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Food insecurity and ART adherence in Swaziland: the case for coordinated faith-based and multi-sectoral action

Arnau van Wyngaard, Robin Root and Alan Whiteside

ABSTRACT

Faith-based organisations (FBOs) have long been involved in HIV and AIDS impact mitigation and humanitarian relief, but most are not equipped to intervene in the structural drivers of food insecurity and attendant health inequities. Acknowledging limitations is as paramount a task for organisational effectiveness as maximising strengths. This article reports findings from a study of HIV-positive care supporters who volunteer with a church-run home-based care organisation in Swaziland. The article seeks to assess the impact of chronic food insecurity on antiretroviral adherence practices and how these individuals manage daily food shortages. Findings highlight the limited capacities of FBOs in highly vulnerable settings and the imperative for international and governmental coordination.

Les organisations confessionnelles sont depuis longtemps impliquées dans l'atténuation de l'impact du VIH/sida et dans l'aide humanitaire associée, mais la plupart d'entre elles ne sont pas équipées pour intervenir sur les facteurs structurels de l'insécurité alimentaire et les inégalités de santé qui en découlent. Du point de vue de l'efficacité organisationnelle, la reconnaissance de ces limites est aussi primordiale que la maximisation des forces. Cet article présente les résultats d'une étude au Swaziland sur les aidants concernant les soins du VIH qui agissent bénévolement dans une structure de soins à domicile, dirigée par une église. L'article tente d'évaluer l'impact de l'insécurité alimentaire chronique sur l'observance des traitements antirétroviraux et examine comment les personnes concernées gèrent les pénuries alimentaires quotidiennes. Les résultats mettent l'accent sur les capacités limitées des organisations confessionnelles dans des environnements à forte vulnérabilité et sur l'urgente nécessité de la mise en place d'une coordination internationale et gouvernementale.

Desde hace mucho tiempo, las organizaciones basadas en la fe (OBF) han dedicado sus esfuerzos a mitigar los efectos provocados por el VIH/SIDA y a prestar ayuda humanitaria. Sin embargo, en su mayoría las mismas no están preparadas para actuar sobre los factores estructurales de la inseguridad alimentaria ni sobre las desigualdades de salud asociadas a estos. En términos de la eficacia de dichas organizaciones, el reconocimiento de ese tipo de limitaciones constituye una tarea tan importante como la de potenciar sus fortalezas. El presente artículo da cuenta de los resultados surgidos de un estudio sobre una organización de fe que, a través del trabajo voluntario de acompañantes seropositivos, presta cuidados de salud en distintos hogares de Suazilandia. En este sentido, el artículo se propuso valorar el impacto que la inseguridad alimentaria crónica tiene en el acatamiento del régimen de tratamientos antirretrovirales por parte de personas

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seropositivas, así como evaluar la forma en que estas personas resuelven diariamente la escasez de alimentos. Los hallazgos al respecto subrayan la escasa capacidad que asiste a las OBF en situaciones de alta vulnerabilidad, además de la imperiosa necesidad de que exista coordinación a nivel internacional y gubernamental.

Introduction

“While reading through the results of semi-structured open-ended interviews conducted with 79 clients of an FBO in Swaziland: The answer to the question, ‘What kinds of things do you need someone to assist you with?’ sounded like a monotonous refrain: Food. Food. Just food. Food. I need food, but not much else. Food. I need food really, nothing else. Food. Food ...” (Van Wyngaard 2013a, 1)

In February 1999, King Mswati of Swaziland declared that HIV/AIDS was a national disaster (HIV/AIDS Crisis Management and Technical Committee 2000). Seventeen years later, in February 2016, the government announced that the country was in the midst of a national drought disaster (Government of Swaziland 2016). This is not the first time these nefarious forces against health and well-being have intersected in people’s lives, and it will not be the last. Indeed, environmental degradation, food and trade policies, as well as the HIV and AIDS epidemic, are three dynamics that impact populations throughout much of southern Africa. They are, therefore, the concerns of faith-based organisations (FBOs), which have long assumed the tasks of “care” and “impact mitigation”, regardless the source of suffering. A major challenge for FBOs is thus to engage both the macro-structural causes of suffering and the immediate felt impact. But when their gaze is lifted from the pressing needs of the present, the enormity of entrenched inequalities in the near and long term is painfully evident. As will be argued in this article, organisational limitations must be faced, articulated, and acted upon.

Food insecurity (often manifesting in uncertainty on how and where food for the next meal will be obtained), and individuals’ efforts to adhere to HIV antiretroviral (ARV) medications (that are believed to require food prior to ingestion), present a tragic conjuncture. To begin to understand the lived experience of this emergent, poorly documented obstacle to HIV-related survival (and HIV prevention, given the important roles of ART for secondary prevention of HIV transmission), in February 2016, as the dire contours of the drought crisis that began in 2014 became evident, we conducted in-person questionnaires with 490 HIV-positive care supporters who volunteer with an FBO, Shiselweni Home-Based Care (SHBC), in southern Swaziland. Our aim was to gain a better sense of the impact of chronic food insecurity on ARV adherence practices, and of how these individuals were managing daily food shortages. The stakes of defaulting on antiretroviral therapy (ART) are high: missed doses risk compromising efficacy and effectiveness, creating drug-resistant strains, and elevating viral counts, thus exacerbating morbidity, mortality, and infectiousness (Bangsberg et al. 2001). Our second concern addressed “food sourcing”, which we have termed “food improvisation”. Last, as vital actors in community health services delivery in much of Africa, care supporters’ well-being is, in many ways, a limiting factor of organisational impact. It was felt that insights into their challenges, in particular, would evidence the urgent imperative for strategic partnerships that do not yet exist in any substantive way, to mitigate environmental-economic disasters as they intersect HIV and AIDS.

Background

Located in southern Africa, the small country of Swaziland has long maintained the unenviable position of the country with the world’s highest HIV prevalence rate. The 2011 Swaziland HIV Incidence Measurement Survey (SHIMS), a survey of Swazi adults aged 18 to 49, was conducted as part of a

national study to evaluate key HIV prevention programmes. HIV prevalence was 32.1%; among women it was 38.8% and among men 24.1% (Bicego et al. 2013). Though HIV prevalence was virtually identical in both urban and rural areas, 84% of the country's "poor people" reside in rural areas, where per capita income is estimated to be four times lower, and food consumption two times lower, than in urban areas (Rural Poverty Portal 2014).

On the treatment front, the government has been commended for its ART rollout, which began in 2003 (Avert 2016), and by 2015 achieved 67% coverage (UNAIDS, AIDSInfo website as at January 2017). But ART access and management is, like food and income, wracked by structural vulnerabilities. Globally there are two standards of care. In higher-income countries (and among the wealthy or insured across the world), the particular viral strains affecting an individual may be more likely to be diagnosed and treatment tailored to the patient's needs, than in lower-income country settings. There will also be a range of ancillary services available, including nutritionists. In more vulnerable, lesser-resourced parts of the world, the clinic staff may give lifestyle advice, but supplementary care and support is rare. Among our study population, first-line ARV treatment is available; if this fails, there is a second line, but few will get to the third line, as this is mostly unavailable or unaffordable in the public sector in sub-Saharan Africa (Boender et al. 2016).

The links between HIV, ART, and food

Southern Africa and its population face more challenges than just HIV. From 2014 to 2016, much of the region, including Swaziland, suffered from a severe drought. This brought the issue of food insecurity in the country to the fore. Despite the Swazi government's activism in the late 1990s to address HIV and AIDS, a former Swazi government official, in 2016, expressed regret that the country's multi-sectoral response did not include, from the outset, planning with the Ministry of Agriculture to enable a coordinated food and HIV and AIDS strategy (Mabuza 2016). This mutually exacerbating impact of high HIV prevalence and food insecurity supports the case made by De Waal and Whiteside for a "new variant famine" hypothesis, where drought and HIV combine as a dual shock on the country, with poor or inadequate nutrition increasing the likelihood and speed of the progression of infection (2003, 1).

In the early days of ART rollout and uptake, ARV procedures posed a challenge in much of sub-Saharan Africa. Apart from the difficulty of swallowing a cocktail of drugs at specific times, three or more times a day, some drugs had to be taken with food while others were preferably not to be taken with food. Individuals without access to regular meals had to choose between defaulting on their prescribed medication regime or taking the medication on an empty stomach, which could cause severe discomfort and pain, described by McGreal (2009) as "like digesting razor blades". More recently, a study in Uganda (Weiser et al. 2010) found food insecurity negatively impacted ART adherence in several ways: ARVs increased appetite and led to intolerable hunger in the absence of food; being hungry exacerbated some of the side effects; malnourishment interfered with optimal absorption of medication, rendering the treatment less effective; and patients believed it advisable to skip doses or not start treatment if they did not have food. The introduction of fixed-dose combination (FDC) ARVs has significantly improved patients' treatment experiences, including greater medication tolerability even in the absence of sufficient food, and the likelihood of adherence success (Calmy et al. 2006; Lamorde et al. 2012). Ensuring optimal nutrition is nonetheless a perennial challenge for PLHIV. Highlighting these continued challenges to HIV-related well-being, a WHO report stated that "[s]tudies suggest that providing nutritional support to people receiving ART reduces the risk of non-adherence among food-insecure individuals" (WHO 2016, 257).

Food and faith-based organisations

Addressing food insecurity in a programmatic way has not, historically, been a primary focus of many FBOs. At least, there is little evidence to show such involvement, although there are some dispersed

examples. In the early 1980s, faced with an economic recession and cuts in the social budget, private food programmes and emergency food banks were established in various cities in the US that distributed surplus agricultural commodities to the poor. As economic growth resumed, these relief programmes continued to respond to the chronic problems of urban life (Cooper 2015). During the famines of the 1970s and 1980s in Ethiopia, FBOs played a prominent role in coordinating relief initiatives as well as serving as outlets for international philanthropic organisations, “using their structural advantage due to their extended and multiple human, technical and institutional capacities at grassroots level” (Dalelo and Stellmacher 2012, 26).

Goldsmith, Eimicke, and Pineda (2006) have argued that FBOs have particular strengths and resources which make them exceptionally effective in community development, including that: (1) they are generally trusted by community members as uniquely endowed with a special “heart”; (2) the trained volunteers and the women in particular, are increasingly recognised as community leaders; (3) they have access to human and financial capital in the form of volunteers and donations; and (4) they typically have a more holistic approach, essential to effectively addressing HIV and AIDS (see Root 2011; Whiteside and Whalley 2007).

Although it was estimated in 1953 that religious agencies were responsible for 90% of all post-war relief (Desmond Tutu Peace Foundation 2012), there has been divided opinion among funding bodies about the relationship between faith and development. This was partially driven by the strict viewpoint that state and faith needed to be separated, and the ensuing fear that donors might unwittingly be funding denominations or sectarian organisations (Olarinmoye 2012). Detractors of faith-based development initiatives have also argued that religion is counter-developmental and that reason and faith are “*oppositional, mutually incompatible spheres*” (Clarke and Jennings 2008, 1).

More recently, however, there has been a marked transition from faith-based “*estrangement to engagement*” (Clarkson 2014, 18) in conventional “development” agendas, a shift that started in the latter part of the twentieth century. This was a direct result of acknowledging that cultural norms and values have a stronger influence on development than formerly recognised (Lunn 2009). Many FBOs have become involved in emergency food relief (Olarinmoye 2014). For example, the Mennonite Central Committee (MCC) became involved in Kenya, assisting the Masai people to improve food security by growing more drought-tolerant maize, sorghum, and beans (Dicklitch and Rice 2004). The influence religion and faith can have on health and development processes was hereby acknowledged. This also confirms the importance of giving greater credit to FBOs and, more specifically, to faith, for the increasingly prominent role they play in providing emergency relief and other social services worldwide, including sub-Saharan Africa (Cooper 2015).

A challenge nonetheless remains: FBOs, especially those new to community development programmes, often face constraints which prevent them from reaching their full potential in terms of achieving their desired impact. Mobilising volunteers, one of the definitive strengths of FBOs (Goldsmith, Eimicke, and Pineda 2006), frequently can become the cause of some of its weaknesses – including a lack of organisational skill and having to compete for funding with more experienced secular organisations. Furthermore, FBOs often have to deal with negative perceptions from community members, particularly where community members suspect discriminatory practices in the rendering of services. Some FBOs are also unwilling to collaborate with local governments, fearing that they may compromise their values (Goldsmith, Eimicke, and Pineda 2006).

However, it is now widely acknowledged that FBOs were involved in the response to HIV from the beginning. Initially the main function was providing palliative care for people as they died. One of the early examples was the Strategies for Hope series, comprising books, manuals, and DVDs, a programme founded in 1989 and supported by ActionAid. In addition, scholars have traced and guided the response to the epidemic (see Haddad 2011; Denis 2013, on the extensive involvement of FBOs in the field of HIV and AIDS). Internationally, many FBOs provide social services among the most difficult to reach, often making use of volunteer labour.

Food, health, and ART in Swaziland: Shiselweni Home-Based Care

SHBC is an FBO that is distinctive in that it has a long-standing project of data collection and monitoring of the basic socio-demographics and health status of its clients and care supporters (Root, Van Wyngaard, and Whiteside 2015). SHBC was initiated in 2005 by Dr van Wyngaard (a long-time pastor and co-author here) and 32 members of the Swaziland Reformed Church (Shiselweni Congregation). This was a response to the perceived suffering of their communities in the Shiselweni region – informally establishing a home-based care project whose religious ethos was to act as “the hands and feet of Jesus Christ”. This project was subsequently formalised and registered with the Swazi government in 2008 as SHBC, a self-governing FBO, affiliated with the Swaziland Reformed Church.

In 2008 the organisation was the recipient of the Courageous Leadership Award, co-sponsored by the Willow Creek Association and World Vision, in recognition of the organisation’s compassion and resourcefulness in providing care for people infected with HIV. By 2016, 1,250 volunteers were working in 45 sites, each overseen by a care coordinator, caring for almost 5,000 clients, about half of who were known to be HIV-positive. One of the most significant outcomes of the holistic caring (physical, social, psychological, and spiritual) approach of the volunteers has been the recorded decline among SHBC clients in overall mortality from 32.2% to 9.2% over a five-year period – making the mortality rate among SHBC clients 50% lower than the national average (Root, Van Wyngaard, and Whiteside 2016). Apart from giving holistic care to clients in their own homes, in 2016, SHBC operated four early education centres, attended mostly by orphaned and vulnerable children, as well as providing daily meals for 800 children at seven neighbourhood care points.

SHBC adopted a servant leadership model, embodied in its non-hierarchical organisational design as well as its consensus-based decision-making process. At the heart of the African culture one finds the philosophy of uBuntu – the belief that all people should be recognised, respected, and valued. This culture expresses itself through the philosophy of “*I am because we are*”. UBuntu is built upon several maxims (Curle 2015) of which two have particular relevance for SHBC. First, to be human is to affirm one’s humanity by recognising the humanity of others and, on that basis, establish respectful human relations with them; second, when one is faced with a decisive choice between wealth and the preservation of the life of another human being, then one should opt for the preservation of life. This philosophy also has implications for SHBC’s budget, where 90% of the annual income is spent directly on the support of caregivers and clients, mostly by way of food. This is made possible because SHBC exclusively makes use of volunteer caregivers. SHBC has an “Adopt-a-Caregiver” initiative through which donors, including individuals, congregations, and funding organisations can contribute funds which are used to purchase food.

Research methodology

In February 2016, 45 SHBC care coordinators were invited to administer a voluntary, confidential face-to-face questionnaire, once a month from February to May 2016, among their respective teams of caregivers who were willing to disclose their HIV status. The study was jointly run and analysed by international researchers and embedded SHBC staff. The purpose of the study was twofold: first, to assess the current impact of Swaziland’s food insecurity on ART adherence; second, to determine household strategies for addressing food shortages on a day-to-day basis. Coordinators were encouraged, over the subsequent three months, to follow up with the first cohort to assess patterns in adherence default and food sourcing practices. Over the four-month period, from 42 community sites, a total of 490 questionnaires were collected: 296 participants responded once; 119 on two occasions; 56 on three occasions; and 19 on all four occasions when the questionnaire was administered.

Sampling criteria were that participants had to be both a SHBC caregiver and HIV positive.¹ In this regard, it was felt that the study would also contribute to the relative paucity of home-based care

literature focused on caregivers' health needs. All care supporters undertake ethical training before joining SHBC, and before commencing with study questionnaires, coordinators secured informed consent from each participant. The questionnaire was intentionally simplified in order to reduce the burden of administration and to collect data on a situation of rapidly worsening urgency, focusing on past and current experiences of ART adherence in relation to food shortage, as well as future expectations regarding ART adherence. The questions asked were: (1) Have you missed any ART doses because you didn't have sufficient food?; (2) Will you be able to adhere to your ART perfectly over the next month?; (3) If not, is inadequate food one of the reasons?; (4) Has SHBC helped you personally with the problem of food shortage?² (see Table 1).³ Once the questionnaires had been completed, they were returned to one of the authors for circulation among co-authors for analysis.

A limitation of the study were possible sampling biases, in terms of disproportionately recruiting the particularly vulnerable and/or those hoping to secure food aid from participation, although coordinators made it very clear that participation did not entail compensation or reward. In addition, the primary researcher (and lead author) also works with and was one of the founders of SHBC, so this raised issues of potential bias in analysis and interpretation of results that was managed through self-reflexive practice by the research team.

Results

ART default and hunger

Question 1 determined the relationship between food shortage and ART adherence, and also exposed a perceived belief that food insecurity necessitated defaulting on ART. Of the 296 individuals who completed the questionnaire at least once, 37.8% indicated that they had defaulted at least once because of a lack of food to eat.

Question 2 investigated whether the interviewee considered the possibility of defaulting in the future, in the light of the effects of the drought. Of the total sample of 490 questionnaires completed over the four-month period, 36.1% anticipated the likelihood of them defaulting within the following month because of a lack of food.

Question 3 queried whether the anticipated default indicated in Question 2, could be directly ascribed to the lack of food. Of the 177 who had indicated in Question 2 that they thought it possible that they would default within the following month, 90.4% linked this directly to a shortage of food.

SHBC supports clients through the caregivers with food as far as the organisation is financially capable of doing so. Question 4 indicates to what extent the caregivers themselves benefit from the food assistance. Of caregivers who had completed the questionnaire, 65% indicated that they

Table 1. Responses to questions 1–4.

Month	Questions	Sample size	Yes	No
February (T1)	Q1	176	73 (42%)	103 (58%)
	Q2	176	108 (61%)	68 (39%)
	Q3	68	63 (93%)	5 (7%)
	Q4	176	96 (55%)	80 (45%)
March (T2)	Q1	114	26 (23%)	88 (77%)
	Q2	114	86 (75%)	28 (25%)
	Q3	28	24 (86%)	4 (14%)
	Q4	114	59 (52%)	55 (48%)
April (T3)	Q1	109	51 (47%)	58 (53%)
	Q2	109	63 (58%)	46 (42%)
	Q3	46	38 (83%)	8 (17%)
	Q4	109	61 (56%)	48 (44%)
May (T4)	Q1	91	49 (54%)	42 (46%)
	Q2	91	56 (62%)	35 (38%)
	Q3	35	35 (100%)	0 (0%)
	Q4	91	45 (49%)	46 (51%)

had been helped by SHBC at some point. With 1,250 caregivers, it is clear that many of the caregivers find themselves in situations as dire as their clients.

To identify any significant patterns regarding respondents' answers to the first three questions, the number of individuals from each of the caregiver groups who had completed the questionnaires more than once over the full period was calculated. Caregiver groups with fewer than seven respondents were ignored for the purposes of this part of the analysis. The general trend is that those caregiver groups with a higher percentage of respondents, who adhered to their ART at all times, had a smaller possibility of defaulting in the future and vice versa.

Food sourcing

In Question 5 and Question 6 participants were asked whether they secured food from the following sources: own food (home-grown or purchased); friends; government; World Food Programme; church; and other. Answers suggested extreme variability in food sourcing practices. A majority (63.6%) reported that they sourced most of their food on their own, but this portion fell substantially when asked where the following day's meal was coming from, to only 40.9%. Nearly 30% (28.9%) sourced most of their food from friends, while slightly fewer (24.4%) anticipated remaining dependent on their friends for their next meals. The World Food Programme and churches played a fairly negligible role in terms of food supply. "Church" was interpreted as the local congregation to which the interviewee belongs. Given the financial constraints most – if not all – rural churches in Swaziland are faced with, it came as no surprise that very few people received sustainable support from their church for their daily meals. Those who did not receive support from their friends or family relied primarily on help from the Swazi government, consisting mainly of bags of maize meal delivered to drought-stricken areas, although this support is known to be erratic (Dlamini 2016).

Of the total number of interviewees who completed the questionnaire at least once, 60.1% indicated that they relied on sourcing food independently. For those who completed a second questionnaire, 46.2% still relied on sourcing food independently. By the third questionnaire the number was 35.7% and by the fourth, 10.5%.

Using the same method to compare the responses over four months of those who indicated from the start that they depended on social capital (which could include relatives within Swaziland or relatives working in South Africa and who regularly send money), 28% indicated in their first response that they relied on sourcing food from social capital. For those who completed the questionnaire a second time, 25.2% still relied on friends as their main source for food. By the third questionnaire the number was 32.1% and by month four, 68.4%. In other words, as the effects of the drought worsened, fewer people were able to rely on sourcing food independently, and a higher percentage of people relied on the help of friends and family.

From the responses of the 22 groups with seven or more respondents, the plight of those suffering from the effects of the drought becomes even more apparent. Of the three groups where 100% of respondents answered the question of where food was obtained, that they sourced their food independently, only one group gave the same answer to Question 6 in response to where their next meal would come from. None of the other groups anticipated 100% that they would be able to source their food independently for their next meal, while six groups had no hope whatsoever that they would be able to source food independently for their next meal.

Discussion

In February 2015 the World Bank recognised that poverty cannot be eradicated without partnering with FBOs and religious leaders (World Bank 2015). Our study illustrated the impact of food insecurity on ART adherence in a chronically impoverished region and PLWHA modes of daily survival. Individuals – and therefore households and communities – were experiencing ARV treatment defaulting

pressures and extreme food shortages, exacerbated by a two-year drought. Our study population was particularly vulnerable on three fronts: they were HIV positive, many suffered from food shortages, and they were unpaid care supporters delivering vital health counselling in an impoverished region of Swaziland.

Driven by a perception that ARVs should not be taken on an empty stomach, a significant number of the cohort defaulted on their ART because of food insecurity. This led to the daily lives of participants being dominated by an immediate uncertainty about whether ART adherence was going to be possible. Importantly, we also discovered that there may be considerable confusion among patients and health personnel alike about whether and which ART medications require food for tolerance. Further research was subsequently undertaken in collaboration with Médecins Sans Frontières (MSF) in Swaziland about the safety of using ARVs on an empty stomach. In October 2016 MSF held a conference in Swaziland on this question, where attendees were sent away with the message that all ARVs currently available in Swaziland can be taken with or without food: *“Even if you don’t have food, please take your ARVs. There is no negative impact by taking ARVs on an empty stomach”* (Zabsonre 2016). If patients are defaulting out of misunderstanding prescription guidelines, then immediate treatment education is needed.

There is also a tremendous variability in food sourcing from day to day, which reflects both the contingent reality of food availability and access, and a lack of confidence that there will be sufficient food for adherence in the future. Although depending on social networks for survival is common in impoverished communities, it falters in moments of catastrophe such as droughts and is therefore not sustainable. Under these circumstances, emergency food action is needed, and ought to be integrated into HIV and AIDS services delivery and vice versa.

Situating our findings in the FBO, HIV and AIDS, and food aid literatures is not easy, as there is little in the way of scholarly work on the challenges and synergies of these policy and programmatic domains. The result above, that churches played a “negligible” role in food sourcing, needs to be unpacked a little further. The broad literature on faith and development, or faith and HIV, holds massive anecdotal evidence that faith entities and communities engage in formal and informal food provision, although there is little to no formal evidence on the extent of this provision (see Olivier and Smith 2016). The fact that respondents did not source their food from “church” is therefore a very interesting finding. It is possible (and even likely) that respondents did not consider FBOs such as SBHC as being “church”.⁴ Nevertheless, the finding that local churches were not perceived to be primary sources of food relief runs counter to the broader literature, and requires further investigation.

Faith (individual and collective), disease management, and food security are inextricably tied and central to the well-being of the Swazi people. In research on the effectiveness of SHBC’s caregiving programme in Swaziland, van Wyngaard concluded that faith formed an essential part of the success of the organisation’s holistic approach to the needs of the clients. In the words of one of the SHBC clients: *“the caregiver is a Christian and I am also a Christian; she understands me very well”* (2013b, 238), a basis which helped in developing a constructive relationship between the client and her caregiver (Root 2011).

As noted earlier, SHBC has since responded to these contextual concerns by addressing the shortage of food in two ways. Through its Adopt-a-Caregiver initiative, donors, including individuals, congregations, and funding organisations, contribute money to assist SHBC in purchasing food which is then distributed to the caregivers, albeit with limited success, due to the high number of volunteer caregivers forming part of SHBC and the shortage of donors. Although there is no expectation from them in this regard, this food is often shared with their clients who may be in an even less fortunate position than the caregivers themselves (Maartens 2012). Furthermore, as a result of SHBC’s partnership with an international fund, approximately 800 children receive a cooked meal daily at eight neighbourhood care points. With the money donated, food is bought, prepared, and served by volunteers to orphaned or vulnerable children. Such activities highlight

the need for holistic and integrated approaches to ART – and for multi-sectoral cooperation between varied sectors.

The intersection of the dynamics of food insecurity and ART adherence, as well as their impact on HIV and TB-related well-being, requires urgent short-term interventions and long-term strategic planning. Adequate nutrition and reliable treatment are essential to the well-being of PLWHA. Both matters need to be addressed as a matter of urgency. Our findings are significant for the assessment of the impact of food insecurity on HIV-positive care supporters' well-being. They are a population for which, throughout Africa, there are sparse data, and on whom governments and global health agencies increasingly rely for many important health outreach services, including ART adherence counselling and support. National health ministries and global health organisations must coordinate policies and programming with economic planning units and international development organisations, as well as recruit and resource community-based organisations to this urgent undertaking. In the absence of structural interventions to redress the entrenched poverty, agencies and governments must support community networks and FBOs to help implement emergency food relief and health services initiatives. As highlighted by the Desmond Tutu Peace Foundation:

“The example of the Dutch Interchurch Aid organization’s 1983 warning of a looming hunger crisis in Ethiopia is worth considering. As expected their warning was ignored until it became a big media-driven crisis in the 1990s. More of this early-warning action on issues of poverty and suffering can be critical in finding solutions.” (2012, 1)

Similarly, we view these SHBC data on HIV-positive care supporters, who are volunteers with a vitally important local FBO, and their experiences of defaulting and hunger as more than a canary in the mine.

In relation to what this means for Swaziland, an emergency plan is needed to redress what is potentially a life-threatening misunderstanding of treatment guidelines. The National Emergency Response Council on HIV and AIDS (NERCHA) needs to take note of the outcome of this research and a clear message needs to be communicated that PLWHA should continue with their ART regime, in spite of the food insecurity they may face. This needs to be communicated to as wide an audience as possible, making use of multiple media channels in Swaziland. On the international front, closer consideration is needed of complex issues which straddle sectors requiring multi-sectoral and integrated response.

Notes

1. Caregivers are not required to disclose their HIV status, but where they had voluntarily disclosed this, they were invited to participate in the study.
2. From time-to-time, the entire group of caregivers is issued with food parcels. However, during the four-month period of the research, SHBC did not issue food parcels to the caregiver group as a whole.
3. These were the four core questions, while further questions (5 and 6) were asked to obtain related information on food sourcing.
4. Question 5 and Question 6 specifically used the term “church” as one of the options from where food is sourced and might have been interpreted as an entity apart from other FBOs, thus resulting in some respondents acknowledging that they had received food from SHBC while simultaneously indicating that they had not received food from “church”.

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Disclosure statement

No potential conflict of interest was reported by the authors.

Notes on contributors

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