Accounting for the Experiences of Participants in the Evaluation of HIV/AIDS Home Based Care Programs in Zimbabwe

John Mazzeo, DePaul University

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Experiences of collaboration, coordination and efficiency in the delivery of HIV/AIDS home-based care in Zimbabwe

John Mazzeo* and Loveness Makonese

1 Department of Anthropology, DePaul University, 2343 N. Racine Avenue, Chicago, Illinois 60614, United States
2 Department of Sociology and Anthropology, Rhodes University, PO Box 94, Grahamstown 6140, South Africa
* Corresponding author, e-mail: jmazzeo@depaul.edu

The difficulties of achieving successful collaboration between stakeholders can lead to uncoordinated and fragmented outcomes for HIV/AIDS programming, which has consequences for the immediate health and livelihood security of the intended beneficiaries. This article examines the collaboration between local, national and international partner organisations in the delivery of and coordination of HIV/AIDS home-based care in Zimbabwe. The purpose of the research was to provide an external assessment of home-based care and to identify the problems that impede the delivery of health resources. Fieldwork was conducted between 2005 and 2008 at rural and peri-urban locations in Zimbabwe, using a combination of informal interviews, focus groups and participant observation. The findings suggest that the delivery of healthcare is impeded by problematic relationships between programme stakeholders — government, non-governmental and community-based. The outcome of poor service delivery is demonstrated to have a direct negative impact on the access to services, quality of care, and health outcomes for programme participants. The methods and findings of this research highlight the use of rapid ethnographic appraisal by social scientists to represent the interests of HIV/AIDS-affected populations in programme and policy design. This approach is crucial in situations such as in Zimbabwe where beneficiaries are less willing to voice their opinions for fear of being cut off from what little assistance is available in case what they say is viewed as uncooperative or noncompliant with a programme’s objectives. The findings question the widely held assumption that multisectoral relationships are the most efficient way to deliver services.

Keywords: community organisations, ethnography, multisectoral collaboration, non-governmental organisations, programme implementation, rapid assessment procedures, southern Africa, vulnerable populations

Introduction

Home-based care (HBC) is the main strategic approach for delivering care to people living with HIV or AIDS (PLHIV) in most southern African nations, but few studies have critically examined the challenges of implementing and coordinating HBC (exceptions are: Ncama, 2005; Shaibu, 2006; Akintola, 2008a). In Zimbabwe, HBC has been in existence since the 1980s to provide services for people suffering from chronic and life-threatening terminal conditions. With the advent of the HIV epidemic and the growing economic burden faced by healthcare centres, HBC programmes have been scaled up to accommodate patients discharged from hospitals to be cared for at home. HBC is an essential component in bridging the ongoing care and support required by PLHIV. Most HBC programmes provide caregivers with medical supplies, health education and referrals to social support groups. In 2008, HBC programmes in Zimbabwe provided services to more than 172 000 clients (National AIDS Council [NAC], 2009). The National AIDS Council of Zimbabwe has a mandate “to provide for measures to combat the spread of HIV, and the management, coordination and implementation of programmes that reduce the impact of HIV and AIDS” (NAC, 2000). Zimbabwe’s Minister of Health and Child Welfare, Dr Parirenyatwa, describes HBC as, “Essential if we are to achieve our objectives as laid down in the Zimbabwe National HIV and AIDS Strategic Plan” (Government of Zimbabwe, 2007). HBC programmes funded by international donors and supported by community-based structures for HIV-prevention account for the majority of services for PLHIV.

Since Zimbabwe’s NAC rolled out its national HBC policy in 2001, no empirical studies have been undertaken by external researchers to explore the effectiveness of HBC programmes and policies. Existing publications have been prepared in collaboration with the NAC but lack critical assessment (Health Development Networks & Southern Africa HIV and AIDS Information Services, 2008; Partners Zimbabwe, 2008). Other documentation consists of internal reports prepared by non-governmental organisations (NGOs) or by paid consultants. Many of these reports are unavailable to the public and most highlight programme successes. They do not critically analyse the challenges of HBC implementation and coordination between governmental, non-governmental and community programme partners. The absence of critical assessment by outside researchers is especially alarming given the enormous financial and material resources being committed by foreign donors and the Government of Zimbabwe into scaling up HBC as part of a national strategy.
This article follows a growing trend in research on HBC in southern Africa, which challenges widespread assumptions about the effectiveness of dominant HBC models. Although most authors agree that HBC offers a favourable alternative to the care provided by most public health systems, these authors are also critical of the way that these programmes are structured. Recent studies critical of the HBC model have challenged assumptions about cost-effectiveness. Previous studies have demonstrated that official HBC costs do not account for the value of unpaid work by female extended family members (i.e., Lindsey, Hirschfeld, Tiu & Ncube, 2003; Robson, 2004; Kipp, Tindyebwa, Rubaale, Karamagi & Bajenja, 2007; Van Blerk & Ansell, 2007). These findings emphasize the need to value the contributions of women who are often overwhelmed by the amount of labour involved in caring for someone living with HIV or AIDS in addition to their domestic and livelihood responsibilities. Caregivers often lack of basic health education and can suffer from social isolation, stigma, and psychological distress as a result of their work (Lindsey et al., 2003).

Additionally, evaluations of HBC cost-effectiveness do not account for the significant personal difficulties experienced by community volunteers in the provision of unpaid caregiving services (Akinola, 2008b; Rajaraman, Earle & Heymann, 2008). The financial and time costs of home visits by community health workers, including telephone and transport fees, are often ignored because they are often donated by volunteers and are not reported as official programme expenses (Hansen, Woelk, Jackson, Kerckhoven, Manjonjon, Mamba et al., 1998). A benefit of critical research about HBC, such as those described above, is that it has been to assist implementing organisations to improve the efficiency of programming.

The goal of this research is to expand the critical assessment of HBC beyond cost-effectiveness to include the state of collaboration between partner organisations. Our findings question the efficiency of this collaboration as the most efficient way to coordinate and deliver HBC. Zimbabwe’s NAC views partnership as the best model for HBC. "Effective partnerships between affected communities, nongovernmental organisations (NGOs), governments, and international organisations/agencies are essential to HBC, and this should be reflected in future HBC-related policies" (Partners Zimbabwe, 2008, p. 6). A finding of this article is that the roles and responsibilities of HBC partners are not well defined. Even in situations where guidelines are established, the implementation of the partnership does not reflect the nature of the agreement. The result is a breakdown in communication, resistance to cooperation, inefficient use of limited resources, poor targeting, lowered morale, and an overall decline in the performance of HBC.

The difficulties of maintaining effective collaboration can lead to uncoordinated and fragmented outcomes that have real consequences for the immediate health and livelihood security of the intended beneficiaries. If partnerships are assumed to be the best way to deliver HBC in Zimbabwe, it is worth examining the challenges of implementing this model for the purposes of informing practice and policy.

This article examines several HBC programmes operating in Zimbabwe and highlights the consequences of failing to carry out a collaborative model in terms of the lives of the patients. Our purpose is not to single out and criticise specific HBC programmes. Many of the problems identified are found not only among the organisations we worked with, but are widespread. The goal of this critical assessment is to encourage further research on this topic and to promote productive dialogue between all stakeholders that will hopefully lead to more effective practices and policies. Ultimately, we believe that our research best serves the interests of the patients in HBC programmes across Zimbabwe.

Methods

This research used a rapid ethnographic appraisal method for examining home-based care (HBC) services for PLHIV and the relationships between stakeholders to coordinate the delivery of services. Rapid ethnographic appraisal was developed in the 1980s and 1990s for the purposes of capturing knowledge from a community relating to a specific topic (such as agriculture, natural resource management, health, diet and nutrition) and applying this knowledge to improving development projects (Chambers, 1992). Ethnography is an approach to interpreting socio-cultural phenomena that relies on a variety of qualitative methods to collect local knowledge during an extended field stay (Bernard, 2001). Rapid ethnographic appraisal also relies on qualitative data collected in the same fashion, but ciphers in the amount of time dedicated to fieldwork and its intended audience (Chambers, 1992). Similarly, the design of our rapid ethnographic appraisal relied on detailed, qualitative information solicited from those who were most closely involved or affected by HBC programmes. The initial findings from our research were originally submitted as unpublished technical reports to identify the programmatic needs and challenges of HBC in Zimbabwe.

Fieldwork was carried out over three years, from July 2005 to November 2008. Several localities were included in the research design to provide a variety of experiences. The authors worked in rural parts of Zaka, Chiredzi and Chipinge districts, and in one peri-urban community, Hatcliff extension, located in the capital city Harare. During this time, the authors worked closely with several NGOs providing HBC and used rapid ethnographic appraisal to help the NGOs accomplish their monitoring and evaluation objectives. Studies employing a rapid ethnographic appraisal method often have a connection to community development and are designed to be cost-effective and time-efficient ways of collecting programme-relevant information (Bently, Pelto, Straus, Schumann, Adegbola, De la Pena et al., 1988). Rapid ethnographic appraisal is ideal in situations where the time for data collection is limited, the objectives are narrowly defined, and the findings are intended to have direct policy and programmatic applications. Several other studies on HBC and caregiving in Zimbabwe have employed similar methods to challenge assumptions and demonstrate problems with HBC programmes according to the experiences of the stakeholders (e.g., Rooson, 2004; Akinola, 2006 and 2008b; Kipp et al., 2007; Van Blerk & Ansell, 2007; Waterman, Griffiths, Geilard, O’Keefe, Oliang, Ayuyo et al., 2007).
A significant methodological concern when doing rapid ethnographic appraisal is to incorporate techniques for ensuring the validity and reliability of the findings. This challenge to ensuring validity and reliability has to do with a short research timeframe, small sample size, and purposive sampling technique (Chambers, 1992). One approach is to triangulate information by using multiple methods, field sites and investigators. This approach enabled us to crosscheck our responses and to compare findings across sites to more closely identify patterns. Another approach is to diversify the kind of information we collected by purposively recruiting a variety of perspectives. This principle helped guide selection of the participants for interviews and focus group discussions. We maximised variability by age, gender and wealth. Finally, we were able to cross-check and update our information by revisiting sites for follow-up interviews with beneficiaries and HBC programme staff. This was particularly helpful as HBC programmes changed the services they provided over the duration of the fieldwork.

All participants were purposively selected because of their affiliation with one of four HBC programmes. The HBC programmes included in this study follow a comprehensive model with an integrated, collaborative management structure (see Ncama, 2005). Each HBC programme depends on community health workers to provide in-home support services, varying degrees of palliative care, family caregiver education, and material support, such as food, medical and hygiene supplies. The management structures of the HBC programmes examined in this study fall into the NGO-initiated and NGO-driven category and they attempt to integrate patients into an extensive network of community resources. The programmes accomplished this through collaboration with community stakeholders, such as health clinics, local social welfare departments and district AIDS Action Councils.

The data were collected through in-depth interviews, focus group discussions and participant observation. In-depth interviews provided first-hand experiences from HBC patients, household caregivers, community health workers, and NGO and government staff. Table 1 summarises the number of individuals who participated in the in-depth interviews and focus group discussions. The interviews used an open-ended question format to help guide conversations. Open-ended questions captured a broad range of knowledge and gave participants the most freedom to describe their experiences and express their opinions. In situations where vague or brief responses were given, probing questions were asked to help illicit additional information. Interviews with HBC patients were conducted at their homes and sometimes included household caregivers. Interviews with community health workers were completed either at their homes or at a prearranged location in the field after they had visited a household receiving HBC. Interviews with NGO and government staff were conducted at their place of work. This last category includes staff at clinics and other participating local institutions, representatives from the district NAC, and field officers working for NGOs.

During the focus group discussions, we asked a combination of open- and close-ended questions in gender-segregated groups of ten participants. The focus group discussions followed a semi-structured format and gave the participants an opportunity to talk about their experiences with HBC programmes. A focus group moderator introduced questions from a script and was assisted by a facilitator who helped promote dialogue. Focus groups were useful in revealing the range of general perceptions and in building consensus around a specific topic or question. The focus group also provided a description of the day-to-day contexts in which patients, families and community caregivers make decisions. We conducted 14 focus groups that included a total of 140 individuals — six groups with HBC patients, four with household caregivers, and four with community health workers (Table 1).

Participant observation involved immersion into a social setting for an extended period of time for the purpose of learning about the location’s day-to-day realities through involvement in activities (Bernard, 2001). In this case, the social setting we immersed ourselves in was the day-to-day operations of NGOs. The authors' relationship as consultants with the NGOs in this study provided an opportunity to learn more about the factors that influence the management of HBC programmes. The types of information collected using this method included direct observation and an intimate knowledge of the NGO’s structure, programme objectives, and institutional values. This information was recorded in various formats, including field journal notes, institutional reports, meetings, and site visits to the NGOs' field offices.

In both the interviews and focus group discussions, open-ended questions were used to encourage participants to provide in-depth narratives about their experiences with HBC. Some of the questions asked during the individual interviews with HBC patients included: “Can you describe your illness from when it began to now?”; “What kinds of care have you received during your illness?”; “How has home-based care provided you with assistance?”; and “What kinds of challenges or problems have you had with home-based care?” The questions asked during focus

<table>
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<tr>
<th>Type of participants</th>
<th>In-depth interviews</th>
<th>Focus group discussions</th>
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<tr>
<td>Home-based care (HBC) patients</td>
<td>12</td>
<td>60</td>
</tr>
<tr>
<td>Household caregivers</td>
<td>5</td>
<td>40</td>
</tr>
<tr>
<td>Community health workers</td>
<td>5</td>
<td>40</td>
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<tr>
<td>NGO or government staff</td>
<td>8</td>
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<td>Total</td>
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group discussions with community volunteer caregivers included: ‘What kinds of services do you provide to HBC patients?’; ‘Can you describe what a typical day for you is like when you are caring for patients?’; and ‘What are the challenges you face in carrying out your responsibilities as a community caregiver?’ Finally, questions asked to the NGO and government staff during individual interviews included: ‘Can you describe the responsibilities of [your organisation] in the HBC programme?’; ‘What kinds of relationships do you have with your HBC partners?’; and ‘What kinds of challenges have you encountered in these collaborations?’

Conversations that were recorded using handwritten notes and an audio recorder were later transcribed electronically. After all data were entered, themes were identified through a careful reading of the transcripts. Several main themes were broken down into subthemes. Each theme and subtheme received its own code, and codes were applied to the electronic transcripts. This approach prepared the data for a thematic analysis using a grounded theory approach wherein theories or main findings are drawn inductively from the data (Bernard, 2001). The three main themes addressed in our analysis were: 1) obstacles to effective care faced by HBC participants, 2) HBC collaboration with government partners, and 3) HBC collaboration with community-based organisations.

The authors worked with four NGOs, each of which managed a different HBC programme. The first NGO was CARE Zimbabwe and its HBC programme in Zaka district, Mavingo Province. This programme provided a combination of community healthworker training for home visits, caregiver education, and monthly health and hygiene supplies. The patients and caregivers also benefitted from food aid provided through CARE and were part of a clinical referral programme. CARE Zimbabwe’s HBC programme received most of its funding from the British Department for International Development (DFID) and has had great success in building collaborative partnerships. At the time of the study, this programme did not provide access to ARVs.

The second HBC programme was operated by Plan in Chirezi district, Mavingo Province. Plan is a United States-based NGO funded by AusAID (Australian Government Agency for International Development) and can be found in Chirezi and Chipinge districts. Plan Zimbabwe works to reduce child vulnerability to HIV and AIDS through raising awareness of the disease, providing support for orphaned or vulnerable children and people living with HIV and AIDS, training community health workers, and assisting in the establishment of counselling and medical services. The goal of Plan’s HBC programme is to reduce the vulnerability of children, their families and communities to the impact of HIV and AIDS. The programme integrates strategies to promote human rights and reduce stigma and discrimination. Its interventions are designed to strengthen the capacity of community-based groups, local NGOs and governments in order to meet the physical and social needs of people affected by HIV or AIDS (Plan, 2008). Plan’s model of reducing vulnerability to HIV and AIDS has received the most funding, but their partnerships are not clearly defined.

The third programme was Integrated Sustainable Livelihoods (ISL), who obtained funding from the International Organization for Migration (IMO) for its HBC activities in Mashonaland West Province. This was the smallest NGO included in the research and their work targets populations from former white-owned commercial farms. ISL also partners with Population Services International to assist its HIV-prevention activities. This NGO works with community-based organisations (CBOs) responsible for implementation.

The fourth HBC programme was operated by St Gerard’s Catholic Church, a faith-based organisation (FBO) located in Hatcliff extension, a peri-urban neighbourhood in Harare. This programme targeted HIV-infected and AIDS-affected individuals and households who are benefiting from two different donor-funded antiretroviral treatment (ART) support centres in Harare. Some of their target beneficiaries are receiving ART support services from Newlands ART centre, which received support from the Global Fund, while other beneficiaries are getting ART support services from government-initiated and run programmes located at Parirenyatwa Hospital and other state hospitals.

Results and discussion

The results of this research are organised according to the three main themes that guided the analysis of the data. The first section, obstacles to effective care, describes the need for home-based care (HBC) programmes within the study area and the experiences of PLHIV as they attempt to access care. It highlights the need for outside interventions to replace a non-functional public health system. The second section, HBC collaboration with government partners, explores the problems of HBC collaboration between international NGOs and their government partners in the coordination of HBC projects. The last section, HBC collaboration with community-based organisations (CBOs), examines the problems faced by CBOs as they implement the HBC services designed and funded by NGOs and government. Our results demonstrate how the breakdown in services due to ineffective partnerships between NGOs, government, and CBOs ultimately has real health impacts on PLHIV.

The experiences of PLHIV with HBC programmes in Zimbabwe

This section describes our findings related to the experiences of PLHIV as beneficiaries in HBC programmes. We first describe the PLHIV population targeted by HBC programmes by summarising epidemiological data and providing a description of the socio-economic conditions at the field sites. We discuss the reasons for individuals’ resistance to HIV testing and problems that PLHIV have in obtaining support after testing HIV-positive. Finally, it describes the barriers to receiving integrated care that includes both health and livelihood support.

Adult HIV prevalence was relatively high at all the study sites; there was little difference between urban and rural areas (19% and 18% HIV prevalence, respectively), but estimates did vary slightly between the areas included in the research: 20% prevalence in Mancalland Province, 19% in Harare, and 16% in Mavingo Province (Central Statistics Office, 2006).
Zimbabwe’s national HIV prevalence has dropped from approximately 25% in 2003 to 18% in 2006. This decline has been attributed to behaviour change, but epidemiologists at UNAIDS are more cautious in their interpretation of these estimates. Despite the goal of HIV/AIDS programming to change behaviours, UNAIDS cautions that “the decline is neither a necessary nor a sufficient indication of programme impact” (UNAIDS, 2005, p. 5). The difference in estimated prevalence could reflect biased antenatal clinic data collected in prior years, recent changes in the surveillance methods, or possibly the spread of HIV infection into and within different population ‘risk’ groups. Explanations for a decline in prevalence also cite increasing poverty, food insecurity and a decline in public health services. Worsening health conditions and a shorter life span from the time of initial infection among PLHIV are an outcome of the collapse of Zimbabwe’s healthcare system and increasing hunger and malnutrition caused by rampant inflation and low harvests (UNAIDS, 2005). The problems posed by limited access to healthcare and low food security were emphasised by the participants. During interviews and focus group discussions, participants highlighted the lack of staple foods (e.g. ground maize meal), the absence of ARVs, and insufficient medical care for opportunistic infections.

Our findings also suggest that the need for HBC services is greatest among women and single female-headed households due to the combination of higher HIV prevalence and the socioeconomic demands placed on single women to support their households. Our findings support epidemiological data that show the greatest need for HBC services is among women. In Zimbabwe, women face higher HIV prevalence (21% among women and 15% among men) and greater social vulnerability in a patriarchal system (Central Statistics Office, 2008). In Masvingo and Midlands districts, female-headed households face higher levels of food and livelihood insecurity as compared to male-headed households (Mazzoo, 2007). Women are expected to be caregivers for themselves and their husbands and are also expected to contribute to production activities such as farming or market sales.

One of the barriers to care faced by PLHIV was the lack of coordination between HIV testing and referrals to HBC. HIV testing, which is advocated by HBC programmes and district HIV/AIDS-education campaigns, is viewed as the first step toward living positively with HIV. However, HIV testing is neither popular nor effective as a means of enrolling PLHIV into HBC programmes. Few people know their HIV status or choose to be tested despite the availability of free HIV testing. A HIV-testing programme in Chipinge refers people who test positive to HBC programmes for counselling, health and livelihood support activities. However, the experiences of the participants suggest that these referrals do not always guarantee that services can be obtained. Despite the investments being made into making HIV testing available, community members expressed a common resistance to HIV testing based on the consensus that HIV testing without follow-up and support is more dangerous that not being tested at all. For instance, one interviewee, a retired civil servant, tested HIV-positive at a mobile clinic. He went for testing after one of his three wives died of a prolonged chronic illness. He described his frustration with the lack of follow-up and explained that his experience was not unique but was one of the reasons why HIV testing is extremely unpopular:

“I was tested through a mobile testing unit and I was given pamphlets on positive living. These mobile units are killing people. They assume that once they refer you to an NGO, you automatically get support and counselling. In my case, I nearly lost my mind. I realised you start living with HIV, not the moment you are told about your status, but when you are alone at home. Their [mobile clinic] slogan is — Get REAL and be tested — but the reality is once the unit has left the district, you realise that living with HIV is not as simple as people would want to portray it, because the support you thought would be easy to get is impossible to find.”

The resistance of PLHIV to HBC activities stems from a perception that the potential benefits of assistance may not outweigh the expense of being exposed as HIV-positive. Being HIV-positive or living with AIDS makes individuals the target of unwanted gossip and social discrimination. The enhanced visibility of PLHIV was a problem created by HIV testing as well as enrolment into HBC programmes. Being HIV-positive is still understood as a ‘death sentence’ and misconceptions about HIV transmission create fears that can lead to quarantining of the sick. According to a woman who was caring for someone with AIDS:

“I try by all means to interact with them socially, but I fear contracting the disease. They say you do not have to throw away their leftover food, but I can’t do that. I think I will get the virus in the food. The sick are given their own plates of food to eat from. When they are finished, their leftover food is given to the dogs.”

Even if a beneficiary wanted to keep their HIV status secret, visits by community caregivers and sacks of WFP maize meal mark them as beneficiaries. Also, receiving priority treatment during times of widespread hunger, such as after a severe drought, can ignite jealousy and anger in the rest of the community.

The barriers to care faced by PLHIV begin with the limited availability of clinical services. In all field sites, we observed the near absence of government-funded public health services. Districts have a network of rural clinics connected to regional hospitals. Rural clinics provide primary healthcare, diagnostic services, and, when necessary, refer patients to hospitals. Hospitals offer specialised care and can accommodate patients during treatment and recovery. The deterioration of Zimbabwe’s public health system has left a gap in terms of healthcare delivery that has been filled by international NGOs and HBC programmes. In a discussion with community members from Zaka district about access to healthcare, the participants made clear the need for HBC to provide services to any population far from formal healthcare centres and to fill a gap left behind by the collapse of Zimbabwe’s healthcare system. A focus group participant explained:

“People will only go to the clinic only when they are seriously ill. Some people walk up to 15 kilome-
tres from their homes. Those who are bedridden have to be taken to the hospital in [ox] cart or even a wheelbarrow. Sometimes they are carried to the main road and from there they hire a car or truck to the hospital. In most cases when they get to the clinic there are no drugs and referral hospitals are too far and too expensive. Many of the patients who seek care for their symptoms do not have enough food, yet the tablets [for HIV and TB] they are required to take need them to eat a lot.’

A female former HBC patient from Zaka district explained how incompatibility between HBC structures and her livelihood as a seasonal migrant made it impossible for her to obtain consistent care:

‘I returned to my home in Zaka after my second husband died. I was getting antibiotics from the rural health centre. My condition was not improving and I felt that I should be put on ARV therapy. The process of getting the ARV support was not easy or clear. Even the food support I am supposed to be given wasn’t provided. Since then I left Zaka and I have gone to look for work in Harare as a domestic worker. The problem for me is getting my medications. In the meantime, I managed to get a three-months supply of my daily needs, but when they are finished, I am not sure how I can get them where I am staying right now.’

According to Physicians for Human Rights, the problems within Zimbabwe’s public health system, especially the delivery of ARVs, are “irregular due to breakdowns in drug delivery, distribution, provision, and theft of ARV drugs from ZANU-PF [President Mugabe’s political party] operatives” (Physicians for Human Rights [PHR], 2009, p. 4). We did not observe the theft of drugs in our research nor did we receive reports of this, but in terms of the inability of the public health system to deliver essential care to PLHIV, our observations were similar to those made by others (e.g. Meldrum, 2008; PHR, 2009). We observed few ARV programmes, a lack of basic medical supplies for treating patients, and a shortage of healthcare workers at public hospitals and clinics. Private mission hospitals accounted for the majority of healthcare delivery in rural areas. Few patients can afford the cost of healthcare under the current circumstances of rising drug and transportation prices due to Zimbabwe’s hyperinflation (PHR, 2009).

The HBC programmes in the study area only met some of the need for these services. The NGOs we talked with described their desire to scale up their projects to better meet demand, but faced shortfalls in donor funding for HBC. International commitments have not kept pace with demand. In 2005, Zimbabwe received far less HIV/AIDS funding from international donors compared to that for the region. In southern Africa, the average annual amount of donor spending per HIV-infected person was US$74 compared to US$4 for Zimbabwe (UNICEF, 2005). In 2007, spending in Zimbabwe had risen to US$17 per person, still far below regional estimates. The number of people receiving ART in 2007 was 40,000 to 60,000, or only 3% to 4% of PLHIV. However, the NAC and its partners are still committed to providing universal access to ARVs by 2010, a commitment that requires tremendous improvements in access, delivery and the economic stability of the nation (NAC, 2009).

One of the most pressing needs voiced by PLHIV was a shortage of food and livelihood support. The synergy between malnutrition and HIV and AIDS accelerates the onset of AIDS illness and mortality. Insufficient quantities of nutritious food combined with inadequate medical care were the greatest challenges to PLHIV in sustaining their health. The World Food Programme (WFP) (2009) reported that 1.8 million people in Zimbabwe relied on food assistance in 2008 and predicted that this number would rise to 5.1 million by February 2009. There was agreement among the participants that HBC programmes should offer a comprehensive package that includes nutritional support and livelihood strengthening activities. In some HBC programmes, participating households received agricultural inputs for maize cultivation (seed and fertilizer), food aid (maize meal, oil and dried beans) and hygiene products (soap, towels and bandages). The WFP has partnered with some NGOs to provide food aid for HBC programmes. Food assistance, received by some HBC beneficiaries, included a monthly, nutritionally enhanced ration intended to support patients on ARVs (WFP, 2009). However, most participants explained that the HBC package is still inadequate, varies without notice, and in most cases is delivered late.

The problem of widespread food insecurity has led many households to sacrifice medical treatment for the sick in order to purchase food. During times of food scarcity, PLHIV will forgo essential healthcare. Households will also sell off livestock, especially cattle, to pay for food. Survival strategies such as these compromise the immediate health needs of PLHIV and place HIV/AIDS-affected households in a precarious situation for dealing with future crises (Mazzeo, 2007). For example, a woman living with HIV explained in an interview how her household had already consumed most of its resources caring for her ailing husband:

‘I used all our money when my husband was sick. We even sold all our cattle. Now I am sick I have nothing to fall on. We have no food. We are selling what livestock we have left, especially chickens, in order to buy food. I refuse to sell my assets, because I want them for the future of my children. I get remittances from my daughter to send my grandchildren to school, and my sister is the one who looks after me since I have become very sick.’

This scenario was common among rural households and demonstrates the loss of wealth and increased vulnerability to future crises among households caring for PLHIV.

**HBC collaboration with government partners**

The next section examines how a failure to collaborate with government partners has compromised the effectiveness of HBC programmes to deliver services. Our findings suggest that the roles and responsibilities of HBC partners are not well defined, and even in situations where guidelines are established, the implementation of the partnership does not reflect the nature of the agreement. The result in many of the programmes we studied was an inefficient use of limited resources, poor targeting, low morale, and an overall decline in the performance of HBC. All of the HBC programmes
we examined involved coordination between international NGOs, local government, and CBOs.

International NGOs bring in donor funding and they work with the District AIDS Action Council (DAAC) to design and implement HBC programmes. The role of DAACs, as established by the NAC, is to "mobilise, coordinate and monitor the multisectoral and community response initiatives on HIV/AIDS in the District" (NAC, 2009). NGOs have benefited from their collaboration with the DAACs, because it provides them with the necessary approval to work in an area. Beyond their official role of sanctioning projects, few DAACs were kept up to date on the activities of the NGOs operating in their area or asked to provide input or assistance. This made it difficult for DAACs to execute their responsibilities, which include: enlisting and coordinating multisectoral involvement in the district response to HIV/AIDS; coordinating and monitoring the district planning process on HIV/AIDS; supporting the intensification of community-based HIV/AIDS interventions; promoting resource mobilisation in support of district initiatives on HIV/AIDS; and ensuring transparency and accountability in the disbursement and utilisation of funds earmarked for HIV/AIDS activities (NAC, 2009).

Carrying out the responsibilities entrusted to the DAAC depended on collaboration with the NGOs operating in their district. It also required a budget, staff and resources that the current level of government funding was unable to accommodate. The offices of the DAACs we visited were in disrepair, filled with broken equipment and suffering from low morale as staff watched as the value of their monthly pay checks shrank, if they arrived at all. This was not unusual for government offices in the rural districts we visited. All aspects of rural government had to contend with limited resources, low morale and difficult working conditions. DAACs were aware they were being sidelined and were frustrated with the unwillingness of NGOs to include them in decision-making. The fact that most of the DAACs derived funding by being included in NGO budgets made them hesitant to challenge the lack of transparency and collaboration offered by NGOs.

A DAAC member from Chiredzi district described his frustration in working with NGOs:

‘In principle, ten organisations are registered to operate here [in the district], but only four out of those ten have visible programmes on the ground. We have asked all these organisations to submit reports showing evidence of what they are doing, but in all their reports to us it is not apparent.’

The NGOs viewed government partnerships as necessary to gain access to PLHIV, but did not view the government as a collaborator.

Some DAAC officials were candid in their characterisation of the challenges in working with international NGOs. In an interview with an official in Chiredzi district, she explained the difficulty of holding NGOs accountable:

‘Coordinating programme implementers who have got money when my organisation is experiencing financial challenges means as a coordinator I have to beg them to support my HBC coordination activities. It then becomes challenging to make them accountable.’

She illustrated the problems of quality control when different NGOs implement similar projects but have vastly different outcomes:

‘If you look at interventions like community gardens; in some places they are doing well and in some areas they are not doing well, depending on who is implementing the project.’

She addressed the bottlenecks in resources and how CBOs rarely received the kind of basic support necessary to carry out their project:

‘When the community level, the grassroots coordinating structures like WAACs [Ward AIDS Action Councils] and VAACs [Village AIDS Action Councils] have been down. For those structures to be effective at community level, they need stationery and subsistence allowances.’

In Zaka district, there were concerns raised about the professional capacity of NGO health workers. One DAAC official felt it was his responsibility to reinforce the role of government as a gatekeeper to the community, but he was powerless to enforce this duty. In an interview he explained:

‘Some people are getting in the field and they do not have a health background and anyone can wake up and start talking like an expert; we need to set professional standards, but at the moment there is nothing we can do apart from working with anyone in the field.’

Similar to Chiredzi district, the DAAC in Zaka district felt that they were unable to hold NGOs accountable because programme-relevant information was being withheld and DAAC officials were not included in the planning process. He went on to describe:

‘In most cases people are not including us. We have put some control measures so that without us, even if you want information, you cannot get it.’

According to their mandate, DAACs are responsible for keeping track of PLHIV requiring HBC services and providing this information to NGOs. Rather than using this information, many NGOs conducted their own data-collection activities for targeting. A DAAC official described this process as an unnecessary investment of resources:

‘The fact that the DAAC should be coordinating the implementation process is there in principle; the reality on the ground is that the NGOs are doing what they want, targeting the people and communities that they want and reporting on what they want us to hear.’

The decision by NGOs not to use DAAC information was based on their observations of political patronage between government officials and their constituency. NGOs have seen the problems these relationships have raised in the past when government food aid was distributed according to political party membership rather than need.

Another type of NGO-government collaboration was partnerships with state hospitals and clinics to provide essential health services to HBC patients, such as diagnostic testing, treatment of opportunistic infections, monitoring of ARV medications, and emergency care. At a state hospital in Chipinge, the failure to communicate...
resource needs compromised their capacity to treat HBC patients. One of the nurses explained:

'The whole process has got challenges. Most NGOs are replicating what other NGOs are doing at district level. Coordinating meetings are happening at national level, but here at district level there is little coordination.'

The lack of coordination becomes evident when essential healthcare resources are unevenly distributed. She went on to explain that:

'Because there is no direct coordination at lower levels, donors delivered all the cotrimoxazole [medication for treating bacterial infections] for the district to a single rural clinic. They oversupplied one area while other clinics went without it.'

At a rural clinic in Chiredzi district, the capacity to administer services was more of a problem than was the lack of resources. An interview with a clinic administrator highlighted the lack of accountability among some NGOs:

'In 2006 an international NGO donated some medications, materials and equipment. But the programme funders withdrew before the materials and medicines had been distributed. Drugs are in short supply and we have a consignment of drugs that are about to expire soon. No one within the Ministry of Health and Child Welfare or DAAC seems to know or care about what is really happening.'

Problems with the delivery of HBC services in Chiredzi district were also evident from the focus group discussions with women. They explained that more women were choosing to give birth at home with the help of a traditional birth attendant. A nurse at a rural clinic confirmed that many pregnant women could not afford to buy sterile gloves and other necessary supplies that patients were required to bring with them to the hospital. Nurses at the clinic also confirmed that more women were giving birth at home. One nurse explained:

'We have no alternative but to turn these mothers away. We can't afford to expose ourselves to the virus [because they can't bring the necessary supplies with them].'

When asked about how they were following up with new mothers to protect newborns from contracting HIV, a health centre official explained:

'We encourage mothers who have been tested to come with their baby to our clinic for nevirapine [ARV medication] within 72 hours of giving birth.'

Some of the mothers we spoke with never sought treatment for their newborns and have stopped going to clinics for antenatal support because they are unable to afford the cost. NGOs need to make greater investments in CBOs, such as capacity-building and leadership training as well as provide these organisations with greater authority over resources. The value of the contributions made by the unpaid efforts of community healthcare workers cannot be over emphasized. Their work is the foundation of HBC, and without them the entire HBC model would not be feasible. Finally, HBC programmes need to invest more in community health workers through training, compensation for basic expenses, greater support to help volunteers deal with the challenges of providing care, and greater input into HBC decision-making (Campbell, Nair, Maimane & Sibiya, 2005; Akintola, 2008a).

Most of the NGOs had agreed to provide CBOs with training, such as sessions to prepare HBC workers. They also provided HBC kits and a uniform (for example, a T-shirt with a logo), and sometimes a small stipend to cover part of a volunteer's travel expenses and to compensate them for their time. Ideally, the NGO-CBO partnership involves ongoing collaboration and mutual accountability. More often, NGO-CBO partnerships read like partnerships in funding proposals but actually resemble patronage relationships during the implementation phase.

The CBOs in Zaka and Chipinge districts described their status as HBC partners as figulative. They recognised the benefits they receive from participation in HBC programmes run by international NGOs, but also that they have little if any power to influence the structure of these programmes. Additionally, the resources initially promised by NGOs during the proposal phase turned out to be inadequate to sustain the intervention or else it never arrived. A CBO member in Zaka described:

'We are called an organisation but we do not have enough resources to implement what we want to do. But as an organisation we have legitimate reason to be there, because we were the first group of HIV-positive to become organised and we lobbied for the formation of the National AIDS Council. Now we are being sidelined because we are not educated. Since we do not have resources to implement programmes, we join other big organisations.'

Many CBOs whose mission was to deliver HBC services were inactive during our field visits. In Zaka district, there were more community organisations claiming to be doing HIV/AIDS work than there were organisations that were actively delivering services. Out of 20 community organisations, only six of these were implementing programmes. Similarly, in Chipinge and Chiredzi districts, only one CBO out of eight was operational.

A retired teacher and volunteer from a CBO in Zaka district questioned the dedication of NGOs and the government to actually deliver services. Like other community workers, she felt that her CBO has been left out of the decision-making process. Political patronage and a desire to profit from HBC funding rather than produce results are obstacles to project success. She also pointed out that volunteers like her are demoralised when they see HBC funding line the pockets of project planners or go to pay for elaborate workshops:

'These big organisations don't treat us as important people. Even at community level, the people who
are chosen by the councillors end up behaving as if these are political institutions and not institutions for helping those with HIV. The representatives in AIDS Action Councils have been handpicked through their various personal alliances and most of them do not understand HIV issues, let alone to represent the interests of the sick people. Some and most of them are not well educated and they have problems compiling reports. Right now they have been selected to attend a workshop at Great Zimbabwe, but when they come back, they expect me to write a report for them.

Widespread food shortages, rising costs of living, and rampant inflation have made the work of CBOs in Zimbabwe difficult to sustain on a small budget. One DAAC representative in Zaka district was sympathetic to the struggle of volunteers to balance their desire to serve PLHIV and at the same time be breadwinners who can provide for their household. In the interview, he described a support group in his area coordinated by HIV-positive volunteers:

'Support groups for HIV/AIDS are not effective at the moment. For support groups of people with HIV to effectively mobilize them and coordinate activities, they need to have adequate access to drugs and food. Support group members coordinating activities are not meeting. If you are hungry, you cannot travel.'

Similarly, the retired teacher and CBO volunteer interviewed in Zaka also emphasized the pressing survival needs of volunteers:

'Our [financial] interests are not well catered for. We end up wanting to sacrifice our role as facilitators to look for other ways to earn money to buy food for our children.'

Jealousy and competition between CBOs happened as a result of the varied levels of funding received from outside donors. CBOs working in the same area with the same population can have vastly different budgets, leading to varying levels of care. For example, in Hatcliff extension, Harare, an organisation working to provide livelihood support programmes to PLHIV was experiencing challenges in regard to their target beneficiaries who were getting support services from two different organisations. Some beneficiaries on ART were getting their support from Newlands ART centre while others were supported through Parirenyatwa Hospital and Harare government hospitals. Newlands ART centre received significant support from the Global Fund and offered its patients a food package along with ART; those served by Parirenyatwa and Harare hospitals only received ARVs and no additional support.

Some HBC patients in Hatcliff extension participated in a focus group discussion and described how varying forms of care within the same community had created tension between patients. The beneficiaries distinguished themselves according to where they were receiving support, explaining that they even say, 'Isu tiri vekuNewlans avo rDvekuparirirenyatwa,' meaning 'We are from Newlands and those are from Parirenyatwa.' Some patients described their attempt to access both forms of support in order to receive the support they needed. Some patients who benefited from ART talked about how they resold medications because they felt that food was a more pressing need for them and their family. In other cases, patients without access to sufficient food were not taking their ARVs as prescribed. They explained that when they took ARVs without eating enough food they became sick and found it difficult to adhere to the prescription instructions.

The incorporation of traditional African medicine can improve the quality of life of patients and ensure greater adherence to treatment (Taylor, Dolezal, Trose & Holmes, 2008). Discussions with community members pointed out that traditional practitioners (n'anga) were also being sidelined. Some beneficiaries explained that their decision to use HIV-testing services was because they had faith in their traditional healers. Many reported that they were using herbs from the traditional healers. Although patients see little conflict in seeking care from both biomedical and traditional practitioners, there is little interaction or cooperation between these two health sectors in Zimbabwe. The DAAC is required to include a traditional leader as a member. However, in Zaka district, one n'anga described that his relationship did not offer a real opportunity to contribute (although the claims of this n'anga to treat HIV and AIDS were not clinically evaluated in the research):

'We have never been given an opportunity to nurse patients but what they do is invite us to their meetings. At the meetings we discuss how patients who are HIV-positive should be treated, how they should get their food, how people should cope with the disease. I am not happy with the relationship n'anga have with DAAC. When we go there we are just told — Don't do this or that with your patient. N'anga are not given the opportunity to add on to the DAAC package. It would be very odd for me to go to the hospital and say I want to see patients. I will be chased away. Yet I have certain patients whom I can cure. The DAAC and Ministry of Health is not giving us the opportunity to visit patients in hospitals. We might want to visit some patients in hospitals and put some scars and herbs on them, but if we do this doctors will become mad at us. I say — You are proud of your own art. As individuals we have different areas of specialisation, and if these areas were captured it would help many people.'

Conclusions

This research relied on rapid ethnographic appraisal to examine the challenges of implementing a collaborative, multisectoral home-based care (HBC) model in Zimbabwe. We relied on evidence collected through fieldwork to represent the range of experiences by HBC stakeholders, including beneficiaries, government DAAC workers, healthcare staff, CBOs and community volunteers. This research in Zimbabwe revealed the experiences and perspectives of partners and beneficiaries in order to offer a critical assessment of the collaborative HBC model. Hopefully, these findings will challenge HBC programmes to reconsider how collaborations are structured. This kind of research follows a
growing trend in research on HBC in southern Africa which challenges widespread assumptions about the effectiveness of dominant HBC models and suggests that the current structure of partnerships is not the most efficient way to coordinate and deliver HBC services.

The article demonstrated that the challenges to collaboration between NGOs, government and CBO partners negatively impacts the effectiveness of HBC programmes and has real consequences for the health and livelihoods of PLHIV. In our discussion of the experiences of PLHIV, we highlighted that HIV/AIDS programming has not managed to provide a link between HIV testing and HBC enrolment. As a result, scepticism has grown within communities about the usefulness of HIV testing as a means for accessing HBC support. Additionally, shortages of donor funding and the difficulties of managing a complex support programme have constrained HBC programmes from providing a comprehensive package that could include food and livelihood support.

The challenges to collaboration were first identified with government partners. DAACs were used by NGOs to gain access to populations, but were excluded from HBC management because the NGOs were sceptical that they could function impartially given their political connections. Despite their mandate to oversee HBC programming in their areas, the DAACs were reluctant to pressure NGOs to comply with transparency and accountability for fear of losing those services. Next, we identified challenges to collaboration with CBOs. CBOs were a critical link in service delivery, but NGOs did not provide them with the necessary resources to carry out their responsibilities. CBOs also faced exclusion from the planning process. The knowledge possessed by CBOs and community health volunteers was not valued by the NGOs and was rarely included in project design.

The findings from this and other studies suggest it is worth investing in the HBC model, having demonstrated that this form of service delivery can more effectively provide ART, increase individuals’ acceptance of an HIV-positive status after testing, and help improve patients’ compliance with medications (see Apondi, Bunnell, Awor, Wamai, Bikaaoko-Kajura, Solberg et al., 2007; Ncama, 2007; Krebs, Chi, Mulenga, Morris, Cantrell, Mulenga et al., 2008). The problems with HBC in Zimbabwe are not unique, but have been found in programmes across the region (Oliveira-Cruz, Hanson & Mills, 2003). However, creating a HBC model that can effectively deliver needed health resources to a vulnerable population is a human rights issue (PHR, 2009). When the delivery of HBC goods and services is obstructed or made grossly inefficient because of a failure of partners to collaborate, this constitutes a human rights offense. According to Farmer (2008, p. 10): “Health and human rights needs to move beyond its traditional exhortatory role, which stems from insistence on respect for conventions to which most states are signatory, and think about such prosaic issues.” Protecting the rights of PLHIV includes assuring that the organisational structures and basic materials necessary for provisioning care are available. In the case of Zimbabwe, this includes significantly expanding access to ART, medications for opportunistic infections and sufficient nutritious food.

In addition, the research has shown that there needs to be greater investment in those institutional structures that ensure that resources reach the people who need them most. To this end, programmes need to ensure that they are providing what their beneficiaries need, are flexible in what they offer, and follow through with their commitments. Some of the conclusions identified by Madube, Bekinska, Ramkissoon, Wood & Fosom (2008) relate to the management of HBC resources and services in South Africa, but apply to the situation in Zimbabwe. The supply of HBC resources for patients needs to be improved to better meet the demand, while the management of the supply-chain needs to be strengthened to ensure consistency and on-time delivery. The referral systems between the various institutions involved in the provision of care, including clinics, hospitals, social welfare programmes and HIV-testing centres, need to be improved and their responsibilities clarified.

Despite the potential success of HBC in Zimbabwe, the absence of real collaboration between HBC partners has greatly compromised the ability of programmes to effectively deliver essential services to a highly vulnerable population. Zimbabwe’s high HIV prevalence, a severe shortage of ARVs, and widespread food and livelihood insecurity have amplified the human consequences of not being able to implement a timely and effective HBC strategy. At the same time, we recognise that given the condition of Zimbabwe’s public health system, HBC is probably the most effective mechanism for the delivery of services. Finally, our study suggests that Zimbabwe’s current HBC structure needs significant revision and a greater commitment to real collaboration, especially by international NGOs, in order to carry out its mandate.

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The authors — John Mazzeo (PhD) is an assistant professor and a faculty member in the master’s programme in public health at DePaul University. He is an applied medical anthropologist whose research in Zimbabwe examines the impacts of HIV and AIDS on the livelihoods of rural populations. His work has contributed to the development of CARE Zimbabwe’s home-based care programme to offer health, livelihood and food aid to support households affected by HIV or AIDS.

Loveness Makanese is a sociologist specialising in HIV and AIDS, livelihoods, food security, marginal communities and development issues. She holds a BSc Honours in sociology from the University of Zimbabwe and an MPhil from the University of the Western Cape (South Africa). Currently, she is a PhD candidate in the Department of Sociology at Rhodes University (South Africa). She has worked in both the public and non-governmental sectors with organisations such as CARE, Plan, ISL and GOAL.

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