

**STRATEGIC ASSESSMENT TO DEFINE A
COMPREHENSIVE RESPONSE TO
HIV IN IRINGA, TANZANIA**

**RESEARCH BRIEF
LINKAGES TO CARE**

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INTRODUCTION

The Iringa region of Tanzania has among the highest rates of HIV in the country at 9.1% prevalence in the general population (Tanzania Commission for AIDS [TACAIDS], 2013). The reasons behind this elevated HIV prevalence are not fully understood, and the response to HIV in Iringa has thus far been insufficient to match the need. The Iringa strategic assessment was designed to inform the development of comprehensive HIV prevention interventions that respond to key factors linked to HIV-related risk in Iringa, Tanzania. The strategic assessment synthesized existing data; conducted additional analyses of representative population-based data from the Tanzania HIV/AIDS and Malaria Indicator Survey; and conducted a large number of qualitative interviews and focus groups with key informants, service delivery providers and clients, and people at heightened risk of HIV in Iringa. Together, these findings provide a better understanding of the reasons behind the high HIV prevalence in the region and help to identify and tailor an appropriate set of interventions to address it. In this brief, we present findings related to Linkages to Care (LTC), the process of successfully connecting people living with HIV (PLHIV) to onward treatment and care services.

Iringa has the second highest HIV prevalence (9.1%) in Tanzania (TACAIDS, 2013). While the drivers of Iringa's epidemic are unclear, data suggest the high prevalence may be associated with low coverage of HIV testing as well as suboptimal levels of linking PLHIV with HIV care and treatment services and clinically staged for initiation of antiretroviral therapy (ART). 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, 2013). Thus, many individuals are unaware of their HIV serostatus and miss the opportunity for linkage to services that HIV testing and counseling (HTC) provides. It is important to note, however, that HTC can only serve as a key gateway to HIV care and treatment services if newly diagnosed PLHIV are successfully and efficiently referred to and connected with these services. To date, no data are available from the region on the proportion of the approximately 240,000 PLHIV in Iringa who were successfully referred to HIV care and treatment services. 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 clinical staging. Finally, country-level estimates suggest that less than one quarter of those currently eligible for ART are receiving it (UNAIDS, 2008).

The Government of Tanzania is committed to improving HIV prevention and treatment efforts and recognizes that linkages to care are important. Research shows that outcomes of HIV treatment programs have significantly improved in other lower-income countries when patients receive HTC, followed by prompt and appropriate care, treatment, management and support. Following an HIV-positive diagnosis, PLHIV who are successfully linked to pre-ART care and support until eligible for ART initiation are more likely to experience reduced morbidity, increased knowledge of HIV and harm reduction techniques, and increased ability to connect with other community resources (Morse, 2005). Additionally, recent findings suggest early treatment can reduce HIV transmission by up to 96% (Cohen

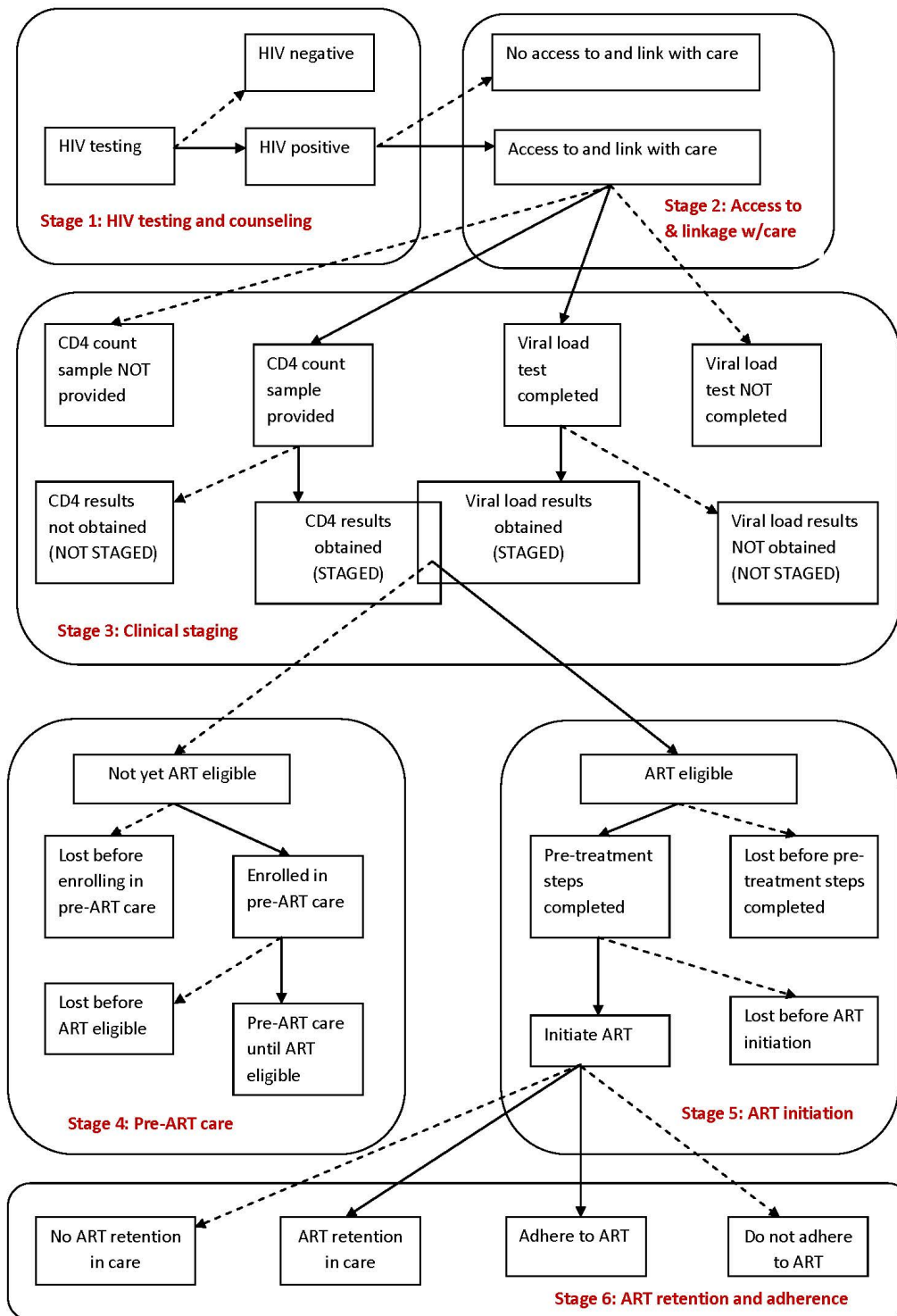
et al., 2011). Before LTC can be enhanced in Iringa, it is necessary to first understand where and why attrition occurs throughout the testing and treatment process.

The continuum of HIV testing & counseling, linkages to care, and treatment

Together with HTC and ART, the process of LTC completes the package of comprehensive HIV prevention and treatment. LTC has been holistically defined as an ongoing process through which an HIV-infected individual “comes to assimilate his/her diagnosis, to understand the implications of an HIV diagnosis for self and others, to opt for appropriate care and services, and to commit to a regimen that enhances one’s own health and protects that of others” (Denver Health, 2009). To begin the LTC process, it is necessary for PLHIV to first undergo HTC and receive their results. After getting an HIV-positive diagnosis, an individual is made aware of his/her need and can thus take action to initiate the LTC process. The individual can then “link” with clinical care (including ART), mental health services, and support programs targeting their psychosocial, legal, and socioeconomic needs.

The conceptual framework in Figure 1 models the stages and links from HTC to ART retention and adherence. It builds on Rosen and Fox’s (2011) pre-ART model (which sequences the events between testing positive for HIV and initiating ART) and includes six stages: (1) HTC; (2) access to and linkage with care; (3) clinical staging; (4) pre-ART care; (5) ART initiation; and (6) ART retention and adherence. The framework was developed to help understand and interpret the data from this strategic assessment, plan for future LTC research in Iringa, and inform the design of a comprehensive HIV prevention and treatment approach for the region.

Figure 1: Conceptual framework of the stages of and links between HTC, access/linkage to care, staging for pre-ART care and ART initiation, retention and adherence



The three stages of linkages to care

This brief focuses on stages 2, 3, and 4 of the conceptual framework (access to and linkage with care, clinical staging, and pre-ART care). These three stages are collectively referred to as the LTC process. Each of these three stages is described below, and further detailed in Appendix 1. Separate Iringa strategic assessment briefs are available on HTC (stage 1) (Research to Prevention, 2013a) and ART initiation, retention, and adherence (stages 5 and 6) (Research to Prevention, 2013b).

Access to and linkage with care

An individual is considered successfully linked to HIV care and treatment (and capable of moving to the subsequent stage of clinical staging) if he/she (1) tests positive for HIV infection and (2) is referred to HIV care and treatment services.

Clinical staging

Once a newly diagnosed person living with HIV has been successfully linked to care, initial staging for pre-ART or ART care (referred to as “clinical staging”) is possible. An individual has successfully completed this stage (and is capable of moving to the subsequent stages of either pre-ART care or ART initiation) if he/she adheres to the CDC’s recommendations (Appendix 1) of seeing a medical provider (ideally within three to six months after diagnosis), receiving full medical evaluation, and having a CD4 cell count and/or HIV viral load test conducted (CDC, 2009).

Pre-ART care

PLHIV are eligible for the pre-ART stage if they were successfully linked with HIV care and treatment services, underwent clinical staging, and were deemed not yet eligible for ART (based on their CD4 and/or viral load counts). Reaching this stage requires retention of patients at each of the prior transition phases. Among those who *do* enter the pre-ART stage, many will only remain for a short period of monitoring and assessment before their condition advances and requires ART initiation, while others could remain in pre-ART care for years. The goals of pre-ART care are to provide regular clinical *assessments for ART*, consistent *HIV care*, and eventually, to effectively transition patients to the ART initiation stage.

Assessment for ART involves regular follow-up and review, as well as clinical staging via CD4 count, biochemistry, and hematology. The World Health Organization (WHO) currently recommends ART initiation when CD4 counts drop to or below ≤ 500 cells/mm³ or the patient presents with severe or advanced clinical disease (WHO, 2013). *HIV care* refers to a comprehensive pre-ART package that complements clinical ART assessment. WHO (2008) developed recommendations for “essential prevention and care interventions” for PLHIV living in resource poor settings for whom ART is not clinically indicated. These guidelines include a core set of effective, simple, and relatively inexpensive interventions to “improve the quality of life, prevent further transmission of HIV and for some interventions, delay progression of HIV disease and prevent mortality.” Appendix 2 lists thirteen areas of intervention recommended.

Attrition during the three stages of LTC

Despite the importance of completing the entire LTC process, global research indicates that there are patient losses at each step of the LTC cascade, beginning with those who do not return for their initial CD4 count results and extending to those who do not initiate ART when eligible. In a systematic review of data from seven sub-Saharan African countries (including Tanzania), it was estimated that 41% of individuals who test HIV-positive are lost between being diagnosed and completing their initial CD4 test or clinical assessment. Less than half (46%) of patients who enroll in pre-ART care return for determination of eligibility for ART (Rosen & Fox, 2011).

Despite the limited data on LTC in Iringa, findings from other regions in Tanzania suggest that major retention gaps exist, posing important barriers to successful HIV prevention and reduction of HIV-related morbidity and mortality. Research from Kisesa, for instance, found that only 68% of patients who tested positive for HIV during HTC later registered at an HIV clinic for pre-ART care or ART initiation (Mshana et al., 2006). A separate study conducted in Mwanza found that of 200 women screened HIV-positive during antenatal visits and subsequently referred for ART assessment, only 62% actually registered at an HIV clinic (Balira, 2010). Thus, in both studies, more than one quarter of participants were lost during the period between access to/linkage with care and clinical staging. The Mwanza study looked further at women who were “successfully linked to HIV care and treatment” and found that, among those referred to and registered at HIV clinics, only 63% were screened or had CD4 counts completed. Thus, close to 40% of study participants were lost during the clinical staging phase, disabling them from proceeding to the final steps of pre-ART care or ART initiation. The reasons for this attrition were not examined, but Ferguson and colleagues (2012) suggested that current HIV-related services for pregnant women in settings such as Mwanza do not effectively integrate CD4 testing and ART provision into prevention of mother-to-child HIV transmission services.

Research from other settings, such as the US, indicates that isolation and stigma prevent many PLHIV from initiating care, and that direct linkages at the time of diagnosis would improve uptake (Pollini et al., 2010). A Kenyan study found that fear of violence or relationship dissolution prevented many women from enrolling in care. For these women, LTC was facilitated by disclosure of status to spouses and family members as well as direct invitations to receive follow-up home visits by PLHIV trained to support them in enrolling in HIV care (Hatcher et al., 2009).

Objective

This brief discusses strategic assessment findings on where and why attrition might occur at each stage along the LTC process in Iringa. It also analyzes trends related to specific stages of the LTC process and the context in which barriers and facilitators occur. Additionally, we consider how an improved LTC package could contribute to the success of combination HIV prevention programs in Iringa.

METHODS

Between January and October, 2012, the Iringa strategic assessment conducted 123 in-depth interviews to gain a variety of perspectives on the proposed combination HIV prevention intervention components. Interviews were conducted with a wide variety of community members, service delivery recipients, and key informants. This included 34 key informants (7 health care workers, 6 religious leaders, 9 non-governmental organization [NGO] workers, 6 government administrators, 2 village leaders, and 4 other individuals), 30 clients of HIV-related services (6 each from HIV testing and counseling, HIV care and treatment centers (CTC), male circumcision, prevention of mother-to-child transmission, and gender-based violence services), and 59 members of populations at heightened risk for HIV (10 sex workers, 10 truckers, 10 drug users, 9 men who have sex with men, and 20 plantation workers).

An interview guide was developed to cover certain key topic areas; however, interviewers were encouraged to probe on responses to explore related topics and experiences. All interviews were conducted in Kiswahili or English, transcribed, and translated into English if necessary. All interview guides contained open-ended questions about linkages to HIV care and/or treatment that allowed interviewers to explore participants' perceptions about current HIV services and related promoters and barriers to their use. Key informants were asked, "What do you know about HIV treatment in Iringa? What do people think about this service? What prevents people from accessing HIV treatment?" Clients of HIV-related services were guided through a comprehensive set of questions on LTC. First, they were prompted to provide feedback on access to and quality of existing services (e.g., narrations of their own experiences with travel time and distance, type of services accessed, motivation to access services, costs incurred and evaluation of quality). Clients were also asked to share their opinions on the attrition during services and ideas for improving quality and linkages. Finally, members of populations at heightened risk of HIV were prompted to share personal experiences with HIV services in Iringa and answer the following questions: "What are the biggest barriers to you in terms of being able to access HIV prevention and treatment services?" and "What would be helpful in terms of services or programs to support you to prevent HIV transmission?"

The questions above were included in the in-depth interview guide, and were suggestions of topics for discussion. Thus, not all of the 123 participants discussed issues related to LTC. However, findings were derived from quotes and themes that were representative of each category of respondents (key informants, HIV-related service delivery users, and members of populations at heightened risk for HIV).

Qualitative data analysis followed Crabtree and Miller's five steps in the "interpretive process": (1) Describing, (2) Organizing, (3) Connecting, (4) Corroborating, and (5) Representing (Crabtree & Miller, 1999). First, regular debriefing sessions were conducted with interviewers and study staff throughout the data collection process to identify preliminary findings for rapid use and to facilitate an iterative process of data collection and analysis. After data collection was complete, full transcripts were analyzed according to a two-step process. To accommodate the large amount data, a simple initial set of codes was first developed to identify text relevant to five key intervention components for the overall Iringa strategic assessment: cash transfers, HIV testing, HIV treatment, male circumcision, and

interventions with sex workers. These codes were applied using the computer software package Atlas.ti (version 5.2, Scientific Software Development GmbH, Eden Prairie, MN).

Following this initial coding, the resultant text coded under the HIV testing and HIV treatment topics was reviewed and a more detailed codebook was developed specifically for the topic of linkage to care. Collaboratively, members of the research team worked to assemble an LTC codebook in Microsoft Excel that incorporated using both priori and iterative (emergent) codes. Matrix tables were created in Excel and organized by the research domains associated with each code in the LTC codebook. Data were condensed and organized by constructing standalone findings and matrices of interconnections (of areas of interest) that allowed for cross-informant analysis. Summary memos were created for each major theme. Corroboration was conducted by going back to the original text as needed. Data from summary memos and representative quotes were developed into the results presented in this brief.

Ethical approval for this study was received from institutional review boards at Muhimbili University of Health and Allied Sciences, Johns Hopkins Bloomberg School of Public Health, and the Tanzania National Institute for Medical Research.

RESULTS

Access to and linkage with care

Participants narrated challenges to successful referral/linkage to HIV care and treatment among PLHIV in Iringa in two main categories: failure to provide referrals to individuals who were newly diagnosed with HIV, and ineffective referrals (e.g., referral letters being required but not provided by the referring medical professional). Some participants shared their own experiences of not being referred for onward HIV-related services after an HIV-positive diagnosis, while others talked about the experience of friends or family members who received a positive diagnosis. Several important obstacles to provision of successful referrals emerged.

First, HTC is offered in Iringa through both facility and community-based mobile approaches. While small-scale community-based efforts increase the availability of testing and counseling services, an apparent shortcoming is the lack of collaboration and referral networks between the clinics, facilities, and organizations offering HTC and care and treatment services. Some HTC providers in Iringa offer HTC services exclusively (i.e., they do not do clinical staging or provide treatment). When clients of these exclusive HTC service providers test positive for HIV, they must be referred elsewhere for clinical staging. However, it was reported that some of the facilities that offer staging and treatment in Iringa, including CD4 and viral load (VL) measurement, provide these services exclusively to existing clients – that is, clients who received HTC at their location. Clients who tested at outside sites might be turned away from care and treatment services, or would have to undergo HTC a second time (which may re-introduce certain barriers to HTC for the client). The quote below was narrated by a woman who worked at a private HIV clinic that provided the full range of HTC, clinical staging, and treatment, but often refused to accept new patients who had not begun the cascade of LTC by testing for HIV at that clinic.

At our HIV treatment and care center all services are there, but for a patient from outside they come with letters to check their CD4, because there I am the one who receives them, and I tell them we can't test you because you're not our usual customer here.

This lack of collaboration between centers has resulted in the limited referral capacity of health professionals at some HTC-exclusive locations. On a related note, many NGOs conducting health education and HTC are unable to provide their HIV-infected clients with treatment and care and refer them to larger facilities that offer these services. However, many participants working in NGOs complained that these facilities, such as the regional hospital, are often understaffed or lack reagents to conduct CD4 or viral load tests, or they lack ART or medicines for opportunistic infections. Therefore, when clients are referred to these centers, they either have to wait for unacceptably long periods of time to receive services or they are turned away due to lack of personnel or supplies (as illustrated in the quote below). These obstacles have contributed to some providers discontinuing referral altogether.

There are times when you tell someone the services are available at the regional hospital. Then that person goes there and finds there is no such service. It seems like

you have lied to that person [for what you have said to him/her] but it's true! The hospitals are the places where the people are expected to go for [CD4/VL] testing. (NGO employee)

Finally, many participants described personal experiences with a passive referral process that lacked coordinated linking of newly diagnosed clients to medical case managers. Many participants mentioned "referral letters" as a main component of successful linkage to care and treatment but one that frequently created inconvenience and frustration. Some PLHIV sought out care and treatment but were denied services because they did not have a referral letter from their original provider. After this rejection, many simply gave up on seeking treatment. Others were provided referral letters but then forgot to submit them at the care and treatment centers, contributing to gaps in record-keeping efforts at the regional level.

A girl came here, tested positive, and was given a referral letter to go to a CTC. When she arrived at the CTC she was accepted and told to come back on Monday but she didn't reappear. When she eventually came back again she was pregnant and her blood pressure was high and we discovered she had never given us her referral letter. We realized she was who came here before but when she returned to the CTC she registered herself as a new client. A thing like that might happen in other centers. It might happen a lot. I am worried about the double reporting. (Health care worker)

Clinical staging

Participants narrated four main challenges for PLHIV to advance to clinical staging after having been successfully linked with care and treatment in Iringa: (1) Distance to and cost of services/medications; (2) Lack of human resources and equipment or supplies needed for clinical staging; (3) Abrasive and judgmental behavior of service providers; and (4) Concerns about discrimination, stigma, and disclosure of HIV serostatus.

Distance to and cost of services

Distance to clinics/hospitals and costs of services were the main barriers reported that could impede an individual who has been diagnosed with HIV to seek out and link to care and treatment services. These two obstacles were mentioned by individuals representing the full the range of participants: key informants, HIV-related service delivery users and populations at heightened risk of HIV.

Distance to HIV CTCs was reported as a common reason clients delayed initiation of clinical staging, did not adhere to the follow-up schedule, or did not undergo clinical staging at all. Government health facilities in Iringa were designed to provide services that were accessible and affordable by being located in densely populated areas and offering services free of charge. However, because of the fact that, until recently, HIV prevention and treatment efforts prioritized the scale-up of HTC, there currently exist more HIV testing points in Iringa than treatment clinics. Therefore, HIV-diagnosed persons from several HTC sites are referred to the same CTCs. While many HTC clinics are centrally located and easily accessible to most patients, this is often not the case when there are less numerous CTC sites. Both patients of and health workers from CTCs commented on the challenge created by the distance to care

and treatment services that many patients are required to travel, as illustrated by the following quote from an interview with a female health care worker:

Most people walk on foot to the health center and because they have to walk such a long distance it really discourages them a lot. There are people who live thirty kilometers from here, so we have to go to them; otherwise, they will not get any services. They cannot walk here and buses do not go there until summer time.

Along with complaints about the distance barrier for many PLHIV, several participants also said the costs related to obtaining services or medications and/or traveling to the clinics were significant barriers to patient retention. A woman receiving services from a gender-based violence prevention organization in Iringa spoke of transportation fees, saying, “There are people who die because they cannot attend services due to lack of bus fare.” Beyond transportation costs, some participants said that they were asked to pay fees at CTCs which they did not have in order to receive basic treatment services.

Lack of human resources and equipment/supplies required for clinical staging

A lack of human resources, possibly compounded by sub-optimal work protocols in health centers, was repeatedly mentioned as a reason PLHIV were discouraged or prevented from receiving care. Many participants said they would arrive at CTCs to find no personnel or only a skeleton staff on duty. Therefore, in order to receive services, clients either needed to wait for a long period of time or return to the center for an additional visit. A truck driver narrated, “It can happen that a health care worker doesn’t see the patient or you take the patient to hospital and you stay for two hours without any service.”

Among those PLHIV who did see a health care provider for an examination, many reported being unable to actually have their CD4 cell count or HIV viral load measured and/or monitored due to a lack of equipment and/or supplies (such as reagents) needed to perform these tests. This was illustrated in the following quote by an employee of a local NGO:

Availability of services is not good here [in Iringa]. When people go to the health centers they may be told “there are no reagents here” and things like that so it makes it very challenging [to get service]. (NGO employee)

A 40-year-old woman shared her challenging experiences with trying to undergo clinical staging after receiving an HIV-positive diagnosis from an HTC clinic in Iringa.

I went to Iringa to check my CD4 count but they told me the machine wasn’t working so I should go the following week, but when I went I found there were many people, some from Mtera. I stayed for two days [...] I was the twenty-fifth in the list.

Abrasive and judgmental behavior of service providers

Judgmental and discriminatory behavior on the part of HIV care and treatment service providers and staff was a frequently reported barrier to uptake and completion of clinical staging in Iringa. Participants clearly valued health care providers who treated PLHIV being treated with dignity and respect. However,

several narratives suggested poor treatment of PLHIV in many CTC centers. Nurses were often described as “abusive” and “bad tempered,” which frequently resulted in patients avoiding their service altogether or refraining from seeking complete information about important aspects of their health care and clinical staging. This sentiment was conveyed through the statement below from an interview with a 24-year-old woman living with HIV who received CTC services in Iringa:

They gave me my results but I did not know how to interpret them [...] I asked, “What does this number mean? Has my CD4 decreased or increased?” but the person [who gave me the result sheet] told me to ask the nurse but the nurse had a bad temper so I was afraid to ask her. I just stayed and thought, “How should I handle the situation?” I was afraid of that nurse because she would tell me to “go and sit! I am disturbing their heads!” So I asked myself, “What will I do?” I just sat there thinking. I decided to wait for the pleasant nurse.

Members of populations at heightened risk for HIV who were also living with HIV were among the participants most deeply affected by stigmatizing, unprofessional behavior of health care providers. Many of these individuals described not only marginalization related to their HIV serostatus, but also associated with their perceived “deviant” or “immoral” status as drug users, sex workers, or men who have sex with men. One man interviewed was a married drug user who described his wife as his only sex partner. They had two children. This man was diagnosed with HIV and soon thereafter tried to undergo clinical staging but was profoundly affected by the poor treatment he felt he received by hospital staff in the region:

A nurse is the first person to use abusive language to you. She is supposed to comfort you as a patient. Then YOU might encourage your fellow “patients” [drug users] along the streets and tell them, “Hello! I have gone to [service delivery location] and I got nice services!” But what happened is the nurse told me, “I will treat you but only if you come back with your wife.” I can’t come to the hospital with my wife for treatment because she will know I am doing evil things. The nurse has to treat me! Upon getting well [...] then maybe she could encourage me to request my wife to come to the hospital so that she can try to test too - even if she hasn’t contracted the disease - but for her to just come for treatment? That’s what happens when you come to despise me. This means when I get out of that place I will be fed up and asking, “Why would I go there when I will be abused?” I can’t go anymore.

Concerns about discrimination, stigma, and disclosure of HIV serostatus

Many people interviewed said they chose not to seek HIV care and treatment services in their own communities because they feared being stigmatized at nearby clinics by both professionals and/or people known to them who would see them accessing the services. Some individuals traveled (or said they wished they could travel) to distant CTCs to maintain privacy. Others talked about the way in which the fear of stigma deterred them from seeking support from friends and family or through local support groups.

There are so many PLHIV around but they do not want to reveal themselves. They should (reveal themselves) to see how their health is and get treatment but they just do not want to reveal themselves, many of them. You see, they are afraid of the humiliation, I can say. They say they are afraid of shame and that everyone will know: “Even the nurse that lives next door to me will know I have the disease!” They are afraid of such things. (Client of prevention of mother-to-child transmission service)

High levels of stigma surrounding HIV and AIDS are thought to result from fears of contagion, poor understanding of the disease, negative, value-based assumptions about people who are infected, and the fact that the main mode of transmission—sexual intercourse—is often a taboo topic in and of itself (UNAIDS, 2008). Even in Iringa, the region of Tanzania with the highest national HIV prevalence, some participants recognized that PLHIV were judged because, as one truck driver stated, you had “sexual intercourse so you have already discriminated yourself from those who abstained [...] We will stigmatize you by saying the kind of disease which you died from: ‘That guy died with AIDS!’ That’s stigma because we are not at all amazed when others die with malaria. HIV/AIDS still amazes us and we see it as a shameful disease.” Others reported that stigma was often based on the belief that PLHIV had been cursed by witchcraft.

According to participants, the adverse effects of stigma and discrimination included poor care within the health sector (discussed above) and feelings of futility (e.g., loss of hope and feelings of worth). All accounts suggested that social discrimination undermined the ability of PLHIV to disclose their status, make proactive decisions about their health, seek care and additional social support, and negotiate with sexual partners to take steps in preventing transmission to others and re-infection of self.

Pre-ART care

Assessment for ART

The same four challenges encountered during clinical staging also applied to PLHIV undergoing regular assessment for ART as part of their pre-ART care. Distance and cost of services, limited resources, negative attitudes of providers, and stigma/discrimination all proved to be obstacles to successfully attending regular follow-ups and reviews and having repeated biological tests conducted.

HIV care

Similar to the barriers mentioned previously, participants cited the limited basic resources and medications available at care centers as limitations in ensuring quality pre-ART care for PLHIV.

Many PLHIV talked about being prescribed Septrin (the locally used brand name for cotrimoxazole), a drug used to treat a range of opportunistic infections associated with HIV, but reported difficulties in obtaining it from clinics/facilities. Participants were under the impression that these drugs should be available free of charge to patients, so they were confused and upset over the fact that they were instructed to purchase the medications using out-of-pocket money at nearby pharmacies, as illustrated by the quote below:

After testing for HIV and being found positive, I was prescribed medication which was not available so I was required to go and buy it at the pharmacy. That was a problem because I had no money so I didn't go to the pharmacy. (Drug user)

Additionally, participants referenced food insecurity, inadequate energy intake, and general malnutrition as serious problems faced by the community at large and more particularly among PLHIV. The lack of nutritional support during pre-ART care was another barrier cited in maintaining health and adherence to medical regimes.

Participants' recommendations for improved linkages to care

Several service delivery providers suggested that access and linkage to care could be greatly improved by introducing a system for patient tracking in Iringa. Participants felt that a tracking system would improve the quality of services provided by health care workers, contribute to a more effective network of care between service providers, and reduce the number of unnecessary procedures conducted. For instance, when talking about her center's capacity to track patients and successfully connect them with other HIV-related services in the region, one health care worker explained how the current lack of data for tracking patients significantly reduced efficiency in this process. She requested "data to improve my work" and explained:

[due to] lack of education, especially in villages, one may test for HIV here but if found positive will not believe it and go repeat the test at even three different centers within town. In that case I may think I have tested 20 people with HIV infection, the Ipogoro centre will also have tested 20 people but in real sense there may be only ten people from Kitwiro who really tested at Ipogoro then went to Ngome. Sometimes we refer patients to CTC Ipogoro but instead you find him/her at ALAMANO. That means he/she repeated the test there. For NGOs, once someone goes there for service, they will start with the patients from the beginning even when they know their HIV status.

With respect to clinical staging, the most common recommendations were provision of transportation allowances, increased human resources, and better logistics to ensure an adequate supply of medications at facilities (especially of ART and medications for opportunistic infections). Systematic home-based care was also suggested as a potential means of limiting the burden on health care facilities.

If we can get help in strengthening the home-based care services, having a large network more than the one just for follow up, it (the system) will be more strong and may reduce (the problem of limited resources). (Iringa government administrator)

Many participants also mentioned the need for efforts to increase education and awareness in the community, including among health care workers, on the importance of keeping PLHIV free from discrimination and its adverse consequences.

Finally, it is widely accepted that adequate nutrition is one of the greatest needs of PLHIV (WHO, 2008). Accordingly, participants in our study highlighted the need for interventions that focus on environmental factors such as lack of resources and inaccessibility of foods.

Maybe the Government or NGOs should try to improve our environment. I am requesting at least we should be given something for example a sack of maize or a capital to start some sort of a business. (CTC employee)

DISCUSSION

This brief presents strategic assessment findings on the three main components of the LTC process in Iringa. Participants narrated several key barriers to access to and linkage with care, clinical staging, and pre-ART care in the region, and provided thoughtful suggestions for how most of these obstacles could be addressed and mitigated.

Absence of onward connections to services and provision of ineffective referrals were highlighted as the main challenges to successful linkage to HIV care and treatment among PLHIV. The introduction of patient tracking systems was suggested as a mechanism for enhancing current linkages in the region. Participants were asked to provide their opinions about a novel system that would store a patient's digital fingerprint (without names or identification) when they accessed an HIV-related service so that providers could track patients. While a few were wary about how this type of tracking would be accepted in the community, most felt very positive about it, making it something worth further examination. The finding on poor tracking highlights the importance of developing closer linkages between HTC centers, CTCs, health facilities, and other providers so as to ensure stronger client tracking to identify reasons for missed visits and loss to follow-up.

Additionally, participants frequently described a lack of collaboration between CTCs and the limitations this imposes on the capacity of providers to make effective referrals. Referral systems need to be strengthened ensure successful links between each level of the LTC process. Innovative referral systems for linking PLHIV with onward care have been found to be successful in other regions of Tanzania and might also be effective in Iringa. For example, in Kisesa, a rural area in the Mwanza region in the northwest of Tanzania, a referral system was implemented that involved two-part referral forms with unique matching numbers on each side. These unique matching numbers were used to connect patients with services, monitor how many clients registered for these services, and track the length of time between each point along the continuum of care. To facilitate clinic attendance, this program also provided transportation allowances, addressing another barrier to LTC highlighted in Iringa. An evaluation found that the Kisesa intervention significantly reduced delays in care seeking and improved monitoring of access to services (Nsigaye et al., 2009). Implementing a similar model for enhancing and monitoring referral uptake and successful LTC could be feasible and effective in Iringa.

Beyond transportation allowances and home-base care, participants also highlighted an urgent need to address poor attitudes among health providers and the larger issue of respectful treatment of PLHIV. In 2008, the Tanzanian parliament passed the *HIV and AIDS Act*, which provides a legal framework for the national response to HIV/AIDS. Two key provisions of this law are: (1) "The Government, political, religious, and traditional leaders and employers in the private sector shall advocate against stigma and discrimination of people living with HIV and AIDS;" and (2) "A person shall not stigmatize or discriminate in any manner any other person on the grounds of such person's actual, perceived, or suspected HIV and AIDS status" (USAID, April 2008). Nonetheless, many participants narrated their own personal accounts (as PLHIV) or observances of PLHIV experiencing prejudice, negative attitudes, abuse, and maltreatment beyond the health care setting. Participants shared stories of being shunned by family members, peers,

and the wider community, much of which was associated with emotional trauma, loss of confidence, and a negative effect on care seeking. These negative experiences, both in the community and health care settings, decreased many people's willingness to undergo clinical staging and to reveal their status to others. Education and advocacy efforts are urgently needed to promote equal respect and non-discrimination for PLHIV. Furthermore, health care professionals should receive training on all provisions of the *HIV and AIDS Act* in order for it to be effective and harmonized with other health care legislation (such as how to treat high-risk groups like sex workers and men who have sex with men).

Finally, PLHIV in Iringa should have access to the range of essential interventions that can prevent illness and HIV transmission. WHO (2008) recommends thirteen "essential prevention and care interventions" for resource-limited settings. Our findings suggest two areas that are particularly challenging in Iringa: cotrimoxazole prophylaxis and nutrition interventions. Cotrimoxazole is recommended by WHO to treat a range of opportunistic infections associated with HIV. WHO recommends providing this drug to all HIV-infected children less than one year of age and to all HIV-infected adults with CD4 count of less than 350, as well as adults with a history of pneumocystis carinii pneumonia irrespective of CD4 levels (WHO, 2008). Because of the challenges participants narrated in accessing this drug, we recommend provision of cotrimoxazole free of cost to patients in Iringa as part of a pre-ART package. We also recommend the introduction of nutritional support in the region. Research is needed to assess the type and magnitude of nutritional needs in the setting so as to design and implement an evidence-based intervention.

Given the high prevalence of HIV infection in Iringa and the findings from the Iringa strategic assessment, we believe an enhanced LTC package could contribute significantly to the success of combination HIV prevention programs in this setting.

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APPENDIX 1

The three LTC stages: access to/linkage with care, clinical staging, and pre-ART care
Access to and linkage with care
During this stage, an individual who tests HIV-positive is referred to HIV care and treatment services. Once this has been achieved, initial staging for pre-ART or ART care is possible.
Clinical staging
An individual is ready for clinical staging after completing the previous stage by testing positive for HIV and being successfully referred to HIV care and treatment services. This individual is now considered “successfully linked to HIV care and treatment” and prepared for/capable of staging for pre-ART care or ART. It is recommended that PLHIV see a medical provider within 3 to 6 months after an HIV diagnosis to receive a full medical evaluation including a CD4 and viral load (VL) count (CDC, 2009). After providing a blood sample he/she must return to receive their CD4 and VL results for referral to pre-ART care or ART initiation. CD4 and VL results also help to understand the magnitude of HIV-related illness which provides useful prognostic information on progression and potential response to therapy (Korenromp, et al., 2009). The amount of time between testing and results notification is contingent upon the laboratory processing capacity and location. An individual has completed clinical staging after receiving his/her CD4 or VL results and being referred onward for pre-ART care or ART initiation.
Pre-ART care
This stage encompasses the interval between enrollment in pre-ART care and determination of eligibility for ART and is only relevant to individuals who completed the previous two stages. Rosen and Fox (2011) found the processes involved in this stage to be highly variable by setting and poorly defined in the literature. At a minimum, pre-ART care was defined to include “regular” (a term not standardized across settings or publications) clinic visits to monitor an individual’s condition (Rosen & Fox, 2011) and repeat CD4 counts for individuals deemed not eligible for ART at previous CD4 counts. WHO guidelines recommend ART be initiated in all PLHIV, including adolescents and pregnant women, with CD4 counts of ≤ 350 cells/mm ³ , regardless of the presence or absence of clinical symptoms. Those with severe or advanced clinical disease (WHO clinical stage 3 or 4) are advised to begin ART irrespective of their CD4 cell count (WHO, 2013). For an individual to complete the pre-ART care stage, ART eligibility must be determined prior to the patient’s CD4 count falling substantially below the eligibility threshold or the patient becoming severely ill (Rosen & Fox, 2011).

APPENDIX 2

The World Health Organization's (2008) recommendations for essential prevention and care interventions for adults and adolescents living with HIV in resource-limited settings covered thirteen areas of intervention:

1. Psychosocial counseling and support;
2. Disclosure, partner notification, and testing and counseling;
3. Cotrimoxazole prophylaxis;
4. Tuberculosis;
5. Preventing fungal infections;
6. Sexually transmitted and other reproductive tract infections;
7. Preventing malaria;
8. Selected vaccine preventable diseases (hepatitis-b, pneumococcal, influenza vaccine, and yellow fever vaccines);
9. Nutrition;
10. Family planning;
11. Preventing mother-to-child transmission of HIV;
12. Needle-syringe programs and opioid substitution therapy; and
13. Water, sanitation and hygiene.