Volunteer home-based HIV/AIDS care and food crisis in Addis Ababa, Ethiopia: sustainability in the face of chronic food insecurity

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Accepted 22 January 2010

Low-income volunteers constitute a major part of AIDS care workforces in sub-Saharan Africa, yet little research has been conducted to determine how poverty and insecurity among volunteers impact their wellbeing and the sustainability of the AIDS treatment programmes they support. This paper presents longitudinal ethnographic and epidemiological research documenting how the 2008 food crisis in Addis Ababa affected AIDS care volunteers’ care relationships and motivations. Ethnographic results highlight the distress and demotivation that rising food costs created for caregivers by contributing to their own and their care recipients’ experiences of food insecurity and HIV-related stigmatization. Epidemiological results underscore a high prevalence of food insecurity (approximately 80%) even prior to the peak of food prices. Rising food prices over the 3 years prior to 2008, underemployment and household per capita incomes averaging less than US$1/day, likely contributed to the very high prevalence of food insecurity reported by caregivers in our sample. We also show that new volunteers recruited in early 2008 by one of the non-governmental organizations (NGOs) involved in this study were more likely to be dependants within their households, and that these participants reported lower rates of food insecurity and higher household income. While this shift in volunteer recruitment may help sustain volunteer care programmes in the face of widespread poverty and underemployment, food insecurity was still highly prevalent (58–71%) among this sub-group. Given the inability of the local NGOs that organize volunteers to address the challenge of food insecurity for programme sustainability, our results raise important policy questions regarding compensation for volunteers’ valuable labour and poverty reduction through public health sector job creation.

Keywords Volunteerism, home-based care, HIV/AIDS, food insecurity, food crisis, Ethiopia
KEY MESSAGES

- Mixing ethnographic and epidemiological methods is essential for understanding the impact of food insecurity on volunteer AIDS care.
- Rising food costs distressed volunteers by contributing to both their own and their care recipients’ experiences of food insecurity.
- Food insecurity was already highly prevalent among volunteer caregivers in Addis Ababa prior to the 2008 food crisis.
- While volunteers appear resilient to socio-economic adversity, food insecurity among them and their care recipients threatens to undermine AIDS care.

Introduction

On the eve of the XVII International AIDS Conference in August 2008, the executive director of UNAIDS, Dr Peter Piot, summed up the effect of the then current global food crisis on AIDS treatment efforts: “We have the paradoxical situation that some people have access to pretty expensive and sophisticated drugs but have no food to eat...or don’t have the money to take the bus to go to the [medical] center, and have no jobs” (reported by Democracy Now, 1 August 2008).

In the context of economic development, an important policy focus is the synergistic threat to human productivity and nutrition posed by AIDS and food insecurity (FI) (Himmelgreen et al. 2009, Gillespie 2006; WFP/WHO/UNAIDS 2008), the latter defined as insecure access to sufficient food for a healthy and active life (FAO 2004). With the rollout of AIDS therapies, low-income volunteers have become a major part of African and global health workforces. FI among AIDS care volunteers, like other biosocial mechanisms linking FI and HIV/AIDS, underscores ‘cycles of poverty’ that must be interrupted at programmatic levels (Ivers et al. 2009). Thus it is imperative to question not only how FI contributes to HIV infection, drug access and adherence, related comorbidities and early mortality (e.g. Mukherjee et al. 2006), but also how FI among volunteers impacts their wellbeing and the important labour they provide. However, to date no studies have assessed how FI specifically affects AIDS care volunteers.

As several policy-oriented researchers have shown, the promotion of volunteer (or unpaid) AIDS care across sub-Saharan Africa is based on the assumption that volunteerism is an economic imperative in settings that combine health professional scarcity with national policies imposed by the International Monetary Fund (IMF) requiring expenditure ceilings on professional services (Dra¨ger et al. 2006; Hermann et al. 2007; Ooms et al. 2007; Akintola 2008b; Campbell et al. 2008; Schneider et al. 2008; Hermann et al. 2009). AIDS care volunteers in sub-Saharan Africa, typically organized by local non-governmental organizations (NGOs), help fill large human and material resource gaps in public health systems, which many scholars attribute to structural adjustment programmes of the 1980s and 1990s (Irwin and Scali 2007). Community volunteers, many of whom have been affected by HIV/AIDS, are often uniquely capable of providing culturally competent and compassionate chronic disease care (Kim and Farmer 2006; Hermann et al. 2009). High rates of successful adherence to highly active antiretroviral therapy (HAART) in low-income settings have been at least partly attributed to the contributions of volunteers as treatment supporters, counsellors and mediators of patients’ access to clinical and NGO resources (e.g. Coetzee et al. 2004; Hardon et al. 2007). However, there is no reason to believe that it is the volunteer status per se that is responsible for these successes; instead it appears to be the important labour performed by volunteers.

Acknowledging the shared social and economic determinants of HIV/AIDS, FI and health professional shortages in Africa, some have advocated that community health workers (CHWs) who serve on a volunteer basis should be incorporated into the public sector and fairly remunerated along with efforts to strengthen public health and social welfare systems in poor countries (Kim and Farmer 2006; Pfeiffer et al. 2008). For many, this policy aims to protect AIDS care workers’ right to fair compensation. Remuneration of workers is also a question of sustainability of health programmes, highlighting the trade-off between losing volunteers through attrition and affording to pay adequate wages (Swidler and Watkins 2009). As national governments struggle to find funding to hire and pay the large numbers of CHWs and health professionals demanded by huge burdens of infectious and chronic disease, many nations will find it very difficult to follow the World Health Organization’s recent recommendation: ‘Countries should recognize that essential health services cannot be provided by people working on a voluntary basis if they are to be sustainable. While volunteers can make a valuable contribution on a short term or part time basis, trained health workers...should receive adequate wages and/or other appropriate and commensurate incentives’ (WHO 2008: 35). In this context, sustainability is largely a question of whether major international donors such as the Global Fund can promise to maintain adequate funding to strengthen public health workforces in Africa (Dr¨ager et al. 2006; Ooms et al. 2007).

As we argue in this paper, FI is particularly demotivating for volunteers, contributes to cycles of poverty and HIV/AIDS (Ivers et al. 2009), and adds strain to the important relationships volunteers maintain with their care recipients who struggle to adhere to HAART. A focus on FI clarifies what is at stake in the ongoing debate over the appropriateness of volunteerism from both human rights and sustainability perspectives, particularly in the wake of the 2008 global food crisis.

The 2008 food crisis represented a major shock to economies at the global, national and household scales. In mid-2008,
global food prices had escalated rapidly, driven by increased demand for food and biofuel crops, rising petroleum costs, climate change, harvest shortfalls and perhaps financial factors (Headey and Fan 2008; Robles et al. 2009). In Ethiopia, one of the world’s poorest countries, the 2008 food price spike was the culmination of a trend that began in 2004. The available data led Ulimwengu et al. (2009) to conclude that the Ethiopian food price index had been consistently higher than the world index since August 2004 (cf. Loening et al. 2009). While food price inflation occurred throughout Ethiopia, since 2006 rates were particularly high in the capital city, Addis Ababa (Ulimwengu et al. 2009).

The beginning of the upward trend in food prices in Ethiopia in fact coincided with the much-anticipated launch of HAART programmes country wide in late 2004. At that time, home-based HIV/AIDS care was promoted at the national level (Ministry of Health 2005). In the face of a late-maturing HIV/AIDS epidemic (National Intelligence Council 2002; Iliffe 2006), volunteerism in community health care has grown substantially over the past decade in Addis Ababa. However, the experiences of volunteer caregivers and CHWs in general in Ethiopia have received very little attention, despite the debate on the sustainability of unpaid community health work in sub-Saharan Africa (Hermann et al. 2009). Recent literature on task-shifting and human resources for health challenges has focused on southern Africa (e.g. Schneider et al. 2008). Hermann et al. (2009), in their appraisal of the sustainability of CHW programmes in Uganda, Malawi and Ethiopia, limited their focus to the experiences of salaried CHWs in Ethiopia’s national Health Extension Program, ignoring even the large number of volunteers who work alongside this programme’s extension workers (JSI 2009).

Our research sought to address these gaps, and extend the focus on HIV/AIDS–FI interactions to AIDS care volunteers, given their importance in prevention and treatment efforts. We conducted longitudinal ethnographic and epidemiological research over 2007–09. In this paper, we show that FI was highly prevalent among volunteers even prior to the 2008 food crisis, and that FI was associated with volunteer caregivers’ household economic status. We then present qualitative evidence that rising food costs in Addis Ababa, on top of chronic FI, were a source of distress and demotivation for volunteer caregivers, contributing to their own and their care recipients’ experiences of economic insecurity in a setting of widespread unemployment. We argue that, while volunteers appear resilient to socio-economic adversity, FI among unpaid volunteers and their care recipients threatens to undermine AIDS care in Addis Ababa and similar settings.

Local setting
Addis Ababa is the capital city of Ethiopia, with a population of over 3 million inhabitants (UN-HABITAT 2008). Volunteer home-based care here is broadly similar to programmes in settings throughout sub-Saharan Africa (see Akintola 2008b). Public health facilities rely heavily on the training of volunteers, who provide home-based palliative care, support drug adherence, and mediate patients’ access to clinical treatment and NGO assistance. Volunteers are not considered government health personnel, but rather are organized under local NGOs with support from international NGOs. Volunteers in the current study setting serve for a period of 18 months, caring for at least five non-kin patients, under the supervision of NGO-salaried nurses. They develop close relationships with one or two of their patients, but maintain regular interaction with all of their assigned patients. After 18 months, patients are reassigned to a new group of volunteer recruits, and ‘graduating’ volunteers exit the service with uncertain prospects for employment. A select few remain on for another term of service; an even smaller proportion gets promoted to low-wage NGO positions. Volunteers receive US$5–10/month, said to reimburse their transportation and telecommunications expenses. Some volunteers received food aid (usually wheat and cooking oil) as a stipend from their NGO. However, this practice was interrupted in early to mid-2008. Those who continued to receive food aid were eligible for reasons aside from being a volunteer.

Methods
Ethnographic methods
We used ethnographic methods to determine how FI affected and was affected by participants’ roles as volunteer AIDS caregivers. Informants were recruited from two local NGOs, Hiwot HIV/AIDS Prevention, Care and Support Organization and Medhin Social Center, which provide home-based care for people with HIV/AIDS accessing treatment at the Ethiopian Ministry of Health’s ALERT Hospital in southwest Addis Ababa. Hiwot runs an Addis Ababa-wide AIDS care programme, with hundreds of volunteers. In contrast, Medhin is a small organization under the auspices of the Ethiopian Catholic Church, which focuses on neighbourhoods adjacent to ALERT hospital. By including volunteers from these two organizations, we intended that the sample would better reflect the diversity of community health volunteer programmes in Addis Ababa.

Ethnography comprised participant observation in neighbourhoods in south west Addis Ababa, including attendance at volunteer trainings, caregiver and care recipient homes, and volunteers’ reporting and planning meetings, conducted over 20 months between May 2007 and January 2009. Informal conversations were held with volunteers and staff within the NGO and hospital administration. A purposive sample of 13 volunteer caregivers (10 women and 3 men) aimed to account for the preponderance of women in the volunteer population, as well as variation in length of service, age, education and socio-economic status. Informants were recruited to complete a series of semi-structured interviews assessing various domains, including volunteer caregiver motivation, costs and benefits, FI, care relationships and wellbeing. Interviews occurred over 8 months in 2008; each informant was interviewed up to seven times, until we had addressed each of the predetermined domains.

Finally, three focus group discussions (FGDs) were conducted during April/May 2009, with similarly purposive samples of six volunteers (four women and two men), six NGO paid community workers (five women and one man) and six NGO supervisor nurses (four women and two men), respectively. FGDs covered volunteer caregiver motivation, challenges, and costs and benefits.
Analysis involved an iterative process of identifying emergent themes and grouping data into coded categories. In-depth interview and FGD texts were analysed by the first and second authors, respectively. Results from these two datasets were compared and found to be consistent. Here, we focus on volunteers’ narratives of how FI intersected with their lives and roles as caregivers.

Epidemiological assessment

Surveys were administered to volunteer caregivers from Hiwot and Medhin NGOs at three rounds (February, July and November 2008). Drawn from NGO rosters, the sample included 110 volunteer home-based caregivers (99 women and 11 men) of adult patients receiving treatment at ALERT Hospital. This sample incorporated 40 randomly chosen participants (out of 60) who had just begun volunteering with Hiwot at the time of the baseline survey; 50 randomly chosen participants (out of 70) who had all been volunteering with Hiwot for 12 months at baseline; and all 20 volunteer caregivers from Medhin, with an average service length of 12 (±4.6) months at baseline. At round 1, 110 participants were surveyed; at Round 2, 106 of the original 110 were surveyed; at Round 3, 107 of the original 110 were again surveyed. Four Ethiopian research assistants were trained prior to each data collection round, and data collection was conducted in pairs. Refresher training and the data collection ‘buddy system’ aimed to maximize data quality.

Study instruments

We assessed FI with a standard scale for international use, the Household Food Insecurity Access Scale (HFIAS) (Swindale and Bilinsky 2006). The nine items of the HFIAS are listed in Box 1. We translated the HFIAS into Amharic, the language of commerce in Addis Ababa, then back-translated and revised. Participants were presented with ‘yes’ or ‘no’ response categories for each item of the HFIAS. Responses pointing towards FI were coded as 1 and negative responses as 0.

Participants’ households were classified into four levels of FI: (1) food secure (participant answers ‘yes’ to none of the items); (2) mild FI (answers ‘yes’ to item 1 or 2 or 3 or 4, but not items 5–9); (3) moderate FI (answers ‘yes’ to item 5 or 6, but not items 7–9); and (4) severe FI (answers ‘yes’ to item 7 or 8 or 9). Using this classification scheme, the HFIAS performed well according to established validation criteria (Maes et al. 2009).

Participants estimated total monthly household incomes at each data collection round. At Rounds 2 and 3, participants reported household composition (i.e. adults and children regularly sleeping and eating in the house). At each round, total estimated household income was divided by the total number of people in the household at Round 1 and by the total number of people in the household at Round 2.

At each round, participants reported whether they were receiving free food aid from NGOs, and what kinds of food they were receiving. Wheat was the most common type of food aid available over the study period; in 2007 and the first part of 2008, free wheat was accessed often from NGOs like Hiwot and Medhin. We categorized participants based on whether they received free wheat as food support at the time of the survey.

Participants reported age, gender, marital status (single, married, divorced/separated/widowed) and years of formal schooling. We also categorized participants according to whether they were in charge of their household food economy: that is, we distinguished between dependants living with parents or guardians, versus male and female heads of household and females living with older parents but sharing food economy responsibilities (shopping and cooking).

Analytic strategy

Our first goal was to demonstrate the prevalence, severity and household economic correlates of FI among volunteer caregivers. Secondly, our ethnographic work suggested that an important factor in household food access was whether a volunteer caregiver was dependent or shared major responsibilities in the household food economy. Household heads who volunteer typically have limited means of generating income, whereas dependants who volunteer typically live with other income-generating adults. Further, it is possible that younger adult dependants, especially young men, are to some extent buffered from FI within their households (cf. Poluha 2004; Mains 2007; Hadley et al. 2008). We also observed that...
Important differences in household economic variables were observed between participants reporting food security and those who were food insecure (Table 2). At each round, food-secure volunteers with larger household incomes ($36.5$ vs $10.1$, $P<0.05$) and higher household income ($45.7$ vs $39.7$, $P<0.05$) than those reporting food insecurity. The proportion of women employed as household heads increased from $36.5$% at Round 1 to $48.1$% by Round 3 ($P<0.01$).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Round 1</th>
<th>Round 2</th>
<th>Round 3</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at baseline, years</td>
<td>$27.7$</td>
<td>$25.5$</td>
<td>$24.8$</td>
<td>$0.05$</td>
</tr>
<tr>
<td>Female gender, %</td>
<td>$90$</td>
<td>$87.6$</td>
<td>$88.1$</td>
<td>$0.34$</td>
</tr>
<tr>
<td>Marital status at baseline, %</td>
<td>Married</td>
<td>Unmarried</td>
<td>Separated/Divorced/Widowed</td>
<td>$26.7$</td>
</tr>
<tr>
<td>Schooling at baseline, years</td>
<td>$6.2$</td>
<td>$6.0$</td>
<td>$5.8$</td>
<td>$0.05$</td>
</tr>
</tbody>
</table>

**Table 2** Household economic variables and self-reporting questionnaire (SRQF) scores by round of data collection and FI status

For continuous variables, multilevel linear models were used to test the effect of round of measurement on household economic variables. For categorical variables, generalized estimating equations were used. Both of these methods account for repeated measurements. For continuous variables, multilevel linear models were used to compare food-insecure and food-secure households. For categorical variables, generalized estimating equations were used. Both of these methods account for repeated measurements.

Household composition was not assessed at Round 1.

Fisher's exact test; only seven participants reported food security and dependent status.

### Results

#### Epidemiology

Sample descriptive statistics are listed in Table 1. Age at baseline was $27.7$ ($6.2$) years. Formal schooling was $10.3$ ($2.6$) years. Ninety percent of participants were women, and $25.5$% were separated, divorced or widowed.

#### Food-secure versus -insecure households

Food-secure versus -insecure households were compared for food insecurity, per capita household income, and household composition.

#### Food insecurity, %

Food insecurity was reported by $82.7$, $77.4$, and $78.5$% of participants at Rounds 1, 2, and 3, respectively.

#### Moderate and severe food insecurity, %

Moderate and severe food insecurity was reported by $60.9$, $50.9$, and $47.7$% of participants at Rounds 1, 2, and 3, respectively.

#### In charge of household food economy, %

In charge of household food economy was reported by $77.6$, $80.7$, and $63.2$% of participants at Rounds 1, 2, and 3, respectively.

#### Receiving free wheat as food aid, %

Receiving free wheat as food aid was reported by $38.2$, $38.5$, and $36.8$% of participants at Rounds 1, 2, and 3, respectively.
by food-insecure volunteers. Participants reporting FI reported increasing income over the three data collection rounds ($P < 0.05$). However, while statistically significant, the increase in per capita income for food-insecure households was on the order of only US$0.05/day.

**Household dependency status and socio-economic status among new volunteer recruits**

The large majority (77.6%) of participants were in charge of or otherwise held major responsibilities in their household food economies; the remaining participants were classified as dependants. We made preliminary observations that volunteers who were newly recruited by the Hiwot NGO and began service in February 2008 were more likely to be young adult dependants. In fact, 34.2% of volunteers recruited by Hiwot in February 2008 were dependants; the corresponding proportion among the other volunteers in the sample, who were recruited by their respective NGOs in early 2007, was only 15.9% ($P < 0.05$).

Characteristics of personal appearance (e.g. clothing and hairstyles) further suggested that these younger newcomers came from higher socio-economic backgrounds. These observations were confirmed by our quantitative analyses. Dependents reported higher household income ($P < 0.001$) and per capita income ($P < 0.05$), and were less likely to report FI ($P < 0.01$) at each round (Table 3). In addition, dependents’ households were approximately 50% larger ($P < 0.0001$) and were less likely to be receiving free wheat as food aid ($P < 0.01$). We return to the significance of these findings in the discussion.

**Ethnography**

FI featured prominently in discussions of care relationships and (the lack of) NGO compensation for volunteers, with important implications for the sustainability of volunteer AIDS care programs in this setting. We discuss these two domains in turn.

**Compensation and motivation**

Although transport allowances and food aid stipends were sometimes referred to as salary (dámez) in the discourses of volunteers and their supervisors, the salary label was often actively avoided. As volunteers, all informants understood that even a modest salary would not be not forthcoming. And yet it was common for volunteer caregivers to express a desire for compensation from the NGO and/or opportunities to turn their volunteer experience into a paid position within the NGO, other NGOs or local public hospitals, and to lament that such opportunities were not available. Interviews made it clear that this ambivalence was exacerbated by rising food prices.

“[The NGO supervisors] give us 100 Birr [about 10 US$] as a monthly transport allowance. I take the 100 Birr and spend it on my food. There is nothing that I do other than spend it on food. Nobody can move without food. Yes, we will continue volunteering. But how can we live with this life condition? [The NGO supervisors] know how much a sack of wheat costs. Nowadays, it is only that life is expensive and there is no employment.” (Male caregiver, December 2008)

Some volunteers expressed that they did not expect compensation for their efforts. As followers of Ethiopian Orthodox Christianity (the religion with which the vast majority of participants identified), volunteers often described their expectations of divine rewards as an important motivation to continue volunteering. The following statement is highly representative of informants’ views on the link between human and divine reciprocity: enjoying the gifts that God bestows on people who help others.

“What motivated me to be a caregiver...[is] to see others’ pains like my own [and] to understand how many hurt people there are. If I am not benefiting in my own way [by directly receiving benefits from the NGO], I will get something from God. God will pay me [back for] my weariness.” (Female caregiver, May 2008)

Despite the motivating power of such spiritual beliefs regarding human and divine reciprocity, all informants expressed some ambivalence in regard to volunteering amidst chronic FI and rising food prices. This ambivalence was structured by genuine interest in continuing to help fellow community members living with HIV/AIDS on the one hand, and, on the other hand, the rising cost of living, high rates of unemployment in Addis Ababa (Serneels 2007) and the naïve yet understandable assumption that local NGOs or the Ministry of Health had the resources to pay volunteers a liveable wage. In fact, the local NGOs were in similar positions, facing reduced support from international NGOs and donors in 2007 and 2008. The male caregiver quoted above on the inadequacy of NGO compensation...
added. “We were given 45 kilos of wheat [by the NGO]. We entered the volunteer programme in the first place depending on that. [The NGO supervisors] are reducing things [i.e. food aid]; but we volunteer caregivers are not reducing our love.” The question on this informant’s mind was how long volunteer caregivers can sustain their ‘love’ (fiqr) and motivation in the face of reduced access to needed resources.

Finally, our ethnographic work showed that volunteer caregivers often depend on family, including spouses, and other social ties to meet their household food needs. Rising food prices put a strain on these social ties.

“When I finish [the spice supply in my home], I go to my extended family. Previously, when they would prepare spice, they would give me some. Nowadays, when life becomes expensive, they become antagonistic. They say, ‘Now you are asking us too much.’ They do not satisfy you as previously.” (Female caregiver, October 2008)

One informant’s relational distress with her husband regarding the household food supply had implications for her motivation to continue volunteering, given her dependence on her husband for both material and moral support as a volunteer caregiver (a situation she shared with a large proportion of her fellow female volunteers).

“When [a particular food in the house] is finished, and my husband wants that, we get into an argument… I never said I should quit volunteering. But sometimes, my husband says, ‘I can give you what I have, but you should also work.’ At first, he was willing. But nowadays, he says, ‘Volunteering has no benefit, and it is tiresome. What are you doing? Why don’t you find another job?’” (Female caregiver, October 2008)

Care relationships
FI also affected volunteer caregivers through their relationships with care recipients. We identified two sub-domains in which volunteers’ comments demonstrated this connection: (1) volunteers’ sympathies with the suffering of care recipients and mental satisfaction from the improved health and status of care recipients; and (2) antagonism that food-insecure care recipients sometimes directed at caregivers.

First, all informants expressed sympathy for their care recipients’ distress in relation to poverty and FI. In their view, this distress was exacerbated by the rising cost of food and the reduction in food aid that occurred over the study period: in 2008 the World Food Programme (WFP) began to require that reduction in food aid that occurred over the study period: in 2008 the World Food Programme (WFP) began to require that food-insecure care recipients be distributed more generously.

“Now I am beginning to feel awful. Almost half of the care recipients who were previously receiving free wheat as food aid are dropped from the food aid programme. That’s it—they are angry. Now you will go to a care recipient’s home and all you see is crying. And they start to cry when they see you.” (Male caregiver, June 2008)

Conversely, all caregivers expressed satisfaction in reaction to cases where the health of a bedridden care recipient improved, allowing him or her to find employment or start an income-generating activity.

“I persuaded a care recipient and he started [HAART]… Now he is walking and working as a daily labourer. And satisfaction means—this person, for example, thanks me every time we meet. He says, ‘It is because of you that I stand up and start to feed myself.’” (Male caregiver, August 2008)

A second important theme was the distress that volunteers experienced when care recipients became antagonistic. This antagonism resulted from a mix of poverty, FI and HIV-related stigmatization. For instance, some care recipients expected volunteer caregivers to provide food or money from their own pockets. These situations often arose when care recipients were relatively healthy (due to the biological effects of HAART), but still very poor and unable to generate income.

“[Some care recipients] have a shortage of food. They say, ‘With what can I take the medication?’ They tell you, ‘My insides are burning with medication only.’” (Male caregiver, November 2008)

“[Some care recipients say:] ‘We are hungry, we are thirsty’. These days, it is when you eat that you’ll be healthy… There are many patients, and sometimes they will insult you. Forget the insults, but they might [physically harm] you. Volunteer caregiving is a sacrifice. It is a risk—when their stomachs are empty.” (Female caregiver, July 2008)

The majority of volunteers interviewed explained that it was beyond their ‘capacity’ (ajir) to give money or food to such care recipients. This often resulted in the care recipient rejecting the psychosocial support, health education and other services that volunteers were prepared to give. This rejection was partly motivated by the care recipient’s fear of HIV-related stigmatization, which could be triggered when neighbours or a landlord observed volunteers associated with known AIDS NGOs visiting the care recipient. A female caregiver, who was herself living with HIV/AIDS while raising a young child with her husband, explained her view on these issues:

“For me, it seems [some care recipients] don’t want you as a volunteer caregiver because there is no benefit they receive from you. The absence of any material benefits causes disagreements between caregivers and care recipients. When they meet us on the road, they think there is something [e.g. food] in the backpacks we carry. But the backpack contains our [nursing] materials. ‘What do you carry in this bag? Why do you have it if it is empty?’ That is what they say…” (Female caregiver, October 2008)

“Actually, the care recipients are victims. Let alone them, even we volunteer caregivers will be happy if we get some benefits. If they get some benefits, I think they will be satisfied. They say, ‘What we get from the NGO is only their name—there is no benefit.’” (Male caregiver, August 2008)

Discussion
By mixing quantitative and qualitative methods, we have shown that FI (including moderate and severe FI) was highly...
prevalent among volunteers, and that rising food costs in Addis Ababa, on top of chronic FI, were a source of added distress and demotivation for volunteer caregivers, exacerbating their own and their care recipients' struggles with economic insecurity, HIV-related stigmatization and HAART adherence. Our epidemiological results highlight significant cross-sectional differences in income between food-secure and food-insecure volunteers rather than changes over time, despite the crisis-level trend in local food prices that occurred during 2008. It is possible that rising food prices in Ethiopia over the three years prior to 2008 led to a high prevalence of FI in our sample. Against this chronic backdrop, the food price spike of 2008, though striking on a graph, may not have had commensurate added effects on the experience of FI for these households. We discuss alternative explanations for these longitudinal findings elsewhere (Maes et al. 2009, 2010). Here, we emphasize that FI was already very high among participants prior to the 2008 food crisis in Addis Ababa.

And yet qualitative data suggested that rising food prices and reduced access to food aid induced demotivation and distress among volunteers. Basically, food insecurity (1) prompted volunteers to question their ability to provide for their own families and their capacity to help impoverished and hungry HAART recipients; (2) strained volunteers' relationships with family members who typically supported them; and (3) impair care relationships that were already beleaguered by HIV-related stigmatization. The chronic suffering and occasional antagonism of care recipients was distressful for volunteers—many wanted to help, but found it beyond their capacity to do so. According to one woman, volunteer caregiving was a ‘risk’ to body and mind, “when [care recipients’] stomachs are empty”. As explained by another female caregiver, many volunteers and care recipients shared similar desires for economic security: “Let alone them, even we volunteer caregivers will be happy if we get some benefits”. Thus for one man, persevering as a volunteer in the face of severe FI was partly a matter of recognizing the lack of other employment opportunities: “Nowadays, it is only that life is expensive and there is no employment”. For another of our female informants, the pressure to quit volunteering came not from within herself, but from her husband, who was unhappy that his wife was not being compensated for her tireless efforts while he struggled to generate income.

In sub-Saharan Africa, both family and volunteer caregivers for people with illnesses such as TB and AIDS may be psychologically overburdened (WHO 2002; Ormer 2006; Akintola 2008a; Kipp and Nkosi 2008). Volunteer caregivers are usually women, who are often socio-economically marginalized, and at increased risk of social stigmatization related to AIDS and other illnesses (Nylblade et al. 2003; Bond 2006). Volunteers in sub-Saharan Africa are critical to local and global economies of AIDS care, especially in the age of HAART (Ogden et al. 2006). But as Escott and Walley (2005) and Akintola (2008a) report, AIDS caregivers in southern Africa have few opportunities to generate income. Kironde and Klassen (2002) found that hope for remuneration was the strongest factor motivating youth to volunteer for a TB control programme. Their study also found high volunteer drop-out rates, with the majority reporting that they wanted to find paid work. These studies have not, however, assessed how FI specifically affects volunteer caregivers.

Our findings corroborate work that has shown how hunger and FI act as barriers to HAART access and adherence (e.g. Hardon et al. 2007). However, our results go beyond previous research by examining how FI impacts AIDS care volunteers. Specifically, our results suggest that a food crisis on top of chronic FI pushes (1) many low-income and underemployed volunteers to reconsider what they deem as appropriate compensation, and (2) many hungry and underemployed HAART patients to reject volunteers and the services they are prepared to provide.

We have also shown that volunteers who were dependants within their households reported lower rates of FI and higher income. As mentioned above, new volunteers recruited during the study period (February 2008) were more likely to be dependants. It is thus tempting to speculate that the households of dependent volunteer caregivers in effect subsidize the collective material and psychosocial burdens of AIDS care (cf. Akintola 2008b), with important implications for the sustainability of volunteerism in this setting. It is notable, however, that even among dependants’ households, FI was highly prevalent and per capita income was less than US$1/day. Thus it is not clear that increasing numbers of household dependants among the ranks of volunteer caregivers in this setting will promote the sustainability of volunteer care programmes in the face of FI.

Though further research is needed to corroborate the results we have presented here, our findings constitute a major complement to existing research, because AIDS care volunteers are not only key witnesses to the paradoxical situation experienced by HAART recipients mentioned by Peter Piot at the opening of this paper, but are also key resources in the effort to sustain and scale up AIDS care and treatment in sub-Saharan Africa. Their continued participation in the face of widespread underemployment and FI is very much in question, in terms of both the right to adequate compensation and programme sustainability. Further, the narratives of our informants call into question policies that promote the harnessing not just of cheap labour but also of local peoples' religious values, norms of reciprocity and 'shared emotional energies' (Collins 2004; Swidler and Watkins 2009).

Conclusion and recommendations

Future research might examine FI as a determinant, among others, of volunteer attrition and reduced recruitment, but future studies should also consider the psychosocial impact of volunteering on volunteers. Even if programmes continue to recruit and retain volunteers, their apparent ‘sustainability’ comes with a cost of overlooking the contextual problem of unemployment, as well as the potentially more invisible problem of insecurity among volunteers who persevere on the front lines of AIDS care and treatment programmes.

Our results reveal a widely overlooked way in which FI threatens to undermine AIDS care and treatment efforts in sub-Saharan Africa. We show elsewhere that FI among volunteers is associated with decreased dietary diversity (Maes et al. 2009) and depression/anxiety disorders (Maes et al. 2010).
The 2008 food crisis and its socio-political aftermath suggest that FI will remain very prevalent in urban Ethiopia and elsewhere unless major international and national policy initiatives are enacted. The local NGOs that organize the volunteer caregivers in this study recognized that FI among caregivers and care recipients undermines their HIV/AIDS programmes, but because the NGOs were also dependent on donor and international NGO support, they were unable to adequately address this problem. FI, we argue, is thus a serious threat to volunteer AIDS care in this context.

Our focus on FI emphasizes the importance of policy questions regarding compensation for volunteers’ valuable labour and poverty reduction through public health sector job creation. Many (e.g. the international NGO Partners in Health) argue that remunerating CHWs is a matter of the right to receive fair wages for one’s labour, as a means to affording household necessities and food security. As policy measures addressing CHW remuneration are enacted, ethnographic and quantitative research will contribute to our understanding of the social and economic costs and benefits of volunteer health care labour from the perspectives of volunteers, their care recipients and the wider public health system.

Acknowledgements

We gratefully acknowledge the institutional support of the School of Public Health of Addis Ababa University, Armauer Hansen Research Institute, ALERT Hospital, the Addis Continental Institute of Public Health, HIVNet HIV/AIDS Prevention, Care and Support Organization, and Medlin Social Center. We thank Cari Williams, Peter Brown, Svea Closser, Ron Barrett and Jed Stevenson for thoughtful comments and suggestions.

The study received ethical clearance from the Addis Ababa University Faculty of Medicine, the Armauer Hansen Research Institute/ALERT Hospital and Emory University Institutional Review Board. Free and informed consent of all participants was obtained.

Funding

This work was supported by the National Science Foundation Cultural Anthropology Doctoral Dissertation Improvement Program (grant #0752966 to K.C.M.), the Emory University Global Health Institute, and the Emory AIDS International Training and Research Program (NIH/FIC D43 TW01042).

Endnotes

1 The informant who offered these quotes was an exceptionally dedicated volunteer caregiver, according to observations and assurances of his peers and supervisors. This heightened the sense of ambivalence involved in wanting to volunteer and yet desiring more ample compensation.

2 It is also not clear that NGOs were attempting to target these younger volunteers. NGO administrators of the programmes involved in this study explained that their recruitment practices focus on any community members who: (1) have reputations for abiding by community norms and avoiding substance abuse, (2) have enough free time to devote to volunteer responsibilities, and (3) are willing to offer their time and efforts without expecting material benefits.

References


