

Access to water, sanitation and hygiene for people living with HIV and AIDS: A cross-sectional study in Nepal



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Cover picture: A women living with HIV with her baby at residential care unit at Silgadhi in Doti District of Nepal.

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Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ART	Anti Retro-viral Therapy
DoHS	Department of Health Services
FGD	Focus Group Discussion
FHI	Family Health International
FSW	Female Sex Worker
HIV	Human Immunodeficiency Virus
IDU	Intra-venous Drug User
IMR	Infant Mortality Rate
IEC	Information, Education and Communication
MSM	Men having Sex with Men
MoHP	Ministry of Health and Population
NDHS	Nepal Demographic Health Survey
NGO	Non Governmental Organisations
NLSS	Nepal Living Standard Survey
OI	Opportunistic Infection
PLHA	People Living with HIV and AIDS
POU	Point of Use
VCT	Voluntary Counselling and Testing
WASH	Water, Sanitation and Hygiene

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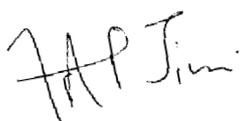
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We hope this study will help inform the strategies and actions of those stakeholders concerned with improving access to WASH for all, particularly those living with HIV and AIDS.



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Executive summary

Background and objective

Water, sanitation and hygiene (WASH) are the basic primary drivers of public health. Access to them ensures personal hygiene and, most importantly, human dignity. People living with HIV and AIDS (PLHA) suffer particularly from the health and social impacts of inadequate water and sanitation as their need for clean water, sanitation and hygiene practices increases as they struggle to protect themselves from infection, or cope with the disease symptoms. PLHAs' experiences of stigma and discrimination have been documented at various levels – household, community and by service providers – with regards to both water and sanitation access.

Access to water and sanitation services is not just a basic need, it is a human right for everyone regardless of HIV/AIDS status. This descriptive cross-sectional study commissioned by WaterAid in Nepal was prompted by the realisation that water, sanitation and hygiene needs, the rights of PLHA and the likely consequences of inadequate access to water by their households, were not being explicitly identified and not being integrated into either HIV and AIDS interventions or water and sanitation sector programmes in Nepal.

The main objective of the study was to increase the understanding of PLHAs' access to WASH and its impact on their daily lives in order to inform the health, HIV/AIDS and

WASH sectors of the various issues involved. Specifically, the study aimed to:

- Assess the prevailing knowledge, opinions and practices of WASH amongst PLHA.
- Learn about the experiences of PLHA with regards to their access to WASH and factors associated with it.
- Gather views of PLHA on WASH and its link to their social lives and health.
- Highlight the need for cross-sector debate and efforts to address the WASH issues for PLHA within the health, HIV/AIDS and WASH sectors.

Methodology

A cross-sectional study using mixed methods (quantitative as well qualitative) was carried out. Data was collected from 196 PLHAs from four different geographical areas of Nepal, covering seven districts – Kathmandu valley (Kathmandu, Lalitpur and Bhaktapur), eastern Terai (Sunsari and Morang), central Terai (Rupendehi) and far-western hill (Doti) – using a structured close-ended survey questionnaire, focus group discussions (FGD), and semi-structured in-depth interviews.

Results

The 196 PLHA participants attending service sites ranged in age from 17 to 67 years (mean age 34 years). The majority of the respondents were male (70%), Hindu (80%), educated to secondary level or higher (57%), engaged in an occupation (63%) and belonged to the fifth socio-economic quintile (74%).

1. HIV/AIDS status: Disclosure and subsequent discrimination

The mean duration that respondents had known about their HIV status was 42 months and in the majority of cases their status

was known to family members (87%) and community members (59%). It was found that there have been positive incremental changes in the attitudes of many community and family members towards HIV and AIDS. However, two out of ten respondents suffered discrimination by their family (18%) and almost half of them by community members (45%). The major reasons for PLHA not to disclose their HIV status were: discrimination (74%), fear (51%) and stigma (25%). Nearly half of the respondents were on Anti Retro-viral Therapy (ART) (46%). About a third of the respondents had one or more family members who were also HIV positive (32%). The main caretakers when the respondent was sick were found to be spouses (42%) and parents (45%).

2. Access to water supply and changing needs

A large proportion of the respondents had access to an improved source of drinking water (85%), however, the rural areas suffer more in terms of acute shortages of water and the quality of the water is reported to be poor. The practice of treating water was almost universal for urban respondents, but it was significantly lower for those in rural areas who actually had less access to safe water. Nearly two third's of households pay for water, the mean monthly payment being Rs. 110. Mean travel time to fetch water among households of the study population was around 20 minutes. Half of the respondents mentioned that their need for water has increased after becoming HIV positive, mostly for drinking (89%), using the toilet/sanitation (83%) and bathing (55%). The PLHA in this study also stressed the increased demand for safe water in keeping the environment of the house and toilets clean in order to reduce the risk of opportunistic infections. Fetching water can be a particular strain for PLHA, who experience fluctuating and diminishing energy levels or side effects from ARV medication.

3. Access to sanitation facilities and changing needs

A large proportion of the respondents used an improved toilet facility (74%). Urban coverage, at 100% for valleys, was significantly greater than rural hill coverage at 15%. In many cases water has to be carried from the water source to the toilet. Mean travel time to finding a place for defecation was around five minutes. On average, five households shared an improved toilet facility. About one third (32%) of all respondents said they needed to access toilet facilities more, particularly during episodes of diarrhoea or general weakness. The study underscored the vital importance of access to toilets for PLHA and pointed out that as people approach the terminal stage, easy access to sanitation facilities becomes even more important as people have lower energy levels and can no longer travel long distances. People defecating by bushes or in open spaces because of lack of access to toilets feeds into the vicious cycle of poverty, disease and bad hygiene for PLHA and other people. The impact on women is greatest because of their additional needs for menstrual hygiene. Of those who disclosed their status, around 7% and 13% said that they were discriminated against while using toilet facilities by family members and community people respectively.

4. Hygiene perception and practice

Hand-washing was reported to be practiced by a large proportion of the PLHA studied – mainly before having food (86%), after having food (96%) and after going to the toilet (100%). In most cases they use only water, except after going to the toilet when 84% use soap and water. They highlighted the issues of not having water available close to toilets – the difficulties in cleaning hands satisfactorily after defecation and the availability / affordability of soap. Eight in ten respondents bathe two or more times a week (79%). Of those who bathe once a week or less, the major reason was that they don't like to (68%). Seven out of ten respondents

have received hygiene related training (72%), in most cases receiving the information from HIV/AIDS service centres (37%) and support groups (35%). The service providers interviewed elaborated that current forms of information, education and communication (IEC) support have concentrated on medical, counselling and ART and not specifically on hygiene practices. There is a general awareness about the link between disease and water, sanitation and hygiene and, as the survey indicates, about seven in ten respondents recognised that there is a close connection between unsafe water and diarrhoea (72%). The perception of risk is higher but many respondents claim that due to the absence of enabling factors eg lack of resources required for the construction and maintenance of clean toilets, hygiene practices are more difficult to implement.

5. *Illness and treatment*

Half of the respondents had experienced a change in health after becoming HIV positive (52%). Four out of ten mentioned having been ill in the last three months (42%) and most of those who became ill had suffered from diarrhoea/dysentery (66%). Increased awareness about HIV and HIV prevention programmes has made PLHA cognisant of the treatment possibilities. Nearly all of those who had become ill had sought some kind of medical service (99%). Half of the respondents who had sought treatment said that the service provider had given WASH related information during their visit (54%). In nine out of ten cases, respondents didn't experience any kind of discrimination from health care providers who were aware of their HIV status. This reflects greater awareness and sensitivity amongst the providers catering for PLHA, thanks to the extensive HIV/AIDS programming. Significant associations have been shown between hygiene training, location of toilets within the compound and socio-economic status (these are reflected in quintiles later in this report).

6. *Stigma and discrimination*

The study explored the discrimination faced by PLHA by family members, communities and health care providers – looking at general behaviour, access to water and sanitation facilities and the provisioning of health care. It was evident that PLHA are facing discrimination and stigma within their families, communities and even from health providers associated with WASH. However, it was clear that the rooted discrimination faced by PLHA was not overwhelming – possibly as a result of extensive HIV programming focused on prevention, treatment and care, including de-stigmatisation. The less than expected reflection of discrimination may also be due to the fact that the study was conducted amongst those who visit a centre for HIV/AIDS related services. As many of the respondents are also affiliated to one or other support group – they may be an advantaged group among the PLHA. Although stigma and discrimination did exist in varying forms, affecting different individuals to a varying degree, the remarkable positive changes in the attitude of the family members, communities and health care providers towards HIV and AIDS is in progress and has to be sustained.

Discussion

The study re-emphasised the fact that PLHA have limited access to safe water and adequate sanitation services, and this is more pronounced in rural than urban areas. There is an increased need for both water and sanitation services as well as proper hygiene practices for PLHA, but they lack the means to meet these needs. Lack of access to WASH, and its effects on quality of life are many and varied, which invariably calls for an urgent address by all stakeholders.

Though it is not reported as grave, the study revealed some evidence of stigma and discrimination faced by PLHA, which does need tackling. There is a positive indication

that awareness about HIV and AIDS has been raised in certain families, communities and village development communities (VDCs) through HIV and AIDS support and advocacy programmes. However, the needs of PLHAs for accurate and adequate information about water, sanitation and hygiene practices, particularly with regards to water treatment and storage, sanitary use of toilets, hand-washing and menstrual hygiene, are high. Limited access to resources eg for storing, managing and treating water, compound the situation. Furthermore, there are several barriers. Weak physical health, particularly due to diarrhoea and further perpetuated by the efforts required to meet water demands, affect the daily lives and routines of PLHA to a varying degree, particularly quality of life and the ability to function independently and earn a livelihood. It is evident that with hygiene promotion, although there is a clear area of overlap in the interests of the water and sanitation sector and the HIV/AIDS sector, it hasn't yet resulted in much cooperation between sectors in practice or in harmonised hygiene promotion messages.

Based on the findings, the study proposes the following possible actions:

- As HIV/AIDS is a multi-sectoral issue, stakeholders in the WASH sector should revisit their policies and programming to mainstream HIV/AIDS and they should reciprocally advocate with government and stakeholders in the HIV/AIDS sector to mainstream WASH in their policies and programming. A thorough gap analysis of these sectors vis-à-vis each others' issues can be the first step towards mainstreaming both sectors' issues.
- Water, sanitation and hygiene programmes need to develop strategic partnerships with other stakeholders working on HIV/AIDS to ensure that PLHA have access to water and sanitation facilities, and practice proper hygiene behaviours. These can include for example, the removal of myths and

misconceptions around HIV transmission – to reduce stigma and discrimination, and simple promotional measures such as providing safe drinking water and clean sanitation facilities at HIV/AIDS service sites (eg ART centres) – which have the potential to reinforce the need for WASH measures at home and in communities.

- Instructions on safe water including point of use, sanitation and hygiene practices can possibly be linked to an expanded programme of HIV education and prevention, including the capacity development of service providers for requisite skills to encourage such practices. Common and simple messages on water including point of use, sanitation and hygiene can be developed and used by both water and sanitation programmes and HIV/AIDS programmes.
- Advocacy is needed for HIV/AIDS programmes and interventions for the provision of water treatment agents as part of PLHAs' medical treatment support packages. Advocacy also needs to be carried out with sanitation sector policy makers and programming professionals and agencies to accommodate special support packages to address the highly increased sanitation needs of PLHA.
- A possible further study is needed to assess who is being excluded from access to water and sanitation services where WASH projects have been implemented. This will inform the exclusion pattern.

Great strides have been made in recent years to dispel myths and misconceptions around HIV transmission. However, much remains to be done with regards to water, sanitation and hygiene – considering the greater need of PLHA. The study helps in substantiating this further in the Nepalese context. It is therefore imperative that gains made by HIV/AIDS prevention programmes are not compromised by lack of attention and efforts to address WASH issues associated with HIV/AIDS.

Background

Introduction

Water, sanitation and hygiene (WASH) are the basic primary drivers of public health. Access to them ensures personal hygiene and, most importantly, human dignity. However, in both rural and urban areas of developing countries, millions of the most vulnerable people lack access to water and sanitation services, making WASH related infectious diseases the most common causes of illness and death. Nepal is not an exception. Amongst the most vulnerable, people living with HIV/AIDS (PLHA) suffer particularly from the health impacts of inadequate water and sanitation as their need for clean water, sanitation and hygiene practices increase as they struggle to protect themselves from infection, or cope with the disease symptoms. Inadequate water supply and sanitation facilities exacerbate their risk and vulnerability, including increasing the rate of progression from HIV infection to the onset of AIDS.

Diarrhoea, a very common symptom of HIV/AIDS, affects 90% of PLHA and results in significant morbidity and mortality (Katabira 1999, Monkemuller and Wilcox 2000). More than 88% of diarrhoeal cases are caused by use of unsafe drinking water, inadequate sanitation and poor hygiene. Research on the co-infection of diarrhoea and HIV/AIDS

shows that morbidity and mortality is even more severe in children.

In the early years of the AIDS epidemic, opportunistic infections (OIs) caused a lot of sickness and deaths. Since the introduction of Anti-Retroviral Therapy (ART), however, far fewer people are getting OIs. It's still not clear how many people with HIV will get a specific OI. The most common are Candidiasis (thrush), Cytomegalovirus, Herpes simplex, Malaria, Tuberculosis (including Mycobacterium avium complex), Pneumocystis carinii and Toxoplasmosis. These can result in a range of infections in different organs both external (skin, oral cavity and genitalia) and internal (lungs, liver, intestines, brain etc) and can be of varying severity depending on the status of HIV patients. Most of the germs that cause OIs are quite common and the risk can be reduced by keeping clean and avoiding known sources of the germs that cause OIs (AIDS info net 2009).

Given the medical and socio-cultural implications of the condition, there are strong reasons to believe that PLHA face additional challenges in accessing WASH services. Several studies in other developing countries document the gravity of the condition, however, in Nepal, the data available on access to water and sanitation services masks the data for PLHA in accessing those services. This study therefore attempts to address this gap by investigating the access status of PLHA to WASH.

In Nepal, national estimates indicate that approximately 70,000 adults and children are infected with HIV and 92% of all infections are in the 15-49 age group (MoHP and

UNAIDS 2008). The same estimates show that 41% of all HIV infections in Nepal are among seasonal labour migrants, 16% among clients of sex workers and 21% are the wives or partners of HIV positive men. The highest burden of HIV infections is found in the Terai highway districts bordering India where 49% of all people living with HIV in Nepal are located. The overall prevalence in the adult population in Nepal is 0.49% (MoHP and UNAIDS 2008). Since the first AIDS case was reported in 1988, the HIV epidemic in

Nepal has evolved from 'low prevalence' to a 'concentrated epidemic'. As of December 2009, a total of 15,043 cases of HIV and 2,729 cases of AIDS have been reported to the National Centre for AIDS and STD control (NCASC) – from 179 Voluntary Counselling and Testing (VCT) sites in the country. The sex ratio (male:female) among HIV positive cases is 1.9:1. Out of the reported HIV cases, more than 13,000 are enrolled in HIV care and about 3,500 are on ART (NCASC 2009).

Literature review

Access to water and sanitation in Nepal

Water supply and sanitation continue to be inadequate, despite longstanding efforts by the various actors, both state and non-state, at improving coverage. The situation is strikingly inadequate for sanitation as only one in three Nepalese has access to improved sanitation facilities (including improved latrines). While the share of those with access to an improved water source (82%) is much higher than for sanitation, the quality of water is poor and most users that are counted as having access receive water of dubious quality and/or only on an intermittent basis.

Although 82% of the population in Nepal has access to an improved water source, nearly one in ten households in rural areas (where 86% of Nepal's population lives) take half an hour or longer to access their drinking water.

No city in Nepal has a full-day water supply. Most cities supply water only for a few hours on alternate days or even less frequently. Women are still responsible for collecting water in both urban and rural areas.

The lack of toilet facilities in many areas also presents a major health risk; open defecation is widespread in rural, and even in urban areas of Nepal as only 23% have access to improved toilet facilities (NDHS 2006). The majority of households in Nepal (85%) still don't treat their drinking water. It is estimated that, more than 10,500 children under five die of diarrhoea in Nepal every year. As indicated below, and in many other studies, there is a strong correlation between WASH and diarrhoea. Studies show that hand washing at critical times with soap decreases diarrhoea up to 45%, adequate sanitation facilities decreases diarrhoea by an average of around 36%, water quantity by 19% and water quality by 15%. The following table shows the direct correlation between access to safe water, sanitation facilities and hand washing practices, and infant mortality rate (IMR).

Nepal context: Correlation of hygiene and sanitation status with IMR

Development region	Population with access to water	Toilet coverage	Incidence of diarrhoea (<5yrs children) /1,000	IMR/1,000 live births	Use of soap at any time	Frequency of hand washing
Eastern	76	42	259	45	67.50	2.20
Central	81	46	218	52	64.30	2.20
Western	85	54	205	56	74.10	2.40
Mid Western	76	31	260	97	55.90	1.80
Far Western	83	29	239	74	51.20	1.70

Source: DWSS/MPPW, 2010. NDHS 2006. District data

Data from the NDHS (2006) also indicates clear regional disparities associated with the provision of sanitation and water supplies. The Nepal Living Standard Survey (2003-04) found that the richest quintile are 13 times more likely to have piped water in their home than the poorest quintile (39 versus 3%) and are nearly eight times more likely to have improved sanitation (79 versus 10%).

HIV, hygiene, sanitation and water

More than 88% of diarrhoeal cases are caused by unsafe drinking water, inadequate sanitation and poor hygiene. Diarrhoea, a very common symptom of HIV/AIDS, affects 90% of PLHA and results in significant morbidity and mortality (Katabira 1999, Bateman et al 2002). Research on the co-infection of diarrhoea and HIV/AIDS shows that morbidity and mortality due to diarrhoeal disease is even more severe in children with HIV/AIDS. A study of HIV positive infants in the Democratic Republic of Congo found that the risk of dying from diarrhoea is 11 times greater than for infants who were HIV negative (Thea et al 1993).

Diarrhoeal disease reduces the absorption of anti-retroviral drugs. Also important to note is that PLHA need more water to keep their environment clean. Fetching water and visiting toilets requires time and energy, both of which PLHA are likely to have increasingly less of as their condition worsens – and indeed as their need becomes greater. It also increases the burden on their caregivers who are often women and girls.

Another study found that although common, diarrhoea-causing enteric pathogens are present in many babies, HIV positive babies with acute diarrhoea were six times more likely to develop persistent diarrhoea. HIV negative babies born to HIV positive mothers were also at 3.5 times greater risk of developing recurrent bouts of diarrhoea than babies born to HIV negative mothers (Keuch et al. 1992).

In both rural and urban areas of low-income countries, millions of the most vulnerable people lack access to improved water and sanitation services. These include over 500

million people with disabilities, growing numbers of frail elderly people, and other groups of people with special needs, including those living with HIV/AIDS. Inaccessibility of water and sanitation services excludes many of these vulnerable groups from getting services which they need every day for their basic survival. In this way inadequate water supplies and sanitation facilities exacerbate the risk and vulnerability for HIV/AIDS through:

- Increased risk of HIV infections.
- Increased risk of opportunistic infections.
- Difficult environments for the proper treatment of HIV.
- Increased socio-economic impacts of HIV/AIDS.

Access to water and sanitation services is not just a basic need, it is a human right for everyone regardless of HIV/AIDS status. PLHA are often excluded from services and their involvement in WASH programme development is not usually sought. As a result, their particular needs are often not addressed in WASH programming.

By recognising the importance of safe water, sanitation, and hygiene promotion in protecting and caring for PLHA, some organisations working in high HIV prevalence countries are integrating water, sanitation, and hygiene improvement into their HIV/AIDS programmes.

The provision of WASH is critical in HIV care and treatment programmes for three reasons:

- 1 PLHA are particularly susceptible to opportunistic infections which include diarrhoea, skin diseases and typhoid.

- 2 HIV positive mothers who do not breastfeed need clean water to make formula.
- 3 Anti-retroviral therapy is better absorbed if patients use safe drinking water.

Similarly, treatment and the safe storage of water at point of use has been shown to reduce the risk of diarrhoea by 30 to 40% among PLHA (USAID, 2004). Presence of a latrine of good quality within the compound was associated with fewer episodes and fewer days of diarrhoea in PLHA (Lule, 2005).

Stigma and discrimination in Nepal

Denial and stigma associated with HIV/AIDS are widespread. HIV/AIDS are considered fatal and contagious diseases. However, levels of knowledge and attitudes about HIV/AIDS, its mode of transmission and its threat as an infectious disease vary widely. Many consider HIV/AIDS to result from immoral behaviour (improper sexual relations). These issues have deep roots in social fear, misconceptions and cultural beliefs towards sexuality and sexual activity. PLHAs' experiences of stigma and discrimination have been documented at various levels – household, community and service providers.

Discrimination is most commonly experienced in relation to toilet use. People widely believe that HIV/AIDS is transmitted through sharing a toilet. There are also a number of reports about discrimination at tap stands or from private vendors who refuse to serve people with HIV/AIDS, either for fear of transmitting infections or of losing business. These factors clearly reflect the issues relating to PLHAs' access to water and sanitation services.

Rationale

In Nepal, as indicated above, data on access to WASH services masks the individual effort that vulnerable groups such as PLHA have to make in accessing those services each day. To date, no study in Nepal has investigated how PLHA are accessing water and sanitation and the physical, financial and social barriers facing them. Considering that HIV prevalence has continued to rise, a study is necessary to fill this data gap by investigating the water, sanitation and hygiene needs and challenges of PLHA, the constraints on meeting these needs and ideas for addressing them.

The study also attempts to identify water, sanitation and hygiene practices (hand

washing, treatment and safe storage of water and sanitation/faeces management) and the perception of health risks which impact negatively or positively on PLHA. The study was conducted in districts where HIV/AIDS projects are implemented (by the HIV/AIDS sector) in order to provide a clearer picture of who is excluded from the services and/or to get an overview of the extent to which PLHA have access to the services.

It is hoped that the evidence from the study will provide an impetus to initiate policy debate for mainstreaming WASH in HIV/AIDS programmes in the sector and vice versa, and beyond. Since evidence based data from the field is lacking in the country, WaterAid in Nepal has undertaken this study with the aim of contributing to a stronger evidence base to support greater advocacy and influence policies, strategies and programming.

Objective

Main objective

The main objective of the study was to increase the understanding of PLHAs' access to WASH and its impact on their daily lives in order to inform the health, HIV/AIDS and WASH sectors of the various issues involved. The study is expected to contribute to generating cross-sector policy debates to address the issues from an equity and inclusion perspective.

Specific objective

- 1 Assess the prevailing knowledge, opinions and practices of WASH amongst PLHA.
- 2 Learn about the experiences of PLHA with regards to their access to WASH and factors associated with it.
- 3 Gather views of PLHA on WASH and its link to their social lives and health.
- 4 Highlight the need for cross-sector debate and efforts to address the WASH issues for PLHA within the health, HIV/AIDS and WASH sectors.

Methodology

Study sites and population

The study was conducted between January and March 2010 in four geographical areas of Nepal covering seven districts – Kathmandu valley (Kathmandu, Lalitpur and Bhaktapur), eastern Terai (Sunsari and Morang), central Terai (Rupendehi) and far-western hill (Doti). The districts were selected to represent different terrains as well as rural/urban areas of the country.

The study sites were in centres providing HIV/AIDS related services (VCT, ART

and/or Intravenous Drug Use (IDU) rehabilitation) in the selected districts. More than one site was involved in each district (see Table A). The study population involved people affected by HIV/AIDS who visit these centres for their services. All PLHA who visited a centre on the days of data collection and were willing to participate in the study were included. In depth interviews and Focus Group Discussions (FGD) also took place with service providers included.

Table A: Study sites

Area (Districts)	Sites
Kathmandu valley (Kathmandu, Lalitpur, Bhaktapur)	Sparsha Nepal, Drishti Nepal, Helping Hands, Prerana
Eastern Terai (Sunsari and Morang)	Dharan Positive Group, Sunaulo Bihani, Dharan Youth Centre, Punarjiwan Kendra, Bishwas Mahilaa Samuha, Richmond Fellowship, Saamudayik Rehab, Sunrise Support Group, Jeewan Bachaau
Central Terai (Rupandehi)	Aastha Samuha, NAPN
Far western Hill (Doti)	District Hospital ART Centre, Samaj Sewa Doti - Crisis Centre

Study design, techniques and tools

A descriptive cross-sectional study design was used for the study. A mixed research methodology – with quantitative method as a core, supplemented by a simultaneous qualitative method – was adopted. Quantitative information was collected through structured interviews using close-ended questionnaires (survey questionnaires) with PLHA, which included high risk (FSW, IDU, MSM, migrant workers) as well as low risk (spouses of migrant workers) population groups. A sample size of 196 PLHA was taken for the survey¹. All PLHA who visited the service site on the day of data collection and showed willingness to participate were purposively sampled for the survey.

For qualitative information, multiple qualitative research tools (in depth interviews with key informants and FGDs with PLHA and service providers) were used. The respondents for in depth interviews and FGDs were purposively selected from the survey respondents, based on their skill in articulation and their interest in further sharing their information. In addition, for in depth interviews and FGDs, the selection was based on respondents availability. Necessary steps were taken to ensure the rights, anonymity and confidentiality of the participants during the whole study.

The data collection tools were first prepared in English and then translated into Nepali. All questionnaires were pre-tested with representative participants in Kathmandu valley prior to finalisation.

Data collection

Data collection was carried out at the service centres on the days they were open with verbal consent from the respondents who participated. The survey, in depth interviews and FGDs were carried out by trained research associates/assistants. A total of 196 (Male:138, Female:55, Third Gender:3) respondents participated in the survey. Four FGDs were carried out with PLHA groups (involving 41 participants), and one with service providers (involving six participants). In depth interviews were conducted with six key informants – three PLHA (two male and one female) and three service providers (two male and one female). With the verbal permission of the respondents, some photographs were taken during the FGDs and in depth interviews, some of which are included in the report.

Data transcription and analysis

Quantitative data from the survey was entered into and analysed using SPSS 13.0 software. Descriptive statistics were generated to show the socio-demographic characteristics as well as the distribution of knowledge, perception, experience, practice and access variables. Cross-tabulation and Chi-square tests were run to see the association between some socio-demographic variables with knowledge, perception, experience, practice and access variables. A standard set of questions was used and analysed using specific scores and formulae in SPSS to generate the wealth quintiles of the respondents.

¹ The sample size was calculated using the Epi-Info software for a minimum sample size estimated for a population survey using random sampling with 95% confidence interval and expected frequency 50% (in centre), precision 7%. The calculated sample size is further verified by using the following formula:

$$\eta = \frac{z^2 p(1-p)}{d^2} \text{ here } n = \text{sample size, } Z = 1.96, p = 0.5, d = 0.07, \text{ which gives us } \eta = \frac{(1.96)^2 [0.5(1-0.5)]}{(0.07)^2} = 196.$$

Qualitative data gathered through six in depth interviews and five FGDs was transcribed verbatim during the process in Nepali and translated later into English. The data was then analysed manually based on recurrent themes and patterns.

Ethical considerations

The rights, anonymity and confidentiality of the respondents were respected in all phases of the study. Informed verbal consent with the centres and respondents were taken before data collection. The type and

purpose of the study, discussion or interview; issues of anonymity and confidentiality; voluntary participation and freedom to discontinue the interview/ discussion at any stage; and absence of any known risk or benefit for participating in the study was explained through a verbal consent process beforehand. Photos were taken with verbal permission from the respondents. To preserve anonymity, all findings are presented without ascribing names or using identifiable personal descriptions.

Results

The crux of the findings, obtained through different methods and tools used in the study, are organised and presented in six sections following a section describing the socio-demographic characteristics of survey respondents. The six sections are:

- 1 HIV/AIDS status: Disclosure and subsequent discrimination.
- 2 Access to water supply and changed needs.
- 3 Access to sanitation facilities and changed needs.
- 4 Hygiene perception and practice.
- 5 Illness and treatment.
- 6 Stigma and discrimination.

The information is presented within each of the following sections along with two

pertinent case studies. After the results section, a discussion of the findings is presented.

Socio-demographic characteristics of respondents

The study was carried out with PLHA attending service sites. A total of 196 PLHA participated in the survey, and out of them 41 participated in the FGD and three in the indepth interviews. Out of 196 respondents, the distribution is very similar across the four geographical areas, with approximately a quarter of respondents from each area. The socio-demographic distribution is outlined in Table 1.

Table 1: Socio-demographic characteristics of the survey respondent (n = 196).

Variable	Frequency	Percent (%)	Variable	Frequency	Percent (%)
Districts:			Marital Status		
Doti	47	24.0	Married	93	47.4
Kathmandu	50	25.5	Never married	55	28.1
Morang	20	10.2	Widow/Widower	38	19.4
Sunsari	28	14.3	Divorced/Seperatec	10	5.1
Rupandehi	51	26.0			
Age in years:			Sex:		
Upper limit		17 Years	Female	55	28.1
Lower limit		67 Years	Male	138	70.4
Mean age		33.9 Years	Third Gender	3	1.5
Cast/Ethnicity:			Education level:		
Brahmin/Chhetri/Thakuri	67	34.2	None	33	16.8
Hill Aadiwasi/Janajaati	50	25.5	Informal	21	10.7
Terai Aadiwasi/Janajaati	34	17.3	Primary	30	15.3
Hill Dalit	35	17.9	Secondary	70	35.7
Terai Dalit	7	3.6	Higher Secondary	30	15.3
Other	3	1.5	Bachelor or higher	12	6.1
Religion:			Occupational status:		
Hinduism	157	80.1	Un-employed	24	12.2
Buddhism	24	12.2	Student	5	2.6
Christianity	10	5.1	Agriculture	36	18.4
Other	5	2.6	Skilled labor	15	7.7
Socio-economic Status (SES)*			Un-skilled labor	25	12.8
First Quintile	6	3.1	Business	28	14.3
Second Quintile	9	4.6	Services(Gov/ Private/NGOs)	61	31.1
Third Quintile	18	9.2	Others	2	1.0
Forth Quintile	19	9.7	Monthly Income:		
Fifth Quintile	144	73.5	Maximum		50,000
* First quintile is low and fifth quintile is high socio-economic status			Minimum		1,000
			Mean		16,045

The age of the respondents ranges from 17 to 67 years, with the mean age being 34 years. The majority of the respondents were male (70%), more than a quarter female (28%) and a few belong to the third gender (2%). Nearly half of the respondents were married (47%) and a quarter either widowed (19%) or separated (5%). Caste/ethnicity-wise the respondents were fairly distributed with about one third Brahmin/Chhetri/Thakuri (34%), a quarter Hill Aadiwasi/Janajaati (26%), one fifth Dalit (22%) and 17% Terai Aadiwasi/Janajaati.

A large majority of the respondents were Hindu by religion (80%), followed by Buddhist (12%). The majority of the respondents were educated to secondary level or higher (57%) and about a quarter had no education (17%) or informal education only (11%). Only a small proportion of the respondents were unemployed (12%) or students (3%), while the remaining were involved in some other occupation including

government, private or NGO service (31%), agriculture (18%) and business (14%). The expressed monthly income of the household of the respondents ranged from Rs. 1,000 to Rs. 50,000, with a mean of Rs. 16,045.

The socio-economic (wealth) status calculated shows that nearly three quarters of the respondents belong to the fifth quintile and less than one in ten belong to the first two quintiles (8%).

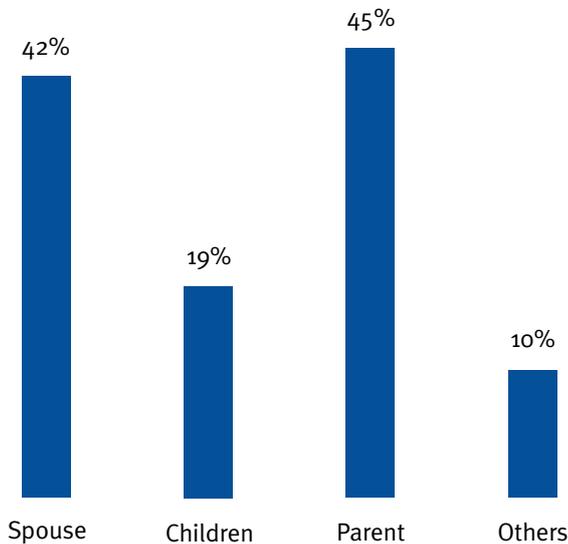
1 HIV/AIDS status: Disclosure and subsequent discrimination

As shown in Table 2, the mean duration that the respondents knew about their HIV status is 42 months, the range being from one to 144 months. About a third of the respondents affirmed that one or more of their family members are also HIV positive (32%). Of them, more than three quarters have spouses who are HIV positive and 16% have children who are HIV positive.

Table 2: HIV/AIDS status (n=196)

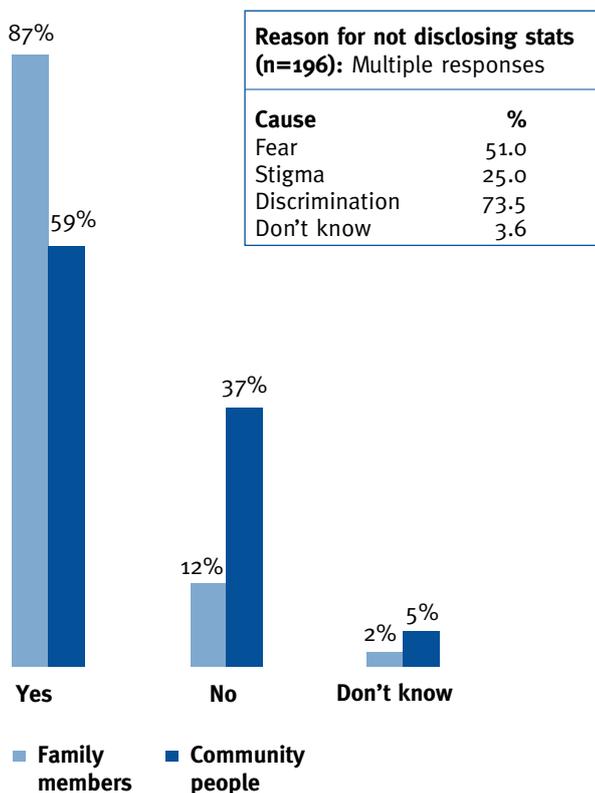
Variable	Frequency	Percent (%)
How long have you known as HIV positive?		
Maximum		144 months
Minimum		1 month
Mean		42.3 months
Is any of your family members HIV positive too?		
Yes	63	32.1
No	118	60.2
Don't know	15	7.7
Who are other family members positive? (N=74)		
Spouse	58	78.4
Children	12	16.2
Parent	1	1.4
Other	3	4.1
Are you on ART?		
Yes	91	46.4
No	105	53.6
How long have you been on ART? (n=91)		
Maximum		84 months
Minimum		0 months
Mean		28.9 months

Figure 1: Main care takers of the HIV Positive People (n=196)



Note: Multiple Response

Figure 2: Disclosure of HIV/AIDS status to Family and community (n=196)

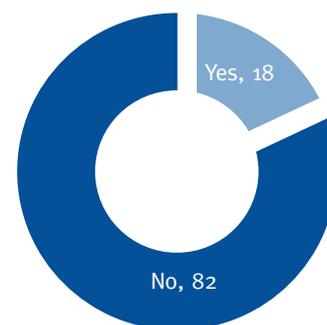


Nearly half of the respondents are on ART. The mean duration that they have been on ART is 29 months. As shown in Figure 1, in most cases, spouses (42%) and parents (45%) are reported to be the main caretakers when the respondent is sick. Remarkably, in about one fifth of cases, children are also reported to be caretakers (19%).

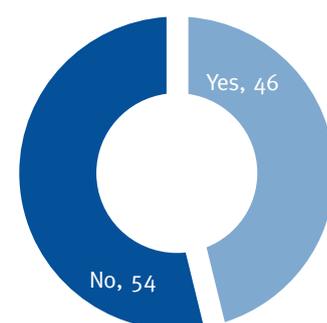
As given in Figure 2, almost nine out of ten respondents said that their family members knew about their HIV status (87%) and about six out of ten said that their community members knew (59%). On being asked what could be the reasons for people with HIV/AIDS not to disclose their HIV status, three quarters mentioned discrimination (74%), followed by fear (51%) and stigma (25%). Of those who responded with a discreet 'yes' or 'no', nearly two out of ten have faced discrimination from their family members (18%) and nearly half of them (46%) from community members (see Figure 3).

Figure 3: Discrimination faced by HIV Positive People

Discriminated by family members (n=170)



Discriminated by Community people (n=115)



On a positive note, it was reported in the FGDs and in depth interviews that there have been incremental changes in the attitude of community members and family members towards HIV/AIDS. One female, aged 35, from Doti, remarked that people's attitudes seem to have changed over the past two years due to the increase in publicity and information about AIDS on the radio, TV and in newspapers. She said that:

“We had to fight for our rights – we had many series of agitation organised to come to this status of certain compromised status. In the process, we had encouragement and moral support from health workers”.

2 Access to water supply and changing needs

Most of the respondents said they had an improved source as their main source of

drinking water (85%). Three quarters of the respondents had piped water as their main source of drinking water (75%), whereas only 16% depend on an unimproved source (well and surface water). Nearly two thirds of households pay for water – the monthly payment ranging from Rs.10 to Rs. 450, with a mean payment of Rs. 110. The travel time to fetch water ranged from 0 to 120 minutes, with the mean being around 20 minutes. The travel time was almost the same during the rainy and dry seasons. The daily use of water by households varies from three to 30 gaagri, with the mean being about 15 gaagri (a gaagri is roughly equivalent to 10 litres). Similarly, daily use by the respondents ranged from one to 11 gaagri, with the mean being 4.6 gaagri. The figures are given in Table 3.

Table 3: Access to Water Supply (n=196)

Variable	Frequency	Percent (%)	
Main source of drinking water			
Piped water in residence	119	60.7	
Piped water to tap in yard, plot	28	14.3	
Well	5	2.6	
Tube-well	13	6.6	
Deep Tube-well	6	3.1	
Surface Water	25	12.8	
Does your household have to pay for water?			
Yes	125	63.8	
No	69	35.2	
Don't know	2	1.0	
How much do you have to pay per month?			
Maximum		Rs. 450.0	
Minimum		Rs. 10.0	
Mean		Rs. 110.0	
Travel time to featch water			
	Minimum	Maximum	Mean time
Rainy season (in minutes)	0 min	120 min	20.41 min
Dry season (in minutes)	0 min	120 min	22.30 min
How many gaagri of water use a day?			
	Minimum	Maximum	Mean time
By Household	3	30	14.8
By HIV Positive personnel	1	11	4.6

Although three quarters of the respondents have piped water in urban areas and this implies that the majority of households in Nepal have access to a water supply, many in the FGDs and in depth interviews reported having to suffer acute water shortages. In fact, one in four did not have access to a water supply that can be considered safe. Also, the quality and regularity in water flow was reported to be poor with it getting much worse during the rainy season when the water is clearly muddy as reported by one female participant from Lalitpur in a FGD:

“There is a tap in the house but what use it is when there is no water supply? We get water only twice a week. In monsoon the water that comes out of the pipe cannot be used for any purpose – it is plain dirty water”.

As shown in Figure 4, only one in ten respondents mentioned having experienced discrimination by family members (11%) and two out of ten by people outside the household, while collecting water.

As can be seen in Table 4, half of the respondents mentioned that their need for water has increased after they have become HIV positive and they mentioned that the increased need is in most cases for drinking water (89%), toilets/ sanitation (83%) and bathing (55%).

Figure 4: Discrimination faced by HIV Positive People to access water

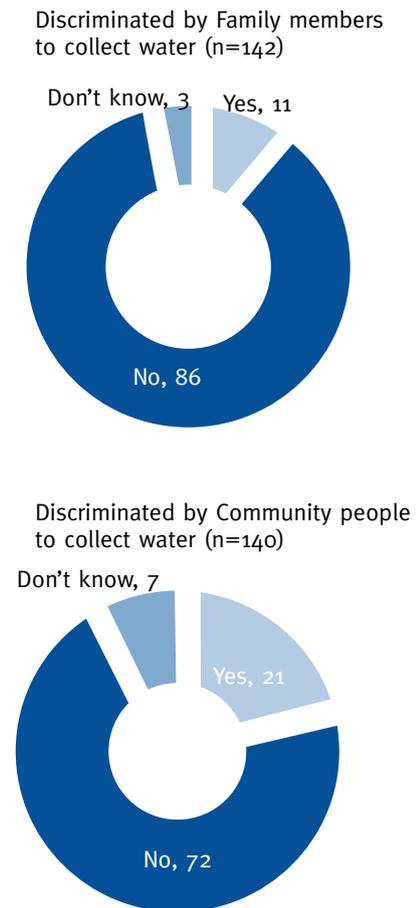


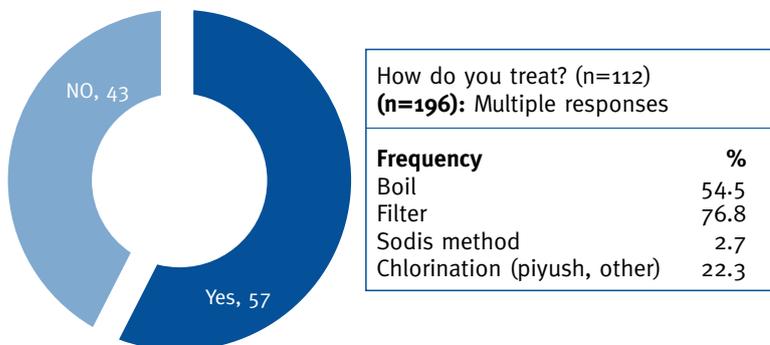
Table 4: Water need after HIV Positive and use (n=196)

Variable	Frequency	Percent (%)
Need of water after HIV positive (n=196)		
Increased changed need of water	102	52.0
What is the increased needs of water for? (n=102)		
Drinking	91	89.2
Toilet/sanitation	85	83.3
Bathing	56	54.9
Washing cloths	38	37.3

Respondents in all FGDs also stressed the increased demand for safe water for keeping the environment of the house and toilets clean in order to reduce the risk of opportunistic infections. The respondents pointed out that PLHA require more water than the standard norm of 20 litres per capita per day. Fetching water can be a particular strain for PLHA who experience fluctuating and diminishing energy levels or side effects from ARV medication.

More than half of respondents (57.1%) treated water before drinking. Of the respondents who treated the water, the majority filtered (77%) and boiled (55%) it (see Figure 5). However, there was a particularly significant urban–rural disparity with 98% of urban households in the valley using filtered and boiled (treated) water compared to rural areas (in hill) which was only 19% ($\chi^2=62.058$, $df=2$, $p=0.000$).

Figure 5: Did you treat water before drinking? (n=196)



3 Access to sanitation facilities and changing needs

As shown in Table 5, most of the respondents said they used an improved toilet facility (flush toilet, closed pit latrine or slab latrine) (74%), however, about one quarter still used unsafe toilets (open pit latrine, bush/field latrine) (26%).

Urban sanitation coverage at 100% for valleys was significantly greater than rural hill coverage at 15% (see Table 6). The travel time

to find somewhere for defecation ranged from 0 to 60 minutes, with the mean being around five minutes. On average, five households shared improved toilet facilities.

Respondents were asked whether they had experienced an increased or changed need for water and sanitation since being tested positive for HIV/AIDS and if there were other issues related to accessing water facilities. About one third (32 %) of all respondents indicated that they needed to use toilet facilities more. When probed further during the FGD, the pattern of this reported daily increase was found to be related to episodes of diarrhoea or general weakness. Participants also shared experiences of the difficulties they faced when they suffered episodes of diarrhoea and needed more water and more frequent visits to the toilet. With regards toilet use, only 7% mentioned discrimination by family members and 12% by people outside the household. (Figure 6).

Though the study recorded improved access to toilet facilities, water still had to be carried from the water source to the toilet. Information from the FGDs underscored the vital importance of access to toilets for PLHA and pointed out that as people approach the terminal stage, access to sanitation facilities becomes more important as people cannot travel long distances with much lower energy levels. People defecating by bushes or in open spaces because of lack of access to toilets feeds into the vicious cycle of poverty, disease and bad hygiene for PLHA and other people. Although all those who lack adequate sanitation facilities are exposed to unpleasant and unhealthy daily routines, the impact on women is greatest. They often suffer discomfort during menstruation when not able to relieve themselves conveniently and safely.

Table 5: Access to sanitation facilities for HIV positive and use (n=196)

Variable	Frequency	Percent (%)
Access to toilet facility at household		
Flush toilet	67	34.2
Closed pit Latrine	71	36.2
Open Pit Latrine	8	4.1
Slab Latrine	7	3.6
Bush/Field as Latrine	43	21.9
How long does it take to go for defecation?		
Maximum (in minutes)		60 min
Minimum (in minutes)		0 min
Mean (in minutes)		4.8 min
How many household share the toilet?		
Maximum		12
Minimum		1
Mean		5
Increased need of toilet after became HIV positive?		
Yes	63	32.1
No	99	50.5
Don't know	34	17.3

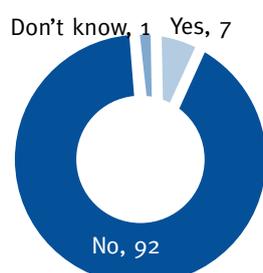
Table 6: WASH status by ecological region (n=196)

Ecological region	Types of toilets	
	Improved	Not improved
Rural hill	7(15%)	40(85%)
valley	50(100%)	0(0%)
Terai	88(89%)	11(11%)

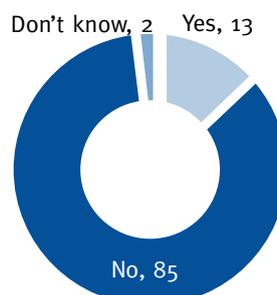
($\chi^2=114.258$, $df=2$, $p=0.000$)

Figure 6: Discrimination faced by HIV Positive to use toilet

Discriminated by Family members to use toilet (n=179)



Discriminated by Community people to use toilet (n=162)



4 Hygiene perception and practice

Hygiene is essentially about people's behaviour, and personal hygiene focuses on keeping the body, and particularly the hands, clean as an effective means of avoiding exposure to food and water borne diseases. In this way people do not act as transmitters of disease.

Table 7 provides an overview of the hand washing, bathing and brushing practices of the respondents. More than nine out of ten said that they washed their hands before having food (86%), after having food (96%) and after going to the toilet (100%). In most cases respondents only use water, except after going to the toilet when 84% use soap as well (please see Table 8). Relatively few respondents mentioned washing hands after working with dust/animal dung (43%), before feeding their baby (19%) and after cleaning their child's bottom (16%). The latter cases could be because not many of the respondents were involved in these tasks.

Some people in the FGD reported that water was not available close to toilets, making it difficult to clean hands satisfactorily after defecation. In addition, people who didn't use soap regularly said it was because it was not readily available or they can't afford it. Respondents said that they didn't use soap when it was not kept nearby. However, many people who didn't use soap used other materials, such as ash or soil, as a cleanser. Hence, it was most common for people to wash their hands with water alone.

Eight in ten respondents bathed twice a week or more (79%) and the rest bathed once a week or less (21%). Of those who bathed once a week or less, the major reason given was that they don't like to (68%). Lack of water (12%), not being able to afford soap (4.9%) and discrimination by family members (2%) were less frequent causes. Almost all respondents brushed everyday (97%), however, only 23% brushed twice or more daily (see Table 7).

Table 7: Hygiene practice (n=196)

Variable	Frequency	Percent (%)
When do you wash your hands?		
Before having food	169	86.2
After having food	190	96.1
After going to toilet	195	99.5
After working with dust/animal dung	84	42.9
Before feeding baby	37	18.9
After cleaning child's bottom	32	16.2
Before taking medicine	16	8.2
How often do you take bath?		
Everyday	34	17.3
Every alternate day	53	27.0
Twice a week	68	34.7
Once a week or less frequent	41	20.9
Why don't you take bath frequently (n=41)		
Don't like to	28	68.3
Don't think necessary	5	12.2
Due to lack of Water	5	12.2
Can't afford soap	2	4.9
Discriminated by family members	1	2.4
How many times do you brush your teeth in a day?		
Once every day	144	73.5
Twice or more every day	45	23.0
Less than once everyday	7	3.6

As given in Figure 7, seven out of ten respondents have received hygiene related training (72%). In most cases they received the information from HIV/AIDS service centres (37%) and support groups (35%).

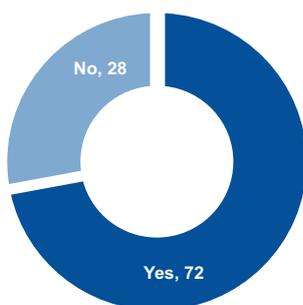
It is important to note that although hygiene practice is mainly a case of developing hygienic behaviour, it is also

enhanced by access to an adequate supply of washing materials (soap, towels, etc) and water. A higher number of respondents reported disliking baths which suggests a gap between knowledge and practice – people do not always use their knowledge and hygiene practices are often not adequate.

Table 8: Hand washing at critical times (n=196)

Hand washing at critical times	Use of cleaning agent during hand washing (n=196)									
	Water only		Soap and water		Ash and water		Mud and water		Nothing	
	N	%	N	%	N	%	N	%	N	%
Before having food	127	64.8	47	24	1	0.5	0	0	21	10.7
After having food	133	67.9	56	28.6	0	0	1	0.5	6	3.1
After going to toilet	1	0.5	164	83.7	19	9.7	11	5.6	1	0.5
After working with dust /animal dung	26	13.3	56	28.6	9	4.6	0	0	105	53.6
Before feeding baby	28	14.3	9	4.6	1	0.5	0	0	158	80.6
After cleaning child's bottom	2	1	27	13.8	9	4.6	3	1.5	155	79.1
Before taking medicine	15	7.7	8	4.1	1	0.5	2	1	170	86.7

Figure 7 : Did you receive hygiene related training? (n=196)



Where did you receive the information from? (n=142)	
Means	%
Family members	1.4
Support Group	34.5
Health post/Hospital	9.2
VCT/ART/PMTCT/Rahab centre	36.6
Radio/TV	15.5
Newspaper/Magazine	2.8

As shown in Figure 7, 28% of PLHA did not receive hygiene related training. The study explored with service providers the information provided to PLHA. Current forms of IEC support have concentrated on medical, counselling and ART and not specifically on hygiene practices.

Table 9 clearly indicates that the majority of respondents believe that PLWH have an increased need for improved hygiene (94%) with the majority saying that it's because PLWH are more vulnerable to illnesses (87%). When asked which illnesses they thought were most frequent among

Table 9 : Perception on hygiene and frequent illnesses (n=196)

Variable	Frequency	Percent (%)
Do HIV positive people have increased need for better hygiene?		
Yes	185	94.4
No	11	5.6
Why do you think HIV positive have increased need? (multiple response)		
They are vulnerable for illnesses	171	87.2
To prevent AIDS	34	17.3
Others	2	1.0
What are the frequent illnesses that HIV positive people suffer		
Diarrhoea / Dysentery	155	79.1
Skin Diseases	46	23.5
Typhoid	8	4.1
Trachoma	1	0.4
Hepatitis / Jaundice	17	8.7
Tuberculosis	78	39.8
Oral thrush	13	6.6
Pneumonia	15	7.7
Don't know	11	5.6
What do you think are the causes of diarrhoea? (multiple answer)		
Unsafe water	171	71.9
Unclean food	128	65.3
Poor hygiene	67	34.2
Unclean surrounding	40	20.4
Improper toilet use	36	18.4
How do you think HIV positive people can prevent diarrhoea?		
Drinking safe water	139	70.9
Eating clean food	122	62.2
Maintaining good hygiene	83	42.3
Keeping surrounding clean	43	22.2
Feaces management	39	19.9

PLWH, the majority of respondents said diarrhoea/ dysentery (79%), tuberculosis (40%) and skin diseases (24%). Unsafe water (72%) and unclean food (65%) were the major causes for diarrhoea listed by the respondents.

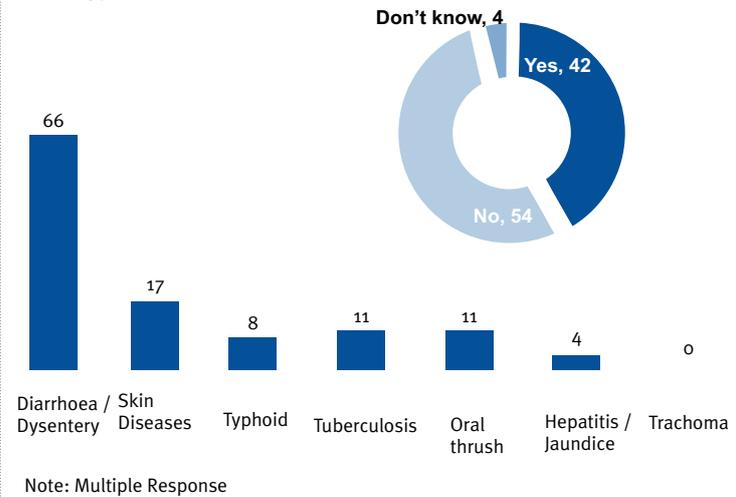
Remarkably, poor hygiene (34%), unclean surroundings (20%) and improper faecal management (18%) were mentioned far less frequently. However, the majority of respondents did say that drinking safe water (71%) and eating clean food (62%) were the major ways to prevent diarrhoea by PLWH. There is also a general awareness about the link between disease and poor water, sanitation and hygiene and, as the survey indicates, about 72% of respondents recognised that there is a close connection between unsafe water and diarrhoea.

With widespread general knowledge about the link between sanitation and disease, one would expect toilets to be everywhere and considered a high priority. However, the link between knowledge and practice seems to be missing. The perception of risk is higher but many claim that due to an absence of enabling factors, eg the lack of resources required for the construction and maintenance of clean toilets, the tasks are made much more difficult.

5 Illness and treatment

Half of respondents said they had experienced a change in their health after becoming HIV positive (52%). Four out of ten mentioned having been ill in the last three months (42%) and most of those who became ill had suffered from diarrhoea/ dysentery (66%), skin disease (17%), tuberculosis (11%) and oral thrush (11%) (see Figure 8).

Figure 8 : Experience of Illness in last three months (n=196) and types of diseases (n=83)



Almost all of those who had become ill took medicines/remedial measures (99%); most of them seeking treatment at government health facilities (70%), NGO facilities (31%) and private health facilities (15%). Half of the respondents who had sought treatment said that the service provider had given WASH related information during their visit (54%). The figures are given in Table 10.

Tables 11a and 11b show some associations between illnesses (particularly diarrhoea) and variables of water, sanitation and hygiene related practice. Significant associations can be seen between hygiene training, location of toilet within the compound and socio-economic status (reflected in quintiles). However, the association between illness and water treatment, hand washing and bathing is not statistically significant.

Many of those who hadn't received hygiene related training in the previous three months reported being significantly ill (59%). Of those who doesn't have a toilet within their compound almost 63% were ill. Those who fall under the lowest quintile were more likely to be

Table 10: Opportunistic infections and treatment seeking practice (n=196)

Variable	Frequency	Percent (%)
Change in health since became HIV positive		
Yes	102	52.0
No	79	40.3
Don't know	15	7.7
Have you been ill in last three months?		
Yes	83	42.3
No	105	53.6
Don't know	8	4.1
What did you suffer with? (n=83) - multiple responses		
Diarrhoea / Dysentery	55	66.3
Skin Diseases	14	16.9
Typhoid	7	8.4
Trachoma	0	0.0
Hepatitis / Jaundice	3	3.6
Tuberculosis	9	10.8
Oral thrush	9	10.8
Pneumonia	8	9.6
Did you take medicines / remedials measures? (n=83)		
Yes	82	98.8
No	1	1.2
Treatment seeking practice (n=82) - multiple responses		
At home only	7	8.5
Government health post / hospital	57	69.5
Private health facility	12	14.6
NGOs facility	25	30.5
Medical shops	2	2.4
Faith-healers	5	6.1
Did service providers give you WASH information? (n=82)		
Yes	44	53.7
No	34	41.5
Don't remembers	4	4.9

ill compared to those with the highest economic status. In the last three months, 83% people from the lowest quintile and only 39% from the highest quintile suffered from diarrhoea.

Increased awareness of HIV/AIDS and HIV prevention programmes has made PLHA cognisant of the treatment possibilities.

Nearly 100% of respondents were recipients of some kind of service – be it directly or indirectly health related. During the FGDs it was clear that many PLHA had an optimistic attitude towards life as a result of easy access to ARV. As one of the female participants from Doti said:

Table 11 a: Cross-tabulation with illness by different variables (n=196)

Received hygiene info/training	Illness in last 3 months		Statistical Significant
	Yes	No	
Yes	51(36)	91(64)	$(\chi^2=8.732, df=1, p=0.003)$
No	32(59)	22(41)	
Toilet located within compound	Illness in last 3 months		Statistical Significant
	Yes	No	
Yes	60(39)	92(61)	$(\chi^2=4.494, df=1, p=0.034)$
No	15(63)	9(37)	
Treat water before drinking	Illness in last 3 months		Statistical Significant
	Yes	No	
Yes	46(41)	66(59)	$(\chi^2=0.174, df=1, p=0.676)$
No	37(44)	47(56)	
SES Status	Illness in last 3 months		Statistical Significant
	Yes	No	
First Quintile	5 (83)	1 (17)	$(\chi^2=5.509, df=4, p=0.206)$
Second Quintile	5 (56)	4 (44)	
Third Quintile	9(50)	9(50)	
Forth Quintile	8(42)	11(58)	
Fifth Quintile	56(39)	88(61)	

Table 11b: Cross-tabulation with illness by different variables (n=196)

SES Status	Suffered with diarrhoea in last 3 months		Statistical Significant
	Yes	No	
First Quintile	5 (83)	1 (17)	$(\chi^2=12.517, df=4, p=0.014)$
Second Quintile	2(22)	7(78)	
Third Quintile	4(22)	14(78)	
Forth Quintile	2(11)	17(89)	
Fifth Quintile	42(29)	102(71)	
Washing hands after cleaning child's bottom with	Suffered with diarrhoea in last 3 months		Statistical Significant
	Yes	No	
Water only	1(50)	1(50)	$(\chi^2=3.190, df=4, p=0.527)$
Soap and water	5(19)	22(81)	
Ash and water	3(33)	6(67)	
Other	0(0)	3(100)	
Nothing	46(30)	109(70)	
Taking bath	Suffered with skin diseases in last 3 months		Statistical Significant
	Yes	No	
Every day	0(0)	34(100)	$(\chi^2=4.595, df=3, p=0.204)$
Every alternate day	6(11)	47(89)	
Twice a week	4(6)	64(94)	
Once a week of less	4(10)	37(90)	

“I think in Doti awareness about HIV and AIDS has improved in the last three years. Lots of efforts have gone into prevention part and making people feel confident that HIV is not a killer disease... that we can get well and live as normally as possible. But still we have to take the medicine.”

Nine out of ten respondents who had sought treatment said that the health care provider was aware of their HIV status and very few felt that they were discriminated by them because

of this. The figures are given in Table 12. It was also evident from the FGDs that most of the respondents who were part of some support group had faced less discrimination from the service providers. This reflects a greater awareness and sensitivity amongst the providers catering to PLHA thanks to the extensive HIV/AIDS programming.

6 Stigma and discrimination

The discriminations faced by PLHA on different occasions from family, communities and/or

Table 12: Discrimination faced by HIV positive people

Variable	Frequency	Percent (%)
Discrimination by Health Providers		
Was the service providers aware of your HIV positive (n=82)		
Yes	74	90.2
No	4	4.9
Don't remember	4	4.9
Did you feel discriminated by service providers? (n=78)		
Yes	6	7.7
No	72	92.3
Discrimination to use water facilities:		
Prevented to collect water because of HIV positive (n=145)		
Yes	17	11.7
No	125	86.2
Don't know	3	2.1
Family member ever prevented from collecting water? (n=142)		
Yes	15	10.6
No	123	86.6
Don't know	4	2.8
Discriminated out-side your household (n=140)		
Yes	30	21.4
No	101	72.1
Don't know	9	6.4
Refused to use toilet		
Refused to use toilet by family members (n=179)		
Yes	13	7.3
No	164	91.6
Don't know	2	1.1
Refused to use toilet by outside family members (n=162)		
Yes	19	11.7
No	137	84.6
Don't know	3	1.9

Note: Responses were asked only to those who disclose their status

health service providers have been mentioned in the relevant sections above. However, to get an overall glimpse of the situation, the figures are presented again in Table 12.

It is clear that the discrimination faced by PLHA is not as high as it could be. This is probably as a result of the extensive HIV programming focused on prevention, treatment and care, including de-stigmatisation. The relatively lower levels of discrimination may also be due to the fact that the study was conducted with those who visit a centre for HIV/AIDS related services, and the fact that many of them are affiliated to one or other support group. As a result, they may be an advantaged group amongst PLHA. However, discrimination is still much more prevalent in the community.

Qualitative information drawn from FGDs and in depth interviews shows that stigma and discrimination exist in varying forms, affecting

different individuals to varying degrees. Fear of disclosure is a form of ‘felt stigma’; an anticipation of the damaging effect disclosure can have on an individual and the possible mistreatment his or her family may face in their community. This anticipated, ‘internalised stigma’ can lead to a self-imposed withdrawal from family and community. One HIV positive individual, aged 29 years old, from Rupendehi, described his perception of the social pressures he felt while concealing his status:

“You know the society... how it is. There are still many people who think that HIV positive is an immoral. So, I strongly feel that one should not disclose the status anywhere you like – but do it discreetly, depending on the need”.

The case study of a young individual from Sunsari highlights this sense of discrimination further (please see Case Study 1 below).

Case study

Case study 1

Mr A, a 28 year old unmarried male from Brahmin/Chettri family, from Sunsari, was an ex-intravenous drug user. He was diagnosed with HIV nine years ago and was on ART for three and a half years. He was affiliated with an NGO working on HIV and AIDS. He came from a middle class family with two older brothers and sisters. He only had primary schooling.

Mr A disclosed his HIV status to his family but unfortunately then suffered continuous discrimination both from family members and his community. He was not allowed to enter the kitchen, share the toilet or even use the tap in the house. He was also restricted from touching other family member’s plates. He was forced to use the public tap in the community – a two minute walk from the house – and had to use it only after everyone had finished their turn. The public tap was usually crowded. He lamented, “Even if the water is overflowing in the house, what to do – I cannot use it”. He drank water directly from the tap and stored water in a plastic bottle which had to last for at least three to four days.

He had to get up early in the morning, before everyone else, so that he could use the toilet. Life was a bit easier in the office due to easy access to water and the toilet. He even brushed his teeth in the office. At night he hit the road looking for a toilet.

Mr A's encounter with discrimination both at the hands of family and community members made him regret his HIV status disclosure. He confirmed, "I have made a grave mistake. If I had not informed others at least I would not have suffered such ill behaviour. Since I have left drugs many unpleasant things have happened to me – when I was on drugs such things never happened to me". The inhuman sufferings made him desperate and he broke down in tears and angry outburst several times. He revealed, "I wish I could transmit the disease to all of them so they would know and feel what it is to live with HIV".

His health continued to deteriorate as he suffered a tuberculosis relapse. [In the interview Mr A was very weak due to severe diarrhoea that he had been suffering from for the past two weeks. He was so weak and thin that he mentioned he did not have the strength to go the hospital nor enough money for medicine. Unfortunately, two weeks after the interview, Mr A passed away in the hospital under the care of a support group. The family members decided not to be involved even in his last rites.]

The insidious form of felt stigmatisation was also expressed by an active 32 year old community mobiliser from Doti who was HIV positive. Though she acknowledged that in Doti over the last ten years people with HIV have become better informed and empowered to accept their status and demand services, she candidly reflected:

"We know that there are still some people in the community who are not open about their HIV status. Yes, they are not open about their status because they are ashamed of their status. They are ashamed and there are still people in the community who will always judge that people get HIV because they did something bad".

It is evident through FGDs and from the survey responses that a remarkable positive change in the attitude of community members, family members and health care providers towards HIV and AIDS is in progress and has to be sustained. Participants talked about their struggles – organising a series of demonstrations both in Kathmandu and district headquarters to

achieve this 'status of certain compromised status' and acknowledged various actors, especially the moral support of the health workers. It appears that in some villages affected by HIV/AIDS, community members have become more accustomed to meeting and interacting with people who have HIV/AIDS and after time have realised that they are not at risk from infection if they take appropriate precautionary measures.

The dynamics of the HIV/AIDS epidemic in Nepal have taken the predictable path of a rapid increase in high risk groups (eg female sex workers, injecting drug users), followed by a spread via 'bridge' populations (eg clients of female sex workers including labour migrants, partners of injecting drug users) and then into the general population (eg housewives and children). Children who are orphaned as a result of HIV/AIDS and are HIV positive experience a particularly tough time. Children are not welcomed by their extended families or relatives and are seen as an unwanted burden. Dispossessed orphans are often obliged to leave their homes and to live in unfamiliar places in Case study 2, below.

Case study 2

Ms B, a 12 year old girl living in a crisis centre, has been orphaned for the last eight years. She has two older siblings, both married and settled. Her eldest brother is working in India. Prior to hospitalisation and referral to the crisis centre she lived with her grandfather and sister-in-law.

She has suffered poor health from childhood. However, her health started deteriorating when she was seven and she was brought to Doti District hospital for a check up and treatment. Tests conducted in the hospital confirmed her HIV status. The premature loss of her parents has translated directly into a loss of love, care, basic security and support. It is reported that she has poor compliance to medication. In addition, her general appearance indicates physically weakness, slow gait, ill-kempt and stunted growth, slurred speech, slow movements and weak expressions. At a crisis centre she was encouraged to go to school but she showed complete disinterest.

Ms B reports a lack of interest (mann na laagne) even for basic self care which is further perpetuated by her decreased strength. Counsellors at the crisis centre have decided to refer her to a more child friendly crisis centre with more specialised psychological support in Dhangadi. It is yet to happen.

Discussion

The study highlights the specific challenges faced by PLHA in accessing clean and safe water, adequate sanitation facilities and basic hygiene behaviours.

It must be noted that there are several important disparities associated with the accessibility of water supply, as highlighted by this study. In Nepal, as in many other developing countries around the world, the rich are more likely than the poor to have improved water. Rural people have lower access to piped water than the urban, and water treatment practice is less frequent in rural areas. The study also documents a clear need to access water both in terms of quality and quantity. As is evident by various studies, the importance of access to safe and clean water cannot be underestimated. It is clear that most PLHA have greater water requirements which increase their burden and mean higher costs, putting both physical and psychological demands on them and their household.

Many people in rural areas don't have access to improved toilet facilities and even in urban areas where people have a toilet, availability of water impedes them in maintaining proper sanitation. Poor health and episodic diarrhoea put tremendous pressure on PLHA to defecate in the open which may increase the risk of opportunistic infections to all users – both PLHA and non-PLHA. It is clear that there is awareness about the need for improved sanitation, but there are a lack of enabling factors such as access to water and finance for construction.

There is a positive indication that awareness about HIV and AIDS has been raised in certain families, communities and VDCs through HIV and AIDS support and advocacy programmes. It appears that in some villages and districts that have been affected by HIV/AIDS, community members have become more proactive, are used to meeting and interacting with people who are infected and, after time,

have realised that they are not at as much risk of infection as they thought. However, at the same time we should not ignore the fact that nearly one third of respondents reported not receiving any hygiene related information during their counselling or stay at the centre. This represents a big missed opportunity. Further, IEC services to PLHA in general are more medically oriented, focusing on the treatment part without the necessary attention to WASH which has a higher importance for this sub-group of the population.

Discrimination faced by PLHA is not reported as grave. The findings suggest that there has been progress in some families and communities in accepting members who have HIV/AIDS. Since all of those interviewed belonged to one or more support groups for PLHA, this could be seen as a positive impact of the psycho-social counselling, care, treatment and support that the households are receiving. An addition, for most respondents, the disease had not yet progressed into AIDS. Literature indicates that stigmatisation is severe once the

disease progresses into AIDS. However, there are clearly many individuals who are still fearful and, as a result, discriminate against people who are HIV positive. The case study of a young HIV positive male shows how stigma and discrimination in families and communities can intersect and heighten deteriorating psychological, socio-economic and physical conditions.

Encouragingly, as revealed in the discussions with service providers, the potentialities of accommodating WASH related information in IEC materials and counselling within HIV and AIDS programmes are tremendous. Similarly, WASH programmes can pave the way in emphasising the need to address misconceptions about HIV and AIDS by community and family members with regards stigma, hygiene and the sharing of a toilet or public tap with PLHA. It is urgent to address this critical issue through the existing care and support programmes for PLHA. In addition, WASH programmes can explore ways of encouraging community engagement in providing water and sanitation access to PLHA.

Possible action

Based on these findings, the study proposes the following possible actions:

- As HIV/AIDS is a multi-sectoral issue, the needs of PLHAs cannot just be addressed medically or by any single sector. Stakeholders in the WASH sector should revisit their policies and programming to mainstream HIV/AIDS and they should reciprocally advocate with government and stakeholders in the HIV/AIDS sector to mainstream WASH in their policies and programming. A thorough gap analysis of these sectors vis-à-vis each others' issues carried out with the close participation of PLHA can be the first step towards
- mainstreaming both sectors' issues.
- Water, sanitation and hygiene programmes should be well positioned to develop strategic partnerships with other stakeholders, such as those working on HIV and AIDS, to ensure that vulnerable households, including those made vulnerable by HIV and AIDS, have access to water and sanitation facilities and practice proper hygiene behaviours. Their work can include the removal of myths and misconceptions around HIV transmission – to reduce stigma and discrimination attached to WASH. While maintaining the focus on PLHA, however, in view of

mitigating the stigma, the approach needs to redress community information and WASH needs on a larger scale, rather than targeting only HIV-affected individuals and families. This can include simple promotional measures such as providing safe drinking water and clean sanitation facilities at HIV/AIDS service sites (eg ART centres) which practically reinforces the counselling and education received in the service site and encourages and motivates PLHA to adapt such WASH measures at home and in their community.

- Based on the study findings, there is an urgent need to jointly develop common and simple messages on the importance of WASH by both WASH programmes and HIV/AIDS programmes, targeting PLHA particularly about safe drinking water including point of use, management of faeces (hygienic use of latrines), hygiene practices and reduction of WASH associated stigma etc.
- Instructions for safe water, sanitation and hygiene practices can possibly be linked to an expanded programme of HIV education and prevention, including the developed capacity of service providers for requisite skills to encourage such practices. Common and simple messages on water, sanitation and hygiene can be developed and used by both water and sanitation programmes

and HIV/AIDS programmes. Guidelines developed by HIV/ AIDS prevention programmes should accommodate WASH issues such as information about ways to keep PLHA and their environment clean and treating water to keep it safe. Opportunities for counselling and/or educating PLHA should not miss out on delivering appropriate messages on WASH issues.

- Advocacy is needed for HIV/AIDS programmes and interventions for the provision of water treatment agents as part of PLHAs' medical treatment support packages, particularly for rural sub-groups who have less access to safe water and practice water treatment less often. Advocacy also needs to be carried out with sanitation sector policy makers and programming professionals and agencies to accommodate special support packages to address the highly increased sanitation needs of PLHA, for example by providing subsidies for improved and accessible sanitation facilities.
- In addition to intervention approaches and collaboration, a possible further study is needed to assess who is being excluded from access to water and sanitation services where WASH projects have been implemented. This will inform the exclusion pattern and provide a clearer picture of who is not getting access to the services.

Conclusion

Great strides have been made in recent years to dispel myths and misconceptions around HIV transmission. However, much remains to be done with regards to water, sanitation and hygiene – considering the greater need of PLHA. Meeting the water, sanitation and hygiene needs of PLHA underscores some of the biggest challenges in basic access to these rights. The study helps in substantiating this further in the Nepalese context. Those people with the greatest needs are often the

most disenfranchised and have the fewest resources available for solving problems in sustainable ways. It is therefore imperative that gains made by HIV and AIDS prevention programmes are not compromised by lack of attention and efforts to address WASH issues associated with HIV/AIDS. There is also an urgent need for greater advocacy to mainstream WASH in HIV/AIDS programming and vice versa by establishing the link between various related sectors.

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Access to water, sanitation and hygiene for people living with HIV and AIDS: A cross-sectional study in Nepal

The study was conducted to generate evidence based from field in order to increase the understanding of PLHAs' access to WASH and its impact on their daily lives thereby to inform the health, HIV/AIDS and WASH sectors in Nepal. The study report further highlights the attached discrimination, stigma and exclusion associated with WASH among PLHAs. Furthermore, the hygiene practices, opportunistic infection and treatment seeking practice of PLHA's were also featured in the study.



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