Equal Access for all? Meeting the needs for water and sanitation of people living with HIV/AIDS

Briefing Note 6 (Water Aid Ethiopia)

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Summary: People living with HIV/AIDS (PLWHA) are particularly vulnerable to the health impacts of inadequate water and sanitation. In seeking to protect themselves from infection, or cope with the symptoms, their needs for clean water and sanitation increase. In Addis Ababa, a city where the poor in general have inadequate water and sanitation facilities, PLWHA often have even more limited access than others, due to discrimination and sickness. However, despite extensive literature on HIV/AIDS, documentation on linkages with water and sanitation is limited, and programming in the two areas is rarely linked. WaterAid Ethiopia, an international NGO dedicated to the provision of safe domestic water, sanitation and hygiene promotion to the world's poorest people, has been prompted by this to undertake research in this area. This research investigates the needs of PLWHA in water and sanitation, their constraints on meeting these needs, and ideas for addressing them through water and sanitation programming by NGOs and government in Ethiopia.

Keywords

AIDS/HIV, Equity, Health, Water, Sanitation



Equal access for all?

Meeting the needs for water and sanitation of people living with HIV/AIDS

Introduction

Everyone needs clean water and sanitation for good health. But people living with HIV/AIDS (PLWHA) are particularly vulnerable to the health impacts of inadequate water and sanitation. In seeking to protect themselves from infection, or cope with the symptoms, their needs for clean water and sanitation increase.

In Addis Ababa, a city where the poor in general have inadequate water and sanitation facilities, PLWHA often have even more limited access than others, due to discrimination and sickness.

However, despite extensive literature on HIV/AIDS, documentation on linkages with water and sanitation is limited, and programming in the two areas is rarely linked. WaterAid Ethiopia, an international NGO dedicated to the provision of safe domestic water, sanitation and hygiene promotion to the world's poorest people, has been prompted by this to undertake research in this area.

This research investigates the needs of PLWHA in water and sanitation, their constraints on meeting these needs, and ideas for addressing them through water and sanitation programming by NGOs and government in Ethiopia.



Equity of access to water and sanitation facilities cannot be assumed. This is because PLWHA often face discrimination in water collection and sanitation.

PLWHA and Water and Sanitation

HIV

Vulnerability

increases (opportunistic disease)

Needs

increase (prevention and control of symptoms)

Access

decreases (sickness and discrimination)

Background

In recognition of the scale of the HIV/AIDS pandemic in Ethiopia, WaterAid aims to integrate the needs of PLWHA into its water and sanitation programming. An estimated 1.5 million people were living with HIV in 2003, with national prevalence at 4.4%, and urban prevalence at 12.6 % (Federal Ministry of Health). However, research on the experiences of PLWHA in Ethiopia with respect to water and sanitation is limited.

This research was carried out by WaterAid and Progynist, a national NGO, in Addis Ababa, from September-December 2005. It builds on a previous research by the same organisations on linkages between HIV/AIDS and water and sanitation. The earlier research "Making the Links" (Mamo and Frazer 2004), found that PLWHA and their carers have increased needs but reduced access to clean water and sanitation facilities, both because of sickness and discrimination. A further finding was that a high proportion of PLWHA suffer from diarrhoea.

The objective of this research is to test the hypothesis that PLWHA have increased needs and reduced access to water and sanitation facilities, and that some modification of current programmes is therefore necessary.

Methodology

The research was undertaken in Lideta, one of 10 subcities in Addis Ababa. Respondents were drawn from a range of wealth groups and water and sanitation access situations, as well as covering different stages of HIV infection and sickness.

Interviews: Twenty-two people living with HIV/AIDS (PLWHA) were interviewed using a questionnaire. They were selected from the beneficiaries of two NGOs working with PLWHA in Lideta sub-city: Progynist, a WaterAid partner, and Dawn of Hope, an urban based voluntary association of PLWHA, with no previous links with WaterAid. The second NGO was included to reduce potential bias from working only with WaterAid partners.

A further 20 people were interviewed as a control sample. They were randomly selected from nearby kebeles (unit of local government). The main reason for using the control was to gauge attitudes of people not affected by HIV/AIDS towards water and sanitation provision for PLWHA.

Focus group discussions: results of the interviews were presented to three groups, a **women's** group and a **men's** group of unknown HIV status; and a **mixed** gender group of PLWHA. The groups then discussed the following topics presented by the researchers:

- Water and sanitation, compared with other problems faced by PLWHA;
- Problems in water and sanitation faced by PLWHA;
- Types of discrimination faced by PLWHA;
- Solutions in water and sanitation for PLWHA. Ranking was done using piles of peanuts, with the size of the pile representing the importance and rank of what was represented.

Problems with toilets and water collection

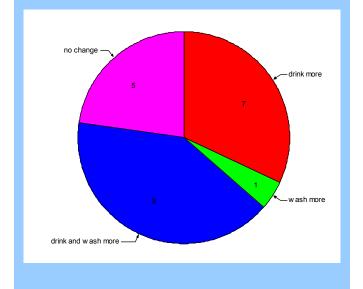
Abeba has HIV and suffers from frequent diarrhoea, but the nearest kebele toilet is 6 minutes walk away. It is also dirty, with 30 households sharing the same toilet. So she uses a potty in the house, which her husband and children then take to the latrine.

Solomon used to live in private rented accommodation. As soon as he started to visit the latrine frequently, his neighbours suspected him of having the HIV virus and locked him out from the toilet and the water tap. They washed the ground where he walked to the toilet, and made him pay extra money for the water he was using.

Lemlem gets her water from a communal water point. After she collects water people wash the tap. They also don't want to put their water container next to hers. Neighbours don't like to lend her bottles, glasses and containers. This is the problem faced by many PLWHA.

(Names have been changed to protect identity).

Why has water consumption changed with HIV/AIDS? (22 cases)



Key findings 1: needs and access

The **needs** of most PLWHA respondents for water and sanitation have increased since they tested positive for HIV, especially during the symptomatic phase. Over 75% were drinking and / or bathing and washing more than previously (see figure above). Fever increases the need for bathing and washing, and diarrhoea and fever require drinking more water. Diarrhoea, which was experienced by two thirds of the HIV positive sample respondents, increases the need for nearby latrines.

Drinking more water also helps reduce side effects from anti-retroviral treatment (ART), used by half of the HIV positive respondents. Increased washing and bathing helps prevent water related opportunistic infections.

However, about one third of respondents experienced reduced **access** to water and sanitation facilities, due to discrimination or sickness, so their needs are not always met.

Other **problems** faced by PLWHA in water and sanitation include insufficient number of communal taps and latrines; inconvenient opening times for communal taps; the high cost of buying water from vendors; and poor maintenance, especially of latrines, which increases the perceived risk of sickness.

The majority of HIV positive respondents buy water from vendors at 10-25 cents per bucket, and use latrines shared by at least three and up to 50 households. Two had no access to latrines at all.

Key findings 2: discrimination

Discrimination in water and sanitation is often part of a complex web of discrimination which also affects housing, employment, medical services, social life and childcare. About two thirds of HIV positive respondents experienced discrimination in at least one of these areas.

Discrimination against PLWHA in water and sanitation use is widespread, and at least one third of respondents had personal experiences. These ranged from refusal to share water containers or washing lines to locking of taps, bathrooms or latrines. It is not limited to those using shared facilities. The minority who have private facilities faced some of the most extreme forms of discrimination from close family members, or private landlords (see case studies).

Most PLWHA are reluctant to reveal their HIV status for fear of discrimination. Any sign of sickness, including taking medication, visiting a health centre, or frequent use of the toilet, triggers suspicion of HIV positive status which in turn often leads to acts of discrimination.

From the **control respondents** of unknown HIV status, about one third were aware of HIV cases in their neighbourhood, while a quarter mentioned suspected cases. Over half acknowledged that PLWHA had increased needs for water and sanitation, and suffered more diarrhoea compared with the general public. However, the majority claimed they were not aware of discrimination in their neighbourhood, and said that they would not mind sharing water points and latrines with people who were HIV positive.

Discrimination in water and sanitation

Eden used to live with her parents. The neighbours suspected she was HIV positive, due to her frequent sickness. They locked the toilet, and poured water and detergent in the toilet when she used it. They spoiled her wet clothes after she had washed them, and they even went to the extent of attempting to throw her baby in the river. They also tried to attack her with a knife. After that she left the place and rented a house in a very remote area where people didn't know her story. Eventually she moved back to a kebele rented room in Addis Ababa, but she still faces discrimination.

Miriam is living with HIV. She washed her clothes and hung them outside in the sun. When she went outside to see if the clothes were dry she found them strewn about on the dirty ground. Next time, she waited outside until the clothes dried. The neighbours reacted by not hanging their clothes on the same washing line, afraid that the virus might be transmitted through it.

Crippling fear of discrimination

Aster is not taking ART, fearing that this will identify her as a positive person, and lead her housemate to throw her out. Her neighbours ask questions even when she takes antibiotics and painkillers. They suspect her HIV status and won't drink coffee with her. She even avoids having the Progynist's social worker visit her. More than anything she is afraid to be identified as a positive person.

Another woman relates:

"I was sick with HIV/AIDS. When my parents heard the news they got mad. They didn't want other people to know about my situation, or to view them as the parents of a daughter with HIV/AIDS. So they locked me in a small room where they kept the dog. They were giving me food with the dog."

Participants' recommendations

Participants in the research believed that **improved** water and sanitation facilities were required for the general public, as well as specifically for PLWHA.

At least 75% of all respondents (including those of unknown HIV status) thought that there were problems with water and sanitation in their neighbourhood, and for 25% this was the most important problem.

Two thirds thought that more water points were needed, while 75% thought more latrines were necessary. Although private provision was preferred many recognised that this was unrealistic, and suggested more communal facilities.

Although most HIV positive respondents as well as some others, felt that PLWHA needed their own latrine, they also recognized the problems of reaching HIV positive people who may not be tested, or may not wish to reveal their status, as well as the risks of increased discrimination as a result of targeting.

For this reason, a majority of all participants recommended **improved facilities for the general population in order to meet the needs of PLWHA**, rather than targeted provision for PLWHA.

HIV positive participants felt that **tackling discrimination** through community counselling and mass media was as important as provision of physical facilities.

Targeting of the chronically sick was also suggested, although this would exclude pre-symptomatic PLWHA for whom improved water and sanitation could prolong their good health. On the other hand, targeting of those who are open about their status excludes the majority of PLWHA in Ethiopia who still prefer not to disclose their status.

Recommendations

- According to the recommendations of respondents, the water and sanitation needs of PLWHA should be met through increased provision of facilities for the whole community, rather than through targeting of PLWHA. More facilities may lead to less discrimination while targeting could increase it. Targeting is also logistically difficult since many people do not know, or do not wish to reveal their HIV status.
- 2. The **needs of PLWHA** should be addressed by including them (or their representatives) in planning, implementation, monitoring and evaluation of all watsan programmes.
- Tackling discrimination against PLWHA is as important as improved provision of physical facilities, according to HIV positive respondents who felt strongly about this issue. Legal provision should be available for those experiencing discrimination.
- Key messages of this research should be disseminated to government organisations, NGOs, UN agencies and participating communities within Ethiopia, as well as internationally.
- 5. Use of **media** such as radio should be supported with accurate medical information in accessible format.

- 4 WaterAid should liaise with other organizations on how to **integrate programming** in water and sanitation with programming in HIV/AIDS.
- 5 Based on the findings of this research, WaterAid and its partners need to integrate HIV/AIDS messages into their hygiene promotion and education work.
- 6 All existing and new water and sanitation facility provision by WaterAid and other organisations should include education on HIV/AIDS in order to tackle discrimination and achieve equity of access.
- 7 Research findings on the water and sanitation needs and access of PLWHA should be incorporated into relevant national policies in the water and sanitation sector, as well as into the Ethiopian HIV/AIDS National Response. Policies should continue to incorporate priority for vulnerable groups, including PLWHA and should tackle discrimination, including through legal provision. Responsibility for sanitation provision to vulnerable groups should be more clearly defined.
- **8** Funding allocated to HIV/AIDS should be reviewed to ensure inclusion of water and sanitation related issues.

Keywords

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Contacts and date of publication

Briefing note: Priscilla Magrath, January 2006 **Full report:** Mahider Tesfu (key researcher) and Priscilla Magrath (author), January 2006

WaterAid-water for life

The international NGO dedicated exclusively to the provision of safe domestic water, sanitation and hygiene promotion to the world's poorest people

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