Access Denied? Consent for HIV testing at antenatal clinics in rural Malawi[1]

Nicole Angotti,[2] Kim Yi Dionne,[3] and Lauren Gaydosh[4]
21 September 2007

Background

Voluntary HIV Counseling and Testing (VCT),[5] has been an important technology in efforts to control the spread of HIV in the West. Central to this approach is that HIV testing must be voluntary and that the results must be confidential. During the last decade, VCT has been exported by humanitarian aid organizations to settings that are quite different in terms of resources, health facilities, and social and cultural practices. The transfer of this approach to testing was based on two assumptions: that those who learned they were HIV positive would change their behavior; and by implication, that a Western public health model embedded in notions of human rights would be effective in other parts of the world. The literature on technology transfer, however, suggests that when new technologies diffuse, they are also adapted by their users to local circumstances. In this paper, we examine one aspect of the way that HIV Counseling and Testing has been implemented in rural Malawi: the extent to which testing is voluntary. We focus on the perceptions of two sets of women. First are those who had been recently tested at antenatal clinics; second are those who had not but may nonetheless share these perceptions. Because our interest is in perceptions, which cannot be adequately captured in short-answer surveys, we use qualitative methods. Though many studies have questioned the wisdom of implementing solely Western solutions to the problems of HIV/AIDS (see Allen 2004; Cleland and Watkins 2006), most studies of VCT in sub-Saharan Africa have attempted to evaluate them solely as public health interventions. Thus, for Malawi, there are studies on the hypothetical acceptability of VCT (Matinga and Yoder 2004), on the actual use of VCT (Department of Nutrition, HIV and AIDS, and Office of the President and Cabinet 2005), and on behavioral change as a consequence of HIV (Thornton 2005). Very few studies have focused specifically on the provision of HIV testing programs (for exceptions see De Cock, Mbori-Ngacha, and Marum 2002). In contrast, we examine the social dynamics of testing: how has it been incorporated in a non-Western, high prevalence, and poor country.

<u>Context</u>: According to UNAIDS, Malawi is eighth on the list of countries hardest hit by HIV/AIDS. In 2005, the National AIDS Commission (NAC) in Malawi reported the adult HIV prevalence at 14% of the population (National AIDS Commission 2005); the 2004 Malawi Demographic Health Survey (DHS) indicated 12% of adults were HIV-positive (National

---

[1] Abstract submission for the 2008 Annual Meeting of the Population Association of America, New Orleans, LA. Funding for this research was provided by the UCLA Globalization Research Center-Africa, The College of Liberal Arts at the University of Texas at Austin, and the University of Pennsylvania.

[2] Department of Sociology and Population Research Center, The University of Texas at Austin, 1 University Station G1800, Austin, TX, 78712 (nangotti@prc.utexas.edu). Corresponding author. The findings presented here are preliminary. Kindly contact the author before citing or circulating.

[3] Department of Political Science, University of California at Los Angeles, 4289 Bunche Hall, Los Angeles, CA 90095 (kimg@ucla.edu).

[4] Invest in Knowledge Initiative, PO Box 26, Mchinji, Malawi (laurengaydosh@gmail.com).

[5] Hereafter, we will refer to HIV Counseling and Testing as *HIV Testing*. *HIV Testing* is often used as an umbrella term to both testing and counseling services (Obermeyer and Osborn 2007).

Statistical Office 2005).[6] A population-based study conducted in the district studied here found its sample to have an HIV prevalence of 7.5% in 2004 (Thornton et al 2005).

VCT first became available in Malawi in the mid-1990s but was only accessible in private health clinics and research hospitals until 2003, when it became available in government hospitals for inpatients. In 2004 and 2005, the Malawi Ministry of Health (MOH) received funding from The Global Fund to Fight AIDS, Tuberculosis and Malaria to scale up the availability of free HIV testing and counseling to all 28 district hospitals, as well as many rural MOH-operated hospitals and clinics. In 2004 there were 128 sites that administered HIV tests. In 2005 that number increased to 184, and in 2006 that number increased again to 249. In the area and period of this study, VCT was available at the two large hospitals in the district, as well as five additional government-sponsored VCT clinics. Only recently was VCT made available in this rural district; previously, residents would have to travel to the capital city to be tested.

In this paper, we focus specifically on the experience of HIV testing in antenatal clinics in rural Malawi, also known as "Prevention-of-Mother-to-Child Transmission Counseling and Testing" (hereafter, PMTCT). PMTCT comprises 15% of cases of HIV testing in Malawi (National Tuberculosis Control Programme et al 2005: 10).[7] Malawi has scaled up significantly its provision of PMTCT services in recent years. In 2002, only seven facilities provided PMTCT services, testing 5,059 pregnant women attending antenatal clinics; in 2004, 31 facilities offered PMTCT services and 43,345 women were tested during antenatal visits[8] (National Tuberculosis Control Programme et al 2005: 16). The national HIV/AIDS policy stipulates routine testing of pregnant women at antenatal clinics "unless they choose specifically not to be tested" (Office of the President and Cabinet and National AIDS Commission 2003: 10).

HIV Testing as a Travelling Technology: The expansion of VCT to rural hospitals and clinics has brought not only the objective availability of VCT, but also the widespread perception that it is available and important, in order "to plan for the future." The central premise of this paper is that the testing encounter is transformed from its Western design by two parallel phenomena, one that is conceptual and the other practical. Conceptually, because HIV testing is a Western import, it follows that the core tenets of the approach—namely that it is voluntary (demonstrated by informed consent) and confidential--accrue different meanings in new settings and by extension, may inform local perceptions of the testing encounter beyond those who were actually tested. Accordingly, we treat HIV testing as a variation of a "traveling technology".[9] The notion of "traveling technologies" seeks to explain why contraceptive methods in new settings take on meanings other than their originators intended (Bledsoe 1990, 1994; Bledsoe and Hill 1993). Amy Kaler has utilized this framework with respect to the birth control pill and the Depo-Provera injection as cultural objects in colonial Zimbabwe (Kaler 2003), and with the female condom as it travels through the circuits of international technological diffusion (Kaler 2001). Similarly, we conceptualize HIV testing in antenatal clinics not as a value-neutral public health

---

[6] NAC figures are based on antenatal clinic sentinel surveillance and the Malawi DHS is a population-based survey, this difference in methodology likely impacts the estimation of prevalence.

[7] The PMTCT program in Malawi had a slow start and was only approved and endorsed in 2005 (National Tuberculosis Control Programme et al 2005: 6).

[8] Despite this incredible increase, the plurality of pregnant women tested (45%) were tested at Kamuzu Central Hospital in Lilongwe, Malawi's capital (National Tuberculosis Control Programme et al 2005: 12).

[9] We are grateful to Amy Kaler for this idea.

intervention, but a practice imbued with ideas that may not resonate the same locally and in effect, may transform the testing encounter in unexpected ways.

On a more practical level, the dynamism that has come to define HIV testing may in implementation increase slippage from its original formulation. In other words, as HIV testing develops, though still firmly embedded in Western ideas of privacy and respect for biomedical ethics, it seems probable that the "rules" are no longer as clearly defined or as sensible to its implementers, who adapt it for a new context and, perhaps, for new objectives. Thus, the arsenal of prevention strategies now include a host of new testing initiatives and approaches including, but not limited to, PMTCT, "routine testing", "diagnostic testing", "opt-in", or "opt-out", none of which are entirely mutually exclusive (e.g., PMTCT is a form of "routine testing" under the wider umbrella of "HIV Counseling and Testing"). Although numerous guidelines have been formulated to improve HIV testing services, there is likely to be great variation in implementation. One reason, of course, is that implementation occurs in a quite different context than that in which the guidelines are developed: for example, where health systems are weak and resources limited, where providers may have had insufficient training, and their workloads may be so heavy that they cannot find the time or space for proper counseling (Obermeyer and Osborn 2007; Rowe et al 2005). But another is that procedures which appear sensible in one context do not in another. In another paper, we examine the issue of voluntariness and confidentiality from the perspective of providers; HIV counselors say they follow both rules, although there are indications of slippage with respect to confidentiality when it appears to them to contradict good public health sense. Here, we focus on the issue of the voluntariness of testing from the perspective of pregnant women. While imported testing models are meant to be voluntary, the experience of pregnant women may suggest otherwise.

Data and Methods

Interviews were conducted alongside a larger quantitative survey-based study on VCT and antiretroviral therapy, led by colleagues at the University of Pennsylvania in conjunction with the District Ministry of Health. Respondents were drawn from the population of VCT attendees at the two hospitals in the district and one of the district-operated clinics. One of the hospitals is the government-run district hospital where services and drugs are free of charge – at least when they are available and accessible. A religious mission operates the second hospital where VCT is free, although other services require a fee. The local clinic only provides VCT.

Our sample included people attending VCT clinics who tested positive for HIV as well as those who tested negative for HIV. We also included in the sample some "near neighbors": respondents living in the same area of the village but not in the same compound as the respective VCT sample respondents. These near neighbors, we believe, may influence the perceptions of the respondents about the VCT experience. Forty-nine interviews were conducted in all:[10]

10 District hospital VCT attendees; 7 near neighbors
10 Mission hospital VCT attendees; 7 near neighbors

---

[10] The research team attempted to interview more than 49 respondents, however, we could not locate all of the VCT attendees, and, because many do not attempt to access ART until they are critically ill, some had died in the time between their VCT visit in November and our research team's visit to their home in June/July.

10 District clinic VCT attendees; 5 near neighbors[11]

Of the 49 interviews, 31 have been transcribed, typed, and analyzed. Of the 31 transcribed interviews, eleven respondents were tested for HIV during an antenatal clinic visit.

The central district in which we conducted our research is large, such that locating VCT attendees from our facility-based sample proved difficult. While the district hospital tests the largest number of individuals, it is located in the trading center where residence is more transient; although only five months had passed, many of those tested had moved away between the time of testing and the follow-up interviews. We hired a scout to assist in locating respondents.[12] The scout would speak to village chiefs, typically a day in advance of the interviewers' arrival: chiefs were told only that the interviews would be about local health services. The scout and interviewers were provided with compensation to cover the costs of public transport or bicycle hires to reach respondents. In the most far-flung areas of the district unreachable by minibus, the research team hired an automobile taxi for the day.

All interviewers were Malawians, fluent in Chichewa and English. All interviews were conducted in Chichewa and translated and transcribed into English by the respective interviewers. Interviews were then typed in the field by the research director. Interviewers were equipped with a digital voice recorder, the interview protocol, a question guideline, a notebook, and a pen. Interview recordings are all archived in digital format. Although all interviewers had previous experience with the longitudinal survey, prior to initiating our fieldwork, interviewers took part in a one-day skills refresher for experienced interviewers.[13] The main emphasis of the training was on informed consent, confidentiality, the techniques of semi-structured interviews, and avoiding closed-ended or leading questions. Follow-up training was also provided after review of the initial transcripts showed a need for rewording of some interview questions[14] and an imperative to establish greater rapport with respondents.

Interviews took place in respondents' homes or in a location of the respondent's choosing and were conducted in privacy. Following a brief introduction, interviewers asked about personal and family health, experience with VCT,[15] knowledge about ART, and local health services. Interviews were semi-structured such that interviewers were equipped with a guideline of proposed questions, but were instructed not to ask questions in a highly structured format.

---

[11] Though near neighbors were not drawn from the HIV testing sample, some had been tested, and one of our near neighbor respondents was tested during an antenatal visit.

[12] In one case, a respondent did not want to be located; the interviewer wrote, "With the scout she was hiding at first, that she never went for VCT, but then she told the scout that she was HIV tested when she was pregnant and her marriage is ended because of her results. During the day of the interview she was trying to hide, but then she revealed [herself]" (file: 07.07.03.5).

[13] All interviewers had previous experience working with a longitudinal survey project in 2006 as well as smaller-scale qualitative projects subsequently.

[14] A major change resulted in asking respondents what they "heard" instead of what they "knew." To "know" something would require a greater deal of certainty than we thought was necessary to understand villagers' perceptions about the VCT experience.

[15] Interviewers did not ask questions that assumed a VCT visit. Questions were worded such that respondents would say what they knew or, more likely, what they "heard" about VCT. Serostatus data was available only to the research director in the field, not the interviewers. It was rare, however, for a respondent to not share his/her own VCT experience (the interviews show that those who have been to VCT tell some friends about it, not just the interviewer).

Rather, we intended for the session to resemble a conversation – but a conversation that addressed all of the issues in the question guideline. The order of topics was less important than allowing for richer content in responses. Sometimes when respondents gave short or conflicting answers, interviewers would revisit questions much later in the interview. Interviewers were instructed to probe when respondents gave short answers, conflicting statements, and/or used social marketing language. Interviews lasted 25 minutes to just over an hour, with typed transcripts ranging from seven to nineteen pages. Interview questions were developed prior to the start of the project, but were revised, and some questions were reworded following a review of the initial transcripts.

Preliminary Findings

Here we present our initial findings, based on an analysis of eleven transcripts of antenatal attendees. We have read but not analyzed the other transcripts and expect the results of the preliminary analysis to be robust. Strikingly, it appears that in practice testing at antenatal visits is not perceived as voluntary. Of these eleven women tested at antenatal visits, seven reported there was no option to refuse the HIV test during their antenatal visit.[16] One respondent said that there "was a rule that anyone who has gone for antenatal should be tested," and an exchange later in the interview demonstrates her belief that there was no ability to opt-out:

> Interviewer: Alright. You said you were told to be HIV tested.
> Respondent: Mmhm.
> Interviewer: Were you given the option in the VCT room to refuse the test or go on with it?
> Respondent: Mmhm, no, there wasn't that option.[17]

One woman elaborated this practice as a law, explaining her fear that without compliance she would forfeit access to care, "[When I went for antenatal] that's when I heard that everyone should have an HIV test."[18] Another respondent similarly described the lack of choice in having an HIV test during her antenatal clinic visit; when asked if she felt pressured to take the test, she responded, "You know at antenatal it's compulsory, whether you like it or not you have to go for an HIV test."[19] A third interview had a similar exchange:

> Interviewer: Were you given the by the counselor to refuse VCT?
> Respondent: No, he told us to be tested.
> Interviewer: Did he give a chance to you that anyone who wants to be tested can do so and anyone who doesn't want cannot be tested?
> Respondent: No he did not give us that chance.
> Interviewer: Okay. Why do you think that you were not given that chance?
> Respondent: Because it was important for women to be tested.

---

[16] Our sample is biased in that it does not include those women who refused to be HIV tested during their antenatal visits. Interviews with these women would shed light on whether refusing an HIV test during an antenatal visit would exclude one from other antenatal services. Though we admit this limitation of our research, the interviews we have are sufficient to illustrate the perspectives of rural Malawians on HIV Testing during antenatal visits, and these perspectives shape actors' decisions in seeking treatment.

[17] Interview file 07.07.03.5.

[18] Interview file 07.07.10.10NN.

[19] Interview file 07.07.07.9NN.

> Interviewer: Alright, did all women who went for VCT that day get tested?
> Respondent: Yes.[20]

While the majority of women in our sample felt there was no option to refuse testing, two antenatal attendees stated that refusals were allowed and reported that women who refused HIV tests were still able to receive the other antenatal services offered. We must consider, however, that our sample consisted only of women who had accepted testing and their near neighbors; we cannot capture the perceptions of women who refused testing at their antenatal visits, perhaps undercounting the percentage of women who perceive testing as compulsory.

A second local adaptation was suggested by a few of the women interviewed: that a woman must be accompanied by her spouse to show that he consented as well.

> It's a new law that every pregnant woman who comes for antenatal should be accompanied by her husband for HIV testing. I told the doctor that I came alone…I will come next week…I went home and told my husband that next week we should go together for antenatal and HIV testing.[21]

While this implies an insistence on the voluntary condition for testing—but takes the couple as a unit, rather than the individual, as the technology was originally formulated-- and thus contradicts the perception of most women in our sample that it is not, it does not appear to be the common practice.

Despite the intentions of the Western and public health communities, our interviews suggest that the imported HIV testing technology has been transformed in the context of antenatal care through the interaction of health care providers and pregnant women. Women perceive HIV testing as compulsory and necessary in order to maintain access to antenatal care.

Implications

Our preliminary findings suggest several important implications. HIV testing in Malawi, as in the West where the technology was developed, is intended to be voluntary. In our sample, however, the majority of women do not perceive it to be voluntary. We suspect that for many their perceptions are correct. It may be that health personnel have a different understanding of what it means to have the option to refuse. More likely, however, is that the health personnel themselves see testing as an important public health intervention, with goals that override concerns about the voluntariness of testing. Based on other work we have done in Malawi, we think this may be especially the case when their clients are rural and relatively uneducated. We also note that the clients themselves may be accustomed to procedures in health facilities that are not voluntary presented to them as voluntary.

---

[20] Interview file 07.07.10.10.

[21] Interview file 07.07.10.10NN.

References

Allen, T. 2004. Introduction: Why don't HIV/AIDS policies work? *Journal of International Development, 16.* 1123-1127.

Angotti, N., A. Bula, et al. 2007. The Fear Factor in HIV Testing: Local Reactions to Door-to-Door Rapid Testing for HIV in Rural Malawi. American Sociological Association Annual Meetings, New York, NY.

Cleland, J. and Watkins, S. 2006. Sex without birth or death: A comparison of two international humanitarian movements. In *Social Information Transmission and Human Biology.* J. Wells, S. Strickland, and Laland. (Eds.). 205-21. London: Taylor and Francis.

De Cock, K., Mbori-Ngacha, D., Marum, E. 2002. Shadow on the continent: public health and HIV/AIDS in Africa in the 21st century. *The Lancet*, *360*, 67-72.

Department of Nutrition, HIV and AIDS, and Office of the President and Cabinet. 2005. *Malawi HIV and AIDS monitoring and evaluation report,* Lilongwe, Malawi.

Kaler, Amy. 2003. *Running After Pills: Gender, Politics, and Contraception in Colonial Rhodesia.* Portsmouth, NH: Heinemann.

Kaler, Amy. 2001. "It's some kind of women's empowerment": the ambiguity of the female condom as a marker of female empowerment. *Social Science and Medicine* 52:783-796.

National AIDS Commission [Malawi]. 2005. *HIV and AIDS Monitoring and Evaluation Report 2005*. Lilongwe, Malawi.

National Statistical Office [Malawi]. 2005. *Malawi Demographic and Health Survey 2004*. Zomba, Malawi.

National Tuberculosis Control Programme, HIV Unit/Department of Clinical Services, National AIDS Commission, [Malawi] and Center for Disease Control and Prevention [USA]. 2005. *Report of a country-wide survey of HIV/AIDS services in Malawi for the year 2004*. Lilongwe, Malawi.

Obermeyer, C. M. and M. Osborn. 2007. "The Utilization of Testing and Counseling for HIV: A Review of the Social and Behavioral Evidence." American Journal of Public Health 10(10).

Office of the President and Cabinet and National AIDS Commission. 2003. *National HIV/AIDS Policy, A Call for Renewed Action.* Lilongwe, Malawi.

Rowe, Alexander K., Don de Savigny, Claudio F. Lanata, and Cesar G. Victoria. 2005. "How can we achieve and maintain high-quality performance of health workers in low-resource settings?" *Lancet* 366: 1026-1035.

Thornton, Rebecca. 2005. “Is It Good to Know? The Demand for and Impact of Learning HIV Results.” Paper presented at the Northeastern University Development Conference, Brown University, Providence, RI, September 3, 2005.

Thornton, Rebecca, Agatha Bula, Kondwani Chavula, Simona Bignami-Van Assche, Susan Cotts Watkins. 2005. “Reactions to Voluntary Counseling and Testing in Rural Malawi.” Unpublished working paper.