

Therapeutic Enclaves in Central Mozambique? Lives Saved, Livelihoods Lost

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Tallying the numbers tested, the numbers saved, and the numbers cared for.

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Introduction

The global effort to expand the provision of antiretroviral treatment in low and middle-income countries initiated in the early part of this decade represents the largest collective medical intervention in history. It has been funded by many organizations, including the Global Fund to Fight AIDS, Tuberculosis, and Malaria, the World Bank, the Clinton Foundation, and the Presidential Emergency Program For AIDS Relief (PEPFAR). These donors often frame the success of their HIV/AIDS treatment interventions in terms of numbers: “lives saved,” “directly supported care,” and “numbers tested.” These claims generate moral capital for some of the most powerful countries, institutions, and individuals in the world, allowing them to show they responsibly respond to the suffering of the poor as the interventions powerfully influence the shape of the public health infrastructure of much of the world, the distribution of health care resources, and the ways people care for themselves and each other.

In this post, I focus on one of the interventions that produce these

numbers, community home-based care programs in Central Mozambique, in the provincial capital of Chimoio. I argue that by relying on underpaid labor, community home-base care is based on extractive and exploitative practices. By working towards narrow aims, quantified at the level of individual lives saved and numbers of patients attended to, these interventions effectively disarticulate HIV/AIDS from local social and economic realities. As a result, the actual benefits of the interventions to individuals and collectivities are limited and short-lived. Even while lives are saved, broader issues of inequality, food insecurity, and unstable livelihoods are unaddressed and may even be exacerbated by the structures being erected.

Community Home-Based Care International

Community home-based care is an internationally circulating model, defined by the WHO in a 2002 report as “care including physical, psychosocial, palliative, and spiritual activities.” It is designed to fill in the gaps of weak and overwhelmed health care networks in resource-limited settings, and is seen as appropriate for these settings because it:

“draws on two strengths that exist throughout the world: families and communities. Families are the central focus of care and form the basis of the CBHC team. Communities are places where people live and a source of support and care the individuals and families in need. The goal of CHBC is to provide hope through high-quality and appropriate care that helps family caregivers and sick family members to maintain their independence and achieve the best quality of life” (2002: 8).

According to this report, CHBC depends on the contribution of volunteers, over 90% of whom are women who struggle to feed and clothe their own families. Volunteers are frequently motivated by spiritual and religious convictions, and often are recruited and organized through places of worship. Acknowledging the demanding nature of the work, the report mentions ways to promote and support volunteerism:

“education, honouring volunteers and providing awards, honoraria and payment in kind are important sources of encouragement for volunteers. In addition, considering group celebrations, badges, uniforms, T-shirts, umbrellas and other forms of volunteer recognition is also important. To encourage and support the vital role that volunteers play, it is important that they feel valued for their work and supported by the community.” (68)

A 2008 WHO report shifts from this policy by acknowledging essential health services cannot be maintained through voluntary labor, and that health workers should “receive adequate wages and/or other appropriate and commensurate incentives” (2008: 35). The extent to which local organizations have followed this shift is unclear, however.

In Mozambique, thousands of home-based care volunteers are working in urban and rural settings. They not only offer palliative care, but also been tasked with gathering basic surveillance data on the patients they visit. These data are sent to provincial and national departments of health as well as to funders and donors, who use them for planning and charting the progress of their programs.

These programs, especially in the WHO’s 2002 framing, rely on taken-for-granted ideas of “family” and “community” as pre-existing resources to be tapped by development initiatives to stand-in for underfunded and undermined public health systems. This turn to community and civil society was a part of the structural adjustment program that gained momentum in Africa the 1980s and diverted foreign aid away from governments and toward the private sector and NGOs. Kubatsirana, the community-based organization discussed here, was created in the 1990s, at a time when the Mozambican health sector was being downsized and the magnitude of the HIV epidemic was just beginning to be acknowledged. The drivers of this organization are internationally connected Pentecostal churches that recruit and convert volunteers. The justification for the creation of the community home-based care program, that health care networks were weak and overwhelmed by HIV/AIDS, was in fact the result of structural adjustment policies that dismantled the public health and social service sectors in Mozambique, creating a vacuum that Pentecostal churches have been filling. While an impressive clinical infrastructure has been mounted to get drugs into bodies and save lives, the community care and outreach component of this effort has been consigned to poorly trained and supported volunteer labor.

Local Administrators and Sustainability

During fieldwork in Mozambique in between 2003 and 2010, administrators of home-based care programs fretted about the issue of volunteer “incentives,” fearing payment of volunteers would make the programs unsustainable because they would be unaffordable. At one meeting of home-based care volunteers where the issue of payment was being discussed, a program coordinator scolded the volunteers, telling them “this work should come from the heart. It should not be done for payment, but to help our neighbors, our brothers and sisters. It is our work that we do. If we get paid, it is not a bad thing, but we do not do this work in order to be paid, and we do the work even when we are not being

paid.”

Another coordinator told me that the essential qualification of a HBC volunteer was “*Tem que ter sentimento*,” literally, “they have to have feeling,” or the capacity for compassion. For this reason, the ideal profile of the volunteer was an older female who had had at least one child. Of course this profile also matched the least educated and least employed, and fulfilled preexisting cultural norms and expectations that women do the work of caring for the sick.

A representative from a Christian faith-based organization went further, explaining that he feared that volunteers motivated by payment would be less effective than those motivated by altruism. Volunteers from faith-based organizations were said to be more motivated by a spiritual calling, rather than material concerns, cleverly converting the “faith-based” component of their mission into a strategy for “sustainable development.” Home-based care volunteers with whom I met and worked in Central Mozambique contested this framing.

A Home Visit

One day last spring, I accompanied a home-based care volunteer, Linda, on her weekly visits to people living with HIV/AIDS in her neighborhood. Linda is a member of Kubatsirana, a community-based organization that specializes in HIV/AIDS outreach and education services through church communities. Home-based care was one of the initial activities of the organization, which was founded in the mid-1990s by Swedish missionaries. Linda had been conducting this work for over ten years, through multiple changes and alterations in the organization. Home-based care volunteers are trained in basic palliative care techniques for the seropositive, HIV counseling for patients and family members, and also referred people for HIV testing in public clinics.

Linda wore her Kubatsirana t-shirt and *capulana*, (or wrap), the uniform that also served as payment for the work, officially termed an “incentive.” The logo emblazoned on the clothing also served as an important part of the organizational branding strategy as different groups vied to establish their turf and competed for grants and contracts. Volunteers from the various home-based care organizations were instructed to always introduce themselves as members of their particular organization.

On this morning, Linda was following up with her group of patients whom she visited on a weekly basis. Volunteers were assigned a number of patients to follow, anywhere from five to ten patients, and could spend two to three days a week on their visits. When the project began in the mid 1990s, the task of the volunteers was to provide palliative care and

support to people who were dying. According to current volunteers and health care providers, hospitals and clinics were overwhelmed and had no treatment to offer. People died at home and the volunteers bathed the sick and helped make them comfortable. As testing and treatment became available, their duties changed, to outreach, education, and recruitment for the services that were becoming available. After antiretrovirals (ARVs) became locally available in 2004, volunteers monitored their patient's health, encouraged them to either test, begin treatment, or stay adherent. They also documented the health status of those they visited, collecting statistics, which would be pooled at the organization level and "uploaded" to the ministry of health and funders. Data collection forms were designed that used pictures for the generally illiterate volunteers and included numbers on ARVs, on TB treatment, on prophylaxis, pregnant, being seen in the clinic, lost to follow-up, and death.

We visited a patient, whom I'll call Madalena, whom Linda had encouraged to test and to begin antiretroviral treatment. Linda was known in her neighborhood as a Kubatsirana volunteer and as someone who the sick could go to for advice and support. Madalena's health had significantly improved in the months since getting tested and beginning ARV treatment. We came upon Madalena's house around lunchtime. A young woman was cooking peas in front of the family hut as an elderly woman and two young children ate porridge the characteristic beige color of USAID corn-soy blend. On the far side of the yard, another young woman and man sat selling *nipa*, a powerful brew of fermented sugar cane.

We entered the hut and after initiating the visit with a short prayer, Linda proudly introduced Madalena, saying: "You see, here is the patient and I can tell you she is already better!" Madalena quickly added: "Yes, I am better, but my stomach hurts!"

In the months since Linda had first seen her, Madalena had begun antiretroviral therapy and her health and appearance had improved significantly. I assumed the stomach pain referred to the common complaint in central Mozambique that antiretrovirals caused hunger, and indeed Madalena did endorse this, commenting that "this medicine, it bites, its not like a normal hunger. If I don't eat when I take it, I tremble and shake. It is said this medicine will kill you if you don't eat with it." She had told the social workers at the clinic that she was hungry, and they awarded her with one of the precious World Food Program ration cards. This entitled her to received 10 kilos of corn-soy blend and 1 kilo of legumes per month, an amount that, when shared amongst her three children, two grandchildren, and her elderly mother, lasted four days. She also sold *nipa* and sought odd jobs.

But Madalena's stomach pain was not simply hunger pangs. In order to access more cash, she engaged in serial short-lived sexual relationships with men who could provide her with small amounts of money and feed her. Her chronic stomach pain was accompanied by a foul-smelling vaginal discharge that she was ashamed to reveal to the clinician whom she saw for her antiretrovirals as she would be rebuked for having unprotected sex. She had been told this was gonorrhea in the past, and she occasionally treated it with antibiotics, when she could afford the time to seek treatment. Linda arranged to accompany Madalena to the clinic later that week to be assessed and receive appropriate treatment.

Several aspects of this encounter point to the extractive nature of these HIV/AIDS treatment interventions. As the lives saved with antiretroviral medications, the numbers tested, and the numbers supported were tallied, many beneficiaries pointed to the irony that they struggled to feed themselves and their families even while they managed to obtain lifesaving pharmaceutical treatment. Food insecurity can even be seen to drive the epidemic, as Madalena's story indicates, but an embarrassingly inadequate amount of resources are devoted to this issue. I discuss this further elsewhere, and here focus on Linda's volunteer labor in the service of providing supportive care and collecting data. Linda likely deserves a great deal of the credit for Madalena's inclusion in the AIDS treatment program, as she continued to encourage her neighbor to remain adherent to treatment.

When we finished our visits that morning and returned to Linda's home for some tea she discussed her long experience being a home-based care volunteer. A widow in her fifties, Linda was recruited to be a volunteer through her church. She recalled her initial motivation: "I heard of this association of people that were coming together from different countries, for discussion and debate, about how to live, about civilization, about religious things, and also about these positive diseases." Not having finished primary school, Linda was interested in the educational opportunity as well as the chance to serve her neighbors and to combat stigma and discrimination against HIV/AIDS. Many volunteers I interviewed voiced similar motivations – receiving an education, a uniform, helping people, and earning the respect and admiration of neighbors were all cited as rewards. Linda was particularly knowledgeable and committed, as she was seropositive herself, and she had lost her husband and son to the disease. She proudly showed me the certifications she had accumulated through the various trainings she participated in. Like all the volunteers, Linda hoped these certifications and her experience would translate into steady, formal employment. The few such opportunities that did arise usually went to the younger and better-educated volunteers, however. While volunteers themselves acknowledged multiple forms of reward and satisfaction they derived from their work, most hoped to

receive remuneration, and insisted they should not be expected to do this work without payment.

Volunteers were also frustrated by their inability to consistently meet the needs of the patients, particularly in terms of food. When they began their work, there were more volunteers than patients. The volunteers provided food supplements that they funded themselves. As their operations expanded, they negotiated their own World Food Program contract, but this contract had not been renewed in over a year. While some other organizations managed to continue providing food, Kubatsirana's patients grumbled that the volunteers were keeping the food for themselves. When their patients were disappointed or when things went poorly, the volunteers frequently bore the brunt of the frustrations of patients and their families. They told stories of being accused of witchcraft and causing disease in neighbors so that they then might be paid for visiting them, or of hoarding the benefits that were meant to be directed towards patients.

Volunteers were also supposed to be outfitted with kits that included soap, bandages, gloves, and analgesics, but these kits chronically ran short, when they existed at all. Training sessions were infrequently held, and the training was of variable quality. There had been numerous organizational problems all along the levels of administration and leadership in the organization, and every few years there were national-level shifts in the emphasis of home-based care programs. While this litany of problems and shortcomings may sound like the description of an underfunded public sector, it is actually the description of a program almost entirely implemented by civil society organizations: NGOs and faith-based organizations, and funded and coordinated by international donors.

The fragmented and inefficient nature of the programs frustrated Linda, who lamented the opportunism she saw within her organization:

“There is no spirit of togetherness. They say that as we are black, we are slaves of foreign countries. Rather than growing our own food, we ask for world food program's donations. When they don't have anything for us, then what?”

These bitter comments reflected her frustration with the short-term goals of projects with 2 and 5-year cycles, along which the rise and fall of community organizations can be charted. Linda compared the underpaid labor of the volunteers to the notorious forced labor programs of Portuguese colonialism, which she had grown up with. Much of the effort of the organization was devoted towards maximizing the benefits received while the project was still active rather than long-term viability. At the time of our conversation, her organization was undergoing a corruption

investigation, as some funds had gone missing. Lacking proper training and oversight, these community-based programs are afterthoughts and window-dressing in the biomedically- driven AIDS treatment effort, and have become even more so with the advent of antiretroviral therapy. The volunteers are nonetheless asked to document their labor and the condition of their patients, to the credit of the sponsoring organizations.

On this day, Linda was especially interested in telling me about the recent change in Kubatsirana's policy regarding the compensation of volunteers. Initially, most volunteers were simply offered incentives, following the 2002 WHO recommendations: trainings and certificates, t-shirts, capulanas, occasional snacks and lunches, and in-kind allotments of rice, corn, oil, or soap. In an effort to regulate the amount volunteers were being paid and to discourage one particularly well-resourced foreign NGO from paying its volunteers more than the state paid its nurses, the Ministry of Health set an official incentive rate for HBC volunteers was at around 60% the minimum wage. This was a recommendation for those organizations that did pay its volunteers, but was not a requirement that volunteers be paid. What they actually received depended on the flows of grant monies, and varied at least as much as the benefits the patients received. Red Cross volunteers in Chimoio received half of the recommended amount. After literally years of demands and appeals made by the Kubatsirana volunteers, they finally had been receiving the recommended amount for the past year, but the grant supplying this incentive was not being renewed, and volunteers were being asked to once again, work for immaterial rewards.

Most volunteers said they would continue the work, which they now considered their duty, as they felt their patients relied on them, but they did not feel this was a just situation. They were rarely much better off than the neighbors they visited, and many were HIV-positive and struggling to eat each day themselves. Linda told me that far more of her colleagues that were initially trained with her had passed away than were alive and working. Outraged at the prospects of once again working without pay, she remarked:

“We are expected to share the burden of labor but not the benefits? Our organization has built a nice office. Those people who work in the office, they drive cars to work. But those of us who do the work in the neighborhoods? This is not our office, and that hurts. We built that office, we built the organization. We arrive at the homes of the sick, and they say, ah, Kubatsirana is here. Yes, we are Kubatsirana. But we are the last to receive and the first to lose. Perhaps we should discuss selling the office.”

These comments suggest that the call for volunteer labor in the name of sustainability, results in the exploitation of the labor of individuals who are already quite marginalized. It maintains a pool of trained but unemployed laborers, anxious for any scraps that may fall their way, all the while collecting the data that are used to justify the funding of the programs and serving as the front line of the global fight against HIV/AIDS.

Life-saving treatment is provided to those who are HIV-positive, who are then encouraged to look to the “community” for support. Those enlisted to care for these subjects are expected to do so voluntarily and altruistically, out of a neighborly duty. Meanwhile, the bulk of development aid dollars end up in the pockets of foreign and private organizations. Sick bodies and cheap labor willing to work for the possibility of potential pay and paltry benefits are the raw materials of a “usable Africa” that fuel a philanthropic industry claiming to prioritize the health of the world’s poor.

Citations and Acknowledgements

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