



Home-Based Care (HBC) Needs Assessment among U.S. Government- Supported Areas in Tanzania

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Cover photo: A healthcare worker pays a home visit to a bedridden HIV-positive father while his son looks on.

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ABBREVIATIONS

ART	antiretroviral therapy
ARV	antiretroviral
CDC	Centers for Disease Control and Prevention
CTC	care and treatment centre
HBC	home-based care
HTC	HIV testing and counseling
MOHCDGEC	Ministry of Health, Community Development, Gender, Elderly and Children
NACP	National AIDS Control Programme
NASTAD	National Alliance of State and Territorial AIDS Directors
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PLHIV	People living with HIV and AIDS
TB	tuberculosis
THMIS	Tanzania HIV/AIDS and Malaria Indicator Survey
USAID	U.S. Agency for International Development
USG	United States Government
WHO	World Health Organization

EXECUTIVE SUMMARY

To address the HIV epidemic and meet the needs of people living with HIV and AIDS (PLHIV), Tanzania's Ministry of Health and Social Welfare—which, since October 2015, has been called the Ministry of Health, Community Development, Gender, Elderly and Children (MOHCDGEC)¹—adopted home-based care (HBC) as a component of the continuum of care promoted by the World Health Organization (WHO) and the United States President's Emergency Plan for AIDS Relief (PEPFAR).

This study seeks to obtain a better understanding of how best to deliver HBC services in the context of changing client needs, as effective and accessible treatment is transforming HIV from a terminal to a chronic condition. MEASURE Evaluation, funded by the United States Agency for International Development (USAID) and PEPFAR, conducted a survey of PLHIV to assess the condition of HBC clients living with HIV and determine needs for and satisfaction with HBC services among those clients. This study took place in five regions of Tanzania between May and August 2015. Study findings can be used to help ensure effective service delivery to better meet the changing HBC client population and to show decision makers how to improve HBC policy and operational guidelines. In particular, findings from this study could be integrated in MOHCDGEC training on HBC guidelines and implementing partner HBC operating guidelines.

The study posed the following research questions: (1) What are the characteristics of all HBC clients in selected wards; (2) What are the types of support that HBC clients who are HIV-positive receive? Are there differences in support received based on characteristics of clients? How helpful do recipients find these services to have been? (3) What are the unmet needs of HIV-positive HBC clients? Are there differences in unmet needs based on characteristics of HBC clients/location? (4) What are the key facilitators and challenges for HIV-positive clients accessing HBC services, including staying on treatment? (5) What are HIV-positive HBC clients' perceptions of their interpersonal relationships and quality of life, including stigma? (6) What are reasons why HIV-positive HBC program participants default from care?

Study Design and Data Collection/Analysis

This was a cross sectional study in the five regions where the U.S. government is funding HBC projects: Dar Salaam, Iringa, Kilimanjaro, Mara, and Mwanza. The sampling frame included all HBC clients located in the five selected regions who had enrolled in HBC at least six months prior to the survey. The sampling strategy involved a three-stage cluster sample; randomization was conducted using the random number generator in Excel. Face-to-face or telephone interviews were conducted using a standardized questionnaire with closed-ended and open-ended responses. Data collection started on May 26, 2015 in Dar es Salaam Region and was completed on August 7, 2015 in Iringa Region.

Data entry began while enumerators were still collecting data in the field to provide timely feedback on data quality to the data collection teams, with subsequent data cleaning measures taken upon completion of data collection. Open-ended responses were translated from Swahili to English and coded for themes.

In accordance with the study design, we sampled an equal proportion of rural and urban residents from our sampling frame. However, our sampling frame had a greater proportion of urban residents (64%, N=1510). Because rural residents were oversampled, we had to apply survey weights in our analysis.

¹ We refer to the Ministry by its old name for purposes of referencing published materials; otherwise, we use the new name.

Key Findings and Recommendations

A total of 3,411 clients were listed in the HBC registers in selected wards; approximately two-thirds of whom were female. Of these, 1,667 HBC clients were found to be eligible for the survey based on the following criteria: 18 and older (from age at time of registration to time of survey); known HIV-positive status (HIV status at time of registration); whose date of registration was six months or more prior to the date of the survey; and whose status of registration was “new,” “continuing,” or “patient voluntarily withdrew from the program.”

A total of 606 HBC clients were interviewed. Nearly 60 percent lived in urban areas, and most had primary-level education. Just under half have been engaged in farming, livestock, or keeping a household garden. On average, clients have known their HIV status for about seven years. The average age was 42 at the time of the study.

In the study sample wards, the overwhelming majority of clients were healthy. Self-reported antiretroviral therapy (ART) adherence was high, although many clients indicated they would prefer getting a bigger supply of antiretroviral drugs (ARVs) at a time. With respect to services, many HBC clients reported receiving different types of services in the past 30 days. However, a majority indicated they needed more, particularly in the realm of emotional and social support and support around issues such as malnourishment, malaria, pregnancy, clean water, and tuberculosis. Several services (e.g., assessment and treatment of pain and treatment of malaria) were more commonly received in urban than rural areas.

Clients largely reported positive experiences with their local health facilities. They had visited a care and treatment center one month previously, on average—a higher frequency than the national guidelines’ suggestion of one visit every two months. Furthermore, clients were highly satisfied with facility services, and nearly all reported that the provider gave them the information needed to manage their condition.

Nearly all clients had had at least one HBC volunteer and were highly satisfied with their interactions with that volunteer. Clients also believe HBC volunteers are working to reduce stigma, and few clients reported being denied health services or social or religious experiences because of their HIV status. Nonetheless, some clients—women more than men—do still experience some stigma.

According to Tanzania’s national HBC guidelines (NACP, 2010), to meet the goals of the HIV/AIDS Care and Treatment Plan, 2003–2008 (United Republic of Tanzania, 2003), intensified efforts would have to be made to identify PLHIV in need of services. Yet, with HBC registers often incomplete and no transition plan when volunteers leave or new programs are put in place, it is possible that clients once registered are no longer served.

Based on our study findings, we suggest the following actions to ensure continued success of Tanzania’s HBC program:

- Consider providing clients with a bigger supply of ARVs at a time.

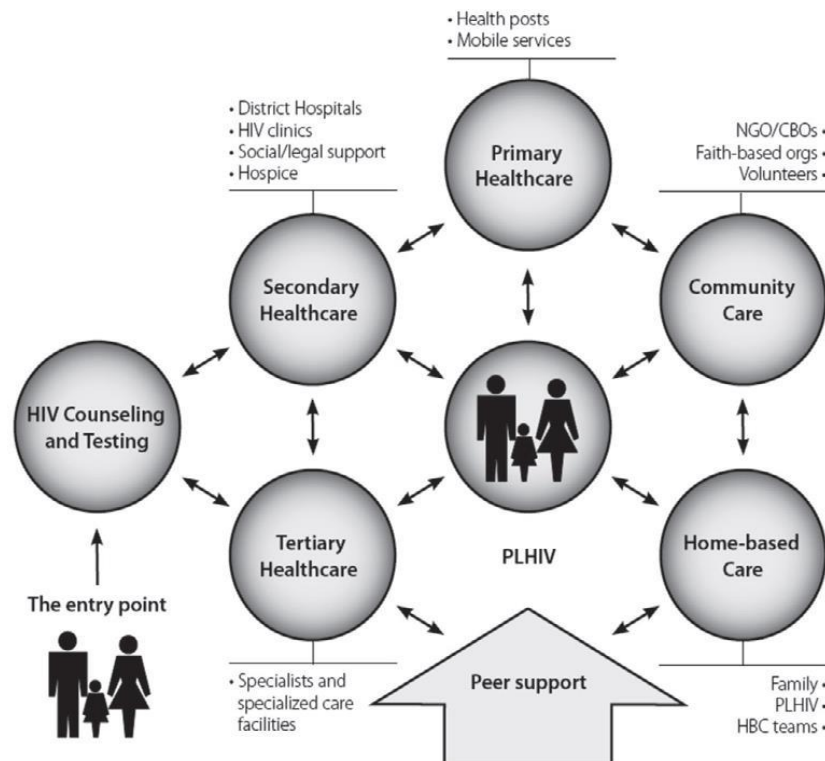
- Develop indicators for provision of comprehensive care and support that capture the different needs associated with long-term care and health maintenance, because HIV is more commonly becoming a chronic condition.
- Measure the capacity of volunteers to deliver HBC services in urban and rural areas and address gaps.
- Ensure that HBC volunteers can offer psychological and spiritual support, in addition to addressing clients' physical needs.
- Explore ways to better engage men living with HIV in HBC programs and ensure their sustained participation and adherence to ART, particularly in urban areas.
- To improve continuity of care, ensure client lists are handed over to new HBC volunteers and/or new HBC programs. New HBC implementing partners should retain previous programs' community volunteers.
- Assess and improve data quality of client registers to ensure clients are getting the support needed.
- Triangulate the findings from this study with other study findings on PEPFAR HBC programs in Tanzania, and update HBC guidelines and training materials accordingly.
- To combat HIV-related stigma and discrimination, HBC programs should continue supporting professionals at health facilities, volunteer health workers, and other service providers who work with PLHIV.

INTRODUCTION

For more than two decades, Tanzania and its development partners have been grappling with the challenges posed by the HIV epidemic. The consequences of the epidemic affect all spheres of life. The human capital loss has a serious social and economic impact in all sectors, and on communities and individuals. While HIV prevalence has dropped, it is still high, at nearly 5 percent (THMIS, 2012). The prevalence of HIV is higher among women (6 percent) than men (4 percent). For both sexes, urban residents have higher prevalence of HIV (7 percent) than rural residents (4 percent) (THMIS, 2012).

To address this epidemic and meet the needs of PLHIV, the Tanzania MOHCDGEC adopted HBC as a component of the continuum of care promoted by WHO and PEPFAR. HBC is defined as any form of care given to chronically ill people in their homes and includes activities that provide physical, psychological, social, and spiritual support (WHO, 1993). HBC is a system with involvement from the central level, health facility level, community level, and household and patient levels. Ultimately, family members and community HBC providers are seen as key players in providing HBC services to PLHIV with support from systems at the community and higher levels (National AIDS Control Programme, 2010). Figure 1 depicts the MOHCDGEC's continuum of care model for PLHIV in Tanzania.

Figure 1: Continuum of care for PLHIV, adapted for Tanzania



Source: National AIDS Control Programme, 2010

STUDY RATIONALE

Tanzania's HBC program guidelines were revised in 2010 to address the changing scope of the HBC program; however, the *Trainers Guide for Home Based Care Providers*, published in 2005 (National AIDS Control Programme), was not revised to reflect these changes. With PLHIV living longer on effective treatment, the demand for nonpalliative care services is increasing. More organizations are providing support for HBC, many with the support of United States Government (USG) agencies (i.e., United States Centers for Disease Control and Prevention [CDC], United States Agency for International Development [USAID], United States Peace Corps, and United States Department of Defense). Given rapid advancements in HIV testing and treatment, it is likely that both the HBC program guidelines and the HBC training manual would benefit from more up-to-date information about the current client population and their needs for HBC services and what services can/should be delivered.

To date, USG has supported two studies to understand more about how to effectively deliver HBC services. The first study, implemented by FHI 360, focused on collecting data from HBC volunteers in select districts in Morogoro, Iringa, and Tanga (Yahya-Malima, 2011). The second study, led by the National Alliance of State and Territorial AIDS Directors (NASTAD) in collaboration with CDC-Tanzania, USAID-Tanzania, and the Tanzania National AIDS Control Programme (NACP), collected qualitative data from a small convenience sample of key informants with HIV through interviews and focus group discussions (Tanzania MOHSW & NASTAD, 2012).

Despite these efforts, key information gaps remain, including (1) how the HBC system is working from the client's perspective, (2) reasons for antiretroviral therapy (ART) attrition, (3) interpersonal relationships with clients and caregivers, (4) satisfaction with services, (5) distance from health facilities, and (6) services needed.

To fill this gap, MEASURE Evaluation conducted a survey of PLHIV to quantitatively assess the condition of HBC clients and determine needs for and satisfaction with HBC services among such clients. This study took place in five regions of Tanzania between May and August 2015 (see Table 1 in the "Data Collection" section for partners worked with, by region). Study findings can be used to help ensure effective service delivery to better meet the changing HBC client population and to show decision makers how to improve HBC policy and operational guidelines. In particular, findings from this study could be integrated in MOHCDGEC training on HBC guidelines and implementing partner HBC operating guidelines.

The research questions are as follows:

- What are the characteristics of all HBC clients in selected wards (i.e., types of health conditions leading patients to be registered in the HBC program; HIV status; age; gender; length of time in the program; length of time since last visit; and status of clients—active or inactive)?
- What are the types of support that HIV-positive HBC clients receive? Are there differences in support received based on characteristics of clients (e.g., rural and urban; male and female)? How helpful do recipients find these services to have been?
- What are the unmet needs of HIV-positive HBC clients? Are there differences in unmet needs based on HBC clients' characteristics and locations (e.g., rural and urban; male and female)?
- What are the key facilitators and challenges for HIV-positive clients accessing HBC services, including staying on treatment?

- What are HIV-positive HBC clients’ perceptions of their interpersonal relationships and quality of life, including stigma?
- What are reasons why HIV-positive HBC program participants default from care?

METHODS

Study Design

This was a cross-sectional study taking place in the five regions where the USG is funding HBC projects: Dar Salaam, Iringa, Kilimanjaro, Mara, and Mwanza. Selection of districts and wards within those regions is described below. The National Institute for Medical Research, in Tanzania, and the Health Media Lab Institutional Review Board, in Washington, D.C., both reviewed and approved the study protocol and consent process.

Sampling

The sampling frame included all HBC clients located in the five selected regions who had enrolled in HBC at least six months prior to the survey. The sampling strategy involved a three-stage cluster sample;² randomization was conducted using the random number generator in Excel. The sampling strategy was as follows:

- For each of the five regions, two districts—one urban and one rural—were randomly selected, for a total of 10 districts (5 regions x 2 districts/region) [Table 1].
- For each district selected, two wards were randomly selected with probability of selection proportional to the number of communities (villages or *mtaa*) participating in the HBC program, for a total of 20 wards (5 regions x 2 districts x 2 wards).

In each of these wards, HBC volunteer registers (Usajili wa Mgonjwa na huduma zitolewazo—Patient Registration and Services) were reviewed. An Excel file of all ever-enrolled clients was constructed for each HBC volunteer, including date of registration, HIV status at the time of registration, age at time of registration, gender, and date of last visit. A predefined macro routine created a second list of clients eligible for interview: 18 and older (from age at time of registration), known HIV status (HIV status at time of registration), and whose date of registration was six months or more prior to the date of the survey. Using the date of the most recent visit in the register, eligible clients were classified as “active” (visit within four months of the survey) or “inactive” (last visit more than four months prior to the survey). From this list, we planned to randomize the list of eligible interviewees by active/male and female and inactive/male and female. Interviewers attempted to interview the first 10 active clients (five male and five female) and the first six inactive clients (three male and three female) from the randomized list. However, with few inactive clients to be interviewed, we interviewed all the inactive clients we could in each of the sampled wards first and selected

²Initially, we had planned a four-stage cluster, with the third stage involving randomly selecting villages from the wards that had been selected. During piloting, however, we discovered immense challenges in sampling from the village level, particularly for the urban areas. HBC volunteers sometimes only covered a street or part of a street, and creating the sampling frame in that manner risked compromising the sampling strategy.

the remaining respondents from the randomized list of active clients. The goal was to select 32 clients per ward for interviews, for a total of 640 clients.

Table 1: List of districts, by implementing partner and region

Region	Implementing partners	District/wards
Dar es Salaam	Pastoral Activities and Services for People with AIDS in Dar es Salaam Archdiocese (PASADA) Management and Development for Health (MDH)	Temeke District: Mbagala Kuu and Tungi Wards Kinondoni District: Makuburi and Manzese Wards
Iringa	Allamano Iringa Mercy Organization (IMO) Both are implementing HBC through the TUNAJALI project	Iringa Municipal Council: Kihesa and Ruaha Wards Iloilo: Ukwega and Udekwa Wards
Mara	Tanzania Interfaith Partnership (TIP): started service delivery in April 2015, replacing Africare, which had provided such services since 2008	Rorya: Nyathorogo and Komuge Wards Musoma: Nyasho and Makoko Wards
Mwanza	Tanzania Red Cross Society (TRCS)	Ilemela Municipal: Ilemela and Bugogwa Wards Misungwi District: Igokelo and Karomije Wards
Kilimanjaro	Tanzania Red Cross: Took over from Mildmay in 2012 for Rombo District, continuing with 6 volunteers out of the original 17 Pathfinder in Moshi Municipality in October 2014	Rombo: K/Samange and M/Keryo Wards Moshi Municipal: Pasau and Njoro Wards

Data Collection

Face-to-face or telephone interviews were conducted using a standardized questionnaire with closed-ended and open-ended responses (see Appendix 1 for the questionnaire, including the informed consent form). The questionnaire covered a broad range of topics: background information on the respondent, his or her quality of life, ART adherence, use of and satisfaction with health facilities, use of and satisfaction with HBC services, other support and services received and services needed, and intrafamily relationships.

The questionnaire was translated and administered in Swahili. The sampling frame process and questionnaire administration were pilot-tested in Bagamoyo and subsequently revised. All data collectors, supervisors, and data entry clerks were trained and provided with manuals tailored to their roles in the study. Data collection started on May 26, 2015 in Dar es Salaam Region and was completed on August 7, 2015 in Iringa Region.

Once in the field, data collection teams visited PEPFAR implementing partner HBC supervisors based at facilities, and they provided comprehensive lists of HBC volunteers. Supervisors then introduced the data collection team to HBC volunteers, who provided access to the HBC registers needed for the sampling exercise described above. Data collection teams endeavored to obtain comprehensive lists from all HBC volunteers and their clients in each ward. When in the field, data collectors realized that there were insufficient numbers of inactive clients and male clients. Therefore, the teams attempted to select replacements from another ward with similar characteristics (i.e., urban and rural) to ensure 32 clients per ward.

Data Management

Two data entry clerks conducted double data entry and validation using Epi Info data entry software and data entry errors were then rectified (Dean, et al., 2011). Data entry began while enumerators were still collecting data in the field to provide timely feedback on data quality to the data collection teams. Upon completion of data collection, the following data cleaning steps were conducted: (1) review of a random sample of 10 percent of paper questionnaires, to ensure that what was on paper was entered accurately in the database; (2) a check of skip patterns, to ensure that questions had been asked correctly; and (3) cross tabulations for data checks. When outliers were identified for continuous variables, completed client surveys were reviewed to eliminate data entry errors. If no data entry errors were present, the outliers with values above and below three standard deviations were treated as missing.

Open-ended responses were translated from Swahili to English and coded for themes.

Data Analysis

In accordance with the study design, we sampled an equal proportion of rural and urban residents from our sampling frame. However, our sampling frame had a greater proportion of urban residents (64%, N=1510). Because rural residents were oversampled, we had to apply survey weights in our analysis. For the analysis, we ran descriptive frequency distributions, cross tabulations, and basic inferential data analyses to describe characteristics of study participants and answer research questions. T-tests were applied to test for difference in the means of the continuous variables by levels of the categorical variables (e.g., difference in the means of age across locality categories). Chi-square tests were applied in cross-tabulations to test the significance of association between two categorical variables (e.g., association between receiving a visit from an HBC volunteer and clients' sex).

RESULTS

Characteristics of HBC Clients

A total of 3,411 clients were listed in the HBC registers in selected wards. Approximately two-thirds of those clients were female (69%) and one-third male (31%). The average age of these clients was 39 years old (SD=14.7, range 1 to 85; median=38, mode=36), and was similar among males and females. Two-thirds of the clients listed in the HBC registers were urban, with more females than males living in an urban setting (67% vs. 62%, $p=0.0028$). Most clients were registered for HBC services because they were HIV-positive (89.3%). Other reasons were tuberculosis (TB) (3.9%), diseases of the heart (1.9%), diabetes and sickle cell (.7% each), and cancer (.5%). A higher proportion of females than males were registered for HIV (91.4% vs. 84.8%, $p<.0001$); conversely more males than females were registered for TB (6.9% vs 2.6%, $p<.0001$).

Most clients were HIV-positive (89.9%); 6.4% were HIV-negative, and the HIV status of 3.7% of clients was registered as unknown ($n=3,411$). For those clients who were HIV-positive ($N=3,067$), all except 27 were registered because of their HIV status. The remaining ($n=17$) were registered for TB. A higher proportion of female clients were HIV-positive (92%) than were male clients (85.4%), $p<.0001$. The average age of clients at registration was 36 (SD=14.7 years; range was 1 to 85; median was 36). There were no significant differences in age at registration between males and females.

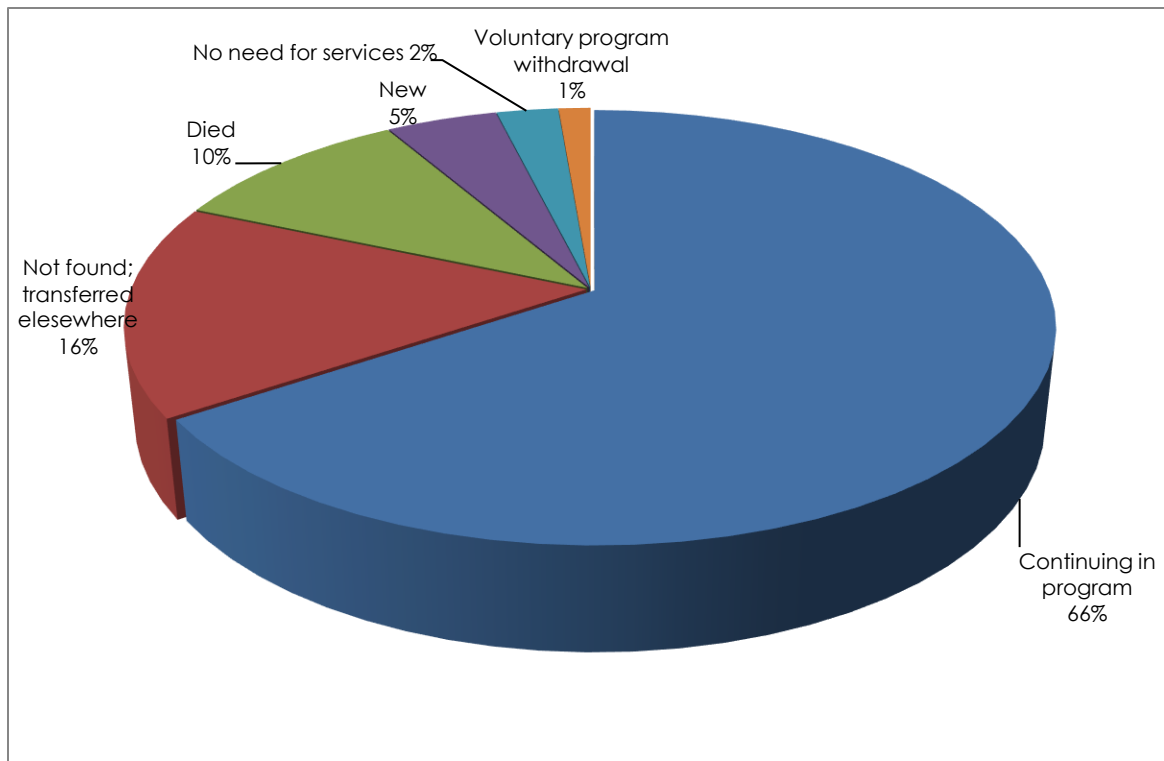
On average, clients were registered for the HBC program for about three years (SD=25 months; range from less than 1 month to 146 months; median=31 months; N=3,400). There were no significant differences in length of time in the HBC program between males and females. Based on client registers, 68.4 percent of clients had been visited in the past four months (time between registration and last visit), with more females than males being visited (70.1% vs. 64.8%, $p<.0025$).

Approximately 70 percent of HBC clients were listed as still receiving program services (either a new client or continuing in the program) (Figure 2). The remaining 30 percent were not actively receiving services for a variety of reasons, including because they had passed away, could no longer be found, had moved, had indicated they did not need any services, or had voluntarily withdrawn from the program. A greater proportion of males than females had died (13.8% vs. 8.4%, $p<.0001$).

The average length of time since the client was last visited at home was 6.5 months (SD=10.7 months, range=0 to 68 months; median=1.4 months; N=3,341). The length of time since the last visit was less for females (6.1 months) than for males (7.3 months) ($p<.004$).

Of the 3,411 clients in the sampling frame, 1,667 were eligible for the study based on the following criteria: 18 and older (from age at time of registration to time of survey) and known HIV-positive status (HIV status at time).

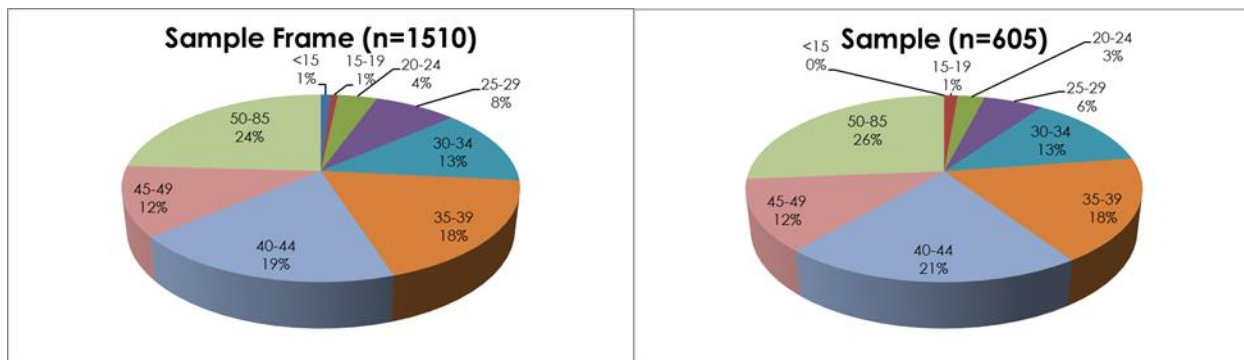
Figure 2: Status of HBC clients



The goal was to interview 640 people, active and inactive. However, 264 clients (54.9% female; 45.1% male) who were selected could not be reached and had to be replaced for the following reasons: 61 percent (n=161) no longer lived in the location indicated in the HBC register, 18 percent (n=47) refused to be interviewed, 12 percent (n=31) were not at home during the visit due to travel, 3 percent (n=8) were deceased; and 7 percent had other reasons, such as being under the age of 18, or that the volunteer was away.

We experienced challenges finding inactive clients and were only able to locate 34. Thus, we focus the analysis on the remaining 606 clients interviewed. The sample of 606 clients did not fully represent the population of eligible active clients (N=1,510): a greater proportion of eligible clients were in an urban setting than clients in the sample (63.8% vs. 48.2%, $p < .0001$) and there were more eligible female clients than in the sample (72.2% vs. 67.5%, $p < .03$). The mean ages of eligible clients (41) and the sample (42) were similar. As such, we weighted responses for the remaining part of the report for locality. (See Figure 3.)

Figure 3: Sample frame and analysis sample, by age group



Characteristics of the Sample

Nearly 60 percent of clients were urban. There are significant sex differences by location, with more males living in a rural than urban setting and more females than males living in an urban setting ($p= 0.0046$).

Table 2: Analysis sample, by sex and location

	Overall (%)	Sex*	
		Male (%)	Female (%)
Urban	58.1	26.4	73.6
Rural	41.9	40.3	59.7

$p<0.01$

The majority of HBC clients had ever attended school, with more males than females attending ($p<.001$). There were no differences in locality for school attendance. Most clients' highest level of education was at the primary level, with more clients in urban than rural settings having obtained secondary education ($p<0.01$).

Table 3: Analysis sample, by sex, location, and school attendance

	Overall (%)	Sex		Locality	
		Male (%)	Female (%)	Urban (%)	Rural (%)
Ever attended school (n=605)	87.8	93.6**	85.0	88.1	87.3
Highest level of school attended (n=517)					
<i>Primary</i>	87.2	85.8	88.0	83.8	92.1
<i>Secondary</i>	10.5	11.2	10.2	13.4*	6.5
<i>University</i>	.1	.4	0	.2	0
<i>Other</i>	2.0	2.6	1.9	2.5	1.5

*Significant at $p < .05$; **Significant at $p < .001$

At the time the survey was administered, HBC clients on average were 42 years of age (n=605). Males were on average three years older than females, and difference in age between urban and rural clients was not statistically significant.

Table 4: Analysis sample, by sex, location, and mean age in years

	Overall	Sex*		Locality	
		Male	Female	Urban	Rural
Mean age (years)	41.8	43.7	40.9	41.4	42.7

*Significant at $p < .05$

Just under half of the clients interviewed (44.4%) had been engaged in farming, livestock, or keeping a household garden. More male and rural clients were engaged in farm-related work ($p < 0.05$). Of the 302 clients that engaged in farm-related work, nearly all consumed the farm products at home, with more male clients and more rural residents both consuming at home and selling for money ($p < 0.05$). Approximately half of the clients interviewed were engaged in other work besides farming (about the same for males and females) and twice as many urban as rural clients had such other work. More females and more urban residents were not involved in farm-related work or any other work ($p < 0.005$).

Table 5: Analysis sample, by sex, location, and type of work

	Overall (%)	Sex		Locality	
		Male (%)	Female (%)	Urban (%)	Rural (%)
Participates in farm-related work (n=606)	44.4	55.9*	38.9	24.7*	71.7
What is done with products (n=302)					
<i>Household use</i>	71.8	62.9	77.9	71.5	72.0
<i>Used and sold them</i>	23.1	31.6*	17.3	15.8*	26.6
<i>Sold them</i>	4.2	4.7	3.8	11.7	0.5
<i>Other</i>	0.9	0.7	1.0	0.9	0.9
Has other work besides farming (n=606)	47.9	46.2	48.7	60.4	30.5
Does not participate in farm related work and does not have other work (n=121)	22.7	14.8**	26.4	28.8**	14.2

*Significant at $p < .05$, **Significant at $p < .01$

The average household size was 5.4 individuals, similar both in urban and rural settings.

On average, clients had known their HIV status for about seven years, though the range was from six months to 22 years. Approximately 16 percent of clients had known their status for two years or less.

Data collectors observed that 98 percent of clients were not bedridden (Table 6). Almost three-quarters of clients reported their health in general to be good or better, and 90 percent reported being healthy on the day of the visit (Figure 4). Despite clients overall being healthy, nearly three-quarters of respondents reported having been sick for three months or more in the past 12 months, and that the illness had prevented them from doing normal activities (Figure 5).

Table 6: Analysis sample, by sex and whether bedridden

	Overall (%)	Sex		Locality	
		Male (%)	Female (%)	Urban (%)	Rural (%)
Observed health condition (n=606)					
<i>Not bedridden</i>	98.4	98.9	98.2	98.2	98.7
<i>Bedridden but talking easily</i>	.9	.7	1.1	1.4	0.3
<i>Bedridden and talking with strain</i>	.6	.4	.8	0.4	0.9

Figure 4: Percent distribution of respondents by sex, residence, and health condition on day of interview

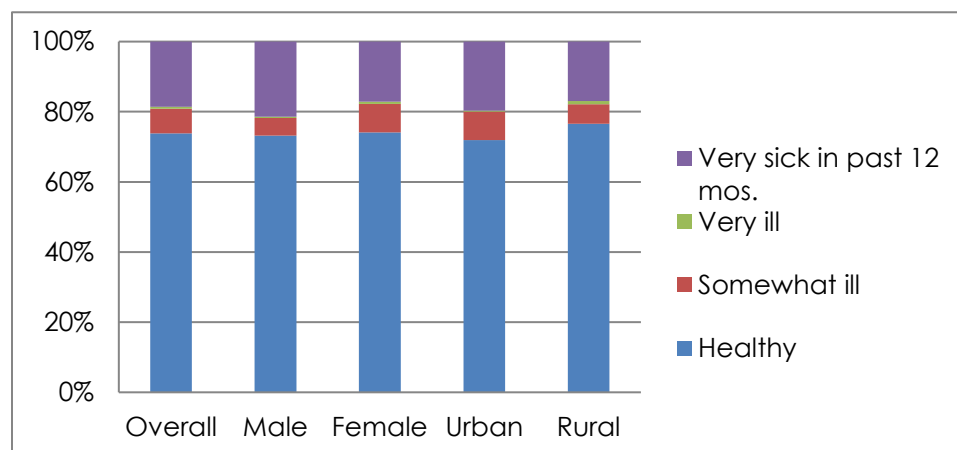
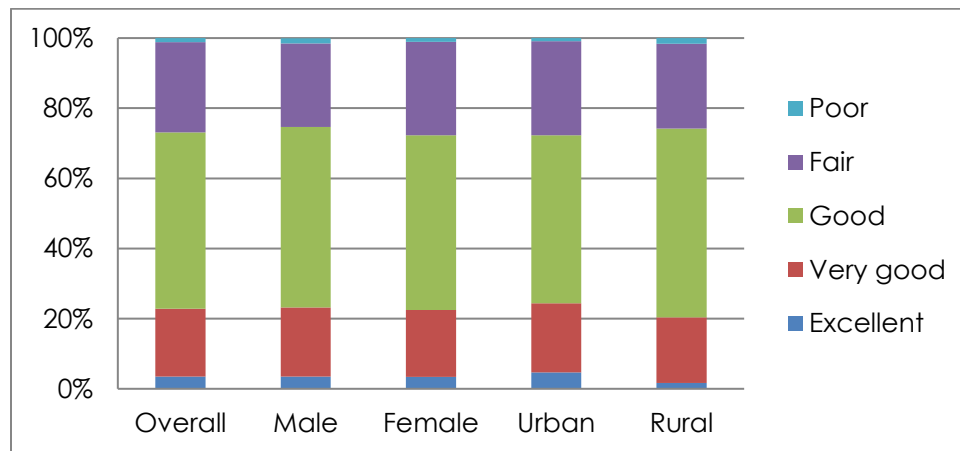


Figure 5: Percent distribution of respondents by sex, residence, and health condition



Types of Support that HBC Clients Who Are HIV-Positive Receive

On average, clients had enrolled in the HBC program four years before ($n=604$; $SD = 4.7$ months; range 1 to 204 months). The difference in length of time enrolled in the program by sex and locality was not significant.

Approximately one-fifth (18.6%) of clients ($n=602$) indicated they had been part of the support groups that the HBC program had started. There were no statistically significant differences in sex or locality.

Just 6 percent of respondents ($n=603$) indicated they had participated in activities to help them earn money to support themselves and their families. Males were almost twice as likely as females to participate in these activities (8.6% vs 4.9%, $p < .001$). There was no statistically significant difference in participation by locality.

Eighty-two percent ($n=585$) of clients reported having an adherence supporter, with no statistically significant differences by sex or locality (Table 7). Clients had different types of adherence supports, with family members being cited most frequently, followed by HBC volunteers. In rural settings, clients were more likely to have had an HBC volunteer supporting them than were those in urban areas. Fewer than 20 respondents indicated they had a friend as an adherence supporter. There were no other statistically significant differences in sex or locality. The overwhelming majority of clients had one supporter, though some had two, and a few had three. Ninety-eight percent ($n=606$) were currently receiving a visit from an HBC volunteer.

Table 7: HBC clients, by sex, location, type, and number of HBC adherence supporters

	Overall (%)	Sex		Locality	
		Male (%)	Female (%)	Urban (%)	Rural (%)
Type of supporter (n=478)					
<i>HBC volunteer</i>	37.5	35.6	38.4	33.7*	42.5
<i>Family member</i>	76.6	80.9	74.3	78.2	74.4
<i>Friend</i>	3.6	1.4	4.7	2.7	4.7
Number of supporters (n=478)					
1	81.7	83.0	81.0	82.9	80.0
2	15.7	14.9	16.1	14.3	17.5
3	1.6	2.0	1.4	1.0	2.5

*Significant at $p < .05$

All respondents were enrolled at a care and treatment center (CTC). Clients had last visited the CTC about one month before (Table 8). Male and rural clients had visited the CTC more recently (in the past 20 days).

Table 8: HBC clients, by sex, location, and mean time since last visit to a CTC, in days

	Overall	Sex*		Locality*	
		Male	Female	Urban	Rural
Mean time since last visit to CTC (days) (n=605)	27.4	20.0	30.8	32.7	20.0

*Significant at $p < .0001$

Clients were also asked about care they had received in the past 30 days (Table 9). Of all the types of services listed, respondents most frequently reported having received psychological services and nutritional advice, with more than 80 percent having received adherence counseling and nutrition counseling in the past 30 days and more than two-thirds of respondents receiving family counseling and/or psychological counseling.

About half of the clients received Septrin/cotrimoxazole and condoms, with more males than females having received condoms in the past 30 days (63.6% males vs. 44.8% females, $p < .001$).

About one-third of clients reported having been visited by religious leaders, having had clinical pain prevention support, having received physiotherapy, and having received family planning support. There were significant differences by locality for assessment of pain (39.6% urban vs. 30.9% rural) and pain treatment (43.6% urban vs. 31.0% rural) ($p < .05$).

A quarter of respondents had received treatment for anxiety or depression and malaria. Three times as many urban respondents had received malaria treatment (36.6%) as rural respondents had (13.1% rural) ($p < .05$).

About 15 percent of respondents had received prophylactic treatments, such as multivitamins, water purification, and TB testing. Fewer than 10 percent of respondents had received nausea, skin rash, and constipation treatment; TB prevention and treatment; and different types of household support such as food, household assistance, and transportation.

Table 9: Type of care and services received in the past 30 days

Question	Response			
	Overall (n=606) (%)	At home (%)	At health facility (%)	Elsewhere (%)
Spiritual				
Visit by religious leader or prayers (n=236)	38.7	76.5	100	32.0
Contact with traditional healer (n=10)	1.4	4	1	6
Psychological				
Adherence counseling (n=528)	86.3	35.7	85.8	1.4
Family counseling (n=425)	69.8	79.2	35.9	1.9
Psychological counseling/therapy (n=369)	60.9	29.9	88.4	1.0
Clinical prevention: pain				
Assessment of pain (n=211)	36.0*	10.9	99.1	.6
Treatment for pain, e.g., morphine, codeine, paracetamol (n=215)	38.3*	20.9	98.5	1.2
Clinical prevention: symptom management				
Anxiety/depression treatment (n=150)	26.0	50.0	77.5	1.4
Treatment for nausea/vomiting (n=36)	5.8	20.9	98.5	1.2
Treatment for skin rash/itching (n=50)	8.4	8.7	89.2	2.1
Treatment for constipation/laxatives (n=25)	4.5	7.9	93.7	1.4
Physiotherapy, i.e., exercises to help improve muscle strength or movement (n=194)	32.7	74.9	16.6	10.0
Clinical prevention: prophylaxis				
Food provided (n=32)	5.7	43.3	32.3	28.3
Multivitamins and/or nutritional supplements (n=93)	15.4	40.4	57.2	7.7
Nutritional advice (n=501)	82.6	36.3	86.5	1.0

Question	Response			
	Overall (n=606) (%)	At home (%)	At health facility (%)	Elsewhere (%)
Products to purify and/or safely store drinking water (n=82)	13.4	34.2	66.9	5.3
Septrin/cotrimoxazole to take every day (n=289)	49.8	12.9	95.3	2.0
TB testing (n=69)	11.8*	1.8	100	0
Isoniazid (INH) to prevent TB (n=50)	8.4*	2.6	100	0
TB treatment (n=28)	4.9	0	95.6	0
Treatment for malaria (n=151)	26.8*	11.8	92.5	2.8
Prevent pregnancy/family planning methods (n=244)	39.6	23.9	98.8	0
Condoms (n=306)	50.9**	23.9	97.2	.6
Social				
Household items (n=2)	.5	1	1	0
Home help (e.g., help with bathing, housework, cooking) (n=10)	1.5	10	0	0
Transportation cost (n=17)	2.2	65.9	35.3	8.7
Legal services (n=3)	.4	0	2	1

*Assessment of pain significant for locality: 39.6% urban vs. 30.9% rural (p <.05)

*Treatment for pain significant for locality: 43.6% vs. 31.0% (p <.05)

*TB testing significant for locality: 15.1% urban vs. 7.1% rural (p <.05)

*Isoniazid to prevent TB significant for sex (12.5% male vs. 6.5% female) (p<0.01) and locality (11.7% urban vs. 3.9% rural) (p <.05)

*Treatment for malaria significant for locality: 36.6% urban vs. 13.1% rural (p <.05)

**Condom distribution significant for sex: 63.6% male vs. 44.8% female (p <.001)

Differences in Unmet Needs Based on Characteristics of HBC Clients

Respondents indicated a need for more services across the service categories (Figures 6 and 7). Additional care and support by counselors or social workers was the most frequently cited need, with 82% of respondents indicating that need. Rural respondents cited that need more frequently than those living in an urban setting. There were no differences by sex. The types of support mentioned were advice, food and other goods, money, and medicine/prophylactics. Others said they needed to be visited and helped with general care/support/encouragement and to be asked about their health status.

Nearly three-quarters of respondents indicated they needed more spiritual care and support from religious leaders or traditional healers, with more female and rural respondents indicating this need. Four-fifths of those needing support indicated they needed prayers or to pray with others. Others indicated they wanted to be visited by community members and receive spiritual guidance or services.

Similarly, around three-quarters of respondents reported needing additional support to help prevent other health-related issues, such as malnourishment, malaria, pregnancy, unclean water, and tuberculosis. More rural than urban respondents reported this need, with about one-third needing insecticide-treated nets or re-treatment of their nets; one-fourth needing nutrition help; and one-fifth needing tests, treatment, or prevention for TB. Others mentioned needing antimalarial drugs; water treatment/storage; family planning and reproductive health services; and vaccines.

About two-thirds of respondents requested more social support to help them get around the house or to the places they need to go. There were no differences in sex or locality. Specific needs mentioned were additional help around the house, money for transportation, and food. Others mentioned wanting more support to start income-generating activities.

Just over half of respondents reported needing more support for pain management, with a greater proportion of rural respondents reporting this need. There were no statistical differences by sex. Of those needing more support, about half indicated a need for painkillers and about 10 percent reported needing support for pain with muscles/the neck/the back/the feet. Other needs were help for lungs/chest/pneumonia issues; stomach pain; headache; fungus/rash; urinary tract infection; and tests.

Approximately one-third of respondents reported needing additional clinical care and support to help manage their symptoms for things like nausea, rashes, and constipation. A higher proportion of male respondents reported this need. Those who provided detailed suggestions said they needed help addressing rash/itching/fungus, digestive issues, and general pain relief. Others mentioned needing help with nutrition, vitamins, and soap.

Figure 6: HBC clients, by sex and needed care

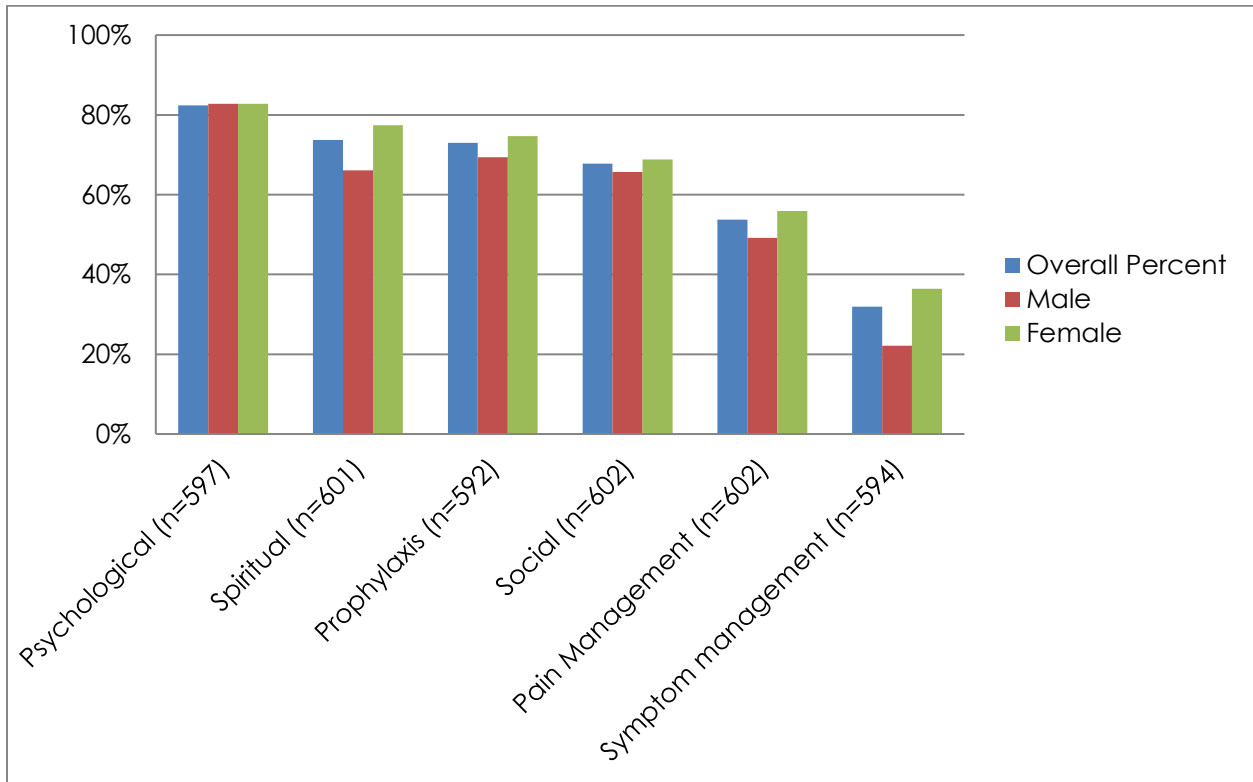
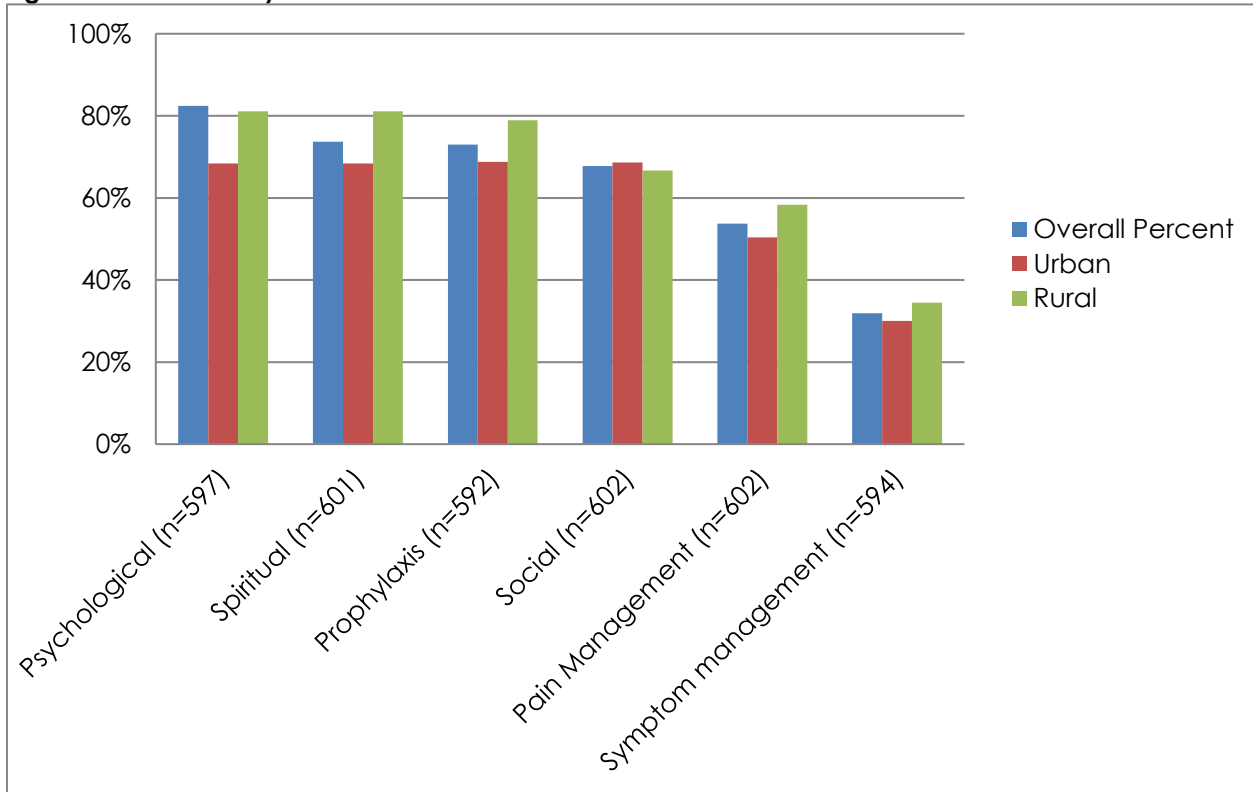


Figure 7: HBC clients by location and needed care



Key Facilitators and Challenges for HIV-Positive Clients Accessing HBC Services and Treatment

Clients were asked about many aspects of program support and their experiences that facilitate or challenge access to HBC services. Overall, our findings are positive, in that clients were highly satisfied with services (except for support group services) (Figure 8) and largely reported being adherent (Table 10).

Figure 8: HBC client satisfaction with services

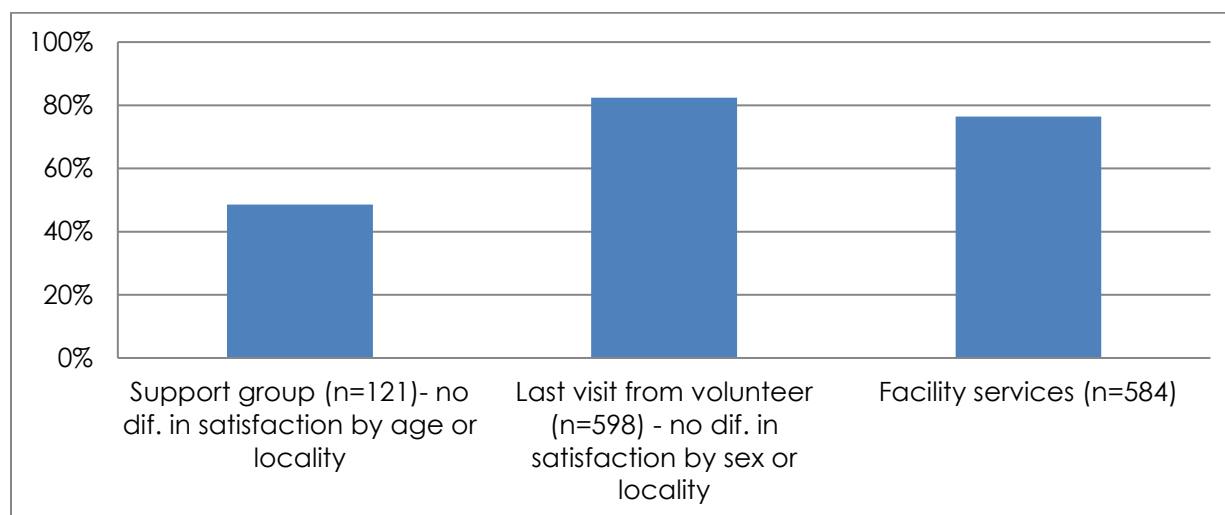


Table 10: HBC client ART adherence practices

ART adherence practices	Provider informed client (n=585)	99%
	Currently using ARVs (n=591)	99%
	Not missed taking ARVs in the past month (n=585)	91.5%
	Not missed ARV refill in the past month (n=585)	91.5%
	Not missed taking ARVs in the past year (n=585)	91.5%
	Want a supply for more than one month (n=584)	77%

Clients first heard about the HBC program in different ways. Nearly half learned about the program from the CTC, about one-quarter had been contacted by an HBC volunteer, and about one-fifth had been referred by a health care worker. The remaining 8 percent had learned about the program in other ways, mostly through family, friends, or community gatherings.

Satisfaction with the support groups varied: approximately half were very satisfied, and one-quarter were somewhat or not at all satisfied (n=121). About 20 percent of participants described why they did not have an adherence supporter. Many (61%) said they know the importance of taking their medicine and can adhere themselves. Another quarter said they don't have a supporter because they live alone. Other reasons cited were losing their supporter due to moving or death; not wanting anyone to know their status; and having no one to support them.

Nearly all clients were currently receiving visits from a volunteer. For the 10 clients who were not, they either did not know why they hadn't been visited, didn't like to be visited, had been traveling, or felt well and not in need of a visit. The most recent visit had occurred on average two weeks before the interview for this study. More than 80 percent were highly satisfied, indicating that the supporter had given good advice and had provided material support (non-ART medication, food, and money), adherence management, and support. About 10 percent of those satisfied indicated that the HBC volunteer treats them well. Those not satisfied indicated that the HBC volunteers don't provide material support (e.g., medicine) (n=7); that the visits are rare (n=4); that the visits make them feel stigmatized (n=1); or that the visits waste their time (n=1).

Of the 585 clients taking ARVs, nearly 75 percent had visited a health facility in the past month. Seventy-eight of the clients indicated that they knew of other facilities but preferred the one they currently went to, primarily because it was closer (59%), was the clinic where they initially registered (58%), or they preferred the quality of services (25%). A few clients indicated that they didn't want to be recognized or that there was easier transport to the current facility.

Satisfaction with facility services was high, with about 75 percent of respondents indicating they were very satisfied and 22 percent indicating they were somewhat satisfied. The 12 participants who were not at all satisfied cited no medications and no CD4 tests available, and in a couple of cases not enough providers. Twenty-five people noted that in the past six months, they had gone to the facility and had not received the services they went for, indicating that the medications had not been available (n=16), that supplies had not been available (n=4), that there had been a long wait (n=2), that the provider had not been available (n=2), that they had had a disagreement with the nurse (2), or that the clinic had been closed (n=1).

For the 42 people participating in socioeconomic strengthening activities, respondents indicated the most helpful had been small-business development (20%), receiving training grants (18.5%), receiving small loans (18%), assistance with small-scale husbandry (10%), receiving school-related expenses (10%), and job counseling (4%).

Nearly all of the HBC clients (97.7%) interviewed reported having ever taken ARVs. For the 15 clients who had never taken ARVs, 14 said they would be very likely to accept ARVs. The one person who was unlikely to take them indicated he/she felt good enough and did not need the medications.

Of the 591 clients who reported having ever taken ARVs, all but six (99%) were currently taking ARVs. For the 585 clients currently taking ARVs, they had been taking ARVs for an average of five years, with male and urban clients taking them longer than female and rural clients, respectively (p<0.01) (Table 11).

Table 11: HBC clients, by sex, location, and length of time taking ARVs, in months

	Overall	Sex		Locality	
		Male**	Female	Urban**	Rural
Length of time taking ARVs (months) (n=585)	66.1	67.9	65.3	67.8	63.9

**Significant at p<0.0001

Ninety-nine percent (n=584) of clients currently taking ARVs reported that their HBC provider had informed

them about the impact of not taking those medications as instructed by their doctor. Clients were able to report correctly what would happen if they did not take their medications as instructed: that the drugs would not work (16%), they could die (28%), their health could get worse (45%), or other issues (11%) could occur.

In the past month, 8 percent (n=48) of clients currently taking ARVs indicated they had missed taking their medication. There was no difference in sex or locality. The main reasons they gave were that they had forgotten to take their medication (32%), they had been traveling (30%), or they didn't have enough food to take with their medication (17%). Other reasons were they ran out of medication (n=2), they didn't like the way the medication made them feel (n=2), they felt good enough (n=1), they didn't want anyone seeing them taking medication (n=1), they were in prison (n=1), they were in labor (n=1), and they were grieving over the loss of a husband (n=1).

Of those clients currently taking ARVs, 8.5 percent (n=52) had missed getting their medications refilled in the past 12 months. There were no statistically significant differences by sex or locality. Reasons they missed getting refills varied, but forgetting was the most common response, followed by being busy working and not feeling well (Table 12). More than 10 percent of clients indicated that the health center had not been open or didn't have the medications when they needed it.

Table 12: Reasons HBC clients missed getting ARV refills in the past 12 months

Reasons why missed getting ARV medication refilled in the past 12 months	Percentage
Forgot to get it refilled	31.6
Too busy working	17.9
Didn't feel well	15.8
Health center not open/out of medicine	13.0
Busy with other things (funeral, visitors)	13.0
Could not afford transportation	9.9
Too busy caring for children	2.1
Didn't want anyone to know I was taking medication	1.2

Clients currently taking medications were typically getting a one-month supply (49%) or a two-month supply (47%) at a time. A few clients were getting a three-month supply (2.8%). There was no statistically significant difference by sex or locality. More than half of the respondents who currently received a one-month supply of medications said would like to receive medications more frequently. Most of the respondents who currently received a two-month supply were happy with this, though about 20 percent of those individuals said they

would like to get a bigger amount of medications. Nearly all the 18 clients currently receiving a three-month supply at a time were satisfied with that amount. (See Table 13).

Table 13: ARV supply received: current frequency versus desired frequency

		Desired frequency for receipt of ARV medications			
		1 month wanted (%)	2 month wanted (%)	3 month wanted (%)	4 or more months wanted (%)
Current frequency for receipt of ARV medications	1 month currently	47.5	37.2	13.1	2.2
	2 month currently	.2	81.0	12.0	6.8
	3 month currently	0	0	97.6	2.4

About 20 percent of respondents described what prevents them from getting the supply of medication they would like. Almost half of those said it was because obtaining medication requires close health monitoring by a medical provider. About one-quarter said there was not enough medication at the clinics to give an extra supply to patients. A handful said providers were worried that they would not adhere to their medication if they were not checking in regularly. Other reasons mentioned by a few people were provider simply refusing to give more; living too far from the clinic; and not requesting more.

Perceptions of Interpersonal Relationships and Quality of Life, including Stigma

Just under half (42 percent) of respondents were currently married or living with a partner (n=606), and 98 percent of them noted that their partner was aware of their HIV status. For households with other adults (n=524), about half indicated that most of those adults knew the respondent's HIV status, 39 percent said some of the other adults knew, and 7 percent indicated that none of the other adults in the household were aware of the respondent's status. There were no differences by sex or locality. In contrast, almost 30 percent of respondents indicated that no community members were aware of the respondent's HIV status, with more female and urban respondents reporting this. (See Table 14.)

Table 14: HBC clients, by sex, location, and awareness of their HIV status

	Overall (%)	Sex		Locality	
		Male (%)	Female (%)	Urban (%)	Rural (%)
Other adults in HH household aware of status (n=524)					
<i>Most</i>	53.2	54.9	52.3	48.8	59.9
<i>Some</i>	39.1	37.3	40.1	40.7	36.8
<i>None</i>	7.6	7.7	7.5	10.5	3.3
Community members aware of status (n=598)					
<i>Most</i>	34.4	41.0	31.3	24.7	47.9
<i>Some</i>	37.6	37.5	37.6	38.8	35.8
<i>None</i>	28.1	21.6	31.1*	36.5	16.4**

*Significant at $p < 0.05$ ** Significant at $p < 0.01$

Nearly 75 percent of clients indicated that participation in the HBC program mostly made it easier for them to get health services; nearly 25 percent said it had no effect (Table 15). Only a little more than a third of respondents indicated that the program made it easier for them to participate in community events. For the eight people who indicated the program made it harder to get health services, the reasons mentioned were that they had to pay for their medication (n=5), the services were far away (n=2), or they didn't get along with someone at the health facility (n=1). For the 15 who indicated that participation in the program made it harder to participate in community events, the reasons given were stigma (n=7), that they didn't feel well (n=3), that they felt isolated (n=1), or that they had to take care of their children (n=2).

Table 15: Effect of client participation in HBC program on getting health services and participation in community events

	Getting health services (n=600) (%)	Participation in community events (n=597) (%)
Easier	74.2	36.3
No effect	24.6	61.2
Harder	1.1	2.4

Most respondents stated that volunteers are working to reduce stigma (86%) (Table 16); there were no differences by sex or location.

Table 16. HBC client opinions on whether HBC volunteers are working to reduce stigma

Do you think HBC volunteers are working to reduce stigma?	Overall percentage
Yes	85.88
No	6.97
Don't know	7.15

More than 500 respondents provided specific examples of how volunteers help to reduce stigma, such as through educating community members (83%), protecting privacy (34%), and being treated well (33%). Nine percent indicated other ways, such as giving good advice and encouragement and advising patients to disclose their status.

Very few clients reported having been denied health services (0.3%) or social/religious experiences (1.7%) (N=606). However, 16 percent of respondents indicated having been verbally teased or abused as a result of their HIV status, with women experiencing this more than men. Eight percent of clients living in households where there were children reported that the children were treated poorly as a result of the client's HIV status. (See Table 17.)

Table 17: HBC clients, by sex, location, and whether HBC client or children in the household have been verbally teased, abused, or treated badly as a result of their HIV status

	Overall (%)	Sex		Locality	
		Male (%)	Female (%)	Urban (%)	Rural (%)
Personally verbally teased, abused, treated badly (n=605)	16.0	10.3	18.7**	16.4	15.4
Child in the household who has been teased, abused, treated badly (n=497)	7.6	5.7	9.3	7.9	8.9

** Significant at p<0.01

STUDY LIMITATIONS

When constructing the sampling frame, data collection teams found many data quality challenges with the HBC client registers. In four of the regions, there were former HBC volunteers either affiliated with a previous HBC program or no longer with the HBC program whose registers could not be accessed, and teams were unable to verify if those volunteers' clients had been reassigned to another HBC volunteer. This means we likely were unable to get a full listing of clients and the sample may have been biased toward active clients.

Many of the HBC volunteers used notebooks instead of the official paper-based register form to record client data. In some cases, names or IDs were missing or incomplete (e.g., using initials for names, using CTC numbers instead of HBC numbers), or other information that teams extracted for the sampling frame. Data collectors did their best to interview HBC volunteers to collect missing information and cross-checked information with the monthly summary reports. The data quality challenges meant that some clients who had been selected as eligible were found not to be so by data collectors. The converse could also be true, which would mean that potentially eligible clients were not interviewed due to a misconception that they were ineligible. However, failure to interview eligible clients would introduce less bias than would ruling out clients originally believed to be eligible.

Initially, we planned to interview clients at their homes, to reduce the burden of them having to travel and to make it easier for bedridden clients. However, some clients preferred to be interviewed away from their homes or by telephone, not wanting to draw attention to their HIV status. All such requests were honored and we provided travel reimbursement to those who were interviewed at a location other than their own.

Data collection teams experienced greater challenges reaching males than females ($p < .0001$) for interviews, either because men were not at home when data collectors arrived or, in some cases, because they refused to participate.

DISCUSSION

The Tanzania HBC guidelines indicate that non-HIV chronic disease is on the rise and that within communities, HBC promotes care and support for people with chronic illnesses as well as awareness of how to prevent infection. The results from our study found that nearly all clients listed in the sampled registers were HIV-positive and that was the primary reason for their enrollment in HBC. This may be due to several reasons, such as that HIV is the primary chronic disease in the sampled wards; that the programs are PEPFAR-funded and may therefore emphasize enrolling HIV-positive clients; or that implementing partners are focusing on HIV-positive clients because most funding, even aside from PEPFAR, is geared toward mitigating HIV and related activities.

The Tanzania HBC model was developed when ART was largely unavailable. Since then, expansion of ART services has transformed the condition of HIV from a terminal illness to a chronic one. Consequently, HIV-positive clients' needs have changed from palliative, end-of-life support to managing ART adherence and other issues associated with chronic care (Phaladze, et al., 2005). Studies have shown that HBC programs can be effective in improving ART adherence and quality of life indicators (Weidle, et al., 2006; Kabore, et al., 2010). Our study supports this finding, at least in the sampled wards, where the overwhelming majority of clients were healthy and self-reported ARV adherence was high.

While most clients were adherent, many indicated they would prefer getting a greater supply of ARVs at a time. For stable patients on ART, the new PEPFAR guidelines have suggested reducing the intensity and frequency of clinical visits (suggested over six to 12 months). In addition, the guidelines suggest separate clinical visits from ART refill visits, with refills being provided for longer durations (suggested every three to six months) (PEPFAR, 2016)

The guidelines also indicate that HBC programs should be comprehensive. They should include medical and nursing care; legal advice; referrals; and emotional, socioeconomic, and spiritual support. HBC clients in this study reported having received different types of these services in the past 30 days. Yet, some services were not cited frequently, such as prophylaxis measures and symptom management. This may be because the service had not been needed in the past 30 days. However, in a later question, the majority of clients indicated they needed more services. Psychosocial support through home visits prevents patient attrition (Wouters, et al., 2012); more than four-fifths of respondents in our study indicated they need more support in this area.

Several services (e.g., assessment and treatment of pain and treatment of malaria) were more commonly received in urban than rural areas, possibly because urban clients have better access to services than rural clients do. When asked about needs, rural respondents reported greater need for many services. Women reported needing more spiritual support and symptom management than males did.

Critical to the success of HBC programs is the ability to obtain high quality services from healthcare facilities and the role of community and family members in supporting clients. In a study in Dar es Salaam, researchers assessed the quality of facility standards and found that not all eligible patients were able to start ART and receive comprehensive care and treatment due to a lack of trained personnel, laboratory equipment, ARTs, and confidential places for counseling (Mapunjo and Urassa, 2006). However, this was not the case with clients in our sample. Respondents had visited CTCs one month before, on average, which is in accordance with the national guidelines that recommend visits once every two months (NACP, 2012). Also, clients in our study were highly satisfied with facility services, and nearly all reported that the provider gave them the information needed to manage their condition.

Several studies have been conducted to assess HBC caregiver satisfaction (Phaladze, et al., 2005; Akintola, 2010, Kangethe, 2010), but limited information has been available on client satisfaction with such HBC programs (McDonnell, Brennan, Burnham, & Tarantola, 1994; Nsutebu, Walley, Mataka, & Simon, 2001). Our study found that nearly all clients had at least one HBC volunteer and were highly satisfied with their interactions with that volunteer. These two predictors of HBC program success appear to be working in the sampled regions, as demonstrated by the high percentage of clients reporting consistent use of ARVs.

In this study, a higher proportion of women were enrolled in HBC than men. We experienced many challenges in accessing men for interviews, particularly in urban areas. Njoroge, et al. and Jefferys, et al. found that male participation in urban areas was much lower than in rural areas, and urban males are more likely to be lost to follow-up (Jefferys, Nchimbi, Mbezi, Sewangi, & Theuring, 2015; Njoroge, et al., 2013). Also, the proportion of males found at home was low in other HIV studies and ART attrition was high (Sekandi, et al., 2011; Novitsky, et al., 2015; Koole, et al., 2014).

In our study, more males reported community members being aware of their status. A study in Uganda found that men struggle between “doing the right thing”—getting tested and taking HIV treatment—and maintaining their reputation among other men (Siu, Seeley, & Wight, 2013).

According to the Tanzania's national guidelines, HBC programs help community members to understand HIV and other diseases, correct myths and misconceptions about HIV and chronic illnesses, and work to reduce stigma. Overall, this study found that clients believe HBC volunteers are working to reduce stigma and that few clients reported being denied health services or social or religious experiences because of their HIV status. Nonetheless, our study shows that some clients—and women more than men—do still experience some stigma.

The national HBC guidelines indicate that intensified efforts must be made to identify PLHIV in need of services, to meet the goals of the national HIV/AIDS Care and Treatment Plan, 2003–2008 (United Republic of Tanzania, 2003). Yet, with registers often incomplete and no transition plan when volunteers leave or new programs are put in place, it is possible that clients, once registered, are no longer served.

Overall, many of the HBC program operational challenges identified by Mohammad and Gikonyo (2005) are being addressed in Tanzania, such as maintaining pain relief of clients and addressing inadequate ART support, lack of proper nutritional support, limited socioeconomic activities, and stigma and discrimination. Our study supports previous research findings of HBC providers being very effective in engaging PLHIV in the continuum of care to address their needs (Layer et al., 2014).

RECOMMENDATIONS

Based on our study findings, we suggest the following actions to ensure continued success of Tanzania's HBC program:

- Consider providing clients with a bigger supply of ARVs at a time. Because HIV is transitioning from a fatal to a chronic condition, and PLHIV are showing greater adherence to ART regimens, it is becoming less critical for treatment refills to be contingent on mandatory monthly patient-doctor consultations. Providing up to a three-month supply of ARVs can save clients considerable time and expense of extra travel to obtain refills.
- Develop indicators for provision of comprehensive care and support. HIV as a chronic rather than fatal condition means that services need to address a different and more complex set of needs beyond palliative care. Indicators should specify what is comprehensive and what should be provided to which type of client and how frequently.
- Measure the capacity of volunteers to deliver HBC services in both urban and rural areas and address gaps.
- Explore ways to better engage men living with HIV in HBC programs and ensure their sustained participation and adherence to ART, particularly in urban areas.
- To improve continuity of care, identify ways to ensure client lists are handed over to new HBC volunteers and/or new HBC programs. New HBC implementing partners should retain previous programs' community volunteers.
- Assess and improve data quality of client registers to ensure clients are getting the support needed, when needed. This can be achieved by strengthening the M&E capacity of health project staff,

particularly on data quality assessment.

- Triangulate the findings from this study with other study findings on PEPFAR HBC programs in Tanzania. Upon verification of findings, update guidelines and training materials to ensure that HBC programs reflect most current client needs and program best practices.
- To combat HIV-related stigma and discrimination, HBC programs should continue efforts to support professionals at health facilities, volunteer health workers, and other service providers working with PLHIV.

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APPENDIX 1. HBC STUDY QUESTIONNAIRE, INCLUDING THE INFORMED CONSENT FORM

This cover page serves two purposes:

1. The first table in this questionnaire should be filled out prior to visiting each household. Your supervisor will complete it with essential information on the household to help you locate it.
2. The second table will be filled in by the enumerator. It indicates the number of times the enumerator visited the household to interview the respondent. It is of utmost importance that the information in the table is correct. Your supervisor will verify if you visited each household at least three times before using a substitute household. Make sure that you do not leave any blank spaces / questions unanswered.

Table 1 – Identification Information

To be filled in by the supervisor prior to visiting each household

Variable Name	Question	Response Category	Code
A001	Survey code/Questionnaire Number	Code	[_____]
A002	Region	Mara Mwanza Dar es Salaam Iringa Kilimanjaro	1 2 3 4 5
A003	District Name	Name	<div style="border: 1px solid black; width: 100px; height: 20px; margin: 0 auto;"></div>
A004	Ward Name	Name	

A005	Village Name	Name	[_____]		
A006	Patient code	ID Number	[_____]		
A007	Patient sex	Male	1		
		Female	2		
A008	Type of Location	Urban	1		
		Rural	2		
A009	Client Status	Active	1		
		Inactive	2		

The survey questionnaire can only be filled in for the HBC client listed above in the table. When you reach the household, ask to speak to the HBC client listed in Table 1 above.

- ✓ Confirm that the person listed in Table 1 lives in the household. If the person does not live in the household, do NOT continue the interview with this person or any other household members and record the situation in Table 2 below. Then identify the next person on the randomized list within the same category (e.g., active/male).
- ✓ Confirm that the HBC client listed in Table 1 is an adult (age 18 or over). If the HBC client is a child (an individual under 18) do NOT continue with the interview and record the situation in Table 2 below. Then identify the next person on the randomized list within the same category (e.g., active/male).
- ✓ If the HBC client is seriously ill, you may ask if he/she would like assistance from another household member in completing the interview. If the client says yes, you may continue with the interview. If the client says no, or is unable to participate on that day, ask if it is possible to come back another time in the same week and schedule the return visit. If the client does not want to be interviewed at any other time, do NOT continue the interview and record the situation in Table 2 below. Then identify the next person on the randomized list within the same category (e.g., active/male).

Table 2

INTERVIEWER VISITS				
	VISIT 1	VISIT 2	VISIT 3	FINAL VISIT
DATE [DD-MMM-YYYY]	_____	_____	_____	Date of final visit [DD, MMM, YYYY]
INTERVIEWER'S NAME	_____ _____	_____ _____	_____ _____	[/ /]
RESULT (see below)				FINAL RESULT []
APPOINTMENTS: NEXT VISIT DATE TIME	_____ _____	_____ _____		Total number of visits []
RESULTS CODE INTERVIEW COMPLETED [answered all sections; if an entire section is skipped, interview NOT complete, select replacement household] INTERVIEW SCHEDULED FOR LATER IN THE DAY/ANOTHER DAY HBC CLIENT IN THE LIST DOES NOT LIVE IN THIS RESIDENCE HBC CLIENT IS UNDER 18 YEARS OF AGE HBC CLIENT IS TOO ILL TO PARTICIPATE CLIENT REFUSED TO PARTICIPATE (AND IS NOT TOO ILL AND DOES NOT GIVE BEING ILL AS A REASON) 66 OTHER (EXPLAIN) _____				You have to return If the result is 3-6, select a replacement household from the random list
I have completed the interview and checked all skip patterns and responses to ensure this survey was completed completely and accurately.				
Enumerator Signature: _____		Date: _____		
Instructions for Supervisor: Before signing this sheet, review responses and ensure the survey was completed fully and accurately. If it is not completed fully and accurately, review the responses and make corrections – re-visiting the household if needed. After corrections are made, then sign the form.				
Field Supervisor Signature: _____		Date: _____		
FIELD SUPERVISOR				
NAME _____ []		OFFICE DATA EDITOR		
NAME _____ []		DATA ENTRY CLERK 2		
DATA ENTRY CLERK 1		DATA ENTRY CLERK 2		
NAME _____ []		NAME _____ []		

Informed Consent and HBC Client Questionnaire

Consent Form

IRB Study: # NIMR/HQ/R.8a/Vol.IX/1738

Consent Form Version Date: May 27, 2014

Title of Study: Assessing Home Based Care (HBC) Client Status among USG- Supported Areas in Tanzania.

Principal Investigator: Molly Cannon, MPH, Futures Group.

Co-Investigator: Sharon Lwezaula, MPH, National AIDS Control Programme.

Funding Source: USAID Tanzania

Name of Local Study Contact: Sharon Lwezaula, MPH, National AIDS Control Programme

Location: Dar es Salaam, Tanzania

Telephone of Local Study Contact: Office - (0) 22 2131 213; Mobile - 0787 435 937

Hello, my name is _____. Government leaders in Tanzania are interested in meeting the needs of its people by improving services and care to those in need. I am here in [community name] to talk with people like yourself, about their experiences with home and community based HIV care and support services. Your experiences will help improve these services.

I would like to invite you to participate in an interview with me today. Kindly permit me to explain what this interview involves, so you can decide whether you want to join or not. Please listen carefully and ask any questions you want before you agree to participate. You may also ask questions at any time after we start the interview.

First, you do not have to be interviewed if you do not want to. Second, you may stop the interview at any time or not answer any question. Your participation and answers will in no way affect any of the services you are currently receiving or services you might want or need in the future.

If you agree, the interview will last approximately 45 to 60 minutes. I will be asking you mostly about services that you need and use, use of medications, and your satisfaction with services.

I will be **marking** your answers on this questionnaire. I will not record your name or where you live, so no one can know that you were interviewed. Your answers will be combined with the answers from the other people who were interviewed. We will keep the information in the computer after the study is completed, but it will not include the name of any participants or the name/location of any communities. Your name will not be used in any report.

During the interview, I will be asking you what it is like to live with HIV. Some of the questions may make you feel uncomfortable. If at any point you do not want to answer a question or continue with the interview, let me know. If you do not want to answer a question or decide to stop the interview, no one

will be angry or upset with you. This will not affect the medical care or services that you receive through the HBC program.

Do you have any questions for me?

This study has been reviewed and approved to make sure that your rights and welfare are protected. If you have questions about your rights, or are unhappy at any time with any part of this interview, you may contact Sharon Lwezaula, Co- Investigator from National Home Based Care Services, National AIDS Control Programme, Ministry of Health and Social Welfare.

His telephone number is also on this card. I will give you a signed copy of this form to keep for reference. You do not need to provide your name if you call.

Do you agree to participate in the interview?

YES.....1 → [DATA COLLECTOR] SIGN BELOW AND PROCEED
NO.....2 → STOP

Verification of Consent

DATA COLLECTOR OBTAINING CONSENT: You must sign below before proceeding with the interview. Your signature certifies that you have read aloud the entire informed consent instructions above to the respondent. It also certifies that you have answered all the questions that the respondent had about the survey, and that he/she has agreed to be interviewed.

X X

Signature of Person Obtaining Consent
Obtaining Consent

Date

Printed Name of Person

Data collector, please verify a copy of the consent form was left with the client by checking this box.

B001	Interview Start Time. Use 24 hour clock	_____ : _____
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SECTION 1 - BACKGROUND INFORMATION

No.	Question	Response Category	Code (Fill in or circle responses clearly)	Skip To
101	How old are you in complete years, that is, how old were you at your last birthday? <i>If s/he does not know her age exactly, help her to estimate her age.</i>	# of years	[_____] years old	If less than 18 STOP interview
		Don't know	88	Continue
		No response	99	
102	Did you ever enroll in or receive services from a program providing home based care for people living with HIV?	Yes	1	Continue
		No	0	End interview
		Don't know	88	
		No response	99	
103a	When did you first enroll in the HBC program? <i>If s/he gives the number of years, convert the response to the number of months.</i>	# of months	[_____] months	Continue
		Don't know	88	
		No response	99	
103b	[Data Collector: Based on respondent's answer, complete the following:]	< 6 months ago	1	<i>If less than 6 months, end interview</i>
		> Or = to 6 months ago	2	Continue

104.	How did you <u>first</u> hear about HBC services, that is, how did you come to enroll? [do not read responses, check only one response]	Care and Treatment Center	1	Continue
		Referred by health worker	2	
		Contacted by HBC worker	3	
		Other (specify)	66	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
105.	Observe: Record client's sex.	Male		Continue
		Female		
106.	Have you ever attended school?	Yes	1	Continue
		No	0	→108
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
107a.	What is the highest level of school you attended: primary, secondary, or higher?	Primary	1	Continue
		Post-primary	2	
		Secondary	3	
		Post-Secondary	4	
		University	5	
		<i>Don't know</i>	88	
		<i>No response</i>	99	
107b.	What is the highest (grade / form / year) you completed at that level? RECORD 00 IF LESS THAN ONE COMPLETED AT THAT LEVEL GRADE	GRADE/FORM/YEAR	[_____]	Continue
108.	In the past month, have you been	Yes	1	Continue

	engaged in farming, livestock, or kept a household garden?	No	0	→110
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
109.	What did you do with any of the crops and/or animals you raised – were they for your household use, did you sell them, or did you do both? [select only one response]	Household use	1	Continue
		Sold them	2	
		Both household use and for selling	3	
		None were ready to be used or sold yet	4	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	

		Yes	1	Continue
110.	[Other than farming], in the past month, have you been engaged in any other work, such as a job, in a business, selling, or some other work?	No	0	→113
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
111a.	How much money did you earn from farming, livestock, or other work in the last month?	Amount of TZ shillings: _____		Continue
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
111b.	Were you paid in kind at all in the last month?	Yes	1	Continue
		No	2	
		<i>Don't know</i>	88	
		<i>No response</i>	99	
112.	This month, would you say that you earned more, less, or about the same as you did one year ago? [select only one response]	I earned more this month than I did the same time a year ago	1	Continue
		I earned less this month than I did the same time a year ago	2	

		I earned about the same as I did last time at this year	3	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
113.	How many of the following people currently live in your household with you?	# of adults 18 and over	_____	Continue
		# of children and/or youth under age 18	_____	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	

Section 2 – Health status

No.	Question	Response Category	Code	Skip To
201a.	How long has it been since you first found out you were HIV positive? <i>If s/he gives the number of years, convert the response to the number of months.</i>	Time in months since found out HIV positive	[_____] months	Continue
201b.	Data Collector: If the respondent is unable to answer 201a ask them how long given each of these categories. If they answered 201a then complete 201b based on their response to 201a.	< or = to one year ago	1	Continue
		More than 1 year ago and up to 2 years ago	2	
		More than 2 years ago	3	
		# of years if more than 2 years ago:	[_____] years	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	

202.	OBSERVE respondent	Bedridden and talking with strain	1	Continue
		Bedridden but talking easily	2	
		Not bedridden	3	
203.	Would you say that in general, your health is: [read responses, check ONLY one response]	Excellent	1	Continue
		Very good	2	
		Good	3	
		Fair	4	
		Poor	5	
		<i>Don't know</i>	88	
	<i>No Response</i>	99		
204.	How would you describe your health today – would you say you feel very ill, somewhat ill, or healthy? [select only one response]	Very ill (bedridden, restricted mobility, talking with strain, need feeding assistance)	1	Continue
		Somewhat ill (needing minimal support and are able to walk short distances, feed yourself)	2	→206
		Healthy (can walk at least 1 km, participate in daily activities)	3	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
205.	How long have you been bedridden/very ill? Would you say less than 3 months, or 3 months or more?	Less than 3 months	1	Continue
		3 months or more	2	→301
		<i>Don't know</i>	88	Continue
		<i>No Response</i>	99	

206.	During the past 12 months, were you so sick for 3 months or more that you could not work or do normal activities?	Yes	1	Continue
		No	0	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	

Section 3: ART Adherence [see how section has been re-ordered and some questions eliminated]

No.	Question	Response Category	Code	Skip To
301.	Have you enrolled for care at a Care and Treatment Center?	Yes	1	Continue
		No	0	→303
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
302.	When was the last time you attended the CTC facility for care services?	Time in months since attended the CTC facility for care services [_____] Months		Continue
		<i>Don't know</i>	88	
		<i>No response</i>	99	
303.	Have you <u>ever</u> taken antiretroviral (ARVs) to treat HIV?	Yes	1	→306
		No	0	Continue
		<i>Don't know</i>	88	
		<i>No Response</i>	99	

304.	If you were offered ARVs to treat HIV, how likely would you be to take them – would you say you would be: [read responses, select only one response]	Very unlikely to accept ARVs	1	Continue
		Somewhat unlikely to accept ARVs	2	
		Somewhat likely to accept ARVs	3	→401
		Very likely to accept ARVs	4	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	

305.	Why do you think you would be unlikely to take ARVs if you were offered them? [read responses, check all that apply]	Do not know where to get ARVs	1	→401
		Cannot get to the facility/place where they give ARVs	2	
		Can't afford ARVs	3	
		ARVs make you feel worse than you are/give you side effects	4	
		I have not told anyone I am HIV positive and don't want them to see me taking medications	5	
		I don't have a place to keep my medications	6	
		I felt good enough not to need any medication	7	
		Other (specify): [_____ _____]	66	
		<i>Don't know</i>	88	
<i>No Response</i>	99			

306.	Are you <u>currently</u> taking antiretrovirals (ARVs) to treat HIV?	Yes	1	→308
		No	0	Continue
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
307.	Why did you stop taking ARVs? [read responses, check all that apply]	Ran out of ARV medication	1	→401
		Couldn't afford ARVS	2	
		Couldn't get to the facility/place where they give ARVs	3	
		I didn't like the way ARVs made me feel	4	
		I couldn't do what I need to do because of side effects _____	5	

		I had not told anyone I was HIV positive and didn't want them to see me taking medications	6	
		I didn't have a place to keep my medications	7	
		I felt good enough not to need any medication	8	
		I didn't have enough food to take my medication	9	
		I kept forgetting to take my medication	10	
		Other (specify): [_____]	66	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
308.	How long have you been taking ARV medications? [convert to months]	Time in months taking ARV medication [_____] months		Continue
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
309.	Did the HBC provider inform you on the impact/effect of not taking your ARV medication as instructed by your Doctor? (Health care provider)	Yes	1	Continue
		No	2	
		<i>Don't know</i>	88	
		<i>No response</i>	99	
310.	What will happen if you do not take your ARVs as instructed by health care providers	The drugs will not work	1	Continue
		I could die	2	
		My health could get worse	3	
		Other/specify: [_____]	66	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
311.	Thinking about the last month, have you missed taking your ARV	Yes	1	Continue
		No	0	→313

	medicine?	<i>Don't know</i>	88	
		<i>No Response</i>	99	
312.	What was <u>the main reason</u> you missed taking your ARV medicine last month? [read responses, check ONLY one response]	Ran out of ARV medication	1	Continue
		Couldn't afford ARVs	2	
		Couldn't get to the facility/place where they give ARVs	3	
		I didn't like the way ARVs made me feel	4	
		I couldn't do what I need to do because of side effects	5	
		I didn't want anyone to see me taking medications	6	
		I didn't have a place to keep my medications	7	
		I felt good enough not to need any medication	8	
		I didn't have enough food to take my medication	9	
		I kept forgetting to take my medication	10	
		Other/specify: [_____]	66	
		Don't Know	88	
		No Response	99	
313.	During the last 12 months/since you started taking ARVs, have you ever missed getting your medications refilled?	Yes	1	Continue
		No	0	→315
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
314.	If yes, what are the reasons for not getting the medications refilled? [read responses, check all that apply]	Could not afford transportation	1	Continue
		Too busy working	2	
		Too busy caring for children	3	
		Didn't feel good	4	
		Didn't want anyone to know I was taking medications	5	
		Forgot to get it refilled	6	
		Other (please describe): [_____]	66	

		<i>Don't know</i>	88	
		<i>No Response</i>	99	
315.	How many months' supply of your antiretroviral medications do you usually get at one time?	Number of months' supply of ARVs able to get at one time: [_____]	# months	Continue
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
316.	How many months' supply would you like to get at one time?	Number of months' supply of ARVs you would like to get at one time: [_____]	# months	Skip to 318 if 316 is NOT different from 315.
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
317.	If the amount you would like to get [Q316] is different from how much you usually get [Q315], please describe what prevents you from getting how much you would like.	Describe: [_____ _____ _____]	66	Continue
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
318.	Do you have an adherence supporter, that is, someone to help you take your ARVs or to remind you to take them?	Yes	1	→320
		No	0	Continue
		<i>Don't know</i>	88	→321
		<i>No Response</i>	99	→321
319.	What are the reasons why you don't have an adherence supporter?	Describe: [_____ _____]	66	→321
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
320.	Who is your adherence supporter? [read responses, check all that apply]	HBC volunteer	1	Continue
		Family member	2	
		Friend	3	
		OTHER (SPECIFY): [_____]	66	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
321.	At which health facility do you currently receive treatment services?	_____ (name of facility)	66	Continue
		I don't go to a health facility	2	→401
		<i>Don't know</i>	88	Continue

		No Response	99	
322.	When was the last time you visited that health facility – would you say [read responses, check ONLY one response]	Within the last week/last 7 days	1	Continue
		More than a week ago but in the last month	2	
		More than a month ago but in the last 3 months	3	
		More than 3 months ago	4	
		Don't know	88	
		No Response	99	
323.	Do you know of any other health facility [besides the facility you go to in Q321] where you could get ARVs?	Yes	1	Continue
		No	0	→325
		Don't know	88	
		No Response	99	
324.	Why do you go to your usual facility [mentioned in Q321] instead of one of the other treatment facilities? [Do not read responses, check all that apply]	It is closer	1	Continue
		So no one recognizes me	2	
		I prefer the services offered	3	
		Transport is easier	4	
		Other (specify): [_____]	66	
		Don't know	88	
325.	Please rate your overall level of satisfaction with services provided at this health facility [facility mentioned in Q321] [read responses, check ONLY one response]	Not at all satisfied	1	Continue
		Somewhat satisfied	2	→327
		Very satisfied	3	
		Don't know	88	
		No Response	99	
326.	What are the reasons you are not satisfied with the services provided at this health facility?	Describe: [_____ _____] [_____]	66	Continue
		Don't know	88	
		No Response	99	
327.	In the last 6 months, have you ever visited this health facility [from Q321] and not received the services you went for?	Yes	1	Continue
		No	0	→401
		Don't know	88	
		No Response.	99	
328.	What was the reason you could	Long wait	1	Continue

not receive services at the health facility [from Q321]? Anything else? [Do not read responses, check all that apply]	Provider was not available	2
	Supplies were not available	3
	Medications were not available	4
	Other (specify): [_____]	66
	<i>Don't know</i>	88
	<i>No response</i>	99

Section 4: HBC Program/Satisfaction

No.	Question	Response Category	Code	Skip To
401.	Are you <u>currently</u> enrolled in any HBC program?	Yes	1	Continue
		No	0	
		<i>Don't know</i>	88	→403
		<i>No Response</i>	99	
402.	How long have you been enrolled in the program? [Data collector: convert response to months]	# of months enrolled in the HBC program: _____	# months: _____	→404
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
403.	Why are you no longer enrolled in the HBC program?	Describe: [_____]	66	Continue
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
404.	Are you currently receiving visits from a volunteer?	Yes	1	→406
		No	0	Continue
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
405.	Why haven't you received a visit from a volunteer?	Describe: [_____]	66	Continue
		<i>Don't know</i>	88	
		<i>No Response</i>	99	

406.	When was the last time you received a home visit from a volunteer? [data collector: indicate days if less than one month, otherwise calculate # of months and round up or down]	# of days since last home visit from a volunteer: [_____]	# of days: [_____]	Continue
		OR # of months since last home visit from a volunteer: [_____]	# of months: [_____]	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
407.	Over the time you have received home visits from a volunteer, how satisfied were you with the way your most recent volunteer served you? [read responses, check only one response]	Not at all satisfied	1	→409
		Somewhat satisfied	2	
		Very satisfied	3	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
408.	What are the reasons you are not satisfied with the way your most recent HBC volunteer served you?	Describe: [_____]	66	→410
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
409	What did you like about the services?? Please explain	Describe: [_____]	66	Continue
410	Did/has receiving HBC services make/made it easier for you to get health services, had no effect on getting health services, or made it harder to get health services for you? [select only one response]	Made it easier to get health services	1	→412
		Had no effect on getting health services	2	
		Made it harder to get health services	3	Continue
		<i>Don't know</i>	88	→412
		<i>No Response</i>	99	
411.	What are the reasons why receiving HBC services make/made it harder to get health services?	Describe: [_____]	66	Continue
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
412.	Did/has receiving HBC services make/made it easier, had no effect, or made it harder to participate in community events? <i>Community events include church</i>	Made it easier to participate in community events	1	→414
		Had no effect on participating in community events	2	

	<i>and mosque, village meetings, religious meetings, community activities, gatherings in the community</i>	Made it harder to participate in community events	3	Continue
		<i>Don't know</i>	88	→414
		<i>No Response</i>	99	
	[select only one response]			
413.	What are the reasons why receiving HBC services make/made it harder to participate in community events?	Describe: [_____]	66	Continue
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
414.	Do you think HBC volunteers are working to reduce stigma [unfavorable attitudes, beliefs, and policies] against people living with HIV?	Yes	1	Continue
		No	0	→416
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
415.	What types of things do HBC volunteers do to help reduce stigma [unfavorable attitudes, beliefs, and policies]?	Educate community members	1	Continue
		Protect my privacy	2	
		Treat me well	3	
		Other: [_____]	66	
		[_____]		
416.	Are you/were you a part of any of the support groups that the HBC project has started?	Yes	1	Continue
		No	0	→419
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
417.	If yes, how satisfied are you/were you with the HBC support groups?	Not at all satisfied	1	Continue
		Somewhat satisfied	2	→419
		Very satisfied	3	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
418.	Why weren't you satisfied with the HBC support groups?	Describe: [_____]	66	Continue
		[_____]		
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
419.	In the past 12 months, have you received any services or	Yes	1	Continue

	participated in any program supported activities to help you earn money to support yourself and your family?	No	0	→501
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
420.	Which of these activities has been the <u>most helpful</u> to you? [read responses, check ONLY ONE response]	Small-business development	1	Continue
		Receiving help with job counselling	2	
		Receiving school-related expenses	3	
		Receiving training grants	4	
		Assistance with setting-up small-scale animal husbandry	5	
		Receiving small loans	6	
		Participating in financial management training	7	
		Participating in other income generating activities: (specify: _____)	66	
		None	9	
			<i>Don't know</i>	88
	<i>No Response</i>	99		
421.	Please describe in what ways this activity has been helpful to you.	Describe: _____ _____	66	Continue
		<i>Don't know</i>	88	
		<i>No Response</i>	99	

No.	Question	Response				
	501. Have you received the following care in the last 30 days under the following categories? Read Options - if yes - check all sources that apply	Care received (check all that apply)				
		Not received= 0	Received = 1	At home	At health facility	Elsewhere
	Spiritual					
a.	Visit by religious leader or prayers	0	1	1	2	3
b.	Contact with traditional healer	0	1	1	2	3
	Psychological					
c.	Adherence counseling	0	1	1	2	3
d.	Family counselling	0	1	1	2	3
e.	Psychological counselling/therapy	0	1	1	2	3
	Clinical Prevention: Pain					
f.	Assessment of pain	0	1	1	2	3

g.	Treatment for pain e.g., morphine, codeine, paracetamol	0	1	1	2	3
Clinical Prevention: Symptom management						
h.	Anxiety/depression treatment	0	1	1	2	3
i.	Treatment for nausea/vomiting	0	1	1	2	3
j.	Treatment for skin rash/itching	0	1	1	2	3
k.	Treatment for constipation/laxatives	0	1	1	2	3
l.	Physiotherapy i.e., exercises to help improve muscle strength or movement	0	1	1	2	3
Clinical Prevention: Prophylaxis						
m.	Food provided	0	1	1	2	3
n.	Multivitamins and/or nutritional supplements	0	1	1	2	3
o.	Nutritional advice	0	1	1	2	3
p.	products to purify and/or safely store your drinking water	0	1	1	2	3
q.	Septrin/cotrimoxazole to take every day	0	1	1	2	3
r.	TB testing	0	1	1	2	3
s.	Isoniazid (INH) to prevent TB	0	1	1	2	3
t.	TB treatment	0	1	1	2	3
u.	Treatment for malaria	0	1	1	2	3
v.	Prevent pregnancy/family planning methods	0	1	1	2	3
w.	Condoms	0	1	1	2	3
Social						
x.	Household items	0	1	1	2	3
y.	Home help e.g., help with bathing, housework, cooking	0	1	1	2	3
z.	Transportation cost	0	1	1	2	3
aa	Legal services	0	1	1	2	3

Section 5: Services Received and Support Needed

No.	Question	Response Category	Code	Skip To
502.	Do you need any <u>additional</u> spiritual care and support that is support you might receive by religious leaders, traditional healers, or others)?	Yes	1	Continue
		No	0	
		<i>Don't know</i>	88	→504
		<i>No Response</i>	99	
503.	Please describe what types of additional spiritual care and support you need.	Describe: _____ _____	66	Continue
504.	Do you need any <u>additional</u> care and support by counselors or social workers?	Yes	1	Continue
		No	0	
		<i>Don't know</i>	88	→506
		<i>No Response</i>	99	

505.	Please describe what types of additional care and support you need from counselors or social workers.	Describe: _____ _____	66	Continue
506.	Do you need any <u>additional</u> care and support for pain management?	Yes	1	Continue
		No	0	
		<i>Don't know</i>	88	→508
		<i>No Response</i>	99	
507.	Please describe what types of additional pain management care and support you need.	Describe: _____ _____	66	Continue
508.	Do you need any <u>additional</u> clinical care and support to help manage your symptoms for things like nausea, rashes, constipation, help with sore muscles?	Yes	1	Continue
		No	0	
		<i>Don't know</i>	88	→510
		<i>No Response</i>	99	
509.	Please describe what types of additional clinical care and support you need to help manage your symptoms.	Describe: _____ _____	66	Continue
510.	Do you need any <u>additional</u> clinical care and support to help prevent other health related issues (e.g., malnourishment, malaria, pregnancy, clean water, TB)?	Yes	1	Continue
		No	0	
		<i>Don't know</i>	88	→512
		<i>No Response</i>	99	
511.	Please describe what types of additional clinical care and support you need to help prevent other health related issues (e.g., malnourishment, malaria, pregnancy, clean water, TB).	Describe: _____ _____	66	Continue
512.	Do you need any additional care and support to help you around the house or getting around to the places you need to go?	Yes	1	Continue
		No	0	
		<i>Don't know</i>	88	→514
		<i>No Response</i>	99	
513.	Please describe what types of additional care and support you need to help you around the house or getting around to the places you need to go.	Describe: _____ _____	66	Continue

514	Are there any other services or support you need? Please describe:	Other (specify) [_____]	1	Continue
		Other (specify) [_____]	2	
		Other (specify) [_____]	3	
		Other (specify) [_____]	4	

Section 6: Stigma

I have a few more questions and then we will finish.

No.	Question	Response Category	Code (Fill in response or circle responses clearly)	Skip To
601	Are you currently married or living with a partner?	Yes	1	Continue
		No	0	→603
		No Response	99	
602	Does your spouse/partner know that you have HIV?	Yes	1	Continue
		No	0	
		Don't know	88	
		No Response	99	
603	The [other] adult members of your household: would you say that most or all of them know you have HIV, that some of them know you have HIV or that none of them know you have HIV?	None of them know	1	Continue
		Some of them know	2	
		Most or all of them know	3	
		No other adult household members	4	
		Don't know	88	
		No Response	99	
604	And the people who live in this community, would you say that many know you have HIV, only a	None of them know	1	Continue
		Only a few know	2	

	few know, or that none know you have HIV?	Many know	3	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
605	Since you found out that you had HIV, have <u>you</u> been denied health services because of your HIV infection?	Yes	1	Continue
		No	0	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	

606	Since you found out that you had HIV, have <u>you</u> been denied involvement in social events, religious services or community events, because of your HIV infection?	Yes	1	Continue
		No	0	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
607	Since you found out that you had HIV, have <u>you</u> been verbally teased or abused because of your HIV infection?	Yes	1	Continue
		No	0	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
608	Since you found out that you had HIV, <u>has any child in your household</u> been teased, abused or treated badly in the community because of your HIV infection?	Yes	1	Continue
		No	0	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
609	Check Question 306	Currently taking ART	1	Continue
		Not currently taking ART	0	→616
610	Check Question 601	Currently married/living with someone	1	Continue
		Not currently married/living with someone	0	→616
611	Check Question 602	Spouse/partner knows HIV status	1	→614
		Spouse/partner does not know HIV status	0	Continue
612	Have you ever <u>been afraid</u> to take your ARV medication because you thought your spouse/partner would find out that you have HIV?	Yes	1	→616
		No	0	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	

613	Have you ever <u>not taken</u> your ARVs because you thought your spouse/partner would find out that you have HIV?	Yes	1	→616
		No	0	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
614	Have you ever <u>been afraid</u> to take your ARVs because you thought your spouse/ partner would be angry?	Yes	1	Continue
		No	0	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	
615	Have you ever <u>not taken</u> your ARVs because you thought your spouse/partner would be angry?	Yes	1	Continue
		No	0	
		<i>Don't know</i>	88	
		<i>No Response</i>	99	

616. Is there anything more you would like to tell us about the things we have been talking about?

616b: Is there anything else you would like me to know?

617: Interviewers Observations and comments regarding the interview (which may affect quality or completeness of the interview)

Thank you so much, that completes all of the questions I have today.

Interview End Time (24hour clock) :]

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