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Working Outside of the Box: How HIV Counselors in Sub-Saharan Africa Adapt Western HIV Testing Norms

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Abstract

The delivery of HIV counseling and testing programs throughout Sub-Saharan Africa relies on the work performed by trained HIV counselors. These individuals occupy a critical position: they are intermediaries between the rule-making of international and national policymakers, and the norms of the communities in which they live and work. This paper explains when, how and why HIV counselors adapt Western testing guidelines (the ‘3Cs’ - consent, confidentiality and counseling) to local concerns, attempting to maintain the fidelity of testing principles, while reducing the harm they perceive may arise as a consequence of strict adherence to them. Data for this study come from Malawi: a poor, largely rural African country, where HIV prevalence is ranked 9th highest in the world. The analysis is based on 25 interviews with HIV counselors and a unique set of field journals, and captures local experiences and the moral quandaries that counselors in rural Sub-Saharan Africa face. The findings of this inquiry provide new insights into the implementation of HIV testing in rural African settings, insights that may guide HIV prevention policy.

Keywords

Malawi; Africa; HIV/AIDS; Counselors; HIV Testing; Consent; Confidentiality; Counseling; rural

Introduction

The delivery of HIV counseling and testing programs (“HIV testing”) throughout Sub-Saharan Africa relies on the work performed by trained HIV counselors (in this paper, I use the term ‘HIV Counselors’, though counselors are referred to typically as ‘VCT Counselors’ (Voluntary Counseling and Testing Counselors)). HIV counselors occupy a critical position: they are intermediaries between the rule-making of international and national policymakers and the norms of the communities in which they live and work. Their task of translation, however, is not untroubled.

An established literature on the role of intermediaries suggests that they modify, transform or even bypass institutional rules in the course of doing their jobs (Merry, 2006; Portes,

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2006). Scant attention has been paid to the work of HIV counselors, however, who as intermediaries directly link the policies and programs of global AIDS interventions to their intended beneficiaries. The work of intermediaries has been the subject of several other empirical studies, including community-based distributors in rural Kenya (Kaler & Watkins, 2001) and colonial Rhodesia (Kaler, 2003); nurses in Kenya (Booth, 2004); and traditional birth attendants and healers in Nepal (Pigg, 1997). In the setting described here, counselors do not always interact with clients categorically as clients, but also as relatives, neighbors, friends, and/or fellow church members (Whyte, Whyte, & Kyaddondo, 2007). Consequently, Western-oriented testing guidelines are altered at the local level as counselors find themselves imbricated in (difficult) situations that necessitate their innovation: they must reconcile the contradictions and conundrums they face in their professional commitments to uphold the ethical requirements of their jobs, with moral concerns for those whom they were hired and trained to protect. A rigorous inquiry into such processes offers new insights into local concerns about testing. Such an inquiry is particularly valuable for those attempting to moderate the pace of the AIDS epidemic in Sub-Saharan Africa, where HIV prevalence is high and where HIV testing is considered a critical measure of HIV prevention and treatment (Ministry of Health [Malawi], 2006; UNAIDS, 2004).

What HIV counselors are trained to do—and what they actually do—is the subject of this paper. I aim to explain when, how and why HIV counselors adapt international and national guidelines for HIV testing in settings far from their international origins. In so doing, I offer an empirical account of the ways in which HIV counselors ‘work outside the box’—figuratively and, even at times, literally—when faced with situations that disturb them. I find that while HIV counselors express an almost slavish devotion to Western testing norms, they have ambivalent views about them. Counselors therefore seek solutions that maintain the fidelity of testing principles, while reducing the harm they perceive may arise as a consequence of strict adherence to them.

Data for this study come from Malawi: a poor, largely rural country of Sub-Saharan Africa, where HIV prevalence is estimated at 12% (National AIDS Commission [Malawi], 2007), placing it 9th highest in world rankings. They include two distinct qualitative sources: 1) 25 interviews with HIV counselors; and 2) a unique set of field journals that capture local experiences with HIV testing.

HIV Testing Norms-From Global to Local

The foundational principles (the “3C’s”) upon which HIV testing rests—(1) that testing includes *counseling*, (2) that testing be conducted with *informed consent*, and (3) that the test result be *confidential* (UNAIDS, 2004)—are quite different from the public health strategies for addressing most infectious diseases. Efforts to control other sexually transmitted or lethal infectious diseases, such as syphilis or tuberculosis, typically involve more stringent measures, such as compulsory testing, contact tracing, and occasionally even involuntary quarantine (Obermeyer & Osborn, 2007). In contrast, the development of approaches to HIV testing has its roots in the early history of the AIDS epidemic in Western democracies (notably the United States), where the disease disproportionately affected stigmatized groups – gay men and injecting drug users – and concerns about the use of prevention measures that would ensure that the epidemic not be driven underground (Bayer, 1991; DeCock, Mbori-Ngacha, & Marum, 2002).

As HIV was recognized as a pandemic, the “3Cs” were institutionalized globally by the World Health Organization (WHO) and The Joint Programme on HIV/AIDS (UNAIDS) (UNAIDS, 1997, 2004; United Nations, 1991; WHO Global Programme on AIDS, 1989). The global justification for the institutionalization of the 3Cs has two foundations: a public

health rationale, which reasons that when testing is voluntary and when it includes counseling on HIV prevention, it is more likely to result in behavior change to avoid transmitting HIV to others; and a concern for the fulfillment of international human rights standards against HIV-related stigma and discrimination (UNAIDS, 2004).ⁱ These testing norms were adopted by national governments, where they were implemented in contexts decidedly different from the West in the epidemiology of the disease, health infrastructure, and community norms and practices.

Malawi is an ideal site to observe the implementation of Western HIV testing norms in a very different setting: it suffers from a severe AIDS epidemic that affects the general population and, especially in rural areas, Western-oriented discourses about human rights are relatively new (see Englund, 2006). It is also a setting where virtually everyone, from members of the National AIDS Commission (NAC) to women talking at the borehole about a sister who seems to have AIDS, is deeply concerned about surviving the epidemic (Watkins, 2004). In Malawi the NAC adopted the “3Cs” principles of the WHO and UNAIDS into its HIV testing programs (Office of the President and Cabinet and National AIDS Commission, 2003). Testing services first became available in the mid-1990s, though they were not widely accessible; in 2004 and 2005, the Malawi Ministry of Health (MOH) received donor funding to expand the availability of free HIV testing to all district hospitals, as well as many rural hospitals and clinics (Ministry of Health [Malawi], 2006).

The expansion of testing services, in Malawi and in other Sub-Saharan African countries, required expanding the numbers of trained health personnel to implement the testing. HIV counselors must be fluent in English, be at least 18 years old, and have a Malawi School Certificate of Education (Form 4 graduate), the equivalent of a secondary school education (Ministry of Health [Malawi], 2007). In some cases, individuals with a Junior Certificate of Education (Form 2 graduate) are considered for training (Ministry of Health [Malawi] 2007), but only if they have a professional background in a field such as teaching. The counselors are individually selected, usually by a sponsoring donor organization, or by the health facilities in which they were employed in a different capacity, to participate in a training course conducted by the Ministry of Health (In 2007), the Ministry of Health reduced the HIV counselor training course from 5 weeks to 3 weeks (the reduction to 3 weeks emerged out of concern that 5 weeks was too long a period to take health workers out of health facilities, where patient demand is high.).

Methods and Local Context

The experiences of HIV counselors in rural Malawi are considered here through two distinct qualitative sources, interviews and a unique set of field journals. These data were collected between 2007–2008, a period of significant change in HIV testing programs in Malawi: testing services, once quite limited, became available in most rural areas; and anti-retroviral treatment (ART) became available in district hospitals for those diagnosed with AIDS. Most central and district hospitals in Malawi have a CD4 count machine to determine ART eligibility. In the absence of one, ART eligibility is determined by clinical staging standards developed by the WHO: on a 1–4 scale, those exhibiting AIDS-related symptoms staged at a 3 or 4 are recommended for treatment (Ministry of Health [Malawi] 2007). In line with changes in international standards set by the WHO and UNAIDS, the MOH replaced the ‘V’

ⁱThe prominence of human rights in the discourse on HIV/AIDS sets it apart from other diseases, and is attributed to the late Jonathan Mann, founding director of the Global Programme on AIDS at the World Health Organization (Altman, 1999). While many observers have noted the positive potential of placing HIV/AIDS in a human rights context (e.g., Gruskin, Mills, & Tarantola, 2007; Mann & Tarantola, 1998), others have criticized the focus on individual rights as an effective public health strategy (e.g., DeCock et al., 2002), particularly outside of Western democracies (e.g., Scheper-Hughes, 1994). These issues are contentious in the global AIDS community. This article takes no explicit side on this debate.

(‘voluntary’) from the long-standing ‘VCT’ acronym (‘voluntary counseling and testing’) with an ‘H’ for ‘HTC’ (‘HIV testing and counseling’), signaling that HIV testing would be routine at antenatal visits and for diagnostic purposes (the acronyms ‘VCT’ and ‘HTC’ are used interchangeably throughout this article). Despite these changes to the institutional and therapeutic context for testing, the 3Cs (consent, confidentiality, and counseling) have remained fundamentally unaltered; for example, though antenatal and diagnostic testing for HIV is now part of routine practice, patients must still provide informed consent before being tested (Ministry of Health [Malawi], 2007:90–91). It is nonetheless probable that some of the observed counselor ambivalence to testing norms is a byproduct of these dynamic changes (also see Yallop, Lowth, Fitzgerald, Reid, & Morelli, 2002).

Interviews

Interviews with HIV counselors were conducted in 11 rural health facilities offering HIV counseling and testing services, including government district hospitals, Catholic mission hospitals, free-standing clinics, and local public clinics. Of the 25 total interviews, all but two took place in a room at the health facility itself (the other interviews took place at the lodge where I was staying), and all but one HIV counselor agreed to be interviewed.

The majority of the counselors interviewed for this study were trained between 2005–2007. Most, though not all, of the counselors were employed at the health centers in other capacities, such as Nurses, Health Surveillance Assistants (HSAs) or Lab Assistants (17 of 25); others were employed solely as paid full-time counselors (5 of 25) (these individuals were either employed at free-standing testing facilities as full-time counselors, or worked as HIV counselors with additional, supervisory job responsibilities as they relate to HIV counseling and testing); the remainder were volunteer counselors (3 of 25). In all cases, the counselors were selected to be trained because they demonstrated good performance in a previous job, because of a dearth of available health workers to serve solely as HIV counselors (see Mullan & Frehywot, 2007), and/or patronage, that is, someone they knew had helped them get the job (Swidler & Watkins, 2009).

The interviews drew upon a loosely structured interview guide, lasted 45 – 60 minutes, and took place in English, the colonial language and the official language in Malawi. I took notes during the interviews, which were transcribed in detail within a day of the interview itself. The interview questions focused on the 3Cs (consent, confidentiality and counseling), specifically how HIV counselors understand these testing guidelines and how they operationalize them in practice. Asking counselors how they understand testing guidelines, however, proved largely unfruitful: the majority simply repeated material from the training manuals. When asked to talk about their actual experiences as it regards counseling and testing, however, it became clear that they have ambivalent views about them. Significantly, counselors also talked about themselves as role models in their communities, as having changed their own behavior on account of their training, and as well-trained missionaries of public health.

Field Journals

The field journals, kept by a Malawian field assistant, capture local experiences with HIV testing in the form of ethnographic texts. Examples of the journals are available publicly at www.malawi.pop.upenn.edu. The journals are part of a larger project in Malawi that aims to learn what people say about AIDS when they are talking with each other in informal conversations in natural and public settings (for a discussion of the journal method, see Watkins & Swidler, 2009). The journals are written in English, and use parentheses or carets (< >) to bracket explanatory comments or expressions that are untranslatable in local languages, chiChewa or chiYao. The field assistant whose journals I utilize here is also a

HIV counselor, and the entries analyzed come specifically from his experience-- and at times, his reports of his colleagues' experience-- with HIV counseling and testing. Ten journals are analyzed, each which average 30 pages in length.

The journal method offers a perspective that is more immediate and thus closer to actual practice than retrospective reports in a formal interview. They allow one to overhear-- albeit at second-hand-- the informal conversations between and among HIV counselors, clients, their families, and other health workers, in effect offering a more dynamic picture of the HIV counseling and testing process, specifically the point at which counselors and clients interact. For the field assistant, the journal writing task is an exercise in reflection, since it does not elicit an immediate response in the same way that a probing interview question would. This has the advantage of permitting the field assistant to illustrate the process of HIV testing in greater detail and depth, as well as a corresponding disadvantage (from a methodological perspective) of allowing more time to edit words with the reader in mind.

Interviews and field journals were coded for content using *NVivo* 8.0, although initial themes were developed during fieldwork. In all qualitative accounts offered, I give pseudonyms to the HIV counselors and any names, including the names of health facilities, clients, family members, or other health workers, to which they refer; for the field journals, I identify the field assistant as 'Sekou.' In the interest of legibility, I insert clarifying or missing words in brackets. Each interview excerpt is noted by the pseudonym I assign to the counselor and the year of the interview (e.g., Agnes interview, 2007); each field journal is dated in a year, month, day format (e.g., 080411).

Data for this study were collected in conjunction with the Malawi Diffusion and Ideational Change Project (MDICP). Ethical approvals for the MDICP, which included the collection of journals, was given by the Institutional Review Board at the University of Pennsylvania and, in Malawi, initially by the Institutional Review Board at the College of Medicine, University of Malawi, and subsequently by the Institutional Review Board at the National Health Sciences Research Council. Additional ethical approvals were provided by the University of Texas at Austin.

Findings: The "3 Cs"

In the sub-sections that follow, I focus on when, how and why HIV counselors adapt globally-endorsed and nationally adopted Western HIV testing norms (the "3Cs") to local concerns at the village level.

Consent

Officially, *consent* means that HIV testing is both informed and voluntary: "Counsellors must obtain their clients' consent to engage in the counseling and/or HIV testing process" (Ministry of Health [Malawi], 2007:258). Most counselors recognize that many clients who come to be tested do so under pressure, or are at times forced, the reasons for which may vary. In many cases, clients are already quite sick; an HIV test, then, may help confirm the source of their illness. Gertrude, a counselor in her mid-40s, explains how she handled a recent case of a client suffering from tuberculosis, which rural Malawians know is one of the major symptoms of AIDS:

*Gertrude explains that the client said, 'I don't want [this blood test]...I can easily die.'*ⁱⁱ *She continues, 'I counseled and counseled and counseled her and made an*

ⁱⁱIt is widely believed that receiving a formal diagnosis as HIV positive is so emotionally devastating that the individual will die more quickly (Kaler & Watkins, 2008).

*appointment for her to return...they must come voluntarily because it [testing] is voluntary.' She said that the client returned on the 22 of June. I express my surprise that she remembered the exact date. Gertrude laughs and says, 'It's my client!' She explains that they are not taught to book appointments in training: 'It's my own [idea]...They told us not to force [people to get tested] in training.' Gertrude reasons, 'It's my job to make a client have a life like I am [like I have]'*ⁱⁱⁱ [Gertrude interview, 2007].

Indeed counselors often gauge the efficacy of their work as hinging on clients agreeing to be tested. Reflecting on her experience with testing pregnant women during their antenatal visits, Alice, a counselor in her mid-20s boasts, '*No one has said no [I don't want an HIV test] to me*' [Alice interview, 2007].

That counselors may try to convince their clients to be tested highlights a key distinction between the Western experience with HIV, where testing norms were developed, and that of Sub-Saharan Africa, where testing norms were imported. In the case of the former, HIV/AIDS is a disease that largely affects particular high risk groups; in the case of the later, the epidemic is generalized, i.e., it occurs mainly through heterosexual sex or from mothers to their babies during pregnancy, labor or breast-feeding. For many counselors, the reality that HIV affects not just individuals, but families, is quite salient to them. If the counselors really believe what they have been taught-- that those who know they are HIV positive and are well-counseled will try not to infect others-- it would be important for them to make every effort to persuade a client to be tested. Thus, counselors may be loath to enforce voluntary testing in its strictest sense.

Malawi's counselors also think about consent differently than the guidelines suggest because they take for granted that families have legitimate claims on their members-- claims which may override individual rights (see Izugbara & Undie, 2008). In the case below, Harold, a counselor in his mid-30s, describes how a more senior counselor advised him to handle cases in which parents send their children to the clinic to be tested. Not only does Harold empathize with the parents' reason for wanting to know their children's HIV status, he also articulates a different ideological heritage from the individualism of the West: rather than the autonomous individual, Harold emphasizes the importance of the collective as he explains to the daughters why they should accede to their father's demand:

A fellow, more senior, counselor told Harold about a case he had of two girls—aged 15 and 17—who were sent by their father to the clinic to be tested. Harold explains that the father came first and was non-reactive [HIV negative] and he wanted to know if the virus was 'with us' [in the family]. The other counselor explained to Harold that he might 'get this situation' and 'not to refuse—there may be a reason why they were sent.' Harold explains, '...people want to know because they think like a family. They want to say we are all non-reactive.' He continues that if the girls felt forced to be tested, 'you show expertise on counseling...you might say [to them], your father is thinking of your future' [Harold interview, 2007].

But sometimes counselors may have a more personal connection: the client in question may be a relative. In this situation, testing norms may not be adapted, but violated. Martha, a counselor in her mid-50s, explains how she handled the case of her own daughter, whom she suspected might be HIV positive. Martha's daughter was pregnant and had refused to have an HIV test during her antenatal visits. Martha clearly thinks her daughter may be infected,

ⁱⁱⁱBy this, the counselor means that it is her job to keep the client alive.

and the family, not only the unborn (grand) child, would be affected. She therefore tests her for HIV without her daughter knowing:

Martha explains that her children all live with her. She was concerned about one daughter in particular, who she says 'moves a lot' [has a lot of sexual partners] and would spend time in rest houses. The daughter is not married and came home pregnant one day. Martha explains that her daughter refused to get tested during her antenatal visits at the health facility nearest to them (and the one where her mother works), and had insisted on giving birth at the District Hospital instead. When the baby was born, Martha asked the midwife not to dispose of the placenta. She took the placenta, and with her hands, delicately illustrates that she tested it herself for HIV. It was then that Martha discovered that her daughter is HIV positive. Martha reasons, 'I've got children and if this daughter of mine does not know her [HIV] status, she can infect us'^{iv} [Martha interview, 2007].

Although Martha would have been taught that it is a 'misconception' that HIV can be transmitted by casual, everyday activities such as sharing plates (Ministry of Health [Malawi], 2007:28), it seems she is not certain that she herself and her other children might not be infected by the daughter. She also was likely taking into account that there are life-saving medicines available for both her daughter and unborn grandchild; and, since the daughter was not married, when the daughter became sick the family would have the responsibility of paying for medicines and trips to the hospital as well as caring for the daughter physically.

In a similar case from the field journals, a client was brought to the health facility, the Tuberculosis (TB) ward specifically, by his uncle-- also a health worker-- for what the client understood to be treatment for a bad skin rash. Once at the clinic, the uncle instructed the health worker at the TB ward to take a sample of his nephew's blood. Thereafter, the nephew goes to see the skin clinician, who tells him, much to his surprise, that his health passbook (medical record carried by the individual) notes that he is HIV positive and that he can be put on ARVs after his skin problem subsides. Below, the hospital staff-- the skin clinician and two HIV counselors-- discuss the situation, which clearly broke the proper testing protocol of seeking informed consent:

After attending to him [the client], Mr. M'phatso, the [skin] clinician, came into the room; this time Sydney [another HIV counselor] had also come into the room. Mr. M'phatso said if we say that you must follow the counseling protocol, you would have killed that client [the nephew] [080416].

The conversation suggests that the peril of waiting for consent-- according to the clinician, and by implication, the client's uncle-- is that it might have prevented the client in question from being tested for HIV, and as a corollary, receiving life-saving, anti-retroviral treatment.

Confidentiality

Officially, *confidentiality* refers to "...the agreement of the counselor not to share anything that is said or done in the counseling room with anyone else without the express permission of the client" (Ministry of Health [Malawi], 2007:73). Of the three testing norms, *confidentiality* is perhaps the most troubling for the counselors. They can all recite what they have been told about confidentiality in their training, and in the interviews they all present

^{iv}In two interviews, including the one with Martha, counselors shared stories about testing a mother whose daughter died of AIDS. In both cases, the mother was the primary caretaker for the sick daughter, and cared for her by bathing her and by cleaning her open wounds with bare hands. While it is uncertain whether these two mothers contracted their HIV infection from their daughters, based on the information the clients shared with them, the counselors believe this is how transmission occurred.

themselves as sticking to the letter of this guideline, and most to the spirit as well. But it clearly bothers them. Chaka, a counselor in his early 50s, explains:

'This confidentiality is not helping on my side [in my opinion].' Chaka explains that sometimes a man comes in for a test, finds out he is HIV positive and then continues having sex with other women. *'This, to me, it breaks my heart.'* He adds that it could be better if people could know the status of others. He continues that he does not know why confidentiality is emphasized so much in training and explains that he once tried to bring up the problems with confidentiality, but it was *'brushed off by some clever people'* [Chaka interview, 2007].

By this, the counselor means that it was a request ignored by educated elites who have influence on testing policies and procedures. Mary, a counselor in her early 40s, articulates a similar sentiment. She recalls a son deeply concerned about the HIV status of his mother. Mary, however, was unable to disclose the mother's test result to her son, placing her in a moral quandary:

Mary asked the mother to whom she would share her results and she said no one, despite her efforts to convince her to do so. When the mother exited the counseling room, the client's son approached her and wanted to know his mother's test results. Mary explained to him, 'I don't have the mandate [to tell you].' The son was very disappointed, but she told him it is *'against our ethics [to disclose results].'* Mary referred the mother for a CD4 count at the District Hospital. She continues, *'I knew he [the son] would know then [that his mother was HIV positive]'* [Mary interview, 2007].

Later in the conversation, Mary reflects on the same case:

'It is very difficult... Sometimes I feel very bad because I'm not telling him [the son] what is there and it is a risk to this person... This is a problem we have as counselors-- at the same time we have to keep confidentiality, we put others at risk. We are left with a dilemma' [Mary interview, 2007].

The core reason that confidentiality troubles the counselors is that they think it is not good public health practice: it impedes, rather than facilitates, the prevention of harm. In the communities of rural Malawi, strict abstinence or fidelity is considered by many to be extremely difficult, if not impossible: thus, partner reduction and careful partner selection are considered as particularly attractive alternative strategies of HIV prevention (Reniers, 2008; Watkins, 2004). Yet if you do not know someone is HIV positive you might unwittingly put yourself at risk if you are married, if you propose marriage or a partnership, or if you accept those proposals. Thus, to many community members and counselors alike, public disclosure of HIV status would contribute to HIV prevention. The pressure for at least limited disclosure may be particularly strong in rural communities, where the village and its surrounding areas serve as the marriage and partnership market, and where HIV counselors, who live there, may well know whose sexual partner is HIV positive.

Even if counselors have been posted from elsewhere, they quickly settle in and make friends, or they may have a relative already living there. Aaron, a counselor in his mid 20s, explains that he frequently fields inquiries from his buddies about who among the local women is a suitable partner. In a boyish encounter on the soccer field, Aaron nimbly deflects one friend's queries about the town's young women:

'You [Aaron] and me [friend], we are both unmarried', suggesting that they might both be vying for the same women. The friend asked Aaron to tell him which girls he thought were 'good ones'. Aaron explained to his friend, 'Brother I can't, it's against my principles.' He continued that he told him that he should go for VCT

and have his girlfriends get tested too. When asked if a friend ever inquired of him about the HIV status of a particular girl, he laughs as if this is common: 'I tell them that they have to ask [the girl]' [Aaron interview, 2007].

Counselors clearly have access to this coveted information. And in some cases, they may wish to exploit it. In an example from the field journals, an HIV counselor was caught by his superiors asking his female clients who tested HIV negative to return periodically to be re-tested. Given the fear in Malawi that one's HIV status will hurt his or her marriage prospects (Kaler & Watkins, 2008), it is reasonable to assume that it is not enough to simply ask someone their HIV status; indeed, those who have been tested may be loath to disclose truthfully if they are HIV positive. Monitoring it yourself, therefore, may be a rational option:

He [HTC Supervisor] then said a certain counselor is proposing [making advances to] women who he finds to be HIV negative by giving them unnecessary review dates [dates to return for testing] so that he will be able to advance his agenda. He continued saying that the said counselor at one time had booked a married woman for review. Unfortunately he did not know that the woman's husband is also a health worker. And when the man asked his wife how come she has to go for review at VCT every week when a person is supposed to go for a retest after 3 months, the woman said it is the counselor who had advised her to visit [go for] VCT for further consultations. The man then told his wife that they will go together on the said review date. When the date was due the man and his wife set off to the VCT clinic and when their turn came they told the counselor that they had come as a couple for counseling. The counselor was shocked because the woman told her husband that the counselor had always insisted that when coming to the clinic she should be alone [080401].

Counselors may also empathize deeply with families who will have to care for individuals who are HIV positive; they may also want to ensure that those who are HIV positive receive the care from their families that they need. Counselors faced with this situation may search for ways to preserve the sanctity of confidentiality, but also reduce the danger that keeping quiet may pose to others. As Chaka explains, *'They [in training] tell us no [you cannot say anything to someone else], but with experience you know what to do, you cannot just leave it like that'* [Chaka interview, 2007].

One way counselors may handle this dilemma is by assuming the moral authority to intervene directly, following the letter but not the spirit of their obligation to confidentiality (also see Datye, Kielmann, Sheikh, Deshmukh, Deshpande, Porter et al., 2006). Later in the conversation, Chaka explains how he handled the case of his neighbor, whose son had tested positive for HIV:

The son of his neighbor, who was a 'drunkard', had come in and was found HIV positive. Chaka explains that he went and persuaded the parents to ask their son about his HIV status. The son was angry and said to Chaka, 'You told my parents [that I'm HIV positive]!' But Chaka then said to him, 'Did I? Go and ask your parents.' Chaka explains that in these situations, you have to find ways to deal with the problem and this was not dealt with in training [Chaka interview, 2007].

Sometimes it is at the request of clients that counselors assume an extra-clinic role, and disclose a person's HIV test results to the family. Felix, a counselor in his mid-20s, describes the case of a friend who tested HIV positive and did not want to share his results directly with his family. Felix clearly sees his role as counseling not only his friend (the client), but also his friend's family members:

'As far as ethics it is not hard [to maintain confidentiality]—it is our duty to maintain secrets.' In reality, he admits, it is difficult, especially in the case of a brother or sister. Felix said he had an example of a friend who was found reactive [HIV positive] and wanted Felix to tell his family so that they could understand and assist him. He said that he was then relieved when the friend asked him to go to his village with him and to tell everyone about his status. Felix said he first told the friend's parents. He said they had some doubts when he told them, because they did not think it could fit with their son's behavior. Felix adds that he could also counsel the family about how to take care of their son [Felix interview, 2007].

In training, counselors are taught that if they are confronted with a situation where someone they know might unknowingly be exposed to HIV, they should *encourage* them, and have them encourage those who might have infected them to be tested, without disclosing the status of the infected partner (personal communication, Nurse, 2009). This strategy, however, may prove too little too late. One journal captures a conversation among a group of off-duty HIV counselors, who are discussing the recent case of a woman who was hiding her antiretroviral medications-- and by extension, her HIV status-- from her husband (also see Smith & Mbakwem, 2007). Given the risk that this situation posed to her husband, the counselors debate the ethics of the confidentiality clause. Not only do they reject it, they also mention their willingness to protect the members of their family from the risk of HIV infection over saving their own credentials:

Arnie told a story of his neighbour who has married a woman who is already on ART. The man had gone for HTC before he got married and when he met the woman [she] also told him that she had HTC done already. The man believed the woman and they got married. Currently the woman is still receiving ART but the man doesn't know. Then Tonya asked, what is the use of confidentiality when it will promote the spread of the virus and later have people die? Jeremiah then said as counselors we need to gang up and organize a march to enlighten the policy makers that another barrier to the fight against HIV and AIDS is the issue of confidentiality. Other counselors said, we second the motion, let it pass... One lady counselor said, as for me if it happens that my sister or brother's partner has been found with HIV, I will risk my job by telling her that your partner has HIV. If I lose my job and they recall my certificate, I can find another career [080601].

Counseling

Officially, *counseling* takes place twice during the HIV testing session: before the administration of the HIV test ('pre-test' counseling), and after the test results are given ('posttest' counseling), when counselors discuss with clients how to take appropriate care of themselves if they are HIV positive and how to avoid infection if they are HIV negative (Ministry of Health [Malawi], 2004). Counseling's stated goals are to: 1) "encourage the client to become self-reliant and feel confident about his/her own ability to make decisions;" 2) "help a client feel better or at least more comfortable particularly in the long run;" and 3) "help a client to become more self-sufficient to deal with on-going and future life situations in a constructive way without requiring continual help" (Ministry of Health [Malawi], 2007:62).

What can be accomplished in the clinic as far as counseling is concerned, however, is often limited. Several structural considerations, for example, impede following mandated counseling procedures: both adequate space and time may be scarce, given the volume of other, perhaps sicker, patients. One way this is handled by counselors-- and endorsed officially as an option, particularly in busy test sites--- is by conducting pre-test counseling with a group of clients, rather than individually, and by keeping the focus on general

information about HIV (Ministry of Health [Malawi], 2007:99). This option may be more often the norm than the exception.

Such group counseling may, however, be insufficient in terms of what clients actually want and need, and how counselors respond to them as a consequence. In practice, counselors counsel not only in the clinic, where it is mandated formally, but also outside of it. Counselors mentioned visiting clients in their homes, or receiving visitors who had come to their home to ask about the HIV status of their partners, or with questions about their own risk for HIV. Gertrude, well known by those in her village, conducted *pre-test* counseling in her home for those who showed up at her door requesting it. She is sensitive to the concerns of her visitors, namely the fear of being seen at a local health facility by others who might question motivations for testing (see Angotti, Bula, Gaydosh, Kimchi, Thornton, & Yeatman, 2009). Gertrude's home affords a place of convenience, privacy and familiarity to discuss HIV:

'I have many clients who say I have saved their lives...they even come to my house.' Gertrude explains that clients say they don't want people they know to see them going for VCT. She continues that she has had 5 couples and 2 individuals visit her at her home at different times. She counseled them in her bedroom, because her husband passed away, and tested them at the hospital. She explains that she knew the clients beforehand: 'Some are my neighbors and others we pray at church together' [Gertrude interview, 2007].

In other cases, *post-test* counseling may occur outside the clinic setting. Simone, a counselor in her late-20s, shares a story about a close friend who comes to the health center to be tested for HIV. The friend was worried that her boyfriend, who refused to use condoms correctly, had infected her with HIV. After Simone tests her, and the friend learns that she is indeed HIV positive, the counselor makes regular visits to her home to follow-up:

Simone says that she has visited her friend since her HIV diagnosis because her friend 'wants to share [religious] ideas.' She explains, 'She is my friend, I can't just leave her.' She continues that her friend has shared her HIV test results with her mother and father and that the parents have asked that Simone visit their daughter regularly to remove her worries [Simone interview, 2007].

According to official guidelines, counselors are not to counsel clients with whom they have had a sexual relationship or with whom they have a current personal relationship (Ministry of Health [Malawi], 2007:260). However, it is clear that in tightly-knit rural communities, and in settings where there is a dearth of health workers, this guideline is highly improbable. Hence, it is often not just the role of HIV counselor with which counselors contend, but also a competing role, such as a friend, fellow Christian, village elder, and/or neighbor. As a corollary, counseling, as adapted by counselors, is not a bounded entity that occurs only in the clinic setting before and after the administration of the HIV test. Rather, it is something they flexibly adapt as the needs of clients-- and as the roles and responsibilities incumbent on counselors in their extra-professional lives-- dictate.

Indeed clients are also well aware that they may need extra help from health personnel, a type of assistance that is not included in official counseling and testing guidelines. As previously illustrated, there are several cases of clients, or their family members, actively seeking help from counselors outside the clinic setting. Often, the situations are grave. In one example from the journals, a pastor had his wife send a message to Sekou requesting that Sekou visit him in his home. The pastor was quite ill—too ill to travel to the hospital and to wait to be seen. But he wanted to be helped:

I made an effort to go and see him... When I reached his house I found that he was sleeping at [in] the sitting room and when I greeted him he told me that he was not feeling well because he had vomited the previous night and now he was weak. He managed to sit up...He showed me his health passbook where the test results were stapled. His CD4 count was below 250; it was at 231 to be precise. Immediately I advised him that at that CD4 count of 231 he was eligible to start ART. He then told me that he had gone to the ART clinic but there were a lot of people and since he was not feeling well he decided that he will have to go there another day. I told him that if he will be feeling better he can make a date with me on Friday the 25th of April so that I can assist him, book for ART Group Counseling and enable him to access the ARVs...[080421].

In another example, a man very sick with AIDS travels to the home of Mr. Nyirema, a health worker, after returning from the hospital to get his ARV medication. He leaves a note with Mr. Nyirema to share with Sekou, whom the client was unable to locate at the hospital. The client knows Sekou personally because they had both been members of the same church choir. His note explains that he is very sick and has no money to buy food. Sekou and Mr. Nyirema decide to make a trip to the client's home, bring him something to eat, and console him. They also meet with his wife, and talk to her about how to best care for her sick husband:

When Mr. Cuzco [the client] saw us he started crying ... 'I never expected that you would come, I am in [have] problems.' Mr. Nyirema told me to go and help him walk to where we had sat and I did so. He walked with some difficulties because he was weak...We encouraged him never to lose hope and give up because he has a very big life ahead of him. We told him that we came because we knew that he is our friend and brother regardless of his HIV status.

We asked him what he had taken [eaten] that morning. He said he had not taken anything apart from the ARV pill for [in] the morning. Mr. Nyirema then advised him that it is not good to stay hungry while he is on medication. He told Cuzco that he should ask his wife to cook porridge for him every morning and if there is groundnuts flour she should add [it] to the porridge. Mr. Cuzco agreed and said his wife left early in the morning because he has developed a hernia and wanted [was looking for] transport to take him to the hospital...I therefore phoned Elizabeth the clinician at the District Hospital...She then advised me to tell the patient to come to the hospital on Monday [when they see hernia patients].

We chatted for a while and in the course of our chatting Mr. Cuzco had gained some strength and he could speak in a very clear voice and he could also laugh with us. We spent an hour chatting with him hoping that by that time his wife might have come so that we could also have encouraged her to be courageous and strong in the meantime...After waiting for an hour and his wife was nowhere to be seen, we started off [on] our journey. As we were about to reach the main road from the village we met two women who stopped us. I realized that the woman who was stopping me was Mrs. Cuzco... We explained to her why we had come and told her that she should make sure that Mr. Cuzco is given some food everyday...while he is taking ARVs [080421].

Discussion and Conclusion

This study examined empirically the ways that HIV/AIDS interventions, and the protocols that accompany them, are adapted by their implementers in settings far from their international origins. Such an inquiry contributes to a vast body of literature on the importation, differential incorporation and local reception of Western practices across

contexts (for examples, see Bledsoe, Banja, & Hill, 1998; Boyle, 2002; Kaler, 2001; Luke & Watkins, 2002; Richey, 2008; Tavory & Swidler, 2008). There are several important implications of the findings presented here for the implementation of HIV testing in rural Sub-Saharan Africa.

HIV testing, as stipulated by the WHO and UNAIDS in Geneva, and by policy guidelines in Malawi, is intended to include *counseling* and be conducted with *informed consent*; all matters discussed between the counselor and client, including the test result, are supposed to be *confidential*. In rural Malawi, however, I found that the implementation of Western testing norms is, at times, quite different from that envisaged in official policy. The protocols that counselors are taught does not—and cannot—cover all contingencies: what counselors do in practice is necessarily discretionary (Carter, 2008; Pritchett & Woolcock, 2004). As these intermediaries implement the policies of consent, confidentiality and counseling, policies that they themselves have not designed—and indeed, had their origin far from rural Sub-Saharan Africa-- they thus actively interpret and reframe them (also see Booth, 2004). In most cases counselors' adaptations of testing guidelines are minor; in other, rarer cases, their adaptations are flagrant. These are cases where the ethics of HIV testing come in conflict with the desire of the counselor to behave in a way that is consistent with his or her sense of morality. This study's major substantive finding is that counselors adapt testing guidelines in a way that allows them to maintain the fidelity of testing principles, or at least fidelity to what they perceive as the program's main aims, while reducing the harm they perceive may arise as a consequence of strict adherence to the actual guidelines.

So how do they adapt testing guidelines and why do they do it? Perhaps the most significant reason is that HIV counselors in rural Malawi are deeply embedded in the communities in which they live and work. As such, distinguishing between their role as a HIV counselor and the competing roles they occupy in their extra-professional lives-- be it as a concerned friend, a fellow Christian, a village neighbor-- is clearly quite difficult for them, as the nature of interaction in these societies is characterized by face-to-face relations where people often know each other or one's family (Weinreb, 2006). From this perspective we can see that their adaptations are not acts of malfeasance, but rather responses to the moral quandaries that the exigencies of their jobs impose. Another important reason is that strictly abiding by testing guidelines often contradicts what they take seriously as their mission: to help those whom they were hired and trained to protect. Indeed, counselors are often quite responsive to the needs of their clients, whose specific cases, questions and concerns inform the testing encounter (also see Datye et al., 2006; Joffe, 1986). This is particularly so in cases when clients are already quite sick and counselors think they should be tested for their own good, and/or when they feel that those who will shoulder the responsibility of caring for them should be informed of their (positive) HIV status. In such cases, counselors perceive official procedures as impeding, rather than facilitating, HIV prevention, as doing harm rather than good. To resolve this quandary in a way that permits them to see themselves as a moral member of their community, counselors distinguish between the office (health facility) and outside the office, where their real work as missionaries of public health can continue. This work is varied and indeed personalized: it may include intervening in clients' family lives, praying with those who are recently diagnosed, and/or delivering food to those who are sick.

How might this study inform policy efforts aimed at improving HIV counseling and testing services? I offer two modest suggestions. First, more training is unlikely to address the issues raised in this study. More training is often touted as an important, if not the most important, antidote when program evaluations yield anomalous results (Kaler & Watkins, 2001; for example, see Paoli, Manongi, & Klepp, 2002). Training, however, focuses on imparting knowledge, skills, and an understanding of the ethics of counseling; it does not

prepare counselors for all the contingencies they will face. More importantly, it is hard to imagine that training could provide counselors with responses that are better calibrated to the variety of moral and ethical conflicts they will experience than the solutions they improvise in the face of specific and unpredictable situations. Thus, policy makers should acknowledge the limits of training and trust the counselors to do what is best in their circumstances.

A second suggestion is to consider supporting alternative approaches to HIV counseling and testing that are not facility-based, approaches that employ HIV counselors who are transient and outsiders to the community, as with some models of home-based testing and mobile testing campaigns. Such tactics have shown marked success in testing uptake in rural African settings, in large part because they assuage concerns of intended clients that familiar health workers would spread one's HIV test result and not keep one's affairs secret (Angotti et al., 2009; Fylkesnes, Haworth, Rosensvård, & Kwapa, 1999).^v Indeed, for counselors greater anonymity might also be desirable: it may serve to attenuate the difficulties they currently face as they reconcile the ethical commitments to their jobs with their moral concerns for fellow members of the villages in which they live.

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^vOther reasons include removing the direct and opportunity costs of travel to reach a health facility and the greater guarantees of privacy in the home (Morin, Khumalo-Sakutukwa, Charlebois, Routh, Fritz, Lane et al., 2006; Wolff, Nyanzi, Katongole, Ssesanga, Ruberantwari, & Whitworth, 2005; Yoder, Katahoire, Kyaddondo, Akol, Bunnell, & Kaharuza, 2006).

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