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Table of Contents

List of Abbreviations	Pg. 3
Acknowledgements	Pg. 4
Introduction	Pg. 5
Background	Pg. 5
Data Analysis	Pg. 6
Possible Actions	Pg.14
Recommendations	Pg.15
Conclusion	Pg.16

List of Abbreviations

Acknowledgements

Introduction

Access to clean drinking water, safe sanitation facilities and adequate hygiene is universally acknowledged as a fundamental building block for life of health, well-being and dignity for all human beings. In case of the PLWHA, the lack of access to these facilities can lead to early death. HIV compromises the immune of system of the infected person, making the PLWHA vulnerable to Opportunistic Infections (OI), like Diarrhea. PLWHA who have accessibility and availability to clean water, safe sanitation and adequate hygiene facilities have demonstrated a decrease in OI and a general improvement in quality of life. Lack of availability and accessibility to safe water encourages usage of unclean water, which further compromises the health of the PLWHA. Water-borne diseases are a menace for most; in case of the PLWHA these can prove fatal.

Background

WaterAid commissioned this study to assess the access of PLWHA to improved WASH facilities, the impact of that on their daily lives, and to then use the findings as an advocacy tool to lobby within the WatSan sector and with the Government. In the first leg of the study, certain baseline indicators have been set by studying the intervention that was made by WaterAid and their partner CREATE. This report will endeavor to outline the final outcomes of the intervention, and to set out some possible actions and recommendations. WaterAid also intends to see if better WASH practices and behavior changes have had any impact on the CD4 count of the PLWHA. Previous studies conducted by WaterAid in four countries including India have demonstrated a direct link between improve in WASH services and behavior change with decrease in Water-borne diseases, skin diseases and OI.



Data Analysis:

This study was undertaken with three objectives. First objective was to understand if there is a linkage between behaviour change of the PLWHA vis-a-vis WASH and better health and well-being? Another objective was to assess the coping strategies of the PLWHA to combat OI. Third objective of the study was to see the impact of the project on the health, quality of life and well-being of PLWHA. CREATE has successfully worked on raising awareness, impacting the existing knowledge and in the process changing practices and behaviors of PLWHA vis-à-vis WASH. The data shows that there indeed is a link, in fact a direct correlation, between behaviour change and better health. The other major finding emerging out of the study is that as the awareness increases, PLWHA integrate the coping strategies against OI into their daily lives. The highlight of the success of the programme is in the fact that this intervention has impacted positively the lives of PLWHA, who are traditionally excluded and marginalized from the mainstream.

Looking at the data generated from this study, we can safely conclude that as people become more aware, their behavior changes and they incorporate better WASH practices into their daily lives, and in turn their health improves. Incidences of diarrhea and other OI decrease. Data also shows that with better access to improved WASH facilities, the CD4 count of PLWHA also increases. However, this cannot be proved medically. There is no clear cut scientific and medical evidence demonstrating whether better WASH affects the CD4 count or not. But the data here seems to suggest that and thus it is a finding of this study, whether scientifically backed or not.

This study was conducted in 6 districts 144 respondents and 23 centers, using a detailed questionnaire based survey. Eighty three percent of the respondents were in 26-50 years age group. Eighty nine percent of the respondents

are on Anti Retroviral Treatment (ART). Fifty five percent of respondents were women and forty five percent were men. Fifty-six percent were married, twenty-five percent unmarried, seventeen percent widowed and the remaining two percent divorced.

Forty eight percent of the respondents use Safe Wat for the drinking water. Half of the respondents said that they cleaned water when the safe drinking water was finished. When asked how should the safe drinking water stored, onefourth said clean water should be kept on height, thirteen percent said that the surroundings where the clean water is kept should be clean, another thirteen percent said that the safe water should be covered and ten percent said it should be both kept on height and covered. Twenty eight percent said all the above methods are right. Half of the respondents said that they stored their water with everyone else's water. Forty seven percent said they used water which filtered and kept in a different pot. Ninety three percent of respondents said they covered their edibles, another ninety four percent said that they ate fruits and vegetables after washing them.

Eighty Four percent of the respondents said they had not had a bout of diarrhea since their newfound awareness and since they got access to better WASH facilities.



As the awareness increases, behavior changes are noticeable. Ninety five percent of respondents said they carry their own drinking water when they go out. Another eighty one percent said they have a designated place in their house to wash hands. Twenty nine percent said that it was imperative to wash hands after defecation, before eating and/ or cooking food, and after field work or dealing with garbage. Eighty four percent said that they used soap to wash their hands before eating food, and seventy five percent after defecation. Eighty five percent used soap before making or eating food, and seventy seven percent after coming back from work, or using garbage. Inducing such behavioral changes by creating awareness is perhaps the biggest success of this intervention.

Interestingly, fifty five percent said they had toilets, whereas only forty five percent admitted to open defecation. Eighty eight percent of the respondents said that their toilets were functional but seventy eight percent also said there was not enough water available for their toilets. Eighty two percent of respondents said that they were motivated to construct toilets by WAI.



More than one third said that having a toilet at home brings down illnesses. One fourth of respondent said that not having to open defecate was great benefit.



Respondents have reported considerable behaviour changes after the awareness building measures by WAI. Almost half of the respondents said that they learnt about best practices like washing hands, using toilets, Diarrhea management, method for handling clean water, methods for cleaning water to make it sufficient for drinking and hygiene tips from the 8-point handbill. All of this knowledge was also increased by the games kit. Sixty one percent attributed their new found awareness and behaviour change to WAI. They said that they found information on best practices of water use, hygiene and sanitation from WAI.



Thirty nine percent had CD 4 count between 101-200 before the WASH awareness. After the WASH awareness was raised through the intervention the CD 4 count of forty five percent of the respondent went above 401. There cannot be a direct correlation between WASH awareness increasing and that impacting the CD4 count. WASH awareness, leading to better WASH practices can protect PLWHA from OI and hence improve their general health and wellbeing.





This was two-tier study, which conducted both with the clients in 6 districts and staff at the twenty three centers; ten DLNs, seven CCCs and six ARTs. In the twenty three centers the study found seventy eight percent of the staff to be male. This could be a deterrent to women coming forward and feeling comfortable enough to use the facilities of the center. HIV positive women might find it easier to speak to women counselors or staff. More women staff and counselors need to be actively recruited, so else a large part of PLWHA will be excluded. The percentage of that women staff at the centers is simply too low compared to the population of HIV positive women.

Fifty seven percent of the centers have water filters, thirty percent have wall mounts and thirteen percent have hand pumps. In almost all centers except one, clean water is stored properly, it is filtered, kept on a height, with clean surroundings and is covered. In forty eight percent of the centers, up to 10 people use water everyday. In thirty five percent more than 25 people use water per day. A forty three percent reduction in Diarrhea has been recorded.



Twenty out of 23 centers have wash basins for hand washing. Nineteen of them have soap. Thirty five percent of the staff said they provide handbills to clients to raise their WASH awareness. Twenty two said they used posters. Twenty two percent said they used all the materials provided to them by WAI. Seventy eight percent said that the game kit was providing all the necessary information on hand washing, water handling, diarrhea management and use of toilets. Forty eight percent of the staff said that they used the game kits to play the WASH games in the meetings and trainings. Very few said they used it daily or weekly.

Eighty-seven percent of the centers recorded functional toilets. This indicator should be a hundred percent. There is no justification for these centers not to have functioning toilets. Ninety two percent of centers recorded having sufficient water for toilets. Seventy four percent said there are no urinals in the centers. Sixty one percent of the staff said that toilets are cleaned everyday. At 35 percent of the centers the staff said that the urinals were cleaned weekly. Again this is a low indicator. Hygiene at the centers has to be impeccable at all times with no compromise being acceptable on this. Hundred percent of the toilets should be cleaned daily.

Seventy four percent of the staff said that they motivate clients to build toilets. This is a good indicator because open defecation is one of the primary drivers of OI, other diseases and illhealth. Eighty seven percent said that they used all the provided materials to raise awareness on WASH at the centers. When in the field, thirty five percent of staff said that they created WASH awareness verbally, twenty six percent used the handbill, and another twenty six percent used all materials provided. Forty four percent of staff used the ORW kit to raise awareness, twenty six percent said counselors used it, and twenty two percent said they did not use it. Sixty percent of the staff said that HIV counseling is provided at their centers.

Data shows very clearly the impact of this intervention has been commendable. Majority

of the respondents have started washing their hands using soap or other disinfectants after defecation, before eating or cooking food. Most of the respondents have started treating the water for impurities before they drink it. They have also started carrying their own treated or boiled water when they go out. More and more people have been encouraged and motivated to build toilets. The respondents are much more mindful of hygiene, personal and of their surrounding, now. Before the intervention sixteen percent of the PLWHA used to wash their hands after defecation, before cooking and eating. After the intervention that number has gone up to twenty nine percent. Earlier, forty-nine percent did not have toilets, now that number decreased to forty-five percent, which is a small but important reduction. After the intervention was made and the findings were documented for the second study, eighty four percent of the respondents said they had not had a bout of diarrhea over last few months, whereas earlier forty five percent had acknowledged frequent bouts of diarrhea. So we see a forty three percent decrease in the cases of diarrhea as the WASH awareness and as the access to facilities grew.

Data shows there is direct correlation between positive behavior change, access to safe WASH facilities and a decrease in OI. Data also shows that increase in awareness induces positive change, which in turn then leads to improvement in the health and well-being of PLWHA. Data also proves that as the accessibility and availability to safe and adequate WASH facilities increases, the well-being of the PLWHA increases as well. This study gives enough evidence to make a strong case that WASH rights are of paramount importance for the well-being of PLWHA. This study gives sufficient insight for spreading the message that better WASH facilities and access to safe and adequate WASH can improve the general quality of life for the PLWHA and ensure health and well-being.

Possible Actions

- The need to spread the message that WASH is a matter of life and death for PLWHA emerges very clearly out this study. Better WASH facilities improve the quality of life of the PLWHA and leads to their general health and well-being. Social media, presentations to donor and other stakeholders, events and workshops using this evidence can be good tools of spreading this information.
- Training and recruiting more women at the centers. This will only increase the involvement of HIV positive women.

- Creating models of community water and sanitation points. If successful these models can then be replicated and scaled up.
- Convincing the HIV and AIDS sector of the importance and urgency of incorporating WASH into their programming. Making presentations to Gates Foundation, Clinton Foundation and other major donors who support HIV and AIDS programmes as to convince to fund WASH related programmes as well.

Recommendations

One of the major recommendations emerging out of the data demonstrates that the onus rests on the WASH sector to build the necessary linkages and to design processes to mainstream WASH rights for PLWHA into their programming.

- Open defecation is a major hurdle in improving the health and ensuring the wellbeing of PLWHA. Community sanitation points should readily available and accessible. The government, private sector and the civil society can collaborate on making this a reality. Lot of lobbying and advocacy should be done with all stakeholders in making this possible.
- Right to Water and Sanitation should be recognized as a human right and guaranteed and protected by the Gol. This should be the central demand around which all the advocacy efforts should be centered. The only country in the world which guarantees a constitutional right to water is South Africa, which states that everyone should have a right to "sufficient" water. In Indian scenario, "sufficient" can be defined as 50 lpcd. Policy advocacy needs to

be undertaken with Gol to get 50 lpcd of water as human right enshrined in the constitution. A human rights centric water policy is needed.

- Focus needs to shift to incorporating hygiene messages into post-test counseling. Also, have hand washing facilities at the testing centers to demonstrate the best practices.
- The most important paradigm that needs to happen is that the PLWHA should be included in decision making process relating to water and sanitation programming. This will not only empower the PLWHA and help the WASH sector serve their needs better, but it will also go a long way to fighting discrimination and the culture of silence around HIV and AIDS.
- Every employer should be mandated to develop and implement workplace HIV policies.
- The WASH sector needs to assess effects of inability of the PLWHA to pay on water systems. In turn they need to develop alternative structures that would facilitate the increased need of PLWHA to be met. Mechanisms for

subsidies and special provisions for PLWHA need to be lobbied and advocated for.

- Developing and promoting new water collection technologies and strategies needs to be prioritized, so that water can be brought closer to the home for the PLWHA. Water saving technologies such as "tippy taps" for washing hands and clothing/linens need to introduced and marketed.
- Women are traditionally left behind from any decision-making process. WASH sector needs to reach out women and children. HIV and AIDS affects women and children differently from men, hence, the sector needs to acknowledge the special needs of this community of PLWHA and develop strategic partnerships with other sectors/stakeholders to address women and children.

Conclusion

Right to Health and well-being and Right to life are two human rights that assume paramount importance in case of PLWHA. Right to WASH is intrinsically linked with these. There is an urgent need to mainstream WASH into programming and planning around PLWHA. A paradigm shift is also needed from a need-based approach to WASH to a rights-based approach. Unless all the stakeholders start considering WASH as a right, the status quo will be maintained, under which WASH will be relegated to a secondary position in the planning and implementation of programmes.



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