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

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People living with HIV/AIDS (PLHA) are one of the most vulnerable people to WASH associated diseases in Nepal. They are still stigmatized while enjoying WASH services and their risk & vulnerability are further exacerbated due to lack of inadequate WASH. A descriptive cross-sectional study was commissioned by WaterAid in Nepal (WAN) with the objectives to increase understanding of PLHA's access to WASH and its impact on their daily lives in order to inform health, HIV and WASH sectors. This was a cross-sectional study used mixed methods. Data were collected from 196 PLHAs from different geographic areas. The study does re-emphasize that PLHA have limited access to safe water and improved hygiene & sanitation services, more pronounced in rural areas than in urban. There is an increased need of WASH for them but lacking to meet the needs. Lack of access to WASH and its effect on quality of life invariably call for an urgent action by all stakeholders. The study also revealed some evidence of stigma and discrimination faced by PLHAs.

Background

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 / AIDS interventions or WASH sector programmes in Nepal.

Objectives

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 about 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%). The crux of the findings of the study is categorized in following sub-headings:

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%).

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.

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.

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 do not 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 e.g lack of resources required for the construction and maintenance of clean toilets, hygiene practices are more difficult to implement.

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).

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. 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 urgently warranted. Limited access to resources e.g 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 can be the first step towards mainstreaming both sectors' issues.

- WASH programmes need to develop strategic partnerships with 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, clean sanitation facilities and proper hygiene messages at HIV/AIDS service sites.
- 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.
- 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 WASH services where WASH projects have been implemented. This will inform the exclusion pattern.

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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