partners and providers)
- Lack of community and male involvement
- Lack of resources
- How to establish or refer for follow up and support services following disclosure
- How to develop appropriate methods of conflict resolution

Immediate interventions: client level

- Promote disclosure of results to "significant" others when safe to do so
- Promote partner communication and couple counseling
- Encourage male involvement
- Form women support groups
- Promote networks among women and couples
- Promote innovative women empowerment strategies
 - e.g. micro credit program help to shift gender norms



Immediate interventions: provider level

- Develop/adapt domestic violence screening and referral tools to identify women at risk of negative outcomes
- Assist women to determine potential for negative outcomes
- Based on screening and self-assessment, prepare clients to share their results
 - Role plays
 - Planned disclosure
 - Mediated disclosure

Immediate interventions: provider manager level



- Establish mechanisms for safe record keeping
- Train counselors to understand the intersection of confidentiality, disclosure, and negative outcomes
- Orient providers at all levels to:
 - Identify and prioritize clients who will benefit from, or be harmed by, disclosure- because women know when it is/is not safe to disclose to partners
 - Provide on going supportive counseling
 - Provide knowledge on benefits of VCT, PMTCT and care
 - Strengthen linkages with community based services
 - Foster community awareness of HIV

Immediate interventions: policy maker level

- Policy makers and community leaders should formulate policy on disclosure together
- Policies should address fundamental human rights
- Clarify "confidentiality"
 - Define confidentiality versus secrecy
 - Define circumstances that warrant breach of confidentiality
 - Develop guidelines for promoting 'shared confidentiality'
- Determine culturally specific partner notification policy
 - Client referral, provider referral, dual referral, and contract referral
- Revise informed consent policies and forms to include options for disclosure
- Establish professional standards for counseling
- Consider legal protection for PLHA

Community level interventions

- Promote establishment of autonomous self-help group
- Broader community-based initiatives
 - Address underlying power differentials in gender relations
 - General efforts to reduce violence against women
 - Target young men and boys to promote relational development
 - Identify alternative conflict resolution and change sexual norms
- Approaches
 - Translate existing research into action; create local ownership
 - Conduct new research
 - Maman et al intervention study in Dar es Salaam, Tanzania
 - Combines drama-based communication and peer support
 - To enable adolescents to initiate HIV preventive behaviors and promote dialogue about HIV risk and violence within young couples' relationships

Intermediate and long-term interventions

- Cross-train domestic violence and HIV providers
- Equip providers to recognize and address consequences of disclosure
- Address gender norms and attitudes targeting young men and boys
- Promote community-based programs to reduce stigma
- Conduct intervention linked research



Summary and Conclusions

- We have more to learn about the complexities of disclosure
- Disclosure is beneficial for most women
- Some women do experience negative outcomes, therefore, how do we:
 - better *target precious counseling resources* to those who need most assistance with disclosing?
 - establish and scale up effective intervention in a manner to *protect* our clients?
 - while *avoiding* the perpetuation of stigma or predisposing clients to negative effects?
 - and at the same time *mitigate* the pandemic?

THANK YOU

