

Reducing Loss to follow-up among Clients Living with HIV through Back to Care Initiative in Kongwa District in Dodoma

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Abstract

Loss to follow-up among People Living with HIV/AIDS at HIV clinics is increasing, as most of the clients enrolled at CTC do not adhere to their scheduled visits. This paper reports on how Back to Care Initiative (B2CI) has reduced loss to follow-up to clients living with HIV/AIDS in Kongwa District in Dodoma. The study was conducted in six health facilities in Kongwa District, which provide Care and Treatment Centre services. We employed descriptive cross-sectional design whereby 35 key informants were purposively sampled and 305 patients living with HIV/AIDS were randomly selected. In-depth interview and structured questionnaire were used to collect information from key informants and patients living with HIV. Quantitative data were analyzed using STATA software pack 13, while qualitative data were analyzed using Atlas. ti software. Findings of the study revealed that the use of patient data from appointment and tracking registers, adherence to counselling and health care confidentiality improved and enhanced patient's retention in care. In addition, involvement of community-based health services volunteers helped in tracing and returning patients into care. We recommend a similar approach to other districts in Tanzania with low- resource settings and a high rate of loss to follow-up patients.

Keywords: Back to Care Initiative, Lost to Follow- Up, Kongwa District, Dodoma, HIV &AIDS Patients

1. INTRODUCTION

Globally improved access to HIV care and especially antiretroviral therapy (ART) has reduced HIV-related morbidity and mortality among people living with HIV/AIDS (PLWH). Retention of HIV care programs is critical for achieving timely treatment initiatives and viral suppression. Disruption of HIV care through missed visits/appointments can undermine clinical outcomes (Rachlis, 2015). HIV infected patients are required to attend to health facilities regularly so that they could be examined for clinical progression, their ART programs monitored and themselves counselled on minimizing the risks of HIV transmission. Despite the need for regular monitoring, loss to follow-up has been demonstrated in ART programs (Franziska, 2011).

In Tanzania, TUNAJALI program was introduced to provide support to people living with HIV/AIDS. In 2013, TUNAJALI launched the campaign of bringing back to care clients 23,366 (36.2%) that were lost to follow up (LTF) (Tunajali, 2013). A campaign with the slogan "We Care for your Health; Get Back to Treatment" was colourfully launched in Iringa town by the U.S. Ambassador to Tanzania in September 2012. Through this campaign, 914 "lost" people living with HIV/AIDS were identified in Iringa and Njombe within the first two weeks out of whom 279 were brought back to care and continued with treatment, 429 were determined to have shifted to other clinics without referrals, and 206 were identified as having died. The initiative was meant to be an ongoing activity through which clinics staff would regularly review patient files to identify patients who miss appointments and follow them up through Community Health Workers or volunteers and through mobile phones. After the initial success in Iringa and Njombe, the program was extended to Morogoro, Dodoma, and Singida in February, March, and April 2013 respectively.

In Dodoma region, there were 7573 LTF clients in 2014, distributed as follows, Dodoma Municipal (4698), Kongwa DC (681), Kondoa DC (523), Mpwapwa DC (466), Chemba DC (469), Chamwino DC (374) and Bahi DC (360) (RACC, 2015). Kongwa DC had the highest number of LTF 681, compared to other councils excluding Dodoma Municipal. Due to an increasing number of LTF to HIV positive clients in the district, 2011-2014 LTF were 430, 482, 466 and 681 respectively. The Council, in collaboration with TUNAJALI, (the implementing partner) decided to conduct a campaign of bringing back to care clients who were LTF.

TUNAJALI "Back to Care Initiative" (B2CI) was implemented in 2013 in Kongwa District. Before its implementation, LTF in Kongwa District was reported to be at 41.2 percent (DACC, 2016). TUNAJALI "Back to Care Initiative" (B2CI) has shown great success by tracing back clients in care up to 24.6 percent by 2015 (DACC, 2016). This paper reports on how Back to Care Initiative has reduced lost to follow-up clients living with HIV/AIDS in Kongwa District in Dodoma.

2.0 METHODS

2.1 Study design and area

The study used a descriptive cross-sectional study design incorporating both qualitative and quantitative research approaches. This study was conducted in Kongwa District in Dodoma. The district is among seven districts in Dodoma Region with a population of 303915 (Census, 2012). It has 3 Divisions, which are Mlali, Kongwa and Zoisa. In addition, it has 22 Wards and 85 Villages. Kongwa District Council has one district hospital, four health centres and 52 dispensaries. Among these health facilities, one hospital, two health centres, and three dispensaries are providing care and treatment services to people living with HIV/AIDS. The district was selected because it has been implementing the TUNAJALI II Comprehensive care and sustainable clinical and community HIV/AIDS services for the past five years from October 2011-Sept 2016. In addition, the district has the highest number of LTF.

2.2 Study Subjects and Sampling

The study recruited 35 respondents from Council Health Management Team (CHMT), all health care providers working at CTC sites in Kongwa District and Community Based Health Service (CBHS) volunteers. The district has 6 CTC sites, and all were included in the study. The respondents were purposefully selected because of their knowledge of the study. Simple random sampling was used to select 305 patients living with HIV/AIDS and attending CTC clinic in all CTC sites. These patients were given a questionnaire to fill in after finishing receiving services at the clinic. The respondents included in this study were health care providers who work at CTC sites and dealing with patient's registration, filling appointment and tracking registers. Health care providers who deal with adherence counselling at CTCs, Community Based Health Service volunteers and patients living with HIV/AIDS enrolled in CTC clinics in Kongwa DC. The excluded respondents were health care providers who were not working at CTC sites and patients living with HIV/AIDS not enrolled in CTC clinics in Kongwa DC.

2.3 Data collection methods

A self-administered questionnaire was used to collect data from 305 PLHIV on HIV/AIDS care and treatment program. Those who did not know how to read were assisted by research assistants. An interview guide was used to gather in-depth information from 35 key informants comprised of DACC, Data clerk, CBHS coordinator, Adherence nurse and CTC i/c at District level. At the Health facility level; Data clerk, CTC i/c, CBHS nurse, and Adherence nurse. At Dispensary level; CTC i/c, Data clerk, ART nurse were interviewed. The questionnaire was pre-tested in Mpwapwa District to get feedback for improving the instrument. Moreover, in-depth interviews were conducted to all Community Based Health service volunteers in each CTC site to solicit information on how B2CI campaign reduced loss to follow up in CTCs. Data were collected from March to April 2018 in office settings and lasted for a maximum of 10 to 15 minutes.

2.4 Data Analysis

Data were analysed using both qualitative and quantitative data analysis techniques. Quantitative Data were entered into an excel work book and later organized with the assistance of STATA software pack13. Data were analyzed in descriptive statistical methods and presented in tables, percentages, and frequencies. Qualitative data were analyzed by Atlas.ti software. After the transcription, the data were organized and read once more to get the intended meaning. Codes were created from the data. The emerged patterns were identified and themes were generated from the codes. The selected themes were arranged and interpreted based on the context and participant's expressions. Quotes from respondents were used to enrich data presentation.

2.5 Ethical issues

The research was approved by the Directorate of Research and Publication and Postgraduate studies (DRPS) Mzumbe University. The permission to collect data from health facilities within the evaluation site was granted by the District Health Secretary of Kongwa District. The respondents were informed about the study and filled in a consent form. Participation was voluntary among the respondents. All data collected were treated as confidential, and were not divulged to any third party. The data were used only for the purpose of the study.

3.0 RESULTS

3.1 How patient's data were used to improve tracing patient back to treatment

The results showed that the patients' data were used to understand the prevalence of HIV infection in the area, and the number of patients who received services. Moreover, the data provided information on the number of patients in the first line or second line drugs. Through patient's data found in the appointment and tracking registers (used at CTC when a client misses an appointment after three days), a client was tracked to establish reasons for missing an appointment. After three months or more have passed, a client is regarded as LTF. One of the key informants had this to say,

“By using appointment and tracking register, all patients who needed to attend the clinic are identified. If some of these patients were not seen on appointment dates we wait for three days, if they are not seen, we put them in tracking register. Then we start using a phone call to trace them or with the assistance of CBHS volunteer. If these patients do not show up for three months, we call them LTF patients. So, through this process, you can identify LTF.”

We also found that patients' data helps to identify who exactly did not attend the clinic on a particular day. Thus, they helped in tracking patients before they become LTF. One of the key informants had this to say,

“From appointments, we know that someone is needed today here in the clinic. So if the patient has not attended, I should track him/her to know what was the problem and find the reason as to why he/she didn't attend the clinic as scheduled.”

Moreover, patients' data show where patients are coming from. The data helped health providers to take care of the next scheduled for the refill and provide the names to CBHS volunteers according to their address to trace them when they miss up an appointment or become LTF. One of the Key informants said,

“From the patient's data, you will know where the patients come from; you can trace that patient and bring him/her back to treatment. Patient data was also used for those who are not LTF, but they missed their appointment. When we trace them, we look at their CTCI card and check out what date the patient was scheduled to attend the clinic.”

3.2 Extent to which adherence counselling improved patient's retention

We asked if the patients had received adherence counselling before starting ART. The majority of respondents 300(98.4%) received adherence counselling, while only 5(1.6%) did not receive adherence counselling. We also asked how many times they received adherence counselling, 119(39%) said weekly, 92(30.2%) monthly and a few only once 89(29.2%). In terms of how long adherence session lasted, nearly a half of the respondents 146(47.9%) said 30 minutes, 65(21.3%) said 20 minutes, 56(18.4%) said more than 30 minutes, and the rest 33(10.8%). As for the time for adherence counselling, 272(89.2%) said time was enough, and only 28(9.2%) said the time was not enough. When asked who provided adherence counselling nurses were reported as the major provider of adherence-counselling {184(60.3%)}, followed by doctors {116(38.0%)}

When asked as to when they started receiving adherence counselling above a quarter of the respondents 97(31.8%) said in the counsellor's room, 96(31.5%) said during testing, 78 (25.6%) said during consultation and only 29(9.5%) reported to be getting adherence in all the departments, that is, from testing, consultation and to the counsellor. Subjects taught were positive life

63(20.7%), primary HIV infection 58(19.0%), what is ARVs 32(10.5%), side effects of ARVs 6(2.0%) and the majority [141(46.2%)] reported to be taught all of the listed subjects (See Table1).

Table: 1 Extent to which adherence counselling improved patient's retention

	Response	Total (N= 305)	
		N	(%)
Receive adherence counselling session before start ART	Received counselling	300	98.4
	Did not receive counselling	5	1.6
Counselling sessions	Once	89	29.2
	Weekly	119	39.0
	Monthly	92	30.2
Time used for adherence tocounselling	10 minutes	33	10.8
	20 minutes	65	21.3
	30 minutes	146	47.9
	> 30 minutes	56	18.4
Whether time spend for adherence session was enough	The time was enough	272	89.2
	It was not enough	28	9.2
Who provided adherence counselling	Nurse	184	60.3
	Doctor	116	38.0
When did you start receiving adherence counselling?	During testing	96	31.5
	During consultation	78	25.6
	To counsellor's room	97	31.8
	All of the above	29	9.5
Lessons taught in the counselling session	Basic HIV infection	58	19.0
	What is ARV	32	10.5
	What are side effects	6	2.0
	Positive lifestyle	63	20.7
	All of the above	141	46.2
	Total	300	98.4

3.3 How involvement of trained CBHS volunteers helped in tracing back patients to treatment

One of the roles of CBHS volunteers is to trace and track LTF. However, they do this in collaboration with health care providers of a particular facility to identify a patient as LTF. After being identified, they provide names to CBHS volunteer to trace them. One of the key informants had this to say,

“LTF are identified through tracking register, database or by file pool. After we have identified them, we trace them through phone calls. If they are not reachable, we provide names and address to CBHS volunteers to track them. The CBHS volunteers know LTF

clients since they stay with them in the village. When they fail to identify them through the address given, they can trace them with the assistance of Street Chairperson of a particular street where they ask if he/she knows someone in his/her street without exposing whether they are LTF."

All CHBS volunteers had registers, which contain numbers for home-based patient services (HUWANYU). These ID numbers were given to all PLHIV clients, so when they become LTF, it is effortless to find them as elaborated by one of key informant had this to say,

"They have registers, when we prepare reports and see these patients were not seen in the clinic, we call CBHS volunteers to check on these patients who were not seen since they were trained and have registers. They know who is lost and provide names, addresses, unique identification number, and HUWANYU number to trace them."

In addition, it was found that CBHS volunteer identified LTF because everyone had patients to serve from respected areas. One of the key informants elaborated,

"They identify LTF because every CBHS volunteer has his/her patients to serve, every new patient who comes to the clinic and diagnoses with HIV infection is provided with health education on the importance of HUWANYU services."

4.0 DISCUSSIONS

Our study shows that the use of patient's data, adherence counselling and the use of trained CBHS volunteers have contributed to reducing LTF in Kongwa District. B2CI in Kongwa District used patients' data from appointment and tracking registers to identify LTF patients. The use of phones and assistance from CBHS volunteers were widely used to trace LTF patients and bring them back to care. These findings are similar to the findings reported in a study by Rosen (2010) in South Africa which showed that patients' data and dedicated patients tracer were used to track patients, know their status and return a handful of them to care. Murray et al. (2019) reported the results of a retrospective cohort study, which compared retention rates at 18 months between two groups of adult patients in Uganda who had returned to care after missing appointments by 8 to 90 days. These patients returned to care after being tracked through telephone contacts or home visits. This result is consistent with the finding reported in the current study on how these Trained CBHS volunteers track LTF clients by a phone call or home visit.

We also found that adherence counselling was necessary for the retention of patients among People Living with HIV in Kongwa District. For instance, adherence counselling helped patients in counting pills. By counting pills, patients were able to use pills as directed by Health Officers. In our study, most of the patients agreed that they were counselled on the excellent use of ARVs. These results are similar to the results reported by Bangsberg et al. (2000) in a study on pill count, which found that thirty-eight per cent of the population had over 90percent adherence by pill count. Similarly, taking pills and adhering to ART were reported as essential to long-term survival for individuals living with HIV and could result in better clinical outcomes in resource-limited settings (Achieng et al. 2013; Thompson et al. 2012).

For excellent retention in care adherence on ART, it is vital that all healthcare providers provide adherence counselling. In a study conducted in Estonia, it was reported that adherence counselling were the tasks of all healthcare providers involved in the delivery of ART in health facilities with better retention in care (Laisaar et al. 2013). In our study, all the interviewed providers in health facilities with better retention in care said that counselling was part of their routine task. They noted that adherence counselling was very crucial for improving the outcome of patients, and it is done

before and after patients were initiated on ART. This was a continuous process every time a patient attended clinic. The World Health Organization, International Association of Providers of AIDS Care (IAPAC) and U.S. Centre for Disease Control and Prevention provide evidence-based recommendations for improving retention in care and ART adherence for PLWH. In this respect, the provision of general education and counselling is one of the recommended approaches (WHO, 2016). A similar approach of using education and counselling by using specific adherence- related tools is recommended by Thompson et al. (2012).

Moreover, our study shows that the involvement of CBHS volunteers in the provision of care to PLHIV contributed towards the identification and retention of LTF patients in care. CBHS provides PLHIV and their families with practical caregiver skills, including palliative care, treatment of opportunistic infections, counselling and emotional support including disclosure, contraceptives, and referrals to the available health services. The findings are similar to the findings in a study conducted in Thailand on the role of AIDS volunteers in developing community-based care for people with AIDS. Their results revealed that community-based volunteers were giving caregiver skills, including palliative care, treatment of opportunistic infections and counselling (Mashimo et al., 2001).

5.0 CONCLUSION

In conclusion, B2CI has successfully managed to reduce LTF in Kongwa District through patient data from appointment and tracking registers, adherence counselling and involvement of CBHS volunteers. We recommend a similar approach to other districts in Tanzania and low- resource settings facing a high rate of LTF patients.

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7.0 CONFLICTS OF INTEREST

The authors declare that they have no competing interests.

8.0 AUTHORS' CONTRIBUTIONS

R.L. designed the study and collected cleaned and analyzed data. L.M. critically reviewed the study, contributed significantly to the development of the study, and drafted the manuscript. All authors read, revised, and approved the final manuscript.

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