# Working Outside of the Box[1]

## *How HIV Counselors in Sub-Saharan Africa Creatively Adapt Western HIV Testing Norms*

Nicole Angotti
Doctoral Candidate
Department of Sociology and Population Research Center
University of Texas at Austin
1 University Station A1000
Austin, TX 78712
nangotti@mail.utexas.edu

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## Abstract:

The delivery of HIV testing programs relies on the work performed by a particular group of individuals: trained HIV counselors. When they are at work, they are intermediaries between international and national policymakers and the members of the communities in which they live. This paper attempts to explain when, how and why HIV counselors adapt testing norms in the course of doing their jobs. Many seek creative solutions to maintaining 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 eighth highest in the world and include two distinct qualitative sources: 25 semi-structured interviews with HIV counselors, and a unique set of field journals that capture local experiences with HIV testing. A rigorous inquiry into health processes offers new insights into local concerns about testing.

## Introduction:

The delivery of HIV counseling and testing programs ("HIV testing")[2] relies on the work performed by a particular group of individuals: trained HIV counselors. HIV counselors occupy a unique, critical position: when they are at work, they are intermediaries between international and national policymakers and the members of the communities in which they live. Their task of translation, however, is not untroubled.

The literature on the role of intermediaries suggests that they do not blindly follow institutional rules; rather, they modify, transform, and bypass rules in the course of their daily interactions (Portes 2006: 242; see Booth 2004; Boyle 2002; Buckley 2006; Carter 2008; Joffe 1986; Kaler 2003; Kaler and Watkins 2001; Luke and Watkins 2002; Merry 2006; Pigg 2001). A rigorous inquiry into health *processes*, therefore, may offer 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 an important measure of HIV prevention and treatment.

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[2] My treatment of HIV testing is as a prevention (and treatment) intervention, not for other public health purposes such as sentinel surveillance.

What the HIV counselors are trained to do-- and what they actually do-- is the subject of this paper. I attempt to explain when, how and why counselors adapt international and national guidelines of HIV testing in the course of doing their jobs. 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 the majority of HIV counselors express an almost slavish devotion to the 'rules' of testing norms, they have ambivalent views about them. Many, therefore, seek creative solutions to accomplish the dual task of maintaining 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 eighth highest in world rankings. They include two distinct qualitative sources: 1) 25 semi-structured 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 unique public health strategies for addressing infectious disease. Efforts to control such infectious diseases as syphilis or tuberculosis, for example, typically involve more stringent measures, such as mandatory testing, compulsory treatment, and/or quarantine (DeCock et al, 2002). In contrast, HIV testing norms developed in the West in battling the spread of a lethal virus disproportionately affecting an historically stigmatized, but politically mobilized group-- gay men-- in the context of their sexual lives, at a time in the epidemic when many were in danger of losing their homes, jobs, or health insurance if found to be HIV positive (Bayer 1989; also see Rosenbrock et al, 2002). As a result, the norms emphasize a private, voluntary practice that protects the individual rights of those infected. As HIV developed into a global pandemic, these norms (the "3Cs") were institutionalized globally by international organizations such as the World Health Organization (WHO) and The Joint Programme on HIV/AIDS (UNAIDS) (see Centre for Human Rights 1991; UNAIDS 1997; UNAIDS 2004). The global justification for the institutionalization of the 3Cs is two-fold: a 'public health rationale', which reasons that when testing is volitional 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). These testing norms were then 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 a model site to observe the implementation of Western HIV testing norms: it is extremely poor, suffers from a severe AIDS epidemic that affects the general population and, especially in rural areas, knowledge of western conceptions of human rights is low (Garbus 2003). 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 worried about surviving the epidemic (see Watkins 2004). In Malawi the NAC adopted the "3Cs" guidelines of the WHO and UNAIDS into its HIV testing programs. Testing services first became available in the mid-1990s, though they were only accessible in private health clinics and research hospitals; in 2003, testing became available in government hospitals for inpatients. In 2004 and 2005, the Malawi Ministry of Health (MOH) received funding to expand the availability of free HIV testing to all district hospitals, as well as many rural hospitals and clinics. In 2004 there were 128 sites that administered HIV tests; by 2006, it nearly doubled to 249 (Angotti et al, 2008).

The expansion of testing services, in Malawi and throughout other Sub-Saharan African countries, required expanding the numbers of trained health personnel to implement the testing. In effect, this meant having to recruit national cadres of paraprofessionals to be trained as HIV counselors, an effort that sparked early concerns among Western testing proponents, among them that reticence might be taken for granted (personal communication with CDC epidemiologist May 4 2007). In Malawi, 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 2007: XVIII).[3] The counselors are individually selected, usually by a sponsoring donor organization such as UNICEF or Save the Children, or by the hospitals in which they were employed in a different capacity, to participate in a 5-week training course conducted by the Ministry of Health. For many, the opportunity to be certified as an HIV counselor is a promise of greater social mobility: Malawi, like many other Sub-Saharan countries, is characterized by pervasive economic insecurity and underdeveloped labor markets (Swidler and Watkins 2007). A certificate in HIV

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[3] In some cases, individuals with a Junior Certificate of Education (Form 2 graduate) are considered for training (Ministry of Health 2007), but only if they have a professional background in a field such as teaching (personal communication with nurse at Lighthouse Trust, Malawi).

counseling and testing affords the added prestige of biomedical and "expert" knowledge on AIDS, as well as the potential to develop contacts with wealthier and more educated professionals, and western donor agencies. It is not surprising, therefore, that many HIV counselors fashion themselves as nascent elites, charged with the mission of helping the nation to avert the spread of a deadly disease and to treat those already afflicted (for related observations, see Booth 2004 for Kenya; Pigg 1997 for Nepal; also see Swidler and Watkins 2009).

## Methods and Local Context:

The data for this study were collected between 2007-2008, a period of significant change in HIV testing programs in Malawi: testing services, once quite dispersed, entered most rural areas;[4] anti-retroviral treatment (ART) is available in district hospitals for those diagnosed with AIDS;[5] and, in line with changes in international policy standards from the WHO and UNAIDS, the Malawi Ministry of Health replaced the 'V' ('voluntary') from the long-standing 'VCT' acronym ('voluntary counseling and testing') with an 'H' for 'HTC' ('HIV testing and counseling'), suggesting the mainstreaming of HIV testing for routine antenatal visits and diagnostic purposes. Despite these changes to the institutional and therapeutic context for testing, the 3Cs [consent, confidentiality, and counseling] have remained fundamentally unaltered.[6] Their applicability and efficacy in the prevention and treatment of HIV, however, have been brought into sharper focus,

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[4] Spatial analysis shows, for example, that the majority of the population in Mchinji, one rural district in the Central region of Malawi, lives within 10 kilometers (approximately 2 hours walking) of a VCT clinic (Fleming, Yeatman, Lungu & Chilonga, 2007)

[5] 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 2007: 26).

[6] For example, though antenatal and diagnostic testing for HIV is now part of routine practice, patients must still provide informed consent before being tested.

both within the international AIDS community (see Bayer and Edington 2008), and in national debates in Malawi. It is probable, therefore, that some of the observed counselor ambivalence to testing norms are a byproduct of these dynamic changes (also see Yallop et al, 2002), perhaps even leaving some counselors confused as to their specific mandate (see Angotti et al, 2008; Pritchett and Woolcock 2004).

*Interviews:* From May-July 2007, I visited 11 health centers in two rural districts in the central region of Malawi. The health centers vary in size, quality and type of facility. They included: two Government District Hospitals, two Catholic Mission Hospitals, 1 Military Hospital, 1 free-standing clinic, and 5 local health facilities. I began by asking a Malawian research assistant for the names of all the health centers that offered HIV testing services in the particular rural district in which I was working. To reach the health facilities, I took public transport or walked; in the case of distant facilities, I hired a driver to take me. Upon arriving at each health facility, I asked to speak first with the Head Matron, Chief Medical Officer, or HIV Supervisor, whoever was in charge of the facility. I explained that I was a graduate student from the United States interested in learning more about HIV testing in Malawi, and of the work of HIV counselors particularly, and asked his/her approval to enter the facility and to meet the HIV counselors on the staff. Once I received initial permission, I introduced myself to the counselor(s) on duty. Following a similar explanation, I asked for permission to meet with them individually, during a time and at a place of their choosing. In most cases, counselors asked that we book a meeting time 3-5 days later, and in the afternoon, when typically the staff is not busy. All counselors were informed of the confidentiality of the interview. Of the 25 interviews I conducted, all but two took place in a room at the health facility itself,[7] and all but one HIV counselor agreed to be interviewed.

The majority of the counselors I interviewed were trained between 2005-2007, when HIV testing services were rapidly expanding. Most, though not all, of the counselors (15 of 25) were employed at the health centers in other capacities, such as Nurses, Health Surveillance Assistants or Lab Assistants; others were employed solely as paid full-time counselors (6 of 25); the remainder were volunteer counselors (4 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, and/or patronage, that is, someone they knew personally had recruited them for the position.

The interviews lasted 45 – 60 minutes and took place in English, the colonial language and the official language in Malawi.[8] I used a loosely structured interview guide, which I had piloted during my field visit to Malawi the year prior (2006). The questions focused on the 3Cs: the testing norms of consent, confidentiality and counseling. I wanted to know how the counselors understand these principles and how they operationalize them in practice. Asking counselors how they understood testing norms, however, was not fruitful: the majority simply repeated material from the training manuals. When I asked them to talk about their actual experiences in testing and counseling, however, it became clear that they have ambivalent views about them.

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[7] The other interviews took place at the travel lodge at which I was staying.

[8] Although all HIV counselors in Malawi must be at least Form 2 graduates, some counselors were more proficient in English than others. In all interviews, I spoke slowly and deliberately. In cases where it was clear that my question was misunderstood, I rephrased the question; in cases where I did not understand a respondent's answer, I repeated back to the respondent what I understood to be the response, allowing him/her to correct me, as needed.

I took detailed notes during the interviews, which I transcribed within a day of the interview itself, when the interview was still fresh in my memory. I never conducted more than two interviews in one day. In the interviews, the counselors often displayed their knowledge of the medical jargon they had been taught, saying “reactive” rather than, as in ordinary conversation, “she‘s positive” or “infected” or “has AIDS”, effectively drawing a distinction between themselves and their clients as individuals well-armed with an elite, Western medical repertoire (for related observations, see Englund 2004). They also use the term “VCT” instead of HIV testing, though those who were trained more recently (i.e., since 2007) often said “HTC”. Significantly, the 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*: I also use a unique set of field journals (6 total, approximately 30 pages each), kept by a Malawian field assistant, that capture local experiences with HIV testing.[9] The journals are part of a larger, on-going project in the Southern region of Malawi based at the University of Pennsylvania that began in 1999, and that aims to learn what people say about AIDS when they are talking with each other in informal conversations in natural and public settings, rather than what they report in a formal interview (for other studies which utilize field journals, see Angotti et al 2008; Kaler 2004; Swidler & Watkins 2007; Watkins 2004). The field assistant whose journals I use is also an HIV counselor, and the entries analyzed here come specifically from his experience-- and at times, the second-hand experience of his colleagues-- with HIV

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[9] Examples of the journals are available publicly at www.malawi.pop.upenn.edu.

counseling and testing. The journals are written in English, though the conversations they capture are in local languages in which the field assistant himself is fluent, either chiChewa or Yao. While the journals and interviews vary with respect to the region of Malawi from which they come, the form and content of HIV counselor training-- as well as the testing protocol itself-- are the same in all regions of Malawi.

I turned to the journals strategically: namely, I wanted a perspective that was more immediate and thus closer to actual practice than retrospective reports in a formal interview and particularly, an interview conducted by a foreigner (see Miller et al, 2001; Weinreb 2006). As anticipated, the journals permit me 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 a methodological presentation of "hearsay ethnography", see Watkins et al, forthcoming). The field assistant-- as an HIV counselor-- is also an object of study himself: his task of journal writing 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 him to illustrate the process of HIV testing in greater detail and depth, as well as a corresponding disadvantage of allowing more time for him to edit his words with his reader in mind. And indeed, as in the interviews, the journals often display a presentation of the counselor as well-trained, mature, and of good moral character.

I coded and analyzed the interviews and field journals for content using NVivo 8.0, although initial themes were developed during the course of fieldwork. In the qualitative accounts offered, I give pseudonyms to the counselors and any names, including the names of health facilities, to which they refer (for the field journals, I identify the field assistant as ‘Sekou’). In the interest of legibility, I insert clarifying words in brackets.

**The Three Cs:**

I focus here on how HIV counselors creatively adapt the practice of globally-endorsed and nationally adopted HIV testing norms: the “3C’s”.

***Consent***

Officially, *consent* means that HIV testing is both informed and voluntary: “Counsellors are expected to ensure that clients have adequately understood all of the issues involved in HIV testing and counseling before giving informed consent for HIV testing” (Ministry of Health 2007: 258). Most counselors, however, 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, confirms 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:

> *The client said, “I don’t want [this blood test].” When I ask Gertrude why the client didn’t want the test, she explains that the woman said, “I can easily die.”*[10] *When I asked Gertrude what she said to the client, she explains, “I counseled and counseled and counseled her and made an appointment for her to return…they must come voluntarily because it is voluntary.” She continues that the client returned on 22 of June. I express my surprise that she remembered the exact date. Gertrude laughs and says, “It’s my client!” I ask if in training they are encouraged to book appointments for clients who wish to think it over and she says, “No, it’s my own [idea]…“They told us not to force [people to get tested] in training.” When I asked why she made the appointment, she replies, “It’s my job to make a client have a life like I am [like me].”* [June 2007].

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[10] It is widely believed that receiving a formal diagnosis as HIV positive is so emotionally devastating that the individual will die more quickly (Kaler and Watkins 2008).

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."[11]

That counselors pressure 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, it is a disease that largely affects particular high risk groups; in the case of the later, the epidemic is generalized, i.e., it occurs namely through heterosexual sex or mother-to-child transmission. 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.

In the case below, Willie, a counselor in his mid-30s, describes how a fellow, more senior counselor advised him to handle cases where parents send their children to the clinic to be tested. Not only does Willie 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 that of the autonomous individual, Willie emphasizes the importance of the collective as he explains to the daughters why they should accede to their father's demand:

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[11] In 2003, the government of Malawi mandated 'routine' HIV testing in antenatal clinics. Under this policy, pregnant women are informed by their providers that they will be tested for HIV *unless they explicitly refuse* (Angotti et al 2008), thereby officially retaining the clause of consent.

*A fellow, more senior, counselor told Willie about a case he had of two girls—aged 15 and 17—who were sent by their father to be tested. Willie 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]. Willie explains that he and his fellow counselor were chatting and sharing experiences about counseling and testing. The other counselor explained to him that he might "get this situation" and "not to refuse—there may be a reason why they were sent." Willie explains to me, "...people want to know because they think like a family. They want to say we are all non-reactive." In the case of this particular family, he explains that the mother and father wanted to know if the girls were well and "both were non-reactive." I then asked him what he does in cases where being sent for HIV testing is forced. Willie replies, "You show expertise on counseling...you might say, 'Your father is thinking of your future'"* [July 2007].

But sometimes counselors may have a more personal connection: the client in question may be a relative. These situations represent the most egregious circumstances where testing norms are not only adapted, but arguably, violated. Martha, a counselor in her mid-50s, explains how she handled the case of her own 20 year-old 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 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 6 children live with her. She was concerned about this one daughter, who she says "moves a lot" [has a lot of sex] and would spend time in "rest houses". The daughter came home pregnant one day and she is not married. She explains that her daughter refused to get tested at Maikindi, the health facility nearest to them and the one where her mother works, during her antenatal visits 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 explains that she took the placenta, and with her hands, delicately illustrates to me that she tested it herself for HIV. It was then that Martha discovered that her daughter is HIV positive. I asked if her daughter was angry that she tested her without her knowing. She said 'no', and adds, "I've got children and if this daughter of mine does not know her [HIV] status, she can infect us"* [June 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 (see Ministry of Health 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, 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 (see Hatchett et al, 2004).

In a similar case from the field journals, a client was brought to the health facility, the 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 the client's blood. Thereafter, the client goes to see the skin doctor, who tells him, much to his surprise, that his health passport notes that he is HIV positive and that he will be put on ARVs after his skin problem has subsided. 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 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* [April 16 2008].

The conversation suggests that the peril of consent—according to the clinician, and by implication, the client's uncle-- is that it may 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 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 themselves as sticking to letter of this guideline, and most to the spirit as well. But it clearly troubles 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. When I asked him why he thinks confidentiality is emphasized so much in training, he said he does not know. He explains he once tried to bring up the problems with confidentiality during the last National Testing Week [annual HIV testing campaign], but it was "brushed off by some clever people"* [June 2007].

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 difficult situation as a consequence:

> *The woman went in the counseling room, while her son waited for her in the waiting area. Her results came back positive. Mary asked the mother to whom she would share her results and she said no one, and adds that she will be discriminated against by her neighbors. Mary explains that she tried all means possible to convince her to share her test results. She continues that when the mother exited the counseling room, the client's son approached her and wanted to know his mother's test results. Mary said to the son, "I don't have the mandate." 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 and explains, "I knew he [the son] would know then [that his mother was HIV positive]…Fortunately, when they went to District Hospital, the boy knew [that his mother was HIV positive]." Afterwards the son returned to thank Mary and to let her know that his mother was now on ARVs* [July 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"* [July 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, HIV prevention. 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 (Watkins

2004). Yet if you do not know someone is HIV positive you might unwittingly put yourself at risk if you are married, propose marriage or a partnership, or accept those proposals. Thus, to community members and counselors alike, public disclosure of HIV status would contribute to HIV prevention. The advantages are likely to be particularly salient 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, as the Ministry of Health encourages, they quickly settle in and make friends, or they may already have a relative already living there. Donna, a counselor in her mid-30s and employed at a military hospital where testing soldiers is mandatory, explains that women in the community know her as an HIV counselor and want to know the HIV status of their husbands. She explains that many wives say to her, "'*We are going to die soon [if you don't tell us]' so that I will tell them more about their husbands*" [July 2007]. In other cases, counselors may vet inquiries from their friends about who among them is a suitable partner. In a boyish encounter on the soccer field, Aaron nimbly deflects a 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.' When I asked Aaron what he said to his friend in response, he explained, "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 I asked if a friend ever asked him about the HIV status of a particular girl, he laughs again (as if this is common): "I tell them that they have to ask [the girl]"* [July 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 grave fear in Malawi that one's HIV status will hurt their marriage prospects (Kaler and 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 loathe to disclosing 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 at] 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* [April 1 2008].

Counselors also empathize deeply with families who will have to care for individuals who are HIV positive and/or want to ensure that those who are HIV positive receive the care from their families that they need. Those 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"* [June 2007].

One way counselors may handle this dilemma is by visiting the home of a client, and assuming a moral authority by intervening in their family lives (see Datye et al, 2006, for India). 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 then angry, and said to Chaka, "You told my parents!" 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* [June 2007].

Sometimes it is at the *request* of clients that counselors assume an extra-clinic role, and disclose one'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 himself with them. 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." When I asked if, in reality, he found it hard, he said yes, sometimes, especially in the case of a brother or sister. Felix said he had an example of a friend in the village who was found reactive and he wanted him to tell his family. 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 man'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. Asked why his friend asked him to tell his parents instead of telling them himself, he said it was so the friend's family could understand and could assist him. He adds that he could counsel them about how to take care of their son* [June 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 with nurse at Lighthouse Trust, Malawi, February 28 2009). This strategy, however, may in fact prove too little too late. Not surprisingly though, this response was a typical one given by counselors when I posed it as a hypothetical situation to those I interviewed.

But when counselors speak with one another informally, outside the context of a formal interview, their response is seemingly different. 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 (for related observations, see Smith and Mbakwem 2007 for Nigeria). 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 in Mazula who has married a woman who is already on ART. The man had gone for VCT 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? Jimmy 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. I was just listening to learn more on how counselors react to the issue of confidentiality. 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* [April 21 2008].

### *Counseling*

According to national policy, HIV/AIDS counseling is "a skilled and confidential communication between a counselor/care provider and a client that uses the general principles of counseling to enable clients [to] make personal decisions and adopt skills relating to prevention, care and living positively with HIV/AIDS, in an atmosphere of trust and acceptance" (Ministry of Health 2007: 69). Counseling is meant to take place twice during the HIV testing session: before the administration of the HIV test, known as 'pre-test' counseling, and after the test results are given, known as 'post-test' counseling, where 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. Much of the counseling, however, appears to be largely didactic (Carter 2008; Angotti et al, 2008; also see Williams et al, 2002), informed by the counselor's perceptions that clients are uneducated. As such, counselors appear to see their mission as communicating with clients by any means possible. As Christina, a counselor in her mid-20s, explains:

*Some mothers are reluctant to answer questions during counseling. When I asked how she handles these situations, she says, "The technique in training is to discuss with them." She continues that when mothers fail to answer her questions during counseling, she "tells them [the information], and they repeat." She says that this is her technique when the women remain silent. She laments, "So what [else] can I do?" When I asked why she handles counseling this way, she says, "I want the mothers to know the real thing...in their villages, they may be cheating [lying to] each other—I want them to have the right [information]." She continues, "Some say HIV is an animal"* [July 2007].

Christina, like other counselors, speaks of the uneducated as if they were ignorant of HIV. Knowledge of HIV in rural Malawi, however, is actually quite extensive, and has been for at least a decade: villages are well aware of how HIV is transmitted and how it can be prevented, and can correctly identify the symptoms of AIDS (Watkins 2004; Santow et al, 2008).

Counseling takes place not only in the clinic setting, as it is mandated formally, but also outside of it. Many counselors mentioned visiting clients in their homes, or receiving visitors in their own homes, who come to them with questions 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 (also see Angotti et al, 2009; Yoder and Matinga 2004). 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." For clarification, I ask her, "They come to your house?" She smiles and says yes, and that clients say they don't want people they know to see them going for VCT. She continues that when she was working at Rhumasi she has had 5 couples and 2 individuals visit her at her home at different times. She counseled them in her house, in her bedroom because her husband passed away, and tested them at the hospital. When I asked if she knew the clients beforehand, she said yes, "some are my neighbors and others we pray at church together"* [July 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 clinic 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 with her:

*When I asked Simone if she had seen her friend since she was tested she says, yes, and that her friend "wants to share ideas." She continues, "She is my friend, I can't just leave her." When I asked what type of ideas they share, she replies, "spiritual stories, bible stories." Simone explains that her friend has shared her HIV test results with her mother and father and that the parents have said "I should visit her regularly to remove her worries"* [July 2007].

Indeed it is not just the role as a HIV counselor with which the counselors contend, but also a competing role, such as a friend, fellow Christian, village elder, and/or neighbor. As a corollary, counseling 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 that can be adapted flexibly as the needs of clients-- and the roles and responsibilities incumbent on counselors in their extra-professional lives—dictate (also see Kaler and Watkins 2001 for Kenya).

What actually can be accomplished in the clinic setting as far as counseling is concerned is often quite 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 2007: 99-100). This option may be more often the norm than the exception.

But it may be insufficient in terms of what clients actually need, particularly as it regards those who are HIV positive. Indeed the wants and needs of clients extend well beyond a test prognosis and lessons about how to use condoms and eat properly, something about which HIV counselors are acutely aware. Ruthie, a counselor in her mid-40s, explains how she handles the cases of women who test HIV positive during their antenatal visits:

> *She said that if they are reactive she will follow-up with them. She explains that they write down their names and their village, and if they have not seen them for ART they go to the village, ask the husband to come and get tested, and give them counseling at home. She said she does this sometimes, and sometimes she sends somebody* [June 2007].

But 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 policies. As previously demonstrated, there are several cases of clients, or their family members, actively seeking help from counselors outside the clinic setting. Oftentimes, the situations are quite 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 is quite ill—too ill to travel to the hospital and to wait to be seen. But he wants to be helped:

> *On Thursday the 24th of April 2008, the pastor sent a message through his wife that he is ill and I have to go and see him. I made an effort to go and see him in the morning around 11:00 am. When I reached his house I found that he was sleeping at 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 and we talked over his CD4 count results. 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 and give him some condoms if he may need them* [April 21 2008].

In another example, a man very sick with AIDS travels to the home of Mr. Njobe, a health worker, after returning from the hospital to get his ARV medication. He leaves a note with Mr. Njobe 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, desperately, that he is very sick and has no money to buy food. Sekou and Mr. Njobe 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 we reached Chirambo's home we only found children playing on the veranda. When we asked where their dad was they told us that their dad was sleeping. We told one of the children to go and tell him that there are visitors...When Mr. Chirambo saw us he started crying ... I never expected that you would come, I am in problems. Mr. Njobe 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.*
>
> *He walked to where we had seated and now he stopped crying and started greeting us. He then started telling us his story. He said that he had thought the moment he had tested his blood to know his status, people would have appreciated that now he knows what has been troubling him all along. He continued saying to the contrary he has faced many challenges because he disclosed his HIV status to his parents. His parents told him that it is all because he left Islam and joined Christianity that is why all these problems have come about and they don't want to associate with Christians because they are unclean.*
>
> *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 told him that we expect those things in this world but they should not stop us from progressing with life. Mr. Njobe consoled him.*
>
> *We asked him what he had taken [eaten] that morning. He said he had not taken[eaten] anything apart from the ARV pill for the morning. Mr. Njobe then advised him that it is not good to stay hungry while he is on medication. He told Chirambo that he should ask his wife to cook porridge for him every morning and if there is groundnuts flour she should add to the porridge. Mr. Chirambo agreed and said his wife left early in the morning because he has developed hernia and wanted transport to take him to the hospital..... That is why he has not eaten anything since morning. I therefore phoned Helen the clinician at the District Hospital who told me that hernia patients are booked on Mondays and go for minor operation/repairs on their affected parts on Tuesday. She then advised me to tell the patient to come to the hospital on Monday for booking whilst waiting for repair on Tuesday.*
>
> *We chatted for awhile and in the course of our chatting Mr. Chirambo 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. We knew that his wife remained the only source of solace to him.*

*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. Immediately I instructed the bicycle driver to stop the bicycle. I realized that the woman who was stopping me was Mrs. Chirambo and she was with another woman whom she introduced to me as the mother to Mr. Chirambo. We explained to her why we had come and told her that she should make sure that Mr. Chirambo is given some food everyday no matter what type it may be. It was not proper for him to stay without eating anything the whole day while he is taking ARVs, it is not good at all, please make sure he eats* [April 21 2008].

## Discussion:

This study examines empirically what often goes unaddressed: the ways that health interventions, and the protocols that accompany them, may be creatively adapted as they travel from their international origins, are drafted into national policies, and ultimately implemented in specific settings far from their origins. This study yields several important implications. HIV testing, as stipulated by the WHO and UNAIDS in Geneva, and policy guidelines in Malawi, is intended to take place following strict guidelines that it include *counseling*, be conducted with *informed consent*, and that all matters discussed between the counselor and client, including the test result, be *confidential*. In rural Malawi, however, the implementation of these norms is evidently quite different from that envisaged in official policy. What happens in practice is indeed discretionary (Pritchett & Woolcock 2003), subject to decisions made by an important group of intermediaries (Merry 2006)-- HIV counselors-- in the course of doing their jobs. In practice, counselors interpret, challenge, and even reframe official, 'expert' approaches to HIV counseling and testing (Booth 2004). In some cases the adaptation of testing norms is seemingly benign; in other, rarer cases, it may be egregious. Counselors creatively circumvent testing guidelines in a way that allows them to maintain the fidelity of testing principles, while reducing the harm they perceive may arise as a consequence of strict adherence to them.

So why do they bend the rules? One important 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 roles as a counselor, and the roles they play in their extra-professional lives, is clearly quite difficult for them. From this perspective we can see that their adaptations of testing norms are not acts of malfeasance, but rather insights into the role conflicts that the exigencies of their jobs impose (Portes 2004). 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 trained to protect. Indeed, the counselors are often quite responsive to the needs of their clients (see Joffe 1986 for the United States; Datye et al, 2006 for India). This is particularly so in cases when clients are already quite sick and counselors think they should be tested, and/or when they feel that those who will need to care for them should be informed of their family member's HIV status. In such cases, counselors perceive that counseling procedures, informed as they are by Western testing norms, as impeding, rather than facilitating, HIV prevention. To address this concern, counselors act creatively by distinguishing between the office (health setting) and outside the office, where their real work as missionaries of public health can begin.

Given the concerns expressed by HIV counselors with respect to the 3C's, what then might explain why Western testing norms are not completely subverted in this setting? The answer, in part, raises an important methodological point, and one with implications for how we understand the interactions between interviewers foreign to the local community and their respondents. We know that in surveys at least some respondents actively shape their responses to Malawian interviewers in hopes that the right answers may bring them material benefits (Miller et al, 2001). When HIV counselors in rural Malawi are speaking to or writing for a Western researcher, as in this study, the possibility of benefits may be even more salient, since their salaries and livelihoods are largely dependent on continued Western donor aid and Western interest in funding HIV prevention efforts in Africa (see Swidler and Watkins 2009). Their responses, therefore, must be viewed in light of this consideration.

How might this study inform efforts policy on HIV testing? More often than not, more training is touted as an important, if not the most important, antidote when program evaluations yield anomalous results (Kaler and Watkins 2001). It is hard to see, however, how training could provide counselors with more appropriate responses to the moral and ethical conflicts they experience in very specific situations than the solutions they creatively improvise. More generally, this study implies that policy makers recognize that it is not only the concerns of those who are HIV tested and counseled that need to be considered in designing programs, but also the concerns of those who counsel them.

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