

Implementing the Continuum of Care for HIV: Lessons Learned from Tanzania

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THE INCREASING AVAILABILITY OF antiretroviral therapy (ART) in sub-Saharan Africa has brought with it the possibility of better health and longevity. But people living with HIV continue to require a broad array of services ranging from psychosocial and medical care to nutritional and legal support.¹ As HIV infection progresses to illness and advanced-stage disease, the patient's psychological, social, nutritional, clinical, and nursing care needs also change in nature and intensity. These needs are determined by biological factors (e.g., age, gender, and nutritional status), social factors (e.g., living environment and poverty level), and health system factors (e.g., distance to a facility and quality of services), and consequently care and support programs were developed in response to these various and changing needs. While life expectancy has improved tremendously with the provision of ART, improved care and support can further enhance a patient's quality of life and well-being. The early experiences of those receiving long-term ART in sub-Saharan Africa show that medical, psychosocial, and nutritional needs persist during treatment and, if properly met, can help improve patient adherence to ART.²

HIV/AIDS-specific interventions and responses cannot operate in isolation; they must be integrated into a broader network of care and support programs within health facilities, communities, workplaces, and households. Now that HIV has become a chronic, manageable disease, proper treatment requires the patient's continual engagement with various parts of the health-care and social-support system. It is therefore necessary that the provision of HIV care be comprehensive in nature and provided along a continuum across homes, communities, and care facilities.

In the late 1980s, local nongovernmental organizations (NGOs) in Uganda, Zambia, and Thailand pioneered a comprehensive approach to HIV/AIDS care and support delivered across a continuum from hospitals to communities.^{3,4} These early continuum-of-care (COC) initiatives were informed by lessons learned from experiences and qualitative studies pointing to the comprehensive needs of people living with HIV and by the fact that most of the care for chronic illnesses in resource-limited settings is being provided in the home.⁵⁻⁷

In response to these findings and the rapid expansion of home-care initiatives, global public-health

institutions such as the World Health Organization (WHO), the Joint United Nations Program on HIV/AIDS (UNAIDS), and international NGOs developed norms and standards in the early 1990s for a comprehensive care approach. These were then adapted into national guidelines in several countries by national AIDS programs within ministries of health.⁸ Soon thereafter, additional norms and standards were adopted for the safe and effective use of ART in resource-limited settings that follow public-health approaches at the hospital and community level.⁹⁻¹¹ Many health authorities at the local level, together with public and not-for-profit health facilities and community programs, are strategizing and implementing comprehensive care activities across a continuum, including the provision of and adherence to lifelong ART.¹²

HEALTH-CARE REFORM AND DECENTRALIZATION

As early responses to the HIV pandemic were being developed in the most affected countries, ministries of health in these countries wanted to shift responsibility for planning and executing HIV care activities away from the central, national level to the district and community level. To accomplish this, a peripheral public administrative unit, called the *district* in anglophone Africa, *cercle* in francophone Africa, or *thana* in Southeast Asia, was created to lead the planning and implementing of HIV care activities for each respective district or community.

By holding district and local health authorities accountable for administering care activities, the governments encouraged collaboration among the relevant providers within the local medical and social sectors. This would mean, for example, that private and not-for-profit facilities, such as NGO and mission hospitals, would work together to:

- share and inform;
- develop action plans and relevant HIV care packages at both the facility and community care level;
- develop district budgets; and
- design functional mechanisms for referring patients between community care programs, home care, and facility-based clinical care.

Working in partnership is particularly important for clinical HIV care providers, as it offers opportunities to standardize essential HIV care packages with the aim of rapidly reaching more people in need while acknowledging individual patient care needs. Cost-recovery modalities are another reform put into practice throughout sub-Saharan Africa, with provisions that exempt some groups from contributing, such as TB and HIV patients, pregnant mothers, and children under five years of age. Through these modalities, patient contributions from general outpatient and inpatient care can be invested at the local level to directly improve patient care for all. However, it is too early to determine whether such health-care reform activities have improved the overall quality of care in general and HIV care in particular. With the concurrent trend toward privatization of health-care delivery, it continues to be difficult to ensure affordable access for the most economically disadvantaged individuals.¹³

In response to concerns about affordability, observational studies began to explore the impact of HIV/AIDS at the household level. A study in Uganda found that it was unrealistic, even at a relatively early stage of the epidemic, to expect extended families to provide the full range of necessary care services to people living with HIV. It was also discovered that extended families in rural and highly affected areas were unable to provide assistance and that many were in fact unwilling to do so.¹⁴

Further research revealed the following:

It is evident that the relatives and friends are valuable resources in times of need. Research has, however, questioned the notion that the extended family is a resource to be relied upon at all times, and has suggested that families may not be able to deal with AIDS as they have with other health problems . . . We must therefore question whether the traditional reliance on extended kin systems will address the needs of HIV/AIDS patients and their informal carers.¹⁵

The authors of this study concluded by asserting that blanket statements about the role of the extended family in African countries serving as a safety net need to be questioned, and assumptions that the extended family will be ready and able to assist sick members should be treated with caution. The extended family, they assert, is a “safety net with holes.”¹⁵

To a certain extent, informal care provision at the household level has been complemented by formal HBC (home-based care) programs.¹⁶ The PHC (primary health care) initiatives started in the 1970s brought with them the establishment of Village Health Committees and trained PHC volunteers. In the mid-1980s, a revival of PHC practice occurred in response to the immediate palliative care needs of people living with HIV within households.^{3,4} With the increased availability of ART since 2005, HBC programs have been strengthened and equipped to provide an essential, comprehensive care package that includes ART services and results in better rates of survival.¹⁷

CONTINUUM OF CARE IN PRACTICE

During the mid- to late 1990s, programmers and policymakers realized that public-sector health-care providers alone were not going to be able to manage the high levels of AIDS-related morbidity. To alleviate some of this burden, they began considering ways to shift the locus of clinical care from the

health facility to the community. Initial efforts in this area were modeled after hospital-based outreach, whereby hospital staff travel directly to patients’ homes to provide care. As Osborne et al explain:

The argument for the hospital initiated home-care models was that, given the limited treatment available in hospital for many AIDS patients, it was neither in the health services’ nor the patients’ interest for them to be in hospital. Instead it was better to care for patients at home, looked after by their own families with dignity. Not surprisingly, however, these outreach programs were found to be time-consuming and expensive, especially in rural areas.¹⁸

Faith-based hospitals, NGOs, and community-based organizations (CBOs) have been particularly adept at responding to patient care needs at the household level through outreach programs. The role of government hospitals and clinics in the implementation of HBC has been largely limited to coordinating functions.¹⁹

In response to the growing recognition that a more programmatic approach to care for people living with HIV was needed to assist and coordinate the many ongoing responses, the WHO, in consultation with a wide group of experts, developed a framework for comprehensive care across a continuum, known as the Care Continuum (Figure 1, next page).²⁰⁻²²

The WHO continuum contains a range of comprehensive services, including counseling and testing, clinical management, nursing care, and community-based social support. The provision of care extends from the individual/home to the hospital, through various levels of care linked with discharge planning and referral networks, and back to the individual/home. The intent of this model is to promote, create, and sustain a holistic approach to care and support for people living with HIV. The framework locates the person living

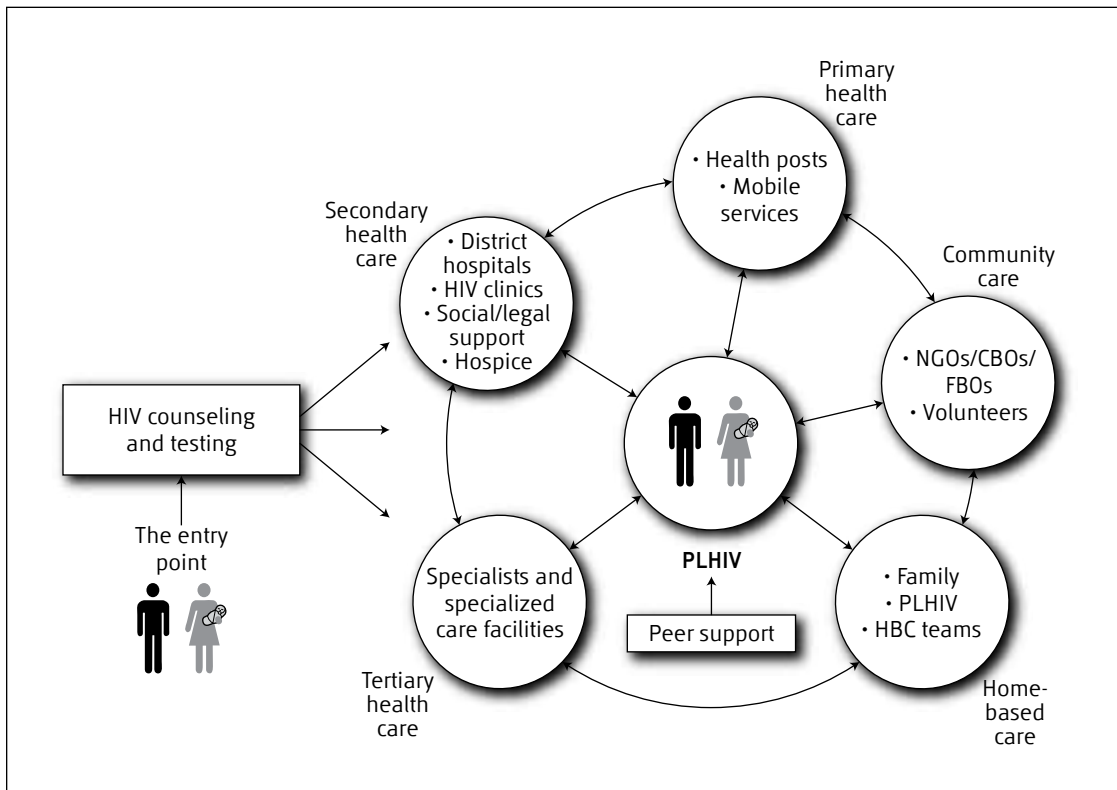


Figure 1. The Care Continuum

NGO = nongovernmental organization; CBO = community-based organization; FBO = faith-based organization; PLHIV = people living with HIV; HBC = home-based care

with HIV at the center of a wide range of actors who are dynamically linked. The entry point to the continuum is counseling and testing for HIV. Home care is one element of this broader system of care provision, and it is an element perceived to be particularly relevant and important in resource-limited settings.

Services that meet the needs of people living with HIV and their families reflect four interrelated domains: medical services throughout all infection stages; psychosocial services, ranging from emotional support to adherence counseling to orphan support; socioeconomic support services; and human rights and legal support services. Over the years, these services have become

known as comprehensive care and support (Figure 2).

The comprehensive Care Continuum framework is an important advance in the development of an agenda for HIV care from an international public-health perspective. It provides a standard that governments can follow to ensure that they enable people living with HIV to receive clinical and nonclinical care in the four domains, while illustrating the need to create linkages between these various care domains. However, viewed through the care-economy lens, and taking into account the common practice of unlinked care, a number of key areas must be addressed to make the COC fully functional.

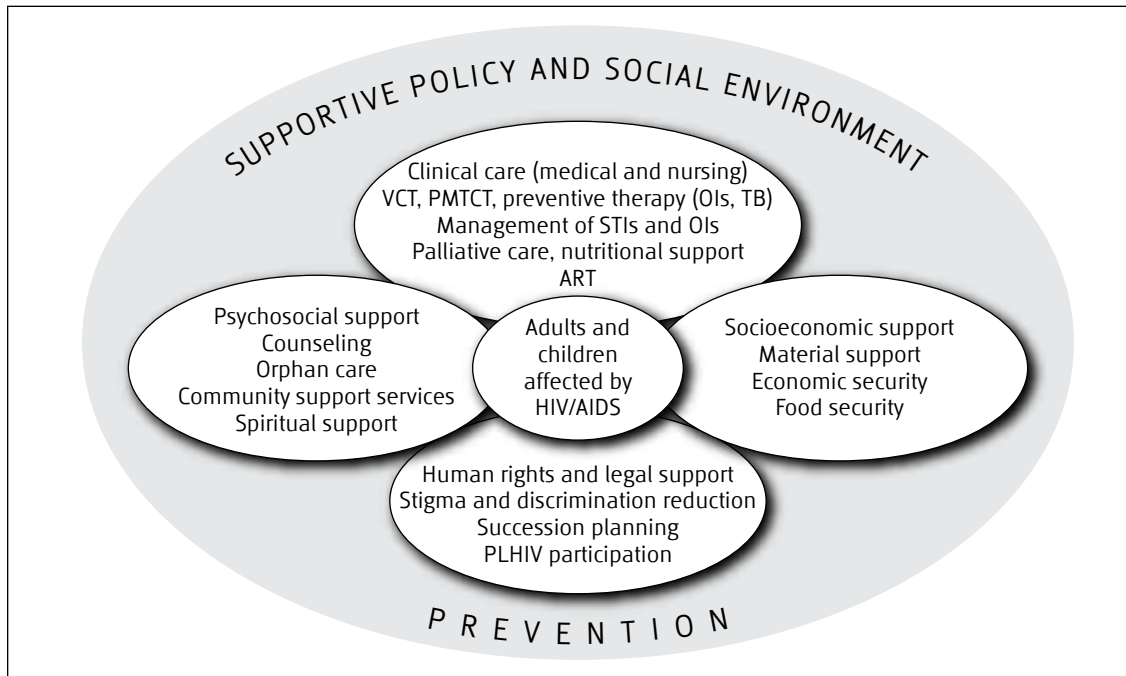


Figure 2. Components of comprehensive HIV/AIDS care and support

VCT = voluntary counseling and testing; PMCTC = prevention of mother-to-child transmission; OI = opportunistic infection; STI = sexually transmitted infection; PLHIV = people living with HIV

Source: Adapted from Family Health International²³

1. Strengthening of the prevention component within care delivery.

The recently developed intervention from the Centers for Disease Control and Prevention (CDC) and WHO calls for essential elements to be considered as part of the intervention, such as the following:

- Psychosocial counseling and support, including disclosure, partner notification and testing, and counseling for prevention and psychosocial adherence support
- Cotrimoxazole prophylaxis
- Screening for TB and TB-preventive therapy
- Prevention of fungal infections
- Sexually transmitted and other reproductive-tract infection services
- Malaria prevention
- Nutritional assessment, support, and micro-nutrient supplements

- Family planning
- Water, sanitation, and hygiene²⁴

2. Operational tools, which are essential to implement a COC. These tools include the following:

- Directory of services (i.e., a listing of who provides what in the district)
- Networking (i.e., well-linked, coordinated collaboration between different comprehensive care programs or institutions in all four domains)

3. Referral systems. Referral relationships must be developed or strengthened within the various hospital units, such as the following:

- Between the ART clinic and counseling and testing services, TB clinic, antenatal clinic (ANC) / prevention of mother-to-child transmission (PMTCT) clinic, and inpatient wards

- Between the hospital and the community-based services, including support services for people living with HIV
- Between district-level facilities and higher-level specialized medical services

LINKING HOME-BASED CARE WITHIN THE CONTINUUM OF CARE IN TANZANIA

Development of Home-Based Care in Tanzania

Implementation of organized HBC services by the Ministry of Health and Social Welfare (MOHSW) in Tanzania started in 1996 as pilot projects in eight districts of the Rukwa and Coast regions with support from DANIDA (Danish International Development Assistance). Findings from the pilots at the community level revealed that the services were highly appreciated and in ever increasing demand. Since then many organizations, including WHO and UNAIDS, international and local NGOs, faith-based organizations (FBOs), and community groups, have joined in to support HBC services in different parts of the country. By 2002, HBC services had been established in 28 districts, and by the end of 2006, the services had reached 70 out of 126 districts, with an estimated 50,000 patients reached.²⁵ However, the pace of expansion is still slow and services have yet to reach the target set by the MOHSW of 320,000 patients in need of HBC and support for orphans and other vulnerable children (OVC).

To support program implementation and monitoring and to harmonize various trainings, the MOHSW, in collaboration with its partners, has developed a national program with manuals, course plans, supervision tools, and guidelines.

HBC service provision in Tanzania follows two approaches: (1) health-care staff trained as HBC providers deliver outreach services on a part-time basis in addition to performing other health-

care duties in hospitals or clinics, or (2) trained community-based providers who are primarily volunteers working for NGOs, FBOs, or CBOs provide HBC exclusively. The latter approach is the approach most often used.

The Importance of a Continuum of Care for Treatment

Before the availability of ART in Tanzania, HBC focused primarily on AIDS-related chronic and terminal illness. Palliative care services focused on nursing care, psychosocial support, and home management of opportunistic infections. With the introduction of ART in the public sector in October 2004, the role of HBC has expanded to include care and support of patients on ART and directly observed therapy short course (DOTS) for TB patients. The role of HBC providers as treatment assistants and in monitoring adherence has proven to be particularly appreciated by people living with HIV; these roles widen the scope of HBC in the context of the COC for people on lifelong ART.

The new ART-related roles of HBC volunteers/providers in all Tanzanian HBC programs include the following:

- Preparing clients, family, and community members by setting expectations concerning treatment
- Addressing issues of disclosure
- Recognizing and linking patients who need referral to HIV care and treatment clinics (CTCs)
- Identifying treatment assistants within the household
- Discussing issues of safe storage of antiretroviral drugs (ARVs) at home
- Monitoring and supporting adherence to ART
- Identifying, managing, and referring side effects of ART as well as nutritional issues

Since ART is initiated at the hospital and clinic level while the majority of ART support services

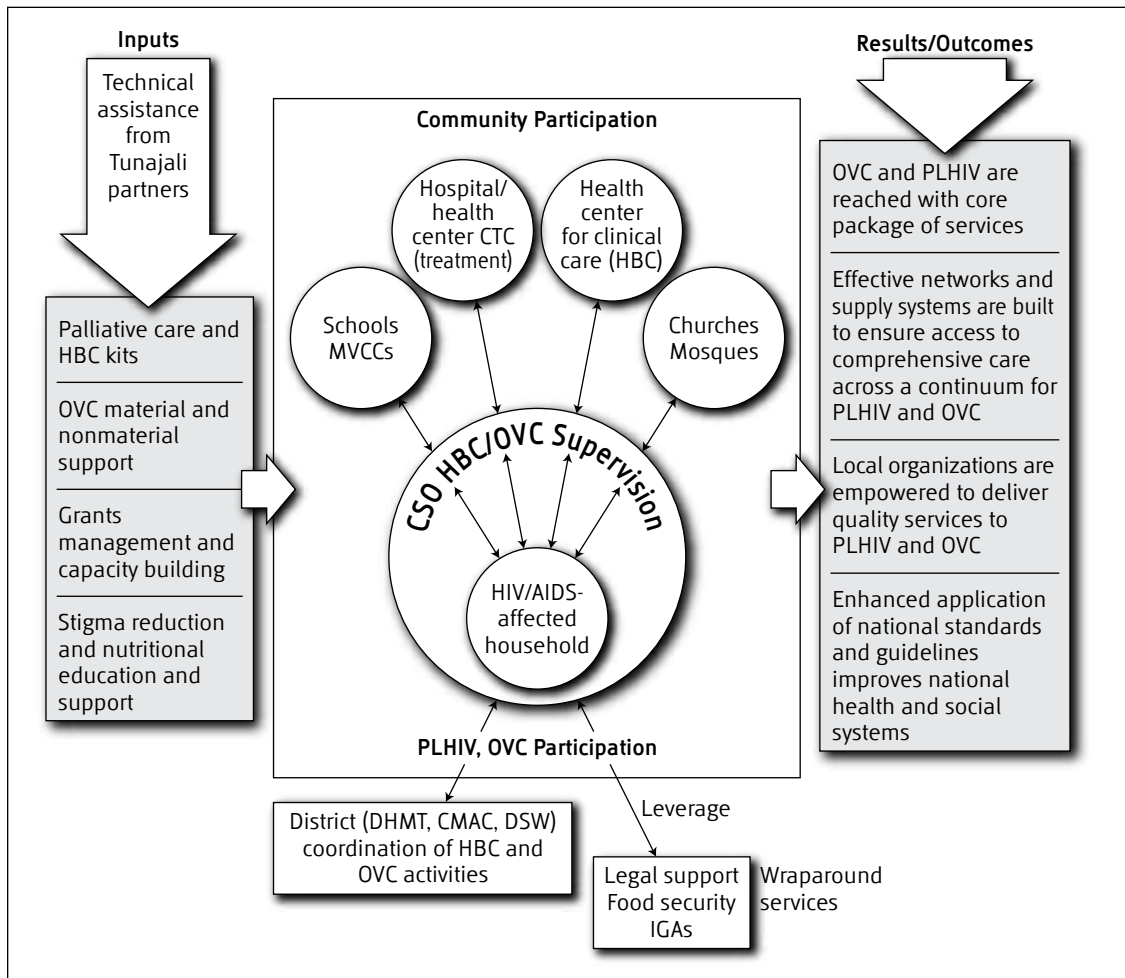


Figure 3. Model for the Tunajali community network for home-based care and care of orphans and other vulnerable children

CSO = civil society organization; CMAC = community medical advisory committee; CTC = care and treatment clinic; DHMT = district health management team; DSW = department of social work; HBC = home-based care; IGAs = income-generating activities; MVCC = most vulnerable children committee; OVC = orphans and other vulnerable children; PLHIV = people living with HIV

are needed at or near the patient’s home, HBC services are well placed to contribute greatly to the success of the COC.

Tanzania has opted for an integrated delivery model for the provision of ART. As part of this strategy, outpatient services at all hospitals in the country will be expanded to include integrated HIV CTCs. Each CTC will include space for triage nursing, clinical and counseling services, and

data management. The CTC will also be closely linked to the TB clinic and the reproductive health department. Among the CTC staff is an HBC focal person who refers informed patients to HBC services. Often staff from HBC programs and/or support groups for people living with HIV serve as go-betweens between patients and providers.

Community- and facility-based care go hand in hand and are mutually reinforcing in making

CASE STUDY: THE TUNAJALI PROJECT

THE *TUNAJALI* (“WE CARE”) partner program is one example of COC implementation in Tanzania. The program operates in three regions—Dodoma, Morogoro, and Iringa—where the capacity of government and faith-based hospitals and community organizations is being strengthened to provide HIV care, HIV treatment, and orphan support across a continuum (Figure 3). Health facilities and community organizations in these three regions are provided with technical, managerial, and financial assistance through the Tunajali project. The project was implemented by Family Health International (FHI) and Deloitte and supported by USAID.

The Tunajali project initiated the nationally mandated steps toward regionalization in the Iringa, Morogoro, and Dodoma regions (Figure 4). Currently all 33 hospitals in the three regions have the basic elements needed to run CTCs, with support from the MOHSW. Tunajali’s financial and technical assistance is helping centers reach more people, maintain quality of care, and integrate the program into the existing health-service delivery system. A major constraint that was recognized early on in the development of the CTCs was the lack of human resources. Staff were unwilling to take on additional tasks or train for new tasks in addition to their ongoing duties in the hospitals. With Tunajali’s major focus on training, supportive supervision, and effective referrals, this was a serious constraint. Few hospital staff were shifted to CTCs full-time, with the majority of CTC positions filled on a rotating basis. Tunajali also began to pilot a strategy that

involved hiring, training, and deploying retired health-care professionals at the major regional and district hospitals in the three regions to alleviate the human resource shortage (i.e., the “Retired But Not Tired” program). An assessment of the functioning of 28 retired hospital workers in four hospitals showed remarkable acceptance by staff and patients and improved efficiency in running the CTC.²⁶

In the same regions, Tunajali is assisting community HBC programs to enroll clients as early as possible into care and treatment programs and to ensure a COC.

Household support offered by various CBOs is emphasized during patient CTC visits, and referrals are made and recorded to ensure follow-up at the next visit. The impact of HBC is magnified by the provision of home care kits to help with immediate medical, hygienic, and nutritional needs. The kits include such items as bed nets, water purification tablets, micronutrients, and pain-relieving and other essential drugs. HBC volunteers are advised to accompany people living with HIV when they go for their hospital visits. This ensures consistency and bridges the gap between the hospital and other clinical services patients may need. Volunteers are asked to follow up with patients to make sure they strictly adhere to their daily treatment schedules and do not miss their clinic appointments.

Tunajali encouraged communities to go one step further by promoting the establishment of income-generating activities to help support families looking after people living with HIV. Animal husbandry is one popular

activity that not only provides income but also helps meet the increased nutritional requirements of patients. Volunteers for these programs are supported with travel stipends, bicycles, and in-service training.

People living with HIV and community members, particularly adult males, still raise the issue of stigma as a hindrance to their access to care. Currently, HIV CTC services reach twice as many adult females as males, and less than 10% of patients enrolled are children.²⁷ The Kimara project, in collaboration with Muhimbili University of Health and Allied

Sciences (MUHAS) in Tanzania, has developed tools that teach people how to discuss shame, blame, and disclosure in an effective way at the community and household level. Training of national facilitators on the use of this tool is ongoing, with 106 trained so far.²⁸ Piloting of the tool has led to a noticeable transformation among staff and volunteers toward greater openness, and they are now capable of training families and communities on how to overcome stigma and related issues. Tunajali plans to apply this tool in all regions where it operates.

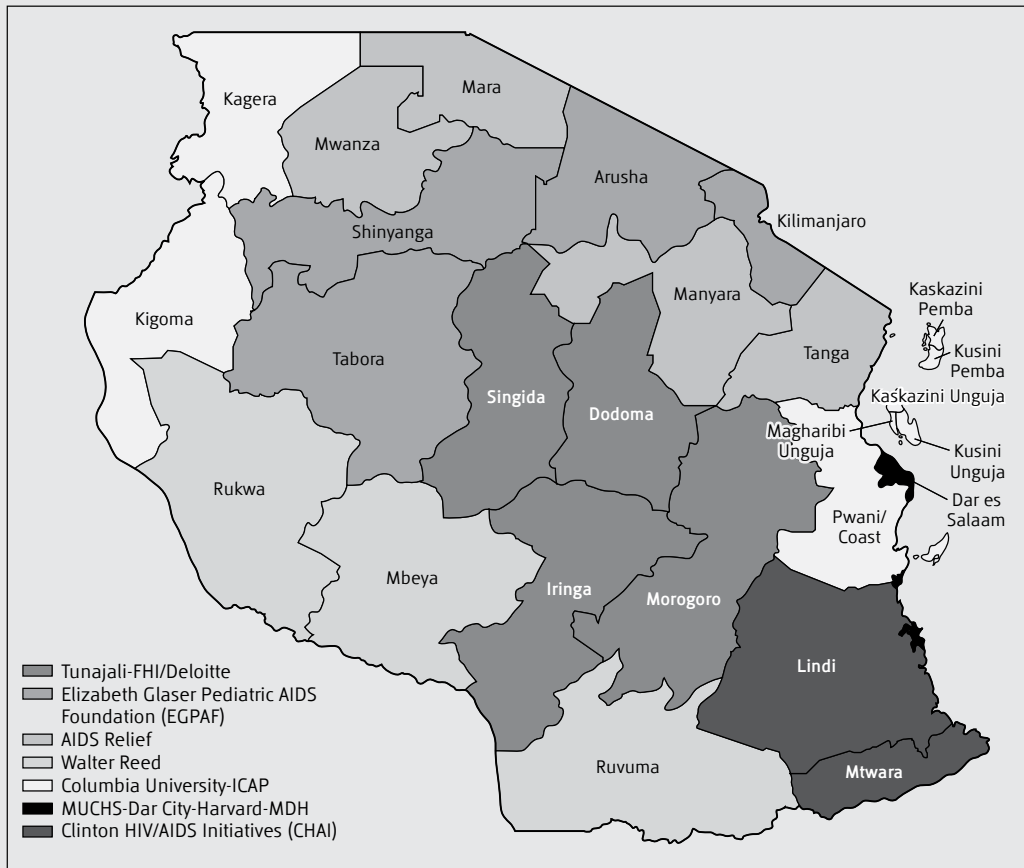


Figure 4. Regionalization of care and treatment services in Tanzania

long-term quality care, treatment, and support possible. This linkage is ensured by the HBC focal persons from hospitals and district health services, who meet with civil society organizations such as CBOs, support groups for people living with HIV, FBOs, and NGOs to coordinate activities. In districts where active HBC programs are adequately funded, district coordinating committees have been formed to ensure effective referrals of patients from one service to another. District directories of services have been established, and these are given to service providers, who use standardized referral forms to refer patients and their families to different types of services that they may need from time to time.

The CTCs have procedures to link patients easily with community and HBC programs, usually run by civil society organizations. Patients can be referred in a timely manner to CTCs to be assessed for clinical or treatment needs. Likewise, patients can be referred to HBC programs close to their homes so that staff and volunteers can provide follow-up, reinforce adherence, and provide other comprehensive care services such as nutritional and emotional support, and prevention education for all household members.

Regionalization of Care and Treatment Services

In 2005, the National AIDS Control Program (NACP), together with key staff of Family Health

International (FHI), WHO, CDC, and the United States Agency for International Development (USAID), developed a novel approach for partners assisting the MOHSW in implementing the COC. Under this plan, formally initiated by the MOHSW in September 2005, partners were assigned specific regions of the country instead of specific hospitals. This lessened the duplication of resources and the administrative burden on care and treatment facilities, because each facility could work with just one partner rather than with multiple partners. The partners then helped regional and district authorities plan and support the scale-up of care and treatment at regional, district, and health center levels.

The goals of regionalization are to reach a greater number of patients more quickly, foster more ownership and commitment among national authorities, make it easier for patients to be referred within the region, and achieve the desired results more cost-effectively.²⁹

CHALLENGES IN MAINTAINING A CONTINUUM OF CARE

In the course of implementing Tanzania's COC approach to reach all in need—estimated to be 400,000 people in need of care, treatment, and support and over one million orphans³⁰—critical challenges still need to be addressed. These challenges, along with key recommendations, are listed in Table 1.

Table 1. Critical Challenges and Recommendations for Implementation of the Continuum-of-Care Approach	
Challenge	Inadequate access to quality continuum-of-care services Care and treatment services have not yet reached most rural areas. Travel to urban district hospitals is unreliable and expensive for the majority of Tanzanians. Although the regionalization process allows for division of resources to cover all facilities, effective referrals and regular follow-up need to be improved.
Key Recommendation	Rather than initially focusing only on hospitals, a district-based approach can be used, whereby <i>all</i> facilities are assessed and receive regular training and follow-up. Regionalization has helped this process in Tanzania and could be explored in other countries.
Challenge	Inadequate infrastructure Obtaining adequate space for care and treatment services has become a huge challenge due to the increasing numbers of patients. Crowding and long waits are reported.
Key Recommendation	The government and supporting partners should continue to mobilize resources to renovate health-facility infrastructure.
Challenge	Human resource constraints Understaffing causes major bottlenecks at most sites in Tanzania. With support from the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund), an emergency hiring plan for 375 posts will be established, but a deficit of 10,000 vacancies remains. The pilot “Retired But Not Tired” project was successful in alleviating some of this burden.
Key Recommendation	The “Retired But Not Tired” model should be extended to all hospitals nationwide.
Challenge	Persistent stigma and low community HIV awareness HIV care and treatment center services reach twice as many adult females as males, and less than 10% of patients enrolled are children. ²⁷ Higher stigma among males, poor community knowledge about antiretroviral (ARV) effectiveness, and missed opportunities to identify exposed or infected children are believed to be some of the reasons for low uptake of care and treatment services by males and children.
Key Recommendation	Activities addressing stigma should be included in care and treatment packages for people living with HIV at all service delivery points across the continuum.
Challenge	Lack of health insurance for people living with HIV Regular visits for treatment and all necessary referrals within the continuum incur travel expenses and often payments to clinics and hospitals. As the great majority of people living with HIV do not have health insurance, all these are out-of-pocket costs.
Key Recommendation	Community-based health insurance schemes should be promoted and piloted to assess their feasibility in resource-limited settings.

Table 1. Critical Challenges and Recommendations for Implementation of the Continuum-of-Care Approach (cont.)

Challenge	Irregular and inadequate supply lines to the various services within the continuum Large numbers of patients enrolled at care and treatment centers and in home-based care programs generate increasing demand for home-care kits and supplies, laboratory reagents, drugs for preventive therapies, and other items. Supplies are largely reliant on external donor funding from the Global Fund, the President's Emergency Plan for AIDS Relief (PEPFAR), or other organizations.
Key Recommendation	Continued pressure is needed to increase the share of gross domestic product (GDP) allocated to the health sector and sustain donor commitments.
Challenge	Low involvement of council and regional health management teams Field observations revealed that key council and regional health management team members are not fully involved in planning, budgeting, and monitoring HIV care and treatment activities in their areas.
Key Recommendation	Health reforms and decentralization should be supported with clear guidance on roles and responsibilities in areas such as networking, coordination of various stakeholders, supportive supervision, and monitoring.
Challenge	Low priority given to community home-based care by donors and national government Most funds are earmarked for antiretroviral therapy (ART) services and management of opportunistic infections, with very few donors supporting the scale-up of community home-based care services. Consequently, the coverage of home-based care services lags far behind that of facility-based care and treatment in several regions.
Key Recommendation	Better and more widespread documentation of the contribution of home-based care service-delivery programs in improving quality of life, strengthening the effectiveness of care and treatment programs, and reviving primary health care is needed to support greater resource mobilization.
Challenge	Poor integration of care, treatment, and support programs with preventive services A good continuum-of-care program should be fully integrated with preventive services. Yet care, treatment, and support interventions are not being integrated with preventive services, leading to many missed opportunities.
Key Recommendation	The international public health community, including major donors and stakeholders, needs to agree on global guiding principles regarding the essential complementary and mutually reinforcing relationship between prevention and care.

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