MULTI-LEVEL FACTORS AFFECTING ENTRY INTO AND ENGAGEMENT IN THE HIV CONTINUUM OF CARE IN IRINGA, TANZANIA
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**ACRONYMS**

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<tr>
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<th>Description</th>
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<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
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<tr>
<td>ANC</td>
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<td>ART</td>
<td>Antiretroviral therapy</td>
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<td>CCP</td>
<td>Center for Communication Programs</td>
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<td>CD4</td>
<td>Cluster of differentiation 4</td>
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<td>CTC</td>
<td>Care and treatment centers</td>
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<td>HIV</td>
<td>Human immunodeficiency virus</td>
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<td>HTC</td>
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<td>JHU</td>
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<tr>
<td>PITC</td>
<td>Provider-initiated testing and counseling</td>
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<td>PLWHIV</td>
<td>People living with HIV</td>
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<tr>
<td>PMTCT</td>
<td>Prevention of mother-to-child transmission</td>
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<td>PLHIV</td>
<td>People living with HIV</td>
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<td>R2P</td>
<td>Research to Prevention</td>
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<td>SEARCH</td>
<td>Supporting Evaluation and Research to Combat HIV</td>
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<td>VTC</td>
<td>Voluntary HIV testing and counseling</td>
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<td>VMMC</td>
<td>Voluntary medical male circumcision</td>
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EXECUTIVE SUMMARY

Introduction
Despite great progress in improving access to antiretroviral therapy (ART) for people living with HIV (PLHIV) in sub-Saharan Africa, ART coverage remains low. Under new World Health Organization (WHO) treatment guidelines, which recommend ART initiation at 500 cells/mm³ or less, ART coverage in low- and middle-income countries was estimated at only 34% of all those who were eligible in 2013 (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2013b; WHO, 2013) and substantial obstacles to universal treatment access exist. Successful ART programs depend on progression of PLHIV through a continuum of care which includes HIV testing and counseling (HTC), access to and linkage to care, eligibility assessment and clinical staging for ART, pre-ART care, ART initiation, and lifelong ART adherence and retention in care. Considerable losses along each stage of this continuum have been well documented, especially in the stages before ART initiation (Kranzer et al., 2012; Mugglin et al., 2012; Rosen & Fox, 2011). This evidence underscores the need to better understand factors that contribute to suboptimal progression at each stage of the continuum of care in order to develop effective strategies to improve access to and retention in care for PLHIV.

In southwest Tanzania, the Iringa region has the second highest HIV prevalence (9.1%) in the country (Tanzania Commission for AIDS [TACAIDS] et al., 2013). Many individuals are unaware of their HIV serostatus, and across Tanzania, many people who have been tested fail to successfully link to further care and treatment services (Ferguson et al., 2012; Mshana et al., 2006). While there is considerable need to improve access to and retention in HIV services in Iringa, little is known about factors affecting engagement in each step of the HIV care continuum in this setting. This study aimed to identify and explore barriers and facilitators to engagement in the HIV continuum of care in Iringa at the individual, facility, community, and structural levels.

Methods
The study employed a mixed-methods approach including: (1) facility-based ecological assessments and interviews with providers and clients of health care facilities providing HIV testing and treatment services; (2) interviews, focus groups, and observation with community-based providers (including support groups, traditional healers, and spiritual/religious healers) and their clients; and (3) longitudinal interviews with PLHIV to understand their trajectories in care.

To examine structural and/or institutional-level barriers and facilitators throughout the HIV continuum of care, we visited facilities providing HIV testing and treatment services, including fixed HTC sites (n=4), care and treatment centers (CTC) (n=4), prevention of mother-to-child-transmission (PMTCT) services (n=4) and voluntary medical male circumcision (VMMC) outreach.
sites (n=1). Methods included 75 in-depth interviews with clients of these services, 26 in-depth interviews with service providers, 12 facility checklists and 15 direct facility observations.

To understand barriers and facilitators among community-based providers of HIV care and support services, we visited PLHIV support groups (n=5), traditional healers (n=12), and spiritual/religious healers (n=2). We conducted a total of 42 in-depth interviews with clients of support groups and spiritual healers; 30 in-depth interviews with leaders of support groups, spiritual healers, and traditional healers; and 4 in-depth interviews with government representatives who had worked with traditional healers in the region. In addition, 5 focus group discussions were held with members of support groups, and 8 direct observations were completed with support groups, spiritual healers, and traditional healers.

To further explore the social context and dynamics throughout the continuum of care in Iringa, we conducted longitudinal interviews with 48 PLHIV followed prospectively at three time points over a six-month period. Participants were stratified by gender, ART status, and urban/rural location. Participants were purposively sampled to ensure a diverse mix of members of key populations (specifically, female sex workers) and the general population. In addition, we recruited 14 participants who had disengaged from care.

We took a narrative and case study approach to data analysis. Interviews and focus groups were recorded, transcribed and translated into English. Analysis of all qualitative data was conducted through a multi-stage narrative process. First, each individual interview was summarized and restoried in brief narrative form. Second, these individual narrative summaries were brought together to develop a case summary report for each facility, community group or cohort participant. Key themes were developed into a conceptual framework summarizing findings across levels and steps in the continuum of care.

Ethical review and approval was obtained from the Muhimbili University of Health and Allied Sciences and the National Institute for Medical Research in Tanzania and from the Johns Hopkins School of Public Health in the United States.

Results

HIV Testing and Counseling
Barriers to HTC at the individual level included fear of HIV testing, reluctance to test while feeling healthy, and distrust in HIV test results. The perception that ART is highly efficacious and a perceived increased risk of HIV infection facilitated HTC. Inadequate provider-initiated testing and counseling (PITC) at routine health services was a facility-level barrier to HTC, while near-universal PITC at VMMC and PMTCT services facilitated this process. Study participants explained that after individuals attended multiple health facilities without receiving HTC and still did not know the cause of their illness, they often visited traditional healers as a last resort.
Facilitators to HTC at the community level included mass media and community mobilization activities, as well as PLHIV motivating others to test for HIV. Structural barriers included widespread and chronic stock-outs of HIV test kits and the policy of antenatal care (ANC) services requiring couples testing.

Access to and linkage to care
Feeling healthy at the time of HIV diagnosis and having faith in God’s ability to cure HIV were mentioned as individual-level barriers to successful linkage to care. At the facility level, PLHIV struggled to successfully link to care when HTC and CTC services were located in separate facilities, when the participant did not receive services during their first encounter at the CTC due to restricted opening hours, limited capacity for enrollment and shortages of providers. Some participants also had negative initial interactions with service providers. Same-day linkages from HTC to CTC services and intensive counseling from service providers, both after receiving an HIV positive diagnosis and after linking to a CTC, facilitated this process. Structural barriers included the passive nature of the referral system, which prevented providers from following up to ensure a client had linked to care, and high work-related mobility and frequent migration of certain patients, such as sex workers.

Clinical staging and CD4 testing
The study included a facility assessment in which most health facilities reported a lack of functioning CD4 machines. This created significant challenges for PLHIV such as delayed clinical and laboratory staging, resulting in delayed ART initiation for some clients. In contrast, one study facility with a functioning CD4 machine, trained laboratory technicians, and the capacity to test all clients on-site provided efficient services which motivated clients and allowed for timely staging and CD4 monitoring.

Pre-ART care
Witnessing visible improvements in one’s health as a result of cotrimoxazole prophylaxis facilitated retention in pre-ART care services, but frequent stock-outs of this medication was noted as a main reason for disengagement from pre-ART care.

ART initiation, adherence and retention
Directives to change practices and behaviors, such as eliminating alcohol and reducing frequency of sexual intercourse, were discussed by clients as a barrier to retention in ART care. For sex workers, this was an additional reason not to disclose their occupation to providers. However, many acknowledged the importance of ART and cited viewing HIV as a “normal” disease as a factor encouraging retention in care. Several factors affected engagement in CTC services at the facility level, including rigid policies surrounding appointments, ART initiation inconsistent with national guidelines, and disrespectful treatment by service providers. Standardized referral/transfer systems, respectful treatment by service providers, and home-based care providers were viewed as facilitators to care and retention. In the community,
traditional healers who treated PLHIV with traditional medicine and spiritual healing practices may prevent engagement in ART services, while social support was discussed as a facilitator. Finally, access to income-generating opportunities was identified as a structural-level facilitator to adherence and retention in care.

Cross-cutting themes
Data revealed several cross-cutting themes that impacted engagement at all steps of the continuum of care. These included lack of privacy and confidentiality at health facilities, patients not receiving needed services, poor client-provider communication, and long wait times for services. Service providers discussed burnout, demotivation and inadequate training which led to lower quality of care and disrespectful treatment of clients. Stigma and discrimination were significant barriers at all stages of the continuum, as were long distances to HIV services and pervasive poverty. Cooperation between government officials and traditional healers were cited as possible solutions to greater engagement in care throughout the continuum.

Discussion
Understanding factors that motivate and prevent PLHIV from engaging in and adhering to each step along the continuum of care is critical to successful HIV treatment and prevention efforts. This study provides a multi-level understanding of barriers and facilitators to engagement in HIV services at all stages of the HIV care continuum.

Individual level
At the individual level, the main factor affecting engagement with HIV services was physical health. A majority of participants in this study received HTC only when they were visibly sick, had ruled out other possible illnesses, and perceived themselves at risk for HIV infection. These individuals often accepted positive HIV test results with a sense of relief for finally knowing the cause of his or her suffering. In contrast, healthy-feeling participants in our study expressed reluctance to receive HTC and were more likely to delay linking to care or else disengage from care and treatment services entirely. As a result, many held the belief that HIV was associated with severe physical symptoms. In order to change the current social norms around HIV, behavior change communication strategies should promote earlier testing and engagement in care by educating the public about personal and public health benefits of early ART initiation.

Facility level
Inadequate PITC was an important barrier to entry into the continuum of care. Very few clients were offered PITC by a service provider; those who were had often been very sick and visited multiple health facilities previously. Increasing education and training among health care workers about the importance of PITC could increase their willingness to routinely offer PITC to clients, which could significantly improve detection of HIV-infected individuals who are currently being missed by the health system.
Post-diagnosis, participants in our study discussed a range of hurdles encountered during the process of linking to a CTC. While co-located HTC and CTC services facilitated same-day linkage to care for newly diagnosed clients, same-day linkages were not often possible. In many areas, HTC and CTC services were not co-located, requiring an individual to travel independently to a CTC. Upon arriving at the initial visit, clients were often told to return on another day due to restricted hours of operation, limited capacity for CTC enrollment, and shortages of health care workers. There is a clear need to develop strategies to simplify the linking and CTC enrollment process to reduce facility-level barriers at this stage.

A majority of study participants struggled to access CD4 testing services due to broken machines or lack of reagents to operate them properly. Point of care CD4 testing, which provides immediate results for use in patient care, could eliminate many of the logistical and operational barriers faced by study participants and improve linkages throughout the continuum. Further, reports of incorrect ART initiation practices are concerning, and refresher training of providers on clinical staging, particularly in the absence of CD4 testing services, should be considered.

Participants described long wait times, congestion, and lack of privacy and confidentiality as barriers to retention in ART care. We recommend expanding strategies to decrease congestion and improve clinic efficiency, such as offering three-month ART supplies and assigning groups of CTC clients to block-scheduled appointments throughout the day.

**Community level**

Pervasive stigma and discrimination were widely discussed as barriers to engagement in HIV-related services and a main reason that people avoided HTC. An HIV-positive diagnosis was often perceived as shameful and many participants feared HIV-related stigma. In order to avoid being seen by people they knew, several participants traveled to more distant clinics, incurring greater costs and travel time. Pervasive stigma against sex work added additional barriers for HIV-positive sex workers, making it difficult to seek care and to discuss sexual risk behaviors and prevention strategies with providers. Our findings highlight the need for stigma-reduction strategies to accompany HIV prevention and treatment efforts in Iringa.

Participation in PLHIV support groups was deemed a positive experience by all support group members. Members of these groups had often publicly disclosed their HIV status and were less likely to cite community-wide stigma as a barrier to their engagement in HIV services. In addition, each support group in this study offered the chance to participate in a savings or income-generating project. Efforts to strengthen the linkage between support groups and HIV services should seek to increase membership in these groups among PLHIV.

Visiting traditional and spiritual healers were common alternate care pathways discussed by participants in our study. We found evidence of some collaboration between government officials and traditional healers in Iringa, but did not find evidence of any communication with
spiritual healers. Increased engagement between government officials and these groups could further a dialogue on how to better link traditional and spiritual healers and the health system.

Finally, community-level programs that encourage engagement in HIV services such as mass media campaigns, community mobilization, and engagement of HBC providers were cited as initiatives that changed attitudes and promoted engagement with HIV services. Similar strategies could be leveraged to further promote HIV testing and linkages throughout the continuum of care.

**Structural level**
Participants in our study discussed persistent stock-out of supplies, including HIV test kits, CD4 reagents, and cotrimoxazole. Strengthening the supply chain management system for these products should be prioritized to eliminate common stock-outs in health facilities, as these stock-outs not only kept patients from receiving important treatment, but also contributed to a growing dissatisfaction with the country’s health system in general.

Negative provider attitudes and disrespectful treatment of clients emerged as the main reason for disengagement from CTC services among ART-initiated individuals. These findings point to a clear need to improve provider-client interactions as a means of reducing disengagement from care. CTC clients reported the most serious conflict with service providers after missing an appointment or arriving late. More flexibility in scheduling and rescheduling patient appointments could decrease some of this conflict and better accommodate client needs. Health-system-level changes to increase human resources, provide adequate support systems and institute ongoing training and supervision may increase service provider motivation and improve interactions with clients.

In this study, pregnant women were required to bring their partners to ANC services for couples testing which created a serious barrier to both HIV and ANC services. Multiple women in our study were denied ANC services or knew of friends who avoided ANC services altogether if they were too scared to ask their husbands to attend or if they did not have a partner. Male participation at ANC services should be encouraged but not required, per national guidelines. While done to engage men in HIV services, this requirement is counter-productive and preventing women at highest risk of HIV from accessing ANC and PMTCT services.

Long distance to facilities, limited or no transportation and lack of money for transportation and other associated costs were structural-level barriers to engagement in HIV services. Participants in our study commonly requested HIV services at the community-level as a way to increase access for rural populations and decrease congestion at current facilities. Community-based HIV service delivery, including home-based HTC and home-based ART initiation and delivery could remove some of these structural-level barriers and strengthen linkages throughout the HIV care continuum.
Conclusion
This study presents a multi-level framework for understanding barriers and facilitators to engagement in the HIV continuum of care in Iringa, Tanzania. Our findings highlight the complex, multi-dimensional dynamics that individuals experience throughout the continuum and underscore the importance of taking a longitudinal and multi-level perspective to understand this process. Addressing barriers at each of these levels is important to promoting increased engagement throughout the continuum of care.
INTRODUCTION

In the past decade, with the rapid scale-up of antiretroviral therapy (ART), great progress has been made in reducing the burden of HIV, especially in eastern and southern Africa, the region most affected by the AIDS epidemic. The Joint United Nations Programme on HIV/AIDS (UNAIDS, 2013a) estimates that 6.3 million people living with HIV (PLHIV) were accessing ART in eastern and southern Africa in 2012, contributing to a 30% reduction in new HIV infections and a 38% reduction in HIV-related death between 2001 and 2011 (UNAIDS, 2013a). Despite these considerable gains, ART coverage remains low. In 2012, treatment coverage in low- and middle-income countries was estimated at 61% of all who were eligible under the 2010 World Health Organization (WHO) HIV treatment guidelines. However, under new WHO treatment guidelines recommending ART initiation at 500 cells/mm³ or less, this ART coverage represents only 34% of the people eligible in 2013 (UNAIDS, 2013b; WHO, 2013) and considerable obstacles to universal treatment access exist.

Successful ART programs depend on progression of PLHIV through a number of stages. This continuum of care, also referred to as cascade of care or HIV care pathway, has been well documented and includes HIV testing and counseling (HTC), access to and linkage to care, eligibility assessment and clinical staging for ART, pre-ART care, ART initiation, and lifelong ART adherence and retention in care. Each of these stages is complex, and different people may define and understand each stage in unique ways in different settings. For the purposes of this study, we defined “linkage to care” as the initial engagement with the health system to receive HIV care and treatment services following an HIV diagnosis. Specifically, for this study, that engagement had to be with a care and treatment center (CTC), which is where care for people living with HIV is organized within the Tanzanian public health care system. We defined “retention in care” as continuous and regular engagement in ART programs. We further use the terms “engaged in care” to refer to individuals currently receiving HIV services at any point throughout the HIV continuum of care and “disengaged from care” to refer to individuals who were once engaged in care at any point throughout the continuum, but no longer receive HIV services.

The HIV continuum of care is important in identifying places where suboptimal interactions with the health care system may affect individual patient success in diagnosing and managing their HIV infection. Three systematic reviews of studies in sub-Saharan Africa have reported considerable losses along each stage of this continuum, especially in the stages before ART initiation (Kranzer et al., 2012; Mugglin et al., 2012; Rosen & Fox, 2011). In addition, median CD4 cell count at ART initiation is low (Lahuerta et al., 2014); an estimated one in four people in low-income settings initiates ART at CD4 < 100 cell/mm³ (WHO, 2013) resulting in high mortality rates during the first few months of therapy (Braitstein et al., 2006; May et al., 2010).
These data underscore the need to better understand factors which contribute to suboptimal progression at each stage of the continuum of care in order to develop effective responses to improve access to and retention in care for PLHIV. However, factors contributing to losses along the continuum are not well understood. A systematic review of factors affecting linkages to ART in sub-Saharan Africa found that key barriers to engagement included transport costs and distance to health facilities, stigma and fear of disclosure, and limited human resources (Govindasamy, Ford, & Kranzer, 2012). MacPherson et al. (2012) reported that socio-cultural norms, support networks, and limited human resource and laboratory capacity affected progression throughout the continuum in Malawi (MacPherson, MacPherson, et al., 2012).

There are variations in HIV epidemics throughout sub-Saharan Africa, and contextual factors affecting progression throughout the HIV continuum of care will vary by location. Understanding the local context is critical to an effective response (UNAIDS, 2007). In southwest Tanzania, the Iringa region has the second highest HIV prevalence (9.1%) in the country (TACAIDS et al., 2013). It is estimated that only 68.6% of women (26.0% in the past year) and 52.7% of men (28.2% in the past year) in Iringa have ever been tested for HIV and received their results (TACAIDS et al., 2013). Thus, many individuals are unaware of their HIV serostatus and miss the opportunity for linkage to further care and treatment services. Consistent with findings throughout sub-Saharan Africa, findings from other regions of Tanzania indicate that a substantial portion of individuals who receive a positive HIV diagnosis are not referred for subsequent care, and among those who are referred, many fail to actually register for services and receive clinical staging (Ferguson et al., 2012; Mshana et al., 2006). Finally, country-level estimates suggest that less than one third of those eligible for ART based on WHO 2013 guidelines are receiving it (UNAIDS, 2013b).

While there is considerable need to improve access to and retention in HIV services in Iringa, little is known about barriers or facilitators to engagement in the HIV continuum of care, although distance to health facilities, stigma and discrimination, fear of disclosure, and disrespectful treatment from service providers have been reported as barriers in Tanzania (Mshana et al., 2006; Nsigaye et al., 2009). In this study, we examined multi-level barriers and facilitators influencing entry into and engagement in the continuum of care in Iringa, Tanzania.
METHODS

To understand barriers and facilitators to engagement in the HIV continuum of care at multiple levels, we conducted a mixed-methods study including: (1) facility-based ecological assessments and interviews with providers and clients of health care facilities providing HIV testing and treatment services; (2) interviews, focus groups discussions (FGDs), and observation with community-based providers and their clients; and (3) longitudinal interviews with PLHIV to understand their trajectories in care.

All data collection was conducted by trained Tanzanian male and female research assistants. Interviews and focus groups were conducted in Swahili and audio recorded with permission of participants. Recordings were then transcribed and translated into English for analysis. Observation notes and checklists were recorded by hand, then entered or transcribed and translated into English as needed. All participants provided full informed consent prior to data collection.

Facility-based ecological assessments and interviews with providers and clients

To assess institutional-level barriers and facilitators throughout the continuum of care at HIV testing and treatment facilities, we conducted ecological assessments of a sample of facilities providing HIV testing and treatment services, including fixed HTC sites, CTC services, prevention of mother-to-child transmission (PMTCT) services, and voluntary medical male circumcision (VMMC) outreach sites. First, maps were used to identify the location of all health clinics in Iringa and select a diverse sample of facilities of different types; given the temporary and mobile nature of VMMC outreach sites, these were conveniently sampled as campaigns occurred in the region. At each facility, a structured checklist was used to gather basic operational information such as hours of operation, number and types of providers, types of services and tests available, and whether or not there was a referral system for services not available at the center. In addition, direct observations were conducted to collect information on the flow of clientele through each facility, provider-client interactions, client-client interactions, wait times, and the general ambience at the facility.

During the facility visits to conduct the ecological assessment, we also conducted qualitative, semi-structured interviews with both health care providers and HIV-infected clients of these services. Semi-structured guides were used to elicit information on barriers and facilitators to progression through the continuum of care from the perspective of the providers and clients at all facilities. Providers were purposively sampled at each site to include a variety of professional positions, including laboratory technicians, managers, nurses, health workers, medical officers and HIV counselors. Clients were also purposively sampled to reflect the diversity of individuals accessing the service. Table 1 presents a summary of data collection performed with providers and clients from health care facilities.
Table 1: Summary of facility-based data collection

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<td>4</td>
<td>4</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>75</td>
<td>26</td>
<td>12</td>
<td>15</td>
</tr>
</tbody>
</table>

Community-based data collection with providers and clients of community-based services

In addition to conducting facility-based data collection, we also wanted to understand barriers and facilitators throughout the continuum of care among community-based providers of HIV care and support services to PLHIV, including support groups, traditional healers, and spiritual/religious healers. In-depth qualitative interviews were conducted with community-based providers of HIV care and support services to elicit information on barriers and facilitators from their perspective. Interviews were also conducted with clients of support groups and spiritual healers to better understand how use of these services promotes or discourages their continued engagement with the continuum of care. In addition, for traditional healers, several in-depth interviews were conducted with government representatives who had worked with traditional healers in the region; although the research team tried to interview HIV-infected clients of traditional healers, we were unable to identify anyone who met these criteria as traditional healers generally did not know the HIV status of their clients. We also conducted direct observations of each of these community-based providers when possible. Finally, five FGDs were organized with existing support groups for PLHIV to generate normative data on the way in which provision and uptake of support services (either in addition to or separate from use of HIV treatment, care, and prevention, services) enhances an individual’s likelihood of long-term linkage and retention into HIV care and treatment services. Table 2 summarizes community-based data collection.

Table 2. Summary of community-based data collection

<table>
<thead>
<tr>
<th></th>
<th>Client IDIs</th>
<th>Provider/key informant IDIs</th>
<th>Direct observations</th>
<th>Focus group discussions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support groups (n=5)</td>
<td>30</td>
<td>10</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Spiritual healers (n=2)</td>
<td>12</td>
<td>4</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Traditional healers (n=12)</td>
<td>0</td>
<td>12</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Government liaison (n=4)</td>
<td>0</td>
<td>4</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>42</td>
<td>30</td>
<td>8</td>
<td>5</td>
</tr>
</tbody>
</table>
Longitudinal interviews with people living with HIV

To further explore the social context and dynamics of barriers and facilitators throughout the continuum of care, we conducted longitudinal interviews with 48 PLHIV followed prospectively at three time points over the course of six months. Participants were stratified by gender, ART status, and urban/rural location (Table 3). We also sought diversity between members of key populations (specifically, sex workers) and general population participants. In addition, we recruited 14 participants (6 male, 8 female) who had disengaged from care. For follow-up interviews, data collectors made multiple attempts to contact cohort participants. If the participant could not be reached after three separate attempts (including phone calls and visits to the participant’s home of record), the participant was designated as lost to follow up. Seven participants (3 females, 4 males) were lost to follow up during the second round of data collection and 2 participants (both male) were lost to follow up for the third round of data collection. The overall retention rate was 81%.

These interviews used qualitative methods to iteratively explore the individual, relationship, family, facility, and environmental-structural factors influencing participants’ experiences with HIV services, and their complex processes of engagement in care along the continuum. In addition to individual attitudes and beliefs, family, friends, and partner dynamics, these interviews also explored environmental-structural factors, such as quality of roads, access to public transportation, and availability of services that inhibited or facilitated the use of services. The interviews also explored issues of stigma and discrimination, social norms, and social support for PLHIV. Finally, participants were asked about experiences with traditional and spiritual healers, including both personal experiences and experiences of friends or family members.

Table 3. Distribution of participants for longitudinal interviews

<table>
<thead>
<tr>
<th></th>
<th>Men</th>
<th>Women</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ART</td>
<td>No ART</td>
<td></td>
</tr>
<tr>
<td>General population</td>
<td>6</td>
<td>7</td>
<td>13</td>
</tr>
<tr>
<td>Rural</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>5</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Rural</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Female sex workers</td>
<td>5</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>Rural</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
<td>11</td>
<td>48</td>
</tr>
</tbody>
</table>

Data analysis

We took a narrative and case study approach to data analysis. Interviews and focus groups were recorded, transcribed, and translated into English. Observations were recorded as responses to prompted questions in a textual observation write-up. Analysis of all qualitative data was conducted through a multi-stage narrative process. First, each individual interview with providers and clients was summarized and re-storied in brief narrative form, with particular attention to structured categories of interest related to progression through the continuum of
care. Second, for each facility, these individual narrative summaries from both client and provider interviews were linked with data from facility checklists and observations to develop a case summary report for each facility. In this way, the analysis brought together a variety of perspectives on individual-level, provider-level, and facility-level barriers and facilitators throughout the continuum for that particular setting. For longitudinal interviews, similarly, individual interview transcripts for each participant were read and re-storied in a semi-structured narrative summary of that participant’s experiences, again with particular attention to issues related to the continuum of care. Key themes were identified across these narratives and developed into a conceptual framework summarizing findings across levels and steps in the continuum of care.

**Ethical review**
Ethical review and approval was obtained from the Muhimbili University of Health and Allied Sciences and the National Institute for Medical Research in Tanzania and from the Johns Hopkins School of Public Health in the United States.
RESULTS

Demographic characteristics
Facility-level data was collected in a range of HIV testing and treatment facilities in both urban and rural areas throughout Iringa region and included static HTC, mobile VMMC, PMTCT, and CTC services. The number of employees at these facilities ranged from 3 to 52. A majority of facilities offered both HTC and CTC services (Table 4).

We interviewed 75 clients at HIV testing and treatment facilities (27 male, 48 female) with an average age of 35.7 (range 19-71). Twenty-six service providers were interviewed for this study (22 female, 4 male), with an average age of 42.7 (range 24-59).

Table 4. Characteristics of HIV testing and treatment facilities

<table>
<thead>
<tr>
<th>Facility type</th>
<th>Urban/rural</th>
<th>Number of staff</th>
<th>Offer HTC services</th>
<th>Offer CTC services</th>
</tr>
</thead>
<tbody>
<tr>
<td>HTC 01</td>
<td>District hospital</td>
<td>Urban</td>
<td>n/a</td>
<td>✓</td>
</tr>
<tr>
<td>HTC 02</td>
<td>Health Center</td>
<td>Rural</td>
<td>14</td>
<td>✓</td>
</tr>
<tr>
<td>HTC 03</td>
<td>Regional hospital</td>
<td>Urban</td>
<td>18 (HTC services only)</td>
<td>✓</td>
</tr>
<tr>
<td>HTC 04</td>
<td>District hospital</td>
<td>Rural</td>
<td>26</td>
<td>✓</td>
</tr>
<tr>
<td>CTC 01</td>
<td>Health Center</td>
<td>Urban</td>
<td>45</td>
<td>✓</td>
</tr>
<tr>
<td>CTC 02</td>
<td>Dispensary</td>
<td>Rural</td>
<td>8</td>
<td>✓</td>
</tr>
<tr>
<td>CTC 03</td>
<td>Health Center</td>
<td>Urban</td>
<td>52</td>
<td>✓</td>
</tr>
<tr>
<td>CTC 04</td>
<td>Health Center</td>
<td>Rural</td>
<td>8</td>
<td>✓</td>
</tr>
<tr>
<td>PMTCT 01</td>
<td>Dispensary</td>
<td>Rural</td>
<td>3</td>
<td>✓</td>
</tr>
<tr>
<td>PMTCT 02</td>
<td>Dispensary</td>
<td>Urban</td>
<td>3</td>
<td>✓</td>
</tr>
<tr>
<td>PMTCT 03</td>
<td>Dispensary</td>
<td>Rural</td>
<td>10</td>
<td>✓</td>
</tr>
<tr>
<td>PMTCT 04</td>
<td>District Hospital</td>
<td>Urban</td>
<td>9 (PMTCT services only)</td>
<td>✓</td>
</tr>
<tr>
<td>VMMC</td>
<td>Outreach</td>
<td>Rural</td>
<td>Varied</td>
<td>✓</td>
</tr>
</tbody>
</table>

At the community level, we conducted in-depth interviews at five support groups with a total of 30 participants (12 male and 18 female) with an average age of 39.0 (range 21-63). A FGD was held at each of the 5 support groups, ranging in size from 9 to 16 individuals. We also visited 2 churches and interviewed a total of 12 clients of spiritual healers (4 male, 8 female, average age=36.8 range=25-52) and 4 spiritual healers (3 male, 1 female, average age=50.0 range=38-65). Twelve traditional healers were interviewed (9 males, 3 females, average age=56.8, range=27-84). Finally, we interviewed 4 government officials who worked with traditional healers (3 males, 1 female) (Table 5).
Table 5. Age and sex of study participants

<table>
<thead>
<tr>
<th>HIV Testing &amp; Treatment Facilities</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Client demographic information</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Male</td>
</tr>
<tr>
<td>HTC</td>
<td>12</td>
</tr>
<tr>
<td>CTC</td>
<td>11</td>
</tr>
<tr>
<td>VMMC</td>
<td>4</td>
</tr>
<tr>
<td>PMTCT</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>27</strong></td>
</tr>
<tr>
<td><strong>Provider demographic information</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>HTC</td>
<td>1</td>
</tr>
<tr>
<td>CTC</td>
<td>2</td>
</tr>
<tr>
<td>VMMC</td>
<td>1</td>
</tr>
<tr>
<td>PMTCT</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>4</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HIV Care &amp; Support Organizations</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Client demographic information</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Support groups</td>
</tr>
<tr>
<td></td>
<td>Spiritual healer</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
</tr>
<tr>
<td><strong>Provider demographic information</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Support groups</td>
</tr>
<tr>
<td></td>
<td>Spiritual healers</td>
</tr>
<tr>
<td></td>
<td>Traditional healers</td>
</tr>
<tr>
<td></td>
<td>Government liaison</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Longitudinal cohort</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td><strong>24</strong></td>
</tr>
</tbody>
</table>

Longitudinal cohort participants (n=48, 24 males, 24 females including 12 FSWs) were recruited in urban and rural areas throughout Iringa region. Participants represented all stages of the continuum of care, including 14 who had disengaged from care. Figure 1 illustrates where in the continuum of care each cohort participant was during the first round of data collection. For example, an individual in the “received HTC” stage had been diagnosed with HIV but never linked to a care and treatment center. Individuals who “linked to care” made initial contact with a CTC but had not yet completed the staging process. Similarly, those in the “ART” stage had progressed through all stages of the continuum of care and had initiated ART. Individuals who were “engaged” in care were currently receiving HIV services, while those who were “disengaged” had stopped receiving services. For example, the disengaged participant in the “received HTC” stage had been diagnosed with HIV but did not progress to a CTC, whereas the engaged participant in this stage had received HTC shortly before the first interview and was planning to link to a CTC. A disengaged participant in the “ART” stage was previously taking ART but dropped out of services and was not currently receiving ART from a health facility. The average age of cohort participants was 35.1 (33.9 for female; 36.2 for male). A majority of male
participants were married while the marital status of female participants varied (9 single, 6 married, 2 divorced and 6 widowed). A majority of participants completed primary school or higher (including all 24 male participants and 18 female participants), while 5 female participants reported no education (Table 6).

**Figure 1. Longitudinal cohort participant current stages in the continuum of care†**

![Graph showing stages of care for longitudinal cohort participants](image)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Category</th>
<th>Male (n=24)</th>
<th>Female general (n=12)</th>
<th>Female sex worker (n=12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (range)</td>
<td>Years</td>
<td>36.2 (21-51)</td>
<td>36.5 (21-50)</td>
<td>31.2 (25-40)</td>
</tr>
<tr>
<td>Location</td>
<td>Urban</td>
<td>13</td>
<td>7</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Rural</td>
<td>11</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Marital status</td>
<td>Single</td>
<td>4</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Married</td>
<td>19</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Divorced</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Widowed</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Education</td>
<td>None</td>
<td>0</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Some primary</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Completed primary</td>
<td>22</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Some secondary</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Completed secondary</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

1 In Figure 1, participants who were in later stages in the continuum had also completed all previous stages. For example, men and women who were currently in pre-ART care had received HTC and been linked to a CTC. Results for each stage in the continuum below reflect all of these participants’ reflections on the stages they had completed, not just the participants who were currently in that stage.
Facilitators and barriers along the continuum of care

Key findings are presented throughout a multi-level continuum of care framework. We present barriers and facilitators to each stage of the continuum of care (HTC, linkage to care, clinical staging, pre-ART care, ART and cross-cutting issues) at the individual/family, facility, community and structural levels (Figure 2).
Figure 2. Factors influencing entry into and engagement in the continuum of care

**Individual level**
- Fear of testing (internalized stigma);
- Reluctance to test when healthy;
- Distrust in HIV test results;
- Perception ART is highly efficacious;
- Increased perceived risk of infection

**Facility level**
- Inadequate PMTCT;
- Integration of HTC into male circumcision and PMTCT services
- Separately located services;
- Denied services at first encounter;
- Initial interaction with providers;
- Same day linkages;
- Intensive counseling
- Access to CD4 testing (limited POC, functionality of machines, reagents to run machines, personnel to run and fix machines)

**Community level**
- Traditional healers encouraging/discouraging testing & linking to other services;
- Mass media/Community mobilization;
- Motivating others to test and link to other services

**Structural level**
- HIV test kit stock-out;
- ANC requiring partner testing
- Passive referral system; Migration/mobility
- CD4 reagent stock-out
- Cotrimoxazole stock-outs
- Income generating opportunities

**Lack of privacy and confidentiality | Not receiving needed services | Poor client-provider communication | Long wait times**

**Stigma & discrimination | Traditional healer-government cooperation**

**Challenges with appointment adherence; Incorrect ART initiation; Service provider sensitivity; Referral/transfer system**

**Visible improvements in health attributed to Cotrimoxazole**
- Understanding importance of ART;
- HIV as a “normal” disease;
- Told to change behaviors
While the organization of the results highlights specific factors that affect an individual’s decision to engage in HIV services, these single barriers and facilitators do not capture the complexity of participant experiences, which often involve multiple competing priorities and multifaceted decisions. To illustrate this complexity, we present four case studies from participants in the longitudinal cohort throughout the results section to contextualize the themes within a person’s life trajectory. These case studies were chosen because they represent a broad range of experiences and demonstrate the complexity one faces while navigating through the continuum of care.

**HIV Testing and Counseling**

HTC is available in Iringa through a mix of client-initiated and provider-initiated services. Client-initiated voluntary counseling and testing (VCT) services are offered through both static and mobile services. Provider-initiated testing and counseling (PITC) is to be routinely practiced in all health facilities. In addition, PITC services are offered routinely with VMMC and antenatal care (ANC) services. In an effort to encourage male engagement in HIV services, the Tanzania Ministry of Health and Social Welfare (2012) recommends that ANC providers promote “couple/partner HIV/STI testing and counseling for all young women.”

According to Tanzanian guidelines, the process of HTC includes both pre- and post-test counseling by a trained service provider. Pre-test counseling for PITC is to be done either individually or in a group setting. Client-initiated VCT is to be performed individually and focus on a personalized risk assessment. An individual is to be provided with the results of the HIV test privately and receive post-test counseling, regardless of the results of the test. HIV-infected individuals are to be given a referral form to take to a CTC for further services.

**Individual/family level**

At the individual level, we identified several barriers to HTC including fear of HIV testing, reluctance to test while feeling healthy, and repeat HIV testing. Factors that facilitated HTC included the perception that ART is highly efficacious and perceived increased risk of HIV infection.

### Participant Story 1: Internalized Stigma

After receiving her HIV-positive diagnosis, this participant was shocked and contemplated killing herself. She recalled, “I wished to take even ten tablets at once so that when I take them I would die. That’s what I was thinking.” However, she noted that several one of her doctors supported her and convinced her to calm down and continue with HIV care and treatment services.

This participant did not disclose her HIV status to her husband or her children for one year due to fear of abandonment and discrimination. She mentioned multiple times that people perceive HIV to be a disease brought about by casual sex, and people living with HIV are viewed as “hooligans” or “prostitutes.” She found this particularly challenging because she is an older woman and feels that she is being harshly judged by people in her community.

This participant’s decision to receive treatment was challenging and complex. When she arrived for services, extremely long lines, poor ventilation, and waiting for long periods in public where others could identify her as HIV-positive, made her feel humiliated. Fortunately, despite these challenges, she recognizes the importance of ART adherence for her survival and continues with her treatment.
Barriers

Fear of testing (internalized stigma)
Study participants discussed a strong reluctance to receive HTC stemming from fear of an HIV-positive test result and of being stigmatized by the community. Many participants explained that people view an HIV-positive diagnosis as a death sentence. As one HTC client explained:

People are intimidated by the idea of testing; whether positive or negative, they are afraid. They don’t go for testing if they are not sick. They have a belief that knowing your HIV status is the end of your life. They think that you will die immediately after knowing your status. (HTC client, M, 36)

The fear of stigma was noted as a main reason people avoid HTC. Many participants explained that people are afraid to be tested because they fear being laughed at and judged by others if they are seen entering HTC services, as they fear they will be labeled as HIV-positive regardless of the outcome of the test.

Reluctance to test while healthy
There is a perception that being HIV-positive is characterized by severe illness and that an infected individual would be visibly sick. One HTC participant explained, “Because one is healthy, not sick, he goes to test and then he says they must have made a mistake. It’s not possible that I am infected with this good health.” It was widely acknowledged that people receive HTC only when they are physically sick, which is consistent with participant experiences in this study.

Distrust in efficacy of HIV test results
Several participants noted that they had tested for HIV multiple times after their initial diagnosis. Most commonly, participants did not believe the accuracy of their first HIV test and tested again to “prove” that the test was accurate. One cohort participant who had tested multiple times expressed little faith in the accuracy of the HIV tests and believed that many produce incorrect results:

So that you get correct results, if you test for the first time, you have to come and test for the second or third time and that’s when you will get your results. Sometimes these testing kits make errors; there are many of them here. (Cohort participant, M, 32)

This man delayed linking to further care and treatment services for two months. During this time, he re-tested twice before accepting his test results.

Hope of a cure from HIV infection
Other participants said that they continue to receive HIV tests with the hope that the disease will eventually disappear. One cohort participant explained why she re-tested: “You know other people say, ‘If you test here and wait for a long time and at the same time don’t have unsafe sex, then you get cured from AIDS. You might find that [the virus] has decreased or it isn’t there.’” One CTC client had tested more than 15 times. He said, “I’ve been tested more than 15 times, because I repeat every year to see if they are still there [HIV virus].” Another cohort participant was reportedly told by a doctor that HIV
would “disappear” if she took ART for long enough, so she re-tested after years on ART to check for a negative result. Finally, clients of spiritual healing services are often told that they can be cured through prayer and are encouraged to re-test to see whether God had cured them of HIV.

**Facilitators**

*Perception that ART is highly efficacious*
One factor that motivated participants to receive HTC was the perception that ART is highly efficacious and saves lives. Seeing people’s health improve dramatically when they initiated ART was discussed as a factor that encouraged people to be tested so that, if they were also HIV-positive, they could benefit from ART.

*Increased perceived risk for HIV infection*
While most participants received HTC only after extended illnesses and ruling out other causes, others sought out HTC at an earlier stage of disease progression for various reasons, including witnessing an AIDS-related death of a spouse or family member, having an extra-marital affair and being concerned they might be infected with HIV, recognizing higher risk due to having had unprotected sex with multiple partners, or simply wanting to know their HIV status. One cohort participant who was a sex worker explained how she was ready to test and ready to accept her status, knowing the risks she encountered on the job:

> I gave myself hope that the kind of work that I am doing comes with these kinds of temptations, and many problems, I cannot say this man lied to me or convinced me in this way, or he is infected or not, that is what gave me strength that I should get tested to see what the problem is, I will have to come to terms with whatever happens. (Cohort participant, F, 31)

**Facility level**
Inadequate PITC at routine health services was identified as a facility-level barrier to HTC by our participants, while near-universal PITC at VMMC and PMTCT services facilitated testing and counseling among study participants. Clients of voluntary HTC services, who initiated the testing process themselves, were generally more likely to accept HIV-positive test results than clients of VMMC and PMTCT services, who were not always mentally prepared to go through the testing process but often felt as thought they could not decline to test.

**Barriers**

*Inadequate PITC*
The Tanzania National AIDS Control Programme (NACP) recommends opt-out PITC at health facilities. According to the National Guidelines for the Management of HIV/AIDS, “Health care providers should recommend HIV testing as a standard of care to all patients in a health facility regardless of whether they have signs or symptoms of HIV infection” (Tanzania Ministry of Health and Social Welfare, 2012).

One HTC provider explained that they regularly practice PITC in health facilities:
Let’s say it’s any normal customer; that is our routine [to offer PITC]. Any customer who enters in this area, whether she came for treatment, or brought a patient ... or came to visit a patient, we convince them that ‘It is important to know your HIV status, testing is for free, come and test.’ For the one who will understand the message, who will be influenced, she will come and say, ‘I want to know my HIV status.’ She will come, and then you will sit and talk until she reaches the conclusion [to test for HIV]. (HTC provider, M, 49)

Our findings suggest that in practice, however, PITC is not routinely offered to all clients, and providers miss critical cases. Many participants shared experiences of attending multiple health facilities when suffering from opportunistic infections without ever being offered an HIV test, and often had to initiate the HIV testing process on their own. Two participants even noted that they were questioned when they tried to receive HTC without visible symptoms. One man recalled that while at the VCT center, a nurse asked him, “Why would you go for testing while you look healthy?” Both of these participants tested positive, despite their physical appearance. This mentality may perpetuate the belief that HTC is intended only for people who are sick.

In addition, several providers explained that they are often reluctant to recommend PITC services to clients when they come in for a different health matter. One HTC provider said that these clients often do not want to test because they have not mentally prepared themselves for the process of being tested for HIV, which may add to providers’ reluctance to regularly practice PITC services. She explained:

They [clients] come here for treatment [for another problem] and they refuse HIV testing if they are asked to do so. [They say], ‘I have come for this problem only and I am not ready for HIV testing. I will think about it and come back on another day.’ So you cannot force such a person or just ask them to go to the laboratory. You won’t help them that way because they are not ready for their results. (HTC provider, F, 41)

**Facilitators**

**VMMC and PMTCT services**

VMMC and PMTCT services in Iringa use an opt-out PITC approach. Clients of these services who participated in this study were under the impression that HIV testing was mandatory and they did not feel that they could decline a test. In addition, PMTCT providers noted that they had never had a woman refuse to be tested, suggesting that this practice may be coercive. Participants of these services who were not aware that they would be tested for HIV were less likely than clients of voluntary HTC services to accept their HIV diagnosis and discussed feeling “shocked” and unprepared to link to further HIV services.

**Community level**

Visits to traditional healers were discussed as a common practice for undiagnosed PLHIV after multiple visits to health facilities, which could create a deterrent to further engagement in HIV services. However, some traditional healers noted that they encourage clients to attend health facilities before treating
them with traditional medicine. Additional facilitators to HTC at the community level included mass media and community mobilization activities, as well as PLHIV motivating others to test for HIV.

**Barriers**

*People lose faith in the health system and believe they are bewitched*

As discussed above, many participants in our study were only diagnosed with HIV after multiple trips to health facilities and after ruling out multiple other illnesses. Study participants explained that undiagnosed PLHIV, who have not received HTC, often turn to traditional healers as a last resort. Often, participants believed that they were bewitched because they had ruled out other health problems. These suspicions were often confirmed by the traditional healers; all cohort participants who had visited traditional healers themselves or knew of people who had gone noted that the traditional healers always told clients that they were bewitched and in need of traditional medicine. One man recalled his experience when he took his wife to a traditional healer after multiple attempts at a health facility with no relief:

> I took my wife to a traditional healer. I thought she was bewitched. I thought she was bewitched because she was being treated [at the hospital] but did not heal. What will he tell you? He will tell you that he has the medicine and that the patient has been bewitched. He cannot tell you that she has HIV. They want her to suffer and most of them are liars ... There isn’t one [who would advise a client to go to a hospital]. (Cohort participant, M, 30)

**Facilitators**

*Traditional healers advise clients to attend health facility*

Several traditional healers interviewed for this study noted that certain diseases such as anemia, tuberculosis and HIV cannot be treated traditionally and must be addressed at a health facility. A majority of traditional healers further explained that they refused to treat clients who visited them before having been to a health facility and advised clients to return only after being seen by a medical doctor. However, no participants in this study reported being advised to visit a health facility for further testing, despite the insistence by some traditional healers that this is common practice.

Advising clients to attend a health facility could facilitate HTC among clients of traditional healers and could be an important alternate pathway to HIV care and treatment services. Very few traditional healers said that they specifically recommend that a person receive HTC, but rather tell them simply to visit a health facility to try to determine what is wrong. Healers noted that if a client comes to them after having been to a facility (whether or not that person has received HTC) the healer will treat that person through traditional medicine.

*Mass media and community mobilization*

Several participants discussed mass media promoting HTC as a reason for being tested, while a few others noted a campaign several years ago in which the Tanzanian president was tested publicly and
encouraged everyone to know their status. Participants also mentioned the availability of mobile HIV testing services, community mobilization, and education as factors that facilitate HTC.

Motivating others to test
Members of all support groups explained that one core purpose of their group was to educate the community about HIV and AIDS and motivate others to receive HIV services. Almost all support group members noted that they had motivated multiple people to test for HIV by sharing their personal experiences to demonstrate that it is possible to be strong and healthy while living with HIV. In addition, members often escorted family members, friends, and neighbors to HTC services and supported them through the linking process to engage in further HIV care and treatment services. As one support group member explained:

We help people to realize that HIV is not such a scary disease … There are a lot of people who are going for testing right now due to our influence. Some come here for advice. They go for HIV testing and are initiated on ART. They are doing well now because of us. They were so afraid of HIV testing before the group was established. I decided to disclose my status in public to save others. Some people who have symptoms come to me for advice. I tell them about everything that they have to do so that they are started on medications. (Support group member, F, 34)

In addition, many CTC clients who were not involved in a support group explained that since enrolling in CTC services and witnessing their own improvements in health, they commonly encouraged others to be tested for HIV and many noted that they had supported multiple other people to enroll in CTC services. It was widely acknowledged that this type of interpersonal communication among friends was an extremely effective method for encouraging people to access HIV services.

Structural level
At the structural level, barriers to HTC included widespread and chronic stock-outs of HIV test kits and the policy of ANC services requiring partner testing.

Barriers

HIV test kit stock-outs
A major barrier to HTC was the persistent stock-out of HIV test kits, which was common throughout the Iringa region for the duration of this study. Of the 13 facilities visited, 5 reported a stock-out of HIV test kits at the time of data collection. However, the research team deliberately chose not to visit some facilities without HIV test kits in order to maximize the number of HTC clients reached, so the proportion of facilities with test kit stock-outs may have been higher. This was described as a major inconvenience and frustration by both service providers and clients. Service providers discussed the courage it took for a person to voluntarily come for HTC and noted the disappointment they felt when they turned a person away. Some providers noted that they referred clients to other health facilities, but those facilities also often lacked test kits. One HTC provider expressed her frustration this way:
We are losing so many clients. It’s very disgusting for someone who leaves his house knowing he is going to the hospital for services. [He thinks] ‘I am going to get [HTC] services.’ And then when he gets there, he finds there are no services. Sometimes I have nothing to help him out ... It’s not only here; this is the problem for all places in this district. I think it’s also in all places in Tanzania ... So that’s a big problem. We face some difficulties in delivering VCT services. (HTC provider, F, 55)

Clients also expressed frustration with the chronic stock-out of HIV test kits. Several told stories of coming more than three times to a health facility to receive HTC, only to be turned away. They explained that this was very disappointing and wasted their time and money. Several participants said that this stock-out has caused many people to give up on HIV testing completely. Another participant attributed his inability to receive an HIV test to witchcraft. He said, “The blood sample was not accepted...tests were not available whenever I came here.” He believes that this is proof that he was bewitched.

**ANC services requiring partner testing**

PITC is a routine service for pregnant women during their first ANC visit and the gateway to PMTCT services, but our findings suggest that women are often denied ANC services unless they bring their male partner to the first ANC visit for couples testing. During a direct observation of a PMTCT facility, a data collector noted a poster on the wall that stated (in Swahili), “It is required for a pregnant woman to come with her husband/partner on her first [ANC] visit. You will not be served without following this.” This was confirmed by a PMTCT provider who explained how her service required men to join their wives for HIV testing:

> When women go to the [ANC] clinic, they are asked to bring their husbands. They don’t get other services until they bring their husbands. So the husbands are motivated because they tell themselves that their partner won’t get the services unless they bring them to the clinic and they can’t stay without those services. That’s how they get tested [for HIV]. (PMTCT Provider, F, 41)

Other providers noted that their policy of requiring men to accompany their wives to ANC services was a way to engage men in the HIV testing process, since men are often reluctant to be tested, but said that they would not deny a woman ANC services if she came alone. However, the experience of PMTCT clients with regard to HIV testing was contradictory to this explanation. Multiple women in our study were denied ANC services because their male partners did not accompany them, and almost all women were aware that ANC clients would not receive services unless their male partner attended the first visit. Several participants were told that they could only receive ANC services if they either brought their husband or brought a stamped, official letter from the village chairman explaining why the husband could not attend. One participant was not given ANC services until she was six months pregnant because the service providers refused her services until she came with her husband, who was traveling most of the time. She explained that she tried to attend but was turned away and told that she must return with her husband. She recalled:
I already knew that when you go to the clinic for the first time, you must go with a man - your partner. But he was not present; whenever I made a phone call to him he was saying, “I will come” or “I will make arrangements.” Time was passing and even when I came for the first time, the nurse sent me back ... The nurse told me, ‘Go to advise your husband [to come with you to the clinic] so that we can help you.’ (PMTCT client, F, 31)

PMTCT clients said that this situation posed a real dilemma for them. They were aware of the importance of receiving antenatal care and, if needed, PMTCT services throughout their pregnancy. However, many women’s husbands refused to attend these services because they were traveling or refused to receive an HIV test. Several women said that they spent months trying to convince their husbands to attend the services with them, resulting in some women waiting until their third trimester to attend ANC services for the first time. A few study participants told stories of their friends who avoided ANC services altogether because they were afraid to ask their husbands to test for HIV, or did not have a partner and knew they would be denied services if they came alone.

Access to and linkage to care
Following HTC, all additional HIV services in Iringa are provided through care and treatment centers (CTCs). After an HIV-positive diagnosis, an individual must link to a CTC in order to enroll in services and progress through the continuum of care. This process includes a referral form, filled in by the HTC service provider, which the client then takes to a CTC to enroll in services. In some locations, the HTC and CTC centers are co-located and a client is able to link to CTC services on the same day, provided CTC services are being offered on that day. Some HTC services are offered in small dispensaries or through mobile services where CTCs are not available, so clients must then travel to a different location to enroll in CTC services. Participants in this study described a range of experiences throughout the process of linking from the HTC to a CTC, which are presented below.

Delay in linking to care
Eight cohort participants reported a delay in linkage to care after initial HIV diagnosis. All 8 of these participants felt healthy at the time of diagnosis.

- Four participants didn’t see a reason to see further care and treatment while healthy.
- One participant was not mentally prepared to accept diagnosis and link to further care and treatment.
- One man did not believe his HIV test results, so received two more HIV tests in the following two months before accepting the results.
- One woman was shouted at by a PMTCT provider while pregnant. She dropped out of PMTCT services at the time and did not link to further care and treatment services until she became visibly sick more than two years later.
- One participant received HTC at a local dispensary. The nearest CTC was not accessible so she did not link to a CTC for one year, until one opened closer to her home.
Individual/family level

 Feeling healthy at the time of HIV diagnosis was one key barrier to successfully linking to care at the individual level. In addition, faith in God’s ability to cure HIV prevented individuals from linking to care.

Barriers

Feeling healthy at time of diagnosis

One common theme discussed by both clients and providers was the importance of mental preparation and acceptance of HIV-positive test results in order for a person to successfully link to a CTC for further care and treatment. Clients were most likely to accept their HIV status and freely link to a CTC when they had been sick for an extended period of time. These clients expressed relief in finally determining the cause of their suffering and were happy to immediately link to a CTC in order to start receiving treatment.

In contrast, participants widely acknowledged that people who test positive while they still feel healthy are much less likely to link to a CTC. HIV was discussed as a disease for “people who are sick and weak,” and many participants noted that when people are healthy, they either do not believe the HIV test results or do not see the point in attending a CTC. For example, one 28-year old woman was diagnosed with HIV while pregnant. After giving birth, she did not follow up with further PMTCT or CTC services. She explained, “I saw that my body was good and I didn’t have any problem. I was not sick so I decided to stay strong like that without following up on anything.” This is similar to two other women who did not feel sick and saw no reason to engage in CTC services at the time of diagnosis. Both of these women waited more than a year before making initial contact with a CTC.

One provider also acknowledged that people often do not immediately link to care if they feel healthy at the time of diagnosis. He gave a hypothetical example of the way a healthy person might delay linking to a CTC:

Because she is fat and not suffering from anything, she goes and folds that [referral] paper and keeps it. She will stay for a long time until she sees that she is very sick. In the future, the coming years or months or the coming days, that is when you can see that this person is sick … I just see that she has so many reasons to defend herself, but that is it when a person is not suffering from anything she sees that she is perfect so it is not easy to come early to CTC. (Provider, F, 56)

Faith in God’s ability to cure HIV

Another barrier to successfully linking to care for some individuals is participation in spiritual healing services. Three clients of spiritual healing services noted that they had been diagnosed with HIV but never linked to further care and treatment services. These individuals all had faith that God would either cure them or stop HIV disease progression, so believed that attending CTC services was not necessary. As one client explained:
These clients said that they would link to CTC services if their health condition severely deteriorated, but at this point they believed that prayers were more important than HIV services. In addition, these clients noted that church leaders had never advised them to attend CTC services, which further supported their decisions not to engage with the health system.

**Facility level**

At the facility level, PLHIV struggled to successfully link to care when HTC and CTC services were separately located, which occurred at all VMMC outreach sites and two PMTCT facilities. Another barrier to successful linkage to care occurred when participants were denied services during their first encounter with a CTC and when they had negative initial interactions with service providers. Same day linkages from HTC to CTC services and intensive counseling facilitated this process.

**Barriers**

**Separately located services**

Many HTC services are stand-alone and are not co-located with a CTC, so clients are given a referral card and told to travel to the nearest CTC on their own. In Iringa region, HTC and CTC services are generally co-located only at larger health facilities such as district and regional hospitals and some larger health centers. Mobile services offering HTC, such as HTC or VMMC outreach services, and smaller dispensaries offering stand-alone HTC, PMTCT or VMMC services, which are often located in more rural areas, are less likely to be co-located with CTC services. In this study, all VMMC outreach sites and half of the facilities offering PMTCT services were not co-located with a CTC. Participants at these services described more challenges linking to care because they were required to travel to an alternate location to enroll in CTC services. Participants noted that separately located HTC and CTC services created two challenges. The client was required travel to a new location which was often further than the HTC service and time consuming to reach, required money for transportation and was often unknown and scary for the client to attend for the first time. In addition, several participants mentioned that the delay in linking from the HTC to CTC gave the participant time to hesitate and re-think the decision to be linked altogether. As one service provider explained:

> [It’s challenging when a client] has tested in centers not having other services whereby you are given a referral letter to another place. When he reaches a certain place [CTC] and starts hesitating, he will stop. But if he tested here, he would be escorted to the CTC by the VCT service provider. (CTC provider, F, 38)

**Denied services at first encounter**

Even when HTC and CTC services were co-located, clients sometimes encountered challenges during their initial visit to the CTC. Many CTC services were available only two or three days per week during set hours. Clients were only able to enroll in these services if they arrived during these specific times and if
service providers were accepting new clients. Many participants told stories of trying to link to the CTC only to find that they did not arrive on the correct day. Others were told that there were too few service providers to help with the enrollment process and were instructed to come back on another day. For example, one CTC client said that when individuals are diagnosed with HIV, they are frustrated by the long and complicated process of linking to the CTC and often give up completely. He gave an example to illustrate this tenuous process:

For example, you can test today. Then they tell you to come back [to the CTC] next week. When you come back the following week, they tell you to return on Thursday for the seminar. When you return on Thursday they tell you come back on Friday. I talked to my friends and they said that if you are lucky, then they will give you medication for 14 days. They can give you medication for 14 days and tell you to come back again on the 14th day. If there is no medication [when you return], they just tell you to come on another day. So we are asking that once a person comes to test and is found to be infected, the time that he spends [linking to services] should be reduced. (CTC client, M, 33)

**Negative initial interaction with service providers**

Some study participants expressed frustration by the way they were treated by CTC providers during their initial visit. In general, clients found their HIV testing experience to be a positive one and were satisfied by the way service providers treated them. Many contrasted this HTC experience with the negative experience they had at the CTC, in which they found service providers to be rude, the center to be congested and where they received little information. One HTC client compared the HTC and CTC experiences:

Let’s say that a person wants to test for HIV so that he knows his health status. And suppose he is found to be infected but still his health is in a good condition. He will give up [trying to link to the CTC] because there are a lot of processes that one has to do, and considering the fact that is very hard to see doctors around [at the CTC]. [At the HTC] he can reach there where people go and test and when the doctor finds him, he just tests his blood sample and within five minutes the results are out. But the process in this place [the CTC]...it’s true there are problems here. Providers here are tired. They are so strict...they are so strict. (Client, M, 33)

Participants also mentioned that clients often did not receive adequate information and felt that service providers ignored them. One HTC client said that when CTC providers did communicate, it was in a very rude way and they did not explain what the patient was supposed to do, leaving the patient confused and frustrated. He explained:

I would expect that when you come here [to the CTC] they should tell someone that you are supposed to do this and that. But here they became so rude and say that “we have told you to do this and this.” So it becomes that you don’t understand what to do because they fail to explain to someone well, and if you make a little mistake then they start to complain and so it happens that you start answering them in a rude manner. (HTC client, M, 33)
Facilitators

Co-located services/same day linkage
Co-located HTC and CTC services were mentioned frequently as a facilitator to linking people to further care and treatment services. Both clients and providers said that linking a person to a CTC on the same day increased that person’s chance of continuing to receive HIV services. This process was further strengthened when a service provider personally escorted a client from HTC to CTC services, which was discussed as a strategy by participants at several facilities in this study. As one CTC service provider explained:

If he [a client] goes and gets tested and is found to be infected, the attendant who tended to him there will come with him straight and bring him here to the CTC and hand him to us. So he will not be able to get lost there in the middle because he will be escorted with the one who tested him and he has already been counseled that if you are found to be like this we must connect to a certain place. (CTC provider, F, 47)

Intensive counseling
Receiving intensive counseling from service providers, both after receiving an HIV positive diagnosis and after linking to a CTC, was noted as a factor that facilitated the linking process. For example, one cohort participant reported that she was “shocked” when first diagnosed with HIV. However, she received 2-3 hours of counseling during the HTC session. When she linked to the CTC, she attended services frequently, even though it was not required, but she felt that she needed the extra counseling. She continued to receive counseling for three months and finally came to accept her HIV status. She credits her acceptance to that intense degree of counseling. Even years later, she continued to attend the CTC monthly, even though with her good adherence, she was expected to come only every three months.

Structural level
The passive nature of the referral system, which prevented providers from following up to ensure a client had linked to care, was discussed as a structural-level barrier to effective linkages. An additional barrier was the high work-related mobility and frequent migration of certain people, such as sex workers.

Barriers

Passive referral system
After an HIV-positive diagnosis, clients were given a referral card to take to the CTC in order to enroll in further HIV care and treatment services. Providers explained that the referral card had two parts: on one part, the health provider wrote information about the HTC facility. The second part was filled out when the client reached the CTC. If the client did reach the CTC, the provider could track that person and see that they had successfully registered, but this was only feasible when the HTC and CTC services were co-located and providers could physically check on the status of their clients. There was no active tracking system to ensure that a person successfully linked at another facility. One HTC provider said that if an HTC client did not link to the CTC, “it means you will not get the feedback that your patient has
reached there or not.” This process limited the ability of providers to follow up with clients to ensure successful linkages to care.

**Mobility/Migration**
Certain segments of the population experienced high levels of work-related mobility or migration. The population from this study most affected by this was sex workers, but it would also likely apply to transport workers, agricultural workers on seasonal plantations such as timber, tea, tomatoes, as well as fisheries in Iringa region. This mobility made it harder for people to engage in and/or stay engaged in care. The difficulties some patients had transferring their files from one location to another were explained elsewhere. One cohort participant explained that she had not linked to a CTC because she was working only temporarily in Mafinga, and wanted to wait until she returned to her home region, Mbeya before enrolling. In the meantime, she bought herself cotrimoxazole at the pharmacy.

**Clinical staging and CD4 testing**
After successfully linking to HIV care and treatment services, an individual undergoes clinical and laboratory staging to determine whether or not he/she is eligible for either pre-ART or ART care. In Iringa, this process most commonly involved a medical evaluation and CD4 testing. According to national guidelines, ART initiation is recommended for individuals with WHO stage 3 and 4 clinical criteria, regardless of CD4 cell count, and for adults and adolescents with a CD4 count < 350 cells/mm³, regardless of clinical symptoms (Tanzania Ministry of Health and Social Welfare, 2012).

**Facility level**
PLHIV experiences of receiving a CD4 test and results varied greatly and are presented below as both a barrier and facilitator to the clinical staging process.

**Barriers**

**Ineffective systems for CD4 testing**
The process of obtaining a CD4 test was a major challenge for a majority of CTC clients in this study. Of the four CTC sites visited, only one had a working CD4 machine, which was donated by a private local organization. Two facilities had CD4 machines that were either broken, lacked reagents or had very limited capacity, and one had no CD4 machine at all which required that clients travel to an alternate facility for CD4 testing. Larger health facilities (often district and regional hospitals) were more likely to have a CD4 machine, but these were not necessarily in working order.
Receiving a CD4 test at an alternate facility was a very challenging procedure for many clients. First, the doctor needed to write a referral letter that the client presented to providers at the alternate facility. Without this letter, an individual was denied services. Clients often travelled long distances and noted that they had to leave their homes at 4 or 5 in the morning in order to arrive before a majority of other clients. CD4 machines often had limited capacity, so centers were only able to test a certain number of clients in one day, and clients who normally attended the facility with the CD4 machine were given preference, making it even more difficult for PLHIV to obtain CD4 testing at an alternate location. In addition to these challenges, several clients noted that their test results had been lost multiple times, forcing them to complete this process again. Because of these inconveniences, participants said that many PLHIV lose hope and drop out of HIV services completely at this stage.

Participants expressed great frustration in this tedious process, which prevented many people from checking their CD4 on a regular basis, and delayed others from initial clinical staging altogether, thereby delaying ART initiation. For example, one CTC client spent six months trying to receive a CD4 test and the results. She was told that Iringa Regional Hospital was the closest facility with a CD4 machine. She went multiple times for testing but was told that the machine was broken; she finally succeeded after three months. After the test, she was told to go back to her regular CTC to receive the results. She again spent three months—and multiple trips to the health facility—waiting for the test results. She noted that this process took a great deal of time and money, and when she received her results six months after first trying to check her CD4, she was told that she needed to initiate ART immediately, suggesting that this process caused her to delay ART initiation. In addition, a cohort participant had gone to get her CD4 tested, but after seeing the long line, she returned home; she explained that she simply could not miss that much time from her business. Another CTC client expressed her frustration with this system:

Participant Story 2: Disengagement after linking to HIV care and treatment services

This participant was diagnosed with HIV and immediately travelled to the nearest CTC, which was more than two hours away via public transportation. However, he became frustrated with the poor quality of care and long distances and disengaged from HIV services after only four visits, before completing the clinical staging process.

The participant’s decision to disengage from care was a culmination of several factors, including inadequate services, being told repeatedly to return on a different day, and the cost associated with each trip. During his visits, he noted that he was not provided with any education or medication. He explained, “I gave them my [CTC] card and they would tell me to come back the next month. I would go the next month, again they would write for you [to come back the next month], without getting any medication.” He also described the challenges he faced with CD4 testing and the process of getting the test results:

In February they said, “You have to check your CD4.” I went to test my CD4, and was told to come the next month to take my results. So when I went there to take my results I saw that they didn’t have the results. They told me again to come back on another day, and then there I was, discouraged ... and when I went the [next time] the queue was very full. [They told me], “You are required to come again next week.” I was discouraged again there ...

Traveling to the CTC facility took more than two hours and multiple modes of transportation. The participant explained that he could not continue to waste his time and money on CTC visits when the quality of services was so low, so he disengaged from care and has not returned.
It was troublesome; we used to wake up at 6 am to get [CD4] testing. When you reach there, you find a long line of people and the machine takes only 50 patients, so when you reach 50 it was finished. The others [who did not get tested] had to leave; I had to go there for about a week. I managed to get tested in the second week ... You have to wake up about 4 or 5 in the morning so that you can be early; when you are later than that you get turned away. (CTC client, F, 45)

**Facilitators**

**Efficient CD4 testing process**

In contrast to the many challenges described above, providers and clients at the health facility with a working CD4 machine had very different experiences. As one service provider explained:

I am happy about the CD4 here at our place ... Our machine does not bring problems like other machines. We just have to take blood and the reagents are available, and there is not any time that we missed reagents for CD4 to date. So it has been a motivational factor for a person to work well, because all the equipment is available at the right time. (CTC provider, F, 35)

Clients of this facility explained that they were able to receive CD4 results on the same day and rarely waited more than one hour. Many of these clients had attended a different CTC in the past and had similar challenges as described above, so they were very grateful for the ease with which they received their CD4 count. Clients who did not have negative testing experiences at alternate locations often had little to say about the process since it was run so efficiently. One provider explained that having a working CD4 machine had increased linkages and retention in HIV care and treatment services. She said:

It has been a great motivation [for clients] because first you might find a patient has come here for VCT. If she tests at the VCT and is found to be positive, on the same day she tests her CD4. For example, those who have come today, it is on the same day they are prescribed to test CD4, so it becomes a great motivation. Because the patient is not late, it is just on the same day that she was found to be HIV-positive, and she tests CD4 on the same day. And on the same day she will begin training for starting medication. (CTC provider, F, 35)

**Pre-ART care**

Following clinical staging, PLHIV who are not yet eligible for ART initiation engage in pre-ART care services until they are eligible to initiate ART. This stage in the continuum of care includes regular clinical assessments for ART eligibility and consistent HIV care. According to Tanzanian guidelines, individuals in this stage of the continuum of care should receive cotrimoxazole prophylaxis, a combination of antibiotics used to treat a range of opportunistic infections associated with HIV, free of charge. Clients are expected to return to the CTC monthly for monitoring and to receive cotrimoxazole and should receive CD4 testing every six months until eligible for ART initiation.
At the individual level, witnessing visible improvements in one’s health facilitated retention in pre-ART care services, while frequent stock-outs of cotrimoxazole prophylaxis created a barrier at the facility level.

**Individual/family level**

**Facilitators**

*Visible improvements in health*

One facilitating factor for retention in pre-ART care was the visible health improvement witnessed by study participants. Several clients of pre-ART care services explained that they were very happy to attend monthly appointments because they had seen drastic improvements in their health since enrolling in pre-ART care and attributed this improvement to their daily dose of cotrimoxazole. These participants were most likely to have been visibly sick when enrolling in CTC services and had since regained their health.

**Facility level**

**Barriers**

*Cotrimoxazole stock-outs*

Many participants enrolled in pre-ART care viewed receiving cotrimoxazole as the main benefit of attending pre-ART care appointments. However, 6 out of 11 facilities reported stock-outs of cotrimoxazole at the time of the facility checklist, while another facility had recently received this medication after a two-month stock-out. Study participants almost universally reported chronic stock-outs of cotrimoxazole and clients were often told to either purchase the medication from a local pharmacy or go to another health facility. Both of these options required that the client pay money, either for the drug itself or for transportation costs, and some could not afford to do this. Several clients explained that they had gone for extended periods of time without taking cotrimoxazole, to which they attributed declining health.

In addition to the inability to purchase cotrimoxazole, several participants explained that people in pre-ART care became frustrated when they were told to buy this medication and decided to stop coming to the CTC every month, since they did not feel they were benefitting in any way from these services. One CTC client explained:

> Frankly speaking there is not enough [cotrimoxazole]. Most of the time this is disturbing us so much. And for other people who are starting [pre-ART care], when they are coming for the first month, they are told to go and buy them [cotrimoxazole], and in the next month they are told to go and buy, and in the next month they are told to go and buy them. Now it reaches a point when he sees that he would be better off to go and buy them rather than coming here [to the CTC]; he is wasting time. (Client, M, 45)
Participants acknowledged that many people drop out of pre-ART care services and only return to the CTC when their health has visibly declined; however several providers said that clients often return only when their CD4 has dropped to a very low level and must then initiate ART immediately.

**ART initiation, adherence and retention**
The next stage in the continuum of care is ART initiation. Current Tanzanian national guidelines recommend ART for individuals with CD4 counts of ≤350 cells/mm$^3$ or those with severe or advanced clinical disease. Before ART initiation, an individual undergoes ART initiation and adherence training consisting of at least three training sessions, often conducted in a group setting. These sessions focus on basic information about HIV and AIDS, the importance of lifelong ART adherence and risk reduction counseling. Following ART initiation, clients of CTC services receive ongoing counseling and education during their CTC visits.

The final stages in the continuum of care are adherence to ART and retention in care (for individuals before and after ART initiation). Below, we present results from these stages together.

**Individual/family level**
Being told to change behaviors was discussed as a barrier to retention in ART care. Facilitators to ART initiation, adherence and retention at the individual level included understanding the importance of ART and viewing HIV as a “normal” disease.

**Barriers**

**Need to change behaviors**
Some study participants, especially female sex workers, reported that providers explained to them the need to eliminate or reduce alcohol consumption and reduce the frequency of sexual activity. Participants explained that alcohol either makes people forgetful, and thus interferes with adherence, or that it interferes with the medications, and thus should not be mixed. A couple of sex workers asked their doctors about alcohol use, if total abstinence was really necessary, and were told they could drink a little as long as they took the medications hours before or after drinking. However, other participants did not ask follow-up questions about alcohol, and thus believed that alcohol use was impossible.

According to cohort participants, the recommendation to reduce the frequency of sexual activity was because sex compromised immunity, and caused loss of energy or weakness; it was thus seen as somewhat dangerous for PLHIV. Some participants in the cohort said that providers told them to abstain from sex, or at least reduce the frequency of sex, in order to avoid new infections of HIV. Sex workers felt this recommendation could be problematic, since sexual activity was essential to their livelihoods. Sex workers wondered how they would continue to earn an income if they reduced their sexual activity, though some reported trying. Sex workers who were receiving HIV care did not disclose their work to providers, not wanting to hear the recommendation to reduce sexual activity when they knew they would not be able to follow the advice.
Facilitators

Understanding the importance of ART
Similar to clients in pre-ART care who had seen visible improvements in their health and therefore continued to engage in HIV services, many CTC clients were very committed to ART adherence and retention in services. Participants explained that they understood the importance of these medications to keep them healthy and had seen the benefits of HIV care and treatment services. Multiple CTC clients explained that when they initiated ART, they were so sick that they could barely walk. They mentioned the dramatic improvement in their health since starting to take ART as the reason they continued with these services. One female CTC client said “When I remember the state I was [in before receiving HIV services], I am really motivated to come for my medicines; I never miss even a day.” However, visible improvements in health also acted as a barrier to retention and adherence. Participants explained that PLHIV often stopped taking ART or disengaged from care when their health improved because they did not see the importance of taking medication while they felt healthy.

HIV as a “normal” disease
Clients additionally discussed how they were motivated to continue with CTC services because seeing other clients at the CTC made them feel that they are “not alone” and helped them to see HIV as a “normal” disease. As one woman explained:

During the beginning when we were getting this [CTC] service there used to be very few people. So I felt very bad when I was told that I had the infection ... later on I felt normal as they [CTC providers] continued giving me this medication [ART], so as the number of people kept on increasing, I kept on encouraging myself that it is better if I continue using the medication. Initially I felt so weak, I felt like my fellows were somehow stigmatizing me. But after the number of people kept on increasing then I felt like it is just a normal thing and since then I have been feeling good. (Client, M, 47)

Facility level
We identified several barriers to retention in care at the facility level, including challenges attending CTC appointments on the assigned time and date, incorrect ART initiation and disrespectful treatment by service providers. Facilitators for this process at the facility-level included respectful treatment by service providers, the referral/transfer system and home-based care providers.
Barriers

Challenges with appointment adherence

In general, CTC clients were required to attend the clinic on a pre-assigned monthly date for a health check-up and to receive ART. While some CTC clients had no problem attending the CTC on their assigned monthly dates, others struggled to regularly attend these appointments for a variety of reasons. First, some clients were employed and found it difficult to get time off work each month to attend the clinic. For example, one CTC client worked as a cleaner at a university in Iringa. She had not disclosed her HIV status to her employer for fear of being fired, so she made up an excuse every month to get a few hours off from her job. She explained that even when she made this effort to reach the CTC, she did not always receive services. She explained:

Currently I am working. So when I am at work there are times that I ask for permission to leave [to go to the CTC] and they refuse, so I usually leave without notifying them ... Usually at work we have only one hour and a half for resting and during that period of time of one hour and a half, you may find the nurses here [at the CTC] are preoccupied with other work. (Client, F, 28)

Other CTC clients worked in locations that were far from the CTC and were unable to access the health facilities on a monthly basis, and several cohort participants dropped out of services completely for this reason. In addition, service providers and clients spoke about the challenge CTC clients faced during cultivation season. Many people owned fields in villages outside of town, and often slept in these areas during the cultivation season, making it difficult for them to return for their monthly visits. Clients also noted that they often needed to travel on short notice to care for sick family members or to attend

Participant Story 3: HIV testing without consent & Balancing employment and CTC appointments

This participant tested for HIV without his knowledge or consent. After being admitted in the hospital, he noted that his clinic exercise book stated that he had been tested for HIV, but he had no recollection of this event. Several days later he was told that he was infected with HIV.

This man works for a Chinese construction company. His workplace is located far from the hospital and he is often unable to attend CTC services on his assigned day since he would be fired from his job if he asked for time off. When he finally managed to attend CTC services, this man was advised to initiate ART, but told that he must attend a series of trainings first. Due to his job, he was unable to arrive at the CTC center in the mornings when these trainings were held, and he therefore had not initiated ART. He also often arrived after CTC providers had left and was unable to receive cotrimoxazole. He noted his frustration and the dilemma that he faces in choosing whether or not to leave work to go to the CTC:

The [service providers] say that the medications are finished. To be honest, they are making us to give up because a patient who has reached [the CTC] is supposed to get services. Now, when you reach there they don’t want to give you the services at the time when you want to go there. I am protecting my health, [but I am also trying to] protect the work which is helping me ... so I am stealing that time from work [in order to] protect my health.

This situation created a serious dilemma of two critical competing demands and needs for this participant; he noted that he would not be able to support himself or his family if he quit his job, but he also could not receive HIV services with the current situation because he was working during CTC hours and realized that his health would continue to deteriorate if he did not initiate ART.
weddings or funerals, which also prevented them from regularly attending the CTC on their assigned date. In addition, women who had not disclosed their HIV status to their husbands had to attend CTC visits in secret and struggled to leave home to attend the clinic all day.

*Incorrect ART initiation*

There was indication from patients that some providers may not have been following guidelines for ART initiation, both taking HIV positive patients off of ART after initiating them, or failing to start patients with extremely low CD4 counts. Several cohort participants reported that they were told by their doctors to discontinue ART when they became healthy. These participants believed that taking ART when healthy could be harmful. For example, one cohort participant initiated ART in 2006. In September 2013, she reported that her doctor instructed her stop taking the ART and continue only with cotrimoxazole because her “CD4 count was high.” She explained, “They say that my CD4 count is good, so why should I continue with medications?”

Other participants explained that they were not initiated on ART, even after their clinical symptoms indicated ART initiation or when their CD4 count was well below 200 cells/mm³. For example, one cohort participant said that she had a CD4 count of 100 and significant opportunistic infections, but was only given cotrimoxazole. She said that doctors were only initiating ART for clients with a CD4 around 50. In addition, some participants explained that doctors were reluctant to initiate ART for PLHIV who were very sick with extremely low CD4 counts; instead, these people were told to wait until they were healthier and their CD4 counts rose in order to initiate ART. This understanding of the importance of ART initiation when healthy was discussed by multiple participants. One woman explained, “If they give you medications when the CD4s are low, you will die.”

*Disrespectful treatment by service providers*

One of the most significant barriers to retention in CTC services discussed by study participants was disrespectful and abusive treatment by service providers. Almost all participants in this study reported negative experiences in which they were treated very poorly by one or more providers. Many clients mentioned that service providers were unmotivated and often in a bad mood. As one CTC client explained:

> Some providers don’t speak nicely, they are not welcoming and even in the class they teach as if teaching children, and they scold us. If you reach there [the CTC] and find them cleaning, they will say, “Sit outside.” You will stay outside until they finish cleaning. When you enter in, you will open the windows and clean the benches on your own while they chat. They come out on their own time and when they feel hungry they just leave us on the benches and go for tea. They are selfish. They let in first their relatives or neighbors, that’s what they do over there. (CTC client, F, 31)

Often, negative encounters with service providers occurred when a client did not obey the rules set out by providers, which most commonly occurred when a client missed a CTC appointment or arrived late for services. Participants described being “shouted at,” “scolded” and “punished” when they missed a scheduled appointment, even if they had a legitimate excuse for not being able to attend, such as
lacking money for transportation, caring for a sick child or traveling to a funeral. When clients returned to the CTC on a day other than their assigned clinic day, or simply arrived late, they were often either denied services completely or forced to wait until the end of the day as “punishment” or “correction” for their behavior. One cohort participant explained that she was punished by a service provider when she arrived late. She said:

When I reached there [CTC] they said, “How many are late?” We raised our hands. They said, “Every day we tell you to come early. When is your time?” One of us raised our hand and said at 8 am. “Why are you coming at 9 and we have much work to do? ...Today you will get service at 12.” And surely we were seen at 12. They left, I don’t know where, maybe to drink tea, until we got tired, that is when they came back and gave us services. (Cohort participant, F, 42)

Many clients said that they had "gotten used to" this kind of treatment and endured this behavior because they realized the importance of receiving ART. However, clients also explained that they knew people who had dropped out of services because of this treatment, while several CTC clients and cohort participants themselves disengaged from these services due to abusive treatment by providers. For example, one CTC client was publicly humiliated by a nurse at the regional hospital, which humiliated her so much that she dropped out of CTC services for more than two years before re-engaging with care at a different location. She recalled:

I was on the waiting bench. That’s where they weigh us before we enter into the doctor’s room. That’s when a nurse said, “You are wearing tight pants and the way you are seated is seductive and you have even applied eye liner. Who are you trying to attract? You just want to hurt others [i.e. infect others].” That was so painful ... I stopped attending those services [at the regional hospital] because of the statements used in there. I just stayed home because I had already lost hope because of the statements used by some nurses over there. There were very good services until one nurse spoke to me in a very bad way that made me feel worthless, maybe because of the way I am. So I felt really sad. My heart doesn’t feel like going back there because I feel sad every time I see her. (CTC client, F, 31)

Cohort participant who had dropped out of care described a reluctance to return. Even though they saw the importance of CTC services, they were afraid of the harsh treatment they might receive from providers as punishment for dropping out.

CTC providers generally acknowledged the importance of treating clients with dignity and respect. One provider explained that if they did not treat clients with respect or communicate well, they would not return for services. She stated, “If I haven’t handled this person correctly in the treatment area, then we have a chance of losing that person.” One factor that contributed to disrespectful treatment was the client record system. Service providers discussed the challenges they faced organizing paper-based client medical files. When a client missed a scheduled appointment, providers often struggled to keep track of the file and retrieve it when a client returned on a different day, which contributed to their frustration and verbally abusive treatment of clients. In addition, one provider explained that they routinely punished CTC clients who arrived late or did not attend the CTC on their assigned date, which
was consistent with several client experiences. She said that they would force the client to wait until the end of the day to receive medication, or they would only give out 3 or 7 days of ART instead of the usual 30 day supply in order to make the person understand that they could not continue their behavior.

**Facilitators**

**Respectful treatment by service providers**

While a majority of participants recalled negative experiences with one or more service providers, clients at all four CTCs also described experiences in which they were treated with kindness and respect. One rural CTC facility was praised by all clients for the high quality and respectful treatment provided. This particular facility opened several years ago, so many CTC clients had previously been enrolled in alternate CTCs and were able to compare the difference in provider treatment between the facilities. In addition, they noted that the quality of treatment at this facility had greatly improved in the past several years. One CTC client at this facility explained that providers were very nice to patients and understood when a problem came up and a patient could not come to CTC services on that day:

> The attendants provide [services] nicely. In fact, they do not anger us. As usual there is no problem ... Others, for example, others would get harsh. Maybe if you are late, she may shout at you and yet you have come from far. But for now it is not like that. Here, they receive you well. Maybe you come from far and there are many problems at home, and you have children at home, and you must take them to school. If you tell her [provider] that I was like this and this, she receives you well. (CTC client, F, 35)

**Referral/transfer system**

CTC clients were occasionally referred to another health facility for a variety of reasons, including for CD4 testing, to receive ART if they were traveling and unable to attend their normal CTC, or to transfer permanently to a new CTC if they moved or if a new and closer facility opened. A CTC service provider explained that because Tanzania used standard CTC forms and referral cards, there was no problem when a person linked to a CTC after being diagnosed with HIV, or even if the person was already on treatment but transferred from another facility. She said, “We receive those patients well. And we cater to them depending on the services they were already receiving at the other place; we continue with the same services...” One CTC client also discussed the ease with which PLHIV could collect ART at different locations:

> There is a possibility for that to happen [miss an appointment] since you may travel. We have cards which allow us to get medications at any place. So I might have gone to Dodoma or Dar es Salaam, but any place I go I can get the medication. (CTC client, M, 43)
In general, clients in our study were successfully able to transfer or receive temporary services at alternate CTC facilities. Many explained that they received a transfer letter from their original CTC which they took with them to the other facility and “received services as usual.” However, several clients narrated challenges with this process, which were most common when the client’s original CTC file was not forwarded to the new facility. For example, in 2009, a new CTC opened which was closer to one client’s house than the original CTC she had been attending. She was given permission to transfer to this new CTC and told that her file would be sent along. She explained that the file was not transferred and she visited the new CTC several times before finally going to retrieve her file herself to bring it to the new center. In addition, one client was told that he could not transfer to a new CTC. He explained:

They say that you have to go to the center which registered you in the first place because the registration is in the network and it’s not functioning well. I think there are technological issues here... They say that it’s not easy to get it from another center so you may not access the services. I don’t understand the interaction between one center and another. These services are not run smoothly...

(CTC client, M, 48)

### Participant Story 4: Disrespectful treatment by service providers

This participant was diagnosed with HIV in 2007 and attended CTC services regularly until 2012 when she disengaged from care after being “severely scolded” by service providers. She missed one CTC appointment because she was working far away and unable to attend on her assigned date. She explained what happened when she returned on another date:

They told me to leave and go back to work. I asked for forgiveness but they didn’t listen to me. I thought about how we work to earn a living [and can’t always attend the CTC on the assigned date]. He chased me when he found out that I was still there, so I left that place. I went back some days later and found that they were still speaking ill of me.

During the period that she was disengaged from care, she purchased cotrimoxazole from the pharmacy and “borrowed” ARV’s from her friends who were enrolled in the CTC. She noted several times that she felt bad about her situation and would like to return to the CTC but was afraid that she would not be allowed to re-engage in care since she had missed so many appointments. She said:

I have to go back because I don’t want to die. I have to take the medications to stay alive. Of course it’s our fault that we are late but we ask God to soften their [service provider] hearts so that they accept a few of us who have dropped out ... I am just praying to God to help me go back to the clinic. I pray that they accept me without scolding.

During the course of this study, this participant was successfully able to re-engage in care. She said that the doctor “warned” her not to repeat missing appointments, but agreed to allow her to continue taking ART. She said that she will not drop out of services, even if she continues to be treated poorly, because she knows that her life depends on adhering to ART.

### Home-based care providers

Service providers discussed the challenges they faced following up with clients who missed appointments. One CTC provider said that they mainly called clients on their phones if they had missed
an appointment. However, she noted that many of their clients did not have cell phones, or had no cell phone reception where they lived, which made follow-up very difficult.

One group of people who addressed these follow-up challenges was home-based care providers (HBCs), which were present in two CTC facilities. HBCs were discussed as a great facilitator to following up with clients. One CTC provider explained that working with HBCs was a very effective system for following up with patients who did not attend their CTC visits. She also noted that this system minimized loss to follow up:

> It is easy [to follow up with clients who miss appointments] currently because of these HBCs. We just look where [the patient] comes from and then we just use the HBC from there. [The HBC] tries to follow [the patient], sometimes someone may die and we don’t have the information. So [the HBC] will give us the information … If [the patient] just decided not to come, then [the HBC] will also tell us, but currently, by using the HBCs, a majority [of patients] have returned back to the service. (Provider, F, 43)

**Community level**
At the community level, barriers to engagement in ART care included traditional healers who treated PLHIV with traditional medicine and spiritual healing practices. Social support was noted as a facilitator to engagement in ART care.

**Barriers**

*Traditional healers treating PLHIV*
Most traditional healers in this study noted that they were unable to treat PLHIV. However, a minority said that they were able to diagnose, treat and even cure HIV. These healers were most likely to believe that people acquired HIV after being bewitched and that traditional medicine was needed to cure them. Most PLHIV who had visited traditional healers also believed that they had been bewitched, and this was the most common diagnosis that these people received.

Traditional healers and cohort participants mentioned that PLHIV often visit traditional healers without disclosing their HIV status, which could lead to unintentional treatment of PLHIV by traditional healers and prevent engagement with the formal health system. In addition, it was noted by one participant that PLHIV sometimes preferred to visit traditional healers as opposed to CTCs because it was less shameful and more private to visit a traditional healer than to sit in a crowded waiting room. One participant also mentioned that PLHIV chose to visit traditional healers because they were located in villages and were more accessible than CTCs, which often required PLHIV to travel long distances.

*Spiritual healing*
All participants who engage in spiritual healing, including clients of these services and church leaders, believed that God could cure HIV. Many participants cited a testimony that they had heard about a person being cured of HIV through prayers, which gave them hope that they, too, could be cured.
Church leaders generally expressed ambivalence to the formal health sector with regard to CTC services for PLHIV. Many leaders agreed that PLHIV should attend CTC services if they wanted to. They all stated that they did not discourage people from attending services, but also generally did not actively encourage attendance at HIV services. One church elder explained, “We don’t prohibit [PLHIV] from going to hospitals for testing when we pray for them; we have no problems with hospitals.” However he only mentioned that they encouraged people to link with health services when they became sick. Another pastor said, “I can say that the medications have their own position but it’s very minor, prayers are the main deal.” While no church leaders said that they encouraged PLHIV to discontinue ART, several study participants knew of people who were encouraged to stop taking ART while participating in spiritual healing services.

Despite the church leaders’ lack of insistence that PLHIV attend CTC services, most clients of spiritual healing services noted that ART was important for PLHIV and most of these clients participated in spiritual healing and also took ART regularly. These clients acknowledged that both prayers and medication were important for one’s health, but also had hope that they would one day be cured of HIV. Several of these participants noted that they planned to test for HIV again because they believed the results would be negative.

None of the clients of spiritual healers interviewed had discontinued ART usage, but several participants shared stories of people who had stopped taking ART because they believed they would be healed by God. Participants noted that these people eventually became very sick and either returned to CTC services or died. As one client of spiritual healers stated:

I haven’t seen a person getting cured after stopping medicine. If she believes that He will help us because He can do anything, we have seen many people die because they stop [taking ART]. Or else she stops medicine and gets sick, then she goes back to hospital but she has already been disturbed very much by stopping medicine. (Spiritual healing client, F, 28)

**Facilitators**

**Social support**

Members of PLHIV support groups benefitted in many ways, which facilitated their involvement and retention in CTC services. These participants explained that they discussed their problems, reminded each other to adhere to ART and attended CTC appointments regularly, and looked after each other when a member became sick. As one member explained:

I am happy with the fact that we help each other in the group; my fellows help me when I am admitted in a hospital. So I am so happy for this group, we help each other. They bring food, money and pay for your hospital bills when you are sick. So the main advantage is the help that we provide to each other. (Support group member, F, 34)
In addition, most group members explained that they were no longer “embarrassed” of being HIV positive and did not feel ashamed to attend CTC services because they knew that they were not alone. One participant explained:

Disclosing your status makes you strong in such a way that you can’t be shaken by any enemy who will try to speak against your status. First and foremost, I have my freedom. I don’t have bitterness. I have peace of mind wherever I go; it’s because of this group.” (Support group member, F, 34)

**Structural level**
Income generating opportunities were identified as a structural-level facilitator to retention in care and treatment programs.

**Facilitators**

*Income generating opportunities*
Each of the 5 support groups visited for this study had some kind of income generation or loan program, which was mentioned as one of the main benefits of membership in the groups. Groups organized micro-loan and savings programs, group agricultural projects and animal keeping. One support group member explained the importance of economic empowerment for PLHIV:

A group member is supposed to support himself economically...We have seen that the important solution is creating economic groups in which there are times when we are distributing the profit among each other. We are distributing among each other and it helps everybody for bus fare for going to take medications or maybe to have nutritious food at his home. (Support group member, M, 39)

Many clients of HIV services who were not members of support groups expressed their desire for more opportunities for income generating activities but were not aware of organized groups in the area.

**Cross-cutting themes**
In addition to the themes presented above which correspond to a specific stage within the continuum of care, several cross-cutting themes were identified which influenced engagement in HIV services at all stages throughout the continuum of care.

**Facility level**
At the facility level, several cross-cutting barriers existed, including lack of motivation among service providers, lack of privacy and confidentiality at health facilities, patients not receiving needed services, poor client-provider communication, and long wait times.
**Barriers**

*Service provider demotivation*

Service providers discussed challenges they faced which ultimately led to burn out and lower quality care, including severe shortages of staff, lack of incentives and inadequate training. First, providers expressed frustration with the number of qualified staff, which was not enough to adequately handle the number of clients at many facilities. Doctors explained that they were often assigned to multiple departments so were forced to juggle their CTC responsibilities with other sections. One provider at a rural health center explained:

> The employees are few. Few employees and even among those few, a majority have not received training. For example, at our center here, we are only two clinicians. When it happens that one of us has travelled, the other is left [alone]. It means that all the responsibilities of the whole center are entrusted to the one who remains. See, now you will have usual patients, patients in the wards and perhaps that day unfortunately is a CTC day, so there it is troublesome, you find yourself leaving here at six o’clock in the evening. Now patients will wait, will become sad, you will pity them but you have no choice. That is the problem when it comes to shortage of service providers, and even some of the service providers that we have still have not received training. (HTC provider, M, 49)

Other providers mentioned that they turned clients away from HTC or CTC services if they arrived towards the end of the day, even if the service was technically still open, since they were too exhausted to provide more services. One provider noted that she realized that these clients are unlikely to return, but simply did not have the energy to continue working.

Service providers also discussed their lack of motivation due to the heavy workload and lack of incentives. One provider explained:

> We are losing hope because we do this hard job with no motivation of any kind. The work is very hard. You just receive people’s problems and you are supposed to help them, but there is nothing that you are going to gain, so it really breaks our hearts ... the work is very hard but the government cannot help us ... there are other times that our fellows [other service providers] have no plans to help patients who are admitted in the ward who needs that service. He might be sick in bed, but he is not attended ... If there were incentives then someone would work wholeheartedly. (CTC provider, F, 55)

Another challenge discussed by providers was the lack of professional development and training opportunities. Several providers said that they used to receive refresher training courses on a regular basis, but those had stopped in the last few years. One provider said that she had not received any training regarding HTC since she was in school and realized that she was not up to date with current best practices and government guidelines. Another provider explained that she felt de-valued because she did not receive training to do her job well.
Lack of privacy and confidentiality
Confidentiality and privacy were valued as very important factors to clients of HIV services, while lack of these was mentioned as a barrier to attending services. Several service providers admitted that their colleagues did not always maintain confidentiality with regard to the HIV status of their clients. One provider said, “The service providers...don’t follow our ethics. Some disclose patients’ secrets.” He further went on to explain:

You would find some of the service providers have friends in the community. Now your friends in the community can ask ‘How is she? Her, how is she?’ You, without understanding your ethics, you can start saying ‘Aah, that lady, that lady is rotten, she has HIV,’ and you associate yourself like that. Now when patients realize this, you find that the relationship with the patients becomes a bit difficult. And if it is your habit, you can find that many people avoid coming to the whole center. (HTC provider, M, 49)

In addition, lack of privacy was commonly noted, especially at CTC facilities. CTC clients discussed being forced to wait in long lines in common areas of the health facility where people walking by could easily identify them as HIV-positive. During several observations, data collectors noted that PLHIV were easily identifiable and confidential interactions between clients and providers were often performed in non-private areas where others could listen to the conversation. As clients so commonly discussed the importance of hiding their HIV status from others, this lack of confidentiality and privacy could be a major barrier for clients’ willingness to continue attending HIV services throughout the continuum of care.

Not receiving services
One major frustration discussed by HTC and CTC clients occurred when a person reached a health facility only to be turned away without receiving services. Participants in our study were denied HIV services multiple times when test kits were out of stock, when they did not receive cotrimoxazole during pre-ART care and when they had had many challenges accessing CD4 testing services. Others arrived outside of normal clinic hours and were told to come back on another day, or found that service providers were too busy to see them when they arrived. Clients expressed great frustration with these experiences, especially since transportation was often expensive and these visits took most of the day. As one CTC client explained:

The ones who are missing CTC services are so many because of the distance. Someone comes, yet he is being told that maybe [cotrimoxazole is not in stock], you see. And most of them are told to go and buy. Then he comes in the next month then they are telling him, “you have not had your CD4 checked so we cannot change the medications for you [i.e. initiate ART], so you are supposed to go and buy [cotrimoxazole] again.” So that situation is what leads to that [dropping out of services]. First, he is looking at the distance and he is wasting his time. On the day that he comes, he has to prepare the whole day for not working. So when he prepares that day and then he sees that he doesn’t get that service, he sees that it is not a productive work going there [to the CTC]. (Client, M, 45)
Poor client-provider communication
Poor communication between providers and clients was discussed as a factor that limited a client’s ability to fully understand their situation or make informed decisions about their health. Several clients mentioned that they did not feel comfortable asking for clarification when they did not understand something they were told by providers, especially in group settings where CTC clients often received education. Clients also said that they did not often ask for clarification because they felt that providers were too busy and that they would be wasting time by asking questions. Many clients, in turn, misunderstood important concepts like CD4 count, the difference between cotrimoxazole and ART, and the importance of lifelong ART adherence.

Congestion/Long wait time
The amount of time clients waited to receive services varied; even within one facility, clients’ wait times varied greatly from several minutes to more than eight hours, which was attributed to the number of providers available on a given day and the speed at which they worked. Clients who said that they normally received services quickly were very satisfied. One CTC client said, “I thank the center for giving me such a fast service and I will thank them if it will continue this way.” Another client mentioned, “The short time in getting my service is what exactly has pleased me.” Several CTC clients discussed recent changes which facilitated efficient services and decreased wait time, including providing a three-month supply of ART for clients or assigning shifts throughout the day in order to decrease the number of clients at any given time.

Unfortunately, not all clients were so satisfied with the time they waited to receive services. Many CTC clients said that they often spent most of their day at the health facility, which was mainly attributed to a shortage of service providers or the slow speed at which service providers worked and some patients reported that fellow patients simply gave up and went home without being seen.

Some participants noted that CTC clients were expected to arrive very early for services, e.g., 6 or 7am, but they often waited several hours before providers began seeing patients, e.g., around 9am. During an observation at a PMTCT facility, a data collector noted the frustration of clients who had waited for more than three hours without receiving services, despite the presence of service providers at the facility. During the observation, several clients discussed their annoyance with the slow pace of services, while another client got up and left without receiving services.

Community level
Stigma and discrimination were identified as significant barriers to engagement in HIV services throughout the continuum of care, while cooperation between government officials and traditional healers may have facilitated this process.

Barriers
Stigma and discrimination
Stigma, discrimination, and internalized stigma were very common themes throughout this study, and may have impeded an individual’s ability to access and participate in HIV prevention, care, and
Assessing Barriers and Facilitators of Linkage to Care in Iringa, Tanzania

treatment services. First, study participants commonly reported that people avoided HTC due to fear of discrimination they would face if others discovered their HIV status. As one HTC client explained, “People think they will bring shame [if they test positive] and find it better to die than know their health status.”

PLHIV commonly discussed the fear of having their HIV status discovered by people in their own communities. Some CTC clients discussed how they travelled long distances to avoid seeing people that they knew from their communities, while others explained the “humiliation” they were forced to endure every time they attend CTC services. Members of PLHIV support groups also widely acknowledged that the most significant barrier for people to join groups was the fear of their HIV status becoming known.

Many clients of HIV services also shared experiences of being discriminated against in their communities. Most often, PLHIV reported being "ridiculed" and "laughed at" by others. One woman, who used to sell food, noted that people refused to buy from her once they discovered that she was HIV-infected. In addition, several participants told stories about discrimination they faced by neighbors or family members. One woman explained how she was stigmatized by her family and neighbors when she was first diagnosed with HIV:

I felt that I was discriminated against by my relatives. My relatives did not even contribute a cent to help me nor did they escort me [to the hospital]. And it is not that my relatives do not have the means, they are people who are able to. I was really discriminated [against]. Even my neighbors, my in-laws would even ban their children from coming to my home. They would say, “You better not eat anything there.” One time, my sister-in-law got sick when she was pregnant, but she said, “I will try, better I hire someone to take care of me. Because my sister-in-law has AIDS, she might infect me.” Therefore I felt bad. (Client, F, 39)

Because of the real and perceived social stigma, many participants noted that they had not disclosed their HIV status to anyone outside of their immediate family, while several PLHIV said that they hid their status from their spouse due to fear of violence or abandonment. Several women who had not disclosed their HIV status to their husbands either took their medication secretly or stopped taking medication altogether for fear of their husbands finding out. For example, one female cohort participant invented excuses to go to the CTC because her husband did not know her HIV status. She sometimes missed clinic days because he had given her work to do around the house, and she couldn’t get away. A PMTCT client told her story of hiding her HIV status from her husband due to fear of violence. Her baby was HIV-negative, but continued to take Nevirapine syrup to prevent mother-to-child transmission. She explained why she was afraid to discuss her health with her husband:

He refused to go for [HIV] testing, and told me to leave his home if I will be found to be positive. I couldn’t take the medications when I was pregnant because of that but I thank God that my baby is not infected ... He is so rude. He tortured me when I was pregnant. He made me sleep outside the house when he knew that I went for HIV testing. I hide my medications under the ground on the house compound. He searched for medications all over the house but found none. (Client, F, 24)
She hid the baby’s medication on top of the cupboard so that her husband would not find it. She explained, “I give the medications to my baby when his father is not around, in day time like this. I don’t want him to see the medications because he refuses any idea of HIV.”

**Facilitators**

*Traditional healer association*

In the past, traditional healers in Tanzania fell under the purview of the Ministry of Culture. However, with the recognition that traditional healers were part of the informal health system in Tanzania, government responsibility shifted to the Ministry of Health. A government representative in each district works with this group and an association of traditional healers has been developed in Iringa which attempts to register all practicing traditional healers in the region, provide an opportunity for collaboration among traditional healers, and increase dialogue between traditional healers and the government.

Traditional healers involved in this association explained that they had received education from government officials about health conditions that must be treated at health facilities, including HIV. The leader of the traditional healer association in Iringa Region explained that he had attended government trainings and had done a lot of work with other healers to stress the importance of referring clients to the hospital if they presented with certain symptoms. He explained:

> Since I am the leader of all traditional healers in this region, I have gone through almost all seminars in all districts; [we have learned] that the patients have many diseases now. They are difficult for us [traditional healers] as experts to treat them; these include malaria, tuberculosis and HIV. It will be difficult for [a traditional healer] to treat an HIV positive person. Here you will waste his time. So I have forbidden traditional healers to treat such people together with those who come with diarrhea and vomiting. (Traditional healer, M, 51)

Despite attempts to engage all traditional healers in dialogue with the Ministry of Health, government officials noted that they did not recognize or allow healer who dealt in “witchcraft” and “fortune telling” to join the association. One official explained:

> Fortune telling is telling a person that someone has bewitched you. So we don’t want [traditional healers] to say that. If you find that he is bewitched, give him medicines, but you shouldn’t say that you will exorcise the witchcraft. We don’t entertain such a thing. (Government official, M, 47)

Traditional healers in this study who admitted to treating people who had been bewitched—and also believed that they could cure someone living with HIV—noted that they were not involved in the association of traditional healers and had not engaged in dialogue with the Ministry of Health. In addition, study participants who had visited traditional healers themselves or knew of people who had all noted that the traditional healers told them they had been bewitched, suggesting that this
association had not reached many practicing traditional healers in the region or the government policy against witchcraft was not fully accepted by many traditional healers.

**Structural level**
Distance to HIV services and pervasive poverty were noted as important structural barriers throughout the continuum of care.

**Barrier**

**Distance to HIV services**
Distance to health facilities was mentioned by a majority of study participants as a key barrier to engagement in HIV services and noted as a reason why people disengage from care or avoid services altogether. Some participants from rural areas reported walking several hours in each direction to reach health facilities for HIV testing, care and treatment services. Many others depended on public transportation, which was often costly and sometimes very infrequent, which discouraged many PLHIV from regularly attending HIV services.

Study participants frequently requested that the government provide CTC services at the dispensary level, which is more accessible to people in rural villages, in order to reduce the distance people travelled. One cohort participant received HTC at a local dispensary. The nearest CTC was a long distance from her home and she was unable to afford transportation costs. She felt relatively healthy at the time of diagnosis so chose not to link to CTC services. One year later, a CTC opened closer to her home and she enrolled in services at that time.

Another CTC client explained that increasing CTCs to rural areas would not only decrease the distance that people in these areas travelled, but would also alleviate some of the congestion in current CTCs by dispersing the clients of these services. He explained:

> Something that needs to be improved is to increase the number of centers [CTCs] in villages. Some people have no ability to reach the services ... If the village population reduces in number [at the current CTCs], the congestion will improve so people in town will also have better access to services and get services earlier. (CTC client, M, 47)

On the other hand, several participants chose to attend CTC facilities far from their homes in order to avoid being seen in their local communities due to fear of stigma and discrimination. In these situations, long distances to facilities were seen as a facilitator rather than a barrier and ensure the individual’s anonymity. These clients often had greater resources and could afford transportation to more distant facilities.

**Pervasive poverty**
In addition to long distances to health facilities, poverty and economic hardship were discussed as significant barriers to an individual’s ability to engage in HIV services. Participants discussed how they struggled to support themselves and their families even before their HIV diagnosis. Finding additional money to pay for transportation to attend HIV services, purchase non-HIV related medications (and
Assessing Barriers and Facilitators of Linkage to Care in Iringa, Tanzania

sometimes also cotrimoxazole), and food during visits was a major challenge for many participants and discussed as a reason for disengagement from care. One cohort participant, who lived far from the nearest CTC facility, disengaged from pre-ART care services because she could not afford the cost of transportation and food during her monthly CTC appointments. Another participant delayed linking to CTC services because she could not afford to spend an entire day at a health facility without making money. She determined that it was more important for her to make money so that she could buy food for herself and her daughter rather than spend an entire day in a crowded CTC waiting room. She said, “I can’t go to the hospital while I have nothing, no food ... How will I make money if I go there [to the CTC] and spend the whole day?”

Participants further discussed how PLHIV often struggled to work when they are sick or weak, which reduced income and further limited their ability to pay for transportation and other related costs. For example, one HTC participant discussed the challenge he faced to regularly attend the health center. It took him two weeks to save up the money (Tsh 3,000 one way, approximately USD2) to travel to the health center for HTC, which was a three-hour journey from his home. He said that it took him longer than usual to make this money because he was sick and “you can’t make money when you are sick.”
DISCUSSION

Understanding factors that motivate and prevent PLHIV from engaging in and adhering to care at each step along the continuum is critical to successful HIV treatment and prevention efforts. Although loss of patients along the HIV care continuum has been documented (Kranzer et al., 2012; Rosen & Fox, 2011), less is known about the complex, multi-layered dynamics which impact linkages at all stages along this continuum. This study provides a multi-level understanding of barriers and facilitators to engagement in HIV services along the entire HIV continuum of care. Findings highlight how individual-, facility-, community- and structural-level factors interact to influence an individual’s decision about and ability to engage in HIV services and underscore the importance of a multi-level response to increase linkages to and retention in care.

Individual level

At the individual level, many factors influenced a person’s decision and ability to enter into and engage in the continuum of care. One main factor affecting this process documented here was a person’s health. A majority of participants in this study received HTC only when they were visibly sick, had ruled out other possible illnesses and perceived themselves at risk for HIV infection, a finding that is not unique to Tanzania (Grant et al., 2008; Mabunda, 2006; P. MacPherson, MacPherson, et al., 2012; Morin et al., 2006). Receiving an HIV-positive diagnosis for these participants was often received with a sense of relief for finally knowing the cause of suffering, and participants often linked to further HIV care and treatment services immediately. Participants who experienced recurrent illnesses were also the most likely to see immediate and visible improvement in their health after initiating cotrimoxazole and/or ART and therefore viewed these medications as important for sustained health.

In contrast, healthy participants in our study expressed reluctance to receive HTC and were more likely to delay linking to care or disengage from care and treatment services. One potential reason for this is the belief that HIV is associated with severe physical symptoms. Participants who felt healthy at the time of diagnosis often expressed distrust in the test results and repeated the test several times (often at different locations) to verify the results before accepting their HIV status. Several studies throughout sub-Saharan Africa also found that HIV clients with less advanced disease progression were more likely to delay linkage or disengage from care than more immunosuppressed clients (Feldacker et al., 2012; Lessells et al., 2011; Tayler-Smith et al., 2010; Topp et al., 2012). Our findings suggest that people in Iringa are very reluctant to receive HTC or link to further care and treatment while healthy and do not perceive the need to engage in HIV services until they become physically sick. As treatment guidelines evolve to recommend ART initiation at a higher CD4 count, more PLHIV will initiate ART before a noticeable decline in health. Identifying these individuals and ensuring successful progression through the continuum of care is critical, but will be challenging. Behavior change communication strategies to promote earlier testing and engagement in care could change the current social norms around HIV by educating the public about personal and public health benefits of early ART initiation.

Many patients reported that providers recommended particular behavior changes for PLHIV, some of which could be difficult to maintain, particularly the recommendation to abstain from alcohol. Some
patients believed that the recommendation to abstain from alcohol was because drinking caused forgetfulness, thus reducing adherence; this “cognitive-impairment mechanism” for poor adherence has been identified elsewhere (Hendershot et al., 2009). However, other participants believed that mixing alcohol and medications was in itself harmful; these “interactive toxicity beliefs” have been identified elsewhere and were shown to be significantly associated with poorer adherence in a prospective cohort of PLHIV (Kalichman et al., 2013). Providers’ recommendations to abstain from alcohol, especially while on ART, are likely to be a barrier for many people; some people who feel they cannot give up alcohol may not take ART or may avoid care altogether. Recommendations regarding alcohol use should be evidence-based, especially considering that the “harms caused by ART non-adherence [or poor adherence] may outweigh those of ART and alcohol interactions” (Kalichman et al., 2013).

The recommendation to abstain from reduce the frequency of sexual activity was also difficult for some cohort participants. Patients explained that this recommendation was the result of a belief that sexual activity was harmful to the immune system and/or drained patients’ energy. While less sexual activity overall would likely reduce transmission of HIV, the recommendation was reported most often not as “reduce number of partners” nor “reduce unprotected sex,” but simply “reduce frequency of sexual activity,” even among monogamous partners using condoms. Further research could illuminate providers’ perspectives on this idea. This recommendation is concerning if it is resulting in lower retention in care, since PLHIV can have normal and healthy sexual lives (WHO & UNFPA, 2006). While it was sex workers who mentioned the recommendation to reduce frequency of sex, it is probable that the recommendation was given to all or most patients, since sex workers did not disclose their occupation or sexual risks to providers. Instead, it is likely that sex workers were the ones who most remembered and were negatively affected by this recommendation, because it directly conflicts with their livelihood. As a result, they did not feel able to take this advice and most simply ignored it. This was a barrier for sex workers in particular, and it may be a factor for some in avoiding care altogether, though this would need further research.

Facility level
Main challenges at the facility level included inadequate PITC, challenges linking to and enrolling in CTC services, limited access to CD4 testing, long wait times, congestion and lack of privacy.

Inadequate PITC was one barrier to entry into the continuum of care. Despite the government policy of standard PITC services offered to all clients, our findings suggest that this service is not widely implemented in health facilities throughout Iringa, as in other settings throughout sub-Saharan Africa (Roura et al., 2013). Very few clients were offered PITC by a service provider, and those who were had often been very sick and visited multiple health facilities with no relief. A study among health care workers in Mbeya, Tanzania found that while all health care workers were aware of PITC, 78% offered the service only to people they perceived to be at high risk of HIV (Kapologwe, Kabengula, & Msuya, 2011). These providers believed that PITC was not relevant to most clients and noted a high patient load, too few providers, lack of PITC-specific training and a shortage of HIV test kits as reasons for not routinely practicing PITC. Addressing these issues among health care workers could improve their
willingness to routinely offer PITC to clients, which could significantly increase detection of HIV-infected individuals who are currently being missed by the health system.

Participants in our study discussed a range of experiences while trying to link to a CTC following diagnosis. Co-located HTC and CTC services facilitated same-day linkage to care for newly diagnosed clients. In some settings, HTC providers personally escorted clients to the CTC to further facilitate this process. Study participants who were able to successfully link to and enroll in CTC services immediately following diagnosis described this process as simple and efficient. However, same-day linkages were not often possible. In many areas, HTC and CTC services are not co-located, requiring an individual to travel independently to a CTC to link to care and treatment services. Study participants discussed multiple challenges with the linking process, including being turned away if they arrived outside of normal operating hours, finding the CTC facility to be confusing, and being told to come back multiple times to complete the enrollment process. A prospective cohort study in Malawi found that same-day staging and eligibility assessments were major predictors of successful ART initiation, and individuals who did not receive prompt assessments had poor uptake of ART and poor retention in pre-ART care (MacPherson, MacPherson, et al., 2012). Many participants in our study did not receive same-day staging due to the factors outlined above, which could contribute to low rates of continued engagement in HIV services. Strategies to simplify the linking and CTC enrollment process should be developed to reduce facility-level barriers at this stage. For example, the hours of CTC enrollment could be made available at HTC facilities so that clients know when services will be provided. In addition, HTC facilities could offer services whereby a HBC provider escorts a newly diagnosed client to a CTC to ensure successful linkages.

One particular barrier faced by a majority of study participants was access to CD4 testing services, which was often required for participants to initiate ART, even if clinical staging warranted ART initiation. Only one CTC facility visited had a working CD4 machine and point of care CD4 testing was not available in any facility. Smaller CTCs often did not have CD4 machines and other facilities reported a lack of reagents and broken machines that were not fixed for extended periods, rendering CD4 machines inoperative. MacPherson et al. reported similar challenges to receiving CD4 testing in Malawi which led study participants to disengage from care before ART initiation (MacPherson, MacPherson, et al., 2012). In addition, prospective cohort studies in Malawi and South Africa reported that only one third and one half of clients, respectively, referred for CD4 testing returned to the clinic with a result, suggesting that challenges obtaining CD4 counts are widespread (Losina et al., 2010). Continued use of CD4 machines for laboratory staging and CD4 monitoring will require increased resources to maintain machines and the availability of trained personnel to operate them, which we found little evidence of in this study. Alternately, point of care (POC) CD4 testing, which provides immediate results for use in patient care, could eliminate many of the logistical and operational barriers faced by study participants. A growing body of evidence suggests that POC CD4 testing has the potential to reduce early loss to follow up (Jani et al., 2011), increase the likelihood of reporting for ART initiation (Faal et al., 2011) and can be successfully administered by nurses and other non-clinician physicians in both urban and rural areas (Wynberg et al., 2014). Finally, service providers should receive additional training to recommend ART
initiation if relevant based on clinical staging, especially with the many challenges to CD4 testing described above.

Long wait time, congestion, lack of privacy and confidentiality were all discussed as facility-level barriers throughout the continuum of care, but were most frequently discussed among clients of CTC services, including both pre-ART care and ART clients. While these challenges decreased motivation for clients to attend services, several study participants discussed ways in which CTCs are working to reduce these barriers. For example, a few clients said that they receive three-month supplies of ART, thereby reducing the frequency with which they must attend services. Other CTC clients noted that they are assigned times throughout the day to attend the clinic, which has reduced congestion and wait time. All of these interventions have been proposed elsewhere (Govindasamy et al., 2012) and were met positively by participants in our study. However, a small minority of participants reported these programs at the facilities they attended, and scaling up these types of innovative services delivery models could help to reduce some of the common barriers we identified.

Community level
A number of community-level facilitators and barriers were identified including stigma and discrimination, PLHIV support groups, alternate healing systems, and community mobilization activities.

Pervasive stigma and discrimination were widely discussed as barriers to engaging in HIV-related services and a main reason that people avoid HTC. Consistent with findings in other settings, it was commonly acknowledged that an HIV-positive diagnosis is perceived as shameful and many participants feared HIV-related stigma (Bwambale et al., 2008; Grant et al., 2008; Maman et al., 2001; Meiberg et al., 2008; Pool, Nyanzi, & Whitworth, 2001; Varga & Brookes, 2008). While several participants explained that levels of stigma have decreased in recent years, most PLHIV still experience discrimination by family or friends, and many participants were reluctant to disclose their HIV status to people outside of their immediate family for fear of judgment and mistreatment. In order to avoid being seen by people they knew, several participants traveled to more distant clinics, incurring greater costs and travel time. Negative health outcomes resulting from HIV and AIDS stigma have been well documented (Bogart et al., 2008; Mahajan et al., 2008; Prachakul, Grant & Keltner, 2007; Sayles et al., 2007; Vanable et al., 2006) and our findings highlight the need for stigma-reduction strategies to accompany HIV prevention and treatment efforts. While little is known about effective interventions to reduce community-level stigma and damaging social norms (Stangl et al., 2013), there is general consensus that that four basic approaches are effective in reducing stigmatizing attitudes among individuals and groups, including information, skills-building, counseling and PLHIV testimonials (Brown, Macintyre, & Trujillo, 2003; Sengupta et al., 2011).

Participation in PLHIV support groups was discussed as a positive experience by all support group members. Members of these groups had often publicly disclosed their HIV status and were less likely to site community-wide stigma as a barrier to their engagement in HIV services. These members encouraged each other to attend CTC visits and adhere to ART and supported each other financially in times of need. In addition, members of every support group in this study participated in some kind of
savings or income generating project. Members discussed the economic benefits of their membership as an additional incentive. Unfortunately, a vast majority of study participants did not belong to a support group and very few non-support group participants were aware of opportunities for joining such groups in Iringa. PLHIV commonly requested opportunities for income-generating activities and a majority of participants said that they would be interested in joining support groups if they were available. Efforts to strengthen the linkage between HIV services and support groups could increase membership in these groups among PLHIV. Support groups could also be leveraged in stigma-reduction efforts. Providing more opportunities for PLHIV to give personal testimonials could help to change attitudes and reduce community-level stigma.

Participants in our study most commonly described visiting traditional healers after multiple visits to a health facility without receiving a diagnosis. A majority of traditional healers said that they do not treat HIV and AIDS and often refer clients to a health facility for diagnosis before treating them with traditional medicine. However, it is plausible that undiagnosed PLHIV, who are advised by traditional healers to first visit a health facility, could return to the traditional healer without having received HTC. Traditional healers acknowledged that they would treat someone as long as they have been to a health facility, whether or not the client received HTC, which could prevent some PLHIV from accessing further HIV services. In addition, healers explained that clients very rarely disclose their HIV status and many healers suspected that some of their clients were HIV-positive. The Government of Tanzania has initiated collaboration between the Ministry of Health and traditional healers. A majority of traditional healers in our study were aware of this collaboration and had heard messages from the government about referring HIV-positive clients to health facilities and requiring clients receive biomedical treatment before traditional medicine. Nonetheless, several traditional healers interviewed claimed that they were able to diagnose and treat HIV, and PLHIV who had visited traditional healers or knew of people who had all said that they were told by traditional healers that they were “bewitched.” Further engagement with these traditional healers will be necessary to develop more effective linkages between all traditional healers and the health system.

Unlike traditional healers, we found no evidence of collaboration or communication between spiritual healers and government officials or the formal health system. Spiritual healers generally expressed ambivalence towards the health sector and did not actively encourage PLHIV to engage in HIV care and treatment services and in some cases actively encouraged them to disengage. Expanding the government initiative with traditional healers to spiritual healers to encourage dialogue and engagement with the health system could initiate linkages between spiritual healers and the health system.

Finally, community-level services which encourage engagement in HIV services, including mass media, community mobilization and HBC providers were discussed as factors which change attitudes and promote engagement and similar strategies could be leveraged to further promote HIV testing and progression throughout the HIV continuum of care.
Structural level
Persistent stock-out of supplies, disrespectful treatment by service providers, provider burnout and demotivation, policies requiring couples testing at ANC services, long distances and poverty were structural-level factors which impacted engagement with the HIV continuum of care.

Participants in our study discussed persistent stock-out of supplies, including HIV test kits, CD4 reagents and cotrimoxazole. For the duration of the data collection period, HIV test kits were out of stock in a majority of health facilities throughout Iringa region. While there are no statistics on the number of clients who missed out on HTC services during this period, service providers noted that they routinely turned clients away and believed that these people would give up and not return at a later date. In addition, clients of HIV services discussed frustrating attempts to receive CD4 testing, which often entailed multiple trips to alternate health facilities, and were routinely told to purchase cotrimoxazole from a local pharmacy due to facility-level stock-outs. Strengthening the supply chain management system for these products should be prioritized to eliminate common stock-outs in health facilities, as patients not only missing out on important treatments due to these stock-outs, but also losing faith in the health system in general. Although the political commitment to fight the HIV epidemic in Tanzania is high, assessment of the overall health sector response and capacity needs to highlight where in the multisectoral strategic framework for HIV and AIDS there continues to be barriers to ensuring regular supply of HIV and other HIV-care drugs. Accurate forecasting of treatment needs, capacity of health centers and health care providers, strengthening of laboratory services, and monitoring and evaluation of existing services and supply chains need to be assessed to ensure adequate provision of HIV treatment and care.

Provider attitudes and treatment of clients was the main reason for disengagement from CTC services among clients of ART care services, which is both a facility- and structural-level issue. All four cohort participants who dropped out of ART care noted that the trigger for their decision to disengage was verbally abusive treatment, which usually occurred after they had missed a visit or arrived late. These findings point to a clear need to improve provider-client interactions as a means of reducing disengagement from care. However, this is a complex issue and our findings suggest that reasons for disrespectful behavior among health care workers are multi-faceted and interventions focused solely on improving provider sensitivity may not be enough to change attitudes and behavior (Manongi et al., 2009). CTC clients reported the most serious conflict with service providers after missing an appointment or arriving late. The rigid clinic policies requiring strict adherence to appointments do not account for the unexpected events that often occur to prevent clients from accessing services on their assigned date. Service providers discussed the organizational challenges they face to keep paper-based client records straight, which is difficult to do when clients miss appointments. More flexibility in scheduling and rescheduling patient appointments and more accessible organization of client records could decrease some of this conflict, better accommodate client needs, and potentially reduce disrespectful treatment.

In addition to rigid clinic policies, service providers discussed burnout, demotivation and inadequate training which lead to lower quality of care and disrespectful treatment of clients. Service providers in
our study acknowledged the importance of treating clients with respect and providing high quality care, but felt overwhelmed by their workload and lack of support and did not feel they received adequate training to do their jobs well. Health-system level changes to including increases in human resources, provision of incentives, provision of adequate support systems and ongoing training and supervision are needed to improve service provider motivation and improve interactions with clients.

Requiring pregnant women to bring their partners to ANC services for couples testing was discussed as a serious barrier to both HIV and ANC services. In its document “Tanzania Elimination of Mother to Child Transmission of HIV, 2012-2015,” the Tanzania Ministry of Health and Social Welfare (2012) has set a target of testing 50% of male partners of pregnant women by 2015 through the promotion of “couple/partner HIV/STI testing and counseling for all young women.” While there is no reference to mandatory couples counseling, our findings suggest that ANC providers throughout Iringa region often refuse to provide services to pregnant women until they bring their partners to the facility for couples testing. Certain facilities have posted announcements that all ANC services will be denied women who do not bring their husbands to their first visit. Multiple women in our study reported being denied ANC services knowing women who avoided ANC services if they were too scared to ask their husbands to attend or if they did not have a partner. Women who do not have steady partners such as adolescents, widows, divorcees and female sex workers are also the most vulnerable to HIV infection (NBS, 2011). While done to engage men in HIV services, this requirement is counter-productive and preventing women at highest risk from accessing ANC and PMTCT services. Male participation at ANC services should be encouraged but not required, per national guidelines.

Long distance to facilities, limited or no transportation and lack of money for transportation and other associated costs were structural-level barriers to engagement in HIV services, and are consistently reported in other settings (Grant et al., 2008; Nuwaha et al., 2002; Råssjö et al., 2007). Participants in our study commonly requested HIV services at the community-level as a way to increase access for rural populations and decrease congestion at current facilities. A growing body of evidence suggests that novel strategies to bring HIV services to the community level are feasible and acceptable. For example, multiple studies in Kenya and Uganda have found home-based HTC to be an acceptable and effective method for identifying HIV-infected individuals (Kimaiyo et al., 2010; Lugada et al., 2010; Tumwebaze et al., 2012; Were et al., 2006) and could be an effective intervention in Iringa. In addition, strategies to bring ART delivery to the home have shown positive results in Uganda and Kenya (Kipp et al., 2010; Mermin et al., 2008; Mpiima, et al., 2012; Weidle et al., 2006; Wools-Kaloustian et al., 2009). These programs trained community health workers or volunteers to deliver ART to clinically stable PLHIV in their homes, provide support, monitor adherence and refer sick patients to the clinic. No differences in health outcomes were found among clients accessing home-based ART delivery compared to standard facility-based delivery systems. Positive side effects of the home-based ART delivery programs included increased community-level social support and decreased discrimination (Apondi et al., 2007; Wools-Kaloustian et al., 2009), and participants reported saving time and money due to reduced clinic visits (Jaffar et al., 2010). Another innovative study involving self HIV testing and home-based ART initiation in Malawi reported substantially higher rates of ART initiation compared to facility-based ART delivery.
models (MacPherson, Laloo, & Choko, 2013). These novel community-based strategies would require significant political commitment and operational research to tailor programs to the local context, but may have the potential to strengthen all stages of the HIV care continuum by improving identification of HIV-infected individuals, simplifying linkages to care, improving retention in ART care programs, reducing structural-level barriers such as distance and cost and reducing stigma and discrimination.

**Strengths and limitations**
Strengths of this study include the large number and diversity of respondents and data collection methods, which provided multiple perspectives on factors affecting engagement in HIV services in Iringa. The longitudinal nature of the qualitative cohort allowed us to gain an in-depth understanding of the complexity of PLHIV’s experiences as they moved through the continuum of care. At the facility level, our interview with clients of HIV services and service providers, direct observations and facility checklists allowed us to triangulate findings. In addition, interviews and focus group discussions with members of support groups, traditional healers and spiritual healers add a unique dimension and understanding to community-level influence throughout the continuum of care.

Despite these strengths, the study has several limitations. First, HIV test kit stock-outs limited our ability to interview newly diagnosed clients, especially those who chose not to link to further care and treatment services, which could have provided valuable insight into barriers at this stage. In addition, due to HIV test kit stock-outs, mobile HTC services were not offered in Iringa during the period of data collection so we were not able to collect data from this service delivery method. Another study limitation is the lack of clients of traditional healers. Traditional healers universally noted that PLHIV do not disclose their status and they therefore were not aware of any HIV-positive clients. While we would have liked to understand the perspective of this group, we were able to capture experiences from other longitudinal cohort participants who had visited traditional healers themselves or knew of people who had. Finally, we used a locally relevant conceptualization of the phases along the HIV continuum of care for this setting; other countries with different health system structures may have slightly different ways of defining the phases along the continuum.
Table 7. Recommended interventions to reduce multi-level barriers to engagement in care

<table>
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<tr>
<th>Level</th>
<th>Barrier</th>
<th>Interventions</th>
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| Individual| Reluctance to engage in HIV services while healthy                      | • Behavior change communication emphasizing the personal and public health benefits of earlier HTC and ART initiation  
• Intensified counseling during HTC and CTC enrollment                                      |
| Facility  | Inadequate PITC                                                        | • Additional health care worker training and supervision in PITC                  |
|           | Challenges with linking                                                 | • Increase communication between HTC and CTC services.                           
• Escort newly infected clients from HTC to CTC  
• Same-day enrollment and staging (including CD4 testing)                                    |
|           | Inadequate laboratory capacity/CD4 testing                             | • Point of care CD4 testing with in-session results available                    |
|           | Congestion/long wait time                                               | • Patient appointment systems                                                   |
|           | Disrespectful provider-client communication after missing visits        | • Dispense three month supply of ART to asymptomatic CTC clients               |
| Community | Stigma and discrimination                                               | • PLHIV testimonials                                                             |
|           | Lack of social support                                                  | • Improve communication between HIV services and support groups                 |
|           | Reliance on traditional and spiritual healing                          | • Improve communication between alternative healers and the health system        |
| Structural| Long distance to facilities; lack of access to transportation           | • Home-based HIV testing and counseling                                         
• Home-based ART delivery by community health workers  
• In-home ART initiation                                                                        |
|           | Stock-outs (HIV test kits, cotrimoxazole, CD4 reagents)                | • Improved supply chain management systems                                       |
|           | Service provider demotivation and burnout                               | • Increase training opportunities for health care workers                        
• Improve supervision structure  
• Task shifting                                                                             |
|           | Limited income generating opportunities                                 | • Increase PLHIV support groups                                                 |
|           | Passive referral system                                                 | • Support linkages to support groups for all PLHIV                              
• Provide business training skills to support groups                                         |
|           | Requiring male partner to attend ANC for couples testing                | • Unique identifier system to track linkages (Nsigaye et al., 2009)             |
|           |                                                                         | • Develop clear policy guidelines towards couples testing that do not prevent pregnant women from accessing ANC services |
Conclusion
This study presents a multi-level framework for understanding barriers and facilitators to engagement in the HIV continuum of care in Iringa, Tanzania. We have identified individual-, community-, facility- and structural-level barriers which are challenging to address from a health systems or socio-economic perspective. Despite this, interventions targeting multiple levels can be implemented, which may improve linkages throughout the continuum of care in the short- and long-term. Table 7 describes interventions at various levels recommended to improve entry into and engagement in the HIV continuum of care in Iringa. Key recommended interventions which could have immediate high impact include:

- Behavior change communication strategies to emphasize the personal and public health benefits of earlier HTC and ART initiation.
- Same-day linkage to care and staging (including POC CD4 testing), such as providing an escort for newly diagnosed PLHIV from HTC to CTC services, when possible.
- Clear policy guidelines and provider training with regard to couples testing at ANC services that do not prevent pregnant women from obtaining ANC and PMTCT services.
- Additional provider training and supervision for PITC, clinical staging and ART initiation protocols.

In the longer-term, we recommend the following interventions to reduce barriers to engagement in the HIV continuum of care:

- Improve supply chain management system to eliminate stock-outs.
- Community-based service delivery models, including home-based HTC, in-home ART initiation and home-based ART delivery systems.
- Simplify patient recordkeeping systems through electronic medical records to allow patient tracking and simplified processes for appointment scheduling and rescheduling.
- Increase staffing, training and supportive supervision for health care workers to decrease provider burnout and promote respectful provider interaction with patients.

Our findings highlight the complex, multi-dimensional dynamics that individuals experience throughout the continuum of care and underscore the importance of taking a longitudinal and multi-level perspective to understand this process. Addressing barriers at each of these levels is important to promote increased engagement throughout the continuum of care.
REFERENCES


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