

**Antiretroviral Therapy Access in Zambia:
Improving the Home-Base Care System**

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Abstract

Zambia is confronted with one of the worst HIV/AIDS epidemics in the world which had a tremendous effect on Zambian health and economy. As of June 2005, ARV drugs officially have been made available free of charge through public health institutions in the country. However, shortage of trained medical staff, distance of ART centers from people's community, and lack of transportation, represent major obstacles to ART access. Social barriers such as stigma, discrimination against HIV-positive individuals, gender inequality, and lack of education also represent great challenges to providing successful ART in Zambia. Home-based care community organizations (HBC) provide psychosocial assistance and education not commonly offered in public health services, which is a key to success of ART. If not dispensing antiretroviral drugs on a significant scale, they are facilitating access to treatment through advocacy, education, voluntary counseling and testing, providing home based care, and mental support. However, the Zambian government and government clinic do not recognize the full capability and value of HBC workers. As a result, government is effectively not involved with HBC. There are not funds allocated to HBC by the government, and there is a lack of referral system between HBC and public hospitals. Thus we propose two ways to improve relations between HBC programs and the government in Zambia. First, workshops for HBC workers, one hosted at the local level for HBC workers and another at the larger scale for HBC managers and government officials, will serve as new avenues for workers and government officials to meet and collaborate. Second, HBC organizations and the government should collaborate to standardize record keeping processes and develop a

centralized database to store information in an effort to increase quality of care for patients with HIV/AIDS.

Background and Motivation

Effects of HIV/AIDS in Zambia

UNAIDS reported at the end of 2001 that an estimated 2.1 million Zambians were living with HIV/AIDS, with an adult prevalence of 21.5% and an estimated 590,000 women infected (out of 1 million infected adults). The HIV/AIDS epidemic began in 1984 and today mainly affects women between the ages of 20-29 and men between 30-39. HIV/AIDS is primarily a heterosexually transmitted disease, unlike in the earliest stages of the HIV/AIDS epidemic in the United States, although mother-to-child-transmission accounts for approximately 30,000 new infections per year.

Compounding the issue of HIV/AIDS in Zambia, the per capita income is \$300, less than half what it was at the time of independence in 1964. Falling prices for copper, high foreign debt, drought, and persistent high population growth rate have contributed to deteriorating economic conditions – the onset of HIV/AIDS has also affected economic growth and exacerbated poverty rates. 2.9 million Zambians, or 29% of the entire population require food aid, with the result that in May 2002 the government has declared natural disaster due to actual and anticipated food shortages. In addition to the health crisis presented by lack of adequate food and water supplies, Zambia bears an enormous disease burden including the HIV/AIDS epidemic, measles, malaria, respiratory diseases, polio, and diarrheal disease. Despite these crises, almost all health facilities, including

hospitals and clinics lack adequate staff and medical supplies (including drugs and equipment) to adequately treat disease. Also, health facilities and medical staff in Zambia are perceived to have high levels of corruption, despite an active campaign hosted by the Zambian government to fight corruption in healthcare.

To date, there are many contributing factors for the growing HIV/AIDS epidemic in Zambia. However, the lack of infrastructure is a major compounding issue. Resolving this issue might be a very effective way to address other corollary issues such as the lack of medical supplies and medical facilities confronting Zambia. Currently patients seeking HIV/AIDS testing and/or treatment often have to walk prohibitively long distances to get to clinics and hospitals with the necessary equipment and supplies. In addition, after testing, samples must oftentimes be transported for analysis at great expense to laboratory facilities far away from the clinic where the sample was drawn, which also implies long waiting periods for the patients who would then have to travel again simply to know the results of the tests (Personal Communication, 2005). Treatment for HIV/AIDS also requires strict lifelong adherence to medication. This is something that has been shown to be very difficult without regular support and observation by healthcare professionals and social support. Requiring patients to travel extensively (which they may not be able to do if they are severely ill) acts as a deterrence to effective treatment.

Zambia is confronted with one of the worst HIV/AIDS epidemics in the world. It must be noted that additional financing is needed to expand HIV/AIDS prevention, treatment, care, support and mitigation activities. To scale up the response to HIV/AIDS in the short-term, Zambia must concentrate on mobilizing non-governmental

organizations, community-based organizations, people living with HIV/AIDS and private sector companies. An estimated 16.5 percent of the adult population in Zambia is infected with HIV. Roughly 84 percent of the total is between the ages of 20 and 29. Only 9.4 percent of women and 13.8 percent of men in Zambia have ever been tested for HIV.

After noting for low testing rates, an estimated 17.8 percent of women and 12.9 percent of men are currently infected. Infection rates are higher in urban Zambia than in rural parts of the country. Sexual contact is the number one mode of transmission for HIV in Zambia, which is roughly 78% of the total number of cases.

HIV/AIDS and the Economy

The HIV/AIDS epidemic in Zambia has led to sharp economic decline. The disease attacks the most productive age group, which has severely impacted the human capacity of Zambia. In addition, the decline in human resource capacity of the health sector (e.g. physicians, nurses, pharmacists) has made a devastating effect on the country's ability to manage the epidemic. For businesses, HIV/AIDS has led to increased expenditure for employee health care costs (e.g. ARV treatment), burial costs, recruitment and training of new employees. As there is a high turnover rate for positions, employees are not as experienced and thus, productivity levels have declined. The decline of the workforce in numbers has led to a decline in total revenues. HIV/AIDS has led to increased absenteeism due to employees coping with the disease, caring for family members of friends with the disease, and attendance of funerals. At the household level, HIV/AIDS has impacted families in which family members are suffering from the disease. An increased financial burden is placed on the family to make up for a loss of a productive wage earner and the high financial costs that come with HIV/AIDS treatment and care.

Critical International Players

Zambia has received a considerable amount of financial support for HIV/AIDS program management and implementation in the past couple of years. The largest international player as of late is the US government.

1) US government

The US government's involvement in Zambia mainly comprises of the regional operations of the CDC and USAID. In addition, USAID funds numerous US-based NGOs (e.g. PSI, CARE, FHI) who also have a major presence in Zambia.

Under President Bush's Emergency Plan¹, Zambia received \$57.9 million to support a comprehensive treatment, prevention, and care program in 2004.

2) The Global Fund

The Global Fund has been granting Zambia with large sums of funding to implement HIV/AIDS programs. The Global Fund provided \$94,675,784.00 to the Zambian government for HIV/AIDS prevention, treatment and care during the Round 4 allotment of funds.

3) The World Bank

The World Bank is funding 'The Zambia National Response to HIV/AIDS Project (ZANARA).' ZANARA aims to reduce the spread of HIV/AIDS by increasing medical access and support for HIV/AIDS patients. By taking control of the AIDS situation, the socioeconomic impact of the disease can also be mitigated. The project focuses on the financing of high priority interventions for which significant funding gaps exist.

¹ In 2003, President George W. Bush announced the Emergency Plan for AIDS Relief, a five-year, \$15 billion U.S. Government initiative that aims to provide treatment to at least two million HIV-infected individuals, prevent seven million new HIV infections, and provide care and support to 10 million people living with and affected by HIV/AIDS, including orphans and vulnerable children.

4) GTZ

Zambia is a priority country in German Development Cooperation. GTZ has been working in the country for 28 years on behalf of the German Federal Ministry for Economic Cooperation and Development (BMZ) and one of its missions is to provide support to implement HIV/AIDS programs.

5) UK Department of International Development (DFID)

DFID has been actively involved with the fight against HIV/AIDS in Zambia. Most recently, they have funded projects on designing a national multi-sectoral response to HIV/AIDS while encouraging appropriate, effective and sustainable responses to the HIV/AIDS epidemic. DFID has also funded capacity-building for the evaluation of HIV/AIDS education in the country through trainings, workshops, and the review of interventions for HIV/AIDS prevention.

What is ART?

The introduction of highly active ART (HAART) in 1996 (where available) was accompanied by a dramatic decrease in the morbidity and mortality related to HIV infections in the world. Successful ART is associated with improved quality of life, suppressed HIV viral load, restored immune functions, and preserved therapeutic options. Another major impact of ART has also been the decline in the major opportunistic infections causing tuberculosis, pneumonia and disseminated cytomegalovirus infections.

Access to ART worldwide and in Zambia

Before June 2005, Zambians had to pay \$150 per year to get access to ART (IRIN, 2004). In a country where 80% of people are under the poverty line, living on less than \$1 a day, and largely unemployed, ART were therefore unfeasible as a treatment option for the vast majority of infected citizens. President Mwanawasa's government is currently covering 15,000 (11%) of patients in need of ART.

On June 13, 2005, the Minister of Health, Dr. Brian Chituwo, announced that ARV drugs would be available free of charge through all public health institutions in the country. The ARVs are also free through Center for Infectious Disease Research in Zambia (CIDRZ). This is a large, PEPFAR funded program, which distributes ARVs in 18 out of approximately 20 government clinics in Lusaka. The ART clinic within the government hospital is where patients go for all of their appointments

Problems

However, shortage of trained medical staff and distance of ART centers from people's community, and lack of transportation, represent major obstacles to ART access. Social barriers such as stigma, discrimination against HIV-positive individuals, gender inequality, and lack of education also represent great challenges to providing successful ART in Zambia.

HBC as Treatment Methodology

Community-based organizations are emerging as a complement to public health efforts in providing ART. If not dispensing antiretroviral drugs on a significant scale, they are facilitating access to treatment through advocacy, education, voluntary counseling and testing, providing home based care, bulk purchasing of medicines and mental support. Therefore, they provide psychosocial assistance and education not

commonly offered in public health services, which is a key to success of ART. They are also focused on helping groups of people who tend to be left out from the public sector healthcare, such as poor, orphans and women gain access to treatment. Community organized Home Based Care (HBC) does not require extensive and costly infrastructure such as hospitals and clinics and simultaneously is a possible solution to issues like treatment adherence and access to healthcare by individuals who may be too sick to attend a hospital/clinic (Wilson, 2005). This approach also allows for patients to receive regular attention by healthcare workers and have their treatment programs supervised.

Zambia has a large number of community based HBC programs providing a wide range of services. For example, CARE International did an assessment of 12 HBC programs in Lusaka and found that 4 are providing ARVs. Other services include basic nursing care (11/12), symptom management (8/12), pain relief (8/12), spiritual and emotional support (12/12), inheritance guidance (6/12), VCT (6/12), TB Treatment (7/12), support for OVCs (11/12), food aid (10/12), and HIV awareness (12/12).

Problems Associated with HBC

HBC community organizations are too facing lack of funds and staff shortage to meet and sustain human and operational needs of their community. The government clinics do not recognize the full capability and value of HBC workers. As a result, government is effectively not involved with HBC. The government provides no funding to HBC community organizations and there is no referral system between HBC programs and government hospitals where ARVs are distributed free of charge.

We propose that organized medical record system at the community organization will better flow of information between 1) HBC worker and the central HBC system, 2) HBC organizations themselves, and 3) HBC and government.

The benefits of better flow of information will ensure higher quality of healthcare provision by HBC workers and hopefully also lead to an establishment of a good referral system between HBC and government hospitals.

Analysis of the current situation

Medical record keeping and flow of information

Center for Infectious Disease Research in Zambia (CIDRZ), which covers most people in Lusaka who are on ARVs, keeps extensive medical records, and compiles all of the information in an electronic database. This is the only organization that keeps electronic data base. CIDRZ has a record keeping system whereby paper forms are filled out by clinicians at the clinics and HBC workers on the field. Data entry clerks enter these forms in to a computerized patient tracking system created by CIDRZ. All other organizations (NGOs, hospitals not covered by CIDRZ, and community organizations) keep paper-based records. There is no standard method of record keeping; Each organization have their own paper forms and procedures.

On the community level there is only minimal, unorganized paper based record. The caregivers working with CIDRZ program have 'official' CIDRZ forms that they are supposed to fill out each time they visit a patient. These HBC workers seem to do

reasonably well in terms of filling them out and returning them to CIDRZ. However, HBC workers have no access to a CIDRZ.

Many HBC programs have a hard time with collecting, keeping, and accessing medical records. One example is an HBC program which operates out of a building on Mother of Mercy Hospice property. The clinical staff of the hospice keeps a basic written medical record of each of the patients admitted to the hospice program and these records are stored in the hospice. At the same time, HBC program keeps their own paper-based record of their patients. Even though, these records are on the same property, the information from the records is rarely transferred between the HBC and the hospice.

HBC records are only accessible to nurses, and information is only recorded when a nurse sees a patient. HBC workers, which see patient much more frequently, do not have access to these records to input new information. They are supposed to keep their own log book on which they record the status of a patient at a time of each visit. However, not many caregivers actually keep a log book. They lack motivation because they do not understand why good health monitoring and recording is important.

Lack of communication

Government clinics do not recognize the full capability and value of HBC workers. As a result, government is effectively not involved with HBC. Officially, the executive body of Ministry of Health, The Central Board of Health (CBoH), has a person appointed to oversee HBC. However, the efforts of this person are undermined by the fact that she is understaffed and underfunded. There is almost no communication

between community-based organizations and government. There is no established referral system between HBC organizations and public hospitals.

The level of communication between community based organizations themselves is minimal. Also, many organizations has complained that CIDRZ does not share information horizontally, such as with other NGO's, clinics, hospices, etc.

The caregivers in HBC programs visit patients as often as 2-3 times per week or as infrequently as once a month. Nurse visits are even less frequent.

Some communities are inaccessible during the rainy season, so during the rainy season the caregivers within the community are solely responsible for the patients, with no external support. There is shown to be great potential for HBC workers to be a major means of increasing access to healthcare, particular with HIV/AIDS, but there needs to be a system in which the HBC visits can be more regular with better trained professionals if the quality of HBC is to be improved and actively utilized as a major healthcare delivery paradigm in Zambia.

Information flow and record keeping

There is no standard way of record keeping. HBC workers are not motivated to keep records because they do not realize its importance and hence do not make efforts to maintain and update existing records nor systematically make efforts to collect and preserve data in a satisfactory manner. Furthermore HBC workers generally do not have access to the medical record base. As a result, they lack critical information about their patients, a lack that could result in reduced quality of care for the patient, particularly when knowledge of past medical history is necessary to make treatment decisions or when giving medical advice.

Given the lack of information flow and substandard record-keeping methodologies, it is critical for any proposed solution plan to have a mechanism to facilitate these aspects. There should be a system in place to provide convenient access to compiled patient information. The information should be easy to read and the system to retrieve information should be systematic and user-friendly so as to prevent errors or have it be prohibitive to use. The healthcare workers should be trained in retrieving data from this database as well as collecting data from their patients. Ideally the information collected from patients will be compiled in a timely and ordered fashion in such a way that later retrieval and analysis will also be possible. Also, there should be a mechanism to create a referral system for care workers and patients.

Concept proposals

Solution 1: Workshops for HBC Workers and Government Officials

The most effective means of building communication and collaboration between HBC workers from different NGOs and with government officials is for people to meet face-to-face. Zambians involved in ART initiatives will recognize each other as allies against a common enemy and hopefully become compelled to collaborate. We propose two different sets of workshops for HBC workers, one hosted at the local level for HBC workers and another at the larger scale for HBC managers and government officials.

At the most local level, HBC workers from different organizations should be able to learn from each other and also coordinate projects as necessary to improve patient care. Organizing local workshops on a monthly basis would provide a time and space for

HBC workers to meet each other. Furthermore, opportunities for education are valued in Zambia, and HBC workers would be motivated to attend these workshops to receive continuing education in care. Workshops would also show care providers how the data they collect via paperwork can indicate trends in patient care, which then produce ideas on how to improve care. Workers would become motivated to improve care by meeting with other HBC providers and by understanding how their day-to-day work affects the larger picture.

The second set of workshops aims to bridge NGO HBC workers and government officials. As stated before, the government of Zambia does not recognize the work of NGO HBC programs. There is a serious lack of communication between NGOs and the government. We hope that by compelling them to meet each other face-to-face in this conference setting, both groups will begin to appreciate each other's work. Ideally, they would begin to collaborate to make ART access in Zambia as effective and efficient as possible. Since these workshops are meant for a larger geographical region, they would only be held every three to six months.

We propose workshops as a means for improving communication for HBC programs both amongst each other and with the government. They are also avenues to provide continuing education and to show the broader picture of how data collection through paperwork can indicate ways to improve the HBC programs. For the future, implementing workshops also will serve as a method to ensure a degree of consistency and controlled quality in the care provided by HBC workers.

Solution 2: Standardization of Paperwork for HIV/AIDS Patient Care

There needs to be initial research into the type of paperwork currently used in HBC systems. A better understanding of how existing systems of paperwork have functioned in Zambia would give us a better idea of how to either improve upon the existing model and/or devise a completely new system. As part of our project is looking into other methods of data collection, such as through the use of PDAs and computer technology, thoroughly looking at how paper-based information collection has worked in Zambia and looking at how effective they have been could be helpful.

In addition, we would like to propose that all HBC workers and staff involved in data collection and management undergo training and workshops to ensure that everyone fully understands the data collection system. Also, we would like direct feedback from the workers and staff who will be administering and maintaining the system to get an idea of what to streamline and to understand and incorporate what would make the system better. A major problem with data management and collection systems designed and administered without continuous development and improvement is that the system will eventually fall into disrepair. Also, systems designed with minimal input from the individuals who will use the system tend to be unsuited to their particular needs, which results in low rates of usage of the system. As we have ease of usage and maintenance as key goals, we would like to look into data systems that are standardized and simplified as much as possible, as well as being tailored to the specific needs of the users and patients.

In addition to actually developing or refining a data management system we also need to have a process by which the system will be introduced into the environment in which it will be used. We would like to ensure that there will be programs that will adequately demonstrate the effectiveness of the system and convince people to utilize it.

There are many benefits in a centralized, electronic database that clinicians, health workers, and researchers could take advantage of. Much of HIV/AIDS care depends on analyzing trends in a patient's health status from month to month – having an electronic database would mean that analyzing data would be simple with the help of software, which would have enormous benefits in patient care. Having a centralized database would also facilitate epidemiological studies of the area, which would mean policies and treatment plans better tailored for that specific area.

Conclusion

ART access in Zambia is a complex problem with no single absolute solution. Our proposal focuses on home-based care systems because we believe that they show high promise as the future of HIV/AIDS treatment in settings with limited resources. Home-based care has been shown to be effective means of treatment support and monitoring, but HBC programs lack coordination and standardization. Another major problem is their lack of collaboration with the Zambian government. We provide two possible solutions that address these issues. Workshops for HBC workers and government officials to meet each other would facilitate communication between these groups. Creating simplified, standard paperwork and a central database for collected data is an important project for HBC programs and the government to collaborate on. These solutions tackle what we believe to be the most glaring problems with home-based care in Zambia.