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HIP HYGIENE IMPROVEMENT PROJECT

FOCUS GROUP DISCUSSIONS AND IN-DEPTH INTERVIEWS TO IDENTIFY “SMALL DOABLE ACTIONS” TO IMPROVE HYGIENE PRACTICES IN THE CARE OF PEOPLE LIVING WITH HIV/AIDS

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List of Acronyms

AEGY	AIDS Education Group for the Youth
AFFORD	Africa Foundation for Development
AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
CATTS	Community ARVs TB Treatment and Support
CBHC	Community-Based Home Care
CBOs	Community-Based Organizations
FBOs	Faith-Based Organizations
FGD	Focus Group Discussion
HBC	Home-Based Care
HIP	Hygiene Improvement Project
HIV	Human Immunodeficiency Virus
IDI	In-Depth Interview
JCRC	Joint Clinical Research Center
NACWOLA	National Community of Women Living with HIV/AIDS in Uganda
NGOs	Non-Governmental Organizations
PLWHA	People Living with HIV/AIDS
PSI	Population Services International
TASO	The AIDS Support Organization
TIPS	Trials of Improved Practices
USAID	United States Agency for International Development
UWASNET	Uganda Water and Sanitation Network
WASH	Water, Sanitation, and Hygiene
WFP	World Food Program
WHO	World Health Organization

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Executive Summary

This review was funded by USAID through the HIP and Plan Uganda to identify a set of potential "small doable actions" to improve WASH practices in the care of people living with HIV/AIDS (PLWHA). The specific objectives were:

- To identify the current high-risk WASH behaviors in relation to the care of PLWHA;
- To identify the motivations and barriers to improving these high-risk behaviors;
- To identify low cost actions that have the potential to mitigate the impact of poor WASH factors on diarrheal disease outcomes in the care of PLWHA.

Methodology

This was a qualitative review drawing on FGDs, IDIs, and observations.

Study Participants

Study participants included the following:

- CBOs affiliated with existing home-based care (HBC) organizations;
- The family-based caregivers who were the family members (including children) who took care of the PLWHA;
- PLWHA identified with assistance from community-based care providers.

Sample Size:

Overall, 29 participants participated in FGDs in Kampala, while 35 individuals participated in Kamuli District. As for IDIs, there were 14 respondents in Kampala and 9 in Kamuli.

Findings

The context dictates the kinds of practices the families adopted by urban and rural families:

- Poor urban families who did not have toilets/latrines found difficulties in disposing of feces;
- In the rural areas, although families had space to put up latrines, most of these areas were in bad condition;

- Sick people in rural areas were cared for by close family members and other relatives. Nevertheless, there were patients without household members to care for them, and they often depended on distant relatives and neighbors for support.

The community-based home care (CBHC) providers have been playing a crucial role in improving WASH conditions of PLWHA as was reported during the study. However, there were still gaps in the services administered by the CBHC providers and information gaps for the CBHC providers. Namely, CBHC providers:

- Did not have adequate information about the critical times to wash hands and had limited ideas of how to facilitate washing of hands;
- Had not considered menstrual blood as a critical hygiene problem;
- Had no clear idea about feces disposal in the urban settings where people lacked access to latrines;
- Lacked information on safe water consumption practices, which were still a problem, especially in relation to treatment and safe storage;
- Were not sure of how to appropriately manage feces for the bedridden patients.

Several barriers that affected adoption of appropriate hygiene practices included overwhelming poverty, stigma, poor sanitation facilities, conflicts that affected the cooperation between patients and caregivers, and gender dynamics (especially the dominance of men in decision making, men not being keen about cleaning, and male patients sometimes coercing women to do what the male patients themselves could have done).

Motivators to good hygiene practices were also discussed. These included the fact that patients could potentially improve their health status with better WASH practices, and this would, in turn, reduce the burden of care and costs that would be incurred during treatment.

Risky practices identified by the review and those which varied from family to family included: not washing hands with soap at critical times, using bare hands when cleaning the patient, throwing feces in the neighborhood and in open spaces (especially in urban areas), using toilets that were not patient-friendly, some patients soiling their beds and the excrement remaining in the sheets for long before someone removed it, not washing the soiled linen but simply putting it outside to be sun-dried before reuse, and washing the soiled linens with bare hands.

Risky practices in the area of safe water also existed with some homes not treating their water before consuming it. Some households stored water in wide-neck containers with no lids, and containers used to transport or store water were in dirty in most cases.

In relation to menstrual blood, some women who were bedridden during their menstrual period did not have access to appropriate materials to absorb the blood or clean themselves. Some of the caregivers were touching the menstrual blood without any kind of protection.

Conclusions

- People did not always wash their hands at critical times (before eating, after using the toilet, before taking medicine, after cleaning the patient, before preparing food, and before feeding the patient or the baby). They only washed when their hands looked dirty;
- Most of the bedridden patients did not have hand washing facilities near their beds to promote regular cleaning. Hence they did not wash hands at critical times, making them vulnerable to infections;
- Use of soap is not considered to be important in hand washing and it was used only when there was visible dirt or bad smell;
- The cost of soap may be a factor hindering the use of soap during hand washing, but also peoples’ lack of understanding of the importance of soap was an issue;
- There were still challenges regarding where to dispose of feces, especially for those who did not have their own latrines or toilets;
- In the rural areas (Kamuli), because they did not have access to land, it was easier to bury feces if they did not have toilets;
- Some mobile patients found it difficult to use pit latrines due to the unstable structures of these toilets;

- Some of the carers' well-beings were at risk of being infected by HIV and/or other pathogens due to lack of protective gear;
- Child caregivers were often overwhelmed by the responsibilities, and some of them did not know what to do in relation to patient care.

Recommendations

Hand Washing

Families should be advised to:

- Place a hand washing station (soap; water vessel/basin, or tippy tap) near the bedridden patient so that caregivers can wash their hands;
- Encourage the caregiver to use a cleanser (soap, ash, sand, or paw-paw leaves) when washing hands, and use running water to rinse;
- Place a hand washing station (soap; water vessel/basin, or tippy tap) near the bedridden patient so that he/she can wash his/her hands;
- Teach the bedridden patient to wash hands with soap thoroughly after defecating.

Safe Water Management

There is critical need to advise the families to treat water with *WaterGuard*/ AquaSafe /PUR or boil it. Families should also be advised to store their water in narrow-neck containers such as jerry cans or narrow-neck clay pots. Families should be advised to always have lids covering their clean water storage containers.

Feces Management

- Advise households without a latrine to throw the feces in the public latrine, or negotiate with a neighbor to get permission to throw the patient's feces in the neighbor's latrine;
- If latrine access is not possible, families should be advised to bury feces;
- Install rope, pole, and/or handle in the latrine for supporting a weak patient who may have difficulty squatting or standing on their own;
- Build a removable seat to use over the hole of the latrine;
- For mobility-challenged patients, provide walking sticks or crutches to get to the latrine and to use for leverage when squatting or standing;

- Use nappies made from old clothes and rags to absorb the feces of bedridden patients;
- Use potty or bed pan for collection of feces of bedridden patients;
- Use a stool with a hole in the middle, with a place underneath the hole for a container to catch the feces;
- Put ash/sand/paw-paw leaves in the bed pan before defecating (to minimize feces sticking to container) and sprinkle ash/sand on top of feces to minimize smell and reduce risk of spreading germs from flies;
- Place water/rags/tissue within reach of patient for his/her use if caregiver is not nearby (to clean him/herself);
- Place a container near the bed to put the soiled material in;
- Place a mackintosh (plastic sheet) covered with a piece of cloth between the mattress and the patient's hips;
- Advise caregivers to use gloves or polythene papers (thin plastic sheets) to protect hands when handling the patient's feces;
- Advise caregivers to wash the soiled linen with soap/pawpaw leaves or any other detergent and dry in the sun before reuse.

Menstrual Blood Handling

Women on their periods should be provided with materials such as pads, cotton, rags, or other locally-available materials (for instance, banana fibers) to absorb the blood.

- Caregivers can pad the patients who are not able to pad themselves.
- Place water and rags next to the bed for the patient to clean blood from her body.
- Put a container next to the bed to place soiled cleaning materials in, where they can later be washed or thrown into the latrine.
- Caregivers should protect their hands by covering them with gloves/polythene bags when handling menstrual blood and when washing rags used to absorb blood.
- Dry the rags in the sun before reuse.

CHAPTER ONE

INTRODUCTION AND BACKGROUND

1.1 Purpose of the Review

PLWHA are at increased risk of opportunistic infections, particularly those that affect the gastrointestinal tract. For example, estimates indicate that as many as 80% of PLWHA suffer from diarrhea. Historically, a number of guidelines have focused on the care of PLWHA (see Maser et al., 2002 for example) but have failed to take into account poor WASH practices in developing countries. There is increasing emphasis on the need to integrate such issues into the care of PLWHA in developing countries (Mermin et al., 2005). A randomized controlled trial in rural Uganda showed a 25% reduction in diarrhea episodes amongst HIV-positive persons with access to a cost-effective (Shrestha et al., 2006) safe water system (that included a narrow-neck water storage container, dilute chlorine solution, and health education) compared to those who received health education alone (Lule et al., 2005). Evidence of the effectiveness of safe water treatment and storage, safe disposal of feces (Fewtrell, 2005; Lule et al., 2005) and hand washing with soap (Curtis and Cairncross, 2003) suggest a number of programmatic opportunities to reduce the burden of diarrheal disease amongst PLWHA in Africa.

The World Health Organization (WHO; 2007) reviewed the scientific evidence and has made three WASH recommendations in relation to the care of PLWHA in developing countries (see box 1). Furthermore, it is encouraging to note that there has been favorable uptake and use of basic care packages (that include safe water systems) where such packages have been provided free of charge in Uganda (Colindres et al., 2007).

Box 1: WHO (2007) WASH recommendations for the care of PLWHA

- *Household-based water treatment methods that are effective in reducing diarrhea and the storage of water in containers that inhibit manual contact are recommended for people with HIV and their households.*
- *Proper disposal of feces in a toilet, latrine, or at a minimum, buried in the ground, is recommended for people with HIV and their households.*
- *Promotion of hand washing with soap after defecation, handling of human or animal feces, and before food preparation and eating, along with the provision of soap, are recommended for people with HIV and their households.*

However, what seems unclear are recommendations where access to basic care resources is limited, that is, with little or no access to safe water systems, latrines and cleansing agents/hand-washing facilities. In response to this, Plan Uganda is partnering with the HIP (which is financed by USAID), the government, and other international and local non-governmental organizations (NGOs), community-based organizations (CBOs), and faith-based organizations (FBOs), to integrate safe WASH into care and support of PLWHA. The HIP conducted a review to identify and test a series of “small doable actions” that HBC workers, families, and PLWHA could incorporate into their regular care routines. This report outlines the findings of “phase one,” which was derived from conducting FGDs, IDIs, and observations to identify potential behaviors to promote. A separate report outlines “phase two,” in which a technique known as Trials of Improved Practices (TIPS) was implemented to test the acceptability and feasibility of the recommended behaviors and/or doable actions at the household level.

1.2 Aim & Objectives

The aim of phase one was to identify a set of potential “small doable actions” to improve hygiene practices in the care of PLWHA. The objectives of phase one were:

- To identify the current high-risk WASH behaviors in relation to the care of PLWHA;
- To identify the motivations and barriers to improving these high-risk behaviors;
- To identify low cost actions with the potential to mitigate the impact of poor WASH factors on diarrheal disease outcomes in the care of PLWHA.

1.3 Methods

Under methods, we shall cover the review design, sample size, participants, review process, data analysis, and limitations of the review.

1.3.1 Review Design

This was a qualitative review drawing on FGDs, IDIs, and observations.

1.3.2 Sample

The FGD and IDI participants included:

Community-Based Care Providers: Individuals with an affiliation with existing HBC organizations. In Kampala, the organizations which participated in the study included Reach Out Mbuya, Nsambya Home Care, and Hospice Africa Uganda. In Kamuli, the organizations we worked with included AEGY, NACWOLA and Plan Uganda. These care providers serve as support to caregivers (family members, friends, and neighbors) of PLWHA and sometimes provide direct nursing care for the patients in their homes.

Family-Based Caregivers: Caregivers were usually family members (including children) residing in the home who took care of the PLWHA. There were also isolated cases where the PLWHA were alone and neighbors and friends provided assistance.

PLWHA: Participants were identified with assistance from HBC institutions. PLWHA included a broad range of age groups and were at various stages of the disease. Some were bedridden, while others were sick but mobile. Others were on and off in terms of being bedridden. The summary of respondents is provided in the matrices below.

1.3.2.1 Sample Size

Overall, there were 29 participants in FGDs in Kampala, and 35 participants in Kamuli. With regards to IDIs, there were 14 respondents in Kampala and 9 in Kamuli, as shown in Table 1 below.

Table 1: Participants in Kampala District

Focus Group Discussions with HBC Providers			
Institution	**Males**	**Females**	**Total**
Reach Out Mbuya	6	2	8
Nsambya Home Care	4	5	9
Hospice Africa Uganda	2	10	12
Total	**12**	**17**	**29**
In-Depth Interviews with Patients			
Nsambya Home Care	0	1	1
Reach Out Mbuya	2	5	7
Hospice Africa Uganda	0	1	1
Total	**2**	**7**	**9**
In-Depth Interviews with Caregivers			
Nsambya Home Care	2	1	3
Reach Out Mbuya	1	0	1
Hospice Africa Uganda	2	1	3
Total	**5**	**2**	**7**
In-Depth Interview with Landlords			
Reach Out Mbuya	1	0	1
Total	**1**	**0**	**1**

Table 2: Participants in Kamuli District

Focus Group Discussions	Males	Females	Total
Post Test Club (Plan International)	6	6	12
AEGY	3	3	6
NABA POTEC (Plan International)	3	5	8
NACWOLA	1	8	9
Total	**13**	**22**	**35**

In-Depth Interviews	Male	Female	Total
Adult Caregivers	1	1	2
Child Caregivers	1	2	3
Patients	2	2	4
Total	**4**	**5**	**9**

1.3.3 Review Process

The data collection process began with FGDs with community-based care providers who were affiliated with HBC institutions. Focus groups usually included 6-12 participants and were conducted at their respective institutions. The interview was facilitated by a trained moderator and a note taker who documented details of the discussion. After the FGDs, the care providers attending the focus group interviews were asked to identify households that cared for PLWHA within their jurisdiction.

Figure 1: Focus Group Interview with Care Providers in Kampala

Households identified by the care providers were visited. At the household level, family-based caregivers who consented to participate in the review were interviewed in their homes. Consideration was taken to make the PLWHA interview as short as possible in order to minimize the impact on (sometimes) critically-ill patients. The tools used in the FGDs and IDIs are provided in Appendix A, B, and C respectively. The observation checklist that was used when visiting homes can be found in Appendix D.

1.4 Challenges and Limitations of the Assessment

1. It was often difficult to recruit bedridden patients as their health unexpectedly improved or declined. Sometimes, the team traveled from house to house for bedridden patients, where community-based care

providers anticipated them to be, only to find that some patients had either died or their health had improved and they had regained mobility. Patients who lacked adequate care from their nuclear family members were sent to distant relatives where they expected better care.

2. It was difficult to recruit child caregivers (younger than 18) since most of them attended school and came back to provide care in the evenings. Some of the interviews were therefore conducted in the evenings.

3. It was not possible to recruit people who did not belong to, or identify with any formal HBC organization. Those who were identified either refused to cooperate, or had just stopped receiving services from some of these organizations for different reasons.

4. Some of the respondents were critically-ill. This affected the amount of time spent with them. The team tried to reduce the amount of time they needed to spend interviewing them.

CHAPTER TWO

FINDINGS OF THE REVIEW

The findings chapter focuses on the following: the key characteristics of the reviewed households that have implications for hygiene, the roles of the community-based care providers and the related service gaps, barriers and motivators for improving hygiene among PLWHA, common hygiene practices, discussions, and low cost actions that have the potential to mitigate against diarrhea among PLWHA.

2.1 Characteristics of the Reviewed Households

The Context: The nature and conditions of respondents and the issues that emerged from the discussions varied between Kampala (urban) and Kamuli (rural) areas.

Kampala: In Kampala, the selection of the respondents was guided by the organizations providing care and support to the people who were chronically-ill. These organizations included Reach Out Mbuya, Nsambya Home Care, and Hospice Africa Uganda. The support from these organizations went to the urban poor who reside predominantly in the slums. Most of these organizations' clients were unemployed, or their incomes were too meager to support them on antiretrovirals (ARVs). They were staying in low cost houses in impoverished and unsanitary conditions. Decisions regarding sanitation were usually made by landlords who tended to be unwilling to incur any additional costs. Consequently, tenants had little or no say in the quality of their sanitation facilities.

The HBC organizations provide home care and support in these communities. In addition to providing materials to use, such as soap and gloves, some of the organizations were also providing advice to family-based caregivers on how to look after their terminally-ill patients. Despite these efforts, there were still challenges to hygiene improvement due to unfavorable environmental conditions. In the urban area, the following characteristics were typical:

Box 2: Characteristics of the Urban Communities

- *Overcrowding*
- *High person to latrine ratio*
- *Latrines in poor condition*
- *Lack of space for improved facilities (for example, tippy taps)*
- *Most of the clients were casual laborers. When they were bedridden, they were unable to earn money for daily expenses and more so their rental costs. Some ended up being thrown out of their houses.*
- *Because they were often indebted to the landlords, it was difficult for clients to ask the landlords to improve on the sanitation conditions.*

Kamuli: In Kamuli (rural), most of the people were subsistence farmers who mainly lived from hand to mouth. Like the urban slum dwellers, their very survival was based on their ability to work for themselves and their children. If they were sick, the consequences on their families' well-beings were significant. Most of the people got their food from the gardens and, on rare occasions, they supplemented this with processed food purchased from the shops in the small trading centers. There was a high dependency ratio with the majority families having approximately 6-12 children per mother. However, due to the polygamous nature of these families, in some instances, the number of children was even higher.

Most of the people stayed near their gardens. It was also common for the people of the same family and the same clan to stay near each other. This helped to reinforce care and support to each other when they were very sick. The following information lists the typical characteristics of rural households with PLWHA:

Box 3: Characteristics of Rural Households with PLWHA

- *Overcrowding*
- *Long distance between the toilets and houses*
- *Few or no hand-washing facilities near the latrines*
- *People used latrines which were in bad conditions (too small, some without doors, others without super structures)*
- *There were many water containers (basins, jerry cans, and pots) which were scattered in a disorderly manner in the compounds. Most of the water containers and the water inside them were very dirty. It was common to find uncovered old pots with water harvested from rain.*
- *There were dish racks with unwashed utensils surrounded by flies enjoying the leftover food.*
- *Sick people were cared for mainly by close family members. However, there were also those with no one to care for them, so they depended on distant relatives. In Busoga, the culture is that all relatives should share responsibility for caring for the very sick. A patient may move between families of different relatives in a bid to get care. Therefore, some of the patients are taken away from their homes.*

In conclusion, the differences between urban and rural communities had much to do with availability of space (where to put latrine/toilet facilities, related facilities such as hand-washing stations, and where to bury feces). The other difference was that people in Kampala (urban) had more access to services, including counseling and clinical care such as access to ARVs. Common characteristics included poverty, which affected the people in diverse settings in different ways, but with the same end result: failure to put in place the required hygiene facilities.

2.2 The Role of the Community-Based Care Providers

In general terms, the community-based care providers were reportedly responsible for checking on the patients, ensuring that they went for treatment of symptomic infections, and with some patients, to check for compliance with treatment. Some care providers said they often gave first aid treatment and, when necessary, provided referrals. At times, they encountered situations where they had to transport very sick patients to the clinics.

> *"We encourage the patients not to lose hope; some people throw away the drugs without taking them. We therefore monitor the patients especially on the consumption of drugs, and make reports about the conditions of the patient."* ***(Nsambya Home Care FGD)***

Some of the care providers said they assist in nursing the patients, which sometimes included tasks such as removing and washing the dirty linen. Apart from promoting hygiene, community-based care providers reported that they actively participate in the cleaning up of the bedridden patients. Health education of family members seemed to be an important component of the HBC activities.

> *"We ensure that all our clients' homes are clean, and we sometimes show them examples by doing the cleaning ourselves. In some of the homes, when the patient/client is bed-ridden, we call the caretaker and we do the cleaning as they look on. In so doing, we show them how to clean patients, and even sometimes, we clean the client's clothes if there is no caretaker available and the clients' clothes are dirty. We also sensitize people in the community about the importance of testing and counseling."* (***Reach Out Mbuya FGD)***

The community-based care providers both in Kampala and Kamuli reported that they have been fighting against stigma at both the home and community levels. Except for AEGY, most of these providers are HIV-positive and this, in their view, makes them better advocates against stigma.

> *"...We have opened up to the community to fight stigma, sensitize the community about HIV by using ourselves as examples, share the knowledge with the patients, monitor and supervise taking of ARVs properly, counseling the patients in the community." (**Nsambya Home Care FGD**)*

Some of the community-based care providers provide some supplies to their patients, including food, gloves, soap, and drugs. Reach Out Mbuya, with support from World Food Program (WFP), provides food to HIV/AIDS patients. Clients coming for services are provided with lunch as well. Some of the clients acknowledged the support they were receiving in relation to food.

> *"Some clients have emergency food. This they normally get from here (Reach Out Mbuya) in collaboration with World Food Program, some of us, Community ARVs TB Treatment and Support (CATTS) Volunteers, use our own money to cater to the small needs of the clients that we visit. For example, you go to a client's home and find no soap at all, yet the cups are dirty and the client is very weak. In this case we buy the soap.*

> *Reach Out Mbuya provides some usables and necessities to the clients, e.g. gloves, soap, Omo and food." (**Reach Out Mbuya FGD**)*

In addition to providing material support, the HBC institutions also encourage self-reliance by facilitating clients to engage in income-generating activities. In Kamuli, for instance, Plan Uganda has been providing PLWHA with animals such as goats and cows to enhance income generation. Reach Out Mbuya provides some funding to their clients to help them become involved in small businesses where they can earn money. With these small investments, they can raise money to meet their basic needs.

> *"For bedridden clients who have no money to pay rent, CATTS goes out of its way and gives them grants to pay their rent, for example, three months rent. Those who are not bedridden, we teach/preach to them the gospel of self-reliance. We encourage them to form groups so as to access money from our micro-finance. This way they get money to start up small businesses to support themselves." (**Reach Out Mbuya FGD**)*

The community-based care providers have reportedly been preaching behavior change to both patients and their carers. For instance, they discourage those behaviors that tend to worsen the health conditions of PLWHA.

> *"Behavior change reduces having sex many times, stops smoking, and proper medication (of taking drugs). We encourage people to come for Health Education programs to share and educate the community members. Through support groups, they share their experiences and knowledge about solving problems. We discourage being there waiting and depending on others to do something on their own." (**NACWOLA Kamuli FGD**)*

The community-based care providers also look into the aspects of social needs of PLWHA by connecting the patients with support for their children's education.

> *"Sponsorship connecting sponsors with the vulnerable children, especially primary school children; every parish commends 2-3 school drop outs, mostly orphans and those whose parents died of HIV/AIDS and the*

*children themselves, sensitization about will-writing and other family benefits." (**Post Test Club Kamuli FGD)***

2.3 Gaps in the Services Provided by the Community-Based Care Providers

Considering the wide range of issues reported above, it is apparent that the community-based care providers were doing a commendable job in support of PLWHA. In the area of hygiene, it was apparent that they were doing all they could to advise the patients and their caregivers on how to remain clean and protect themselves from infections (in the case of the caregivers). However, they had a broad concept of cleanliness, mainly emphasizing use of gloves, washing hands, cleaning the patient properly, using clean utensils, and cleaning the linen for the patients. There were still gaps, especially regarding specific hygiene problems. The following factors were envisaged to be critical gaps:

Box 4: Gaps among Community-Based Care Providers Regarding Specific Hygiene Problems

- *The community-based caregivers, as well as their patients, did not have adequate information about the critical times to wash hands. For instance, they did not know that it is important to wash hands when handing the patient drugs, just after cleaning the patient.*
- *They had no ideas of how to facilitate washing of hands by use of tippy taps near the toilets and having hand-washing stations near the patients.*
- *They had not considered menstrual blood as a critical hygiene problem, especially with bedridden women. In fact, most of them were surprised when asked about issues related to menstrual blood.*
- *They had no clear idea about feces disposal in the urban settings, especially where people did not have access to latrines. Although they were aware of the problem, they had no solutions.*
- *They had no easy solution to the problem of safe water consumption, especially in relation to treatment and safe storage. Although they knew boiling was important, they found it difficult to achieve among their clients, who most often had difficulties in getting fuel for boiling the water. Some of their clients had been introduced to the idea of water vessels and water treatment products such as WaterGuard and AquaSafe. However, their clients met challenges of people's negative perceptions of water vessels and the agents used for the purification of the water. Some of the patients did not know how to use the vessels; the taps had either been removed or broken. As a result, they were using them like any other jerry can.*
- *There was a lot of uncertainty on how to manage feces for the bedridden. Most of them talked of using buckets and basins with no specific measures on how to avoid messing the surroundings of the patient and his/her beddings.*

2.4 Hygiene Practices among PLWHA and Their Caregivers

The subject of hygiene is very complex and cannot be exhausted in a single review. This assessment mainly focused on a limited set of behaviors related to hand washing, feces management, water treatment/storage, and management of menstrual blood.

2.4.1 Hand Washing

In principle, all people should wash their hands with soap at critical times, namely: after using the toilet/latrine, before eating, before preparing food, after cleaning a patient, before feeding a baby, and before giving medication. Although some of the respondents (caregivers and patients) indicated that they usually wash hands after using the toilet, there were no visible water vessels or soap near the latrines in most houses. Some of the caregivers and patients who were interviewed had reported having vessels they were using for hand washing which they kept in their houses, but they had difficulty locating the vessels when we asked them to show them to the team. One blind respondent said he locates the latrine by using the stick, and keeps his soap in the pockets of his trousers and a small jerry can of water near his chair. The hand-washing jerry can he showed was actually very dirty. Another caretaker led our interviewer to an empty jerry can to show the facilities used when washing hands. In Kamuli, one home had a tippy tap, but on close scrutiny, it appeared that the small jerry can that was being used had not been filled with water for a very long time, and there was no soap anywhere. The explanation was that the children always came and played with the water. In Kampala, some respondents said they use small water jerry cans which they put anywhere in the house. In most homes, both urban and rural, there were no hand-washing facilities near the latrine because the toilets were shared by so many families. Moreover, the consent of the landlords was crucial if there was need to put up hand-washing facilities near the toilet. It was the landlord who was likely to enforce this cooperation because he was the one who decided on any additional structures to be made. The landlord who was interviewed was not willing to incur additional costs to improve on the hygiene conditions of his tenants.

Although most respondents acknowledged that hand washing with soap is important, very few were able to have soap specifically for washing hands. For some, the soap was multi-purpose: for bathing, washing clothes, and cleaning utensils. For others, soap was a luxury of some sort, and hence reserved for washing after eating smelly food such as fish, or when their hands were extremely dirty. In Kampala's slum areas, some did not put soap outside of their house for fear that other people would take it. There were very remote indications about other alternatives to soap. Although some respondents said that there might be other people in the community who were using ash and paw-paw leaves, they themselves were not doing it. In Kamuli, there were complaints from some people that soap was too expensive to be used all the time when one was washing his/her hands. People did not wash hands before taking or administering medicine as well.

In this assessment, it was apparent that most people washed hands only when they were visibly dirty; mainly when they were coming back from working in their gardens. People also occasionally washed hands if they were going to have a meal, and very few mentioned that they would wash hands after using the toilets/latrines. More often than not, people did not use soap when hand washing. The depth and regularity of hand washing varied according to the situation. Due to exposure to information, the people in urban areas were more likely to wash hands. In Kampala, children were often reminded that they should wash hands after visiting the toilet/latrine. In both urban and rural areas, people inevitably washed hands only if they appeared dirty.

2.4.2 Protection of Caregivers against Infections

For the context of this review, "protection" is intended to indicate that whenever people are handling body fluids (while nursing a sick person), they need to use gloves or any other devices (such as covering hands with plastic bags) that prevent them from getting in contact with the patient's fluids. Protection is particularly necessary when handling blood, pus, and feces from the sick person. From the interviews with community-based care providers, the patients, and family-based caregivers, it appears that this kind of protection still remains a big challenge. Most of the caregivers had direct contact with the fluids from their patients. Although some were conscious of the dangers, they claimed that they did not use gloves because it sends a message to the patient that they are "abandoning their own." This was common among the mothers of the patients.

> *"Mothers, when looking after their biological children do not protect themselves because they feel by using gloves it is a detachment from their own blood children."* ***(Hospice Makindye FGD)***
>
> *"Some carers don't protect themselves especially when taking care of their beloved children."* ***(Post Test Club group Kamuli FGD)***

Also among these caregivers, there were those who feared that if they used gloves, their patients would think they were discriminating against them. Other caregivers were simply unsuspecting since they had not been told about the HIV/AIDS status of their clients and were not aware of the risk of contracting non-HIV related illnesses from bodily fluids.

> *"…. you find that some patients clean wounds with bare hands. Patients cannot afford to buy gloves and even when we give them gloves, they always don't get enough [to last them] for a reasonable time."* ***(Hospice Makindye FGD)***

Others simply could not afford gloves to protect themselves. One of the child caregivers confessed that she uses bare hands to clean her mother's body. There were few caregivers who tried to protect themselves. Very few used gloves, and others had just improvised by using *buvera* (small plastic bags meant to keep sugar) for protecting their hands. Using buvera was particularly challenging, especially when it came to washing clothes. Most times, they were too small or got torn, and water often passed through and got in contact with the body of the person washing the clothes. The consequence was that sometimes, the linen was not washed properly, and this posed a risk to the patients and their caregivers. The beddings and clothes of the bedridden patients were very dirty. In many cases, they had changed color due to inadequate washing. Heavy duty gloves would be ideal and sustainable, but most of the respondents could not afford them. Use of buvera may not be effective, but it still remains the only option.

2.4.3 Feces Management

The ideal scenario is to get the patient to a latrine where he/she defecates properly and, afterwards, both the patient and the caregiver wash their hands at adequate hand-washing facilities. In case the patient is bedridden and relieves him/herself in bed, the feces must be removed as quickly and as safely as possible (that is, protecting the caregiver, patient, and the rest of the family), and be thrown in the latrine or buried somewhere in the soil when there is no latrine available.

For Kampala (urban), the following issues emerged:

- *Both caregivers and their patients did not like having feces around them. Most of the respondents said they threw the feces into latrines when they had access to one. In most cases, the families' access to a latrine dictates actions taken about the feces. The following were typical scenarios of feces management in the urban areas.*
- *There were those families without toilets/latrines who were often at mercy of neighbors that may or may not allow them to use their toilets. Those without sympathy for neighbors defecated in the nearby bushes or empty spaces behind houses. Others defecated in buckets/basins and disposed of the feces at night in the nearby bushes or empty spaces. Others simply abandoned the buckets with feces somewhere along the way.*
- *In these slums, there were many children who were left unattended and defecated anywhere they pleased. In congested areas of the town, children defecated anywhere and the feces were often not taken care of. Some of the people we interviewed had children's feces scattered in the compounds. Some of the respondents still believed children's feces were not as dangerous as those of adults.*
- *There were some families who had access to the latrines, but most of the latrines were in terrible condition. It was hard for very sick people to use them, even when they were available, since some latrines were crumbling and a weak person could injure themselves when trying to use these unstable structures.*
- *Because the majority of the families in the poor section of the urban areas were sharing latrines, there was no sense of responsibility in terms of cleaning and provision of washing facilities and soap near the latrines. Access to the latrines also depended on what the landlord wanted to give his tenants. If the rent was low, the landlords were not keen about providing for the tenants in terms of quality sanitation facilities.*

In Kamuli (rural):

- *Most of the people had access to latrines;*
- *Most latrines were in bad condition: too small and some without shutters or doors. For others, walls were almost collapsing or did not have super structures;*
- *Animal feces were common in the compounds and most of it was not cleared away immediately;*
- *Children's feces were not thrown in the latrines;*
- *Most of the toilets were not covered and it was common to find flies all over the place;*
- *Flies were also visible on unwashed utensils lying on dish racks in the compounds;*
- *A few of the people who had no toilets and buried the feces in the gardens near their homes.*

Patients who were bedridden found it difficult to defecate and urinate without soiling themselves and/or the bed. The findings indicate that most of the bedridden patients were defecating while they were sleeping and had to be assisted in removing the feces from their beds. It was reported that caregivers removed the clothes and either soaked them or simply dried them in the sun without washing them before reuse. Some caregivers simply removed the sheets and kept them somewhere for the very same patients to wash when they got better. Some of the caregivers who washed the clothes and beddings soaked with feces touched them directly. There were only a few caregivers who used gloves. Others used buvera which were too soft and slippery for washing. In such situations, the caregivers ended up not washing the linen properly because they did not have the necessary implements to do so and also because they feared getting infected.

2.4.3.1 Fecal Disposal Mechanisms

These mechanisms varied between the urban and rural conditions. In urban areas, there were cases where people had no latrines and the common fecal disposal mechanism was to throw feces anywhere away from the house. In Reach Out Mbuya, it was reported that many people in Kinawataka zone were throwing feces along the railway line and nearby bushes. Others simply put the feces on the neighbors' entrance doors.

"In some places, especially the slums, there were very few latrines, which were shared, and maintaining such latrines to the proper hygiene was like a dream. Even if the carers tried to clean, other people brought more dirt shortly. Some latrines were dirty and not even cleaned, some of them were soiled with feces on top, and there was no way someone could use them. In these cases, people dumped feces in drainage channels, along the roads, and in the bushes near homes." **(Nsambya Home Care FGD)**

"Most clients stayed in slums. These had no latrines, and where they existed, the latrines were shared by very many people. This made and complicated the hygiene situation of our clients in these areas. People defecated along the railway line. This was mainly in places of Kinawataka and Acholi quarters. The situation was worse in Kinawataka where people with no latrines at all used the railway line. In some other instances, people defecated near entrance doors of our clients' and the neighbors' houses." **(Reach Out Mbuya FGD)**

"Some people believed that when women sit on top of latrines, they cannot produce children. This was especially in Acholi quarter; in these areas women would not use latrines even when they were available. In this case, buvera were used to defecate on and were later buried in the soil or even dumped in latrines." **(Reach Out Mbuya FGD)**

Where there was vacant land, people attempted to bury the feces in the soil. There were a few cases of people who buried feces in Kampala. In Kamuli, most of the people who did not have toilets instead dug holes in the soil, where they buried their feces.

> *"Some of our patients in places where no latrines exist dig short holes nearby and that's where they bury the feces. Our people use latrines; some dig holes as others use uncovered latrines."* ***(AEGY Kamuli FGD)***

Some people just dumped feces wherever they could:

> *"We don't have a rubbish pit, though we have a particular place where we dump rubbish, and in the whole process of dumping rubbish, some people end up dumping their feces which increases the stench in the area. Pit latrines would be the best option for feces disposal, but due to the overwhelming number of tenants, it is not easy to get everyone to follow what is required of him/her.* ***(Patient-Reach Out Mbuya IDI)***

Some families, both in the rural and urban areas, had latrines which were in dangerous conditions. This forced them to defecate outside the toilets. Some of these latrines were difficult for the people who were very sick and sometimes found difficulties in climbing the high ladders, or were too weak to avoid falling in the pit.

> *"Our toilet is in a dangerous situation. First of all, it is not sheltered fully; both the roof and the walls are crumbling. Even the floor is not fully done because one can see the feces inside and flies keep on going in and out.* ***(Child Caregiver-Kamuli IDI)***

Even where the latrines were well-built and appeared to be strong, very weak mobile patients could not easily use them. They could not easily squat and risked falling down at any time. Some of the patients were not strong enough to run to the toilets. When they had diarrhea, they ended up defecating on themselves while still on their way to the toilet. These latrines lacked sick-friendly structures where the patients could hold on to remain stable when defecating, as seen in **Figure 1** below**.**

Figure 1: One of the Latrines Used by Patients

2.4.3.2 Management of Feces around Bedridden Patients

Management of feces around a bedridden person was very similar in both urban and rural areas. Care for the bedridden patients was largely provided by family members who were either siblings or offspring, and parents (mostly mothers) of the sick persons. In both urban and rural areas, there were situations of patients with no family members to look after them, and these patients were usually at the mercy of the neighbors and community volunteers who checked on them sporadically. In most cases, the support given by volunteers was superficial because they were not regular visitors, hence the deserted patients stayed in soiled clothes and beddings for a long time.

In both rural and urban areas, some bedridden patients did not have facilities around their beds to defecate. Some defecated in the beddings which caregivers later came and removed. After the beddings were removed, caregivers washed the linen with water and soap; others used warm water supposedly to kill the germs, and yet others simply washed and poured the water in the compound or the bathroom. Others would just put the beddings soiled with feces in the sunshine to dry. After they were dry, they returned them (without being washed) for the patients to use. This was very risky considering that the germs remained on the linen which the patient would touch, and then eat food or take medication before washing their hands.

Apparently, diarrhea was not a major problem with most of the bedridden patients, as it was reported that some of the patients did not have an appetite. They ate so little and this minimized the frequency of defecation. Others feared eating because they did not want to inconvenience the already disgusted caregivers. On the extreme end, and as reported in the FGDs, caregivers denied the patients food and drinks for fear of defecating and urinating in the bed which would increase the carers' burden of washing.

2.4.3.3 Fecal Disposal Mechanisms of Bedridden Patients

There were several feces disposal mechanisms mentioned which were used to manage and get rid of the feces. In both rural and urban areas, it was reported that the bedridden patients defecated in buckets, basins, and used *Nomi* (laundry soap) containers, on which they put a cover. One patient in Kamuli was actually defecating in a musical drum. The drum was placed in the bedroom of the patient. To make it easy for removing feces, they would put in large leaves or banana fibers. After the patient had defecated, they lifted the leaves together with the feces which they took and disposed of. According to them, the drum remained clean. They would bring fresh leaves again and place them in the drum for the next use. There were reported instances where some carers used rags as nappies to prevent the patients from defecating in their beddings. They later came and removed the soiled linen. If there was a latrine available, especially in rural areas, they disposed of the feces immediately. In Kampala, if there was no latrine, they waited for darkness so that they could throw the feces in the nearby bushes or behind the house. Here, the risk was that the containers in which the patients defecated were not cleaned sufficiently with soap or any other detergents. They were often unbearably smelly. Some of the people in Kampala had reached an extent of throwing away the Nomi containers with the feces as indicated by **Figure 2** on the following page.

Figure 2: A Nomi Bucket Used for Defecating

"In many cases for bedridden patients, the caretakers help the patients to defecate in basins and use another to cover the used one. Some of them used pampers and other pieces of clothes that were tied around the patient to gather the feces while those who did not have latrines used buvera that were later disposed of in the roads." ***(Nsambya Home Care FGD)***

"Some have opened a hole in the bed and another in the ground, so when the patient is defecating, feces pass through the bed to the hole below. When the caretakers are around, they cover this hole for fear of smelling, but when they are not around, they leave it open so that at any time, the patient just defecates. Some caretakers use buvera in these holes and some dispose of it in the latrine while others dispose of it anywhere near garbage disposal bins." ***(Hospice Makindye FGD)***

"People put kavera [large pieces of plastic] on the bed to protect the mattress; if soiled, some people just dry the kavera under the sun. Others turn the mattress upside-down. Yet, other people wait for the patient until he/she dies and dump the mattress or wash it. Others use a wet cloth to clean the soiled part. Sometimes people dry it on the ground." ***(NACWOLA Kamuli FGD)***

"Some ease themselves on their beddings; some use Nomi buckets, basins, buvera, old clothes. Others also use fresh banana leaves and newspapers, and some caretakers wrap the patients with old clothes." ***(AEGY Kamuli FGD)***

"During the time when Peter was completely down/bedridden, he would not even get his potty to help himself. His brother bought him a special chair. This chair is very comfortable with cushions in the sides and a hole in the middle. He says he would be lifted into the chair and he would defecate and even urinate. Meanwhile below the chair would be a bucket where all the urine and the feces would be collected. He thus would defecate while seated comfortably. Thereafter the bucket would be picked up and the feces would be taken out immediately." ***(Patient-Reach Out Mbuya IDI)***

There were situations where patients defecated in the beddings which were removed by the caregivers and washed. All the bedridden patients who were interviewed did not have bed pans or potties. Although caregivers were handling feces, when cleaning the patients, there were no hand-washing facilities placed near the ones who were bedridden. To clean off feces from the patients, the caregivers mainly used special soft leaves, rags, and sometimes papers torn from used exercise books and newspapers.

The way the feces were managed also depended on the condition of the patients. There were patients who were too sick to talk or even clean themselves. Most of these patients defecated in their beddings. One of the caregivers told us that she only waits for the feces to smell for her to know that the patient has defecated. In such cases, some of the caregivers used polythene sheets in place of mackintosh to cover the mattress to prevent it from soiling. There were others, however, who left the patients simply to defecate on the mattresses. Consequently, the mattresses and other beddings got old very quickly and it was difficult to get replacements. Some of the mattresses appeared to be very dirty.

Although the caregivers tried all they could to look after their patients, they were often involved in risky practices. For instance, most of them were touching the feces directly, and they still were not washing their hands immediately. Others administered medicines and gave food to the patients before they washed their hands. Some of the rooms where the patients were sleeping were often filled with the unbearable stench of urine and feces. However, there were other homes with organized rooms where patients slept in clean rooms and beddings. These were the homes which fell into the category of a higher social class. There were two bedridden patients identified by Hospice Africa in Uganda who were apart of this category. The patients were staying in large houses with adequate water facilities. They were also sleeping in large rooms with decent beddings.

2.4.4 Safe Water Practices

Safe water is a critical issue for individuals with HIV/AIDS. Safe water issues are diverse and this review mainly focused on the methods used to treat drinking water and how it is stored to ensure that it remains safe.

The sources of water differed by urban and rural contexts. In Kampala (urban), tap water was commonly used. Many people were however using water from both unprotected and protected springs commonly found in the slum areas. In Kamuli (rural), the main sources of water mostly included boreholes, streams, rainwater, and water from ponds. In Kampala, the main means of purifying water was boiling, except for a few people who had PSI[1] water vessels and purification tablets in the form of WaterGuard or those from the Africa Foundation for Development (AFFORD) known AquaSafe. People under review in Kampala mostly used charcoal for boiling water, and to a lesser extent, some used firewood and electricity. In all situations, it was expensive to have water boiled. In Kamuli, boiling of water had not been a common practice, especially if the water was drawn from a borehole or it was rainwater. People believed it was safe to drink. Streams and taps would be the sources from which they would decide to boil water. Firewood for boiling water was also not easy to obtain for most families. Other means of purification included adding ash to the water and leaving it to settle for some time. The following comments from FGDs demonstrate the participants' views of what goes on in the community relating to water treatment.

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[1] These are special white jerry cans with a cover and spigot to release water. The cover is only removed when they are either cleaning the jerry can or adding more water. Water from the jerry can is served using a spigot. This is done to keep the container closed all the time in order to minimize contamination. So far, these jerry cans have been part of the package for people who are HIV-positive to help them improve on clean water consumption. These supplies were provided by The AIDS Support Organization (TASO), Joint Clinical Research Center (JCRC), and Population Services International (PSI).

“There are some who do not treat water at all and they do not boil either. People believe that water from protected springs is safe enough for drinking. Rainwater is believed to be clean. This is so because it comes from the sky. Such water is just kept and drunk right away. Most people keep their water in pots and even in jerry cans, especially drinking water.” ***(Reach Out Mbuya FGD)***

“Very few households boil water. They believe water from the boreholes is clean (when you boil water it loses taste). When water is fetched from the boreholes and is covered, then it is clean and safe to drink.” ***(Post Test Club Kamuli FGD)***

“Most people do not boil water. Our water is clean. Borehole water is also clean and does not require boiling. People have used ground water and have not fallen sick or died so why boil water? Some people think WaterGuard is very strong like jik (bleach) and can affect someone’s health. ‘It can wash like jik.’ Even children don’t like the smell of water treated by WaterGuard – people don’t know the effects of WaterGuard; they are blind to it.” ***(NACWOLA Kamuli FGD)***

In Kampala, some children were seen drinking water directly from unprotected springs as shown in **Figure 3** below. There were certain beliefs about the safety of drinking water that influenced the water consumption behaviors. For instance, people may have had narrow-neck vessels with lids, but continued to put fill them with water that was not treated.

Figure 3: Children Drinking Water Directly from a Spring and Filling Jerry Cans at the Spring

“Some clients have WaterGuard for treating their water. Others do boil the water. Some people use ash. They mix ash in water and then serve the water afterwards.” ***(Post Test Club Kamuli FGD)***

“The patient received a water vessel (in fact I saw two of them) together with WaterGuard because water treated with chemicals smells bad to her. At the time of our visitation, she had water, which she had boiled in a kettle and was waiting for it to cool down, and she pours it in a 5-liter jerry can that is white with a red lid.” ***(Patient-Reach Out Mbuya IDI)***

“We get water from the tap which they buy at 100/= per jerry can. When we are preparing water for drinking, we treat it using WaterGuard and keep it in a water vessel which I for one received while I was still with the Reach Out Mbuya program. However, sometimes I take water that has not been treated in any way. I believe water from the tap comes from underground and therefore it is very clean. I just take it.” ***(Client-Reach Out Mbuya IDI)***

It was also evident that some people still regarded water treatment with chemicals as potentially dangerous. Some did not like the smell of the chemically-treated water, while others feared that such water could be dangerous to their health.

Some people were using water vessels from PSI and TASO (which are a different color from those available in the marketplace) but a lot of stigma surrounded the water vessels given out to PLWHA. They thought the vessels were meant to handle water of the HIV-positive people and whoever had them were thought to have AIDS. Yet others thought that there must be some hidden agenda by those who manufactured the chemicals for purifying water. Because of this belief, the use of water vessels and chlorinating chemicals was minimal.

> *"Some people have refused to use the water vessel because of stigma as it's associated with AIDS, yet others don't like using the WaterGuard because it smells; some people prefer boiling water."* ***(Nsambya Home Care FGD)***
>
> *"The problem is that people believe that HIV/AIDS was manufactured by American people and yet some think/know that the water vessels are provided by the same people. There is thus tendency to avoid the water vessels. Some clients say they are allergic to WaterGuard and we advise them to boil their water instead. Some doctors are against the use of WaterGuard. People say they were told, by doctors, not to take WaterGuard-treated water."* ***(Reach Out Mbuya FGD)***
>
> *"There is a lot of stigma that surrounds the water vessels and all people think they are just meant for the HIV-positive people. Because of this, whoever has it is said to have AIDS. Our clients now hide them and do not put them in the place where they can be easily seen. Some people are allergic to WaterGuard-treated water. Some of the people don't treat water at all and just drink it as it is."* ***(Reach Out Mbuya FGD)***

Because of such stigma, some patients were hiding the water vessels. Others simply threw them out along the way or even in the compounds of the institutions which were supplying them, such as Hospice Africa. There are beliefs among some communities that boiled water does not taste good. Besides this, people claim that they have experienced taking unboiled water and do not fall sick. As a matter of fact, people lacked information on the rationale of using the vessels and putting treated water in these vessels.

> *"Local belief: amadi amafumbe gaku tiga gamuka (meaning boiled water) does not taste natural. People have taken unboiled water and have not fallen sick."* ***(AEGY Kamuli FGD)***

Despite some peoples' negative perceptions about WaterGuard and the water vessels supplied by the HBC organizations, there were a few respondents who expressed the need for the WaterGuard and vessels. Actually, some respondents complained that they have been denied the chances to obtain these items.

> *"For the case of the water vessels, it is only given to those patients who are already put on ARVs. How I wish I can get it (water vessel) plus a mosquito net and beddings, but the health workers keep telling me that I have not yet reached the level of getting that vessel. The water I boil gets dirty due to improper containers, as kids get water out by putting their hands in my water pot."* ***(Patient in Nankulyaku, Kulingo Zone-Kamuli IDI)***

Adherence to safe drinking-water use remains a challenge to most homes. In both Kampala and Kamuli, some respondents indicated that they would be willing to boil water for drinking, but they were often handicapped by lack of fuel. Apart from the local beliefs that the WaterGuard negatively affects the taste of the water, people also complained about the related costs.

> *"Very few use WaterGuard and there are very few who have water vessels. Others say WaterGuard is expensive; 500=/ per pack. The volunteers themselves don't use WaterGuard because it is expensive."* ***(Post Test Club Kamuli FGD)***

In Kamuli, almost all of the respondents (except those using water vessels and WaterGuards from TASO) confessed that they drank borehole water without treating it. They were told by those who constructed boreholes that water from the borehole was safe to drink. Most of these people also kept the water in pots with wide necks. It was possible that the water would be contaminated due to poor handling.

> *"The respondent said they use a cup to draw water from the pot for drinking and use the same cup to drink. The cup is then placed on the plate that covers the pot for another person to use to drink water, but it isn't washed first."* ***(Male Caregiver-Kamuli IDI)***

2.4.5 Managing Menstrual Blood

The topic of menstrual blood and bedridden patients was received with astonishment, especially when it was brought out during FGDs. Community-based care providers were surprised to find that it was considered an issue in the hygiene of PLWHA. The discussion of menstrual blood became contentious during the discussions. Some argued that it was not possible for very sick women (bedridden, for that matter) to menstruate. On the other hand, some of the caregivers, based on their own experience and those of their clients, argued that menstruation among the bedridden patients did, in fact, occur. They narrated how they were going about handling it.

Despite these disagreements, all community-based care providers agreed that menstrual blood among the bedridden patients had not been on their agenda. The challenge was that menstruation was taken as a confidential and private issue and hence some patients did not want to show that they were menstruating, and would prefer to handle the blood on their own by padding and disposing of the pads themselves.

> *"When I was sick, I would use rags to pad myself. I would then hide them under my bed and wash them when I would get some energy and when nobody was home. I was weak but could try whenever I got energy and would dry them under the bed. Menstruation issues are private and personal and should be done in private."* ***(Patient-Reach Out Mbuya IDI)***

Some of them were also conscious that they could easily infect those caring for them. One woman noted that she did not allow her children to touch her blood not only for fear of infecting them, but also because in the local culture, children were not supposed to touch the blood of their mothers.

> *"I can never allow my children to touch my blood. Such blood can infect an innocent person. I am their mother. It would not be good for them to touch my blood."* ***(Patient-Reach Out Mbuya IDI)***

Female respondents who were able to help themselves emphasized that they preferred to be left alone during menstruation. Some of the child caregivers were not willing to touch their sick mothers' blood not necessarily because they were sick, but because they felt that blood, and more so blood from the private parts, was sensitive and a private affair.

> *"It is hard to offer the patient any assistance during her menstrual periods. She takes it personal and private. I cannot touch another person's blood."* ***(Child Caregiver-Kamuli)***

One critical risk was when the patients could not move themselves to get the padding materials and clean themselves; they did not remove the blood and risked getting other infections. There were also some patients who were too bedridden to detect whether they were on their periods and the whole responsibility was shouldered by caregivers.

2.5 Barriers to Hygiene Care of PLWHA

From the discussions with the community-based care providers, caregivers, patients, and from observations, there are critical barriers to the support of the PLWHA. Commonly-mentioned topics included poverty, stigma, poor sanitation facilities, conflicts between the patients and their carers, abandoned patients, and people's perceptions.

2.5.1 Poverty

This is a common phenomenon both in urban and rural areas. Poverty-stricken clients and their caregivers could not afford basic requirements, such as food, medicine, house rent (mostly for those in Kampala), hygiene-promoting commodities, and water. Others lacked toilet/latrine facilities and water storage containers.

> *"A client has been chased from the home for not paying rent and generally, he was helpless .A community member offered her garage to stay in for a month, and then they were forced to sell the bed at 20,000/= to buy food for the family. In such cases, there are no solutions."* (***Reach Out Mbuya FGD***)

2.5.2 Stigma

Stigma was manifested in many ways. There were patients who never wanted their family members to know that they were suffering from HIV/AIDS. They did not disclose this information to their caregivers. There were situations whereby after knowing that their patients had AIDS, some caregivers started getting worried and tried to minimize contact with patients. The worst scenario was when some patients were often abandoned by their relatives as a result.

> *"She complained bitterly that her own brothers abandoned her and have never taken time to come and visit her. She explained how they kept blaming her, saying that it was her fault that she had been infected. The patient added on that, the Mbuya CATTS have also helped to take care of her and she said that their support had been shown through counseling her every time. She got regular visits which she said had given her hope because now she knew that though some people had abandoned her, there were also a lot more people who care deeply about her well-being."* (***Patient-Reach Out Mbuya IDI***)

Indeed, stigma is a big issue even when the caregivers sympathize with their patients. It was a common problem that kept emerging during the interviews and TIPS in Kamuli. One of the respondents was a very sick man who had decided to go and live with his sister, leaving his wife and children behind. He wanted to join TASO and he did not want anyone from his family or neighbors to know that he was going for HIV/AIDS-related medication. Although he had taken refuge with his sister's family, the sister who was looking after him was very much worried that the patient would infect her own family members. Because of this fear, and despite him being very weak, the patient was washing his own clothes and no one was willing to touch his things. Stigma affected the level of support the patients received, especially relating to hygiene, whereby some of the caregivers were reluctant to clean their patients. Patients also enforced this stigma by being too sensitive to some practices, such as using gloves. Some patients felt uneasy when someone touched them with gloves. To avoid this feeling, and as will be discussed later, some carers (especially mothers), took risks and touched their patients' blood and other fluids. It is therefore important to understand why there is stigma, especially as a key aspect in protection against infection of HIV. Also, it is thus crucial to address the question of protection against infection. In other words, how can carers provide adequate hygiene care without becoming infected?

2.5.3 Poor Sanitation Facilities

Poor sanitation facilities were a big problem especially in the urban areas. The extreme part of this challenge is where people, especially in urban slums, did not have an idea of where to throw their feces. Details are given in this section on the context of urban areas. In Kamuli, the challenge was with latrines which were not in good condition, thus inhibiting easy utilization, especially by those who were very sick.

2.5.4 Conflicts Between the Patients and Their Carers

There were diverse categories of the patients' conditions, and these variations often affected the way they were cared for, their washing habits, and other behaviors that affect hygiene. It was important that both the patient and caregiver cooperate with certain practices. Patients should always try to be clean if they were able to do certain things and they should respect and appreciate their attendants' efforts. The problem of conflict between patients and their caregivers was mentioned during both IDIs and FGDs. Some of the caregivers indicated that their patients were a burden. Despite the level of effort by caregivers, some patients were unappreciative. On another hand, patients complained a lot about being mishandled. From the patients' perspective, they were not getting sufficient help as expected. From the interviews, it was apparent that cooperation was often lacking as some of the patients were rude and this attitude put off the caregivers. Some patients were angry with caregivers for using gloves or buvera to touch them. To them, this was a signal that they were being stigmatized and worst still, using gloves was a sign of disgust as far as the patients were concerned. Where such conflict seemed to be an issue, cooperation was often difficult and this affected the efforts to improve hygiene on both sides. Caregivers and patients alike faced were emotional challenges as well. There were many reasons for such conflicts and most of them were stigma-related. Some of the family carers, after knowing that their patients were HIV-positive, started blaming them for bringing misfortune to the homes.

> *"Some carers blame the patients, especially the grandparents, saying that they infected their children."* (**Nsambya Home Care FGD)**

For some cases it was almost obvious that the caregivers were tired and as a result of this, patients were neglected. The problem of patients being abandoned was commonly highlighted.

> *“Caregivers are not always there, and what we teach them is not what they do. For example, they keep urine for two days without pouring it away, leftovers stay for two days, they don’t sweep, and in most cases you will see small insects moving around. They leave banana peelings for days without throwing them away.”* ***(Hospice Makindye FGD)***

On the other hand, some carers blamed their patients for demanding too much and for not being cooperative. It was almost obvious from carers’ comments that they were already disgusted with their patients. There were some female carers who felt that caring for the sick took too much time and yet they had to work hard to feed the entire family, which left them exhausted. Conflicts between the patients and their caregivers had wide implications for the care and support the patients got, and in most cases it often led to neglect. In Kampala, there were many such cases of patients abandoned by their partners (male, female) and relatives.

2.5.5 Gender Issues

Both male and female caregivers were interviewed. Variations were noted between females and males in the way that they handled patients and the way they felt about the responsibility of care. Male caregivers were often shy about bathing female patients. Some often called upon their female relatives to assist them, but in such cases, help was not always available. This factor affected the frequency of cleaning up the patients. Male child caregivers often called upon their aunts (or other close female relatives) to come and help when it came to sensitive activities such as bathing patients. Male caregivers (both adults and children) were reluctant to wash linen soiled by their female patients. Calling other people from elsewhere also meant that the cleaning had to be delayed, which was particularly risky since it left the patient in unsanitary conditions.

There were problems of power relations as well. Sick males often coerced their female carers. They commanded them instead of asking them for help. In such cases, some carers did some of the cleaning unwillingly. Some patients preferred that their carers be of the same sex because they thought these carers would understand them more easily. One of the patients who were interviewed in Kamuli, for instance, preferred to have his grandson look after him instead of his wife. Likewise, male carers found it easier to look after male patients such as their uncles, fathers, brothers, or any other male relatives.

Child Caregivers

There were patients who were being cared for by very young children. Some of the children were forced to leave school to attend to their ailing parents. The challenge was that some of the children combined school and providing care for very sick adults. They prepared everything for the patient in the morning and cleaned up later in the evenings. Some of the children had to drop out of school because they had to look after the patients or because their parents were too sick to afford the school fees. Also, some children did not want to touch their mothers’ blood during menstruation. For instance, a young girl referring to her own mother, said that she could not assist her mother when she was on her periods because it is private and personal. “*I could never touch another person’s blood.*” In most of these situations, the patients tried to handle the problems themselves but sometimes had difficulties. The other challenge was that the children may not be able to provide all the required care.

> *"The carer stays in his own house which is near the patient's home. The patient stays alone during the day and the son keeps checking on her to give her medicine which she usually takes in the afternoon. The patient cooks lunch for herself except at night when the granddaughter returns from school and takes over the household chores. In cases where the patient is the carer's mother, culturally there are some activities he is not supposed to do and therefore other people come and take over. He said such activities include bathing his mother, or anything that would require his mother to be naked. According to the respondent, when the patient is very weak, that is when the patient's daughter, sister and the respondent's wife come in to help. When she feels better, they all go back to their home, leaving the patient with the granddaughter and the son (respondent) to care for her."* ***(Male Caregiver-Kamuli IDI)***
>
> *"The respondent's health was very poor in 2006 and he was bedridden for almost the whole year; he could not manage the situation and the kids could not look after him well. He then called a sister to come in and provide some help. It was not long, however, until the sister abandoned him and went away complaining that she was disgusted with treating a poor person. After the sister had gone, then the children took on the care of their father."* ***(Client-Reach Out Mbuya IDI)***
>
> *"Barbra entirely relies on her children for all the support she needs. She said she had to ask her second born to drop out of school and take care of the baby when she was not feeling strong enough to do everything herself. No one has come in to help from either her late husband's relatives or her own relatives because she was born with four brothers who are fully engaged in their own lives and families."* ***(Patient-Reach Out Mbuya IDI)***

Some children knew very safe hygiene practices, critical times to wash hands, and what to do with the feces when there was no toilet. Some children discussed confidently some of the dangers associated with feces if they were not properly disposed of. Some children were conscious of the risk involved in touching their mothers' menstrual blood. As discussed earlier, one of the girls of about 18 told us that she could not touch her mother's blood. However, there were some children who were unsuspecting and handled their patients' blood and feces without any protection this was more so when the patients did not disclose that they were HIV-positive). In Kamuli, most of the patients interviewed had not shared their status with their caregivers who kept referring to the ailments as strange.

2.6 Motivators

Motivating factors for current hygiene practices were diverse and varied from problem to problem. However, it can be said that generally, most of the families would make an effort to clean their patients and give them clean food and water because they wanted them to get better. They also knew that when their patients became well, the burden of care would be reduced.

One of the most apparent motivators was the need to protect themselves against infection (especially HIV) by their patients. There were some respondents who were aware that their patients were suffering from HIV and feared that while nursing the patient, they would contract the disease. They were therefore willing to listen to any measures that would protect them. Some of them were already using gloves and others had improvised with buvera to avoid contact with the patient's fluids. Some of the children indicated that their mothers' menstrual blood was not safe to be touched with bare hands.

> ***Positive living:***
> *"This is the simplest way in which people/patients can change behavior. It makes people do anything in order to remain healthy."* ***(Reach Out Mbuya FGD)***

Caregivers would be willing to engage in those activities that would reduce the burden of care. For instance, they wanted to have facilities that would make feces management for the bedridden less messy. They were interested in those facilities and would be willing to adopt those behaviors which would make them and other family members less vulnerable to infection without compromising care, such as use of gloves when handling the patients. Without being told, some people had improvised using buvera as glove substitutes to protect themselves. Some of the sick people were motivated by the concept of "not infecting their own". Carers felt more confident and secure when using gloves, enabling them to do more intensive washing of linen because they felt safe. Another motivator was that people obviously did not like feces around them. They wanted to avoid bad smell that made them uncomfortable and besides this matter, they wanted to avoid becoming sick from the stench of urine and feces.

CHAPTER THREE

DISCUSSION

Although the quality of care is apparently crucial in HIV/AIDS management, hygiene is still an integral part of the effort needed, as this assessment has demonstrated. The quality of hygiene among HIV/AIDS patients and the people around them is still a big concern. This is due to the fact that current efforts are less specific in relation to hygiene management. Considering the various practices assessed, there were still critical gaps.

People did not always wash hands at all critical times (before eating, after using the toilet/latrine, before taking medicine, after cleaning the patient, before preparing food, and before feeding a baby). They usually washed their hands when they appeared to be dirty. The use of soap was not considered important in hand washing and only seemed necessary when there was dirt or bad smell. To some extent, the cost of soap could be a factor, but also peoples' understanding of the role of soap was a greater issue. Most of the bedridden patients were not staying in clean environments. There were no hand-washing facilities, such as water vessels, near the patient to enhance regular cleaning. Lack of such amenities meant that both the patient and caregiver would not easily wash hands at critical times, making them vulnerable to infections. Simple technologies to help reduce the amount of water used for hand washing, such a tippy-taps, were not being used.

There were still challenges regarding the disposal of feces, especially for those who did not have their own latrines or toilets. In the Kamuli (rural), for those who did not have toilets (because they did not have access to land), it was easier to bury feces. In Kampala (urban), the complexity of the issue was affected by many factors, including lack of space to bury the feces and the fact that many of the poor sections of the population could not afford services for feces disposal. There were only a few families who were able to negotiate with the neighbors to allow them deposit the feces in their neighbors' latrines.

Some mobile patients were finding difficulties using pit latrines due to the unfavorable structures of these facilities. They were meant for strong people who could stand harsh conditions. They had a difficult time using them and often defecated on themselves or along the way to the latrine because they could not get there fast enough. They needed different forms of support (such as crutches) to get to the latrines easily and support mechanisms (such as ropes or handles) to steady themselves to defecate easily.

There were still problems of washing the clothes and beddings of patients, such as not washing them thoroughly and not using soap. Some of the caregivers were using bare hands to wash the soiled linen. Some patients remained in feces after defecating for different reasons. A few patients had nobody to look after them at times because their caregivers were overwhelmed with work or they were simply disgusted with the feces. Patients left in beddings with their own feces lost their dignity and self-esteem. They became desperate and hated those who were supposed to assist them. When the feces were not disposed of immediately, the situation became pathetic and caregivers found it more difficult to care for the patients; this put the patients at risk of further infection.

The assessment also demonstrated that the caregiver’s well-being was at stake. Most of the caregivers were at risk of being infected due to unsafe handling of HIV/AIDS patients through direct contact with blood and cleaning pus from the wounds. Most of the caregivers, especially children and mothers of the patients, were not using gloves when handling feces. Some caregivers were emotionally affected. They hated nursing their patients but had no choice but to continue, as was expected of them. This hatred induced caregivers’ negative behaviors toward those they cared for. Therefore, interventions that addressed the concerns of caregivers for their own health and well-being were crucial. There was need for some kind of support that would make the work of caregiving safer, easier, and less burdensome.

The problem of stigma continues to cause impediments in the care and support of PLWHA. There were two sides to this problem. One side was comprised of the patients who did not want their caregivers to know that they had HIV/AIDS. They continued to hide information about their medication, which affected their compliance since care providers may not follow up in case they become bedridden. Failure to disclose this critical information put the caregivers at risk since they sometimes did not take precautions. The other side was where the caregivers knew that the patient was HIV/AIDS-positive and started blaming them for the misfortune. This blame lead to conflict between the patient and caregiver, and self-denial on the side of the patient. In such cases, caregivers unnecessarily neglected the patients by denying them food. They also did not want to clean them properly and often wished them dead.

Child caregivers were often overwhelmed by the responsibilities. Some of them did not know what to do. They often engaged in risky practices such as touching the blood and other fluids of their patients. Some of the children were traumatized by the situation of their patients and this experience was likely to affect their future development. Engaging in care and support sometimes prevents children from continuing their education. Some children were already out of school because their parents were very ill. From the interviews, it was evident that many of the child caregivers were aware of the required hygiene practices (probably because they had learned them from school). However, it was often very difficult for them to practice what they knew partly due to lack of resources, and because they did not have the necessary powers to influence actions in the homes. They were still going by the orders of their patients/elders, making it difficult to influence the thoughts of the patients.

Factors Influencing Hygiene Practices

Key factors influencing hygiene practices were diverse, ranging from lack of knowledge, misinformation, economic conditions, and their own values and understanding of the information they had been receiving.

From the discussions with the various respondents in the review, it was evident that some of the community members lacked information about certain aspects of hygiene in general, and more specifically, HIV/AIDS-related hygiene. Many of the respondents did not know all the critical times to wash hands. The majority also did not know how to deal with feces of bedridden patients. Others did not know of alternative detergents to use for cleaning, such as ash. In Kamuli, people believed that borehole water was safe for drinking. Many of them did not know the risks of handling patients' blood and feces without any form of protection. Many of the caregivers did not consider menstrual blood to be a risk to both the patient's and caregiver's health. Although contact with menstrual blood was sometimes avoided for cultural reasons, it is crucial that people are given more information in these areas.

Economic conditions have been crucial for hampering hygiene promotion in many households. Some of the households were too poor to afford storage vessels and treatment tablets for drinking water. They could not afford appropriate gloves, so they improvised by using buvera (which were sometimes inadequate) when cleaning the patients. In Kampala, patients could not afford decent accommodations where conditions would promote good hygiene. Hence it is important to look at cheap options, that is, options which the majority of the households could afford. Most of the families could not afford to purchase gloves and mackintosh to keep patients from soiling their beds. These findings yielded a number of insights in relation to basic care for PLWHA in poverty-stricken conditions. It is crucial to consider the intersection between practices and the social, economic, and community realities. It is imperative that consideration is given to context-specific interventions when proposing and interpreting "small doable actions" for TIPS.

The assessment results also show a divergence between theory (ideal) and practice. Most of the people could not afford the recommended hygiene practices to the letter. For instance, not everybody could afford soap. Therefore, there is a need to be more flexible and come up with more affordable options. Instead of soap, people could use ash. There is also a need for flexibility and dialogue in a bid to come up with the most feasible interventions.

There is a need to empower the patient and caregiver to enhance a mutual relationship between the two. Such empowerment would include enforcing mutual respect, empowering the patients to do certain things for themselves where they can. Both patients and caregivers should share ideas on how to improve the situation.

There was a lot of uncertainty about management of feces around bedridden patients. Already, there were some low cost innovations to build on, such as using buckets and Nomi containers for the bedridden patients to defecate in. Although these innovations made a huge contribution to maintaining cleanliness around the bedridden patients, they needed modifications to make them more comfortable, convenient, and decent. The findings also showed that soiling of the bedsheets and simply drying them without washing was a common problem surrounding bedridden patients. After the sheets were dry, some of the feces would be shed off and the stench would be reduced, but not cleaned. This was mostly common among patients who had nobody to look after them. Such practice was not the appropriate disposal of feces and put both the patient and the caregiver at risk of getting diarrhea. In order to improve on feces management around bedridden patients, better supplies such as bed pans and potties should be made available for the patients to easily defecate in. It should also be noted that the bedridden patients were not all at the same level of severity. Some of the patients could hold on to something and help themselves, while others were unconscious and could not even tell whether they had defecated or not. Therefore, proposals need to be created that would accommodate for the diversity of the situations that patients are in. Economic conditions of the home would also dictate the kind of beddings used. Some of the families could not afford mattresses and were using mats and grass for the patients to sleep on. In these situations, it would require that the grass be replaced from time to time. Those who have mattresses could use mackintosh to cover the mattress. A piece of bedsheet should be placed over the mackintosh to stop the patient from getting bed sores due to the heat and friction caused by the mackintosh.

Low Cost Actions with a Potential to Improve Hygiene in Homes

In the left-hand column of the following table, there are summaries of the current practices that represented poor WASH behaviors that were identified during the FGDs and IDIs. The right-hand column provides a list of alternative actions that represent WASH behaviors that can be implemented to improve the conditions for the patients and their households. The “improved” behaviors in the right-hand column represent possible “small doable actions” that can be tested using TIPS to determine if the proposed “improved” behaviors are feasible and acceptable for caregivers, patients, and household members to implement.

Table 3: Current Practices List of the “Small Doable Actions” (Proposed “Improved” Behaviors Whose Feasibility and Acceptability Can Be Tried Out During TIPS)

A. HAND WASHING	
▪ **Caregivers do not wash hands with soap <u>before</u> providing food and giving medicine to the patients.**	▪ Place a hand-washing station (soap; water vessel/basin or tippy tap) so that caregivers can wash their hands. ▪ Encourage the caregiver to use a cleanser (soap, ash, sand, or paw-paw leaves) when washing hands and use running water to rinse.
▪ **Bedridden patient does not wash hands after defecating because there is no soap and water available.**	▪ Place a hand-washing station (soap; water vessel/basin or tippy tap) near the bedridden patient so that they can wash their hands. ▪ Teach the bedridden patient how to wash hands thoroughly with soap after defecating.
▪ **Mobile patient does not wash hands after defecating (no hand-washing facility is available).**	▪ Establish hand-washing station (water vessel/basin or tippy tap; soap or ash/sand/paw-paw leaves). ▪ Place a hand-washing station (soap, water vessel/basin, or tippy tap) nearby. ▪ In the urban area, the design and placement of the hand-washing facility will depend on the preference of the household (inside house, near latrine, etc.).
▪ **Soap is rarely used when washing hands after defecating. People only use soap to remove visible dirt and bad smell.**	▪ Use soap (or ash/sand/paw-paw leaves) and running water to rinse every time to wash hands after defecating. Possible suggestions: ▪ Obtain soap and cut soap into smaller pieces. Leave small chunk at hand-washing station. ▪ If no soap is available, use ash/sand/paw-paw leaves.
B. SAFE WATER	
▪ **Water is not treated before consumption.**	▪ Treat water with WaterGuard/Aqua Safe/PUR or boil it.
▪ **Water is stored in wide-neck containers with no lid.**	▪ Use narrow-neck container (jerry can, narrow-neck clay pot) to store water. ▪ Put a lid on the storage container.
▪ **Containers to transport**	▪ Wash inside and outside of containers at least once

/store water are dirty.	a week with soap or detergent.

C. SANITATION/FECES MANAGEMENT	
▪ **Some people throw feces in the neighborhood close to the house or near a neighbor’s entrance area (in crowded slums).**	▪ Households without a latrine should throw the feces in the public latrine or negotiate with a neighbor for permission to throw the feces in the neighbor’s latrine. ▪ If latrine access is not available, bury feces (if possible).
▪ **Some patients do not use latrines because they are not patient-friendly. Weak patients cannot easily use them because there are no support structures to assist the patients in squatting or standing back up.**	▪ Install rope, pole, and/or handle in the latrine to allow weak patient to squat or stand on their own more easily. ▪ Build a removable seat to use over the hole of the latrine. ▪ Provide walking sticks or crutches to get to the latrine and to use for leverage when squatting/standing.
▪ **Bedridden patient soils the bed, and the excrement remains in the sheet until someone removes it.**	▪ Use nappies made from old clothes and rags to absorb the feces. ▪ Use potty or bed pan for collection of feces for bedridden patients. Two possible options for the bed pans: ▪ A middle-size jerry can turned on its side, with a hole cut in the middle, can be put under the patient when they need to defecate or urinate. ▪ A stool with a hole in the middle, with a place underneath the hole for a container to catch the feces. ▪ Put ash/sand/paw-paw leaves in the bed pan before defecating (to minimize feces sticking to container) and sprinkle ash/sand on top of feces to minimize smell. ▪ Place within reach of patient (for patient’s use if caregiver is not nearby): ▪ Water/rags/tissue to clean him/herself ▪ Container to put the soiled material in. ▪ Place a mackintosh covered with a piece of cloth between the mattress and the patient. Have more than one piece of cloth and mackintosh within easy reach of patient (so he/she can exchange soiled material with clean material if caregiver is not nearby).

▪ **Caregivers do not protect hands when handling patient’s feces.**	▪ Use gloves and buvera to protect hands when handling the patient’s feces.
▪ **Caregivers leave soiled linen to dry in the sun and then place it back under the patient without washing it.**	▪ The soiled linen should be washed with soap, paw-paw leaves (or any other detergent), and dried in the sun before reusing.

D. MANAGEMENT OF MENSTRUAL BLOOD	
▪ **During their menstrual period, bedridden women do not have access to appropriate materials to absorb the blood.**	▪ Women on periods should be provided with materials such as pads, cotton, rags, and other locally available materials (for instance, banana fibers) to absorb the blood. ▪ Caregivers can pad the patients who are not able to pad themselves.
▪ **During their menstrual period, bedridden women do not have access to material to clean themselves.**	▪ Place water and rags next to the bed for the patients to clean blood from their bodies. ▪ Place a container next to the bed where the soiled cleaning materials can be put until they can be washed later or thrown into the latrine.
▪ **Caregivers touch the menstrual blood without any kind of protection on their hands.**	▪ Caregivers protect their hands by covering them with gloves/buvera when handling menstrual blood. ▪ Caregivers can also cover their hands with gloves/buvera when washing the rags used to absorb blood. Dry the rags under the sun before reuse.

APPENDIX A:

FOCUS GROUP INTERVIEW WITH CARE PROVIDERS

My name is _________ and my colleague here is _____________. We are trying to learn about current hygiene practices especially in relation to people living with HIV/AIDS. At the end of the review we will make recommendations for integration of hygiene into HIV/AIDS programming. The discussion takes about 45 minutes to an hour. Participation is voluntary and all the issues discussed will be kept confidential.

Thank you very much for coming today. We are looking forward to learning from you. I would like to ask your permission to take notes and tape record the interview. Because what you have to say is important to us and we do not want to forget what you tell us, we will have one person take notes *and* tape record our discussion to make sure we have understood what you have said. The tapes will be locked in a safe place and be destroyed once the review has been completed. Is this okay? If yes, thank you very much. *[Proceed with the interview.]*

A. Introductory Questions

Ask each of the participants to introduce themselves providing information on:

- *Organization they work with;*
- *Years of experience;*
- *Their sex (male/female);*
- *Any other thing they feel is important to the discussion.*

1. What are your roles as home-based care providers?

2. What are your main activities?
(Note: Anything related to hygiene and sanitation including bathing patients, cleaning them, and helping them to go to the toilets)

3. What type of patients/families do you support? **(e.g. with HIV/AIDS, cancer, etc.**

4. What, in your opinion, are the main hygiene problems in the care and support of the people who are critically-ill?

5. What exactly do you tell family caregivers/family members in relation to hygiene?

6. What materials, if any, do you use to educate family members in relation to hygiene?

B. Feces Disposal

1. Where do most patients defecate when they are mobile or have limited mobility?

- Latrine, open field (probe: where if buried, burned, or left out in the open), flush toilet (in urban areas)?
- If and when a patient needs assistance to defecate, who usually helps them?
- Family member or someone from the outside? Is it the same person all the time?
- When would someone else help the sick person get to the latrine?

2. How do people in the household help patients get rid of their feces when they are completely bedridden?

- Potty, basin, mat, plastic sheet (kavera), banana leaves, newspaper, anything else?

3. Where are the feces disposed of?

- Latrines, open field (buried, burned or left), or other?

4. Is this the same place you use to dispose of:

  a. Materials used to clean the patient;
  b. Menstrual blood;
  c. If not, why not? Where are the other materials disposed?

5. If basin/potties, kaveras or any other reusable materials are used, how are they cleaned?

- Water only, water with soap (or any other disinfectant) or any other material (if so which)?

6. What do most family members use to protect their hands/themselves when handling feces and/or cleaning the patient?

- Do not protect themselves, gloves, plastic bags, old rags, anything else?

7. How do they clean bedridden patients after defecating?

- Private parts? Are detergents used?

8. If bedding and/or clothes are soiled, how are they cleaned?

- Washed with water, boiled, washed with water and detergent, left out to dry?

9. Where is the waste water from cleaning bedding/linen/clothing disposed of?

10. What happens when a mattress is soiled?

- Washed and left to dry (how), replaced (what are the criteria used to decide to get rid of mattress)?

11. Are other materials available to replace/compliment mattress while they are drying or if they need to be thrown away (e.g. thick blankets, mats)?

- Are these readily available? Are they expensive?

12. Is there anything that the bedridden person can do if they need to defecate/urinate if the caregiver is not around?

C. Menstruation

1. How do women who are bedridden, or with very limited mobility, dealt with their blood during menstruation?

2. How does the caregiver help them?

3. What materials do women use to absorb the blood?

- Is the same material always used?

4. What do most family members use to protect their hands/themselves when handling menstrual blood and/or cleaning the patient?

- Do not protect themselves, gloves, plastic bags, old rags, anything else?

5. How do they clean bedridden patients during menstruation?

6. If bedding and/or clothes are soiled, how are they cleaned?

- Washed with water, washed with water and detergent, left out to dry.

7. Do you have any recommendations to improve the way that family members help bedridden women who are menstruating?

D. Hand Washing

1. Do most family members wash their hands after cleaning patients?

- If yes, how? With what?
- If not, why not?

2. Is soap available?

- If yes, what kind? Where do they get it? Is it available all of the time/sometimes [why]?
- If soap is not available, what other materials do people use to wash their hands? Water only; if other materials are used, what are they? How are they sourced/made? How expensive are they?

3. Where do they wash their hands?

- With what (tippy tap, jerry can, etc.)?

4. Do they encourage patients to wash their hands?

- If patients wash their hands, where do they wash their hands? In the room or do they have to take the patient outdoors?
- If the sick person is bedridden, how do you help them wash their hands?
- How difficult or easy is it to wash patients' hands when they are really sick? Why?

5. What would make it easier for family members to wash their hands/their patients' hands?

E. Water Storage and Treatment

1. Where do most HIV-positive households get their water from? Communal tap, communal well, river/stream/dam, flush tap (urban?).

2. How do they get it to the homes?

3. How is it stored in the home? Jerry cans, pots, or other?

- Do the containers usually have a lid? Is the lid attached to the container/on floor?
- Where are the containers stored?
- How clean are the containers?

4. How is water taken out of the containers?

- Cup, ladle, scoop, plate?
- Where is the utensil stored? (Floor/table)

5. How is the water treated?

- Left untreated, boiled, chlorine (Which product?), left in the sun?
- How do you think water handling can be improved? [*Interviewer, please thank the participants for their time.]*

APPENDIX B:

IN-DEPTH INTERVIEW GUIDE (CAREGIVERS)

Hello, I am _________ from ___________. I am talking to some families in this community where there are sick people in order to better understand their health problems. We hope that what we learn will help us design better programs that respond to what people like you say they need and want. Please feel free with the discussion:

- You can say anything you want;
- There is no right or wrong answer, only your own ideas and opinions;
- We are going to use the information that you give us to help provide better care to the people who are sick. Be assured that I will NOT tell anyone what YOU as an individual said. Your name will not be used, and no one will be told about what any one person says.

Would you be willing to talk with me for about one hour? *[If person declines to be interviewed, ask why, try briefly to convince, but do not pressure. Thank the person and leave. If s/he is willing, continue.]*

I am really interested in learning from you, so if you have any questions during our interview, I will make a note of them and answer them when we are done talking about my questions.

A. Introductory Questions

1. [*For child carer only*] How many brothers/ sisters do you have?

2. [*For child carer only*] How many of them stay here with you?

3. Who else lives in your home besides you? *[Interviewer: please note relationships to the respondent.]*

4. Who is sick that you are taking care of? *[Interviewer: please note relationships to the respondent.]*

5. Does anyone else from outside of the family help you take care of (name of sick person) [the sick family member]? Who is this person? How does this person help you?

   - *I know it can be hard to talk about very private things, like what happens when someone has to go to the latrine, but I would like talk to you about how you help your sick family member deal with going to the* *latrine because we are trying to help caregivers provide better assistance.*

B. Knowledge about Feces

1. What is the best way to get rid of feces?

2. Can they cause illnesses? Which illnesses?

3. Are children's feces the same as adults'? If not, how are they different?

4. Are animal feces the same as human feces? If not, how are they different?

5. Many times when people are sick, they get diarrhea. Do you believe it is possible to prevent diarrhea? If not, why?

- If the answer is yes, how can diarrhea be prevented?
- Do you do anything to prevent diarrhea? Please explain.
- Are there other things that you would like to do to prevent diarrhea, but do not for some reason?
- If the answer is yes, what are they? Can you tell me what prevents you from doing these things?
- Does the person you care for sometimes get diarrhea? If yes, then ask:

i. In the past 2 weeks? Yes ___ No ___

ii. In the last 24 hours? Yes ___ No ___

C. Feces Disposal

1. Does your family have a latrine they can use?

2. If not, where do they defecate?

i. Is it the same place for day and night? Yes ___ No ___

ii. Is it the same place all year round? Yes ___ No ___ If not, why not?

3. Is the sick person able to go to the latrine by themselves?

- If not, can he/she do it with help? *[If they are completely bedridden, please go to question 4.]*
- What kind of help?
- Who helps (Do they help all of the time? If not, who helps and when?)

4. If he/she can't go to the latrine and defecates in bed, how do you help them to defecate/urinate in their bed?

- What kind of help do you give them?
- What items do you use to help them defecate/urinate in the bed? (Bed pan, potty, basin, kavera, plastic bags, newspaper, rags, leaves, and so forth)
- What kind of items do you use to help clean the person after they have urinated/defecated? (Rags, newspapers, rags, old clothes)
- Where do you dispose of the feces? (Latrine, open field, buried, burned)
- How do you clean the reusable items (Basins, potties, and so forth)? Do you use water only, water with soap, or any other detergent), jik, or hapik?
- Where do you get rid of the disposable items such as leaves, newspapers, and plastic bags? (Latrine, pit, burned, buried)

5. If you help them defecate <u>in the latrine</u>, what kind of items do you use to help clean the person after they have urinated/defecated? (Rags, toilet paper, newspaper)

- What kind of help do you need to get the patient to the latrine and use it properly?
- After we have finished talking, can you please show me your latrine?

6. Do you use anything to protect your hands when dealing with your sick family members' urine/stool? What do you use? (Gloves, plastic bags, rags)

7. How do you clean the sick person's linen or clothes if they have been soiled? Do you use water only, water with soap, or any other detergent, jik, harpik, or let it dry in the sun?

8. How do you clean the mattress if it has been soiled? (water only, water with soap, or any other detergent) jik, hapik, left to dry in the sun)

9. Where is the water used to wash the soiled bed linen, clothes, and mattress disposed of?

10. What can make it easier for you to help the sick person (who cannot get out of bed themselves) when they need to urinate/defecate?

D. Hand Washing

1. As a caregiver, when do you wash your hands?

- After handling the sick person's feces?

- Before feeding the sick person?
- Before/after tending to open sores?

2. How many times have you washed your hands today?

3. Please show me where you usually wash your hands. *[Note if there is water, soap or a substitute, a basin to catch the waste water, pitcher or tippy tap to pour water for hand rinsing.]* Please wash your hands the way you usually do. [Ask if the caregiver uses water and from where, uses soap or a substitute, rubs hands together at least 3 times, dries hands and how. Also look for a regular place for hand washing, presence of a washing basin or tippy tap, water drainage and cleanliness of material used for drying.]

4. If the person did not use soap when washing their hands, ask: Do you have soap in the house?

- If no, ask prevents you from having soap in the house?
- Do you ever make soap at home? Do you know how?
- Have you ever used anything else besides soap or water to wash your hands? (Ash, sand)
- Why or why not?
- How available is this material?

E. Drinking Water

1. Where do you store your water for drinking? (Container with a lid, container with a spigot, container on the floor or off the floor on a table)

2. How is the water taken out of the container? (Probe for whether they use ladle, cup to scoop the water from the container)

3. Where do you store the utensils used to draw the water? (On the floor, on the table, attached to the wall, in the container, any other location)

4. Do they do something to their water before drinking it to make it safer? (Probe for boiling, chlorination, using sunlight, etc.)

APPENDIX C:

IN-DEPTH INTERVIEW GUIDE (PATIENTS)

Hello, my name is _________________.
I am talking to some families in this community where there are sick people in order to better understand their health problems. We hope that what we learn will help us design better programs that respond to what people like you say they need and want. Please feel free with the discussion:

- You can say anything you want as long as that is truly how you feel;
- There are no right or wrong answers, only your own ideas and opinions;
- We are going to use the information that you give us to help provide better care to people who are sick. However, be assured that I will NOT tell anyone what YOU as an individual said. Your name will not be used, and no one will be told about what any one person says.

Would you be willing to talk with me for about one hour? *[If person declines to be interviewed, ask why, try briefly to convince but do not pressure. Thank the person and leave. If she/he is willing, continue.]*
Do you have any questions?

A. Introduction

1. Who else lives in your home besides you?
2. What is each person's relationship to you?
3. Who helps take care of you from the family?
4. Does anyone else from outside of the family help take care of you?
5. How is your health?
6. How are you feeling today?

- *I know it can be hard to talk about very private things, like what happens when you have to go to the toilet, but I would like to learn from you because we are trying to help caregivers provide better assistance to people like you.*

B. Feces Management

1. Where do you usually go to help yourself?
2. If participant uses a latrine, ask:

  - Are you able to go to the toilet by yourself?

- If not, does anyone help you? Who?
- Are the same people always available to help you?
- Who would you prefer to help you? Why?
- What happens if help does not come in time? (Do they defecate in bed? If so, ask appropriate questions from question 3 below).
- How do they help you to get in and out of the latrine?
- Is it always possible for them to help you get into the latrine? If not, where do you use the toilet?
- What do you like about using the latrine?
- What do you not like about using the latrine?
- What do you think can be done to improve the way you use the latrine?

3. If participant is <u>bedridden</u>, ask:

- How do you help yourself if you cannot get out of the bed? (Basin, potty, on the sheet)
- What happens to your feces? [If not mentioned, ask about throwing in latrines, in the bush, in a hole or garbage pit, in the garden]
- Who helps you to defecate?
- Are the same people always available to help you?
- Who would you prefer to help you? Why?
- What does this person do to help you? What materials does he use to clean you? (Probe for the materials used to clean the genitals)
- How long does it take for help to come so you can be cleaned?
- What do you find difficult when defecating?

Is there anything that can be improved to help you when you have to go to the toilet in the bed?

C. Hand Washing

1. After you leave the latrine, do you wash your hands? Why or why not? (If they need assistance) Does the person who helped you wash their own hands? Why or why not?

2. What other times do you wash your hands? (Probe before eating)

3. How many times have you washed your hands today?

4. Where do you usually wash your hands?

5. Please show me how you wash your hands the way you usually do. *[If mobile, ask client to take you where they wash their hands. If bedridden,* *ask caregiver to bring supplies that are usually used to wash hands. Note if a person uses water and from where, uses soap or a* <u>*substitute*</u>*, rubs hands together at least 3 times, dries hands and how. Also look for a regular place for hand washing, presence of a washing basin or tippy tap, water drainage, and cleanliness of material used for drying.]*

6. (If soap was not provided with washing supplies) Do you have soap in the house?

- [If no, ask] why not?

D. Menstruation (for Female Patients Only)

1. When you are bedridden, how do you deal with your blood during menstruation?

2. What materials do you use to absorb the blood?

- Is the same material always used?

3. Have you ever needed someone to assist you when you were menstruating?

- Who helped you?
- Who would you prefer to have helped you?

4. Do you have any recommendations to improve the way that family members help bedridden women who are menstruating?

E. Knowledge

1. What do you think is the best way to get rid of feces?

2. Can feces cause illnesses? How? Which types of illness?

3. Do you believe it is possible to prevent diarrhea? If not, why?

4. Do you do anything to prevent diarrhea? Please explain.

5. Are there other things that you would like to do to prevent diarrhea but do not for some reason?

6. (If yes) What are they? Why don’t you do these things?

7. Have you ever had diarrhea? Have you had diarrhea in:

- In the past 2 weeks? Yes ___ No ___
- In the last 24 hours? Yes ___ No ___

Thank you very much! I am done asking questions.
Do you have any questions for me?

APPENDIX D:

OBSERVATION CHECKLIST

Household identifier: ___________________________________

Interviewer name: ______________________________________

Date: ____

1. Is there a separate space available (outside or inside) for hand washing?

Yes	No

2. How far is the hand-washing space from the latrine?

Close	Far	Not sure

3. Is soap available near where hands are washed?

Yes	No

4. Is clean water available for washing hands?

Yes	No

5. Is there clean material to dry hands available?

Yes	No

6. Container used for washing hands is:

Open	Closed	Tippy Tap

7. Is the container likely to be contaminated by hands or in any other way?

Yes	No

8. The water container appears:

Clean	Dirty	Cannot tell

9. For bedridden patients, what materials are the patient lying on? *(Please pick more than*

Foam mattress	Grass mat	Blankets/linen	Other materials Specify___________	Not applicable

10. <u>For bedridden patients</u>, is there a space (with water) for washing hands close to the bedridden patient?

Yes	No	Not applicable

11. If so, is there soap near the space?

Yes	No	Not applicable

12. What kind of latrine is available to the family?

Household	Community	No latrine

13. The latrine appears to be:

Used for defecating/urinating	Not used: check to see if path is used or if other things are stored in latrine

[Note distance from home and water, type of latrine, condition of path to latrine, cleanliness of latrine, smell, wiping material, privacy afforded, other uses such as storage or bathing, bugs, vermin, mosquitoes, hole or seat appropriate for child. Ask about light to use day and night, and if people outside the family use it.]

14. Latrine appears:

Clean	Dirty	Cannot tell

15. Evidence of feces in the compound?

Yes	No

16. Is there a specific place for people to:

- Bathe?

Yes	No

- Wash dishes?

Yes	No

- Wash clothes?

Yes	No

17. *[Ask someone in the household to show you]* Where is waste water from washing hands, laundry, or dishes disposed?

Disposed in the yard (e.g. behind house)	Latrine	Separate	Gutter

18. Is there a pit for people to put their trash?

Yes	No

19. Are there flies in the compound or home?

Yes	No