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The complexity of consent: women's experiences testing for HIV at an antenatal clinic in Durban, South Africa

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Abstract

Informed consent has historically been a cornerstone to ensuring autonomy during HIV testing. However, recent changes to global guidance on HIV testing have led to substantial debate on what policy provisions are necessary to ensure that consent remains meaningful in the context of testing. Despite disproportionate rates of testing during pregnancy, pregnant women's perspectives on the HIV testing process are underrepresented in the testing discourse. This study explores women's experiences with HIV testing and the consent process in a public antenatal clinic in South Africa. Qualitative interviews with 25 women were conducted at the clinic at either an antenatal visit or an infant immunization visit that followed HIV testing. Interviews were transcribed, translated, and coded for analysis. Women were categorized into one of the three groups based on their perceptions of choice in consenting for an HIV test. Matrices were used to allow for cross-category and cross-case comparison. Half of the women described having a clear choice in their decision to test. Others were less clear about their choice. Some women felt they had no choice in testing for HIV. None of the women stated that they were tested without having signed a consent form. We found that half of the women's narratives illustrated direct and indirect ways in which providers coerced them into taking an HIV test while receiving antenatal care. As the new guidance on HIV testing is implemented in different settings, it is critical to monitor women's testing experiences to ensure that a woman's right to make an informed, voluntary choice is not violated. Furthermore, models of testing that allow us to meet broader public health goals while simultaneously respecting women's autonomy are needed.

Keywords

HIV/AIDS; qualitative research; human rights; pregnant women; informed consent

Introduction

“Informed consent,” defined as an individual's right to make an informed, voluntary decision authorizing or refusing a medical intervention (Beauchamp & Faden, 1995, p. 1240), has historically been regarded as a cornerstone to ensuring autonomy during HIV testing. However, recent changes to global guidance documents on HIV testing have led to substantial debate on what policy provisions are necessary to ensure that consent remains

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meaningful in the context of testing. In countries with generalized epidemics, the new WHO/UNAIDS guidance document advocates for Provider initiated counseling and testing (PITC) for all individuals attending health facilities. Under this model, individuals will be tested for HIV unless they specifically opt-out of, or affirmatively decline, testing. Additionally, pre-test counseling requirements have been abbreviated to “pre-test information” sessions (Maman & King, 2008; WHO & UNAIDS, 2007). Several writers have suggested these changes are part of a wider trend to de-emphasize, or “streamline,” the consent process (Csete & Elliott, 2006; Gostin, 2006; Maman, Groves, King, Pierce, & Wykhoff, 2008; Schuklenk & Kleinsmidt, 2007; Wolf, Donoghoe, & Lane, 2007).

Proponents of opt-out HIV testing argue that the method of obtaining consent under previously endorsed testing approaches was “ethnocentric Western rhetoric” (Holbrooke, 2004), which “exceptionalized” HIV and was a barrier to uptake (Bayer & Fairchild, 2006; K.M. De Cock, Mbori-Ngacha, & Marum, 2002; K.M.D. De Cock & Johnson, 1998). Advocates in favor of “streamlined” consent point to consistent increases in testing uptake under opt-out policies as evidence that earlier consent processes impeded testing. They also assert that the method of obtaining consent under the new model is still protective of autonomy (De Cock et al., 2002).

Those who question the “streamlined” consent process highlight how opt-out testing approaches may erode the principle of informed consent. Some doubt that we can ever ensure informed consent within the context of a routine offer of HIV testing (Bennett, 2007; Csete, Schleifer, & Cohen, 2004). Others argue that power inequities between patients and providers can inhibit a patient's ability to decline HIV testing (Rennie & Behets, 2006).

Several others have also questioned how different policies' consent provisions might affect pregnant women. Pregnant women are disproportionately tested for HIV since they come into contact with the health care system regularly for antenatal care (Csete et al., 2004; Gruskin & Ferguson, 2008). Pregnant women may also be at increased risk of violence or discrimination when their HIV status becomes known (WHO & UNAIDS, 2007). It is critical to ensure that consent provisions protect a pregnant woman's right to decide whether an HIV test is in her best interest to the fullest extent possible.

Despite the ongoing debate about what policy provisions are adequate to protect consent, there has been limited study of how pregnant women experience consent during the HIV testing process. Two recent studies focused on pregnant women's perceptions of the consent process within different PITC approaches in Western settings and both found that at least 1/5 of the women felt their consent was compromised (see Table 1). These examples highlight the challenges of ensuring consent under PITC models of HIV testing and raise questions about the degree to which PITC policies might uphold consent in settings with potentially greater power differentials between patients and providers. Although we found no other studies that explicitly sought to understand the process of consent from the pregnant woman's perspective, others studies also suggested consent may be compromised under opt-out testing approaches in sub-Saharan Africa (see Table 1).

It is clear that further research is needed to explore what consent means to women who test for HIV in settings heavily burdened by the epidemic (Maman et al., 2008; Rennie & Behets, 2006). The purpose of our study is to explore women's perceptions of testing for HIV at an antenatal clinic in Durban, South Africa.

In 2007, South Africa's HIV testing policy is as follows: women are routinely offered HIV testing and counseling when they attend antenatal care and have to opt-in to test. The policy outlines South Africa's commitment to counseling, confidentiality, and consent. The policy calls for a group information session and individual pre-test counseling and explicitly

indicates that consent (written and verbal) should be obtained after pre-test counseling. All women are to receive individual post-test counseling (South African National Department of Health, 2001).

Methods

We conducted qualitative research from July to December 2007 to learn about women's decision-making processes around disclosure, infant feeding, and contraceptive use after learning their HIV status during pregnancy. The data were collected to inform an intervention that provides integrated care to pregnant women testing for HIV at an antenatal clinic in a township near Durban (for details, see Maman, Moodley, Groves, & Smith, 2007). Institutional Review Boards at the University of North Carolina and the University of KwaZulu Natal approved the research.

Women are eligible to attend the antenatal clinic if they live in the catchment area in the township. HIV prevalence among women attending the antenatal clinic is 42%. There are about 9000 first visit antenatal attendees per annum. Approximately 25% are primigravida. The average gestational age at first visit is 28 weeks. This community has one hospital, which serves the surrounding area. Most women are seen in the clinic for all prenatal visits, and then they deliver their babies at the hospital.

All pregnant women at this antenatal clinic receive group HIV pre-test information from a health educator during their first visit. She informs women that trained lay counselors are available for HIV testing in a building adjacent to the antenatal clinic. Women receive individual pre and post-test counseling from the lay counselors.

We purposively sampled 25 participants who had been tested for HIV during their most recent pregnancy. We recruited these women at a subsequent antenatal visit or an infant immunization visit such that all women had been pregnant within the last year. Trained ethnographers obtained informed consent and interviewed women in Zulu in a private room. The interviews were audiotaped. The ethnographers used a semi-structured guide to ask about HIV testing, disclosure, infant feeding, and contraception.

All interview transcripts were transcribed and translated verbatim. The primary author and a research assistant read through each transcript and created summary memos for each one. We then created a codebook based on the initial review. The codebook included topical codes like "HIV testing experience" and "disclosure to partner." The primary author coded the interviews using Atlas.ti (version 5.0).

To understand how individuals perceived their choice in consenting for an HIV test, we created three separate matrices: (1) women who clearly felt they had a choice; (2) women who felt that their choice was less clear; and (3) women who felt they had no choice in HIV testing. We categorized women into one of these groups based on their narratives of the HIV testing process. We conducted cross-case comparisons of women's testing experiences within and across each matrix.

Results

Half of the women described having a clear choice in their decision to test. Others were less clear about their choice. Some women felt they had no choice in testing for HIV. None of the women stated that they tested without having signed a consent form. Women across the groups were demographically similar, although women who perceived they freely consented were less likely to be married/cohabitating than women in other categories (Table 2). Their experiences in testing for HIV are described as follows.

Women who felt they made an informed choice to test

Described positive interactions at the antenatal clinic—Women who perceived they had a choice in testing for HIV during pregnancy described positive experiences during group and individual education sessions. One woman recounted positive experiences in both sessions, despite later testing HIV +:

There's a lady here in the clinic called M. She counseled us on this disease. She said "anyone who wants to (test) can come and see me."...I don't know maybe the reason for my being so comfortable has something to do with the way she was talking. And the way she explained everything because I understood everything. (Age 24, living separately from partner)

Described an autonomous decision-making process—The majority of women who felt they had a choice in testing for HIV had thought about the issue prior coming to the clinic. Although many of these women discussed testing with family or partners before seeking antenatal care, they felt the final decision was theirs alone. One woman described a conversation she had with her husband prior to attending antenatal care:

My husband and I talk about many things; he doesn't seem to be having a problem. **[But did you talk about this one (getting tested for HIV)?]** Yes, he even told me that I'll have to choose, (he said) "I also want you to do it but I don't know if you want to or not." (Age 28, married)

There were also some women who felt they had a choice in testing for HIV who had not thought about testing prior to their first visit. One woman described how she deliberated before testing:

I then went home thought hard about it. I came back again. I didn't just do it when I arrived there, I had to wait and think again. (Age 22, living separately)

Women whose perception of choice in testing was less clear

Described more ambiguous interactions at the antenatal clinic—There were a number of women who used less clear language to describe their experiences testing for HIV. For example, one participant describes her own motivations to test while simultaneously discussing pressure from the clinic staff.

I usually tell myself that if you are pregnant, you are very lucky because a lot of people are scared to get tested. You are lucky if you are pregnant because you are forced to get tested, because not only will you be doing yourself a favor but the baby also. **[What exactly forces you?]** Not that I want to test. My pregnancy forced me to. I did it for my child. The baby forced me to, not that I wanted to ... and that they insist (on getting tested) here *laughing*. (Age 27, living separately)

Sense of autonomy in decision-making process less clear—These women provided conflicting accounts of how they decided to test. In their narratives, there were moments where they felt they had clearly chosen to test and others where they described feeling forced. As one woman described:

You are forced to do it but in a helpful kind of way. **[A helpful kind of testing?]** Yes, they would tell you in the clinic and if you didn't want to, you were free not to do it. The nurses in the clinic do not beg, if you don't want to do it, you simply just don't, but you would have a problem where you would be giving birth. (Age 28, cohabitating)

Although a number of patients described wanting to test because they were now *living for two*, the nurses did not encourage women to consider their own potential risks in testing in addition to taking steps to protect their baby. This participant decided to test after the nurse said the following:

“When you test you are not doing it yourself but for the baby's safety. If you want to die you can do it on your own but you need to keep the baby safe”...and she said, “you know, there's this mother whom we advised to test but she didn't, it's very painful to see her and her child sick.” (Age 30, cohabitating)

Women who felt their choice in testing for HIV was compromised

Described negative interactions at the antenatal clinic—Women who did not feel they had a choice to test described their experience differently. More than one participant described nurses telling them they had to test, as illustrated by this participant:

They used to tell us here that we all have to get tested whether we like it or not due to the fact that we were pregnant, so there was no beating about the bush, you just had to get tested for your baby's sake. (Age 34, living separately)

Another woman described being told by the nurses that all women more than seven months pregnant must be tested for HIV on that day:

I thought that next week, when I come back, I will then go for counseling...they told me that now that I am 7 months I would need to go this way (to the building where testing is conducted). We then came with other women, but some ran away. As you know, you first start from the other side (ANC clinic) and then you end up here (the testing building). They ran away after coming from the other side and I came straight here. (Age 27, living separately)

Sense of autonomy in decision-making process was compromised—Most of the women who did not feel they had a choice in testing had not thought about HIV testing prior to coming to the clinic and did not feel that they had made a decision to get tested.

[Please tell me about how you took the decision to get tested?] *sighs* I was nervous – but there wasn't – I was forced to get tested because I was pregnant. So it was a bad experience when I found the results that it was like this (HIV+). (Age 34, living separately)

Multiple women also described a decision-making process based on fear of negative repercussions for not testing, as shown through this participant's narrative:

[Can you just tell me how you decided to test for the HIV in this clinic?] I told myself – but I was afraid. But because the nurses had told us that if you didn't test you would not be assisted when giving birth because the same thing applies even if a person goes to a labor ward in a hospital. Then I was just scared ...so scared. (Age 33, cohabitating)

Discussion

The informed consent process is upheld by a patient's capacity to make an informed, voluntary decision to accept or refuse an HIV test. A voluntary decision is one that is “free of controlling influences” (Childress et al., 2002, p. 175). Nearly half of the women felt their sense of voluntariness, and thus, their autonomy, was compromised. Women's narratives illustrated direct and indirect ways in which providers compelled or coerced them into testing for HIV while receiving antenatal care.

Direct coercion

Women who felt coerced into testing for HIV consistently described the nurses as authoritative. While women complied with the nurses' requests, their anxiety about their lack of control over the testing process was clear. Many also recounted hearing that their future health care was contingent on testing. Women across the consent spectrum believed they would not be able to deliver at the local hospital if they refused testing. This perception of direct coercion was the primary motivating factor for some women who tested. These findings are similar to a study 10 years ago, where 28% of women at a hospital in Durban felt that refusing to participate in the Prevention of mother-to-child transmission of HIV (PMTCT) study would affect their ability to receive future care (Karim, Karim, Coovadia, & Susser, 1998). A woman who tests for HIV because she fears negative repercussions of not being able to receive future care has not freely consented for the procedure. Furthermore, direct threats to withhold care for refusal to test counter both South Africa's testing policy and WHO's guidance document (Bennett, 2007; WHO & UNAIDS, 2007) and fail to uphold patient autonomy.

Indirect coercion

A dominant message that pregnant women received at the clinic is that being tested for HIV is the right thing to do for the health of the baby. Although that message may be accurate, it excludes any concern for the health and well-being of the woman independent of her pregnancy. Perpetuation of such messages could further isolate and stigmatize the non-testers. Such value-laden messages ultimately undermine autonomy.

Reasserting autonomy

There are various ways in which women exert control over their testing experience. One way is to opt-out of the encounter all together. Prior to the onset of rapid testing, many researchers have reported high uptake of testing, yet low rates of follow-up to collect results (Jurgens, 2007; Kiarie, Nduati, Koigi, Musia, & John, 2000). In our study, one participant described other women running from the clinic to avoid testing. Kiarie, Nduati, Koigi, Musia, and John (2000) speculated that not returning for test results may be more culturally acceptable than declining a test; thus, not returning – or running away – may be one strategy to maintain autonomy.

Limitations

A few key aspects should be considered when interpreting our findings. First, we did not interview pregnant women who declined HIV testing during pregnancy nor did we ask women who felt coerced into testing to describe why they did not want to be tested. These perspectives are critical to better understand reasons women decline testing as well as ways in which women in this setting (re)assert their autonomy. Second, we did not interview nurses or providers of HIV testing. Understanding their perspectives of the provision of HIV testing within antenatal care, particularly in settings heavily burdened by the HIV epidemic, would shed further light on patient-provider power dynamics. Third, since we sampled women who were seeking either antenatal or postnatal care at the clinic, some women in our sample were tested for HIV up to one year ago. This time period may have affected their ability to recall the details of their testing experience. Future researchers should interview women about their HIV testing experiences closer to the actual time of testing. Finally, this analysis is restricted to a small group of women ($n=25$); their experiences are not generalizable to the larger population of pregnant women who test for HIV. Future research is necessary to determine whether pregnant women in other contexts describe similar experiences.

Conclusion

Our findings highlight the ways in which autonomy is compromised for some women under a provider-initiated opt-in model of testing. This is of concern given that opt-in testing is generally considered to be more protective of women's autonomy than that which is currently advocated in global guidance documents. While it is imperative to scale up HIV testing to provide treatment and care to those in need and to prevent the further spread of infection, the challenge lies in increasing uptake of testing in a way that values a woman's assessment of risks and benefits of testing for both her and her unborn child. As long as we remain committed to non-mandatory approaches to HIV testing, we are tasked with finding models of testing that help us to meet broader public health goals without sacrificing women's autonomy in the process.

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Table 1

HIV testing literature that describes the consent process.

Authors	Setting	Description of study	Description of testing	Results
de Zulueta and Boulton (2007)	London	Qualitative, cross-sectional with pregnant women ($n = 32$)	Provider-initiated, opt-out; women did not have to sign a consent form and had to actively decline testing during antenatal care	An estimated 22% described experiences in which their consent was compromised
Guenter et al. (2008)	Toronto	Quantitative, cross-sectional with pregnant women ($n = 299$)	Provider-initiated, opt-in; women receive information about testing, were supposed to have an opportunity to accept or decline the test	An estimated 30% did not believe they had been given an option to decline the test; 7% did not think that they had been tested during pregnancy
Karim, Karim, Coovadia, and Susser (1998)	Durban	Quantitative post-counseling questionnaire for assessment of issues relating to participation in Prevention of mother-to-child transmission of HIV (PMTCT) study ($n = 56$)	Pregnant women provided with group counseling about research study and HIV testing and offered HIV test after consenting to enroll in study	An estimated 88% of participants felt compelled to participate in the study (which included HIV testing)
Weiser et al. (2006)	Botswana	Quantitative, cross-sectional population-based survey five months after introduction of new testing policy ($n = 1268$)	All patients to be routinely tested unless they explicitly refuse. Patients should be educated about HIV testing and their right to refuse	An estimated 68% of individuals felt they could not refuse a test that was routinely offered to them

Table 2

Demographic characteristics of sample.

	Women who perceived that they clearly consented (<i>n</i> = 13)	Women whose perception of choice was less clear (<i>n</i> = 7)	Women who perceived their choice was compromised (<i>n</i> = 5)
Age (mean, SD)	27.46 (4.37)	26.71 (3.90)	29.80 (3.42)
Married/cohabitating(%, <i>n</i>)	46.15% (6)	71.43% (5)	60% (3)
Parity (mean, SD)	1.85 (0.80)	1.71 (0.95)	1.20 (0.44)
Education (mean, SD)	10.46 (2.02)	11.14 (0.69)	10.60 (2.07)