

“We Smoke the Same Pipe”: Religion and Community Home-Based Care for PLWH in Rural Swaziland

Robin Root^a, Arnau Van Wyngaard^{b,c}, and Alan Whiteside^d

^aDepartment of Sociology & Anthropology, Baruch College, City University of New York, New York, New York, USA;

^bDepartment of Science of Religion and Missiology, University of Pretoria, Pretoria, South Africa; ^cShiselweni Home-based Care, Swaziland; ^dCGI Chair in Global Health Policy, Balsillie School of International Affairs, Waterloo, Canada

ABSTRACT

We draw on a study of a church-run community home-based care organization in Swaziland to explore how individuals living with HIV perceived caregivers' impact on well-being. Our primary concern was to examine how religion, as a heuristic practice of Christian-based caregiving, was felt to be consequential in a direly underserved region. Part of a larger medical anthropological project, we conducted semi-structured interviews with 79 community home-based care clients, of whom half (53%) said they would have died, some from suicide, without its services. We utilized a critical phenomenological approach to interpret semantic and latent themes, and explicated these themes within a 'healthworld' framework. Participants were resolute that caregivers be Christian, less for ideological positioning than for perceived ontological sameness and ascribed traits: "telling the truth" about treatment, confidentiality, and an ethos of unconditional love that restored clients' desire to live and adhere to treatment. Findings are intended to help theorize phenomenological meanings of care, morality, health, and sickness, and to interrogate authoritative biomedically based rationalities that underwrite most HIV-related global health policy.

KEYWORDS

Africa; ART/ARV;
biomedicine; HIV/AIDS;
phenomenology

Addressing another's pain is . . . about how a particular kind of relationship can be inhabited or enacted. (Talal Asad, 2003:82)

If these caregivers weren't Christian, I think I would be dead. (48-year-old Swazi woman)

Oppositional rhetoric, competing funding, and institutional politics have long characterized academic and policy debates concerning religion and HIV/AIDS (Parker 2009; Burchardt, Hardon, and de Klerk 2009). Probing these epistemic frames, scholars have theorized the reciprocal mediation of religion and HIV/AIDS health policy and programming (Cochrane 2011; African Religious Health Assets Programme [ARHAP] 2006), civil society mobilization, and new modes of citizenship (Robins 2004), church roles (Prince, Denis, and van Dijk 2009), HIV-health practices (Trinitapoli and Regnerus 2006), and theologies of HIV/AIDS (Van Wyngaard 2013; Paterson 2009; Haddad 2009). In light of global health agendas designed increasingly to 'task shift' HIV and other health services to community health workers (World Health Organization 2013), faith-based organizations, with their deep institutional and grassroots networks, may play an 'exceptional' role (Vitillo 2009) in an arguably 'exceptional' epidemic (Whiteside and Smith 2009). Religion has, in fact, long figured in community home-based care (CHBC) for people living with HIV (PLWH) (Rödlach 2011), yet scant research exists on the experiential and institutional mediation of religion and CHBC, and the ways it may inform theoretical and applied inquiry in medical anthropology. Toward this end, we focus on

experiences of HIV/AIDS and religion instantiated through church-run home-based HIV/AIDS care in Swaziland.

Swaziland is an ideal, albeit tragic, venue in which to address these questions. The population suffers the world's highest HIV and tuberculosis (TB) prevalence rates; the government's HIV/AIDS strategies rely substantially on CHBC services (Government of Swaziland, n.d.); and the country's institutional landscape, from governance to medicine to kinship, is characterized by a plurality of Christian denominations. Conducted in 2009 and 2011, in our two-phased study, we explored the significance of religious-based CHBC to caregivers and clients of a rapidly expanding organization in rural southern Swaziland. In this article, we draw on the notion of 'healthworlds,' conceptualized as "an anthropologically rooted dimension of the lifeworld that thoroughly traverses it" (Cochrane 2011:12), to explicate CHBC practices that PLWH felt improved their well-being, and to consider whether religion, as a heuristic practice of Christian-based, HIV-related caregiving and care-receiving, was felt to be consequential.

Research methods and setting

A small, landlocked country bordered by South Africa and Mozambique, Swaziland is known for its verdant, mountainous landscape and for being one of the world's few absolute monarchies. It is also known for its intractable HIV/AIDS and TB epidemics. Nearly one in three adults (32%) aged 18–49 years is HIV positive. Gender disparities across women's and men's lifetimes reflect entrenched vulnerabilities. Below age 25, female HIV infection rates are five times that of males (26% compared with 5%) and they peak at an earlier age (30–34 years) and a higher rate (54%) than men's highest rate (47% between age 35 and 39 years) (Bicego et al. 2013:3). In recent years, however, some progress has been made. Between 2001 and 2011, new HIV infections dropped 37%, and in 2012 Swaziland was one of only five countries in sub-Saharan Africa to achieve > 80% antiretroviral coverage (UNAIDS 2012). The government's current aim to vigorously pursue a treatment-as-prevention strategy, however, hinges significantly on expanding CHBC.

A majority of Swazi (80%) identify as Christian (Pan African Christian AIDS Network 2008), although denominational affiliations may be fluid across an individual's life course. A ratio of one public health clinic to 6451 Swazi versus one church per 200 contrasts a lack of ready access to formal health services with the institutional saturation of Swazi society by religious networks. Environmental vagaries, unproductive growth strategies, pervasive monarchical entitlements, and global commodity markets have wrought havoc on land use and food prices in direly injurious ways (Hickel 2012). Sixty-three percent of the population lives below the national poverty line (World Bank 2014) and a majority (70%) relies on subsistence agriculture for livelihood (Central Intelligence Agency 2013), albeit insufficiently. In 2011, the World Bank reported that Swaziland was "facing a social disaster of colossal dimensions" (2011).

Shiselweni Home-Based Care (SHBC) delivers services exclusively in the rural areas of southern Swaziland, where subsistence farming is practiced by a majority of the population. These families, like most in Swaziland, live on the "King's ground" for which there are no title deeds. Rather, through an intricate system of chiefs in different areas, any Swazi citizen may apply for a piece of ground where he or she can build a home, keep some cattle and goats, and plant maize, cabbage, and other vegetables. Those to whom SHBC provides home-based care services endeavor to subsist on their own food production. They are totally dependent on rain for the success of their crops, and severe droughts mean that the area SHBC serves has at times become a virtual desert, yielding no crops, and during which time cattle die from lack of feed.

Case organization: Shiselweni Home-Based Care

Several scholars of religion have called for a focused theological response to HIV/AIDS (Bongmba and Cochrane 2007; de Gruchy 2011). Toward that end, a South African theologian (one of the

authors) with three decades of missionary experience in Swaziland founded SHBC in 2006,¹ when he proposed an initiative for Swazi parishioners to assist the unwell in their midst. From 32 volunteers initially, by 2014 SHBC's caregiver base had grown to approximately 1000 caregivers serving 3500 clients in 39 rural communities across 1095 square miles of southern Swaziland. Having implemented a rigorous data collection system in 2008, by 2013 SHBC demonstrated dramatic declines in client mortality (71.4%) (Root, Van Wyngaard, and Whiteside 2015). While causality between SHBC caregiver interventions and health outcomes is impossible to establish, the significance of religion to client experiences emerged as worthy of inquiry. And though there are government rural health motivators and some assistance programs run by World Vision in the area SHBC serves, these are not home-based care; rather, they require individuals to receive services at care points.

Three sociocultural and epidemiological processes help to explain SHBC's rapid uptake. First, high HIV morbidity and mortality meant that individuals who had long been caring for sick family members were keen to participate in SHBC training opportunities. Second, community leaders, including local chiefs, who had been unable to alleviate the suffering of their constituents, observed SHBC's wide-scale impact and requested SHBC train their own volunteer corps. Third, ubuntu, a philosophy of humanity indigenous to southern and eastern Africa, prescribes a sociality wherein "respect for an other [is] as a *religious* other" (Louw 1998, original italics). At its core, ubuntu structures individual consciousness in communitarian terms, serving both as an "indigenous knowledge system" and a collective identity (Forster 2007). By articulating an ontological empathy of self as other, ubuntu compels people to care for others in the belief that writ into society, into human consciousness, is a collective responsibility to care for others. SHBC's Christian ethos hews to the ubuntu worldview and is thus profoundly resonant among caregivers and clients alike.

SHBC's one-week trainings educate caregivers on conventional counseling practices concerning HIV prevention/testing, AIDS/TB treatment uptake/adherence, disclosure brokering, and basic first aid. To cultivate religious care practices, SHBC grounds its care ethos in a servant-leadership model based on the parable of Jesus who instructed his disciples to "wash one another's feet" (John 13:14). Extrapolated to a contemporary setting marked by extreme suffering, the parable is enacted in SHBC's 'graduation' ceremony, whereby the founding pastor bathes the feet of initiates to symbolize the dual physical and spiritual caregiving roles they will play in their communities, which include sponge bathing the client (and demonstrating for family members how to do so) and the diverse religious-based practices described.

Methodology

The concept of religious health assets as direct and tangible, indirect and intangible (Olivier, Cochrane, and Schmid 2006:11) framed our initial aim to explore and explicate the significance of church-run home-based HIV/AIDS care. For its epistemological focus on embodiment and (inter) subjectivity, and concern with how inequalities are implicated in patterns of sickness experiences (Good 1994), a critical phenomenological approach guided the design of interview schedules and analysis. A critical phenomenological approach was generative as well for its focus on how structural and "discursive formations intersect with the operations and felt immediacies of bodies" (Desjarlais and Throop 2011:90). Hermeneutic interpretation (Kinsella 2006) of study results was also informed by each author's longstanding engagement with Swaziland,² which has included field research and scholarship on socio-religious and economic aspects of HIV/AIDS over several decades and throughout Swaziland (Root 2009; Root and Van Wynaard 2011; Root and Whiteside 2013; Van Wyngaard 2013; Whiteside and Henry 2011; Whiteside, Cohen, and Strauss 2015).

Our two-phase study of SHBC was initiated in 2009, with a study of caregiver experiences (Root and Van Wyngaard 2011). In 2011, semi-structured interviews were conducted with 79 HIV-positive SHBC clients, which are the basis of this article. Experience was operationalized in terms of perceived well-being; urgent needs and help-seeking practices; perceptions of SHBC caregivers; disclosure experiences; HIV health practices; and the significance of caregivers' Christian affiliation

and care practices.³ Our interview schedule was comprised of structured (“Would you say your health is better, about the same, or worse since the care supporter began visiting you?”, “If better or worse, how so?”) and unstructured questions (e.g., “What is the most important thing [care supporters] do for you?”), formulated to explore individuals’ experiences of community home-based care.

Participants were notified of the study in advance by SHBC caregivers. Informed consent was secured when the interview was conducted in person. Requisite criteria that the participant was HIV-positive status and a current SHBC client were confirmed before interviews commenced. Most interviews were audio-recorded, for which separate informed consent was secured. Hard copies of an English language version of the schedule were printed, brought to the research site, translated into siSwati by SHBC’s Swazi chief operating officer, and reverse translated. With Swazi interpreters from SHBC, a principal investigator (first author) and a US Fulbright Scholar⁴ conducted the bulk of the interviews, which required about 30 minutes to administer and were conducted in secluded spaces in community settings: at churches, a chief’s residence (*umphakatsi*), an orphan care point (*gogo center*), and a chief’s administrative center (*inkhundla*). Translated responses were summarized on the interview form. Concurrency of data collection and analysis is characteristic of much qualitative research (Thorne 2000:68) and manifest in our study to the extent that a few questions were dropped and others added as new meaningful probes emerged. Thus, the number of participants who responded to a few questions varied. The Institutional Review Board of Baruch College, City University of New York approved the research protocol.

Study limitations

The sampling frame for the study included all SHBC clients, and the sampling strategy was self-selection. There are inherent limitations to all non-probabilistic strategies to consider when interpreting study findings. As a self-selected cohort, participants may have had particularly compelling SHBC experiences and therefore been inclined to vocalize those experiences, biasing results toward common rather than divergent accounts. However, because participants were sampled from multiple SHBC-serviced communities, the potential for this bias was likely minimized. Second, participants might have been available for the study because they were in overall better health than nonparticipants who might have been too unwell, thus biasing findings towards individuals who have benefited more than others from SHBC. Third, two-thirds of participants were women, which may skew findings toward female experiences; however, because 62% of SHBC clients are female, the gender ratio was expected. Last, by providing translation and paraphrasing participant responses, interpreters may have influenced content. Because SHBC caregivers are highly respected as uncommon guardians of confidentiality, their involvement in this regard likely was not limiting.

Sample

Approximately two-thirds (64.6%) of the sample were women. The average age was 44 years, and ranged from 17 to 75. Half (50.7%) were aged 25–44 years, and one in four (22.8%) was aged 55 years or older. One-half (54.4%) had attained some primary schooling. Virtually every participant experienced HIV positivity amidst extreme material scarcity. Forty-four percent reported that they were single/never married, although many cohabitated with a sexual partner. However, conventional demographic categories such as ‘marital status’ mask the complex marital, familial, and sexual realities beneath these rubrics that impact individuals’ experiences of HIV/AIDS. One participant, for example, a 57-year-old woman, described her status as ‘single/unmarried’ and ‘separated.’ The multiphased marriage process in Swaziland that results in a woman’s patrilocal move to the groom’s homestead likely was never realized. We indexed her liminal marital status as single/unmarried.

Results and analysis

Integrating results reporting with analysis, as we undertake here, demonstrates the fundamentally interpretive endeavor that much medical anthropological research entails, especially of a phenomenological bent (Desjarlais and Throop 2011). We provide a descriptive analysis of structured responses in tandem with an applied thematic analysis of open-ended content, whereby analysis of “text [was] a proxy for experience” (Guest, MacQueen, and Namey 2012). Close iterative readings and manual coding of participants’ reports generated 32 codes (Table 1). These were inductively abstracted to seven main categories (Table 2), which accords with the three to eight main categories characteristic of general inductive studies (Thomas 2006).

A primary thematic finding was that Christianity constituted a distinctive resource for SHBC caregiver impact on clients’ subjective well-being. Semantic analysis of participant reports suggested that caregivers achieved this impact through three domains of HBC practices: they rendered conventional HIV/AIDS scripts both actionable and personally relevant, provided essential material and custodial assistance, and offered real-time support that is generally glossed in clinical and health-oriented literature as ‘psychosocial.’ Latent thematic analysis generated insights on how Christianity mediated the impact of each domain in ways that participants felt were integral to their well-being. We turn now to a thematic conceptualization of how religious mediation of bodies, relationships, and privations, instantiated between caregivers and clients, was believed to have this impact.

Embodying well-being

An overwhelming majority (92%) felt their health had improved since caregivers began visiting them. Across participant reports, caregivers’ ascribed authority to normalize an HIV status was instrumental to impact on participants’ well-being. Caregivers understand HIV-positive suffering, said one participant, and “encourage me to not kill myself as other HIV-positive people do.” Suicide prevention, and alleviating the suffering associated with suicidal ideation, emerged as critical, life-saving interventions. About half (53%) indicated that they would have died, a few from suicide, if caregivers had never come into their lives. For a 37-year-old man, ‘better health’ meant “I could live with HIV; I wouldn’t kill myself.” Creating safe spaces to express grief about an often frightening and isolating diagnosis, caregivers were sources of concrete health information and culturally relevant

Table 1. Selected Codes for Religious Mediation.

Category Codes
Keeps confidentiality better
“Tells the truth” about where to seek treatment
Has a “unique heart”
Instructs how to behave—moral disciplinary care
“Trust” because both are Christian
Caregiver power/love channeled from God
Qualities to “adopt” from Christian caregivers (aspirational)

Table 2. Thematic Analysis: Seven Main Categories.

Category Title	Description
Category 1: Stigma reduction	The role of HIV stigma and impact of stigma reduction by care supporters
Category 2: Comprehensive health impact	Caregivers provided material, psychosocial, physical relief
Category 3: Talk as intervention	Dialogue with caregivers transformed the meanings of being HIV positive and HIV health practices
Category 4: ‘Home-based’ HIV-positive experiences	Impact of caregivers’ modeling of ‘love’ on family care practices and PLWH experiences of ‘home’
Category 5: Self-care practices	Cultivating PLWH self-efficacy by enabling real time HIV healthy practices
Category 6: Caregiver limitations’	Frustration with material constraints
Category 7: Religious mediation	Christianity as a distinctive comprehensive resource for HIV/AIDS care

insight about how to build a new life in a severely resource constrained, high HIV stigma setting. Asked how she felt at the start of the interview, a 37-year-old participant, her infant against her breast, said she was feeling “so happy today.” However, “if the caregiver didn’t come to my house [that first time], I was ready to commit suicide, because I know the disease that I have is incurable.” The caregiver resuscitated her desire to live by explaining how “everyone is living with HIV. People are living, and they are going to live.” It was felt by some participants that discontinuance of SHBC services would pose a serious challenge to their survival.

Christians as truth tellers: Credible counsel and confidentiality

A large majority of participants (86%) viewed caregivers as both ‘health’ and ‘religious’ people, a finding that likely reflects the authors’ reductive, etic framing of health/sickness and religion as discrete, *sui generis* constructs. In their study of religion and health in Lesotho, researchers with ARHAP likewise found what they conceptualized as a failure of Western secular frames to achieve a “translation” between incommensurable epistemologies of religion/health: a failure, thus, to appreciate and incorporate “the reality” of persons whose healthworld arises from “socialized forms of knowledge linked to the full range of relevant action contexts that confront a human being in life” (Cochrane 2011:12).⁵ Asked to describe the religious aspects of care, a 63-year-old woman answered, “They greet me, pray, preach, and say continue [antiretrovirals].” Equipped with a Bible in their first aid backpacks, SHBC caregivers often enacted some religious care practice, in most instances reading aloud from the Bible and praying for and with the client. Most participants (77%) said their religious feelings had changed since a caregiver began visiting them, becoming more intense, which could manifest in more frequent church attendance and internalizing a sense of God’s love. And although a minority (15%) of participants said they themselves did not identify as Christian, nearly every participant felt it was important that caregivers be Christian.

Paramount to SHBC’s impact was participants’ construction of Christian caregivers as vigilant guardians of confidentiality and attribution of credibility to caregivers’ HIV/AIDS counseling. As a 43-year-old man explained, “(i)n our churches, there are HIV-positive people, so it is easier to preach the gospel of [HIV] testing if the caregiver is a Christian, because she’s also a believer.” This production of ontological sameness, a shared teleology toward well-being, infused participants’ healthworld as “a way of knowing and acting in the world that is intrinsically and holistically redemptive” (Germond and Cochrane 2010:310). Twinning religious support with treatment adherence counseling was fundamental to many participants’ SHBC perceptions of how caregivers enhanced their well-being. A 32-year-old woman felt “encouraged, because God helps me to not stop taking my pills.” Caregivers’ HIV-related communication was felt to be exceptionally clear, compassionate, and judgmental to the extent that caregivers ‘judged’ clients worthy of God’s love and therefore of antiretrovirals [ARVs].

In a setting marked by competing, pluralistic claims on the source of sickness and healing modalities, many participants felt Christian caregivers “tell the truth” about seeking HIV-related treatment at the clinic. Caregivers’ authority on HIV health practices derived significantly from their religious authority: “Whatever they teach me,” said one participant, “I believe it, especially when they say I should drink the tablets [ART] and that I must ask help from God to open the minds of doctors to give me the correct medicine.” Where other researchers have described “competing healthworlds” as sources of “collective wisdom” that individuals can draw upon (Fried et al. 2015:631), participant reports in our study suggested these competing healthworlds had to be strenuously navigated, and caregivers were instrumental in this effort. More than one in four (27%) participants said they had been “discouraged” from taking ART by friends, family members, or colleagues. Some were pressured to desist from ARV, told they were wrongly influenced by caregivers, and threatened with violence. In the face of marginalizing and stigmatizing pressures to desist from ARVs, participants’ ascription of medical and moral credibility to caregiver counsel was therefore felt to be especially important to well-being.

Christians don't have a "hard-hearted heart"

Participants' overwhelming preference for Christian caregivers was explicable less in terms of religious orthodoxy than because they were constructed as people who give credible health counsel, protect confidentiality, and have the "heart" to endure the ongoing tribulations HIV-positive clients face. "A Christian accepts you with the disease," said a 46-year-old woman, "(so that) person will understand my suffering." A 48-year-old woman explained how they "help me in all ways, spiritually and physically. If these caregivers were not Christian, I think I would be dead." A caregiver's Christian identity is important, explained a 31-year-old man, because "if a caregiver is a Christian, with the love of God, that person transfers the love of God to sick people." This material conveyance of Godly love was contrasted with non-Christians' lack of it: "If you are a Christian, you get the power to do all those (good) things from God. If you're not a Christian, you have a hard-hearted heart." Likewise, a 53-year-old male conferred upon caregivers a unique healing power that augmented ART. "We are getting help through the caregivers because of God's love," he said. "If God's love was not there, we would not have these caregivers."

Through their embodied and enacted 'love,' caregivers were often authoritatively positioned to thwart this life imperiling process at a site that clinic personnel could neither reach nor readily influence but which was all important: the home. Golomski has described the sociocentric and socioreligious *modus operandi* of 'love' in Swazi society: "Love is effected by, originates from, and is equivalent to God. Love facilitates sociality, be it between families, spouses, partners, neighbors, or members of the same church or organizations" (2011:7). Having a Christian 'heart' thus emerged as a culturally potent, indigenous competency that enabled caregivers to tend to clients' affective and bodily needs amidst entrenched HIV stigma and dire material constraints. Demonstrated in the presence of family members, caregivers' love for their client was an intangible care practice that could be direly consequential for the client's wellbeing, in part because the family (*umuti*) in Swazi society "is the primary agency for realizing and assuring [a person's] birthright to support and sustenance ... when he is ill or infirm" (Ngubane 1983:103). Without *umuti*, whether because of HIV stigma or because an individual is too unwell to contribute to homestead livelihood, personhood and well-being could be imperiled. In the lives of some participants, caregivers' 'heart' and its associated care practices, enacted in the public/private space of homesteads, appeared to reincorporate clients into that critical and culture-specific fold.

HIV stigma and the loss of legitimate personhood, suffered by many HIV-positive persons, meant restoring personhood was the first step in achieving HIV-healthy practices. The health impact of conjoining treatment counseling with religious care practices was evident in the report of a 48-year-old widow who explained how "my caregiver shares the word of God with me ... and encourages me to go on with my medications." Treatment adherence was construed and experienced by participants as a religious obligation as well as a 'health practice.' A 57-year-old woman described how religious intensification, expressed through prayer, facilitated ART adherence: "God, since you know that I am now HIV positive, help me to be perfect in taking my medications." Feeling "more religious" after a caregiver entered her life, a 32-year-old woman said, "I've raised myself a lot. ... I am encouraged because God helps me to not stop taking pills." To be deserving of love was to be deserving of life and therefore of medications.

A paramount feature of many participants' lives prior to caregivers' arrival was social isolation. However, in a setting where reciprocity is a key social and economic dynamic, social isolation was rarely only social. A 43-year-old woman described caregivers' unique and indispensable roles: "I think if there were no caregivers, I would die; I see the help I get from them. Without them, I would have to go to the police station and say, 'please take care of me, even if you must put me in prison as a prisoner, because I have no place to stay.'" Asked what would happen should the caregiver no longer visit, several participants said it would be "painful." A 42-year-old woman explained how caregivers' mobilization of religion in the project of self-care effectively "translated" for the authors how (our) parsing of religion and health risked missing the precise means by which caregivers

achieved their impact. Without SHBC caregivers, she explained, she would continue going to the clinic, “but I wouldn’t keep myself well. The caregiver helps and encourages me [through] Christianity.” The locus of health, and therefore of (ethically-framed) health practices, thus originated not in the singular individual but in relationships that shared the same goal of comprehensive well-being.

Moral authority: Reducing stigma and shaping HIV health practices

More than one in four (27.9%) participants sought HIV testing and nearly a third (31%) initiated ART after a caregiver began counseling them. Asked why it mattered whether caregivers were Christian, a 53-year-old woman answered, “Because we smoke the same pipe.” This cultural idiom captured the shared quality, a kind of ontological sameness that bound the caregiver with the participant in ways that deepened the impact of HIV/AIDS counseling. This “subject-subject response to illness or dysfunction,” wrote Germond and Cochrane, is “a *sine qua non*,” refracted in our study through church-run HBC that demonstrated the seamlessness of religious with health phenomena and epitomized the “coherent, organized patterns of interpretation that guide” health practices (2010:320). A 37-year-old woman explained that “there is nothing to adopt (learn) from a non-Christian caregiver,” and a Christian caregiver counselled that “no matter the disease, you must accept yourself as you are. When you take (ARVs), you must also accept Lord Jesus Christ as your Savior.” To accept Jesus was to simultaneously accept an HIV-positive *status* and one’s HIV-positive *self*; together, this trinity of Jesus, status and self restored to many participants a sense of personhood worthy of life and thus of ARVs.

In contrast with clinic staff and care point assistance (both very important), through home visitation SHBC caregivers accrued the necessary insights about an individual’s life to prevent suicidal ideation on an ongoing basis. Christian care practices figured substantially into this project. For a 56-year-old woman, a caregiver would ideally be Christian because HIV-positive individuals may feel discriminated against to the point where they may wish to end their lives. A Christian caregiver instructs that it is not right in front of God to kill yourself: “‘Just repent,’ the caregiver will say, ‘God is there.’” The despair that caregivers dissipated in this manner could profoundly influence participants’ and their families’ lives. A 42-year-old woman likewise felt it was important that a caregiver be Christian, because “I want to raise my kids, and the caregiver encourages me to refrain from killing myself as other HIV positive people do.” Caregivers convinced her that God loved her and suicide would be a sin.

Religious care practices were disciplinary in other ways believed to enhance well-being. A 48-year-old woman whose husband and son had died felt that caregivers’ religious moralizing was an important and desirable care practice. The caregiver “will help me when I’m going astray,” for example, if she sought traditional healing or perhaps a sexual partner. Her caregiver chided her, “No, a child of God doesn’t do this.” A 42-year-old woman likewise said that she and her caregiver discussed adopting new behaviors. Asked what behaviors, she explained, “A person on ARVs must be a Christian and must not roam around, because you are HIV positive. You must change your behavior because God likes people who respect themselves.” Such moralizing tones would discomfort many ‘Western’ health professionals for whom secularity is a precondition for effective health programming. However, in our study, HIV health practices inhered in ‘moral’ adherence in such a way that each domain, the biomedical and the religious, exercised respective disciplinary imperatives that participants felt helped them.

Religious moralism in our study was thus experienced less as judgmental dictates than a form of desirable “moral formation” (ARHAP 2006:78), an intangible asset manifest as a shared wisdom that restored participants’ sense of “moral agency” (ARHAP 2006:75). Prince and colleagues have likewise written that it is important to explore “the disciplining and the liberating potential of Christianity in these contexts” (2009:xiii). Repentance, for example, was often experienced among some participants as a portal to legitimate personhood and social incorporation that trumped others’ stigmatizing

judgment: “If you have the disease, the word of God encourages you, because God still loves you,” explained a 47-year-old woman. Christian SHBC discourses enabled an ontological sameness not only between caregiver and client, but between the HIV-positive and HIV-negative person as well. Asked how it felt to be encouraged by his caregiver to repent, a participant said it made him feel “very happy—I feel I am just the same, like any other person; there is no stigma.” In his mind, “I just forgave myself, and said, ‘no, I am just the same as others.’” The notion that repentance could be lifesaving is especially noteworthy to a secular audience, given its ‘outside’ connotations as a conservative discourse that overwhelmingly blames and shames. In contrast, participants described Christian care scripts that sourced an HIV-positive personhood infused with self-worth using moralizing language that discomfort conventional health researchers, in part because such moralizing has, at times, had nefarious effects, especially with respect to fueling HIV stigma. However, our study findings corroborate ARHAP studies in Zambia and Lesotho that likewise found home-based care groups “to do well” in moral domains of study participants (ARHAP 2006:95).

Discussion

Anthropological discourses of religion vis-à-vis HIV/AIDS have been, at times, curiously dismissive of its complex semiotics and institutional significance, assuming instead political/polemical positions that flatten experiences of risk, gender, and sickness across cultural milieus (e.g., Schoepf 1995; Susser 2009). To be sure, religious responses have often undermined HIV/AIDS interventions with a ‘blame and shame’ attitude (Campbell, Skovdal, and Gibbs 2011) that reifies “sexual morality . . . at the expense of other pressing issues” (Bongmba and Cochrane 2007:3). An ethnographic literature has emerged over the past decade, however, that theorizes these dynamics in ways resonant of anthropology’s longstanding focus on religious collectivities, beliefs, and practices, and that integrates critical readings of biomedicine, neoliberalism, and globalization (Dilger, Burchardt, and van Dijk 2010; Dilger and Luig 2010). Studies of new communal formations and national HIV/AIDS policies in Uganda (Gusman 2009), ontological insecurities and “strategies of action” among HIV-positive women in South Africa (Burchardt 2010), and the transnational production of confessional technologies and “therapeutic evangelism” in Burkina Faso (Nguyen 2009), reflect this emerging ethnographic exegesis of the frictions that inhere in globalizing flows of capital, people, disease, and discourses, both biomedical and religious.

To contribute to this expanding literature, our study was designed to explore subjective experiences of church-run home-based care among people with HIV in rural Swaziland. Drawing on phenomenological approaches in medical anthropology that examine the ways “distress is experienced and expressed through the body in everyday life” (Becker 2004:126), we queried how it feels to HIV-positive individuals to participate in church-run HBC in a high vulnerability, high HIV stigma setting. Embodiment was a productive heuristic because it “poses additional questions about religious experience” (Csordas 1990:40). The notion that some religious discourses may have “‘better words’ (for) questions of corporeality and finitude, person and individuality” (Germond and Cochrane 2010:319) than biomedicine was evident in participants’ descriptions of caregivers’ counsel as something more than mere health counseling; for many participants; it felt life envisioning. Klaitis found in Botswana that “religious languages help authorize particular understandings of responsibility, subjectivity, and intersubjectivity” that informed potent forms of HIV-related care and “love” through prayer (2009:4). It may be that SHBC’s impact was thus largely attributable to the ways that shared Christian ethos, identities, and practices were described as restoring a sense of legitimate personhood to HIV-positive individuals. This legitimate self was empowered to act upon the(ir) body, specifically by taking up caregivers’ counseling to seek testing, adhere to treatment, and, as appropriate, disclose an HIV-positive status.

Prince and colleagues have examined the colonial histories of religious-based health services in Africa that continue, in various organizational and institutional modes, to the present, observing also how HIV/AIDS “is contributing to the popularity of Christian values in public life: values of love,

brotherhood, equality, and honesty, which, while not specific to Christianity” offer a means of transcending public perceptions of an “increasingly immoral public sphere” (2009:ix). The articulation of these values and their structuring of identities, social relationships, and institutions in many regions of Africa have inspired new frameworks for comparative study of their significance for health and sickness. The concepts of religious health assets (RHA) and healthworlds were central in our study to explicate the social production and significance of religious-based HBC in participants’ lives. Intangible RHA resided in SHBC’s cultural capital, both its tangible (human) resources—caregivers and compassionate care—and the discursive and nondiscursive ways in which they interpolated biomedical with religious-based care practices in ways that informed new HIV subjectivities (Burchardt et al. 2009). Similarly, ARHAP studies in Zambia and Lesotho found that “spiritual (Christian) encouragement (was) perceived by far to be the strongest contribution of religion to health and wellbeing (and included) hope, faith, prayer, and trust and builds resilience and inner strength to deal with the health crisis in which people find themselves” (ARHAP 2006:126). The second most important contribution to health and well-being in the ARHAP study was “compassionate care,” a feature that was foremost in our study as well, and framed (ethically) in religious terms.

In many ways, SHBC functioned as a “regulator of hope” (Masquillier et al. 2014:1) in a profoundly potent configuration of participants’ lifeworlds—the home. It was ‘here’ that caregivers strengthened treatment uptake and adherence, and in so doing demonstrated a specific teleology whereby, according to Germond and Cochrane, the “healthworld is linked to agency governed by an interest in restoring, maintaining or increasing health; it is the framework that directs health-seeking behaviour” (2010:310). As households are “conventional sites for the social reproduction of Swazi persons” (Golomski 2011:5), home risks becoming, through abandonment and alienation of PLWH, of their exclusion and devaluation, the primary site wherein the social destruction of Swazi personhood may also be experienced; this risk is arguably why home-based care is so consequential to PLWH well-being. SHBC operated ‘here,’ at the pulse of experiences of self/other and sickness/wellness, in participants’ lifeworlds. In her classic ethnographic of Swaziland, Kuper described the organizing principle of Swazi personhood, writing that a “(Swazi) person is a meeting point of identities—the identity of siblings, the identity of lineage, the identity of the age group” (1986 [1963]:59). Personhood derives, as well, from an individual’s ability to fulfill affective, material, and ritual obligations to family, living and deceased (Golomski 2013:39). With improved health came restored physical strength and the capacity to contribute to household wellbeing, a *sine qua non* for legitimate personhood.

The potent health impact attributed to SHBC caregivers can be explained, thus, by the ways in which moral experience is “emergent in everyday life if, and perhaps only if, it is supported by cultural concepts of the person that make people ‘present’ to each other in particular ways” (Parish 2014:33). At the heart of caregivers’ and participants’ recovery enterprise was a specific “relationality” (Cochrane 2011:9). By speaking with and touching the client (“becoming the hands and feet of Christ”), these relational, embodied, metaphoric encounters emerged as the locus/nexus of new meanings tied to empathy, sociality, ontology, sickness, and resilience. Theorizing the body as the nexus and locus of emergent meanings of HIV/AIDS and religion contrasts with secular HIV messaging that, grounded in a particular rationality, may be less resonant.

The metaphor of a Christian client and a Christian caregiver smoking “the same pipe” suggested an additional reading of the interpolation between religion and health. Drawing on the ARHAP primarily Lesotho-based study of religion and health, ARHAP researchers found that their etic ‘block of meaning’ (the divisibility of health and religion) was subverted by an authoritative, emic block: the indivisibility of self and others/ancestors/natural world, of health and religion in sickness, a shared *telos* of religious/health processes toward comprehensive well-being, and the intrinsic indispensability of social relationality to healing and well-being (2011:9-10). The benefits of these practices are attributable a “subject-subject response to illness” (Germond and Cochrane 2010:320), predicated on

the availability of reliable and affordable treatment, and specific forms of communicative action entailed in religious-based home-based care and HIV/AIDS counseling.

Caregivers' embodied enactment of this relationality was effected through Christian discourse, doctrine, and disposition that transformed the meanings and experiences not only of HIV subjectivities but of religious morality: to be moral was to care for HIV-positive persons, and to care for PLWH was a moral as well as health-supporting practice. Moral experience, writes Parish, is generated in the "space between persons" (2014:33). In this study, that space was constituted by relationships between caregivers and clients through HIV care practices with substantial religious valence. Csordas' theorizing of "care as essential to the moral domain" (2014:139) provides one reading of these insights: religious talk, HIV-health practices, and restored strength constituted a moral experience for most participants. To adhere to treatment (health practice) was also a religious imperative that, if heeded, helped to restore a moral personhood.

Church-run CHBC functioned thus as a specific horizon of action that, like the ARHAP study in Lesotho, pointed to specific "fundamental features of those dimensions of human experience we (biomedically oriented health professionals) label religion and health, although without any implied dualism" (Cochrane 2011:12). Whereas HIV stigma, expressed and felt through pejorative words, physical separation, and marginalizing practices, violently disarticulated the moral person from the HIV-infected body, Christian-derived care scripts and practices appeared to collapse this dualism in transformative ways, showing how embodiment "really does advance our understanding of a particular practice [and of] how practices are related among themselves" (Csordas 1990:28). The transformative, mutually reinforcing practices in this instance may be understood as two secularly constructed epistemic frames, religious and health-related.

Conclusion

Our aim has been to demonstrate how experiences of religious home-based care must be understood in the context of cultural notions of personhood, relationships, and well-being, and in settings marked by unrelenting poverty, entrenched gender inequalities, and pervasive HIV stigma (Shamos, Hartwig, and Zindela 2009). In rural Swaziland, SHBC caregivers were described as founts of unconditional love, limited material support, vital HIV/AIDS education, and anti-HIV stigma sentiments whose discourse was discursively Christian. By sourcing new forms of moral personhood that legitimated PLWH in the eyes of HIV-positive home-based clients themselves as well as family members, these discourses and associated care practices constituted a religious subjectivity that empowered many participants to access health services in ways they previously had not. The immanence of religion and biomedicine to HIV-positive experiences in these examples, and of biomedicine to religion, showed up some of the limitations of Western, secular behavior change interventions that fail to appeal to, or to heal, the broken and exhausted hearts and bodies in empirical, culturally relevant, and health-enhancing ways.

In light of the global health politics that have long surrounded religion and HIV/AIDS at the policy/program level, a phenomenological approach framed within the explanatory concept of a 'healthworld' demonstrated the critically important ways that religious discourses restored, invigorated, and advanced the perceived well-being of many participants. 'Better health' was experienced as a dynamic cultural and phenomenological enterprise. Fusing the sick self with a discursive belief in Jesus' 'unconditional love,' caregivers, by their physical presence in participants' lives, embodied SHBC's ethos to be "the hands and feet of Christ" and, as such, articulated a new personhood for their clients, one worthy of a religious-framed love and therefore of ART. We theorized this embodied mediation in part to nuance the zero-sum analysis of religion and science that has often dominated global health debates (when it is discussed at all); we did this by describing the embodied synergies of bio-scientific and socio-religious discourses in people's lives.

The concept of the healthworld is not devoid of structural concerns, such as lack of access to and availability of reliable treatment. Rather, in positing the notion that illness and well-being are socially

constituted phenomena, the concept of healthworlds foregrounds for researchers a cognizance of how ideal care pathways must integrate the representations of illness/religion of its intended beneficiaries, and vice versa, as well as why such pathways might be interrupted (Fried et al. 2015:629). Ironson and colleagues (2002) found enhanced health among PLWH who demonstrated high religiosity and spirituality. Similarly, the religious and biomedical operated among our participants not as two mutually exclusive epistemologies; rather, they synergistically enabled restoration of a self-worth living through sustained HIV care practices. This distinction between a religious-mediated self deserving of biomedical treatment points up the ill-fitting etic framing of these experiences as separate, whereas here we found they are intrinsically, mutually constituted.

Clearly, further comparative research is needed to examine the experiences, operations, and impact of various religious and non-religious health entities in their mediation of health, self, and sociality. Such a project would both advance medical phenomenological studies of moral experience, sickness/health, self/sociality, and inform applied understandings of new modes of citizenship and social capital in settings of worsening vulnerabilities. Echoing oft-stated recommendations for strengthening community health services in Swaziland (Escott and Walley 2005) and elsewhere, properly scaled linkages between CHBC and other health services are both lacking and essential; these are dire deficiencies given concerns over further burdening women with task-shifting and if CHBC is to be a centerpiece of global and national health agendas. A more thoroughgoing understanding of these conceptual, institutional, and experiential axes is essential not only for theorizing anthropological epistemologies of religion/health and the ontological significance of CHBC for people living with HIV, but to conserving the vital and vulnerable human capital that caregivers, who may also have HIV, constitute throughout Africa.

Note

1. The Dutch Reformed Church (DRC) in South Africa was founded by Dutch missionaries in South Africa in the late seventeenth century. In 1945, the DRC established a missionary outpost in Swaziland that, over time, became indigenized as the Swaziland Reformed Church. The Swazi denomination has more than 2000 members regularly meeting in homes and church buildings.

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Notes on contributors

Robin Root, MPH, PhD is professor of Anthropology, Department of Sociology & Anthropology, Baruch College, City University of New York, and a medical anthropologist who has explored social aspects of HIV/AIDS in Swaziland since 2005.

Arnau Van Wyngaard, PhD, has been a missionary pastor in Swaziland for the past 30 years and published extensively on theologies of HIV/AIDS. He is a research associate, Department of Science of Religion and Missiology, University of Pretoria, and CEO of Shiselweni Home-Based Care.

Alan Whiteside, OBE, DEcon, was brought up in Swaziland and has been engaged in economic analysis and HIV research for over 30 years. He is the founder and former director of Health Economics and HIV/AIDS Research, University of KwaZulu-Natal, and CIGI Chair in Global Health Policy, Balsillie School of International Affairs, Canada.

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