University of Alberta

The effectiveness of a volunteer community health worker program to support an antiretroviral treatment program for AIDS patients in western Uganda

by

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DEDICATION

To the community volunteers in Rwimi subcounty who have worked selflessly and tirelessly to serve their communities. They exemplify of the best qualities of humanity and are my inspiration.

ABSTRACT

Background: A research team from the University of Alberta and Uganda established a community based antiretroviral treatment (ART) program for AIDS patients in rural western Uganda. This program engaged laypersons as volunteer community health workers (CHWs) to support ART activities.

Research Questions: This study examined whether CHWs could effectively perform a range of activities to support ART, how the elements of a volunteer CHW program functioned, and what patients, health workers and CHWs felt were the benefits to patients of using volunteer CHWs.

Methods: This was a mixed methods study. Between 2006 and 2008, cross-sectional and longitudinal data were obtained from CHW surveys and focus groups, health worker focus groups, patient interviews, clinic charts, and program documents.

Results: CHWs were able to effectively deliver drugs, monitor adherence to ART, and promote behaviour change and condoms for the prevention of HIV transmission. However, findings pointed to concerns regarding the ability of CHWs to identify side-effects of ART. After two years, 65.7% of patients achieved virologic suppression and 16.9% died. In multivariate analyses, having to travel one or more hours to the patient, compared to less than one hour, was the only statistically significant CHW characteristic that predicted virologic failure (adjusted OR = 0.29, p = 0.002) and mortality (adjusted HR = 4.52, p = 0.026). Patients and health workers attributed positive ART outcomes to the role of the CHWs in reducing the transport burden and wait times for patients. Patients valued the emotional and compassionate support to patients. The biggest challenges for CHWs were distances they had to travel, patient stigma, patient social issues, and community misperceptions about the CHW role. Some issues resolved with time and experience. Despite these challenges, the attrition rate for CHWs was only 2.4% over the two year period. CHWs felt highly motivated by the recognition and appreciation of the community and the opportunity to help reduce mortality within their community.

Conclusions: The CHW program contributed to positive treatment outcomes for rural AIDS patients and provides recommendations for replication of this program to other areas of sub-Saharan Africa.

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LIST OF ABBREVIATIONS

ABC	Abstinence, behaviour change and condom use
AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
CBART	Community-based antiretroviral treatment
CBD	Community-based distributor
CHW	Community health worker
CI	Confidence interval
DDHS	District Director of Health Services
DOT	Directly observed therapy
DOTS	Directly observed therapy, short-course
FGD	Focus group discussion
GTZ	Gesellschaft für Technische Zusammenarbeit (German Agency for International Cooperation)
HAART	Highly active antiretroviral therapy
HIV	Human immunodeficiency virus
HR	Hazard ratio
HRQOL	Health related quality of life
IQR	Interquartile range
JCRC	Joint Clinical Research Centre, Uganda
MSF	Médecins Sans Frontières
NGO	Non-governmental organization
OR	Odds ratio

PHW	Peer health workers
PMTCT	Prevention of mother to child transmission
RNA	Ribonucleic acid
RR	Relative risk
SD	Standard deviation
TASO	The AIDS Support Organization
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV and AIDS
VCT	Voluntary counselling and testing
VHT	Village Health Team
WHO	World Health Organization

CHAPTER 1—INTRODUCTION

1.0 OVERVIEW

1.01 The global burden of HIV and AIDS

HIV infection has added significantly to the global burden of illness, with approximately 34 million people globally (or 0.8% of adults aged 15–49) currently living with the infection at the end of 2011.[1] The burden of the epidemic varies among regions, with sub-Saharan Africa bearing 69% of the worldwide burden.[1] In 1987, the first antiretroviral (ARV) drugs were approved for antiretroviral therapy (ART) to treat HIV related acquired immune deficiency syndrome (AIDS).[2] Since then, improved drug combinations have led to better treatment, and to the current standard treatment for AIDS known as highly active antiretroviral therapy (HAART). The goals of ART[*] are to ensure a maximum and sustained suppression of viral load, a restoration and preservation of immunologic function, and a reduction in AIDS related morbidity and mortality.[3] Despite significant advances in the efficacy of AIDS treatment and reductions in the cost of drugs, a cure remains elusive leaving the health care system to treat AIDS as a chronic disease managed through life-long ART.

The advent of ART has significantly reduced morbidity and mortality from AIDS. Though much of the early gains were in resource rich countries, AIDS treatments have also progressed in resource poor settings. In 2005, Ivers et al.[4] found that the proportions of virologic suppression among patients in resource poor environments were as high as 69.7% after six months (95% CI=58.2–81.2) and 57.3% after 12 months (95% CI=43.2–71.5). They noted that these proportions were similar to those found in higher resource countries. In 2006, Braitstein et al.[5] looked at mortality due to HIV infection for those receiving ART and found that mortality had also decreased in low income countries, though the decrease

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[*] In this manuscript ART will be used to refer to the treatment of AIDS using HAART

was not as much as in higher income countries due to mortality arising from delayed treatment. Based on promising results from ART, the World Health Organization (WHO) and the Joint United Nations Programme on HIV and AIDS (UNAIDS) embarked on a “3 by 5” program to provide ART to three million people in low and middle income countries by 2005.[6] Though the “3 by 5” initiative failed to reach its 2005 target of three million on ART (1.3 million were reached by 2005[7]), the continued momentum of and funding for global initiatives resulted in ART reaching eight million by the end of 2011.[1] Because of these initiatives, the number of people dying from AIDS related causes has declined substantially. In 2011, 1.7 million people globally died from AIDS related causes. [1] This was a 24% decline compared to 2005 when 2.3 million deaths occurred. In sub-Saharan Africa, mortality from AIDS related causes declined at a greater rate of 32% between 2005–2011.[1]

Despite advances in expanding ART over the past decade, substantial gaps still remain in ART coverage. In sub-Saharan Africa only 56% of eligible individuals were on ART at the end of 2011.[1] Antiretroviral treatment coverage is higher for women (68%) than for men (57%) in low and middle income countries. Beyond the initiation of ART, the long-term retention on life-long treatment is an important issue. Estimates suggest that in certain parts of sub-Saharan Africa 40–50% of the people who start treatment programs drop out within five years.[1] Therefore, treatment must be made more accessible and steps must be taken to ensure individuals who are receiving treatment continue to remain on ART.

1.02 Challenges in scaling up ART

One challenge is the human resources available for scaling up ART. Most health systems in sub-Saharan Africa struggle to provide basic health needs to their local populations,[8] mainly because of a shortage of human health resources.[9-14] A 2006 report by the WHO estimated that sub-Saharan Africa had 11 percent of the world's population and 24 percent of the global burden of disease, but only 3 percent of the world's health workers.[15] In 2012, the average number of physicians and nurses per 100,000 population for low income countries stood at 21 and 53, respectively. In contrast, the ratios for high income countries were 277 and 708, respectively.[16]

The current workforce is insufficient to achieve universal coverage of ART.
A model developed by Barnighausen et al.[17] suggests that sub-Saharan Africa would have to double the current health workforce every year for the next 10 years to reach universal ART coverage by 2017. Muula et al.[18] estimate that for Malawi to reach universal coverage, 93% of its available physician workforce would have to work full time in ART programs, leaving little time for other health issues. This problem is further compounded by attrition due to AIDS deaths of health workers.[19] As countries move toward the adoption of new World Health Organization ART guidelines that lower the threshold for starting ART, the demand for ART will continue to grow.[20,21]

The shortages in the health workforce are more acute in rural areas. Rural areas of sub-Saharan Africa, where the majority of people live, have lower physician to population ratios than urban areas. Thus, ancillary health providers, rather than physicians, provide most health services through basic primary health care clinics. Those who need services unavailable in these primary health care clinics have to travel long distances to obtain more sophisticated care, including ART.[22-25] It is difficult for a sick person to sustain continuous travel and this can discourage participation in life-long ART.

High adherence to the daily ART regimen (i.e. not missing tablets) is necessary in order for patients to achieve virologic suppression and avoid drug resistance.[26] Studies have found that adherence to ART in sub-Saharan Africa is actually quite good, with pooled estimates of 77% adherence (95% confidence interval, 68%–85%) in African studies compared to pooled estimates of 55% adherence (95% confidence interval, 49%–62%) in North American studies.[27] However, not all patients adhere well to ART. Studies have shown that barriers to adherence to ART in low income countries include the stigma associated with HIV, forgetting to take the drugs, not understanding treatment instructions, financial constraints, complicated treatment regimens, complacency once treatment begins to work, changes in body image, and challenges in refilling prescriptions.[28] A study by Senkomago et al.[29] found that patients attending rural clinics in Uganda had significantly lower adherence to ART than those attending an urban clinic (odds ratio (OR) = 0.045, 95% CI = 0.008–0.269). Even if a patient adheres to ART and his or her immune system improves, he or she might still develop side-effects or resistance to treatment.[30] These issues can be addressed through regular and life-long monitoring and support.

There is also a need for programs to retain patients who start on ART (i.e. reduce the numbers who do not return for their drug refills and monitoring). A review by Rosen et al.[31] found an average retention of 60% of patients after two years of treatment in sub-Saharan Africa, with the major cause of attrition being patients lost to follow-up. The authors recommended better patient tracing, which can be a challenge in rural areas where populations are dispersed and where roads and transportation systems are poor or nonexistent.

1.03 HIV and AIDS in Uganda.

In sub-Saharan Africa, Uganda saw the earliest impacts of HIV and AIDS. In the 1990s, during the early years of the epidemic, the prevalence of HIV was estimated to be as high as 30% among adults in urban areas.[32] Substantial efforts by the government to control the epidemic were successful in decreasing the incidence and prevalence of HIV. Despite these efforts, HIV continues to inflict large social and economic costs due to the reduction of the labour force and the associated reduction in productivity, especially agricultural productivity.[33] Between 1981 and 2005, AIDS claimed 1.37 million lives and reduced the life expectancy from 56.9 years to 48.9 years.[34] Most of those who died were working-age adults, the most productive members of the country.

The Uganda AIDS Commission estimated the prevalence of HIV in 2004/2005 to be approximately 6.4%.[35] In the same year, Hladik et al. estimated that 915,400 people were living with HIV and 76,400 had died due to AIDS.[34] These authors found that the majority (79.8%) of people living with HIV lived in rural areas.[34] Between 2005 and 2011, the situation became worse and prevalence rates climbed to 6.7% by 2010/11.[35] Whereas the increase in prevalence is partially due to people with AIDS living longer with the disease, a significant part of this increase is due to an increase in new adult HIV cases, which rose from 87,727 new cases in 2007 to 102,157 new cases in 2010.[35] Currently, 1.1 million live with HIV in Uganda with more women affected than men.[35] In 2005 an estimated 194,900 individuals were eligible for ART with only 57,000 (34.6%) actually receiving ART.[34] Although 62% of eligible Ugandan adult patients were receiving ART in 2011, 38% of those eligible for treatment, mainly rural dwellers, were not receiving ART.[35] Uganda's HIV and AIDS programs rely heavily on external donors and partners. Recent estimates show that in 2010/11, annual spending had reached 378.3 million US$, of which 10.5% was funded by the government of Uganda and 89.5% by bilateral and multilateral partners.[35]

Urban or periurban based facilities provide most of the ART services in Uganda because rural areas have limited resources and infrastructure to meet the guidelines for initiating and monitoring ART.[36] The ART guidelines are formidable; they include (a) testing of individuals to determine whether they are

HIV positive; (b) additional testing or clinical determination that the HIV positive individual is at the stage of infection where ART is appropriate; (c) for HIV positive individuals not eligible for ART, counseling on prevention, treatment of opportunistic infections, and ongoing monitoring for eligibility for ART; (d) counseling to inform the individual about what is involved in ART to improve patient compliance; (e) tuberculosis (TB) treatment, if required, prior to initiation of ART; (f) daily ingestion of ARV drugs for the rest of the patient's life; (g) consistent and timely stocking of ARV drug supplies; (h) periodic testing to assess response to treatment and verify compliance; (i) adherence counseling, and reinforcement of prevention messages such as safe sexual practices; (j) promotion of community based support in routine patient management to improve the likelihood of treatment success; (k) periodic treatment of opportunistic infections (reduced but not eliminated by ART) and assessment of nutritional status; and (l) change in drugs for those not responsive to original prescription. Trained health workers are required to initiate and manage these complex services.

In Uganda's decentralized system of health service delivery, higher level structures supervise lower levels. The first and lowest level of service delivery occurs through Village Health Teams (VHTs) where volunteer laypersons provide education on health issues and facilitate referrals to health facilities. The second level, a Health Centre II, serves a parish (group of villages). In this facility, nurses, midwives, and nursing assistants provide outpatient care for common diseases and provide antenatal care. The third level, a Health Centre III, serves a subcounty (multiple parishes). A clinical officer[†] supervises this facility and works with a team of nurses, midwives, and nursing assistants to provide outpatient care, routine deliveries, and antenatal care. The fourth level, a Health Centre IV,

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[†] A clinical officer has a lower level of training compared to a physician, but is licensed to diagnose, treat, prescribe and refer patients.

operates at a county level. One or two physicians work with a team of clinical officers, nurses, midwives, and other care providers to provide both inpatient and outpatient care and emergency operations. Beyond these facilities are the regional and national referral hospitals. Health departments in districts manage the VHTs, health centres, and regional hospitals. In 2005, ART provision was concentrated at the regional and national hospitals, in private urban clinics, and in research centres located primarily in urban centres. Over time, the government has scaled up the number and type of facilities providing ART. In 2011, 90% of Health Centre IVs and 6% of Health Centre IIIs were providing ART services; this still represented only 20% of the formal health facilities available in the country.[37] The ability of these facilities to provide universal access to all who are eligible for ART and maintain treatment over their lifetime is unknown. However, statistics show that only 45–60% of the minimum required health worker positions in district health facilities are filled,[37] suggesting a high level of pressure on these facilities, which will only grow as more patients start and stay on ART. The recently announced decrease in government investment in health ,from 9.6% of government spending in 2009/10 to 8.3% in 2011/12,[37] will add additional pressure .Most of this decrease in funding has been attributed to reduced donor funding linked to mismanagement of donor funds.[38]

1.04 Community support for ART as a potential solution

The WHO has recommended a public health approach to scale up ART.[39] This approach recommends a shift from the western model of specialist physician management and advanced laboratory monitoring to simplified treatment protocols, decentralized service delivery, and simple tools and approaches to clinical decision making that enable lower level healthcare workers to deliver care. Some researchers have suggested that lower level health care workers, especially community health workers (CHWs) could be used more efficiently to address the health care worker deficit for HIV care, especially in sub-Saharan Africa.[40,41]

The concept of community participation and engagement in health service delivery through CHWs is not new. The Declaration of Alma Ata (Kazakhstan) at the International Conference on Primary Health Care in 1978 promoted CHWs as a cornerstone for comprehensive primary health care due to their potential to reach remote populations and fill the largely unmet need for health services in many countries.[42] However, in the 1990s, interest in CHWs began to wane as a result of challenges in scaling up these programs as well as the perceived greater success of vertical programs, such as immunizations and diarrheal disease control[43] In the early 2000s, interest in CHWs was renewed when the WHO recommended CHWs as way to alleviate the health human resource crisis.[44]

Community health workers are volunteer or lower paid level health care service providers who usually live in the local communities they serve.[45] Lewin et al.[46] defines CHWs as "any health worker carrying out functions related to health care delivery, trained in some way in the context of the intervention, and having no formal professional or paraprofessional certificated or degreed tertiary education." In many regions, but particularly in low income countries, CHWs take part in many aspects of health care, from health promotion to case management and service delivery, and facilitate communication between professional health staff and the community.[42,47] Whereas there have been mixed perspectives about the success of CHW programs, there have been positive experiences when communities have been mobilized to support health programs and explore opportunities for community participation to meet needs of and address gaps in health services.[47,48]

Within Uganda, the concept of using CHWs for the implementation of ART has received government attention. The Uganda AIDS Commission has recommended community mobilization and participation to strengthen and empower existing HIV and AIDS services at the community level.[49]

In 2004, the District Director of Health Services (DDHS) for the Kabarole District, researchers from Makerere University Institute of Public Health (later the Makerere University School of Public Health), and researchers from the University of Alberta Department of Public Health Sciences began to discuss opportunities to expand ART in the Kabarole District. Particular issues that would need to be accommodated were: (a) a large proportion of the population (85%) lived outside of the main urban town of Fort Portal; (b) the only physicians trained in ART implementation and monitoring did not practice outside of town; and (c) the budget for the district could not support hiring additional health workers in rural areas. An earlier research study by the same group found that individuals living with HIV in the Kabarole District would accept monitoring of their treatment by laypersons.[50] The possibility of mobilizing CHWs to mitigate the problems cited above led the group to explore the creation of a CHW supported pilot ART program in one of the rural areas of the Kabarole District.

1.1 LITERATURE REVIEW

To help guide the development of a CHW program for ART, between 2005 and 2006, I began to search for reports of community health workers working in a range of treatment programs in sub-Saharan Africa. The two-fold purpose of the literature review was to identify experiences with CHWs in treatment programs and to identify structures of and processes in CHW programs that appeared to maximize program effectiveness and sustainability.

I conducted the literature search of MEDLINE, EMBASE, CINAHL, Global Health, Cochrane Library, and Web of Science databases. I selected the following terms as keywords and subject headings: "*community health worker* OR *community health volunteer* OR *community volunteer* OR *village health volunteer* OR *village health guide* OR *lay health worker* OR *community based distributor* OR *task shifting* OR *community based intervention* OR *village health worker* OR *home based care.*" I limited articles to "*Africa* OR *Asia* OR *developing countries.*"

1.1.1 CHW involvement in treatment programs

In the first part of the review, I examined whether others had used CHWs to support patient access to ART, whether they had monitored patients receiving ART in low income countries, and what they found to be the outcomes of this support. Of particular interest were experiences in rural areas of sub-Saharan Africa. Recognizing that ART was in the earlier stages of implementation in sub-Saharan Africa, I also looked for experiences in low income countries outside of sub-Saharan Africa and experiences with CHW involvement in non-ART treatment programs in sub-Saharan Africa.

1.1.1.1 CHWs and ART

In 2006, few studies had examined the engagement of CHWs to support patients with HIV. One of the earliest programs in a low income country was a pilot directly observed therapy program in Haiti that used laypersons to support and supervise ART treatment.[51] Implemented in 1998 and modelled on the successes of directly observed therapy,short-course (DOTS) for tuberculosis (TB), the program assigned each HIV patient an "accompagnateur" to observe the ingestion of pills, respond to patient and family concerns, and offer moral support.[51] These CHWs were paid a small stipend. A qualitative study in Kenya described a program in which hundreds of laypersons were trained to provide home based care to HIV positive individuals in rural areas where patients did not have access to ART.[52] This program trained CHWs in HIV prevention and the care and management of individuals who were sick and dying from AIDS. Data from this study showed that home based care had a positive impact on the ability of individuals with HIV and AIDS to manage and cope with their illnesses. The AIDS Support Organization (TASO) in Uganda used paid peer counsellors to help those living with HIV cope with their illness and the psychosocial impacts of the disease.[53]

1.1.1.2 CHWs and other treatment programs

I also found examples of successful CHW engagement in non-ART treatment programs. Adatu et al.[54] described the use of community members to support DOTS in TB patients in Uganda. Their findings showed that community based DOTS patients had higher treatment success and lower treatment interruptions than patients under facility based DOTS, and that patients accepted the use of community members to supervise DOTS, primarily because of decreased costs and less travel for patients. Escott et al.[55] found that community treatment support for TB was preferred to hospital based care in rural Swaziland and that overall treatment outcomes were positive despite some logistical and programmatic shortcomings. Lwilla et al.[56] in a cluster randomized trial in Tanzania that compared community based DOTS to institutional based DOTS for TB, found that cure rates were similar and concluded that community based DOTS could be viable for areas where people live far from health facilities. CHWs had been involved in treatment programs for pneumonia; Sazawal et al.[57] found that CHWs have had a significant positive impact on reducing mortality due to childhood pneumonia in low-income countries, including those in sub-Saharan Africa. CHWs had also been involved in the management of fevers. Menon et al.[58] found that rural Gambian children aged 3–59 months who received chemoprophylaxis and treatment for malaria from a village health worker had a 49% reduction in mortality and 73% reduction in attacks of clinical malaria following the introduction of the village health worker. Delacollette et al.[59] found that villages with a CHW trained in managing fevers in Zaire (now the Democratic Republic of Congo) saw decreases in mortality up to 50% over a one year period, whereas villages without a CHW had no change in mortality. Ghebreyesus et al.[60] reported that volunteer CHWs in Ethiopia providing services for diagnosis and treatment of malaria and chemoprophylaxis during pregnancy enabled more pregnant women to access treatment for malaria at the village level. Finally, programs have had positive experiences with community based distributors (CBDs)—CHWs who deal primarily with the distribution of contraceptives and drugs. In Ghana, volunteer CBDs involved in diagnosing active trachoma and distributing azithromycin made the correct decision to treat in more than 83% of cases, and only rarely encountered individuals who refused examination or treatment by CBDs.[61,62] In Nigeria, the involvement of volunteer CBDs allowed for the scale up of ivermectin distribution for onchocerciasis.[63]

1.1.1.3 Gaps in the literature

The literature revealed some gaps in the use of CHWs in ART programs. Most studies engaged volunteers in a small set of activities (e.g., adherence monitoring) that would relieve some but not the entire burden of ART monitoring in busy rural clinics. The study in Haiti focused on adherence monitoring through observation of pill taking but did not examine other aspects of ART such as drug delivery, the monitoring of side-effects, and prevention counselling. Also, they used paid CHWs instead of volunteers. The studies in Kenya and Uganda were limited in scope and focused on non-ART services, though the Kenya study did use volunteer CHWs. Overall, experiences with CHWs in non-ART treatment programs such as for TB, malaria, pneumonia, trachoma, and onchocerciasis, together with the experiences from Haiti, suggest that CHWs could handle a range of activities, from diagnosis to treatment monitoring to drug distribution. However, whether CHWs could undertake a combination of these activities over an extended period for a chronic disease like AIDS was not clear from a study of the literature. Finally, I found gaps in this literature regarding the structures and processes needed to sustain volunteer CHW programs and thus support the long-term treatment of patients with AIDS.

1.1.2 Recommendations for a volunteer CHW program

In the second part of the literature review, I looked at the CHW literature for recommended methods our group could use to develop a comprehensive volunteer CHW program for ART. I focused on the important elements identified for volunteer programs in high income countries such as recruitment and selection, training, program management, and retention,[64-66] as these were thought to be important universal elements that would be also relevant in low income contexts.

1.1.2.1 Selection of CHWs

Bradner[67] suggested that effective recruitment entails knowing what characteristics you need, knowing how to find volunteers who have these characteristics, and knowing how to screen potential volunteers to ensure you have selected the right individuals. The CHW literature recommended CHWs should be selected from the community in which they serve[45,68] as this increases volunteer motivation and ensures community trust. Armstrong[69] suggested that successful CHWs are good listeners, nonjudgemental and respectful, trustworthy and able to keep secrets, able to get along with people, sympathetic, self-confident, and committed. Ofosu-Amaah[70] found evidence to suggest that respect and trustworthiness are more likely to be found in older CHWs while a review by Lehmann et al. [45] reported that mature age and married status are preferred criteria for CHW recruitment. Bhattacharyya et al.[42] found that literacy was an important characteristic because health programs require CHWs to document activities and health information. Literacy did not necessarily mean formal education, as experience showed that uneducated individuals were able to handle documentation requirements with appropriate training and support.[71] The literacy requirement could conflict with the need to recruit older CHWs (as suggested earlier), as older individuals are less likely to be literate.[42] Stekelenburg et al.[72] recommended that the community be made aware of the selection criteria; the authors noted that CHW performance was negatively affected when communities did not know about the selection criteria or what it entailed. Bhattacharyya[42] recommended that health workers play an active role in developing the selection criteria after which the community can be engaged to help to identify suitable candidates.

1.1.2.2 Training of CHWs

Lulewicz[73] believed that CHW training should consider both volunteer and organization needs. Program developers need to determine what skills and knowledge are important for the program and what the volunteers already possess before training occurs so they can predict what resources will be necessary and how much training will be required. The CHW literature recommended an approach that provided CHWs with the skills to address the everyday types of activities they will face, that is, not only disease specific information but also soft skills in how to communicate with and counsel people who face health issues in the community.[43,45] This should entail (a) social orientation to link volunteers to the people they will be working with to enable them to better fit into their work environment, (b) position orientation to enable volunteers to understand the details of their role, and (c) system orientation to enable volunteers to understand the broader program and system they will be working in.[74] In a review of CHW programs, Lehmann et al.[45] found no consensus on the optimal length of time, depth, or organization of training, or responsibility for CHW training. Several studies recommended that training be continuous throughout the work to keep up CHW skills,[42,45,75] but also to motivate and retain

CHWs.[70] Bhattacharyya et al.[42] recommended refresher training to enable CHWs to learn new skills they may not have acquired or internalized in the initial training, to keep the work of CHWs interesting, and to further the personal development of CHWs. Experience suggests that training and training materials be kept simple because most CHWs in resource limited environments have low literacy and educational levels.[45]

1.1.2.3 Program management

Stepputat[76] recommended that volunteer programs consider recruitment, training, recognition, retention, evaluation, and selection of the right volunteer administrator to support the volunteer program. Several authors observed that the appropriate management of CHWs is a crucial but neglected element of most CHW programs.[45,70,77] Bhattacharyya et al.[42] identified supervision as an important way to keep CHWs connected to the health care system after their training and deployment in the field. Regular supervision can also provide CHWs with opportunities to discuss challenges, exchange information, and gain knowledge. It can reduce isolation and feelings of helplessness in the field[78] and can help to build self-esteem.[42] Supervision also has to be frequent and regular in order to be effective.[42] Bhattacharyya et al.[42] identified weak or inconsistent supervision as a cause of low CHW retention.[42] On the other hand, Stekelenburg et al. [72] found no correlation between supportive supervision and CHW performance in a program in Zambia.

The literature identified the need to develop clear roles, responsibilities, and work targets for CHWs and regular coordination and communication.[69] A regular and accessible supply of clinical resources (including drugs) can ease the work load and proper remuneration will encourage good CHW performance.[79] CHW roles should be appropriate to their scheduled work time and their abilities and the geographic catchment area has to be manageable and congruent with available transportation.[42] Programs should also consider the cultural, ethnic, religious or language barriers that CHWs might encounter.[42]

1.1.2.4 Remuneration and incentives

Timely and appropriate remuneration or incentives motivate volunteers to undertake program activities and to stay in the program. There are lively debates about the need to pay CHWs for their service. Some believe it is wrong to ask a person to volunteer for work that would be paid for in many other regions, especially if the volunteer lives in poverty and faces his or her own hardships.[80] Others believe that CHW payment is unsustainable (and can actually be a disincentive if irregular or terminated in the future[42]). In reality, areas with high needs and limited resources have few options other than to engage CHWs as volunteers. It is suggested by some field studies that nonfinancial incentives can act as suitable motivators.[42] In my literature review I focused on nonfinancial remuneration as the Kabarole District had limited resources to provide salaries and stipends to CHWs.

To plan appropriate incentives, it is important to understand what motivates volunteers. The Horton-Smith theory, as described by Esmond et al.,[81] maintains that volunteer motivation can be altruistic (intangible rewards) or egoistic (tangible rewards). Volunteers do not always distinguish between different motives, and generally seek a combination of intangible and tangible rewards.[82] Esmond et al.[81] found that the three most important considerations for volunteers followed the order: (1) importance of helping others, (2) reciprocity (the belief that something good will come of doing good), and (3) recognition.

Patel et al.[83] point to a deep spirit of volunteerism in Africa. Historically, African societies relied on community support to meet their human needs, and this collective responsibility is still encouraged by many cultural beliefs and practices. The same authors found a high degree of volunteerism even among those living in poverty; they found that 69% of Malawi households are part of a community based organization while 17% of South Africans volunteer their time. Kaseke et al.[84] found that to individuals in South Africa the word “volunteering” suggested working toward a noble or good cause and encouraged their involvement, whereas the word “service” implied that the work was linked to government or state compulsion.

Studies have shown that nonmonetary incentives can motivate CHWs and that these incentives do not have to be large or costly. Identification badges, job aids such as supplies,[42] a token of appreciation like a bar of soap, some salt, or a lunch allowance[85] can inspire a CHW. Certain incentives, such as a bicycle, can support the work of a CHW and also enable geographical expansion of the program.[52] The idea behind these incentives is to provide some compensation to volunteers while recognizing their contributions.[86] Incentives can be related to the CHWs’ work requirements or environment—e.g., raincoats, backpacks, and educational materials.[42] Recognition or appreciation can be conferred by preferential access to and treatment at clinics, access to credit programs or training, or even public praise on radio shows and other public forums.[42] Some have motivated CHWs by showing them how their work was linked to the recovery of patients.[42] Bhattacharyya et al. [42] found that giving volunteers the responsibility to distribute drugs increases their standing and credibility but cautioned that incentives given too often or in too many forms can, in the long-term, defeat the goals of motivating volunteers, though they did not clarify how and why this would occur.

1.1.2.5 Recommended models for CHW programs: gaps in the literature

The CHW literature provided a range of methods for setting up important elements of a volunteer CHW program. However, these elements had never been tested within a long-term initiative such as ART and not all elements had been tested using volunteer CHWs. Most of the programs studied had supported short-term or acute care needs of patients and the methods used might not work well in an ART program. When experience with ART programs was reported, information was lacking about important elements such as the expected workload for volunteer CHWs, the optimal ratio of patients to CHWs, and the time CHWs would require to care for HIV patients.

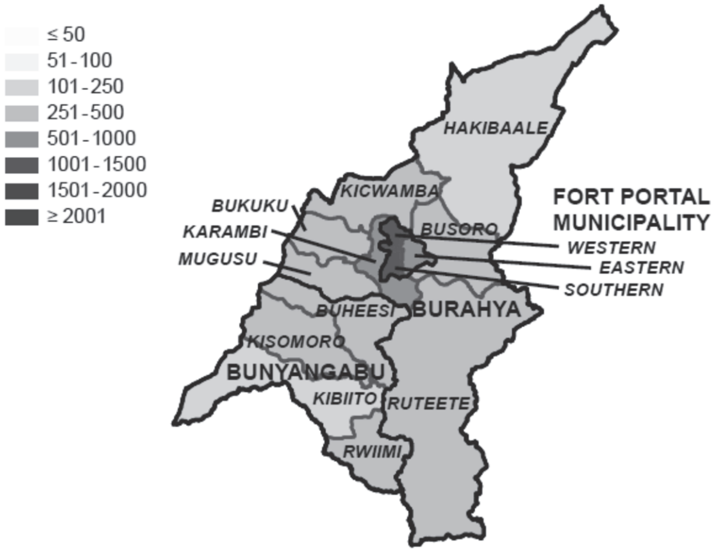
1.2 RESEARCH QUESTIONS

The Kabarole District sought to scale up ART to rural areas of the district where infrastructure and human resources are limited. To explore the possibilities and limitations of such an expansion, researchers from the University of Alberta[‡], researchers from Makerere University and policy makers from the Kabarole District Health Department decided to employ a research study to test the effectiveness of a pilot community based ART (CBART) program in a rural subcounty over a two year period. We established this study in the Rwimi subcounty of the Kabarole District located in western Uganda (see Figure 1-1). In 2005 the Kabarole District had a population of 403,200. The Rwimi subcounty had an estimated population in 2005 of 25,000 and a population density between 251–500 persons/km^2. Subsistence farming and trading are the main sources of income in the Rwimi subcounty. Rwimi has one Health Centre III and three Health Centre II clinics that provide basic outpatient health services. Prior to the implementation of this study, the nearest ART clinic was located in Fort Portal, approximately 50 km north of Rwimi. In 2005, there were no Village Health Teams in the district. There are no health statistics for Rwimi. However, in 2005 the prevalence of HIV in the Kabarole District was 11.6% which was above the national average of 6.4%.[87] Based on this figure, in 2005 an estimated 2,900 individuals in Rwimi were living with HIV of which 450 (15%) were estimated to be eligible for ART.

[‡] I was part of the team from the University of Alberta and acted as the research coordinator for the study.

Our CBART program had three main components. The first was the establishment of appropriate clinic resources in the Rwimi Health Centre III that allowed patients to begin ART and provided the six month scheduled monitoring of treatment required by the Ministry of Health. The second was a collaboration (similar to the DOTS program for TB) with treatment partners who would support adherence to treatment by observing patients taking their drugs twice a day. The third component, and the focus of this thesis, was the establishment of a volunteer CHW program to support the delivery of ARV drugs to patients and to monitor patients in their homes. Recommendations in the literature regarding CHW programs were applied in building the CHW program.

Figure 1-1: Map of Kabarole District[88] with population densities (population/km^2)



The broader CBART study explored whether a CBART program located in a rural setting could provide good quality clinical outcomes. Our group has described findings of this study in various publications.[89-94] The purpose of this substudy was to understand if CHWs are capable of undertaking a range of tasks to support ART, and whether the structures and processes around the elements of recruitment, training, management and motivation recommended in the literature for CHW programs would work with volunteers supporting ART over a two year period. These findings can guide other ART programs as well as the expansion of the CBART program to other areas. In my assessment of the CHW program, I focused on answering the following research questions:

1. Can a CHW program successfully support community based ART? Specifically:
   a. Can volunteer CHWs effectively perform a range of activities necessary to support ART?
   b. How did the different elements of a volunteer CHW program function to support an ART program?
   c. What CHW characteristics are associated with positive ART outcomes?

2. Based on their experiences with the CBART program, what are the perspectives of:
   a. Patients, clinic staff and CHWs on the benefits to patients of using CHWs to support ART?
   b. CHWs on the challenges they faced in supporting ART and what helped and motivated them?

I then use these findings to develop a set of recommendations for an effective volunteer CHW model for ART that we and others could use to expand a CBART program within the Kabarole District as well as in other rural areas in sub-Saharan Africa.

CHAPTER 2: DESCRIPTION OF THE CHW PROGRAM

2.0 OVERVIEW OF THE CBART PROGRAM

The CBART program implemented by our research team had three main components. The first was the clinical arm and involved the establishment of ART services in the Rwimi Health Centre III and six month clinical monitoring of patient CD4 cell counts and viral loads. A voluntary counselling and testing (VCT) program was already in place prior to this intervention. The establishment of the ART program involved minor infrastructure development to create private areas for clinic staff to assess patients, and training of clinic staff on ART based on the Uganda National Guidelines for ART.[36] The Rwimi clinic had a regular staff complement of one clinical officer, two nurses, and one VCT counsellor at the beginning of the study period. After one year, the Kabarole District government hired a second clinical officer. The health department of the Kabarole District paid and supervised the staff. We hired a Ugandan physician to train the clinic staff how to follow the ART guidelines and advise them on complex clinical issues as they arose. The ART program began accepting HIV patients for ART in February 2006 based on criteria described in the research methodology in Chapter 3. Patients eligible for ART started on an ARV drug combination consisting of stavudine, lamivudine, and nevirapine (or efavirenz for patients on rifampicin). All patients also received daily co-trimoxazole to manage opportunistic infections. The country's AIDS program supplied the ARV drugs while the Kabarole District and the research project supplied the co-trimoxazole as well as maintained a buffer stock of ARVs for short-term drug stock-outs.

The second component of the CBART program was the involvement of treatment partners to support adherence to ARV drugs. Each patient enrolled in the study identified a treatment partner (either a relative, someone in their household, or a close friend or neighbour) who would observe and record the occurrence of their twice a day ARV medication.

The third component was the establishment of a volunteer CHW (CHW) program to support community based treatment. The model envisioned for the CHW program had five key elements: (1) identification of core activities for CHWs; (2) recruitment of CHWs; (3) provision of essential information and training; (4) establishment of a management and supervision structure; and (5) establishment of a system to motivate and retain CHWs. I guided the establishment of the CHW program based on recommendations from the literature, with adaptations made, as necessary, to accommodate the needs of the ART program and the available local capacity.

2.1 CORE ACTIVITIES FOR ART

We worked with the Kabarole Health Department to identify core CHW activities based on evidence of appropriate activities for laypersons.[51] In this work we aimed to reduce the burden on clinic staff already busy with the provision of health services for other diseases. We also considered the personal capacities of the CHWs and their own personal and family responsibilities. A key principle of the project was to utilize the CHW to support rather than replace a health worker.

These core activities included weekly monitoring of adherence to ARV drugs and identification of treatment side-effects, monthly deliveries of ARVs and co-trimoxazole to the patients[§], and prevention counseling and condom distribution to support the prevention of HIV transmission. Each weekly visit was recorded on a volunteer log sheet (see Appendix A) and presented to the volunteer administrator for data entry and storage at the monthly volunteer meeting.

[§] In the CBART program, project staff, patients, and health workers often referred to patients as “clients” and community health workers as “volunteers”. In this manuscript, I will use the terms patient and community health worker (CHW).

Based on CHW feedback, after six months we changed the frequency of visits to patients who were doing well on treatment (as determined by the clinic) from weekly to biweekly and then to monthly.

A system was set up to monitor adherence to ARV drugs through pill counts conducted during each visit which the CHW then matched to an expected pill count. Community health workers also matched their pill counts with the treatment partner's record of pills taken by the patient. We provided training to CHWs on how to calculate expected pill counts based on the previous visit's pill count, the days between visits, and new ARV drugs delivered to determine the number of pills that the patient should have on hand.

At the beginning of the study, CHWs had to empty pills from opaque bottles, count these and then return them to the bottle. After one year, we provided all patients with transparent pill boxes compartmentalized by day of the week that stored a four week supply of drugs. This enabled CHWs to count drugs without having to remove the pills from their packaging. Community health workers recorded the pill counts in their volunteer logs. At the beginning of the program, CHWs had to reconcile the difference between the number of tablets counted and the number of tablets expected to be available, based on the number of tablets that patients were expected to have swallowed since the last visit. We changed the forms after the first six months and removed the calculation requirements. The volunteer administrator took on the task of performing the calculations for the CHWs using data from the volunteer logs they submitted at the monthly volunteer meetings. Community health workers discussed discrepancies with the patient and provided advice on the importance of adherence to medication and suggested different approaches the patient could use to remember to take his or her drugs.

An infectious disease specialist from our team helped to set up a guide for monitoring side-effects to ARV drugs and to drugs for other patient illnesses. The guide relied on direct observation and questioning of the patient to identify three major side effects—jaundice, skin rashes, and neuropathy—and provided appropriate recommendations based on the severity of the side effect. For patients with yellowing of the eyes, indicating jaundice, the recommendation was referral to the clinic. For patients with serious rashes, indicated by blisters, fever, bumps, and mouth sores, the recommendation was also immediate referral to the clinic. For those with mild rashes or numbness or a feeling of burning in the toes, suggesting mild neuropathy, the recommendation was ongoing monitoring and referral to the clinic if the symptoms continued for more than six weeks. If the CHW was uncertain about the symptoms or the need to refer the patient to the clinic, the recommendation was to contact the volunteer administrator for advice or to proceed with the referral.

Each month, the CHWs picked up a monthly prescription of ARVs and co-trimoxazole from the clinic and delivered them to their patients at the next scheduled visit. At the same time, CHWs could also pick up condoms from the clinic to distribute to male and female patients who were sexually active and who accepted receiving condoms.

2.2 RECRUITMENT AND SELECTION OF CHWs

Our concern for patient stigma and confidentiality led us to seek CHWs who were respected and trustworthy. We accepted the recommendations from the literature that CHWs should come from the communities they served, and should be selected by community members based on clearly identified criteria. The CHWs had to be literate to document their activities and have basic English literacy to interact with us and collect data in English for the research study.

Our final selection criteria for CHWs included maturity (over the age of 20 years), a basic ability to read and write English, and being well known and well respected in their own villages. Formal education was not a criterion. Experience in North America has shown that staff who work alongside volunteers need to be supportive of the volunteer and the program.[95] Therefore, we asked the clinic staff to undertake the identification and selection of potential CHWs from various parishes in the catchment area of Rwimi Health Centre III. Clinic staff and community leaders approached these potential CHWs and invited them to attend an orientation session to learn more about the program.

The volunteer administrator matched patients enrolled in treatment with CHWs from the same parish. The volunteer administrator based the number of patients assigned to each CHW on the number of enrolled patients from a village where the CHW lived and on the CHW's perception of how many patients he or she could comfortably supervise.

2.3 CHW TRAINING

We set up a training and orientation curriculum to provide both technical and soft skills based on Graff's[74] recommendation to provide social orientation, position orientation, and system orientation. We aimed to provide CHWs with the knowledge and training essential for their work without overburdening them with unnecessary information.

In November 2005 we held a two day training session as part of the volunteer orientation. We developed training materials based on materials from the International HIV Alliance[96-99] and the Department of Health, South Africa.[100] The training involved a series of lectures and a series of role-playing activities to simulate a patient visit. The training focused on three aspects. The first was on clinical information regarding HIV infection and prevention, AIDS symptomology, and ART. Prevention training focused on promoting “abstinence, being faithful, and condom use” (“ABC”), the message favoured by the Ugandan Government. Studies have shown that the “ABC” message played a big role in the reduction of HIV infections in Uganda in the 1990s and 2000s despite the simplicity of this strategy and its lack of consideration for the complexities inherent in promoting behaviour changes to reduce HIV transmission.[101-103] The second aspect was on building practical skills for CHW activities, such as calculating adherence to medication, filling out volunteer logs, and showing patients how to use condoms using wooden penis models. The third aspect was on CHW-patient interactions. We showed different approaches for interacting with patients (referred to as “clients” by the CHWs) in a positive manner. The Ugandan physician, a physician from the University of Alberta, and a clinical officer hired by the project team as the volunteer administrator provided the training. We provided CHWs with a handout that covered some of the materials from the training session (see Appendix B) and a job description (see Appendix C). At the end of the training program, the Kabarole District and the study team provided CHWs with certificates of training (see Appendix D).

The volunteer administrator provided one-on-one training for 11 additional CHWs recruited after the formal training session. The volunteer administrator and clinic staff continued to provide ongoing training at the monthly volunteer meetings. Community health workers could also contact the volunteer administrator on his mobile phone at any time to request information or advice. There were no costs for CHWs to contact the volunteer administrator as they could “beep”[**] the volunteer administrator who would then call them back. All CHWs either had a mobile phone or access to a mobile phone.

[**] “Beep” refers to calling a number and hanging up immediately and before the other party answers the call. This provides the recipient of the call with the phone number of the original caller. Beeping is a commonly used method to indicate a request to call back when the caller does not have enough airtime credits to make a call or if he or she wishes to have the recipient pay for the call. In Uganda, only the caller incurs mobile phone charges; incoming calls are free.

2.4 PROGRAM MANAGEMENT AND CHW SUPERVISION

The literature on CHWs recommended strong supervision and competent administrative support. Therefore, we based the CBART volunteer management system on a central administration model in which a volunteer administrator was responsible for recruitment, retention, and motivation of CHWs and for ensuring the proper deployment, training, and monitoring of the CHWs. We included a system of regular communication with CHWs and processes to ensure that resources for ART and CHW activities were available. Finally, we developed a set of incentives linked to the work of the CHWs (see section 2.5).

We hired a volunteer administrator who had a clinical background (a clinical officer) and experience working with volunteers. Because working with HIV patients can be emotionally difficult, we selected a volunteer administrator with experience in counselling CHWs who had experienced grief and challenges.[104] We instructed and oriented the volunteer administrator on the objectives of the CHW program and worked with him to identify and resolve complex CHW issues. Although there were no formal program policies, we provided the volunteer administrator with a formal job description that outlined his specific duties (see Appendix E). The volunteer administrator was responsible for assigning and introducing CHWs to patients enrolled in ART and maintaining the roster of CHWs and patients. He arranged for temporary coverage for those unable to make a weekly visit. As the need arose, the volunteer administrator worked with local community leaders and clinic staff to recruit and train new CHWs. Our intent was to eventually recruit patients to be CHWs themselves. Russel et al.[105] believed that HIV patients who experienced positive outcomes could provide greater motivation and passion for this work than those who had no experience with living with HIV. However, it was not necessary for us to replace any CHWs during the first two years as CHW attrition was low. The volunteer administrator was available to the CHWs in person on Mondays and Wednesdays in the clinic and at any time by mobile phone to handle all types of queries. The volunteer administrator organized all volunteer meetings as well as the annual community volunteer recognition programs (see section 2.5).

The CBART program established monthly meetings of CHWs, the volunteer administrator, and a representative from the clinic staff. The CHWs appointed a Chairperson and Secretary (to take minutes) from among themselves. A typical meeting agenda consisted of a prayer (a typical way to begin meetings in this region), welcoming remarks from the chairperson, project and patient updates from the volunteer administrator, and opportunities for CHWs to present issues and questions. Community health workers worked with the volunteer administrator and the clinic staff person to identify solutions. From time to time, the volunteer administrator used the meetings to provide ongoing training. Prior to adjourning the meeting, the CHWs decided on a date for the next meeting. After the meeting, the volunteer administrator stayed behind to collect the volunteer logs and answer individual questions.

Clinic staff organized the drug and condom supply for the clinic and informed the volunteer administrator of shortages. We provided the CHWs with the volunteer logs and stationery, which the volunteer administrator distributed.

2.5 CHW MOTIVATION AND RETENTION

Our motivation and retention systems and activities were developed to ensure that a range of volunteer incentives was available. We did not pay the CHWs; rather, we provided them with nonfinancial incentives and tools to support their activities. I developed a guiding document for the project staff regarding nonfinancial incentives for CHW motivation and retention (see Appendix F) based on recommendations from the literature. These incentives considered the need for personal recognition, a need for volunteers to see the benefits and outcomes of their work, the importance of personal faith, values, and development, and the value of social networks. The CBART motivation strategy attempted to incorporate all of these motivators through (a) establishment of recognition programs and activities at the community and clinic level, (b) establishment of activities that created a supportive environment for CHWs, and (c) distribution of nonfinancial material resources to support CHW activities.

As incentives we provided each CHWs with material resources that could help with the work. These included a bicycle, bicycle lock, tire pump, raincoat, gumboots, watch, vinyl bag, and a calendar diary. Each year we provided a new set of bicycle tires and a new diary. We informed the CHWs they could keep the bicycle after working one year as a CHW. Community health workers were also given a lunch allowance and transport refund of 5,000 shillings (US$2.94 at 2006 exchange rates) for each volunteer meeting they attended.

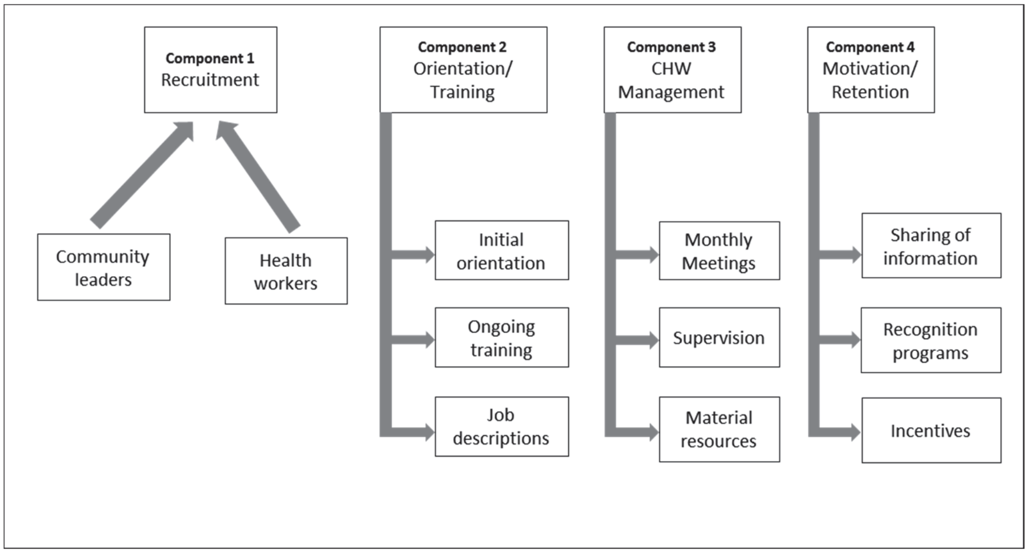
During the monthly volunteer meetings we tried to provide a supportive space for the CHWs. The CHWs were encouraged to share success stories that highlighted their positive impact in addition to bringing up issues and challenges. We also used these meetings to share aggregate treatment results of patients to show CHWs the impact of their work.

Finally, each year we organized a volunteer recognition day in the community. Community and political leaders, clinic staff from Rwimi Health Centre III, and CHWs and their families were invited to participate in the program to recognize the work of the CHWs. Dignitaries, CHWs, and patients gave speeches, followed by a meal and entertainment. We presented CHWs with token gift items as well as replacement tires and diaries. The funds for this program came from our research budget. The clinic staff recognized the work of the CHWs by arranging preferential access to the Rwimi Health Centre III for CHWs and their families, allowing them quicker access to care.

2.6 CHW PROGRAM MODEL SUMMARY

Figure 2.1 outlines the main components of the CHW volunteer program model that was established for the CBART program. In summary, the first component, recruitment, involved the engagement of community leaders and health workers to select the CHWs from the community. The second component, orientation and training, was supported through an initial two-day training workshop, the provision of job descriptions, and ongoing training as required. The third component, CHW management, was supported by monthly meetings where CHWs discussed issues and challenges, a volunteer administrator who provided various levels of supervisory and technical support to CHWs, and material resources to help CHWs undertake their activities. The fourth component, CHW motivation and retention, was supported by the sharing of information on patient progress in order that CHWs could see the benefit and impact of their work, annual community recognition programs, and material incentives as a tangible form of appreciation of their work.

Figure 2-1: CHW Program Model



CHAPTER 3 – RESEARCH METHODS

3.0 OVERVIEW

I used a mixed methods design to try to answer the two research questions for this thesis.

The first research question was: Can a CHW program successfully support community-based ART? The first two parts of this question related to understanding: (a) can volunteer CHWs effectively perform a range of activities necessary to support ART? (b) How did the different elements of a volunteer CHW program function to support an ART program? To answer these, I collected and extracted longitudinal and cross-sectional data that I used to produce descriptive statistics. I looked at how the CHWs performed in managing routine visits, monitoring adherence to treatment, identifying side-effects, and providing prevention messages. I also explored the dimensions of recruitment and retention, workload, training, and management of CHWs. To investigate recruitment and retention, I asked the following subquestions: What types of individuals volunteered for this program? How did they find out about the program? How many volunteers stayed with the program over a two year period? To better understand the workload of the CHWs, I counted the number of patients each CHW had to supervise and the time it took for the CHW to complete the required activities. I assessed training by asking the following subquestions: Did the training format lead to knowledge gains for the CHWs? I assessed CHW management by asking: How many CHWs attended the meetings? What issues and solutions were brought forward in these meetings?

The third part of the first question related to understanding: what CHW characteristics are associated with positive ART outcomes? To answer this, I extracted data from our larger prospective cohort study on CBART patients. I used these data to develop multivariate regression models to explore the associations between various demographic, geographical, and socioeconomic characteristics of CHWs and positive ART outcomes, namely, virologic suppression and patient survival.

The second research question was: based on their experiences with the CBART program, what are the perspectives of (a) patients, clinic staff and CHWs on the benefits to patients of using CHWs to support ART? (b) CHWs on the challenges they faced in supporting ART and what helped and motivated them? I used a qualitative descriptive approach to answer these questions. Here, I asked patients, clinic staff, and CHWs what benefits CHWs brought to patient ART. I also asked each CHW: What challenges have you faced in volunteering in the program? What helped you to manage these challenges? What kept you motivated?

3.1 STUDY POPULATIONS

I collected data from CBART patients, CHWs, and clinic staff. Between February 2006 and November 2006, our research team recruited and enrolled patients for the CBART study. Patients were eligible for the study if they were: 18 years of age or over, HIV positive, treatment-naïve, eligible for ART according to the Uganda National HIV guidelines[36] which called for a measured CD4+ cell count of < 200 cells/µL and/or a WHO AIDS clinical stage measure of three or four, willing to have a family member or friend provide daily treatment support, and willing to have a CHW visit them weekly. A physician with training in and experience with ART obtained informed consent and enrolled patients as they sequentially presented at Rwimi Health Centre III. By November 2006, the study had enrolled 185 patients. After two years, 129 patients remained in the study (32 had died and 24 had left the study). Two patients died prior to being assigned a CHW and were not included in the final analyses.

Our research team recruited CHWs into the program and study through a multistage selection process. We initially asked clinic staff at the Rwimi Health Centre III and community leaders from Rwimi to identify potential CHWs who were 20 years or older, spoke and wrote English, and whom they considered to be respected members of the community. They invited these potential CHWs to a two-day training session where our research team and our staff described the program activities to them. Those who said they wanted to join were invited to participate as CHWs. Thirty CHWs were engaged in November 2005 prior to the February 2006 start of the CBART program and another 11 CHWs were recruited between February 2006 and November 2006 as patient enrolment increased. I invited all five Rwimi Health Centre III staff involved in ART to participate in the study. This included two clinical officers, one nurse, one health counselor, and one laboratory technician.

3.2 DATA SOURCES AND DATA COLLECTION

Between November 2005 and December 2009, I collected quantitative and qualitative data, including cross-sectional data from questionnaires, in-depth interviews, and focus group discussions (FGDs) as well as longitudinal data from clinical records and patient monitoring logs. I also extracted data from existing project records, including volunteer meeting minutes and patient and CHW rosters. Table 3-1 summarizes the data sources for this study. I describe the data and the data collection process in detail in the following sections.

Table 3-1: Data collected for this study.

Research Questions 1a and 1b – experiences within the volunteer program

Indicator	Primary source of data	Data collected/extracted
Completion of routine visits	Volunteer visit logs	▪ Frequency of visits to patients
	CHW two-year survey	▪ CHW reported missed visits
Adherence monitoring	Volunteer visit logs	▪ Pill counts
	CHW two-year survey	▪ CHW perception of adherence monitoring
Identification of side-effects	Volunteer visit logs	▪ Identification of side-effects and recommendations
	Clinic charts	▪ Diagnosis of major side-effect
Prevention activities	CHW two-year survey	▪ CHW perceptions on distributing condoms
Recruitment/ Retention	Program records	▪ Number of CHWs and volunteering start/end dates
	CHW two-year survey	▪ Where CHWs heard about the program
	CHW baseline survey	▪ CHW characteristics
Workload	Volunteer visit logs	▪ Time spent with patient
		▪ Time to travel to patient
	Program records	▪ Number of patients for each CHW
	CHW two-year survey	▪ CHW perceptions on number of patients supported
Training	Pre- and post-training questionnaires	▪ Knowledge of HIV, AIDS, ART, and prevention
Management support	Volunteer meeting minutes	▪ Meeting attendance
		▪ Issues and solutions discussed by CHWs

Research Question 1c – CHW characteristics associated with treatment outcomes

Indicator	Primary source of data	Data collected/extracted
Virologic suppression	Clinic charts	▪ Patient viral load
Mortality	Clinic charts	▪ Patient deaths
Independent variables	CHW baseline survey	▪ CHW age, sex, marital status, occupation, education
	Volunteer visit logs	▪ Missed visits
		▪ Time to travel to patient's home
	Program records	▪ Number of patients supervised
	Clinic charts	▪ Patient age, sex, marital status, education

Research Question 2 – Patient, health worker and CHW perceptions

Indicator	Primary source of data	Data collected/extracted
Value of the CHW	Patient in-depth interviews	▪ Patient perspectives
	Clinic staff FGD	▪ Clinic staff perspectives
	CHW FGDs	▪ CHW perspectives
Challenges and motivators	CHW FGDs	▪ CHW perspectives

3.2.1 Volunteer logs

Community health workers recorded the details of all visits to each patient in their weekly (later biweekly, then monthly) volunteer logs (see Appendix A). The volunteer logs captured the visit date, the duration of the visit, the number of ARV tablets delivered, the number of ARV tablets on hand with the patient, the common side-effects observed, the recommendations provided to the patient, and the time taken to travel to the patient. As part of the two-day orientation and training session, the volunteer administrator showed the CHWs how to complete the volunteer logs; he then provided refresher training as needed during the volunteer meetings. We gave each CHW a wristwatch to measure the time to travel to the patient and the length of time they spent with the patient. Community health workers determined the number of ARV tablets remaining with the patient through a pill count conducted at each visit. Community health workers calculated adherence to treatment as the difference between the expected ARV pill counts and the actual pill counts. The expected pill count was calculated as the number of tablets available at the last visit, plus any new tablets given minus two times the number of elapsed days (patients took two tablets per day) minus one tablet because the patient would not have taken his or her evening dose on the day of the pill count. The volunteer administrator double-checked the calculations after each volunteer meeting. Based on feedback from CHWs, the study team later had the volunteer administrator take over the responsibility of calculating adherence to medication using the information provided by CHWs in their volunteer logs. A Ugandan research assistant entered two years of visit data (over 12,000 visits) from the volunteer logs into a Microsoft Access® (Microsoft: Redmond, WA) database.

3.2.2 Volunteer meeting minutes

The Secretary of the CHW team documented the minutes of the monthly meetings in English. The meeting minutes captured the issues and questions brought forward by CHWs and the discussions related to these issues. The volunteer administrator checked the handwritten minutes for accuracy before submitting them to one of the research team staff to type using a word processor. I reviewed the typed minutes and extracted information on meeting attendance, the issues and challenges identified by CHWs, and changes and solutions proposed by the group.

3.2.3 CHW surveys

All CHWs participated in a baseline survey (see Appendix G) in April 2006 to identify the demographic and socioeconomic characteristics of the CHWs. The socioeconomic data was an attempt to use asset ownership as a proxy for household wealth. However, many respondents chose not to answer these questions, thus preventing me from using these data in my analyses. In April 2008, all CHWs participated in a two-year follow-up survey (see Appendix H) to assess their perceptions of volunteering in the program. A combination of closed and open-ended questions aimed to gather information about the CHWs' perceptions of their activities, their relations to their patients, their motivation to volunteer and continue volunteering, and their perceptions of personal effectiveness. I developed the questionnaire using the areas of inquiry summarized in Table 3-2.

Table 3-2: Areas of inquiry guiding the two-year CHW survey

Theme	Areas of Inquiry
Recruitment	▪ Previous volunteering ▪ Where they heard about the program
Training	▪ Usefulness of training ▪ Role of volunteer administrator
Activities	▪ Time to complete tasks ▪ Difficulty in completing tasks ▪ Number of patients ▪ Missed visits ▪ Personal effectiveness
Management	▪ Perception of meetings ▪ Attendance of meetings
Motivation	▪ What motivated the CHWs ▪ What resources were made available ▪ Community, health worker and patient appreciation ▪ Benefits for self
Effectiveness of the model	▪ Benefits to patients

A Ugandan research assistant fluent in Rutooro translated the questionnaires into the local language. To enhance the reliability of the survey instrument, a second Ugandan research assistant, also fluent in Rutooro, back-translated[106,107] the Rutooro questionnaires into English. Both research assistants reviewed identified discrepancies and made the necessary corrections to the satisfaction of both. Due to the small number of CHWs in the program, it was not possible to pretest the survey instrument without excluding a significant proportion of the CHWs from the final survey. The volunteer administrator, multiple research assistants, and two project staff reviewed the final Rutooro questions in order to ensure that the CHWs could understand the questions. Trained research assistants administered the questionnaires and recorded the responses directly onto the questionnaire in English. The research assistants coded close-ended questions into nominal or ordinal data, based on a guide I prepared for them. A Ugandan research assistant trained in data entry entered the questionnaire data into a Microsoft Access® (Microsoft: Redmond, WA) database.

3.2.4 Clinical data

I obtained data on baseline patient demographics and six-month, one-year, and two-year clinical data from the larger CBART study's databases and patient charts. As the research coordinator for the study, I directed and provided oversight for the collection of data for these databases. These databases included patient demographic data, patient enrollment data, laboratory test data, and the current status of the patient (as active, left the study, or died). The Joint Clinical Research Centre (JCRC) in Fort Portal, which is part of a network of laboratories with international quality control, carried out the HIV-1 RNA viral load laboratory tests. Due to patient deaths and decisions by some patients to leave the study, two-year viral load data were available for only 128 patients. I exported data from the various databases into Stata IC 11® (StataCorp: College Station, TX) for data analysis.

3.2.5 CHW focus group discussions

In June 2008, I arranged for four focus group discussions (FGDs) with CHWs. These FGDs were held in a private room at the Rwimi Health Centre III and had between 8 to 12 participants each. All 40 CHWs retained in the study after two years participated in one of the four FGDs. One FGD consisted of eight female CHWs only and one FGD consisted of 12 CHWs who lived furthest away from the health centre. The other two FGDs consisted of CHWs of both sexes who lived variable distances from the health centre. I used the findings from the two-year CHW survey to develop a CHW FGD topic guide (see Appendix I) to further explore the CHWs' perceptions of their activities, the impact of their activities, and their motivation to volunteer. I provided training to the research assistants regarding how to conduct FGDs, including how to: manage group conversations; spur discussion using the topic guide; change the topic of conversation; and probe further into points of interest.[108] One research assistant facilitated the

FGDs in Rutooro while the other observed and took notes in English to help me follow the conversations. I was present at the FGDs and observed the discussions. The research assistants audio-recorded the discussions and used these recording to simultaneously translate and transcribe the discussions into English.

3.2.6 Health worker focus group discussions

In June 2008, I arranged a FGD with clinic staff. Five clinic staff involved with ART (one clinical officer, two nurses, one counsellor, and one laboratory technician) participated in the FGD. I developed a topic guide (see Appendix J) to explore clinic staff perceptions of CHWs and their activities. For this FGD I recruited one research assistant from Kampala and one from the Kabarole District. I provided training to both of them on the topics described earlier. One research assistant facilitated the FGD in English while the other took brief notes. I was not present at this FGD. The research assistants audio-recorded the discussions and used the recordings to prepare written transcripts.

3.2.7 Patient interviews

In October 2008, Ugandan research assistants conducted semistructured in-depth interviews in Rutooro with 20 patients to assess their perceptions of the CHWs and the CHW activities (see guiding questions in Appendix K). I used a purposeful sampling approach to select an equal mix of male and female patients for the in-depth interviews to obtain gender-balanced perspectives. I separated the original list of 129 remaining patients into male and female groups and selected 10 patients from each category. Each patient was interviewed by a pair of research assistants either in the patient’s home or in the nearest health centre, based on the patient’s preference. One research assistant conducted the interview and the other took notes. I was not present at these interviews. The research assistants audio-recorded the interviews and used these recordings to simultaneously translate and transcribe the interviews into English.

3.2.8 CHW training tests

All 30 CHWs who attended the two-day orientation and training session completed self-administered pre- and posttraining knowledge tests (see appendix L) formulated to measure the knowledge gained from the training. I used the training materials from the training session to develop questions to assess the knowledge acquired by CHWs. I focused on the important information that CHWs needed to know to help their patients understand their illness and maintain adherence to treatment. Research team members from Canada and Uganda reviewed the questionnaire to ensure that the questions were appropriate and could be well understood. As all CHWs had a working knowledge of English, I used an English questionnaire. I distributed the pretraining test to all CHWs before the first day's training session. I administered the posttraining test to all CHWs present at the end of the second day of the training session. I entered the data into Microsoft Excel® (Microsoft: Redmond, WA) and exported it into Stata IC 11® (StataCorp: College Station, TX) for data analysis.

3.3 DATA ANALYSIS

3.3.1 Quantitative data

From the questionnaires and the pre- and post-tests for knowledge, I generated descriptive statistics on the characteristics of CHWs and their perceptions of the program, and perceptions of the impact of their activities. As the data from the pre- and posttraining tests were not normally distributed, I used the Wilcoxon signed-rank test for paired data to test for statistically significant differences between the pre- and posttests. I used two tailed t-tests to test for statistically significant differences in continuous data. For categorical data, I used chi-squared tests, unless cell sizes in n × n tables were small, in which case I used the Fisher's exact test. I based statistical significance on $\alpha \leq 0.05$. In some instances, small sample sizes prevented me from using tests of statistical significance. In these instances I presented data without any calculations of statistical significance or confidence intervals. I analysed all data using Stata 11 IC® (StataCorp: College Station, TX).

I developed univariate and multivariate logistic regression models to assess the odds of achieving virologic suppression in relation to CHW characteristics. Virologic suppression is a gold standard measure of treatment success and is indicated by a decrease in a patient's HIV RNA level (or viral load) to below detectable levels.[109] Viral load is considered to be the best indicator for measuring the effectiveness of antiretroviral treatment due to its sensitivity and specificity in measuring the response to treatment.[109] The CBART study team defined viral suppression as < 400 copies/ml as this was the threshold for the Amplicor HIV-1 Monitor Assay (Roche Molecular Systems™) machines[110] used at the JCRC laboratory where study participant blood samples were analyzed. I created a dichotomous dummy outcome variable for virologic suppression with a value of 1 if the patient's viral load was below 400 copies/ml and 0 if their viral load was higher than 400 copies/ml or if they died or left the study (I considered patients who left the study to not have achieved virologic suppression.)

I developed univariate and multivariate Cox proportional hazard models to examine associations between all-cause mortality and CHW characteristics. I took a conservative approach and looked at all-cause mortality rather than HIV-specific mortality due to a lack of detailed clinic or autopsy data that made it difficult to assess cause of death.

I examined CHW characteristics (age, sex, marital status, occupation, education), frequency of visits, time to travel to a patient's home, and number of patients supervised separately as independent variables for predicting virologic suppression and mortality in univariate logistic regression and univariate Cox proportional hazard models, respectively. I examined patient characteristics (sex, age, marital status, and education) in the univariate models to determine which patient characteristics to control for in the multivariate models. I selected all independent variables that had a p-value of < 0.20 in unadjusted univariate regression models[111] for inclusion in the multivariate models. Since multiple patients shared a CHW, the data for these patients were correlated. To compensate for this correlation, I used the generalized estimating equation (GEE) approach for logistic regression and Cox regression in the models.[112-114] I created the models in Stata 11® (StataCorp: College Station, TX) using the cluster option to compensate for the expected correlation. I checked the logistic regression models for multicollinearity, interactions, and specification error. I tested the proportionality of hazards assumption for each variable in the Cox regression model as well as the model as a whole by analyzing the Schoenfeld residuals.

3.3.2 Qualitative data

I used a qualitative descriptive approach[115,116] to analyse patient interviews and CHW and clinic staff FGD transcripts. This approach takes a descriptive attitude where "what is described is what presents itself as it presents itself."[117] Rather than interpreting the meanings behind experiences and perceptions of respondents, this approach focuses on providing a rich and direct description of experiences and events, and is considered appropriate for mixed methods types of studies such as this one.[116] In analyzing the data, I followed Sandelowski's[115] recommendations for analyzing data in descriptive qualitative studies whereby codes are systematically applied to the data to categorize the data for presentation. A member of my supervisory committee and I initially reviewed the transcripts to develop a coding framework that consisted of multidimensional categories and subcategories. We identified coding categories using a thematic analysis approach in which the identification of categories was informed by the content of the data rather than by preconceived notions of what the codes should be. I applied the codes to the transcripts and documents using this coding framework and identified themes that emerged from the coded data. I used these themes to organize the data into summary descriptions of events and perspectives.[115] I used NVivo 9® (QSR International: Doncaster, Australia) software to assist with the coding of data.

3.4 DATA QUALITY

I used a variety of approaches to ensure the validity and reliability of the quantitative data and the quality and rigour of the qualitative data.

Ugandan research assistants collected the survey data and administered the questionnaires in the local language (Rutooro) to ensure the respondents had adequate comprehension of the questions. Administration of the questionnaires ensured that literacy was not a barrier to completing the questionnaire in Rutooro and provided opportunities for the research assistants to provide clarification of questions that participants had difficulty understanding. During my training session with the research assistants, I went through each questionnaire in detail and had them practice administering the questionnaires to our research staff. During the actual data collection, I checked participants' responses right after administration of the questionnaire and had the research assistant clarify missing information or inconsistencies with the respondents before they left the session. To ensure data entry accuracy, I had a Ugandan research assistant enter the questionnaire data twice into a Microsoft Access®

(Microsoft: Redmond, WA) database. I then compared the two sets of data and corrected inconsistencies using information in the written questionnaire.

For all quantitative data, I generated frequency distributions and graphed the data to identify missing data and outliers. The two-year CHW survey was the only data source to have missing data; that is, one CHW did not provide responses to three questions. I checked unexpected values by consulting the paper documents from which the data were entered and, where possible, corrected mistakes by seeking clarification from the data sources.

According to Guba et al.,[118] authenticity and credibility of the data is an important aspect of rigour or “trustworthiness” in qualitative analysis. Trustworthiness relates to confidence in the “truth” of the findings in the context where the data were collected, applicability of the findings to other subjects or contexts, consistency in the findings when repeated, and neutrality of the findings with respect to biases, motivations, interests or perspectives of the inquirer.[118] To increase the authenticity and credibility of the qualitative data collection, I used the practical techniques recommended by Milne et al.[119] for improving rigour. These techniques included enabling the freedom of participants to speak, probing for clarification and depth, and ensuring accurate translations. In this study, research assistants with previous experience in qualitative data collection conducted the FGDs with CHWs and interviews with patients in the local language to ensure that participants adequately understood the questions and could express themselves clearly without a language barrier. I also trained and encouraged research assistants to use probing techniques, and methods for seeking clarification of answers. To create a comfortable space for open discussion, research assistants interviewed patients in private areas, away from places where they could be seen or heard. To create a discussion setting that promoted an atmosphere of inclusiveness, research assistants conducted

FGDs in a private room in the Rwimi Health Centre III and had participants sit in a circle alongside the moderator and note taker. In their training, I encouraged research assistants to observe the surroundings carefully and ensure that everyone felt free to participate. According to Patton,[120] reactions of participants to the presence of researchers and fieldworkers might make a difference in certain settings. Before the patient interviews, research assistants asked participants if they were comfortable having a foreigner present at the interview. Since the first two patients interviewed expressed some discomfort, I chose not to be present at these and the remaining interviews so that patients could be comfortable speaking and expressing themselves. The research assistants asked CHW FGD participants the same question. The CHWs were comfortable having me present, though I sat outside of the circle of participants to avoid possible distractions from the presence of a foreign face. Patton[120] suggested that the presence of a fieldworker might motivate participants to perform in a manner seen as exemplary in order to be seen in a more positive light. Since the clinic staff knew me well and associated me with the resources provided to the clinic, I refrained from attending their FGDs to minimize response bias toward remarks they felt would please me.

I also applied techniques to improve trustworthiness of the data during the recording and analysis of qualitative data. The interviews and FGDs were tape recorded and transcribed and translated as soon as possible by the same research assistants who conducted the interviews and FGDs to ensure the discussions remained recent in their minds. A research assistant who was not part of the interviews or FGDs match selected sections of the audio recordings of interviews and FGDs to transcripts to check the accuracy of transcription and translation. During data analysis, I looked for negative cases that might indicate deviations from the dominant themes emerging from the data.

Leininger suggested that an important criteria for evaluating qualitative studies is "meaning in context"; that is, data are understood within the particular situation or environment of the people studied.[121] My eight years of research experience in this particular community and my access to local informants contributed to my understanding and interpretation of information emerging from the data.

I used the opportunity to triangulate[122] among multiple sources of data in order to better interpret the findings. Craswell et al.[123] defined triangulation as a validity procedure wherein researchers search for convergence among multiple and different sources of information to form themes or categories in a study. In this study, I correlated findings from the CHW FGDs to the two-year survey of CHWs and to volunteer meeting minutes to verify certain findings and identify inconsistencies.

3.5 ETHICAL ISSUES AND INFORMED CONSENT

I obtained ethics approval for this study from the University of Alberta Health Research Ethics Board (Panel B). Our research team obtained approval from the Uganda National Council for Science and Technology. Research assistants provided participants with information related to the objectives of the study, the use of data, and confidentiality and anonymity. Information letters and consent forms (Appendix M) were provided to patients and CHWs in Rutooro and to clinic staff in English. Research assistants verbally read out the information letter and consent form to illiterate individuals and obtained informed consent in writing. Participants who could not sign used a thumbprint to confirm that they understood the information conveyed to them and agreed to participate in the study. Research assistants informed participants that they were free at any time during the entire project to refuse to participate in the study and that there would be no repercussions on their work, their participation, or their treatment if they refused to participate. Project staff and research assistants signed confidentiality agreements.

I did not pay participants. I offered FGD participants (CHWs and clinic staff) 5,000 Uganda shillings (US$2.50) to cover transport costs to travel to the clinic and light refreshments after the FGD. I offered patients a bag of sugar as a token of appreciation for their participation in in-depth interviews.

CHAPTER 4 – RESULTS: EXPERIENCES WITHIN THE CHW PROGRAM

4.0 OVERVIEW

In this chapter I provide information to answer the two parts of research question 1: (a) Can volunteer CHWs effectively perform a range of activities necessary to support ART? (b) How did the different elements of a volunteer CHW program function to support an ART program? In the first part of this chapter, I assess the performance of CHWs in undertaking their activities. In the second part of this chapter, I examine the recruitment and retention of CHWs, their workload, the training activities, and the management of CHWs to better understand how the various elements of the volunteer program functioned within our ART program. I used data from volunteer visit logs, the CHW surveys, the pre- and posttraining surveys, program records, and volunteer meeting minutes to compile this information.

4.1 CHW PERFORMANCE

I assessed the performance of CHWs based on their ability to complete a schedule of routine visits, successfully monitor treatment adherence, identify side-effects, and provide HIV prevention messages. I describe these findings below.

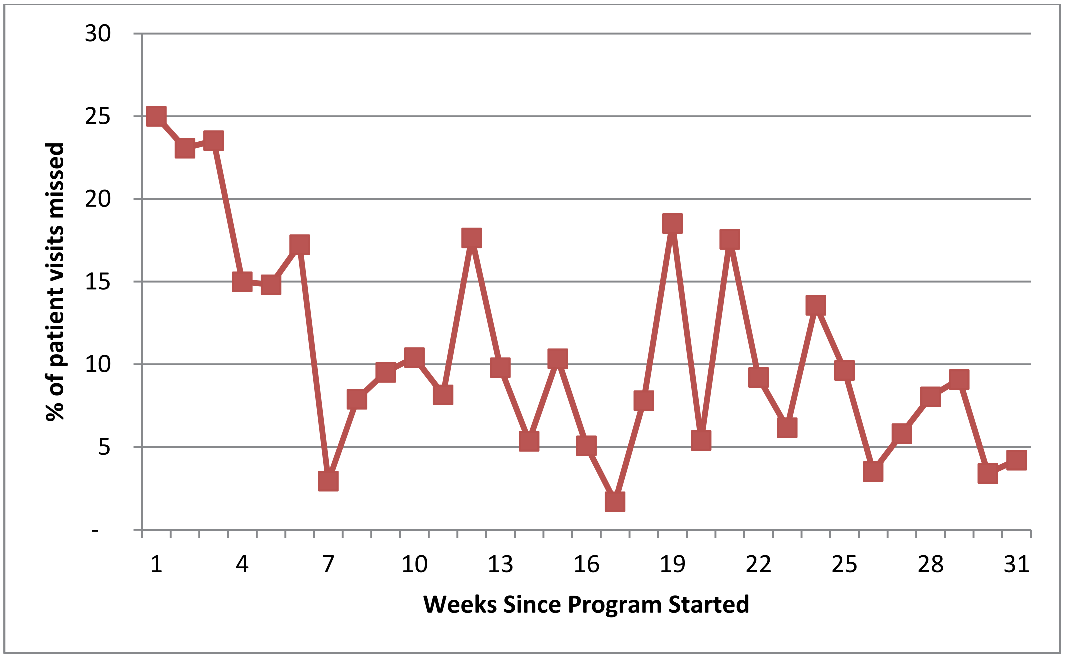
4.1.1 Completion of weekly visits

All CHWs attempted weekly visits to patients in the first six months of the program. In the one-year survey, 16 CHWs (39.0%) mentioned missing a scheduled visit. However, based on an analysis of the volunteer logs, 36 CHWs (87.8%) missed at least one expected visit in the first six months of visits to their patients. Most CHWs (30 CHWs or 73.2%) who missed a visit missed less than 20% of the visits they were supposed to have made over the first six months (Table 4-1). An analysis of missed visits over time showed a larger proportion of missed visits over the first three weeks of the program, after which the proportion of missed visits steadily dropped (Figure 4-1).

Table 4-1: Proportion of visits missed by CHWs in the first six months of the CBART program

Percent of missed visits	Number (percent) of CHWs
< 10	12 (29.3)
≥ 10 and < 20	18 (43.9)
≥ 20 and < 30	7 (17.1)
> 30	4 (9.7)

Figure 4-1: Percentage of visits missed by CHWs since the program began



The two-year CHW survey data showed that 3 (7.3%) CHWs felt it was difficult or very difficult to distribute the drugs to patients, 5 (12.2%) felt it was neither easy nor difficult, and 33 (80.5%) said it was easy. It was not possible to determine whether patients missed receiving any antiretroviral drugs as a result of missed visits.

According to the volunteer logs, 126 (68.8%) patients experienced a missed visit in the first year. I did not find any statistically significant associations between missed visits and the distances the CHWs had to travel to visit the patients (Table 4-2). However, there was a statistically significant correlation between the number of patients who experienced a missed visit and the distances these patients lived from the Rwimi Health Centre III. Patients who lived five or more kilometers from the clinic experienced fewer missed visits by CHWs than patients who lived less than five kilometers from the clinic (62.9% vs. 84.3%, p= 0.005) (Table 4-2). In the two-year survey, CHWs mentioned illness (9 CHWs), being busy with other work responsibilities (3 CHWs), feeling that the patient was doing well (2 CHWs), and poor road access (1 CHW) as reasons for missing weekly visits.

Table 4-2: Geographical factors associated with missed patient visits

	Number (percent) of patients whose CHW missed 1 or more visits (n = 126)	Number (percent) of patients whose CHW did not miss any visits (n = 57)	p-value*
CHW distance from patient			
< 1 hour	38 (67.9)	18 (32.1)	0.847
1+ hours	88 (69.3)	39 (30.7)	
Patient distance from clinic			
< 5 km	43 (84.3)	8 (15.7)	0.005
5+ km	83 (62.9)	49 (37.1)	

*Chi-squared test.

4.1.2 Adherence to treatment: monitoring and counselling

According on the volunteer logs, CHWs encountered 212 occasions on which patients missed taking one or more of their tablets in the first two years of the program. The main reason patients gave CHWs for missing their tablets was forgetting to take them (149 instances, 70%); other reasons included illness (13 instances, 6.1%) and problems with side-effects (one instance, < 1%). In 49 instances (23.0%) the reason for not taking a tablet was not documented.

Analysis of the volunteer log data showed that the proportion of patient visits in which CHWs discovered patients had missed taking their ARV drugs was consistent over the two-year period (Table 4-3). CHWs noted missed tablets in 2.6% of visits between 0–6 months, 2.3% of visits between 6–12 months, 1.9% of visits between 12–18 months, and 2.1% of visits between 18–24 months. A chi-square test for trends showed that this change over time was not statistically significant (p = 0.143).

Table 4-3: Adherence to ARV drugs by visit over a 2-year period

Time Period	Total number of patient visits	Number (percent) of visits with at least 1 missed tablet	p-value
0–6 months	3,233	83 (2.6)	0.143*
6–12 months	2,634	60 (2.3)	
12–18 months	1,942	37 (1.9)	
18–24 months	1,541	32 (2.1)	

* Chi-squared test for trend.

However, the percentage of patients missing at least one tablet fell over successive 6-month periods (Table 4-4). CHWs identified 24.9% of patients who had missed at least one tablet between 0–6 months, 21.3% between 6–12 months, 17.5% between 12–18 months, and 13.2% between 18–24 months. The decrease in the proportion of patients who had missed at least one tablet over these time periods was statistically significant (p = 0.008).

Table 4-4: Adherence to ARV drugs by patient over a 2-year period

Time Period	Number of active patients	Number (percent) of patients who missed at least 1 tablet	p-value
0–6 months	169	42 (24.9)	0.008*
6–12 months	141	30 (21.3)	
12–18 months	137	24 (17.5)	
18–24 months	129	17 (13.2)	

*Chi-squared test for trend.

Data from the two-year CHW survey, which was conducted after administrative changes were made to the forms and pill boxes were provided for the ARV drugs, showed that all 41 CHWs found counting of tablets to be “*very easy*” or “*easy.*”

Only 2 (4.9%) CHWs felt that the forms were "*not easy but not difficult*" to fill out, with the rest feeling that it was "*very easy*" or "*easy*" to complete the forms. In addition, 35 (85.4%) CHWs said that they thought counselling patients on missed tablets was "*very easy*" or "*easy*" while 4 (9.8%) found it "*not easy but not difficult*" and 2 (4.9%) found it "*difficult.*" Similarly, 35 (85.4%) CHWs found that it was "*very easy*" or "*easy*" to answer patients' questions. The correlation between counselling patients on missed tablets and answering patient question was weak (correlation coefficient = 0.34, p = 1.45) suggesting that the same CHWs who found it difficult to counsel patients on adherence to medication did not necessarily find it difficult to answer patient questions. Finally, 40 CHWs felt that they had been "*very effective*" in ensuring that patients remembered to take their tablets and 1 CHW said that he had been "*a little effective.*" None of the CHWs said he or she was "*not effective*" in this task.

4.1.3 Identification of major side-effects and referrals

Data from the two-year survey showed 36 (87.8%) CHWs found the task of identifying side-effects "*easy*" or "*very easy*" while 4 (9.8%) found the task "*not easy but not difficult*" and 1 (2.4%) found the task "*difficult.*" In the same survey, 38 (92.7%) CHWs said that they had been "*very effective*" in identifying side-effects of treatment and 3 (7.3%) said that they had been "*a little effective.*" None of the CHWs said that they were "*not effective*" in this task.

Based on the volunteer logs, in the first two years of the study CHWs identified 14 instances of potential jaundice (as identified by patients having yellow eyes) and referred 9 of these patients to the clinic. Community health workers also identified 40 instances of likely neuropathy (as identified by patients having a tingly sensation or a numbness in fingers and toes) and referred 32 of these patients to the clinic. Finally, CHWs identified 40 instances of skin rashes and referred 34 of these patients to the clinic.

I also looked at the how the referrals by CHWs in the first year for side-effects matched to information in the patient's clinic chart (Table 4-5). In the first year, CHWs identified 9 patients with potential jaundice and referred 6 of these patients to the health centre. In the clinic charts, however, there was no mention of jaundice in these patients, indicating that either they did not attend the clinic or were not diagnosed with jaundice. Community health workers identified 27 patients with possible neuropathy and referred 25 of them to the health centre. I found a diagnosis of neuropathy for 7 of these patients, but not for the other 18. Community health workers identified 2 additional patients with neuropathy, but did not refer them, though I found a diagnosis of neuropathy for these 2 patients in their charts. Community health workers had not identified an additional 15 patients who had a diagnosis of neuropathy in their patient charts. Finally, CHWs identified 35 patients with a skin rash and referred 30 of these to the health centre. I found a diagnosis of a skin rash in the patient charts of 4 of these patients only. Community health workers had not identified an additional 12 patients who had a diagnosis of a skin rash in their patient charts.

Table 4-5: Clinic referrals by CHWs based on identification of side-effects

	Side-effect identified by CHW and referred to clinic		Side-effect recorded in patient chart		
Side-effect	**Record of side-effect in patient chart**	**No record of side-effect in patient chart**	**Not identified by CHW**	**Identified by CHW but not referred to clinic**	**Total number of side-effects**
Jaundice	0	6	0	0	6
Neuropathy	7	18	15	2	42
Skin Rash	4	26	12	0	42

4.1.4 HIV prevention activities

In this study, I only surveyed CHWs on their condom distribution activities and did not collect any data on their other prevention activities. Data from the two-year survey showed that 26 (63.4%) CHWs felt that it was "*easy*" or "*very easy*" to distribute condoms to their patients whereas 15 (36.6%) CHWs felt it was "*not easy, but not difficult.*" Twenty-seven (65.9%) CHWs said they knew their patients were using condoms whereas 8 (19.5%) knew their patient was not using condoms, the main reason being that the patient was no longer sexually active. Community health workers also mentioned only 2 cases where patients they believed were sexually active were not using condoms. Six (14.6%) CHWs did not know whether their patients were using condoms or did not answer the question.

4.2 RECRUITMENT, RETENTION, WORKLOAD, TRAINING, AND MANAGEMENT OF CHWs

To understand how recruitment functioned and how effective our retention methods were, I looked at the characteristics of CHWs who joined the program, how they found out about the program, and how many stayed with the program. The number of patients the CHWs had to supervise and the time it took them to complete their activities helped me to evaluate the human resource needs for this program. I looked at whether the orientation training session led to knowledge gains for the CHWs and what gaps in knowledge CHWs identified that clinic and project staff had to address after the initial training session. The attendance at volunteer meetings gave me information about our management of CHWs and the issues and solutions CHWs discussed at the volunteer meetings helped me to understand the types of problems CHWs faced in the field.

4.2.1 Recruitment and retention

I used data from the baseline and two-year CHW surveys to create a summary of the demographic characteristics of the individuals who chose to serve as a CHW for the CBART program (Table 4-6). The mean age of CHWs was 39.8 years (standard deviation (SD) = 9.0 years) with the youngest being 26 and the oldest being 62 years of age at the time of joining the program. More men volunteered than women (68.3% vs. 31.7%). Most CHWs (85.4%) were married with the rest being single (12.2%) or widowed (2.4%). None of the CHWs indicated he or she had no religious affiliation; most (92.7%) indicated that they belonged to a Christian faith. Most CHWs (75.6%) were heads of their households. Of the 28 male CHWs, 26 (92.9%) were heads of their households; of the 13 female CHWs, 5 (38.5%) were household heads. Most CHWs (65.0%) were farmers or housewives. All of the CHWs had some level of education. Most CHWs (59.5%) had some level of secondary or postsecondary education. In contrast, 30.6% of patients enrolled in this study had no education, 57.4% had some level of primary education, and only 12.0% had some level of secondary or postsecondary education. The difference in education levels between patients and CHWs was statistically significant ($p < 0.001$).

Table 4-6: CHW characteristics

Age in years (mean, SD)	39.8 (9.0)
Sex (n, %)	
Male	28 (68.3)
Female	13 (31.7)
Marital Status (n, %)	
Married	35 (85.4)
Single	5 (12.2)
Widowed	1 (2.4)
Religion (n, %)	
Catholic	22 (53.7)
Protestant	16 (39.0)
Muslim	2 (4.9)
Other	1 (2.4)
Head of Household (n, %)	
Yes	31 (75.6)
No	10 (24.4)
Occupation (n, %)*	
Farmer/Housewife	26 (65.0)
Employed/Businessperson	14 (35.0)
Education (n, %)*	
Primary	16 (40.0)
Secondary	17 (42.5)
Post-Secondary	7 (17.5)
Missed any scheduled visits (n, %)*	
Yes	16 (39.0)
No	24 (58.5)

**One CHW did not provide information on occupation, education, income, and missed visits.*

Data from the two-year CHW survey showed that 31 (75.6%) CHWs heard about the call for CHWs from the clinic staff and 9 (22.0%) heard the call from community leaders. Of the 41 CHWs who joined the program, 38 (92.7%) had previously volunteered in the health system as community-based distributors for ivermectin for onchoceriasis treatment and control or Homapak for malaria treatment, or had previously participated in community awareness or sensitization activities. Twenty-five (61.0%) CHWs mentioned that they were concurrently volunteering in family planning programs, TB and malaria drug distribution programs, or immunization programs. Of the 41 CHWs our program recruited, 40 were still active after two years. One CHW left when her spouse received a transfer of employment to another area.

4.2.2 Workload

4.2.2.1 Number of patients per CHW

The volunteer administrator assigned CHWs to patients based on the need in their geographical location of residence or their capacity to handle patients. My review of administrative records maintained by the research project found that 1–8 patients were assigned to a CHW (Figure 4-2), with a mean of 3.8 patients per CHW and a median of 3 patients per CHW.

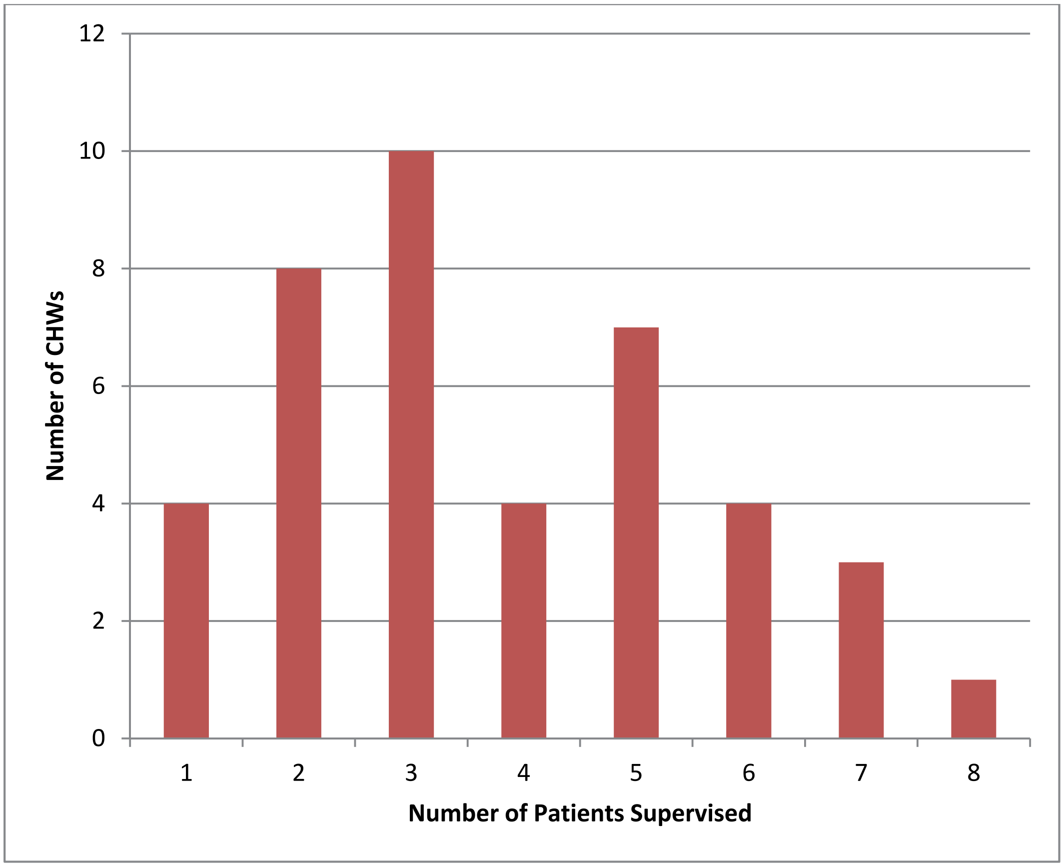
Data from the two-year CHW survey showed that 31 (75.6%) CHWs felt that the number of patients currently supervised was just right or too few while 10 (24.4%) CHWs felt that they had too many. Table 4-7 summarizes these responses and indicates the number of patients that the CHW supervised. Those with more than three patients were more likely to say that they had too many, with the differences being statistically significant (p = 0.008). However, more than half of the CHWs with more than three patients to supervise thought that the patients were too few or just right. Overall, only 10 CHWs (24.4%) thought they had too many patients.

Table 4-7: CHWs feelings about the number of patients they had to supervise

Number of patients currently supervising	Number of CHWs (percent) that had "Too few or just the right number of patients"	Number of CHWs (percent) that had "Too many patients"	p-value
1 to 3	22 (91.6)	2 (8.4)	0.008*
4 to 8	9 (52.9)	8 (47.1)	

*Fisher's exact test

Figure 4-2: Number of patients supervised by CHWs



4.2.2.2 Time spent on CHW activities

Data from the two-year CHW survey showed that 20 (48.8%) CHWs felt that they had correctly estimated the time it would take to perform their activities, 7 (17.1%) felt that they had underestimated the time, and 14 (34.1%) felt that they had overestimated the time. In the survey, 23 CHWs (56%) estimated volunteering time at one to three hours a week, 9 (21.9%) said it took four to nine hours a week and 9 (21.9%) said they spent over 10 hours per week volunteering. A Fisher's exact test showed that there was no association between the number of patients managed by a CHW and his or her reported volunteering time per week (p = 0.133).

Community health workers recorded their travel time and the time spent with the patient in their weekly volunteer logs. Data from the first two years showed that the total time spent by CHWs to travel to patients and monitor patient ranged from 15 minutes to 275 minutes with a mean time of 108 minutes (SD = 39 minutes).

I conducted a separate analysis for time to travel to the patient's home and time spent at the patient's home. The mean time for CHWs to travel to a patient's home was 87.6 minutes (SD = 38.2 minutes). The minimum time was 1 minute (they were neighbours) and the maximum time was 260 minutes. Most patients (127 patients, 69.4%) lived more than one hour's travel time away from their assigned CHWs.

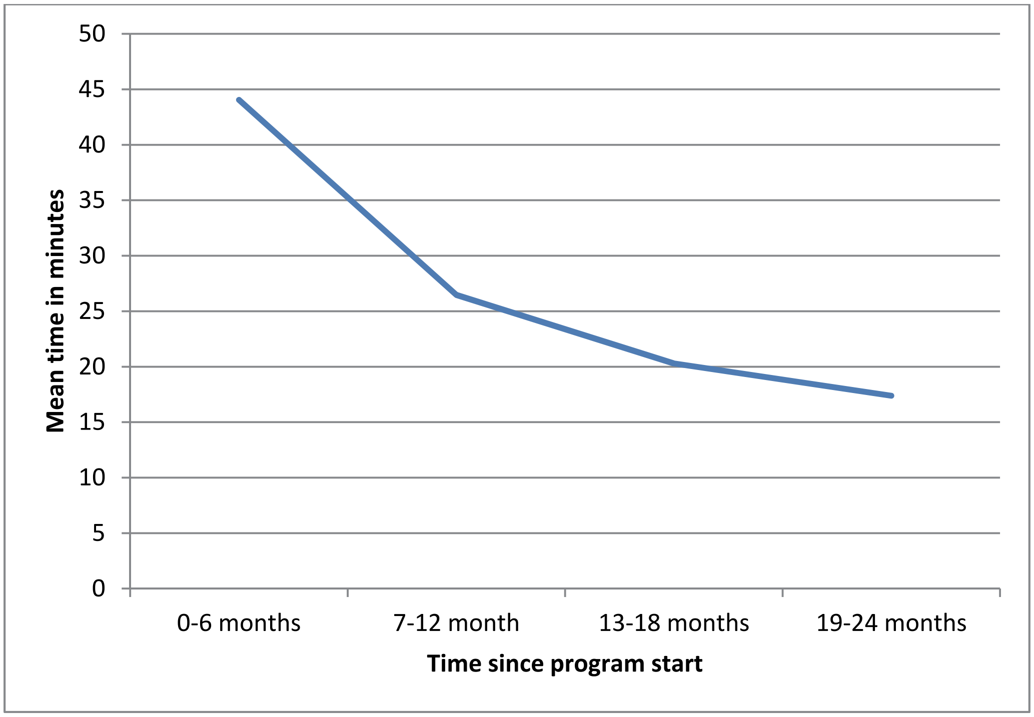
Patient monitoring involved a range of activities that varied from week to week. Over a two-year period, the time CHWs spent with patients ranged from 5 minutes to 150 minutes with a mean time of 22 minutes (SD = 13 minutes). The difference in time with the patient between CHWs who travelled less than 1 hour to their patient (20 minutes with the patient) compared to those who lived one or more hours away from their patient (23 minutes with the patient) was not statistically significantly different (p = 0.289). Though the travel time remained constant, the mean time with the patient varied over the course of the program. Table 4-8 and Figure 4-3 show that the mean time spent with the patient over six month periods spanning the two-year evaluation consistently decreased over the two years. In the first six months of the program, CHWs spent an average of 44 minutes with their patients. In the last six months of the program (19–24 months), this decreased to 17.4 minutes. Each period saw a statistically significant decrease in time spent with patients compared to the previous period.

Table 4-8: Time CHWs spent with patients over two years

Period since program start	Mean time with patient per visit (min)	p value (difference from prior period)*
0–6 months	44.0	
7–12 months	26.5	< 0.001
13–18 months	20.3	< 0.001
19–24 months	17.4	< 0.001

*Two-sample t-tests.

Figure 4-3: Mean time spent by CHW with patient per visit over the 24-month study period



4.2.3 Training

Of the 30 CHWs that attended the training session, 29 completed both the pre-training and posttraining knowledge surveys (1 CHW left the session before completing the posttraining survey). Data from two surveys showed a statistically significant gain in knowledge after the training session (Table 4-9). Notable gains in knowledge were made on the following items: (1) the number of tablets a person on ART should take was identified by 10.3% pretraining and 65.5% posttraining; (2) 20.7% pretraining and 0% posttraining said it was permissible for a person receiving ART to miss tablets; and (3) the three points in the Ugandan prevention message (the “ABC” of prevention) were identified: abstinence (24.1% pretraining, 79.3% posttraining) being faithful (20.7% pretraining, 72.4% posttraining), condom use (34.5% pretraining, 69.0% posttraining). Regarding routes of infection and whether ARV drugs cure AIDS completely, gains in knowledge were apparent but not statistically significant. After the training, a few CHWs still believed that ARV drugs were a cure for AIDS. As a small number of CHWs still had poor knowledge of HIV and AIDS after the training, the program provided all 30 CHWs with refresher training in February 2006, around the time the CBART program began recruiting patients. At the refresher training, the volunteer administrator placed emphasis on the information that the CHWs had scored poorly in during the posttraining test.

Table 4-9: Results of pre- and posttraining tests

	Number of answers (percent) (n = 29)		
Question	**Pretraining test**	**Posttraining test**	**p-value***
You can get infected with HIV by			
Unprotected sex	22 (75.9)	24 (82.8)	0.517
Contact with infected person's blood	17 (58.6)	22 (75.9)	0.162
Unsterilized or dirty needles	12 (41.4)	17 (58.6)	0.189
Do ARV drugs cure AIDS completely?			
Yes	5 (17.2)	2 (6.9)	0.227
No	24 (82.8)	27 (93.1)	
How long does a person with AIDS have to be on ARV treatment?			
For Life	22 (75.9)	26 (89.7)	0.164
Other	7 (24.1)	3 (10.3)	
Is it okay for a person taking ARV drugs to stop taking them for a few days or a few weeks?			
Yes	6 (20.7)	0 (0.0)	0.009
What are the ABCs of HIV prevention?			
Abstinence	7 (24.1)	23 (79.3)	< 0.001
Being Faithful	6 (20.7)	21 (72.4)	< 0.001
Condoms	10 (34.5)	20 (69.0)	0.009
Other Response	13 (44.8)	3 (10.3)	0.003
How many tablets a day should a person on ARV take?			
Two	3 (10.3)	19 (65.5)	< 0.001
Other or did not know/answer	26 (89.7)	10 (34.5)	

* Wilcoxon t-test for paired data

In the two-year CHW survey, 37 (90.2%) CHWs said that the program's training activities gave them enough information to perform their activities. Suggestions made by CHWs for improving training included training on non-HIV health issues (3 CHWs), training on stigma reduction (2 CHWs), additional education on prevention of HIV infection (2 CHWs), and training on giving advice on family planning (2 CHWs). Thirty five (85.4%) CHWs felt that it was "*easy*" or "*very easy*" to answer patients' questions on treatment; 3 (7.3%) CHWs felt it was "*not easy, but not difficult*" and 3 (7.3%) felt it was "*difficult.*"

At the monthly meetings, CHWs brought up a number of questions about program administration and how to deal with clinical issues. CHWs were uncertain about:

- How often people should be tested for HIV to confirm their HIV status.
- How to deal with doubts about the accuracy of HIV tests.
- How to advise a patient who has a reaction to Septrin (co-trimoxazole).
- What to do if a patient forgets to take a tablet at the exact time and a few hours have elapsed.
- How to advise patients on family planning if they are motivated to have children.
- Whether pregnant women can start on ARV drugs and what to advise about prevention of mother-to-child transmission.
- What advice to give to patients who want to get married and start a family.
- What CHWs should do if patients disclose the status of other patients.
- How to deal with co-trimoxazole being out of stock in the clinic.
- What advice to provide about ART for those under the age of 18 years.
- What days the clinic provides clinical examinations for pregnant women.
- How to deal with a patient who was not happy with the way clinic staff served them at the health centre.
- How to deal with improperly filled out treatment partner logs.
- How to handle requests from patients who want to relocate and have their treatment managed elsewhere.

Clinic staff and the volunteer administrator were able to provide immediate answers to the questions above, but the following clinical topics were addressed through short training sessions. These included:

- Understanding the causes of diarrhea and how to treat and prevent this.
- How to properly fill out volunteer logs, identify side-effects, and provide advice on adherence to treatment.
- The importance of using condoms, even if patients start to feel better.
- Understanding malaria and its interaction with HIV, AIDS, and ART.

- Dealing with patient monitoring and clinic visits during an Ebola outbreak (precipitated by an Ebola outbreak in the area).

4.2.4 Program management activities

4.2.4.1 Attendance at volunteer meetings

The CBART study organized 23 volunteer meetings in the first two years of the study. According to data from the two-year CHW survey, 21 (51.2%) CHWs said that they had missed at least one volunteer meeting. The volunteer minutes showed that all but three meetings had one or more than one missing attendee, though overall attendance was high. There were no meetings with less than 85% attendance. Table 4-10 provides a breakdown of the attendance at volunteer meetings. Community health workers provided reasons for missing volunteer meetings that included their own illness or illness in the family (15 CHWs), other work/responsibilities (4 CHWs), and not being properly informed of the meeting date (2 CHWs).

Table 4-10: Volunteer meeting attendance over a 2-year period

Percentage attendance	Number of meetings (n = 23 meetings)	Percentage of meetings
100	3	13
95–99	9	39
90–94	8	35
85–89	3	13

4.2.4.2 Issues raised by CHWs

Volunteer meetings covered a range of activities including: questions about administrative or clinical aspects of the program, discussions of strategies and solutions to deal with CHW challenges, and attempts to answer CHW questions. In these meetings CHWs brought up a number of challenges they faced in attempting to complete their activities. Notable issues included difficulties in collecting drugs from the clinic, in counting tablets, and in filling out forms; also, patients were sometimes not home when they visited and they were not sure how to deal with community misinformation, patient expectations, patient stigma and substance abuse.

4.2.4.2.1 Drug collection

In the two-year CHW survey, 8 (19.5%) CHWs mentioned some level of difficulty in distributing drugs. One specific issue mentioned in the meetings was unreliable drug collection at the clinic. After travelling to the clinic to obtain drugs for their patients, CHWs occasionally found clinic staff too busy to distribute drugs or no staff responsible for ART were at the clinic To resolve this problem, clinic staff and CHWs agreed to establish Tuesdays and Thursdays as drug collection days, as activities at the clinic were light and clinic staff were likely to be on-site on those days. Another problem was what to do when drugs were out of stock. When ARV and co-trimoxazole drugs were out of stock, CHWs had to make repeat visits to the clinic. In one instance, a patient needed drugs to treat an adverse effect of treatment; when he found the drugs were out of stock he refused to return to the clinic. The volunteer administrator brought the drug bottleneck to the attention of the research team who subsequently purchased and maintained a buffer stock of ARV drugs and other drugs. To further rectify this problem the volunteer administrator arranged for CHWs to deliver drugs weekly or biweekly when supplies were too low to provide all patients with a month's worth of ARV drug refills.

4.2.4.2.2 Locating patients

According to volunteer meeting minutes, patients were not always home when CHWs called on them. This challenge increased over time, and especially as patients' health improved and they became more mobile and resumed their work activities. One CHW tried to visit a patient at his shop, but the patient was busy and turned the CHW away. The volunteer administrator suggested that CHWs schedule appointments with patients in advance, a plan the CHWs agreed to try. Our research team provided CHWs with diaries to help them schedule and record appointments. CHWs also decided to ask patients to identify responsible individuals in their area that CHWs could leave the drugs with in case the patient was not at home.

4.2.4.2.3 Counting and documenting pill counts

The volunteer administrator noted that CHWs were not completing their volunteer logs and they were making mistakes in the pill counts. Community health workers also mentioned the difficulties in counting pills (this was prior to the changes we made), especially when they had to remove pills from opaque bottles when their hands were not clean (one time a CHW accidentally dropped a tablet in the dirt and it had to be thrown away). Also, patients kept pills in different bottles and either did not give the CHWs all of the bottles to count or gave the CHWs bottles with different pills inside that then had to be sorted out. Community health workers expressed difficulties in completing the calculations to identify missed tablets. Community health workers mentioned that when the national HIV program temporarily changed the treatment regimen from one pill twice-a-day to two pills twice-a-day, patients became confused; this affected the pill counts as well as the patients' adherence to treatment.

The volunteer administrator trained the CHWs to handle tablets hygienically using a piece of notebook paper. Later, the study team tested transparent refillable dosette boxes (pill boxes) with a few patients, and later purchased these for all patients. These pill boxes had 28 compartments that held a four weeks' supply of drugs, and were labelled by week number and day of week (Monday to Sunday). Two ARV tablets fit in each compartment. In response to the CHWs issues, the study team made changes twice to the volunteer logs. The first change simplified the calculations of missed drugs. However, as the calculations were still too difficult for CHWs, the study team made a second change that made CHWs responsible only for indicating drugs delivered and pills counted. The volunteer administrator performed the calculations when the CHWs handed in their forms at the monthly meetings. As a result of this change, CHWs provided adherence to treatment advice at the visit if a patient self-reported a missing a tablet or if the treatment partner's log indicated that a patient had missed a tablet. If the volunteer administrator's calculations showed a missed tablet, he would inform the CHW at the next meeting (if the number of missed tablets was low) or by telephone (if the number of missed tablets was large enough to be of concern).

4.2.4.2.4 Dealing with misinformation

Community health workers mentioned that they sometimes encountered community misinformation, which made it difficult for them to promote adherence to ARV drugs. One source of misinformation was a reported radio broadcast that incorrectly reported shortages of ARV drugs and caused patients to be concerned about drug access. According to the CHWs, patients were less willing to accept adherence to treatment advice if they felt uncertain about the drug supply. Another radio report mentioned that a certain ARV drug was banned (no mention was made in the minutes as to why this drug was banned); this resulted in patients questioning the efficacy of the drugs they were being given. When local individuals promoted sales of a nutritional supplement that patients misunderstood to be a cure for AIDS, some stopped taking their ARV drugs. Finally, multiple instances of faith healers and faith groups promoting prayer as a cure for AIDS led to three patients temporarily abandoning their treatment. Community health workers found these situations difficult to deal with and asked the volunteer administrator and clinic staff to intervene with these patients.

4.2.4.2.5 Dealing with patient expectations

Community health workers mentioned that patients sometimes asked them for money or transport to go to the clinic, either for a routine visit or to follow-up on a CHW referral. Community health workers also said they received requests from patients for food, which were possibly prompted by patients' experiences with programs that provided food. Apparently, in some instances patients thought CHWs were refusing to furnish material assistance that the study had provided for patients. Some CHWs felt that this was because some patients received financial or material incentives for participation in interviews and focus groups, and in one case received a refund for transport costs to attend a volunteer recognition program to give an unsolicited personal testimony; these events raised patient expectations of material gain.

4.2.4.2.6 Patient stigma and patient substance abuse

Some patients, especially in the early stages of the program, felt uncomfortable having CHWs visit them for fear that they would be identified as HIV positive. Over time, CHWs felt that patients were less stigmatized as they were more willing to meet with and talk to the CHWs. In a few instances patients were reluctant to accept advice to abstain from sex and to accept the condoms that CHWs brought with the tablets. One patient who had registered dissatisfaction with the condoms received from the CHW was not, on further investigation, using the condoms properly.

Alcohol abuse interfered with CHWs' visits and counselling in a few cases. In addition to missing tablets, these patients were rude to the CHWs and to their treatment partners.

4.3 SUMMARY OF FINDINGS

This chapter provides answers to the two parts of research question 1: (a) Can CHWs successfully perform a wide range of activities to support ART? (b) How did the different elements of a volunteer CHW program function under an ART program? Research question (a) queries whether CHWs can be useful in an ART program. The data showed that CHWs did well in maintaining regular visits to patients, with few missed visits relative to the number of visits that were completed. Community health workers said they felt it was easy to monitor adherence, side-effects, and provide HIV prevention messages. Adherence to treatment was generally high with few patients missing tablets, especially in the later years of the program. However, the analyses also pointed to issues about the identification of side-effects, especially in side-effects diagnosed by the clinic but missed by the CHWs.

Research question (b) asks how the volunteer CHW model functions in an ART program. Recruitment for the program tended to target individuals who had already volunteered in the health care system, more males than females, and individuals who had at least some formal education. The program's retention of CHWs (97.6%) was very high over the two-year period. CHWs apparently felt comfortable managing 3–4 patients. Though the range was from 1–8 patients, few CHWs thought they had been assigned too many patients. Most CHWs had to travel more than one hour to visit patients. Over time, CHWs spent less time with their patients once they reached them. The orientation training provided some foundational knowledge to CHWs, though there were gaps that the program had to address through continuing education. Many gaps related to very specific issues patients brought up. The volunteer meetings were generally well attended and were a forum for issues that needed redress. CHWs and the research team worked together to identify practical solutions to problems brought forth in the meetings. Table 4-11 provides a summary of CHW performance in certain activities.

Table 4-11: Summary scores on different dimensions of CHW performance

Dimension	Raw Score	Score expressed as a percent
Retention	40/41	97.6
Mean posttraining knowledge score[§]	12/14	85.7
Maintenance of ≥ 80% of visits	30/41	73.2
Proportion of patients who did not miss any tablets (during 18–24 months since starting treatment)	112/129	86.8
CHW missed capturing side-effect	27/84	67.9*
Attendance ≥ 90% at volunteer meetings	20/23	86.9
Mean (unweighted) performance score		**83.0**

[§] Calculated as mean score of all CHWs based on correctly answering 14 questions.
*Inverse score to reflect % positive performance.

CHAPTER 5 – RESULTS: ASSOCIATIONS BETWEEN CHW CHARACTERISTICS AND TREATMENT OUTCOMES

5.0 OVERVIEW

In this chapter I provide information to answer research question 1(c): What CHW characteristics are associated with positive ART outcomes? I begin with a summary of the treatment outcomes of patients in our CBART program. This includes six-month and two-year virologic suppression, mortality over the two year period, and changes in health related quality of life of patients after one year. I then explore the associations between CHW characteristics and two of the important treatment outcome measures—two-year virologic suppression and two-year mortality.

5.1 SUMMARY OF ART OUTCOMES

Two publications by our research team[93,94] provide an overview of the virologic suppression and mortality outcomes of our CBART patients. These findings, which we based on intent-to-treat analyses, show that after six months on ART, 124 (67.8%) of 183 patients achieved virologic suppression. Of the remaining 59 patients, 20 (10.9%) were alive and still participating in the study but had not achieved virologic suppression, 24 (13.1%) had died, and 15 (8.2%) had left the study for various reasons. After two years of ART, 120 (65.7%) patients had achieved virologic suppression. Of the remaining 63 patients, 9 (4.9%) were alive and still participating in the study but had not achieved viral suppression, 32 (17.3%) had died, and 24 (12.9%) were lost to follow-up. The two-year findings are comparable to two-year treatment outcomes in an urban hospital in the same district; in the urban cohort, 124 (62.0%) of 200 patients on ART achieved viral suppression, 23 (11.5%) had died, and 35 (17.5%) were lost to follow-up. All eight children born to patients in the CBART program tested negative for HIV.

A related study by our research team (where I was the lead investigator) found that patients in the CBART program showed significant improvements in the health related quality of life after one year of ART[124]. Assessments of physical and mental health scores, using a standardized health related quality of life (HRQOL) instrument, found statistically significant increases in mean physical scores and mean mental health scores in patients after one year of ART. Patients experienced notable improvements in physical functioning, role functioning, and social functioning suggesting that they were able to resume physical activities in their daily lives.

5.2 ASSOCIATIONS BETWEEN CHW CHARACTERISTICS AND ART OUTCOMES

5.2.1 Virologic suppression

To analyze CHW related predictors of virologic suppression, I created a dichotomous dummy outcome variable where a value of 1 indicated virologic suppression at two years and 0 indicated no virologic suppression, death, or the patient left the study at the two-year point. While it is possible that patients who left the study continued ART elsewhere and could have achieved virologic suppression, in this study I categorized the decision to leave the CBART program as a negative outcome.

Table 5-1 describes patient and CHW characteristics associated with patient virologic suppression two years after starting ART. The cross tabulations (unadjusted) show that the CHW’s age and time to travel to the patient were statistically significant factors in the differences in treatment outcome.

Table 5-1: Patient and CHW characteristics associated with two-year virologic suppression

	Characteristic	Virologic Suppression	Virologic Failure/Death/Left	p-value
Patient Characteristics	Patient Sex, n (%)			
	Male	44 (57.9%)	32 (42.1%)	0.065[a]
	Female	76 (71.0%)	31 (29.0%)	
	Patient Age in years, mean (SD)	36.7 (8.8)	35.2 (11.5)	0.323[b]
	Patient Education, n (%)			
	None	33 (58.9%	23 (41.1%)	0.144[a]
	Primary	75 (71.4%)	30 (28.6%)	
	Secondary/Postsecondary	12 (54.6%)	10 (45.4%)	
	Patient Occupation, n (%)			
	Housewife/No Occupation	27 (65.9%)	14 (34.1%)	0.984[a]
	Farmer/Nonprofessional	77 (65.8%)	40 (34.2%)	
	Professional/Businessperson	16 (64.0%)	9 (36.0%)	
	Patient Marital Status, n (%)			
	Single	12 (46.2%)	14 (53.8%)	0.079[a]
	Married	50 (68.5%)	23 (31.5%)	
	Widowed/Divorced/Other	58 (69.1%)	26 (30.9%)	
	Patient Distance from Facility, n (%)			
	<5 km	36 (70.6%)	15 (29.4%)	0.375[a]
	>5km	84 (63.6%)	48 (36.4%)	
CHW Characteristics	CHW Sex, n (%)			
	Male	77 (63.1%)	45 (36.9%)	0.322[a]
	Female	43 (70.5%)	18 (29.5%)	
	CHW Age in years, mean (SD)	41.7 (9.3)	38.5 (1.0)	0.026[b]
	CHW Education, n (%)			
	Primary	59 (71.1%)	24 (28.9%)	0.272[a]
	Secondary	38 (58.5%)	27 (41.5%)	
	Postsecondary	21 (63.6%)	12 (36.4%)	
	CHW Occupation, n (%)			
	Farmer/Housewife	77 (66.4%)	39 (33.6%)	0.763[a]
	Employed/Businessperson	43 (54.2%)	24 (35.8%)	
	Missed any visits, n (%)			
	Yes	49 (61.2%)	31 (38.8%)	0.276[a]
	No	67 (69.1%)	30 (30.9%)	
	Time to Travel to Patient, n (%)			
	<1 hour	47 (83.9%)	9 (16.1%)	0.001[a]
	1+ hours	73 (57.5%)	54 (42.5%)	
	Max. Patients Supervised at One Time, n (%)			
	1	2 (28.6%)	5 (71.4%)	0.492[c]
	2	13 (61.9%)	8 (38.1%)	
	3	23 (67.7%)	11 (32.3%)	
	4	16 (64.0%)	9 (36.0%)	
	5	29 (69.1%)	13 (30.9%)	
	6	18 (64.3%)	10 (35.7%)	
	7	12 (66.7%)	6 (33.3%)	
	8	7 (87.5%)	1 (12.5%)	

[a] Chi-squared test. [b] t-test. [c] Fisher's exact test.

Table 5-2 summarizes the results of univariate and multivariate logistic regression models for important predictors (CHW characteristics) of patient virologic suppression. In the univariate models, the CHW's age, education, and the times to travel to patients were significant predictors of virologic suppression. Older CHW age predicted virologic suppression (unadjusted odds ratio (OR) = 1.04, 95% CI = 1.10–1.07, p = 0.002); each additional year of age of the CHW increased the odds of virologic suppression by 4.0%. Having a CHW with a secondary education predicted lower odds of virologic suppression (unadjusted OR = 0.57, 95% CI = 0.33–0.99, p = 0.049) compared to having a CHW with only primary education. Having a CHW that had to travel one or more hours to the patient also predicted lower odds of virologic suppression (unadjusted OR = 0.26, 95% CI = 0.11–0.59, p = 0.001) compared to having a CHW who had to travel less than one hour. I also assessed associations between patient characteristics and patient virologic suppression to identify which patient factors to control for in the final multivariate model. In the univariate analyses the patient's marital status was statistically significantly associated with virologic suppression. Patients who were married had higher odds of achieving virologic suppression (unadjusted OR=2.53, 95% CI=1.02–6.34, p=0.046) as did those who were widowed, divorced or previously married (unadjusted OR=2.60, 95% CI=1.06–6.40, p=0.037) compared to those who were single. I used the tests of statistical significance in the univariate analyses (using a threshold of $p < 0.20$) to select CHW age, education, distance from the patient, and number of patients supervised at one time as important predictors to test in the multivariate analysis. Using the same tests of significance, I considered patient sex, education, and marital status as important variables that I needed to control for in the multivariate analysis.

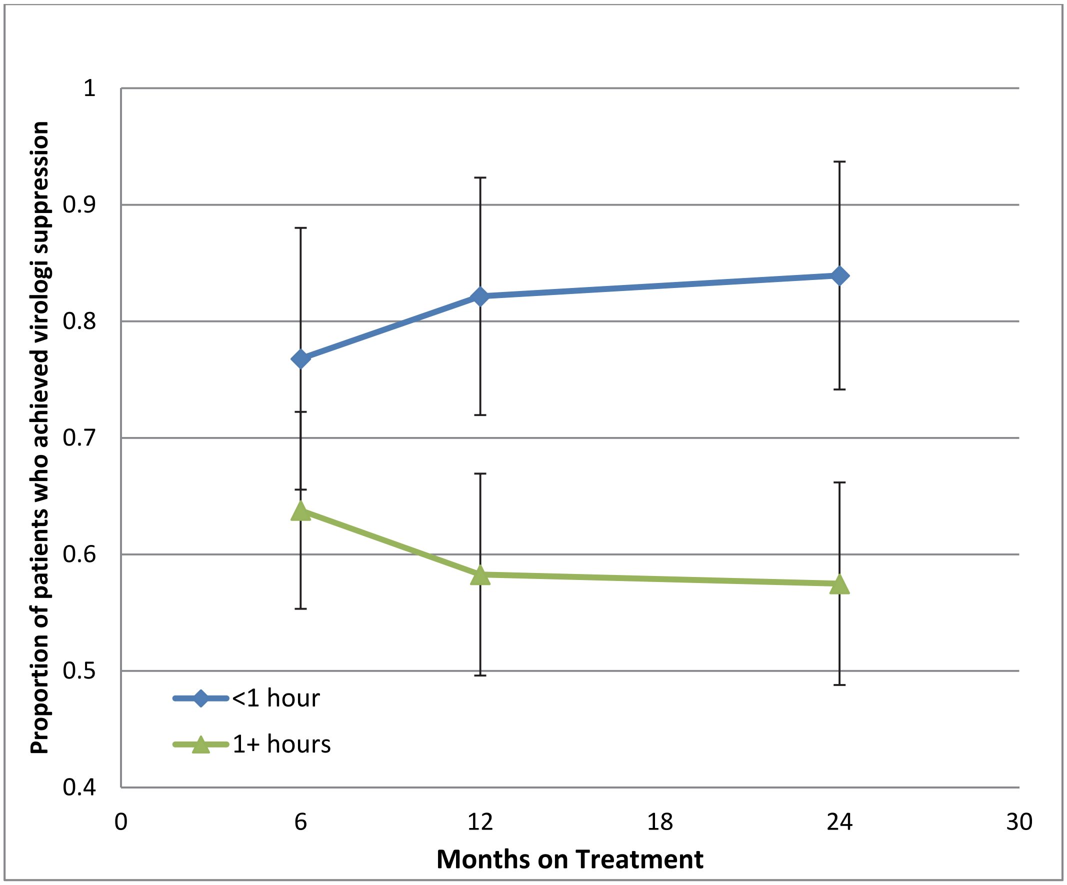
Table 5-2: Logistic regression analysis with two-year virologic suppression as the dependant variable

Characteristic	Univariate Unadjusted Odds Ratio	Univariate p-value	Multivariate Adjusted Odds Ratio	Multivariate p-value
Patient Sex				
Male	1.0		1.0	
Female	1.78	0.067	1.99	0.027
Patient Age	1.02	0.323		
Patient Education				
None	1.0		1.0	
Primary	1.74	0.110	1.98	0.039
Secondary/Postsecondary	0.84	0.725	0.88	0.855
Patient Occupation				
Housewife/No Occupation	1.0			
Farmer/Nonprofessional	0.99	0.996		
Professional/Businessperson	0.92	0.878		
Patient Marital Status				
Single	1.0		1.0	
Married	2.53	0.046	2.74	0.034
Widowed/Divorced/Other	2.60	0.037	2.31	0.142
Patient Distance from Facility				
<5 km	1.0			
>5km	0.73	0.262		
CHW Sex				
Male	1.0			
Female	1.40	0.254		
CHW Age	1.04	0.002	1.02	0.138
CHW Education				
Primary	1.0		1.0	
Secondary	0.57	0.049	0.83	0.518
Postsecondary	0.71	0.391	1.03	0.930
CHW Occupation				
Farmer/Housewife	1.0			
Employed/Businessperson	0.907	0.730		
Missed any visits				
Yes	1.0			
No	1.41	0.206		
Time to Travel to Patient				
<1 hour	1.0		1.0	
1+ hours	0.26	0.001	0.29	0.002
Max. Number of Patients Supervised at One Time	1.14	0.092	1.15	0.099

In the final multivariate model, after adjusting for the patient's sex, education, and marital status, the time to travel to patients was the only statistically significant CHW characteristic that predicted virologic suppression. Patients whose CHWs had to travel one or more hours to them had a 71% lower odds of virologic suppression compared to patients who lived less than one hour away from assigned CHWs (adjusted OR = 0.29, 95% CI = 0.13–0.65, p = 0.002). Alternatively stated, patients whose CHWs had to travel less than one hour to reach them had 3.45 times greater odds of virologic suppression compared to patients whose CHWs had to travel one or more hours to visit them. The patient characteristics I controlled for in the multivariate model, namely patient sex, education and marital status, continued to be statistically significant predictors of virologic suppression. Interactions between the CHW's time to travel to the patient and patient sex, education, or marital status were not statistically significant predictors of virologic suppression and, therefore, were not included in the final model.

Since the time of travel by the CHW to the patient was significantly associated with virologic suppression, I explored this association further. An analysis based on unadjusted proportions showed that the gap in the virologic suppression between CHWs who had to travel less than one hour compared to those that had to travel one or more hours existed early on in treatment (at six months) and the gap increased over the duration of the follow-up period (Figure 5-1)

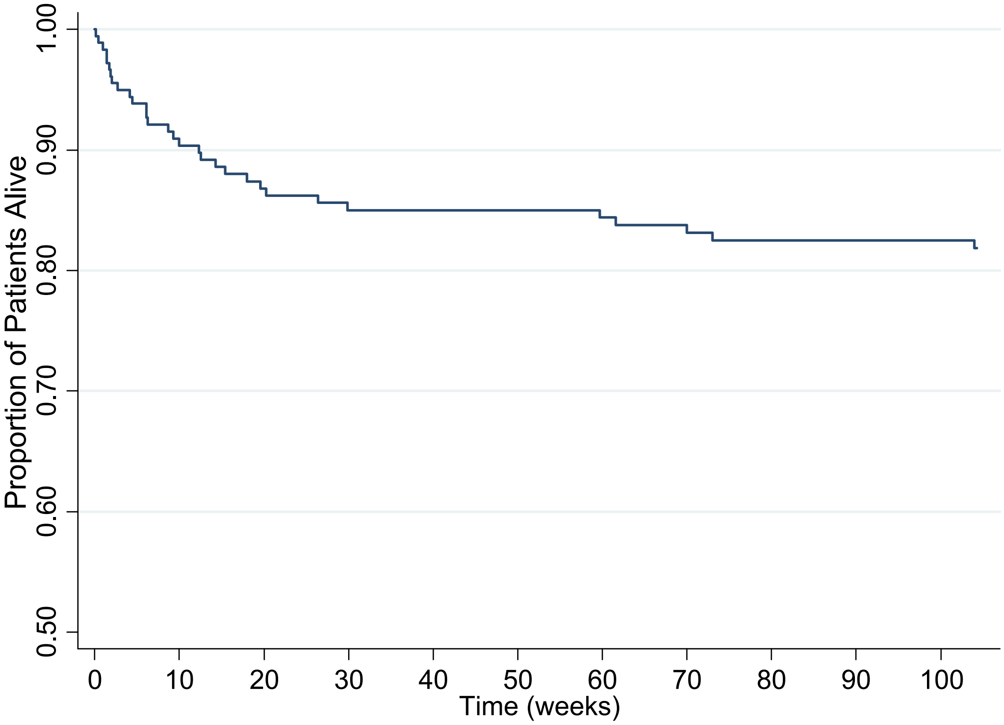
Figure 5-1: Assessment of virologic suppression based on CHW travel time



5.2.2 Mortality

Thirty-two patients (17.5%) in our CBART program died over the two-year period of analysis. A Kaplan-Meier survival curve (Figure 5-2) shows that while patient deaths occurred throughout the period, most of the deaths occurred within the first 10 weeks of treatment.

Figure 5-2: Kaplan-Meier survival curve for patients in the CBART program



A descriptive analysis of patient and CHW characteristics associated with all-cause mortality (Table 5-3) showed that patients' sex, marital status, and the time it took for their CHW had to travel to them were statistically significant factors associated with mortality within two years.

Table 5-3: Patient and CHW characteristics associated with two-year all-cause mortality

	Characteristic	Died	Alive	p-value
Patient Characteristics	Patient Sex, n (%)			
	Male	18 (23.7%)	58 (76.3%)	0.040[a]
	Female	13 (12.2%)	94 (87.8%)	
	Patient Age in years, mean (SD)	36.3 (10.0)	35.4 (9.0)	0.621[b]
	Patient Education, n (%)			
	None	14 (25.0%)	42 (75%)	0.182[c]
	Primary	14 (13.3%)	91 (86.7%)	
	Secondary/Postsecondary	3 (13.6%)	19 (86.4%)	
	Patient Occupation, n (%)			
	Housewife/No Occupation	8 (19.5%)	33 (80.5%)	0.756[a]
	Farmer/Nonprofessional	18 (15.4%)	99 (84.6%)	
	Professional/Businessperson	5 (20.0%)	20 (80.0%)	
	Patient Marital Status, n (%)			
	Single	10 (38.5%)	16 (61.5%)	0.004[a]
	Married	12 (16.4%)	61 (83.6%)	
	Widowed/Divorced/Other	9 (10.7%)	75 (89.3%)	
	Patient Distance from Facility, n (%)			
	<5 km	9 (17.65%)	42 (82.4%)	0.874
	>5km	22 (16.7%)	110 (83.3%)	
CHW Characteristics	CHW Sex, n (%)			
	Male	20 (16.4%)	102 (83.6%)	0.780[a]
	Female	11 (18.0%)	50 (82.0%)	
	CHW Age in years, mean (SD)	40.8 (9.0)	39.7 (9.5)	0.538[b]
	CHW Education, n (%)			
	Primary	13 (15.7%)	70 (84.3%)	0.486[a]
	Secondary	10 (15.4%)	55 (84.6%)	
	Postsecondary	8 (24.2%)	25 (75.8%)	
	CHW Occupation, n (%)			
	Farmer/Housewife	18 (15.5%)	98 (84.5%)	0.500[a]
	Employed/Businessperson	13 (19.4%)	54 (80.6%)	
	Missed any visits, n (%)			
	Yes	17 (21.3%)	63 (78.7%)	0.166[a]
	No	13 (13.4%)	84 (86.6%)	
	Time to Travel to Patient, n (%)			
	<1 hour	3 (5.4%)	53 (94.6%)	0.005[c]
	1+ hours	28 (22.1%)	99 (77.9%)	
	Max. Patients Supervised at One Time, n (%)			
	1	1 (14.3%)	6 (85.7%)	0.956[c]
	2	5 (23.8%)	16 (76.2%)	
	3	4 (11.8%)	30 (88.2%)	
	4	4 (16.0%)	21 (84.0%)	
	5	8 (19.1%)	34 (80.9%)	
	6	4 (14.3%)	24 (85.7%)	
	7	4 (22.2%)	14 (77.8%)	
	8	1 (12.5%)	7 (87.5%)	

[a] Chi-squared test. [b] t-test. [c] Fisher's exact test.

Table 5-4 summarizes the results of univariate and multivariate Cox proportional hazards models to assess CHW characteristics associated with all-cause mortality of patients on ART. I also assessed associations between patient characteristics and patient virologic suppression to identify which patient factors to control for in the final multivariate model. In the univariate model, the time to travel to the patient was the only statistically significant factor associated with mortality. Patients whose CHWs had to travel one or more hours had a 5.03 times higher probability of death than those whose CHWs had to travel less than one hour to them (unadjusted hazard ratio (HR) = 5.03, 95% CI = 1.49–16.97, p = 0.009). Patient sex, education, and marital status were also statistically significant factors associated with two-year mortality.

I used the tests of statistical significance in the univariate analyses (using a threshold of $p < 0.20$) to select missed visits and distance from the patient as important predictors to test in the multivariate model. Using the same tests of significance, I considered patient sex, education, and marital status as important variables that I needed to control for in the multivariate analyses.

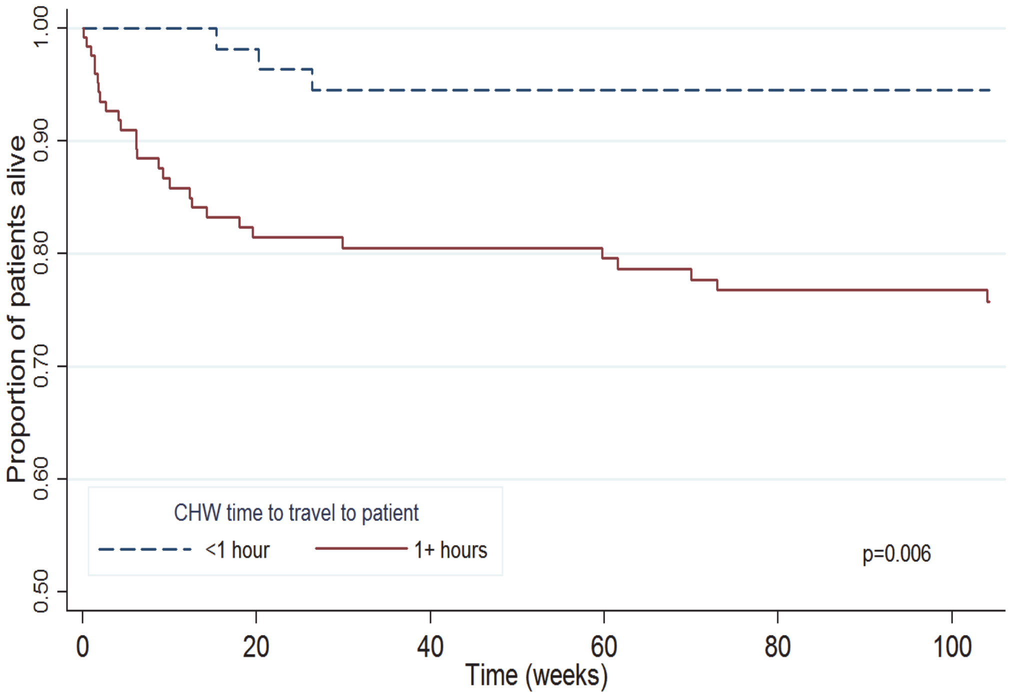
In the final multivariate model, after I controlled for patient sex, education, and marital status, the only CHW characteristic that remained statistically significantly associated with mortality was the time to travel to the patient. Patients whose CHWs had to travel one or more hours had an all-cause mortality hazard rate 4.52 times higher than those whose CHWs had to travel less than one hour (adjusted HR = 4.52, 95% CI = 1.20–17.09, p = 0.026). Patient sex, education and marital status remained statistically significant predictors of mortality in the multivariate model. The interactions between the time to travel to patient and patient sex, patient education, and patient marital status were not statistically significant and were not included in the final model.

Table 5-4: Cox regression analyses of two-year all-cause mortality

Characteristic	Univariate		Multivariate	
	Unadjusted Hazard Ratio	p-value	Adjusted Hazard Ratio	p-value
Patient Sex				
Male	1.00		1.00	
Female	0.47	0.036	0.45	0.026
Patient Age	0.99	0.523		
Patient Education				
None	1.00		1.00	
Primary	0.53	0.090	0.44	0.014
Secondary/Postsecondary	0.60	0.427	0.51	0.383
Patient Occupation				
Housewife/No Occupation	1.00			
Farmer/Nonprofessional	0.76	0.524		
Professional/Businessperson	1.04	0.940		
Patient Marital Status				
Single	1.00		1.00	
Married	0.33	0.010	0.30	0.024
Widowed/Divorced/Other	0.21	0.001	0.23	0.004
Patient Distance from Facility				
<5 km	1.0			
>5km	0.96	0.895		
CHW Sex				
Male	1.00			
Female	1.07	0.828		
CHW Age	0.99	0.363		
CHW Education				
Primary	1.00			
Secondary	1.05	0.880		
Postsecondary	1.55	0.271		
CHW Occupation				
Farmer/Housewife	1.0			
Employed/Businessperson	1.26	0.79		
Missed any visits				
Yes	1.00		1.00	
No	0.58	0.075	0.68	0.219
Time to Travel to Patient				
<1 hour	1.00		1.00	
1+ hours	5.03	0.0096	4.52	0.026
Max. Number of Patients Supervised at One Time	0.99	0.883		

Since the distance that CHWs had to travel to patients was an important factor in survival, I explored this variable further. Kaplan-Meier survival curves based on the time for CHWs to travel to their patients (Figure 5-3) showed that the higher mortality observed in patients whose CHWs lived one or more hours away was present from the outset of treatment. After 20 weeks on treatment, the mortality rate stabilized and continued to decrease over the remainder of the study period. In contrast, patients whose CHWs had to travel a lesser distance experienced fewer deaths in the comparable 20 week period on treatment with no additional deaths after 30 weeks on treatment.

Figure 5-3: Kaplan-Meier survival curves for CBART patients based on CHW travel time



5.3 SUMMARY OF FINDINGS:

A large proportion (65.7%) of AIDS patients in the CBART program achieved virologic suppression after two years. Of the patients who started on ART, 83.1% were, to the best of our knowledge, alive after two years. After controlling for patient factors, the only CHW characteristics associated with virologic suppression and mortality was the CHW's time to travel to the patient. A patient with a CHW who had to travel less than one hour had 3.85 times higher odds of virologic suppression compared to patients with CHWs who had to travel one or more hours. A patient who lived one or more hours from his or her CHW had a 4.52 times greater chance of dying than a patient who lived closer to his or her CHW.

CHAPTER 6 - RESULTS: PERSPECTIVES ON COMMUNITY HEALTH WORKERS AND PROGRAM ACTIVITES

6.0 OVERVIEW

In this chapter, I provide information to answer the two parts of research question 2: (a) What were the perceptions of patients, health workers, and CHWs on the benefits to patients of using CHWs to support ART? and (b) What were the perceptions of CHWs on the challenges they faced in supporting ART and what helped and motivated them? I outline the perspectives of patients, CHWs, and clinic staff on the effectiveness of the CHWs and the volunteer model as they relate to patient outcomes and the structures and processes that supported the model. I obtained these perspectives using qualitative data from four FGDs attended by 40 CHWs, 20 patient interviews, and one FGD with five health workers.

A number of themes emerged in relation to stakeholder perspectives. These can be broadly categorized into: (1) contributions made toward improving the well-being of patients, (2) challenges faced by CHWs, (3) dealing with CHW challenges, and (4) CHW motivation.

6.1 IMPROVING THE WELL-BEING OF PATIENTS: GOING BEYOND ACCESS TO TREATMENT.

Community health workers, patients, and clinic staff all believed that the volunteer program helped patients to overcome the challenges they had in accessing ART. These challenges primarily revolved around time and resources needed to access overcrowded and busy clinics located at some distance to where patients lived. CHWs had advantages that health workers didn't have. CHWs had closer proximity to, and more time to spend with, patients than health workers. As a result, CHWs could provide better access to treatment. However, access to treatment was not the only benefit identified. Patients and

CHWs both brought forward unexpected elements of support provided by CHWs such as friendly and caring advice, consolation, and the provision of material items—benefits that were not part of the CHWs' required activities. Thus, patients acquired additional support from the volunteer program that contributed to their broader well-being. Patients, health workers, and CHWs felt that the volunteer program improved patient care and reduced the AIDS death toll because of the greater access to care and the stronger support provided by the CHWs. I discuss these perspectives in more detail below.

6.1.1 Access to ART

6.1.1.1 Busy clinics – Health care workers will not "bend low" to serve patients

Community health workers felt that the distance to the clinic, the clinic schedule, and overcrowding at the clinic made it difficult for patients to access services and drugs in a timely fashion. They believed the clinic's operating times were insufficient to meet the needs of the large number of HIV patients in the area. In practice, patients who had walked long distances to the clinic and waited to see a health worker were either rushed through the clinic or sent home without being attended to. Some CHWs observed health workers being inflexible or unaccommodating to the needs of patients and felt that CHWs were more likely to ensure that patients were seen on schedule and that their concerns were heard. One CHW mentioned:

> 'But us volunteers, if it's your week, your week to visit the patients, you make sure you have visited all of them and listened to each one's complaints and problems. The staff are earning their salary, so they don't bend low for anyone – they give numbers and those are the only people they attend to on that day.' (Community health worker 01)

Community health workers felt that the outreach aspects of their work were the most important. They acknowledged that health workers were busy as a result of the large number of health issues they had to address in the clinic and it was not feasible for them to travel to visit rural and remote patients. Doing so would take health workers away from other important clinical duties for non-HIV diseases:

> ‘I look at ourselves [volunteers] as mobile clinics and we help control overcrowding here at the clinic. If our services were to stop then the clinic would not treat other diseases but only HIV and AIDS.’ (Community health worker 16)

Community health workers felt they enabled access to treatment by compensating for the limitations health workers faced in reaching a large number of patients who were spread over long distances:

> ‘According to me, [patients] wouldn’t manage … we have done a great job in our villages. When we spread the gospel, a lot of people listen to us … it would be very hard for the nurses to come from here to go and do what we are doing in the villages … the volunteers keep on encouraging the people each and every day.’ (Community health worker 01)

> ‘… the clinic can get so many problems without … the volunteers. For example during the rainy season or on a rainy day, a health worker from here cannot go to the villages, and that means the patients will miss their doses, and even the patients themselves can decide to stop the medication, especially if it requires them transport to come here. But for us volunteers, we are forced to do the best we can under any circumstances for the [good] of our patients.’ (Community health worker 13)

The CHWs realized that patients valued and appreciated this outreach service. One CHW mentioned:

> ‘… when I told my patients that … I am going to just visit you and bring for you the drugs for only these years, and the following years you are to go be collecting the drugs by yourself … they were sad and said, oh, no, Jesus [you] should not do that. We still need you to visit us and bring drugs for us. They continued saying that “for me going to Rwimi to collect … those drugs, I can get tired, and I don’t think I can manage.”‘
> (Community health worker 06)

6.1.1.2 Health worker workload – “they have eased it for us”

Clinic staff also acknowledged the support provided by the CHWs in reducing overcrowding in the clinic and in helping them to meet the needs of AIDS patients. They felt that a CHW would be better suited for certain ART tasks as they were geographically and socially closer to their fellow villagers than a health worker who didn’t live in the village. One health worker stated:

> ‘It would not be possible for us to do their work … you cannot run the work at the health facility [and] at the same time go to the community and do the work volunteers are doing. It would take me more time to get [become friends with] you than your neighbour who already knows you. So for them, working with those people is easier than we would do it – so they have eased it for us.’ (Health worker 2)

Clinic staff felt that, as a result of the CHWs’ support, patients had much better access to ART which then led to improved adherence to treatment. When the

FGD facilitator asked them about differences in patients with and without a CHW, one health worker stated:

> 'The difference is there because sometimes those clients who are not helped by volunteers miss drugs because they have to come here themselves or send relatives, so because sometimes they have not informed these relatives on time, or that person stays alone or with young children, you find sometimes they miss, but those ones who have volunteers don't miss.' (Health worker 3)

Clinic staff also felt that CHWs helped to improve patient care by strengthening communication between staff and patients, especially those who didn't live nearby. As a result, clinic staff felt that CHWs were better placed to deliver health education messages through one-on-one contact and could also help staff to quickly track patients who had not returned to the clinic for some time. This timeliness in their communications with patients may have prevented or minimized adverse side-effects of treatment:

> '… when the community recognizes them, people can always listen to them and they can assist us on health education and communication … and sometimes we miss following those clients who are not assisted by volunteers, because if the person wants to transfer to some other place, the volunteers tell us that so and so shifted or so and so died or so and so is very sick and has been taken to this place. But for the other one who is not assisted by the volunteers, he may fall sick they take him [to another clinic], you wonder why this person is not coming to pick [up] his or her drugs but you don't get the answer.' (Health worker 3)

> '… they are linking us in that in case a [patient] gets a problem it comes [in a timely fashion] before it has become adverse. Because by the time we would get there maybe the [patient] has got side-effects. Maybe, by the time the [patient] gets here or we decide to go maybe the [patient] has gotten so bad and we may not reverse it.' (Health worker 3)

6.1.1.3 Patients – we "wouldn't manage" without a volunteer

Patients also discussed how CHWs provided important services that helped them cope with their treatment. Patients mentioned a range of activities that CHWs supported, including delivering drugs, assessing adherence to treatment, answering questions about their health conditions, distributing condoms, and providing advice. When the interviewer asked which activities the patients could not do without, almost all mentioned the delivery of drugs. The other activities were seen as beneficial but not as essential as the physical access to drugs. The biggest barrier to "managing" was access to transport. When asked by the interviewer if, aside from transport issues, they could manage their treatment, most patients said they could:

> 'Apart from transport – do you think you would have managed your treatment without a volunteer?' (Interviewer)
> 'Yes.' (Patient 05)

> 'Apart from transport nothing else would fail me … with transport I think I can manage without a volunteer.' (Patient 08)

The value of physical access to the drugs was based primarily on the challenges patients faced in reaching clinics, but also waiting for care at overcrowded clinics. In regard to overcrowding, one patient mentioned:

> '… we have a lot of responsibilities – gardens, animals, the family, and … I feel frustrated when I have to go to the clinic and almost spend the whole day there waiting to be attended to. It's not a problem of health workers but the [patients] are many – they overwhelm them. Maybe sometimes I would forget and miss some doses.' (Patient 20)

6.1.1.4 A knowledgeable and caring source of advice – "she knows what she is doing"

Patients also appreciated the different types of advice given by CHWs related to their care and well-being. This ranged from nutrition advice, advice about taking alcohol and cigarettes, personal and household hygiene, sexual relations, and personal home situations. Patients felt that this information had been useful, and some felt that this advice had saved their lives. Patients spoke about the types of advice provided by their CHWs in the following ways:

> 'She advised me to be patient with myself, take my drugs on time without missing them. I should never forget the drugs, I should protect myself or even abstain from sex, I should not drink alcohol and not to smoke – such things [have been useful] because I used to smoke but now I stopped, I used to drink alcohol I also stopped it. But if she hadn't told me I would still be smoking and drinking alcohol and maybe the drugs wouldn't have worked and I would be dead.' (Patient 16)

> 'She has told me to be patient, do what I can manage and afford, to forego what is out of my reach otherwise I will get stressed, have other illnesses, headaches, and die. She tells me to do what I feel I can manage … she knows I have a lot bothering me – school fees, food – but she has advised me to accept the little I have.' (Patient 15)

> ‘… he tells me to avoid promiscuous behaviour, that this may increase the virus in my body and I will die very fast … he even advises me to avoid getting pregnant because this also weakens me and shortens my life.’ (Patient 01)

Almost all patients felt that their CHWs were knowledgeable and had confidence in the advice given to them by CHWs. One patient felt her CHW was knowledgeable as he provided advice similar to what she received from the clinic staff:

> ‘… I see him [volunteer] telling me the same things the doctors told me when I was starting on … treatment [even though he was not present at the time].’ (Patient 05)

> ‘… whatever the problem she [has an answer]. She knows what she is doing.’ (Patient 17)

6.1.2 Going beyond access to ART – “they care about our lives so much”

Beyond the provision of services by CHWs, patients also spoke of the close bonds with the CHWs that went beyond what they would have experienced with a regular health worker. The perception of CHWs as caring individuals who provided comfort and consolation came up a number of times in the patient interviews. Patients talked about CHWs spending time with them to listen to their issues, providing advice in a polite manner and going beyond their duties to help them with other needs. Quite a few patients mentioned that CHWs provided monetary support and food for them:

> ‘… sometimes I am very sick and [he] even brings me food … [and] gives me some money at times.’ (Patient 02)

> '… sometimes as she comes from purchasing things from her small shop she passes by and leaves me with half a kilo of sugar.' (Patient 17)

> '… one day he helped me. I was sick, I didn't have any money on me – he paid a bodaboda (motorcycle) which took me to Rwimi and brought me back.' (Patient 01)

> '… she is my good friend. Even if she has something about me which my father would even be scared of telling me about … the volunteer will come and tell me – you are doing this and that and it's wrong, better leave it – so this shows that they care about our lives so much.' (Patient 20)

Patients mentioned that they felt very comfortable in talking to their CHWs. They felt that they could freely discuss personal matters with their CHWs, matters they could not discuss with others as others might not understand what they were facing. Part of this comfort came from the feeling that their CHWs could keep secrets and could be trusted with very private information. Some saw them as good friends:

> '[I] tell her that I have such a problem as a parent, she is the one I take to be like my, my mother (crying) because I cannot run to my mother telling her of my problems. Even if I am traveling I have to inform [her] but I cannot tell my mother.' (Patient 16)

> 'I am so grateful – my volunteer is a person who understands, has no rumours, we talk freely, I even tell her my secrets. There was a time I got misunderstandings with my husband and I told her, she counseled us and

> we again got better and it ended there. No one else heard about it.' (Patient 11)

> 'I cannot hide anything from [her] – if I can tell her of the wounds in my private parts – what then do I hide from her? Everything concerning my health she knows.' (Patient 20)

Patients also received a sense of comfort from the length of time CHWs spent with them which enabled them to discuss a variety of issues without feeling rushed to end the conversation:

> 'We take about 30 minutes – sometimes even an hour – it depends on the time she [volunteer] has – sometimes she will take long advising you maybe to feed well … [if] you are overworking she then advises you to reduce on the work you are doing … she tries to comfort you in all ways.' (Patient 08)

In the eyes of the patients, gender seemed to be irrelevant when it came to the support provided by CHWs at all levels and even when dealing with very private health matters. The most important attribute to them was that the CHWs were caring; they listened and acted to help them. When the interviewer asked if patients had issues they didn't feel comfortable talking about with their CHW, almost all said there was nothing they didn't feel comfortable discussing:

> 'Nothing. I told you [volunteer] is better than my mother, even if I feel I want sex I tell her – condoms – what other big issue if not that? I tell [her] everything that concerns me. She knows I am sick, she knows I am on drugs – what else do I hide from her? Nothing.' (Patient 16)

> ‘Nothing. There is nothing that I fear telling him, he is my volunteer. Even if I have an infection in the private parts I will explain to him because he is the one who advises me or even gets me drugs.’ (Patient 10)

Despite the positive feelings felt by almost all patients, there was one patient who had very negative feelings about her CHW. She based these negative feelings on her observations that this CHW missed his appointments and was spending more time on his own family’s HIV needs and little to no time on her needs. As a result, most of the perspectives of this patient of the value of the CHW and the role he played in the patient’s health were negative;

> “…I somehow don’t feel happy because of my volunteer – my volunteer is not fulfilling his work, he doesn’t care about us his patients…the volunteer and [his] wife are also sick so they have the drugs ready with them, so then why should they mind about other people” (Patient 06)

6.1.3 CHWs – “if our services stopped…our patients will lie [as] dead as poisoned rats”

The CHWs felt they had played an important role in keeping people alive. More specifically, CHWs mentioned they believed that without their support there would be a dramatic increase in patient deaths from AIDS:

> ‘… if our services stopped … our patients will lie dead as poisoned rats but if this [program] continues as it has been, the fact is, people will not die of AIDS. [The loss of volunteers] would need a very big clinic and more staff.’ (Community health worker 16)

> 'Me, I am also saying that patients are very many in the villages … if the volunteers stop, the patients will die … many of them will die.' (Community health worker 10)

Community health workers felt that the poor would face the biggest impact due to their limited awareness of the importance of treatment and the increased challenges they faced in travelling to clinics:

> 'Now me in my own thinking – I think if … the volunteers stop, the people who are relatively rich are the only ones that are going to survive. But all the poor are going to die. And in these poor ones – that is where you find people with little understanding … they need counseling all the time. They have this thinking that if they ever miss taking tablets, it has no effect on them because he or she thinks they are fine – the virus no longer lives in them and they are cured. Now you find people like that … [who] don't bother to collect the next dose at the hospital and leave.' (Community health worker 26)

Many of the patients interviewed had similarly strong beliefs that without the CHWs they would be dead:

> '… he has given me this life I have. Everything [he does] is necessary and the man has fulfilled his job.' (Patient 09)

> 'It's the life I have now, the breath I am breathing. If it wasn't for her I would be dead. She has helped me live.' (Patient 12)

> '… I was meant to die but he saved my life.' (Patient 14)

6.2 CHALLENGES FACED BY CHWS

While CHWs had positive feelings about their work, they also mentioned that they faced a number of challenges in undertaking their activities. These challenges could be broadly classified as: (a) mastering new and difficult tasks; (b) travelling long distances; (c) coordination and communication of activities; (d) dealing with negative perceptions; and (e) stigma and social issues. However, volunteers also mentioned that most of these challenges were present in the early stages of volunteering, and that some were resolved over time and with more experience.

6.2.1 Mastering new and difficult tasks – it was "difficult for us and scared us a little"

Community health workers mentioned that they had initial difficulties with things such as counting tablets and completing the paperwork required to record the tablet counts. These were unfamiliar tasks that confused them. It was not just the accuracy of counting the tablets that made the task difficult, but the unexpected situations of having to locate tablets that might have been stored in different containers at the patient's home, discerning between ARV drugs and other drugs that the patient had (e.g., for opportunistic infections), or finding a clean place to lay out the tablets and count them. Their challenges with the paperwork were sometimes related to literacy, but more often to the calculations needed to measure adherence to ARV drugs:

> '… sometimes [the patient would take] … two tablets and tie them in [his or her] handkerchief … afterwards that handkerchief gets lost.'
> (Community health worker 15)

> 'When you counted quickly-quickly – you find that you have so many tablets you have skipped counting. And when you go back the next week,

> you find [mistakes] there just because you counted badly. So you find the previous information on the form is different from today's information.' (Community health worker 26)

Early in the program, CHWs felt overwhelmed and scared by the work. These were new activities and there was more paperwork than they had experienced in the past. For some, instructing patients, monitoring side-effects, and counselling on adherence to treatment was seen as technical work normally done by a doctor. Some were uncertain that they would be able to continue. However, CHWs mentioned being glad that they had not quit and had stayed with the program as, over time and with experience, the work got easier:

> 'Just because some of us volunteers had done volunteer work before, so we thought that also this work would be easy. But because this was different because some things were new, that kind [of] made it difficult for us and scared us a little. But after we learnt them, the work became easy.' (Community health worker 32)

> 'I gave it a try. But as we continued to work, I found it simple. Now it is on the calendar in the head – I know now my patient so and so is supposed to get the medicine on such and such a date …' (Community health worker 31)

> 'You know when you are starting something new it is always difficult. So there we first got some difficulty. But as time went on slowly by slowly we found ourselves that we also are now technicians – and are able to count drugs very well and fill forms well.' (Community health worker 28)

The CHWs also mentioned that the changes made to simplify the forms eliminated the calculations and the clear pill boxes provided made their work easier and more comfortable:

> ‘But now that box they gave us – you can count the tablets from there without getting in contact with the tablets. And can easily get the number of tablets the patient has taken by … simply multiplying by two.’ (Community health worker 26)

Community health workers felt some tasks were easier than others to complete. They felt that identifying and advising on side-effects of treatment was not difficult and that with the training received they were able to perform this task with ease. The ongoing training and opportunities to ask questions at volunteer meetings also increased their confidence and comfort with this activity:

> ‘It was not hard for us [as] they trained us and sensitization was happening … this information helped us at least to see to it that you tell the patient about the side-effects. So then when the patient swallowed medicine and their eyes turned [yellow], they could be able to know that that was a side-effect of the medication or when they swallow the medicine and get swelling on their body [we] were able to tell that this is a side-effect.’ (Community health worker 05)

However, one CHW mentioned that he felt confused when the side-effect was not resolved after the patient visited the clinic, suggesting that the training might not have addressed the duration of side-effects for some CHWs:

> '… sometimes my patients' side-effects confused me because even if I send them here at the clinic to see the doctor they still complain of the same problems.' (Community health worker 15)

It was not just the mistakes made by the CHWs, but also mistakes made by patients and treatment partners that made the CHWs' work difficult. For example, the forms that patients and their treatment partners had to fill out were not always complete or accurate, making it difficult for CHWs to see if the patient had adhered to his or her medication. This seemed to improve with time and especially as patients became more comfortable in discussing their difficulties and mistakes in filling out the forms with their CHWs:

> 'Aaah – our patients – we would find some mistakes they have done and the mistakes would be on drug … the patient would [tell us] they have very many opportunistic diseases that would disturb them. And these others – the treatment partners – others you would find they did not even know how to write – they again disturb you. You find how you instructed him or her to fill the form, [but] they have made mistakes – so you have to teach them again and this went on for some long time to see that she or he understands the things and learns how to do it.' (Community health worker 26)

> 'At the beginning when the patient made a mistake, they would hide for fearing you. Even if you tried to ask – here and there, they would refuse to tell anything or give any correct information. But now if they make any mistake and you ask them they cannot hide anything, they would tell you everything. They can tell you that there was such and such a problem – then they explain to you.' (Community health worker 32)

Community health workers felt that some of the patient mistakes might be due to patient confusion and misunderstandings. One example given was about a patient misunderstanding the life-long nature of treatment:

> ‘Some clients, after their health improved … decided to stop taking the drugs. However I tried to explain to them [but] some wouldn’t listen. One used to think he was just taking a dose like that of malaria, that after he got better he stopped. It was hard for me to convince him.’ (Community health worker 18)

6.2.2 Long distances – “you travel eight hours on a bicycle and another eight hours returning back”

In addition to difficulties in the technical aspects of the work, CHWs also mentioned that they had difficulties in coping with the time required to complete tasks. Almost all CHWs found the distances that they had to travel to perform their activities to be a challenge. They mentioned that they had to travel many times, from their homes to the clinic to pick up drugs and then from their homes to the patients. Long distances sometimes required CHWs to find alternative means of transport, including hiring motorcycle transport at their own expense to take them to the patient’s home:

> ‘Aaah! This work, according to me, I saw it as a simple work, but when I started I found out that this work was hard … it consumed time … you could ride a bicycle and come here and collect the drug[s], take it back to the village and [once] in the village … you will have to get time to reach the patient’s home …’ (Community health worker 26)

> '… for instance I have a patient who lives far away on the top of Mount Rwenzori – you travel eight hours on a bicycle and another eight hours returning back.' (Community health worker 33)

Many CHWs expressed the challenge of discovering that patients were not home when they came calling, and thus had to make another trip to see them. This became worse as the patients' health improved and they became more mobile, allowing them to resume their work and run errands outside their homes. Community health workers felt both happiness for the visible improvements seen in patients and frustration in having to travel multiple times or longer distances to find a patient to be able to complete their monitoring tasks:

> '… we are putting much emphasis on transport because our patients have now recovered – you go to someone's home two, three times without finding them; we have to travel long distances to find them maybe where they are working from.' (Community health worker 17)

> '… our patients have reached where they have improved in their health. Now you go there and you don't find them, go back again, still you don't find them there. So this forces you to take a longer time.' (Community health worker 06)

6.2.3 Coordination and communication of activities

Another challenge for CHWs that occurred predominantly in the early stages of the program, was the lack of communication and coordination of activities, especially in relation to picking up drugs from the clinic. Some CHWs mentioned instances when clinic staff were not prepared for CHWs to pick up patients' drugs, but there were no opportunities to pick up drugs on alternative days if they couldn't come on the scheduled day. In addition, there was an initial confusion between patients and CHWs about who was to pick up drugs. Other challenges included having to work with different dose or tablet schedules when the brand of drugs was changed and the rationing of drugs during shortages led to more frequent pick-ups and deliveries.

The CHWs mentioned that, over time, the coordination of activities and mutually agreed upon timings for picking up drugs improved. A positive aspect of the improved coordination was a better relationship with clinic staff and a greater sense of belonging to the clinic felt by the CHWs:

> '… I see that our relationship with staff (health workers) here is very good … at first, we were not used to them and they also weren't used to us. But right now, considering the time we have spent working with them, all of us are now used to one another.' (Community health worker 26)

6.2.4 Dealing with negative perceptions

Some members of the wider community and some patients had negative perceptions of CHWs. These were related to misunderstandings about resources and might have been exacerbated by the incentives and other forms of appreciation used by the program and the expectations communities had of foreigner-led programs. Other negative impressions came as a result of misunderstandings about and a fear of ART and the consequent distrust of those associated with ART. I discuss these in more detail below.

6.2.4.1 Community distrust of CHWs – "they are getting rich because of the patients"

Community health workers mentioned that some members of the wider community had negative impressions about them. They believed that this stemmed from a perception the community had that CHWs were being paid for their work, but were hiding this from others. When corrected, some community members felt that CHWs were foolish to undertake this work for free. Others refused to believe the CHWs as they saw them with new bicycles and other incentives such as bicycle tires, boots, and blankets. Some CHWs mentioned villagers believed that they were exploiting patients in order to receive money:

> '… at first, the time we started – when we opened up for those people and told them we work for no pay, they called us stupid and foolish. Now that time came when they saw us … come with the bicycle, they said uh, they are lying — those people are being paid. So we were done with the bicycle … and now when they saw us come with the spare tires then they said, aaah, those people are lying they have money. (laughs) And recently when they saw us carrying our blankets going home they said, "No! Those people are lying."' (Community health worker 06)

> 'I have heard people in the villages saying that those ones (volunteers) are getting rich because of the patients [with] AIDS. If they were not there, would they be getting all that? (laughs) They are getting rich because of the patients.' (Community health worker 07)

This community perception was confirmed by health workers, one of whom stated:

> '…the general public, they think these volunteers are facilitated[††]– I think most of them. However some of them may [understand] that they are volunteers but some people think these people are facilitated.' (Health worker 3)

[††] "Facilitated" in Uganda means being paid.

Health workers thought the perception that CHWs were paid was due to the presence of outsiders and the sense that a foreign project brings a lot of resources in and pays the people engaged in the project:

> '… they feel these people are facilitated, they have a lot of things they get and especially because they saw whites bring a lot of money, so they think these people are facilitated.' (Health worker 1)

Community health workers thought that this perception occurred primarily in the earlier stages of the program and that the perception faded over time, especially as the community got to know more about the CHWs' activities and the outcomes of the program. Community health workers mentioned the volunteer recognition programs as being especially useful in informing villagers of the work of the CHWs. However, some CHWs mentioned that community members still harboured some envy of CHWs because they received tangible benefits such as incentives:

> 'But others (community members) say let them get those gifts – they have moved a lot helping these [patients] – let them be rewarded. And those who had called us foolish and stupid realized we had spent a long time working. That thing of calling us foolish – they stopped but what they do now is to envy us. They wish they were like us.' (Community health worker 07)

6.2.4.2 Patient misperceptions – "people think maybe we are being corrupt"

Patients also had negative perceptions of the CHWs, not because they thought that CHWs were lying about not being paid, but because they thought CHWs were not distributing resources that were meant for them. This was partly because patients heard about other programs in the area that were providing additional material support for patients, and they expected this program to do the same:

> '… some people have continued to ask us saying some programmes, after people test HIV positive, on top of treatment they are given some other help … like soap, salt, and other things and now people think that maybe we are being corrupt and take their things.' (Community health worker 16)

> '[I said to the volunteer] I hear some people like us in other areas like Bushenyi get things. What about us? And she said that this project doesn't give those things … like cooking oil, sugar, and rice.' (Patient 20)

Some patients seemed to be unfamiliar with the notion that volunteers could provide the type of support they were receiving. Many patients believed our program paid the CHWs and expressed their surprise or disbelief when told that they were unpaid volunteers. Patients did not mention any resentment or concern about CHWs being paid, but rather admired the CHWs for doing this work without pay:

> 'According to me, the volunteers get a monthly salary – they get money though she has never told me, but according to me I think she is paid because no one can work for nothing – for free.' (Patient 16)

> 'The way she treats me – the love and care, the way she talks – that shows she gets something – if she was not being paid she wouldn't have that love and time to check on me.' (Patient 17)

> ‘It’s surprising because it’s hard for someone to give [themselves] to work without pay. They waste a lot of their time visiting us and maybe forego their work – it’s surprising! Most people say without money Ugandans cannot work – it’s surprising!’ (Patient 05)

6.2.4.3 Misinformation regarding ART – “these people had brought drugs to kill us”

Community health workers also had to deal with the stigma of drugs, which they felt was brought on by misinformation about treatment and the perception that antiretroviral drugs were being brought to kill patients:

> ‘The job at first was hard because patients were scared for their lives. They were saying that these people had brought these drugs to kill us. So it was at first [our role] to convince these people.’ (Community health worker 29)

The stigma associated with the ill-effect of drugs seemed to have been a result of early negative experiences within another program led by an external non-governmental organization (NGO). These misperceptions were difficult for CHWs to deal with and led the CHWs to feel stigmatized and also reluctant to be associated with an AIDS program. It took positive experiences in the CBART program for the community to see the benefits of the drugs:

> ‘there are some who were very weak now when [NGO] came, some people joined it but some of them were very weak, they were not eating or drinking and when they took these drugs they died – so people said that these drugs are killing people. But people who were a bit strong took these drugs and survived and are still living.’ (Community health worker 06)

> ‘… as volunteers from the villages we were also still stigmatized – we used to fear … to be associated with HIV and AIDS.’ (Community health worker 16)

6.2.4.4 Stigma and social issues

Community health workers mentioned having to deal with the challenges of patient attitudes toward ART. One of these attitudes – and associated behaviours – related to the stigma that some patients felt around being HIV positive. Another related to patient attitudes as a result of substance abuse, complacency as patient health improved, or misplaced beliefs.

6.2.4.4.1 Stigma – “… we had to hide away somewhere to be able to talk”

Some CHWs felt that their work was more difficult and took more time in the beginning because patients did not want neighbours and friends or relatives seeing the CHWs in their homes. These patients had not always disclosed their HIV status to others and felt that the presence of the CHW would reveal their HIV status. There was also a feeling that this stigma impacted patient adherence to treatment:

> ‘To me, in the beginning it took me a lot of time because the patients had a lot of stigma – for example, if you found another person at the patient’s home, it meant we had to hide away somewhere to be able to talk. So it would take a lot of time.’ (Community health worker 20)

> ‘… in the beginning the patients were stigmatized so they wouldn’t give you a chance to sit and count in fear that other people would find you and then know that they are on drugs. But with time they became less and less stigmatized.’ (Community health worker 03)

> ‘… some hadn’t told their partners so they wouldn’t take the drugs in the presence of their partners and they wouldn’t allow you to even count the drugs in the presence of their partners.’ (Community health worker 21)

Community health workers pointed out that this stigma was more common during the early stages of the program, and that over time the situation improved. The eventual reduction in patient stigma made their work easier, especially as patients came forward to talk to others about their illness and encouraged others to seek treatment:

> ‘But now that kind of stigma [has] stopped – now they want to associate with you – calling you to come and visit them and even sending other people to you who would like to test and start [on] medication. You see now they are easy with it because our volunteer service has something [that] has helped them with their health – they got strength that they managed to stand firm and testify to others who are still stigmatized … we started this job when it was hard but because the patients are firm and can teach their fellows – it is now easier for us.’ (Community health worker 31)

> ’… but now they are less stigmatized – they don’t fear; anytime you get there they just freely talk to you and this [work] takes you little time.’ (Community health worker 20)

6.2.4.4.2 Patient behaviours

A difficult hurdle for CHWs was patient behaviour that led to noncompliance with recommendations and created extra work for CHWs. This included alcohol abuse and following preachers who advocated prayer instead of antiretroviral drugs. Most CHWs felt that these situations were too difficult to handle alone and they needed the support of the volunteer administrator to counsel patients and confirm and validate the information provided by CHWs:

> ‘I have one patient who drank … a lot of alcohol and even fell at the roadside, and he also would get involved with so many women. Because the administrator came there … he saw that we were many on his case and overpowered him – tightened him – that is when he started changing a bit.’ (Community health worker 32)

> ‘… I had a patient who used to drink alcohol and even smoke, I tried to tell him that would deteriorate his life, that he would even develop TB but he couldn’t listen to me until when I told our administrator [and] he came and counseled him.’ (Community health worker 13)

> ‘there is one [patient] in my village … some old woman told her that they were going to take her somewhere to be prayed for, so it was hard for me to take her the drugs as she would refuse them but then the [volunteer administrator] came and talked to her; she started again and up to now she says it was because of the [volunteer administrator] that she again started the drugs.’ (Community health worker 11)

Many CHWs noticed that, as their health improved, some patients would start engaging in negative behaviours or stop following the CHW’s recommendations. This was seen as a problem that required the intervention of the volunteer administrator:

> ‘Another issue is the young men and women we have as our clients. Now that their health has improved compared to how they were very sick

> before they started on the treatment they have become very promiscuous.’ (Community health worker 17)

> ‘… the reason why these clients no longer listen to us is because their health has improved so they do what [they] feel is right for them. They listen to us less – for example, one who had a partner who was very sick and they were using condoms but now that they see their partners are okay, they even do not accept the condoms, so that is why we decided that we can always have the administrator so he can give more advice.’ (Community health worker 09)

> ‘Another thing – for me I have a client who told me that she no longer wants my drugs because God has healed her – I tried to explain and advise her in vain …[she told] me to take away my drugs. This forced me to tell the [volunteer administrator] who came and counseled her about two times and she accepted to again take the drugs and she is now okay.’ (Community health worker 21)

Community health workers mentioned the difficulty they had in getting some patients to accept their HIV prevention advice and use condoms. The reasons for this behavior were largely attributed to patient stubbornness and nondisclosure of their status to their partners, although, in one case, the behavior was due to past negative experiences with condoms that had not been used properly:

> ‘… and he tells his wife that he is not going to use those condoms. Whenever I took them to him he would say to me, “put them there.” But the wife would tell me that he refused to use them – he doesn’t use them. They tried to use them once but I think they didn’t use them well – so I tried to explain to him how to use it. I think when he uses this

> condom, he didn’t put it on well and it stuck in the woman – so that disturbed him and he decided never to use it again.’ (Community health worker 07)

However, some CHWs found that because some patients were engaging in risky behaviours, they appreciated the HIV prevention messages and the resources offered by the CHW:

> ‘And he is busy sleeping with other women in secret. But he tells me, “please send me condoms” and I do … send them to him.’ (Community health worker 08)

6.3 DEALING WITH CHALLENGES

In spite of the challenges that CHWs faced, they felt that eventually they were able to deal with most challenges. The ability to deal with challenges came from: (a) the strong support from the volunteer administrative structure; and (b) time and experience that led to efficiencies and also to better relations with patients.

6.3.1 Support from the volunteer administrative structure

Almost all CHWs noted the importance of the support provided by the volunteer administration structure, especially the volunteer administrator, in helping them to complete their work more effectively. This support included: regular opportunities to discuss issues and find solutions, the presence and reliability of a volunteer administrator who helped them with difficult situations, and the provision of material resources for their work.

6.3.1.1 “We should always have our monthly meetings”

An important forum for training was the monthly volunteer meeting. Community health workers greatly appreciated the ongoing training and information they received. These enabled them to feel more comfortable in managing their activities and in answering patient questions, especially about topics that had not been discussed in the initial CHW training:

> '… what was so helpful to us was the monthly meeting … when we could come here for those meetings the [volunteer administrator] would correct and show us how we have done things in the previous month – show us our errors and correct them and teach us.' (Community health worker 29)

> '… there were some patients I could visit and this patient has [illness] like in the private parts. This patient can be in pain but has no way he can explain to you. But when we got the chance to come for these monthly meetings, this helped us on solving the side-effects identification problems.' (Community health worker 29)

When the FGD moderator asked how they would feel if the program had to change due to a lack of resources, CHWs believed that, at a minimum, the monthly meetings should continue:

> '… we should always have our monthly meetings because it's during those meetings that we share our different problems encountered and we get solutions.' (Community health worker 13)

In addition to their own training, CHWs felt that the ongoing education of patients and treatment partners also helped them with their tasks:

> ‘Another important thing was that there was a time when they called on the patients and taught them … [that helped] in making easier our work as volunteers.’ (Community health worker 06)

The opportunities at the monthly meetings to communicate with the volunteer administrator also helped CHWs to express their challenges and to find solutions. It reduced their workload greatly to be advised on different ways to approach their tasks.

6.3.1.2 “The king doesn’t have respect from his home”

Community health workers expressed very positive feelings toward the personality and work of the volunteer administrator. They regarded him as a highly knowledgeable, patient, caring, and trustworthy individual. The CHWs said that they relied heavily on the volunteer administrator to answer their questions and especially to deal with a range of difficult or complicated situations with patients, including helping to deal with patient expectations, handling patients’ negative behaviours, and confirming their recommendations when patients had doubts or did not follow their instructions:

> ‘… when the administrator comes, he helps us answer certain questions, like that of gifts [or] goats some of our clients were given. So all the others were supposed to receive those gifts. So some of those questions we [did] not [have] answers [for] but when the administrator came he explained how those gifts were given out and this helped us.’
> (Community health worker 20)

> ‘… we appreciate him [volunteer administrator] because he helps our clients – those who had refused to take the drugs now take the drugs and

> those who had continued taking alcohol have also stopped. We really appreciate him.’ (Community health worker 03)

> ‘You find others caught this disease [HIV] when they had not had babies or they had babies of single sex and now they want the other sex, or the number of children he wanted. So you find our training is not enough to help them or advise them but the administrator has a bigger picture of these things more than us – he can advise these people more well [to] give birth to … children who are alive.’ (Community health worker 31)

The CHWs felt that the volunteer administrator had the patients’ trust, especially since he worked closely with the clinic staff to arrange for testing and the enrollment of patients on ART:

> ‘[patients] … will pay less attention on what we tell them unless the administrator keeps on reminding them of what we tell them – they believe in him because they know he is the one who tested them and knows what is happening in their lives.’ (Community health worker 25)

Others felt that it was simply that an individual from outside their community reinforced their messages that led to more trust among patients:

> ‘As you know we are treating people from our own villages and there is this saying that “the king doesn’t have respect from his home.” So if a person sees a new person but with the same message that you gave these people believe in us – the message gets more weight.’ (Community health worker 19)

The reliance on the volunteer administrator was the strongest when CHWs faced what they called “stubborn” patients. These were patients who did not follow the CHWs’ guidance, including those who drank alcohol and refused to use condoms even though counselled by CHWs not to do so. For the rest of their tasks, they felt that they could manage working with patients without his direct intervention:

> ‘To add on that, me, I see that for people who are just stubborn – that is when the administrator is needed – but in others – many of the other places, the administrator is not needed.’ (Community health worker 26)

6.3.1.3 Access to material resources and management of resources

Community health workers mentioned that the resources provided by the program, including bicycles, boots, and raincoats, helped with their work. The geographical distances they had to cover, especially during the rainy seasons, were less difficult to traverse because of these items. When asked about resources that were not provided, but which could have helped further, CHWs mentioned more transportation support such as motorcycles, and mobile phones for communication. The other important resource that CHWs found important was information, specifically the sharing of information and statistics on the health of patients in the program. They especially appreciated information on patient CD4 cell counts and viral loads as a gauge for measuring their own progress in supporting their patients.

When asked if they would continue working in this program if we handed it over to the local district to manage, most CHWs said they would not want to. They felt very strongly that they would not be happy working in a district-led program. They talked about the potential introduction of politics into the selection of CHWs and in their management. They felt that the underlying corruption in the district system would take away their resources and incentives and put these into the hands of politicians and their families. In addition to this distrust, they felt that the program would become disorganized, meetings would be postponed or delayed without notice, and that the coordination of activities within the program and with other stakeholders that they had come to enjoy would be disrupted. Finally, they felt they would not be afforded the courtesies, appreciation, and respect they currently received as this was not the way of district managers and politicians. These feelings seemed to emanate from past experiences working with government-led programs that were compared to the support they felt our CBART program provided.

6.3.1.4 Time and experience

Outside of programmatic support, there was also an underlying theme that time helped CHWs deal with the challenges of their work. When CHWs described their challenges, they mentioned that most challenges resolved themselves over time and with more experience. This was partly because the CHWs became familiar with their activities. Patients too became accustomed to their treatment regimen and the monitoring activities; also, patients experienced improvements in their health and were thus better able to manage their own care. These aspects were described in earlier sections. In addition to remedies of time and patience, the gradual building of patient trust and confidence allowed CHWs to complete their tasks with greater ease.

6.3.1.5 "They started believing what we were telling them"

Community health workers felt that patients were initially confused about the roles of CHWs and that patients had doubts about the impact that ARV drugs would have on their health. This reduced the patients' trust in CHWs. With time, and especially when the benefits of the drugs were realized, CHWs felt that patients began to have more trust and confidence in them. Patients later related to CHWs in the same way they related to their family members. The CHWs mentioned that the process to develop trust was slow:

> '… when this programme had just started the patients did [not] have hope that the drugs would help them. That was what made them complicated in the beginning but after they slowly started improving … they slowly developed confidence in us … for example, all my patients are women but they talk to me as if I am their brother and they are my sisters.' (Community health worker 16)

> 'So when we started to teach them slowly by slowly they started believing what we were telling them and taking this medicine – and people started getting better and stronger. Those who were down started getting up and getting better and those who were not eating started eating and so on and so forth; side-effects cured and patients really improved – then those who were misguiding the patients started believing in us and saying – it is true these drugs are working and there is no problem with them.' (Community health worker 07)

Community health workers felt that this trust led to patients being more comfortable in discussing sensitive and private issues. This then helped the CHWs better understand the needs and issues of patients that needed to be addressed. Some CHWs said that as they gained more trust it was easier for them to provide the more difficult HIV prevention messages:

> '… they [now] know us as their doctors and they know whatever they tell us we cannot let out, so they trust us with their secrets so they tell us their pain and your work is to deliver the drugs and treat them.' (Community health worker 22)

> ‘So now I find myself being trusted and [an] easy person [to approach]. Men … and also women they find [it] easy to approach [me]. And also tell me their problems; we do our things in secret. Before they never wanted to use the condoms especially men and also would swallow their medicine in hiding, don’t want to mention it to their wives …’ (Community health worker 04)

When patients believed trust was broken, they felt disappointed. One health worker discussed an instance when he heard a patient complaining about a CHW:

> ‘Some have said – actually one told me that the volunteer has not kept confidentiality. Sometimes when he [the volunteer] takes some booze he discusses the client with other people and actually the client feels hurt when he knows he is being discussed especially after you have taken booze and you discuss me you can discuss me anywhere. So there confidentiality is lacking.’ (Health worker 1)

6.4 CHW MOTIVATION

An important area of inquiry in this study was CHWs’ perceptions of what motivated them to initially volunteer and then to stay with the program. The responses from the CHWs revolved around themes of: (a) receiving appreciation and respect; (b) contributing to the lives of others as part of their faith and personal beliefs; (c) personal benefits; and (d) the incentives provided. Community health workers placed the highest importance on the appreciation and respect gained from volunteering as well as being able to make a significant contribution to the lives of others.

6.4.1 Appreciation and recognition – “now people in the village call us doctors”

Appreciation by others in their village was an important theme that emerged from the focus groups with CHWs. Community health workers talked about encouragement by some of their fellow villagers to volunteer and the appreciation expressed by them as a motivation to continue volunteering. Community health workers saw a lot of positive appreciation emanating from the annual volunteer appreciation event hosted by the CBART program. They highly valued and appreciated this recognition. Others saw appreciation coming from time to time from patients whose health had improved. Some felt respected by villagers who saw them as health professionals, namely, “doctors:”

> ‘I am saying that now people in the village call us doctors.’ (Community health worker 06)

The discussions around appreciation for CHWs’ work brought out many positive feelings about the volunteer appreciation event. Community health workers saw this program as a highlight of their work, especially since many prominent local politicians and leaders attended and talked highly of the work done by the CHWs. Some CHWs talked about the fame it brought them, or how it dispelled negative perceptions that some people had about them in the beginning. Other CHWs appreciated the opportunity to hear from people outside of the program talk about the significance of their work:

> ‘Even the people in the villages, even these ones we were bringing the medicine [to] start respecting us so highly and saying how will people see you bringing me the medicine and also [those] who were saying that we are just walking idly from clinic to villages without any pay realized that we are important and started coming to us to ask for advice on how they

> should join the programme. But before we could tell [they used to] look down on you. But after that day they believed in us and knew that we are recognized.’ (Community health worker 07)
>
> ‘That day [volunteer appreciation event] for me, actually, it makes me very happy. We are recognized among so many people. They invite the [local Council] and other district leaders, officers like that … come and be with us on this day. We get excited with them and celebrate with them and even the community. You find others coming from the center (villages) there and that is when they get to know that the work we are doing was important and was helping the community.’ (Community health worker 08)
>
> ‘… it’s very good if you get time to sit down and reflect on the work you have done. It’s like sitting down after work and taking a cup of water – you are able to see what good things you have done. It also encourages us when our work done is appreciated. It’s like sitting down with your employer to share a cup of tea, that shows that he is appreciating the work done and this motivates me the more.’ (Community health worker 19)

Community health workers also mentioned initially feeling underappreciated in their homes. The volunteer appreciation event helped their spouses to understand what they did and the importance of their work:

> ‘When we come with our loved ones like our husbands, wives, when we reach [the event] … patients who have come start testifying about themselves. So then your husband or wife gets to know that you really work here. Because every day he or she sees you going and you say, “I am

> going to work.” So he or she asks him or herself where is that lady or man going? (laughs) So when we come to the Recognition Day with them, then they also understand that we people really work – my wife/my husband really works!’ (Community health worker 08)

6.4.2 Saving lives – “[it] gives me the energy to keep on working”

Some CHWs said they were motivated by the concept of service to their communities, especially to save lives. Community health workers talked about seeing people die around them and the hardships the community faced due to the burden of AIDS. They talked about their sense of obligation to help and fight against this disease for the benefit of their fellow villagers. Some talked about the inherent happiness and self-satisfaction they received in being able to contribute something toward the suffering felt by those infected with HIV in their communities:

> ‘Me, what forced me to come in this job was because I saw that there were very many people I know that died … when I heard about this chance that we got and there were drugs that were coming and for free, and people would stay alive for some long time – then I said, no! I too have to join in volunteering and help my fellow people.’ (Community health worker 28)

> ‘… saving people’s lives – this has really kept me with the courage to keep on helping people … this gives me the energy to keep on working.’ (Community health worker 13)

> ‘Because the life of your fellows is very important, and also you cannot know how you will end. So that feeling made me desire to do the work of

> a volunteer even if they are not paying me.' (Community health worker 07)

The CHWs, primarily the females, mentioned that their religious faith or personal convictions to help others led them to volunteer and motivated them to continue volunteering. The beliefs of being repaid for their work by God and doing this work for God were important reasons for volunteering:

> '… [we volunteer] without any hope that you are going to be paid but most of us we always hope that God is the one that will pay us.' (Community health worker 04)

> 'I am working for my God and my country and my fellow people and brethren of my own country – it's not about me alone but now I am used to work for my people for free and it is I who decided.' (Community health worker 08)

6.4.3 Personal benefits – "I can also know how to look after someone, care after my life"

Some CHWs mentioned volunteering in order to help themselves and their family. These benefits were not necessarily financial, but rather the acquisition of knowledge, especially to protect themselves and their families. There was also mention of new friendships with patients who might help them in the future:

> 'I also get some knowledge most especially about ARVs. Voluntary work had helped me so much, to be aware … I can also know how to look after someone, care after my life.' (Community health worker 08)

> ‘What encourages me [is] to know that a person who has been sick can again live a normal life – this makes me know that I can also live again in case I got sick. And the people I have treated are now fine, they have become real friends who can even help me in case I got any problems and I also help them. I feel happy. I know I haven’t lost anything in doing this.’ (Community health worker 02)

> ‘… we also train our relatives and chose people those not yet infected how to protect themselves.’ (Community health worker 17)

6.4.4 Material incentives – “if you have something, even if it’s small”

The CHWs did not explicitly mention the incentives provided to them (bicycles, boots, bags, lunch, and transport allowances for volunteer meetings) as reasons for volunteering or staying with the volunteer program. They did, however, mention that they appreciated these incentives as they saw them as a way of helping them to carry out their work, and also as a token of appreciation by the program for their work. They believed it was important for the program to continue to provide these:

> ‘… I am also respected especially when people from the villages see me “carrying something” and I also tell them I have been rewarded for working as a volunteer – no pay.’ (Community health worker 23)

> ‘But now if they don’t recognize us as the project has been doing and providing us with incentives and showing gratitude with gifts – but just say thank you without giving us anything – that will discourage us … but if you have something, even if it is small … the volunteer will understand and be encouraged and happy and work more.’ (Community health worker 26)

When asked by the FGD moderator if they would continue to volunteer without incentives, most CHWs felt that they would continue volunteering, though they felt that this would create a hardship for them in travelling to visit their patients. They saw their incentives being almost necessary for them to be effective in their tasks, but they expressed that they would continue even with the additional hardships:

> '… even if it rains a lot, and I have noticed that my patient doesn't have medicine or it is over, I have to come and get it for them because there is that help. Now if I don't have gumboots, [a] rain coat or any way to go there or transport – then you even start using your own transport – then it will be so hard, and for the patient – I will be at that task to see to it that he/she doesn't miss taking the tablets.' (Community health worker 32)

However, when the FGD moderator asked CHWs about improvements to the program, there were lots of discussions that focused on providing additional material support for the CHWs. This ranged from the provision of motorcycles and mobile phones, to paying for school fees for the children of CHWs or buying land for CHWs to grow their own crops.

6.5 SUMMARY

The various groups that were part of our CBART program provided some interesting perspectives on the impact and effectiveness of the CHW program. They saw the biggest impact being the access to life-saving ART for rural patients who faced barriers trying to access ART by themselves. Community health workers provided a range of support to patients, which patients appreciated.

However, the support patients most appreciated and felt they couldn’t do without was the delivery of drugs.

Community health workers mentioned a number of challenges that they faced. They had to learn theory and procedures and master new and difficult tasks such as counting pills and making difficult calculations in confusing situations. The CHWs equated the work they were doing with work done by “doctors.” They didn’t see all tasks as being difficult; they felt that some tasks such as identifying and advising on side-effects were easy to complete. A big challenge was travelling the long distances to patients and to the clinic which required an investment of their time and their own money. Travel time increased with repeat visits becoming necessary as patients’ health improved and patients began to move outside their homes. Problems in communication and coordination of activities with the clinic created some challenges in the beginning, but these were resolved. Finally, CHWs had to deal with negative perceptions, stigma, and social issues, burdens that took time and sometimes the intervention of the volunteer administrator to manage.

Community health workers cited four important factors that helped them deal with these challenges. The first was a supportive management structure that provided them with opportunities to meet and discuss their issues. The second was a volunteer administrator who provided timely feedback and helped them to gain knowledge and manage difficult issues. The third factor was the incentives and resources they received that helped them deal with practical problems like timekeeping and travel in inclement weather. The fourth was time, whereby they became familiar with their responsibilities and the patients began to trust them and their advice. Trust enabled patients to feel comfortable discussing a range of issues with a CHW. Patients and CHWs felt no gender related barriers in their interactions.

Community health workers provided important insights into their motivation to volunteer and to stay with the program despite the challenges. They mentioned four important motivators. The first was feeling appreciated and respected by patients, the community, and their own families. The second was being able to realize their personal obligations to serve others based on faith or personal beliefs, especially regarding activities that prolonged and increased the quality of lives. The third was the knowledge they gained that they believed could one day help them and their families. The fourth was the material incentives that they felt were important symbols of appreciation.

CHAPTER 7 - DISCUSSION

7.0 OVERVIEW

In 2006, our research team established a unique pilot community based ART (CBART) program in a subcounty in the Kabarole District. This program was a response to the growing need for ART in underserved rural areas where the infrastructure and human resources for providing ART were low. The CBART program was made up of three components that worked together to provide rural populations access to ART. The first was a clinical component established in the Rwimi Health Centre III to initiate ART and manage the distribution of ARV drugs and routine monitoring of AIDS patients in the clinic's catchment area. The second was a treatment partner component in which patients would select someone from their family or neighbourhood to help them adhere to ART by observing them taking their ARV drugs. The third was a community health worker (CHW) component in which volunteer laypersons from the community would deliver drugs, monitor adherence to and side-effects of ART, and provide HIV prevention guidance to one or more ART patients living in their community.

This study focused on the CHW component of the CBART program. The study aimed at determining whether CHWs effectively handled the drug delivery and patient monitoring activities, what impact they had on patient access to ART, and how the established program functioned over a two year period. The results of this study were used to provide recommendations for other CBART programs and for a scale-up within the Kabarole District. I reviewed the CHW component of the CBART program based on the following research questions:

1. Can a CHW program successfully support community based ART? Specifically:
    a. Can volunteer CHWs effectively perform a range of activities necessary to support ART?

   b. How did the different elements of a volunteer CHW program function to support an ART program?
   c. What CHW characteristics are associated with positive ART outcomes?

2. Based on their experiences with the CBART program, what are the perspectives of:
   a. Patients, clinic staff and CHWs on the benefits to patients of using CHWs to support ART?
   b. CHWs on the challenges they faced in supporting ART and what helped and motivated them?

In section 7.1 I review the unique aspects of this research in relation to similar studies. In section 7.2 I highlight and comment on the main findings of this study as they relate to the two research questions. In section 7.3 I use the findings from this study to provide recommendations for an effective and sustainable model for engaging CHWs to support ART in rural areas of sub-Saharan Africa. Limitations of the study are discussed in section 7.4.

7.1 UNIQUE ASPECTS OF THIS RESEARCH

At the time we implemented the CBART program, I did not find any programs like ours in the published literature. Since the implementation of our program, more CHWs supported programs for ART in sub-Saharan Africa have been reported. Most programs have engaged CHWs primarily for adherence to treatment support and have assessed the impact of CHWs on various outcomes of ART. A study of AIDS patients at five ART sites in Zambia by Torpey et al.[125] found that the use of paid CHWs to monitor adherence to treatment reduced waiting times for adherence counseling and led to a decrease in patient loss to follow-up (from 15% to 0%) over a 12 month period. Chang et al.[126] described the use of paid CHWs to monitor adherence to treatment in an urban ART program in Uganda and found that 86% of patients achieved virologic suppression after two years. Fatti et al.[127] evaluated 57 South African programs and found that patients receiving treatment adherence support from CHWs had a 35% mean reduction in mortality and a 37% mean reduction in patient loss to follow-up over a five year period. Pearson et al.,[128] in a randomized control trial of peer-delivered directly observed therapy (DOT) over a six week period, found higher adherence to treatment in patients with DOT support after 12 months of ART. Arem et al.[129] and Chang et al.[130] looked at the outcomes of a randomized control trial to assess the impact of peer health workers (PHWs) recruited from existing HIV patients in rural Uganda. These PHWs provided adherence to treatment monitoring at clinic sites and periodic home visits over a four year period. This study found no associations between PHW activities and virologic suppression in the first 96 weeks, but found a statistically significant lower risk of virologic failure in patients attended by PHWs after 96 weeks (relative risk (RR) = 0.50, 95% CI = 0.31–0.81) and after 192 weeks (RR = 0.067, 95% CI = 0.0065–0.71). Franke et al.[131] found that CHW treatment adherence support in Rwanda was associated with greater virologic suppression (RR = 1.15, 95% CI = 1.03–1.27) and a reduction in the risk of patient death or patient loss to follow-up (hazard ratio (HR) = 0.17. 95% CI = 0.09–0.35) after one year. None of these studies provided any information regarding the performance of CHWs or their management.

Other programs have used CHWs for a different or smaller range of activities compared to our CBART program. A program in Cameroon provided literate female birth attendants with additional training on prevention of mother to child transmission (PMTCT) of HIV including HIV testing and administration of ARV drugs.[132] The Global Health Workforce Alliance[19] has described three examples of ART programs that engaged CHWs: in Côte d'Ivoire, CHWs provided HIV counselling and started pregnant women on ART; in Mozambique CHWs took blood samples and provided bedside HIV care such as infection prevention; and in Ethiopia CHWs provided HIV related prevention, care, and support services. In Kenya, researchers evaluated a program that paid CHWs to observe patients taking their ARV drugs; however, the researchers assessed only whether patients accepted the CHWs.[133] None of the above programs studied patient outcomes or the effectiveness of CHWs in detail.

I found only one program with a range of CHW activities similar to our CBART program. Zachariah et al.[134] described a program in Malawi that recruited volunteer CHWs to support 895 patients on ART. The CHWs worked with community nurses to identify opportunistic infections, provide support to family carers, refer patients with possible drug reactions and risk signs, provide adherence to treatment counselling, and conduct defaulter tracing, but did not deliver drugs. Each CHW cared for eight to ten patients. The program trained CHWs how to recognize adverse effects of ARV drugs and refer the patients to appropriate facilities and provided care kits of basic drugs and supportive material to CHWs for first-line care administration in patients with minor conditions. Similar to our program, the Malawi program did not pay CHWs but provided incentives such as boots, raincoats, and bicycles, and seeds and fertilizer for their private or community farms. After about one year, there were statistically significant differences in the relative risk of patient death (RR = 0.22, 95% CI = 0.15–0.33) and the relative risk of patients being lost to follow-up (RR = 0.02, 95% CI = 0.0–0.12) for those with community support compared to those without community support.

According to the research studies published to date, only the Malawi study by Zachariah et al.[134] has assessed the use of volunteer CHWs for multiple treatment support activities similar to our CBART study for rural patients on ART, with the exception of the delivery of drugs to patients. Their study assessed important outcomes such as patient mortality and retention of patients on treatment, but did not look at the performance of the CHWs or their perspectives on volunteering. The current study provides new knowledge on: (a) the performance of CHWs in performing range of ART activities; (b) experiences in managing volunteer CHWs in an ART program; and (c) patient, health worker, and CHW perspectives of the impact and contributions of CHWs to patient ART. This study helps to address an important general gap in the literature on optimal models for CHW engagement to support ART for rural populations. This study also addresses specific gaps in the literature: first on the ability of volunteer CHWs to undertake a range of drug delivery, monitoring and advisory activities to support ART (see section 7.2.1), and second on the CHW time requirements and CHW to patient ratios ART programs could expect in this type of rural context (see section 7.2.2.4).

7.2 REVIEW OF THE MAJOR FINDINGS

7.2.1 The performance of CHWs

I first review my findings on CHW success in performing a range of planned drug delivery, treatment monitoring and prevention activities to support ART. These activities included weekly visits to patients during the first six months of the program, support of patient treatment adherence, accurate identification of drug side-effects in patients, and provision of HIV prevention messages to patients.

7.2.1.1 Maintaining scheduled visits

Though most CHWs missed one or more of their expected weekly visits, the overall rate of missed visits was not high, especially considering the significant burden of distance and time they faced in making these visits. According to the volunteer logs, most CHWs missed 20% of all visits they were supposed to have made over the first six months; most missed visits occurred early in the program. Interestingly, the two-year survey revealed a discrepancy between CHWs' perceptions of missed visits and the volunteer logs, with CHWs underestimating the number of missed visits. Many of the missed visits might have been forgotten as time passed and performance improved. Alternatively, CHW inexperience and lack of familiarity with the tasks might have taken a toll on the weekly visits in the first few weeks of the program when there would have been more confusion about expectations and schedules.

Community health workers cited personal issues such as their own illness, other work responsibilities, and a lack of transportation to explain missed visits. One CHW said he missed a visit because he felt the patient was doing fine. Such complacency could become an issue in the long-term for life-long treatment programs such as ART. Although distances to travel to patients were cited as a hardship, only one CHW indicated this as a reason for missing a visit. Since CHWs brought up the transportation burden frequently, it is unlikely that CHWs would have forgotten this issue when thinking about reasons for missed visits. The association found in the data between patients living more than five kilometers from the clinic and having fewer missed visits was unexpected. Possibly CHWs had a heightened sense of duty to patients who faced a hardship in accessing care due to geographical barriers. More research is required to understand this association.

7.2.1.2 Adherence monitoring

While most CHWs felt that it was initially difficult to count pills and complete volunteer logs, they felt these activities were easy to complete after the research team had made changes to the forms and eliminated the calculations. These changes, however, meant that CHWs had to rely on patient self-reports of having missed tablets or the treatment partner logs. However, there were no observable changes in patient adherence to ART after we made these changes. Most CHWs felt that it was easy to provide counselling on treatment adherence, though some found this task to be a bit difficult. Community health workers also mentioned difficulties in counseling patients on adherence to treatment when they faced issues such as patient confusion, misinformation, and substance abuse. These issues required the intervention of the volunteer administrator, and reflected the need for a volunteer administrator to handle the complex drug adherence issues that were experienced in this program.

In an earlier study we found that patient adherence to treatment in the CBART project was high, with most patients maintaining adherence to more than 95% of their pill regimen over a two year period.[94] In the current study I found that 25% of patients had missed at least one tablet in the first six months of the study, but this dropped to 13% in the last six months of the study. In a separate unpublished set of analyses, we found that 85% of patients had ≥ 95% adherence to treatment in the first six months of ART, which dropped very slightly to 83% in the last six months of the study. (Kipp, Walter, personal communication, August 2010) Adherence in the CBART cohort was higher than the average adherence rates of 77% (95% confidence interval = 68% – 85%) observed in non-CHW ART programs in sub-Saharan Africa.[28]

In a systematic review of adherence in sub-Saharan Africa, Mills et al.[135] identified the cost of transport, difficulties in following complex regimens, disease stigma, and alcohol abuse as major factors affecting treatment adherence. In the CBART studies, the CHWs significantly reduced the transport burden on patients and were able to provide weekly advice to educate patients regarding their drug regimen. Alcohol abuse is a significant barrier to adherence. A meta-analysis by Hendershot et al.[136] (which did not include studies from sub-Saharan Africa) found that alcohol users were 50 to 60% less likely to adhere to

ART compared to patients who abstained. Hahn et al.[137] found a similar association of lower adherence to ART of alcohol drinkers in a literature review of the impact of alcohol on HIV in sub-Saharan Africa. In the CBART study, CHW patient visits provided an opportunity for early identification and referral of these challenging cases to health workers or to the volunteer administrator who were then able to help patients understand and manage these issues.

7.2.1.3 Identification of side-effects

Most CHWs said that, based on their training, they had no difficulty in identifying side-effects of ART; all CHWs felt that they had been effective in this task. However, my analyses showed discrepancies between what the CHWs identified and what the clinic identified. In the case of jaundice, there were no records of this side-effect in any of the patient clinic charts, despite CHWs identifying and referring these patients. Given the serious nature of this side-effect, it is possible that the CHWs may have been overly cautious and over-identified this specific condition compared to clinic staff. Their lay training told them to look for yellow eyes which could appear from environmental conditions. Patients and CHWs brought up challenges posed by overcrowded clinics and the burden of transportation; these factors may have created a barrier for patients to act on referrals to the clinic, which would have led to fewer cases presenting to the clinic. Another reason for the discrepancies could be poor record keeping at the clinic. This is not uncommon given the heavy workload faced by health workers in rural health centres, and has been reported elsewhere.[138] Members of our study team have worked in this district for 10 years and have encountered incomplete charts in many clinics in the district.

I was more concerned about side-effects that the clinic had diagnosed and the CHW had missed. It is possible that patients bypassed the CHW and went straight to the clinic. However, given the impact of ARV drug side-effects on patient quality of life and ART adherence,[28,139] programs such as ours will have to pay attention to this issue. Proper training, documentation, and better procedures for tracking patient referrals to the clinic can help. Médecins Sans Frontières (MSF)[30] also identified this issue, and has recommended more education for patients and CHWs to minimize problems of ART side-effects not being identified and referred. Despite these issues, over the two-year period none of our patients experienced a side-effect serious enough to require a change to second-line treatment.

7.2.1.4 HIV prevention activities

We opted to use a simple approach toward HIV prevention in which CHWs would counsel patients on the "ABC" (abstinence, be faithful, condoms) approach to prevention and distribute condoms to them. The clinic staff and volunteer administrator provided additional information on horizontal and vertical HIV transmission when requested by CHWs. As the volunteer meeting minutes show, CHWs had to answer patient questions about HIV prevention, especially questions related to HIV transmission for HIV discordant couples who wanted to have children. While our study did not measure horizontal transmission to a sexual partner, we found that vertical transmission to children born to study participants (n=8) was absent. This might point to the impact of the CHWs in providing useful HIV prevention information to patients.

Most CHWs felt that it was easy to provide HIV prevention messages and distribute condoms. Most thought they knew if their patient was sexually active and using condoms. However, a few CHWs suspected that patients were not listening to their advice and some patients refused to accept condoms. The study findings show that CHWs generally felt they could manage giving HIV prevention advice, and when they couldn't they sought help from the volunteer administrator.

Studies have shown that transmission of HIV is extremely low when patients have good drug adherence and are able to maintain virologic suppression.[140,141] As most of our CBART patients achieved and maintained virologic suppression, prevention of HIV transmission was a lesser issue for this group. However, not all patients achieved virologic suppression, so programs should be careful about neglecting this aspect of ART support.

7.2.1.5 Summary of CHW performance

I believe the study findings show that CHWs can maintain regular visits to patients and can play an important role in helping patients achieve high rates of treatment adherence in rural areas. This study found that drug adherence, measured as the proportion of patients missing at least one tablet in-between visits (per week), improved over time, though I was not able to assess whether this was due to better patient experience with ARVs, better CHW experience with treatment adherence related activities, or a combination of the two. CHWs were able to counsel patients on HIV prevention and provide condoms, though some faced difficulties with these activities. In their focus group discussions, CHWs talked of the complexity of the tasks they were expected to perform and suggested that these were tasks that “doctors” would perform. This can explain why it took time for them to become accustomed to these tasks, and might throw light on the missed visits recorded in the early days of the program. Interestingly, some CHWs did not seem to perform well in identifying side-effects of the treatment, despite their confidence in being able to undertake this activity. I believe more research is required to better understand what their challenges were and what programs can do to overcome these challenges, including additional training.

7.2.2 Experiences in managing volunteer CHWs

We put a set of program structures and processes in place to manage the work of the CHWs. Groups such as the Earth Institute[47] and researchers such as Hermann et al.[142] emphasize that appropriate program structures and processes can help to avoid the past failures of CHW programs. Past failures include poor selection, recruitment, and training of CHWs, insufficient technical and financial support, and lax or unorganised supervision. Campbell et al.[143] suggested that HIV and AIDS programs have not achieved desired outcomes because of ineffective community mobilization. Baker et al.[144] state that establishing the training and selection of CHWs, clinic referral policies, and other support systems necessary for the long-term success and sustainability of CHW programs is vital to avoid fragmentation, duplication, inefficiency, and confusion.

In this section I discuss how the volunteer model functioned in the areas of CHW recruitment, training, management, and motivation. I also discuss the CHW workload from the perspective of the number of patients CHWs felt they could reasonably manage and the time that it took them to complete their activities.

7.2.2.1 Recruitment and selection of CHWs

Our CHW selection criteria specified mature individuals, trusted in the community, who were literate in English. Thus, our recruitment and selection approach identified CHWs who were older, better educated, and more likely to be married than the general population of Rwimi. Almost all of the CHWs had volunteered in health programs in the past; this may have been a result of asking health workers to identify potential CHWs. Health workers may have intentionally looked for volunteers they had worked with in the past either to find the best volunteers or because it was the most convenient approach. It may be more difficult to introduce our CBART model in areas that do not have a pool of volunteers with previous experience in health. The selection of experienced

CHWs might have had an influence on our study findings as experienced CHWs could be more motivated to volunteer for and might be more competent in performing the activities required by the program.

This study looked at CHW characteristics that were associated with positive treatment outcomes, namely, virologic suppression and survival, in order to help guide the selection criteria for other ART programs. My analyses found that the time to travel to the patient was the only statistically significant CHW factor associated with the achievement of virologic suppression and survival. Patients with CHWs who had to travel longer to reach them fared worse than patients with CHWs with shorter travel times. The higher odds of a negative outcome for these patients was not because their CHW missed more visits as the multivariate model adjusted for this confounder. I also did not find any statistically significant differences in the time the two groups of CHWs (long travel and short travel) spent with the patient, so this also did not explain the differences in outcomes. One possible explanation for this association may be that CHWs who have to travel longer are tired or frustrated when they reach the patient and less effective in guiding and counselling them. The other explanation is that CHWs who live closer to their patient might see them more frequently outside of scheduled visits or casually check up on them to find out how they were doing and at the same time reinforce treatment adherence messages. This is an area for more research. The fact that there were no statistically significant associations between characteristics such as the CHW’s age, gender, or education suggests that selection criteria pertaining to these variables might be relaxed if other factors such as training, close proximity to patients, good program management, and supervision are maintained. However, readers should interpret the finding on education with caution; there were no CHWs in the study without formal education which prevented me from looking at associations between CHWs having no formal education and treatment outcomes.

Our CBART recruitment approach resulted in a CHW ratio of two males to one female. A health worker (Kisembo, Sylvester, personal communication, November 2010) and the Rwimi Town Council Chairman (Ngomayondi, Abel, personal communication, November 2010) explained that the caregiving role women assumed in this region was time consuming, leaving men more time than women to volunteer. My analyses showed no statistically significant difference in treatment outcomes between patients assigned to male or female CHWs. In the patient interviews and CHW FGDs, I explored perceptions of issues related to CHW gender. Neither patients nor CHWs identified any barriers in dealing with a patient or CHW of the opposite gender. Tarimo et al.[145] found that care provided by women in Tanzania created economic hardships for women and that CHW programs need to consider this gender related barrier, especially given the tendency for CHW recruitment programs to target women. Female CBART CHWs mentioned experiencing family tensions as a result of having less time to complete their household chores but stated that these tensions were not significant barriers to volunteering and were resolved over time. Our findings contrast with those of Olang'o et al.[146] who studied a CHW program in Kenya where female CHWs were encouraged to leave the program by their partners who saw their work as a "waste of time" in terms of contributing to the family's livelihood.

7.2.2.3 Training

My evaluation of training showed that the training session led to gains in CHW knowledge, although, some CHWs did not fare well in the posttraining tests. However, the reader should interpret some of these findings with caution. More specifically, after administration of the knowledge tests, I discovered that individuals in rural areas were not all familiar with the acronym “ABC” for HIV prevention, even though they knew about the prevention behaviours referred to in the acronym. By focusing attention on the acronym, we may have created some confusion among CHWs. Overall, 90% of CHWs felt that their initial and ongoing training provided them with the skills they needed to effectively complete their tasks. Though the initial training was at a basic level, it endeavored to cover the essential clinical information the CHWs needed to understand HIV, AIDS, and ART. A CHW program for ivermectin distribution in Ghana also found that a short training was adequate to allow CHWs to undertake their treatment related activities.[147] Some CHWs were recruited later and received one-on-one training and orientation instead of the formal two day training. None of these CHWs felt that their training was inadequate, and appreciated and felt they benefited from continuous training at their volunteer meetings. Community health workers made no mention of the information handouts prepared for them.

The WHO has identified the continuous education of CHWs to be an essential element of successful programs, but state that this rarely happens.[148] A study by Ayele et al.[149] in Ethiopia found that CHWs who received refresher training courses were more effective compared to those that did not. Some authors have found that refresher training can also serve to motivate CHWs, especially those with lower education who may face stress and burnout in trying to accomplish their tasks.[69,70] In our CBART program, clinic staff and the volunteer administrator provided ongoing training. These trainings were usually responses to questions from volunteers about topics such as HIV testing, family planning, managing pregnancies, non-HIV diseases, as well as program administration. The posttraining sessions helped to answer a number of questions that the study team had not considered during the development of the original training curriculum. One topic that deserves more attention in initial and continuous training is the identification of side-effects of ART. Within our program, additional training, including clinical demonstrations in which trainees were able to observe side-effects in individual patients, probably would have enhanced their ability to identify side effects.

7.2.2.4 Workload

Most CHWs stated that they either correctly estimated or overestimated the time that it would take them to complete their ART activities. Most CHWs said that they spent one to three hours a week on their activities, though a few said they spent more than 10 hours a week. The volunteer logs showed CHWs spent most of this time travelling to patients' homes. The decrease in time spent with patients over the course of the two-year program shows that CHWs had to invest more time at the beginning of the program. Community health workers talked about the early challenges of becoming familiar with tasks and making mistakes, and said that over time they became more comfortable with their activities and completed them more quickly. Program changes such as simplifying the volunteer logs and the introduction of pill boxes might have reduced the time CHWs had to spend with patients later on in the CBART program. The overestimation by some CHWs of the time they thought it would take to complete their tasks could have been due to past experiences in previous government programs. In the FGDs, CHWs mentioned that government programs are less organized than CBART and poorly coordinated, leading to postponed or delayed meetings and more expense of CHW time.

Community health workers looked after an average of four patients each, though some had only one whereas others had eight. The volunteer administrator assigned patients to CHWs based on geographical proximity, and, more importantly, on the CHW's perception of the number of patients he or she could handle. CHWs with more than three patients shared a sense of having too many patients, not a surprising finding given that the average patient visit took 108 minutes (which is an underestimate as it does not include travel time back from the patient’s home). Our program change to reduce the frequency of patient visits to biweekly and then monthly (for patients doing well on ART) reduced the number of visits, alleviating this CHW burden considerably. Over time, CHWs found that they had to spend less time with the patient because of improved patient health but also improved familiarity with their tasks. I discuss CHW issues of travel distance to patients, locating patients, and stigma experienced in more detail in section 7.2.4.

7.2.2.5 Management and supervision of CHWs

The volunteer meetings at the clinic and the volunteer administrator were two valuable points of support for CHWs. Community health workers felt that the monthly volunteer meetings were beneficial and necessary and placed a high value on them. These meetings provided a forum for continuous education and for the identification and resolution of issues. The high attendance by CHWs at volunteer meetings, despite the distances CHWs had to travel to attend these meetings, attests to the significant of these meetings for CHWs. Aggregate statistics on the clinical improvement of patients were shared with CHWs at the volunteer meetings; CHWs saw this as additional motivation to continue working with the program. Similar results were obtained in a program in Ethiopia where CHWs were motivated to attend monthly volunteer meetings because of the opportunity to review their accomplishments.[150] The main reasons given in the CBART program for missing monthly volunteer meetings were similar to reasons for missing patient visits, namely, personal illness and work related issues. Two CHWs missed meetings because they were not properly informed of the meeting date, which points to a need for better program management. None of the CHWs complained about the meetings or felt that the meetings were not useful.

The volunteer administrator hired by the CBART program was a clinical officer with experience in managing volunteers in health programs. He acted as a trainer and adviser of CHWs and as a mediator among CHWs, patients, and health workers. Community health workers found the role of the volunteer administrator to be crucial. The volunteer administrator brought legitimacy to the CHWs due to his own legitimacy as a health worker. There were no negative comments made by the CHWs about the volunteer administrator or his support in the surveys or in the FGDs. Close consistent supervision by experienced personnel, especially a health worker, has been identified by van der Walt et al[151] as an important factor in the success of CHW programs. However, the same authors cautions against reliance on one individual which can lead to the collapse of a program should the individual leave.

Community health workers identified the annual volunteer recognition programs and the resources provided by the CBART program as being important for their mental and physical wellbeing, respectively. The volunteer recognition program provided an opportunity for the community to recognize the CHWs and helped families, particularly spouses, to understand the contributions CHWs were making in the community. Community and CHW spouse perceptions of CHWs improved as a result of the volunteer recognition program. Community health workers similarly appreciated the supplies and incentives provided by the CBART program that eased the burden of the work. I discuss the impact of the annual recognition program and incentives on CHWs in more detail in section 7.2.2.6.

7.2.2.6 Motivation and retention of CHWs

A motivated CHW will work harder and better and will stay with the program.[42] In this program, the volunteer CHW attrition rate was 2.4% over a two year period. According to a review of multiple CHW programs by Bhattacharyya et al.[42] attrition rates can be as low as 3.2% and as high as 77%, with higher attrition rates for volunteers compared to nonvolunteers.[42] A study in Kenya found an attrition rate of 33% for volunteer CHWs in an HIV program, with most attrition attributed to the eventual need for salaried employment by the CHWs.[146] Marincowitz et al.[152] found an attrition rate of 27% among volunteers after one year in a home based HIV care project in South Africa. The CBART program attrition rate was much lower than rates reported in other volunteer programs, indicating that our CHWs continued to be highly motivated for two years.

Community health workers identified many factors that contributed to their motivation, but the importance of appreciation and respect by others was particularly highlighted. The appreciation of the community, patients, and even their families were the most important factors in CHW motivation. Other important motivators were service to the community, which was based on personal beliefs or religious faith; the knowledge acquired that could help them in the future; and, to a lesser extent, the incentives the program provided. These findings are in line with Horton-Smith's theory that volunteers are motivated by both altruistic motives and egoistic motives,[81] and agree with Esmond's[81] finding that the top three motivational factors are "values," "reciprocity," and "recognition."

Altruistic motivations have been reported in other CHW programs in sub-Saharan Africa.[27, 32, 34, 36-42] South African volunteers[153] were highly motivated by the appreciation of their services by the community. In Ghana,[154] material rewards were not the primary factor motivating volunteer CHWs in a Guinea worm eradication program, but rather the decline in cases and an improvement in their social status. Volunteer CHWs in Ghana[147] were motivated to become ivermectin distributors by a desire to help others. Two-thirds of volunteer CHWs in a family planning program in Egypt[155] said their main motivation to work was that they like to serve people. CHWs in a nursery feeding program in Malawi[156] were motivated by a moral obligation guided by their religious convictions, but also expressed reciprocity as a reason for volunteering with the hope that they or their families would be helped in the future. Volunteers caring for chronically ill patients in Malawi[157] expressed their desire to help others in greater need as the reason they volunteered; their work was based on feelings of empathy and altruism and on religious convictions. CHWs in Ethiopia[150] took on the volunteer role to learn how to keep themselves and their family healthy. Some studies have found that CHWs volunteer to gain future employment in the health sector[153,157]; however, none of our CBART CHWs mentioned this as a reason for volunteering.

In the CBART study, the program supported CHW motivation through public recognition, material incentives, and recognition of CHW activities in relation to patient outcomes. The low attrition, the efforts CHWs made to not miss patient visits, and the CHWs' provision of their own material resources to their work and to patients show a high level of motivation among the CHWs in the CBART program. This program was established in a low resource environment, thus, the study team was unsure whether we could retain CHWs and motivate them without material incentives. In this study, CHWs stated their appreciation of incentives provided by the study in recognition of their work; however CHWs said that while the lack of incentives would have been a demotivator, it would not necessarily have stopped their work. Despite the fact that CHWs may continue working without material incentives, programs should be careful about removing these incentives from programs. Over time, non-material incentives may lose their impact, especially in cases of chronic diseases like AIDS where treatment provides a dramatic visible effect on patient health in the short-term, but where the long-term effects of treatment are invisible. Incentives do not have to be large or expensive. Flaherty et al.[85] suggested that something as small as a bar or soap or a lunch can indicate appreciation for a CHW's efforts and act to motivate him or her.

Flaherty et al.[85] emphasized that appreciation needs to be sincere and that sincerity can be reflected in actions such as listening to CHW concerns, taking CHWs' opinions seriously, and following up on promised actions. In this program, our research team provided opportunities for the CHWs to express their issues and concerns and made two significant changes based on their concerns; the requirement for CHWs to make adherence calculations was dropped and the frequency of CHW visits to patients was reduced.

7.2.3 Impact and contributions of CHWs to patient ART

We established the CHW component of the CBART program to provide patients greater access to ART and to improve patient ART outcomes. In this section, I review the impact the CHWs had on patient treatment and treatment outcomes. I begin with an exploration of the clinical outcomes of the CBART pilot study. I then review health worker, CHW, and patient perceptions of the role CHWs played in the achievement of patient ART outcomes.

7.2.3.1 Overall treatment outcomes

Studies on the treatment outcomes of CBART patients[89,91-94,124] showed that a large proportion of patients achieved virologic suppression over a two year period, resulting in good survival and improved health related quality of life. We found that 68% of CBART patients achieved virologic suppression after two years, a result that surpassed the 57% of patients who achieved virologic suppression after two years in a home based care program located in an urban area of Uganda.[126] Other ART programs in Uganda have shown higher virologic suppression rates of 75%[158] and 76%,[159] but these were more resource intensive programs that used higher cadres of health workers and were either located in hospitals[158] or had better transport access to patients.[159] Our findings are also better than those reported in a meta-analysis of 25 studies in low income countries, which estimated that 57.3% of patients achieved virologic suppression after one year.[4] The positive outcomes seen in the CBART study are not surprising given that other studies[31,127,131,160-162] have found that ART programs that use CHWs have higher patient treatment adherence and improved outcomes.[31,127,131,160-162] Mortality in the CBART cohort, 17% after two years, was similar to the 18% mortality finding of Chang et al.[126] in a CHW supported urban based program. We observed an improvement in the health related quality of life of CBART patients after one year of ART; this brought their quality of life indicators to a level similarly observed in non-HIV individuals in Uganda.[124] However, not all ART programs have seen benefits in using CHWs. A study in Zaire found that living in a village with CHW support was not associated with improved treatment outcomes.[163] However, the authors of that study felt that this may have been due to the benefits of extra efforts by the clinic to prepare patients for treatment and ongoing clinic based adherence counselling during ART that limited the impact of the CHWs.[163] In a randomized control trial, Chang et al.[130] found that the use of peer health workers (PHWs) in Rakai, Uganda, was not associated with high treatment adherence or short-term (<96 week) virologic suppression in patients, though patients with PHWs had a statistically significant lower risk of virologic failure after 96 weeks. Arem et al.[129] evaluated the Rakai program and noted that the lack of association with low virologic failure in the early period might have been a result of contamination between the PHW and non-PHW trial arms.

Patient retention is another measure of treatment success. Patient retention in the CBART study was 70% after two years,[93] higher than the weighted mean retention of patients at 24 months of 62% in a systematic review of non-CHW ART programs in sub-Saharan Africa.[31] Other CHW based ART programs have also seen high rates of patient retention. Patient retention was 85% after one year in studies in Zambia[125] and Rwanda[131]; both results were higher than the 75%

retention in our CBART program over the same one year period. Early initiation of treatment in Rwanda, based on a CD4+ threshold of ≤ 350 cells/µL versus our threshold of ≤ 200 cells/µL, might have contributed to the higher rates of retention. Overall, our study findings and the findings of other programs show that programs that make use of CHWs have high levels of patient retention.

7.2.3.2 Benefits and impact of the CHWs on the CBART program

The CHW program was one of three components of the CBART program. Therefore, it is difficult to determine the selective impact the CHW program had on the clinical outcomes described above. I solicited the perspectives of patients, health workers, and CHWs to find out what they believed CHWs contributed toward patient treatment.

Patients and health workers felt that CHWs played an important role in the CBART program and that the program's activities would not have been possible without their involvement. Their primary value was in helping patients avoid the burdens of transport to and waiting at the clinics. Other studies have identified transport issues and long waiting times at clinics due to health worker workload as important barriers for patients to start and stay on ART.[22,139,164] Interestingly, out of the three groups (CHWs, health workers, patients), CHWs made the broadest claims about the value they provided to patients and the program. The CHWs believed that without the CBART program, mortality would have been higher, especially among the poorest patients. Their perceived value of their role may reflect a strong belief in the program that was reinforced by seeing people who they expected to die (usually the most financially disadvantaged) being revived. A five country study in southern Africa found similar beliefs in the population that the benefits of voluntary service should accrue to the most disadvantaged.[83] CHWs saw their role in ART differently from clinic staff. Clinic staff saw them as a lower level complementary resource while CHWs saw themselves as similar to the clinic staff. This may be due to different perceptions of the activities themselves; trained health workers who have a lot of complex tasks may see the drug distribution, monitoring, and referral tasks as more mundane whereas the CHWs, as laypersons, may see the added responsibility as being quite significant. Some commented that they felt they were doing the work of "doctors." Stekelenberg et al.[72] found similar CHW perceptions in Zambia—they felt like they were doctors. An inherent danger in this perception is that CHWs may overreach their scope of practice if they believe they have skills similar to those of trained health workers.

Health workers appreciated the role that CHWs played in strengthening the links between themselves and patients. They saw the CHWs as an additional benefit to patients and themselves. Schneider et al.[165] found that health workers in South Africa had similar perceptions of CHWs whom they felt acted as mediators between the clinical facility and the community. Clinic staff in Rwimi did not bring up any concerns about CHWs working on sensitive and complex tasks related to ART. In contrast, health workers in a South African program felt that it was not appropriate to delegate sensitive tasks such as HIV counselling to untrained and inexperienced CHWs who might not remain in the program long.[165] In our program, the good relationships between CHWs and health workers may have mitigated resentments or concerns about CHWs undertaking complex tasks.

Patients expressed positive perceptions of the impact that CHWs had on their treatment. Patients saw value in the range of monitoring activities, but believed the delivery of drugs to be the most important activity of CHWs. It is likely that at the time of their interviews, patients had become used to treatment and may have felt that they could manage the other aspects of ART on their own. Drug delivery would have remained a priority as it still required investments of money for transportation and time to wait at a clinic. While this finding points to opportunities to reduce the workload of CHWs as patients gain experience, it also shows that there is a sense of ongoing dependency on CHWs by patients for at least one significant aspect of ART.

Patients also said they saw value in the broader role that CHWs played in their care, care that went beyond what they felt they would have been received at a clinic. Patients described and acknowledged the value of advice and personal consolation they received from CHWs. Some of this advice went beyond clinical topics to more personal and psychological support. The patients felt that CHWs were caring and knowledgeable and felt very comfortable discussing a range of personal issues with them. Patients also noted being satisfied with the length of time CHWs spent with them. In some instances, CHWs provided personal resources to help their patients. The opportunity costs of providing someone else with resources in this region are high, so this is a strong statement of CHW commitment. These descriptions illustrate the lengths CHWs went to in order to provide the support they felt their patients needed; these efforts were especially admirable considering how complex patient needs might be in a chronic, stigmatizing disease like AIDS. Torpey et al.[125] also observed similar emotional and psychosocial support by CHWs providing clinic-based adherence support in Zambia. Health workers in that study discussed how CHWs could forge closer relationships with patients than they could. However, the extra support provided could raise patient expectations risking future overburdening of CHWs. Olang'o et al.[146] found that patient expectations of support such as food, soap, and medicine made it difficult for CHWs in a home based HIV and AIDS program in Kenya to visit patients, with the result being higher attrition of these CHWs.

7.2.4 Challenges faced by CHWs

In FGDs, CHWs brought up a number of challenges they faced in undertaking their work. The distances they had to travel came across as a major challenge. With a reported median time of one-way travel to patients' homes of 81.4 minutes, the CHWs faced a significant travel burden. This travel burden is not unusual for the mountainous and muddy terrain in the Rwimi subcounty. Other CHW programs have documented this challenge of distances and transportation.[160,166-168] While the bicycles our program provided may have alleviated some of that burden, it did not seem to be enough to offset the frustrations that some expressed about long travel times. Community health workers also brought up the added frustration of having to travel to patients' homes only to find they were not there. Though the CHWs implemented their recommendation to make appointments, aided by the study team's provision of diaries, there was no mention made in the focus groups of whether this helped. Despite the time to travel and the repeat visits to patients, slightly more than half of the CHWs reported their activities taking only one to three hours per week. Given the longer times recorded in their logs, their perceived time seems to have been greatly underestimated. It is possible that CHWs were referring to the actual time spent with the patient rather than the travel time when they provided these estimates.

Another challenge brought up by CHWs was dealing with patients they saw as uncooperative. These were patients who they believed had incorrect information or ideas about treatment or who drank too much alcohol, and who, as a result, stopped taking their drugs or delayed seeking care when referred to the clinic. The CHWs perceived this to be a sign of patient ignorance and noncooperation. Takasugi et al.[167] found that CHWs in Kenya who encountered low community knowledge had similar perceptions of patients being uncooperative and ignorant. CHWs believed some patients were uncooperative because of misinformation obtained from other sources, and felt frustrated that their patients didn't follow their advice and stopped taking their drugs or delayed seeking care when referred to the clinic. Amere[150] found that volunteer CHWs in Ethiopia also experienced frustrations because the community did not accept their information. This suggests that there is a need for programs to educate patients about treatment and to provide them with continuous education to dispel myths and misinformation that comes from outside sources. Community health workers also brought up examples of misunderstandings about material resources available to patients. The practices of other programs that provide material resources to patients and our own study's practice of giving small incentives to patients for participating in data collection, created patient expectations of receiving or continuing to receive material resources. Community health workers described how these expectations led to accusations that they were hiding these resources from patients.

Community health workers and clinic staff noted being challenged by poor coordination between the two groups early in the program. The initial negative perceptions each group had toward the other during this period underscores the need for better coordination and communication between CHWs and health workers right from the start. Haines et al.[43] have called for strong links between CHWs and health clinics to create better dialogue and coordination between the two and avoid conflicts. The strategies put in place by our program, such as scheduled drug collection days, seem to have resolved this issue as the CHWs and clinic staff stated that there was subsequent good cooperation and relations between the two groups. The issues among CHWs and health workers raised in the CBART project were not as significant as conflicts experienced in other CHW and CBD programs in western Uganda. (Kipp, Walter, personal communication, Jan 2013)

Patient stigma made it difficult for CHWs to carry out their tasks. The lack of disclosure by patients to family and neighbours, though not surprising given the stigma associated with HIV,[33] created delays and additional workloads for CHWs early in the program. Kaler et al.[169] also reported the early discomfort CBART patients had in disclosing their HIV status. Motswasele et al.[170] found that stigma toward individuals with HIV made the work of home based volunteers more difficult as patients did not open up to the volunteers or delayed seeking care. Interestingly, CHWs said they had felt stigmatized themselves through their association with the CBART program, especially in relation to the initial negative impression some had about ARV drugs. Because stigma related to HIV is difficult to overcome, Dlamini et al.[171] recommends increased sensitization and education of the community as a way to help CHWs working in ART programs and to improve patient outcomes. Experiences in Kenya have shown that focusing sensitization and education on community leaders and CHWs can be effective in reducing the stigma around HIV.[172] Community health workers stated that over time patients felt less stigmatized and this eased their work. A study on the treatment partners of CBART patients by Kaler et al.[169] found low levels of stigma in this population after one year of patient treatment, though there was no baseline assessment to compare the one-year results with initial stigma levels. Other studies have shown that patients on ART supported by CHWs feel less stigmatized over time. Roura et al.[173] reported that patients on ART in Tanzania became more comfortable with their HIV status over time; this was attributed both to improvements in physical health and to the emotional support received from health service providers. Castro et al.[174] noted a similar reduction in stigma among Haitian ART patients supported by CHWs.

An important issue associated with stigma is disclosure of a patient’s HIV status. Médecins Sans Frontières[30] identified the need to disclose HIV status to the community as one of the disadvantages of community support for ART programs. However, it is difficult for patients to receive social support and timely access to drugs without disclosing their HIV status. Disclosing their status to a trusted source who can assist them could also be seen as a way to help patients protect their confidentiality if, as a result, patients no longer have to disclose their status to other community members to get help from them. For CHWs to work effectively with HIV patients, they have to be trusted to keep the information confidential.[175] Our research team discussed the importance of confidentiality with CHWs during their training and orientation session. We also selected mature and respected individuals from the community whom patients would find trustworthy and who would be able to keep matters confidential. The challenge for our program and for other community based programs was finding ways to avoid disclosure when it was necessary for a CHW to associate with a patient during their visits. In this context, the risk of disclosure may be unavoidable. A similar situation of unavoidable disclosure occurs regularly in Uganda when patients seek HIV care and treatment in clinics that don't have the resources to create an environment of privacy.

Last, there were challenges brought on by misperceptions, especially among the wider community, about the CHWs. Early in the program, CHWs confronted negative perceptions about themselves from community members. Some community members thought that CHWs were hiding the salaries or other financial incentives they were receiving or that they were being idle. Attempts at the beginning of the study to protect patient confidentiality by maintaining a low profile of the program and the CHWs might have contributed to community misperceptions. In this region, other programs typically provide incentives that prominently feature the logo or brand of the program or supporter. Community experiences with relatively generous remuneration or incentive packages provided by other NGOs in the area might have led to the perception that CHWs were hiding payment or financial incentives or profiting from the suffering of

AIDS patients. Ridicule of CHWs, including perceptions that these individuals were being idle or unproductive or secretly accruing money, have been reported in other programs in Uganda.[85] Such perceptions have the potential to demotivate CHWs. A study by Amare[150] in Ethiopia found that volunteer CHWs were demotivated by community perceptions that they were being remunerated for their work and thus primarily motivated by self-interest. In South Africa, Akintola[176] reported that a lack of community appreciation and a hostility to volunteers can be a big source of stress for volunteers. In the CBART study, this negative perception seems to have lessened or been eliminated over time through initiatives such as the volunteer recognition programs that stimulated public recognition of the contributions CHWs were making to the community.

Our program and the clinic staff used the term “volunteer” rather than community health worker to refer to the CHWs, starting from the time that patients were introduced to their “volunteer.” Thus it was unexpected when patients mentioned being surprised that their CHWs were not paid. There might be a different perception of volunteerism or what it means to be a volunteer in the Ugandan context, which needs further study.

7.2.5 Dealing with challenges

Community health workers said that, with time, they gained more experience with ART, as did their patients. This then alleviated some of the issues they faced earlier. This is not unusual given the CHWs’ feelings of the novelty and complexity of these tasks. The program management structures and processes seemed also to play a big role in helping the CHWs to complete their tasks. There was a sense that the ongoing training received by the CHWs was helpful and appreciated as were the monthly meetings when there was an opportunity to share issues from the field and find solutions as a group. Abdullatif[177] suggested that having communities appraise real life situations and identify methods to develop the confidence to tackle problems could improve the sustainability of community based programs. The volunteer administrator was integral in helping CHWs manage their difficulties. This individual was respected and regarded as an important support in answering questions, dealing with difficult issues, and building the legitimacy of the CHWs in the eyes of patients.

Ultimately, positive experiences with CHWs and confirmation of their legitimacy helped to build trust of the CHWs among patients. Hall et al.[178] defined trust, in a medical context, as "the optimistic acceptance of a vulnerable situation in which the truster believes the trustee will care for the truster's interests." CHWs spoke of the importance in gaining the trust of patients and how this eased their work. Trust was also a factor in community perceptions; early negative community perceptions arose due to mistrust of CHWs, and the situation ultimately improved when trust built up through more accurate knowledge of the CHW program and CHW activities. Patients also talked about the importance of being able to trust and confide in their assigned CHWs. Other than to confirm that it takes time for trust between patients and CHWs to develop[179] not much has been written about patient-CHW trust in the literature. However, there are examples in the medical and nursing field in high income countries that relate to the experiences with the CBART program. In their reviews of the literature on patient-provider trust, Hupcey et al.[180] found many studies had also identified the need for time for nurse-patient trust to develop. They identified that prior to making the decision to trust, the patient must have a need "that cannot be met without the assistance of another individual," and that the patient faces the risk of putting himself in a vulnerable situation. In the CBART study, the patients' need for access to ART and the associated support might have made them amenable to placing trust in their CHWs, despite the risk of disclosing their HIV status. Hupcey et al.[180] suggest that trust is usually associated with respect and positive interactions and experiences, so the choice of our research team to select CHWs with traits associated with community respect as well as the kindness and compassion of CHWs experienced by patients probably played a big role in helping to build trust. Two negative cases reflected the importance of positive experiences in building trust. In one patient interview the patient expressed that the CHW did not provide the support and services he needed. The patient felt that the CHW was interested only in his own needs. The second came to light in the health worker FGD when one of the clinic staff mentioned that a patient believed his CHW was talking about him in public.

A patient’s trust or lack thereof in a CHW can be a function of his or her trust in the CBART program. Building trust between patients and the health care system can lead to improved health seeking behaviours and an increase in the utilization of health services.[181] The CHWs’ trust in the program is equally important. Within our study, we gave selected patients a small nonfinancial compensation for their time or reimbursement for transport to participate in interviews and focus groups. It came to our attention that this was a matter of displeasure among patients who did not receive this compensation. The volunteer administrator had to explain the study-related payments to both patients and CHWs and CHWs had to further explain this to their patients to regain the patients’ trust. Our concern was that a loss of trust could demotivate CHWs in the same way that past government programs had done. In Kenya,[146] CHW’s mistrust in the use of funds and nepotism in the selection of those who received incentives led to demotivation and attrition. CHWs in Tanzania expressed mistrust of district workers whom they believed were using funds and resources, such as bicycles, that were meant for the CHWs. [182]

7.3 RECOMMENDATIONS FOR A VOLUNTEER CHW MODEL FOR ART

These findings suggest that the CHW model developed for the CBART program can effectively support ART in a rural area of Uganda and can be sustained over a two year period, at least, given certain supports and resources. This study showed that the right incentives can help to motivate CHWs to work on a voluntary basis and that public recognition of volunteer CHWs can engender community support of the program.

Based on our experience with the CBART program and suggestions in the literature, I recommend the following program components for ART programs in sub-Saharan Africa that intend to engage volunteer CHWs.

7.3.1 Recommendations for recruitment and selection

Community health worker selection criteria ensure that potential candidates have characteristics that will enable them to undertake the tasks they will encounter in an ART program. In the CBART study, the CHWs' age, gender, and marital status were not associated with successful ART outcomes. Similarly, there were no associations between higher education and treatment outcomes, so CHWs with basic primary school education could be expected to function well in an ART program. Literacy was important for the documentation of CHW activities, so minimum literacy criteria are important. For the CBART study, CHW competency in English was a prerequisite for ease of data collection for research purposes. However, a locally managed program without a need for data in English could consider engaging CHWs who were literate in the local language only. The literacy threshold could be further lowered by enabling reporting through diagrams or by assigning scribes to help CHWs document their activities.[69]

Since CHW demographic characteristics were not associated with ART outcomes, I believe programs have room for flexibility in demographic selection criteria. Schenider et al.[165] point out that an important, sometimes forgotten, criterion in community participation is inclusiveness and representation of underrepresented groups. Demographic flexibility could be used to incorporate underrepresented segments of the community as CHWs to strengthen community engagement.

In the CBART study, trust and confidentiality were important for patient acceptance of CHWs. The perception, mentioned by CHWs in their FGDs, that women were more trustworthy and better able to keep secrets, suggests female CHWs should be preferred in areas of high HIV stigma where confidentiality is needed to protect the patient. Travel distance to the patient was an important factor in treatment success outcomes, thus, an optimal travel distance to the supervised patient would be no more than one hour.

One of the shortcomings in our CBART program was a low level of community engagement in the selection of CHWs. Some groups have recommended that CHWs be selected by members of the community to capitalize on CHW familiarity with the community and to increase CHW accountability to the community.[80,148] Had the community been more involved in the earlier stages of the program, there might have been fewer misunderstandings about the role and remuneration of CHWs. Health workers should not be excluded from the CHW selection process as they need to approve of the CHWs to ensure good coordination and communication between the groups. I recommend that health workers and community leaders work together to discuss, establish, and document the selection criteria. The concept of volunteerism and voluntary service may be new to some, so orientation of community members to these concepts could help them to select appropriate CHWs.

Finally, while the turnover of CHWs in this program was low, it was not possible to know how long CHWs would continue to volunteer their services. Other studies have found high attrition rates among volunteer CHWs.[42,146] The need for life-long support for patients requires the introduction of strategies to replace CHWs that choose to leave the program. One of the opportunities not explored in the CBART study (as the need did not arise) was the engagement of patients as CHWs; this was done in Rakai, Uganda with some success.[129,130]

7.3.2 Recommendations for key ART activities

Van der Walt et al.[151] and Phillips et al.[183] emphasized the need for CHW programs to have tasks and expectations commensurate with the skills and capacity of the individuals employed. These tasks should also not create a burden on CHWs. Within the CBART study, patients felt that the most important service that the CHWs provided was the delivery of drugs. The costs of transportation and time for rural patients will continue be a significant barrier to patient access and adherence to ART. Therefore, I recommend that the delivery of drugs is essential to ensure good treatment adherence. Because an important purpose of CHW support is to reduce the patient load and burden on busy rural primary health care clinics, I recommend that programs continue to consider ART monitoring as an important activity for CHWs. This especially pertains to treatment adherence monitoring, which the CHWs were able to manage well. Given that discrepancies in the data prevented a good assessment of how well CHWs could identify side-effects, I recommend further investigation of this activity. Improved tracking of patient referrals to the clinic would eliminate the discrepancy between CHW logs and clinic records experienced in the CBART program and better training for CHWs would improve their ability to identify side-effects. Visual demonstrations for CHWs of the physical manifestations of side-effects would be a constructive addition to the program. The push by advocates to use ART to prevent HIV infection as a global strategy has put more emphasis on early ART initiation and ongoing maintenance of ART to prevent horizontal and vertical transmissions of HIV.[184] However, Shelton[185] believes that maintaining strong treatment adherence in the real-life contexts of sub-Saharan Africa is a challenge, and he and others[141,186] recommend the inclusion of complementary prevention activities alongside ART. I recommend that activities to promote behaviour change and the use of condoms continue to be part of the repertoire of CHW activities.

Based on the study findings, weekly visits would be appropriate in the earlier stages of ART as patients begin to familiarize themselves with the treatment regimen. The frequency of visits can be lowered to biweekly and then to monthly visits when patients are able to manage certain aspects of ART without the help of CHWs. As patients get more experienced with ART, they may have less need for frequent monitoring of adherence and side-effects. As drug distribution was a challenge in the CBART program, more distribution zones should be created (e.g., at lower level Health Centre IIs as suggested by CHWs in the focus groups) where CHWs could pick up drugs for the patients. This would reduce the time CHWs spent in travelling to the clinics to get drug refills for their patients.

7.3.3 Recommendations for training CHWs

I believe a short intensive training program on technical and practical knowledge delivered through lectures and role playing can provide the necessary background and orientation for CHWs, if combined with ongoing training. Regular CHW meetings can provide a good forum for continuous training. The identification of topics and short training sessions should be a part of all CHW meetings.

Programs should consider education sessions for patients that cover the roles and activities of CHWs to manage patient expectations and to encourage follow-through with CHW recommendations. Such education sessions could be used to dispel misconceptions and myths about HIV, AIDS, and ART. Patient education programs should be ongoing to deal with issues that arise during treatment that require the support or awareness of patients.

Community health workers identified a need to raise awareness in the community of the program activities in order to destigmatize the work of the CHWs and to ensure that they are duly recognized for their work. However, attempts to do this risk a breach of confidentiality of the HIV status of patients who may be identified when known CHWs visit their homes. In this particular study, the issue of stigma was present early in treatment but patients were more comfortable with their status being identified after they had started treatment. I recommend that the issue of community awareness be discussed and negotiated according to the context in which a program is established and depending on the relative levels of stigma in the community. In the initial stages of the program, generic awareness sessions on local myths and misconceptions about HIV, AIDS, and ART should be delivered to the community, perhaps through broad-reaching media such as the radio or at community meetings.

7.3.4 Program management

7.3.4.1 Recommendations for the supervision of CHWs

There is no doubt that the presence of a good volunteer administrator was crucial for the success of the CBART program. This individual acted as a trainer, a source of advice, and a mediator among CHWs, patients, and health workers. The volunteer administrator for the CBART program was a clinical officer with experience in managing volunteers in health programs. I recommend using a health worker with experience or training in working with community members in any new program. This individual should have a good understanding of the key principles of volunteerism, namely the voluntary nature of the activities, how to support busy people to successfully complete their work, the factors that motivate volunteers, and how to build on these motivators in the daily interactions the CHWs have with patients and health workers. The administrator should also have training or experience in dealing with the complex types of cases that were apparent in our CBART program, particularly those that CHWs referred to our volunteer administrator. Using a health worker or trusted authority in health care as a volunteer administrator can also add legitimacy to the work of the CHWs.

It is a challenge to find the health human resources needed to run government led programs like CBART in rural areas. Thus, I see the possible success of a model in which a nonhealth-trained person supports the administrative and nonclinical aspects of volunteer supervision and works with the clinical officer or nurses to support clinical needs for CHWs to provide patient support and education. This model would have to include field visits by the volunteer administrator to guide patients who do not follow the recommendations made by CHWs.

7.3.4.2 Recommendations for documentation and coordination

In the CBART program, the original volunteer logs and original algorithms for assessing treatment adherence through pill count calculations to measure pill ingestion were difficult for CHWs to manage. The revised forms, which recorded pill counts, but left the pill ingestion calculations to the volunteer administrator were easier to complete. The CHWs did not mention that the sections in the volunteer log on side-effects were difficult to complete, so we did not change these. Therefore, I recommend using a simple volunteer log that collects the basic information required for clinical monitoring, leaving treatment adherence calculations to others. Transparent pill boxes made the pill counts straightforward and protected the pills from contamination. The use of referral forms that would enable clinic staff to identify patient referrals to the clinic by the CHWs should help to coordinate referrals for side-effects by the CHWs and treatment for side-effects by clinic staff, as there was some confusion in this paperwork in the CBART program. Because patients become more mobile as the treatment progresses, I recommend that CHW patient visits be scheduled. This was effective in reducing the CHW travel burden when random CHW visits failed to locate patients and repeated trips had to be made.

7.3.4.3 Recommendations for regular volunteer meetings

Like the volunteer administrator, the monthly volunteer meetings were integral to CHW effectiveness. I recommend that a CHW program hold meetings at a frequency that is convenient for the CHWs. In the CBART study, the volunteer meetings provided a focal point for ongoing CHW training and a medium to address problems in the field. New activities were introduced at the volunteer meetings and resources were distributed. We found the volunteer meetings to be a suitable forum to share accomplishments of the program; these highlighted small victories that further served to motivate the CHWs. In the CBART study, the monthly volunteer meeting was a (relatively) costly endeavor due to the transportation and lunch allowances we provided to the CHWs. However, the value derived from these meetings justified the costs. Thus, I recommend that programs find the resources to hold regular volunteer meetings. Larger programs could hold multiple meetings in decentralized locations to ease the transportation burden on CHWs.

7.3.4.4 Recommendations for motivating CHWs

Community health workers said that they felt motivated by a sense of purpose to save lives and the associated recognition of their contributions toward this purpose. I recommend programs align their management structures and activities to maximize opportunities for CHWs to realize the purpose of their work and be recognized. One way to make community health workers aware of their progress toward achieving improved patient outcomes is to share aggregate statistics on the clinical improvement of patients. These clinical statistics can compensate for the lack of visible improvements in patients in the long-term. Other programs, especially those that start patients on treatment earlier, may not be able to rely on having visible manifestations of improvement in patient health. In Rwimi, our program filled a long-standing gap in access to ART. As a result, we enrolled many sick patients with visible signs of AIDS; these patients then experienced dramatic physical improvements in health which were visible to CHWs.

Programs should endeavor to recognize CHWs internally (within the program) and externally (within their community) for their contributions. Community health workers greatly appreciated the annual recognition programs, so I strongly recommend the use of this type of program. These recognition programs should include district leaders as well as local leaders, and, more importantly, CHW family members should be welcome to attend.

Incentives are important motivators for CHWs, especially when the CHWs are unpaid. In addition to supporting CHW duties (e.g., the bicycles, raingear, and bags eased the travel to patients and the clinic), in the CBART program the incentives signified our appreciation for CHW contributions. Travel distances were a constant source of frustration for CHWs. Resources for transport, such as bicycles, can help alleviate some of this transport burden. Programs should consider the repair and replacement of incentives due to wear and tear, for instance, bicycles need the regular replacement of tires. The CHWs in the CBART project requested motorcycles and mobile phones. While motorcycles would not be a cost-effective and affordable option for most programs, the ever-reducing cost of mobile phones and the ability afforded to “beep” the volunteer administrator and health workers (“beeping” was described in the introduction) would make this a cost-effective incentive to reduce some travel burden.

I recommend that programs build strong links between CHWs and clinic staff from the outset. Such bonds facilitate dialogue and coordination between the two groups. The ability of the clinic to provide the additional benefits to CHWs that they offer to other health workers (e.g., opportunities for extra work during immunization programs and preferential access to care) can motivate CHWs to cooperate with health workers. As I found in this study, health workers can learn to recognize and appreciate the benefits of CHW efforts through increased dialogue and interaction.

7.3.4.5 Recommendations for building trust

Programs can flourish only by ensuring that a relationship of trust exists among the various stakeholders. In a program like CBART, the stakeholders include CHWs, government, patients, health workers, and the wider community. In our study, trust enabled CHWs to effectively perform their duties and reduced the stigma felt by patients. However, trust can be easily eroded—for example, the CHWs were not enthusiastic about the government’s management of past health programs. Where there are past negative experiences, there is a need for a stronger effort to build and earn trust by governments and NGOs. In the CBART program, we achieved CHW trust by delivering on the promises we made to build a positive work environment for CHWs. However, in many jurisdictions, this will require a reorientation of focus regarding government policies and strategies. Perceptions of volunteerism can differ, leading to the failure of agencies, usually government agencies, to recognize the importance of promoting the concepts of volunteerism in volunteer based CHW activities. As an example, in Uganda, the recent policy to formally establish Village Health Teams (VHTs) in all districts has not identified the principles of volunteerism in their strategy and has put limited structures and processes in place for volunteer management and motivation.[187] These limited structures and processes typically end up being omitted from the implementation of programs due to financial constraints.

7.3.5 Considerations for program scale-up and sustainability

I have based the above recommendations on experiences in a small pilot project. The large gap in access to ART, especially for those living in rural sub-Saharan Africa[1] calls for more ART programs and larger ART programs. Studies have found that small scale projects are more successful as they can easily manage support and supervisory mechanisms, whereas larger programs are usually not able to achieve this in a consistent manner.[80]

There are very few examples of effective expansions of “pilot projects” in which program conditions, process indicators, and outcomes have been monitored to generate evidence and experience for scaling up small programs. In an example in Kenya in the 1990s, community based distributors (CBDs) for oral contraceptives were trained and a community based family planning program was established in three provinces in western Kenya by the German agency Gesellschaft für Technische Zusammenarbeit (GTZ). (Kipp, Walter, personal communication, Jan 2013) Approximately 11,000 unpaid CBDs were trained and were supported with nonfinancial incentives. This program ran for 10 years and reduced the total fertility rate in the project area from 5.4 to 3.9 children per woman. After 10 years, the external funding ended and the community based CBD program disintegrated shortly thereafter. This example demonstrates that a large number of unpaid volunteers can be supported over a long period to provide health services, but the program can fail without a long-term commitment to provide human and financial resources. Our community based ART model shows that the involvement of unpaid CHWS in the relatively complicated handling of antiretroviral drugs was successful on a small scale. A scaled-up version of this model might be successful as well, if the political will exists and the required resources are available for an extended time frame.

One challenge in scaling up a CBART-type project is the mobilization of required resources. In the CBART project, CHWs chose to support a median of three patients each and one volunteer administrator managed 41 CHWs. Using these ratios, a scaled up program would have to support a very large number of CHWs. For example, approximately 12,000 patients in the Kabarole District require ART. This is based on a district population of 440,000 (220,000 adults), an HIV prevalence of 11%, and a conservative assumption that 50% of HIV positive adults would qualify for ART under current treatment guidelines. A scale-up of our program to the entire Kabarole District would require 4,000 CHWs and 100 volunteer administrators. This is unrealistic in most low resource environments in sub-Saharan Africa. An alternative may be to adjust the ratios, for example, having each CHWs manage up to 10 patients and each volunteer administrator manage 50 CHWs. These were the ratios described by Zachariah et al.[134] in Malawi. Programs could find a way to make the workload manageable, especially if there were opportunities to reduce the frequency of visits and distances to travel by CHWs. Under these assumptions, the district would require 1,200 CHWs and 24 volunteer administrators, which could be feasible for the Kabarole District. There is a widely held misconception by health planners that community based healthcare using volunteers is cheap. One estimate suggests that a CHW program would requires $3,500 USD per CHW per year just to train, equip, and maintain CHWs.[47] Our own program, which did not pay CHWs, required an average of $370 per CHW per year in direct costs (materials, incentives, and volunteer administrator salary). Based on our costs, a district that had to support

1,200 CHWs would require $440,000 per year. A program with a higher ratio of patients to CHWs and CHWs to volunteer administrators would cost less than this.

Another question that remains unanswered is the sustainability of such programs, even at a smaller scale. Following our research study, the CBART program continued for one more year under the support of our research project. During this period, we arranged to hand over the program to the Kabarole District Health Department. Two years after this handover, approximately 50% of the CHWs were still active in supporting their patients' needs. This attrition was mainly because there was no supervision mechanism and no resources were put in place to continue to manage CHW activities. The clinic also had to implement a new national policy for reporting patient ART progress monthly to the national government. The lack of coordination and little communication with CHWs led to a decision to have patients come to the clinic monthly to monitor their progress. CHWs began to feel less relevant and stopped their work. Those that remained mentioned continuing in the program out of a sense of compassion toward their patients, despite feeling unappreciated and demotivated in their work. This "natural experiment" (which happened because the original research team was not able to secure research funding for a timely handover of the project) clearly shows that these programs need ongoing management support or they can quickly collapse.

7.4 LIMITATIONS

There were some limitations to this study that might influence the findings. The first is that most of the data were collected in a language other than English. As a result, there was a strong reliance on the translation of data from Rutooro to English. Some of the impacts of this were mitigated through the data quality controls mentioned in Chapter 3 and the use of interviewers and translators who had been provided extensive training. However, due to the time lag between data collection and translation, data analysis for qualitative data could not be conducted simultaneously with data collection, nor could the researcher himself intervene during the interviews and focus group discussions to get more elaboration on a concept or probe further. This is a recognized challenge of cross-cultural qualitative research.[188]

A second limitation was the small sample size of volunteers and patients available for this study. The numbers were fixed by the original study parameters. Smaller sample sizes increase the possibility of a type II error where the null hypothesis would not be rejected if the alternative hypothesis were true. For this study, the small sample sizes would result in not finding significant differences between groups if there were true differences.

A potential third limitation was a social desirability bias in the way participants responded to questions. Patients may have responded more positively to the program based on a perception that a negative response might jeopardize the program and the benefits they received. Health worker and CHW responses may have been similarly motivated and perhaps also motivated by a desire for more incentives or remuneration.

A fourth limitation was the lack of a validated survey instrument for collecting data on volunteer perceptions and the associated limitation of not being able to properly validate the instrument developed for this study. Pretesting with CHWs was not possible due to the small sample size available because pretesting would have removed a significant portion of participants from the final survey. The questions were not relevant to any other groups in the area so could not have been pretested outside the CHW cohort. Test-retest methods could not be applied due to logistical issues in bringing CHWs back to readminister the survey.

A fifth limitation was related to the characteristics of CHWs recruited by the health workers. The fact that 38 out of 41 CHWs had previous volunteering experience reduces the generalizability of the findings to programs that can recruit experienced laypersons, which may not be possible in all settings.

A sixth limitation was uncertainty about the quality and completeness of data collected by the CHWs and health workers as part of their routine work. The volunteer logs were completed by laypersons who, though they had been trained to complete the forms, expressed difficulty in being able to do so in the field. Therefore, there were missing data and possibly incorrectly captured data. The logs were checked monthly by the volunteer administrator for obvious mistakes related to pill counts and visit frequency, and to confirm important side-effects that may have required additional monitoring; all identified mistakes were corrected. The clinical officer responsible for reviewing clinic charts to document visits for side-effects noted that there were instances of charts being incomplete. The health workers at the clinic confirmed that there were times when their workloads prevented them from properly documenting diagnoses and treatment plans in patient charts. This may have contributed to the discrepancies seen in the capture of side-effects by CHWs and health workers in the clinic.

CHAPTER 8 – CONCLUSIONS

This thesis provides an overview of a novel study that assessed the effectiveness of community health workers (CHWs) in supporting a range of activities for antiretroviral therapy (ART) in a rural setting. Using both quantitative and qualitative methods, I found that, with appropriate training and supervision, lay volunteer CHWs can effectively undertake a variety of tasks related to ART: drug distribution, drug adherence monitoring, and HIV counselling. Findings suggest that the CHWs made an important contribution to the high levels of virologic suppression measured, the low (for a fatal disease) patient mortality realised, and improvements in the health related quality of life observed in patients. This report provides evidence that a community based ART program, built on positive community engagement and careful management, could address the gaps in ART coverage prevalent in rural areas of sub-Saharan Africa.

The CHW model described in this thesis was successful in a rural area of western Uganda where formally trained health care workers are in short supply. The model could be used to expand ART provision in rural areas where geographical and financial barriers limit access to treatment. Our program was a pilot that accrued the benefits of small size and in which one volunteer administrator was responsible for only 41 CHW volunteers. Whether a scaled-up version of the model would provide similar positive outcomes needs further investigation.

A successful implementation of this model would have to be based on the local context. In this study, we made ongoing adaptations to the program according to identified needs; this included reducing the frequency of CHW visits to patients (to reduce the CHW travel burden) and streamlining the paperwork (to simplify CHW field calculations). The model should be viable to local circumstances. For instance, the number of available CHWs might be limited in other contexts, in which case the workload of the CHWs would increase. Geographical terrain and the structure of communities would also influence the human and management resources required. The accurate recognition and handling of side-effects of ART by CHWs was a weakness in our model and further research is needed to improve CHW instruction in this aspect of ART.

Our study team is now working with the Kabarole District on a new research study to establish a locally managed and locally funded CHW program that builds on the best practices and recommendations of my study and the larger community based ART (CBART) program. We will work with local partners to transfer the knowledge gained from our research project and help them adapt our recommendations to match the available resources in the community. This new project will serve a larger pool of patients using a larger pool of volunteer CHWs. The new project aims to test the sustainability of the adapted model in the hands of local management and to test the effects on the CBART model of a gradual scale-up. Our subsequent evaluation of the handover and scale-up of the adapted model will generate additional useful information to help guide the expansion of community based ART programs in resource-limited settings.

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APPENDIX A: INITIAL MONTHLY VOLUNTEER LOG

Name of volunteer: ______________________________

Name of patient: ______________________ **HAART ID:** ______________

Date and time of visit	**Treatment partner present (yes, no)**	**Treatment card correctly filled (yes, no)**	**Number of tablets missed as per card**	**Reason tablets are missed:** 1. Forgot 2. Side effects 3. Illness 4. Other	**Suggestions for adherence** 1. Fill card well 2. Improve adherence 3. Other (specify)	**Side effects** 1. Yellow eyes 2. Numbness of finger and/or toes 3. Skin rash	**Other health problems** 1. Severe headache 2. Vomiting 3. Cough 4. Difficult breathing 5. Persistent fever 6. Diarrhea 7. Severe stomach pain 8. Muscle weakness 9. Other	**Recommendation for side effects and health problems** 1. Good diet 2. Improve hygiene 3. See doctor (other health problems) 4. Urgent referral to HC (side effects) 5. Others (specify)

Estimated travel time for 4 weeks (filled by volunteer coordinator):______________

Drugs given

Date	Septrin 2x1 (60 tabs)	Multivitamins 2x3 (84 tabs)	ARV Drugs	Condoms given	Signature of Clinic Staff Dispensing Drug	Signature of Volunteer	Signature of Patient

ARV adherence monitoring

Date of visit	Tablets by pill count	Tablets taken since last visit	Days since last visit	Tablets which should have been taken since last visit	Tablets missed since last visit (by pill count)	New ARV tablets given	Total tablets at end of visit	Time of Departure

APPENDIX B: VOLUNTEER TRAINING HANDOUT

Community-Based ARV Project
Volunteer Handout

OVERVIEW OF PROJECT:

This is a project between the Kabarole District and the Canadian Government to provide treatment to people in Rwimi Subcountry. Over the next four years, we will look at ways to provide treatment to people with HIV/AIDS without them having to travel to Fort Portal or Kibiito. The drugs will be provided by the government for the patients in Rwimi.

Right now, if people want treatment for HIV/AIDS, they have to go to the Buhinga Hospital or Virika Hospital to get tested and to get their medication. Every month they have to travel to Buhinga Hospital or Virika Hospital so that the doctors there can make sure that they are taking their medication and will then give them more tablets. If they do not go to Fort Portal, then they cannot get treatment. However, it is difficult for people in Rwimi to travel all the time to Fort Portal. Instead, we are trying to help them in their own village.

This is where we need the help of the village. You have been chosen by the community to help people in your own village who have HIV/AIDS. You will help them get their medication and take their medication. They will also have a family member or friend who will help them every day. Your job will be to help them once a week at first and then every two weeks. With your help, we can make sure that people will get treatment and can start to get better. The key to successful treatment is taking the drugs every day.

If we are successful in Rwimi, then we can show the rest of the country that they can do something similar in other subcounties in Uganda. That is why we are starting in Rwimi – we want to make sure that the program works and that a community can help their own village members to get better.

BACKGROUND INFORMATION ON HIV, ARVS AND PREVENTION

FACTS ON HIV/AIDS

- HIV stands for the 'Human Immunodeficiency Virus'. Someone who is infected with HIV is said to be ' 'HIV positive'.
- A person cannot be sure whether he or she is infected with HIV until a special blood test is done. If the HIV test is positive, the person is infected with HIV.
- There isn't any way to tell just by looking if someone's been infected by HIV. But a blood test can detect infection from about three months after the virus first entered the body. A person infected with HIV may look and feel perfectly well for many years and may not know that they are infected.
- At first, HIV infection does not make a person very ill. He or she may continue to have a healthy life for some months or many years.

HOW IS HIV TRANSMITTED?

- HIV is found in the blood and the sexual fluids of an infected person, and in the breast milk of an infected woman. Someone can get HIV if enough of these fluids get inside someone else's body. There are various ways a person can become infected with HIV.
    - Unprotected (without a condom) sex with an infected person
    - Contact with an infected person's blood by transfusion or contact with a used needle

  - From a pregnant or breast feeding woman to her child
- It is not possible to become infected with HIV through :
  - sharing crockery and cutlery
  - insect / animal bites
  - touching, hugging or shaking hands
  - eating food prepared by someone with HIV
  - sharing a toilet or latrine

WHAT IS AIDS?

- After some time, a person who is HIV positive may develop AIDS (acquired immune deficiency syndrome). This happens when the person's body defence has become weak and cannot repair or protect the body in the usual ways that keep humans healthy.
- A person who develops AIDS may start to lose a lot of weight, feel very tired and be unable to do all their usual daily activities. Illnesses also start to happen, especially infections such as tuberculosis (TB), chronic diarrhea, and other skin or chest infections.
- If people with AIDS do not get treatment, they will gradually become very ill and are likely to die.

WHAT IS ARV TREATMENT?

- Antiretroviral (ARV) treatment is treatment for HIV infection. ARV drugs greatly reduce the number of viruses in their body, but they cannot eliminate the virus from the body.
- ARV treatment must be taken for life. If not, the virus will start to reproduce again and will cause AIDS.
- ARVs can bring a person with AIDS back to good health and keep a person with HIV healthy.
- A person who takes ARVs can live a much longer and healthier life than someone who does not.
- A person with HIV also needs to have good medical treatment for illnesses such as TB, skin or chest infections.
- A person with HIV needs good food and clean water, as well as good basic care when they are ill. People with HIV need more protein and vitamins in their food than other people. This means having meat, beans, fish and plenty of vegetables and fruit.
- ARV treatment usually starts only when HIV has damaged a person's immune system
- A doctor can find out what is happening to the immune system of a person with HIV by carefully examining them and checking for any illnesses or problems. Special blood tests can be used.

HOW IS ARV TREATMENT USED?

- ARV medicine comes in tablets. These are taken by mouth.
- The ARVs commonly used in Uganda can be taken with or without food.
- ARVs must be taken at the same time each day, about 12 hours apart. This is because the amount of drug in the body must remain at the same level all of the time.
- ARVs do not cure HIV. So, treatment must continue every day for the rest of a person's life
- Since someone who is being treated can still infect others, prevention of infection by abstinence or condom use needs to continue every day for the rest of a person's life.

WHAT IS ADHERENCE TO ARV TREATMENT?

- Adherence means taking doses of drugs and sticking to the treatment plan exactly as prescribed. It means taking the correct amount of drugs, at the correct time and in the correct way every day.

- Adherence is especially difficult if people are isolated, depressed, forgetful or worrying too much about the effects of their medication, if they are drinking too much beer or if they don't understand how important adherence really is.

WHY IS IT IMPORTANT FOR A PERSON WITH HIV TO ADHERE TO ARV TREATMENT?

- If ARV treatment is used correctly, it can improve a person's health and quality of life and enable them to live for a long time.
- If adherence is very good, the amount of HIV in a person's body will reduce very quickly after a few weeks or months.
- Good adherence is needed for ARVs to work effectively. Missing even a few doses can cause treatment to fail.
- Failure to adhere to ARV treatment might involve a person:
    - Missing one or two doses of drugs occasionally.
    - Stopping the treatment completely.
    - Taking smaller doses of drugs than the amount prescribed.

WHAT HAPPENS IF A PERSON'S ADHERENCE TO ARV TREATMENT IS NOT GOOD ENOUGH?

- Poor adherence to ARV treatment allows a person's levels of HIV to stay high and their immune system to stay weak. It means that they face an increased risk of severe illness, more time in hospital and early death.
- Poor adherence can also cause the virus to become resistant to the drugs and the treatment to stop working
- If treatment fails or the virus becomes resistant, that treatment will never work well again, even if the patient starts taking it properly again.

WHY MIGHT A PERSON FAIL TO ADHERE TO ARV TREATMENT?

- Some of the common reasons why a person with HIV misses a dose of ARVs include:; being busy; falling asleep; being depressed; worry about side effects; drinking too much beer, feel that there are too many pills; tired to having to take tablets every day for the rest of their lives; or they are sharing their tablets with someone else.
- If a person wants to stop treatment, they must discuss it fully with their doctor before making any final decision.

WHAT SHOULD A PERSON DO IF THEY FORGET TO TAKE THEIR DRUGS ONE DAY?

- If a patient forgets to take their morning tablet, they can take two tablets in the evening (but no more than 2 for that day). However, this is only if they forget to take their tablet. Otherwise, it is very important that they take their tablets at the correct time.
- If a person forgets to take their evening tablet, then they should just miss that tablet.
- The important thing is to make sure no one takes more than 2 tablets a day.

WHAT ARE THE SIDE EFFECTS OF ARV DRUGS?

- Side effects are the negative effects of a drug.
- All medicines can cause side effects. They can vary from small inconveniences to serious problems.
- Different ARV drugs cause different side effects. Not everyone will experience a side effect. Only a few people will have a serious side effect.

- The side effects that are the most dangerous in this program are:
    - Jaundice (yellow eyes), which often happens during the first six weeks after starting treatment. If this happens, the patient should see a clinical officer immediately.
    - A serious rash, often with blisters, fever, bumps and sores in the mouth can occur. If this happens, the patient should see a clinical officer immediately.
- Other side effects that patients may experience, but which are not as dangerous are:
    - Numbness, and feeling like the toes are burning. This is called neuropathy. It almost always affects both feet equally. This is not an urgent or dangerous side effect. However, it may get worse if the treatment is continued. If the patient has this for more than 6 weeks, especially if it is getting worse, they should be advised to see a clinical officer.
    - A mild rash is common in the first 6 weeks after starting ARV's. It will usually go away if treatment is continued.
- There are many different ways to manage side effects. However, if they are severe, a person's doctor might decide to change their treatment.

WHAT IS THE ABCS OF PREVENTION?

- 'A' refers to abstinence. This means not having sex, or waiting until you get married or are in a faithful relationship.
- 'B' refers to being faithful. If you do have a sexual partner, you should remain faithful to that partner. This is a good way for someone to avoid HIV infection, as long as their husband or wife is also completely faithful and doesn't infect them.
- 'C' refers to using condoms. A condom, *when used properly*, prevents infected fluid getting into the other person's body.
- All three components A+B+C are important ways for a person to protect him or herself, and to prevent someone who is infected infecting others.
- If a person is infected and their partner is not infected, it is very important for the couple to practice safe sex, which means the use of a condom. This is true even if the infected person is on treatment.
- If a couple are both infected, they should consider safe sex. However, it is not as important for them to practice safe sex with a condom compared to a situation where only one partner is infected.
- If a couple where one or both partners are infected want to have a child, they should talk to a Clinical Officer or Medical Officer to get advice. Even if they are on treatment, they can still pass on the HIV infection to their child.

ARE YOU AT RISK AS A VOLUNTEER?

- There is no risk of you getting infected if you make sure that you do not:
    - Have sex with someone who is infected
    - Come in contact with the blood of someone who is infected
- You cannot get infected with HIV by touching someone who is infected or by sharing their utensils or drinking from the same bottle.
- You cannot get infected with HIV if someone spits on you, sneezes on you, or from their tears.
- If you think you may have come in contact with an infected person's blood, then report this immediately to the clinical officer who will assess whether there is any risk and make sure that you get tested and get some drugs immediately if you need them.

APPENDIX C: VOLUNTEER JOB DESCRIPTION

Community-Based ARV program

Volunteer Job Description

Volunteers in the Community-Based ARV program will have the following responsibilities:

- To distribute drugs to the patient on a monthly basis:
    - Pick up the drugs from the dispensary in Rwimi
    - Count the number of tablets received for each family and sign that you have received the tablets
    - Deliver the drugs to the patient or the treatment partner only. Do not give the drugs to anyone else.
    - Have the patient or treatment partner sign that they have received the drugs.
    - Return the form back to the clinic.

- To monitor treatment adherence:
    - Visit each patient once a week and make sure that they have filled out their treatment form. Sign the treatment form when you visit.
    - Count the number of tablets remaining and compare this to the chart to identify how many there should have been.
    - If someone has missed taking a tablet, ask them why. Write this down in your log book and on the treatment form. Let the patient know that it is important for them to take their tablets and by not taking their medication, they may have complications of treatment in the future.
    - If the patient keeps missing taking their tablets, let the volunteer administrator know.
    - At the end of the month, collect the forms and return them to the volunteer administrator.

- To monitor side-effects of treatment:
    - If the patient is complaining of minor side effects such as nausea, diarrhea, burning toes, a mild rash, or being tired, let them know that this may happen sometimes and that it will go away. If this continues for more than a week, advise that they should see a clinical officer.
    - If the patient is complaining of jaundice (yellow eyes) or a bad rash with blisters or anything that looks serious (like a fever, they cannot get out of bed), then let the clinical officer know that the patient may need to be checked.

- To provide the patient with information on preventing others from being infected
    - When a patient starts to feel better, let them know that they still have the virus and need to continue on their medication.
    - The patient should be told that they can still transmit the infection to others. Therefore, they need to either abstain from sexual activity, or be faithful to their partner and that they or their partner should always use a condom.
    - Distribute condoms to the patient. These can be obtained from the volunteer administrator.

You will choose how many patients you wish to support. You will be provided with a log book to record your visits to each patient. Write down the date and the name of the patient you visit every time you visit them. Make a note of any missed medication or problems that the patient may be having in taking their medication or with side effects. Report these to the volunteer administrator and the clinical officer when you meet with them.

You will be required to attend a monthly meeting with the rest of the volunteers and the volunteer administrator. At this meeting, you can bring up problems that the patients are having or which you are having with the program. The volunteer administrator will try to help you solve these problems.

You should not give the patient any other medication other than the ARV. If the patient is ill, they should see the clinical officer or other medical doctor.

APPENDIX D: VOLUNTEER TRAINING CERTIFICATES

CERTIFICATE OF COMPLETION OF TRAINING

This certificate is granted to

Name

to certify that he/she has completed to satisfaction

COMMUNITY VOLUNTEER ARV TRAINING PROGRAM
FOR THE RWIMI COMMUNITY-BASED ARV PROJECT

Project Principal Investigator　　Date

Kabarole District Administration　　Date

APPENDIX E: VOLUNTEER ADMINISTRATOR JOB DESCRIPTION

Community-Based ARV Project
Volunteer Administrator Role Description

Purpose of the Volunteer Program:
To support the treatment of Persons Living With HIV/AIDS (PLWHA) in their own communities by undertaking key activities such as distribution of ARVs, monitoring of adherence, monitoring of side effects, and dissemination of prevention messages.

Role Description

- To oversee the activities of the community volunteers
    - To ensure that the volunteer activities are maintained
    - To ensure that volunteer activities are correct and appropriately delivered.
- To recruit volunteers for the program
- To provide orientation and training
    - Continuous training for the current cadre of volunteers
    - Detailed orientation and training for new volunteers
- To ensure that volunteers concerns are acknowledged and addressed if possible.
- To create a welcoming and social work environment
- To set and convey clear and reasonable work expectations for the volunteers
- To provide meaningful recognition and appreciation activities
    - Personal recognition
    - Community recognition
- To encourage new ideas and feedback
- To conduct monthly meetings with volunteers.
    - To identify issues and develop solutions
    - To provide continuous training
    - To thank and appreciate volunteers
- To document all activities and changes to the program
- To compile and storage the documents used by the volunteers.
    - Treatment adherence forms (at the end of the month)
    - Drug distribution forms (when complete)
    - Volunteer activity log (when complete)
- To enter the data collected from volunteer activities into an electronic record.
- To link the volunteer to the health services required for patients.
- To provide general troubleshooting support.
- To provide volunteer support to patients as necessary (usually when the volunteer is not available or is away).

APPENDIX F: NON-FINANCIAL INCENTIVES FOR VOLUNTEER MOTIVATION AND RETENTION

Non-Financial Incentives for Volunteer Motivation and Retention
Community-Based ARV (CBARV) Project – Rwimi

Background:
- Volunteers are a crucial part of the treatment intervention in Rwimi.
- Their work supports the health care system and health workers through monitoring of adherence and side effects for clients on treatment, delivery of drugs to clients, and promoting prevention messages.
- Volunteers are not paid for this work, but carry out their tasks for a variety of reasons – thus their motivation is multi-factorial and so any incentive program should consider this multi-factorial aspect.
- The purpose of this strategy is to identify what may motivate a volunteer and how we might be able to enable the volunteers to continue to be motivated to serve their communities.

Motivating Factors:
- Recognition by the community - volunteers may be motivated by being appreciated and recognized for the important work that they are doing. Recognition by the community they serve could be an important motivating factor for the CBARV project.
- Seeing positive outcomes – volunteers may be motivated to participate in a program because they believe in the benefits and outcomes of the program. Awareness of the outcomes of the project, especially the benefits to the community, may be an incentive for some volunteers.
- Service as part of their faith or beliefs – volunteers may be motivated by religious beliefs about charity and service to the community. Reinforcement of the importance of their work by religious leaders may be an incentive for these volunteers.
- Personal development – volunteers may be motivated by the feeling that they gain experiences and knowledge either for the sake of getting the experience itself or to enhance their employment and livelihoods in the future. Positive experiences, positive supervision and ongoing training may be an incentive for these volunteers. The opportunity to enhance their livelihood through job opportunities from the organization they are working for may be another incentive.
- Recognition by the health system – volunteers who participate in health programs may do so out of a feeling that they want to contribute to the health of their community. For these volunteers, acknowledgement and acceptance by the health care system (leaders, health staff) may be an incentive.
- Building social networks – volunteers may participate to build personal relationships with like-minded individuals. Opportunities for socialization, networking and the development of spin-off groups such as co-operatives may be an incentive for these volunteers.
- Positive working environment – once a volunteer has joined an project, they are more likely to stay if they have a positive working environment where resources they need to do their work are available, where they don't feel overburdened, and where their work and time are appreciated and respected. Providing tools and supplies on time, keeping meeting times, keeping the workload appropriate for the volunteer's capacities, and providing forums to be heard are important incentives for most volunteers.

Motivation Strategy for the CBARV Project

Understanding that volunteers are individuals with diverse needs and have diverse motivations for volunteering, the CBARV needs to identify multiple incentives that address all of the factors identified above. The following are programs that have been identified for implementation:

1. Establishment of a Community Volunteer Appreciation Day. This would be more appropriate to be held as an annual event as the resources required for the planning and implementation of this program would be high. We propose that beginning Feb 2007, an annual event be established in the Rwimi sub-county where we invite the community and religious leaders, clinic staff, district leaders, and ARV clients to gather at a meeting point to celebrate and appreciate the CBARV volunteers. The program would consist of speeches by the invited dignitaries, songs and dancing and light refreshments. The media (radio and newspapers) would be invited to attend. During the program, we would also invite the volunteers to say a few words about their work. It will be important to maintain confidentiality of the clients, so care should be taken that no client is identified as such during this program. If the program would like to have one of the clients address the group, then the client should acknowledge that they consent to having their status as a client disclosed.

2. Acknowledgment by community and health leaders. We will arrange for the volunteers to be introduced to community leaders at the LC3 and LC2 levels as well as with religious leaders in the community. The purpose of the introductions is to promote awareness of the CBARV project as well as the contribution of the volunteers. We will seek the leader's encouragement of volunteers to continue to make a significant contribution to the community. We will have to ensure that the religious and community leaders support the ARV project before we initiate the introductions.

   We will also request the District Health Officer to provide a written letter of appreciation to all volunteers who participate in the project. This letter will identify their valuable role in the community and as partners in the health care system as a result of the role that they play.

3. Preferential access to the Rwimi Clinic. We will seek permission from the District to allow volunteers and their immediate families (children, spouse, parents) preferential access to the Rwimi Clinic for ARV and non-ARV care. Preferential access will entail not having to wait in a line-up to be seen. However, this will not include a reduction in costs where costs are normally applied, nor access to services that are not normally provided to the community-at-large.

4. Resources to support volunteer activities. Volunteers currently receive a bicycle (with pump and lock), boots, a t-shirt, a watch and a bag to support their activities. Volunteers also receive a diary, notepads and pens. We will continue to provide these to new volunteers who join. Based on feedback from the volunteers, we will now provide a new set of bicycle tires each year and a raincoat to the volunteers. Limited resources for the project will prevent us from providing any additional supports. However, it is important that the volunteers receive the above-mentioned items on time and in good condition.

5. Celebrations of success. At each monthly meeting, we will start with a success story from a volunteer. The story should be around how their client has improved, including resumption of work, care for their family, and other progress that the client or family has made. This will enable the volunteers to see the benefits of their work. The regular meeting schedule will address barriers, challenges and issues, so we will not diminish from that important aspect of the meeting, but will make sure that we also include the positive component.

   We will also provide aggregate findings from the research project to the volunteers. Examples would include the proportion of clients who have undetectable viral loads after six-months. A sharing of the findings of the project (which we hope are positive) will probably add to the celebration of our successes.

6. Creating a supportive environment. The project will endeavor to create a supportive environment for the volunteers through:
   - Regular meetings where volunteers can bring forward their issues and challenges and receive the supervision and guidance they need.
   - Quick follow-up of their requests to deal with an issue they are facing.
   - Respect for the time of the volunteers – this includes keeping the meetings as short as possible, starting meetings on time, calling volunteers if meetings are postponed or cancelled.
   - Realistic workload schedules that do not put unnecessary burdens on the volunteer. This includes not adding new tasks and not asking volunteers to handle more clients than they have capacity to handle.
   - Delivering on supplies (based on what has been approved) to the volunteers without delay.
   - Reimbursing them for lunch and transport costs for monthly meetings.
   - Talking to and treating them respectfully.
   - Supporting volunteer initiatives such as the development of cooperatives or work opportunities. Our support will have to be limited to moral support and providing linkages with other organizations – we cannot provide financial support.

7. Providing training and work opportunities. Volunteers should be provided with comprehensive baseline training according to the protocols established. At the end of the training, they should be presented with a certificate acknowledging completion of training. New volunteers should have the same training opportunity and should also be provided with a certificate.

   Ongoing refresher training should be provided to reinforce messages, correct errors and to answer questions that volunteers bring up. This can build self-confidence in the volunteers and act as an incentive.

   The Rwimi clinic and external organizations should be encouraged to consider employing the volunteers when they recruit for new staff. We have already seen the clinic give the first opportunity to our volunteers to work as field staff during Child Immunization Days. We should encourage and facilitate this where possible.

APPENDIX G: CHW BASELINE SURVEY

Survey Form for Baseline Data on CHWs

Date____________________________________

Name of Volunteer ______________________________________ Gender: ☐ Male ☐ Female

Name of Interviewer(s) ________________________

A1. What is your age? __________ years

A2. Are you married? ☐ Married ☐ Single ☐ Divorced ☐ Widowed

A3. What is your occupation? ______________________________

A4. What level of education have you completed?

☐ None ☐ Primary ☐ Secondary ☐ University

A5. How many people in your household?

____ adults (relatives) ____ adults (others) _____ children (own) ______ children (others)

B1. Does your household have running water? ☐ No ☐ Yes

B2. Does your household have electricity? ☐ No ☐ Yes

B3. What kind of property is your house?
☐ Self-ownership ☐ Rental ☐ Other, please specify________________.

B4. What is the main material of the walls of your household?
☐ Mud/Soil ☐ Wooden (boards) ☐ Iron or other metal sheets ☐ Brick or concrete ☐ Other

B5. What is the main material of the roof of your household?
☐ Thatch ☐ Wooden (boards) ☐ Iron or other metal sheets ☐ Tiles ☐ Other

B6. What is the main material of the floors?
☐ Dirt ☐ Cement ☐ Wood, ceramics or other kinds of tiles ☐ Other

B7. Number of rooms in the household (including the kitchen, living room, bedrooms, bathrooms and other rooms).
_____________ rooms in total.

B8. Which of the following does your household own?
☐ Radio ☐ Cassette/CD Player ☐ TV ☐ VCD/DVD ☐ Computer ☐ Water heater
☐ Mobile Phone ☐ Electric Iron ☐ Stove for cooking (gas/electric only) ☐ Refrigerator/Freezer

B9. Please check the average monthly <u>household</u> income bracket that reflects how much <u>cash</u> income is earned by members of the household (all members, including yourself). Please select one category (amounts in shillings per month):
☐ Below 25,000 ☐ 25,000– 50,000 ☐ 50,001–75,000 ☐ 75,001–100,000
☐ 100,001–150,000 ☐ 150,001–200,000 ☐ 200,001–250,000 ☐ 250,001-300,000
☐ 300,001–400,000 ☐ 400,001– 500,000 ☐ Above 500,000

APPENDIX H – TWO-YEAR VOLUNTEER QUESTIONNAIRE

APPENDIX H: CHW TWO-YEAR FOLLOW-UP SURVEY

Date___________________________________

Name of Volunteer ____________________________________

Gender: ☐ Male ☐ Female

Name of Interviewer(s) _______________________

A. Demographics

1. What is your age? __________ years
2. Are you married? ☐ Married ☐ Single ☐ Divorced ☐ Widowed ☐ Living with partner
3. What is your religious affiliation?

   ☐ Catholic ☐ Protestant ☐ Muslim ☐ Other ________________________-
4. What is your tribe?
5. Are you the head of the household?

   ☐ Yes ☐ No → if no, the head of the household is my ____________________

B. Volunteer Activities

6. How long have you volunteered for?

   ☐ Less than 3 months ☐ 3-6 months ☐6-9 months ☐ more than 1 year

7. How did you hear about the volunteer program?

   ☐ Community leader ☐ Health Clinic ☐ Relative or friend who is a volunteer

   ☐ Relative or friend who is not a volunteer ☐ Radio ☐ Other ________________________

8. How many hours a week did you think the volunteer job would take when you first started? __________

9. How many hours a week does it actually take you to complete your work? _________________

10. How would you rate the difficulty of the tasks you had to perform?

	Very Easy	Easy	Not easy, but not difficult	Difficult	Very Difficult
Counting tablets					
Identifying side-effects					
Counselling on missed tablets					
Distributing condoms					
Filling out forms					
Distributing drugs					
Answering patient's questions					

11. How many patients do you currently supervise? ___________________

a. For you specifically, is this: ☐ Too few ☐ Too may ☐ Just right

b. What is the most number of patients you think a volunteer should be asked to supervise? ______________

12. Have you missed any scheduled visits? ☐ Yes ☐ No

a. Why did you miss your visits?

13. Did you provide patients with condoms? ☐ Yes ☐ No
If yes, do you know if they used them?
☐ Yes they did use them ☐ No they did not use them ☐ Don't know
If no, what prevented you from distributing condoms?

Administration and Training
14. Have you missed any volunteer meetings? ☐ Yes ☐ No

a. If yes, what were the reasons you missed the meetings?

15. Were the monthly meetings helpful? ☐ Yes ☐ No
a. If yes, what were the most helpful parts of the meeting?

b. If no, what can be improved?

16. Did the training sessions provide you with enough information to do your volunteer work with the patients? ☐ Yes ☐ No

If no, how the training could be improved?

17. What are the most important things that the Volunteer Administrator did for you?

18. Are there any things that you wanted the Volunteer Administrator to help you with, but which he did not help with? ☐ Yes ☐ No

a. If yes, what were these things?

Motivation

19. Did you have all the resources you needed to be effective as a volunteer? ☐ Yes ☐ No

a. What resources were the most helpful?

b. What resources would have needed to help you be more effective?

____

____

____

____

20. Have you ever volunteered in the health system in the past? ☐ Yes ☐ No

21. Are you volunteering anywhere else now ? ☐ Yes ☐ No

    a. If yes, where else ____

22. What part of the volunteering did you like the best?

____

____

____

____

23. What part of the volunteering did you like the least?

____

____

____

____

____

24. How much long are you willing to continue as a volunteer in this program?
    ☐ 1 more year ☐ 3 more years ☐ 5 more years ☐ 10 more years ☐ Other ____________

25. Have you, at any time, thought about leaving the volunteer program? ☐ Yes ☐ No

    a. If yes, why did you want to leave?

____

____

____

____

____

26. Do you think the community knows of your work? ☐ Yes ☐ No

27. Do you think the community appreciates your work? ☐ Yes ☐ No

28. Do you think the clinic workers appreciate your work? ☐ Yes ☐ No

29. Do you think the patients appreciate your work? ☐ Yes ☐ No

30. Do you think the ARV project team from Fort Portal appreciates your work? ☐ Yes ☐ No

Outcomes of Program

31. Have your patients benefited from the program? ☐ Yes ☐ No
    a. How?

32. Have you or your family benefited from the program? ☐ Yes ☐ No
    a. How?

33. Has your volunteer program brought any hardships on your or your family? ☐ Yes ☐ No
    a. If yes, what hardships?

34. Do you feel you have gained skills from being a volunteer? ☐ Yes ☐ No
    a. If yes, what skills?

Volunteer and Treatment Effectiveness

35. How effective do you think you were in helping your patients access treatment?
    ☐ Very effective ☐ A little effective ☐ Not effective ☐ No opinion

36. How effective do you think you were in ensuring that your patients remembered to take their tablets twice a day?
    ☐ Very effective ☐ A little effective ☐ Not effective ☐ No opinion

37. How effective do you think you were in identifying side effects of treatment in your patients?
    ☐ Very effective ☐ A little effective ☐ Not effective ☐ No opinion

38. Did any of your patients not do well on treatment? ☐ Yes ☐ No
    a. If yes, why do you think they did not do well?

39. Do you think your patients would have received treatment if this program did not exist and they had to go to another clinic? ☐ Yes ☐ No

40. How was your relationship with your patients?

Patient 1: ☐ Very positive ☐ Somewhat positive ☐ Neutral ☐ Somewhat negative ☐ Very negative
Patient 2: ☐ Very positive ☐ Somewhat positive ☐ Neutral ☐ Somewhat negative ☐ Very negative
Patient 3: ☐ Very positive ☐ Somewhat positive ☐ Neutral ☐ Somewhat negative ☐ Very negative
Patient 4: ☐ Very positive ☐ Somewhat positive ☐ Neutral ☐ Somewhat negative ☐ Very negative
Patient 5: ☐ Very positive ☐ Somewhat positive ☐ Neutral ☐ Somewhat negative ☐ Very negative
Patient 6: ☐ Very positive ☐ Somewhat positive ☐ Neutral ☐ Somewhat negative ☐ Very negative

General Opinions:

41. What do you think would have happened to the patients and the program if there were no volunteers to help?

42. What do you like about the volunteer program?

43. What do you not like about the volunteer program?

44. How can the program be improved?

45. Do you have additional comments not covered in this survey?

APPENDIX I: CHW FOCUS GROUP DISCUSSION TOPIC GUIDE

General Questions

1. Volunteers told us that they thought the work would take longer than it actually did take. Is this true? If yes, why did you initially think the work would take longer?
2. The volunteers told us that it is now easy to count tablets. Was it difficult in the beginning? What aspects were the most difficult? How did you correct yourself?
3. Were there any difficulties in identifying side effects or symptoms? If yes, what were these difficulties?
4. Volunteers suggested that the volunteer administrator should spend more time with the volunteers in the village? What was meant by this? What additional benefit would this bring? Can this benefit be realized through the monthly volunteer meetings?
5. How was the communication and cooperation between yourselves and the health workers? [Discuss this in general as opposed to specifically about one individual] [Depending on answer, probe further to find out more about the positive and negative things regarding this interaction.] What would have improved the interactions between yourselves and the health workers?
6. Why did you choose to volunteer in this program? What motivates you? What do you think motivates others [outside of this group gathered here today] to volunteer in this program?
7. When the district or the subcounty takes over the running of the project, how long do you plan to volunteer for this ARV program? Would you continue to volunteer if the transport and lunch refund were no longer available? If no, what other non-monetary incentives would motivate you to stay in the program?
8. If the ARV clinic in Rwimi continued, but the volunteers were no longer available, what would be the impact on the patient? Is it necessary to have volunteers in order for treatment to be successful? Would the clinic be able to manage on their own?
9. What does the volunteer recognition program mean to you? [If the majority talk about the incentives then ask – if we now gave you the gifts and the lunch at a regular volunteer meeting, is it then necessary to have the volunteer recognition program?] How does this program impact your motivation to volunteer in this program?
10. Do male and female clients respond differently to male volunteers vs female volunteers? Do you think people prefer female or male volunteers? Do males and females have different preferences for either a male or female volunteer?

Women:

11. For you as a women, what does it mean to be a volunteer in this program.
12. What are some of the difficulties faced by women in volunteering in this program that are not experienced by men?
13. What are some of the things that women can do in this program better than men?
14. What do you feel about the incentives that were given? Were they appropriate for women? What would have been a better alternative?
15. How does your husband (or how do family members) feel about your involvement in this program.

Distance:

16. What do you think about volunteers who live far away from Rwimi collecting drugs and managing their patient's issues from a HCII closer to where they live? Are there any positive aspects? Are there any negative aspects?

APPENDIX J: HEALTH WORKER FOCUS GROUP DISCUSSION TOPIC GUIDE

1. What are your thoughts about the role that volunteers play in:
    - Delivering drugs
    - Monitoring adherence
    - Monitoring side effects of treatment
    - Providing advice on prevention and distributing condoms

    What do volunteers do well and what could they improve upon *(probe on specifics depending on the answers they give)*?

    Do you believe volunteers have the skills and training to take on these roles?

    Do you think there was any duplication between the work of volunteers and your work? *(if yes, find out which areas were duplicated)*

2. How is the working relationship between yourselves and the volunteers?
    [probe to identify specific positive and negative aspects of the relationship]

3. Have the volunteers made your work easier or more difficult? *[probe to identify what aspects have been made easier and what has been made more difficult]* Are there instances where you have to do more work to support the volunteers?

4. Have the volunteers enhanced patient care? If yes, what do they provide that other patients in your clinic who do not have volunteers do not get?

5. What have patients said to you about the volunteers? What are the positive and negative things you have heard?

6. How effective was the volunteer administrator in coordinating the communication and activities between the volunteers and yourselves. What are the things that he did well? Are there any things that he did not do that you felt he should have done? Were you able to provide feedback to the volunteer administrator on the work of the volunteers?

7. If this program was established in another sub-county which did not have a volunteer administrator, do you think that clinic staff could take on the role of training and supervising volunteers?

8. What they feel about the incentives that volunteers received – just enough, too little or too much?

9. Have the volunteers made any unreasonable demands? How did you deal with these?

10. Do you see the volunteers as part of your team? Is there anything that you can recommend to improve the teamwork?

11. Would you make a recommendation that other health units engage volunteers to help them? Why or why not?

12. Are there any other thoughts that you would want to share with me about the volunteers? *(ask only if there is extra time available at the end of the focus group session).*

APPENDIX K: PATIENT SEMI-STRUCTURED IN-DEPTH INTERVIEW GUIDING QUESTIONS

Please let the client know that the purpose of this interview is to collect information about the ARV program and how we can improve. The conversation today will be very useful to us. Only the project team will know what is said here today, so they can be open. We will not tell the volunteers or the clinic staff what is discussed today, so they can be free with talking to us.

Understanding the need for a volunteer:

1. Do you know why you have a volunteer? Can you tell us what the volunteer is supposed to do for you *(intent is to identify if they understand the purpose of the volunteer in this program)*?
2. How do you feel about having a volunteer helping you with your treatment *(want to identify positive or negative feelings and to probe on any interesting things that may be said)*?
3. Do you think you could have managed your treatment without the volunteer *(probe to find out why they felt this way)*?

Frequency of visits:

4. How often does the volunteer come to visit you? How much time does the volunteer spend with you?
5. How often would you like the volunteer to come visit you and how much time would you prefer that they spend with you *(probe to find out why they have this preference)*?
6. For how long would you want to have a Volunteer supporting your treatment *(probe to find out why they picked the duration they did)*.

Volunteer roles:

7. What are the most important thing the volunteers do for you?
8. Are there things the volunteers does that you think may be <u>unnecessary</u>? What are these things?
9. Are there things the volunteer <u>does not do</u> that you think they should do?
10. What advice has the volunteer given to you? Has the advice been useful?
11. Are there questions you had that the volunteer was not able to answer *(make sure that you capture what these questions were)*?

Interactions with volunteer:

12. Would you have liked to choose your own volunteer? *(want to identify they were happy with the volunteer that was assigned to them)*
    a. If yes, who would you have picked and why would you have picked them?
13. How do you feel about the time that the volunteer spent with you *(want to identify positive or negative feelings and to probe on any interesting things that may come up)*?

Interactions with the volunteer administrator:

14. Has the volunteer administration (Peter Rwakilembe or Deo Tumukunde) come to visit you?
    a. If yes, what did they do when they visited you? Was their visit useful?

Voluntary aspect:

15. Do you think the Volunteers get Salary for the work they do? If yes, what kind of a salary do you think they get? If yes, would you be surprised to hear that they are not paid a salary?
16. Why do you think the volunteer does this work *(want to see how the patient perceives the motivation behind the volunteer's work. The question may depend on the answer given previously)*?
17. Someday, would you consider being a volunteer?
    a. If yes, why?
    b. If no, why?

APPENDIX L: PRE- AND POSTTRAINING KNOWLEDGE TESTS FOR CHWs

Volunteer Training Program
Pre-test

1. You can get infected with HIV by (tick all correct responses):
   - ☐ Unprotected sex
   - ☐ Contact with infected person's blood
   - ☐ Insect bites
   - ☐ Unsterilized or dirty needles
   - ☐ Toilet seats
   - ☐ Shaking hands

2. Have you heard of Antiretroviral (ARV) drugs? ☐ Yes ☐ No

3. Do ARV drugs cure AIDS completely? ☐ Yes ☐ No

4. What do you think ARVs can do for a person with AIDS?

____

____

5. How long does a person with AIDS have to be on ARV treatment?
   - ☐ One week
   - ☐ One month
   - ☐ One year
   - ☐ For life

6. Is it okay for a person taking ARV drugs to stop taking them for a few days or a few weeks?
   ☐ Yes ☐ No

7. Can a person on ARV treatment still infect others with HIV?
   ☐ Yes ☐ No

8. What are the ABCs of HIV prevention?

   ____

   ____

9. What are some of the major side effects of ARVs when a patient should see a clinical officer?
   - ☐ Being tired
   - ☐ Loss of feeling in both feet
   - ☐ Skin rash
   - ☐ Fever
   - ☐ Diarrhoea
   - ☐ Feel like vomiting
   - ☐ Jaundice (or yellow eyes)
   - ☐ Cannot see

10. How many tablets a day should a person on ARV take? ____________________

Volunteer Training Program
Post-test

1. You can get infected with HIV by (tick all correct responses):
   - ☐ Unprotected sex
   - ☐ Contact with infected person's blood
   - ☐ Insect bites
   - ☐ Unsterilized or dirty needles
   - ☐ Toilet seats
   - ☐ Shaking hands

2. Do ARV drugs cure AIDS completely? ☐ Yes ☐ No

3. What do you think ARVs can do for a person with AIDS?

____

____

____

4. How long does a person with AIDS have to be on ARV treatment?
   - ☐ One week
   - ☐ One month
   - ☐ One year
   - ☐ For life

5. Is it okay for a person taking ARV drugs to stop taking them for a few days or a few weeks?
   ☐ Yes ☐ No

6. Can a person on ARV treatment still infect others with HIV?
   ☐ Yes ☐ No

7. What are some of the major side effects of ARVs when a patient should see a clinical officer?
   - ☐ Being tired
   - ☐ Loss of feeling in both feet
   - ☐ Skin rash
   - ☐ Fever
   - ☐ Diarrhoea
   - ☐ Feel like vomiting
   - ☐ Jaundice (or yellow eyes)
   - ☐ Cannot see

8. How many tablets a day should a person on ARV take? ____________________

9. What are the ABCs of HIV prevention?

____

____

____

APPENDIX M: INFORMATION LETTERS AND CONSENT FORMS FOR PARTICIPANTS

UNIVERSITY OF ALBERTA

Information Letter
Volunteer Surveys and Focus Groups

Study Title: Community-Based Antiretroviral Treatment for AIDS Patients in Rural Uganda

Investigators
Arif Alibhai, Department of Public Health Sciences, University of Alberta (Tel: 0774-441188)
Dr. Walter Kipp, Department of Public Health Sciences, University of Alberta (Tel: +1-780-492-8643)

Study Purpose

The purpose of study to develop and test a model of community-based treatment for HIV/AIDS for patients living in rural areas of Uganda. We have recruited patients from the Rwimi sub-country to be part of a group who receives treatment in the Rwimi Health Centre III supported by a community volunteer and treatment partner. We are going to compare this treatment to one delivered in Fort Portal to see if the benefits are the same or better. As part of this study, we are also going to evaluate the benefit provided by the volunteer program.

Procedures

As a community volunteer in this treatment program, you are being asked to participate in a survey at this time and then a focus group a few months from now. As part of the surveys and focus groups, you will be asked to:

- Provide us with some basic information on yourself;
- Tell us your thoughts and perceptions of being a volunteer
- Identify positive and negative things about the volunteer program.

The survey should take no more than 45 minutes to complete and will be done at the Rwimi clinic . The focus groups will take approximately 2 hours and will also be done at the Rwimi clinic.. You will be reimbursed 2,000/= for transport for attending the interview and 2,000/= transport for attending the focus group.

Benefits

You will help the researchers and the Kabarole District better understand and improve the volunteer program. There are no direct personal benefits to you.

Risks

There are no risks to participating in the study. Your role as a volunteer will not be affected.

Confidentiality

The researchers will keep your information confidential and your name will not be reported with any of the results that are published. While we will do everything in our power to ensure confidentiality, we cannot guarantee that others in the focus group will do so. Data will be stored for five years in a locked cabinet at the Community-Based ARV Project Office in Muchwa as well as in a locked area at the University of Alberta in Canada. Only researchers and project staff will have access to the data.

Freedom to withdraw

You don’t have to take part in the study at all, and you can stop your participation at any time.

Contact

If you have any concerns about any aspect of this study, you may contact Dr. Joa Okech-Ojony from the Kabarole District Administration office at 0772-482106

UNIVERSITY OF ALBERTA

Information Letter
Health Worker Focus Groups

Study Title: Community-Based Antiretroviral Treatment for AIDS Patients in Rural Uganda

Investigators

Arif Alibhai, Department of Public Health Sciences, University of Alberta (Tel: 0774-441188)
Dr. Walter Kipp, Department of Public Health Sciences, University of Alberta (Tel: +1-780-492-8643)

Study Purpose

The purpose of study to develop and test a model of community-based treatment for HIV/AIDS for patients living in rural areas of Uganda. We have recruited patients from the Rwimi sub-country to be part of a group who receives treatment in the Rwimi Health Centre III supported by a community volunteer and treatment partner. We are going to compare this treatment to one delivered in Fort Portal to see if the benefits are the same or better. As part of this study, we are also going to evaluate the benefit provided by the volunteer program.

Procedures

As a health worker providing or supporting treatment in the Health Centre III, you are being asked to participate in a focus group. As part of the focus group, you will be asked to:

- Provide us with some basic information on yourself;
- Tell us your thoughts and perceptions of the volunteer program associated with the community-based treatment program.

The focus groups will take approximately 2 hours and will be held at the Rwimi Clinic. You will be reimbursed 2,000/= for transport for attending the focus group.

Benefits

You will help the researchers and the Kabarole District better understand and improve the volunteer program. There are no direct personal benefits to you.

Risks

There are no risks to participating in the study. Your role as a health worker will not be affected.

Confidentiality

The researchers will keep your information confidential and your name will not be reported with any of the results that are published. While we will do everything in our power to ensure confidentiality, we cannot guarantee that others in the focus group will do so. Data will be stored for five years in a locked cabinet at the Community-Based ARV Project Office in Muchwa as well as in a locked area at the University of Alberta in Canada. Only researchers and project staff will have access to the data.

Freedom to withdraw

You don’t have to take part in the study at all, and you can stop your participation at any time.

Contact

If you have any concerns about any aspect of this study, you may contact Dr. Joa Okech-Ojony from the Kabarole District Administration office at 0772-482106

Information Letter
Patient Interviews

UNIVERSITY OF ALBERTA

Study Title: Community-Based Antiretroviral Treatment for AIDS Patients in Rural Uganda

Investigators

Arif Alibhai, Department of Public Health Sciences, University of Alberta (Tel: 0774-441188)
Dr. Walter Kipp, Department of Public Health Sciences, University of Alberta (Tel: +1-780-492-8643)

Study Purpose

The purpose of study to develop and test a model of community-based treatment for HIV/AIDS for patients living in rural areas of Uganda. You are one of the patients from the Rwimi sub-country who is receiving treatment in the Rwimi Health Centre III supported by a community volunteer and treatment partner. As part of this study, we are also going to evaluate the benefit provided by the volunteer program.

Procedures

As a patient receiving treatment from the Rwimi Health Centre III under the Community-Based ARV program, you are being asked to participate in an interview about your experiences with your volunteer. We will be asking you what you think of the volunteer program and how it can be improved. Based on your decision, the interview will either be held at your home or at the Rwimi clinic and will take approximately one and a half-hour to complete. If you have to travel to the Rwimi clinic for the interview, you will be reimbursed 2,000/= for transport.

Benefits

You will help the researchers and the Kabarole District better understand and improve the volunteer program, which can also help improve your treatment. There are no direct personal benefits to you.

Risks

There are no risks to participating in the study. Your role as a patient will not be affected.

Confidentiality

No one except the researchers will know you're taking part in the study. Your name and your information won't be seen by anyone except the researchers. Data will be stored for five years in a locked cabinet at the Community-Based ARV Project Office in Muchwa as well as in a locked area at the University of Alberta in Canada. Only researchers and project staff will have access to the data.

Freedom to withdraw

You don't have to take part in these interviews and can choose to stop at anytime. If you choose not to participate or wish to stop your participation in the interview, you can do so freely without any impact on your treatment.

Contact

If you have any concerns about any aspect of this study, you may contact Dr. Joa Okech-Ojony from the Kabarole District Administration office at 0772-482106

Consent form for Patients/Health Workers/Volunteers

UNIVERSITY OF ALBERTA

Title of Project:
Volunteers in a community-based AIDS treatment program in Western Uganda: a sub-study of the Community-Based ARV Project

Part 1: Research information

Name of principal investigator: Arif Alibhai
Affiliation: University of Alberta
Contact information: 0774441188

Name of supervisor: Dr. Walter Kipp
Affiliation: University of Alberta
Contact information: +1-780-492-8643

Part 2: Consent of Subject

	Yes	No
Do you understand you have been asked to participate in a study?		
Have you read and received a copy of the information sheet?		
Do you know the risks and benefits of participating in the study?		
Have you been able to ask questions and discuss the study?		
Do you know that you can withdraw anytime without an explanation? You have the right to refuse to participate.		
Do you understand confidentiality? Do you know who has access to your personal information?		

Part 3: Signatures

The study was explained by: ____________________________ Date: _____________

I agree to take part in this study:

Signature or thumbprint of participant: _______________________________

Date: _______________________

Printed name: ______________________________________

Thumbprint

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of investigator: ____________________________

The Information Sheet must be attached to this Consent Form and a copy given to the research subject