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Dynamics of Care, Situations of Choice: HIV Tests in Times of ART

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Abstract

In the 1990s, African AIDS programs followed a voluntary counseling and testing (VCT) approach to HIV testing. In the wake of large scale AIDS treatment programs, policymakers opted for routine provider-initiated testing (PITC) with less emphasis on counseling, which led to concerns about the ethical conduct of HIV testing. Inspired by Annemarie Mol, we ask if PITC can be framed as good care, rather than as medical domination that threatens to violate patients' rights. Based on fieldwork in Ugandan and Kenyan health facilities, we reveal that situations of choice vary: patients in hospital wards, are given time to decide whether they want a test, while in antenatal care testing women find it very hard to optout. We argue that the medical context inherent in PITC provides an attractive moral space for people to undergo HIV tests.

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HIV testing practices in East Africa have changed dramatically in recent years with scaling up of antiretroviral treatment (ART) programs. Pre-ART, HIV tests were offered mainly through voluntary counseling and testing (VCT) programs in which individuals were expected to take the initiative to be tested and counselors were to ensure that they made an informed choice. Pre-test counseling was considered essential because of the stigma and discrimination related to HIV. Clients needed to be aware of these risks and be “ready” to confront them. In the wake of ART rollout in East Africa, policymakers and public health experts suggested that provider-initiated HIV testing and counseling (PITC) should be offered routinely in health care services to commence more people on treatment. In PITC, health providers recommend an HIV test and provide pretest information. The HIV test is performed unless the patient declines (World Health Organization/UNAIDS 2007). Human rights advocates expressed concerns with this approach and continued to call for client-initiated testing and full counseling as the primary way to scale-up HIV testing.

In this article, we contribute to this policy debate, not by denouncing one or the other position but by presenting ethnographic insights into the “practice” of HIV testing in various situations of choice. Our case study is inspired by Annemarie Mol who, in her recent book *The Logic of Care* (2008), argued that patient choice is not (always) as liberating as it is claimed to be. Using the term “logic” to emphasize the rational underlying medical practices and the way they somehow fit together, Mol (2008:9) illustrated how the logic of choice follows a linear accountancy model: costs and benefits are weighed and decisions taken. By making choices, patients are expected to become masters in their own lives, using medical technologies that promise accurate diagnosis and a return to health and happiness. But everyday life with diabetes—the condition that Mol chose for her ethnography—does not fit this logic. Despite the constant self-monitoring of blood sugar levels and diet by people with diabetes and regular collaborative consultation with their doctors, it can still be hard for them to stabilize their condition. In everyday life, doctors and patients jointly “tinker with bodies, technologies and knowledge” (Mol:14). This joint tinkering is good care. The logic of choice, Mol argued, erodes good care by emphasizing the health benefits of pharmaceutical products without giving enough attention to the care work of doctors and patients confronting ill health.

Can routine provider-initiated testing, as proposed by public health experts, be framed as good care rather than as medical domination that threatens to violate patients’ rights? What is good care in the case of HIV and AIDS? In this article, in the context of competing policy paradigms (VCT and PITC) in East Africa, we present the views of people attending testing services and of the nurses and counselors conducting tests both in VCT and PITC. We describe a variety of situations of choice and dynamics of care, with an aim to identify the logic at stake in situ.¹ This analysis reveals that in the health facilities where we conducted fieldwork, logics of choice and care are intertwined. Furthermore, choice does not erode good care but rather complements it.

FROM CHOICE TO CARE: EVOLVING TESTING CONSTELLATIONS

Voluntary counseling and testing was introduced in Africa in the 1990s, with international standards, developed by the US Centers for Disease Control (1994, 2001) and UNAIDS (2000), stipulating that HIV tests in these programs were to be accompanied by extensive pre-test counseling. Before testing, trained counselors and clients were expected to jointly assess the client's sexual risk behavior, discuss coping strategies related to the test results, review prevention options, and reaffirm the decision to test. During post-test counseling, counselors were to give clients their HIV test results, and in the case of a positive result, discuss how to reduce sexual risk and how to disclose their HIV status to their sexual partner(s). Ron Bayer (1989) described the exceptionalism of early HIV testing when human rights advocates in the US and Europe pushed for such extensive counseling and informed consent procedures, because of the risks for HIV patients of discrimination and stigma and the lack of access to treatment at the time.

Uganda was unusual in Africa because of its early emphasis on VCT. Africa's first VCT clinic, the AIDS Information Center (AIC), opened in Uganda in 1990 and pioneered the concept of "Post Test Clubs" to provide long-term support to anyone who had been tested, regardless of their HIV status. VCT was introduced in Kenya over a decade later in 2001 by Family Health International with funds from USAID. USAID considered VCT to be an important HIV prevention tool and supported scaling-up of the services in Kenya and Uganda. By the time we started the present study in 2008, every district in Uganda and every province in Kenya had VCT centers, mass campaigns had promoted uptake of testing, and training for VCT counselors had been scaled up. This led to a whole new category of health personnel providing clients with opportunities to make choices and take responsibility for their health.

However, despite these efforts, uptake of VCT was relatively low. The demographic health surveys report that awareness of HIV status was only 15 percent in Kenya (Central Bureau of Statistics/Ministry of Health/ORC Macro 2003) and 20 percent in Uganda (Uganda Bureau of Statistics/Macro International 2006). As anthropologists illustrated, in everyday life, HIV risk was perceived not in psycho-medical but in moral terms, involving blame and shame (Dilger 2003; Thomas 2008; Simpson 2009; Smith 2003). People feared that their partners would leave them if they tested HIV positive, and they could lose their jobs because of AIDS related stigma and discrimination. What was there to gain from attending VCT facilities, given that an HIV-positive diagnosis in the pre-treatment era was seen as equal to social death (Posel 2004; Simpson 2009)?

Low acceptance of HIV testing became an operational problem for large-scale ART programs, such as the World Health Organization's (WHO) call to initiate three million people on ART by the end of 2005 (WHO 2003). After all, how can people access treatment if they do not (want to) know their HIV status? WHO's policymakers therefore suggested scaling up PITC in health facilities (UNAIDS/WHO 2004). No opportunity to test should be

¹The term "situations of choice" is used by Mol (2008). Analyzing the way HIV tests and counseling are conducted in the prevention of mother-to-child transmission programs in Vietnam and Indonesia, Hardon and colleagues refer to "dynamics of care" to describe the processes at stake and the interactions between the people involved in the programs (Hardon et al. 2009).

missed. Health workers should propose HIV testing and counseling to all patients in generalized epidemic settings to identify people infected with HIV who are therefore eligible for treatment. In PITC, the “C” deliberately follows the “T”: the emphasis is on encouraging people to know their status rather than on the process of counseling.

With ART scale-up, HIV tests in Uganda and Kenya changed face. Whereas at the beginning they were mainly used as part of a prevention strategy, tests are now essential diagnostic tools and a key component of AIDS care programs. The testing technologies have also changed, enabling more rapid testing. In the recent past, testing facilities would take blood from patients and send it to laboratories for diagnosis; patients had to return for their results. Nowadays nearly all health facilities use rapid testing kits requiring only a finger prick to extract a few of drops of blood—and thirty minutes later the results can be known.

As described by Bayer and Eddington (2009), policy proposals to implement PITC were accompanied by much normative debate within the global health arena (Brockway 2007). Proponents such as Kevin De Cock (who had worked in Kenya for the Centers of Disease Control and later become head of WHO’s Department of HIV/AIDS) and colleagues argued that routine, provider-initiated testing is “good” diagnostic practice for tuberculosis (TB) and sexually transmitted diseases, provided that people are given the opportunity to “opt-out” of the test procedure (De Cock, Bunnell, and Mermin 2006). They argued that since treatment for HIV/AIDS is now available, so called AIDS exceptionalism was no longer needed.

By contrast, advocates of VCT argued for an “opt-in” approach and for pretest counseling to continue to be comprehensive. Intensive pre-test counseling should, in their view, continue to help clients make a conscious choice for the HIV test, enabling them to confront the outcome of the test (Yeatman 2007). Proponents of VCT also argue that people who receive comprehensive counseling are more likely to be committed to the prevention of HIV transmission and to disclosure if they are HIV-positive. They fear that PITC testing approaches may harm individuals who are HIV-positive and even lead to social death through severe stigma and discrimination.

In 2007, WHO/UNAIDS published guidelines on how PITC should be conducted. These guidelines adopt an “opt-out” approach, enabling someone who does not wish to have an HIV test to freely decline the offer.² In 2008, when we started fieldwork on HIV testing and counseling in Kenya and Uganda, both countries routinely tested pregnant women (so that if positive, they and their babies could be given ART to prevent the transmission of the virus from mother to child), and PITC was being introduced into hospital outpatient departments, on the wards, and in TB care. Some programs had also started home-based HIV counseling and testing programs.

²The PITC guidance acknowledges that in some circumstances, such as in health facilities that serve highly vulnerable populations, opt-in approaches merit consideration, and stresses: “whether patients ‘opt-in’ or ‘opt-out’, the end result should be the same: an informed decision by the patient to accept or decline the health care provider’s recommendation of an HIV test” (WHO/UNAIDS 2007:20).

Perhaps contrary to what the proponents of VCT would have expected, our health worker informants reported increases in demand for HIV tests in PITC facilities. Nurses in the Ugandan referral hospital said they could not keep up with demand. A few quantitative studies from Sub-Saharan Africa confirmed that acceptance rates for PITC in hospital, home-based, and antenatal care settings were very high: in Botswana (94 percent accepted the offer of an HIV test in a household survey), in Uganda (95 percent and 98 percent in two hospital-based studies), in Malawi (95 percent of women attending antenatal care), and Zimbabwe (93 percent of women attending antenatal care) (Nakanjako et al. 2007; Wanyenze et al. 2008; Cockcroft et al. 2007; Mugore et al. 2008; Weiser et al. 2006; Manzi et al. 2005). Wanyenze and colleagues attributed the high acceptance of PITC to the fact that the tests are free of charge and that they are associated with improved access to HIV care and treatment. Most of these studies, however, were conducted in relatively well-funded programs early on in the scaling up-of access to ART.

THE HIV TESTING POLICY FRAMEWORKS IN UGANDA AND KENYA

The testing practices that we observed took place in particular national policy frameworks. In Uganda, the National Policy on HIV Counseling and Testing was published in September 2005 (Ministry of Health [MoH; Uganda] 2005), and states that VCT has been and remains the primary approach for delivery of HIV Counseling and Testing (HCT).³ The Kenyan National Guidelines were published three years later, in May 2008 (NASCOP 2008). They formally lay out a *modus operandi* for the increasingly routinized approach to HIV testing and counseling (HTC) that emerged during this three-year period, such that “HTC should be offered to all clients or patients attending any health facility as part of routine care, but failure to offer HTC in the following situations is unacceptable and will be considered negligent: Mother and Child Health care; Adult and paediatric inpatient facilities; TB clinics; STI clinics; Post rape patients; Occupational exposure clients; Family Planning clinics; General outpatient services” (NASCOP: 5).

The overall rules for obtaining consent to test an individual are similar in Kenya and Uganda. The 2005 Ugandan policy states, “All HIV testing should be done with the client’s knowledge and consent” (MoH [Uganda]: 7); the 2008 Kenyan guidelines are almost identical: “No person shall be tested without their consent” (NASCOP: 21). These rules apply whether in a VCT or PITC setting. Consent is still required, therefore, even when the logic of care takes precedence over the logic of choice. The emphasis on consent reflects the concerns of human rights advocates that PITC would encourage medical domination and that consequently in PITC people would *not* have choice.

While the requirements for consent are similar, significant differences emerge in the policies with respect especially to pre-test counseling. The Ugandan policy maintains that counseling should be “comprehensive,” unless the extra time required to do this “causes a barrier to testing itself” (MoH [Uganda] 2005:8). Under normal circumstances, clients should therefore receive a full pre-test counseling session, usually with an individually tailored risk

³At the time of our study, however, the above mentioned above mentioned PITC programs mentioned were underway, which contributed to a policy review in late 2009 after our field study was completed.

assessment. Routine provider-initiated testing in Uganda is called HCT (note that the “C” continues to come before the “T”—perhaps because of the long history of VCT in the country). By contrast, in Kenya where VCT was introduced little more than a decade ago, the newer policy gave less emphasis to pre-test counseling. Within PITC (i.e., logic of care) settings, pre-test counseling is now put forward primarily as a means for obtaining consent. Conducting an individual risk assessment for each client is an additional and optional activity. This policy implies a form of triage practiced post-test, with those who receive an HIV-positive test result entitled to comprehensive post-test counseling, while HIV-negative clients are given less attention.

HIV TESTING PRACTICES IN TIMES OF ART

What happens in practice, in routine conditions in Uganda and Kenya, where ART and PITC programs are rapidly scaled up? Does initiating an HIV test for a patient—PITC—reflect medical domination, and do opt-out procedures necessarily threaten human rights? Next, we describe how health workers and patients engage with HIV testing and counseling technologies under routine health care conditions. Our concern is with how HIV testing is practiced and experienced, with a focus on the interactions between diverse actors (including the HIV tests, which mediate information on HIV sero-status) and the diverse “situations of choice” in which these occur. We explore how testing practices shape and are shaped by the institutional and cultural settings to which they travel. We specifically examine whether the testing practices reflect a logic of care and/or choice. We approach the health facilities not as islands operating with a site specific biomedical culture, but as institutions that reflect and reinforce core values and beliefs in society (Van der Geest and Finkler 2004). Good care and free choice are such corevalues.

Fieldwork for this project was conducted as part of the Multi-country African Testing and Counseling for HIV Study (MATCH), which was carried out in 2008 and 2009 in Burkina Faso, Kenya, Malawi, and Uganda. The fieldwork in Kenya and Uganda involved observations in health facilities, interviews with clients and providers, and focus group discussions with people living with HIV and AIDS.⁴ Our study was approved by ethics committees of the relevant bodies in Uganda and Kenya.

Through informal conversations and interviews we learned about testing practices under routine conditions in health facilities, where health workers are under pressure both from above (policymakers want to scale-up testing) and from below (people are demanding tests). We learned that what they do is not always in line with the official guidelines. In fact, often there were no guidelines in the health facilities. Our aim here is to give voice to these people—those conducting the testing programs and those receiving the tests—as an input to the normative debates that take place in global health arenas, not as judgment of the ethical conduct of these actors. We use pseudonyms to protect informants’ privacy.

⁴Specifically, we conducted: observations in three faith-based, eight public, and one nongovernmental health facility in Kenya (Nairobi and Central Province), and five public health facilities in Uganda (Kampala, Soroti, and Mpigi districts); 58 in-depth interviews with clients in Kenya and 19 such interviews in Uganda; 6 single-sex focus group discussions recruited through support groups in Uganda, and two recruited through HIV Comprehensive Care Centers in Kenya; and interviews with health workers, mainly nurses and counselors (28 in Kenya, 21 in Uganda). The MATCH study also involved client and provider surveys, the results of which we are still analyzing.

PITC—GOOD CARE?

We asked clients and health care providers for their views on and experiences with provider-initiated (logic of care) testing and with VCT. Many respondents argued that it is good if the provider initiates the testing for diagnostic purposes, because choosing voluntarily to be tested is difficult: going voluntarily to a VCT clinic is tantamount in some people's eyes to an admission to having "slept around." People would rather not do that. For example, Mary, in her mid-20s, fell sick with malaria and typhoid, and was taken to casualty at Nairobi's National Referral Hospital. Upon admission she was tested for HIV for diagnostic purposes and was found to be HIV-positive. "If people at home know you are going for VCT," she explained, "they will assume you have AIDS, so the provider-initiated [approach] is much better." A male community health worker in Kenya's Central Province agreed: "VCT is associated with promiscuity. That is the mentality here. People try to avoid VCT; they don't even want to be seen near it."

Another important perceived advantage of PITC concerned the follow-up care and support that a client could receive. Maureen, an experienced counselor working at the National Hospital in Nairobi, explained: "The big difference between PITC and VCT is that in PITC there is that follow-up. After the test the doctor follows and explains about the condition and ARVs. So it is a way forward." This point was also made by Rose, a patient at a Comprehensive Care Centre (CCC) for people with AIDS in Nairobi. "PITC is a good thing," she said. "If you are sick and you are not tested, then you cannot really be helped properly. If my husband had been tested in the hospital when he was admitted, he would still be alive today."

When we asked respondents about the problems associated with PITC, many said that they felt there were none. Their view was that PITC would prevent people from dying, and babies from becoming infected, and effectively it had no down side. Very few of our respondents had concerns. For example, one HIV-positive woman (late 20s, Kampala) argued, "Mandatory tests for women at ANC have created problems for women, since they are the first to know, unlike their husband, and they are accused of having brought the infection to the man." Note the use of the word "mandatory," suggesting that some pregnant women perceive that they have little room to opt-out.

In discussing the pros and cons of VCT and PITC with clients and providers, it became apparent that the distinction between these modes of testing was not entirely clear-cut for many of our informants. VCT assumes that an individual makes an individual choice, but this is rarely the case: family members, partners, peers, religious leaders, and friends often play a role in a person's decision to have a test, whether at VCT or PITC facilities. For instance, Constance (late 20s, Uganda), concerned about her "bad past sexual relationships" explained, "I read about AIC in one of the magazines and by this time I had a new partner, and we both wanted to know the truth. So we decided to test together." Simon (HIV-positive, early 40s, Kampala) told us how his mother warned him about HIV: "My son," she said, "you are still young, be very careful with that woman. She is very bad hearted, she is HIV infected, and she infects men." His lover consoled him and took him for testing. Simon tested positive and was advised to go to The AIDS Support Organisation for further

counseling and treatment. The head of the VCT center in the National Hospital in Nairobi noted a trend: “Women in Nairobi in the past rarely came to VCT centers. These days they do, with some cajoling their male partners to accompany them.”

People use VCT and PITC sites pragmatically. In some cases, one partner may test at a PITC facility, inspiring the other partner to test either at the same PITC site as an associated family member or at a VCT site. Margaret (mid 40s, Nairobi) tested HIV-positive in 2007:

My husband became sick and I took him to a private clinic where we live. His condition became worse at night, so I brought him here to Kenyatta National Hospital, and he was admitted. A nurse came around and asked if anybody wanted to be tested for HIV. My husband agreed and was tested. He came back and told me he was positive. He told me not to worry about it. He said that since we were getting sick all the time, he decided to get tested to know his status. He asked me whether I also wanted to test my status. And I said yes. I was supposed to come to Kenyatta National Hospital to pick up some medicines, so I came to the VCT up there and told them I wanted to be tested. I told them that my husband had been admitted here and he tested positive.

Quality of care can influence decision making. Referring to PITC, as Joshua, a VCT supervisor at Kenyatta National Hospital explained, “Some patients have been tested and found the service is good and then they tell the counselor their husband will be visiting and the patient would like the counselor to test both the patient and the husband together.”

In the policy debate on VCT versus PITC, much emphasis is given to whether the provider initiates the test. In practice, situations of choice are not so clear-cut. In PITC facilities, health workers often take the initiative. But in other cases health workers are merely gatekeepers for the tests, and agency lies very much with the clients, who see themselves, their families, and their partners as being at risk. Patients consider provider-initiated tests to be “good care,” as it enables them to access antiretroviral treatment if they are found to be HIV-positive. VCT clinics, set up to cater for people who take the initiative themselves to come for tests, in many cases have become referral sites for health workers who conduct PITC.

CONSENT PROCEDURES—CHOICE?

Given the blurring boundaries between VCT and PITC, how is consent obtained? The PITC guidelines of WHO refer to the need to obtain consent (verbally), by providing patients pre-test information, including the fact that the patient has the right to decline the test (WHO/UNAIDS 2007:9). Opt-out, we have argued, fits within a logic of care. In VCT, counselors are expected to inform clients fully about the advantages and possible negative consequences of having an HIV test, enabling clients to make an informed choice—to opt-in. Opt-in reflects a logic of choice.

The Kenyan and Uganda HTC/HCT guidelines both state that no client should be tested without consent, but the pre-test procedures differ. The Ugandan HCT policy maintains that counseling should be comprehensive, unless there is not enough time for it, suggesting that

opt-in is the norm. The Kenyan HTC policy states that pre-test counseling should mainly involve obtaining consent, without making clear if clients are to be enabled to make an informed choice.

In practice, consent procedures vary within both countries: different professional groups conduct consent and pre-test counseling procedures in different ways, and institutional policies differ. Nurses and lay counselors are more likely to follow opt-in procedures; doctors and midwives (in antenatal care) generally practice opt-out testing; clients do not always value the difference.

Opt-out consent procedures are the norm in antenatal care in both countries, where nurses and midwives conduct HIV tests. Susan (20, Kenya) describes how in her case pre-test counseling was absent: “They took us to a certain room one by one. They did not tell us what we were going to do inside there. When I entered, I was told that I was being tested for HIV. I was told that if I see one line [on the rapid test kit] it means I am negative and if I see two lines, I am positive. When I entered I didn’t know what was going to happen. I just decided to stay and be tested.” Note that Susan also says she “decided” to be tested (she didn’t opt-out), despite finding herself in a relatively coercive situation.

Doctors in hospitals in both countries follow the logic of care: they refer patients for an HIV test as part of a diagnostic procedure, and at times they do not even inform patients that the test will be done. Nurses and counselors perform the tests. Patients are ill and accept the tests as routine health care procedures. Mary (mid-20s, Kenya), for example, had been ill for a long time before she was finally tested for HIV. She reports: “I became very bitter with those doctors [at the health facility in a low income part of Nairobi] since they were giving me different medicines and yet I was not getting better. Then they referred me to the National Hospital at the casualty department. They did very many tests and they were all negative. I didn’t have malaria, or typhoid but I was weak. I was then referred to the lab, where I was tested for HIV and found to be positive.” Mary was not told that she would be tested for HIV: “That door I walked in is written with VCT. So I just figured it out for myself that I was going for the test. I just decided that I should know my status, once and for all, regardless of what the results would be. I was thin; I could not walk for more than 20 minutes without taking a break to sleep. I prayed to God and asked for courage to accept the results.” For Mary, the consent procedure involved being sent to the VCT clinic, where she was informed about the testing procedure. Mary suggests that she “opted in”: she decided to walk through the door.

In some health facilities in Uganda, however, opt-in procedures are followed, with people receiving information on HIV and HIV tests as part of a general health education session conducted by nurses. Non-HIV— related topics include immunization, hygiene, and breast feeding. Individual pre-test counseling and tests may follow, depending also on the availability of rooms and counselors. However, the potential social risks of knowing one’s status (e.g., the loss of a job or a partner, or being evicted) are not addressed in these group sessions, suggesting that the health education sessions are more oriented towards marketing of tests than enabling patients to make an informed choice.

We observed more elaborate opt-in procedures in a TB ward in Kenya. Jennifer (a nurse) explains how in her ward inpatients are encouraged to go for the tests, but they are given time to do so, given that they are in the hospital anyway:

For those referred we talk to them about HTC and tell them it is not a must. If they are not ready they may not take the test. So, we tell the client this is what we will do if you accept but if you do not accept we do it another day. Then the patient is asked, "Do you feel we can do it?" If yes, the HTC is done. If no, we do not do it. Patients who have suffered with illnesses for a long time, those who have been very sick for a long time, consent very fast. They have suffered for a long time with illnesses and really want to know the cause of their illness. Most of the patients we receive here have gone to different places in search for treatment with no improvement, and when they come they really need help. So when you initiate the HTC they accept because they are tired with the illnesses, they need a solution.

Consent procedures are generally verbal in both countries. But there are exceptions. In the VCT clinic of a referral hospital in Kenya, written opt-in consent procedures are still the norm. Jane, a counselor at this clinic, reports:

In VCT there are a few cases of patients who do not want it to be known that they were at the VCT ... They do not want anybody to see them coming into or from the VCT. So to them they will feel [that in] even giving that written consent somebody will know they were at the VCT ... One could have a relative coming in and will identify their signature. For other clients they will say, "I have brought myself, why should I sign? I have volunteered to come here for the test, why should I give consent for the test again? The consent of coming here is already enough." Therefore for them it is hard to consent to sign.

WHEN THE TEST IS POSITIVE

The material presented suggests that because of the widespread promotion of HIV testing within the context of a logic of care, people generally know they are likely to be offered a test when they go to certain health facilities, and in some cases, they are not given much space to decline the test. Others actively seek the HIV tests, encouraged to do so by family or friends. But what happens when the test turns out to be positive?

Several women who tested positive at antenatal care services stressed that they were shocked:

She told me that the two lines mean that I was positive. I cried a lot, for almost one week, and I even contemplated doing an abortion to get rid of the baby. She allowed me to cry for a while and then she said the kits were very accurate and that was it. It was a very traumatizing experience. (Patricia, FGD, Kenya)

I could not even hear what he was telling me ... he kept emphasizing that I was now weak and needed more care. I would have preferred him to encourage me instead, because later I came to realize that this is not a death sentence. He was telling me that I would never be the same again, since I am sick. (Anna, 33, Kenya)

Anna, now a researcher for the National AIDS Control Council, elaborates: “I now know that you need to prepare the person for the test. You need to understand the person’s fears, calm the person, and prepare for the test. After the results the same person should calm you down, so that you have the energy to go home.”

A few respondents reported that they were confronted with negative moral judgments. For example, Mary, who tested positive after being ill for a long time, was scolded by her counselor post-test: “You have tested negative for many ailments, but it seems that you have been sleeping around.”

We found, however, that the main messages in post-test counseling are concerned with future treatment, and the advice on how and where to seek treatment, even if accompanied with other lifestyle prescriptions such as no alcohol or smoking, is generally experienced positively. People are relieved, especially when they have been ill for a long time. The outcome of their HIV test is not a dreadful confrontation with social death, but rather a future with a life on medicines. As Frank (32, Uganda) explained: “The stigma towards people living with HIV/AIDS has changed in recent years. And another informant, Samuel (46, Kenya) narrates:

She had told me that if there were two lines on the testing machine, it means that my results are positive. I was very sad when I saw the results. She tried to encourage me by saying that I am not alone in the situation. She told me that I can start taking ARVs which I should take every day so the virus levels in my blood can be contained. She told me that I don’t have to die if I follow the doctor’s advice. She told me that I would be strong and able to live my life as normal as before. I was happy to hear that.

Since the primary objective of large-scale HIV counseling and testing is to identify HIV-positive people for follow-up care and support, it is essential that this care and support is available. We observed well-funded examples of good practice in this area, such as a facility in a large low income area of Kampala, which, in addition to providing ART, runs Post Test Clubs for mutual psychosocial support, a youth friendly IEC and counseling center, and provides information about such issues as inheritance and children’s rights. As the head counselor explained, “This is like a supermarket. All the services are here.”

Similarly, a psychosocial support group at a Nairobi antenatal clinic, in its next few scheduled meetings, will be discussing self-acceptance, disclosure, infant feeding, stigma reduction, family planning, stress management, safe delivery, ARVs, and safer sex. A stand-alone VCT facility in Kampala offers a wide range of post-test services directly after an HIV-positive diagnosis, including treatment of any sexually transmitted infections, screening for TB, provision of cotrimoxazole prophylaxis, information on family planning, advice on disclosure (which may include role play exercises), and, if they want, recruitment to a Post Test Club. For discordant couples, special counseling is provided on issues such as safer sex. And a well-funded community-based HCT program in Kenya has developed an innovative mechanism for following up HIV-positive clients. Clients receive a referral form to take with them when they go for care at the District CCC, a copy of which is retained by the counselors. The latter also includes the client’s name, a mobile phone number they can

be reached at, and a GPS reading giving their home's location. With this, the provider can determine through the CCC's records if a given client has gone for follow-up, and those that have not done so can then be contacted.

But can such good follow-up care be guaranteed now testing and treatment are being scaled up? The official in charge of an urban Ugandan HCT facility was concerned: "Testing is so high that we cannot provide the follow-up services for everyone who is HIV-positive." And a nurse in a rural facility in Kenya said that, "If the result is HIV-positive, clients have to understand what this means. We refer them to our CCC, from where they can receive cotrimoxazole the moment they are registered. But some clients can't comprehend what has happened, and they leave. There is no mechanism for following them up to see if they go on to receive care and support."

CONCLUSION

In the global health policy arena, there has been fierce debate about the appropriateness of provider-initiated testing and counseling. The assumption of human rights advocates has been that voluntary counseling and testing poses fewer adverse social risks. By contrast, those who have advocated large-scale provider-initiated testing and counseling focus on the possibility of bringing many people onto treatment, thereby extending both the quality and length of their lives, and reducing the number of babies born with HIV.

Rather than judging these contrasting HIV testing and counseling procedures against the norms embedded in international and national guidelines, we have sought to provide insight into everyday testing practices. The concerns of health workers, counselors, and clients sometimes coincide with those of human rights advocates, in other cases they diverge.

Overall, the medical context inherent in PITC services provides, it seems, an attractive moral space for people to undergo HIV tests. Here HIV is associated with access to life-saving treatments and follow-up care. For many of our informants, provider-initiated testing is better than presenting for VCT, which is at times seen as admitting sexual promiscuity.

In under-staffed and under-resourced health facilities, the dynamics of care and situations of choice are shaped by the specificities of the care provided, the professional training and human resource constraints, and by the reality that nowadays HIV-positive people in the two countries can often, if not always, access life-saving drugs. When offered to sick people in outpatient clinics, HIV testing tends to be incorporated into a diagnostic process and medical care logic. Health care workers refer patients, often without much pre-test counseling other than basic information on HIV and the test, sometimes as part of general health education sessions. While in inpatient wards in TB clinics, patients are given time to decide whether they want a test, antenatal care testing in both countries has become part of a standard procedure, and women find it very hard to opt-out.

Different professional groups conduct consent procedures in different ways. Nurses and lay counselors are more likely to follow opt-in procedures; doctors and midwives who work in antenatal care clinics generally practice opt-out testing. Counselors and nurses are trained to offer people options and psychosocial support, and lead the way post-test by encouraging

people infected with HIV to live positively: to disclose their HIV status to their sexual partner(s) and family, to refrain from unhealthy habits such as drinking and smoking, and to eat a healthy diet. However, some counselors were criticized for not providing adequate psychosocial support, and some were reported to be actively hostile towards newly diagnosed HIV-positive clients.

Deciding to go for an HIV test in practice is rarely a completely voluntary individual act. Family care networks and sexual partners play an important role in the “decisions” of people to access testing services. Patients value the counseling and the care provided in the clinics, while they also exert agency in terms of “deciding” to undergo the test that is offered, in light of considerations related to their own health, relationships, and future life plans.

Thus, our study shows how, like water pumps in Zimbabwe (De Laet and Mol 2000), HIV testing technologies are fluid. They take on different shapes in the hands of different actors, and in diverse situations of choice. In some instances HIV tests are markers of promiscuity, in others they are diagnostic tools enabling access to treatment and a return to health.

Our initial question was whether diverse testing practices reflect a logic of choice or of care. We found that these logics co-exist and are intertwined. Pre-test counselors in both VCT and PITC settings work within a logic of choice, providing their clients with information and options, with an underlying aim of empowering them to look after their own lives.⁵ Doctors in out-patient departments and TB clinics prescribe tests for diagnostic reasons—they test people in order to treat them if they are HIV-positive—reflecting a logic of care. Post-test, the logic of choice is less present, and the logic of care takes over. Counselors and nurses provide social support to patients, enabling them to disclose their status to their families; doctors provide access to treatment and help patients overcome barriers to adherence.

In AIDS care, the logic of choice does not threaten to erode good care (cf. Mol 2008). One could argue that it complements the care provided in clinics. It creates empowered patients who want to take control of their own lives with HIV, and critically judge the care provided to them in PITC. But the “good” and the “bad” in HIV testing are not clear cut: they need to be defined in local settings in consultation with health workers, counselors and their clients.⁶ In some cases, choice is not considered desirable by our informants because it requires them to single themselves out as being at risk of HIV, in other cases care is perceived to be inadequate, for example when nurses post-test scold an HIV patient for having slept around, or when they fail to refer HIV-positive persons for follow-up care.

Human rights advocates who promote VCT at the global level call for good pretest counseling with opt-in procedures to enable choice. But in the Ugandan and Kenyan health settings where we conducted our study, people were most concerned about the quality of post-test care. This suggests that ethical debates about HIV testing should give equal consideration to the provision of good post-test care as to freedom of choice.

⁵One could argue that in this sense VCT has contributed to “therapeutic citizenship”, defined by Nguyen as a “system of claims and ethical projects that arise out of the conjugation of techniques used to govern populations and manage individual bodies” (2005:126).
⁶See also Mol and colleagues (2010), who encourage us to conduct detailed ethnographic studies of the “goods” and “bads” at stake in situated care practices.

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