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Free love: A case study of church-run home-based caregivers in a high vulnerability setting

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The purpose of this study is to explore the concept of religious health assets (RHA) and its relevance to HIV/AIDS. This manuscript describes the experiences of caregivers with a church-run home-based care organisation in Swaziland, site of the world's highest HIV prevalence (42%). In light of reduced antiretroviral treatment rollout in some areas of Africa, strengthening mechanisms of treatment support with HIV prevention has never been more critical. One modality may be community home-based care (CHBC), a core feature of the World Bank's Multi-Country HIV/AIDS Program for Africa. Yet, these entities, and the frontline activities of local congregations, remain underexplored. Part of a larger anthropological study of religion and HIV/AIDS in Swaziland, this manuscript draws on 20 semi-structured caregiver interviews to discern patterns in motivations; perceived client needs; care practices; and meanings of religiosity. Thirteen participants were care coordinators who oversaw approximately 455 caregivers across nearly half of the 22 communities served. Grounded theory analysis suggested that caregivers facilitated vital decisions around HIV testing, HIV disclosure, treatment uptake/adherence, as well as reduced HIV stigma. Also salient was the importance of a Christian ethos, in the form of 'talk' and 'love', as critical culturally situated care practices. Having expanded to an estimated 600 caregivers and 2500 home-based clients between 2006 and 2009, participants' reports intimated their roles as agents of broader social transformation. This article contributes to the expanding study of RHA and challenges authoritative global public health strategies that have largely marginalised local religious aspects of HIV/AIDS. Future applied research examining how 'home' and 'church' may be vital public health settings outside of, but integral to, formal health services and HIV programming is warranted.

Keywords: religion; health; HIV; gender; home-based care; stigma; Africa

Introduction

'I told the man, "I have a plan [so you can tell your wife you're HIV positive]". I knew the husband and wife each was positive, and that the other didn't know. I told him I'd come to their home one Saturday with a slaughtered chicken and ask her to cook it with porridge ... I visited and we all told stories. Then the man said, "Now, my wife, what if I told you I'm HIV positive?" She said, "I would just accept you as you are, because you are still a human being". I said, "This is your chance". So he said, "I am HIV positive". She said, "I'm also positive", and went to get her handbag. "You see this? I never, ever put it

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down, because it has my tablets [antiretroviral therapy]''. My heart was so sad, because the man had hidden his tablets under a tree outside the homestead. He dug a hole and everyday he'd go to the tree [to take the ART in secret].[1]

– *Church-run home-based caregiver*

Faced with the world's highest HIV prevalence rates, poor health care infrastructure and limited economic resources, hard-hit communities in many parts of Africa have mobilised to mitigate worsening conditions. Although these 'variables' are common across many resource-limited regions of the world, they are also culturally situated. This means that in places where religion is a salient feature of social life, investigation of the roles that religion, broadly conceived, may play in mediating multiple vulnerabilities is critical. In Swaziland, site of the study described here and the world's highest national population-based adult (25.9%, Central Statistical Office 2008) and antenatal (42%, UNAIDS 2009) HIV prevalence rates, there has been substantial growth in registered church organisations since the 1990s (Pan African Christian AIDS Network 2008). The country's institutional saturation by local congregations and their possible relevance to HIV/AIDS are indicated by the estimated one church per 183 Swazis (personal communication, B. Langa, July 2006) versus one HIV testing and counselling site (HTC) per 6180 (National Emergency Response Council on HIV/AIDS [NERCHA] 2010). To explore one aspect of this institutional efflorescence, the manuscript draws on focused ethnographic and formal qualitative data to explore the experiences of volunteer caregivers with a church-run home-based care organisation in Swaziland. More broadly, the article aims to identify whether and in what ways local religious modalities might mitigate HIV/AIDS in places where conventional public health resources cannot reach people's homes.

Investigation of religion and HIV/AIDS is important because to many health researchers and policy-makers, the idea of Christianity benefiting HIV/AIDS initiatives in Africa may seem unfamiliar or even uncomfortable. While concerns over religious obstacles to condom promotion are well-founded, to limit scholarly investigation of Christianity and HIV/AIDS to debates over abstinence, fidelity and condom campaigns (Allen and Heald 2004) may negate the deeply felt and institutionalised presence of Christianity (Meyer 2004, Gifford 2008) that affects millions of people living with HIV/AIDS (PLWHA) and their families in Africa on a daily basis (Agadjanian and Sen 2007, Becker and Geissler 2007). As a result, assumptions that religion inherently obstructs HIV/AIDS programming may have eclipsed opportunities to deliver HIV/AIDS services. In light of these politics, the article seeks to contribute to an emergent social scientific literature that examines the multifactorial significance of religion and HIV/AIDS (Cochrane 2006, Adogame 2007) in many parts of the world that challenges authoritative global public health strategies that have often marginalised and politicised religious aspects of HIV/AIDS. The African Religious Health Assets Programme (ARHAP), an international network of scholars and practitioners originating out of the University of Cape Town, has introduced the concept of religious health assets (RHA) to begin theorising the complex dynamics of religion and HIV/AIDS, primarily as a means of enhancing public health systems and community well-being (ARHAP 2006). In both respects, RHA provides the framing conceptual framework of this article.

Research setting

The Kingdom of Swaziland

Swaziland offers both the sociocultural and, tragically, the epidemiological context for exploring relationships between religion and HIV/AIDS. With the world's highest HIV prevalence, a 33% orphan rate, and an estimated 46-year life expectancy at birth (World Bank Group 2010), the social fabric of Swazi society is wrent in unprecedented ways. From one-room wattle and daub to expansive concrete structures, churches are ubiquitous features of the country's physical and social landscape, a terrain where Swazis say 'people are dying left and right'. In 2008, 22 facilities provided antiretroviral therapy (ART) (UNAIDS 2008). However, with only 15 physicians (NERCHA 2008) to treat the 190,000 children and adults (HIV InSite 2010) known to be infected with HIV, and 35.4% (NERCHA 2008) of those with advanced HIV infection on treatment, a critical mass of PLWHA remain under-served. In light of reductions in donor funds for ART rollout in Africa, comprehensive treatment and prevention is all the more critical.

As with any HIV/AIDS intervention, support modalities lie at the nexus of economic resources, government services, social collectivities and individual health practices. In Swaziland this nexus arises in a distinct cultural and socio-economic setting where certain practices may exacerbate the vulnerabilities many individuals, particularly women, face in their local lifeworlds. These include wife inheritance, polygamy and male sexual and reproductive entitlement to wives' younger sisters (Whiteside *et al.* 2006). They are home-based practices, moreover, that constitute the home (an extended family homestead) as an organising principle of Swazi life (Kuper 2006). For this reason, 'home' is theorised here as the physical and social space where PLWHA well-being may be most enabled or imperiled; a site that falls outside the purview of biomedically based public health research.

Shiselweni Reformed Church Home-based Care Organisation

A registered non-governmental organisation in Swaziland and South Africa, the Shiselweni Reformed Church Home-Based Care (SRC-HBC) Organisation began in 2006. The church-run project was initiated by Arnau Van Wyngaard, a theologian and South African minister with the Swaziland Reformed Church. Witnessing the impact of HIV/AIDS, he invited parishioners of his Swazi congregation to assist the many households in the community afflicted by sickness and poverty. Thirty-two individuals volunteered. Four years later, the SRC-HBC had grown exponentially to approximately 600 caregivers, serving 2500 clients in 22 communities across 100 square kilometres of Southern Swaziland. Caregivers are mostly female – though men are increasingly taking part – multi-denominational, and non-binding in religious participation.

Two seasoned caregivers have been informally trained by a volunteer nurse in HIV/AIDS education and basic first aid. They lead one-week trainings for new caregivers at the rate of about one new group every two months. The organisation is guided by scriptural maxim, 'At the Hands and Feet of Christ Serving the Community'. A South African Zulu pastor instructs modes of sharing Christian beliefs with clients. At the end of the one-week training, caregivers receive an informal certification, which culminates in a ritual whereby Mfundisi (Pastor)

Van Wyngaard bathes and washes the feet of new members to symbolise and enact the spiritual and physical caregiving roles they will serve in their communities.

The organisation is funded through small donations from individuals and religious organisations in the USA and South Africa. When available, caregivers are equipped with first aid backpacks that include a Bible. The SRC-HBC maintains vigilant data reporting processes. Caregivers record each home visitation and submit monthly reports to community coordinators. They in turn prepare reports for the regional coordinator, who details the number and gender of caregivers, the number of home visits and the number of clients, including those who are new or have moved, died, are terminal or who have chronic ailments. This information is conveyed to Pastor Van Wyngaard for oversight and to direct further health training and spiritual counselling needs.

Methods

As part of a larger medical anthropological project on religion and HIV/AIDS in Swaziland (Root 2009, 2010), started in 2005, the manuscript draws on semi-structured open-ended interviews with 20 volunteer community home-based caregivers in rural Swaziland (January and August 2009). The regional coordinator who oversaw all daily operations was also interviewed. Participants were identified through a combination of purposive and convenience sampling. The former consisted of 13 coordinators who, collectively, constituted about half of the communities served in 2009 and oversaw approximately 455 caregivers. Thus, while the number of interviews is low, the broader perspective they provided on the research question offered substantial exploratory power. Given that respondents were active in SRC-HBC groups that were diverse in the size and history of their operations, findings are felt to be reflective, though not representative, of many caregivers' experiences in the case organisation at large. Accompaniment on client home visitation, as well as extensive focused conversation with the organisation's nurse trainer and its director, provided additional primary data.

The interview schedule was operationalised to explore caregivers' motivations, perceptions of clients' needs, caregivers' HIV-related and other care practices and perceptions of the role of Christianity in home-based caregiving. English and siSwati are the official languages of Swaziland; however, residents in rural areas speak siSwati almost exclusively. Thus, because the author does not speak siSwati, when English language skills permitted, interviews were conducted one-on-one with the respondent. The remainder drew on translation assistance from fellow caregivers. Interviews were transcribed in South Africa and the USA. Given the demonstrated benefits of grounded theory analysis (Ryan and Bernard 2003, Charmaz 2006) to qualitative health research (Miller and Fredericks 1999) a grounded theory approach was used to elicit key themes from interview data. Research procedures were approved before research commenced by Baruch College's Human Research Protections Program, City University of New York (USA).

Results

Caregivers' responses to semi-structured interview questions are reported here in categories that reflect experiential patterns of providing church-run home-based care.

Motivations: love and/of knowledge

The opportunity afforded by the SRC-HBC to acquire biomedically based HIV/ AIDS knowledge, and to intervene where the state fails, for example, to facilitate critical care follow-up, was a key motivator for joining the SRC-HBC. Knowledge of the organisation generally came through direct observation and word of mouth. Nocawe saw caregivers in action and asked to join, 'so I can learn about taking care of people. After they trained me, they said I can ask others interested in caregiving, so they can be trained, too'. Where some participants said they had not reached out to the afflicted prior to becoming caregivers, others recalled their struggles to extend ad hoc support to those around them. Sibusiso described how she 'would share whatever I have with sick people ... Then the pastor came round to teach about [the SRC-HBC] and I saw it as an opportunity to continue helping others. Now, I feel more empowered to do so'. Cebile joined because she saw 'people suffering in different ways'. She was frustrated that she had 'no knowledge' of the diseases that plagued her community. 'That is why I volunteered myself, so that I [can] help these people and teach them what I have learned'. For Nomusa, the SRC-HBC was a chance to channel her own anguish at others' suffering: 'I volunteer, because I saw that some people [needed help] ... I can't express what I feel about these people'.

Unrequited empathy emerged as a key characteristic among many participants. Asked the difference between herself and those who do not volunteer, Nomusa said it came down to deeply felt sentiments towards others' suffering: 'They don't [understand], because they don't feel what I feel about these people [who suffer]'. Specifically, the distinguishing feature was a feeling of love. 'It's because I have love', explained Futhi, 'and the love I have, I want to share with other people'.

Many participants swelled with satisfaction over their greater care competency – a competency they attributed in part to the collective problem solving that fuelled a social production of HIV care knowledge. According to Nocawe, 'Being in a group is better because you share knowledge. You may know something another person doesn't, so the care becomes better because of joint efforts and general knowledge of everybody'. Seconding the view of knowledge synergies arising from caregiver meetings, Nompumelelo explained, 'As a group it's different because every Friday we come here to report situations. We are scattered, so when we're together we share the challenges we face ... We try to come with an idea how we can help'. Collective action made it possible to address a range of vulnerabilities resulting from extreme poverty. 'If I am only one person', said Nompumelelo, 'and the client needs shelter, I can't do it [alone], so we gathered together and built the client a house'. A collectivity also provided a reserve of HIV knowledge that, by knowing one another's strengths, could be drawn upon strategically. Nocawe recalled a caregiver whose client 'was on ARV [antiretroviral medications] but was given traditional medicine [too], and their abdomen became distended'. Use of traditional healing was a culture-specific challenge reported by a number of caregivers. The caregiver sought help from the group, so a second caregiver visited the client and instructed him to cease the traditional treatment and adhere to the ARV. 'Because of her knowledge', Nocawe said, 'they stopped [the traditional treatment]'.

The caregiver–client relationship

Asked how a caregiver relationship was initiated, Futhi described an ordinary introduction at the home of a potential client: 'We greet them and introduce ourselves, "We are so and so, and we are caregivers. We would like to be part of their family". We give them time to introduce themselves to us, and we start that relationship'. In different ways, caregivers also let it be known they are Christians, for example, by asking permission to pray after the introduction. Nompumelelo described how she integrated health and spiritual care practices: 'As we help clients, we also share the word of God'. Asked about clients' reactions, she said, 'Some are very excited, and others, they look as if we are just wasting our time, because we can't change them'. Whether a client identified as a Christian was no basis for withholding care; if prayer made the client uncomfortable, the caregiver would not impose it.

Interviews suggested five main reasons why a household might seek or accept caregiver services: (1) sporadic access to painkillers; (2) occasional material support; (3) assistance with household tasks, such as hauling water and preparing food; and (4) performing the most challenging of care duties, including helping clients to use the toilet and bathing them. As well, interviews suggested that caregivers were acquiring a reputation as HIV/AIDS educators who were eager to share their knowledge in non-pedantic ways. According to one participant, clients even became 'choosey', requesting one caregiver over another, apparently because the other was perceived to have more HIV knowledge. Caregiver services were readily received in Simangele's area, because the chief and his advisors, having been informed in advance by the coordinator, 'called on the people and told them about us'.

Despite the perceived benefits of home-based care, analysis suggested three reasons why households might refuse SRC-HBC outreach: First, fear that gossip had precipitated caregivers' visits. Reported Vuyisa, 'Some don't want to see a care supporter coming into their homestead without [being] invited. They ask 'Who has told you there is a sick person here? Why are you here?' Second, clients may refuse a care supporter who visited and presumably gossiped afterward. Third, caregivers sometimes belonged to the communities they served. Proximity was productive, in so far as caregiving was logistically convenient. However, the mundane tensions of neighbourly co-existence and risks of breached confidentiality could obstruct the caregiver–client relationship. Regardless, virtually every participant said that suspicion or disparagement of their care work was diminishing. Now, Futhi said, 'they can see that, really, we're doing something good'.

Caregivers' authoritative knowledge, however, was occasionally complicated by aspersions of moral superiority. According to Futhi, negativity towards caregivers could be such that 'you cannot continue with the work you are doing'. If it was felt that she had done something wrong, 'people no longer regard you as a "personal person"', a colloquialism for 'friend'. For example, if she told someone – a client or member of the community – '"If you continue doing this [e.g., drugs or alcohol], you will lose your life"', they think you [think you're] better than them'. She would try to defend herself, explaining that she was not chastising the person, but rather caring for them: 'I was trying to help him to know what is good and what is not; he must decide what to do now'. Detractors accused her not only of

arrogance, though, but of ignorance, pointing out that 'even if you don't drink alcohol, you still die'.

Social challenges aside, caregivers described economically impoverished conditions, which they too suffered, that often felt insuperable: 'Almost all the clients [are] dead in their life. They are too poor', reported Vuyisa. A majority of caregivers reported food shortages to be among the greatest sources of suffering and obstacles to ARV adherence. Lack of funds for clinic transport was also a pervasive problem. Clients themselves were sometimes flummoxed, unable to square caregivers' empty hands with their offers of care. Lack of material resources limited some caregivers' own self-perceived effectiveness. Nocawe lamented, 'The worst thing for me is to go to somebody without aid ... Then what do I do?' It was important to set clients' expectations. Vuyisa tried to explain to clients, 'At the moment, we don't have anything'. They mustn't expect some painkillers when they see us coming ... We don't have enough, and I don't think we'll ever have enough'. Nonetheless, her training and sense of indefatigable pathos trumped any perception that her care work was futile: 'I've saved many people. I can't stop ... Because in my family there are those with HIV...Even though there are some people that have died, I've tried my best...I spend my time, my money, my cell phone...It's impossible for me to stop now, really impossible'.

HIV/AIDS care practices

Participants estimated that much of their care work resulted from the exacerbating impact of HIV/AIDS, poverty and famine on households. Broken out here for purposes of analysis into conventional silos of HIV interventions, in reality each domain was intertwined in an ongoing caregiver–client dynamic of cultural/public health knowledge, relations and practices.

HIV testing

The first question Nomusa says she must ask a client is, 'Have you been tested?' Encouraging HIV testing, often without using the acronym itself, was a near universal practice reported by caregivers. The testing imperative was often inserted into counselling discourses of comprehensive disease testing, nesting it in more socially acceptable diagnoses. Despite her perceptions that people were better educated about HIV than in the past, Nomusa said, 'still, people won't talk about it'. Some, she added, even continued to deny HIV. So intense was fear of a positive diagnosis, explained Vuyisa, that 'even if one is sick, going to test is the last thing they do'.

Fear of HIV stigma bled into caregivers' efforts in multiple ways. Nompumelelo described how some clients asked that caregivers not use the latex gloves they are trained to use, which ran the risk of creating potentially risky situations. She explained their clinical imperative by embedding protective gloves in a caring relationship: 'We just share the idea of using gloves, that it's not that they are very sick...We try to make clear that maybe we are positive; we don't want to pass it [to them]'. By asserting that she herself might be HIV positive, Nompumelelo accomplished three enormous feats. She normalised an HIV diagnosis, preserved the client's sense of dignity and sustained the caregiving relationship.

Caregivers interacted not only with their clients but clients' families as well. Usually, Futhi said, families 'become happy because they see that you'll help them in other ways'. The participant described these 'ways', which may be highly consequential for managing the individual and household impact of HIV/AIDS, especially after ARVs are introduced. The practices are also culturally situated, reflecting the local history of the epidemic and the entrenched HIV stigma, even within families: 'We educate the family members on how to take care of the sick members'. Family members may entreat the caregiver to intervene, believing the caregiver to have a special status to the client. Futhi described a client who refused HIV testing, and whose family asked her to intervene: 'She's refusing to go', they told her. 'Maybe she will understand you...Could you please talk to her?' Futhi requested she speak with the client in private. Alone, her strategy, like other caregivers', was to normalise HIV testing by situating it within a comprehensive health seeking endeavor that often neutralised the HIV component: 'I tell them, when you're sick, you need to check everything – diabetic, or if you have TB, all those things, then include HIV testing'. Sometimes clients followed through, participants reported and sometimes not. Regardless, the caregiver in this scenario both empowered and supplemented family efforts to optimise the client's chances of survival.

ART treatment

Facilitating ART uptake and adherence were priority practices for caregivers. Like many participants, Nomusa described an integrated stepwise approach. If the client reported that they had not sought testing, but wished to do so, she offered 'by all means' to get them to a clinic. If the person had been tested, she inquired about their status. If they were HIV positive, she advised clinic follow-up. This could be a challenge: 'Some people are shy, and afraid' to seek follow-up. 'That's where you must come close to them'. If the client had commenced ART, she went to the home every day: 'What time is it? Have you taken your tablets?' If she says 'no', I say 'Remember, let's do it'.

Thulisile described a different challenge, whereby cultural and migration processes intersected in ways that could undermine clients' ART adherence: 'HIV is one of the conditions [where] ignorance is a major problem. We motivate a person to take ARVs, but after she takes the ARVs, when the festive season come, people from Joburg and all over the country [visit], they say [to the client], "No, don't take these tablets, you'd rather take this traditional medicine", and in that way we lose a lot of people, so then it's ignorance that's also a problem'. Nompumelelo echoed others who described the exacerbating combination of food insecurity and treatment, 'We encourage [clients] to follow up their treatment, but we've got people saying 'we [want to], [but] we're starving ... I'm supposed to take my tablets. If I take them without food, I feel very weak'. She had helped mobilise two support groups to try to coordinate members' treatment follow-up and medication refills; a logistical hurdle to 'free' treatment that, by trying to clear it collectively, likely had secondary benefits of reducing stigma, providing psychosocial support and normalising a positive diagnosis.

Disclosure and secondary prevention

Some caregivers noticed an increasing trend towards disclosure within the caregiver–client relationship. Ascendant comfort levels appeared relative, since many participants said clients disclosed only when their family was not present. 'It's not easy for them to tell us', Nomusa said, 'but the way we are talking with them, now they are telling us ... That's why we try to give them some gloves ... or soap'. Talking was itself a salient care practice. Caregivers wove empathic compassion with concrete counsel. Said Sibusiso, 'If somebody confides in me [who is HIV positive], I keep it discreet, and we discuss and hug each other. I don't even tell my family. I don't even tell my children. It's between me and my client'. Managing HIV disclosure was among the most complex roles that caregivers assumed. 'Talking' was a primary means of eliciting and conveying vital HIV information, especially following a disclosure: 'Some of them are very brave. They say, "Eh, my friend, I've went for checking [testing], and unfortunately, I'm HIV positive. Now where do I go?"' Vuyisa advises going to the voluntary counselling and testing (VCT) centres and preparing to start ARVs. 'But if you don't want to start on ARVs you must listen to what [clinic personnel tell] you to do, and be very careful ... Keep on checking the CD4 count'.

Tholakele described how she handled fears of abandonment and disparagement clients sometimes felt they risked, if they disclosed to family members: '[The client] tells you their secret, so...you give her that love'. Because she cannot be with the client around the clock, she advises the client to 'tell one of your family members who is going to be with you almost seven days a week'. If a client asks Tholakele to assume that task of telling them, she declines and instructs the person to name a family member. Tholakele calls for that person: 'I say, "This one is very sick, as you know, but now they know their status ... So he just needs help from you at times"'. Many caregivers counselled the importance of disclosing to sexual partners, as well. 'It's important that the partner must know', Futhi told her clients, 'so that they have protected sex and help each other [e.g., remind you to take your drugs]'. Sibusiso described a softer approach, counselling that they 'must try and tell their sexual partners – it's difficult, but at times, eventually you find that some [have] opened up to each other'.

Gender vulnerabilities and home-based care

Some husbands' resistance to HIV testing, and obstructions to wives' attempts at HIV care were challenges many caregivers faced. The nurse trainer explained: 'It becomes very difficult for us. I've got a typical case. He hasn't tested, but it's typical that [he] may be positive, but when we ask him to test, he says the [wife] must go and test. If ever she is found positive, she will have to pack her bags and go'. Futhi described an HIV positive woman whose husband was aware of his wife's status and that she was on ARVs, whereas he was not. One day, when the woman was away from home, she returned to find that her husband had thrown her medications down the toilet. 'The woman became very sick', recalled Futhi. 'She waited for a long period [to return to] clinic for more tablets; they were busy fighting and talking'. Asked about recurring reports of men's apparently greater reluctance to test, Nocawe said, 'Men are just like that; they prefer to die rather than go on ARV'. Her own son, she said, had been put on ART, yet he refused to

take them: 'He says he'd rather die than take so many tablets'. In some instances, though, vulnerabilities were successfully resolved with home-based brokering strategies not possible in a clinic setting. Futhi had a female client who had commenced ART, but the husband, despite knowing his wife's status, refused testing. Futhi told her, 'We'll find a day to visit when [you and your husband] are together, and [I'll] educate about HIV and AIDS, how to use safe sex – all those things'. Afterward, the caregiver returned to find that the husband had finally agreed to test.

Religion and home-based care

An important aim of the interview design was to understand caregivers' views on the signifiance of being a Christian in providing home-based care. 'This work needs somebody who knows about Jesus', Nomusa explained. Pressed, she concretised what it meant 'to know' Jesus in her world: 'It's because you have to be faithful. If you give me something to give my clients [e.g., food], I must do that. If I'm not faithful, I will eat it myself. If I tell my clients, "I will come to you at nine o'clock", [and I'm not there], the client will [doubt me]'. The rhetoric of religion became a discourse of love, and then a care practice, since the care work itself could be off-putting. 'You can't be a caregiver when you don't have love', she insisted. 'You can't, because some clients are so sick they can't go to the toilet, so you have to help them'. This could include cleaning up diarrhoea and using her own money to wash clients' linens. In short, being faithful to a Christian ethos of Jesus' love was enacted and experienced as a seemingly boundless faithfulness to clients' needs. Identifiable by the group's mustard coloured jersey, inscribed with the group's scriptural maxim, caregivers like Nomusa felt households were more receptive than in the past: 'They call me even if I am away. People need me'. At the same time, it was an activity that chagrined some community members. Some called her a 'fool' for working for nothing. Asked how a spirit of volunteerism could grow in such an environment, Nompumelelo felt that teaching gospel could help to create 'that spirit of pity in someone', a precursor to the compassion that appeared to enable all caregivers' practices.

Although HIV/AIDS knowledge was acquired through training, 'love' and 'talk' were paramount care practices that benefted by modelling. With prior HIV/AIDS training from a Lutheran Development Center, the SRC-HBC asked Vuyisa to 'accompany [caregivers] to clients' homes to show them how to speak to [sick] people'. Cultivating 'love' and 'talk' among caregivers was also necessary to create a cohesive care group, which was essential for extending care to clients. Asked about the challenges of coordinating 49 caregivers, Nomusa intimated that caregivers are still people amongst whom tensions can arise. One of her biggest challenges was to get caregivers to 'love one another', a task she undertook by having them 'talk, talk, talk'. She explained, 'Everything – we have to start with the Bible'. Such love was 'something [they said they] didn't have before'. But since becoming volunteer caregivers, they told her, 'We are getting love, loving other people thinking about helping someone'.

Caregiving and care of self

Given the little research that exists on caregivers' well-being, the schedule included questions about participants' health and who takes care of them. The question often elicited a chuckle at the irony that caregivers might be uncared for. However, a number of participants said that their SRC-HBC peers did. One of the strengths of a semi-structured format is the dialogic space it creates for respondents to reconfigure the interview question itself. This occurred when Sibusiso explained how she looks after her own well-being. She began by saying she uses the protective gloves; she then segued to the subjects of marriage and abstinence: 'As it is, I wasn't likely to be married, but now I just abstain from everything and stay with my children'. Christianity served as a resource for self-preservation of body and spirit: 'My faith is keeping me going, because I believe I'm the temple of God. I've got to keep myself clean and safe. That's how I keep myself going'. Asked whether she felt abstinence could really prevent HIV in Swaziland, she wove Christian teachings with public health imperatives: 'It's going to be very difficult for people, but I preach this. Each time we meet, I try to preach to the caregivers that we need to abstain, because this [body] is the temple of God ... But we also need to abstain because of the diseases that are around. Some are beginning to follow the example, but some still find it very difficult to stay without men'. She then proceeded to indict marriage on public health grounds, detailing its risks to women. 'What's the use of going around sleeping with a man, when you know the marriage is not going to last? It's very shaky ground ... Like, you're in a marriage that can break tomorrow. What's the purpose?' She was frustrated that she could think of no strategy that a married woman could deploy to refuse sex, since bride price rendered her his family's property. 'But those who are not married?' she concluded, 'It's not worthwhile'.

Discussion

Theoretical framework

By situating clinical phenomena in locale-specific constellations of social experience (Bolton and Singer 1992) that are often marked by structural vulnerabilities (Farmer 2001), medical anthropology is uniquely well suited to generating new insights on HIV/AIDS and religion at multiple levels (Pfeiffer 2005, Dilger 2007). The concept of RHA helps to deepen this inquiry with the notions of tangible assets, understood as 'compassionate care, material support and health provision', and intangible assets, described as 'spiritual encouragement, knowledge giving and moral formation' (ARHAP 2006, p. 3). In some regards, RHA can be understood as social capital. However, because RHA also encompasses religious identities, social networks and ideologies (Olivier *et al.* 2006), findings from this study demonstrated how RHA offers considerably greater explanatory power than social capital concepts alone. These findings suggest compelling public health relationships, analysed below, between diverse aspects of religion and caregivers' perceived impact on individual, household and community well-being – impacts *in situ* to the local research area, and also, possibly, to vulnerable settings with similar structural, cultural and epidemiological profiles.

HIV/AIDS knowledge: training and empowerment

To theorise religion and public health dynamics in sub-Saharan Africa (SSA), RHA, as an emergent concept, benefits by research that documents the diverse kinds of AIDS work that religious entities undertake in different settings (Schmid *et al.* 2008, p. 3). Such documentation was a key aim of this study. As a religious organisation originating in one local congregation, the SRC-HBC provided much-desired opportunities for HIV/AIDS training. The HIV/AIDS-related care practices caregivers described, and their religious consciousness of these practices, suggested activities with substantial public health significance. Their reports of the most critical HIV-related decision-making processes an individual faces (testing, disclosure, treatment uptake, gender vulnerabilities and pressures to use traditional healing) constituted empirical data of both client needs and the tangible 'compassionate care' and intangible 'knowledge giving' assets that the SRC-HBC mobilised as a response. And unlike sporadic non-contextual HIV/AIDS slogans and well-scripted clinic counselling, participants' reports of HIV education in familiar church settings, in groups assembled under trees, and one-on-one indicated 'the impact that religio-cultural frameworks' (ARHAP 2006, p. 5) may have by transforming HIV information into real-time actionable knowledge – a response to community (and individual) suffering that often felt meaningful and effective.

An expanding literature has profiled community caregivers serving as ARV and TB treatment supporters in SSA (Weidle *et al.* 2006, Apondi *et al.* 2007). Studies of community home-based care (CHBC) (Ncama and Uys 2006, Shaibu 2006, Ncama 2007) and HIV/AIDS care continuums (Uys 2003, Thomas *et al.* 2006) have suggested that, properly designed and supported, different forms of home-based care may address a range of PLWHA needs. Ideally, home-based and community-based care would help to provide palliative relief from the physical pain of HIV-related cancers and, unlike formal health care services, tend to the daily psychosocial and spiritual challenges patients and their families face (Sepulveda *et al.* 2003). Despite the urgency of local needs and potential wealth of assets inherent in CHBC (Olenja 1999), little is known of the operational challenges these diversely constituted groups face (Mohammad and Gikonyo 2005). According to participants in this study, treatment support required caregivers have basic knowledge of ART, acknowledge the limits of their knowledge and work within material and social constraints. Showing up the limits of silo-constructed HIV interventions, caregivers often described clients' disclosures as intensely private moments that precipitated highly consequential decisions for household relations and HIV health practices.

Single service home-based care is distinguished by its volunteer operations (Van Dyk (2005) summarised in Mulenga 2007, pp. 111–112) and church-run modalities in particular by members' shared scriptural ethos of empathic engagement with others' suffering (Mulenga 2007). This engagement, involving people, relationships and emotions reflects the proposition by Olivier *et al.* (2006) that 'what often makes RHAs different from other health associations, institutions or structures lies in what is not visible – the volitional, motivational and mobilising capacities that are rooted in vital affective and symbolic dimensions of religious faith, belief and behaviour' (p. 11). Thus, compared with VCT counselling, this study's caregivers, having already established special relationships, were strategically positioned to explain and re-explain pre- and post-diagnosis practices at a pace, and in a place, that heeded

clients' HIV understanding, emotions and personal circumstances. Moreover, cognisant of clients' potential vulnerabilities, especially those faced by wives, some caregivers endeavored to broker safer disclosure between sex partners. To address these public health challenges, caregivers innovated a purposive, culturally situated strategy of 'talk' and 'coming close'; a step-wise approach to enculturating a spectrum of HIV health practices. Such practices constituted uniquely situated HIV interventions beyond the geographic reach of formal health care. They were public health practices, moreover, whose framing context was discursively articulated in Christian terms, of serving communities and alleviating suffering.

Leveraging assets: religion and social transformations in care/knowledge

Opportunities for HIV/AIDS training alone did not explain SRC-HBC's rapid expansion. Religious identity, leadership and scriptural ethos emerged as part and parcel of HIV/AIDS care and demonstrated the synergies of tangible and intangible RHA. Interpreted by the director, the Bible's paramount lesson was the love of giving freely (voluntarily and unconditionally) – a subjective emotion and care practice that cross-cut many interviews. Its maxim communicated a grounding ideology and guiding ethos that integrated volunteerism and HIV care. From a public health perspective, the heuristic distinction between ideology and ethos is important, first, to situate the group's evangelical aspects in a local setting, and second, to begin to identify potential collaborative challenges between religious and non-religious health entities. As an ideology, defined as a 'body of doctrine [...] along with the devices for putting it into operation',[2] evangelism was a discursive feature of SRC-HBC training in so far as, explained the director, it '[helps caregivers] to speak about their faith in such a way that people can understand the message, yet do not feel they are being forced into "repenting" – as so often happens'. As an ethos, the maxim reflected the 'character or disposition of a community, group, [or] person'.[3] In this study, the collective disposition was to 'love' freely and unconditionally.

From participants' perspectives, this religious ethos was an indispensable feature of caregiving – a finding that augments the core meaning of asset in RHA, understood as an 'endogenous' resource that can be 'leveraged and grown' in the service of public health (Haddad *et al.* 2008, p. 4). Subjective and agentive experiences, such as those described in this study, are critical data that bear on enacting endogenous assets. Faced with overwhelming suffering and chronic shortages of food and medicine, caregivers struggled with their care limitations. They were supposed to be 'caring', yet they often had nothing to give. A deeply felt Christianity helped assuage this troubling disconnect. Lacking food or painkillers for clients, Nocawe said, 'Really, you can't cope [as a caregiver], unless you've got a heart to do it'. Asked how religion provided that 'heart', she explained that in faith or religion, you pray to get the strength to go on, 'and even if you don't have anything, when you get to the patient you can pray; that's a pillar of strength for me'.

Caregiver reports suggested that the SRC-HBC was transformative for many individuals and the communities they served. The feedback loop of knowledge acquisition and action through caregiving had become a discursive feature of a caregiver identity. 'How can I stop home-based care?' one participant said. 'I think, what must I do now? I need more training'. By identifying the substantive

functionality that 'love' and 'talk' played as culturally situated care practices, this study surfaced deeply felt experiences of self that, in turn, suggested new notions of personhood. This reflexivity, moreover, conveyed ways that religious consciousness and HIV training were leveraged as care 'interventions' and intimated a self and social transformation that likely would not have developed in the absence of a scriptural ethos and church-run organisational structure. Communities directly witnessed SRC-HBC caregivers in action, igniting discussion of hidden agendas, moral superiority and admiration; all elements in an alchemy of sociocultural change. 'When I'm dressed like this [the group's jersey]', said Sibusiso, 'people start being attracted to me, and I tell them who I am and what [I do]'. Asked what people actually see, she detailed care tasks that were simultaneously mundane and sacred: 'They see how we help other people. If you're not able to fetch water, we go to the river for you. If you're unable to wash yourself, we wash you. People look at us … "We would like to be like them"'. Witnessing caregivers' work, Sibusiso said, was having the effect of converting some individuals 'because of what we're doing'.

It is important to grasp that these public care practices are enacted in a society marked by considerable HIV stigma (Dlamini *et al.* 2007, Root 2010). At the same time, they transpire in domestic spaces conceptualised in the sociological literature as private. They are practices, moreover, discursively articulated in Christian terms. Witnessing caregivers' work, she said, was having the effect of converting some individuals 'because of what we're doing'. To the extent that this may be the case across the organisation's 22 communities, the SRC-HBC response to collective suffering may transform aspects of religion, and religion, in turn, transform aspects of HIV/AIDS. This transformation was conceptualised by many in this study as a religious ethos of selfless love, made real through practices that offered ongoing support to clients and caregivers alike. The shift – from individuals extending ad hoc care to teams of caregivers who were attributed with important health skills – seemed to give rise to a new subjectivity: a state of mind of 'how to be' under conditions of extreme suffering; a caregiving self-astute to the diversity and complexity of client relationships; a sensitivity to others' needs and their own limitations; and supportive peer relationships that did not exist before.

Religiosity as a feature of RHA is little explored. Asked how long she would be a caregiver, Nomusa answered, 'Until I die, because when I die being a caregiver, I will die in Christ'. Christianity provided the foundation for Sibusiso's pro-sexual abstinence stance as a form of self-care; however, it did so in ways that would likely be unrecognisable to most scholars. Sibusiso leveraged its empowering aspects in sociocultural environments where church is often one of the only sites where women congregate on a regular basis outside the home (Taylor 2006), and in doing so problematised reductive notions of Christianity as exclusively oppressive of women. In the USA, in particular, sexual abstinence often is the Maginot Line that defines whether a researcher or policy-maker is a progressive or conservative voice in AIDS programming. Yet, despite investigation into other social aspects of HIV/AIDS, the multiple meanings that sexual abstinence might have in distinctive cultural settings have engaged little research. That Sibusiso counselled sexual abstinence, using a mélange of religious and biomedical discourses, to members of a church-run HBC group is potentially culturally transformative. It featured a woman in a poor rural area publicly denouncing the institution of marriage in Swaziland, because of the

risks of infection she said it poses. Sexual abstinence for her was positioned as a protest against male sexual prerogatives. This is a distinctly different abstinence discourse than in the USA. Hers was a rationale in religious and culture-specific terms that most AIDS researchers, by virtue of the latter's 'local' culture-specific politics, have neglected to investigate.

Conclusion

This manuscript contributes to an expanding body of peer-reviewed research that examines the multifactorial significance of religion to subjective experiences of and community responses to HIV/AIDS, especially local churches, whose institutional presence far exceeds those of formal health care settings in many areas of the world. On a programmatic level, a deeper understanding of how religious entities engage HIV/AIDS, operationally and ideologically, is necessary to strengthen multisectoral collaboration (Olivier *et al.* 2006, p. 59). Designed to collect experiential data from caregivers who volunteer with a church-run home-based care organisation, the study generated insights on the tangible and intangible assets that were mobilised to assist hard-hit communities in Swaziland and the subjective experiences of doing so. The organisation's RHA 'portfolio' included a dynamic constellation of leadership, organisation, networks, practices and identities. Where generosity and caregiving certainly were not unknown prior to the SRC-HBC, the formalisation of these characteristics, the scale at which they are practiced and their public enactment traced the outlines of new categories of personhood that challenge the HIV/AIDS status quo of sickness and stigma.

Overall, the interviews provided a compelling picture of essential site-specific conversations around HIV/AIDS that happen on clients' own terms, in their own spaces, in order to navigate the material constraints and gender vulnerabilities that many faced. Analysis of how caregivers engaged these challenges shed light on the limitations of an inadequate health system whose clinical milieus cannot eliminate entirely the fear, reluctance and distrust that often mediate daily health practices. Finally, the significance to caregivers of acquiring and enacting HIV/AIDS knowledge as part of a scriptural ethos *of* pathos foreground some of the shortcomings of authoritative public health discourses around religion and HIV/AIDS. In addition to furthering research on RHA, such data are essential to nuance debates that have arguably impeded deeper investigation of Christian religion and HIV/AIDS in Africa. Studies are needed to further document and theorise the ways in which conservative religious discourses in one cultural setting, resituated in another, may become progressive in innovative ways that could strengthen HIV/AIDS programming.

Notes

1. Participants' quotes have been edited for clarity and word count. Efforts were made to retain as much of intended meanings as possible.
2. Dictionary.com. *Dictionary.com Unabridged*. Random House, Inc. Available from: http://dictionary.reference.com/browse/ideology [Accessed 19 June 2011].
3. Dictionary.com. *Dictionary.com Unabridged*. Random House, Inc. Available from: http://dictionary.reference.com/browse/ethos [Accessed 19 June 2011].

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