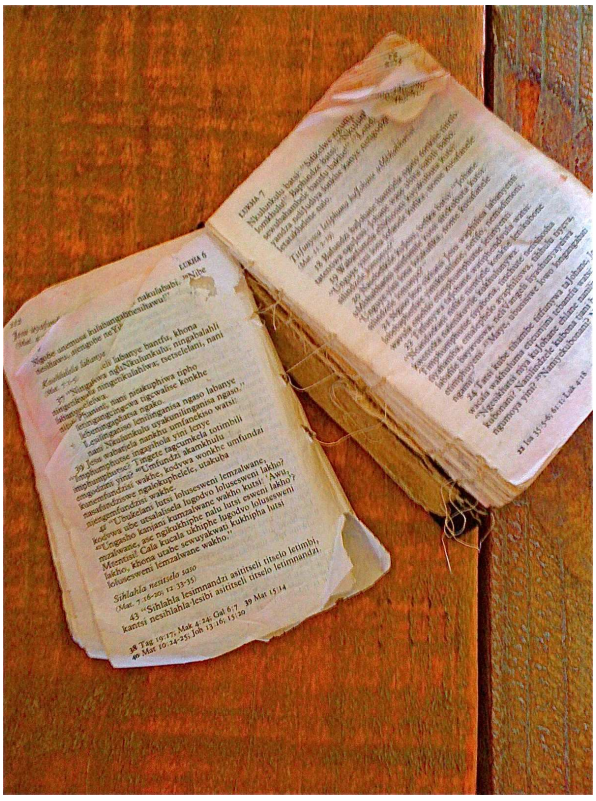
"That's When Life Changed":
Client Experiences of Church Run Home-based HIV/AIDS Care in Swaziland



A report for the Health Economics and HIV/AIDS Division (HEARD)

Prepared by Robin Root, MPH, PhD

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"That's when life changed":
Client experiences of church run home-based HIV/AIDS care in Swaziland

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I. Executive Summary

Oppositional rhetoric, frames of reference, and politics have long characterized religion and HIV/AIDS at the policy and programmatic levels (Toefy 2009:248). However, a substantive literature has emerged in recent years that describes and theorizes the complexity of religious responses to the epidemic, especially with respect to Africa. In addition, an increasing number of studies has shown the potential effectiveness of home-based care to help mitigate the impact of the epidemic in multiple ways. In light of these two research streams, the objectives of the current study were two-fold. First, it sought to investigate the impact of a church run home-based care organization on the perceived wellbeing of its HIV positive clients (PLWH) in Swaziland, site of the world's highest HIV prevalence and where Christianity is a salient feature of social life. Second, in examining the significance of caregivers' affiliation to the Christian organization's HIV/AIDS care practices, it seeks to explain some of the mechanisms of that impact. Conceptually, the project was designed to explore in what ways 'home' and 'church'[3] may be vital public health settings outside of, but integral to, a continuum of care that advances national and international HIV/AIDS and other public health objectives.

In many parts of the world, 'home' is ground zero of 'being' HIV positive. Home is where stigma and/or support are manifest and where health-related decisions often are rendered. As a result, any 'intervention' inside such a space has the potential to be transformative of the individual who is afflicted and his or her kin. Church congregations, conceptualized in this report as social collectivities led by religious leaders who often carry substantial moral and other forms of authority, are, like 'home,' potent places in which to experience an HIV positive status. Yet, "very little empirical evidence exists on how religion intersects with other processes to impact on the dynamics of HIV/AID behavior (Toefy 2009:237). Nor is there much research on the intersection of religion and home-based HIV/AIDS care, despite the longstanding involvement of faith-based entities in providing HIV/AIDS care (Agadjanian *et al*. 2007). Thus, home and church intersected in this study in the form of church run home-based HIV/AIDS care. The 'lived intersection' was the client-caregiver relationship.

Given the dearth of research on these dimensions of HIV/AIDS, inductive qualitative inquiry (Schatz 2003; Thorne 2000) provided the primary methodological approach in this study, since "an inductive research design favours emergent research processes, and is based on the premise that the patterns and themes that emerge from the literature and interviews will form the basis for

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[3] In this report, the term 'church' refers to a social collectivity, akin but not equivalent to local congregation, that coheres by virtue of members' religious faith or affiliation. This usage contrasts with that used by the African Religious Health Assets Programme, whereby "the term has occasionally been used to indicate Christian denominational structures at a regional/national/international level" (ARHAP, Appreciating Assets, 2006: 38-39).

further knowledge-building" (Clark *et al*. 2010:11). The study's key concept, 'PLWH experiences of church run home-based care,' was operationalized in terms of the following variables: PLWH critical needs, social networks for meeting those needs, perceptions of caregiver practices, HIV/AIDS communication with caregivers, family reactions to the caregiver, personal religiosity, and assessment of the significance of being a Christian to HIV/AIDS caregiving. A semi-structured, face-to-face questionnaire was conducted with 79 individuals in 11 communities served by the case organization[4] in Shiselweni, Swaziland. Purposive sampling criteria were that participants be a current client of the case organization and have been diagnosed with HIV. Structured responses provided the descriptive statistics that helped sketch the basic outline of participants' experiences of church run home-based care. Constant comparative analysis of open-ended responses generated the deeper thematic categories that helped to discern key patterns in participant experiences.

Overall, findings suggested that caregivers' impact was often life-saving and life-preserving in ways that have been little examined in the social scientific and public health literature. A major finding was that an estimated **53% of participants indicated that they would have died, a few from suicide, if the care supporters had never come into their lives**. Were caregiver services to be discontinued, about a quarter of participants felt they had acquired sufficient self-care skills to continue on their own, but a majority reported that it would be "painful" to no longer have the organization's caregivers in their lives. For some, it was felt that discontinuance would pose a serious challenge to their survival. Three categories of life-saving and life-preserving interventions emerged from the analysis to help explain this critical significance. Caregivers rendered the scripted HIV/AIDS information of mass campaigns both actionable and personally relevant; they provided essential material and custodial assistance; and caregivers offered ongoing educational and psychosocial support in various religious and non-religious forms that supported antiretroviral treatment (ART) adherence. Importantly, 92% of participants felt their health had improved ('better health') as a result of caregiver involvement in their lives.

Heeding the HEARD call for investigation of factors that may impede ART uptake and adherence, participant reports of the social pressures they faced to desist from their antiretroviral regimen highlighted the importance of community home-based caregivers to reduce barriers to uptake and embolden individuals' decisions to adhere to their prescribed ARV regimens. **Nearly 30% sought HIV testing and initiated ART <u>after</u> the caregiver intervention.** Caregivers were involved in the HIV disclosure decisions of approximately 25% of participants. Caregivers' roles in assisting participants to adhere to antiretrovirals (ARVs) regimens were absolutely vital. ART support was an arguably radical activity, given the 27% who reported that they had been discouraged from taking ARVs by family members or others in their community.

Participants were often resolute in their conviction that a caregiver would ideally be a Christian. This preference was less for ideological reasons than because a Christian caregiver was constructed as someone who gives credible health counsel, protects confidentiality, and has the "heart" to endure the ongoing tribulations PLWH face. Moreover, because of the moral authority that (good) Christians are endowed with, caregivers' compassionate treatment of participants helped, in some cases, to transform family relations by reducing stigma and encouraging a new mode of HIV positive personhood. Among some, a renewed sense of legitimate personhood facilitated ART adherence. The caregiver relationship was, in effect, the intervention, one in which all range of difficulties could be discussed, and possibly resolved, in real-time. This real-time aspect of home-based care contrasted with episodic (but equally vital) clinic visits that were inadequate to the chronically acute stresses of participants' daily lives.

This client-caregiver relationship can be said to have been successful in part because it leveraged both tangible and intangible religious health assets (RHA) in ways that maximized

[4] The Shiselweni Reformed Church Home-based Care group is a registered non-profit organization in South Africa and Swaziland.

social, material, and clinical resources. Tangible RHA included the "material support and health provision" caregivers offered, and intangible RHA, the "spiritual encouragement, knowledge giving and moral formation" (African Religious Health Assets Programme [ARHAP] 2006:3). RHA seemed to be not only productive but indispensable to the lives of participants. In an epidemiological setting of extremely high HIV and TB prevalence, gender violence, and poverty, religious dictates that, to an outsider, may appear 'conservative' and therefore antithetical to HIV/AIDS programming, became, in a sense, 'progressive,' since care supporters were often viewed as fonts of material and psychosocial support, HIV/AIDS knowledge, and anti-HIV stigma action.

While the categories 'biomedical' and 'socio-religious' functioned in this study as productive analytic constructs, participant reports of being HIV positive and of receiving church run home-based care demonstrated the warp and weft of multiple influences on wellbeing and survival. Rather than the result of one intervention, 'better health' emerged as an ongoing enterprise; an enterprise at the heart of which was the dynamic interpolation of clinical medicine with locale-specific phenomena, including religion, kinship, gender relations, and economics, all of which caregivers reportedly navigated to help enhance participants' wellbeing. As a result, study findings suggested potentially innovative modes of HIV prevention, treatment, and stigma reduction that have been little explored, most notably the distinctive and substantive roles that Christianity often appeared to play in the care relationship, thus affecting HIV health-seeking practices, household and family relations, and a positive HIV positive personhood, where before discrimination and despair may have prevailed.

Findings suggested three interrelated domains for future research and programming.

At the individual client and caregiver level:

- In order to maximize human and material resources, are there core self-efficacy skills that clients (PLWH) need and that that caregivers could help to cultivate, beyond which the clients could manage their HIV status without the caregiver?
- How are individuals who become caregivers, by choice or necessity, to be supported and/or compensated?

At the family/household level:

- To what extent do the information and compassion extended by caregivers have a ripple effect on families and households? For example, caregivers in this study helped some participants to disclose their HIV status and were able to influence the HIV testing decisions of at least three clients' husbands. In addition:
  - Does caregiver involvement in clients' lives socialize clients' children into health-enabling HIV practices as well as encourage positive attitudes towards PLWH, for example, vis-à-vis HIV positive children at school?
- To what extent are men currently involved in the "care economy" and what home-based care roles might they play?

At the community/national level:

- In what ways might new religious-based organizations (as opposed to 'legacy' missionary health systems), such as the one profiled in this report, be linked to Swaziland's national plans to decentralize and integrate health services?
- Are there productive linkages to be forged with the informal health sector (indigenous healers, pharmacists (often Chinese), chemists, herbalists, prayer healers), as well? Doing so could help to dispel the confusion and misinformation that fuels HIV denialism and discourages ARV adherence.

The report concludes that the organization's care supporters are innovatively advancing Swazi government and donor aims of improving PLWH life expectancy and quality of life, thus also addressing the challenges of the country's escalating orphan and vulnerable children (OVC) rate. At the same time, like so many grassroots entities, especially those that are volunteer based, the organization faces material and human resource challenges. One challenge is the attrition of some care supporters to better resourced foreign and international organizations that provide monetary compensation for caregiver work and a degree of symbolic capital, or status, that volunteer work does not always carry.

In the short term, two "low hanging fruit" that the SHBC might reach for include strengthening linkages with nearby clinics and health centers. Formalized resource sharing and knowledge exchange between nurses (or other appropriate health personnel) and care supporters might serve to alert nurses to the real-time challenges patients face, whereas nurses could apprise caregivers of changes, for example, in HIV testing methods or treatment protocols. Linkages with national HIV/AIDS support organizations, such as the Swaziland National Network for PLWHA (SWANNEPHA) and Swaziland for Positive Living (SWAPOL), could also prove beneficial, as these would allow for cross-fertilization of support mechanisms for individuals of diverse religious and non-religious identification.

II. Introduction

A. Swaziland: An 'exceptional' situation in need of 'exceptional' initiatives

Facing financial collapse, closure of its national school system, and a shrinking inventory of vital medications, including antiretroviral therapies for HIV/AIDS, on August 3, 2011 the Kingdom of Swaziland [Appendix A] made plans to receive an emergency loan of $368 million from the South African government (Agence France-Press 2011). However, as of early September, no payments had been made (Reuters 2011). Currently, economic poverty, poor governance, and inadequate health infrastructure threaten to undermine the very foundations of Swazi society: the family, the monarchy, and the nation. With a daily mortality rate that exceeds threshold indicators used to categorize disasters, Swaziland represents what experts have called a new form of emergency and humanitarian crisis (Whiteside *et al.* 2007). HIV/AIDS is a key factor in this crisis equation, and as such, constitutes an 'exceptional disease' (Piot 2005; Montaner 2006). This exceptionalism is attributable not only to Swaziland's high HIV infection rates, but to the epidemic's multisectoral drivers and impact, starkly unequal distribution, and attendant loss of human life and capital (Smith *et al.* 2010). This is the 'long wave' impact of HIV/AIDS that policies and programs must now address.

Of an estimated total population of 1,018,449 in Swaziland (UNAIDS 2010), approximately 20% (202,948) are projected to be HIV positive by the year 2012 (Tsela *et al.* 2007). The epidemiology of the epidemic reflects the fault lines of economic inequality, where a majority (69%) of the population endeavors to survive below the national poverty line, and gender inequalities that likely exacerbate women's vulnerabilities (Whiteside *et al.* 2006). Between the ages of 15-19, HIV prevalence is considerably higher in females (31%) than in males (20%), and women's infection rates peak a decade earlier than men's, between ages 25-29 (49%) and ages 35-39 (45%), respectively (Central Statistical Office 2008). Other alarming statistics, including the 41% of children categorized as orphaned or vulnerable and a precipitous decline in life expectancy since the 1990s to 47 years, in 2009 (World Health Organization [WHO] 2011), have been circulated so widely in 'health and development' networks, and even some mainstream publications, that the tragedy of HIV/AIDS has become nearly synonymous with Swaziland itself.

In response to this worsening scenario, the Swazi government introduced a National Strategic Framework (NSF) in 2009 to reduce HIV incidence, promote safer sex, improve PLWH quality of life, and assist households to cope with the impact of the epidemic (UNAIDS 2010:3). That same year, Swaziland secured a Partnership Framework with the United States government through the President's Emergency Plan for AIDS Relief (PEPFAR). "[I]mproving and decentralizing the quality of treatment and care" is one of five priority areas (PEPFAR November 2010:60). The plan also aims to integrate a continuum of HIV services by "bringing together Swazi communities and diverse health and social welfare services" (PEPFAR June 2009:3). On the multilateral front, the World Health Organization's *Global Health Sector Strategy on HIV/AIDS 2011-2015* has stated its goal to "catalyse" a continuum of HIV diagnosis, treatment, care and support. Community and home-based care is identified, as it has been elsewhere, as an integral feature of this continuum, "essential for the delivery of integrated, decentralized services, expanding national HIV responses and improving health outcomes" (WHO 2011:14).

However, in light of the cataclysmic and likely permanent declines in government revenues resulting from revisions in the Southern African Customs Union (SACU) revenue sharing formula, it is unclear how the WHO's catalytic aims will be achieved without substantial foreign donor support, governance reforms, and innovations in the organization and delivery of comprehensive HIV/AIDS and TB services. One such innovation may come from the faith-based sector[5] (Vitillo 2009), which, elsewhere in sub-Saharan Africa, reportedly delivers more than 40% of health care services for the rural poor (Lee 2003, in Miller and Rubin 2007:588). In Swaziland,

[5] A faith-based organization has been defined as "a general term used to refer to religious and religious-based organizations, places of religious worship or congregations, specialized religious institutions, and registered and unregistered non-profit institutions that have religious character or missions." (Woldehanna, S. *et al.* 2005:27).

with approximately one local congregation per 183 individuals versus an estimated one HIV testing and counseling center (HTC) per 6,180, the institutional embeddedness of diverse religious entities indicates the potential for untapped resources that may help to achieve selected NSF and WHO policy objectives.

B. The current study

This report describes findings from a case study of a church-run community home-based care organization, Shiselweni Reformed Church Home-based Care (SHBC), in the southern district of Shiselweni, Swaziland [Appendix B]. The objectives of the study were two-fold. First, it sought to investigate the impact of the organization on the perceived wellbeing of its HIV positive clients. Second, in examining the significance of caregivers' Christian affiliation to client experiences of the organization's HIV/AIDS care practices, it seeks to explain some of the mechanisms of that impact. Conceptually, the project was designed to explore in what ways 'home' and 'church'[6] may be vital public health settings outside of, but integral to, formal health services infrastructure. In doing so, it aims to address the dilemma that "very little empirical evidence exists on how religion intersects with other processes to impact on the dynamics of HIV/AID behavior" (Toefy 2009:237). The report thus is intended to contribute to an expanding literature on home-based HIV/AIDS care by incorporating religious health assets (RHA) into its analysis. RHA is an emergent concept that helps to theorize the complex roles that religion plays in mediating sickness and health, in part by identifying the tangible and intangible assets that religious entities bring to the public health enterprise (African Religious Health Assets Programme [ARHAP] 2006).

The report is informed by the principal investigators' published research on the same organization, which examined church run home-based care from the perspectives of the caregivers themselves (Root and Van Wyngaard 2011). It also builds upon the Health Economics and HIV/AIDS Research Division's (HEARD) annotated bibliography of HIV/AIDS care, which highlighted as one of several key domains in need of further research, the importance of better understanding the impact of antiretroviral treatment on the "changing nature of care" (Gibbs *et al*. 2010).

[6] For the purposes of this report, the term 'church' refers to a social collectivity, akin but not equivalent to local congregation, that coheres by virtue of members' religious faith or affiliation. Such usage contrasts with that used by the African Religious Health Assets Programme, whereby "the term [church] has occasionally been used to indicate Christian denominational structures at a regional/national/international level" (ARHAP, Appreciating Assets, 2006: 38-39).

III. Background

A. Home-based HIV/AIDS care

In light of diminished HIV/AIDS funding in many parts of the world, identifying and strengthening innovative mechanisms of treatment support, and combining them with HIV prevention, have never been more critical (Weidle *et al.* 2006). Community home-based care (CHBC) may be uniquely situated to provide a portion of these services and is a core feature of the World Bank's Multi-Country HIV/AIDS Program (MAP) for Africa. Yet key questions concern which services CHBC may be ideally suited to deliver, especially in resource limited settings (WHO 2002). As a category of service, **home-based care** (HBC) varies depending on the "delivery scheme, mix of services, staff and reach" (Mohammad *et al.* 2005:2). **Community** home-based care generally refers to integrated, informal, or single service models (Uys 2003:5). Within this taxonomy, **church-run** community home-based care is often a form of single service, volunteer run operation (Van Dyk 2005:262 summarized in Mulenga 2007:111-112). One hallmark of such an entity would, according to Mulenga, be caregivers' shared scriptural ethos of empathic engagement with PLWH's suffering (2007:17, 120-121).

The Gaborone Declaration on Community Home-based Care provides an operational definition of CHBC as "care given to an individual in their own natural environment by their families and supported by skilled social welfare officers and communities to meet spiritual, material and psychosocial needs" (Health & Development Networks 2001:15). However, critiquing the vagueness of the term 'care' as it is often used in policy and programming lexica, the International Center for Research on Women (ICRW) has conceptualized 'care' both more broadly and in greater detail. Care "refer[s] to the full range of activities undertaken by family members in the home, including psychosocial support (emotional and spiritual), custodial care (cooking, cleaning, feeding, helping with toilet needs, etc.), and the ministration of remedies and treatments, and those more subtle elements such as love and 'healing" (Ogden *et al.* 2004:3). Rather than focus on the care provided by family members, though, this study focuses on care provided by care givers who, for the most part, did not reside in the same household as the afflicted person.

However, despite the urgency for innovative strategies and the potential of CHBC (Olenja 1999) to deliver selected HIV services, little is known of the operational challenges and limitations such groups face (Mohammad *et al*. 2005). Allied heath (nursing) studies are perhaps the most significant, though not exclusive, source of scholarly insight on CHBC. Published data suggest that CHBC may substantially strengthen adherence and responses to ART in rural, resource limited settings, especially where transportation to a health center is an intractable obstacle to adherence (Weidle *et al.* 2006). Studies have indicated the potential effectiveness of integrating community home-based care into a health services continuum to improve treatment adherence in remote rural areas (Shaibu 2006; Ncama 2007; Apondi *et al*. 2007). CHBC may also be effective in providing palliative relief from the physical pain of HIV-related cancers and tending to the psychosocial and spiritual challenges patients and their families face (Sepulveda *et al.* 2003); agony on a macro scale that, fortunately, is no longer a paramount feature of HIV/AIDS infection in better resourced countries.

Amidst hopes that home-based care might alleviate considerable HIV-related suffering, a number of scholars have expressed concerns, arguing that home-based care and volunteerism are inadequate substitutes for building effective health systems (Avert 2011). Also, because home-based care involves tasks that are associated with culturally constructed gender roles, HBC initiatives risk exploiting an already vulnerable, overburdened, and unremunerated demographic: girls, women, and the elderly (UNAIDS 2006; Akintola 2004; Lindsey *et al.* 2003). The notion of a "care economy" as the provision of "fundamental public goods" has focused policy critiques on disturbing trends in some international and national HIV/AIDS policies that divest governments and other actors of their mandate to develop effective programs, where "simply downloading responsibility for care onto women, families and communities can no longer be a viable, appropriate or sustainable response" (Ogden *et al.* 2006:333; George 2008). UNAIDS has reported concern over the compounding care burden many women shoulder as a result of poorly conceived development strategies:

> [P]overty reduction strategies and national AIDS plans seldom take women's caregiving into account. In developing nations, poverty and the privatization of public services have combined with AIDS to turn women's care burden into a crisis with far-reaching social, health and economic consequences. (Erb-Leoncavallo *et al.* 2004)

Concerns, thus, are that policy reification of home-based care runs the risk of devolving substantive HIV/AIDS care onto already distressed households (Heymann *et al.* 2009; Ogden *et al.* 2006; Avert 2011).

One of the challenges of navigating the opportunities and concerns that home-based care presents is the fact that homesteads, as extended family compounds, are central to the social organization of relatedness in many parts of Africa. They are therefore integral to experiences of 'being' HIV positive. This means that medication regimens laid out at the clinic must be translated into individuals' daily practices upon return home, if interventions are to have their desired impact. This 'translation,' however, is often possible only if individuals on the patient's homestead are willing and able "to care" for the afflicted individual. The benefits of directly observed therapy (DOT) for PLWH in sub-Saharan Africa have been reported in the clinical literature:

> Indeed, in settings with high HIV status disclosure rates, community based DOT-ART with a patient nominated treatment *accompagnateur* or supporter [cites] has been reported to be feasible and helps to improve or maintain high levels of ART adherence. (Mills *et al.* 2006:688)

In this light, 'home' becomes the primary physical and social space where PLWH quality of life, and quality of death (Sepulveda *et al.* 2003), may be most empowered or imperiled. Leveraging home-based care in ways that support caregivers, whether these be family or community members, as opposed to burdening them further, is therefore essential. A detailed analysis of the impact of community care supporters on PLWH's perceived wellbeing, as this report aims to provide, may offer some insight on how to assess and value CHBC and thus to achieve this goal.

B. Religion and HIV/AIDS

Incorporating faith-based entities into Global Fund to Fight AIDS, Tuberculosis, and Malaria Coordinated Country Mechanisms has been identified as a complex and much needed approach to comprehensive HIV/AIDS programming (Lee *et al.* 2002). A conspicuous shortcoming of religious responses to HIV/AIDS has been that "[f]or the most part religious communities have focused on sexual morality alone at the expense of other pressing issues" (Bongmba *et al.* 2007:3). Religious obstacles to condom promotion and the exacerbation of HIV and sexuality-based stigma by religious authorities, most recently in Uganda in 2011, too often have undermined HIV/AIDS programming in many parts of the world. In Swaziland, socio-religious taboos regarding sexuality, especially proscriptions against premarital sex for women, were found to influence beliefs and behaviors regarding HIV/AIDS, in some cases inhibiting preventative measures such as condom use (Tobias 2001:106). Yet, to limit scholarly investigation of Christianity and HIV/AIDS to debates over abstinence, fidelity and condom campaigns (Allen *et al.* 2004), eclipses the deeply felt and institutionalized presence of multiple forms of Christianity (Bediako 1995; Meyer 2004; Gifford 2008) that affect millions of PLWH and their families in Africa on a daily basis (Agadjanian *et al.* 2008). It also overlooks the longstanding, comprehensive, and intensely engaged involvement of many faith-based organizations, such that, by 2004, the WHO estimated religious institutions and FBOs to constitute 20% of the total number of HIV/AIDS agencies (2004:46). In South Africa alone, a 2005 national survey of FBO responses to HIV/AIDS showed a 50% and 32% growth in faith-based projects in rural and urban areas, respectively, since 2000 (Toefy 2009:242).

Over the past several years, a substantive scholarly literature has emerged, traversing the clinical, social scientific, and humanities fields, that documents the diverse ways in which religion articulates with HIV/AIDS in people's local worlds (Muñoz-Laboy *et al.* 2011). Studies have demonstrated the multifactorial significance of religion to HIV/AIDS (Haddad 2011; Rohleder *et al.* 2009; Becker *et al.* 2007; Cochrane 2006; Adogame 2007) that contrasts with operative assumptions

in some policy and scholarly realms that religion is peripheral or counterproductive to HIV/AIDS. Conceptualized and operationalized differently across disciplines, religion has been associated with a range of HIV-related health behaviors (Trinitapoli *et al.* 2006; Takyi 2003; Agadjanian 2005), HIV disclosure practices (Zou *et al.* 2009), and better health outcomes among HIV/AIDS patients (e.g. Carrico *et al.* 2006), including survival (Ironson, *et al.* 2002). In their review of the clinical literature on religion and HIV/AIDS, Pargament *et al.* (2004) argue that religiosity and spirituality often are salient and complex features of being HIV positive among some individuals, and that empirical and evidence-based evaluation of spiritually integrated interventions are warranted.

ARHAP,[7] an international network of scholars and practitioners, has introduced the concept of religious health assets (RHA) to strengthen investigation of the dynamics of religion and HIV/AIDS (ARHAP 2006). An emergent concept, RHA have been operationalized in terms of 1) tangible religious health assets, including facilities, personnel, and activities, and 2) intangible assets – "the volitional, motivational and mobilizing capacities that are rooted in affective, symbolic and relational dimensions of religious faith, belief, behavior and ties" (Cochrane 2006:64-65). Framing the study of these dynamics from a more subjective/socio-political perspective, Dilger *et al.* ask how "the emergence of HIV has been co-productive in the emergence of new religiosities (i.e., devotional life) that inform individual and social identities, and which consequently have a bearing on policies and political and economic realities" (2010:373-374). Faith-based and religious organizations' engagement with HIV/AIDS has been described at considerable length in the grey literature (Taylor 2006; Woldehanna *et al.* 2005), but continues, with some exceptions (Agadjanian *et al*. 2011; Patterson 2010; Otolok-Tanga *et al.* 2007), to be an important, albeit broad and under-theorized dimension of these new 'realities.' Pfeiffer *et al.* (2007), for example, explicate the spread of church movements in Mozambique as institutional responses to globalizing inequalities that, in turn, may be leveraged in the service of comprehensive HIV/AIDS initiatives:

> The spread of both Pentecostalism and HIV has been hastened by the same trends in economic disparity and gender inequality exacerbated by SAPs [structural adjustment programs], which dismantled the few social protections the poor majority ever had. As the most dynamic actors in civil society now in the bairros and shantytowns of southern Africa, the churches may provide the partners so desperately needed to mobilize communities around HIV testing, treatment, and prevention efforts as underfunded health systems struggle to reach the poor. (Pfeiffer *et al.* 2007:698)

In a region of rural South Africa, Campbell *et al*. observed that church networks are the "biggest and best established social network in the area," constrained by a "shame and blame" attitude towards HIV/AIDS, yet deeply affected in ways that potentially could be tapped in community wide partnerships to support PLWH (2008:515-516).

Taken together, this rising tide in religion and HIV/AIDS research has both deepened and broadened a scholarly understanding of an integral feature of the epidemic. However, parlaying this knowledge into actionable HIV/AIDS programming remains a foremost challenge.

[7] The African Religious Health Assets Programme is currently transitioning its name and expanding research agenda to the International Religious Health Assets Programme.

IV. Research setting

A. Swaziland: health systems and religious organizations

In late June 2011, the Swazi government's Minister of Health reported that the nation's hospitals, which provide free ARVS to more than 60,000 individuals, had a remaining inventory of only two months (Kaiser Family Foundation 2011). This distressing alert was deeply unsettling for many reasons. In addition to HIV/AIDS, the health system is shouldering a high multidrug-resistant tuberculosis (MDR-TB) and TB/HIV burden (Mauch *et al.* 2009:5). Health centers are often situated at too great a distance, and at too costly a transport fee, for the sick and poor to access. Yet, relative to other ART rollouts in sub-Saharan Africa, Swaziland arguably had achieved some success. By 2007, there were 22 sites that provided free or low cost ART (UNAIDS 2008). Moreover, though just 35.4% of individuals with advanced HIV infection were estimated to be on treatment in 2007, more than two-thirds of that group (64.5%) was still on ART one year post initiation (NERCHA Jan 2008), demonstrating that ART adherence in resource limited settings is possible.

In terms of religious organization, Swazi Christian denominations fall into seven loosely bound categories: Zionist, Evangelical, Mainline, Pentecostal, Independent, Roman Catholic, and 'other' (PACANet 2008). From one-room wattle and daub to expansive concrete structures, churches are ubiquitous features of Swaziland's physical and social landscape. An updated survey is needed, however, in the early 1990s, an estimated 80% of the Swazi population reported a Christian affiliation, and13% that they attend church (PACANet 2008:7). Both Christian and non-Christian Swazi practices infuse matters of governance as well as medicine, a dynamic institutional and ideological saturation that makes 'religious health assets' a productive concept in this study's investigation of PLWH experiences of church run home-based care.

Framing its health services and religious organization, Swaziland's political-economic environment is marked by domestic and exogenous factors that have undermined equitable socio-economic development (World Bank 2011). The country's classification as a lower middle income nation, moreover, has compromised its access to foreign government aid (with the exception of the International Bank for Reconstruction and Development[8]) as well as NGO assistance (Phakathi 2011). The inflated ranking is, in part, an artifact of economic growth that occurred between the 1970s and early 1990s (World Bank 2011). It also belies the country's starkly unequal income distribution, measured by a Gini index score of 50.7 (Human Development Report 2009), whereby 10% of the population controls 60% of the country's wealth (Phakathi 2011). Swaziland, reports the World Bank, is "facing a social disaster of colossal dimensions" (World Bank 2011).

B. Case study and collaborating organization

A registered non-governmental organization in both Swaziland and South Africa, the Shiselweni Reformed Church Home-based Care (SHBC) group began informally in January 2006. At that time, Dr. Arnau van Wyngaard, a South African theologian and founding director of the case organization with two decades of pastoring experience in Swaziland, called for volunteers from his Swazi congregation to assist the many families in their community afflicted with sickness and poverty. Thirty-two individuals volunteered. As of January 2011, the SHBC had grown exponentially to 750 caregivers, serving 2,500 clients in 27 communities across 100 kilometers of southern Swaziland.

Originating in the Swaziland Reformed Church mission, the SHBC organization asserts a Christian religious identity; is multi-denominational in composition, including at least one Muslim

[8] "IBRD borrowers are generally considered to be middle-income countries, roughly defined by the IBRD as countries with a per capita income between US$936 to US$11,455." (Bank Information Center (BIC) 2011, available from: http://www.bicusa.org/en/Institution.Lending.5.aspx)

caregiver; and non-binding in religious participation. Its ethos, inscribed on care supporters' T-shirts, is "To become the hands and feet of Christ in the community." The organization is characteristic of many care groups that have mobilized throughout Africa – relatively small scale (though rapidly expanding), volunteer run, and comprised primarily of women. Caregiver training takes place over the course of about one week. Training is provided by two care coordinators, each of who has been educated by a South African nurse in basic knowledge of HIV/AIDS primary prevention, HIV testing, confidentiality protection, antiretroviral treatment regimens, treatment adherence, and positive (secondary) prevention. Training also includes a religious component, which is deemed relevant given the high percentage of Swazis who identify as Christian. According to the organization's founding director:

> Generally [home-based care] clients appreciate it when the caregivers pray for them, and the majority of clients give permission that a portion from the Bible may be read to them. In both of these instances, the caregivers are encouraged not to take it for granted that the client would want the caregiver to read and/or pray for them. As the Christian faith is built upon the reconciliation between God and man through the death and resurrection of Jesus Christ, permission may be given, after a bond of trust has been built between the caregiver and the client, that the caregiver may share with his/her client how to start this relationship with Jesus Christ. This is done with great sensitivity, ensuring that nobody is forced into a decision for Christ. (Van Wyngaard, correspondence, October 9, 2011)

Caregivers travel in pairs and record each home visit, after which weekly reports are submitted to the community coordinator. These culminate in monthly reports detailing, per community, the number and gender of caregivers; the number and gender of clients; total number of home visits; number of new clients, and those who have moved, died, are terminal, or who have chronic ailments.

V. Study Methodology[9]

A case study methodology has been described as "the best method of investigation" to examine small rural congregations in Africa (Hendriks 2004:233). It was thus an optimal approach to begin exploring whether the church run community home-based care organization described here was advantageously situated to deliver critically needed HIV/AIDS services. There were two parts to the case study. The first was a qualitative (grounded theory) analysis of **caregivers' experiences** of providing church run home-based care to PLWH (Root *et al.* 2011; see also Akintola 2010). The second was an inductive qualitative analysis of **client experiences** of church run home-based care. The latter is the focus of this report. Both phases aimed to identify and elucidate the interpolation of biomedical and socio-religious aspects of being HIV positive and church run home-based care in order (1) to inform HIV policy and programming initiatives with insights on innovative, context-specific interventions that otherwise may be eclipsed by conventional clinical and public health models of outreach and wellbeing; and (2) to contribute to an emergent theory of religious health assets.

Research instrument: Design of the semi-structured questionnaire [Appendix C] was informed by the academic and grey literature on home-based care and HIV/AIDS in Africa and on religion and HIV/AIDS in Africa. The author's published research on HIV stigma in Swaziland (Root 2010), the significance of religious participation to PLWHs in Swaziland (Root 2009), and home-based caregivers' experiences of the case organization (Root *et al*. 2011) was also instructive in formulating the research question and questionnaire. To explore PLWH experiences of church run home-based care, the **research question was operationalized** in terms of the following variables: clients' critical needs; social networks for meeting those needs; perceptions of caregiver practices; HIV/AIDS communication with caregivers; family reactions to the caregiver; personal religiosity; and the significance of caregivers' Christian affiliation.

Sample: Eleven out of the total 27 communities in which the SHBC provided care services were purposively sampled as sites of investigation based on the following criteria: (1) duration of operations, including some of the earliest (2007) versus more recently established (2009) care groups, as well as (2) general performance, referring to communities with low monthly client visits despite a high number of care supporters as well as those with high caregiver attrition rates[10] [Table 1]. Across these 11 sites, semi-structured, face-to-face questionnaires were conducted with 79 individuals between January 17-28, 2011. Purposive sampling criteria were that the individual have been diagnosed with HIV and a current client of the SHBC case organization. Participants were notified of the study in advance by their care supporters and informed consent secured when the questionnaire was conducted in person. Though the number of participants per community is small, in its entirety the study sample was sufficient to discern patterns in HBC experiences.

[9] Research protocol were reviewed and approved by Institutional Review Board of Baruch College, the City University of New York.
[10] These indicators did not factor into this report.

Table 1: SHBC sample communities (N=11) and number of participants (N=79), by community*

Community	Year started	Number of care supporters	Number of clients	Number of study participants
Matsenjeni	2007	32	65	10
Mbangweni	2007	28	135	13
Jerusalem	2007	17	38	5
Ezikhoteni	2007	35	77	8
Somtongo	2007	27	116	7
Nsalitje	2008	19	76	7
Mahlalini	2008	29	164	10
Mantambe	2008	41	99	8
Etjeni	2008	20	81	3
Madulini	2009	43	97	4
Mbilaneni	2009	37	172	4
Total	**2007-2009**	**328**	**1,120**	**79**

* As of January 2011

Implementation: Hard copies of an English language version of the questionnaire were printed and brought to the research site. It was subsequently translated into siSwati by a leader in the case organization and then back-translated for confirmation. After informed consent was secured and with the assistance of translators from the case organization, interviewers conducted the face-to-face questionnaire (N=79),[11] reporting and summarizing participant responses in writing on the questionnaire form. Many sessions were also audio recorded, with permission from the participant, which facilitated subsequent checking or elaboration of written responses, as needed during analysis. The bulk of the questionnaires was conducted by one of the study's principal investigators (N=48) and a Fulbright Scholar doctoral candidate (N=27) from the United States, whose area of expertise is the rise of the mortuary business in Swaziland and associated changes in religious ritual practices. A South African woman who had been assisting the case organization in its development conducted four questionnaires. The questionnaire took on average approximately 30 minutes per participant to administer. Questionnaires were conducted in community settings: inside churches, when services were not being held; in churchyards, outdoors; and at a chief's residence (*umphakatsi*), an orphan care point (*gogo center)*, and a chiefly administrative *(inkhundla)* center. One participant, too unwell to travel, was interviewed in his home. The questionnaire data subsequently were input to Qualtrics survey software.

Data analysis: Structured responses provided the descriptive statistics that helped sketch the basic outline of participants' experiences of church run home-based care. Constant comparative analysis of open-ended responses generated the deeper thematic categories that helped to organize and articulate key patterns of participant experiences reported below. This 'lived articulation' is especially important in light of the silence that otherwise surrounds HIV/AIDS on the ground and the all too often reductive debates over the role of religion in HIV/AIDS policy and programming at the macro level. The questionnaire was, to a limited degree, flexible and responsive to client reports. When it became evident early on in the data collection that a question was eliciting redundant or not eliciting noteworthy responses, the question was discontinued.[12] By the same token, if early reports indicated an experience was worth tracking across the remainder of the

[11] Denominators vary minimally from baseline N of 79 participants, with the exception of a question added on site regarding changes in family attitudes towards the participant as a result of caregiver involvement (N of approximately 51 responses).

[12] This was the case, for example, with the structured question of whether participants had sufficient food, since many respondents were already reporting lack of food in the earlier open-ended question, "What kinds of things do you need someone to assist you with?"

cohort, questions were added.[13] Concurrency of data collection and analysis, whereby "new analytic steps [inform] the process of additional data collection and new data [inform] the analytic processes," is characteristic of much qualitative research (Thorne 2000:68). Allowing for a more a focused and nuanced probe of participants' experiences, these on-site iterative adjustments to the instrument resulted in a different denominator (N) for some responses.

[13] For example, "Has your family learned to take better care of you as a result of the care supporters' visits?" was added to the questionnaire.

VI. Results and discussion

Socio-demographics: Approximately two-thirds (64.6%) of the study sample were women and the remainder (35.4%) men [Table 2]. The average age was approximately 44 years, and ranged from 17 to 75. About half (50.7%) of the study participants were between the ages of 25-44 years, which would typically encompass an individual's most productive and reproductive life phases. Nearly one in four participants (22.8%) was age 55 or older. A sizeable proportion (21.5%) of the sample reported that they had received no schooling. The educational attainment of more than half (54.4%) was limited to some primary schooling. Nearly 18% attended secondary levels and 5% high school. Forty-four percent of respondents reported that they were single/never married, though many cohabitated with a sexual partner. Approximately one in five indicated that they were married, and nearly a third said that they were widowed.

Table 2: Study participants – key demographics

Sex	**% (N)**
Male	35.4 (28)
Female	64.6 (51)
Total	*100 (79)*
Age	**Years**
Average	44.4
Range	17 – 75
Age range distribution	**% (N)**
17-24	5.1 (4)
25-35	20.3 (16)
36-44	30.4 (24)
45-54	21.5 (17)
55-75	22.8 (18)
Total	*100.1 (79)*
Schooling	**% (N)**
No schooling	21.5 (17)
Primary	54.4 (43)
Secondary	17.7 (14)
High school	5.1 (4)
Other (Sebenta, adult education)	1.3 (1)
Total	*100 (79)*
Marital status	**% (N)**
Single, unmarried (includes some co-habitation)	44 (35)
Married (Christian and/or Swazi custom)	22 (18)
Widowed	30 (24)
Divorced/separated	3 (2)
Total	*100 (79)*

It is important to note that conventional demographic categories such as 'marital status' can mask the complex marital, familial, and sexual realities beneath these rubrics that impact individuals' experiences of HIV/AIDS and thus care supporters' strategies for supporting client health. One participant, a 57-year old woman, vacillated between describing herself as 'single/unmarried' or 'separated.' The multi-phased marriage process in Swaziland that results in a woman's patrilocal move to the groom's homestead had not been completed. The interviewer therefore indexed her liminal marital status on the questionnaire as single/unmarried A second example of the dissonance between demographic category and individual reality was a male participant who had had three wives. One had died and the other two divorced him. He was categorized as widowed, though such a profile eclipses the social fact that two wives had left him. To have labeled him 'divorced' would have overlooked that a spouse had died.

These examples intimate some of the socio-cultural, economic, and sexual dynamics that participants and their care supporters often navigated in pursuit of a state of wellbeing, or survival, including HIV testing, ART uptake/adherence, stigma reduction, disclosure negotiation, and condom promotion.

A. *"That's when life changed"*: The significance of church run home-based care supporters

In contrast to the reductive oppositional forms that religion and scientific medicine and have sometimes taken in HIV/AIDS scholarship and policymaking, participants' reports of being HIV positive and of receiving church run home-based care demonstrated the warp and weft of multiple influences on wellbeing and survival. Though 'socio-religious' and 'biomedical' are bracketed here as discrete variables for purposes of data reporting, analysis of participants' experiences suggested that the impact of the case organization resulted from the dynamic interpolation of clinical medicine with locale-specific phenomena, including religion, kinship, gender relations, and economics. The substance and significance of this impact was best captured through two open-ended questions: (1) 'What do you feel would have happened if the care supporter had never come to your home?' (2) 'What do you feel would happen if the care supporter were no longer able to visit you?' Responses to these two hypothetical scenarios are analyzed below.

(1) What do you feel would have happened if the care supporter had never come to your home?

Approximately 53% of participants felt that they would have died, a few from suicide, if the care supporters had never come into their lives. Asked to elaborate, responses indicated **three categories of caregivers' life saving intervention** [Table 3].

Critical to all three interventions was that the client-caregiver relationship transpire in real-time. In other words, by entering into the rhythms of participants' daily lives, care supporters were present as problems and questions arose, or, in best case scenarios, were able to address challenges preventatively. "When I fell sick from the side effects of ARVs," said one participant, "the care supporter was the first to come and check on me. She encouraged me I must go to speak to the clinic." This real-time quality contrasts with the episodic (and equally vital) nature of clinic visits, indicating the potential synergies to be had from potential care continuums.

The **first category of life saving intervention** rendered conventional HIV information actionable. The care supporter provided information about HIV testing and treatment, especially ARV adherence, that the participant either did not have before, had not adequately understood, or had difficulties implementing. "I could have died," reported a 65-year old woman, "because the care supporter is the one who just came and told me all about the ARVs and TB tablets." According to some participants, the care supporters were the only people to come explain health-related issues and, furthermore, to assist them in enacting that information by devising and maintaining medication routines.

The **second life saving intervention** was material and physical, often in the form of providing food or money for clinic transport. Approximately 95% of participants reported that they did not have sufficient funds to travel to the clinic. In an extreme case, the care supporter of a 39-year old widow came to her home with a wheelbarrow, lifted the participant into it, and, with the woman's children, carried her to the clinic. Once there, the woman was diagnosed with HIV and put on ARVs. Other participants described the risks of living alone, or only with small children, and being too sick to move, languishing indoors without food or water, beyond the purview of the formal health and social welfare system. A care supporter's unsolicited arrival in such instances could be life saving.

The **third intervention** is generally termed in the academic and policy literature as psychosocial support. In the study setting, psychosocial support included helping clients to manage the fear, stigma, and shame that was often attendant being HIV positive in Swaziland (Shamos *et al.* 2009). Under such conditions, care supporters were a vital emotional safety valve, creating safe spaces to express grief about being diagnosed and a source of insight and information about how to build a new life around a frightening and isolating diagnosis. For some participants, caregivers 'normalized' an HIV diagnosis, thus reducing the intensity of shame they

might feel and staving off a depression that could be life threatening. Asked how she was feeling at the start of the questionnaire, a 37-year old participant, with a baby in her lap, 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 reassured her "everyone is living with HIV. People are living, and they are going to live." Reinforcing the life saving impact of care supporter's psychosocial roles, a 53-old woman said she had been unable to share her problems with anyone around her, but when the care supporter arrived, "That's when life changed." Life changed as well for a 48-year old widow who lived alone. Demonstrating the link between psychosocial support and enhanced ARV adherence, the participant felt she would have died without the care supporter's intervention, "because I was alone with nobody." The care supporter made a difference, she said, "because she shared the word of God with me, giving hope, encouraging me to go on with my medications." The caregiver had also spoken with the woman's natal family, counseling them to give the participant "more love," as she was without a husband, her in-laws had rejected her, and she was HIV positive. As a result, the participant said, her parents were now taking good care of her.

Table 3: Care supporters' lifesaving interventions: real-time relationships

Intervention type	Implementation
Actionable HIV/AIDS education	Caregivers rendered conventional HIV/AIDS information intelligible and actionable in real time, e.g., ARV adherence.
Material and custodial support	When possible, caregivers provided food and monies for clinic transport. They also performed essential custodial tasks, such as food preparation or helping in the fields.
Psychosocial support	Caregivers enhanced participants' self-efficacy skills through ongoing encouragement; reduced stigma and restored a sense of legitimate personhood, preventing potential suicides; increased participants' self-confidence in their ability to manage being HIV positive by reducing social isolation and helping to develop ARV adherence routines.

Among participants who did not speculate directly that they would have died, many nonetheless felt their lives would have been considerably more difficult, either from lack of actionable HIV knowledge about managing their diagnosis or inadequate material and emotional support. A few participants reported that they felt they had been sufficiently educated by the clinic, and supported by their family, prior to the caregiver' arrival, though caregiver support generally was still welcome.

(2) What do you feel would happen if the care supporter were no longer able to visit you?
Participants were asked to assess what they felt would happen if their care supporters could no longer visit them. The question was intended to gauge two aspects of client home-based care experiences. First, to what extent are the SHBC care services a conventional 'intervention' in the sense of being time limited, with a beginning and an endpoint that produces self-sufficient PLWH? Second, is church run home-based HIV/AIDS care in any way substantively different from such interventions, and if so, did this difference matter to the lives of HIV positive individuals? Responses ranged from very few reports that the participant would be all right because he or she already had support systems in place to, at the other extreme, one woman who said, "If there are no more care supporters, I would just commit suicide." In between, about a quarter of participants felt that as a result of the caregiver relationship, they had achieved the knowledge and self-efficacy skills needed to manage their HIV positivity on their own. In this

regard, the caregiver had 'intervened' at a key juncture in the individual's sickness and as a result of the relationship, the participant was reasonably confident in his or her ability to live being HIV positive. "Life could still go on," said a 62-year old man who at first feared the caregivers had come to laugh at him, "because now I've got the knowledge [of how to live] from the care supporter and the clinic." As a result of their encouragement to adhere, he said he was able to hold the hoe when plowing and that he was strong enough to weed. A 32-year old woman felt similarly equipped: "Even if they stop coming, I can go on, because they have taught me how to go on with my life." Another said that not only would she be able to manage on her own, but she could share what the care supporter had taught her with others. A 56-year old woman exclaimed that she would survive because, "When the caregivers came, I couldn't do anything, but now I can do anything. I'm plowing!"

However, the majority of participants reported that no longer having the SHBC caregivers in their lives would be "painful." For some, discontinuance would pose a substantial challenge to the participant's survival. Reasons for this 'pain' reflected the importance of the material support (e.g., food and money for clinic transport) that care supporters were sometimes able to provide, participants' ongoing need/desire to be reminded and encouraged to take ARVs, and the vital and otherwise unavailable psychological support caregivers offered, which assuaged fear of death, social isolation, and daily struggles for survival. A 62-year old woman who described her husband as "aggressive," and whom she had not yet told of her HIV status (they maintained separate bedrooms and engaged in no sexual activity) responded to the interviewer's question with her own: "To whom would I send my children to come wake me up?" should a dreaded day come when she does not awaken. For some, the care supporters were the only readily accessible resource they had. If his care supporter no longer visited, "who would help me if I have a problem?" answered a 49-year old man. A 43-year old woman whose natal family, she said, discriminated against her, felt she would die if her caregiver stopped coming. She provides food, assistance in her fields, and encouragement. "She is like [a] mother. I have no secrets with her." The only alternative, she continued, would be to go to the police station and to prison, as she would have no other means of being looked after.

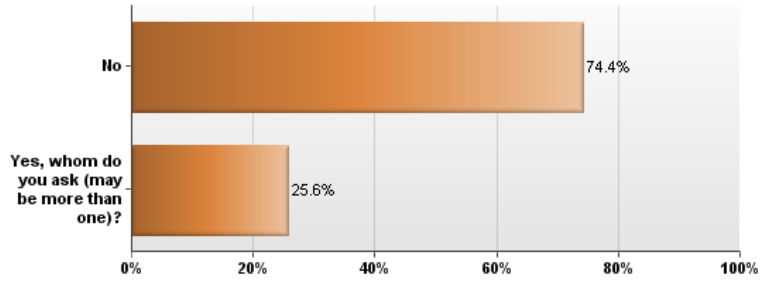
A 44-year old woman sought HIV testing after she witnessed her husband's second wife fall very ill, presumably with HIV/AIDS. Her husband still refused to test or to use a condom, she said, so she abstains from sex with him. She described how painful it would be if there were no SHBC caregivers. "There is a full hope within our hearts" that caregivers bequeath to their clients and which they seemed uniquely positioned to provide. She differentiated clinic from home-based care, explaining that while the health center had provided her with "full counseling," the "care supporters are nearer to us each and everyday. They are close to us. And we are open to speak to the care supporter about things that we are afraid to speak to the nurses about." The synergies of clinic with church run home-based care were most evident in responses that referenced both the biomedical and the socio-religious aspects of 'better health.' If the caregivers stopped visiting, "I would continue going to the clinic," said a 42-year old woman, "but I wouldn't keep myself well. The caregiver helps and encourages me in Christianity." For some, the caregiver relationship alleviated the rigors of daily life and demands of a medication regimen in critical ways. A 63-year old woman testified, "The caregivers motivate me to continue with life and to take food with the ARVs." A participant who felt she needed the care supporter in her life for many reasons, from food assistance to dealing with abuse, sparked a laugh when she answered the question of what would happen if her care supporter no longer visited, "If my care supporter stopped coming, I'd go and find her!"

The report turns, now, to an analysis of the 'lived reality' between the two hypothetical scenarios described above – if the caregivers never came or stopped coming – to better understand the concrete mechanisms, the care discourses and practices, that rendered the client-caregiver relationship a distinctive and vital one in such a high vulnerability setting.

B. PLWH needs and networks

Most participants experienced HIV positivity amidst extreme material scarcity and, often, HIV-related stigma (for an excellent discussion of gendered as well as 'felt' and 'enacted' HIV stigma in Swaziland, see Shamos et al. 2009) that stymied attempts to achieve a state of wellbeing. Reports of dire food shortage and lack of monies for clinic transport revealed the insuperable threats that rural poverty, and its macro-economic drivers, posed to individual and household survival. To assess the role of individuals' social networks in buffering the impact of chronic deprivation, participants were asked if they solicited assistance to meet their most urgent needs [Figure 1]. Nearly 75% of participants reported that they did not, thus rendering the outreach of the SHBC group all the more significant. Of the 26% who did make their needs known, neighbors, for example, were entreated for even short term employment, such as weeding a neighbor's garden or tailoring clothes, remuneration of which might cover the cost of a trip to the clinic.

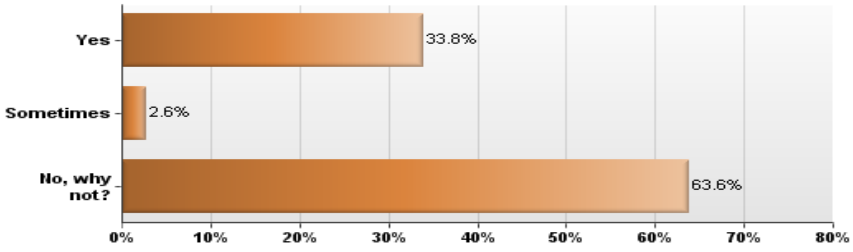
Figure 1: Do you ask someone to assist you with your needs?



Alternatively, a 31-year old man prevailed upon the compassion of his pastor and congregation for transport funds. Often, requests for help were met only episodically and unreliably. One participant said the Red Cross provided relief on one occasion. Another had sought assistance at the local rural development office, yet this path proved fruitless when the person in charge died.

The question of whether participants sought help from others did not preclude seeking assistance from family members; however, participants were also asked to comment directly on whether they felt comfortable doing so [Figure 2]. The aim of this question was to identify different forms of social relatedness that may bear on experiences of HIV/AIDS, and as a consequence what might be needed of their SHBC care supporters. Only about one third of participants (34%) said they felt comfortable asking family members for help, leaving nearly two out of three to experience dire needs, mostly food and money for transport, without recourse to kin.

Figure 2: Do you feel comfortable asking family members for help?



Reasons for not seeking family support fell into two non-mutually exclusive categories: material and psycho-social. In the first, electing not to call upon family members was often a function of generalized poverty. "They are poor like me and can't help[14]," reported a 42-year old woman. If a participant did seek assistance, they might do so only once and never again: "I'm scared if I ask once, then I ask again, I fear they will say I am a burden to them." Psycho-social constraints on help seeking manifested in fears of HIV-stigma and the dissolution of family networks. HIV stigma is a complex conceptual category that bears significantly on HIV/AIDS in multiple ways (Holzemer *et al.* 2007; Parker *et al.* 2003). Stigma is often defined, following sociologist Erving Goffman, as a social process of spoiling an individual's identity (1963). In a study of felt and enacted HIV stigma in Swaziland, Shamos et al. (2009) quote one Swazi participant who defined stigma as, "Basically, it means being identified by a feature in your body that you are not proud of" (2009:1679).

Often, the complex processes – sociosomatic, intersubjective, moral – that produce the experience of HIV stigma (Yang *et al.* 2007) can be difficult to discern empirically and even more challenging to theorize. For example, a 56-year old woman said that it was due to stigma from family members that she did not seek their help. Asked what kinds of stigma would stop her from asking for the food she desperately needed, she explained that seeking assistance on one occasion was acceptable, but with repeated requests, the family's attitude became one of annoyance, that, in their eyes, presumably because of her HIV positive status, she felt entitled to receive food from them. Reflecting the same devaluing dynamic, a 51 year old man said he told himself if he got HIV, he couldn't ask others for help, and that he was scared to do so. Exacerbating participants' paucity of social capital was the dissolution of kin networks, whether through sickness and death or migration, that in the past would have functioned as a safety net. Reports that "all the family members have died," "the parents are dead," or that family had moved too far away to be of assistance traced a 'local world' in which social isolation and material deprivation were the desperate backdrop to the SHBC care supporters' arrival on participants' doorstep.

C. First impressions: Care supporters enter the homestead

When introducing themselves to potential clients, caregivers in at least one SHBC community often endeavored to identify some form of clan, inter-clan marriage, or other relational connection on which to begin building a trusting bond.[15] Asked to recall their impressions when the care supporter first introduced themselves, the majority of participants described not just relief at the possibility of material assistance but of a restoration of wellbeing, hope, and legitimate personhood. A 34-year old man described the significance of the SHBC caregivers to his physical and psychological survival: "I was so scared, thinking I would die, because my friends had neglected me." A 60-year old man who had two wives who had died said the first time he met the care supporters, "I thought they came to laugh at me. To my greatest surprise, they came to help me." Fear of being laughed at was not uncommon. "I thought she would laugh at me because I was taking ARVs," recollected a 39-year old female. Instead, because hunger was impairing the woman's ability to tolerate the ARVs, the supporter brought her thin porridge for breakfast and reminded her to take her medications. That caregivers sometimes brought a bit of food, soap, pain killers, and occasional funds for clinic transport meant a great deal to participants. So, too, did their knowledge of HIV/AIDS. "I was happy [when the caregivers arrived]," said a 56-year old woman, "because I admire that they have come to teach about healthy living, and happy that there are people who are teaching us about HIV/AIDS." Pressed about the significance of this function given that media and health centers already provide HIV/AIDS information, she explained that having care supporters come to the home was critical: "I don't have money to go everyday to the clinic to attend courses there. Instead I get more when they come to my house."

[14] Participants' open-ended statements were paraphrased. In doing so, every effort was made to preserve the integrity of the intended meanings.

[15] I am indebted to Casey Golomski for this insight, gleaned from his field research with caregivers from one of the communities (Madulini) in which the SHBC operates.

Another participant was pleased, "because [before the caregiver came] no one cared for me. The caregivers arrived, inspected [the home], checked on me. They washed clothes and dishes for me, and accompanied me to the hospital." A 48-year old widow who lived alone and whose dilapidated home was toppling in on her was relieved to discover, when the caregivers arrived, that people cared for her: "I am also a human being." Two consequences of pervasive HIV stigma are denial that HIV and AIDS exists as a disease entity and denial that one is, or may be, HIV positive. For some participants, the sickness sequelae that follow from denial of one's HIV status would have worsened without caregiver intervention: "When the caregivers came to me, I was so happy. They counseled me. I was doubting myself. Some days I denied I was HIV positive; some days I accept it. When I was with other people, I was afraid to eat or talk with them. But when the caregivers came, it became simple to mix with other people." In a sense, caregivers helped participants to consolidate a new personhood, from which new routines and social relations felt possible. In a high stigma environment, some participants had to overcome initial suspicions of care supporters' intentions. At first, one participant, a 62-year old male, didn't trust them, as he feared they would gossip. But then he realized they had come to care for him, and that everyone is sick, "so why should I not tell these care supporters [I am HIV positive]?" When a care supporter appeared at the home of another participant, the woman wanted to know how the caregiver knew she was sick. The care supporter explained that her own children attend the same school as the participant's. One day, the care supporter's children told her that the child was no longer at school and had to remain home tending to the sick mother. The participant said she was very happy, then, thinking even if she dies, her children would be looked after by the care supporter. It was as a result of the caregiver's instruction and encouragement that the woman sought testing and found she was HIV positive and started ARVs. In a setting where 41% of children are deemed orphaned or vulnerable, such unsolicited outreach opened the door to reducing this woman's isolation, enabled the exchange of vital health information, and may have made it possible for her child to return to school.

By many accounts, care supporters elevated participants' health by restoring clients' personhood and enhancing their perceived self-efficacy, a concept explored by Campbell in her study of the shortcomings of conventional HIV/AIDS policies and recommendations for innovative HIV/AIDS programming in South Africa (2003:156). For Campbell, peer education and relationships were central to achieving self-efficacy in the face of HIV/AIDS. With the SHBC care supporters, sometimes the relationship was less peer-based than parental or pastoral. Nonetheless, the same empowerment objectives were at play. "The first thing that came to mind," recalled a 26-year old woman, "was wondering if the care supporter would be a part of my life, helping me with being HIV positive." What it means to be "helped with being HIV positive," or even the meanings of "being HIV positive" are a powerful and underexplored aspect of HIV positivity, especially its significance in remote or rural areas. Care supporters' ability, and authority, to normalize an HIV status appeared to be instrumental to some clients. "I was happy," explained a 65-year old man, "when the care supporter came to me because she advised me, and told me I will continue with my life because almost all the people are now HIV positive." A 43-year old man said that they tell him "the world is full of people like me, and they answer questions." In doing so, care supporters effectively rendered the epidemiology of HIV/AIDS in Swaziland a felt reality among their communities in ways that conventional public health awareness campaigns often have not.

Notably, among some participants, this 'new' reality seemed to reduce physical and social isolation and to foster hope and optimism about their personal futures. A 58-year old woman, many of whose family members were in Mozambique, had become fearful of meeting with other people, concerned that she would infect someone just by using the same dish and dreading the possibility that she would be stigmatized for her HIV status. In addition to collecting firewood, helping to prepare food, and reminding the participant to take her ARVs, the care supporter had enabled her to once again attend church and community meetings. Asked how the care supporter helped her to overcome these fears, she said the caregiver had educated her and read a verse from the Bible which stated that in the 'last days,' there will be many diseases, that HIV is one of those

diseases, so anyone could be infected. While such a discourse may be unfamiliar, even uncomfortable, to many HIV/AIDS scholars, policymakers, and activists, it is important that this mode of normalizing an HIV status be understood. It was this knowledge, the participant said, in tandem with a clearer understanding of HIV infectivity, that helped her to feel better and less afraid, and for these reasons, she felt her health had improved.

A few clients expressed frustration with care supporters' limitations. One man was perplexed. "What do they give us, as we are their clients? They say they have nothing." Regardless, he said he still he lets them visit, because "they do care for us. I want them to give me food." The first phase in building a client-caregiver relationship could also be rocky. A 29-year old man, bedridden when the care supporter first arrived, recalled feeling angry. Very ill, he didn't want to go to the health center because it was a "disgrace to find that you are HIV positive." The care supporter spoon fed the young man until he had regained a modicum of physical strength and advised him to go to the clinic. Asked how the care supporter convinced him to go test, he said she explained that he mustn't think that many people will know his status, or that they will "spill out" that he is HIV positive. He agreed to test and was put on ARVs. The ongoing dialogue between the client and his caregiver, in his home, had effectively dissolved the self-stigma that was preventing him from going to the clinic at risk of death. Such communication – and subsequent change in health practices – likely would never have occurred in the formal health system, because the participant might not have entered its sphere in the first place.

D. The family: home-based care and household dynamics

The family dynamics into which care supporters inserted themselves were an important variable in the client's experience of HIV and home-based care. While much more research on family experiences of home-based care is needed, this study asked clients to report on *their* perceptions of family reactions to caregiver interventions. In the vast majority of cases, families were happy that the participant had a care supporter to assist them. One participant's husband was very pleased about the caregiver's presence in their lives, as the caregiver acted as a conflict mediator, negotiating the wife (client's) concern that because there was no food in the home, she needed to work, and the husband's dictate that she not. The children of a 48-year old participant were happy because they were acquiring important HIV/AIDS care knowledge, including the importance of wearing gloves when caring for her and reminding her to take her ARVs.

However, at times, family reactions were mixed. A 43-year old woman, who lived with her two children and granddaughter, explained: "Some [family members] are happy. Some are not." Her own family, she said, discriminates her, and while they said they supported her decision to go on ARVs, once she did so, they seemed to want nothing to do with her. She felt closest to her care supporter, whom she had had for approximately four years. "They [relatives] blame me for gossiping to my caregiver about them, because sometimes she and I discuss issues until 7 pm, when she goes back to her house." A few participants reported that family members became "jealous," either because a care supporter was providing a bit of money to the sick participant or because, in the case of a 65-year old woman, as her health improved, she regained her ability to work. As a consequence, her female in-laws were "unhappy because I do my handicraft to make some money, [so] they are jealous." Another said that her in-laws were not happy with the caregiver assistance she received, because "other people don't what to see you being helped by others." These negative instances aside, a majority of participants felt their families were pleased and relieved that the participant was receiving additional support, materially, physically, and emotionally.

For many participants, care supporter interventions were instrumental in improving the participant's experience of HIV in his or her own home. Given the arduous lengths to which participants often went to acquire their ARVs, daily support – as opposed to rejection, hostility, and withholding of food – was essential. Such support, however, could be taxing on families' economic, emotional, and physical resources. A primary metric of family responses to caregiver interventions was whether the participant felt their families had been influenced by the caregivers. Two interrelated questions were added approximately a third of the way into the data collection.

"Has your family learned to take better care of you?" and "Has your family accepted you more?" The first question was intended to elicit data on both the physical and psychosocial aspects of caring for a sick person, from medication support to nutrition to moral support, and the latter specifically to household stigma reduction. However, 'to care' and 'to accept' were often simultaneous and twinned processes. In other words, learning the importance of nutrition might also include – and entail – expressing positive emotions towards the HIV positive family member that helped them feel more accepted. Many participants responded that their families were both caring and accepting, sometimes prior but more often as a result of caregivers' teaching and modeling of care practices. "They learned to give me more love," said a 43-year old man, "not to discriminate me from themselves. They do everything together with me. They are there for me." One woman said her family had already been caring for and accepting of her, but the caregiver taught them to show her even "more love." According to another participant, many things might have gone wrong if the care supporter had never appeared. "At times," she said, one's family "looks down on you when you are sick, but when the caregiver comes, then they think they should also join in [caring for the sick person]." Learning to take 'better care' for another woman meant that her husband learned from the caregiver that he must get tested, which he did, and found that he was HIV positive.

Asked what it meant for their families to take better care of them, participants reported a combination of more material assistance, especially in the form of food, and show of greater concern and empathy. "My family takes better care of me – they [no longer] discriminate, because now they give me a full diet. Before, they didn't know anything about the condition." A 63-year old participant whose adult daughter was also HIV positive felt her daughter began bringing her mother water, money, shoes, and food, as well as accompanying her on clinic visits, as a result of her caregiver's involvement. (This situation, however, does raise the 'care for caregiver' question of who is caring for the HIV positive daughter.) In some cases, caregiving produced concrete changes in family relations that significantly improved participants' quality of life and wellbeing. A 65-year old woman was pleased that as a result of the caregiver's involvement, her husband "gives me love," and that her children accept her more, evidenced by the fact that "even if I am out in the fields, if I am late, [my children] will send someone to fetch me to come back and take my food and tablets [ARVs]."

Despite caregiver involvement in participants' lives, household stigma in various forms persisted in a few cases. The family of one woman continued to believe that she had killed her husband, so they treated her poorly. Overall, however, participants described a shifting landscape of household experiences of being HIV positive. One participant was extremely pleased when her neighbors, who had been worrying about her struggling alone, began checking on her regularly, a routine that commenced after the caregiver spoke with them about the client's situation. Prior to that, said the 54-year old woman, "no one was checking over me." Being checked on by a neighbor, having family members remind you to take your medications, being offered food – all of these constituted reassurance that the individual was still a part of the social body and that their needs mattered, even if they could not always be met. Under extremely vulnerable conditions, an otherwise routine question, "How do you feel today?," could feel radical. Thus, where silence, denial, and discrimination may have marked a participant's experience of their family or surrounding community prior to the caregiver's arrival, the enhanced care and compassion modeled by the care supporter's visitation was, for some, transformative of their HIV experience.

E. Brokering HIV disclosure

A family's handling of a family member with confirmed HIV often hinged on whether they were aware of the individual's HIV positive status. Few studies have explored the rationales, emotions, and patterns of HIV disclosure in Africa, especially to non-sexual partners (Miller *et al.* 2007:589). This caesura in HIV/AIDS research, of examining disclosure in different relational contexts – to one's young and adult children, natal family members, and in-laws, as well as neighbors and others in one's community – warrants deeper investigation especially, argue Miller and Rubin, with respect to the roles of churches and religious leadership:

> African social networks, as opposed to U.S. social systems, provide a different set of organizations and opinion leaders to whom individuals in crisis can turn for advice and assistance, among the most influential of which are Christian churches and pastors. (Hastings, 1995; Lonsdale, 2002, cited in Miller *et al*. 2007:588)

In this study, many participants described having been counseled about self disclosure by clinic staff and rendering the decision to self-disclose to selected others on their own. But approximately one in four (23%) [Figure 3] reported that their SHBC care supporter had helped them to disclose to family members, either by encouraging them to do so, discussing strategies for how to do so, at times joining the participant in disclosing to the family, or even, with the participant's permission, telling the spouse on behalf of the participant.

Figure 3: Has the caregiver helped you tell some family members that you were diagnosed with HIV?

Decisions to disclose can be complicated by the fact that families were not uniform entities. Members might respond differently to the afflicted person and to the subject of HIV/AIDS. After telling her adult children, ages 36 and 21, that she was HIV positive, a 58-year old participant said they were "shocked and stigmatized her and did not want to share food with her." But after the care supporter counseled them, the younger one came to accept her mother's HIV positive status a bit more. This acceptance had more than psychosocial consequences. The participant felt that if the care supporter had never intervened, her children's stigma would have killed her – or that she would have killed herself.

One man was instructed at the hospital not to tell anyone except his caregiver. However, he decided to tell his sister-in-law as well, who, he said, accepted him and encouraged him to adhere to the medications. Moreover, whereas the clinic may provide counseling regarding disclosure to a sexual partner, back home it may fall to the care supporter to encourage the client's spouse to seek testing. Asked what would have happened if the care supporter had never arrived, a 32-year old participant described the wall of silence her care supporter – and thus, public health campaigns more broadly – had to break through: "Maybe my husband would never have gone and tested or gotten on treatment. My mother-in-law didn't want us to test, and she doesn't want me to talk to other young wives about HIV or to encourage them to test. Even my father-in-law is HIV positive, but still my mother-in-law wants to hear nothing about HIV."

In general, care supporters felt it was important for at least one family member to be cognizant of the client's HIV positive status. This was the case with a 34-year old man who, having been advised by his care supporter, disclosed to his family. Though they were saddened to learn, he recalled, that he was HIV positive, they accepted him. A 39-year old mother was likewise advised by her care supporter to tell her five children, who ranged in age from seven to 26 years, in order that they could remind her to take her ARVs. The woman felt her "mind was not in good condition" and that these reminders were especially important since they had seen their father, who refused to take ARVs, die. A third participant had dreaded telling her family she had HIV, but having done so, she found that they were grateful that she had.

HIV disclosure emerged from participant reports as a complex psychosocial process, punctuated by instances of telling different people at different times that elicited a range of reactions. Such processes could be fraught by the interlocutor's own fear of sickness and death and of the stigma and shame of having HIV. A 60-year old man was motivated to disclose in order to save his sick brother, hoping that by sharing his own HIV status and invoking his improved health as evidence of ARV effectiveness, that his brother would seek testing and treatment. He advised his brother, "Look here, I'm HIV positive, and I've started these ARVs. I was just like you, so now you go and have the HIV test and get these tablets." The brother reacted by threatening the participant with violence and denying that he might have HIV: "He wanted to kill me, because I tried to explain everything to him about the CD4 count. He said, 'Eh, there's nothing like that.'" Eventually, the brother capitulated. On ARVs now, "[my brother] is 'sharp' [and] thanked me. Now he preaches the gospel [of testing and treatment] to other people; that they must go for the HIV test or else they will end up very sick."

But self disclosure, even when mediated by a care supporter, ran the risk of further complicating what others believed about HIV/AIDS and ARVs, especially if an HIV positive person appeared well as a result of ARVs. This was the case with a 32-old year woman who, like the man above, disclosed to her sibling in an effort to save her:

Participant [P]: The care supporter helped me to tell my family, because my sister was also sick. I was afraid to tell her, because I thought she would say that I am laughing at her or bluffing. So the care supporter advised me to make an example with my life. But my sister couldn't accept the [HIV] positive life, so she passed on [died]. My family did not believe I was being helped by the ARVs to get well. They said I was just telling stories. Since my sister died, [though], they try to believe me…To my husband's family, I decided on my own to tell them I am living positively. Even they don't believe I have HIV [because participant appeared well]. My mother-in-law reminds me when to take the ARVs, but doesn't believe I have HIV.

Interviewer: How does that make [you] feel that they don't believe [you]?

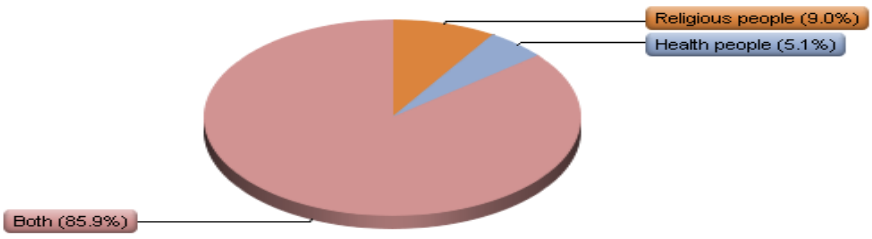
P: It hurts me a lot, because they're busy dying left and right. Because they do not believe what I am saying. So, I pray one day that they may accept that I am HIV positive.

Thus, for others to accept that the participant was HIV positive required, at the same time, that they believe in the potential effectiveness of ARVs. Unfortunately, to believe in ARVs was to concede the harsh and frightening reality of HIV/AIDS, which some individuals reportedly were unwilling to do.

F. Biomedical aspects of church run home-based HIV/AIDS care

Given the diverse roles care supporters played as HIV educators and spiritual counselors, and their church run home-based care affiliation, participants were asked whether they perceived their care supporters to be religious people, health "people," or both [Figure 4]. A large majority (86%) reported that they viewed care supporters as both.

Figure 4: Would you say the care supporters are religious people, health people, or both?



The significance of caregivers' dual identities lay in the synergies that each domain, marked by their respective biomedical and socio-religious discourses and practices, had on participants' lives. These synergies contrast with the unproductive tensions that have long strained religious and biomedical approaches to HIV/AIDS. I turn now to an analysis of the biomedical and socio-religious content of participants' experiences to better understand whether and in what ways these synergies were discernible, actionable, and potentially replicable in places with similar epidemiological, sociocultural, and economic profiles.

1. Elevating health: the power of 'talk'

It is important to distinguish between HIV/AIDS 'talk' and HIV/AIDS education. Much of the impact that care supporters appeared to have on participants' wellbeing was the result of ongoing conversations between the care supporter and the client, wherein different aspects of being HIV positive were talked about. The regular, ongoing, and real time nature of care supporter involvement in clients' lives contrasts with (vital) episodic encounters clients had with clinic staff. Participants often described how a care supporter changed their health practices and sense of self over time, making them more willing to test, to seek out clinic advice, to involve families in their care, and to accept and care for themselves without shame.

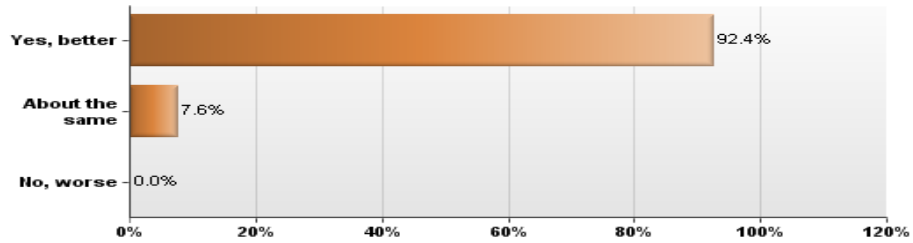
At its most impactful, a care supporter helped participants to cultivate self-care skills that help to support wellbeing. A 30-year old man explained: "The caregivers teach me how to care for myself with this condition [HIV] and to live my life." Developing self-care skills required, first, that clients and care supporters talk about HIV/AIDS and being HIV positive. Nearly every participant reported that they were **comfortable speaking about HIV/AIDS** with their care supporter [Table 4]. The only individual who did not feel comfortable was a 52-year old woman who said she was shy, so she didn't want to talk about it anyway.

Table 4:Caregiver-client communication

Is it comfortable speaking with care supporters about HIV/AIDS?	%
Yes	99
No	1

An overwhelming majority (92%) of participants reported that they felt their health had improved since a care supporter began visiting them at home; a very significant indicator of care supporters' 'impact' on participants' perceived wellbeing. The remainder reported that their health remained unchanged. None indicated that their health had worsened.

Figure 5: Would you say your health has changed since the care supporter started visiting?



Asked to explain what **'better health'** meant to them individually, participants described a state of elevated wellbeing that reflected the interdependence of the physical, material, psychosocial, and socio-religious factors in their daily attempts at managing sickness. For a 37-year old man, 'better health' meant that "I found I could live with HIV. I wouldn't kill myself. I know to check and test again." Explained one participant, "I don't understand things about the sickness. At times, I may think I'm not HIV positive and may want to stop the ARVs, but [the care supporters] answer my questions."

Reports also helped to concretize the otherwise often nebulous notion of 'care.' Given the multiple ways in which participants described caregivers' support, participants were asked to specify the **'most important'** aspect of care supporters' involvement in their lives. Recalled a 29-year old man, "when I was bedridden, the caregiver spoon fed me, bathed me, and took me to the health center." At times, care supporters managed to secure funds for clinic transport and often provided food, mostly pap, which facilitated taking the ARVs. They provided oral rehydration salts and pain killers when they had these items on hand, as well nappies, latex gloves, soap, and cooking oil. Sometimes care supporters helped cultivate a field and straighten up yards. They cleaned the home, did laundry, and fetched water and firewood until participants recovered sufficient energy to resume such tasks, if they were able.

Often, 'better health' was the direct result of care supporters' efforts to have their clients, especially those who were very sick, tested for HIV and, if necessary, put on ARVs. More than one in four participants (27.9%) sought **HIV testing** after a care supporter began visiting them [Table 5].

Table 5: HIV testing

When did you get tested for HIV?	%
Before care supporter intervened	72.2
After the care supporter intervened	27.9

Care supporters often encouraged that clients test for a variety of diseases (Root 2011), couching HIV in one of many less stigmatizing conditions, in part to normalize HIV testing and render the decision less threatening. Combined with reassurance and encouragement that proactive steps could be taken if the test was positive, a number of clients felt that without this gentle 'push,' they might not be alive. At times, care supporters even accompanied participants to the clinic or provided the funds to get there. Besides serving as the informational, logistical, and emotional bridge for many participants to access clinic health services, clients described other aspects of essential HIV-related care talk. This 'talk' might include the health of participants' children and husbands' HIV status. In at least three cases, the care supporter was instrumental in persuading participants' husbands to get tested and/or to initiate ARVs. For example, though one woman had already tested positive and disclosed to her husband, he did not believe her. Yet after the care supporter took him aside and counseled him to get tested, he did so immediately. Much of the talk around HIV testing concerned the cascade of HIV health practices that begins upon diagnosis. These included encouraging the participant to have children tested, condom use during

sexual intercourse, and retesting, presumably as a form of monitoring clients' CD4 counts in order to maintain an optimum ARV regimen. Care supporters emerged as pivotal players particularly when clients experienced apparent medication side effects or developed other sicknesses, encouraging them to find a way to return to the clinic for follow up.

A majority of participants discussed HIV testing and ARVs with their care supporter, if only to alert the care supporter that they had already tested and started medications. Importantly, nearly one in three participants (31%) commenced ARVs after, and largely as a consequence of, their care supporter intervention [Table 6]. In an environment of entrenched stigma and gaping voids of silence around HIV/AIDS, this 'talk, for some, was an extraordinary process. They described the synergies derived from care supporters' advice that echoed and supplemented counsel they had been given at the clinic. Ongoing instruction regarding ARV adherence ("they helped me to take the pills: eat first, wait, then take pills – I used to vomit") and encouragement ("life continues even when one is HIV positive") were frequently cited as key factors in why a care supporter relationship was felt to have improved their health.

Table 6: ART uptake

When did you initiate ART?	%
Before care supporter intervened	69.2
After the care supporter intervened	30.8

* One participant had not commenced ARV treatment.

Most ARV-related conversations between participants and their caregivers entailed vital reminders about the importance of adherence and creating adherence routines. They also included counsel to visit the health center if adherence problems arose, for example, if side effects became unbearable. Lacking transport funds and adequate food, and in some instances suffering stigma and shame, participants often conveyed the importance of caregivers' moral support, encouraging clients to do their utmost to stick to the prescribed regimen despite the manifold deprivations they faced. Some participants said their care supporters inquired about the specific ARVs they were taking. If the participant did not know, she or he was advised to find out and to tell a family member, so that in case of complications or an accident whereby the participant ended up in the hospital, that they or family member could tell doctors what had been prescribed.

Caregivers' targeted support of ARV adherence was often embedded in the social process of relationship building, one in which caregivers immersed themselves in the daily tragedies and tribulations their clients faced – and which, importantly, caregivers themselves often suffered. A 43-year old participant said she was "so happy" when the care supporter first came to her home, as she had longed for that person to become her "friend." The participant had witnessed the woman to have a "good heart." Unwell, she had gone to a number of clinics but with no improvement. The care supporter encouraged her to request an HIV test, which she did. HIV positive, she had her CD4 count checked, and returned to her care supporter to discuss next steps. The caregiver asked the participant her thoughts, to which the participant replied, "There is no alternative. I accept it. I am going to take the ARVs, so I started." Discriminated against by her family, in part because of their negative views of ARVs, the caregiver continued to play an indispensable role in the woman's survival, acting as both "mother" and "pastor" to ease her pain. When her 25-year old daughter died, recalled the participant, neither family members, fellow church parishioners, nor even her pastor attended the funeral, but her care supporter, flanked by other care supporters, did.

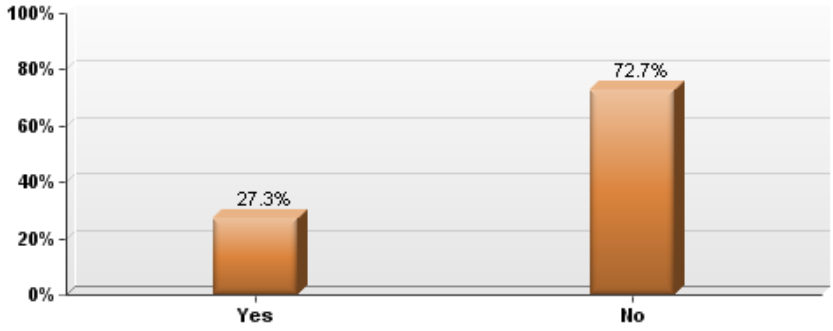
2. "The care supporter is always there": ARV adherence and social change

In a meta-analysis comparing ARV adherence among HIV/AIDS patients in sub-Saharan Africa (SSA) with those in North Africa, the authors found that PLWH in SSA may practice better regimen adherence than PLWH in North America (Mills *et al.* 2006). In this study, a

commitment to ARV adherence was a salient feature of participants' reports, as was the importance of care supporters' encouragement to do so. "Sometimes there are side effects," said a 60-year old man, "and the care supporter is always there for me, telling me, 'go straight to the doctor and tell him.'" The vast majority of participants lacked sufficient funds to get to the clinic, whether for check ups or medication refills. This meant that regardless of their state of ill health, participants walked as much as four hours, or as one woman reported "hitchhiking three cars," to reach a clinic. Caregivers often struggled to provide food and money for clinic transport, and helped to devise strategies of disclosure to a family member, whereby the client could take the ARVs freely, without fear of stigma.

Alongside the economic constraints that undermined adherence, approximately 27% reported that they had **felt or been discouraged from taking their hard earned ARV medications** [Figure 6]. Mills *et al.* have pointed up the importance of "understanding culturally specific barriers to adherence" as these "will be important in developing evidence-based interventions targeted at the individuals with poor ART adherence" (2006:688). Participants reported caregivers' ongoing ARV encouragement, their counsel to avoid traditional herbs, and their readiness to respond to HIV-related questions (or to refer them to clinic) as among the 'most important' roles they played in improving their health. In doing so, care supporters strengthened a broader social process of mitigating peer pressure against using ARVs, a subject (discouragement, resistance) in need of much more research, that reportedly came from friends, family members, colleagues, and other members of the community.

Figure 6: Has anyone ever discouraged you from taking ARVs?



The question of whether participants had ever been "discouraged" from taking ARVs initially was designed to explore the 'local world' of health seeking practices, in particular social pressures to utilize traditional healing modalities for apparent HIV infection. Participant responses, however, pointed up a myriad of non-mutually exclusive ways that ARV discouragement was perpetrated and the ways that PLWH resisted such pressures in order to maintain adherence. Care supporters played an integral role in such resistance. Three such discouragement processes are described here:

a. ARV discouragement as part of a generalized denial of HIV/AIDS

Demonstrating the broader influence that care supporters appeared to be having at the community level, a 32-year old woman said the men of her community discouraged her from taking ARVs, insisting that there is no such thing as HIV and AIDS. "You are being influenced by these caregivers," they told her, "so you must stop taking the tablets." She said she stands firm against these men's disapprobation: "No, I won't discontinue. I will continue [taking the ARVs]." Prior to her care supporter's intervention, this participant had feared joining others at meals and on some days even denied her HIV positive status. She said she believed in ARVs, "because I saw

that I was almost dead." With the care supporter's encouragement, she rejoined her social world and accepted her HIV status. With her personhood restored, she responded to her detractors, "No, I will not discontinue. I will continue [taking my medications]."

b. "It's my life": ARV discouragement and the association with being HIV positive

In many instances of ARV discouragement, the social friction was less with ARV as a treatment modality than its association with the fact of a person's being HIV positive. If a person is on ARVs, it is known that that person is HIV positive. Thus, asking about 'discouragement' elicited accounts of the role that ARVs play in constituting an HIV positive identity. A 48-year old woman said her neighbors discouraged her from taking the ARVs, because it would cue others to her HIV diagnosis. She responded that she would not stop taking her ARVs, because "it's my life," a discourse of self-ownership echoed by other participants and which care supporters helped to strengthen through ongoing education and encouragement. A 42-year old widow whose husband had been supportive of her but who sadly had passed away, said her in-laws protested her use of ARVs, refusing to enter her house or to eat any food that she prepared, because "you are eating ARVs." They "hated" that she was on ARVs. With the translator's assistance, it became clear that the question of 'discouragement from using ARVs' was understood not just as pressure not to take ARVs but a participant's *feeling* of 'discouragement' since if one takes ARVs, it is because one is HIV positive, which constitutes grounds for social denigration and rejection. Thus, it appeared that the participant's in-laws might have entered her home if she stopped the ARVs, as this would erase the fact that she is HIV positive, and thereby restore to her an acceptable personhood. ARV discouragement of this kind constituted a social process that overlapped with HIV stigma and ongoing 'HIV/AIDS denial' described below.

Focusing on an individual's ARV regimen seemed to provide an additional means of diminishing an individual for being HIV positive, producing a feeling of discouragement. One participant recalled how the rural health motivator (RHM) in her community, a person who is tasked by the government to provide basic health information and outreach, would be dismissive of the participant. If they bickered, the RHM would maintain that the participant was being difficult because she was taking ARVs. Others in her community disparaged and discouraged this participant from taking ARVs as well. She would retort, "Even if I take the ARVs, I am very fortunate because I know my [HIV] status. What about you? It's highly possible that you have only five CD4 count." That she invoked self-knowledge of her CD4 count as a sign not of inferiority but as a source of defiant pride reflects not just a heightened degree of HIV/AIDS literacy but the seed of a new mode of HIV positivity.

Negative associations between ARVs and 'being HIV positive' fueled feelings of discouragement in other ways as well. One participant said there were people who felt it was a disgrace to carry ARVs, for example, to a funeral, which might last all night, and to take them in front of people – a form of poor etiquette. However, adhering to a regimen schedule might require such discipline. A second participant described how his colleagues at work (as a taxi driver) called him stupid for taking the ARVs, saying that if they themselves were HIV positive, they would have no need to rely on the tablets as he does. "They think they are clever," said the participant. "They are stupid." Asked how he reacts when they say such things, he said, "I just keep quiet because I know what I'm doing for my life."

c. Challenging ARV efficacy and pressures to use non-biomedical modalities

A final means of discouraging an individual from taking ARVs was to call into question the effectiveness of the medications and to challenge the participant's confidence in their clinical efficacy. At least two participants had been told by peers that taking ARVs would make them very sick and that they would die, as a result. One was a participant who described a family dispute in which her father-in-law insisted they she must not take the ARVs, but rather ingest herbal medicines, as ARVs will cause her to die. Asked how she responded to such pressure, the participant said she insisted, "No, you are the one who is going to die!" These were some of the family dynamics that care supporters might have to navigate in an effort to support their clients.

Besides pressures to use traditional healing, a pastor, and certain churches were reportedly propagating prayer for treatment of HIV/AIDS and against ARVs. In this setting, the fact that the organization's care supporters were perceived as *both* religious and health 'people' was extremely significant. As agents of Christianity and HIV/AIDS educators, they were well-positioned to authoritatively discourage non-biomedical modalities for HIV/AIDS and to promote the use of ARVs. A 48-year old participant described a product called Forever Living that was gaining popularity, so much so, that even at a cost of 200 rand a bottle, people were switching from their ARVs to use it. She felt that many in her community had died as a result. The same product was mentioned by another participant, a 58-year old woman, who said people had discouraged her from taking ARVs, pressuring her to use Forever Living instead. One participant who, though diagnosed HIV positive in 1999, had yet to need ARVs (she said she had a CD4 count of 500), described how friends tell her she must not take them. She said she pushes back, telling them, "I won't [discontinue], because I was taught how to care for myself. They teach me that if I am supposed to take ARVs, I must take them my whole life."

Taken together, these reports paint a scene in which already vulnerable individuals found themselves defending their medical decisions to family members, community members, neighbors, and others. Conventional HIV/AIDS programs have yet to address these serious obstacles to ARV uptake and adherence, and to grasp how HIV stigma plays out through multiple religious and non-biomedical discourses to complicate HIV health seeking practices and to compromise a healthy HIV positive identity. Under such conditions, caregiver support for ARV adherence was uniquely positioned both to facilitate an adherence regimen, and to serve as a significant source of PLWH empowerment as it relates to adherence, as well.

G. "*We smoke one pipe*": Socio-religious dimensions of home-based care

Though approximately 15% of participants indicated that they did not identify themselves as Christian, nearly every participant felt it was important that a care supporter be a Christian. I turn now to an analysis of participant reports on why Christianity mattered as a feature of the home-based care that they received, in part so that the politics of religion and HIV/AIDS at the policy and programming levels may be better informed by the lived experience of religion and HIV/AIDS on the ground [Table 7].

Table 7: Significance of a Christian caregiver

- Christians were believed to give **credible health counsel** and to **protect clients' confidentiality**, presumably better than non-Christians would;
- Christians have **"the heart"** of giving and **compassion** that is needed to tend to the extreme and ongoing needs of PLWH in their communities;
- Christian caregivers were attributed with a **moral authority** that served two purposes with respect to being HIV positive: 1) their compassionate statements on being HIV positive helped to trump the malicious moralizing that fueled much HIV stigma and; 2) the disciplinary elements of caregivers' moral authority, for example with respect to sexual activity, helped some participants to make what they felt were HIV healthy decisions.

a. Credible counsel and confidentiality

Care supporters' counsel and regular presence factored significantly into many participants' daily lives. The most important aspect of her care supporter relationship, said a 39-year old woman, is that she "can talk about anything to [the caregivers], even frictions within the family." The care supporters felt like parents to her, she continued, and "to your Mom you say everything." Christian care supporters were frequently constructed as guardians of confidentiality, able to create safe spaces for clients to speak about all manner of concerns. The importance of confidentiality was found to be critical in a project by the United States Centers for Disease Control with the Ministry of Health of Swaziland, which found that once individuals were assured that confidentiality of test results was protected, home-based TB and HIV testing

and counseling services were well received and facilitated disclosure (University Research Co., LLC 2010). Like the study data presented in this report, the project demonstrated the centrality of confidentiality and its particular importance in domestic household spaces to successful outreach as a means of bringing patients into the formal health system fold. While Christianity was not identified as discrete variable, a better understanding of its significance to certain populations, as this study aimed to provide, may be productive in designing and implementing future home-based HTC initiatives.

b. Christians have "the heart" to care

The notion that a Christian will not abandon a sick person was a recurrent theme in explanations for why it is important that a caregiver be Christian. In this light, care supporters were attributed with almost supernatural patience. A Christian, explained a 34-year old man, doesn't get tired of comforting and advising, but a non-Christian says, "'Eh! Now, I'm sick and tired of this person,' and leaves just like that." A 60-year old participant felt that if his care supporter were not a Christian, he would be dead. Asked why, he said he felt it was due to Christianity that "the care supporter is taking care of me in the first place." Being a Christian is important, answered a 31-year old male, because "if a care supporter is a Christian, with the love of God, that person transfers the love of God to sick people […] Some people do not like to spend most of the time with sick people, so I feel all care supporters must be Christians […] 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." Having a Christian 'heart' thus emerged from questionnaires as a special competency that enabled care supporters to tend to clients' needs indefinitely, as best they could, and to engage in ongoing communicating about HIV/AIDS that was clear, compassionate, and non-judgmental.

The compassion shown by caregivers was often attributed to a Christian personhood, a correlation which suggests a distinctly different (progressive) interpretation of Christianity than one might glean from public health debates over the appropriate role of religion in HIV/AIDS initiatives, with the exception of faith-based orphan care. "A Christian accepts you with the disease – the person will understand my suffering," explained a 46-year old woman. Moreover, the actual tasks care supporters performed were felt to reflect and constitute an ideal Christian. "She cares for me," said one participant. "She wants to know, did I get food. She reminds me of the days of going to the hospital to get some ARVs, if it is my date." The sentiments of 53-year old male suggested a progressive relationship between Christianity and HIV/AIDS that was both immanent and self-evident in caregiver practices:

> Participant: It's important that a caregiver be a Christian, because we are all God's creatures.
> Interviewer: Why is that important with caregiving?
> P: We need to love God. We are getting help through the care supporters because of God's love. If God's love was not there, we would not have these care supporters. We are getting help through these care supporters who are helped by God to do the work.
> I: So, non-Christians would not have that?
> P: Yes [that's right].

Finally, a Christian caregiver was able to provide essential spiritual support that a non-Christian caregiver would likely not be equipped to do. Thus, a 48-year old woman said she felt it was "so important" that the care supporters be Christian, in order that they can "help me in all ways, spiritually and physically. If these caregivers were not Christian, I think I would be dead." It is important, said a 62-year old man, "because she's going to help me if I am depressed. She lifts me up…When she speaks to me, I hear the words she is speaking to me, and these words are healing. These words are from a Christian."

c. Moral authority: reducing HIV stigma and HIV health practices

The belief that Christian care supporters' words are truthful and trustworthy, with respect both to explanations of HIV and God's love, was foundational to the client-caregiver

relationship. A 53-year old woman felt it was important for a caregiver to be Christian, "because we smoke one pipe." Although a non-Christian care supporter could provide assistance with household tasks, at times one needs spiritual support, she explained, to sit down and discuss issues that a non-Christian could not. This shared quality – "the caregiver is a Christian and I am also a Christian; she understands me very well" – appeared to deepen the trust, and therefore the relationship, that a client and caregiver could develop. Having a Christian care supporter was important to a 55-year old man, because "a Christian must not be a choosey [judgmental] person, saying who is a good person and who is a bad person, or who is deserving of health." Virtually every participant reported that there were **religious aspects** to care supporter home visits. These included praying and Bible reading. Care supporters sometimes encouraged their clients to attend church and to repent. To many 'outsiders,' discourses that redound upon conservative Christianity as a source of HIV stigma reduction may seem quixotic. Yet, with 85% of participants claiming a Christian affiliation, and 77% reporting that their **religious feelings had changed** since a care supporter began visiting them [Figure 7], the majority of these feeling an intensified religiosity, Christian discourses and practices were a salient and, on the whole, welcome feature of the home-based care experience.

Figure 7: Have your own religious feelings changed since a care supporter started visiting?

For some clients, the care supporters' modeling of a compassionate as well as morally disciplined personhood seemed to inspire opportunities for personal growth and development. According to one 30-year old woman, "a care supporter helps you become a Christian, because you see what they are doing for you. You wish to become a Christian." Given that they are not positioned – nor is it their mandate – to insert themselves into the rhythms of patients' everyday lives, clinic personnel may lack the necessary insights about an individual's life to prevent suicide or suicidal ideation on an ongoing basis, in real-time. For a 56-year old woman, a care supporter would ideally be Christian. At times, she said, people who are HIV positive "feel they are discriminated against" to the point where they may wish to end their lives. But a care supporter who is Christian will explain that it is not right in front of God to kill yourself. 'Just repent…God is there.'" The despair that caregivers dissipated was profound. A 42-year old woman felt it was important that a care supporter be a Christian, because "I want to raise my kids, and the caregiver encourages me to refrain from killing myself as other HIV positive people do."

Given the HIV stigma and the potential loss of moral personhood suffered by many HIV positive persons, the Christian dimension of the organization's home-based care offered participants who desired it a restoration, or re-creation, of a new form of moral personhood, not despite the religious care component but because of it. "If you have the disease, the word of God encourages you, because God still loves you," explained a 47-year old woman. To still be "loved" could be life saving, yet "love" is not a term commonly found in conventional biomedical HIV/AIDS parlance. "The care supporter encourages me to read the Bible," said one woman, "and quotes verses of Jesus preaching and healing a woman, and the story of Job. That

encourages me, because even if my children stigmatize me, God still loves me." Another woman felt her caregiver relationship had intensified her religiosity because of the solace the religious care practices brought her. "When I feel disappointed, and I don't know what's wrong, the caregiver comes and reads verses, and I feel motivated." Asked to name her favorite verse, she identified Psalm 103. The passage reads, in part, "Praise the LORD, my soul…who forgives all your sins and heals all your diseases…The LORD works righteousness and justice for all the oppressed" (Biblica 2011). In light of the social isolation many participants experienced, its emphasis on love and compassion, and self elevation, as conveyed through a relationship with a care supporter underscored the importance of both Christianity and the caregiver relationship.

Care supporters were often attributed with credibility on health issues and thus imbued with a moral authority to intervene, when appropriate, in family and sexual dynamics in ways that conventional public health programs generally cannot for two reasons. First, these interpersonal, dynamics often transpire too far afield of the formal health services for clinic staff to intervene at the scale needed. Second, the religious moralism that some participants felt was important is arguably negated by the implicit secularism of biomedical HIV/AIDS discourses. Fearlessness, truth, HIV, sex, and Christianity were intermingled and essential to the home-based care experiences of one woman:

> Participant: A [Christian] care supporter is not afraid to tell the truth.
> Interviewer: Truth about what?
> P: She encourages me not to leave my home, for example, to go find another husband, and not to return to my family's homestead, abandoning my children. The care supporter will even be able to tell my husband, you should use a condom when you have sex. The care supporter won't be afraid to tell my husband what he must do, and that I must stay.

In fact, the participant felt her husband began using condoms as a result of the care supporter's intervention. A correlation among truth, Christianity, and HIV in participant experiences of church run home-based care was likewise voiced by a 56-year old man, who claimed "a care supporter can speak the truth, and the truth is with God." A non-Christian, explained another participant, could lead a person astray into traditional healing or even bring evil spirits that could harm one's children.

In addition to being knowledgeable about HIV/AIDS, a Christian care supporter could also serve as a source of disciplinary intervention. A 48-year old woman whose husband and son were dead felt the religious moralizing component to be an important part of her home-based care. As a Christian, the care supporter "will help me when I'm going astray," intimating that she might otherwise seek out traditional healing or perhaps a sexual partner. A Christian care supporter will intervene and guide her, telling her, 'No, a child of God doesn't do this.'" A 42-year old woman explained changes in her own risk related behavior, that she had become more religious since her care supporter entered her life: "All the things I was doing wrong, I've changed, like sleeping with many men." The very language that has arguably fueled religious moralizing and marginalized PLWH in more secular settings might be experienced as trustworthy counsel about personal risk management in another. A 42-year old woman said that she and her care supporter talked about adopting new behaviors and an HIV positive personhood that prioritized self-preservation. Asked what kinds of behaviors she was referring to, 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." In this way, Christian discourses and practices were inextricably bound up in HIV health practices that affected participants' wellbeing, practices which conventional HIV/AIDS interventions seek, often with limited success, to influence.

Thus, to assess the impact of caregivers' evangelizing practices outside of participants' local context, and outside of the care relationship itself, would be to miss the deeper significance of Christianity to cultivating a proactive HIV positive self. For example, the prayers of a 57-year old woman emboldened her in the face of the rigors of an ARV regimen in order to successfully adhere: "God, since you know that I am now HIV positive, help me to be perfect in taking my

medications." Feeling "more religious" after a care supporter entered her life, a 32-year old woman said, "I see now I've raised myself a lot. Life will be there. I am encouraged because God helps me to not stop taking pills." Knowing that their care supporters prayed for their health and provided spiritual counseling were among the "most important" practices they performed. A 56-year old woman described how these practices both assisted and uplifted her in essential ways: "The caregivers do things that show they are Christian. Like, if we are sick, they clean for us. They teach us that HIV is not a death sentence. 'God is there, and he still loves you.'" Enacted in front of a family that may fear or discriminate against their HIV positive family member, these religious and biomedical care practices, of love/religious faith inextricably tied to ARV adherence, had the potential to be transformative of participants' – and household – experiences of HIV/AIDS. The experience of religious moralistic dictates must therefore be understood within an epidemiological setting of extremely high HIV and TB prevalence, gender violence, and poverty; a social setting where the SHBC care supporters were viewed by many as fonts of unconditional love, critical HIV/AID education, and anti-HIV stigma sentiments.

VI. Conclusion and recommendations

This report describes findings from a study of the impact of a church run home-based care organization on perceived wellbeing among its HIV positive clients in southern Swaziland. Overall, findings suggested that caregivers' impact was often life-saving and life-preserving in ways that have been little examined in the social scientific and public health literatures. Given recent decreases in donor government funding for HIV/AIDS (Kates *et al.* 2011) and the politics that have long surrounded religion and HIV/AIDS, the study aimed to contribute to a deeper understanding of both home-based care and the interplay between religion and biomedicine in the lives of PLWH and their families. Though focused on a faith-based entity, it also is meant to contribute to a programmatic interest in mobilizing "local networks" to create "'health enabling community contexts" (Campbell *et al.* 2008:508).

In many parts of the world, 'home' is ground zero of 'being' HIV positive. 'Home' is where stigma and/or support are manifest and where health-related decisions often are rendered. As a result, any 'intervention' inside such a space has the potential to be transformative of the individual who is afflicted and his or her kin. Churches, conceptualized in this report as social collectivities led by religious leaders who often carry substantial moral and other forms of authority, are, like 'home,' potent places in which to experience an HIV positive status. Situated outside the formal health sector but profoundly affecting many individuals' health, 'home' and 'church' intersected in this study in the form of church run home-based HIV/AIDS care. That 'lived intersection' was the client-caregiver relationship, through which 'care' exercised its impact on participants' perceived wellbeing. Knowledge of the mechanisms by which that impact was achieved could well inform government and donor efforts to decentralize and integrate health and social welfare services.

The concept of religious health assets (RHA) was instrumental to framing the research question and interpreting study results. Just as RHA are conceptually divisible into tangible and intangible domains, client needs and caregiver impact were analytically separable into tangible (e.g., food, money for transport) and intangible (e.g., treatment support, both logistical and attitudinal, and stigma reduction) categories. However, participant reports illustrated how deprivation or assistance in each category exacerbated or reinforced the other to dramatically impact wellbeing. If assets "are not used, then they remain at rest, but always available for use through some agentive act" (Bongmba *et al.* 2007:3). The 'agentive act' – the leveraged asset – in this study was case organization, through caregivers' material, educational, psychosocial support to PLWH, the value of which was often augmented by their Christian affiliation and practices.

Categorizing biomedical and socio-religious aspects of participants' HIV/AIDS care experiences was of heuristic value in designing the questionnaire and reporting study results. Analysis showed, though, that the lived reality of PWLH was a dynamic interpolation of biomedical and socio-religious practices that a discursive dyadic representation can only approximate. In many instances, the radical shift in individuals' willingness to test for HIV and to adhere to ARV regimens as a result of caregiver 'interventions' (relationships) was inextricably tied to the attributes participants assigned to Christian caregivers – attributes that a 'hard hearted person' reportedly does not have. Whether through caregivers' direct reminders to take medications or shared rituals of prayer, many clients felt better able to achieve ART adherence as a result of that relationship. This immanence of religion to biomedicine, and of biomedicine to religion, shows 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 on meaningful and actionable terms.

"That's when my life changed," said one participant, describing the significance of the caregiver entering her life. Cultivating relationships between HIV positive individuals and caregivers constituted, in public health parlance, a vital 'intervention.' A new form of social relation, client-caregiver relationships felt exceptionally 'safe' to many participants, even to those who did not identify as Christian, in part due to caregivers' Christian affiliation. The

particular significance of Christianity to participants, as a sign of reliable knowledge, solace, and well kept secrets, was profound. Many participants were resolute in their conviction that it was important that a caregiver be a Christian, less for ideological purposes than for the traits attributed to them. For some, seemingly 'conservative' Christian discourses provided ready language, relevance, and opportunities for 'progressive' self-acceptance and re-integration. Religious moralism thus tended to be experienced less as judgmental dictates than a shared wisdom that helped inform participants' health practices and, as needed, to restore a sense of legitimate personhood.

Speaking against collective misinformation and HIV stigma, these real time ongoing conversations – talk – emerged as powerful instruments of individual wellbeing and, potentially, household and community health as well. Among the newly diagnosed or very ill, 'talk' could be life saving. In some instances, care supporters played salient suicide or suicidal ideation prevention roles. 'Talk' between client and caregiver was often reported as the requisite trigger for constructive HIV-related action (testing, disclosure, ARV uptake and adherence). To a certain extent, neither clinics nor mass health campaigns are designed or capable of facilitating HIV/AIDS 'talk' at the scale or intensity that is needed to reduce household and community stigma and embolden individual HIV health practices, such as treatment adherence. Multiplying the number of safe, constructive, and progressive conversations around HIV/AIDS appeared to be one of the organization's key impact mechanisms.

Heeding the HEARD call for investigation of factors that may impede ART uptake and adherence, participant reports of the social pressures they faced to desist from their ARV regimen highlighted the importance of community home-based caregivers to reduce barriers to uptake and embolden individuals' decisions to adhere to their prescribed ARV regimens. High ART adherence in resource limited settings in Africa have been reported (Miles *et al*. 2007). In fact, a meta-analysis of ART adherence in sub-Saharan Africa and North America concluded that "[t]he expectation of poor adherence in Africa is not an evidence-based rationale for delaying the expansion of ART programs in resource-poor settings […] [T]he focus (or priority) must now be to maintain these ART adherence rates by increasing access to affordable ART" (Mills *et al.* 2006:688). The authors also found that "the most important and prevalent factors that have been reported to negatively affect adherence in sub-Saharan Africa are cost, not disclosing HIV status to a loved one or fear of being stigmatized, alcohol abuse, and difficulty in following complex drug regimens" (Mills *et al.* 2006:687), internal citations excluded). Similarly, participants in this study described their strenuous attempts to adhere, a primary obstacle being lack of funds for clinic transport, exacerbated by a lack of sufficient food. On the subject of regimens, participants made clear their need for, and appreciation of, reinforcement of clinic guidelines once they returned home, counseling regarding side effects, and ongoing encouragement to keep persevering under the duress of daily life. Care supporters in the study area appeared to be unique in that they had both the organizational structure and ethos to help clients manage that duress in real-time. Escott *et al.* have likewise highlighted the social aspect of adherence support in a study of a community-based tuberculosis DOTS Programme in Swaziland, writing that "the role of the treatment supporter is wider than being just a DOT provider—more than just observation of treatment" (2005:1707). Adherence thus emerged as more than just a regimen, but rather as a social practice embedded in complex social relations, which the client and caregiver often navigated together.

Finally, to many 'outsiders,' a study of the significance of Christianity to home-based HIV/AIDS care evades the issues of structural inequalities that ultimately undermine participants' wellbeing. In Swaziland, for decades, subsistence agriculture has been rendered untenable by environmental vagaries, unproductive national economic strategies, entrenched monarchial entitlements, and global commodities markets that have wrought havoc on land use and food prices. British writer and activist George Monbiot writes of Swaziland:

> It doesn't get madder than this. Swaziland is in the grip of a famine and receiving emergency food aid. Forty per cent of its people are facing acute food shortages. So what has the government decided to export? Biofuel made from one of its staple crops, cassava […] It would surely be quicker and more humane to refine the Swazi people and put them in our tanks […] This is one of many examples of a trade described last month by Jean Ziegler, the UN's special rapporteur, as "a crime against humanity." [2006, internal citations excluded]

Amidst such ongoing 'crimes against humanity' and the 'new' forms of humanitarian crisis described at the start of this report, church run home-based care constituted a new mode of community engagement in the study area, precipitated by calamitous conditions, that drew upon an already extant church network. Over time and across geography, the organization's networks have expanded, in many cases transforming the meaning of being HIV positive, encouraging HIV healthy practices, and, according to participant reports, preventing suicide. While prayer and Bible reading may sound, to many researchers, like rote rituals, ineffectual in the face of macro-economic processes, to the extent that church run home-based care may help strengthen individuals' overall health and household relations, it may also provide a foundation for more broad-based, and in 'western' secular terms, progressive social mobilization around PLWH rights to health resources and dignity.

Study findings suggested three interrelated domains for participatory research on religion, home-based care, and HIV/AIDS:

Findings suggested three interrelated domains for future research and programming.

At the individual client and caregiver level:

- In order to maximize human and material resources, are there core self-efficacy skills that clients (PLWH) need and that that caregivers could help to cultivate, beyond which the clients could manage their HIV status without the caregiver?
- How are individuals who become caregivers, by choice or necessity, to be supported and/or compensated?

At the family/household level:

- To what extent do the information and compassion extended by caregivers have a ripple effect on families and households? For example, caregivers in this study helped some participants to disclose their HIV status and were able to influence the HIV testing decisions of at least three clients' husbands. In addition:
  - Does caregiver involvement in clients' lives socialize clients' children into health-enabling HIV practices as well as encourage positive attitudes towards PLWH, for example, vis-à-vis HIV positive children at school?
- To what extent are men currently involved in the "care economy" and what home-based care roles might they play?

At the community/national level:

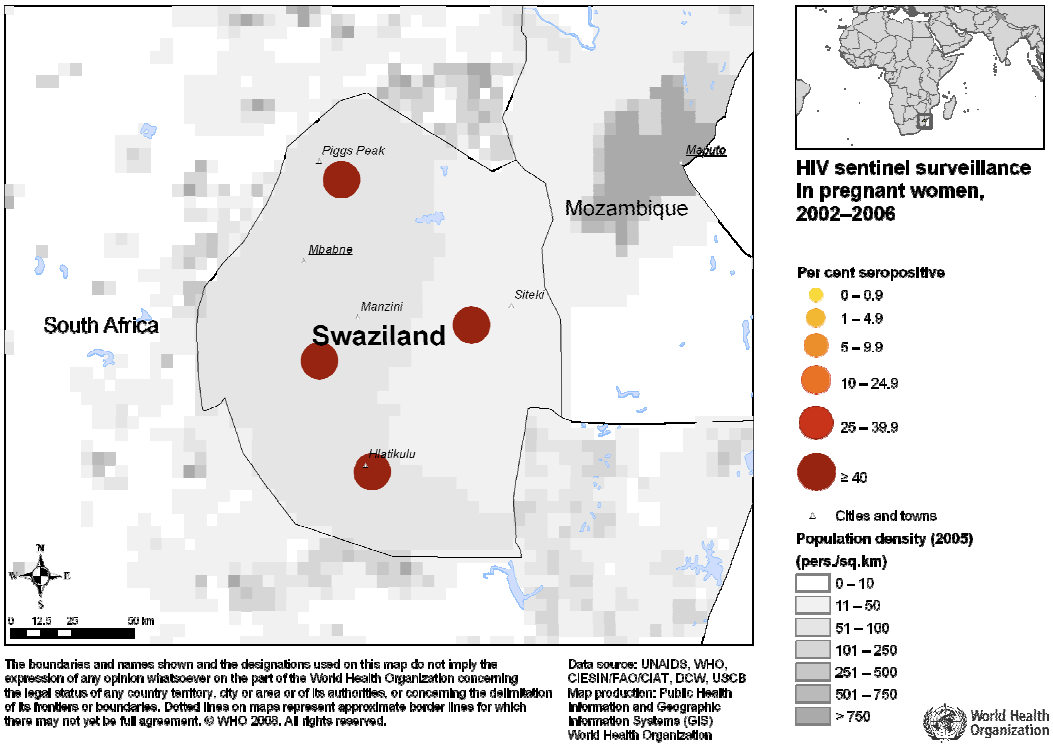
- In what ways might new religious-based organizations (as opposed to 'legacy' missionary health systems), such as the one profiled in this report, be linked to Swaziland's national plans to decentralize and integrate health services?
- Are there productive linkages to be forged with the informal health sector (indigenous healers, pharmacists (often Chinese), chemists, herbalists, prayer healers), as well? Doing so could help to dispel the confusion and misinformation that fuels HIV denialism and discourages ARV adherence.

In conclusion, the SHBC appears to be innovatively advancing Swazi government and donor aims of improving PLWH life expectancy and quality of life, thus also addressing the challenges of the country's escalating OVC rate. At the same time, like so many grassroots entities, especially those that are volunteer based, the organization faces material and human resource challenges, including attrition of care supporters to better resourced northern and international organizations.

In the short term, two "low hanging fruit" that the SHBC might reach for include strengthening linkages with nearby clinics and health centers. Formalized resource sharing and knowledge exchange between nurses and care supporters might serve to alert nurses to the real-time challenges patients face, whereas nurses could apprise caregivers of changes, for example, in HIV testing methods or treatment protocols. Linkages with national HIV/AIDS support organizations, such as the Swaziland National Network for PLWHA (SWANNEPHA) and Swaziland for Positive Living (SWAPOL), could also prove beneficial, as these would allow for cross-fertilization of support mechanisms for individuals of diverse religious and non-religious identification. Continued research on the SHBC group as it expands geographically will shed further light on the roles that church run home-based care might play as a potentially 'exceptional' asset in an 'exceptionally' challenging setting.

Appendix A

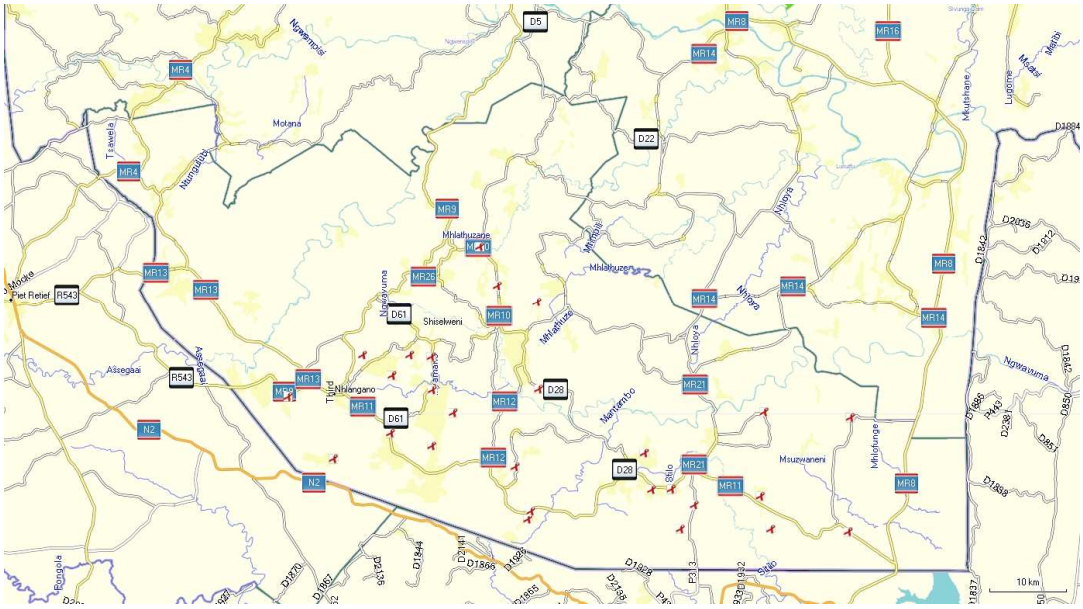
Map of Swaziland and Geographic Distribution of HIV Prevalence



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

Appendix B

Shiselweni Home-Based Care: Communities Served
Southern Swaziland



Source: Arnau van Wyngaard, 2011
Note: Purple line marks Swaziland's southern border with South Africa. Shiselweni district, where study data were collected, is outlined above it. Red 'ribbons' denote SHBC served communities.

Appendix C

Semi-structured questionnaire (face-to-face)

Client experiences of church run home-based care among PLWH in Swaziland[16]

Q1. **Community Background**
Community Name
Year SHBC group started
Number of caregivers
Number of clients
Permission to participate was yes from all participants. Permission to audio record?
Q2. **Client Demographics**
Gender
Age
Schooling
Q3. **Client marital status**
single, never married widow/er (spouse died)
married, monogamous separated, divorced
married, polygamous Click to write Choice 6
Q4. **How are you feeling today?**
Q5. **Do you know what sicknesses are ailing you [Interviewer: If the person does not say HIV, see if it can be delicately determined in questions 20 and 21 below]?**
Yes Sometimes No, why not?
Q6. **So, what kinds of things do you need someone to assist you with?**
Q7. **Do you ask someone to help you with these things?**
No
Yes, whom do you ask (may be more than one)?
Q8. **Do you feel comfortable asking family members for help?**
Q9. **Do you have a SHBC care supporter?**
Yes No
Q10. **How long have you had one?**
Q11. **What did you think when the care supporter first came and introduced themselves to you?**
Q12. **What's the MOST important thing they do for you?**
Q13. **Would you say your health has changed since the care supporter started visiting?**
Yes, better About the same No, worse
Q14. **If better, how so? If worse, how so?**
Q15. **What are your family's feelings about having a care supporter come help? [Interviewer probe: Are some members happy and others not so happy about it?]**
Q77. **Does your family take better care of you as a result of the care supporters' visits? Do they accept you more? [question added on site]**
Q16. **In your view, would you say the care supporters are religious people, or health people, or both?**
Religious people Health people Both
Q17. **Is it comfortable talking about HIV/AIDS with the care supporters?**
Yes No NA
Q18. **Has HIV/AIDS come up in conversation between you and your care supporter?**
Yes No NA
Q19. **(If yes) may I ask what kinds of things come up in such conversations?**
Q20. **Have you ever discussed HIV testing?**

[16] On-site adjustments were made to better capture emergent knowledge on client experiences. Concurrency of data collection and analysis, whereby "new analytic steps [inform] the process of additional data collection and new data [inform] the analytic processes," is characteristic of much qualitative research (Thorne 2000:68).

Yes No NA
Q21. **(If yes) can you describe the conversation for me? [Probe: Did the conversation make you more willing to go get tested?]**
Q22. **Have the care supporter and you ever talked about ARVs?**
Yes No
Q23. **(If yes) can you describe the conversation for me? [Probe: Did the conversation make you more willing to start ARVs? Does the care supporter help you to stay on ARVs?]**
Q26. **Have you been able to tell any family or friends about your situation of HIV?**
Yes No
Some of them. Who?
Q27. **Has the care supporter helped you to tell some family members that you were diagnosed with HIV?**
Yes No
Q28. **If yes, can you describe for me what happened when you first told that person/those people about your HIV situation?**
Q29. **Are there religious aspects to the support the caregiver provides? [Probe: If yes, what are the religious aspects?]**
Q30. **Can you tell me, is it important to you that a care supporter be a Christian, or does it not matter? [Probe: If yes, it is important, why?]**
Q31. **Do you consider yourself a Christian?**
Yes No
Q32. **Have your own religious feelings changed since the care supporter started visiting?**
Yes No
Q33. **If yes, do you feel more or less religious?**
Q34. **Do you consider yourself to have repented, or to be born again? If yes, which one?**
Q35. **Was the repenting (or born again) experience before or after your HIV diagnosis? If after, why?**
Q36. **Do you feel life for your family is easier because of the care supporter visits? [deleted]**
Yes No
Q37. **(If yes, life for the family is easier), how so? [deleted]**
Q38. **What do you feel would happen if the SHBC had never come to your home, or stopped coming to visit?**
Q80. **What do you feel would happen if the care supporter could no longer visit you?**
Q39. **May I ask, how is your family's food and money situation? [**some sub-questions deleted on site**]**
Do you have sufficient food?
Did you work before you got sick?
If yes, doing what?
Are you able to work now? If yes, doing what?
What is the family's main source of income?
Are you able to afford medications?
Do you have enough money to go to the health center when you need to?
Q40. **Just one last question, has anyone ever discouraged you from taking ARVs? [Probe: If so, what did they say? how did you respond?]**
Yes No/Notes
Q79. **Miscellaneous notes from this interview**

References Cited

African Religious Health Assets Programme (ARHAP), 2006. *Appreciating assets: the contribution of religion to universal access in Africa. Mapping, understanding, translating and engaging religious health assets in Zambia and Lesotho in support of universal access to HIV/AIDS treatment, care and prevention*. Cape Town: ARHAP.

Agadjanian, V., 2005. Gender, religious involvement, and HIV/AIDS prevention in Mozambique. *Social Science and Medicine*, 61,1529–1539.

Agadjanian, V. and Sen, S., 2007. Promises and challenges of faith-based AIDS care and support in Mozambique. *American Journal of Public Health*, 97, 362–366.

Agadjanian, V. and Menjívar, C., 2008. Talking about the 'epidemic of the millennium': religion, informal communication, and HIV/AIDS in sub-Saharan Africa. *Social Problems*, 55(3), 301–321.

Agence France-Press, 2011 (3 August). Swaziland gets $368-mln bailout from S. Africa. Available from: http://www.google.com/hostednews/afp/article/ALeqM5jmqNigmiMDRxKHyRX6_eog1KtuoA?docId=CNG.36d823b9bf2d04b0f273f684bcc5f17c.401 [Accessed 3 August 2011].

Akintola O., 2004. *A Gendered Analysis of the Burden of Care on Family and Volunteer Caregivers in Uganda and South Africa*. Health Economics and HIV/AIDS Research Division (HEARD). Durban, South Afica: University of KwaZulu-Natal. August.

Akintola, O., 2010. Perceptions of rewards among volunteer caregivers of people living with AIDS working in faith-based organizations in South Africa: a qualitative study. *Journal of the International AIDS Society*, 13 (22), 1-10.

Allen, T. and Heald, S., 2004. HIV/AIDS policy in Africa: What has worked in Uganda and what has failed in Botswana? *Journal of International Development*, 16, 1141–1154.

Apondi, R., Bunnell, R., Awor, A., et al., 2007. 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.

Avert, 2011. *HIV and AIDS Home Based Care*. Avert. Available from: http://www.avert.org/aids-home-care.htm [Accessed 30 July 2011].

Bediako, K., 1995. *Christianity in Africa: The Renewal of a Non-Western Religion*. Edinburgh, Scotland: Edinburgh University Press.

Biblica. 2011. Psalm 103 (New International Version). Available from: http://www.biblegateway.com/passage/?search=Psalm+103&version=NIV [Accessed 27 August 2011].

Bongmba, E. and Cochrane, J., 2007. Theology, HIV/AIDS and public policy in Africa. *Religion and Theology*, 14, 1-5.

Campbell, C., Nair, Y., Maiman, S., Sibiya, Z., 2008. Supporting people with AIDS and their carers in rural South Africa: Possibilities and challenges. *Health & Place*, 14, 507–518.

Campbell, C., 2003. *'Letting them die': Why HIV/AIDS prevention programmes fail*. Bloomington, Indiana (USA): Indiana University Press.

Carrico, A.W., Ironson, G., Antoni, M., Lechner, S.C., Durán, R., Kumar, M., and Schneiderman, N., 2006. A path model of the effects of spirituality on depressive symptoms and 24-hurinary-free cortisol in HIV-positive persons. *Journal of Psychosomatic Research*, 61 (1), 51–58.

Central Statistical Office (CSO) [Swaziland], and Macro International Inc., 2008. *Swaziland demographic and health survey 2006-2007*. Mbabane, Swaziland: Central Statistical Office and Macro International.

Clark, H., and Quadara, A., 2010. *Insights into sexual assault perpetration: Giving voice to victim/survivors' knowledge (Research Report No. 18).* Melbourne: Australian Institute of Family Studies.

Cochrane, J., 2006. Religion, public health, and a church for the 21st century. *International Review of Mission*, 95 (376/377), 59-72.

Dilger, H., Burchardt, M., and van Dijk, R. eds., 2010. Introduction – The redemptive moment: HIV treatments and the production of new religious spaces. *African Journal of Aids Research* (Special Issue), 9 (4), 373-383.

Erb-Leoncavallo, A., Holmes, G., Jacobs, G., Urdang, S., Vanek, J., and Zarb, M., 2004. *Women and HIV/AIDS: Confronting the Crisis. Executive Summary.* A Joint Report by UNAIDS / UNFPA / UNIFEM. Available from: http://www.unifem.org/materials/item_detail.php [Accessed 25 September 2011].

Escott, S. and Walley, J., 2005. Listening to those on the frontline: Lessons for community-based tuberculosis programmes from a qualitative study in Swaziland. *Social Science & Medicine,* 61 (8), 1701-1710.

George, A., 2008. Nurses, community health workers, and home carers: gendered human resources compensating for skewed health systems. *Global Public Health*, 3, Supplement 1, 75-89.

Gibbs, A. and Smith, J. 2010 (January). *Annotated bibliography on care in the context of HIV/AIDS.* Health Economics and HIV/AIDS Research Division. Durban, South Africa: University of KwaZulu Natal. January. [Document is not paginated.]

Gifford, P., 2008. Trajectories in African Christianity. *International Journal for the Study of the Christian Church*, 8 (4), 275–289.

Goffman, E., 1963. *Stigma: notes on the management of spoiled identity*. New York: Simon & Schuster.

Haddad, Beverly, ed., 2011. *Religion and HIV/AIDS: Charting the Terrain*. Durban, South Africa: University of KwaZulu-Natal Press.

Health & Development Networks, 2001. *"Sharing responsibilities for quality care," Findings and Recommendations.* 1st Southern African Regional Community Home Based Care Conference, 5th – 8th March 2001. Gaborone, Botswana.

Hendriks, J., 2004. Studying Congregations in Africa. Wellington, South Africa: Lux Verbi.

Heymann, J. and Kidman, R., 2009. HIV/AIDS, declining family resources and the community safety net. *AIDS Care*, 21 (S1), 34-42.

Holzemer, W., Uys, L., Makoae, L., Stewart, A., Phetlhu, R., Greeff, M., Kohi, T., Chirwa, M., Cuca, Y., and Naidoo, J., 2007. A conceptual model of HIV/AIDS stigma from five African countries. *Journal of Advanced Nursing*, 58, 541-551.

Human Development Report, 2009. United Nations Development Programme. Available from: Human Development Report 2009, available from: http://hdrstats.undp.org/en/indicators/161.html

[Accessed 14 October 2011].

Ironson G., Solomon G., Balbin E., O'Cleirigh C., George A., Kumar M., Larson D. and Woods T., 2002. The Ironson-Woods Spirituality/Religiousness Index is associated with long survival, health behaviors, less distress, and low cortisol in people with HIV/AIDS. *Annals Of Behavioral Medicine*, 24 (1), 34-48.

Kaiser Family Foundation. *Swaziland's Supply Of Antiretroviral Drugs Running Low*. Kaiser Daily Global Health Policy Report. Kaiser Family Foundation. June 29, 2011. Available from: http://globalhealth.kff.org/Daily-Reports/2011/June/29/GH-062911-Swaziland-AIDS-Drugs.aspx [Accessed 29 July 2011].

Kates, J., Wexler, A., Lief, E., Avila, C. and Gobet, B., 2011. *Financing the response to AIDS in low- and middle-income countries: international assistance from donor governments in 2010. Kaiser Family Foundation and UNAIDS*. August 2011. Available from: www.kff.org/hivaids/upload/7347-052.pdf [Accessed 28 September 2011].

Lee, C., 2003. *Global fund responsiveness to faith-based organizations: An update—Report of a survey by Christian Connections for International Health and Ecumenical Pharmaceutical Network*. McLean,VA: Christian Connections for International Health.

Lindsey E, Hirschfeld M., and Tlou, S., 2003. Home-based care in Botswana: experiences of older women and young girls. *Health Care Women International*, 24 (6), 486-501.

Mauch, V. and Oey, L., 2009. *Report of KNCV visit to The National Tuberculosis Control Program of Swaziland 07 – 17 July, 2009 Report 2*. KNCV Tuberculosis Foundation. Available from: www.stoptb.org/.../1_3_33_ KNCV%20Report%202%20Swaziland%20July%2009.pdf [Accessed 13 October 2011].

Meyer, B., 2004. Christianity in Africa: from African Independent to Pentecostal-Charismatic churches. *Annual Review of Anthropology*, 33 (1), 447–474.

Miles, K., Clutterbuck, D., Seitio, O., Sebego, M. and Riley, A., 2007. Antiretroviral treatment roll-out in a resource-constrained setting: capitalizing on nursing resources in Botswana. *Bulletin of the World Health Organization*, 85 (7), 555-560. Available from http://www.who.int/bulletin/volumes/85/7/06-033076/en/index.html [Accessed 24 September 2011].

Miller, A. and Rubin, D., 2007. Factors leading to self-disclosure of a positive HIV diagnosis in Nairobi, Kenya: people living with HIV/AIDS in the Sub-Sahara. *Qualitative Health Research*, 17 (5), 586–598.

Mills, E., Nachega, J., Buchan, I., Orbinski, J., Attaran, A., Singh, S., Rachlis, B., Wu, P., Cooper, C., Thabane, L., Wilson, K., Guyatt, G. and Bangsberg, D., 2006. Adherence to antiretroviral therapy in sub-Saharan Africa and North America: a meta-analysis. *Journal of the American Medical Association*, 296 (6), 679-690.

Mohammad, N. and Gikonyo, J., 2005. *Operational challenges: community home-based care for PLWHA in multi-country HIV/AIDS programs for Sub-Saharan Africa*. Africa Region, Working Paper Series, No. 88. The World Bank Group.

Monbiot, G., 2006. *"The Western Appetite for Biofuels is Causing Starvation in the Poor World."* George Monbiot. November 6, 2006. Available from: http://www.monbiot.com/2007/11/06/an-agricultural-crime-against-humanity/ [Accessed 28 September 2011].

Montaner, J., Hogg, R., Wood, E., Kerr, T., Tyndall, M., Levy, A. and Harrigan, P., 2006. The case for expanding access to highly active antiretroviral therapy to curb the growth of the HIV epidemic. *Lancet*, 368, 531–36.

Mulenga, K., *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.

Muñoz-Laboy, M, Garcia, J, Moon-Howard, J. Wilson, P. and Parker, R., 2011. Religious responses to HIV and AIDS: Understanding the role of religious cultures and institutions in confronting the epidemic. *Global Public Health*, 6 (Sup2), S127-S131.

National Emergency Response Council on HIV/AIDS (NERCHA), 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].

National Emergency Response Council on HIV/AIDS (NERCHA), 2010. Monitoring the declaration of commitment on HIV/AIDS (UNGASS). Swaziland country report. Mbabane, Swaziland: The Government of the Kingdom of Swaziland. March 2010.

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

Ogden, J., Esim, S. and Grown, C., 2004. *Expanding the Care Continuum for HIV/AIDS: Bringing Carers into Focus*. Horizons Report. Washington DC: Population Council and International Center for Research on Women. June 2004.

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

Otolok-Tanga, E., Atuyambe, L., Murphy, C., Ringheim, K. and Woldehanna, S., 2007. Examining the actions of faith-based organisations and their influence on HIV/AIDS-related stigma: a case study of Uganda. *African Health Sciences*, 7 (1), 55–60.

Pan African Christian AIDS Network (PACANet), 2005. Situational Analysis: Swaziland Report. Available from: http://pacanetusa.com/search?keywords=swaziland [Accessed 13 October 2011].

Pargamet, K., McCarthy, S., Shah, P., Ano, G., Tarakeshwar, N., Wachholtz, A., Sirrine, N., Vasconcelles, E., Murray-Swank, N., Locher, A. and Duggan, J., 2004. Religion and HIV: A review of the literature and clinical implications. *Southern Medical Journal*, 97, 1201-09.

Parker, R. and Aggleton, P., 2003. HIV/AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science & Medicine*, 56, 13-24.

Patterson, A., 2010. Church mobilisation and HIV/AIDS treatment in Ghana and Zambia: a comparative analysis. *African Journal of AIDS Research*, 9 (4), 407–418.

Pfeiffer, J., Gimbel-Sherr, K. and Augusto, O., 2007. The Holy Spirit in the household: Pentecostalism, Gender and Neoliberalism in Mozambique. *American Anthropologist*, 109 (4), 688–700.

Phakathi, M., 2011. Middle-Income Status Reflects Only King's Lifestyle. All Africa, 31 March, 2011. Available from: http://allafrica.com/stories/201103311150.html [Accessed October 14, 2011].

President's Emergency Plan for AIDS Relief, 2010. *The US President's Emergency Plan for AIDS Relief (PEPFAR). Fiscal Year 2009: PEPFAR Operational Plan*. November 2010. Available from www.pepfar.gov/documents/organization/124050.pdf [Accessed 26 September 2011].

President's Emergency Plan for AIDS Relief, 2010. *Partnership Framework on HIV/AIDS 2009-2013. A Collaborative Effort of the Government of the Kingdom of Swaziland and the Government of the USA*. June 2009. Available from: http://www.pepfar.gov/frameworks/swaziland/124993.htm [Accessed 26 September 2011].

Piot, P., 2005. *"Why AIDS is exceptional."* Speech given at the London School of Economics and Political Science, London, 8 Feb 2005. Available from: http://data.unaids.org/Media/Speeches02/SP_Piot_LSE_08Feb05_en.pdf [Accessed 26 September 2011].

Reuters, 2011. *Swaziland crisis deepens as South Africa loan stalls*. September 2, 2011. Available from: http://uk.reuters.com/article/2011/09/02/uk-swaziland-loan-idUKTRE7811TD20110902 [Accessed 7 October 2011].

Rohleder, P., Swartz, L., Kalichma, S. and Simbayi, L., eds., 2009. *HIV/AIDS in South Africa 25 Years On: Psychosocial Perspectives*. New York: Springer Press.

Root, R. 2010. Situating PLWHA Experiences of HIV-related Stigma in Swaziland. *Global Public Health*, 5 (5), 1744-1692.

Root, R., 2009. Being Positive in Church: Religious Participation and HIV Disclosure Rationale Among People Living with HIV/AIDS in Rural Swaziland. *African Journal of AIDS Research*, 8 (3), 295-309.

Root, R. and van Wyngaard, A., 2011. Free love: A case study of church-run home-based caregivers in a high vulnerability setting. *Global Public Health*, Special Supplement: Religious Responses to HIV/AIDS, 6 (2), S174-S191.

Schatz, E., 2003. Comparing, Contextualizing, and Conceptualizing: Enhancing Quantitative Data on Women's Situation in Rural Africa. *Demographic Research*, Special Collection 1, Article 5, Social Interactions and HIV/AIDS in Rural Africa, 143-174.

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

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

Shamos, S., Hartwig, K., and Zindela, N., 2009. Men's and women's experiences with HIV and stigma in waziland. *Qualitative Health Research*, 19 (12),1678-1689.

Smith, J. and Whiteside, A., 2010. The history of AIDS exceptionalism. *Journal of the International AIDS Society*, 13:47, 1-8.

Takyi, B., 2003. Religion and women's health in Ghana: insights into HIV/AIDS preventive and protective behavior. *Social Science & Medicine*, 56 (6), 1221–1234.

Taylor, N., 2006. *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.

Thorne, S., 2000. Data analysis in qualitative research. *Evidence Based Nursing*, 3, 68-70.

Tobias, B., 2001. A descriptive study of the cultural mores and beliefs toward HIV/AIDS in Swaziland, Southern Africa. *International Journal for the Advancement of Counseling*, 23 (2), 99-113.

Toefy, Y., 2009. HIV/AIDS, Religion and Spirituality. *In* Rohleder, P., Swartz, L., Kalichman, S. and Simbayi, L, eds. *HIV/AIDS in South Africa 25 Years On: Psychosocial Perspectives*. New York: Springer Press. Pp. 237-251.

Trinitapoli, J. and Regnerus, M., 2006. Religion and HIV-risk behaviors among married men: initial results from a study in rural sub-Saharan Africa. *Journal for the Scientific Study of Religion*, 45 (4), 505–528.

Tsela, S. and Odido, H., 2007. *Swaziland HIV Estimates and Projections Report, December 2007*. National Emergency Response Council on HIV/AIDS and UNAIDS. Mbabane, Swaziland: The Government of the Kingdom of Swaziland.

UNAIDS, 2006. *High-Level Meeting on AIDS/ Uniting the world against AIDS*. 31 May — 2 June, 2006. United Nations, New York. Available from: http://www.un.org/ga/aidsmeeting2006/declaration.htm [Accessed July 30, 2011]. [Article 32]

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

University Research Co., LLC., 2010. *Increasing HIV Testing and Counselling in the Kingdom of Swaziland. Technical Brief. Swaziland*. October 2010. Available from: 64.210.231.184/uploads/resourcefiles/Swazilandtechnicalbrief.pdf [Accessed 4 September 2011].

Uys, L., 2003. A Model for Home-based Care. *In* Uys, L. and Cameron, S., eds. *Home-based HIV/AIDS Care*. Oxford: Oxford University Press. Pp. 1-15.

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

Vitillo, R., 2009. Faith-based responses to the global HIV pandemic: exceptional engagement in a major public health emergency. *Journal* of *Medicine* and the Person, 7, 77–84.

Woldehanna, S., Ringheim, K., Murphy, C., Gibson, J., Odyniec, B., Clérismé, C., et al., 2005. *Faith in Action: Examining the Role of Faith-based Organizations in Addressing HIV/AIDS. A Multi-Country, Key Informant Survey*. Washington, D.C.: Global Health Council.

Whiteside, A., Andrade, C., Arrehag, L., Dlamini, S., Ginindza, T., and Parikh, A., 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.

Whiteside, A. and Whalley, A., 2007. *Reviewing 'Emergencies' for Swaziland: shifting the paradigm in a new er*a. Mbabane, Swaziland: National Emergency Response Council on HIV/AIDS and Health Economics and HIV/AIDS Research Division.

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

World Health Organization, 2011. Swaziland. Available from: http://www.who.int/countries/swz/en/ [Accessed 14 October, 2011].

World Bank, 2011. *Swaziland country brief*. Available from: http://go.worldbank.org/5XUKCEC850 [Accessed 14 October, 2011].

World Health Organization. 2002. *Community home-based care in resource limited settings: A framework for action*. Geneva: World Health Organization.

World Health Organization, 2004. *World Health Organization Report. Changing History*. Geneva: World Health Organization.

Yang, L., Kleinman, A., Link, B., Phelan, J., Lee, S. and Good, B., 2007. Culture and stigma: Adding moral experience to stigma theory. *Social Science & Medicine*, 64,1524–1535

Zou, J., Yamanaka, Y., John, M., Watt, M., Ostermann, J. and Thielman, N., 2009. Religion and HIV in Tanzania: influence of religious beliefs on HIV stigma, disclosure, and treatment attitudes. *BioMed Central (BMC) public health*, 9 (75), no pages available.