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## TECHNICAL REPORT

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# A Baseline Assessment of Self-management and Community Support for HIV/AIDS Patients at Four Facilities in Morogoro, Tanzania

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NOVEMBER 2011

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This report was prepared by University Research Co., LLC (URC) for review by the United States Agency for International Development (USAID). It was authored by Faridah Mgunda (URC), Suzanne Gaudreault (URC), Mary Nzowa (Ministry of Health and Social Welfare, Tanzania), Raymond Shitima (Ministry of Health and Social Welfare, Tanzania), and Fazila Shakir (URC). The assessment was funded by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) and carried out under the USAID Health Care Improvement Project, which is made possible by the generous support of the American people through USAID.



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## DISCLAIMER

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

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## Abbreviations

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
CBO	Community-based organization
CD4	Human T helper cells expressing CD4 antigen (T helper cell)
CTC	Care and Treatment Center
FBO	Faith-based organization
FHI	Family Health International
HACOCA	Huruma AIDS Concern and Care
HBC	Home-based care
HCI	USAID Health Care Improvement Project
HIV	Human immunodeficiency virus
MOHSW	Ministry of Health and Social Welfare
MTCT	Mother-to-child transmission of HIV
N/A	Not applicable
NGO	Non-governmental organization
OVC	Orphans and vulnerable children
PLHA	Persons living with HIV and AIDS
PMTCT	Prevention of mother-to-child transmission of HIV
URC	University Research Co., LLC
USAID	United States Agency for International Development
WAVIUMKA	Wanaoishi na VVU Mkambarani
WAVUMO	Watu Wanaoshi na VVU Morogoro
WAVUNGE	Wanaoishi na VVU Ngerengere
WHO	World Health Organization

# EXECUTIVE SUMMARY

## Introduction

As in most low-income countries, the Tanzanian health care system is not well adapted to the complex needs of people living with chronic illnesses. In many countries, including Tanzania, the global initiative to rapidly expand access to HIV treatment has resulted in the first large-scale attempt to systematically establish systems for the care and treatment of a chronic illness. Essential tools and practices for providing long-term health services for people living with HIV are now in widespread use in health facilities which, in the past, only had the capacity to provide quality care for acute illnesses. While this foundation has been established, it is not sufficient for HIV care and treatment programs to achieve and sustain the best possible outcomes for the populations they serve.

Since its development in 1996, the Chronic Care Model has been successfully used in over 1500 health facilities to guide the redesign of health care systems to meet the complex needs of chronic illness patients (Coleman et al. 2009). Recently, several Ministries of Health, including the Tanzania Ministry of Health and Social Welfare, incorporated Chronic Care principles into their plans and certain guidelines aimed at health systems strengthening (Ministry of Health and Social Welfare 2010). Self-management support is a key aspect of the Chronic Care Model. To achieve sustained improvements in patient outcomes and quality of life, patients need support which increases their knowledge about their health and helps to build their skills and self-confidence to self-manage their illnesses.

In an effort to identify gaps in patient self-management of HIV and to inform the planning of interventions aimed at strengthening self-management support, the USAID Health Care Improvement Project (HCI) worked with the Tanzania Ministry of Health and Social Welfare to conduct a baseline assessment in the region of Morogoro. The assessment examined the extent and effectiveness of patient-centered self-management support provided to people living with HIV and identified community resources available to support self-management for patients with HIV.

## Methodology

Three different questionnaires were developed for the study, including both open-ended and closed-ended questions covering a variety of topic areas. Interviews were conducted with health care providers at HIV care and treatment centers (CTCs), representatives of community-based organizations (CBOs), and patients with HIV. Eleven health service providers were interviewed at four CTCs: Kingolwira, Ngerengere, Sabasaba, and Shalom (private facility). The eight CBOs that participated in the assessment all had some direct link to one or more CTCs, all included people living with HIV as members, and were all staffed by volunteers and paid staff. In all, 53 HIV patients were interviewed: 38 females and 15 males. Information from patients was disaggregated by gender.

## Findings

- *Care and Treatment Centers:* All four health facilities reported working with home-based care workers; however, only the three public facilities reported that they provide some home-based care services. All facilities reported that they provide support to groups that promote community awareness and also reported having some working relationships with community leaders. All centers also reported that they refer patients to CBOs, although only Sabasaba reported the use of referral documents. In terms of self-management support, all facilities reported that they provide basic education about the nature of HIV and about adherence as listed on the national antiretroviral therapy (ART) card. Sabasaba also provides HIV education for family members. In regards to health service providers, all 11 reported that they provide patient education both on the first visit and periodically, as indicated on the CTC card. Regarding education and skill-building for self-management, only Ngerengere reported that counselors and drug dispensers teach such skills during each client visit. All health facilities reported teaching their clients the importance of disclosure of

their status to their close family members and friends and also reported that they discuss the importance of nutrition. All facilities reported providing some psychosocial support to clients, but none of the facilities reported making self-management plans with their patients.

- *Community-based organizations:* Challenges and successes varied with each organization. Some CBOs expressed dissatisfaction with their limited capacity to provide expected services to clients. Several organizations had systems in place to refer patients to and from CTCs; however, some reported that no systems exist to assure that patients referred to CBOs actually come into contact with them or enroll. All CBOs expressed a willingness and desire to collaborate more with CTCs. To mitigate the significant problem of stigma or fear of stigma among people with HIV, all organizations provide education to spouses, families, and communities.
- *HIV patients:* A larger number of female patients were available at the health facilities on interview days, likely reflecting the higher proportion of female patients enrolled in HIV care. The lack of patient awareness of the mother-to-child mode of HIV transmission, especially among males (1 of 14), was significant. When asked whether HIV is a condition that is fatal, curable, or treatable and chronic, 75% of clients knew that HIV is chronic and treatable, but a significant proportion believed that it is either curable or fatal. When asked how to prevent HIV transmission, most respondents noted use of condoms while only a minority mentioned abstaining and being faithful. Although a somewhat larger proportion of females reported receiving support from their providers to self-manage, a larger proportion of males seemed confident that they could achieve goals and solve problems. Interestingly, a higher proportion of males reported feeling psychologically affected by stigma (feeling sad), and a relatively higher proportion of females reported experiencing fear of stigma (self-stigmatization). A higher proportion of males reported feeling supported by their community, including friends.

## **Conclusions and Recommendations**

This assessment was intended to inform the design of a prototype initiative to improve the quality of patient self-management support in the region of Morogoro. Many deficiencies were uncovered in the areas of patient self-management, including gaps in patient knowledge, skills, and self-confidence to effectively self-manage. At the facility level, provider self-management support skills should be developed. In order to effectively provide self-management support, however, facilities must also put into place operational changes which facilitate delivery of these services. Needed operational changes would address other elements of the Chronic Care Model, including delivery system design, decision support, clinical information systems, and community support.

In addition, gender issues should be explored further, particularly with respect to male enrollment and retention in HIV care and treatment, self-confidence to self-manage among females, knowledge about mother-to-child transmission and PMTCT among both genders, and support group enrollment among males.

## I. INTRODUCTION

As in most low-income countries, the Tanzanian health care system was primarily developed for the purposes of treating acute illnesses. This has resulted in processes of care which are not well adapted to the complex needs of people living with chronic illnesses. In many countries, including Tanzania, the global initiative to rapidly expand access to HIV treatment has resulted in the first large-scale attempt to systematically establish systems for the care and treatment of a chronic illness. Essential tools and practices for providing long-term health services for people living with HIV, such as longitudinal records and basic patient education, are now in widespread use in health facilities which, in the past, only had the capacity to provide services for acute illnesses. While this foundation has been established and continues to be rolled out as part of the emergency response to the HIV/AIDS epidemic, it is not sufficient for HIV care and treatment programs to achieve and sustain the best possible outcomes for the populations they serve.

Particularly in the context of limited resources, there must be a systematic approach to transforming the current system of care and treatment to achieve sustained improvements in coverage of HIV-infected persons, retention of HIV patients in care and treatment programs, and clinical outcomes for patients retained in these programs. Because HIV is a chronic illness, health system improvements aimed at addressing its chronic nature can be of great service in informing the development of health care tools and processes that can be used for the treatment of other chronic conditions, such as hypertension, diabetes, and asthma, which pose a rapidly growing disease burden in low-income countries but which have thus far received less attention in health care programming.

Since its development in 1996, the Chronic Care Model, developed by Wagner et al., has been successfully used in over 1500 health facilities, mostly in high-income countries, to guide the redesign of health care systems to meet the complex needs of chronic illness patients (Coleman et al. 2009). This evidence-based model offers an approach to quality improvement in health care which combines an interrelated set of principles, each of which contributes to a system of care that is ideally adapted to meet the needs of people living with chronic conditions. In the United States, the Chronic Care Model is being implemented as part of the widely spreading Patient-Centered Medical Home, and the World Health Organization (WHO) has endorsed this model for use in low-income countries as well (Kilo and Wasson 2010). More recently, several Ministries of Health, including the Tanzania Ministry of Health and Social Welfare, have incorporated Chronic Care principles into their plans and certain guidelines aimed at health systems strengthening (Ministry of Health and Social Welfare Tanzania 2010).

The aspect of chronic care which has the most immediate and direct impact on a patient's actions in dealing with her/his condition is self-management support. This is a key principle of the Chronic Care Model which recognizes that a substantial portion of chronic care takes place outside of formal health delivery settings. In fact, most of the decisions for managing a chronic condition like HIV/AIDS are made on a daily basis in the home environment by patients living with the condition (and/or their caregivers), rather than by health care providers. People with chronic conditions (and/or their caregivers) are ultimately responsible for most of their own care, and consequently for the clinical outcomes resulting from self-care. To achieve sustained improvements in patient outcomes and quality of life, patients need support which not only increases their knowledge about their health but also helps to build their skills and self-confidence to self-manage their illnesses.

Effective patient self-management depends on patients' ability to:

- a. Deal with the condition itself;
- b. Work through condition-associated psychological and social issues; and
- c. Maintain a normal life despite the special challenges posed by the condition (Gifford et al. 2005).

Organized patient self-management support complimented with a robust referral system can significantly improve health and physical function as well as patient satisfaction. Particularly when community resources are effectively leveraged for its implementation, self-management support can also alleviate the workload of health care workers and improve the long term cost-effectiveness of care and treatment programs (De Silva 2011).

In order to identify gaps in patient self-management of HIV and to inform the planning of interventions aimed at strengthening self-management support, the USAID Health Care Improvement Project (HCI) conducted a baseline assessment in the Morogoro Region at four health care facilities and with community organizations associated with the populations served by these facilities. The assessment was designed to examine the extent and effectiveness of patient-centered self-management support provided to people living with HIV (PLHA) and to identify and describe community resources available for supporting self-management for patients with HIV. Questions regarding home-based care were included in the assessment due to its established integration into the Tanzanian health system and its conceptual linkage to chronic care by the Tanzanian Ministry of Health and Social Welfare (MOHSW).

### **Objectives of the assessment:**

1. Gain a basic understanding of the extent to which health care providers apply patient-centered approaches, including use of community resources, in supporting self-management.
2. Determine the degree of linkage between health facilities and community resources in caring for patients with HIV.
3. Identify and describe the available community resources for facility-community partnerships and continuity of care.
4. Determine the level of knowledge patients have regarding their condition and gain insight into the level of skills they possess regarding its management.
5. Explore experiences and perceptions regarding stigma and fear of stigma and how they may impact patient self-management.
6. Examine the extent of communication between health care providers and patients in supporting decision-making by patients on self-management issues.
7. Explore possible gender-specific issues in patient self-management.

## **II. METHODOLOGY**

A literature review on the principles of chronic care, with a particular focus on self-management support, was conducted to inform the design of this baseline assessment. Data collection tools were developed and pretested. They included both open-ended and closed-ended questions covering the topic areas of interest.

Three different questionnaires were prepared, one designed for each of the following (see the data collection tools included in the Appendix):

1. Health care providers at HIV care and treatment centers (CTCs);
2. Community-based organizations (CBOs); and
3. Patients with HIV.

Interviews were conducted with leaders from eight CBOs (including non-governmental organizations and community groups of PLHA), patients, and health care providers. Four health facilities were selected for this assessment, one rural public (Ngerengere health center), one urban public (Sabasaba health center), one peri-urban public (Kingolwira health Center), and one urban private (Shalom Medical Center). A total of 53 HIV patients (38 females and 15 males) and 11 providers were interviewed at

four different CTCs. Information from patients was disaggregated by gender. Selection of interviewees was based on participant availability on interview days and willingness to participate. Therefore when interpreting these results, it is important to note since the study population was selected using convenience sampling, the patients interviewed do not necessarily represent the general patient population at each clinic.

### III. FINDINGS

#### A. Care and Treatment Centers

Eleven HIV service providers were interviewed in the CTCs at Kingolwira, Ngerengere, Shalom, and Sabasaba in order to gather information about services provided and to gain provider perspectives on the challenges and strengths of the health system in providing support for patient self-management.

##### 1. Home-based care

All three public facilities included in the assessment reported that they support some home-based care services. The private facility, Shalom, does not provide home-based care. Kingolwira's services are delivered both by designated staff and by volunteers. In Ngerengere and Sabasaba, there are no staff assigned only to home-based care (HBC), but HBC support is included among regular duties for some staff. Services provided through HBC include treatment for minor ailments and opportunistic infections and overall hygiene and care. Other services include: tracking and follow-up of patients who are lost to follow-up from the treatment facility, updates on patients receiving treatment, and food support. Ngerengere reported that they have designated two days per month for staff to provide HBC services, but that they often do not have time for this activity. Sabasaba has no staff dedicated to HBC. Instead, regular staff members support volunteers who provide the services. None of the three health facilities pay HBC volunteers any salary, but volunteers are being provided with incentives, such as meal allowances and bicycles, by community-based organizations.

##### 2. Other community services

All four health facilities reported that they provide support to community awareness raising groups but that they do not provide support for other services like income generation, food support, or social services. All reported some working relationships with community leaders. Activities stemming from these relationships include meetings between facility personnel and CBO management committees, referral of patients to and from communities, and participation of some CBO members in facility seminars.

##### 3. Facility linkages to community-based and faith-based organizations (CBOs/FBOs)

A number of CBOs are active in providing support to clients served by the CTCs. Background on the CBOs and the support they provide to people living with HIV are discussed in the next section. While Sabasaba reported involvement by four different CBOs, only one CBO, Tunajali (FHI), was actively involved with clients served by all four of the health facilities (Table 1). All facilities reported that they refer patients to CBOs, but this is not done systematically for all patients. Reasons for referral to CBOs include: need of assistance with child care or other support, other complex psychosocial problems, and need for regular home care.

Although all sites reported referral of patients to CBOs, only Sabasaba reported use of referral documents. The other facilities simply tell patients to enroll.

Sabasaba has a general referral form which they also use for CBO referrals. The bottom part is designed to be torn off and sent back to the referring health facility. Beyond simple referral, no other measures are taken by CTCs to facilitate enrollment of patients at CBOs.

All facilities reported working with home-based care workers whose tasks included educating villagers, encouraging self-referral for HIV testing and support, and follow-up of clients on antiretrovirals (ARVs).

**Table 1: CBOs mentioned by CTC providers as being active in supporting clients**

NGO or Community-based organization	Facility (CTC)			
	Sabasaba	Kingolwira	Shalom	Ngerengere
World Vision (including Wavunge)				X
Faraja				X
Tunajali	X		X	X
Wavumo	X		X	
HACOCA	X			
<b>Referral system for patients at CTC</b>				
Facility refer patients to CBOs	Yes	Yes	Yes	Yes
Referral documents available	Yes	No	No	No
Have referral register	No	No	No	No
Helps patients enroll in CBO	No	No	No	No

#### 4. Self-management support: Information and skills

Self-management support varies between health facilities. Common across the facilities is basic education about the nature of HIV and about adherence. The national antiretroviral therapy (ART) card includes a check list of basic HIV topics which should be discussed with patients. All responding health facilities reported addressing these items. Sabasaba and Shalom do not discuss certain items on the check list, including: “how the virus becomes resistant to ARVs” and “how to avoid resistance.” All providers reported that they provide the patient education indicated by the CTC card, both on the first visit and periodically. Providers reported that understanding of basic information is assured through repetition, asking patients questions, and further explanations based on responses to the questions. Group discussions, sometimes held in the mornings and led by health providers, are another mode of educating clients about HIV. Topics include: general HIV education, treatment adherence, sanitation, health screens, and HIV testing.

In addition to the basic education for patients, Sabasaba reported providing some HIV education for family members. All respondents also reported that patients receive orientation to the CTC and learn what a clinic visit entails.

None of the facilities reported making self-management plans with their patients. Regarding education and skill building for self-management, only Ngerengere reported that counselors and drug dispensers teach such skills during each client visit. All health facilities reported teaching their clients the importance of disclosure of their status to their spouses, important family members, and close friends. They also report that they discuss the importance of nutrition and how patients can manage their own nutrition. Apart from this basic nutrition education, no other nutritional support is provided. Facility practices and patient education on some specific self-management issues are listed in Table 2.

Methods recommended by providers for remembering to take pills include phone alarms, clock alarm, being reminded by mosque or church signals, involving relatives, and putting pills next to a tooth brush, near clothes, under a pillow, or in the front of a door.

Providers were questioned about their knowledge on available services outside of facilities. All were aware of various services offered by CBOs and NGOs. Some providers mentioned that these services are not distributed equitably to those who need them.

**Table 2: Self-management topics, practices, and services**

<b>Topic</b>	<b>Kingolwira</b>	<b>Ngerengere</b>	<b>Sabasaba</b>	<b>Shalom</b>
Opportunistic Infections	YES	YES	YES	YES
Adherence	YES	YES	YES	YES
ARV resistance	NO	YES	NO	NO
Vomiting ARVs	YES	YES	YES	Incorrect
What to do if forget dose	YES	YES	YES	YES
Run out of ARVs	YES	YES	YES	YES
How to remember dose	YES	YES	YES	YES
Recommend two caregivers for children	YES	YES	YES	N/A
Treatment buddies	YES	YES	YES	YES
Improving adherence	YES	YES	YES	YES
Adjust visit timing according to how patient is doing	YES	YES	YES	YES
Written materials on HIV	YES	YES	YES	YES

## **5. Psychosocial support**

All facilities reported provision of psychosocial support to clients. Psychosocial support is provided by a mental health worker from World Vision in Ngerengere and a dedicated trained nurse at Shalom. Kingolwira, and Sabasaba reported that it is the role of all staff to provide psychosocial support. The type of psychosocial support mentioned was: information on how to live with hope, how to decrease stress, how to avoid depressing situations, and how to minimize self-stigmatization.

All responding facilities reported that they have a staff meeting to discuss and obtain help in treating clients with difficulties.

### **B. Community-based Organizations**

Information was gathered from eight organizations: Faraja Trust Fund, WAVUMO, WAVUNGE, NEEMA, Matumaini Women Group, Mehayo, HACOCA, and WAVIUMKA. All of these have some direct link with one or more CTCs and/or are engaged in advocacy and/or income-generating activities with patients of the CTCs.

#### **I. Membership and employees**

All organizations include people living with HIV as members. Faraja Trust Fund employs many volunteers, most of whom are not people living with HIV, to deliver home-based care. Mehayo, HACOCA, NEEMA and Matumaini include people affected by HIV/AIDS and orphans and vulnerable children (OVCs), as well as mentally and chronically ill people. The number of members in each organization ranges from only 19 adults and six children in Matumaini to 1536 members in HACOCA. WAVUMO has 451 members, including only people living with HIV, but reaches 2457 beneficiaries. The CBOs are staffed both by volunteers and by paid staff as depicted in Table 3.

**Table 3: Staff and volunteers at each CBO**

	<b>Paid staff</b>	<b>Volunteers</b>	<b>Total</b>
Faraja	15	70 (rural, HBC) 20 (urban, OVC)	105
WAVUMO	11	117 (HBC)	128
WAVUNGE	0	Not applicable	Not applicable
Matumaini	0	19	19
WAVIUMKA	0	8	8
NEEMA	9	54	63
HACOCA	31	95	126
Mehayo	No response	20	20

- Paid staff: Faraja 15, Wavumo 11, Wavunge none, Matumaini none, Waviumka none, NEEMA 9 and HACOCA 31.
- Volunteers: Faraja 70 rural (home-based care) and 20 urban (OVC), WAVUMO 117 (home-based care), WAVIUMKA 8, Matumaini 19, Mehayo 20, NEEMA 54, and HACOCA 95.

## **2. Linkages to Care and Treatment Centers**

Of the eight organizations investigated, Faraja and Matumaini work directly with CTCs, though they do not have members or staff working in the CTCs themselves. In addition WAVIUMKA and WAVUMO reported having regular communication and/or collaboration with CTCs, including referrals and counter-referrals. The CBOs also reported providing patients with services such as: counseling, psychosocial support, home-based care, and some medical supplies.

## **3. Types of services provided and funding sources**

The organizations provide a variety of services and receive funding from several different sources (Table 4). Some expressed dissatisfaction with their limited capacity to provide expected services to clients.

## **4. Referral to and from and collaboration with treatment facilities**

WAVUMO, Matumaini, HACOCA, and NEEMA all refer patients to Morogoro Hospital CTC, Mzingo CTC, and Sabasaba CTC. WAVUMO serves people enrolled in treatment at all eight CTCs in the city of Morogoro. Faraja and WAVUMO use referral and feedback slips for referral to and from CTCs, and WAVUMO volunteers verify that referred patients have actually enrolled at the CTC. For Matumaini and HACOCA, referral is facilitated by the HBC provider but there are no referral forms. NEEMA and WAVUNGE simply advise patients to visit the CTC. There is no formal referral system between the other CBOs and the CTCs. Some inquiry was made as to whether patients referred to CBOs were enrolled immediately. Matumaini reported that they are immediately enrolled while NEEMA reported that it takes about 12 hours.

Faraja, WAVUMO, WAVUNGE, and Mehayo reported receiving referrals from CTCs, but no systems are in place to assure that patients referred to these CBOs actually come into contact with them and or enroll.

When asked about ways which they would like their organization to collaborate with CTCs to provide better services for people living with HIV, suggestions included: better linkage of patients to services, improved counseling on self-management, regular meeting and exchange of notes, run joint clinics/services, provision of medicine and supplies, and regular visits by health workers to CBOs. All CBO interviewees expressed a willingness and desire to collaborate more with CTCs.

**Table 4: What services or what kind of support does your organization provide?**

<b>Services provided</b>	<b>Faraja</b>	<b>WAVUMO</b>	<b>WAVUNGE</b>	<b>NEEMA</b>	<b>Matumaini</b>	<b>HACOCA</b>	<b>Mehayo</b>	<b>WAVIUMKA</b>
Food support				YES		YES	YES	YES
Other material support (e.g., clothing)		YES		YES	YES	YES	YES	
Financial support				YES	YES	YES		YES
Employment assistance/ sustainable live hoods	YES		YES	YES		YES	YES	YES
Small business loans (micro enterprise)	YES					YES		YES
Support groups	YES	YES	YES	YES		YES		YES
Adherence support, adherence clubs	YES	YES				YES		YES
Social activities						YES	YES	YES
Crisis assistance	YES	YES				YES	YES	YES
Community awareness-raising		YES		YES		YES	YES	YES
Counseling and testing	YES			YES		YES		
Expert patient or counselor support to facilities				YES		YES		YES
Home visits or home-based care	YES	YES		YES		YES		YES
Services delivered during home visits	C&T, refer, psycho-social and med support	Distr. mosquito nets, refer, prev. Education	N/A	various	N/A	various	N/A	various
Funding sources	FHI mostly, PACT, PSI, Int'l Child Care Trust, others	FHI	Member fees, World Vision, Area Dev Program	TACAIDS SATF, Municipal budget	Declined to disclose this info.	Tunajali, Swiss Fund, USAID	Swiss-TZ fund, Ireland Finland	GOT, self contribution

## **5. Challenges**

Faraja Trust Fund: Duplication of services occurs for some people with HIV while others in need are neglected due to poor coordination of services.

WAVUMO: Supervisors lack transportation assistance. Although loan programs for small enterprise exist, people lack skills to manage the loans.

WAVUNGE: Members of this grassroots support group for the Ngerengere area feel the need to be empowered to provide support for each other to manage their condition and crises associated with their condition, rather than depending on HBC workers from other organizations.

NEEMA: Members discussed the following challenges in trying to provide support to clients: limited funding, limited nutrition counseling, and limited knowledge.

Matumaini: Limited funding and lack of male participation were mentioned.

WAVIUMKA: Lack of adequate food for patients, inability of OVCs to attend support services, and lack of office supplies were discussed.

## **6. Notable successes**

WAVUNGE: This is a large support group consisting of over 100 members. The group has been successfully subdivided into subgroups based on shared income-generating activities (e.g., chicken-raising). Members suggested that subgroups could also serve as “self-management support groups.”

Matumaini: The ability to participate in income-generating activities contributes to family well-being.

WAVIUMKA: Successes in counseling and ARV intake, which as a result increased communication between family members and ability to resume economic productivity.

## **7. Stigma**

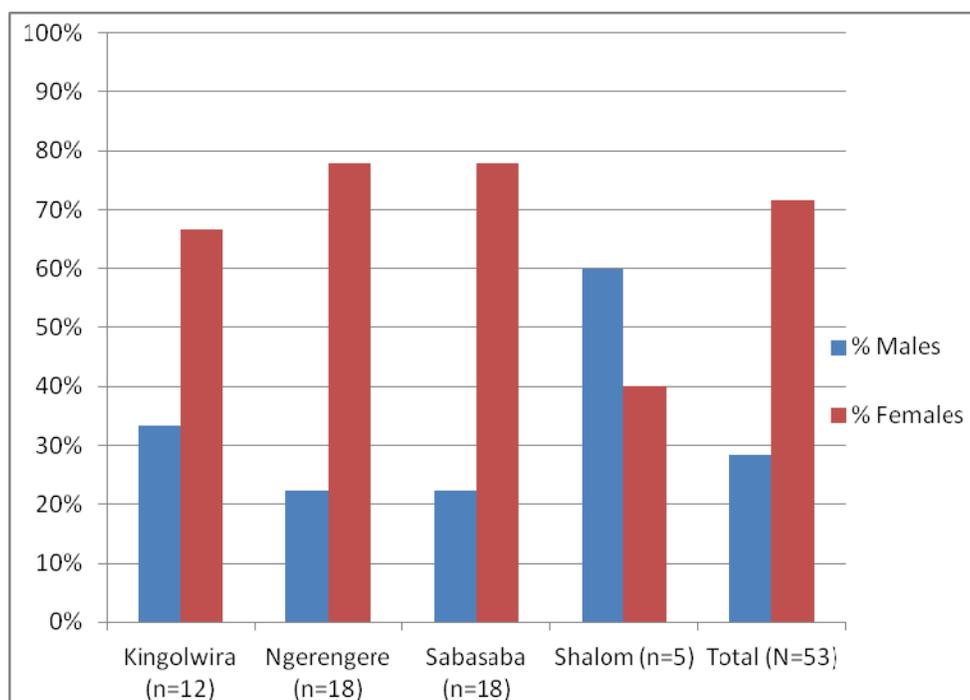
All organizations reported that stigma or fear of stigma is still a significant problem among people with HIV. People often prefer to receive treatment far away from home to avoid stigma. NEEMA members explained that poor people have no choice but to attend nearby services, while the well-off hide or go very far from their homes (where they will not be recognized) for treatment and other care needs. In mitigating all types of stigma, all organizations provide education to families, spouses, and communities. Despite advances in ARV availability and cross-cutting strategies to address stigma and self-stigmatization, they remain a significant problem.

## **C. Patient Interviews**

### **I. Interviewee characteristics**

Of the 52 patients interviewed, 38 (73%) were female with males predominating only at Shalom, the private facility (see Figure 1). The mean age of the females interviewed was 37, and the mean age of the males was 44. Overall, the study population had been attending HIV services for a mean of 37.5 months, while their mean duration on ART was 28.8 months.

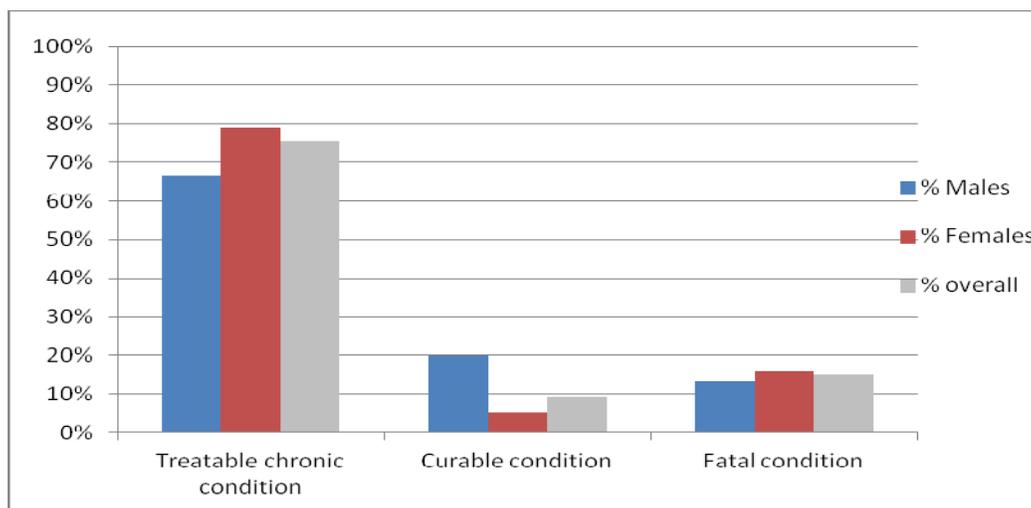
**Figure 1: Clients interviewed by gender and facility (n=53)**



## 2. Knowledge about HIV

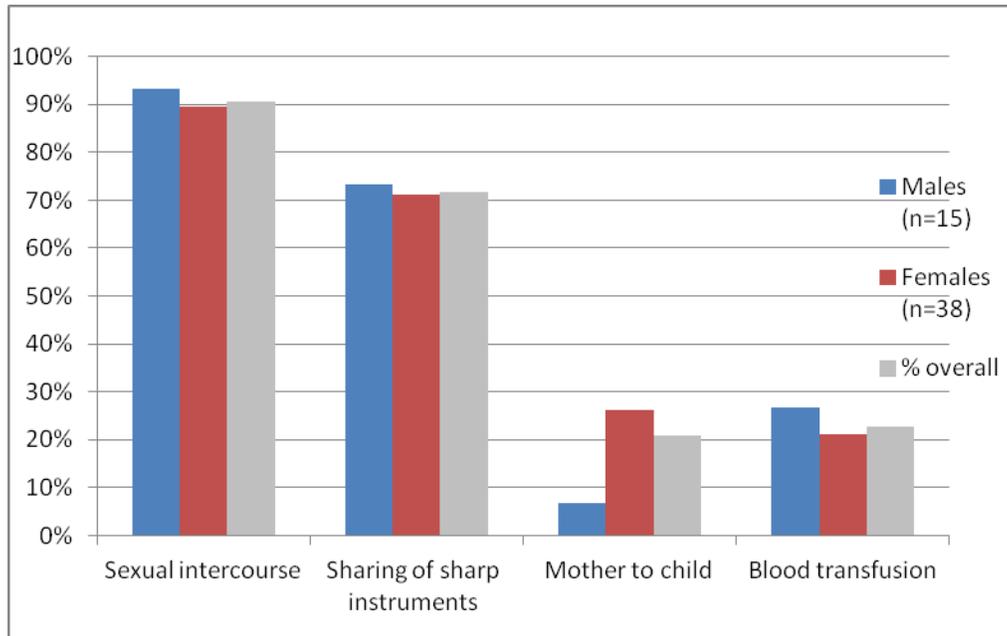
When asked whether HIV is a condition that is fatal, curable, or treatable and chronic, 75% of clients knew that HIV is chronic and treatable, but a significant proportion believed that it is either curable or fatal (Figure 2).

**Figure 2: Responses when asked if HIV is fatal, curable, or treatable chronic condition (n=53)**



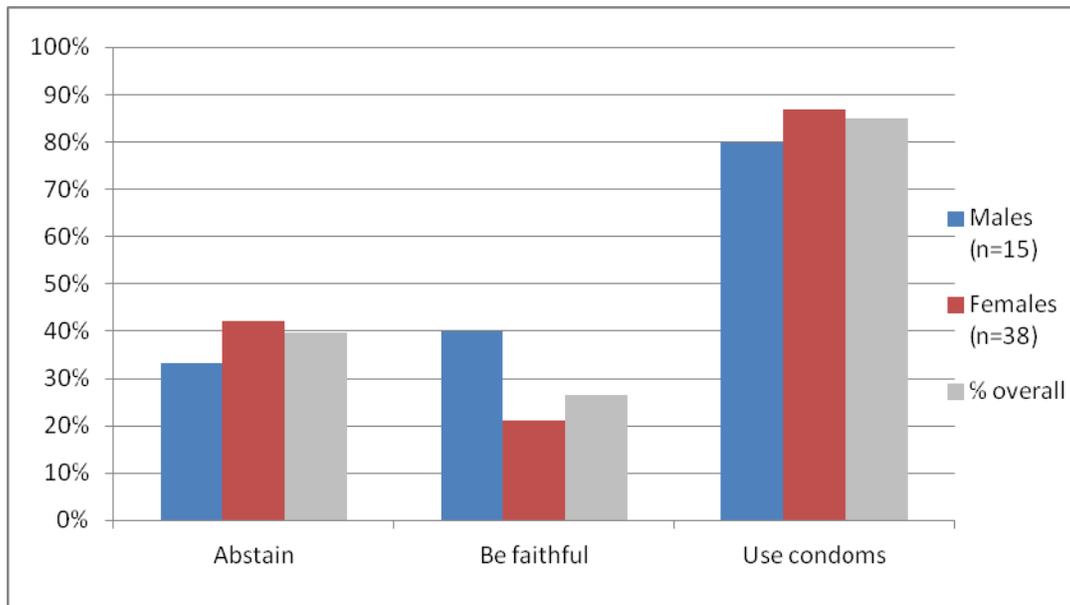
Although most participants knew about the sexual mode of HIV transmission, and a majority reported that the virus could be transmitted through reused needles and sharp objects, very few, particularly very few of the males (1 of 14), responded that the virus could be transmitted from a mother to her infant.

**Figure 3: Knowledge about modes of HIV transmission (n=53)**



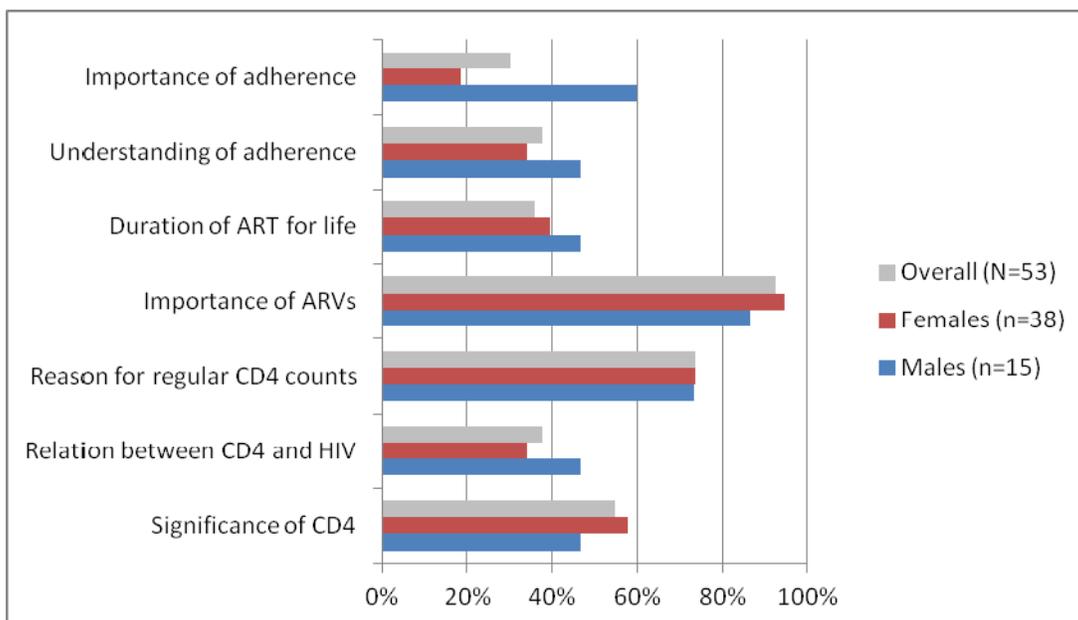
When asked how to prevent HIV transmission, most respondents noted use of condoms while only a minority mentioned abstaining and being faithful (Figure 4).

**Figure 4: Knowledge about preventing HIV transmission (n=53)**



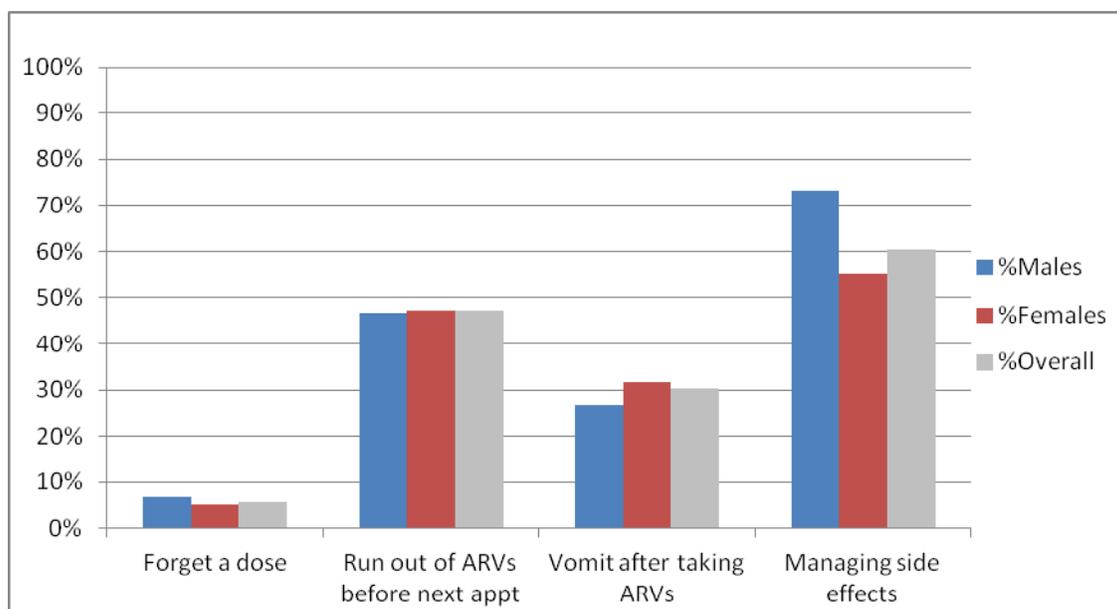
Participants were questioned about their understanding of ARVs and CD4 counts, and although most had a basic understanding of the importance and function of ARVs, only about half had a similar understanding of CD4 counts. When further questioned about duration of ART and the importance of adherence, only a minority understood that ART must be taken for life or the importance of adhering to a prescribed ARV regimen (Figure 5).

**Figure 5: Understanding of CD4 and ART (n=53)**



Participants were asked what to do about two common problems that can occur when taking ARVs: vomiting and side effects. While a majority knew what to do about side effects and other difficulties taking ARVs, few knew what to do about vomiting after taking them (Figure 6).

**Figure 6: Answering correctly to questions on how to handle problems with ARVs (n=53)**



**3. Patient-provider relationship and personal responsibility**

Participants were questioned about their relationship with providers since this can have a major impact on patient self-management and retention in care. Almost all participants reported that they are able to ask health care providers questions about their condition and that providers respond to their questions satisfactorily. When participants were asked who the main person responsible for their health is, 60%

responded that it is someone other than themselves however (Figure 7). This belief was more pronounced among the females interviewed than among the males.

**Figure 7: Who is the main person responsible for your health? (n=53)**



#### 4. Partnering with providers, setting goals, and problem-solving

Participants were asked whether they could talk with providers and find solutions to help improve their health. A moderate proportion (71.2%) responded that they felt they could (Table 5), while a much lower proportion reported that clinic staff actually work with them to set health goals (25%).

Furthermore, a very small proportion reported that they developed action plans related to their identified health goals (9.6%). Only a minority of patients felt that they had achieved any health goals that they had set for themselves or were able to solve problems that affect their health. While females more frequently reported working with facility staff address health issues, males expressed more achievement of goals and confidence to solve health-related problems.

**Table 5: Goals and problem-solving**

Function	% Responding yes		
	Overall (n=52)	Male (n=14)	Female (n=38)
Do you feel you can talk through your problems and find solutions to help improve your health during your clinic visits?	71.2	61.5	73.7
Do you work with the clinic staff to set health goals for yourself (i.e. improve adherence, clinic attendance)?	25.0	15.4	28.9
Do you normally develop an action plan related to your health goals with support from your provider?	9.6	7.7	10.5
Have you been able to achieve any health goals that you have set for yourself?	30.8	38.5	29.7
Do you feel you can solve problems that interfere with your health care?	38.5	46.2	36.8

#### 5. Access to services and information

Very few participants reported having received health services by facility providers at home, though more than half reported having access to relevant health information (Table 6), and most felt that they could access health services in an emergency. This belief was considerably higher among females than males.

**Table 6: Accessing and seeking expert medical care and advice**

Item	% Responding yes		
	Overall (n=52)	Male (n=14)	Female (n=38)
Do you or have you ever received any services from providers at this CTC at home?	7.7	7.1	7.9
Do you have access to information on your health or HIV disease and treatment?	57.6	50.0	60.5
If you have a health emergency, do you have a way to access care?	75	57.1	81.6

## 6. Stigma

About 40% of the respondents reported having experienced stigma (Table 7). Of these, only a few reported that stigma had prevented them from coming to the clinic, and a few reported that stigma had caused them not to take their medicine. Self-stigmatization (fear of stigma) was recognized as an issue by a significant number of participants. Feelings of sadness were brought on both by stigma and by self-stigmatization for a large proportion of those reporting have experienced them.

**Table 7: Stigma experiences by gender**

Stigma	% Responding yes		
	Overall (n=52)	Male (n=14)	Female (n=38)
Have you ever experienced stigma due to your HIV?	40.4	42.8	39.5
If yes, has it prevented you from coming to the HIV clinic?	9.5	0	13.3
If yes, has it prevented you from taking your medicine?	14.3	16.7	13.3
Has it made you feel sad?	61.9	83.3	53.3
Have you ever been afraid of experiencing stigma (self-stigmatization)?	36.5	30.8	40.5
If yes, has it prevented you from coming to the HIV clinic?	21.0	25.0	20.0
If yes, has it prevented you from taking your medicine?	26.7	25.0	26.3
Has it made you feel sad?	89.5	100	73.3

## 7. Social support

The assessment explored the support which patients feel they receive from their families and communities (Table 8). Most respondents reported that family members helped them with their health. An equally high proportion of females, but somewhat lower proportion of males (69.2%) reported that friends also helped them. The level of support perceived to be provided by the community, apart from family and friends, was much lower, especially among females (18.4%). A high proportion of respondents reported that family members and close relatives provide help to care for their health. In contrast, a low proportion, especially of female respondents, reported receiving community support for dealing with health problems.

**Table 8: Family and community support**

Community support item	% Responding yes		
	Overall (n=52)	Male (n=14)	Female (n=38)
Does your family or close relatives help you take care of your own health?	84.6	84.6	84.2
Does the community help you take care of your health?	21.2	30.8	18.4
Do you have friends who help you take care of your health?	42.3	46.2	39.5
Do you belong to a community based organization or a faith-based organization?	44.2	28.6	50.0

## IV. DISCUSSION

### A. Self-management Support in Morogoro

This assessment explored the availability and effectiveness of self-management support and community support for people living with HIV in a section of the Morogoro Region of Tanzania. The assessment evaluated support provided by facilities through simple interviews with facility staff. Because this assessment did not include actual observation of facility activities, neither the degree to which facilities are able to implement reported interventions nor the consistency or structure of these interventions could be evaluated. While it is clear that some basic self-management support has been integrated into the systems of care and treatment for people living with HIV, this support appears to be insufficient in accomplishing the objective of helping patients become good self-managers.

Home-based care has been institutionalized in Tanzania since early in the HIV epidemic. Facilities in this assessment collaborate with CBO-supported HBC volunteers to provide some services to HIV patients at home. Originally introduced to provide palliative care for terminally ill AIDS patients prior to scale-up of ART, the HBC system appears to be outdated. In response to the changing needs of HIV patients, the MOHSW of Tanzania is currently re-designing the HBC system with support from HCI and has included chronic care principles into its vision for how the system should be re-designed. This provides an excellent opportunity to establish patient self-management support as a major function of HBC, using home-based care as a much-needed way to extend the reach of self-management support from the facility to the community.

Community support is a key principle of the Chronic Care Model which is linked to and can enhance most other elements of chronic care. The HIV-infected populations addressed by this assessment are supported by several very active community-based organizations which provide a variety of services, including home-based care. The system of referral and linkage between the facilities and the CBOs is not well organized, however, and many people with HIV who are in need of these services are probably not accessing them. In order to enhance community support for patient self-management, improved communication and linkages between CBOs and facilities will be needed.

Tanzania's national ART card includes a checklist of information designed to prompt providers to provide basic information on HIV and HIV self-management to their patients. There is however, important information which is not included in the list. Furthermore, because health workers are frequently overburdened and rushed, much of this information is likely not communicated effectively or consistently. This is suggested by the patient interviews, which revealed many gaps in patient knowledge. These gaps can lead to ineffective "prevention with positives." For example, fewer than 30% of women and fewer than 5% of men could name mother-to-child transmission (MTCT) of HIV as one mode of transmission of the virus. This very poor awareness about MTCT among men is reflected in their generally poor participation in and support for PMTCT interventions for their partners and infants. Insufficient patient knowledge, such as that revealed by the finding that a majority of patients neither understood the importance of adherence nor the fact that ART is for life, can lead to poor adherence and retention in care and treatment programs.

To achieve and sustain effective self-management, it is fundamental to understand that the person primarily responsible for one's health is oneself, yet only 40% of interviewed clients recognized that they themselves are primarily responsible for their health. Some providers reported helping patients with problem-solving and other self-management skills. The patient interviews revealed that this probably can only be done under certain circumstances, and there appears to be no consistent system for self-management skill-building activities. Although the majority of clients felt that they could talk to their health providers about problems, most were not engaged in goal-setting or active problem-solving and did not feel confident to solve problems related to self-managing their condition. To sustain good clinical outcomes, patients must develop problem-solving skills to effectively self-manage.

Stigma and fear of stigma (self-stigmatization) are known to adversely affect adherence, retention in care, and long-term clinical outcomes. Based on reports both from clients and from CBO members, stigma and self-stigmatization are still significant barriers which patients face. Major community-awareness raising efforts have been undertaken for several years in the Morogoro Region to eliminate the problem of stigma, and it can be difficult to distinguish the degree to which people with HIV are affected by self-stigmatization versus actual stigma. The topic of stigma and how it affects self-management should be further explored so that it can be addressed in the context of supporting self-management.

## B. Gender

Although the limited design of this assessment precludes drawing any definite conclusions about gender differences, there are a few trends in the patient interview data which reflect known issues related to HIV and gender or which suggest that further exploration is warranted.

First, a larger number of female patients were available at the health facilities on interview days, likely reflecting the higher proportion of female patients enrolled in HIV care. It is well known that females are accessing HIV services more than males in Morogoro, as in most high prevalence areas. The reasons for this are many and beyond the scope of this discussion. However, interventions and/or approaches aimed at enhancing male HIV testing, enrollment, and retention in care should be explored and included in programming to improve self-management and community support. Second, the lack of patient awareness of the mother-to-child mode of HIV transmission, especially among males, was significant, and if these data reflect the general trend, it could also be a major barrier to PMTCT uptake. Third, although a somewhat larger proportion of females reported receiving support from their providers to self-manage, a larger proportion of males seemed confident that they could achieve goals and solve problems, possibly reflecting a higher degree of self-confidence among males than among females in general. Interestingly, a higher proportion of males reported feeling psychologically affected by stigma (feeling sad), and a relatively higher proportion of females reported experiencing fear of stigma (self-stigmatization). Finally, it should be pointed out that males are disproportionately less likely to be enrolled in support groups than females, a finding which is actually reflected in gender-disaggregated CBO enrollment data. Interestingly, however, a higher proportion of males reported feeling supported by their community, including friends.

## V. CONCLUSIONS AND RECOMMENDATIONS

This assessment was designed to inform the design of a prototype initiative to improve the quality of patient self-management support in the Morogoro Region. Many deficiencies were uncovered in the areas of patient self-management, including gaps in patient knowledge, skills, and self-confidence to effectively self-manage. At the facility level, provider self-management support skills should be developed. In order to effectively provide self-management support, however, facilities must also put into place operational changes which facilitate delivery of these services. Needed operational changes would address other elements of the chronic care model, including delivery system design, decision support, clinical information systems, and community support. For example, in order to allow enough patient-provider contact time to help patients with self-management issues, lay workers could be introduced to enhance the *delivery system design*. People living with HIV—“expert patients”—would be well-suited to teach patients about HIV and could offer first-hand experience of how to self-manage. Additionally, *decision support* tools, such as job aids to assist health workers, would help in providing consistently high quality self-management support. Furthermore, *health information systems* should include documentation, in addition to the patient education check list on the national ART card, to record patient self-management interventions.

Finally, *community resources* must be better linked to facilities in order to assure that people living with HIV have consistent access to and receive the maximum benefit of both. Again “expert patients” could be of great assistance in addressing this issue by serving as facility-based connections to community-

based organizations, home-based care, and other community resources. Other possible interventions for linking facilities and community resources include mapping of community resources and creation of a standardized and sustainable referral system between facilities and known community resources.

Gender issues should be further explored, particularly with respect to male enrollment and retention in HIV care and treatment, self-confidence of females to self-manage, knowledge about mother-to-child transmission and PMTCT among both genders, and support group enrollment among males.

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## VII. APPENDIX: DATA COLLECTION TOOLS

### A. Community Organization Assessment

Name of the organization: \_\_\_\_\_

**CBO or FBO (circle the most appropriate one)**

1. Who are the members of this organization?
  - a. People living with HIV/AIDS? Y/ N
  - b. People affected by HIV/AIDS? Y / N
  - c. Others: Please specify \_\_\_\_\_
  
2. Approximately how many members are there? \_\_\_\_\_
  
3. How many people are employed by this CBO? \_\_\_\_\_
  
4. How many people volunteer at this CBO? \_\_\_\_\_
  
5. What are the roles of:
  - a. employees \_\_\_\_\_
  
  - b. volunteers \_\_\_\_\_
  
6. Are there any employees or volunteers from this organization that work at the CTC?  
Y / N
  
7. Is there any regular communication or collaboration between this organization and the CTC?  
Y/N  
If yes how \_\_\_\_\_
  
8. What services or what kind of support does your organization provide?
  - a. OVC services? If so what services? (Tick accordingly)
    - i. Food support?
    - ii. Other material support (e.g. clothing)?
    - iii. Financial support?

- iv. Employment assistance/sustainable livelihoods?
  - v. Small business loans (micro enterprise)?
  - vi. Support groups?
  - vii. Adherence support/adherence clubs?
  - viii. Social activities?
  - ix. Crisis assistance?
  - x. Community awareness-raising?
  - xi. Counseling and testing?
  - xii. Expert patient or counselor support to facilities?
  - xiii. Home visits or home-based care?
  - xiv. If home visits are provided, what services are delivered during these visits?
  - xv. Others, specify\_\_\_\_\_
- b. Where does your funding come from?

9. What other organizations are active in providing support to people infected with and affected by HIV in this area?

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**Community-based organization linkages to HIV treatment facilities:**

10. Does this organization refer patients to CTCs? Y / N

11. What does the referral process consist of?

i. Is there a way of verifying that referred patients have been enrolled? Y / N

If yes please explain\_\_\_\_\_

ii. Are the clients referred to CTC enrolled immediately? Y / N

If no please explain\_\_\_\_\_

iii. Are there forms for referral/counter-referral? Y/ N

If yes can I have a copy?

12. Do treatment facilities refer patients to this organization? Y/ N

If so, is there a counter-referral process? \_\_\_\_\_

13. What is the process of enrolling clients in this organization?
- a. Are there enrollment fees? Y/ N
  - b. If so is there a fee waiver program for those who cannot pay? Y/ N
14. Can you think of any ways which you would like for your organization to collaborate with the CTC to provide better services for people living with HIV? Please explain.
- 
15. Can you list some of the challenges you face in your day to day support to clients?
- a. \_\_\_\_\_
  - b. \_\_\_\_\_
  - c. \_\_\_\_\_
16. Can you share with some of your success stories?
- a. \_\_\_\_\_
  - b. \_\_\_\_\_
17. Is stigma or fear of stigma a problem among people with HIV? Y/N
18. How does it affect the way people with HIV take care of their health?
19. Does this organization do anything to address stigma? If so what?

## B. Patient Questionnaire

Name of Region: \_\_\_\_\_ Name of District: \_\_\_\_\_  
 Name of Facility: \_\_\_\_\_

Patient Chart ID: \_\_\_\_\_ Patient Age: \_\_\_\_\_

Sex of patient (Circle one): M / F

### Background Questions:

- How long have you been receiving ARTs? \_\_\_\_\_(years)
- How long have you been receiving HIV services at this health facility? \_\_\_\_\_ (years)

### 1) Knowledge about HIV disease

Questions	Responses
a. Is there currently a cure of any kind for HIV?	[ ]1= Yes [ ]2=No [ ]9=Don't know
b. Once infected, how long does a person remain with HIV?	[ ]1=For life [ ]2=Other [ ]9=Don't know
c. Is HIV currently fatal, curable, or is it a treatable life-long condition?	[ ]1=Fatal [ ]2=Curable [ ]3=Treatable, life-long condition [ ]9=Don't know
Please explain why	
d. How is HIV transmitted?	<ul style="list-style-type: none"> <li>• Sexual intercourse</li> <li>• Sharing of sharp instruments</li> <li>• Mother to child</li> <li>• Blood transfusion</li> <li>• Other specify _____</li> </ul>
e. How do you avoid transmitting HIV to others?	<ul style="list-style-type: none"> <li>• Abstain</li> <li>• Be faithful</li> <li>• Use condom</li> <li>• Others _____</li> </ul>
f. How does HIV affect the body?	
g. What does a person with HIV need to do in order to live and be healthy for a long time?	
h. What is a CD4 and how does it relate to HIV/AIDS?	

Follow-up question: Why is blood drawn to measure CD4 counts regularly?	
i. Once HIV has grown strong enough to make a person sick what can make them health again?	<input type="checkbox"/> 1= ARVs <input type="checkbox"/> 2= Traditional medicine <input type="checkbox"/> 3= Religious leaders / prayer <input type="checkbox"/> 4= Nothing <input type="checkbox"/> 5= Other

**2) Effective communication skills**

During your visits to the clinic...

- Do you feel that you can ask questions about HIV disease and treatment? Y/ N /Others
- Does the staff answer your questions in a way that you can understand? Y/ N /Others
- Do you feel you can talk about your health problems and concerns with the staff? Y / N / Others

When others explain \_\_\_\_\_

**3) Actively partnering with providers in decision-making (self-efficacy)**

- Who do you think is responsible for managing your HIV disease? (ie. *health worker, family member, or self*)
- Who is the main person generally responsible for your health?

\_\_\_\_\_

**4) Practice goal setting, action-planning and problem solving**

- Do you feel you can talk through your problems and find solutions to help improve your health during your clinic visits? Y / N
- Do you work with the clinic staff to set health goals for yourself (i.e. improve adherence, clinic attendance)? Y / N
- Do you normally draw together with your provider action plan related to your health goals with support from your provider? Y / N
- Have you been able to achieve any health goals that you have set for yourself? Y / N
- Do you feel you can solve problems that interfere with your health care? Y / N

**5) Self-monitor symptoms and follow treatment directions**

- How long must you take ARVs?

- 
- What do you understand by 'adherence'?

- 
- What is the importance of adhering to ARVs?

- 
- What is the importance of adhering to all other medications given by the provider?

- 
- How does the virus become resistant to ARVs?

- 
- How can you keep the virus from becoming resistant to ARVs?

- 
- What should you do if you are running out of ARVs and you don't have an appointment at the CTC?

- 
- What should you do if you:

- Vomit after taking your ARVs? \_\_\_\_\_

- Have side effects from the ARVs or find it difficult to take them for other reasons? Y / N

- Forget a dose? (should take the forgotten dose if is less than 12 hours following the exact time you should have taken it; if it is more than 12 hours just consider it a missed dose and take the next dose at the regular time.)  
\_\_\_\_\_

- What do you do to be sure to remember to take all your ARVs and to take them on time?  
\_\_\_\_\_

- What can you tell me about nutrition and HIV? (It is important that people eat a diet that is as balanced as possible, It is important not to lose weight. If you are losing weight you must tell your provider. ...etc....) \_\_\_\_\_

- What do you do if you start to feel sick (fever, severe headache, diarrhea, become bedridden, symptoms of TB or malaria, etc.)?  
\_\_\_\_\_

**6) Accessing and seeking expert medical care and advice**

- How often do you need to visit the CTC in order to manage your illness?  
\_\_\_\_\_
- How long will you need to receive follow-up care and treatment for HIV at the CTC?  
\_\_\_\_\_
- How does the CTC help you take care of your own health?  
\_\_\_\_\_
- Do you or have you ever received any services from providers at this CTC at home? Y / N  
If so, what services? \_\_\_\_\_
- Do you have access to information on your health or HIV disease and treatment? Where do you get this information?  
\_\_\_\_\_
- If you have a health emergency, do you have a way to access care? Y /N  
If so, how? \_\_\_\_\_

**7) Stigma**

- Have you ever experienced stigma due to your HIV? Y/N  
If so, by whom?  
How has this affected your ability to take care of your health?  
Has it prevented you from coming to the HIV clinic?  
Has it prevented you from taking your medicine?  
Has it made you feel sad?  
What other problems have been caused by stigma?
- Have you ever been afraid of experiencing stigma (self-stigmatization)? Y/N  
If so, how has this affected your ability to take care of your health?  
Has it prevented you from coming to the HIV clinic? Y/N  
Has it prevented you from taking your medicine? Y/N  
Has it made you feel sad? Y/N

What other problems have been caused by this fear of stigma?

**8) Use family, peer, and community support resources**

- Does your family or close relatives help you take care of your own health? Y / N

If yes, how? \_\_\_\_\_

- Does the community help you take care of your health? Y / N

If yes, how? \_\_\_\_\_

- Do you have friends who help you take care of your health? Y / N

If yes, how? \_\_\_\_\_

- Do you belong to a community based organization or a faith-based organization? Y / N

If yes, which one? \_\_\_\_\_

How does this organization help you take care of your health?

\_\_\_\_\_

- Do you attend church or mosque? (Underline the appropriate one). If yes, does this help you take care of your health? Y / N How? \_\_\_\_\_

- Who else helps you to take care of your health? \_\_\_\_\_

**9) How do you maintain your emotional and psychological balance? (tick the most appropriate)**

- Talking to providers (facility or HBC)
- Talking to family members
- Talking to friends
- Talking to religious leaders
- Talking to traditional healers
- Engaging in sports and games
- Others (praying, listen to music etc)

**10) Practice health-enhancing behaviors**

- What else do you do to take care of your health? (*eat well, sleep enough, practice safe sex, etc.*)

\_\_\_\_\_

**OTHER:**

- Who or what makes it difficult to take care of your health? (*economic difficulties, spouse, family problems, etc...*)\_\_\_\_\_

- Who or what could help you take care of your health? \_\_\_\_\_

And what else? \_\_\_\_\_

**Patient Activation Measure (PAM)**

The questionnaire used in the Patient Engagement survey contains a 22 item scale that assesses the extent to which people feel confident and able to self-manage their own health and health conditions. The scale consists of a series of statements, with five possible responses:

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- Not applicable.

Your Name: \_\_\_\_\_  
Today's Date: \_\_\_\_\_

For Official Use only: MRN \_\_\_\_\_

## Me and My Health

**INSTRUCTIONS:** For each statement below please mark an X in the box to the right that best describes how much you disagree—agree with the statement as it applies to you personally.

There are no right or wrong answers. Your answers should be what is true to you and not just what you think the doctor wants you to say.

	Strongly Disagree	Disagree	Agree	Strongly Agree
1. When all is said and done, I am the person who is responsible for managing my health condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Taking an active role in my own health care is the most important factor in determining my health and ability to function.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I know what each of my prescribed medications do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I am confident I can tell a doctor concerns I have even when he or she does not ask.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I am confident that I can follow through on medical treatments I need to do at home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I understand the nature and causes of my health condition(s).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I know the different medical treatment options available for my health condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I have been able to maintain the lifestyle changes for my health condition that I have made.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I know how to prevent further problems with my health condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I am confident I can figure out solutions when new situations or problems arise with my health condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(PAM)

**C. Facility Assessment**

**Name of District:** \_\_\_\_\_

**Name of Facility:**\_\_\_\_\_

**Community Resources:**

**Facility-based community resources:**

1. Is there a home-based care program associated with this facility? Y / N

1.1 What staffs are involved? \_\_\_\_\_

1.2 Regular facility staff? Y/ N

1.3 Special staff designated for home-based care only? Y/N

1.4 Volunteers?  
  
\_\_\_\_\_

2. What services do they provide?

3. How much time do they spend on this activity?

3.1 When? \_\_\_\_\_

3.2 How often?\_\_\_\_\_

4. Approximately how many patients receive HBC each month?\_\_\_\_\_

5. Do the HBC workers receive a salary? Y/N

Do they receive other incentives? Y/ N What kind of incentives?\_\_\_\_\_

If the HBC workers are not employed by the facility, who manages them? \_\_\_\_\_

6. Are there any social services that the CTC refers patients to? Y/ N

If so, what are these social services  
  
\_\_\_\_\_

7. Are there other community services provided by the facility?
- i. Food support? Y / N
  - ii. Other material support (eg. clothing)? Y / N
  - iii. Financial support (eg. school fees, bus fare)? Y / N
  - iv. Employment assistance/income-generating assistance? Y / N
  - v. Support groups? Y/N
  - vi. Social services (domestic violence, orphans)? Y/N
  - vii. Community awareness groups?  
Others? Specify \_\_\_\_\_

8. What working relationships does this CTC have with community leadership (eg. Village health committees, village HIV/AIDS committees)?

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**Facility linkages to community-based organizations (CBOs/FBOs):**

9. What CBOs or FBOs are active in providing support to the clients served by this CTC?  
Please mention them \_\_\_\_\_

10. Does this CTC refer patients to CBOs? Y / N

11. Under what circumstances do you refer patients to CBO?  
\_\_\_\_\_

12. What is the referral process?
- i. Is CBO referral documented? Y/ N
  - ii. Do you have referral registers? Y/ N
  - iii. Is there another way of verifying that referred patients have been enrolled in the CBO? \_\_\_\_\_
  - iv. Is any support provided to help patients enroll in a CBO (eg. transport, accompaniment)? Y / N

- v. Are there forms for referral/counter-referral to CBOs? Y / N
  - 1. If yes can I have a sample?
  - 2. If no, what do you use to refer the patient?

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13. Do these organizations charge fees? Y / N

If so is there a fee waiver program? Y / N

14. Do you have expert patients? Y/ N

What tasks do they perform or services do they provide?

**Self-management:**

15. What do providers do to support self management?

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- a. Do patients receive an orientation to the CTC, learn what a clinic visit entails, and who provides the various services in the facility? Y / N
- b. Do providers and clients make a self management plan that has to be followed by both? Y / N

16. Do clients receive education about the nature of their condition here? Y / N

- i. If so, who provides this education?
- ii. If so what kind of information do they receive and how?

***Checklist:***

1. Patient's role:

That HIV is managed first and foremost by the person who has it, but that the best outcomes are when the person does this in partnership with health care providers and other treatment supporters.

2. Knowledge of HIV/AIDS

- a. How HIV is transmitted.
- b. How to avoid transmitting HIV to others and how to avoid new HIV infections.
- c. How HIV affects the body.

- d. That an infected person has HIV for life or until a cure is found.
  - e. There is currently no cure, traditional or otherwise for HIV.
  - f. That HIV is now considered to be a long term chronic disease because a person with it can live in good health for along time if it is managed well?
  - g. What an HIV-infected woman who is pregnant needs to do to minimize the risk of transmitting the infection to her baby.
  - h. What the infant of an HIV-infected mother needs to stay healthy?
  - i. Importance of testing all children and family members of HIV-infected people
    - i. Breastfeeding
    - ii. ARV prophylaxis
    - iii. Cotrimoxazole
    - iv. Testing
  - j. The importance of male involvement in PMTCT.
  - k. Is it clear to patients that they will need to visit the CTC regularly in order to manage their illness?
  - l. What is CD4 and its role in HIV/AIDS.
  - m. Why blood is drawn to measure CD4 counts regularly.
  - n. That only ARVs can keep people with HIV alive and healthy once the HIV has grown strong enough to make a person sick.
  - o. That ARVs must be taken for life.
  - p. How ARVs fight the HIV virus.
  - q. How the virus becomes resistant to ARVs.
  - r. How to avoid resistance.
  - s. The importance of adhering to ARVs.
  - t. The importance of adhering to all other medications given by the provider.
3. When is this education provided?
- i. First visit only? Y/ N
  - ii. Periodically? Y/ N
  - iii. If yes, how often \_\_\_\_\_
  - iv. Under what circumstances?

4. How do you know that the patient has understood all the information?  
(tick the most appropriate)
  - i. Do you quiz the patient or ask them to repeat back information to assure they understand?
5. Are clients educated on how to manage their condition themselves? Y / N
  - i. By whom? \_\_\_\_\_
  - ii. How often? \_\_\_\_\_
6. Under what circumstances (eg. before starting ARVs [how many sessions?], when problems with adherence arise, etc.) \_\_\_\_\_
7. Are clients educated and encouraged to disclose status to spouse, other family member or close friend? Y / N
8. Are they educated about the effect of HIV on nutritional status and how to manage their nutritional status? Y / N
9. Is any material assistance (such as high-nutritional value food products) available to help patients with nutritional problems? Y / N  
If so, how is it managed? \_\_\_\_\_
10. Are clients educated about opportunistic infections and what to do about them? Y / N
11. Do they receive counseling on adherence? Y / N
  - i. Importance of adherence.
  - ii. The permanent nature of ARV resistance once it develops.
  - iii. Importance of sticking to prescribed regimen (triple therapy and dosing times).
  - iv. How adherent they must be in practical terms (ie. maximum number of pills [95%] they can miss per month before resistance develops).
  - v. What to do when they have problems with their pills.
    - Vomiting \_\_\_\_\_
    - Side effects \_\_\_\_\_
    - Forgetting doses \_\_\_\_\_
    - Running out of pills \_\_\_\_\_
  - vi. Methods of remembering to take their pills.
12. What else is done in the facility to assist patients with self-management?
  - i. Are 2 caregivers strongly recommended for children. Y / N

- ii. Are adult clients encouraged to have treatment buddies to help them remember to take their medicines? Y / N
- 13. Are difficulties adhering to ARVs discussed and plans for improving adherence established together? Y / N
- 14. Is the frequency of visits adjusted by how well they self-manage (ie. clients with a history of excellent self-management can have more widely spaced visits)? Y / N
- 15. Do patients receive written materials to inform them about their disease or to help them with self-management? Y / N Can you show us copies of these?
- 16. Does the CTC track defaulters? Y / N
  - If yes, how? \_\_\_\_\_
  - If no, why not? \_\_\_\_\_
- 17. What services are provided outside the CTC to assist with self-management?
  - a. Food support? Y / N
  - b. Other material support (eg. clothing)? Y / N
  - c. Financial support (eg. school fees, bus fare)? Y / N
  - d. Employment assistance/income-generating assistance? Y / N
  - e. Support groups? Y/N
  - f. Social services (domestic violence, orphans)? Y/N
  - g. Community awareness groups? Y / N
  - h. Others? Specify \_\_\_\_\_
- 18. Do you provide psychosocial support to patients? Y / N
  - a. Who provides this support? \_\_\_\_\_
  - b. What kind of psychosocial support? \_\_\_\_\_
  - \_\_\_\_\_
- 19. Do providers have a forum to discuss and obtain help in treating clients with difficulties?  
Y / N



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