Free Love: Religion and Community Home-based Care in Swaziland

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Abstract

To explore the concept of religious health assets (RHA) and HIV/AIDS, this manuscript describes the experiences of volunteer caregivers with a church run home-based care organization in Swaziland. In light of reductions in donor funds for ART rollout in Africa, strengthening mechanisms of treatment support with HIV prevention has never been more critical. Community home-based care (CHBC) is a core feature of the World Bank's Multi-Country HIV/AIDS Program for Africa, yet little is known of how CHBC may be leveraged towards such goals. Likewise, insufficient attention has been paid to the frontline activities of local congregations. Part of a larger anthropological study of religion and HIV/AIDS in Swaziland, this manuscript draws on longitudinal field research and 20 semi-structured interviews with caregivers to discern patterns in motivations; client needs; HIV/AIDS care practices; and religiosity. Grounded theory analysis suggested caregivers cultivated vital roles promoting HIV testing, brokering HIV disclosure that may reduce gender vulnerabilities, enabling treatment uptake/adherence, and diminishing HIV stigma; evidence of the 'tangible' and 'intangible' assets that comprise RHA. Analysis also identified the importance of a Christian ethos to CHBC. Given the organization's expansion to 600 caregivers and 2,500 home-based clients between 2006-2009, analysis intimated caregivers as agents of a broader social transformation. The article has implications for better understanding RHA, and for challenging authoritative global public health strategies that have largely marginalized and politicized local religious aspects of HIV/AIDS. Future research on the ways that "home" and "church" may be vital public health settings outside of, but integral to, formal health services is warranted.

Key Words: religion, HIV/AIDS, disclosure, home-based care, stigma

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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 down, because it has my tablets [ART].' 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]."[3]

– Regional Home-based Care Coordinator

Faced with some of the world's highest HIV prevalence rates, poor health care infrastructure, and limited economic resources, hard hit communities in many parts of Africa have mobilized 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 religious ideologies, organizations, and participation may play in mediating multiple vulnerabilities is critical. In Swaziland, site of the study described here and the world's highest HIV prevalence rate, there has been an estimated 350% growth in registered church organizations since the 1990s (Pan African Christian AIDS Network [PACNET] 2008).[4] The country's institutional saturation by local congregations, and their possible relevance to HIV/AIDS, is indicated by the estimated one church per 200 (personal communication, B. Langa, July 2006)[5] Swazis versus one HIV counseling and testing site (HCT) per 10,170 (National Emergency Response Council on HIV/AIDS [NERCHA] 2008).[6] 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 organization in Swaziland [DELETE].[7] Such experiences are central to understanding whether and in what ways local faith-based resources might mitigate HIV/AIDS in places where conventional public health resources cannot reach – people's homes.

Investigation of religion and HIV/AIDS more broadly is important because to many health researchers and policymakers, the idea of Christianity benefiting HIV/AIDS initiatives in Africa may seem unfamiliar, 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 (Heald 2002)[8] may negate the deeply felt and institutionalized presence of Christianity (Gifford 2008, Meyer 2004) that affects millions of PLWH and their families in Africa on a daily basis (Agadjanian & Menjivar 2008, Agadjanian & Sen 2007, Becker & Geissler, 2007). As a result, assumptions that religion uniformly 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

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[3] *Due to limitations on word count and to facilitate reporting, participants' quotes reflect the author's paraphrasing and attempts to retain participants' meanings.*

[4] Pan African Christian AIDS Network, 2008. *Situational Analysis: Swaziland Report.* Available from: http://www.pacanet.net/index.php?option=com_docman&task=cat_view&gid=23&Itemid=40 [Accessed 6 May 2010].

[5] *[DELETE, NOT NECESSARY] Swaziland National Church Forum, July 2006. Personal interview with [former] director. of the Mbabane, Swaziland. [Estimated 6,000 local churches.]*

[6] National Emergency Response Council on HIV/AIDS (NERCHA), January 2008. *Monitoring the Declaration of Commitment on HIV/ AIDS (UNGASS). Swaziland Country Report. Mbabane, Swaziland: The Government of the Kingdom of Swaziland.* Available from: http://data.unaids.org/pub/Report/2008/swaziland_2008_country_progress_report_en.pdf [Accessed 6 May 2010].

[7] *DELETE: Findings are preliminary as not all transcripts have yet been analyzed.*

[8] Heald, S., 2002. It's never as easy as ABC: Understandings of AIDS in Botswana. *African Journal of AIDS Research,* 1 (1), 1-10.

the multifactorial significance of religion and HIV/AIDS (Adogame 2007, Cochrane 2006, Denis 2002)[9,10] in many parts of the world that challenges authoritative global public health strategies that have often marginalized and politicized religious aspects of HIV/AIDS.

BACKGROUND

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[11] (49% among women age 25-29) (UNAIDS 2009), a 33% orphan rate, and an estimated average life expectancy of 37 years, 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 ART (UNAIDS 2008)[12]. However, with only 15 physicians (NERCHA 2008)[13] to treat the 190,000 children and adults (HIV InSite 2010)[14] known to be infected with HIV, and just 35.4% (NERCHA 2008)[15] of those with advanced HIV infection on treatment, a critical mass of PLWH are underserved. In light of reductions in donor funds for ART rollout in Africa, ART support 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 & Andrade et al., 2006).[16] They are home-based practices, moreover, that constitute the home (an extended family homestead) as an organizing principle of Swazi life (Kuper 2006).[17] For this reason, "home" is theorized here as the physical and social space where PLWH wellbeing 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 Organization

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[9] Adogame, A., 2007. HIV/AIDS support and African Pentecostalism: the case of the Redeemed Christian Church of God (RCCG). *Journal of Health Psychology* 12, 475–484.

[10] Moved.

[11] UNAIDS, 2009. *AIDS Epidemic Update 2009*. Joint United Nations Programme on HIV/AIDS (UNAIDS) and World Health Organization (November 2009).

[12] UNAIDS, WHO, UNICEF., October 2008. *Swaziland. Epidemiological Fact Sheet on HIV and AIDS: Core data on epidemiology and response*.

[13] National Emergency Response Council on HIV/AIDS (NERCHA), January 2008. *Monitoring the Declaration of Commitment on HIV/ AIDS (UNGASS). Swaziland Country Report*. Mbabane, Swaziland: The Government of the Kingdom of Swaziland, January 2008. Available from: http://data.unaids.org/pub/Report/2008/swaziland_2008_country_progress_report_en.pdf [Accessed 6 May 2010].

[14] HIV InSite, 2010. *Swaziland Comprehensive Indicator Report*. University of California, San Francisco. Available from: http://hivinsite.ucsf.edu/global?page=cr09-wz-00&post=19&cid=WZ [Accessed 2 May 2010].

[15] Redundant.

[16] Whiteside, A., Andrade, C., Arrehag, L., et al., 2006. *The Socio-Economic Impact of HIV/AIDS in Swaziland*. Mbabane, Swaziland: National Emergency Response Council on HIV/AIDS (NERCHA) and Health Economics and HIV/ AIDS Research Division.

[17] Kuper, H., 2006. *The Swazi: A South African Kingdom*. New York, Holt, Rinehart and Winston.

A registered non-governmental organization in Swaziland and South Africa, the Shiselweni Reformed Church Home-Based Care (SRC-HBC) organization 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 2,500 clients in 22 communities across 100 sq kilometers 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 organization is Christian in ethos, guided by the scriptural maxim, "To Become the Hands and Feet of Christ in 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 Mfundi (Pastor) Van Wyngaard bathes and washes the feet of new members to symbolize and enact the spiritual and physical caregiving roles they will serve in their communities.

The organization is funded through small donations from individuals and religious organizations in the US 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 their coordinator, each of who oversees between 20-50 caregivers. Community coordinators prepare individual reports for the regional coordinator, who in turn compiles a report detailing the number and gender of caregivers; total number of home visits; number of clients; and clients who are new or have moved, died, are terminal, or who have chronic ailments. Final reports are submitted to Pastor Van Wyngaard for oversight and to direct further health training and spiritual counseling needs.

METHODS

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 was comprised of 13 coordinators who, collectively, constituted more than half of the communities served in 2009, overseeing a total of approximately 455[18] caregivers. Thus, while the number of interviews is low, the broader perspective they provided on the research question offered substantial exploratory power. The remaining seven participants were sampled by availability. Because respondents were active in SRC-HBC groups that were diverse[19] in the size and history of their operations, findings are felt to be reflective, though not representative, of many caregivers' experiences in the SRC-HBC organization at large. Field research, including observation at caregiver meetings and on client home visitation, as well as extensive focused conversation with the organization's nurse trainer and its director, provided additional primary data.

The interview schedule was operationalized 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 United States. Given the demonstrated benefits of grounded theory analysis[20,21] to qualitative health research,[22] a

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[18] Arnau: I guesstimated that each coordinator oversaw about 35 caregivers in 2009 (13 coordinators x 35 caregivers=455). Does that sound about right?

[19] Arnau: On the claim of diversity, would you agree that those caregivers and coordinators whom I interviewed did come from care groups diverse in the manner described here?

[20] Charmaz, K., *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. Los Angeles, CA: Sage Publications, 2006.

grounded theory approach was used to elicit key themes from interview data.[23] Research procedures were approved before research commenced by Baruch College's Human Research Protections Program, City University of New York (USA).

DISCUSSION

A fundamental premise of medical anthropology is that it is epistemologically disingenuous and weak health programming to treat physical and psychological afflictions, or material poverty and lack of access to health facilities, as mutually exclusive 'variables.' (Dilger 2007, Pfeiffer 2005, Farmer 2001)[24,25] By situating clinical phenomena in dynamic and locale-specific constellations of social experience, medical anthropology is uniquely well-suited to generating new insights on HIV/AIDS and religion at multiple levels.[26,27,28] The concept of religious health assets (RHA) helps to deepen this inquiry by conceptualizing the intangible and tangible assets that religious institutions and activities bring to the public health enterprise in sub-Saharan Africa.[29] RHA can be understood in part as social capital; however, because RHA also encompasses religious identities, social networks, and ideologies, it offers considerably greater explanatory power than social capital concepts alone.

Data from studies of community home-based care[30,31,32,33] have suggested that properly designed and supported, CHBC can be leveraged 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;[34] agony on a macro scale that, fortunately, is no longer a paramount feature of HIV/AIDS

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[21] Ryan, G.W., and Bernard, R.H., Techniques to identify themes. *Field Methods* 15:85-109, 2003.

[22] Miller, S.I., and Fredericks, M., How does grounded theory explain? *Qualitative Health Research* 9(4):538-551, 1999.

[23] Participant quotes have been edited for clarity; however, efforts were made to retain as much of participants' verbatim quotes as possible and to convey the intended meanings of the longer passage from which the quote was excerpted.

[24] Pfeiffer, J., 2005. Commodity fetichismo: the Holy Spirit, and the turn to Pentecostal and African Independent Churches in Central Mozambique. *Culture, Medicine and Psychiatry, 29 (3), 255–283.*

[25] Farmer, P., 2001. *Infections and Inequalities: The Modern Plague.* Los Angeles, CA: University of California Press.

[26] Bolton, R., and Singer, M., eds., *Rethinking AIDS Prevention: Cultural Approaches.* Philadelphia: Gordon and Breach Science Publishers, 1992.

[27] Thomas, L., Schmid, B., Gwele, M., et al., 'Let us embrace': The Role and Significance of an Integrated Faith-based Initiative for HIV and AIDS. Cape Town, South Africa: African Religious Health Assets Programme, 2006.

[28] Hartwig, K.A., Kissioki, S., and Hartwig, C.D., Church leaders confront HIV/AIDS and stigma: a case study from Tanzania. *Journal of Community and Applied Social Psychology* 16:492–497, 2006.

[29] African Religious Health Assets Programme, 2006. [See URL below]

[30] Shaibu, S., Community Home-Based Care in a Rural Village: Challenges and Strategies. *Journal of Transcultural Nursing* 17(89):89-94, 2006.

[31] Ncama, B.P., Acceptance and disclosure of HIV status through an integrated community/home-based care program in South Africa. *International Nursing Review* 54:391–397, 2007.

[32] Apondi, R., Bunnell, R., Awor, A., et al., Home-based antiretroviral care is associated with positive social outcomes in a prospective cohort in Uganda. *Journal of Acquired Immune Deficiency Syndrome* 44(1):71-76, 2007.

[33] Weidle, P.J., Wamai, N., Solberg, P., et al., Adherence to antiretroviral therapy in a home-based AIDS care programme in rural Uganda. *Lancet* 368:1587–94, 2006.

[34] Sepulveda, C., Habiyambere, V., Amandua, J., et al., Quality care at the end of life in Africa. *British Medical Journal* 327(408): 209-213, 2003.

in better resourced countries. Yet despite the urgency of local needs and the potential wealth of assets inherent in CHBC,[35] little is known of the operational challenges these diversely constituted groups face.[36] Church-run community home-based care is distinguished by its volunteer operations[37] and members' shared scriptural ethos of empathic engagement with others' suffering.[38]

HIV/AIDS Knowledge: Production, Empowerment, and Public Health Significance
The opportunity afforded by the SRC-HBC to acquire concrete HIV/AIDS knowledge, and to intervene where the state failed, for example, to provide follow up to individuals released from the hospital yet who were still sick, was a key motivator among many caregivers to join the organization. Direct observation of and word of mouth marketing were integral to the first step in joining. J#7 saw caregivers in action "*and realized I liked it. I asked to join so I can learn about taking care of people; after they trained me, they said I can ask others that are interested in caregiving, so they can be trained, too.*" Where some participants said that prior to joining the SRC-HBC, they had not reached out to the afflicted in their communities, others recalled 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 felt more empowered to do so." A#11 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.*" Unlike sporadic non-contextual HIV/AIDS slogans and clinic counseling, ongoing HIV/AIDS education in familiar church settings[39], in groups assembled under trees, and one-on-one between caregivers transformed HIV information into real time actionable knowledge; a response to community (and individual) suffering that felt meaningful and effective, albeit limited by material constraints.

Many participants swelled with satisfaction over their greater care competency; a competency they attributed in part to the collective problem solving that fueled 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 the 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 are together we share the challenges we face…We try to come with an idea as to how we can help them.*" Collective action made it possible to implement comprehensive interventions resulting from extreme poverty. Nompumelelo provided an example*: "If I am only one person, and the client needs shelter, I can't do it. So we gathered together to build the client a house.*" A collectivity of caregivers 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 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

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[35] Olenja, J., Assessing community attitude towards home-based care for people with AIDS (PWAS) in Kenya. *Journal of Community Health* 24(3):187-199, 1999.

[36] Mohammad, N., and Gikonyo, J., Operational Challenges Community Home Based Care for PLWH in MAP in Africa. Africa Region Working Paper Series No. 88. The World Bank Group, 2005.

[37] Van Dyk, A., *HIV/AIDS & Counselling: A Multidisciplinary Approach*, 2005 [p. 262]. Cape Town, South Africa: Third Edition, Maskew Miller Longman, cited and summarized in Mulenga (2007:111).

[38] Mulenga, K.C., Empowering church-based communities for home-based care: a pastoral response to HIV/AIDS in Zambia. Masters thesis, Faculty of Theology. South Africa: University of Pretoria, November 2007.

[39] Arnau: are these settings where training is provided? I know these are where I saw some of the caregiver mtgs being held.

the client: *"Because of her knowledge, they stopped. She said, 'No, you cannot mix the two. You use this type of treatment, and you stop the other treatment'."*

Despite empowerment from their HIV training, 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: *"The worst thing that is most difficult for me is to go to somebody without aid…Then what do I do?",* Nocawe lamented. It was therefore 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 HIV training and sense of indefatigable empathy trumped any perception that her care attempts were futile: *"I've saved many people. I can't stop…Because in my family there are those with HIV, I know what it is to be HIV positive. Even though there are some people that have died, I have tried my best... I spend my time, my money, my cell phone…It's impossible for me to stop now, really impossible."* The feedback loop of knowledge acquisition through training and action through caregiving had become a discursive feature of her self: *"How can I stop home-based care?"* she continued. *"I think, what must I do now? I need more training."*

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; 4) performing the most challenging of care duties, including helping clients to use the toilet and bathing them. Caregiver services were readily received in [A#4] area, because the chief and his advisors (*induna*), having been informed in advance by the SRC-HBC coordinator of the proposed services, *"called on the people and told them about us."* Last, interviews suggested 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 had even became *"choosey,"* requesting one caregiver over another, apparently because the other was perceived to have more HIV knowledge.

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, that doing drugs or drinking alcohol was *"not good,"* that *"'if you continue with this, you will lose your life', they think you [think you] are better than them."* At times, she defended 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 know what is not good; and he must decide what to do now."* Detractors accused her, as well, not only of arrogance but of ignorance, pointing out that *"even if you don't drink alcohol, you still die."*

Despite the benefits of receiving care, analysis suggested three reasons why households might refuse SRC-HBC outreach: 1) Fear that gossip had precipitated caregivers' visits: "They hate that we have seen them sick," 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, caregiving in one's own community could also be counterproductive. The mundane tensions of neighborly co-existence, and risks of breached confidentiality, even unintended, could obstruct the caregiver-client relationship. Regardless, virtually every participant said that suspicion of their work, which at times was outright disparagement, was diminishing. Now, Futhi said, *"they can see that, really, we're doing something good."*

Asked how the care relationship was initiated, Futhi described an ordinary introduction, made in an extraordinary context – people's homes: *"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 [A#1]. Nompumelelo described her integration of health with 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. Caregivers interacted not only with their clients, but the client's family as well. Usually, Futhi said, *families "become happy because they see that you will help them in other ways."* The participant described these "ways," which, from a public health perspective, are social practices that are highly consequential for HIV/AIDS. They are also culturally situated, reflecting the local history of the epidemic and the entrenched stigma, even within families, that its spread has produced: *"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. She described a client who refused HIV testing, whose family asked her to intervene: *"She's refusing to go…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 normalize HIV testing by situating it within a comprehensive health seeking endeavor that often neutralized 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 optimize the client's chances of survival.

Participants estimated that much of their care work resulted from the impact of HIV/AIDS, poverty, and famine on households. The potential public health significance of the organization cannot be understated. 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 knowledges and practices. Yet, so deep and diffuse does HIV stigma run in much of Swazi society that nearly every HIV care practice was at the same time an effort to reduce its intensity and impact on client and household wellbeing.

HIV testing: The first question Nomusa says she must ask a client is, *"Have you been tested?"* If the client hasn't the funds, *"I say I will try by all means to take you to the VCT."* Despite her perceptions that, overall, 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."* To overcome these hurdles, Nomusa, like other caregivers, cultivated a purposive, culturally situated strategy of HIV talk and "coming close"; a step-wise approach to enculturating HIV health practices. 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.'"* Such home-based care practices constitute uniquely situated HIV interventions beyond the geographic reach of formal health care. They are practices, moreover, aimed at creating the physical and psychological safety, and providing the material support, often required to get individuals to the clinic, without which diagnosis and treatment cannot commence.

ARV Treatment: There is an expanding literature on community caregivers serving as ARV and TB treatment supporters in SSA.[40] Knowledge of how such practices are enacted in different settings is important for evaluating such initiatives. According to participants in this study, treatment support required caregivers have basic knowledge of ART; acknowledge the limits of their clinic knowledge; and work within constraints, economic and stigma-based, that obstruct testing, disclosure, and treatment. Explained Nompumelelo*, "We encourage them to follow up their treatment, but we've got people saying 'we [want] to follow up our treatment, [but] we are starving…I am supposed to take my tablets. If I take them without food, I feel very weak."* She had helped mobilize 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,

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[40] Insert cites.

likely had secondary benefits of reducing stigma, providing psychosocial support, and normalizing a positive diagnosis.

Disclosure and positive prevention: HIV disclosure can be experienced at once both as an intensely private and public event; an event that becomes a highly consequential process towards either treatment and/or stigmatization. Some caregivers noticed an increasing trend towards disclosure within the caregiver-client relationship. Nomusa explained*, "It's not easy for them to tell us; 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: [J#9, Sibusiso]*"If somebody confides in me [they're 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 VCT and preparing to start ARVs. *"But if you don't want to start on ARVs you must listen to what [clinic personnel tells] you to do, and be very careful…Keep on checking the CD4 count."* Although HCT staff had likely instructed the client when they provided the test results, the caregiver, having already established a special relationship, was present to explain those next steps at a pace, and in a place, that heeded the client's HIV understanding, emotions, and personal circumstances.

Ascendant comfort levels appeared relative, however, since many participants said clients disclosed only when their family was not present. A#10 described her handling of such situations*: "That person tells you their secret, so…you give her that love… Now I know [your] status, [but] I [can't help] enough because I'm not staying with you. You have to tell one of your family members who is going to be with you almost seven days a week."* There are times when the client asks her to tell the family member. She says no, but to name a family member whom she calls for. *"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 participants counseled the importance of disclosing to sexual partners. Futhi advised clients, *"It's important that the partner must know, so that they have protected sex and help each other [e.g., remind you to take your drugs]."* Sibusiso described a softer approach, advising clients 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."*

While advisement could happen within a clinic counseling context, a caregiver is likely cognizant of client circumstances, and able to broker disclosure in the safest way possible. Husbands' resistance to testing, and their obstructions to wives' attempts at HIV care, were challenges many caregivers faced. The nurse trainer[41] 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 would not. One day, when the woman was away from home, she returned to find that her husband had thrown her drugs 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."* In some instances, 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 client, *"We'll find a day to visit when [you and your husband] are together, and [I'll] educate them about HIV and AIDS, how to use safe sex – all those things."* The caregiver returned to find that the husband had finally agreed to go test. 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 very own son, she said, had been put on ARV, yet he refused to take them: *"He says he'd rather die than take so many tablets."*

Fear of stigma bled into caregivers' efforts in multiple ways. Nompumelelo described how some clients asked that caregivers not use the latex gloves caregivers are trained to use. She explained their clinical imperative by situating protective gloves in a caring relationship: *"We just share the idea of using gloves, that*

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[41] .

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 normalized an HIV diagnosis, preserved the client's sense of dignity, and sustained the caregiving relationship.

[where? J#8, p.2. ARV, culture, migration intersect at the point of taking ARVs in the household, amongst kin or privately. "HIV is one of the conditions and uh, ignorance is a major problem because 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 [note: presumably to visit], they say 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."]

Church-based Ideology, Ethos, and Social Transformation
Opportunities for HIV/AIDS training alone likely does not explain the organization's rapid expansion and the passionate commitment conveyed in interviews. Religious identity, leadership, and scriptural ethos emerged as part and parcel of HIV/AIDS care. Identifiable by the group's mustard colored jersey, inscribed with the group's maxim, "At the Hands and Feet of Christ Serving the Community," caregivers like Nomusa felt households were more receptive than in the past, when motives might be suspect: *"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 enabled all care practices.

At the organizational level, the SRC-HBC maxim provided both a grounding ideology and guiding ethos of volunteerism and HIV care. This heuristic distinction is important for situating the group's evangelical aspects in a local setting beset by famine, poverty, and sickness, and not as Christian evangelism that isolates and stigmatizes nonbelievers. Defined as a "body of doctrine […] along with the devices for putting it into operation,"[42] the evangelical 'ideology' served as a discursive feature of SRC-HBC training. According to the founder, the evangelical training[43] "consists in helping [caregivers] to speak about their faith in such a way that people can understand the message, yet do not feel that 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."[44] The SRC-HBC's ethos was one of pathos. For Nomusa, this pathos was almost ineffable: "I *volunteer, because I saw that some people [needed help] …I can't express what I feel about these people."* Feelings of pity emerged as a care imperative for many. 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."*

As interpreted by the SRC-HBC founder, the Bible's paramount lesson was the giving freely (voluntarily and unconditionally) of love – a subjective emotion and care practice that cross-cut many interviews. As discrete care practices, love and talk benefited by modeling. With prior HIV/AIDS training from a Lutheran Development Center, the SRC-HBC asked Vuyisa to *"accompany [its caregivers] to clients' homes to show them how to start speaking to the people who are sick."* Cultivating "love" and "talk" among caregivers was also necessary to create a cohesive care group, which was an essential first step towards caring for 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."* Caregivers told her they were learning *"more and more"* about *"loving people."* Such love was

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[42] Dictionary.com for both definitions. Accessed June 21, 2010.

[43] Arnau: is it ok if I quote from your email? It's a perfect explanation.

[44] Dictionary.com for both definitions. Accessed June 21, 2010.

"*something [they] didn't have before.*" But since becoming volunteer caregivers, "*We are getting love, loving other people, thinking about helping someone.*" Such reflexive sentiments suggested a self and social transformation that likely would not have developed in the absence of a scriptural ethos and organizational structure dedicated to providing CHBC.

An important aim of the interview design was to understand caregivers' views on the role of the church and being a Christian in providing home-based care. "*This work needs somebody who knows about Jesus,*" Nomusa explained. Pressed, she concretized 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]".* At the level of direct care, the rhetoric of religion became a discourse of love, 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 diarrhea 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. Religiosity was described as an indispensable feature of caregiving for other reasons as well. In the face of 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, and connecting home-based care to the church, helped assuage this troubling disconnect. Lacking food or painkillers, Nocawe said,"*Really you cannot 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 church-run CHBC was transformative for many individuals and the communities they served. The transformation was conceptualized in a religious ethos of selfless love and made real through practices that offered ongoing support to clients and caregivers alike. This shift, from a few individuals extending ad hoc care to teams of public caregivers who were attributed with important life-saving 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 was central to articulating these experiences, and infused care practices addressing HIV/AIDS. Asked how long she would serve as a caregiver, Nomusa answered, "*Until I die, because when I die being a caregiver, I will die in Christ.*"

These deeply felt experiences of self, in turn, suggested emergent notions of personhood. Generosity and caregiving certainly were not unknown prior to the SRC-HBC, but the formalization of these characteristics, the scale at which they were practiced, and their public enactment traced the outlines of new categories of personhood that challenged the HIV/AIDS status quo of sickness and stigma. Communities directly witnessed SRC-HBC caregivers in action, igniting discussion of hidden agendas, moral superiority, and admiration; all elements in an alchemy of socio-cultural 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 are not able to fetch water, we go to the river for you. If you are unable to wash yourself, we wash you. And people look at us…'We would like to be like them'.*" It is important to grasp that these are public care practices enacted in a highly stigmatizing environment. At the same time, they transpire in domestic spaces conceptualized in the sociological literature as private. They are practices, moreover, discursively articulated in Christian terms. As a result, observations of caregivers' work, she said, were having the effect of converting some clients and members of the community "*because of what we're doing.*" To the extent that this may be the case across the organization's 22 communities, the dire impact of HIV/AIDS is transforming aspects of religion, and religion, in turn, transforming aspects of HIV/AIDS.

Given the little research that exists on caregivers' wellbeing, 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.

However, 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 wellbeing. 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 just stay with my children."* Christianity was a resource for managing risk, protecting her body, and preventing suffering: *"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."* Religion provided the foundation for her pro-sexual abstinence views; however, it did so in ways that would likely be unrecognizable to most scholars. In the US, sexual abstinence advocacy is the Maginot Line that often defines whether a researcher or policymaker is a progressive or conservative voice in AIDS programming. Yet, despite investigation into other social aspects of HIV/AIDS, the multiple meanings sexual abstinence might have in distinctive cultural settings has engaged little research. The details of Sibusiso's response are therefore important because they problematize reductive notions of Christianity, especially in socio-cultural environments where church is often one of the only sites where women congregate on a regular basis outside the home.[45] 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."* Abstinence was difficult to preach, she said, "*my God is faithful*." 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.*"

That Sibusiso counseled these cautionary practices, using a mélange of religious and biomedical discourses, to caregivers with a church-run group is potentially culturally transformative. It features a woman in a poor rural area publicly denouncing the institution of marriage in Swaziland, because of the sexual risks of infection it poses to women. Sexual abstinence for her was positioned as a protest against the male sexual prerogatives inherent in Swazi polygamous kinship. This is a distinctly different abstinence discourse than in the US. Hers was a rationale in religious and culture-specific terms that most AIDS researchers, by virtue of their 'local' culture-specific politics, have neglected to investigate.

Conclusion

This manuscript has aimed to contribute 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. Designed to collect experiential data from caregivers who volunteer with a church run home-based care organization, the study generated insights on the tangible and intangible assets that the church run organization leveraged to assist hard hit communities in Swaziland. Its religious health assets were a dynamic constellation of leadership, organization, networks, practices, and identities. Overall, the interviews provided a compelling picture of essential site-specific conversations around HIV that happen on clients' own terms, in their own spaces, and with sensitivity to the material constraints or gender vulnerabilities an individual (woman) could face. Analysis of how this was handled pointed up the limitations not only of an inadequate health system, but whose milieus and social relations are not designed to chip away at the fear, reluctance, and distrust that mediate health practices. 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 western/biomedical public health discourses around religion and HIV/AIDS. Such data are

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[45] Taylor, N., *Working Together? Challenges and Opportunities for International Development Agencies and the Church in the Response to AIDS in Africa.* Tearfund HIV and AIDS Briefing Paper No. 7. Middlesex, UK, Tearfund, 2006. [Confirm, or Pacnet.]

essential to nuance debates that, in the US in particular, have arguably impeded deeper investigation of Christian religion and HIV/AIDS in Africa.   Future research is needed to document and theorize the ways in which conservative religious discourses in one cultural setting, resituated in another, may become progressive in ways that could strengthen HIV/AIDS programming.

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