

An offer you can't refuse? Provider-initiated HIV testing in antenatal clinics in rural Malawi

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International organizations promote provider-initiated, 'routine' HIV testing of pregnant women seeking antenatal care as an effort to curb mother-to-child transmission. We offer an account of the perceptions of HIV testing at antenatal clinics in rural Malawi. Although it is both international and Government of Malawi policy that women must be explicitly informed of their right to refuse testing, analysis of in-depth interviews, focus group discussions and evidence from observational field journals show that rural Malawians do not perceive HIV testing as a choice, but rather as compulsory in order to receive antenatal care. This study illustrates dissonance between global expectations and local realities of the delivery of HIV-testing interventions.

Keyword HIV testing, antenatal care, rights, Malawi

KEY MESSAGES

- Rural Malawians perceive routine testing for HIV at antenatal clinics as compulsory to receive antenatal care.
- Many respondents considered the benefits of antenatal testing more important than choice.
- People may increasingly avoid government hospitals for antenatal services to escape what they perceive to be a mandatory testing requirement.

Introduction

The study of local perceptions is critical to understanding the impact of the global AIDS intervention. International organizations and Western donors promote HIV testing and counselling as an important intervention for HIV prevention and treatment (UNAIDS 2004; WHO 2007), particularly in sub-Saharan Africa where HIV prevalence is disproportionately high (UNAIDS 1998; World Bank 1999; WHO 2002, 2003). Nonetheless, within the global AIDS community, provider-initiated HIV testing is controversial (Dixon-Mueller 2007; Yeatman 2007). Yet the debate surrounding the global endorsement of provider-initiated 'routine' HIV testing¹ occurs far from the multiple sites of implementation, giving little voice to those who are experiencing the epidemic firsthand. We situate our study in this debate by studying local reactions to HIV testing offered to pregnant women seeking antenatal care, an approach

advocated to avert mother-to-child transmission. We use original data from Malawi, a poor, largely rural country in southern Africa where HIV prevalence is ninth highest in the world. Our study elucidates how local implementation and reception of internationally developed strategies differ from the original design by offering an account of the perceptions that surround a pregnant woman's 'decision' to take an HIV test.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO) promote routine, provider-initiated HIV testing (UNAIDS 2004; UNAIDS 2005; WHO 2007) in addition to client-initiated HIV testing policies. Routine testing, at least on paper, allows governments to aggressively pursue the public health goal of promoting widespread testing, while keeping the choice to be tested with the individual (Rennie and Behets 2006). The protocol is simple: all patients in a clinical setting are informed that they

will be tested for HIV *unless they explicitly refuse*. The current WHO/UNAIDS guidelines for provider-initiated HIV testing elaborate: 'Patients must receive adequate information on which to base a personal and voluntary decision whether or not to consent to the test, and be given an explicit opportunity to decline a recommendation of HIV testing and counselling without coercion' (WHO 2007: 33).

Malawi, the focus of our investigation, has an estimated HIV prevalence of 12% (National AIDS Commission [Malawi] 2007). Testing for HIV first became available in Malawi in the mid-1990s but was only accessible in private health clinics and research hospitals. Since 2003, testing has expanded, first to government hospitals in major cities, and, since 2004, to district hospitals and even some rural clinics. Malawi expanded significantly its provision of prevention of mother-to-child transmission (PMTCT) services in recent years; these services include both HIV testing of the mother and, to a far lesser extent, the provision of prophylaxis to the mother, the child, or both.² In 2002, only seven facilities provided PMTCT services, testing 5059 pregnant women attending antenatal clinics (HIV Unit *et al.* 2006: 23); by 2006, 149 antenatal clinics offered PMTCT services and 137 996 women were tested during antenatal visits (HIV Unit *et al.* 2007: 28–29). In 2003, the government mandated routine HIV testing of pregnant women (Office of the President and Cabinet and National AIDS Commission 2003).³ When rapid HIV testing was implemented in four urban antenatal clinics in 2003, the percentage of attendees accepting HIV testing increased from 45% to 76%; when routine testing was implemented at the same four clinics two years later, the percentage of expectant mothers tested during antenatal care reached 99% (Weir *et al.* 2008: 95–96).

The national adoption of routine testing was accompanied by guidelines for local clinic personnel. However, there was no systematic evaluation of the extent to which these guidelines were understood or followed, nor, crucially for the consequences of the new policy, of the reactions of pregnant women for whom opt-out testing had been mandated. The only other empirical study to our knowledge that has considered responses to routine testing in a high-prevalence African setting was a population-based study in Botswana conducted one year after the introduction of a routine testing policy (Weiser *et al.* 2006). The authors found that 68% of individuals tested for HIV felt they could not refuse the test, and 43% believed routine testing would lead people to avoid going to the doctor for fear of testing.

In our study we use the specific case of routine HIV testing in antenatal clinics in rural Malawi to explore more generally the local realities of the implementation of a global intervention and how those realities conform to global expectations. As policy makers promote routine HIV testing, this study asks two questions of empirical import: what are the local perceptions of routine HIV testing, and what are the potential consequences of those local perceptions?

Methods

Because our primary interest is in rural Malawians' perceptions of routine antenatal HIV testing, we use qualitative research methods. Our data include: (1) semi-structured interviews

covering perceptions of and experiences with HIV testing; (2) focus group discussions capturing reactions to HIV testing in antenatal clinics; and (3) observational field journals documenting informal conversations about AIDS in local social networks. The data cover a 4-year period following the introduction of the routine testing mandate in Malawi (2005–09).

Semi-structured interviews

We conducted interviews in June and July 2007, alongside a study on HIV testing and treatment surveillance led by the University of Pennsylvania in conjunction with the District Office of the Ministry of Health in Mchinji District. The intention of the study was to understand local perceptions of HIV testing more generally. However, because the analytic focus of this paper is on perceptions of testing in antenatal clinics, our analysis draws only from interviews with those respondents who were HIV-tested during an antenatal visit. Our general sample of respondents was drawn from the population of attendees undergoing HIV testing at the two hospitals in the district and one government clinic, to which we refer hereafter as the testing attendee sample. One hospital is the government-run Mchinji District Hospital, where services and drugs, including anti-retroviral treatment (ART), are free of charge—at least when they are available and accessible. At the second hospital, Kapiri Mission Hospital, testing is free, although other services, such as CD4 count, require a fee. The local clinic, Tembwe Clinic, is a very basic government health centre that provides HIV testing and limited drugs and services.

In June 2007, we selected our sample from all clients who had been tested for HIV in November and December 2006; these two months were the only months for which we had information from the larger study and consent for follow-up.⁴ We restricted the sample to respondents over 18 years of age with complete identifying information from the clinic survey.⁵ We stratified the registers by facility and HIV status, and sorted the six samples by day of clinic visit; we then drew every eighth respondent on the list until we had selected 16 respondents from each facility, 10 HIV-positive and 6 HIV-negative. The research team attempted to interview a total of 44 respondents sampled from the clinic registers. At the time of our study, however, 14 of the 44 sampled respondents could not be interviewed, because they had died, moved, were out of town or hospitalized. The remaining 30 respondents were successfully interviewed, 10 from each facility.

We also interviewed a second sample of 19 'near neighbours' of our testing attendee sample to learn about the perceptions of villagers who were presumably similar to those in the testing attendee sample, but who were not selected into the sample by virtue of not having been tested for HIV at the study clinics in late 2006. The decision to include near neighbours in the sample was motivated by our desire to capture the opinions and experiences of a quasi-randomly selected sample of Malawians who were similar to our testing attendee sample in that they lived in the same village, but were different from our testing attendee sample because their inclusion in the study did not rely on their having been previously tested for HIV. The near neighbour sub-sample was intended to serve as a comparison

Table 1 Characteristics of interview respondents

	<i>n</i>	%
Sample		
Testing attendee sample	12	66.7
Near neighbour	6	33.3
Gender		
Women	17	94.4
Men ^a	1	5.6
Marital status		
Married	16	88.9
Divorced/separated	2	11.1
HIV status		
HIV positive	5	27.8
HIV negative	12	66.7
Unknown	1	5.6

Notes: There were 18 interview respondents in total. The average age of respondents was 26 years (range 18–42).

^aThe male respondent in this sample was HIV-tested when accompanying his wife to the antenatal clinic.

group for the entire testing attendee sample, to observe how perceptions of health services differed amongst those who had not necessarily utilized nearby HIV testing services. Near neighbours were selected during the visit to the respondent from the testing attendee sample: one interviewer located the house of the testing attendee sample respondent, then the other interviewer went to the nearest home in the village that was not part of the same compound; the interviewer spoke with either the man or woman of the neighbouring house,⁶ and asked if they would be willing to chat about health services in Malawi. In the event that there was more than one adult at home, the interviewer asked to speak with the head of the household.

Forty-nine interviews were conducted in all: 30 from the testing attendee sample and 19 near neighbours. During the interviews, 10 near neighbours reported previous HIV testing. Of the total 40 respondents who had been tested, 18 were tested during an antenatal clinic visit (12 from the HIV testing attendee sample and six from the near neighbours sample).⁷ As stated earlier, the analytic focus of this paper draws only from interviews with these 18 respondents who were HIV-tested during an antenatal visit. Table 1 provides a summary of the characteristics of our interview respondents.

Interviews were conducted in private in respondents' homes or, very occasionally, in a location of the respondent's choosing. Interviewers asked about personal and family health, experience with HIV testing,⁸ knowledge about ART and local health services. Though interview guides were developed for implementation with all respondents, not just antenatal attendees, they included questions about the consent process and the possibility of refusal, allowing interviewers to explore the voluntariness of antenatal testing and HIV testing in general. Interviews were semi-structured; interviewers had a question guideline but were instructed not to ask questions in a highly structured format. Rather, we explained that we intended for

the session to resemble a conversation. Interviewers were instructed to probe or revisit questions when respondents gave short answers, conflicting statements, and/or used social marketing language (e.g. 'It's important to know your status'; 'I wanted to plan for the future'). Interviews lasted 25 minutes to just over an hour, with typed transcripts averaging 11 single-spaced pages.

Interviews were read and coding schemes were developed around emerging themes. We studied interviews for content on perceptions of the voluntariness of testing during antenatal care. We analysed all interviews discussing testing in the antenatal setting ($n=18$) and coded whether respondents found antenatal-clinic HIV testing to be compulsory ($n=14$) or voluntary ($n=4$). We identified passages elaborating these perceptions and draw from those passages to provide context.

Focus group discussions

We also conducted focus group discussions in Balaka District with men and women in June and July 2009 to further our understanding of perceptions about HIV testing in the general rural population. We conducted five focus groups, each with five to eight respondents: three groups had men and women; one group only women; and one group only men. The focus groups lasted between 40 and 60 minutes. Respondents were recruited for voluntary participation in one of two ways: either the village headman helped enumerators locate members of his village, or the enumerators approached individuals already congregating in open settings, such as a group of women seated on a veranda braiding each others' hair, or a group of men chatting outside a local grocer.

In the discussions, respondents were presented with a series of vignettes about HIV testing. The first vignette posed the following scenario: 'Lucy is pregnant and goes for antenatal services for the first time. When she goes to the antenatal clinic, what do you think will happen?' Throughout the discussion, enumerators interjected as appropriate with related questions such as: 'What if Lucy refuses the HIV test?', and/or 'What if her husband does not want her to be tested?' Respondents discussed HIV testing in antenatal clinics; in some cases, they described their own experiences with the antenatal testing process, or the experiences of those familiar to them. The responses generated by this vignette were analysed for content and the major findings presented here.

All interviewers and focus group enumerators (referred to collectively here as 'facilitators') were Malawian, fluent in Chichewa, the local language, and English. Interviews and focus group discussions were conducted in Chichewa and translated and transcribed into English by the respective facilitator. Transcripts were typed in the field, providing an opportunity for us to ask facilitators about any exchanges or English words that were unclear in the translations as well as to suggest areas for future elaboration and probing. Facilitators were equipped with a digital voice recorder, consent forms, the question protocol, a notebook and a pen. All recordings are archived in digital format. Although our facilitators had considerable research experience, prior to initiating our field-work they took part in a short training for this particular project.⁹ We provided follow-up training as needed throughout the course of data collection.

Observational field journals

Finally, we take advantage of a rich set of observational field journals collected over the past decade in Balaka District (Watkins 2008). The aim of the journal project, with which we have all been involved, is 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.¹⁰ Several village residents were asked simply to listen to conversations they overheard or participated in during the course of their daily lives and then record their recollections in a field journal. The conversations they capture are varied, ranging from graveside condolences following a funeral, talk between neighbours at a borehole, or men's conversations on the bus. Field assistants have the equivalent of a US high school education, but no college; all rely on subsistence agriculture, supplemented by casual labour, small-scale retail or intermittent research projects. They write the journals in English, though the conversations captured are in local languages in which the field assistants themselves are fluent. We recognize that this method is unusual, but its analytic utility and shortcomings have been well documented elsewhere (see Kaler 2004; Watkins 2004; Watkins and Swidler 2009).¹¹

We used Boolean text searches to identify conversations about HIV testing at antenatal clinics in all journals written since 2005. Using the qualitative data analysis software package *NVivo*, all journals were scanned for the words 'antenatal', 'prenatal' or 'natal'. Our analysis includes conversations explicitly mentioning HIV testing as part of antenatal care ($n=16$).¹² In the observational accounts in this paper, we retain the words of the field assistants despite grammatical errors, bracketing explanations of segments that may be unclear. Names of people and places have been changed to protect the identities of the participants.

Findings

In the following section we first present data on local perceptions of routine antenatal HIV testing, specifically whether respondents perceive HIV testing as compulsory in order to receive antenatal care. We then present results of our analysis on the reactions to and consequences of local perceptions about routine HIV testing. In particular, we ask how the perception of compulsory HIV testing in antenatal clinics might shape subsequent antenatal care-seeking patterns among women and their partners who do not want to be tested for HIV.

Routine HIV testing: 'opt-out' or no option?

The majority of our interview respondents who had been tested during an antenatal visit told us that they were not given the option to refuse the HIV test. One woman said that there was "a rule that anyone who has gone for antenatal should be tested" (Interview #5). Another woman 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" (Interview #9NN). A third interview (Interview #10) had a longer exchange:

Interviewer: "Were you given the option by the counsellor to refuse VCT [HIV testing]?"

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 is important for women to be tested."

Respondents who shared their HIV testing experience were asked directly if they were given the option to refuse the HIV test. Only four of the 18 women tested during an antenatal visit stated that refusals were allowed and reported that women who refused an HIV test were still able to receive the other antenatal services offered. The majority of our respondents, however, perceived that there was no option to refuse testing.

We find similar perceptions of testing at antenatal clinics in the focus group discussions. In all five focus groups, respondents stated that women will be tested for HIV as part of their antenatal care visit, along with other routine examining procedures. In two focus groups, respondents explained that women will be tested "whether you [the woman] like it or not" (Mixed Focus Group #2; Mixed Focus Group #3). One woman elaborates the testing process in detail:

Woman #2: "Now it's mandatory. At the hospital it is such that if you want antenatal services, blood test then the ticket and cotton on your hand showing that you have been pricked is your ticket for antenatal clinic. No ticket, no services. They enlighten you first on the goodness of blood test for child to be born because you are preparing the baby's future..." (Mixed Focus Group #1)

Another woman elaborated the testing requirement as law for pregnant women, a belief that her fellow female respondents corroborate:

Enumerator: "What if she [Lucy] refuses the blood test?"

Woman: [inquiring] "Is she pregnant or not?"

Enumerator: "She is a pregnant woman."

Woman: "Whether she likes it or not, by force she is supposed to enter the testing room because it is a law to get tested for pregnant women. That is why they say no one is above the law, whether she likes it or not. If she does not get tested, it means she will not access antenatal services. She will have to go back and on delivery day she will not go to the hospital as well."

[Majority of women agree in humming chorus] (Women Focus Group #1)

When asked by the enumerator what would happen if a woman (e.g. Lucy) did not want to be tested, some respondents stated that she can indeed refuse. Her refusal, however, implies that she is also refusing all antenatal care. As one man notes:

Man #4: "The way it is nowadays you cannot go to the antenatal clinic. It is not possible to access services without knowing your

body status [HIV status]. So if you go to the antenatal clinic it means you have accepted everything that will take place there.” (Men Focus Group #1)

In cases where pregnant women do not want to be tested, some respondents argued that it was incumbent on the clinic staff to intervene:

Man #2: “Yes if she refuses, she should not be forced and be told that well it’s voluntary, but advised accordingly so that she understands the importance [of being tested]. Don’t just say ‘Oh you have refuse[d] go...go.’ That’s not right. She needs help.”

Man #3: “. . . [Lucy is given] counselling and given other advices before antenatal [care]. . . So Lucy needs assistance. . . she should be ask[ed] why she came to the antenatal clinic: ‘So if you are refusing antenatal care, what did you come here for?’ Just as [Man #2] said here, the counsellor, in a nice and proper way, should talk to Lucy and I hope [believe] she cannot refuse.” (Mixed Focus Group #1)

Finally, the informal observational journals also suggest that testing at antenatal clinics is perceived locally as compulsory. One field assistant, who was pregnant and visited an antenatal clinic herself, wrote that “. . .the nurse told us that the government of Malawi has decided to force all the women who are pregnant to be tested for HIV so that if they are found with that problem [HIV], they should be helped. . .” (Journal from Alice, 27 July 2006).

In another journal entry, a field assistant, who is also a volunteer HIV counsellor at a health facility that offers antenatal services, describes a case of a pregnant woman sent to him by one of the nurses for an HIV test. The woman’s encounter with the nurse shows that if she were to decline the test, she would forfeit access to antenatal care:

“Whilst I was working suddenly a pregnant woman opened the door. . . I enquired from her what assistance she needed from the [VCT] centre. She smiled lightly and said, I came to the antenatal clinic and the nurse has asked me to come for an HIV test. . .The woman said she has come because the nurse has told her that if she doesn’t go for an HIV test she should not come back to the antenatal clinic the next visit. . . I asked her if the nurse had explained to her the importance of the test results to her and unborn baby which she was expecting. The woman said that the nurse told [said], ‘Go to the VCT to know your HIV status whether you will cry is none of my business. If you don’t go there never come back here.’” (Journal from Mavuto, 1 December 2008)

The field assistant later reflects on the interaction between the nurse and the woman. He corroborates what the majority of the respondents in our study perceive: in practice, Malawi’s routine testing policy requires pregnant women be HIV-tested as part of antenatal care:

“I was shocked with the behaviour of the nurse, because it was only a month ago when it was reported in the news that Madindi District Hospital is forcing pregnant women to have an HIV test if they want to have antenatal clinic services. The Ministry of Health refuted the allegations saying HIV test[ing] is a routine test for

pregnant women and is not compulsory.” (Journal from Mavuto, 1 December 2008)¹³

Another field assistant heard his female relatives debating antenatal testing. The excerpt below suggests that even women who are not themselves going for antenatal care perceive testing as compulsory from the stories shared with them by their friends and neighbours. He recalled:

“She [the field assistant’s relative] found that those women who went to this clinic for antenatal services, they were being told by the nurses that before they were assisted with antenatal services, they had to undergo blood tests [HIV tests] first and that this is a must in these days and that some of the women were not happy with this demand.” (Journal from Diston, 11 January 2007)

The consequences of ‘compulsory’ antenatal HIV testing

Do women object to what they perceive as compulsory testing? We find mixed reactions. Many respondents consider antenatal testing—or perhaps just compliance with what they understand to be the government’s rules—more important than choice; others respond to the perception of antenatal HIV testing as mandatory with scepticism and, seemingly, fear.

Several interview respondents said that pregnant women should be tested for HIV. One woman explained that compulsory antenatal testing is acceptable because “it is important for women to be tested” (Interview #10). Other women echoed this sentiment in language that mirrors what they have heard in the clinic or on the radio: that testing is “good for the baby”, or “when we know our status, we will know how to care for the baby” (Interview #25). In the focus group discussions we find similar sentiments, though expressed differently. Participants described women who did not want to have an HIV test as having a “bad mentality” (Men Focus Group #1) and that by refusing she is “killing two lives” (Mixed Focus Group #1), “does not wish the child well” or is “going to destroy her future and that of the child” (Mixed Focus Group #2). In short, for many of our respondents, testing is *understandably* compulsory for pregnant women.

But how do people deal with the consequences of having to confront testing that they perceive as compulsory when it is something they do not want, or significantly, something unwanted by their partners? One consequence is that women may avoid hospitals for antenatal care where the testing requirement is perceived as mandatory, as featured in a recent newspaper article in one of Malawi’s leading papers (see Kumwenda 2006), or use their husbands’ disapproval as an excuse for declining antenatal services. Or they may get tested, and then “run away” when it is time to learn their test results. As one woman regales of her own experience:

Woman #3: “. . .I got tested together with 3 other women. After we gave blood for testing and it was time to get results, I went inside to get my test results and found that the other woman—we got tested together—just sat outside. So when they called for number 49 she was quiet and I said, ‘It is this one.’ She then ran away.”

Woman #2: “It means she was suspecting that she is infected.”

Woman #3: *"Yes she was afraid that she is infected. She reached the doorway and we told her to get in, she turned and went back [home], and she failed to go for antenatal service..."* (Women Focus Group #1)

Alternatively, women may turn to traditional birth attendants (TBAs) when they are ready to deliver, rather than government health facilities. Consequently, the Government of Malawi has cracked down on traditional birth attendants (*Nyasa Times* 2009), as one woman notes and others affirm:

Woman #1: *"...People from villages run to TBAs. That is why the traditional birth attendants are currently not allowed to help pregnant women to deliver their babies. TBAs are the ones who make the virus to spread to babies because women run from the hospital saying they do not want to get tested and go to traditional birth attendants to deliver."*

[Women agreeing in chorus] (Mixed Focus Group #3)

That some husbands object to their pregnant wives being tested is also significant. One journal entry reports a conversation that suggests that with 'compulsory' testing, husbands may forbid their wives from going for antenatal services:

"Then brother Lawrence laughed and said, 'I can also see that most of the men will not be sending their wives to the clinic for antenatal services fearing the same programme ['compulsory' HIV testing].'" (Journal from Diston, 8 March 2007)

A conversation from a focus group discussion corroborates Lawrence's speculation:

Woman #3: *"There are certain men who do not want their wives to go for [an] HIV test."*

Woman #2: [agrees] *"Yes, they say, 'no'."*

Man #2: [agrees] *"Yes, they do that."* (Mixed Focus Group #2)

One woman who was tested at an antenatal clinic and found to be HIV-positive encountered conflict at home when sharing her results with her husband, who admonished her to no longer seek antenatal care at the clinic:

"Her husband shouted that the doctor has lied to her... She said that her husband spoke many things that encouraged her to disobey the advice [from the antenatal clinic], that she even stopped going to antenatal clinic and she thought that she will deliver at home." (Journal from Patuma, 15 October 2006)

A particularly vivid example of the lengths to which men might go in order to escape testing was observed by a field assistant, who happened to see a man passing by, carrying his pregnant wife on his bicycle. After they are out of earshot, the man's neighbours talk about him. One said:

"...the husband who was cycling his wife is afraid to be tested blood for AIDS status. She went on saying that the woman (his pregnant wife) went to Mwendu Hospital to start antenatal clinic because of her pregnancy and she was told that she should first of

all be tested for AIDS status before everything and she was told to go and bring her husband to undergo the process while together and when she was told that she came out of the hospital and meet with her husband who was waiting [for] her outside the hospital (with the bike – I hope [believe]) and when she told her husband about that the husband was against that move and said 'let's go home' and they run away from there and now they are going to Vingula dispensary [clinic] thinking that they are not going to be tested." (Journal from Simon, 14 August 2007)

The field assistant's concluding comment that the man on the bicycle and his wife were *"thinking that they are not going to be tested"* suggests that it is impossible to evade testing at antenatal clinics because all have the same requirement.

Discussion

We present data showing that rural Malawians do not perceive HIV testing in antenatal clinics as a choice; on the contrary, the majority perceive HIV testing as compulsory to receive antenatal care. We also consider the consequences of the perception of 'compulsory' antenatal testing, specifically as it affects pregnant women. One important consequence is that people may avoid government hospitals for antenatal services to escape what they perceive to be a mandatory testing requirement. By collecting and analysing data on how this practice is perceived by the women who are expected to benefit, this study, to our knowledge, is one of the few that offers evidence to those who debate the potential advantages and disadvantages of routine testing in high-prevalence countries. As proponents of testing would expect, we find the number of rural women tested for HIV in Malawi increased dramatically after the government mandated routine testing at antenatal clinics.¹⁴ We also find that the concerns about violations of international conceptions of human rights are justified, although the interviews and focus group discussions show a general acceptance of the seemingly compulsory nature of routine antenatal HIV testing. We do not contend that our data are representative of the general Malawian experience or that our results are generalizable; nevertheless, they undoubtedly shed light on our presently dim understanding of reactions to and perceptions of rapidly scaled-up provider-initiated testing and suggest areas for future investigation.

Interview and focus group respondents' favourable comments about HIV testing in antenatal clinics should not be surprising. Social marketing campaigns in many high-prevalence countries like Malawi emphasize the importance of learning one's HIV status as a way to 'plan for the future'.¹⁵ The recent availability of ART has also altered the context of testing such that many now see taking an HIV test as potentially life-saving, rather than as a death sentence. Furthermore, when HIV tests are offered at people's homes or in mobile clinics, thus obviating the costs in money and time of travelling to a health facility, acceptance is high (Matovu *et al.* 2002; Wolff *et al.* 2005; Yoder *et al.* 2006; Byamukama *et al.* 2008; Thornton 2008; Angotti *et al.* 2009; Obare *et al.* 2009).

But do the ends justify the means? In the course of antenatal care, having an HIV test is meant to provide information that could lead to treatment, preventing transmission of HIV to

children of HIV-positive mothers. Unfortunately, the rapid scale-up of HIV testing in antenatal clinics is not matched with an equally scaled-up provision of Nevirapine prophylaxis to HIV-positive expectant mothers to protect their newborn children. The main barrier to access to Nevirapine is insufficient stock. In 2006, the last year for which data are available, only 57% of women who tested HIV-positive at antenatal visits received a maternal dose of Nevirapine; of the 157 audited antenatal clinics in Malawi, half experienced stockouts of Nevirapine prophylaxis and 27 clinics provided *no* prophylaxis for HIV-positive expectant mothers the entire year (HIV Unit *et al.* 2007: 25–39).

Limitations of the study

As with any study, our findings should be attenuated by the limitations of our research. The sample of respondents in the interview study could suffer from bias in two ways. One potential problem with the interview study sample is the research team's inability to locate 14 of the 44 sampled respondents. Of these 14 respondents, eight had tested HIV-positive at the clinic visit. One explanation for this high non-response rate might be that individuals who visit the clinic for HIV testing are often sick with AIDS and seeking ART enrollment; it is possible that many had died of AIDS in the six months between clinic attendance and data collection. Another possible explanation is the prevalence of misreporting in clinic registers; people sometimes use fake names, making follow-up difficult. Finally, the location of the District—on the Zambia–Malawi border—facilitates mobility and migration. We cannot ascertain whether these 14 respondents were tested as part of antenatal care, so it is unclear whether our inability to locate them in the general study would matter for the antenatal-specific context we study here. Were any of those 14 respondents tested in the course of antenatal care, we have no hypothesis about how they would perceive routine testing.

An additional potential bias of the interview study sample is that it comes from a population of individuals undergoing HIV testing. This meant that we could not identify, and thus could not interview, those women who refused HIV testing as part of their antenatal care nor women who chose not to seek out antenatal care, perhaps biasing our analytic sample in favour of those who perceive HIV testing as mandatory. We address this limitation with the integration of a near neighbour sample (though we recognize that for the study presented here, that sample is quite small) as well as with focus group discussions with the general population. We cannot discount, however, the extent to which respondents may actively shape their responses to interviewers (Miller *et al.* 2001). To account for these limitations, we integrate observational field journals of local conversations in the wider community about antenatal HIV testing, which offer insights into what individuals say to one another. Although we cannot make a numerical comparison, we perceive that there is more sympathy for compulsory testing when respondents are talking with an interviewer than when people are talking with each other in natural settings.

Implications and directions for future research

There are important substantive, methodological and policy-relevant implications of our study. Provider-initiated or

'routine' HIV testing, as stipulated by the WHO and UNAIDS in Geneva and as national policy in Malawi, is intended to take place only with informed consent, which is presumed to be given if the individual does not explicitly opt-out. In our study, however, the majority of our interview and focus group respondents, along with the data from the observational field journals analysed for this study, portray a perception that there is no right to refuse the test. Though it is possible that antenatal clinic personnel were in fact punctilious about explicitly offering each woman the right to refuse an HIV test, we have no direct evidence that this is the case and evidence from three sources—including perceptions of women who were themselves tested at an antenatal clinic—convince us that it is not.

What might explain the deviation between global expectations and local realities of routine HIV testing? It may be that health personnel have a different understanding of what it means to have the option to refuse, perhaps because it has been specified to them incompletely or imperfectly in their training or training manuals (Pritchett and Woolcock 2004). Alternatively, health personnel themselves may see testing as an important health intervention, with goals that override concerns about the strict voluntariness of testing (Angotti 2010). Constraining choice may be especially likely when clients are women, rural and relatively uneducated compared to health personnel (Rutenberg and Watkins 1997; Booth 2004; Datye *et al.* 2006). Clients themselves may also be accustomed to procedures in health facilities that are not voluntary, though presented to them as such, or might want providers to make decisions on their behalf (Maman and King 2008). Indeed, the very establishment of a health policy that offers a test sends a powerful normative message that taking the test is the best thing to do (Rennie and Behets 2006; Dixon-Mueller 2007). Future research might study more directly the constraints and motivations of antenatal clinic personnel as well as the interactions between antenatal clinic staff and clients.

Our paper also raises an important methodological consideration for the evaluation of innovations in HIV prevention and other public health interventions. Typically, evaluations of responses to an intervention are based on data collected in structured formats, such as clinic records, individual interviews or focus groups (MANET 2003; Scotland *et al.* 2003; Kadiyala 2004; Murphy *et al.* 2005). Clinic data provide only a numerical snapshot of uptake without an opportunity to understand the perceptions of intended beneficiaries. Interview and focus group data may reflect the respondents' hope that the respondents may benefit materially if they provide what they understand to be the correct answer (Miller *et al.* 2001). With this in mind, we integrated strategically three different forms of qualitative data: interviews, focus group discussions and observational field journals. Though all three sources suggest that rural Malawians perceive antenatal testing as compulsory, we find more favourable responses to the perceived mandatory testing requirement in the interview and focus group discussions than in the observational field journals (also see Thornton *et al.* 2005; Angotti *et al.* 2009). The journals provide the perspective of both men and women without the imposition of an official facilitator, perhaps reducing social desirability bias and thereby

offering insight into any negative attitudes towards compulsory testing.

Our study also has meaningful implications for policy. If increasing the proportion of those tested in the short term were the only goal of routine HIV testing, then its merit is uncontested by our study. But if the introduction of routine testing aims simultaneously to protect the individual rights of pregnant women, then routine testing—in rural Malawi, at least—seems to be imperfect at best and counterproductive at worst. Our analysis shows intended beneficiaries of routine testing perceive HIV testing as compulsory to receive antenatal care. For some, this means they forfeit all access to care, either because providers fail to give them another option or because their partners object to testing. Our study thus suggests that greater attention be given to how health policy is implemented in practice, in the setting in which health professionals and their clients interact. The social relations in which HIV testing occurs in rural Malawi may not represent the idealized notions assumed by global or national policies.

Endnotes

- ¹ There are two types of HIV testing programmes: *client-initiated* approaches, whereby a client self-presents at a health facility for testing; and *provider-initiated* approaches, referred to as either 'routine', 'diagnostic' or 'opt-out', whereby clients are offered an HIV test by a provider in a clinical setting with the option to refuse. In this paper, we use the terms 'routine testing', 'provider-initiated testing' and 'opt-out testing' interchangeably.
- ² There is currently lack of capacity and resources to administer prophylaxis to all women who test HIV-positive in Malawi.
- ³ Though the policy for opt-out testing of pregnant women was established in 2003, the policy was not implemented until 2005 (Weir *et al.* 2008: 96).
- ⁴ The greater study's ethical approval required previous consent before any follow-up interviews.
- ⁵ The clinic survey includes name, gender, residence and age.
- ⁶ If this house did not have anyone at home, and that resident could not be located, the interviewer moved on to the next nearest home.
- ⁷ One additional respondent said she was tested after being encouraged by the clinician she saw while at the antenatal clinic, but we do not include her in the count here because the interview transcript leads us to believe she sought out testing after her antenatal visit at a place other than the antenatal clinic (Interview #27).
- ⁸ Interviewers did not ask questions that assumed an HIV testing visit. Questions were worded such that respondents would be asked what they knew about testing. Biomarker data were 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 experience with testing; the interviews show that those who have been tested tell some friends about it, not just the interviewer. A study from rural Malawi on HIV status disclosure finds that only approximately 3% of women and 1% of men report having told no one their HIV status (Anglewicz 2008).
- ⁹ Facilitators had previous experience working with a recently fielded longitudinal health survey as well as smaller-scale qualitative projects.
- ¹⁰ Based on our previous experience conducting surveys in Malawi as well as analyses of the quality of survey data in Malawi and elsewhere in the region, we expected that interview respondents might report a more flattering picture of interactions at a clinic than they had actually experienced (Miller *et al.* 2001).
- ¹¹ Examples of the journals are available publicly at <http://www.malawi.pop.upenn.edu>.
- ¹² Though the journals cover a decade-long period (1999–2009), these 16 conversations date from 2006 to 2008.

¹³ The journalist refers to Misunje (2008), an article in the major daily newspaper in Malawi.

¹⁴ As stated earlier, in 2002, 5059 women were tested at antenatal clinics, whereas in 2006, 137 996 women were tested (HIV Unit *et al.* 2007: 52).

¹⁵ 'Plan your future, go for a HIV test today' was the slogan of Malawi's 2007 National Testing Week campaign.

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References

- Anglewicz P. 2008. Disclosure of HIV status among rural Malawians. Paper presented at the Annual Meeting of the Population Association of America, New Orleans, LA, April 17–19.
- Angotti N. 2010. Working outside of the box: how HIV counselors in sub-Saharan Africa adapt Western HIV testing norms. *Social Science & Medicine* **71**: 986–993.
- Angotti N, Bula A, Gaydosh L *et al.* 2009. Increasing the acceptability of HIV counseling and testing with three C's: convenience, confidentiality and credibility. *Social Science & Medicine* **68**: 2263–70.
- Booth K. 2004. *Local Women, Global Science: Fighting AIDS in Kenya*. Bloomington, IN: Indiana University Press.
- Byamukama D, Mulenga M, Bowie C, Nkhwazi D, Tenthani L. 2008. Pioneering district-wide door to door HTC: early program experiences in Zomba District. Paper presented at the National HIV and AIDS Research and Best Practices Conference, 27–27 June 2008, Lilongwe, Malawi.
- Datye V, Kielmann K, Sheikh K *et al.* 2006. Private practitioners' communications with patients around HIV testing in Pune, India. *Health Policy and Planning* **21**: 343–52.

- Dixon-Mueller R. 2007. The sexual ethics of HIV testing and the rights and responsibilities of partners. *Studies in Family Planning* **38**: 284–96.
- HIV Unit, Department of Clinical Services, Ministry of Health; Lighthouse Trust Lilongwe; Centers for Disease Control and Prevention Malawi. 2006. *Report of a Country-wide Survey of HIV/AIDS Services in Malawi for the Year 2005*. Lilongwe, Malawi: Ministry of Health.
- HIV Unit, Department of Clinical Services, Ministry of Health; National TB Control Program; Lighthouse Trust Lilongwe; Centers for Disease Control and Prevention Malawi. 2007. *Report of a Country-wide Survey of HIV/AIDS Services in Malawi for the Year 2006*. Lilongwe, Malawi: Ministry of Health.
- Kadiyala S. 2004. Scaling-up HIV Interventions Through Expanded Partnerships (STEPS) in Malawi. 2004. FCND Discussion Paper. Washington, DC: International Food Policy Research Institute.
- Kaler A. 2004. The moral lens of population control: condoms and controversies in southern Malawi. *Studies in Family Planning* **35**: 105–15.
- Kumwenda O. 2006. Pregnant women shun hospital fearing HIV test, pregnant women complain. *The Nation*. Blantyre, Malawi.
- Maman S, King E. 2008. Changes in HIV testing policies and the implications for women. *Journal of Midwifery and Women's Health* **53**: 195–201.
- MANET (Malawi Network of People Living with HIV/AIDS). 2003. Voices for Equity and Dignity: Qualitative research on stigma and discrimination issues as they affect PLWHA in Malawi. Lilongwe, Malawi: MANET.
- Matovu J, Kigozi G, Nalugoda F, Wabwire-Mangen F, Gray R. 2002. The Rakai Project counselling programme experience. *Tropical Medicine and International Health* **7**: 1064–7.
- Miller K, Zulu E, Watkins S. 2001. Husband-wife survey responses in Malawi. *Studies in Family Planning* **32**: 161–74.
- Misunje M. 2008. Chief claims couples forced to test for HIV; DHO refutes claims of mandatory HIV testing. *The Nation*. Blantyre, Malawi.
- Murphy L, Harvey P, Silvestre E. 2005. How do we know what we know about the impact of AIDS on food and livelihood insecurity? A review of empirical research from rural Sub-Saharan Africa. *Human Organization* **64**: 265–73.
- National AIDS Commission [Malawi]. 2007. *2007 Sentinel Surveillance Results*. Lilongwe, Malawi: National AIDS Commission.
- Nyasa Times. 2009. TBAs ban in deliveries will help reduce child mortality rate. *Nyasa Times*. Blantyre, Malawi.
- Obare F, Fleming P, Anglewicz P *et al.* 2009. Acceptance of repeat population-based voluntary counselling and testing for HIV in rural Malawi. *Sexually Transmitted Infections* **85**: 139–44.
- Office of the President and Cabinet and National AIDS Commission [Malawi]. 2003. *National HIV/AIDS Policy, A Call for Renewed Action*. Lilongwe, Malawi: National AIDS Commission.
- Pritchett L, Woolcock M. 2004. Solutions when the solution is the problem: arraying the disarray of development. *World Development* **32**: 199–212.
- Rennie S, Behets F. 2006. Desperately seeking targets: the ethics of routine HIV testing in low-income countries. *Bulletin of the World Health Organization* **84**: 52–7.
- Rutenberg N, Watkins S. 1997. The buzz outside the clinics: conversations and contraception in Nyanza Province, Kenya. *Studies in Family Planning* **28**: 290–30.
- Scotland GS, van Teijlingen ER, van der Pol M, Smith WCS. 2003. A review of studies assessing the costs and consequences of interventions to reduce mother-to-child HIV transmission in sub-Saharan Africa. *AIDS* **17**: 1045–52.
- Thornton R. 2008. The demand for, and impact of, learning HIV status. *American Economic Review* **98**: 1829–63.
- Thornton R, Bula A, Chavula K *et al.* 2005. Reactions to voluntary counseling and testing in rural Malawi. Unpublished working paper.
- UNAIDS. 1998. *Report on the Global HIV/AIDS Epidemic*. Geneva: UNAIDS.
- UNAIDS. 2004. *UNAIDS/WHO Policy Statement on HIV Testing*. Geneva: UNAIDS.
- UNAIDS. 2005. *Consultative Meeting on HIV Testing and Counseling in the Africa Region*. Johannesburg, South Africa: UNAIDS.
- Watkins S. 2004. Navigating the AIDS epidemic in rural Malawi. *Population and Development Review* **30**: 673–705.
- Watkins S. 2008. Malawi Conversational Journals Project. Philadelphia, PA: University of Pennsylvania. Partially available online at: <http://www.malawi.pop.upenn.edu>.
- Watkins S, Swidler A. 2009. Hearsay ethnography: conversational journals as a method for studying culture in action. *Poetics* **37**: 162–84.
- Weir S, Hoffman I, Muula A *et al.* 2008. *Final Report Malawi Prevalence Study*. Lilongwe, Malawi: UNC Project-Malawi.
- Weiser S, Heisler M, Leiter K *et al.* 2006. Routine HIV testing in Botswana: a population-based study on attitudes, practices, and human rights concerns. *PLoS Medicine* **3**: e261.
- WHO. 2002. *Scaling up Antiretroviral Therapy in Resource-Limited Settings*. Geneva: World Health Organization.
- WHO. 2003. *Treating 3 Million by 2005: Making It Happen: The WHO Strategy*. Geneva: World Health Organization.
- WHO. 2007. *Guidance on Provider-Initiated HIV Testing and Counselling in Health Facilities*. Geneva: World Health Organization.
- Wolff B, Nyanzi B, Katongole G *et al.* 2005. Evaluation of a home-based voluntary counselling and testing intervention in rural Uganda. *Health Policy and Planning* **20**: 109–16.
- World Bank. 1999. *Confronting AIDS: Public Priorities in a Global Epidemic*. Washington, DC: World Bank.
- Yeatman S. 2007. Ethical and public health considerations in HIV counseling and testing: policy implications. *Studies in Family Planning* **38**: 271–8.
- Yoder P, Katahoire A, Kyaddondo D *et al.* 2006. *Home-Based HIV Testing and Counselling In a Survey Context in Uganda*. Calverton, MD: ORC Macro.