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**DELIVERING WATER, SANITATION AND HYGIENE SERVICES
IN AN UNCERTAIN ENVIRONMENT**

**Assessing the water, sanitation and hygiene needs of
people living with HIV and AIDS in Papua New Guinea**

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People living with HIV and AIDS (PLHIV) are susceptible to opportunistic infections, and access to safe water, adequate sanitation and hygiene (WASH) are crucial to safeguarding the health of PLHIV and their families. This study was designed to gain an understanding of how WASH affects the lives of PLHIV in Papua New Guinea (PNG). The research was conducted in partnership with WaterAid and Anglicare PNG. Anglicare staff administered surveys to 93 respondents across urban, peri-urban and rural PNG. The research revealed that PLHIV in PNG have increased needs for WASH, and that these needs are not being adequately met. Stigma and discrimination were found to be barriers to access to WASH for respondents and their families. In addition, this study identified priorities of where service providers can direct their future activities and best integrate WASH into programming for PLHIV.

Background

In 2010, approximately 32,000 people were living with HIV in Papua New Guinea (PNG) (National AIDS Council Papua New Guinea, 2011). PNG has a generalised HIV epidemic and it is predicted that the number of people living with HIV and AIDS (PLHIV) will increase over the coming years (UNAIDS, 2012). As comprehensive care, treatment and preventative services improve across PNG, it is anticipated that PLHIV will live longer and healthier lives. However, PLHIV are susceptible to illness and opportunistic infections. Many life threatening opportunistic infections are caused by exposure to unsafe drinking water, inadequate sanitation and poor hygiene (World Health Organization, 2010). Diarrhoea is one of the leading causes of infections among PLHIV; over 90% of PLHIV in developing countries will experience persistent episodes of diarrhoea (Thom and Forest, 2006). This susceptibility decreases as a person commences anti-retroviral (ARV) therapy. However, up to 40% of PLHIV on treatment will continue to experience at least one diarrhoeal episode per month (Knox *et al*, 2000). Additionally, diarrhoea may affect the absorption of ARV medication and reduce the medication's effectiveness. This reduction in effectiveness can result in poorer health outcomes for PLHIV (Bushen *et al*, 2004).

Access to safe water, adequate sanitation and hygiene (WASH) behaviours can mitigate the risk of diarrhoeal disease (Bateman *et al*, 2002; Curtis and Cairncross, 2003; Fewtrell *et al*, 2005). When practised together, behaviours such as the treatment and safe storage of water, safe disposal and handling of faeces and hand washing with soap have been found to reduce the prevalence of diarrhoeal disease by approximately two thirds (Bateman *et al*, 2002). The Water and Sanitation Program (2007) found that HIV-affected households require more than twenty litres of water per person, per day. Furthermore, a recent study conducted by WaterAid Nepal revealed that 52% of PLHIV expressed an increased need for water for drinking, bathing and sanitation. This increased need for water may increase the burden of care a family provides to family members with HIV during periods of illness (WaterAid, 2010). Therefore, critical to the care and health of PLHIV, is the provision of adequate WASH tailored to their specific needs.

In PNG, WASH-related health statistics are among the worst in the Pacific region. Nationally, only 40% of the population has access to safe water and 45% to improved sanitation. However, national figures do not reflect the discrepancy between rural and urban coverage; urban PNG has higher access to safe water and sanitation, at 87% and 71% respectively, compared to access in rural population, at 33%

and 41%, respectively (Joint Monitoring Program, 2012). The coverage has remained largely unchanged over the last 10 years.

Description of the research

Anglicare, one of the largest NGOs working in HIV and AIDS in PNG, and WaterAid, recognise the poor WASH coverage in PNG and the pressing need to introduce WASH practices into HIV programming. Existing literature acknowledges the importance of WASH for PLHIV, yet knowledge and practices surrounding WASH is variable and context specific. Therefore, in partnership, this research was designed to elucidate the specific WASH needs of PLHIV in PNG to inform future Anglicare initiatives and programming for PLHIV. Specifically, it aimed to assess the current WASH knowledge, perceptions and practices of PLHIV in PNG in order to identify gaps and recommend ways in which WASH can be mainstreamed into HIV services.

The four objectives this research aimed to address were:

1. Gather baseline information on PLHIV's access to water and sanitation by location and identify factors which may contribute to vulnerability among PLHIV.
2. Investigate PLHIV's experiences with stigma and discrimination as it relates to accessing water and sanitation facilities and services.
3. Investigate PLHIV's health knowledge and health seeking behaviours regarding the causes of WASH-related illnesses, particularly diarrhoea.
4. Identify opportunities and provide recommendations for integrating WASH messaging and programming into existing HIV care, treatment and support services.

Methods

A structured survey with closed-ended questions was used in this study to elucidate the WASH knowledge, perceptions and practices of PLHIV in PNG. The survey tool was developed with Anglicare staff in PNG. Key-informant interviews (KIIs) were conducted with Anglicare staff in rural, peri-urban and urban areas in PNG. The data gathered from the KIIs was triangulated with relevant WASH and HIV literature, and the survey tool was designed based on this data. The survey tool was firstly tested in Port Moresby and Mt Hagen in the Western Highlands Province before being administered across selected Anglicare project sites.

A purposive sampling method was adopted for this study. This was chosen for two main reasons. Firstly, as the needs of people living in rural, peri-urban and urban areas may differ, PLHIV were selected to participate from each of these regions to provide an analysis of PLHIV's WASH needs across urban and rural areas in PNG. Secondly, it was important to avoid singling out PLHIV in an environment or setting which would make it possible to identify them as being HIV-positive. Therefore, it was decided that staff was to collect survey data during the regular course of their work.

Additional ethical considerations were taken into account. Culturally appropriate and comprehensible explanations about the study were prepared to enable informed consent. The study was discussed in detail with participants at the commencement of the survey, with an emphasis on the participants' right to withdraw from participation at any time. Verbal consent was sought from all participants prior to undertaking the survey. The identities of the participants were not recorded.

The study was carried out at four Anglicare program locations: Begabari Clinic in Port Moresby, Anglicare Popondetta in the Oro Province, Anglicare Wabag in Enga Province and Anglicare Mt Hagen in Western Highlands. Anglicare staff were trained in data collection prior to administering the surveys. Data were collected October-November 2012.

Results

Anglicare staff administered 93 surveys across the 4 sites. The majority of respondents were female (74%) and from urban areas (67%). Respondents typically lived in large households, with 36% living with more than 8 people.

HIV status

The average time respondents had known their HIV status (defined as time since diagnosis) was 7.3 years. Nearly all (90%) respondents were receiving ARV treatment and the average length of time they had been on treatment was 5.2 years. Just over half (57%) of the respondents reported having a family member who was also HIV positive. Overall, respondents were positive about their health status with 60% reporting that they were 'healthy' or 'very healthy'.

Water access and use

Half (52%) the respondents accessed water via a piped water supply, whereas 32% collected water from a lake, river or spring and 10% relied on unprotected wells or uncovered drums of water. Respondents from rural areas were more likely to rely on unprotected sources, such as uncovered wells and unprotected surface water, than those from urban areas. Overall, most respondents (64%) accessed water via a public source, while 36% had access to a private water source.

Most respondents stored water in bottles (60%) or a covered vessel (32%). Overall, knowledge and practices regarding water treatment were low. Most respondents (85%) did not treat water, with the majority citing that they felt it was not necessary. 'Cost' and 'time' were also expressed as barriers to water treatment. If water treatment was performed, common methods for treatment were chlorination and leaving water in the sun (SODIS). However, the frequency of treatment was variable, ranging from 'every day' to 'once every two weeks'.

When asked if needs for water had changed since becoming HIV positive, almost all respondents (95%) reported that it had increased. The main uses for extra water were drinking (90%), bathing (76%), sanitation (47%), laundry (66%) and cooking (72%).

Sanitation access and use

In response to the use of sanitation facilities, improved pit latrines were the most commonly used latrine type among respondents (37%), with 31% using unimproved pit latrines and 25% a flush toilet. Only 6.5% of respondents reported practicing open defecation. Travel time to toilet varied from one minute to forty minutes. Most respondents described the cleanliness of their toilets as 'good', while 19% said 'fair' and 22% reported as 'poor'. On average, respondents shared a toilet with at least ten people.

Hygiene practices

Almost all respondents (94%) acknowledged that hygiene was more important for PLHIV. Most stated that this was because PLHIV were more likely to get sick (64%), because it helped PLHIV to live longer (67%) and because hygiene was important to keep PLHIV healthy (62%). The survey found high rates of self-reported hand washing. Over 60% reported hand washing after using the toilet but only 44% reported washing hands before eating. Of those respondents with children, 27% reported washing their hands after changing their child's nappy. Only 6% reported not washing their hands at all.

Health knowledge and health seeking behaviours

The vast majority (95%) of respondents said they had experienced a significant change in their health since becoming HIV positive. Diarrhoea was cited by 90% of respondents as the most common opportunistic infection they experienced. Other responses included skin conditions (68%), eye infections/trachoma (44%) and tuberculosis (51%). Over half the respondents had been ill in the last two months. These were commonly reported as being coughs/colds (35%), tuberculosis (19%), skin conditions (13%) and diarrhoea (33%). One quarter reported having a bout of diarrhoea in the last two weeks.

Most respondents were able to correctly identify at least one of the major causes of diarrhoea. The most commonly cited cause was dirty water (88%), followed by dirty hands (87%), uncooked food (63%) and poor sanitation (63%). In response to being surveyed regarding prevention of diarrhoea, over 80% of respondents stated clean water, food safety and personal hygiene as the main ways to prevent diarrhoea. Sanitation and the safe disposal of waste were also mentioned by 67% of respondents.

When asked about their treatment practices for diarrhoea, most were likely to increase water intake (75%). Approximately half the respondents stated that they would seek treatment for diarrhoea at a health care centre and one quarter stated they would seek traditional therapies and treatment. The type of health care sought was not mutually exclusive; some respondents reported seeking both western and traditional treatments. Respondents were also surveyed about their exposure to health and hygiene information. Over three quarters of respondents (80%) had received hygiene health messages in the past twelve months. The main sources of this information were government health centres (58%), and NGO centres (56%). A quarter of respondents also stated that they had received hygiene information through HIV-specific services.

Stigma and discrimination

Due to their HIV status 41% of respondents reported facing stigma and discrimination from their family and 36% from their community. Several respondents (18%) indicated that they had been prevented from collecting water because of their HIV status and some respondents also reported (18%) that members of their family had been prevented from collecting water in the past.

Discussion

Overall, respondents reported a good knowledge of the importance of WASH and acknowledged the benefits this had for promoting good health. However, this study revealed that there are several WASH needs for PLHIV that must be acknowledged and addressed for programming. Additionally, this survey highlighted that HIV positive parents have particular WASH needs when caring for their children. Box 1 highlights the preliminary results that the survey revealed. The needs of parents with HIV were not the focus of this study. However, as Box 1 demonstrates, further study into this area is warranted.

Box 1. WASH needs of parents and children in families living with HIV

Increased illness among PLHIV may also increase household illness, particularly diarrhoea. Research has shown that children born to HIV-positive mothers are more at risk of diarrhoeal disease compared to children born to mothers without HIV (Keusch *et al*, 1992). The risk for children is much higher if an HIV positive mother has had diarrhoea in the last seven days and/or the child is also HIV positive (Peletz *et al*, 2011; Thea *et al*, 1993). Additionally, HIV positive mothers may choose to replacement feed and/or wean their children off breast milk to avoid vertical transmission of HIV. Replacement feeding can increase the risk of exposure to unsafe water (Peletz *et al*, 2011; Arvelo *et al*, 2010). Over half the respondents (53%) in the current study had children, of which 39% were under the age of 5. Almost one quarter (23%) of these children were HIV positive. Knowledge and available information about the safe preparation of formula was limited as only 36% of respondents stated that they had received appropriate replacement feeding information through a HIV setting, Government clinic or hospital, community health worker or family member. Only 27% of respondents reported washing their hands after changing their child's nappy. This highlights the need for the safe handling and disposal of faeces to be promoted as a key WASH behaviour. Additionally, the safe preparation of formula must also be incorporated into HIV health promotion activities. The results here demonstrate that further research is required into the specific needs of PLHIV with respect to caring for themselves and their children, particularly to minimize the risk diarrhoeal disease among children under the age of five. As more than 50% of respondents had family members with HIV, and families were often cited as a key source of information, health information provided to respondents is likely to have a benefit that extends to the rest of the family.

Access to adequate sanitation and improved water sources differed between the urban and rural respondents. Those from rural areas were more likely to use unprotected water sources, more likely to share a toilet with a large number of people. It must be noted that most respondents in this survey were from urban areas. Therefore, the respondents did not represent the rural-urban spread in PNG. Nevertheless, the survey revealed a disparity of WASH access between urban and rural respondents, replicating trends present in national statistics for the general population (Joint Monitoring Program, 2012). This indicates that the WASH requirements of PLHIV in rural areas need to be prioritised for programming.

Knowledge and practices of water treatment were poor among respondents. This finding is similar to Gautam *et al's* (2011) study on the WASH needs of PLHIV in Nepal. Gautam *et al* (2011) found that rural respondents had low rates of appropriate water treatment in Nepal. Both the current study and the Nepal research highlight that PLHIV have increased needs for water since diagnosis. Therefore, it is essential that education regarding the safe storage and treatment of water is adopted into care guidelines for PLHIV. This is particularly pertinent during times of illness. A quarter of respondents stated they had experienced diarrhoea in the last two weeks and the majority acknowledged that increased water intake was important during diarrhoeal treatment. These data suggest that a comprehensive guidance on self-

treatment of diarrhoea for PLHIV, including the safe treatment and storage of water, could play an important role in promoting good health.

Knowledge of the causes of diarrhoea among respondents was high overall. However, there is still room for improvement, particularly in regards to acknowledging the role of sanitation in preventing diarrhoea. Most respondents shared a toilet with at least ten people which, according to the MDG indicators, may not be as hygienic as private facilities (Joint Monitoring Program, 2012). As PLHIV are more likely to experience diarrhoea and are at greater risk of opportunistic infections, in communities where toilet coverage is low, programming should aim to encourage households to construct and maintain latrines. However, the promotion and construction of latrines alone will not address all sanitation needs for PLHIV. This research supports the need to improve the health literacy of PLHIV overall. However, health literacy regarding the role of sanitation in preventing diarrhoea was particularly low. Therefore, there is a need for appropriate guidance on how to properly manage, as well as avoid, diarrhoea. While the survey did not attempt to evaluate respondents' knowledge about the causes of all opportunistic infections, there may be some benefit in incorporating information on the role that hand washing can play in preventing colds and coughs, as respiratory infections remain a major cause of morbidity and mortality of PLHIV (Davis *et al*, 2008).

This study was intended to be small and due to the number and location of respondents, was not designed to be generalisable to the entire PLHIV population in PNG. Furthermore, the participants were PLHIV that are reached through Anglicare services and may not reflect the needs of all PLHIV in PNG. The respondents may be in a more privileged position compared to those who do not have regular contact with service providers. Nevertheless, despite accessing care and treatment services, this study found that respondents face substantial rates of stigma and discrimination from their family and community and that this stigma impacts their access to WASH facilities. Therefore, continued education on the transmission of HIV to all in the community is critical to alleviate common misconceptions about the nature of HIV transmission. This education could be incorporated into existing health promotion and community based awareness raising activities.

Conclusion

This study revealed a need to systematically incorporate comprehensive WASH messages and practices into existing HIV activities in PNG. Specific areas that require addressing that were highlighted in this research include:

- Prioritise programs for PLHIV in rural areas;
- Provide comprehensive guidance on the self-treatment of diarrhoea to PLHIV and their carers;
- Prioritise latrine construction in communities where there is low sanitation facility coverage and a known high HIV prevalence (taking care to not disclose any member of the community's HIV status);
- Education and guidelines regarding the safe treatment and storage of water should be integrated within existing health promotion activities for PLHIV to safely address the increased needs PLHIV expressed for water;
- Education around the transmission of HIV should be tightly integrated in all programming of PLHIV, particularly as stigma can prevent PLHIV accessing WASH facilities that are essential for their health and wellbeing, and
- Further assess the specific needs and care practices of families living with HIV and their children.

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