

Acceptability of a Modified Directly Observed Therapy Approach to Improve Adherence to Antiretroviral Therapy

A pilot program to introduce highly active antiretroviral therapy (HAART) in public sector facilities for the management of HIV-infected persons has been introduced in Mombasa, Kenya. Provision of HAART in the public health sector is a new concept, especially in Africa, and a major concern is patients' ability to adhere to the strict HAART medication schedule. Patients need to take at least 95 percent of their medications in order to achieve undetectable viral loads, which is the goal of HAART therapy.

One method to enhance adherence to antiretroviral (ARV) medications is known as directly observed therapy (DOT). This treatment strategy, originally developed for tuberculosis patients, uses health workers or community volunteers to watch clients take each dose of their medication. A DOT strategy for AIDS treatment is called DAART, for "directly administered antiretroviral therapy," and supports patients in taking medications as required, as well as in helping them to develop good medication-taking behavior for long-term use.

Theoretically, a modified DAART strategy could be carried out through frequent visits, either by the patient to the clinic or by a provider to the patient's home. To develop a strategy acceptable to patients and health workers, Horizons and its research partner, the International Centre for Reproductive Health (ICRH), conducted a qualitative study in Mombasa, Kenya, from August to September 2002. Specifically, researchers sought to determine the acceptability of a clinic-based approach versus a home-based approach, the potential role of family members and support groups in fostering adherence, and clients' willingness to pay for drugs and monitoring tests.



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DAART nurse Raymond Ngwai and community health worker Zilfa Mohammed of Likoni Health Centre, one of the clinics in the study.

Methods

Researchers interviewed people living with HIV and AIDS and health workers at health facilities providing HIV/AIDS care services in Mombasa. In-depth interviews were conducted with 38 purposively selected clients of four HIV care clinics and one home-based care program. Of the total, eight were using services at the COPHIA home-based care program, 18 were undergoing preventive treatment with INH and Septrin at two HIV care clinics, eight were receiving care at the provincial public sector hospital, and six had been in the Kenya Ports Authority workplace ARV program, which was ultimately discontinued due to lack of funding.

Recruitment of subjects was limited to those receiving care at the main public health facilities, since these individuals had already identified themselves as HIV-infected and would be among those patients most likely to seek treatment when HAART services were subsequently introduced. Because support groups for people living with HIV/AIDS are not very active in Mombasa, and most HIV-infected persons have never been tested for HIV, this restricted the identification of eligible persons within the community for this study.

Researchers conducted focus group discussions (FGDs) with health workers (including doctors, clinical officers, nurses, counselors, pharmacists, and nutritionists), community health workers (CHWs), and peer educators and from six health facilities. In all, 31 health workers, seven CHWs, and seven peer educators participated in six FGDs. Key informant interviews were also conducted with site managers from Coast Province General Hospital, Mkomani-Bomu Community Care Clinic, Magongo Municipal Clinic, and Kenya Ports Authority.

Subjects

Slightly more than half of the sample of people living with HIV and AIDS was female (20/38), and about half had attended secondary school (19/38). Subjects ranged in age from 21 to 64 years, with more than a third of the sample between 21 to 30 years old (14/38). The majority of subjects were unemployed (21/38), and nearly a third did not live with their immediate family (12/38) but with extended family members, friends, and others, or by themselves.

Key Findings

Most clients disclosed their HIV status within the family but not in the community.

The vast majority of respondents (34/38) had undergone HIV testing and were aware of their HIV-positive status. But four respondents who were using HIV care services had, in fact, not been tested. Three of these individuals were receiving home-based care services from the COPHIA Home Based Care Program, where community health workers visited them at home to provide nursing care.

Nearly all of the subjects who had been tested (31/34) had disclosed their HIV-positive status to someone in their family. Disclosure of HIV status was most often made to a partner or spouse (15/31), followed by siblings (12/31). Disclosure to parents, children, or other relatives and friends was observed less often. Respondents often disclosed their status to more than one person within their family. According to a 29-year-old female respondent, "I told my husband, my elder sister, and my doctor." While disclosure of HIV status within the family was fairly common, disclosure to persons within the community or neighborhood was infrequent. According to a 33-year-old female respondent, "I don't think any of my neighbors or friends know about my status. This is a secret between me and my sister."

Respondents cited several reasons for disclosing their seropositive HIV status to family members. Some felt that a spouse or partner was closest to them and therefore naturally the person with whom they could share their HIV status. Others wanted to prepare the family psychologically in the event of early death or to ensure that someone could care for their children. A few disclosed to their partners in order to protect them or because they wanted to encourage them to get tested.

"There was no need to hide this from her [spouse] because we are staying together and anyway she was bound to see me swallowing the ARVs and ask about them."
47-year-old male respondent

"I told my sister because she is the one I am close to. She could help me in case I am too sick with taking care of my children in the event that I die."
33-year-old female respondent

Most clients were willing to take ARVs if available, but felt they did not need any help with taking medications.

Even though they used HIV care services, respondents' understanding of HIV and AIDS was poor. Only half of the patients were able to make a correct distinction between HIV and AIDS, a third believed that the disease was curable, and only a third could correctly identify the major modes of transmission of HIV.

Respondents also had low levels of awareness of antiretroviral treatment; only a quarter of the respondents had heard of ARVs for the management of HIV disease. When told about ARVs, almost all respondents expressed a willingness to take them when they became available. But the majority (24/38) felt they did not need any help with taking medicines if they were given clear instructions. However, others acknowledged the need for reminders to take medicines.

"I need to be reminded to take them first as my daughter does for the TB medicines."
36-year-old female respondent

"Not while I am still able, but when I am bedridden I will need help, reminding me to take medications at regular intervals."
28-year-old male respondent

Health workers felt that follow-up at the clinic and at home would be acceptable to most clients, although they cited barriers to both options.

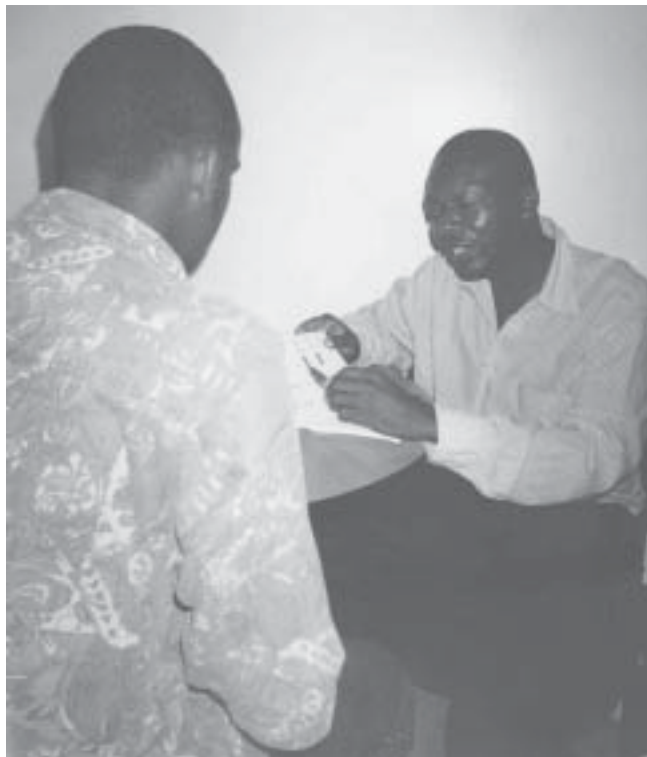
The prevailing opinion among health workers was that clients would come to the clinic for follow-up, but that most would not be able to come every day or even five days per week. They cited barriers such as severe ill health, distance from health centers, transportation costs, lack of financial means, inability to take time off from work, and lack of family support. The preferred frequency of follow-up, according to health workers, ranged from monthly to twice weekly. Suggestions to foster clinic attendance included good patient counseling, a home tracing system for defaulters, family involvement, offering incentives (e.g., milk, food), locating follow-up centers close to patients, providing transportation costs to those who need it, and improving community awareness.

While most health workers felt that clients would be willing to be visited frequently at home, others felt that fear of stigma and loss of confidentiality posed major barriers. According to one health worker, “Some might not find it right to be visited because of fear and suspicion about what the neighbors would say on seeing strangers visiting them.”

Health workers’ suggestions to make home visits more acceptable included visiting at the patient’s convenience, not wearing uniforms, carrying food and medications with them, increasing community awareness, and improving patient counseling. In most of the focus groups, the prevailing opinion was that home visits should be made by community health workers.

Clients preferred facility-based to home-based follow-up.

The research team examined clients’ views on whether followup was preferred at the clinic or at home, and the frequency of follow-up. First they asked clients whether they would be willing to visit the health facility five days per week for a period of two months. Most (27/38) said that they would be willing to visit the clinic, but 12 of these respondents mentioned various conditions that would need to be met: the health facility should be close by, they should be physically fit and able, they would have to arrange to get away from work, and so on. Clients were then asked about a reduced frequency of visits—two or three days per week—but for a longer period of four months, and a greater number responded affirmatively (30/38).



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A community health worker talking to a client.

When asked about follow-up at home, most clients (27/38) were willing to let a health worker visit them daily. The majority, however, expressed a strong preference for qualified professional health workers to make home visits, with the expectation of medications being delivered to their home. This was in contrast to health workers who felt that home visits should be made by community health workers. Clients also emphasized the need for health workers to maintain strict confidentiality.

“This would be a good way of monitoring those of us who may be sick. This would be fine if we have professional people visiting the patients, [but] it would not be good if people without medical knowledge visit the sick.”

32-year-old male respondent

“It is OK as long as they come when my children are not at home.”

40-year-old female respondent

Clients provided several reasons that supported the home-based approach. Being monitored and treated in the convenience of the home was the most frequently cited reason for supporting home-based follow up which suggests that respondents may have interpreted these visits to be regular clinical follow-up visits. Other reasons cited less frequently were encouragement and emotional support from health workers, help with medications, reduced travel time, and cost of travel.

When clients were asked to choose between a home-based and a health facility-based follow-up, most opted for follow-up at the health facility (29/38). Greater confidentiality and perception of better care and monitoring of the disease were the main reasons for this preference. A few respondents said they did not want home visits if they were healthy enough to go to the clinic, which would allow them to feel in control.

“If it is possible, as long as the patient is fit enough to move, I would rather go to where the health worker is and I’d want to see the same person all the time. This person becomes familiar with my problems and is able to follow up on my condition all the time.”

36-year-old male respondent

Clients see family members as important sources of assistance and support.

The majority of respondents (29/38) said they would want to bring a family member to the clinic for follow-up visits. Almost half wanted to bring along a partner or spouse, and a quarter wanted to bring along a sibling or cousin. A few mentioned parents, uncles or aunts, children, and friends.

When asked about the kind of help they expected from family members, 25 of the 38 respondents said they would need help to take medications, nine said they would ask family members to collect medications from the health facility, and three wanted family members to go to listen to doctor’s instructions.

“I would inform my husband, who would help me take the medicines as required by the health workers. I would bring my husband because I’m close to him.”

32-year-old female respondent

“I would come with my brother because he has a ‘strong ear,’ [but] my wife may not be willing to come because she has not had an HIV test.”

39-year-old male respondent

About half of clients (18/38) were taking preventive therapy for six months involving Septrin and/or isoniazid prophylaxis. Among those who reported taking therapy regularly (16/38), clients cited help from family members as a key reason for being able to follow the medication schedule.

Support groups were not well known by clients, but most were willing to have members visit them at home to help with taking medications.

Health workers from all the focus groups knew of support groups active in their area and some had worked with these groups. The prevailing opinion in most of the focus groups was that support group members could help clients by motivating and encouraging them to take their medications, by becoming role models, and by accompanying them to health facilities. Most health workers also felt that clients would be willing to let other people living with HIV and AIDS visit them at home if they were known to them or their friends and if they delivered medications.

When asked about local support groups for people living with HIV and AIDS, almost two-thirds (25/38) of clients had not heard of such groups, and the vast majority (31/38) had never received any support from them. According to a 39-year-old male, “I have not heard of such groups, people take the issue of AIDS with a lot of secrecy.” Of the few who had received support from these groups, most of it was in the form of counseling and education or financial assistance.

Despite lack of awareness and contact with support groups, two-thirds of clients (26/38) were willing to let people living with HIV and AIDS visit them at home. But others had serious reservations. When asked specifically about home visits to help with medications, slightly fewer clients were willing (22), 13 refused outright, and three refused to comment.

“Yes, [I would have problems with that, since] people would start gossiping and speculating, this may thus be demoralizing to us.”

27-year-old male respondent

Most respondents were willing to pay for drugs but not for monitoring tests.

Clients were asked about their willingness to pay for required drugs and monitoring tests to determine whether a fee structure could potentially have an impact on treatment access and adherence. About two-thirds of respondents (23/38) were willing to pay for drugs. The median amount they were willing to pay was 500 Kenyan shillings (approximately US \$6.50) per month, with a mean of 720 and range of 50 to 3,000 Kenyan shillings. But far

fewer were willing to pay for monitoring tests (12/38). This may be due to lack of understanding among respondents about the benefits of monitoring tests.

Program Implications

The results reveal an overall preference for at least twice-weekly health facility-based follow-up visits by clients. The following emerged as key issues that have implications for designing specific aspects of a DAART strategy.

- o **Patient confidentiality.** Confidentiality was an important factor in client preference for a health center-based follow-up. Patients perceived a greater degree of confidentiality at a health facility as compared to their homes. It is important to ensure that health workers are well trained and maintain confidentiality for their patients, which would contribute greatly to uptake of services when introduced.
- o **Quality of health care.** Clients emphasized the need for good quality care. Most seem to perceive a link between facility-based follow-up and good medical care, well-trained health workers, ready availability of medical care when needed, and space and time to be able to talk to a doctor or other health worker in an uninterrupted manner. There was also a perception that health care is linked to a health facility.
- o **Desire to feel in control.** The formative assessment highlights the importance of independence and control that people living with HIV and AIDS want and suggests that this is more readily achieved through facility-based follow-up. Clients do realize that they might need home-based care services once they become too sick to move about independently.
- o **Willingness to pay for ARVs, but limited ability to pay.** Clients were willing to pay for ARVs, but the amount they were willing to pay was limited, and as many as one-fifth said they were unable to pay any amount. The implication is that the program needs to offer exemptions from fees for those unable to pay to ensure adherence to drug protocols.


Next Steps

The intervention study, which began in late 2003 and was designed based on the formative research results, compares the adherence of clients in a modified DAART program with that of a control group of clients receiving HAART that is not directly observed. Clients are randomly chosen to participate in either the DAART or the HAART program. Both groups of clients are required to visit a central treatment site monthly for routine monitoring.

In addition, DAART patients are required to visit an observation site twice a week for a period of six months, to pick up medications and to ingest one dose in the presence of a health worker. Three satellite observation sites were opened to supplement the four original treatment sites, giving clients more options in finding a site close to home. To better serve

clients who work during the day, some centers open early. At the first client visit, each health provider introduces a community health worker whose tasks are to help clients keep appointments, bring medication to bed-ridden patients, and link clients to services. No fees are being charged for the drugs or monitoring tests.

The intervention study is also examining changes in sexual behavior among clients and in perceived stigma and discrimination among clients and health workers against people living with HIV and AIDS.

Final study results are expected June 2006. 

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Investigators for the formative research were Mark Hawken of the International Centre for Reproductive Health (ICRH), and Avina Sarna and Susan Kaai of Horizons/Population Council. Intervention and study partners include Horizons, International Centre for Reproductive Health, Coast Provincial General Hospital, FHI/IMPACT, MSH/RPM+, and the Kenya Ministry of Health..

For more information about the formative research findings or the follow-on operations research study, please contact Avina Sarna (asarna@pcindia.org) or Susan Kaai (skaai@pcnaïrobi.org).

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