



Access to Water and Sanitation for People Living with HIV and AIDS: An Exploratory Study

Diana Nkongo and Christian Chonya
WaterAid Tanzania and AMREF in Tanzania

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Exchange Rate

USD \$ 1 = Tshs 1150/=

Overview

This study was a collaborative effort between WaterAid Tanzania and AMREF in Tanzania. It was prompted by the observation that the water and sanitation needs of people living with HIV and AIDS (PLHIV) and the likely consequences of inadequate access to water by their households were not being explicitly identified, and not being integrated into either HIV and AIDS interventions or water and sanitation sector programmes.

The study found some evidence that PLHIV have an increased need for both water and sanitation services, but lack the means to meet these needs. It confirmed that there is lack of clear arrangements on access to water and sanitation for PLHIV. It found some evidence of stigma, although this was not reported to be a major problem. And it found, in hygiene promotion, a clear area of overlapping interests between the water and sanitation sector and the HIV and AIDS sector, though this hasn't yet resulted in much cooperation between sectors in practice or in harmonised hygiene promotion messages.

Based on these findings, the study makes the following recommendations:

For water and sanitation programmes

- Water and sanitation programmes should develop strategic partnerships with other stakeholders such as those working on HIV and AIDS to address the most vulnerable including PLHIV,
- Develop alternative strategies to ensure that vulnerable households, including those made vulnerable by HIV and AIDS, have access to water and sanitation facilities,
- Common messages on water and sanitation hygiene should be developed and used by both water and sanitation programmes and HIV and AIDS programmes to improve chances of message uptake.

For HIV and AIDS programmes

- Home base care guidelines should give extra attention to water, sanitation and hygiene issues, such as by including information on the need for, and the amount of water needed to keep PLHIV and their environment clean, and on safe sanitation and hygiene practices,
- HIV and AIDS programmes and interventions should consider costing and advocating for provision of water treatment agents as part of PLHIV medical treatment support packages.
- Common messages on water and sanitation hygiene should be developed and used by both water and sanitation programmes, and HIV and AIDS programmes to improve chances of message uptake,

Possible further studies

- Further research is needed to assess who is being excluded from access to water and sanitation services where projects have been implemented. This will help to give a clearer picture of who is left out of the service and/or to what extent PLHIV have access to the services,
- A comparative study could look into the question of how access to water services affected PLHIV, to see, for example, if PLHIV in the area with adequate water are better off in hygiene compared to those living in areas with less water,
- An argument could be made for more rigorous medical research to investigate the contribution of improved water and sanitation services in keeping PLHIV healthy, although the high cost of such an exercise make it an unlikely prospect.

Abbreviations and Acronyms

AIDS	Acquired Immune Deficiency Syndrome
AMREF	Africa Medical and Research Foundation
FGD	Focus Group Discussion
HH	Household
HIV	Human Immune Deficiency Virus
IGA	Income Generating Activities
MWAVIUM	Muongano wa Wanaoishi na Virusi vya Ukimwi Mkuranga
PASADA	Pastoral AIDS Activities and Services for PLHIV in Dar Es Salaam Dioceses
PLHIV	People Living With HIV and AIDS
Tshs	Tanzania Shilling
UKIMWI	Ukosefu wa Kinga Mwilini (Swahili acronym for HIV)
URT	United Republic of Tanzania
WEDC	Water, Engineering and Development Centre

1 Background and Rationale

In both rural and urban areas of low-income countries, millions of the most vulnerable people lack access to improved water and sanitation services. These include over 500 million disabled people, growing number of frail elderly people, and other groups of people with special needs, including those living with HIV and AIDS (WEDC, 2005).

In Tanzania, data on access to water and sanitation services hides the individual effort that vulnerable groups have to make in accessing those services each day. Inaccessibility of water and sanitation services excludes many of these vulnerable groups from getting services they must have every day. In rural areas, it is often believed that communities have their own mechanisms of identifying and taking care of the vulnerable people. How well such mechanisms work in practice, and whether they include PLHIV, is not well understood. In urban areas where water supply and sewerage utilities are operating, they are yet to set clear and targeted mechanisms for ensuring access to such services for the vulnerable within their mandated service areas.

Recognizing these challenges, specific efforts have been taken to identify and understand the constraints faced by some groups of vulnerable people in order to cater for their needs. For example, manuals have been published for promoting water and sanitation facilities that are appropriately designed to allow easy access and use by the physically challenged (WEDC, 2005). A study to investigate how physically vulnerable groups (the elderly and disabled) are accessing water commissioned by WaterAid found that this group requires greater amount of water than the general population but have poorer access due to a combination of physical, financial and social barriers (Holding, 2007). However, these efforts have so far largely ignored the particular water and sanitation related needs and challenges facing PLHIV. Given the clinical nature of the condition and the socio-cultural attitudes, there are strong reasons to believe that PLHIV face additional challenges in accessing water and sanitation services and may require targeted measures to promote adequate access even in areas where these services are available. Box 1 outlines some of the ways in which water, sanitation and hygiene practices impact negatively or positively on PLHIV.

This research is designed to fill this gap, by investigating water and sanitation needs of people living with HIV and AIDS (PLHIV), their constraints on meeting these needs and ideas for addressing the gap.

This study was prompted by the observation that water and sanitation needs of PLHIV and the likely consequences of inadequate access to their respective household were not being explicitly addressed or integrated in either HIV and AIDS programmes or the water and sanitation sector programmes.

As an example, WaterAid Tanzania's service delivery work does not integrate HIV and AIDS. Likewise AMREF has intervention projects on water, sanitation and hygiene, prevention of mother to child transmission of HIV, voluntary counselling and testing, care and support, and economic empowerment for people infected and affected by HIV and AIDS and more, but do not specifically address HIV and AIDS in water and sanitation interventions. The study was therefore motivated in part by a desire to improve the work of WaterAid and AMREF.

The study was also motivated by the desire to increase broader understanding on the links between water and sanitation, and HIV AND AIDS in Tanzania, with a view to influencing a range of actors in both sectors, including policy makers and practitioners from both government and civil society.

Box 1: Linkages between water, sanitation and hygiene and HIV AND AIDS

The relationship between HIV and AIDS, and water, sanitation and hygiene is multi-faceted. Some aspects of how PLHIV are affected by the quality, quantity and availability of water, sanitation and hygiene are as explained below:

Staying Healthy

The main objective of the water supply sector is to improve people's health by providing access to safe water supply and (environmental) sanitation. With HIV AND AIDS, this becomes even more urgent because water and sanitation related diseases such as diarrhoea and various types of skin diseases are among the most common opportunistic infections. Thus, adequate Water supply and sanitation are of the utmost importance for HIV infected people to remain healthy as long as possible and for people with AIDS to reduce their exposure to opportunistic infections. Water and sanitation is key in ensuring one is healthy. You can neither cook nor drink unsafe water due to risks of being infected with diseases. Opportunistic infections like diarrhoea are also caused by lack of clean water and proper sanitation. Ensuring that people living with HIV and AIDS have access to clean water and sanitation reduces the risk of developing diarrhoea and cholera. People living with HIV and AIDS die because of opportunistic infections.

Infant Feeding

If a mother is HIV positive, there is a risk that she may transmit the virus to her baby through breastfeeding, even if the child is born HIV negative. The 'obvious' solution would be not to breastfeed the child. However, this has proven to be very difficult because of social, cultural and financial reasons, including the cost and availability of powdered milk, stigma and tradition. Whether breast feeding or not, clean water is crucial for infant feeding and HIV positive babies need to be protected even more from unsafe water because it will weaken their resistance and shorten their lives.

Hygiene as Part of Home-Based Care

The majority of AIDS patients are being cared for within their local communities, often by trained volunteers: this is called home-based care. For this care, good access to safe water and sanitation is indispensable. Water is needed for bathing patients, washing soiled clothing and linen and keeping the home environment clean. Safe drinking water is needed for taking medicines and making food easier to eat for patients suffering from mouth ulcers or oral thrush. Water supply points and latrines have to be accessible and close to where they are needed to reduce the burden of distance and to maintain a sense of dignity for patients and caregivers. The caregivers need to be trained in safe water handling and sanitation practices, personal hygiene, domestic hygiene, food hygiene and safe waste water disposal and drainage to effectively reduce the exposure to water and sanitation related diseases of their patients. Therefore, hygiene education must be one of the elements during training on home-based care. Most training manuals for home based care do mention the need for hygiene and the use of safe water and latrines, but the manuals are based on an assumption that everyone has access to safe water and sanitation. They provide no information on safe water handling practices. The advice that most caregivers give to household with PLHIV is to boil water for drinking. This is not always realistic.

Household Economy and Productivity of PLHIV

Increased access to sustainable water sources near household reduces the time and effort spent looking for water by families taking care of People Living with AIDS. The time spent can be invested productively by the families to do other tasks and enterprises that depend on adequate water supply. Unavailability of safe water may lead to buying of safe water, resulting in addition household expenses. Lack of water may lead to disruption of those productive tasks that are based on availability of water such as farming. Productivity of infected people goes down due to illnesses while productivity of other family members may go down due to increased burden of care and support of sick people, again leading to reduced income levels.

A Gender Perspective

Most of the time the caregivers in household are girls, women, and children, mainly because of the gender constructs and socially defined roles in different cultures. Time spent in fetching water in case of the unavailability of water may affect taking care of PLHIV, hence reduces the time they would otherwise spend on other tasks around the household. Such paucity of time may even impact on children's education, leading to dropouts especially for girls.

2 Research objectives

The specific objectives of this research were:

1. To gather views from PLHIV and their caregivers in relation to issues of accessing water, sanitation and hygiene services
2. To gather case study evidence illustrating key water, sanitation and hygiene issues from the perspective of those living with HIV and AIDS
3. To learning from PLHIV and caregivers on the forms of and different support provided in accessing water supply and sanitation and coping strategies by PLHIV.

For Water and Sanitation sector, it is anticipated that findings from the study will help organizations like WaterAid, AMREF and others to become more aware of the inter-linkages between water and sanitation and HIV and AIDS, and therefore also how to incorporate HIV and AIDS issues into Water and Sanitation programmes. For policy makers, the findings would provide help provide ideas on how best to implement the existing policy of incorporating the needs of PLHIV in water and sanitation projects.

In the HIV and AIDS sector, it is anticipated that the study will open up room for practitioners to think beyond the current thinking of HIV preventive measures (*ABC strategy*) and care and support (*providing medicine to infected persons*), and recognise the importance of incorporating water and sanitation into HIV and AIDS interventions and programmes.

3 Methodology

3.1 Selection of study locations and data collection

The study focussed on districts that either WaterAid or AMREF had intervention projects. The presence of clubs of PLHIV was an important criterion. It was also seen as important to cover different water and sanitation characteristics and to represent rural and urban settings. From this, four districts were selected, namely Mkuranga, Mvomero, Morogoro Urban and Kinondoni. Mkuranga and Mvomero are rural districts while Morogoro Urban and Kinondoni are urban.

At each site, information was collected at household and community levels. Households were purposively selected to include those known to have PLHIV. Total number of household at each location for interviewing PLHIV and/or caregivers was ten (10). In some household primary¹ caregivers were not present at the time of the interview. Secondary² caregivers therefore provided the information. A semi-structured questionnaire was used³. At community level, focus group discussions, one at each location were conducted with a mixed group of PLHIV. Key informants and relevant institutions were also approached to provide and or clarify information from community members. A summary of the specific information collected is presented in Table 1. Apart from household characteristics, other information sought was of a qualitative nature. Where quantities were estimated it was mainly for purposes of verifying whether the expressed views were supported by everyday practices such as views on increasing use of water.

¹ Parents/guardians or close relatives above 18 years were considered as primary care givers

² Children especially girls under 18 years were considered as secondary care givers

³ See appendices for copies of all survey tools.

3.2 Validation and analysis workshop

The study was conducted as a rapid appraisal and therefore the team was only able to spend one day at each site. Since the study relied mainly on qualitative information, and given the sensitivity around HIV and AIDS, the team needed to be in the field for a longer time than was provided in order to get the feeling and touch of the key issues and how they manifest themselves. Recognising this limitation the team decided to address it by incorporating a 'validation and analysis workshop' as part of the methodology. Once all the data was corrected and analyzed, a group of relevant stakeholders/practitioners in water, sanitation, and HIV and AIDS sectors were called in to validate and where appropriate provide additional information and to strengthen the analysis and interpretation based on field experience. The workshop also provided an avenue to add and clarify information especially with regards to support given to PLHIV.

Table 1: Information and sources of information

Information	Data collection technique/tool	Target
<ul style="list-style-type: none"> General characteristics of a location (social services in the area, HIV and AIDS specific services, water supply and sanitation services, education, other community services) Specific actions for supporting and enhancing access to services for PLHIV 	FGD	Females, males members of community, institutions, PLHIV
<ul style="list-style-type: none"> Household characteristics Access and use of sanitation facilities (<i>explore differential access/changed access by various individuals within household</i>) Amount of water used (<i>specify uses and if any increase is linked to presence of PLHIV</i>) Cost (<i>monetary and non-monetary costs including time and effects of discrimination and other physical constraints where applicable</i>) incurred getting water and coping strategies where costs are considered unaffordable Specific measures taken to improve access to WSS and other services for PLHIV 	Questionnaires	HH, caregivers (women, men and children), PLHIV

3.3 Characteristics of focus group discussion participants and sampled household

A total of 4 focus group discussion were carried out, one in each of the study location. The focus group discussion comprised of mixed group of PLHIV who were registered in organizations of PLHIV. Interviews were carried out to cover 42 household. One member in a household was interviewed. Of the 42 individual interviewed; 25 were PLHIV and 17 were the caregivers. Majority of the household members were primary school leavers. Only a small proportion (9.7%) were secondary school leavers and above. The majority of the household had a family size above the national average of 4.7. The largest proportion of household members was below 18 years. Those with an age range of 18 -35 years were 25.8% while 20.4% were adults and the rest (5.8%) were of old age. This indicates that there are a big number of non productive members in the surveyed household. Of the surveyed urban household 100% depend on piped water as their main water source, while among rural household interviewed, only 40% depend on piped water, with the remainder depending on boreholes (10%), protected wells (15%) and unprotected wells (35%).

Table 2: Characteristics of respondents and members of household

Characteristics	Urban	Rural	Total
Category of Respondents: (No. of Respondents)			
PLHIV	12	13	25
Caregivers	9	8	17
Total	21	21	42
Number of permanent members in HH			
1	1	0	1
2	0	0	0
3	4	2	6
4	1	4	5
5	0	3	3
6+	15	9	24
Total	21	18	39
Mean HH Size	7.0	5.4	6.3
Education level of members in HH in %			
None	16.1	13.8	15.2
No formal education	2.8	13.8	7.2
Primary incomplete	29.4	27.7	28.7
Primary complete	42	35.1	39.2
Secondary and above	9.8	9.6	9.7
Total	100.0	100.0	100.0
Age interval of members in HH in %			
Children (0-17)	51.4	42.7	47.9
Youth (18 -35)	27.1	24.0	25.8
Adults (36 -60)	18.1	24.0	20.4
Old (> 60)	3.5	9.4	5.8
Total	100.0	100.0	100.0
Source of drinking water:			
Piped	100.0	40.0	70.7
Borehole installed with pump	0.0	10.0	4.9
Protected well	0.0	15.0	7.3
Unprotected well	0.0	35.0	17.1
Total	100.0	100.0	100.0
<p>Note: Primary complete means completed standard 7 or 8, trained after primary or pre-form one; Secondary and above includes those who attended secondary education whether or not that level was completed plus training after secondary and/or university related; None means a child who below the age of five or attending kindergarten; No formal education means a person is old and never attended any formal education.</p>			

The majority of the HIV-positive respondents reported that the local community were aware of their HIV sero-status (18 out of 29) – see table 3.

Table 3: Status of respondents and community awareness of their status

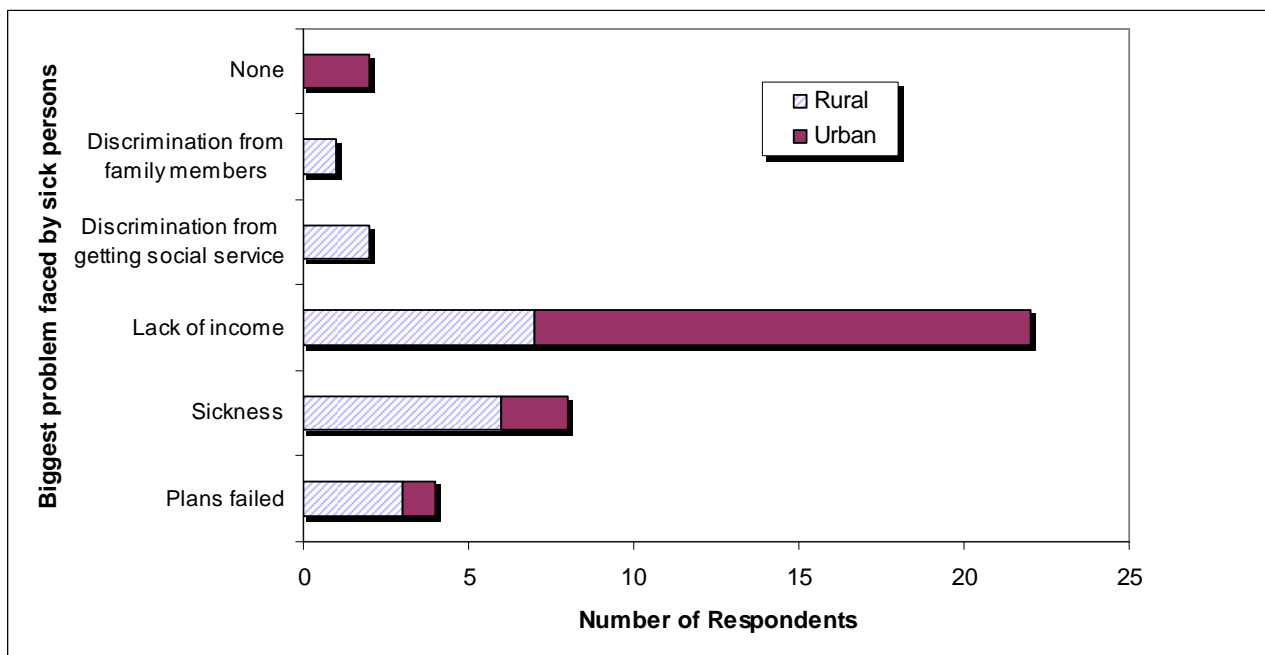
Status of respondents	Community awareness of status	Rural	Urban	Total
Seriously sick	Yes	0	0	0
	No	2	1	3
Fair	Yes	5	9	14
	No	1	3	4
Good	Yes	2	2	4
	No	0	4	4
Total		10	19	29

4 Findings

4.1 General challenges facing PLHIV

In addition to issues directly related to provision of water supply and sanitation services, respondents identified a number of issues in relation to their day-to-day life some of which had implications for accessing water and sanitation services. In the quantitative analysis, lack of income scored highest points followed by sickness. Box 2 explains a particular case in more detail. Table 4 below shows that approximately 74% of these households estimated their total household monthly earnings as less than Tshs 100,000/=. The increasing prices for most food and other household items made it difficult for people to satisfy their basic needs especially since majority of household reported to have more than 5 members in their families.

Figure 1: Problems reported by PLHIV and caregivers



Box 2: Economic and Other Constraints

A widow woman 36 years of age, living in Kinondoni municipality in a very poor housing facility is affected by HIV and AIDS. During the interview we found her fairly ill, suffering from tuberculosis. There was no adult to look after her apart from her three children of 13 years, 6 years and 4 years and the HBC personnel who pay regular visits. She declared to have problems of accessing water especially when she is serious sick. At her current condition, she can not do petty business which helps her generate income for survival.

Table 4: Estimated monthly earnings

Estimated total household earnings per month	Frequency	Percent	Cumulative Percent
Less than Tshs 60,000/=	24	57.14	57.14
Tshs 60,000/= or more but less than Tshs 100,000/=	7	16.67	73.81
Tshs 100,000/= or more but less than Tshs 300,000/=	2	4.76	78.57
Tshs 300,000/= or more but less than Tshs 500,000/=	1	2.38	80.95
Don't know	8	19.05	100
Total	42	100	

Discrimination from family and community members in accessing social services was not ranked high and it was only reported in rural households. None of the urban dwellers mentioned it as one of the problems during household interviews. Since most of those interviewed either belonged to or were caring for those belonging to one or more clubs for PLHIV, this could fairly be seen as a positive impact of the psycho-social counselling, care, treatment and support that the household were receiving. Also for most of respondents, the disease had not yet progressed into AIDS. Literature indicates that stigmatization is severe once the disease progresses into AIDS and a patient is therefore sick most of the time.

When probed further during FGDS, the issue of stigma surfaced in relation to how other community members perceived with regards to sharing latrines, washing patients clothes (see section 4.3 below) and supporting certain form of income generating activities of PLHIV. This was especially the case if those income generating activities were related to food vending – see box 2 for an example from Mkuranga. It may also be that stigma is an issue for many of the respondents, just not as pressing as their financial situation.

Box 3: Discrimination after revealing HIV status

“...I was working in a restaurant but because of frequent illnesses I lost my job. I joined Muungano wa Wanaoishi na Virusi vya UKIMWI Mkuranga (MWAVIUM) and I started baking bread for sale. When members of the community realized that I was HIV positive, all customers stopped buying bread from me. I do not have other income generating activities other than the money I get from PASADA as one of their volunteers on ‘home based care outreach’. I have three children all of them still in school...”

4.2 Accessing water supply services

Majority of respondents used water sources located within their own houses or in neighbors’ yard (table 5). All respondents indicated that they used less than 30 minutes to fetch water (Table 6). With location and duration for fetching water not featuring as one of the constraints, the study team probed more into other factors, which were specific to respondents’ status as PLHIV.

Table 5: Location of water sources used by surveyed household (% distribution)

Location of water point used by surveyed household	Residence		Total
	Urban	Rural	
In own House	14.3	5.0	9.8
In own yard/plot	14.3	5.0	9.8
In neighbours house/yard	61.9	45.0	53.7
At kiosk	9.5	5.0	7.3
At Institutions	0	25.0	12.2
Water vendors	0	10.0	4.9
Others (Traditional sources)	0	5.0	2.4
Total	100.0	100.0	100.0

Table 6: Time taken for fetching water

Time to fetch water (min)	Frequency	Percent	Cumulative percentage
0	13	30.95	31.71
1	2	4.76	36.59
4	1	2.38	39.02
5	8	19.05	58.54
6	1	2.38	60.98
10	4	9.52	70.73
15	6	14.29	85.37
20	1	2.38	87.80
30	5	11.90	100
Total	41	97.62	
Missing case	1	2.38	
	42	100	

4.3 Water Supply – increased need and/or a changed need?

Respondents were asked whether they have experienced an increased need or a changed need since tested positive and if there are other issues related to accessing water and sanitation facilities ever since. Other common constraints of accessing water services such as duration, location, ownership and affordability were also investigated.

About two thirds of all respondents indicated that they had increased their daily water consumption (Table 7). The increased daily consumption was due to washing (59.5%), and bathing (35.7%) (Table 8). When probed further during the FGD, the pattern of this reported daily increase was not necessarily related to the condition of the PLHIV, cost for accessing the water or rural-urban location.

Table 7: Views on changes in daily water consumption since tested positive

	Number of household		
	Rural	Urban	Total
Yes, increased	12	13	25
No change	9	8	17
Total	21	21	42

Table 8: Increased daily water consumption since tested positive (% distribution)

Water consumption	Water for washing	Water for drinking	Water for bathing	Water for drinking and bathing
Increased	59.5	26.2	35.7	9.5
No increase	40.5	73.8	64.3	90.5
Total	100.0	100.0	100.0	100.0

Health and hygiene information and messages are part of the care and treatment support provided to PLHIV and their household. The decision to increase the amount of water could be a positive impact of the uptake of good hygiene practices as a contribution to fencing off water related diseases. It was also revealed that the reported increase of water consumption was in some cases not directly related to the use by PLHIV, but by other household members who lived with and cared for them such as changing practices of washing patients' clothes and some caregivers boiling patients' clothes before washing them using their hands. These practices on water consumption related to PLHIV increased the amount of water that would normally be used.

Box 4: Increased use of water

One member of MWAVIUM in Mkuranga District told a story from before she knew that she was HIV positive. She was using any source of water and as a result she was suffering from diarrhoea over and over again as well as having rashes. After counselling, she agreed to go for voluntary testing, and realized that she was having HIV. The HBC service provider continued to visit her and educate her on how to take care of herself including the use of clean water and on proper hygiene. This helped her improve her hygiene behaviour. She acknowledged of washing hands after visiting toilets and bathing twice a day.

There is also some evidence of increase water use by other household members. For example, one respondent explained during a focus group discussion in Mvomero district, that “... *some household members where I stay would pour hot water after my visit to a toilet...*”

4.4 Access to sanitation facilities

Accessibility to sanitation facilities was encouraging, at least in terms of basic latrines. Among all surveyed household, respondents said that they had access to latrine facilities – see table 9. The majority of these latrines were located in household's dwellings or compounds.

Table 9: Type of Latrines

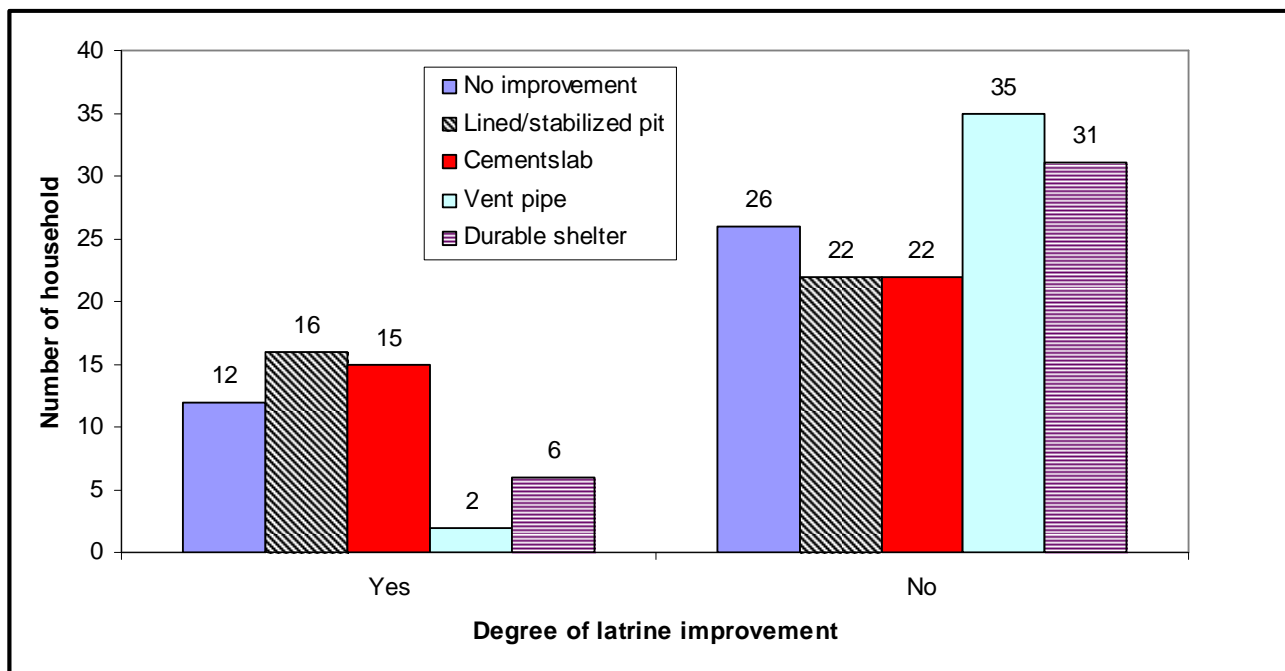
	Rural	Urban	Percentage of Total household
Type of latrine			
Flush toilet	1	5	14%
Pit latrine	18	16	81%
Public flush toilet	1		2%
Other	1		2%
	21	21	
	Rural	Urban	Total
Toilet Location			
Yes, in dwelling or compound	70.0	100.0	85%
No, outside dwelling or compound	30.0	0.0	15%
Total	100.0	100.0	100.0
User perception in terms of privacy and cleanliness			
Poor	38.1	42.9	41%
Fair	42.9	23.8	33%
Good	19.0	33.3	26%
Total	100.0	100.0	100%
Covering of pit holes			
Yes, covered	42.1	25.0	33%
No, not covered	47.4	60.0	54%
Not pit latrine	10.2	15.0	13%

However, when respondents were asked to give their perception on privacy and cleanliness of those facilities, only 26% said they were good. Additionally to that, researchers made observations to find if the pit holes were covered, and found that only one third of them were covered while over half were not.

Similarly most of the pit latrines were not of improved nature as indicated in figure 3. Almost 1 in 3 of the surveyed latrines reported to have some improvement. Very few latrines were observed to have vent pipe and durable shelter. This is similar to what one would expect in any survey of latrine facilities and shows that poor quality of most latrines may contribute to vulnerability of PLHIV and the general community (Box 4⁴).

⁴ Names changed for confidentiality purposes

Figure 2: Degree of improvement of Household Latrines



Box 5: Danger of unimproved latrines

Fatima is a middle aged woman, seriously sick in bed cared by her grand mother. Her grandmother is old and is tired of taking care of her. Sometimes she used to beat her and even deny her from food. Neighbours normally supported Fatima by providing her with water and food. One day Fatima’s leg slipped into the pit latrine and was rescued by neighbours. The latrine used by Fatima was one of the poorest quality; with neither roof, nor durable shelter or good slab.

4.5 Latrines – Increased need and/or a changed need/practice?

Similar to what was reported for water supply, just over half of all respondents reported to have increased usage of sanitation facilities since they had tested positive, with a significant number reporting a great increase (Table 10). Again the responses did not seem to vary in any particular fashion in relation to condition of the patient or type of facilities. During focus group discussions, most members stated that the use of toilets had not increased except when they had diarrhoea.

Table 10: Views on changes in daily latrine use since tested positive

Daily latrine use	Rural	Urban	Total
Yes, greatly increased	8	8	16
Yes, increased	3	3	6
No change	10	10	20
Total	21	21	42

4.6 Sanitation – An stigma issue of stigma?

One particular issue that was raised in several FGDs as a challenge for PLHIV regarding the use of latrines was how uncomfortable they might be made to feel given the reactions of others where facilities were shared by many. The majority of respondents who were PLHIV were happy to share latrines (Table 12), and the majority reported that they were sharing their latrine with at least 6 other people (Table 11). However, information from FGD indicated that some members poured hot water before using a latrine following a visit by a PLHIV. In practice, this did not prevent PLHIV from visiting latrines, though it could have some psychological effects. This does not contradict the earlier view from stigma is not a big issue but could also be taken as an indication of resilience by PLHIV to the adverse treatment they sometimes experience.

Table 11: Number of persons sharing a latrines

No. of people sharing one toilet	Rural	Urban	Total
1 – 5 people	7	2	9
6 – 10 people	11	11	22
11 – 15 people	3	4	7
16 – 20 people	0	1	1
20+ people	0	3	3
Total	21	21	42

Table 12: views on sharing latrines

Views on sharing latrine	Frequency	Percent
Happy	29	69.05
Unhappy	11	26.19
Neutral	2	4.76
Total	42	100

4.7 Hygiene practices and diseases

Clean and adequate sanitation is vital in protecting PLHIV and their families from the spread of water related diseases and essential for recovery from illnesses. It also ensures that PLHIV are able to return to work and assume their day to day life as quickly as possible. Hygiene practices such as hand washing, food preparation, safe water storage and disposal of household and human waste are all equally essential for all the family to protect those who are more vulnerable within the household.

During the study, it was found that a total of 38 household out of 42 reported that, they wash their hands after visiting toilets. Likewise, 36 household out of 42 said they had hand washing facilities but when observed the availability of cleaning facilities only 6 household were having the facilities either inside or outside the toilet. Hand washing at critical times was a key message for good hygiene practices. Practitioners in water and sanitation are challenged because; most surveys indicate that household do not always follow good hygiene practice.

Looking at the prevalence of diseases, findings showed that on average, six out of 39 household reported to have one among the five diseases listed in Table 13.

Table 13: Prevalence of diseases as reported by the respondents

Diseases	Incidence of diseases for the past three months	
	Yes	No
Diarrhoea	6	33
Typhoid	5	34
Tuberculosis	9	30
Skin disease	8	31
Cholera	0	39

4.8 Care and support services from community, institutions and individuals

The study also looked into the care and support services that PLHIV and their caregivers were receiving. Specifically the study looked at problems faced by caregivers and type of external support that they receive. The study also investigated whether PLHIV were comfortable with the care and support they were receiving from the caregiver, community and any other organization. The discussion covered four types of support: emotional support, material support such as food and water, medical support (including health information) and physical support such as getting helped with household activities like cleaning of toilets and compound.

Results (table 15) showed that 69% of the household do not get any type of support, while 31% received some kind of support. Data showed some of the household had access to more than one type of support: a small number (14%) of household got emotional support, around one third (36%) got material support, the same number got medical support and a very small number (2%) of household got physical support. Provisional of medical support was found to be most common especially to those who were registered in organizations of PLHIV and less to other non-registered members. Material support was limited to food and soap, which were not provided on regular basis.

Table 14: Carers for people living with HIV and AIDS

Persons responsible for caring a sick person	% distribution		
	Rural	Urban	Total
Women	71.4	76.2	73.8
Men	9.5	9.5	9.5
Girls	0.0	4.8	2.4
Children	9.5	0.0	4.8
Others (grandparents)	9.5	9.5	9.5
Total	100.0	100.0	100.0

Table 15: Types of care and support available to people living with HIV and AIDS

Support	Frequency	% of Total
Emotional support	6	14.3
Material support	15	35.7
Medical support	15	35.7
Physical support	1	2.4
No support	29	69

4.9 Community support mechanisms enabling PLHIV to access water?

There was only very limited evidence of formalized forms of support or specific arrangements for PLHIV to access water and sanitation facilities. Some vulnerable community members receive special support to access water and sanitation because they were older persons or had physical disabilities. In only one case, in Mvomero, PLHIV were included in this mechanism and allowed to access water from community kiosks free of charge. However, it was also clear that some community members objected to this arrangement. They complained that some people pretended to be HIV positive and poor so that they might get community and institutional support. Some members of the community felt that PLHIV should be fending for themselves through work as anyone else, with the justification given that it is possible that more out there are HIV positive but just because their status is not known they are not benefiting from this kind of community support. This could be interpreted to imply that community members are more willing to support older persons, the chronically ill and the disabled but may not fully comprehend that support for PLHIV is important especially before they become chronically ill.

Box 6: Caring and supporting PLHIV by enabling access to water

In Yombo Vituka, Nuru PTC is doing voluntary work to the seriously sick PLHIV. One of the major obstacles they are facing is caring for a person who has not bathed for many days. The group acknowledges water is a serious problem and especially for PLHIV who can not afford it. In the area there is a community water project but PLHIV are not allowed free access. However, in Yombo Relini ward, the Ward Executive Officer has allowed a person living with HIV and AIDS to fetch water free of charge but few community members disagreed with that arrangement pointing out that the person is capable of paying for the water service.

5 Discussion of critical issues and possible measures

5.1 Increased use of clean and safe water, increased cost

The importance of safe and clean water for PLHIV is clear. Majority of PLHIV indicated increased daily use of water and in turn this was expected to increase the cost of accessing the water, which places extra demands to household resources. This is a particularly critical issue as low financial capacity was reported at a major problem by households involved in this study.

One option to address this would be for care and support programmes for PLHIV to include a component of easing access to water supply. Current forms of HBC support have concentrated on medical, counselling and some material support such as occasional food items, bed nets etc. However, it is not straightforward to increased access to water directly for a specific group. This could be achieved by increasing access for the whole community, though this is the major challenge that the water sector is already struggling with. A second approach would be to use measures that increase water quality rather than quantity, such as water purification, which would at least reduce the risk of water-borne disease even if not addressing the issue of increased need for water. A final option would involve some form of subsidy for PLHIV. Although this study has shown that this may not have full community support, this option would have the advantage of being feasible for both HIV and AIDS programmes and water projects. Water and Sanitation programmes should engage with communities in finding acceptable ways of subsidising and providing access to water to PLHIV.

5.2 Sanitation and hygiene education

In relation to sanitation and hygiene, home based care guidelines include a component of water and sanitation, and hygiene in their training manual with information on the importance on safe and adequate water, proper storage, and chemical treatment of the water for maintaining good health for PLHIV. Water and sanitation programmes emphasise sensitization and training of community on stigma, hygiene, usage and sharing of water and sanitation facilities with PLHIV.

Both HIV and AIDS and water programme have sanitation, hygiene and stigma messages in their intervention packages. Are these messages harmonised or delivered in a consistent way? Such consistent delivery of messages has been shown to be a critical factor in achieving behaviour change.

5.3 Latrine facilities, hygiene and stigma

In most settings latrines do not meet the quality criteria, though this is no different to latrine standards in the wider community. However, for PLHIV, poor latrine standards can create two additional problems. First, inadequate sanitation increases the chances of opportunistic infections and therefore a risk to users.

Second, the poor quality of latrine facilities could be contributing to stigma to PLHIV. If latrine facilities were of adequate quality, many people would be more comfortable sharing the facilities with PLHIV and would not have at the back of their minds the last person who used the facility. At the moment they are aware of how unsafe their facilities are in transmitting germs and therefore this could be contributing to shaping their behaviour. For water and sanitation practitioners, community mobilisation for improved latrines and spelling out stigma becomes even more important.

6 Conclusion and Recommendations

The study revealed that there are specific challenges that PLHIV face in accessing water and sanitation and in most cases there are no clear arrangements for supporting and removing the barriers towards to access water and sanitation. Therefore, this study calls upon water and sanitation programmes to include community sensitization and training on care, stigma mitigation and hygiene through usage and sharing of water and sanitation facilities with PLHIV during project implementation. HIV and AIDS programmes, on the other hand should train people on proper water and sanitation, and hygiene issues. Most training manuals for home based care do mention the need for hygiene and the use of safe water and latrines, but the manuals are based on an assumption that everyone has access to safe water and sanitation. Further, the manuals do not provide information on safe water handling practices.

While evidence is growing on the effectiveness of integrating safe water, hygiene, and sanitation interventions into HIV and AIDS programs, little specific programme guidance exists. The following are recommendations based on the research findings:

6.1 For Water and sanitation programmes

- Water and sanitation programmes should develop strategic partnerships with other stakeholders such as those working on HIV and AIDS to address the most vulnerable including PLHIV,
- Develop alternative strategies to ensure that vulnerable households, including those made vulnerable by HIV and AIDS, have access to water and sanitation facilities,
- Common messages on water and sanitation hygiene should be developed and used by both water and sanitation programmes and HIV and AIDS programmes to improve chances of message uptake.

6.2 For HIV and AIDS programmes

- Home base care guidelines should give extra attention to water, sanitation and hygiene issues, such as by including information on the need for, and the amount of water needed to keep PLHIV and their environment clean, and on safe sanitation and hygiene practices,
- HIV and AIDS programmes and interventions should consider costing and advocating for provision of water treatment agents as part of PLHIV medical treatment support packages.
- Common messages on water and sanitation hygiene should be developed and used by both water and sanitation programmes, and HIV and AIDS programmes to improve chances of message uptake,

6.3 For further research

- Further research is needed to assess who is being excluded from access to water and sanitation services where projects have been implemented. This will help to give a clearer picture of who is left out of the service and/or to what extent PLHIV have access to the services,
- A comparative study could look into the question of how access to water services affected PLHIV, to see, for example, if PLHIV in the area with adequate water are better off in hygiene compared to those living in areas with less water,
- An argument could be made for more rigorous medical research to investigate the contribution of improved water and sanitation services in keeping PLHIV healthy, although the high cost of such an exercise make it an unlikely prospect.

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QUESTIONNAIRE: ACCESS TO WATER AND SANITATION SERVICES FOR PEOPLE LIVING WITH HIV AND AIDS

I. BACKGROUND INFORMATION

- (1) Name Interviewer _____
 (2.) Date of Interview _____
 (3.) Ward _____
 (4.) Village/Mtaa _____
 (5.) Sub-village _____

Questionnaire Number: _____

II. HOUSEHOLD MEMBERS INFORMATION

Name	Age	Sex	Relation to Head of HH	Marital Status	Highest grade	Main activity for the last 12 months
.....
.....
.....
.....
.....
.....
.....
.....
.....

(Earlier question on name, age, sex, relationship To head, marital status)			
1. Relationship to Head of HH	2. Marital status	3. What is the highest grade (Name) completed? If currently attending put highest completed	4. During the last 12 months what was your main activity?
Enter code Wife.....1 Husband.....2 Child.....3 Relative.....4	Enter code Married.....01 Divorced.....02 Unmarried/Single.....03 Widow/widower.....04 Separated.....05 Cohabit.....06	Enter code Under std 1/Child.....00 Std 1.....01 Std 2.....02 Std 3.....03 Std 4.....04 Std 5.....05 Std 6.....06 Std 7.....07 Pre-Form 1.....08 Form 1.....09 Form 2.....10 Form 3.....11 Form 4.....12 Form 5.....13 Form 6.....14 University/related.....15 Trained after primary.....16 Trained after secondary.....17 Adult education.....18 No formal education.....19	Enter code Farming/Livestock keeping.....01 Fishing.....02 Paid Employee: - Government & parastatal.....03 - Private.....04 Self Employed (Not in agricultural, livestock keeping, -with employees.....05 -without employees.....06 Unpaid family helper in a business: Non-agriculture.....07 Not working & available for work.....08 Not working & not available for work.....09 Housemaker/Housewife/HH chores.....10 Student.....11 Unable to work (Too old/Retired, Sick, Disabled).....12 Other (Specify).....13 Child.....14 Petty Cash/Small Business.....15

III. HOUSING PARTICULARS

5. What is the main building material used for the roof of the main dwelling?
- | | |
|----------------|---------------------------|
| 1. Iron sheets | 5. Grass (Leaves, Bamboo) |
| 2. Tiles | 6. Grass and mud |
| 3. Concrete | 7. Other |
| 4. Asbestos | (specify)..... |
| | |
6. What are the main building materials used for the walls of the main dwelling?
- | | |
|---------------------|-------------------------|
| 1. Stones | 5. Poles and mud |
| 2. Cement bricks | 6. Timber |
| 3. Sun dried bricks | 7. Grass |
| 4. Baked bricks | 8. Other (Specify)..... |
7. How many rooms in your household are used for sleeping (including rooms outside main dwelling)?
.....

IV. HOUSEHOLD ASSETS

8. Does your household own the following:

Asset	Yes = 1; No = 2
Radio (Radio cassette, Music system)	
Bicycle	
Telephone (Mobile/Landline)	
Iron (Charcal/Electrical)	
Motorcycle	
Car	
Refrigerator	
TV	
Milling machine	
Shop	
Other...	
	Number
Number of cows	
Number of goats/sheep	
Number of chickens	
Number of donkeys	

V. HOUSEHOLD FACILITIES

9. What is the main source of energy used for lighting in the household?

1. Main electricity
2. Solar
3. Gas (Biogas)
4. Paraffin-Hurricane lamp
5. Paraffin-Pressure lamp
6. Paraffin-Wick lamp
7. Candles
8. Firewood
9. Other (Specify).....

10. What is the main source of energy for cooking in the household?

1. Electricity
2. Solar
3. Bio-Gas
4. Bottled gas
5. Paraffin/Kerosene
6. Charcoal
7. Firewood
8. Animal dung
9. Crop residuals
10. Other (Specify).....

VI. PERSONAL INFORMATION OF THE RESPONDENT

11. (a) Name of Respondent _____

- A. Patient B. Caregiver

11. (b) If B What is the relationship with the patient

- (i) Wife (ii) Husband (iii) Child (iv) Relatives

11. (c) How is the condition of the patient

- (i) Serious sick (ii) Fair (iii) Good

12. Age _____ (years)

13. Sex (1) Male (2) Female

14. Marital status

- i. Married
- ii. Divorced
- iii. Unmarried/Single
- iv. Widow/widower
- v. Separated
- vi. Cohabit

15. Position in the household:

- (1) Head of household (2) Spouse (husband/wife) (3) Child (4) Relative

16. Highest Level of education (**Choose code according to Quest 3 of sect II**).....

VII. LIVELIHOOD/ECONOMIC ACTIVITIES

17. How much total income is earned by your household members per month all sources - work, business sources, and relatives?

- (1) less than Tshs 60,000
- (2) Tshs 60,000 or more but less than Tshs 100,000
- (3) Tshs 100,000 or more but less than Tshs 300,000
- (4) Tshs 300,000 or more but less than Tshs 500,000
- (5) Tshs 500,000 or more
- (99) Don't know

18. Who own the house you live?

- (1) Family house (2) Personal (3) Rented (4) Other types (specify) _____

19. For how long have you been living in this house?

- (1) Less than one year
- (2) More than a year
- (3) Since I got sick
- (4) I have born here

20. What were the reasons for you to move to this house?

- (1) Thrown out of previous accommodation
- (2) Look for employment
- (3) Married
- (4) Wants to live with parents/relatives during my sickness
- (5) I have been told so with the caregiver
- (6) To give care and support to the patient
- (7) Others specify

VIII. ACCESS TO WATER SUPPLY

21. (a) What is the main type of water source used by your household use?

- (1) piped
- (2) borehole installed with pump
- (3) protected well
- (4) unprotected well
- (5) protected spring
- (6) unprotected spring
- (7) Surface source (dam, river, stream, pond)
- (8) Covered rainwater tank
- (9) Uncovered rainwater tank
- (10) Other (specify).....

(b) Is the water point (i) Private (ii) Public

22. Does your main water source last throughout the year? (1)Yes (2) No

23. Where is the location of the water point used by your household?

- (1) In own house
- (2) In own yard/plot
- (3) In neighbours house/yard
- (4) At a kiosk
- (5) At an institution (mosque, church, school etc.)
- (6) Water vendor
- (7) Other (specify).....

24. Do you pay for water used? (1)Yes (2) No

25. How much do you spent on water? Per dayTshs
Per monthTshs

26. On average, how many buckets of water do your HH use every day?

27. What is the cost of 20 litres bucket of water?

28. What is the max time spending for collecting water?.....

IX.. SANITATION AND HYGIENE

Excreta Disposal

29. What toilet facility does this household use? (*Circle all that apply*)

- (A) Flush Toilet/WC
- (B) Pit Latrine
- (C) VIP Latrine
- (D) Public Flush toilet
- (E) Public Latrine/Shared
- (F) Other (specify)
- (G) No facility

30. **Observe: If any type of pit latrine , are the hole(s) covered?**

- (1) **Yes**
- (2) **No**
- (3) **Not a pit latrine**

31. **Enumerator to observe cleanness of latrine:**

- (1) **Visible faecal matter**
- (2) **Smell**
- (3) **No privacy**

32. If the toilet facility is a pit latrine what improvements have been made to the latrine? (*Circle all that apply*)

- (A) None

- (B) Lined/stabilised pit
- (C) Cement slab
- (D) Vent pipe
- (E) Durable shelter

33. Is the toilet located within your dwelling, or yard or compound?

- (1) Yes, in dwelling/yard/compound
- (2) No, outside dwelling/yard/compound

34. How many household share the toilet?

35. How many people share this toilet?.....

36. How would you describe the quality of toilet in terms of privacy and cleanliness? [User perception]

- (1) Poor
- (2) Fair
- (3) Good
- (99) Not Applicable

37. How many times has this toilet facility flooded in the last six months? (*If never write 0*).....

38. What did you do, when your toilet was full?

- (1) Emptying
- (2) Construct another toilet
- (3) Switch to another chamber

39. Do you wash your hands after visiting toilet?

- (1) Yes
- (2) No

40. What facilities do you use for hand washing?

- (1) Soap
- (2) Ash
- (3) None
- (4) Other (specify)

41. **Enumerator to observe if cleaning facility is available**

- (1) Available**
- (2) Not available**

42. Who maintains the toilet?

- (1) Women
- (2) Men
- (3) Girls
- (4) Boys
- (5) Helper
- (6) Care giver

43. Have you ever had either of the following diseases for the last three months?
- | | | | | |
|------------------|---------|--------|----------------|-------|
| (a) Diarrhoea | (1) Yes | (2) No | How many times | |
| (b) Typhoid | (1) Yes | (2) No | How many times | |
| (c) Tuberculosis | (1) Yes | (2) No | How many times | |
| (d) Skin disease | (1) Yes | (2) No | How many times | |
| (e) Cholera | (1) Yes | (2) No | How many times | |

X. PATIENT CARE

44. Who is responsible of taking care of a sick person in the household?

- 1) Women
- 2) Men
- 3) Girls
- 4) Boys
- 5) Children
- 6) Grand Parents

45. How many bucket of water does a sick person need per day?

46. What support does a sick person get from the community?

.....

.....

.....

.....

.....

47. What is the biggest problem faced by a sick person?

- b. Plans failed
- c. Sickness
- d. Lack of income
- e. Discrimination from getting social service

48. What are your views about discrimination/stigma?

.....

.....

49. Do community know about his/her status?

- a. Yes
- b. No

50. Should people with HIV AND AIDS be open about their status?

- a. Yes
- b. No

51. Is his/her needs to access toilet has increased?

- a. Yes, greatly increased
- b. Yes

c. No

52. Since he/she has tested positive is his/her daily water consumption increased?

- a. Yes, washing
- b. Yes, on drinking
- c. Yes, bathing
- d. Yes, drinking and bathing
- e. No

53. What is your view for a sick person sharing water and sanitation facilities?

- a. Happy
- b. Unhappy
- c. Neutral

54. What do you think should be done for PLHIV in water and sanitation

- a. Private provision of latrine or latrine and water for PLHIV
- b. Need for education against discrimination
- c. Need for improved provision of facilities
- d. Both education and provision of facilities should get equal weight
- e. Education to tackle discrimination over provision of facilities

55. Any Other Comments

.....

.....

.....

.....

FOCUS GROUP DISCUSSION GUIDE: WATER AND HIV AND AIDS STUDY

⇒ Discuss and rank problem faced by People Living With HIV and AIDS (PLHIVs) (see methodology Ethiopia study)

- a) Employment/income
- b) Housing
- c) Water and Sanitation

⇒ Discuss forms of discrimination experienced by PLHIVs

- a) Medical
- b) Watsan
- c) Employment
- d) Housing

⇒ Problem faced by PLHIV in water and sanitation

- 1) **Access to water:** Location, price (affordability), Opening hour, Discrimination.
- 2) **Access to latrine:** shortage of latrine,,

⇒ Need and access to water and sanitation for PLHIV

	Water		Sanitation	
FGD	Increased need	Change need	Increased need	Change need
Women				
Men				
Mixed				

⇒ Discuss on what should be done for PLHIV in water and sanitation

⇒ Discuss on how should education against discrimination be done e.g. mass media, personal testimonies, medical information e.t.c.

PARTICIPANTS OF THE VALIDATION AND ANALYSIS WORKSHOP

NO.	NAME	ORGANIZATION
1.	SALTIEZ KIMARO	AMREF
2.	SUZAN KIPUYO	AMREF
3.	DANIEL SEMPEHO	PATHFINDER INTERNATIONAL
4.	BEN TAYLOR	WATERAID
5.	VIVIENNE ABBOTT	WATERAID
6.	ROBERT MWANDISHI	OXFAM
7.	GEORGE M. JOHN	UMATI
8.	KAISI KYAMBA	TAWASANET
9.	REHEMA TUKAI	REPOA
10.	DIANA NKONGO	WATERAID
11.	DORISIA MULASHANI	Ministry of Water and Irrigation