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# ADDRESSING GENDER ISSUES RELATED TO HIV TREATMENT ADHERENCE PROGRAMS



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The views expressed in this publication do not necessarily reflect the views of the U.S. Agency for International Development or the U.S. Government.



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- National Council of People Living with HIV/AIDS (NACOPHA)
- National Network of Tanzanian Women with HIV/AIDS (NETWO+)
- Network of Young People Living with HIV/AIDS (NYP+)
- Service, Health, and Development for People Living Positively with HIV/AIDS (SHDEPHA+)
- Tanzania National Network of People Living with HIV/AIDS (TANEPHA)
- Tanzanian Network of Women Living with HIV/AIDS (TNW+)

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## EXECUTIVE SUMMARY

During 2009 and 2010, the USAID | Health Policy Initiative, Task Order 1 designed a short-term, pilot activity to identify and address HIV-positive women's and men's ability to adhere to HIV treatment in Tanzania. The purpose of the activity was to assist local groups of HIV-positive people in better understanding gender issues related to HIV treatment adherence as a first step in increasing adherence levels.

Gender inequity is recognized as a major barrier to effective care, treatment, and prevention efforts. As treatment programs are rolled out and scaled up, gender inequity can adversely affect adherence in different ways for HIV-positive women and HIV-positive men. An International Community of Women with HIV/AIDS report (Rwechungura and Kayitare, 2006) identified factors affecting HIV-positive women's ability to access antiretroviral drugs, such as financial and time costs of traveling to service points, lack of confidentiality, and the need to seek permission from partners to access services. Similar data for men's gender barriers have not been well researched or discussed.

The pilot activity was developed in partnership with a local HIV-positive women's network, the National Network of Tanzanian Women Living with HIV/AIDS, and included the following components:

1. Integrate gender into NETWO+'s existing HIV treatment literacy training materials
2. Pilot revised materials with HIV-positive women and HIV-positive men in a treatment literacy workshop in Morogoro region
3. Follow up the workshop through group discussions with participants three months after the pilot workshop

The activity successfully brought gender issues to light at the community level by integrating the issues into an existing training HIV treatment literacy program and piloting the approach during two workshops in Morogoro, Tanzania. The overall workshop objective was to raise awareness among HIV-positive women and men about gender issues related to adherence to HIV treatment so they can effectively address and act on adherence issues in their communities. At the end of the workshop, participants were expected to be able to

- Demonstrate a heightened awareness and knowledge of gender issues related to HIV treatment adherence;
- Feel comfortable discussing the issues with community- and home-based care providers, HIV-positive women and men, and others;
- Be familiar with materials, techniques, and exercises on gender issues related to HIV/AIDS treatment adherence; and
- Be able to discuss differences between men and women with respect to gender adherence issues.

Three months after the workshop, NETWO+ undertook a follow-up visit to Morogoro to meet with the workshop participants to discuss how the training had affected participants' lives, how participants have been able to educate and support others in the community, the approaches they used and challenges they faced, and what they plan to do next. During the discussion, workshop participants reported that they are better able to understand HIV treatment and adherence with respect to gender relations in their communities. They reported the following outcomes of their workshop participation:

- Improved ability to adhere to treatment and help families and friends also on treatment by sharing what they learned in the workshops.
- Confidence to speak to their communities about HIV and AIDS, treatment adherence, and gender issues, such as men's ability to support their partners with their treatment. Some have been able to disclose their HIV status and can now educate others.

- Ability to exchange ideas with other PLHIV and build a communication network for future collaboration.
- Improved ability to provide home-based care to PLHIV, including increased motivation to work in difficult conditions with scarce resources.
- Skill in using mass media, particularly the radio, to discuss HIV treatment, gender, and adherence during HIV programs, as with the Ukweli, Mapambazuko (Ifakara), and Jamii (Kilosa district) radio stations.
- Capacity to reach out to others at care and treatment centers. Some have organized training sessions for their support groups, such as the Hekima group in the Kichangani ward and the Haruma group of the Kiwanja cha Ndege ward.
- Speaking up and discussing the importance of adherence and the gender issues that affect it (such as men's reluctance to test for HIV and/or disclose a positive status) in meetings and training sessions organized by other organizations.

The follow-up discussion also revealed that, despite the short period of time for activities, workshop participants have successfully engaged their communities in HIV education. The discussion facilitators estimated that each workshop participant has reached an average of 35 “contacts,” for a total of 1,054 contacts. If workshop participants continue educating and supporting their communities at that rate, they will have spurred great change in just one year. Of the workshop participants, female versus male participants were able to reach a larger number of PLHIV. The difference may relate to the fact that women place greater importance on educating others or have had more time to deal with HIV-related issues; after all, most male participants had not previously attended a similar training session. Furthermore, men may be more likely to experience self-stigma and fear community stigma.

While most of the treatment adherence issues (e.g., poverty) facing women and men require significant resources and long-term investments, the pilot activity was able to expand on existing efforts and build the capacity of PLHIV to initiate awareness-raising and education activities related to issues in their communities. The workshops provided participants with the education and confidence they needed to undertake small initiatives in their own communities. The follow-up discussion showed that participants have provided outreach in numerous ways without specific resources. Participants' openness about their own status has facilitated their ability to gain other PLHIVs' trust and serve as educators. With time, participants increased involvement in their communities will likely lead to stronger HIV networks that work with District AIDS Committees and provide a broad level of support.

Even though the pilot activity provided insight into gender issues that affect women's and men's experiences related to HIV treatment literacy and adherence in Tanzania, the primary result lies in the strengthened involvement and engagement of PLHIV. With an improved ability to educate and support other PLHIV in their communities, the Morogoro participants are well positioned to lead and engage in additional HIV efforts.

## ABBREVIATIONS

AIDS	acquired immunodeficiency syndrome
ART	antiretroviral treatment
ARV	antiretrovirals
CDC	Centers for Disease Control and Prevention
CTC	care and treatment center
CTP	Care and Treatment Plan
DACOPHA	Dar es Salaam Coalition of People Living with HIV/AIDS
GBV	gender-based violence
HIV	human immunodeficiency virus
ICAP	International Center for AIDS Care and Treatment Programs
ICW	International Community of Women with HIV/AIDS
PLHIV	people living with HIV
NACOPHA	National Council of People Living with HIV/AIDS
NETWO+	National Network of Tanzanian Women Living with HIV/AIDS
NYP+	Network of Young People Living with HIV/AIDS
PPTCT	prevention of parent-to-child transmission
SHDEPHA+	Service, Health, and Development for People Living Positively with HIV/AIDS
TANEPHA	Tanzania National Network of People Living with HIV/AIDS
TNW+	Tanzanian Network of Women Living with HIV/AIDS
USAID	United States Agency for International Development
USG	United States government

## I. BACKGROUND

### HIV in Tanzania

Tanzania's latest HIV survey (2007–2008) shows that 6 percent of Tanzanian adults (ages 15 to 49) are infected with HIV (TACAIDS et al., 2008). Prevalence is higher among women than men (7 versus 5 percent). While the majority of Tanzanian adults report that they know where to get tested for HIV (81% of women and 86% of men), most Tanzanians have not been tested and do not know their status (TACAIDS et al., 2008). The HIV survey also revealed that only 37 percent of women and 27 percent of men have ever been tested and received results.

The Tanzanian government is committed to making free antiretroviral treatment (ART) available to its citizens. In 2004, the government began scaling up ART as stated in its five-year national Care and Treatment Plan (CTP) (Hanson et al., 2009). The CTP's aim is to provide ART for "as many HIV-infected residents as possible," with 420,000 on ART by mid-2009. However, by February 2008, only 143,000 Tanzanians had initiated treatment (Hanson et al., 2009).

Given the data on women and men who seek and receive voluntary counseling and testing services, the number of Tanzanians on ART is far below the national goal. While the success of ART programs depends on health care systems' ability to scale up, it also depends on patients' ability to adhere to medication once treatment is initiated (Sokol et al., 2005).

### Treatment Adherence

Adherence to medication, including antiretrovirals (ARVs), is most often measured as taking 95 percent of prescribed pills (Mills et al., 2006). Poor adherence to ARVs can cause HIV to become resistant to medications (see Box 1) and lead to transmission of drug-resistant forms of the virus. Poor adherence can also result in increased costs to health and society in terms of direct financial costs of failed treatment and higher hospitalization rates.

A recent meta-analysis of 13 African countries found that a pooled estimate of 77 percent of patients achieved adequate adherence (Mills et al., 2006). However, the analysis suggested that approximately 40 percent of all ART clients may have died or discontinued treatment within two years of initiation (Mills et al., 2006). An Ethiopian study determined that 10 percent of a study population was lost to follow-up and presumably alive (dropped or lost) from study facilities in an 18-month period (Mekonnen et al., 2010). These drop-out levels need to be examined for a better understanding of patient experiences with ART.

#### **Box 1. What Is Adherence?** (Treatment Action Campaign 2006)

Adherence is a word to describe taking your drugs exactly as they are prescribed. It includes taking them at the right time and in the right doses.

#### **Why is adherence to HIV treatment important?**

- HIV drugs will work only if you keep a constant minimum level of each drug in your body at all times.
- If each drug drops below this level, then your virus can develop resistance to the drugs, and the drugs will stop working.
- A little HIV medication is dangerous—with HIV, you need to take all or nothing. You need to develop a routine for taking your medication, even if you take only one pill twice a day.
- It is important to take medication exactly on time.
- It is important to pay attention to dietary restrictions for different drug combinations; ignoring these can be like taking only half a dose. You will not absorb enough of the drug for it to work properly.
- Missing one or two doses a week can have a big impact on the chances of successful treatment. But, if you take every dose, you will get much better results.

Understanding the barriers faced by people living with HIV (PLHIV) in adhering to HIV treatment every day, along with factors that facilitate their ability to adhere, can help policymakers and program managers take steps to support and maintain good adherence. Researchers have initiated studies to assess ART adherence and reasons for discontinuation, thereby assisting national efforts in understanding how best to sustain and expand ART programs.

## **Barriers**

International studies have identified a range of barriers to treatment adherence at different levels. Drawn primarily from studies based in Africa, this section provides a brief overview of these barriers.

**Disclosure/stigma and discrimination.** The fear and experience of stigma and discrimination often prevent PLHIV from disclosing their HIV status. Low rates of HIV disclosure and high levels of perceived HIV-associated stigma can pose a barrier to adherence (Watt et al., 2009). In Ethiopia, a study found that PLHIV who have not disclosed their HIV-positive status and/or fear stigma often travel long distances to obtain anonymous treatment and then hide or skip pills to ensure that others, such as families and employers, do not learn about their status (Mekonnen et al., 2010). Such measures can compromise adherence.

**Lack of support.** A Tanzanian study discovered that a perceived lack of family support led some PLHIV to drop out of treatment, despite evidence of improved health and a high level of personal motivation (Roura et al., 2009). In some cases, the influence of family members was so significant that relatives such as parents or husbands made treatment decisions, including the decision to interrupt ART (Roura et al., 2009).

**Poverty.** Poverty can be a barrier to adherence (Watt et al., 2009). Indirect and direct costs are a burden on PLHIV, forcing them to discontinue treatment. Costs include those associated with transportation to service points, laboratory diagnosis, and drugs for opportunistic infections (Mekonnen et al., 2010).

**Nutrition.** Inadequate nutrition is a factor in postponing or missing appointments or discontinuing ART (Roura et al., 2009; Mekonnen et al., 2010). A study in Ethiopia determined that most ART users are poor and that their access to resources, including food, is further limited by their HIV status. Many discontinue treatment because they do not have adequate food with which to take medication (Mekonnen et al., 2010).

**Self-assessment of health status.** Mekonnen et al. (2010) found that PLHIV often decide to discontinue ART based on self-assessments of their health status. For example, PLHIV may stop treatment when it does not seem to be working or when their health improves to the extent that they believe they are cured and need no further treatment. PLHIV may also discontinue treatment when they experience unmanageable side effects; experience treatment fatigue; or lack commitment to continue treatment for life (Mekonnen et al., 2010). Sustaining life-long treatment can be particularly challenging for rural residents who must travel regularly to central hospitals for follow-up appointments and to obtain prescription refills (Roura et al., 2009; Mekonnen, 2010).

**Perceptions of HIV and treatment.** Some PLHIV do not have a good understanding of HIV. Common beliefs about the causes of HIV and basic etiology of HIV can reduce motivation for treatment (Roura et al., 2009). In addition, misconceptions and rumors related to ARVs can affect adherence (Roura et al., 2009). In Ethiopia, religious PLHIV often take holy water as treatment for HIV instead of ARVs (Mekonnen et al., 2010).

**Disruption in schedules.** A Tanzanian study showed that PLHIV adherence is affected by disruption in daily life schedules (Watt et al., 2009), including travel out of town for work or to visit family, busy schedules, and long hours of absence from home (Watt et al., 2009).

**Program-level factors.** Roura’s Tanzanian study (2009) determined that program-level factors also shape individuals’ cost-benefit analysis of seeking and sustaining treatment. For example, the distance to medical services, the financial and opportunity costs of travel, and quality of care such as waiting time, providers’ attitude, and ease of following instructions are all determinants of treatment compliance (Roura et al., 2009).

## Facilitating Factors

While research has named numerous barriers to treatment adherence, studies have also identified a range of factors that facilitate adherence.

A recent study by Watt et al. (2009) examined the dynamics of good adherence to ART among patients receiving free ART and HIV-related services from a clinic in Arusha, Tanzania. The study revealed five factors that, despite barriers, facilitated high levels of adherence:

- After starting ART, respondents experienced a significant improvement in their health, giving them confidence in the medication and motivating them to adhere to their treatment regimen.
- Respondents were motivated to stay healthy because they wanted to be able to meet family responsibilities.
- Respondents developed specific strategies to remember to take pills, particularly by creating a routine for taking pills at the same time as certain daily activities or events.
- The material and emotional support of others was pivotal in facilitating adherence.
- Respondents trusted the advice and instructions of their health care providers, who regularly emphasized adherence.

### Box 2. Patient Factors Associated with Adherence

#### Strongly Associated

- Lack of depression
- Lack of active alcohol/substance abuse
- Self-efficacy (belief in one’s ability to take medication as instructed)
- Belief that medications can be fit into daily activities
- Understanding the relationship between viral resistance and adherence
- Previous adherence

In addition, a study by Roura et al. (2009) on ART patients’ health-seeking behavior identified similar facilitating factors related to adherence, such as personal motivation, self-efficacy, and perceived health benefits or disease severity. Anderson (2005) also derived a list of patient factors strongly associated with adherence (see Box 2).

**Social support.** Studies have shown family and friends who support PLHIV can influence PLHIV’s behavior and decisions regarding treatment (Roura et al., 2009). Individuals can develop a willingness to sustain adherence in a challenging context but are more likely to do so within supportive family and community environments (Roura et al., 2009). A South African study found that social support was instrumental in helping ART patients achieve compliance beyond the first three months of treatment (Nachega et al., 2006 in Roura et al., 2009). Those who disclosed to families or friends that they were on ART reported to have benefited from disclosure, as they could now adhere to treatment without fear and achieve a high adherence level. Similarly, PLHIV participating in a study in Ethiopia who disclosed to family or friends that they were on ART reported receiving assistance from

“My close friend always reminds me the time that I should take the tablets [ART]. Even when she is away, she calls me from her cell phone.”

—ART user (Mekonnen et al., 2010)

family and friends who functioned as “treatment buddies,” reminding PLHIV to take their pills and stay on schedule (Mekonnen et al., 2010).

## Gender and Treatment Adherence

For the most part, adherence studies have not paid much attention to gender issues except for presenting sex-disaggregated data. Few studies have examined the significance of women’s and men’s experiences related to treatment adherence. However, research has shown that HIV-positive women often experience gender-related barriers to accessing health services (ICW, 2004; Eckman, Huntley, and Bhuyan, 2004). The International Community of Women Living with HIV/AIDS (ICW) has found that gender inequality within families is a barrier for women’s access to treatment and other health services (ICW, 2004). For example, many women have to obtain permission from a husband or a relative to seek HIV care, which is difficult when women have to ask for money, take time away from household chores, or have not disclosed their positive status to families (ICW, 2004). In addition, where costs for treatment are involved, families may prioritize paying for men’s treatment (Eckman, Huntley, and Bhuyan, 2004). HIV-positive women’s access to information, treatment and support is also affected by stigma and discrimination because of social values surrounding the importance of female purity and virginity (ICW, 2004). With these barriers to health services, among others, it is important to explore how gender issues may have an impact on HIV-positive women’s and men’s ability to adhere to treatment.

Recently, studies have started to explore women’s and men’s experiences related to adherence by including discussions of gender issues. For example, Muula and Kataika’s (2008) assessment of the uptake of ARVs in Malawi discovered that men were unlikely to access treatment out of fear of marital consequences. That is, men testing positive were perceived to have contracted HIV as a result of infidelity; most women think that HIV transmitted from one spouse to another is indicative of husbands’ infidelity (Muula and Kataika, 2008). Given that the desire for marital harmony affects men’s willingness to access testing services, men clearly face a barrier in obtaining and maintaining treatment.

In Ethiopia, Mekonnen et al. (2010) explored equity and access to ART, looking at barriers to accessing ART to gain a better understanding of those people both currently undergoing ART, as well as those who need ART but are prevented from accessing it. The findings included gender differences—men were more likely than women to discontinue ART. While there was no explicit gender analysis of this finding, common reasons included lack of resources, such as food and money for transport and medical costs, and situational factors, including stigma, addiction, and incarceration (Mekonnen et al., 2010).

In Zambia, Human Rights Watch (2007) discovered that gender-based violence (GBV) has affected women’s access and adherence to HIV treatment. Women report a range of abuses, from beatings and rape to loss of property upon divorce or death of a spouse. These abuses, along with fear of abandonment, influence women’s behavior. For example, many women make excuses for time away from home when in reality they are making clinic visits or participating in support groups. Some reported that they initiated ART without telling their husbands and, as such, hide their medication in flower pots, holes in the ground, food containers, suitcases under their beds, or in aspirin and panadol containers (Human Rights Watch, 2007).

“I take the medicine out of the bottle and put it in a plastic [bag] or in a paracetamol box [container].... Sometimes I would miss a dose.”

—Zambian woman (Human Rights Watch, 2007)

“I do not take my medicine in front of my husband. He told me that he would beat me if he saw me taking the pills. He did slap me when he saw me take them. I did miss taking some of the pills because I was scared of my husband. It was very difficult for me to take the medication in the beginning because of him.”

—Zambian woman (Human Rights Watch, 2007)

Such behavior can affect adherence to treatment. Some women said they missed ART doses as a result of the need to hide their medications and take them in private (Human Rights Watch, 2007).

Women whose husbands continually beat them or otherwise abused them sometimes missed ART doses whether or not their husbands knew about their HIV status or treatment (Human Rights Watch, 2007). One woman said that, when she is locked out of the house and goes to the neighbors, she misses doses. Other women told Human Rights Watch that their husbands beat them or threatened to beat them if they saw them taking ART (Human Rights Watch, 2007). As a result, they missed some pills because they were scared that their husbands would see them doing so.

An assessment undertaken by ICW in Tanzania identified several gender-related barriers that women encounter in accessing HIV treatment. Women reported that their partners pressure them, even threatening violence, to share their medication (Rwechungura and Kayitare, 2006). At a health center, researchers discovered that many men refuse to visit the center for HIV testing and counseling, even when their wives already tested positive during antenatal care. Instead, men ask their wives to bring ARVs home. They share the medications with their wives without benefit of testing to determine their status or without the knowledge that they do or do not need treatment (Rwechungura and Kayitare, 2006).

“Most of us as women living with HIV and who are using ARVs, we face a common problem that our husbands or partners tend to force us to give them our ARVs dose while he has not tested for HIV and doesn’t know his CD4 counts. They do not want to go for testing while they show all HIV symptoms. Even if you refuse, he will find where you keep your medicine and steal them.”

– Tanzanian woman  
(Rwechungura and Kayitare, 2006)

While Roura’s 2009 study did not discuss gender issues, it mentions family influence on decisionmaking, particularly the influence of men who may threaten wives interested in availing themselves of services. In this study (Roura et al., 2009), a home-based care provider said, “You may find that perhaps a woman is forbidden by her husband. You might find that a woman is ready to go there but her husband tells her ‘but I don’t have that disease perhaps it’s you who has got it. And if you want to continue going there you should leave my place,’ so the woman stops to go there for her CD4 results and there is no way of telling that woman to go for CD4 test again.”

While the above studies explore barriers faced by women and men in adhering to treatment, only a few have drawn conclusions on factors that facilitate women’s and men’s adherence. Watt et al. (2009) found that men were motivated to adhere to treatment because it provides them with an opportunity to return to work, support their families, and care for their children. More men than women (7:2) expressed children as a motivator (Watt et al., 2009). The same study revealed that women have set schedules, often bound to responsibilities of the home, make it easier to incorporate pill-taking (Watt et al., 2009).

Few studies have considered healthcare providers’ ability to address gender issues related to treatment adherence. Human Rights Watch (2007) found that health care providers were not aware of women’s experiences with GBV. Most HIV counselors said they do not screen for gender-based abuses, offer service referrals, discuss safety strategies, assess how safety affects treatment, or otherwise address abuses (Human Rights Watch, 2007). Treatment adherence counselors said they count women’s remaining pills and discuss obstacles to adherence other than gender-based abuses. Almost all, however, were willing to start dealing with GBV with proper training and support (Human Rights Watch, 2007).

Overall, the studies show some evidence, albeit small and largely qualitative, that gender issues do have an effect on women’s and men’s ability to adhere to HIV treatment and thus warrant further research. Watt et al (2009) concluded that, while few gender differences in adherence facilitators emerged in their study, the issue demands further exploration, particularly given the different social influences of men and

women and the fact that all four patients who reported missing pills in the past month were women. Muula and Kataika (2008) suggest further investigation into the barriers faced by men in Malawi in accessing care, along with further assessment of the factors affecting adherence (Muula and Kataika, 2008).

## II. PROJECT ACTIVITIES

With the previous context in mind, the USAID | Health Policy Initiative, Task Order 1 designed a short-term, pilot activity to further examine gender issues related to HIV-positive women's experiences in adhering to HIV treatment in Tanzania. The activity would also address HIV-positive women's ability to adhere under a pilot intervention. Overall, the activity would assist local HIV-positive women's groups in better understanding gender issues related to HIV treatment adherence as a first step in increasing adherence levels among HIV-positive women.

### Program Development

To initiate the activity, two members of the Health Policy Initiative Gender Working Group, based in Washington, D.C., traveled to Tanzania in August 2009 to (1) introduce and initiate the activity on adherence to HIV treatment with PLHIV networks and U.S. government (USG) partners; (2) meet with national and local PLHIV networks and other partners to discuss gender issues related to adherence; and (3) plan the remainder of the activity in collaboration with Tanzania project staff.

To inform program development, the Health Policy Initiative met with the following international and local partners to discuss gender issues related to adherence:

- **Local partners**
  - Dar es Salaam Coalition of People Living with HIV/AIDS (DACOPHA)
  - National Council of People Living with HIV/AIDS (NACOPHA)
  - National Network of Tanzanian Women with HIV/AIDS (NETWO+)
  - Network of Young People Living with HIV/AIDS (NYP+)
  - Service, Health, and Development for People Living Positively with HIV/AIDS (SHDEPHA+)
  - Tanzania National Network of People Living with HIV/AIDS (TANEPHA)
  - Tanzanian Network of Women Living with HIV/AIDS (TNW+)
  
- **International partners**
  - International Center for AIDS Care and Treatment Programs (ICAP)—Columbia University, funded by the Centers for Disease Control and Prevention (CDC)

### Gender Issues Related to Adherence

In a group setting, the activity team led discussions about women's and men's experiences in adhering to HIV treatment; current programs focusing on improved adherence in Tanzania; and ideas for activities to improve adherence in Tanzania. Discussions yielded important findings, including the following factors affecting adherence to HIV treatment:

- Men and women are both affected by stigma, but in different ways. For example, HIV-positive women may be perceived as sex workers; HIV-positive men are perceived as weak for carrying a woman's disease.
- Men and women do not disclose their status for various reasons. Women may not disclose to partners out of fear of abandonment or violence. Men may not disclose because they do not want to change their lifestyle.

- Women lack the financial resources needed to travel to clinics, especially in rural areas, and the number of service delivery points is insufficient to meet the needs of rural women.
- Men are often reluctant to leave work for treatment out of fear of losing their job or income, which is associated with their role as provider and with masculinity; taking medication is associated with weakness. In addition, men may not want to take treatment at work for fear of disclosure. Conversely, men may prefer to take treatment at work to keep their partners or families from discovering their status.
- Women often need to request money (for transportation or other costs) or support from their partner to seek treatment. When male partners are not supportive, they may flush medications down the toilet.
- Men are often reluctant to seek HIV testing. In some cases, men share their partner's medication without knowing their own status. Some men force their female partner to share her ARVs, compromising her ability to adhere properly to the regimen; as a result, neither partner takes the prescribed dose.
- Men and women often lack proper nutrition. In particular, women face serious financial constraints to nutrition. Families often blame women for bringing HIV into the household. As a result, men divorce or abandon an HIV-positive spouse, leaving her without resources for treatment. Some women stop taking ARVs because they cannot afford food to eat with their medication; they return the ARVs to the clinic, saying they cannot take them without food.
- Women often discover their HIV status through PMTCT programs. The programs provide little follow-up on HIV treatment once women return home, and women often do not have the resources to return to health facilities and must care for a newborn.
- Women may adhere to HIV treatment better than men because of a greater concern for their health, better access to health care, and a strong desire to take care of the family. Men's responsibility to the family is often equated with providing financial support rather than taking care of their own health.

### **Current Adherence Activities**

Discussions with the networks and organizations revealed that current activities in Tanzania addressing adherence issues include community and clinic-based treatment literacy programs and clinic-based PLHIV peer education programs. For example, ICAP operates an extensive peer education program in collaboration with PLHIV networks. At the time of the Health Policy Initiative's first visit, ICAP had collected data from its service delivery sites on reasons for discontinuation and lack of adherence to HIV treatment but had not analyzed the data by sex or identified gender-based patterns. The Health Policy Initiative's visit prompted discussion at ICAP about delving deeper into the data to see what sex- and gender-based issues might be revealed.

### **Ideas for Addressing Adherence**

Stakeholders provided ideas for how to improve adherence to HIV treatment. Most informants identified poverty as an overall barrier to adherence and called for income generation activities. Informants also discussed how families can play a role in adherence by reminding members to take their medication. Stakeholders spoke about education, noting a need to educate PLHIV on adherence to treatment, including the role of proper nutrition and how to deal with side effects. Women noted a need to work with men on HIV issues, particularly educating HIV-positive men about testing and treatment. Some informants reported that men are best reached by other men.

Meetings with networks and ICAP revealed that, despite numerous treatment literacy programs (including those run by PLHIV networks), none focuses explicitly on gender issues, such as issues brought up during the group discussions. Stakeholders indicated a need to include gender in treatment literacy training rather than concentrating strictly on medical issues. In some cases, women's PLHIV networks have undertaken

treatment literacy training with women alone but have identified a need to train men as well. Stakeholders reported that reaching men is a critical part of successfully addressing gender and adherence issues through training.

### **Workplan Development**

Initial discussions with HIV-positive networks in Dar es Salaam led to a partnership with NETWO+ to integrate gender into its existing treatment literacy training program and to pilot the expanded program with one group of women and one group of men. At the time, NETWO+ held treatment literacy training programs for their members—only women—as funds were available. These members had varying levels of community involvement related to HIV. The Health Policy Initiative and NETWO+ team decided to take this opportunity to pilot the program with both women and men, and require them to engage their communities in awareness-raising or support activities after the workshop.

NETWO+ identified a particular need to involve men in such training programs, as men often do not have opportunities to participate in trainings related to HIV. There are fewer support groups or networks for HIV-positive men in Tanzania. NETWO+ felt that men's limited knowledge affects their partners' health and treatment behavior as well as their own health and treatment behavior. This reflects a finding from the group discussions with local partners, where many participants said that few men seek HIV testing in general. Discussing adherence with men is only relevant if they know their status. A few participants reported that in some cases, men share their partner's medication without knowing their own status and some men force their female partner to share her ARVs.

After meeting with NETWO+, the Health Policy Initiative designed a pilot activity with the following components:

- Integrate gender into NETWO+'s existing HIV treatment literacy training materials
- Pilot revised materials with HIV-positive women and HIV-positive men in a treatment literacy workshop in Morogoro region
- Follow up the workshop through group discussions with participants three months after the pilot workshop

The team envisioned making the associated training manual available for use with PLHIV support groups and networks in Tanzania and other countries interested in addressing gender issues related to treatment adherence.

## **Integrating Gender into Treatment Literacy Program: Pilot Workshops**

The activity team worked with in-country staff and partners to integrate gender issues into NETWO+'s existing treatment literacy workshop materials. The team referred to international training materials on gender, HIV, and adherence and adapted them to the local context (see Health Policy Initiative, 2010 for the range of materials adapted). The team designed the workshop manual with the objective of raising awareness among HIV-positive women and HIV-positive men about gender issues related to adherence to HIV treatment so that participants would be able to share and act on the information in their communities. A local translator translated the English-language training manual into Kiswahili.

When creating the workshop manual, the team focused on simplifying existing materials for participants who were new to the concept of gender. As a result, the manual includes basic activities to introduce the concept of gender, gender related to HIV vulnerability, and how gender can impact women's and men's access to treatment and services. While more advanced training materials exist around sophisticated gender concepts and gender analysis, the team felt that this audience needed a more basic introduction to gender.

In March 2010, the Health Policy Initiative and NETWO+ held the two workshops—*Community Treatment Literacy: Gender Issues in Relation to HIV Treatment Adherence*—in Morogoro region of Tanzania. The first workshop included 15 female participants from five districts (Mvomero, Morogoro Municipal, Morogoro Rural, Kilosa, and Kilumbere) in Morogoro. The second workshop brought together 15 male participants from four districts of Morogoro region (Mvomero, Morogoro Municipal, Morogoro Rural, and Kilumbere). The women were members of NETWO+, and many had attended HIV workshops before. The men were largely from the same districts as the women and were invited through local PLHIV support groups, as there are no HIV-positive men’s networks.



Male workshop participants, Morogoro, Tanzania, March 2010.

NETWO+ consultants—including a doctor and nurse from Morogoro (Dr. Kazitanga and Nurse Susan Bisanda from Sokoine University Hospital and Morogoro Regional Hospital)—and Health Policy Initiative consultants and staff facilitated the workshops (Annex A presents the agenda). Facilitators conducted the workshops in Kiswahili. At the end of the workshops, participants were expected to

- Demonstrate a heightened awareness and knowledge of gender issues related to HIV treatment adherence;
- Feel comfortable discussing gender issues with their support groups and other HIV-positive women and men, community- and home-based care providers, and others
- Be familiar with materials, techniques, and exercises on gender issues related to HIV treatment adherence; and
- Be able to discuss differences in gender adherence issues between women and men.



Workshop facilitator, Nurse Susan Bisanda, Morogoro, Tanzania, March 2010

At the beginning of the workshop, the women were open about expressing their HIV status and their desire to meet other women living with HIV and AIDS for purposes of networking and advocacy. During the men’s workshop, only two participants shared their HIV status and said that they would like to support men through counseling to disclose their status to their partners.

### **Gender and HIV**

In initial discussions of women’s and men’s vulnerability to HIV, participants in the two workshops identified the following issues:

- Women's poverty and economic disadvantages often lead to high-risk behavior and thus increased risk for HIV.
- Women's lack of decisionmaking power increases their vulnerability to HIV.
- Serial polygamy and multiple concurrent partners expose men to HIV infection.
- Men demonstrate limited tolerance to stigma and discrimination and normally keep their status secret in case of an HIV-positive test result.
- Many men fear HIV testing and use the status of a newborn or their wife to determine their own status.



Female participants at pilot workshop, Morogoro, Tanzania, March 2010

Women expressed problems in convincing their sexual partners to remain monogamous, noting that their HIV-positive status decreased their bargaining power in relationships and their ability to demand monogamy.

### Gender and Adherence

Both female and male participants noted that it is difficult to discuss men's adherence to HIV treatment without first discussing HIV testing. Participants said that women carry the face of AIDS in Tanzania and that, as a result, it is difficult to convince men to undergo HIV testing. Some male participants shared their HIV testing experience, many reporting that they were not tested until they became very ill and sought care; healthcare providers then initiated HIV testing. Only a few male participants were tested through the VCT process. One said that he heard about testing through the media and wanted to know his status. For the women, several discovered their status during pregnancy through routine HIV testing for pregnant women.



Male participants during small group work, Morogoro, Tanzania, March 2010

Participants reported that most testing centers have no support systems and usually refer HIV-positive clients to other services. Participants' ability to adhere to treatment, especially among men who underwent testing while sick, was a function of the receipt of appropriate counseling during and after testing. As a result, men had limited knowledge of the importance of adherence. Furthermore, several male participants did not know the names of the medications prescribed for them. Participants also reported that some centers do not offer ARVs. In addition, they noted that they had to wait a long time before being attended to and that health workers use medical language that can be difficult to understand.

Women had many questions and issues for clarification concerning adherence to ARVs, including how to take medication when pregnant or planning to become pregnant and how to deal with serious side effects such as lipodostrophy, which changes fat distribution in the body and seems to affect only women.

Participants in the two workshops identified the following barriers to adherence:

- Lack of disclosure within families—women often fear a partner’s violent reaction, and men often do not want to change their lifestyle. Both women and men may take medication in secret. Some men hide their medication in another wife’s house.
- Lack of HIV testing for men—men with HIV-positive wives often take their partner’s medication rather than undergoing an HIV test and receiving their own ARVs. Male participants reported that they sought HIV testing only when they became very ill.
- Cultural roles and expectations--women are overburdened and overworked, affecting their ability to adhere to treatment protocols.
- Fear of stigma—women may be rejected by the household; self-stigma can prevent men from seeking HIV testing. In particular, to ensure confidentiality, male participants may travel long distances to access treatment.
- Other high-risk behaviors--sometimes men’s drinking affects their ability to remember to take ARVs. Drinking may also interfere with timing of doses and may encourage other high-risk behavior.
- Need for information—men’s lack of treatment and treatment literacy, combined with cultural practices that hinder men from certain practices such as visiting hospitals frequently, affects their ability to adhere to treatment. Men may focus more on supporting their families than on ensuring their own health.

“There is no one as difficult as a man.”  
– *Male participant, Morogoro workshop*

Men do not like to attend information sessions on HIV; they fear that their participation will cause people to think that they are HIV-positive, leading to stigmatization.

Participants discussed ways of overcoming barriers to adherence, including the following:

- Develop a longstanding and trusted relationship with a health care provider
- Create reminders for times to take medication by, for example, scheduling medication times with a regular activity (e.g., when children leave for school)
- For men, set up community support groups to encourage and facilitate disclosure

## **Workplans**

As the last component of the workshop, participants brainstormed about how to address issues of HIV treatment adherence and related gender issues in their own communities. Workshop facilitators encouraged participants to think about concrete steps they could take on their own, with minimal resources, such as becoming “treatment buddies” to PLHIV in their communities so that PLHIV in turn might support others in adhering to their HIV treatment.

Participants worked in small groups—based on where they came from—to outline a few activities. Workshop facilitators had to provide considerable assistance with this exercise, as participants wanted to undertake large-scale efforts that would have required significant resources and time beyond the project’s means. In addition, participants who had not previously attended workshops were inexperienced in formulating workplans and understanding how to set an objective and achieve it.

By the end of the workshop, participants successfully conceptualized activities to undertake in their communities within the following three months. Female participants decided to disseminate information on gender issues and treatment in their communities through their families, communities, support groups, and District AIDS Committees. Male participants planned to mobilize men for HIV testing and disclosure, along with forming an HIV-positive men's network.

### **Pre/Post-Workshop Assessments**

To gather evidence on participants' abilities at the beginning and end of the workshops, workshop organizers undertook a pre- and post-workshop assessment. They analyzed the results to inform revisions to the workshop, including the manual's content. For example, responses to the statement "If I am taking ARVs, I do not need to practice safe sex" did not change in the pre- and post-workshop assessments (two women and four men said this statement was true). As a result, the workshop organizers recognized that participants could benefit from an activity on HIV prevention and further discussion of the issue in relation to treatment. This material was added to the final workshop manual.



Male participants during small group work, Morogoro, Tanzania, March 2010

The assessment showed that female participants were well grounded in HIV facts and had a general knowledge of gender, HIV treatment, and adherence issues. For example, all female participants gave the correct answer of "false" with the statement "Gender and sex have the same meaning" during the pre- and post-workshop assessments. Fewer men were able to provide the correct answer (10 of 15 during the pre-workshop assessment and 11 of 15 during the post-workshop assessment). Women and men also showed changes in beliefs related to women's and men's experiences with HIV. At the beginning of the workshop, the majority of women (10 of 14) agreed with the incorrect statement "Women and men face exactly the same stigma for being HIV positive." At the end of the workshop, only five of 15 women said the statement was true. In the pre-workshop assessment, 13 of 15 male participants said "true" for that statement and in the post-workshop assessment, eight of 15 men said "true."

The post-workshop assessment showed that the workshop dispelled women's few misconceptions about HIV treatment, as demonstrated in the pre-workshop assessment. For example, few women (4 of 13) correctly identified this statement as true before the workshop: "Women and men have different reasons for not adhering to HIV treatment." By the end, 11 women said the statement was true, demonstrating increased knowledge in how gender affects men's and women's experiences with treatment. Male participants, however, were not as knowledgeable about HIV treatment. Men had limited or no exposure to HIV and AIDS seminars and workshops. As a result, they entered the workshop with a weak knowledge base and misconceptions about HIV treatment adherence issues. For example, in the pre-workshop assessment, seven (of 15) men incorrectly responded to the following statement as "true": "Everyone who is HIV positive should be on ART." After the workshop, there was a minimal improvement—six of 15 men correctly identified the statement as false. According to the post-workshop assessment, male participants showed a slight improvement in their knowledge of these issues from the workshop but still needed more education.

## Evaluation

In the workshop evaluation, the majority of participants reported that the training was useful and easy to understand. As one male participant said, “The workshop was different from other ones. The facilitators used a lot of their knowledge and experience to make the participants understand.” A female participant said that she learned about the proper use of ARVs, acknowledging that she never received instruction in ARV use and was not taking her medications correctly.

When asked how the workshop could be improved, participants said it was essential to conduct workshops at the district level, and some felt that workshops should be offered at the village level. Recognizing that some men are prepared to advocate for HIV-related issues, male participants expressed desire for the creation of a network for HIV-positive men and requested more information specific to men. They also said that men should be provided with opportunities to obtain information on HIV, particularly workshops that would involve husbands and wives in discussing issues together. Both female and male participants said that the participation of men and women in the workshops would have resulted in for a higher level of participation and interaction. Furthermore, all participants requested additional education through HIV training and support in order to implement activities in their communities.

“Men don’t have their network because as men we are very behind in fighting HIV.”

– Male participant, Morogoro workshop

## Lessons Learned

The pilot workshops succeeded in building women’s and men’s knowledge of HIV, gender issues, and adherence to HIV treatment. In some cases, the workshops ultimately covered more HIV-related content than planned. The workshop planning team and facilitators assumed that participants already knew most of the facts about HIV but discovered otherwise as participants asked questions and sought clarification on a range of issues. As a result, the workshops involved more time than planned and required deviation from the material in the training manual. It was evident that both male and female participants had several misconceptions about HIV transmission and prevention that needed to be clarified, including the following:

- The role of condoms in preventing HIV infection
- The origin of HIV and AIDS
- Testing for HIV; methods and false test results
- Discordant couples and how serodiscordancy occurs
- Issues related to preventing parent-to-child transmission (PPTCT)
- False cures/faith healing of HIV and whether they work

In response, the workshop team determined that revisions to the workshop manual should include content on HIV transmission, HIV prevention (including PPTCT and serodiscordancy, particularly issues related to prevention), and disclosure.



Women’s illustrations of occupations in a group exercise on “gender” and “sex,” Morogoro, Tanzania. March 2010

The workshop team also made the following observations about the female and male participants' knowledge and experiences in the workshops:

- HIV-positive women were aware of and able to identify gender issues related to HIV but focused on (1) men's influence over women and (2) women's lack of status to address issues of power.
- HIV-positive men believed that HIV education has failed to reach them. Most had not previously participated in HIV training and lacked the requisite knowledge about HIV treatment.
- Many HIV-positive men had not previously been exposed to gender issues. They had limited knowledge and experienced difficulty in differentiating between "gender" and "sex." A number of male participants defined "gender" as meaning women. The men need additional training and follow-up in order to conceptualize and understand gender issues and how they relate to HIV treatment and care.

While the pilot activity was originally initiated with women through NETWO+, the activity team followed NETWO+'s recommendation to include men in the workshops. Recognizing, however, that men often influence women's ability to adhere to HIV treatment and need to understand the importance of learning their own status, the activity team organized separate workshops for men and women. The sex-separated workshops gave each group the latitude to discuss matters freely and bring up critical issues without fear of offending or being intimidated by the opposite sex. In the end, male and female participants said that a combined workshop would have helped facilitate communication, particularly if couples had attended the workshop together.



Dorothy Odhiambo and Lydia Rwechungura, members of the workshop team, Morogoro, Tanzania. March 2010

However, given that the male and female participants had dramatically different levels of knowledge, it was worthwhile to hold the workshops separately and train to that level of knowledge. Now that the groups have the same level of knowledge, they may benefit from integrated workshops in the future.

### **Morogoro Region Notes Adherence Workshops**

The workshops were covered by the media, with an article in the *Mwananchi* daily newspaper, a story on the local television channel ITV, and a story on BBC radio in Tanzania.

The *Mwananchi* article focused on the women's workshop, noting that some women who are on ARVs are prevented from following their treatment regimens because men take the women's prescribed medications. Health Policy Initiative staff Lydia Rwechungura was quoted saying that there is a need to educate PLHIV on ART compliance, including a special effort to reach men to improve their understanding of the importance of correctly using ARVs. Ms. Rwechungura shared anecdotal knowledge of men who have taken their wives' medicine without seeking medical advice from a doctor.

She went on to say, "As a result of this situation, we saw that there is a need to build the capacity of men so that they can take their medication openly and be treatment compliant—so that they use the medicine in the proper way and at the prescribed time."

The article also shared NETWO+'s Secretary Theresia Hakili's observation—based on NETWO+ research in Morogoro—that many women are more open than their partners and that they may have been the first to disclose their status, to be tested, and to use ARVs. She said that women and men adopt different perspectives on HIV. Men do not want to be open about their status and, as a result, may take their medicine without following instructions. She noted that, in Morogoro in general, communities have not received sufficient ART education, particularly about adherence.

—*Mwananchi daily newspaper, March 13, 2010, Morogoro, Tanzania.*

### **Workshop Follow-up**

In May 2010, NETWO+ invited workshop participants back to Morogoro for a group discussion as follow-up to the workshop. Twenty-nine of 30 participants attended, with one participating by telephone. NETWO+ organizers led a discussion on how the training had affected participants' lives, how participants have been able to educate and support others in the community, the approaches they used and challenges they faced, and what they plan to do next.

District AIDS Coordinator of Mvomero District Liberatus Rwechungura attended the group discussion and was impressed by the work undertaken by NETWO+, the Health Policy Initiative, and the workshop participants. He promised to support the participants' activities in his district in their awareness-raising activities and other HIV efforts.

### **Outcomes**

During the discussion, workshop participants reported that they are better able to understand HIV treatment and adherence with respect to gender relations in their communities. They reported the following outcomes of their workshop participation:

- Improved ability to adhere to treatment and help families and friends also on treatment by sharing what they learned in the workshops.
- Confidence to speak to their communities about HIV and AIDS, treatment adherence, and gender issues, such as men's ability to support their partners with their treatment. Some have been able to disclose their HIV status and can now educate others.

- Ability to exchange ideas with other PLHIV and build a communication network for future collaboration.
- Improved ability to provide home-based care to PLHIV, including increased motivation to work in difficult conditions with scarce resources.
- Skill in using mass media, particularly the radio, to discuss HIV treatment, gender, and adherence during HIV programs, as with the Ukweli, Mapambazuko (Ifakara), and Jamii (Kilosa district) radio stations.
- Capacity to reach out to others at care and treatment centers. Some have organized training sessions for their support groups, such as the Hekima group in the Kichangani ward and the Haruma group of the Kiwanja cha Ndege ward.
- Speaking up and discussing the importance of adherence and the gender issues that affect it (such as men's reluctance to test for HIV and/or disclose a positive status) in meetings and training sessions organized by other organizations.

Participants noted that, since disclosing their HIV status, other PLHIV in their communities have been motivated to seek them out for support. Participants then used that opportunity to share what they learned in the workshop. Female participants were more successful than male participants in reaching other PLHIV in their communities. Aside from one man who fears stigma and discrimination, all were able to take some level of action.

### **Challenges**

During the group discussion, participants revealed that stigma and discrimination is still a significant barrier to HIV education. Participants said that most PLHIV in their communities do not want to interact with them because PLHIV do not care to be associated with people who live openly with HIV. In one case, one workshop participant said that his mother treats him poorly in response to his HIV status. As a result, he fears stigma and discrimination and is not prepared to share knowledge gained from the workshop. Participants identified the following challenges to their work with PLHIV:

- To some community members, the concept of treatment and adherence is new; they need time to understand it.
- Some participants are limited by transportation—they have difficulty traveling within Morogoro to reach the PLHIV they work with.
- Some PLHIV have been receptive to education and adhere to treatment but then give up because of poor nutrition.
- Some PLHIV have had negative responses, requiring a participant to make several visits.
- Men living with HIV are not receptive to hearing about HIV mainly because they do not want others to know about their status.
- Some local leaders do not give workshop participants a chance to speak at social meetings; they do not want to hear about HIV.
- Many parents caring for children living with HIV do not want their children to know that they (the children) are HIV-positive. As a result, parents may not share basic facts about HIV treatment.
- Some participants' support groups believed that workshop participants received "secret" funding from NETWO+ or the Health Policy Initiative to implement activities, thereby leading to conflict.
- Participants lacked a proper mechanism for tracking the progress of their activities.

### **Future Outreach**

While participants have limited resources and received limited training, they pointed out the following ways in which they can continue their efforts:

- Educating their communities on an individual or group basis to ensure that they have correct and relevant information on HIV/AIDS, treatment, gender, and adherence
- Undertaking advocacy with government leaders to improve HIV treatment and nutrition services
- Disclosing their HIV status (among those who have not yet done so) so that they can feel at ease in educating communities and other PLHIV
- Maintaining educational and supportive relationships with other PLHIV in their communities while involving new people in education activities
- Seeking additional opportunities to speak at social gatherings and political meetings to educate more people about HIV/AIDS, treatment, gender, and adherence
- Providing gender and treatment adherence education in workplaces and schools
- Using mass media for education purposes and to establish new relationships with other PLHIV for further support

### **Lessons Learned**

The follow-up discussion demonstrated that, when PLHIV make efforts to educate the public about HIV, their experience in living with HIV helps them draw attention. Thus, PLHIV must be empowered so that they can gain confidence in working on HIV-related issues in their communities and, possibly, even at the national level. Participants pointed out that they can raise important issues through existing forums and representatives, such as District AIDS Committees.

During the follow-up discussion, participants said that PLHIV's involvement in decision making in Morogoro region has been limited. For example, PLHIV have not been fully involved in the process of forming NACOPHA. They suggested that NETWO+ should use district AIDS coordinators to link PLHIV in Morogoro region to NACOPHA.

The follow-up discussion also revealed that, despite the short period of time for activities, workshop participants have successfully engaged their communities in HIV education. The discussion facilitators estimated that each workshop participant has reached an average of 35 “contacts,” for a total of 1,054 contacts. If workshop participants continue educating and supporting their communities at that rate, they will have spurred great change in just one year. Of the workshop participants, female versus male participants were able to reach a larger number of PLHIV. The difference may relate to the fact that women place greater importance on educating others or have had more time to deal with HIV-related issues; after all, most male participants had not previously attended a similar training session. Furthermore, men may be more likely to experience self-stigma and fear community stigma.

It is important to note that many workshop participants have engaged in outreach without outside resources. The results show that participants grasped the idea of a personal workplan—small-scale, local efforts. However, participants could benefit from minimal resources, such as bus fare to travel to PLHIV in their districts.

Finally, discussion facilitators visited several workshop participants in their villages and spoke to PLHIV with whom participants have worked since the workshop (one in Mzumbe ward, two in Turiani, and five in Morogoro municipality). All the PLHIV reported receiving education and support from workshop participants. While they appreciate the support, they also identified key challenges that continue to affect their ability to live positively, including the distance to care and treatment centers (CTC), queues at CTCs, low income and its effect on their ability to afford proper food, a shortage of medication for opportunistic infections, and stigma and discrimination.

### III. CONCLUSION

The pilot activity provided important insight into gender issues that affect women's and men's experiences related to HIV treatment literacy and adherence in Tanzania. Given that women and men face different barriers in adhering to treatment, it is important that program managers and policymakers recognize and act on these differences to create and maintain sustainable ART programs.

While most of the treatment adherence issues (e.g., poverty) facing women and men require significant resources and long-term investments, the pilot activity was able to expand on existing efforts and build the capacity of PLHIV to initiate awareness-raising and education activities related to issues in their communities. The workshops provided participants with the education and confidence they needed to undertake small initiatives in their own communities. The follow-up discussion showed that participants have provided outreach in numerous ways without specific resources. Participants' openness about their own status has facilitated their ability to gain other PLHIV's trust and serve as educators. With time, participants increased involvement in their communities will likely lead to stronger HIV networks that work with District AIDS Committees and provide a broad level of support.



Female workshop participants and workshop organizers, Morogoro, Tanzania, March 2010

In addition, the activity successfully brought gender issues to the community level through an innovative workshop. By integrating gender issues into an existing training HIV treatment literacy program, the activity engaged PLHIV in new discussions. The pilot workshops provided important insights into women's and men's HIV and gender knowledge. As such, they revealed a need for continued HIV education in Morogoro region, particularly given that men evidenced a low level of HIV knowledge and little exposure to gender issues. Furthermore, men, lacking the support of a men's HIV network, are less vocal and active than women with respect to HIV in their communities. On the other hand, female participants had fairly high levels of HIV education and were willing to discuss their HIV status openly, along with gender issues. Women's discussions of gender issues largely focused on men's influence on women; yet, women needed to be reminded to think about how gender norms affect men and adherence.

Moving forward, this workshop manual should be considered for use with PLHIV depending on the extent and aim of treatment literacy programs and their audiences. The manual would be most effective with participants who have general understanding of HIV and gender and have attended workshops before. The pilot experience with the male participants revealed that without this basic level of knowledge, the gender concepts are difficult to fully comprehend and explore in relation to HIV. Furthermore, participants who have not previously engaged in action planning and are not familiar with the concepts or tools may find it challenging to design an action plan to address gender issues. In the future, NETWO+ should use the expanded curriculum with active PLHIV community members who have had basic training and are motivated to address the issues. In addition, this methodology should be shared with and considered by similar treatment literacy programs that are equipped to provide and support gender training.

## Next Steps

The pilot workshops elicited additional issue areas that women and men must address in dealing with gender as related to HIV treatment adherence. In subsequent meetings with the Health Policy Initiative, Task Order 5, the activity team provided recommendations for supporting follow-on work, including the following:

- **Support formation of an HIV-positive men's network.** As discussed in the men's workshop, HIV-positive men in Morogoro do not have access to a men's support group such as NETWO+. Workshop participants said that they need such a group in order to build support at the community level. They felt that capacity building could assist them in taking steps to organize a group.
- **Design trainings focused on disclosure.** Women and men identified the lack of disclosure of HIV status as a major barrier to adhering to HIV treatment. Thus, Morogoro region needs disclosure training with PLHIV networks and support groups.
- **Address GBV at the community level.** Women and men said that HIV-positive women often face violence, which affects their ability to maintain HIV treatment. Men can benefit from training on gender-based violence in order to understand its effect on women's and men's health and well-being.

With an improved ability to educate and support other PLHIV in their communities, the Morogoro participants are well positioned to participate and assist the Health Policy Initiative, Task Order 5 in any follow-up activities, as outlined above.

## ANNEX A: SAMPLE WORKSHOP AGENDA

Day 1	Time
<b>Session 1: Workshop Introduction</b>	8.30am–9.15am
<b>Session 2: Exploring HIV and AIDS</b>	9.15am–10.15am
<b>Tea Break</b>	10.15am–10.45am
<b>Session 2 (continued)</b>	10.45am–12.45pm
<b>Lunch</b>	12.45pm–1.45pm
<b>Session 3: HIV Treatment and Adherence</b>	1.45pm–3.15pm
<b>Tea Break</b>	3.15pm–3.45pm
<b>Session 3 (continued)</b>	3.45pm–5.45pm

Day 2	Time
<b>Session 4: Introduction to Gender and Health</b>	9.00am–10.30am
<b>Tea Break</b>	10.30am–11.00am
<b>Session 4 (continued)</b>	11.00am–12.00pm
<b>Lunch</b>	12.00pm–1.00pm
<b>Session 5: Gender and HIV</b>	1.00pm–3.00pm
<b>Tea Break</b>	3.00pm–3.30pm
<b>Session 5 (continued)</b>	3.30pm–3.45pm
<b>Session 6: HIV and AIDS Status Disclosure</b>	3.45pm–4.45pm

<b>Day 3</b>	<b>Time</b>
<b>Session 6 (continued)</b>	9.00am–10.30am
<b>Tea Break</b>	10.30am–11.00am
<b>Session 7: Gender and Adherence to HIV Treatment</b>	11.00am–12.30pm
<b>Lunch</b>	12.30pm–1.30pm
<b>Session 7 (continued)</b>	1.30pm–3.00pm
<b>Tea Break</b>	3.00pm–3.30pm
<b>Session 7 (continued)</b>	3.30pm–4.30pm

<b>Day 4</b>	<b>Time</b>
<b>Session 8: Workplan and Closing</b>	9.00am–10.00am
<b>Tea Break</b>	10.00am–10.30am
<b>Session 8 (continued)</b>	10.30am–12.30pm

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