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Mapping of Community Home-Based Care Services in Five Regions of the Tanzania Mainland

June 2006

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List of Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
CBOs	Community-Based Organizations
CMACs	Council Multisectoral AIDS Committees
CHWs	Community Health Workers
CHBC	Community Home-Based Care
DCCO	District AIDS Control Coordinator
FBO	Faith-Based Organization
FGD	Focus Group Discussion
HBC	Home-Based Care
PASADA	Pastoral Activities and Services for People with AIDS Dar es Salaam Archdiocese
PMTCT	Prevention of Mother-to-Child Transmission
PLWHA	People Living with HIV/AIDS
TACAIDS	Tanzania Commission for AIDS
TIS	Tanzania HIV Indicator Survey
VCT	Voluntary Counseling and Testing

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Nelson A. Keyonzo
Country Representative, Pathfinder International/Tanzania

Executive Summary

Introduction and rationale

Since December of 2001, Pathfinder International/Tanzania has supported Home-Based Care (HBC) activities in the regions of Arusha and Dar es Salaam. Pathfinder plans to expand its HBC support to more wards in these two regions and to the regions of Tanga, Morogoro, and Kilimanjaro.

Pathfinder commissioned this study, with funding from the Centers for Disease Control and Prevention, to determine which Nongovernmental Organizations (NGOs), Community-Based Organizations (CBOs) and Faith-Based Organizations (FBOs) are providing HBC to people with long-term chronic illnesses—the majority of whom are assumed to be People Living With HIV/AIDS (PLWHA)—in the five program regions. The study also aimed to identify the significant gaps, challenges, and successes of HBC.

The objectives of the study were to:

- Review available information to understand the magnitude of the problem, the number of PLWHA, and the extent to which their basic needs and those of their caregivers are being met in the five program regions;
- Identify potential partners on the basis of their comparative advantage for comprehensive HBC in Dar es Salaam and Arusha municipalities and in the new regions of Morogoro, Tanga and Kilimanjaro;
- Assess the effectiveness of community AIDS committees established by local government authorities in supporting Community Home-Based Care (CHBC)[1] programs;
- Identify existing resources for a two-way referral system and assess the capacity of existing service networks; and
- Identify local organizations best positioned to holistically address the needs of PLWHA and their communities.

Intended use of the study

The study documents the concerns of PLWHA, Community Health Workers (CHWs), primary care providers, and other stakeholders to inform Pathfinder's support to national efforts to scale-up CHBC. The proposed project aims to replicate Pathfinder's successful CHBC model for PLWHA in other areas and improve access to HBC for more Tanzanians.

Data and Methods

The data is mostly qualitative, collected through focus group discussions, key informant interviews, and literature review. Data collection took place over two weeks in November 2005.

The study was conducted in ten municipalities and district councils in five regions of the Tanzania mainland including: Arusha municipality and Arumeru district in the Arusha region; all districts in Dar es Salaam; Moshi municipality and Moshi rural in Kilimanjaro; Morogoro municipality and Mvumero district in Morogoro; and Tanga municipality in Tanga. All focus group discussions included both men and women.

[1] Home-Based Care (HBC) services are provided in the home through outreach from a static medical facility. Community Home-Based care is similar, but the service provider is a community member trained in health care, rather than a professional based in a clinic.

Government leaders at the national and sub-national level, members of Council Multisectoral AIDS Committees (CMACs) at the municipal, district, and ward levels, and officials responsible for referral for medical, legal, spiritual, and material support, participated in key informant interviews. By virtue of their positions as heads of NGOs and municipal and district functionaries, the majority of the key informants were also council multisectoral HIV/AIDS co-opted or full committee members.

Under the guidance of the team leaders, eight trained interviewers collected data for two weeks, spending two days per municipality or district. Team leaders performed the key interviews at the national level.

Significant Findings

Magnitude of the problem and meeting needs: Key informants and CHWs were asked for information on areas in their localities that have higher HIV transmission rates. Interviewees consistently mentioned the same places and similar reasons for the high transmission. Such places tended to be more populated, urban or peri-urban centers. Some have major factories (e.g., sugar factory in Morogoro, cement factory in Tanga, and livestock market in Dar es Salaam). Commercial sex and alcohol were described as major risk factors. National HIV prevalence information for the five regions shows that Dar es Salaam has the highest prevalence at 10.9%, followed by Kilimanjaro (7.3%), Tanga (5.7%), and Morogoro (5.4%). The lowest prevalence is in Arusha at 5.3%.

In the five project regions, CHWs trained by HBC programs were found to have an average of five clients each. They train family caregivers in basic nursing, management of minor ailments, referral for complications, legal and spiritual services, and voluntary counseling and testing. CHWs also perform a variety of services both to demonstrate care to family members and to serve as an important link in the continuum of care. Overall, it was estimated that about a third of PLWHA do not have people to care for them, indicating a significant unmet need for HBC. For patients who do not have any family members to care for them, their CHWs may be the only people providing care.

HBC Partners: Organizations providing HBC are shown in Annex 2. There were 30 organizations identified in Arusha, 24 in Dar es Salaam, 22 in Morogoro, 35 in Kilimanjaro, and 18 in Tanga. Seventeen organizations had a presence in more than one of the study districts or municipalities. Pathfinder, Walio Katika Mapambano ya AIDS (WAMATA), and Service Health Development and Education for People Living With HIV/AIDS (SHIDEPHA) operated in four or more districts. Forty-seven percent of the organizations provide HBC. The remaining 53% provide services supportive of HBC, including information, education, and communication, voluntary counseling and testing, material support, legal aid, health services (some including antiretroviral therapy and prevention of mother-to-child transmission), research in traditional and herbal medicines, orphan and widow support, and income generating activities.

Functioning of HIV/AIDS Committees: Council Multisectoral AIDS Committees have been established in all of the municipalities and districts surveyed, however ward committees were only functional in Kinondoni and Morogoro urban areas. Poor performance of committees was blamed on lack of funds. The majority of the key stakeholders interviewed recognized the need for HBC.

But the need for HBC was not featured as an issue warranting specific strategy and support in CMAC deliberations or plans.

Referral Systems: Most of the organizations refer clients to hospitals or other facilities for services that they themselves do not provide; though only few had systems for two-way referral. Lack of fare for transport during referral is often a significant barrier to patients accessing services. There is a significant deficiency in the availability of legal services, with the exception of Kilimanjaro. The need for legal services is enormous in light of prevailing stigma, which leads to abuse of rights.

Inadequate food for PLWHA and their families is also a problem. Some NGOs in the referral networks provide food support, but very few did so regularly and in sufficient quantities. Malnutrition negatively affects the health and recovery of PLWHA from opportunistic infections. The study also found incidences where food shortages compromised use of antiretroviral therapy.

Local organizations best positioned to address community needs: It was not possible to identify which of the local organizations were most suited to holistically address the needs of the community. Instead, the study team is recommending criteria to be used for identifying such organizations among the long and growing list of organizations. The proposed criteria is: presence in the district; capacity as determined by number and skills of staff, range of services offered, geographical coverage or plans for expansion; and willingness to partner with Pathfinder.

Recommendations and the way forward

The following recommendations are made.

- More effort should be made to advocate for and support NGOs and CBOs to provide quality HBC.
- Before expansion of the Pathfinder CHBC project, capacities of potential partner NGOs, CBOs, and government agencies should be assessed.
- Simple methods of assisting in legal issues should be explored and implemented. This will reduce a number of contraventions on the rights of PLWHA in employment, ownership of assets, inheritance, housing, and access to resources.
- Since most of the people who are eligible for HBC are poor, expenses including clinic or hospital admission and laboratory fees should be waived—no matter how minimal.
- Each ward should have a HBC strategy and plan. Pathfinder should facilitate and support the development of ward HBC strategies and plans in conjunction with national HIV/AIDS policies and guidelines in the districts where Pathfinder operates.
- More strategic networking and coalition building among the NGOs and CBOs providing HBC is required. This will facilitate the provision of a wider range of services.
- An increase in CHWs allowances should be explored due to reported inadequacy of funds for facilitating transport and maintaining supplies.

Background

HIV/AIDS Situation in Tanzania

For over two decades, Tanzania and its development partners have been grappling with the challenges posed by the steadily-increasing HIV prevalence rate. The HIV/AIDS epidemic is having an enormous impact on Tanzania's health care system and social structure. With overall adult prevalence of 8.7%, there are over 1.8 million people infected with the virus, and nearly 11% of children in Tanzania have been orphaned.[2]

A young orphan who has been reached through Pathfinder's CHBC program

HIV/AIDS and the associated opportunistic infections have contributed heavily to increasing morbidity, mortality, and declining productivity in all sectors of the economy, and have put a heavy burden on the already overstretched public health system. The increasing number of patients with chronic HIV-related illnesses results in health facility overcrowding and lower quality of care. It is estimated that 50% to 60% of bed occupancy in Tanzanian hospitals is attributable to HIV-related illnesses.[3]

Home-Based Care

The Home-Based Care (HBC)[4] concept is an innovative approach to comprehensively meeting the needs of People Living With HIV/AIDS (PLWHA) in resource-limited settings. It bridges the gap between health facilities and home care by enabling PLWHA to receive quality and dignified services in their homes, most often provided by family members. According to the Tanzania HIV Indicator Survey (TIS), there is a lot of community willingness to take care of PLWHA; 88% of females and 90% of males say they would be willing to provide such care.

HBC relates well to the traditional African way of responding to both acute and chronic illnesses whereby a family member or neighbor—usually female—would move over to tend to the ill, sometimes for a protracted period of time. Such a person would then be responsible for seeing to the patient's feeding, personal hygiene, nursing care, and even spiritual care if needed.

The Tanzanian Ministry of Health guidelines (2005) list the following components as the minimum package of services for HBC programs:

- Access to counseling and testing;
- All elements of palliative care including pain management;
- Ensuring patients' medical adherence;
- Functional referral system;
- Psychological support;

[2] Ministry of Health Tanzania Mainland, National AIDS Control Program, HIV/AIDS/STI Surveillance Report, January–December 2004
[3] AIDS Policy Research Center, Country AIDS Policy Analysis Project, HIV/AIDS in Tanzania, July 2004
[4] Home-Based Care (HBC) services are provided in the home through outreach from a static medical facility. Community Home-Based care is similar, but the service provider is a community member trained in health care, rather than a professional based in a clinic.

- Nutrition guidance and food support;
- Participation of PLWHA in programs;
- Male involvement;
- Care of the primary care givers;
- Health care for children, orphans, and vulnerable children, including sick children;
- Record and reporting system; and
- Prevention interventions—Information, Education, and Communication (IEC), Prevention of Mother-to-Child Transmission (PMTCT), and access to condoms.

Pathfinder's CHBC Program

In December 2001, Pathfinder International, through private donations, initiated a three-year Community Home-Based Care (CHBC) program for PLWHA in Tanzania, named *Tutunzane*. *Tutunzane*, a Kiswahili word meaning, "let's take care of one another," was adopted to reflect the caring philosophy driving the project. The three-year CHBC project was implemented in partnership with local government departments and partners in a total of 16 urban wards, of which 9 are in Dar es Salaam and 7 are in Arusha. Today the project is in the second year of a five-year cooperative agreement with the United States Centers for Disease Control and Prevention. The project provides training to a core group of Community Health Workers (CHWs) who in turn train primary caregivers, usually family members, in basic nursing skills relevant to palliative care of HIV/AIDS. These Primary Care Providers (PCPs) receive information and training on how to provide basic nursing care, maintain a good standard of sanitation and personal hygiene, and prevent cross infection. They also receive information and training on how to assist PLWHA in taking care of themselves, including adherence to treatment and access to other reproductive health services such as family planning and PMTCT.

Cognizant of the importance of community support, the *Tutunzane* program invests in community mobilization activities to promote community awareness and knowledge about HIV/AIDS and its prevention. It also works to heighten the perception of HIV/AIDS as a community problem in need of community action. The *Tutunzane* program also bolsters community support for PLWHA and their families through collaboration with a wide range of community groups such as Faith Based Organizations (FBOs) and Community Based Organizations (CBOs) to meet the full spectrum of the needs of PLWHA, including material support, counseling, and emotional, spiritual, and legal aid.

The model also strengthens the links between various CBOs, FBOs, and health facilities through the establishment of a two-way referral system and expansion of Voluntary Counseling and Testing (VCT) services. To date, the *Tutunzane* project has reached more than 7,000 people.

Objectives and Methodology

The results of this study are expected to inform the scaling-up of Pathfinder's CHBC program. The mapping exercise was undertaken with the following specific objectives:

- Review available information to understand the magnitude of the problem, the number of PLWHA, and the extent to which their basic needs and those of their caregivers are being met in the five program regions;
- Identify potential partners on the basis of their comparative advantage for comprehensive HBC in Dar es Salaam and Arusha municipalities and in the new regions of Morogoro, Tanga, and Kilimanjaro;
- Identify existing resources for a two-way referral system and the capacity of existing service networks;
- Assess the effectiveness of community AIDS committees established by local government authorities in supporting CHBC programs; and
- Identify local organizations best positioned to holistically address the needs of PLWHA and their communities.

A team comprised of eight interviewers and two team leaders conducted field-level data collection. Interviewers were selected from a pool of experienced researchers, with backgrounds and skills in training, nursing, medicine, data collection and analysis, and social science. The team leaders reoriented the eight interviewers on research ethics, qualitative data collection methods, policies and other basics of HBC. Training was provided on the use of the interview guides, which were translated into Kiswahili and piloted in Dar es Salaam.

Data used in the mapping exercise is mostly qualitative and was collected through Focus Group Discussions (FGDs) and key informant interviews for a period of two weeks in November 2005. A total of 45 focus group discussions were conducted, including 13 with PLWHA, 17 with PCPs, and 15 with trained CHWs. Each group consisted of 8 to 12 people. Forty-three interviews were also conducted with key informants, including national and sub-national government leaders, members of district and sub-district Council Multisectoral AIDS Committees (CMACs), officials of NGOs, and staff from referral points for legal, spiritual, emotional, medical, nursing and material support for PLWHA. (See Annex 1 for a list of interviewees.) The table below shows the distribution of FGDs and in-depth interviews by region.

Table 1
Distribution of FGD and In-depth Interviews

Region	Districts	FGD Interviews	Key Informant Interviews	Total
Arusha	Arusha Municipality	6	4	19
	Arumeru District	7	2	
Dar es Salaam	Ilala District	4	3	28
	Kinondoni District	7	6	
	Temeke District	5	3	
Tanga	Tanga Municpality	3	8	11
Kilimanjaro	Moshi Municipality	4	3	15
	Moshi Rural District	4	4	
Morogoro	Morogoro Municipality	3	6	15
	Mvomero District	2	4	
Total		45	43	88

A trainer provides refresher-training to CHW supervisors

Pathfinder facilitated the recruitment of respondents through its established network in Arusha and Dar es Salaam. Where Pathfinder was not yet fully operational, as was the case in Morogoro and Tanga, Pathfinder collaborated with the Red Cross to make arrangements for the study team. Data collectors met with respondents who consented to be interviewed both verbally and by thumbprint. (See Annex 2 for consent forms.) Table 2 shows the sex and occupations of the FGD participants.

There were more females than males in the FGDs with PLWHA and CHWs. But there were more male than female PCPs. This is surprising since interviews with PLWHA indicate that most of the people who care for them are female. Data taken from FGD respondents revealed that about half of the female and one-quarter of male PLWHA are unemployed. It was expected that more females would be unemployed. Subsistence farming and business are the two main occupations of all respondents.

Information was recorded in cassettes on site and verbatim transcription was completed in the field. Transcripts were translated from Kiswahili into English in the office. The English transcripts were then read, analyzed, and presented per objective of the study.

Additional information was gathered through a literature review to supplement FGD and interview data. Resources included the National Policies and Guidelines on HBC, published by the Tanzanian Ministry of Health, the TIS Pathfinder project proposals, implementation reports and assessments, and evaluation reports. A complete list of documents reviewed appears in Annex 3.

Table 2
Sex and Occupation of Focus Group Discussion Participants

Current Occupation	PLWHA		PCPs		CHWs	
	Men (n=45)	Women (n=78)	Men (n=71)	Women (n=63)	Men (n=32)	Women (n=81)
Unemployed	24.4	48.7	8.5	34.9	0	6.2
Farmer (subsistence)	33.3	16.7	56.3	28.6	31.3	9.9
Business	35.6	26.9	26.8	20.6	43.8	46.9
Employed	6.7	7.7	8.5	15.9	25.0	37.0
Total	100	100	100	100	100	100

Facilitating Factors for the Study

A number of factors have facilitated the HBC mapping exercise. It was discovered during fieldwork that Tanzania Commission for HIV/AIDS (TACAIDS) had requested CMACs to develop an inventory of all organizations that work in HIV/AIDS in each

region. But not all councils and districts had done so and some were at very early stages of undertaking the inventory. For those who had completed an inventory, information on the name of the organization, contact address, when the organization was established, geographical coverage, number of members by sex, issues being addressed by the organization, main sources of funding, other resources or assets that the organization owns, and a summary of future plans was included. In the districts and CMACs that had this information, it was an important addition to the list of NGOs cited by the various informants.

The presence of the Pathfinder officer responsible for overseeing the recruitment of respondents during fieldwork allowed team members to focus on interviews and timely processing of transcripts. Also, incredibly open and willing stakeholders at all levels devoted time to share experiences and information with the study teams.

Limitations and challenges

Some organizations were only known by their acronyms and since time did not allow for visiting all organizations cited, some are only listed by name or with minimal detail. It is recommended that further details be gathered as follow-up to this study.

It was not possible to differentiate between "home-based care" and "home visits" in the study. While home visits are limited to going to greet the patient with minimal or no other service offered, HBC involves provision of actual services to the patient. It is quite possible that a number of the organizations that reported provision of HBC may only conduct home visits. In this case, the list presented in Annex 4 may overestimate the actual number of HBC provision organizations.

Findings

The findings are presented in two sections. Section one is findings from FGDs, separated by cross-cutting issues and specific findings by group. Section two contains the team's observations of cross-cutting issues of relevance.

Findings from Focus Group Discussions: Cross-Cutting Themes

Available information on the magnitude of the problem

Information on the areas most affected by HIV/AIDS was obtained from CMAC members, CHWs, and other key informants. The aim was to identify wards and villages that could be prioritized for CHBC interventions. The wards most affected and reasons believed to contribute to relatively high HIV prevalence are presented below, along with the HIV prevalence in each region (as reported in the 2005 TIS). From a regional perspective, Dar es Salaam and Kilimanjaro have higher HIV prevalence rates than Arusha, Tanga, and Morogoro which are below the national average of 7%.

Arusha Region (HIV prevalence = 5.3%)

District/Municipality	Areas Most Affected	Main reasons advanced
Arusha Municipality	Levolosi, Sombetini, Unga Limited and Kimandolu wards	High levels of interaction occasioned by high concentration of population
Arumeru District	Ngaramtoni, USA river, Maji ya Chai, Tengeru, Kikatiti, Mbuguni and Kisongo wards	High and mixed population concentration in townships along Nairobi-Dar es Salaam road, livestock markets, and mines

Dar es Salaam Region (HIV prevalence = 10.9%)

District/Municipality	Areas Most Affected	Main reasons advanced
Kinondoni District	Kinondoni Hanansif ,Kawe, KimaraTandale and Mwananyamala wards	Reported to harbor many commercial sex workers
Ilala District	Buguruni, Vingunguti and Kiwalani wards	Many lodging facilities and high population density. Also it is a main truck route to and from Dar and also it is the location of a big livestock market.
Temeke District	Ferry fishing area and Mgulani	Fishermen coming from different regions all along the coastal area and military for Mgulalni

Morogoro Region (HIV prevalence = 5.4%)

District/Municipality	Areas Most Affected	Main reasons advanced
Morogoro Urban	Chamwino, Kihonda, Mafinga, Mwembesongo, Mzinga and Kingolowira wards	Delay in implementing preventive measures; Traditional ngomas practicing accompanied with heavy drinking put many at risk of HIV infection
Mvomero District	Mtibwa, Tangeni and Mzumbe wards Mazimbu	High levels of interaction among densely populated sugar estates, military base and University

Kilimanjaro Region (HIV prevalence = 7.3%)

District/Municipality	Areas Most Affected	Main reasons advanced
Moshi Municipality	Kiboroloni, Longuo, Njoro, Korongoni, Pasua and Majengo wards	High population concentrations and unemployment
Moshi Rural District	Mwika North, Mwika South, Mamba North Mamba South, Marangu East, Makuyuni, Kahe, Mabogini, Arusha Chini (TPC) and Kindi wards	High levels of interaction occasioned by business activities and large population concentrations in commercial coffee and sugar plantations

Tanga Region (HIV prevalence = 5.7%)

District/Municipality	Areas Most Affected	Main reasons advanced
Tanga Municipality	Pongwe Kisosora-Nguvumali, Mabawa, Chumbageni, Chamwino Majengo and Amboni wards and Mabokweni	High and mobile population at the cement factory; Truck drivers using highway route to Mombasa

High levels of population interaction, unemployment, commercial sex, and alcohol use were blamed for high transmission of HIV.

Stigma

Stigma is prevalent, though there is a consensus especially among PLWHA in Arumeru-Arusha and in Tanga that it is much less than was the case a couple of years ago. Stigma often leads to marginalization, embarrassment, abuse, neglect, and violation of rights. Incidents of forced eviction of tenants, loss of employment, relatives pushing food to patients at an end of a long pole, and even schools refusing to register a child whose parents have died of AIDS are common occurrences. Sadly, stigma is even seen among health care professionals whom one would expect to have enough understanding of HIV/ AIDS to have overcome stigma. “As soon as the director found out that I am HIV positive he ordered that I should not be allowed to eat at the work canteen with other staff

members. In no time at all, my services were terminated," reported a female PLWHA. Where training of family caregivers has taken place, the PLWHA they care for have noted marked improvement in the treatment they receive.

Availability of Caregivers

The majority of PLWHA in FGDs reported having someone (e.g., family member, neighbor) to care for them, but close to a third had no caregivers. Table 3 below shows the breakdown by type of primary caregiver for the PLWHA that took part in the FGDs.

Table 3
Persons taking care of PLWHA

Primary care provider	Number	%
Self (no caregiver)	21	26.9
My children	10	12.8
Wife	9	11.5
Brother	7	8.9
Sister	6	7.7
Neighbor	5	6.4
Parents/mother	9	11.6
Others (in-law, husband)	11	14.1
Total	78	99.9*

*Note: Not all PLWHA responded

In all five areas (Arusha, Tanga, Kilimanjaro, Morogoro, and Dar es Salaam), there is a significant portion of people without anyone to attend to them—begging the question whether this phenomenon is seen more in groups of PLWHA, or whether the same is the case with people ill with other diseases. While a high level of willingness to care for PLWHA (88.6%) has been reported (TIS, 2005), care providers find it hard to manage caring for chronic illnesses and maintain a livelihood and other daily routines. There were reports of relatives and spouses giving up after long periods of nursing when the disease worsened. For fear of being stigmatized, some people preferred not to be visited until they were totally moribund and could not cope without help. This was reported mostly in Mvumero, and may be a result of comparatively fewer HIV/AIDS intervention efforts. A few of the patients had relocated far from their original places where they have families and therefore could only be cared for by neighbors, CHWs, and religious organizations.

CHWs that took part in FGDs also reported that, "There are some very desperate patients with no caregivers. They just look after themselves on their own. [They have] no place to sleep and no food. They are in a pitiful state." CHWs gave a number of reasons for the patients being left without a caregiver, including stigma, fear of infection, poverty on the part of the family and community, and fear of disclosure by the patient. The CHWs explained the fear of infection, as illustrated with the following quotes: "Because of the fear that people might still have, a patient may start off with a caregiver, but as time goes on, and as the condition of the patient worsens, they end up running away." "I, for one, had a lot of problems and misgivings when I started dealing directly with HIV/AIDS patients . . . giving education, mobilizing people is quite different from actually doing the work. It is a problem that makes people panic, and I did panic. I had to be counseled too!" Many CHWs noted a difference in attitude among caregivers and community members as a result of HBC educational efforts, as one describes: "Their relatives used to alienate them before we gave them training. After realizing that this disease is not infectious in the ordinary manner, they [the relatives] attend them very well."

Poverty was also mentioned as a reason for lack of caregivers, particularly as the patient's condition worsens. "You know we Tanzanians, most of us depend on manual activities to earn our daily lives, thus attending a patient for a long period of time deteriorates one's economy," said one. Another

explained, “Sometimes the patient may call her [the caregiver], but she is elsewhere, for instance, taking care of cattle, cooking, washing, or attending small children who are there, you see? Therefore it is very difficult to be with the patient for 24 hours beside her bed.”

Another CHW described the patient’s fear of disclosure saying, “There are some patients who refuse altogether that anyone other than the CHW should know about their health status. Even if you cajole them and ask them what might happen if they are completely bed-ridden, they still refuse to give in.”

Coverage of HIV Testing

As shown in the table below, data taken from FGD respondents revealed a high willingness to test for HIV, especially among the PCPs and CHWs. The majority of PLWHA that took part in FGDs, especially females, had already been tested, as had about a third of PCPs and half of CHWs. It is interesting to note that almost 20% of male PCPs were reluctant to test for HIV. This is consistent with anecdotal evidence from CHWs in Arusha that men are more reluctant to declare their sero-status.

HIV Testing

	PLWHA		PCPs		CHWs	
Wish to test for HIV?	Men (n=45)	Women (n=78)	Men (n=71)	Women (n=63)	Men (n=32)	Women (n=81)
Yes	13.3	5.6	42.3	65.5	40.6	40.7
No	2.2	2.8	19.7	7.3	0	8.6
Have Tested	84.4	91.7	38.0	27.3	59.4	49.4

Access to VCT was reported as “better than before” in almost all areas except in Mvumero, where the district relies only on the one factory health facility. Stigma and fear of HIV/AIDS is a hindrance for use of VCT services. Some health providers refuse to counsel and test older men who have opted to test. A sixty year-old participant reports to have been refused VCT by a health worker saying, “You are an old man. The test is for young people. You are now not interested in women.” Refusal to test older people reflects the health provider’s lack of knowledge about reported cases of older people with HIV/AIDS. The number of sexual abuse cases reported in the media as perpetrated by older men is adequate justification for not discouraging requests for VCT by older people.

Organizations Providing HIV/AIDS Services

A directory of partners working in HIV/AIDS in the regions visited has yet to be established. Among the challenges for developing an up-to-date directory is the sheer number of organizations that have resulted from a rapid proliferation of agencies. To fill this gap, TACAIDS established and funded Regional Facilitating Agencies to build the capacity of local NGOs in executing HIV/AIDS programs and to initiate a nationwide exercise of constructing an inventory of NGOs and CBOs working in HIV/AIDS. This activity was ongoing in Tanga and Kilimajaro. Morogoro had just started. For those who had completed an inventory, information on the name of the organization, contact address, when

the organization was established, geographical coverage, number of members by sex, issues being addressed by the organization, main sources of funding, other resources and assets that the organization owns, and a synthesis of future plans was included. In the districts and councils that had this information, it was an important addition to the list of NGOs cited by the various informants.

Information was also gathered from CHWs, PCPs, key informants, and to a lesser extent, PLWHA on the HIV/AIDS services provided in the five regions. The organizations identified as providing services, and the types of services provided, are listed in Annex 3.

Table 4 shows that apart from HBC, 35% of the organizations identified also provided HIV/AIDS informational services, income generating activities, and VCT. About one tenth offered food to PLWHA and their families. Few organizations provide Antiretrovirals (ARVs) or training on documenting last wishes and preparing wills.

Table 4
Services provided by organizations (all Districts/Municipalities)

Service provided	No.	%
Information, Education and Communication (IEC)	33	35.1
Income Generating Activities	21	22.3
Voluntary Counseling and Testing	16	17.0
Providing food	10	10.6
Train/prepare PLWHA to write wills	8	8.5
Others (ARVs, PMTCT)	6	6.5
Total	94	100.0

The IEC activities target communities, family members, and specific groups such as youth and older populations to address HIV/AIDS prevention and stigma reduction, attempt to instill a sense of societal responsibility for care and support of families affected by HIV/AIDS.

Of the organizations identified, 18% had a presence in more than one of the districts surveyed. Pathfinder, Walio Katika Mapambano ya AIDS (WAMATA) and Service Health Development and Education for People Living With HIV/AIDS (SHIDEPHA) were the only three that operated in four or more of the districts. Forty-seven percent of the listed organizations provide HBC. The remaining 53% of the organizations provided services that were supportive of HBC. Such services include VCT, material support, legal aid, health services, a few of which included antiretroviral therapy, research in traditional and herbal medicines, orphan and widow support, and income generating activities.

Organizations providing HBC are shown in Annex 2. There are 30 organizations that were identified in Arusha, 24 in Dar es Salaam, 22 in Morogoro, 35 in Kilimanjaro and 18 in Tanga.

Religious organizations provide significant support to PLWHA, way beyond the traditional spiritual support. This was noted particularly in Arusha and Kilimanjaro regions, where church-related women's groups conduct home visits, provide clothing, food, and support for schooling of orphans, as well as counseling, emotional, and spiritual support. The same was observed in Tanga where the Anglican Church and Mosque women's groups organize themselves to regularly provide HBC. One participant said, "When we cannot afford the fare to the hospital, and the situation worsens, we call the pastor. He usually helps."

The support systems for PLWHA preparing for death are very limited. Trained CHWs in Arusha and Tanga are able to counsel PLWHA and encourage them to document their wishes after death. The Tanzania Women Lawyers Association (TAWLA), Kilimanjaro Women's Group Against AIDS, SHIDEPHA, and Tanga AIDS Working Groups are among the few organizations with a system for assisting PLWHA to write wills. In some of the groups and communities, writing of wills is against cultural norms. "The best procedure is to leave the patient alone as far

An annual meeting of CHWs

as those matters are concerned. For one of the things that might make a patient despair or lose hope is to ask him or her to talk about his or her end of life issues. It is completely discouraging because deep down one knows that he or she is nearing one's end. It would be like adding fuel to a burning fire," said a Morogoro urban family caregiver of PLWHA. But increasingly, PLWHA are encouraged to document what they wish to happen after their death and are assisted in having these wishes legally recognized and respected by their communities. Referral for such legal services is an area that showed a major gap. Kilimanjaro has the highest number of organizations that provide legal and paralegal support for PLWHA to document wishes.

There often is no savings for burial expenses. Families expect the NGOs that support them during life will continue to do so thereafter. "If a patient is approaching death, I believe everything will come from Pathfinder . . . they have not committed themselves but we do hope they will not refuse when we ask them for burial support," said a Kisarawe II resident when asked about preparing for funeral.

It was not possible to identify which of the local organizations were most suited to holistically address the needs of the community. Instead, the study team is recommending criteria to be used for identifying such organizations.

Existing resources for a two way referral system and the capacity of existing service networks

Since it may not be feasible for a single organization to provide the whole range of services, establishing strategic partnerships and links with other NGOs, CBOs, FBOs, and governmental agencies is a prudent strategy so that agencies can refer cases for services that they are unable to provide. To ensure links are established, the *Tutunzane* project leadership routinely contacts health facilities and sensitizes health workers to the *Tutunzane* project.

Most NGOs, FBOs and CBOs refer PLWHAs to health facilities and other services as appropriate, including support group systems. This was mostly seen among the stronger NGOs in Tanga, Moshi, and Morogoro towns. The groups have their own transportation to take clients from their homes to health facilities.

Frequent episodes of illness are often managed at home by CHWs and PCPs. PCPs are trained to know when to refer cases. Clients are referred for health care, VCT, antiretroviral therapy, PMTCT, issues relating to housing, spiritual and legal services, support for Orphans and Vulnerable Children (OVC), and food. Faith leaders are called for spiritual support or volunteer their services even if not called. In some cases, if there is a doctor in the neighborhood, she or he will be called to treat the patient at home.

PLWHA supported by Pathfinder through the *Tutunzane* project and members of PLWHA support groups are referred by CHWs to health facilities using a referral note which has a detachable section for return referral. After treatment, or upon discharge, the return referral section is completed by the attending facility staff with information on prevailing diagnosis, treatment prescribed, and date of next appointment. CHWs trained by Pathfinder in Arusha and Dar es Salaam have established this system for referral and they estimate that on average, they receive the return referral section in about 75% of the cases they refer. Referral back is highest where CHWs escort their clients to health facilities, a practice more prevalent in Arusha and Tanga. Where a two-way referral system exists, it ensures prompt attention, registration, treatment, and admission fee waiver. Information on the return form is used to facilitate treatment compliance and prompting clients and family members to return on appointment dates. Except for communities where there was no HBC program, the description of the referral process reported by PLWHA respondents in FGDs is similar to that described by CHWs in their FGDs.

Patients have indicated that the referral note increases the likelihood that they will enjoy free health services. However, many must also show proof that they are HIV positive in order to access free services. Yet, in a few cases (in Arusha Municipality and Arumeru), regardless of a two-way referral system, some FBO health facilities are reported to charge an admission fee, X-ray, and laboratory investigation fees. PLWHA also noted that while they were usually able to access free services, their children could not. Therefore, most cannot afford to get their children adequate medical care.

When patients are referred to a hospital or clinic they are often escorted by CHWs or relatives, however, CHWs, PLWHA, and PCPs have all noted that a main constraint for referral to health facilities is lack of means of transportation and inability to afford transport costs. CHWs occasionally have to meet the cost of transporting their clients. One CHW said, “You may come across a seriously ill patient and bed ridden, and hiring a car from there is so expensive. The patient really suffers.” When referral is required, the patient often has to be transported on a bicycle, motorcycle, or car. Renting a bicycle was reported to cost between 1000-1500 Tanzanian shillings ($.53-$.79), a cost that some were not able to afford.

Another cost issue reported by many PLWHA was the unavailability of medicines at hospitals (with the exception of ARVs which seemed to be readily available). Medicines that are not available at the hospitals must be purchased at a high cost from pharmacies. One PLWHA said, “You might get a few [pills], when you come again, you find nothing. Sometimes, there is a certain amount of money you are given, if there isn't any money, you go and die alone! For example, I was prescribed some medicine, but I had no money. And it costs 15,000. When I came here they told me they are able to help me by a half and I pay the other half I told them that I have nothing. I'm not able to pay even a single cent. So they gave me that half.”

In some cases, patients refuse to carry out referrals for fear of stigma and of further burdening their families. Explained one CHW, "The problems we get are with the patients themselves. Some completely refuse to be taken to the health centers and hospitals for further management and treatment." Another described patient fears and the effect it has on seeking treatment: "If you just give the patient the special form and leave him or her to go on their own the patient has a lot of fears as to where they are going." "You know, even the patient knows that being admitted is rather expensive . . . it will cost the family concern," another CHW explained.

Another major challenge is ensuring patients receive effective services when referred. "Some time ago we had a lot of problems with the hospital. They used to not give satisfactory service to our patients, but now things are changing," explained one CHW. "We often escort them ourselves. If you make your physical appearance there, they receive you very fast and serve you very quickly," said another. "A patient can reach the hospital, stay there from morning to afternoon without being attended because the doctor may not be there, is on call somewhere else. So you cannot be attended by any other doctor. You find a patient may go two or three times, and eventually give up," said another CHW.

In addition, some PLWHA noted that they are given less preference if they are not paying for services. PCPs also said that some health facilities and staff are discriminatory in their service provision towards clients.

Results of Focus Group Discussions by Group:

Focus Group Discussions with People Living with HIV/AIDS

Three participants in the PLWHA discussion groups were not HIV positive. One was hypertensive, another was diabetic, and the third was having muscular and joint disabilities. Most of the PLWHA have undergone VCT (84.4% among men and 91.7% of women), thus chronic illnesses in the context of this report are assumed to be HIV/AIDS related.

There was not much difference between the responses of male and female FGD participants, therefore unless otherwise stated, the findings are presented as one group.

Elements of HBC:

During FGDs, PLWHA frequently mentioned that their CHWs provide the following services:

- Help with sanitization and prevention and treatment of bed sores and rashes;
- Educate caregivers on how to wear gloves and prevent their own infection;
- Often bring soap, gloves, and oil with them;
- Provide referrals to patients who need to go to the hospital or clinic and they often escort them there; and
- Provide counseling on nutrition and PMTCT.

Findings from FGDs showed inconsistency of condom provision and counseling on preventing further infection through sexual intercourse. Most PLWHA indicated that CHWs could not provide legal aid or provide referral for legal services. Few mentioned that they could be referred for spiritual

services but most said that if they needed spiritual counseling they would seek out a religious leader on their own. It should be noted that in some cases, primary service providers and CHWs were indistinguishable, but the services mentioned are assumed to be those provided by CHWs.

Involvement of PLWHA in HBC programs

Some of the healthier PLWHA in particular areas have had the opportunity to be trained as CHWs and are now providing services to other PLWHA. One such PLWHA explained: "We are trained that when we give home-based service we should cover our wounds, wear gloves, be careful in the use of sharp vessels. So this education is provided and we are careful when we provide the service to others."

However, most PLWHA indicated that they had not been involved in the planning and implementation of the project, and some added that they felt that while they had been asked for recommendations, there had been no change in the project.

Although both male and female PLWHA emphasized that they would receive better and more empathetic care if PLWHA were empowered to care for their own peers, it would have been interesting to see whether there was a difference in the quality and range of care provided by fellow PLWHA—all other factors being the same. This issue remains an operational research question of interest.

Major constraints identified by PLWHA

In most cases, PLWHA noted that a major gap in services was a lack of adequate food. PLWHA indicated that while ARVs were available, inadequate access to proper nutrition was preventing them from getting better. One PLWHA noted: "Nutrition is really affecting us . . . how do you take the ARV without food . . . so we implore the government, the donors to consider us." Many PLWHA felt that CHWs should be equipped with more resources to contribute to their patients when they come on visits, especially food. PLWHA also cited lack of transport to hospitals and clinics as a major challenge and in some cases they felt that CHWs did not visit frequently enough.

Other issues of concern mentioned by PLWHA included:

- Women being pressured to marry dead husband's relatives;
- High levels of stigma in some areas;
- Poverty;
- Men refusing to test for HIV, but still pressing for unprotected sex (despite being told that wife has tested positive for HIV);
- Lack of legal support;
- Medicines that are supposed to be provided free are often found to be unavailable in public health facilities. Clients then must purchase drugs from private pharmacies or do without if they cannot afford them;
- Lack of confidentiality among health staff (in three districts); and
- Lack of support for their children.

Recommendations made by PLWHA

PLWHA recommended that programs supporting HBC should train more PLWHA to care for their peers. They strongly felt that they are more empathetic towards each other and are more familiar with the issues and concerns. Secondly, in six of the FGDs PLWHA requested support to run income generating activities (for those whose health allows them), which will alleviate poverty and improve their quality of life. A third common recommendation was for the government to remove all health facility fees.

PLWHA felt that they should be more involved in the planning of programs that target them. They felt that programs would then be more relevant to the client's perspective and more focused on their concerns. PLWHA who benefited from HBC were highly appreciative of the care and emotional and material support they received. But over half of them felt that there were not enough CHWs to serve the quickly growing number of PLWHA.

Focus Group Discussions with Community Health Workers

Selection of CHWs

While the majority of the CHWs selected for the FGD were operating under the Pathfinder supported project, some had been trained and were working under other NGOs. Some of the CHWs were also PLWHA.

CHWs are selected by the communities with the general aim of maintaining a gender balance in each locality. Qualifying criteria for CHWs include literacy, permanent residency in the area, respect by the community, socially amicable, and cooperative.

The majority of the focus group respondents noted that they were not involved in the project until they received letters telling them they had been selected to be a CHW. Most agreed however, that they were involved in planning and evaluation of the project. According to one, "We are often asked of our opinion or suggestions when we meet in our meetings or seminars. So they receive our recommendations and work on them."

Training and responsibilities of CHWs

CHWs receive a three-week training on how to care for people with chronic illnesses, how to train family care providers to care for PLWHA, report back to the supporting NGO, and interact with and educate community members. Community meetings where CHWs discuss HIV/AIDS prevention, try to reduce stigma, advocate for community support for PLWHA, and raise awareness about HBC are held every six months. These meetings also offer opportunities for people to ask questions about HIV/AIDS to clear up misconceptions.

CHWs meet with their supervisors at least once a month to present and discuss some of the challenges of their day-to-day work, report on progress, and share experiences. In addition to the meetings, they prepare regular reports that their supervisors share with local authorities, district health offices, and Pathfinder.

CHWs who have received training in HBC typically describe their responsibilities as

- Counseling of their patients and family members;
- Conducting community meetings in collaboration with local leadership to listen to community problems and gather information on where HBC services are needed;

- Encouraging patients and family members to make use of legal services;
- Educating patients about good nutrition, encouraging and demonstrating gardening of vegetables and fruits on small plots of land to generate income;
- Linking patients with similar HBC programs when they move to other areas within the region;
- Preparing monthly reports on PLWHA progress and on activities;
- Identifying another CHW who would take over one's responsibilities when the local CHW is away;
- Occasionally helping distribute food items provided by various NGOs for their clients; and
- Referring clients as needed to supporting services.

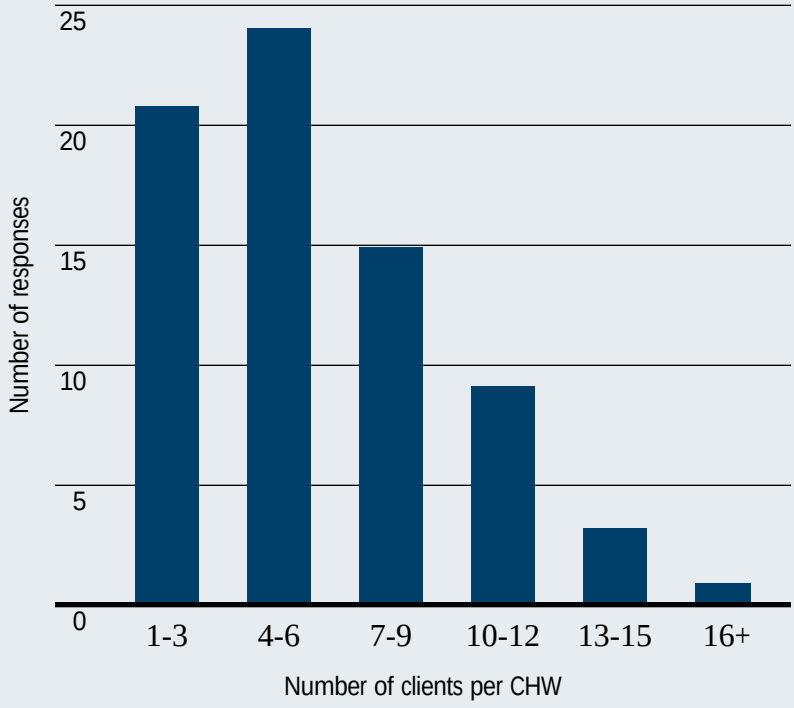
Recruitment of PLWHA

CHWs and local authorities are mainly responsible for the recruitment of PLWHA. At community meetings, CHWs are introduced and the concept of HBC for chronically ill people is presented and discussed. The opportunity is used to educate people on wider HIV/AIDS prevention matters including stigma and community responsibility to contribute to the support and care of PLWHA. Some of the meeting participants provide information on households where PLWHA can be found. CHWs and local leaders also conduct house visits and the CHWs routinely conduct house visits alone. At these visits CHWs give a more detailed explanation of their role and further explain the training of PCPs, the advantages for participating in the HBC program, and the expected roles of primary care providers and their patients. CHWs collaborate with their supervisors in the assignment of patients.

The highest number of clients per CHW was 21, six of whom were in the same house in Kinondoni, Dar es Salaam. However, the majority of CHWs had less than six clients to care for. According to CHWs, caring for more than the current level of clients would considerably increase the burden of work, probably compromise the quality of support and care they provide, and make it difficult for them to pursue their normal livelihood activities.

Factors influencing the frequency of visits to households included: health status of client, whether there was anyone to reliably care for the client, the total number of clients the CHW was serving, and distances from CHW residence to the clients' homes. Forty-three percent of CHWs visited each client once a week. Thirty-two percent of CHWs reported making two weekly visits. Daily visits are done if the client is very sick or does not have a reliable PCP.

Figure 1
Client Load per CHW



Two CHWs listen during a training session

Challenges faced by CHWs

CHWs listed a number of challenges in their day-to-day work. The major challenge reported among the CHWs was poor access to food by PLWHA. CHWs noted that caregivers and patients often expect the CHW to bring them money, food, or other items. "Custom requires that you cannot visit a needy person empty handed," one CHW explained. "If you go visiting a patient the first time empty handed, when you visit a second time, they hide the patient from you. So giving out these small items helps you become accepted in the family circle," another added. Many CHWs explained that the situation is compounded by the fact that communities think that the CHWs are getting paid and as such are able to pass on money to the patients. "To make things worse, the patients think that we are given some aid by these organizations. Due to that thinking, the patients [think] we have money," said another CHW.

The second most identified constraint was lack of means for transporting patients to referral health facilities. The majority of CHWs noted that patients often live far away, and the allowance they receive is very small. "For some patients, you have to board two buses each trip you make. Now the patient may have body sores which need cleaning. You cannot wait a whole week before you make another visit," said one CHW. "I would be able to visit more than three if I had means of transport that would enable me to get early to the patient without getting tired. Then I will be able to visit a large number of patients per day," another noted.

Lack of supplies was also cited as a major concern. "We were supplied gloves long ago, and they are finished," exclaimed one CHW. "You do not have even a single tablet to offer. When you are asked about it, you say you have none. We have no medicine, but some arrangement is being made to get some," another said.

In addition, the following concerns were raised:

- A number of people are sick but have no one reliable to care for them.
- The travel allowance of 7,000 Tanzanian shillings (US $3.70) a month provided by Pathfinder was too little.
- There is a general feeling among the public that HIV/AIDS programs have a lot of money. This leads to high expectations which, if not met, people think the money is being misused.

- There is inadequate access to HIV testing facilities, especially in the rural areas.
- Stigma continues to hamper community response to care and support and for PLWHA to openly claim their right for such service.
- Males do not adequately participate in HBC activities, females are therefore overburdened.

Recommendations made by CHWs

Recommendations included:

- Bicycles should be provided to CHWs to facilitate their access to patients.
- The allowance should be increased to at least 10,000 Tanzania shillings ($5.30).
- Regular distribution of medicines, gloves, and disinfectants must be ensured.
- Due to new developments related to ART, CHWs should receive refresher training so they are better able to serve clients on treatment.
- More effort should be put toward educating communities on risk factors and prevention of HIV/AIDS.
- Organizations working on HBC should include food for PLWHA as one of the services. In the event that they cannot, they should link with partner organizations that can do so. This recommendation was made with specific mention of Pathfinder linking with the United Nations World Food Program.
- Municipal councils and ward development committees should be more involved in HBC activities. They will then be more supportive and more likely to plan for and contribute towards HBC.
- More organizations should support PLWHA to establish and maintain income generating activities.

Focus Group Discussions with Primary Care Providers

Selection process

Identification of PCPs begins with community meetings initially conducted by local leaders to introduce CHWs and later conducted by the CHWs every six months. At these meetings participants are informed about HBC and are requested to participate in identification of households that have chronically ill persons. PLWHA present at the meetings also refer themselves to CHWs. Once the clients are identified, CHWs explain their role and the expected role of the PCP. CHWs then provide on-going coaching and mentoring of PCPs.

PCPs have listed their tasks as:

- Providing basic nursing care, assurance and comfort;
- Cleaning up the living quarters, bathing the PLWHA, cooking, and other household chores;

- Knowing when to refer cases, where to refer them, and sometimes escorting the patient to health facilities;
- Reporting on the status of the PLWHA to health workers and CHWs;
- Advising on preventing cross infections and actively control infection between patient and primary caregiver;
- Addressing stigma among other family members and community;
- Helping patients walk and exercise;
- Recognizing and managing minor ailments; and
- Encouraging PLWHA, with community involvement, to document their wishes after death.

How Primary Family Care Providers view CHWs

About a third of the PCPs have not yet had any training on how to care for PLWHA. Those who have benefited from training have, in general, a positive view of the CHWs they work with. They see them as helpful, caring, and a "shoulder to cry on" when the going gets rough. Some refer to them as reliable relatives. In addition to training of the caregivers, CHWs significantly reduce the burden of caring for the patients, provide medicine, counsel patients to go for VCT, sometimes bring food, and help pay for referral and funeral costs. "CHWs have lessened the burden for us, they are committed and come when you call them. Health facilities now accept us and we easily get treatment, unlike before," one female PCP noted. PCPs receive soap, gloves, petroleum jelly, skin oil, antiseptic supplies, torches, raincoats, and umbrellas (the items may vary depending on which organization the CHWs represent).

Responsibilities of primary care providers

Family members are trained to care for chronically ill persons, wash and care for patients' personal hygiene, provide emotional support, treat certain illnesses (e.g., fevers, sores, skin lesions, and abdominal pains), prevent bed sores and re-infection, and recognize symptoms that necessitate referral. They accompany patients to the health facility and advise on feeding—frequency, type of foods, composition and consistency, depending on the patient's health condition. For a few, training also consists of assisting the patient to document his or her wishes on disposal of assets and other relevant family issues and on providing the last service i.e., cleaning the body immediately after death and paying final respects. Participants valued the assistance received and the training, which has enabled them to undertake their tasks with more confidence, less fear of being infected, and with the knowledge that there is a backup in the form of CHWs.

Difficulties faced by primary care providers

Most PCPs mentioned that their primary challenge is shortage of food, both for PLWHA and their families, followed by lack of money for transport of patients who need referral. Other difficulties experienced were:

- An inadequate number of CHWs to cover the number of chronically ill people needing help—especially in Kisarawe II and Mvumero District in Morogoro,
- Lack of confidentiality among health facility staff,
- Lack of gloves and inadequate and irregular supply of medicines,
- Some people not wanting to reveal that they are HIV positive and some knowingly spreading HIV, and
- Lack of male involvement in caring for PLWHA.

Recommendations made by primary care providers

Many PCPs recommended that more PCPs should receive training. Some PCPs still needed training and others who had already received training recommended that other potential caregivers and family members in the households be trained.

Other recommendations made were:

- To scale up HBC and expand coverage to patients, more CHWs should be trained.
- NGOs supporting HBC should facilitate access to IGAs for PLWHA and PCPs.
- Payments for medicines and laboratory tests in the NGO and FBO facilities should be waived.
- Gloves should be supplied on a monthly basis.
- The cost of ARVs should be reduced. (Some clients are required to pay for ARVs. The study could not establish whether this was at public, NGO, or private sector facilities.)
- Government should discourage media reports on traditional healers who claim they can heal HIV/AIDS.
- Community education to address prevention and reduce stigma should be increased.

Consultations with CMAC members and Key Informants

Background

The Tanzania government established TACAIDS to facilitate an effective multisectoral HIV/AIDS response. To accelerate the process of reaching wards, villages, and households and mainstreaming HIV/AIDS into local development planning processes, Council Multisectoral AIDS Committees (CMACs) were established by the President's Office of Regional Administration and Local Government (PORALG) using local government bylaws 7 and 8 of 1982, and TACAIDS Act no 22 of 2001 part IV on AIDS committees, item 13 (1). CMACs were then assessed for their ability to coordinate a multisectoral HIV/AIDS response at the district and council levels. Findings resulted in the development of 10 training modules for building the capacity of the CMACs. A total of 116 CMACs received this training by mid-2004.

The mapping exercise sought information on the process of committee formation at different levels and the ability of committees to coordinate and monitor HBC activities for PLWHA.

Key informants

Most of the key informants were members or co-opted members of the CMACs. Other key informants were staff from select NGOs, National AIDS Control Program and TACAIDS. The report refers mostly to CMAC members, since they comprised a majority of the key informants.

Composition of the CMAC Members

Membership on the CMAC is comprised of the deputy mayor (chairperson), council director, one male and one female ward councilor; representatives of each of the major religions, one male and one female PLWHA, an influential community member and members of parliament. Co-opted members include the health HIV/AIDS coordinator and the multisectoral HIV/AIDS coordinator from the Department of Community Development.

CMACs have been established in all districts covered by the study. Ward and village level multisectoral HIV/AIDS committees were established only in Arusha Municipal and Kinondoni districts but neither has received training. There were no HIV/AIDS committees below the ward level.

Some CMACs have assumed responsibilities as per the directive from TACAIDS and PORLAG while others are reported to be "dormant" because of lack of funds.

The perception of CMAC by some district and council members is that these are "TACAIDS Committees" and therefore TACAIDS has the responsibility of providing necessary resources for the committees to function. "TACAIDS committed themselves to CMACs. It is the responsibility of TACAIDS to mobilize resources for CMACs. If funds are available to regional facilitating agencies, why not to the councils?," asks a CMAC Member in Arusha.

Under the multisectoral framework, coordination of district HIV/AIDS response moves from the portfolio of the District AIDS Control Coordinator (DACC) in the health department to the Council HIV/AIDS Control Coordinator (CHACC) in the Department of Community Development. This transition has been slow and sensitive, and a source of tension in some of the districts visited. Currently, coordination of CBHC activities is weak in all districts because of the limited human and financial resources at the district level and inadequate functioning of the CMACs in some districts.

Functions of Active CMACs

Members were requested to list committee functions. Tasks listed included:

- Coordinating all HIV/AIDS initiatives,
- Developing HIV/AIDS plans and strategies,
- Setting aside funds for implementing committee activities,
- Determining the extent of the problem of HIV/AIDS in the municipality,
- Ensuring that ward committees are established and functional,
- Receiving and discussing reports from implementing agencies,
- Following up on matters discussed in previous meetings,

- Ensuring that monies targeted for HIV/AIDS were judiciously used,
- Educating ward committee members on their expected responsibilities, and
- Encouraging people to go for VCT.

The above list also reflects the national vision of the role of CMACs.

Table 5
Functioning of District and Council Multisectoral AIDS Committees

District/Council	CMAC STATUS	
	Active	Dormant
Kinondoni District	✓	
Temeke District	✓	
Ilala District	✓	
Morogoro Urban	✓	
Mvomero District		✓
Tanga Municpality		✓
Moshi Urban		✓
Moshi Rural		✓
Arusha Urban		✓
Arumeru District		✓

Frequency of CMAC meetings

All meetings were initially held monthly, but it was observed that only a few committees (Tanga, Ilala, and Kinondoni) maintained this frequency. The other committees gradually reduced their frequency to three or four meetings a year. Ad hoc meetings are held when there is an urgent issue that requires committee attention. The Morogoro committee had not met for seven months prior to the study. The reasons given by CMAC members for not holding meetings more frequently were lack of resources for transport fare and for paying sitting allowances for attendees, not having an agenda to discuss, and unavailability of key committee members. The frequent absence of members of Parliament was a cause of frustration for most committees.

Resource mobilization by councils is seen as a challenge because of the decline in revenues in all councils, occasioned by the revision of income tax regulation, which abolished many taxes levied by local government authorities. One district AIDS control coordinator said, "Only the Finance and Planning Committee functions, others have stopped meeting for lack of funds. The financial situation is alarming, especially after the reduction of the sources of revenue to the council." It also appears that the costs of running a regular CMAC meeting can cost up to 1 million Tanzanian shillings (Tshs). Sitting allowances of members range between Tshs 5,000 for co-opted member to Tshs 50,000 for a full member.

The Dar es Salaam CMAC and district committees appeared most active, met most frequently, and had action plans that included HBC and youth income-generating activities. Ward committees were reportedly established in Arusha municipality and Kinondoni district.

Sample Agenda Items of CMAC meetings

It was not possible to review proceedings of committee meetings but members made reference to issues that have been discussed in their meetings. In an effort to see whether HBC was discussed in meetings, members were asked to name what they recall to have been agenda items for their previous meetings. The following list provides examples of the range of issues discussed by the committees that participated in the study:

- Risk factors leading to high transmission and strategies for addressing them; examples of the risk factors were opening hours of drinking places, high migrant population, and population density;
- Low knowledge of HIV/AIDS and unwillingness among the population to change risky behavior;

- Low access to antiretroviral treatment;
- Assistance to PLWHA, especially fare to hospitals, and loans to widows and guardians of orphans; and
- Schedule of visits to ward multisectoral AIDS committees where they have been established and urging establishment of committees where they have not been formed.

Challenges and constraints identified by key informants

According to most of the members, their biggest challenge was ensuring that there is adequate budget to implement committee activities. Other challenges included:

- Low level of community knowledge about HIV/AIDS;
- Slow or unwilling behavior change on the part of the population in reducing the spread of HIV;
- Stigma;
- High levels of poverty among PLWHA resulting in inability to pay for medicines, transportation for medical care, and food;
- Inadequacy of HBC (particularly in Mvumero); and
- Absenteeism among members at meetings, especially among members of parliament.

Membership of the CMAC was also a contentious issue and cited as a challenge in three regions. Sentiments were expressed that health sector membership such as those from the DACC should be awarded full membership not co-opted membership because their permanent presence is important for the maintenance of technical and medical input in the committee. Poor adherence to government guidelines on the formation of CMAC was another complaint. “Local Government issued some guidelines on membership of AIDS committees, which were ignored in some districts. You find people selecting their own children and relatives,” said a CMAC member.

Recommendations made by key informants

Key informants recommended increasing and strengthening HBC because they felt there are many PLWHA who have not yet been reached. Other recommendations made were:

- Remove members of Parliament from the committees because their attendance is so inconsistent,
- Community HIV/AIDS education should continue and be strengthened, and
- Provide soft loans with unrestricted conditions to PLWHA and families taking care of orphans.

Discussion

Positive lessons learned from HBC

The HBC program has had a number of positive outcomes as listed below.

CHWs have noted improvement in the quality of HBC services since the Pathfinder project began. Notable improvements include less fear of infection among family members and some PCPs have taken the initiative to coach their fellow community members on cross transmission, behavior change, and available referral sites. Stigma has also been somewhat reduced but is still prevalent. Though access to treatment is still not optimal, more people are declaring their status and seeking treatment since the initiation of antiretroviral therapy. Patients who were being turned away from health facilities unattended are now well received and are welcomed for examination and treatment.

Good rapport has been established between CHWs and the health facilities where they refer patients. Some clients commend the services they receive, and named CHWs who have been particularly empathetic and supportive. But a few have also cited examples of being ignored, abused, and made to feel even more hopeless by health facility providers.

There is better knowledge and understanding of HIV/AIDS among the PLWHAs and PCPs who have undergone training in HBC. When the disease takes a bad turn, they report having "fewer feelings of hopelessness."

PLWHAs live positively and with hope, in knowing that some of their concerns are taken care of by the CHWs. They get to know sources for medicine, food, ARVs, and in a few cases, have access to legal assistance and sources of help for schooling of the orphans they care for. "The burden that the family has to bear is somewhat less. The CHWs have very good training. Believe me—the services they offer make one feel so close to them, more than to a relative," said a PLWHA.

There has been a positive response to the establishment of council multisectoral AIDS committees at municipal, district, and in few cases ward levels. As often the case, leadership is an important factor in moving the HIV/AIDS agenda forward. The success of the committees that were described as good, useful, or active was often attributed to very active deputy mayors and the presence of members of Parliament at meetings.

Overall Challenges

Infection Prevention

Willingness and ability of the stakeholders to aptly deal with HIV/AIDS prevention, and prevention of re-infection, appears weak. In all study areas, the supply of gloves for PCPs and CHWs was inadequate and irregular. CHWs use gloves for demonstration when they visit clients, but often do not leave any behind for the clients to use. PCPs must improvise with plastic bags or resort to sharing gloves. In addition, issues of PMTCT are rarely addressed. As noted in the TIS, PMTCT knowledge is still low in Tanzania. In the study regions, with the exception of Dar es Salaam, PMTCT knowledge was less than 15%. The level of comprehensive HIV/AIDS knowledge is still modest, which might explain some of the risky behaviors exhibited by Tanzanians, such as women being pressured to marry widowers whose wives were known to have died of AIDS.

There is inadequate attention paid to other reproductive health needs of PLWHA. Some of the female PLWHA who are of reproductive age are not aware that they have options and rights to make reproductive decisions and choices, nor are they aware of implications of deciding to have children, and how to minimize risk of infection to their babies. For those who received counseling,

information was primarily related to pregnancy prevention, but not followed up with family planning services or a referral for family planning. While some of the NGOs did provide male condoms to their clients who are known to be HIV positive, the practice was not uniform among the agencies. Clients have the right to be informed about the risk of re-infection and of infecting others, and that both can be prevented. Information that would allow prudent decisions about reproduction is critical to be included as a service by all organizations.

Stigma

Some PLWHA complained of waiting up to six hours, especially if seeking services at the larger district regional hospitals. Some patients felt that they were being ignored at health facilities because they are known to be HIV positive.

Poverty

The general issue of poverty is perhaps the biggest challenge faced at all levels. Many CMACs are not functioning properly due to lack of funds. CHWs complain of inadequate allowances and supplies, and PCPs and PLWHAs constantly mention lack of food, money for transport, and fees for hospitals and medicines as major barriers to their care.

Specifically, one of the main challenges to establishing and maintaining a functional two-way referral system is lack of transportation and inability to afford transport costs. CHWs have reported that they often have to pay for their patients and themselves when they are escorting patients to the hospitals, and often their allowance does not cover these costs. PLWHA and PCPs also often mentioned that they are unable to pay for transport and are therefore unable to access services.

For those who are able to obtain transport to local hospitals, clinics, or other health facilities, they are sometimes burdened with further costs such as registration fees, fees for needed medicines that were not available at the hospital, and laboratory or x-ray fees.

A major constraint noted by most stakeholders, especially PLWHA, in all the areas visited, was lack of, or inadequate food. Subsistence farmers who had lives reliant on what they produce from their farms can no longer farm. They often do not have any reserves and have to rely on relatives and the few organizations that provide food. Hunger and lack of food has robbed PLWHA of the hope that ARVs brought. Methods of food distribution ranged from cafeteria-style cooked food ready to eat on specific days a week to periodic provision of dry food items like maize flour, oil, sugar, and lentils. There appears to be no network for ensuring equitable distribution to all who are needy. Food distribution to some was reported to be erratic, ranging from once a month to once every six months.

Finally, the poverty of PLWHA and the PCPs often compounds the poverty of their children. While PLWHA are generally able to access free medical services with proof of their HIV status, their children cannot. Lack of money for school uniforms and fees was also cited as a challenge by many PLWHA. The status of OVC and their current level of support should be explored further.

Gender

Most family caregivers are females. This has implications on the burden of work they face which likely translates into reduced opportunities for other gainful employment, and reduced time for schooling. Men are reported to distance themselves from caring for people with chronic illnesses. Even when both partners are ill, the female member is expected to take care of herself and the spouse.

Overall Recommendations

The following recommendations are made:

- More effort should be made to advocate for and support NGOs and CBOs to provide quality HBC.
- Before expansion of the Pathfinder CHBC project, capacities of potential partner NGOs, CBOs, and government agencies should be assessed.
- Simple methods of assisting with legal issues should be explored and implemented. This will reduce a number of contraventions on PLWHA rights in employment, ownership of assets, inheritance, housing and access to resources.
- Since most of the people who are eligible for HBC are poor, expenses including clinic and hospital admission and laboratory fees—no matter how minimal—should be waived.

Conclusion

PLWHA have needs other than the traditional medical and nursing care provided by the health care system. Meeting the psychological, spiritual, economic, nutritional, and legal needs of PLWHA remains one of the greatest challenges in Tanzania. Without adequate resources, the challenges for comprehensively meeting the needs of an ever-increasing number of PLWHA are enormous, especially for food security and health care referral. The study has shown that the need for HBC far exceeds the supply. Most of the organizations providing HBC tend to cover small geographical areas and offer a limited range of services. There is a clear need for forming coalitions to complement each other's efforts and improve access to the range of services provided as part of HBC.

In addition to prevention and treatment, CMACs have to address HBC issues as a matter of priority and plan and budget for HBC.

The study reinforces issues raised in previous studies, underscores the gaps that still exist in HBC, and confirms the importance of HBC. Existing services are appreciated by communities but there is a need for more HBC services than currently exist, hence the unanimous recommendation made by all FGDs and key informants for more services.

This study further recommends:

- Each ward should have a HBC strategy and plan. Pathfinder should facilitate and support the development of ward HBC strategies and plans in conjunction with national policies and guidelines in the districts where Pathfinder operates.
- More strategic networking and collaboration among the NGOs and CBOs providing HBC. This will facilitate the provision of a wider range of services, especially food support, OVC support, and transport for referrals.
- An increase in CHWs allowances should be explored due to reported inadequacy of funds for facilitating transport and maintaining supplies.
- Efforts around community mobilization should be continued and scaled up especially in selected areas of expansion where stigma is a major issue.

Annex 1: List of People Contacted

Ms. R. Tembele	TACAIDS - District Response Manager
Mr. Babu Lolepo	TACAIDS
Dr. G. Mpangile	Family Health International
Doctor (exact name unknown)	PASADA
Dr. Ny'anganyi M.	National AIDS Control Program
Ms. Mary Misokia	Pathfinder Field Manager - Arusha
Ms. Fatuma Msimbe	MOH/HBC Coordinator, Pathfinder Project Arusha
Dr. Solomon Ole Logilunore	DAC and CMAC member, Arusha Municipality
Ms. Vicky Moshi	CDO Arusha Municipality
Dr. A.S. Msuya	District Medical Officer - Arumeru
Dr. J. Babu	District AIDS Control Coordinator - Arumeru
Dr. Mbatia R.	Health Expert & Technical Adviser, RFA Tanga-Kilimanajaro
Dr. C. Mtamakaya	Municipal Officer for Health - Moshi
Mr. P.S. Shayo	CHACC Moshi Municipality
Dr. Ngomuo	District Medical Officer - Moshi Rural District
Mr. Stephene Mwatambi	District AIDS Coordinator - Moshi Rural
Ms. Nguluma	HBC Coordinator - Moshi Rural
Ms. Kaduma	Health Secretary - Moshi Rural District
Dr. Samuel Mtulu	Tanga Working Group
Dr. Pili Kindamba	DMO, Tanga Municipality
Mrs. Husna Rajab	DAC, Tanga
Mrs. Lucy	MAC, Tanga
Mr. Charles Ramadhan and Rehema	SHIDEPHA+ Tanga
Mr. Muna Jasson	Tanga Youth Alliance
Dr. G. J. B. Mtey	DMO Morogoro Municipality
Ms. Mary Nzowa	HBC - Morogoro
Mr. B. F. Moshi	DACC - Morogoro
Ms. Monica Lindi	CHACC Morogoro
WAVUMO Representatives	Mr. Mabura and Mama Ngao
Two Senior Counselors	Representatives of FARAJA Trust Fund
Dr. Nicholous Chiduo	DMO
Mr. Ramson Fue	DAC Mvumero
Mrs. Bahati Chogohe	MAC
Seleman Salum Mlima	Patron, Tuliani Youth Organization Against AIDS

Annex 2a: Key Informant Interview Consent Form

PATHFINDER INTERNATIONAL HOME BASED CARE MAPPING

Consent Form

Key Informant Interview

[Greetings]

My name is ……..

I am working for Pathfinder International in Tanzania, an international NGO working with the Government and other partners in providing home based care services to chronically ill people including people living with HIV/AIDS.

The home based care project in Tanzania started in Dar es Salaam and Arusha regions and has been found to be very successful. Pathfinder International and her partners are planning to expand the project to three new regions of Morogoro, Tanga and Kilimanjaro. As the first step towards the expansion Pathfinder is collecting information to assess the demand for services as well as compile an inventory of potential partners to network with for the provision of comprehensive home based care services in the new regions.

Our discussion today is estimated to take about 1 and a half to two hours. You will not be required to sign anywhere instead I am requesting your permission to record our discussion on a tape recorder including your verbal consent.

All information shall be treated in confidence as much as possible; your name will not be recorded in the cassette or in any records which one can use to know what you said. In addition all cassettes shall be destroyed once the research has been completed.

Your participation to the discussion is voluntary. There are no risks for refusing to participate. For example, Pathfinder will not deny you the right to home based care services to their clients should they refuse to participate in the discussions. You may be uncomfortable with some questions. In that event you are free not to answer specific questions or end the discussion.

Likewise, there are no direct benefits for accepting to participate in the discussions besides the potential benefit the research has on improving home based care services upon the use of the findings by Pathfinder International and other partners in the improvement of home based services to the community.

The National Institute has approved this research for Medical Research (NIMR), which ensures the rights of participants are not violated.

Should you have any question with regard to this research or your rights as a study participant you may write to any of the undersigned.

READING ENDS HERE

Questions about the Study or Rights of Participant

Mr. Nelson Keyonzo
Country Representative
Pathfinder Tanzania,
S.L.P 77991,
Dar es Salaam
Tel:022-2117088-9

Dr. A. Y. Kitua
National Institute for Medical Research (NIMR)
S.L.P 9653,
Dar es Salaam.
Tel: 0744-383142
Tel: 022-2130770

Ms. Caroline Mushi,
Project Manager,
Pathfinder Tanzania
S.L.P 77991,\
Dar es Salaam
Tel:022-2117088-9

Dr. Fatma Mrisho
Principal Investigator,
S.L.P 3131,
Dar es Salaam
Tel: 0744-877739

Annex 2b: Consent Form for FGDs

PATHFINDER INTERNATIONAL HOME BASED CARE MAPPING

Consent Form - Focused Group Discussion

[Greetings]

My name is ……..

We are working for Pathfinder International in Tanzania, an International NGO working with the Government and other partners in providing home based care services to chronically ill people including people living with HIV/AIDS.

The home based care project in Tanzania started in Dar es Salaam and Arusha regions has been found to be very successful. Pathfinder International and her partners are planning to expand the project to three new regions of Morogoro, Tanga and Kilimanjaro. As the first step towards the expansion Pathfinder is collecting information to assess the demand for services as well as compile an inventory of potential partners to network with for the provision of comprehensive home based care services in the new regions.

Our discussion today is estimated to take about 1 and a half to two hours. You will not be required to sign anywhere instead we are requesting your permission to record our discussion on a tape recorder including your verbal consent.

We will treat all information in confidence as much as much as possible. Your name shall not be recorded in the cassette or in any records which can be used to link responses to participants. The final analysis shall focus on what was said in general on different topics and not what was said by individuals. In addition all cassettes shall be destroyed once the research has been completed.

Although we will treat all information in confidence, other participants in the discussion shall hear your contribution and they can tell others what you said. We shall request all participants in the discussion not to tell others what they hear from the discussion.

Your participation to the discussion is voluntary. There are no risks for not participating. For example, Pathfinder shall not deny you the right to home based care services should you refuse to participate in the discussions. You may be uncomfortable with some questions. In that event you are also free not to answer specific questions or end the discussion.

Likewise, there are no direct benefits for accepting to participate in the discussions besides one piece of insect treated net (ITN) which will be given to you to thank you for participation and refund of travel expenses if you incurred any expenses. The real benefit of this study lies in its potential impact on community home based services upon the use of findings by Pathfinder International and other partners to that effect.

The National Institute has approved this research for Medical Research (NIMR) which ensures the rights of participants are not violated.

Should you have any question with regard to this research or your rights as a study participant you may write to any of the undersigned.

READING ENDS HERE

Questions about the Study or Rights of Participant

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S.L.P 77991,\
Dar es Salaam
Tel:022-2117088-9

Dr. Fatma Mrisho
Principal Investigator,
S.L.P 3131,
Dar es Salaam
Tel: 0744-877739

Annex 3: List of Reviewed Documents

1. Marie Coughlan FHI, IMPACT, CDC, USAID, Rapid Appraisal of Palliative Care and Community and Home Based Care in Abidjan, Cote D' Ivoire, Summary Report
2. Family Health International, IMPACT; Overview of Community Home-Based Care Services for People Living with HIV/AIDS and Other Chronic Illnesses in Tanzania, Prepared for USAID Tanzania, 2002.
3. FHI, IMPACT, CDC, USAID (2005) Rapid Appraisal of Palliative Care and Community Home Based Care in Abidjan, Cote D'Ivoire
4. Ellen Israel & Georgianna Platt, Pathfinder International & COPHIA Kenya (Oct 2003) Trip Report and Mid-Term Review of Community Home-Based Care Project Tanzania.
5. Ministry of Health /NACP (February 2005) Guidelines for Home Based Care,
6. Ministry of Health/NACP (August 2005) Revised Course Plan for Training of Home Based Care Providers,
7. Ministry of Health/NACP (August 2005) Trainers Guide for Home Based Care Providers,
8. Ministry of Health/NACP (April 2005) National Guidelines for the Clinical Management of HIV and AIDS
9. Osborne, C. M, Eric van Praag, Helen Jackson (1997) Models of care for patients with HIV/AIDS. Rapid Science Publishers. AIDS (suppl)B: 5135-5141
10. PASADA (2003) Pastoral activities and services for people with AIDS, Dar es Salaam Archdiocese, Annual Report.
11. Pathfinder International (Dec 2003) "PATHFINDER" Home-Based Care Program for people living with HIV/AIDS in Tanzania, Program Summary Report
12. Pathfinder International (Dec 2003) Home-Based Care for people living with HIV/AIDS Program in Tanzania, Annual Report Year 3
13. Daniel E. Pellegrom, John J. Dumm, Beverly Armstrong, Pathfinder International & Interchurch Medical Assistance (July 2004) Scale-up of Community Home Based Care activities for people living with HIV/AIDS in the United Republic of Tanzania (PA 04208),
14. Pathfinder International, Dar es Salaam City Council/Municipal Council (2003) CCBRT Home-Based Care Service in Dar es Salaam City, Quarterly Reports. June
15. Pathfinder International, Introduction to Home Based Care (HBC), Trainer's Guide for HBC Provider
16. Prime Minister's Office (2003) National Multisectoral Strategic Framework on HIV and AIDS
17. Prime Minister's Office (2001) National Policy on HIV and AIDS
18. TACAIDS, NBS and ORC Macro (2005) Tanzania AIDS Indicator Survey 2003-04

Annex 4: List of NGOs, FBOs, CBOs and Local Government Working in HIV/AIDS

Arusha

District	Name of NGO or CBO	Areas of Operation	HBC Related Activities
Arusha Municipality	ALHPA	An NGO of PLWHA	HBC
	TUMAINI	Levolosi, Lemara, Kaloleni and Kikatiti wards	HBC, medical services including ARVs,
	Catholic Archdiocese		Periodic supplies of food, clothes and facilitate patient referral, home visits
	Global services		HBC, food, trains CHWs
	Heifer International	Arusha, Manyara	Provide high milk yield goats to PLWHA as an IGA and for nutrition support among PLWHA
	KALOLENI		VCT
	LIVE CONCERN		
	Marie Stopes		PMTCT, Reproductive Health
	SDA		HBC, Training of CHWs, IEC and medical services
	St Lucia	Buli Ward	Operates a nursing home, food supplies; Supports orphans and abandoned people
	THE NEED HOSPICE		HBC
	Pathfinder		HBC, provision of gloves, soap, vaseline, and bleach. Training for service providers, NGOs, FBOs and CBOs; strengthening two-way referral systems and peer support groups. Promoting behavior change to limit infection and re-infection and strengthening multisectoral AIDS committees at District and Ward levels
	Uhai Center	Ngaramtoni, Usa River	Mobile VCT, ARV at St Elizabeth, Food Support and micro-credit to PLWHA
	Uzima		Counseling Services
	WAMATA	4 villages	Provide VCT at the office, Nursing care services in 4 villages, Run a peer education program
	WANALE		
	WIA	Ngaramtoni Sokoni and Sambazini	Food for PLWHA, NGOs and CBOs. Trains for care of widows and orphans, provides soft loans for IGA
Arumeru District	ANGAZA	Arumeru town	VCT, IEC targeting especially youth
	TUMAINI	Usa River, Ngaramtoni, Kisongo, Mbuyuni, Ngarenanyuki and Tengeru	HBC, Counseling, food, medical and supports orphans
	Marie Stopes	Established clinic at Usa river	VCT and limited HBC services, PMTCT and RH
	Nkoaranga Lutheran Hospital	Whole district	VCT services, PMTCT and nursing care to PLWHA. Content of HBC not known
	Selian ELCT hospital	Based in Ngaramtoni	VCT, ARV, PMTCT, Nutritional counseling
	UCHA		
	Uhai Center	Tengeru, Maji ya Chai	HBC, Trains family care-givers, provides medical and nursing care, food supplies and supports IGAs,
	UPENDO		HBC
	VET AID	Ngaramtoni	Support IGAs in animal husbandry for PLWHA and CBOs
	WAMATA	Tengeru	HBC, counseling, legal assistance, referral, orphan support
	WIA	Ngaramtoni, Sokoni and Sombetini wards	HBC, Supports Small scale IGAs Supports widows and orphans
	World Vision Tanzania	Kingpri and Moshono	HBC, and an HIV component focusing on prevention among youth

Dar es Salaam

District	Name of NGO or CBO	Areas of Operation	HBC Related Activities
Kinondoni District	ANGAZA	Kinondoni Center	VCT, IEC targeting especially youth
	CMV		
	JUHUDI		Nutritional counseling and sanitary supplies for PLWHA
	KIMODA		
	PASADA	Whole District	HBC, trains family care givers, provides legal support – training in preparing wills, medical and nursing care including ARVs and TB treatment
	TUMAINI		HBC, counseling, food, medical and supports orphans
	WAMATA	District wide	HBC, counseling, legal assistance, referral, orphan support
Ilala District	AMREF/ANGAZA	Sites in District	VCT, IEC targeting especially youth
	AXIOS Foundation		ARV and treatment of opportunistic infections
	CCBRT	Cover 18 out of 22 wards	HBC, trains family caregivers, provides food, clothes and medical/nursing care
	Msimbazi Centre	Ilala Wards	
	PAELA		
	PASADA	District wide	HBC, trains family care givers, provides legal support – training in preparing wills, medical and nursing care including ARVs and TB treatment
	SHIDEPHA+	District wide	HBC, VCT, IEC, Reducing stigma at work place
	Pathfinder	Gerezani, Kariakoo and Jangwani	HBC, provision of gloves, soap, Vaseline for skin care, and bleach. Capacity building for service providers, NGOs, FBOs and CBOs Establishing/strengthening a two-way referral system and peer support groups. Promoting behavior change to limit infection and re-infection and strengthening multisectoral AIDS committees at district and ward levels
	WAMATA	District wide	HBC, counseling, legal assistance, referral, orphan support
Temeke District	ANGAZA	Sites within District	VCT services
	CCBRT	Whole district	HBC and Legal Aid Services
	CSPD	Kisarawe II	Medical and nursing services, Including VCT services and referrals
	KIWOHEDE		HBC
	PASADA	Whole district	HBC, trains family care givers, provides legal support – training in preparing wills, medical and nursing care including ARVs and TB treatment
	SHIDEPHA+	District wide	HBC, VCT, IEC, reducing stigma at work place
	Pathfinder	Kisarawe II and Kibada	HBC, provision of gloves, soap, Vaseline for skin care, and bleach. Capacity building for service providers, NGOs, FBOs and CBOs; Establishing/strengthening a two-way referral system and peer support groups. Promoting behavior change to limit infection and re-infection and strengthening multisectoral AIDS committees at district and ward levels
	UMATI	Sumangila, Sandali and Chang'ombe wards	VCT, FP, gynecological cancer screening, IEC

Morogoro Region

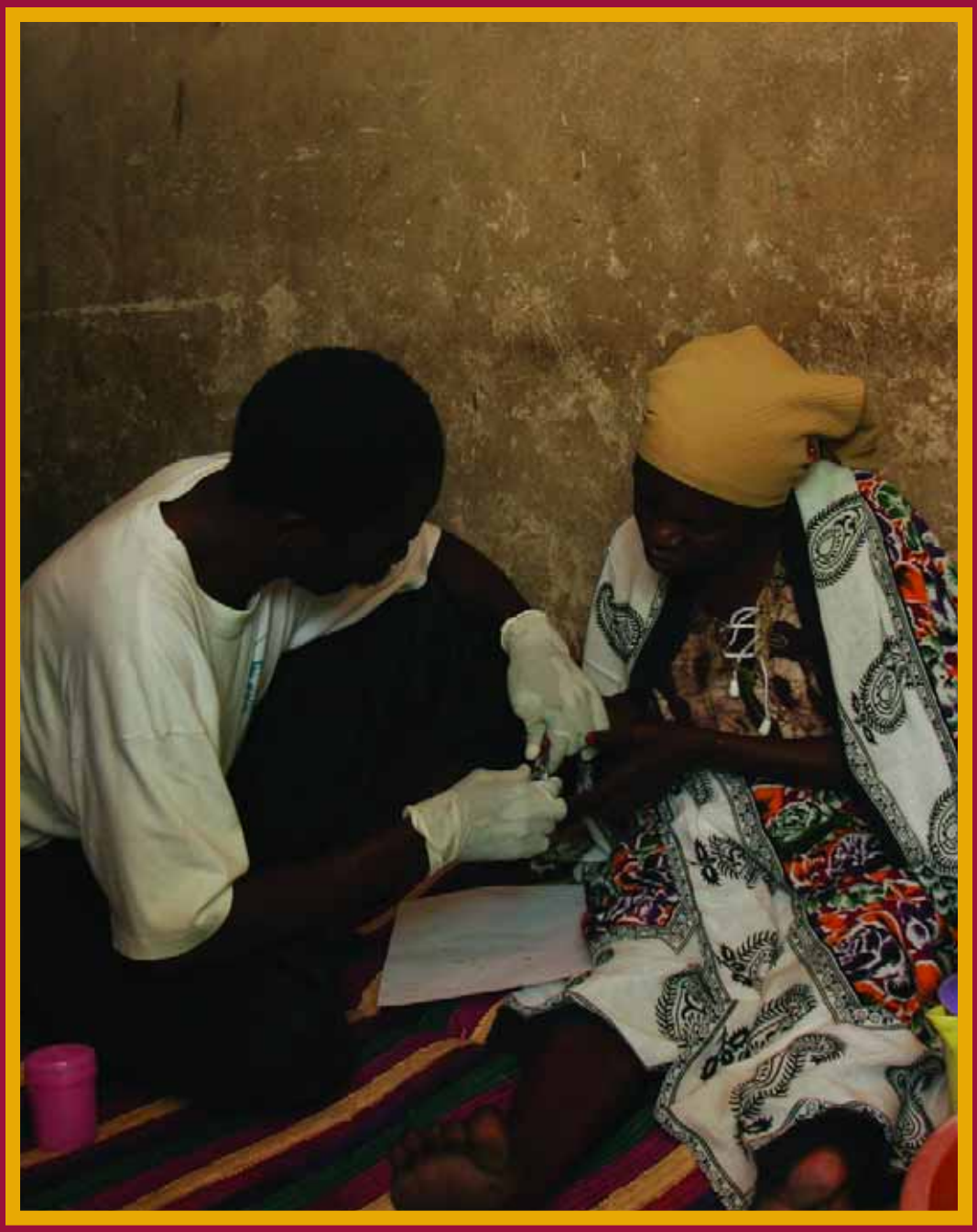
District	Name of NGO or CBO	Areas of Operation	HBC Related Activities
Morogoro Urban	ANGAZA	Whole district	Training Ward multisectoral AIDS committees, VCT services and IEC targeting youth
	FARAJA TRUST FUND		Training of CHW for HBC, community-based counseling, VCT, training family care providers; traditional therapy, food supplies for PLWHA, IGA and loans, legal assistance
	GALILAYA		
	GOOD LIFE		
	Kiwanja Cha Ndege Mission		HBC, training of CHW for HBC
	NEEMA Resource Foundation (NEREFO)	Morogoro Municipal, Mazimbu	HBC, Community IEC with emphasis on youth. VCT. Supporting schooling for orphans
	Red Cross Society		Planning to start HBC program in 2006
	RESOURCE FOUNDATION		
	SHIDEPHA+	Municipality	HBC, training of CHW for HBC; Loans for PLWHA; schooling for orphans; IGA for youths
	Solidarity Women Group	Boma, Kiwanjandege, Kingulwira, Sangasanga	HBC targeting pastoral communities, IEC
	TAWLA		Legal support
	Union Of Non-Governmental Organizations (UNGO)		HBC, IEC in schools and university; Coordinates member organization activities; small scale entrepreneurial activities and IEC
	Wanaoishi Na Virusi Vya Ukimwi Morogoro (WAVUMO)	Morogoro municipality Kilosa, Kilombero and Mvumero Districts	HBC, counseling, community IEC, VCT, medical, legal and IGA support to PLWHA
	YOUTH CONCERN		Nursing care and referral for medical services
	Youth Empowerment And Sustainable Development Foundation (YES)	Bigwa village, Misongeni, Mtaa wa Upendo	HIV and AIDS public education targeting youth and sensitising HBC family caregivers against stigma
Mvomero District	HURUMA		HBC
	KKKT Church		Food support to widows and orphans
	Okoa Maisha Tangeni	Mzinga, Tangeni and Mzumbe Wards	Nursing care and IEC
	SHIDEPHA+	Whole district	HBC, VCT, IEC, reducing stigma at work place
	Turiani Youth Group	Mtibwa ward	Peer counseling, educate; Using traditional drama
	UNET	Mtibwa ward	Support orphans with uniforms and food supplies
	Wanaoishi Na Virusi Vya Ukimwi Morogoro (WAVUMO)	Mvumero District	HBC, counseling, community IEC, VCT, medical, legal and IGA support to PLWHA
	Turiani Youth Organization Against AIDS		IEC, home visits

Kilimanjaro Region

District	Name of NGO or CBO	Areas of Operation	HBC Related Activities
Moshi Municipality	ANGAZA		Training Ward multisectoral AIDS committees, VCT services and IEC targeting youth
	Catholic Community Groups (Jumuiya)		Spiritual support
	Diocese of Moshi Rainbow Centre		VCT, Spiritual counseling, material Supplies and IGAs
	Enviro Care		Legal aid
	KIKOSETI		Material support, nursing care
	Kilimanajaro Community Trust Fund	Longuo ward	IEC and support to PLWHA and Orphans
	KIWAKUKI	Whole region	Legal aid, Nursing care and IGA, medicines and orphan school support
	KINSHAI	Whole district	Legal aid, VCT and IGA
	KOWEKU		Legal aid
	Matumaini		HBC
	MAU	Dhobi and Njoro ward	Orphan and PLWHA support and condom promotion
	PROCOSEP	Whole district	IEC, IGA and condom promotion
	YMCA	Whole region	VCT, Nursing care, Orphan support
Moshi Rural District	ANGAZA		Training Ward multisectoral AIDS committees, VCT services and IEC targeting youth
	Amani Group	Mshiri Ward-Marangu East	IGAs to support PLWHA
	BATAMU	Kibosho West	Fight discrimination, IGAs and orphan support
	Catholic Community Groups (Jumuiya)		Spiritual support
	CHAWAVUMA	Kindi ward	Nutritional counseling and IEC
	HOFMI	Mwika and Mamba wards	Counseling, IEC and IGA
	Huruma Women Group	Old Moshi West	IGAs and fighting stigma
	KIKUKUKM	Mshiri ward, Marangu East	IGAs and food support
	KIKOSETI		Material support, nursing care
	KINSHAI	Whole district	Legal aid, VCT and IGA
	KKT Usharika wa Kirimeni	Mwika and Rombo	Nursing care, IGAs for PLWHA, And Support to Orphans
	KIUVIMWI	Whole district	IEC, IGA and orphan support
	KIWAKUKI	Moshi Rural –East and West	Legal aid, Nursing care and IGA
	KIWAKI	Kirima ward	Nursing care and IGAs for PLWHA
	KUKUWA	Masia Ward-Marangu East	Nursing care and support to PLWHA
	KUNMASIA	Masia Ward-Marangu East	IGA to supports orphans and widows
	MAYEFIA	Masia Ward-Marangu East	Food support to orphans and widows
	SAKUVI	Old Moshi West	IEC, Counseling, and medicines for PLWHA
	Tanzania 4H Organization	Whole district	IEC and IGA
	Umoja wa Mapambano Dhidi ya UKIMWI	Marangu East	Counseling, IEC and nutritional counseling for PLWHA
	Upendo Group	Masia Ward-Marangu East	Supports Orphans and PHLAs
	White Orange Youth	Whole district	IEC and IGA

Tanga Region

District	Name of NGO or CBO	Areas of Operation	HBC Related Activities
Tanga Municipality	AFRIWHITE		Orphan schooling support
	ANGAZA	Whole district	Training Ward multisectoral AIDS committees, VCT services and IEC targeting mainly youth
	Anglican Church of Tanzania	Whole district	Nursing, medical care and Material support
	Comfort Women Relief Foundation	Tanga Municipality	HBC, IEC and Nutrition education
	Faraja Trust Fund		Nursing, medical care and Material support
	Old Nguvumali Women	Nguvumali Mabokweni and Mzizima Wards	HBC, IECC for VCT, Nutrition for PLWHA and OVCs. Also targets youth
	SHIDEPHA+	Whole district	Medical, nursing, food supplies. And referrals for ARVs at Regional Hospital
	TANGA AIDS WORKING GROUP	Tanga Municipality, Handeni, Korogwe, Lushoto, Muheza and Pangani Districts	HBC, Medicines, Traditional remedies, referral for ARVs, VCT, food and feeding and legal assistance, PMTCT
	Tanga Elderly Women Resources Center (TEWOREC)	Maramba, Mhindoro, Gombero Wards	HBC, research on effect of HIV and AIDS on the elderly. IEC targeting older people Legal issues on widow inheritance, divorce and marriage
	TAWLA	Whole district	Legal aid
	Tanga Together Trust (TTT)	Nguvumali, Pongwe, Mabawa, Tanga Sisis, Tongoni, Marungu	HBC, IEC, assisting orphans and supporting small scale IGA
	Tanga Youth Aids Environmental Conservation Association	Chumbageni	Training on HIV policy to youth groups; Forestry and environmental education
	TAYODEA		
	Tanga Youth Survival Group (TYSG)	Tanga Municipality	HIV Inter-education using theatre; Training and support on IGA
	TUMAINI Working Group	Tangasisi Ward, Neema Village	IGAs for youth, Training on rights targeting women and Education for AIDS orphans
	UMAKI (linked to Anglican church)	Nguvumali and Chumbageni	Nursing care, food support And spiritual services
	UMATI	Tanga, Handeni and Korogwe Districts	Community IEC, VCT and Family Planning
	Upendo Medical Youth Center	All villages in Pongwe, Maweni, Marungu and Tongoni Wards	HBC, IEC targeting youth,Referral for VCT and male condom distribution



A CHW attends to a client

Pathfinder International/Tanzania
Chato Street, Plot No. 260
Off New Bagamoyo Road, Regent Estate
Dar es Salaam, Tanzania
Tel: 255-22-2700726 OR 255-22-2700729

Pathfinder International/Headquarters
9 Galen Street, Suite 217
Watertown, MA 02472
USA
Tel: 617-924-7200

www.pathfind.org

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