

How big of a problem is ART adherence in Zambia?

When people start feeling better, they stop taking their drugs. This is the biggest problem. People need to be educated about why it is so important that you take ALL of your drugs FOR LIFE.

Is there a central monitoring entity/location (nationally, locally) in Zambia?

National AIDS Council (project from Central Board of Health (CBoH), which is currently being dissolved into Ministry of Health) holds any statistics that exist. Refer to "The HIV/AIDS Epidemic in Zambia" (A few copies were sent to you) (esp. p.87) book which has charts, statistics. This is the type of information which is available and gathered on a national and local level. NGOs, etc gather statistics, but NAC takes the responsibility for compiling the statistics and gives an overall picture of statistics country wide.

Is there a centralized database of HIV patients' information?

UTH is beginning to computerize medical records, so they probably have the information from UTH patients. However, UTH does not have information for other patients, and this system is just being started. This database is being based on the medical record number that the patient is given (this is the same medical record number used for patient's blood samples that are sent to Kalingalinga lab).

CIDRZ also keeps extensive medical records, and compiles all of this information in an electronic database. So all information for all CIDRZ patients (which is most people in Lusaka who are on ARVs) is in this electronic database. However many organizations have complained that CIDRZ does not share information horizontally (ie with other NGOs, clinics, hospices, etc). CIDRZ may share information with CBoH, but this would likely be aggregate data in a periodic report. Again, this database is based on a medical record number, not the patient's name.

How involved is the government with home-based care?

Government is NOT involved with HBC. There is a person at CBoH who is supposed to oversee HBC, however she is not able to do much, as she is underfunded and understaffed. She does not even know what/where all of the HBC programs in Lusaka are. She does have an HBC manual produced by CBoH, but many HBC programs do not even use this manual (they have produced their own manuals).

Government clinics in general do not even recognize the full capability and value of HBC workers. However CIDRZ has involved HBC workers with their ART program and patients.

Do Zambians trust the local or national government? What about NGOs?

When it comes to the constitution of the country, Zambians do not trust the government, they trust the NGOs. For ARVs, people trust NGOs more, because through NGOs (mainly CIDRZ) they get free ARVs, but through the government they have to pay for ARVs.

Some NGOs have been working with the community for a long time (ex. Kara Counseling, where Dr. Steve Gerrish works, and World Vision), so people trust these programs. They provide continuous, reliable care, unlike the government.

Healthcare is under the national government, not the local government. Local government is supposed to monitor sanitation and hygiene, but they don't do a good job of monitoring this, so people don't trust them.

What services do HBC programs generally provide (ie. Treatment for opportunistic infections) and how often?

Many HBC programs only provide basic household support (washing dishes, cleaning the house, fetching water), and basic care for the patient (bathing the patient, monitoring their progress and reporting it, providing adherence support, providing emotional support, and education. In some programs, a nurse will occasionally visit the patients and prescribe drugs. However regular caregivers can not distribute drugs. The caregivers in HBC programs visit patients as often as 2-3 times/week or as infrequently as 1 time/month. Nurses visit patients even less often. HBC visits depend on location of the program and patients, transportation to get to the patients, number of staff in the HBC program. Another point is that 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.

CARE International did an assessment of 12 HBC programs in Lusaka. Results of how many HBC programs provide different services were published in the report, and are as follows: HBC programs provide basic nursing care (11/12), symptom management (8/12), pain relief (8/12), spiritual and emotional support (12/12), inheritance guidance (6/12), bereavement counseling (11/12), hospice care (0/12), VCT (6/12), TB Treatment (7/12), support for OVCs (11/12), food aid (10/12), HIV awareness (12/12), ARVs (4/12 – 2 of the 4 programs that provide ARVs are based in a hospital).

Report by CARE International: "Home Based Care in Zambia: A Rapid Assessment of Optimum Practices of 12 Home Based Care Organizations in Zambia" August, 2005

How involved are HIV patients on ART with the HBC programs? How can we motivate them to be more involved?

Most of the counselors at VCT centers are HIV positive. It is better for VCT counselors to be positive because they can relate personal experiences, and say "I am going through this as well." It makes more of an impact.

Also there are support groups for HIV + people, which are generally also led by HIV+ people. The people in the support groups are good for educating others (about getting tested, how to take the ARVs properly, how to treat side effects, etc), encouraging people to get tested and get on/stay on ARVs.

What would you identify as the biggest problems with ART access?

Distance of ART centers from people's community, and transportation to get patients to these ART centers, is the biggest problem. ART centers need to be in every community so that they are easy for patients to get to. Many people know that if they get to an ART center, they can get ARVs, but they just can't get to the center (lack of transportation). This is even worse in the rural areas, where ARVs are in the government clinic, which is in the provincial town, but many people live outside of the provincial town, so for them

to get to the government clinic is very difficult even once, let alone multiple times or every month.

Do patients pay for treatment at all?

Patients do not pay for ARVs. They are free through CIDRZ, and through the government. (Before ~June 2005 you had to pay ZMK 40,000 per month to get ARVs, but now the government provides ARVs for free). If patients are enrolled in the CIDRZ program, then anytime they are sick they go to the ART clinic run by CIDRZ (but physically located at government clinics) and receive all treatment, drugs, etc for free.

For general healthcare for patients who are NOT on ARVs, people generally go to their local government clinic. At the government clinic, you pay a monthly “scheme” fee (like insurance) of ZMK 2,500 – 5,000 per month. If you pay this monthly fee, you then receive all your treatment and drugs at the clinic for free. You have to pay additional fees if you get referred to a specialized center (usually UTH) for things like X-rays or surgery.

What is the mobile cell network coverage like in rural vs urban areas?

Celtel covers a 30km radius from each of the 9 provincial centers (including Lusaka). So in the very rural areas more than 30 km from a provincial center, there is not much coverage. These 30 km radius circles around each provincial center do NOT overlap, so there are gaps in coverage.

There is land line coverage EVERYWHERE in Zambia. But this does not mean everyone has one (many people can not afford one).

In rural areas, most people rely on radios for communication (hospitals, some schools police stations, and clinics in rural areas communicate with each other through radios)

How many people have cell phones in Lusaka vs rural areas?

Population of Lusaka = 2 million

Telecel has 90,000 subscribers

Celtel has >100,000 subscribers

Safe to say that <25% of people in Lusaka have cell phones.

In Lusaka, there are “pay phones” everywhere. These pay phones are a wooden booth, where a man stands inside with his cell phone, and you can pay him to use his cell phone.

Quote from Chisimba: “In rural areas there are land lines and radios. That’s it.”

There are ~500,000 civil servants (government workers) in Zambia. About 50% of these people have cell phones.

List of community-based organizations in Zambia?

Register of Societies run by the government. All organizations are supposed to be registered with this group. A fee of ZMK 200,000 is required to register. It is unclear how much information the Register of Societies maintains about each organization (ie do they just have a list of names of the organizations, or do they actually have information about them?).

Are they providing ART?

ART is generally provided through a clinic, hospital, etc, not through community-based organizations.

What are their technical capabilities in keeping track of patients, activities and spending?

Essentially all record keeping is done on paper (the only main electronic database/record keeping is the CIDRZ database). Organizations each have their own paper forms and procedures for record keeping, there is not a centralized method or system. Many organizations do not do much record keeping on the community (HBC) level. Organizations (on a higher level) will maintain records of activities and spending (ie at the CARE International office they will keep records of spending), but on the community level/government clinic level there is only minimal, unorganized paper based record keeping.

What is the level of communications between community-based organizations and government?

There is almost no communication between community-based organizations and government. There is communication between HBC programs and the ART clinics run by CIDRZ. The ART clinics are physically located at the government clinics, but the HBC programs do not generally go beyond CIDRZ (ie they don't interact with the government).

What is the level of communication between community-based organizations in Zambia?

Minimal.

There are some NGOs that cover a large area (ie Catholic Archdiocese has ~60 HBC sites all over Lusaka, World Vision covers a large part of Southern Province), so in this respect these organizations cover a large physical area, and interact with a large number of people.

What is the level of involvement of PLHA in providing healthcare in Zambia?

See "How involved are HIV patients on ART with the HBC programs? How can we motivate them to be more involved?" answer above.

Is there an incentive to involve PLHA in providing healthcare?

It is definitely good to involve PLHAs (as stated above) in more social aspects of healthcare (VCT, counseling, support groups).

Is there a strategy developed for doing this?

Nope.