

[This document was prepared for students at MIT to instruct them on "Continuum of Care" in the Matero community.]

Continuum of Care: Lessons from the Matero Compound template for community-based healthcare

On October 3, 2005, the University of Zambia and Ridgeway Medical students visited the Matero Compound to learn first-hand how the community-based health network operates. The goal of the day in Matero was to give students a complete picture of the "continuum of care" within one urban community in Zambia. Students spoke in small groups with representatives from the community pediatric hospice and home-based care program. The day also included songs/performances by local orphans and vulnerable children and programs by community peer educators, both focusing on HIV/AIDS. The children first welcomed us with a song in Bemba, recited poems about HIV/AIDS and the effects on their family, and performed a skit about the abuse of a school girl who was forced to find a "sugar daddy" when her parents died from HIV/AIDS. Peer education in Matero is done through a series of performances in local bars, schools, and homes on subtopics that include VCT, PMTCT, STIs, and abuse. We saw performances about VCT and PMTCT. Through this program, the students had an in-depth look at not only community health workers in Matero, but also the people affected by HIV/AIDS and what is being done within the community, by the community to promote awareness and education. Below is a compilation of the student interviews with health workers from each step along the community continuum of care.

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Subtopic: Hospice
Katebe Sakala, Mike Tongo

Because of the escalating levels of HIV positive people and those who are sick with full blown AIDS, there has been a rise in the need for these people to be cared for in an environment of cleanliness, care and love. It is comforting to see that a number of hospices are being set up to provide a place where these sick people can die peacefully. One such initiative is the Matero pediatric hospice which is currently under construction. Hospices have been seen to be very important because they provide specific healthcare. To help us get an in-depth knowledge of what a hospice is all about and its other operations, we talked to John, a clinical officer at the Matero hospice.

Part of John's work involves training community-based health workers. A hospice caters for everyone in a community and beyond, and when a patient is referred to a hospice from a district clinic, tests are done. Care and counseling are provided but not the administration of ARVs.

John trains CBHW to identify people with diseases such as TB and also train them as how to monitor patients. These trainings are done through seminars or personal talks. Health workers are trained to go into the community to bring those who are very sick. At a hospice HIV test is done on all patients to determine their status. Sometimes when the patient is not in a critical condition this test is done without the patient's consent, but the patient is talked to after the test. A hospice receives patients from home based care, Clinics etc. Families usually are the ones who decide to send their sick to a hospice. The hospice does not only rely on patients referred by district clinics. The problem is that the government does not really offer any support, hence the cost of drugs are quite expensive. ARVs are given by clinics but monitoring is done by community health workers. [Note: this has recently changed, and now ARVs are provided free of charge to patients. Before June 2005, ARVs cost each patient 40,000 Kwacha per month (~9USD)].

Access to healthcare is being improved throughout the teaching of community health workers, teaching people preventative measures and how to monitor patients on ART. Since some people have negative attitudes towards a hospice, the health workers have to make sure that people are getting better for others to get encouragement.

One of the greatest challenges in caring for the sick are that for some people, a hospice is a scary place – it is a place of death. The challenges of money, manpower, materials, medicine and equipment cannot be overlooked. An emotional challenge that health practitioners face is the limit of how far they can go to help out also the challenges of telling the patient's family of the plight of the patient. Seeing people die after caring for them is an emotional strain. There is a need to motivate health workers to be committed to the sick.

The number of people with HIV AIDS has increased; hence there are long lines of people waiting to be given ARVs. The good thing is that nowadays, people have confidence in ART, in spite of their side effects. A hospice normally keeps people until they are stable, recover or die. Some people decide to be discharged on their own free will; they choose to die at home.

At district hospitals, follow-ups of the patients on ARVs are not done properly, only the hemoglobin test is done when the patient goes for review. A general check on the patient's condition is not done. In contrast, a hospice's follow-ups are done through training of family members; hence there is always a link between the patient and the hospice. Some patients are referred to the University Teaching Hospital if their condition cannot improve.

In conclusion, some of the above raised issues require serious attention for us to ensure that the needs of the patients are met.

Subtopic: Community Nurse (CN)

Kateula Sichalwe

The community nurse (CN), Christopher, has been working in the various zones of Matero and nearby places. The church has been very actively involved in the fight against HIV/AIDS. Records are collected on paper and kept under lock and key. Christopher feels that government clinics have respect for the referrals made by the CN and community nursing assistants (CNAs). The major challenge is to have people talk.

Subtopic: Community Nursing Assistants (CNAs) via the community nurse

Chishimba

The Matero home-based care program focused on pediatric care called "Arms Reach Care". 30 community nursing assistants (CNAs) have been training for 7 weeks for arms reach care. The program aims to reach the homes of 150 pediatric patients, all of which will be monitored by the community nurse, thus allowing a greater number of patients to be effectively monitored and treated. Many of the patients are recommended by the church.

By 3 October, 2005, the home launched its initial CNAs who will handle the already identified 30 pediatric patients and training family care givers (FCGs). Before the launch of the 6 CNA's, the community nurse trained the CNAs. The community nurse trained the FCGs and made rounds on patients. He trained the first 30 FCGs for 5 days. Currently, the model of ARC is:

PATIENT ↔ FCG ↔ CNA ↔ CN ↔ Matero Clinic

Interview:

1- describe your role in community-based healthcare in terms of the types of services you provide and the patients you treat

A: The patients are children 15 years and younger, with chronic illnesses but not permanently disabled.

2- Where do you get the resources?

A: Currently, the program is donor funded. Only a single donor is funding the program but applications have been made to the global fund for HIV/AIDS and to funding organizations.

2b: What about transport

A: There is not vehicle but the CN has petty cash he can use for the hospital and to take busses. When there is a patient to be serviced he hires. The CNAs don't have any form of transport but they stay in the communities so should have easy access to patients.

4- How do you identify patients?

A: Mainly with the help of the church and also during the focus group discussions. Lately, guardians bring their kids to the program. Of course, they have to meet its criteria. The guardians of the patients are trained as FCGs.

5-How do you identify CNAs?

A: Mainly via the churches. Must meet a set of requirements [note: these clinical requirements help to identify HIV+ children who are not currently on ARVs].

6- How do you keep records?

A: First, there is a standard form which the CNA fills in at every visit. It also acts as guidance to the necessary clinical parameters. Everything that is done to the patients is recorded, whether by the CNA or the FCG. This is then handed to the CN who files it. A referral form from UTH has been standardized between the program and the clinic. The CN helps fill this in.

7- How are your services linked with other types of community healthcare in the district health clinics?

A: Because of regular meetings with all stakeholders, all service and healthcare providers are known. When a patient requires special medical attention, s/he is referred to the (government) clinic. IF a case outgrows pediatrics, s/he is referred to healthcare providers for adults.

8- How is your relationship with government healthcare?

Currently it is not much. The program refers to the government clinics, who have agreed on a standard of information to be passed. But government clinics do not recognize the CNAs (as health workers). There is a need to improve.

9-What is your greatest challenge?

-To have the patients tested for HIV;

-Technically, the laboratory process because blood samples get lost and the child has to come back to the clinic, sometimes 3 times to get the same sample collected.;

-Over- dependence, sometimes people expect that the CN came do more than provide healthcare, e.g. give them money and food.

10- If the resources were available (e.g. money and workers) what additional services would you like to be able to provide?

- Psychological counseling

- Laboratory facilities