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Adherence and the Lie in a HIV Prevention Clinical Trial

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Abstract

The lie has been presented as a performance that protects identities against moral judgment in the context of power imbalances. We explore this assertion from the perspective of a pre-exposure prophylaxis trial to prevent HIV for African women in South Africa, in which context biological evidence of widespread lying about product adherence was produced, resulting in a moral discourse that opposed altruistic and selfish motivations. In this article, we seek to understand the meaning of the lie from the perspective of women trial participants. Seeing the trial as representing a hopeful future, and perfect adherence as sustaining their investment in this, participants recited scripted accounts of adherence and performed the role of the perfect adherer, while identifying other participants as dishonest. Given that clinical trials create moral orders and adherence is key to this, we argue that women embraced the apparatus of the clinical trial to assert their moral subjectivities.

Keywords

Adherence; clinical trials; lying; morality; pre-exposure prophylaxis

The lie is somewhat ubiquitous in medical settings: “(L)ying turns out to be current practice in the relationship between doctors and patients” (Fainzang 2002:118). Many medical professionals utilize a form of benign deception, concealing a serious diagnosis or prognosis from patients in order to spare them distress (Hancock et al. 2007:514). This practice has

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received substantial attention from medical ethicists (Jackson 1991; Sokol 2006), and been critiqued as an expression of “medical paternalism” (Backhurst 1992:63). In many parts of the world, doctors are also known to lie or distort information in order to secure approval from third-party payers for patient procedures (Freeman et al. 1999).

Lying is not the sole preserve of doctors, however, who may assume their patients are lying, even if unintentionally (Barnes 1994). Hippocratic writings dating from the fourth and fifth centuries BC warn doctors of the tendency of patients to “lie about the taking of things prescribed” (Sokol 2006:632). Indeed, patients may lie about their adherence to treatment or use of alternative therapies—often to remain eligible for care (McKay 2012) or to escape censure. For example, in Senegalese clinics, patients with obstetric complications provide false information to health providers to avoid being prosecuted for inducing an abortion (Suh 2014). In psychiatric practice, clinicians are attuned to the practice of “malingering” or “symptom exaggeration” (Resnick 1994:1). Paradoxically, patients’ intentional concealment or distortion of information can become barriers to receiving effective treatment (Fainzang 2002).

Much more than a simple omission of information or an inaccurate response to a misunderstood question, however, a lie could be understood as a statement made with the intent to deceive (Backhurst 1992). Importantly, by lying to others, “one controls the information available to them and thereby influences their actions” (Nachman 1984:538). Within doctor-patient interactions, lies may reinforce but also challenge power relations. By not fully disclosing diagnoses or side effects, medical practitioners exert their authority, but there is scope, too, for the patient’s resistance: the patient “cannot be forced to speak; he or she has the ability to remain silent, or to lie” (Lupton 2003:119). Patients’ lies may thus serve to defy medical authority—even when embedded in seemingly passive displays of submission.

Lying may also control the flow of information to manage social identities and the stigma associated with illness and taking medication (Goffman 1963). In this case, the lie is theatre, a performance enacted to avoid opprobrium in contexts of unequal power relations: “a strategy to survive unbearable and disgraceful situations. It is a resistance against exclusion. By making theatre of the lie, people safeguard themselves against hopelessness, degradation and moral judgment” (van Dongen 2002:150). Lying is closely linked to morality, as truth and honesty are cherished social values (van Dongen and Fainzang 2002). However rather than assuming that morality holds a static social value we could consider peoples’ moral lives to be “closely tethered to ‘what is at stake’ for them in the context of their everyday struggles to cope with their shifting passions, hopes, joys, regrets, losses, suffering, and pain” (Zigon and Throop 2014:4).

In clinical trial settings medical researchers are acutely aware of the potential for dishonesty. Researchers and patients/participants usually encounter each other as total strangers with the expectation of sharing intimate details openly and honestly, yet sensitive questions can force “polite informants into lying ones” (Bleek 1987:314). In a microbicide trial in South Africa, 79% of trial participants admitted to lying in face-to-face interviews: 34% lied due to politeness, while 24% said they feared criticism, and 18% lied due to embarrassment.

Respondents also lied because they feared not being eligible for the trial or being asked to leave the trial (Turner et al. 2009:761).

The clinical trial method requires a level of secrecy and employs technologies of concealment. The randomization of participants to study arms is obscured, and participants who receive a placebo are required to accept that it may or may not be an active substance. These examples of legitimate secrets and half-truths serve the needs of science and are therefore beyond question; they are also set up by those with the power to control the flow of information. Trial participants are placed under increasing scrutiny by new methods of interrogating bodies to assess medication adherence. Trial investigators, wary of relying solely on interviews, have turned to computer-aided methods, blood tests, pill counts, and vaginal gel applicator screenings. These technologies re-establish the explanatory power of the biomedical over other forms of evidence, reasserting its “privileged authority as ‘truth’ teller,” as indisputable (Marshall 2005:2516).

By contrast, the importance of full compliance with the study product in microbicide and pre-exposure prophylaxis (PrEP) trials (since it is difficult to prove efficacy without this) shifts the power—to establish, refute, or conceal the truth—to participants. Without their ‘cooperation’ in this regard, the entire operation is undermined. Participants’ lies may be subversive because these involve an implicit challenge to the power of science and biomedicine to establish when the truth may be legitimately concealed, and by whom.

Taking inspiration from conceptualizations of the lie as a source of power and as a performance, we seek to explore allegations of lying that abounded in a HIV prevention clinical trial. The trial took place between 2009 and 2012 in 15 clinic sites in South Africa, Zimbabwe, and Uganda and enrolled 5029 HIV negative women. Called “VOICE” (“Vaginal and Oral Interventions to Control the Epidemic”), it tested the effectiveness of a daily dose of antiretrovirals (ARVs) in tablet form (either tenofovir or Truvada) or as a vaginal gel (one percent tenofovir) by comparing these to matching placebos. Following recommendations made by the trial data safety and monitoring board (DSMB) in September 2011 and November 2011, the oral tenofovir (TDF) and the vaginal tenofovir gel arms were discontinued respectively, leaving the Truvada arm and placebo to continue until August 2012. In March 2013 the final results of the trial—that none of the products tested were effective in preventing HIV acquisition—were made public. This was attributed to insufficient adherence to the study drug, although participants reported good adherence, defined as daily application of the gel and daily tablet use (Marrazzo et al. 2015).

Employed as social scientists to explore experiences with product use, we conducted qualitative research in one VOICE site in Johannesburg, South Africa. Here, 354 women were enrolled in the trial, and a randomly preselected subset was invited to participate in VOICE-C, a qualitative ancillary study. In depth interviews (IDI) were undertaken with 41 trial participants, and 21 participated in serial interviews, during the trial, while seven focus group discussions (FGD) were held with 40 unique participants upon exiting from the trial.

Researchers (two female and one male) conducted interviews and focus groups in local languages (SeSotho or IsiZulu) at the clinic site or at the participants’ home, or in some

cases in a public park or café. Transcripts were translated and uploaded into Nvivo ethnographic data analysis software. The VOICE-C researchers developed a codebook based on the key themes. Further details on the study design and data management and analysis procedures are published elsewhere (van der Straten, Stadler et al. 2014).

Media reports emerging around February 2013 that berated the dishonesty in the trial, and blamed ‘African women’ for the trial’s ‘failure’ sparked our initial interest in further exploring the ‘lie.’ Looking to understand how women demonstrated adherence, we searched the database for personal accounts of adherence. And, aware that trial participants spent many hours gossiping in the trial clinic waiting room we looked for their accounts of what they had seen and heard from other trial participants.

The lie in the trial

Recent enthusiasm for technologies to prevent HIV acquisition was buoyed by the discovery that ARV drugs prescribed as PrEP were effective. Four PrEP trials had positive outcomes leading to the licensing of oral Truvada as PrEP in the United States and ongoing studies of tenofovir intravaginal gel. In this light, the results of the VOICE trial that used the same agents as other trials were a major disappointment, prompting questions about the behavior of the women trial participants.

During the VOICE trial participants were questioned about product adherence and they were asked to return unused gel applicators and pill bottles to the clinic. Levels of adherence based on questionnaires were high (90%) as were audio computer assisted self-interviews (ACASI) (88%). The tally of returned gel applicators and pill bottles supported impressions of high adherence (86%) (Marrazzo et al. 2015). After trial completion, pharmacokinetic (PK) tests were undertaken by assaying plasma for tenofovir in both tablet and gel in a random sample of 647 participants for whom 2987 plasma samples were available for testing. This revealed that 50%–58% of women on active products had no drug detectable in any of their plasma samples, suggesting low product adherence (Marrazzo et al. 2015).

Once the results were released in 2013 and published in 2015 (Marrazzo et al. 2015), attention turned to the discrepancies between what women said about adherence and the PK evidence from blood tests. Labeling trial participants as dishonest, a dialogue surfaced in the popular press that blamed trial participants for the disappointing trial outcomes. The South African *Weekly Mail and Guardian* noted “Women Confound HIV Researchers” (March 8, 2013), while the *Daily News* claimed “Human nature sinks HIV prevention trial” (March 7, 2013). In the *New York Times*, McNeill pointed to trial women’s “elaborate deceptions” to access cash and care (February 4, 2015).

Trial participants were not only implicated in the discouraging trial outcomes, but also in prolonging the spread of HIV, as this excerpt from an article published in the *Daily News* (March 5, 2013) suggests:

It was hoped that it would be the solution to one of the world’s worst pandemics and the end to a global scourge of death and disease. But the study failed because

most of the women participating in the trials, including at sites in KwaZulu-Natal, did not take the medication.

Seeking to explain such widespread dishonesty, medical researchers turned to a familiar discourse differentiating between altruistic and selfish motivations. Trial participants considered ‘professional’ or ‘veteran’—partly because they volunteer for multiple trials—apparently know how to work the system for personal gain (Tishler and Bartholomae 2003). Cast in this fashion, the VOICE participants were represented as impoverished African women motivated by self-interest, who fabricated their adherence reports to remain in the trial.

Just as deception and dishonesty apparently emerge from selfish motives, the reverse is held to be equally true: altruism is “crucial for patients to become good, compliant subjects in a clinical trial” (Fisher 2009:89). In the context of research seeking to alleviate the burden of high HIV prevalence, this altruism took on a distinctly utilitarian hue, emphasizing participant’s contribution to the common good. Regarding the VOICE results, a microbicide advocate expressed the perception that women had violated the sentiment of altruism:

I think it is unfair to everyone, especially highly impacted communities where HIV rates are soaring, and where the crisis is anything but over, for trial participants to sign informed consents and derive individual benefits from trials without fully engaging in the study protocols that would allow for potential population benefits. (Picket 2013)

Yet this is also a context of poverty and limited health infrastructure within a highly inequitable and inefficient health care system (Harris et al. 2011). Securing continued access to quality health screening and treatment through trial participation is often as important as cash remuneration (Delany-Moretlwe et al. 2011). Attempting to contextualize the VOICE trial results, a social scientist commented:

A lot of folks in really resource-limited settings might quite sensibly say, “Well, I could get money for participating in this trial, and I’d get a lot of health benefits—monitoring of my health and wellness, good counseling, access to condoms—so it’s a good deal. I have no intention of taking the pill, but I’m not going to say that.” (Auerbach 2013)

Ironically, the same structural factors that place African women at risk of HIV—poverty, social inequalities, and migration—could be said to drive women’s enrolment in clinical trials and produce unreliable participants. It is to this context that we now turn.

The context of the lie: An economy of hopefulness

The Johannesburg VOICE trial clinic is housed in the basement of a university student residence in Hillbrow. On the edges of Johannesburg’s inner city, Hillbrow is spread over one square kilometer, has a population of approximately 100,000 people, and is characterized by high-rise apartment blocks, a shopping district, and public parks (Venables 2011). From its beginnings as a quiet residential suburb in the 1930s, Hillbrow was transformed in the 1960s when apartment buildings were constructed to accommodate

young, white working class families and European immigrants. It was also one of the first urban areas to challenge segregationist laws under apartheid in the 1980s. Today it serves as a receiving area for young families and migrants from Southern and West Africa (Morris 1999). Yet, while many South Africans remember the Hillbrow of the 1970s and 1980s as a vibrant, trendy neighborhood of restaurants, nightclubs, record bars, bookshops, delis, and bakeries, most of the stores have now closed down, replaced by taverns and fast food restaurants, or have been vandalized and are boarded up. In the public imagination, Hillbrow is diseased, dirty, and dangerous (Stadler, et al. 2013; Venables 2011), due in part to the presence of sex workers (Stadler and Delany 2006), criminal gangs, and the illegal drug trade (Leggett 2002). Hillbrow is also located in the center of a massive HIV epidemic. Compared to other major metropolitan areas in South Africa, Johannesburg with a total population of 8.8 million people has the highest number living with HIV, an estimated 980,000, based on a prevalence of 11% (Shisana et al. 2014).

Despite its reputation, Hillbrow represents an escape from poverty through participation in informal and formal economic opportunities. It is often the first drop-off point for economic refugees, centrally situated near a major transport hub. Historically mainly a male pursuit, migration in the postapartheid era is increasingly pursued by young, single women, seeking work and establishing their own households within a context of a decline in marriage, increasing unemployment and vulnerabilities of young women (Hunter 2007). The profile of the women enrolled in the VOICE trial in Hillbrow reflects these broad demographic processes.

Although resident in Hillbrow, many VOICE participants hailed from the rural areas of South Africa and neighboring states, notably Zimbabwe, and only a few (29%) identified Hillbrow as their actual 'home.' They were overwhelmingly young (an average age of 27 years) and unmarried (78%). Half were employed (51%) mainly in retail and hospitality industries, but as we see, this belies their constant struggle to sustain employment. Women migrants experience the disruption of social networks and frequently have no choice but to engage in exploitative relationships with men, employers, the police, and landlords (Kihato 2007), and those who sell sex are dependent on brothel managers for accommodation (Stadler and Delany 2006).

The precariousness of livelihoods in this urban environment is apparent in the following brief vignettes of individual participants. Tanaka¹ arrived in Johannesburg in 2005 from Zimbabwe where she had been a temporary teacher. As a 32-year-old mother, she lived alone with her child in rented accommodation in Hillbrow and worried that her landlord might rape her daughter while she worked nights at a restaurant. As an illegal immigrant the hidden costs of employment included bribes paid to the police to avoid arrest. As a more recent migrant, 30-year-old Aneni had completed her schooling and a secretarial course in Zimbabwe. Initially a waitress in a restaurant and later at a catering agency in Johannesburg, work was sporadic and unpredictable. Regular, full-time employment had also eluded Nono. By the time she was 24 years, she had already held down several 'piece jobs' as a domestic servant in the suburbs and completed a training course in security, yet had not managed to

¹All personal names are pseudonyms.

find full-time employment. “I have no other choice—jobs are scarce,” she said. For these women, survival was a daily struggle that impacted profoundly on their relationships with partners and family members. As 26-year-old Nkosiyabo said, she had to “fight with someone to give me money.” Tanaka summed it up by saying: “we are just begging ... we are just holding on.”

Women such as Tanaka and Nkosiyabo spoke openly of their intimate relationships as conflict-riven and often violent. Tanaka described her estranged husband as “quiet but abusive” but felt that she was forced to live with him to survive. The father of Nkosiyabo’s child was a migrant who had left her without cash for rent or food while visiting his family in Pakistan. Upon his return he found out that she had been unfaithful and forced her to be tested for HIV. She complied because he cursed her and beat her on her head with a cricket bat. Although Aneni’s husband was initially supportive, she had since confirmed her suspicions that he had a girlfriend. Other women narrated similar experiences of violence, abuse, and infidelity, describing situations of mistrust and duplicity.

In these circumstances the trial was a symbol of hope. In stark contrast to its chaotic and dirty surroundings, the trial clinic was neat and functional, yet comfortable and welcoming, comparable to private clinics in the city. “There is no clinic as good as the study,” remarked Nandi. Well trained, conscious of their bioethical obligations, and eager to please trial participants, clinic staff served tea and sandwiches to participants, and there were televisions and a play area for children. Satisfaction is reflected by high study retention rates: 91% of women remained in the study suggesting that they valued participating in the trial (Marrazzo et al. 2015). Participants extolled the regular health check-ups, HIV testing, and the quality of care received at the clinic and welcomed the travel stipends (ZAR150 = USD \$15) disbursed at each visit, but often complained about the lengthy waiting times during clinic consultations (Magazi et al. 2014).

The travel stipend was not an unimportant reason to enroll in the trial, but as 21-year-old Mpho points out, this was not the only motivation for participation:

I mean people want the one fifty [ZAR 150/USD \$15]. A number of people are dependent on that one fifty because they are not working and the others maybe get their money from their boyfriends. I think other people are attending the study out of goodwill, while on the other hand some people attend because of money ... they will be happy because of the money (laughs). When [I] told them that when I do an HIV test I get one fifty they were more excited than when I didn’t mention the money.

As a hopeful enterprise, however, the trial stood for more than immediate monetary gain. Regarding the trial as offering the promise of a ‘better life,’ this phrase popularized by the African National Congress in its election campaigns was often repeated in interviews. Lily (age 40) said: “You know as women we want to have a better life,” while 19-year-old Siya commented that her involvement in the trial made her believe “I have a brighter future.” Aneni said: “sure they are making my life better” and another told her partner that their participation in the trial was important “for the sake of our future.”

This forward-looking anticipation of a better future is not unusual in HIV projects in Africa, and forms part of a “fashioning [of] the self as a particular kind of actor,” namely, an empowered actor (Prince 2014:75). These narratives are all the more significant against the backdrop of the ever-decreasing opportunities for employment amongst young Black South Africans. With unemployment amongst this demographic officially estimated at 36% (Statistics South Africa beta2.statssa.gov.za), volunteering for unpaid work, especially within the AIDS industry, is often the sole option for participating in the redistributive economy. For some, trial participation was even seen as part of an aspiring trajectory toward potential full-time employment. Ngoli (31 years) felt that being in a trial could be a long-term career: “that would be my job. I would join different studies.”

For many women like 21-year-old Palesa, the trial also broke the monotony of staying at home, unemployed with no money. She said the trial “is lovely for us ... it’s a boring thing to stay at home” and said she was “happy” when her clinic visit was due because she could go to town and “check out some things.” Andricia (30 years) expressed similar sentiments “I just don’t want to sit around and do nothing hey.”

Women also spoke of personal fulfillment from their involvement in the trial. Although only 21 years, Nyelethi endorsed these sentiments “[for] once in [my] lifetime, I was dedicated to something yeah.” The trial embodied the potential to find a solution to the spread of HIV and being part of this discovery was extremely meaningful. Their participation in a trial could translate into recognition and respect from others. Thabisa said that if the trial were successful she would tell people: “I was in this research. I am one of the people who found out that that thing helps.” Stressing the “sacrifice” she had made to be in the trial, Siya said that she did this to “help people who need help.” But as 33-year-old Khulekani noted, the trial was not for those women who are “weak” and “who do not have that hope for the future ... but for people who have got something in their minds.” In other words, it required sacrifice and commitment.

Entwined with this narrative was the belief that through repeated HIV testing and receiving negative results trial participants became healthy and virtuous. Mthunzi (age 25 years) remarked, “It is nice to keep hearing about your health. You know about your body; how it is, whether there is something wrong.” This knowledge of the body not only enabled women to take control of their health, it also held the potential to shift the dynamics of power within sexual relationships. Mthunzi added that regular HIV tests would make her partner hesitant to cheat on her, as a HIV-positive test result would cause him extreme embarrassment. The regular testing procedures thus provided women with a means to scrutinize their male partners’ behavior. This hints at the potential for clinical trials such as VOICE to create moral orders. As we see, product adherence is an integral part of this process.

Performing adherence perfectly

VOICE women presented themselves in interviews as fully adherent, only occasionally missing a dose (van der Straten, Stadler et al. 2014), yet biological testing contradicted their statements. A subsample of VOICE participants’ bloods (n = 647) in all sites was tested for presence of drug. Of these, 16 were included in the VOICE C sample; we found little

correlation between what the blood tests revealed and what women said. Plasma drug detection ranged from 0%–100%, with an average detection level of 33%. Five women had no evidence of drug in their blood, eight had drug detectable less than 50% of the time, and three had drug detectable more than 50% of the time. Although Icici (24) had no evidence of drug in her blood she stated that she used the gel every day. Similarly, Zodwa (23) had no blood samples with detectable drug, but said, “I cannot miss a dose. At exactly ten o’clock [in the morning] or before ten I take them”: Lihle (31 years old) compared taking the tablets to being HIV positive and said this was what encouraged her, but had drug detected only one third of the times she was tested. Rukudzo used the gel intermittently, resulting in a 17% PK score. She said that she found the gel desirable, but often ran out of it.

Then, while others in the subsample reported not taking the trial drug on occasions, this was contradicted by the PK test results. For example, Nonhlanhla (40 years) said she did not take the tablets consistently, although according to the blood tests her drug detection frequency was 100%. In short, there was little congruity between women’s self-reports of adherence and what the drug levels from blood tests indicated: the respective ‘truths’ revealed by discourse and biology was widely divergent.

This exposes limitations in the PK tests: a positive drug test could be due to taking the drug shortly before being tested. Nonhlanhla may have taken her drug shortly before coming to the clinic for her visit and tested positive for drug. Commonly referred to as the ‘white coat effect,’ women interviewed in a follow up study acknowledged this behavior (van der Straten et al. 2015).

Well aware of the difficulties in achieving adherence to an experimental product, adherence counseling in VOICE was designed to promote use within the context of everyday life by “fostering motivation” (Amico et al. 2013). Departing from the authoritarian medical model (‘finger wagging’) trialists envisaged adherence as a conscious choice made by individual women. The counseling approach in VOICE aimed to “increase openness in discussions around product use” (van der Straten, Mayo et al. 2014). This mirrors a recent shift in biomedical discourses on adherence, from the authoritarian and coercive notion of ‘compliance’ to one that emphasizes personal responsibility and “self-empowerment” (Maskovsky 2005:136). Yet, this sentiment was not narrated in trial participants’ statements about adherence.

Responses in interviews about adherence appeared to be scripted, often paraphrasing the advice of clinic staff: For instance to schedule their adherence to coincide with a nightly television show or to use their cell phone alarms as a reminders. Twenty-six-year-old Phindile made use of this strategy: “Uh, I can say I was also helped by the TV at night, before Generations [a television soapy] starts broadcasting I say, yoh! It is the time ... you see! I go and take my tablets.”

This was indeed a neat integration of ‘product use into daily life,’ with habitual activities serving as mnemonics to support adherence. Importantly, participant narratives depicted *perfect* adherence. Nono even used those words: “When it came to the tablets I was quite perfect at taking them.” Ironically, in creating an impression of faultless adherence, women

portrayed themselves as lacking in agency, somewhat at odds with the trial coordinators' conceptualization of adherence as a conscious, responsible choice.

Women narrated the experience of having become 'used to' taking the tablets or inserting the gels as if this was an embodied, automatic act over which they had little control. Elaborating, Aneni said, "If it is the time for me to insert the gel I could feel it" while Ziyanda (30) commented "It has become ingrained in my mind that each and every day when I wake up I must take these tablets." Yibanathi, (24) said: "If I do not take the tablets I can feel it. My body has adapted to the tablets. I *have* to take them every day" (her emphasis). Similarly, Funani (24) said she was conditioned so that "at that particular time I swallow the tablet." Even after discontinuing the tablets Pinky (36), remarked that the compulsion to take them had remained: "My life has changed because I am used to taking the tablets at a certain time." Nono occasionally forgot to take her tablets at the correct time but would "feel anxious after eight [o'clock at night] and I would get out of bed and take them." Lungelo remarked that taking the tablets was "recorded in my mind (...) when it's about ten o'clock my mind tells me there's something that you have to do (...)." These experiences of product taking are inconsistent with the idea of adherence as an act of self-empowerment (as the trialists would have it), but also with participant narratives that cast trial participation as deliberate acts of altruism or self-advancement.

As perfect adherers, women were able to claim full membership of the trial, yet maintaining this image required concealing those occasions when doses had in fact been missed. As Nono admitted: "I stopped taking them once when I was at home [away from Hillbrow] but I didn't tell anyone that." Nyelethi overheard a participant saying: "No I didn't tell them at the interview that I didn't use the gel and I also lied in the ACASI [Audio Computer Aided Self Interview] because I want to be perfect." Yet there was always perceived danger that their lies could be exposed resulting in forceful removal from the trial. A rumor alleged that a woman was arrested after being found without evidence of drug in her blood. Another asserted that blood tests were used to remove nonadherent women from the trial.

Participants were aware that blood assays could ultimately reveal the 'truth' about their adherence. The informed consent forms stated that blood draws were to be used to measure levels of drug in their blood ("Give blood for tests to check the amount of medication (Truvada or Tenofovir) in your blood"). However, the significance of this was only fully comprehended when the two arms were discontinued. Kudzanai (28 years) was randomized to the gel arm and exited the trial when the gel was discontinued. She recalled: "I was using the gel ... but I heard ... we have been taken out because when doctors took our blood samples there they saw that we do not use the gel." From the four blood samples tested, Kudzanai had zero evidence of having used the gel. While there was a perception that nonadherence would result in being told to leave, not only was participation in the trial at stake but also women's reputations. This becomes clear when considering waiting room gossip.

In the clinic waiting room, participants exchanged stories about women who had deceived the trial. Commenting on what she had overheard, Farisai (29) exclaimed: "Oh! Oh my God, I just don't want to lie you know about the tablets; I have never met anyone who is using

them.” Likewise, Zanele (28) recalled hearing another participant who said: “I do not use that thing [gel applicator] I just put it there. I do not insert it.” They described participants who dumped their pills and gels and even feigned the side effects. Angel (29 years) said she had seen a participant flushing her pills in the clinic toilet. She recommended installing cameras to catch others who did the same. Rukudzo said she had heard a participant say that she only pretended to use the gel, dumping the contents of the applicator: “... squeeze them and then bring back the container [to the clinic]” and then pretending to know the side effects such as foul smelling discharge.

The clinic staff regarded waiting room gossip as a subversive activity that could disrupt the trial by spreading incorrect information. Our interviewees endorsed this view and regarded the types of stories that circulated in the waiting room as reflecting the immoral acts of trial participants who seemed indifferent to the trial aims. They suggested that the trial would fail because of the women who only pretended to use the study drugs. Zanele (28) insinuated that this was a conspiracy of deception: “Maybe they discussed it among others as to how they will do it.” Calling attention to the distinction between honest and dishonest women, Thuli narrated a verbal exchange that took place in the reception area of the clinic between her and another participant:

There is one lady who says exactly (...) “I don’t use it; I just take the gel and put it there. I take the money and go home.” I said, “Now who are you fooling because you are cheating yourself. It’s like you are playing. You are doing nothing.” She got angry with me when I said that.

By casting other participants as devious and disobedient, participants highlighted their own personal integrity.

Some women feared that an HIV-positive test result during the trial would be read not as evidence that the products were ineffective, nor as a sign that their partner had cheated on them, but rather as proof of their own sexual promiscuity. Nyelethi explained: “If I lie and say I am using the gel every day, then if they found out that I am HIV positive they would assume that I am having sex with different men.” Just as a woman’s HIV-positive test result could ‘expose’ this promiscuity, the trial itself fashioned a moral order in which one’s behavior could result in the loss of respect. Ngoli (31 years) said that frequent testing helped her to “love myself” and that if she was promiscuous the trial staff would know “if I have done something dirty.” Andricia felt that her participation in the trial exerted a positive influence on her sexual conduct: “When I began using the gel then I didn’t tell myself that I was going to begin sleeping around. I didn’t come here to do that thing hey [laughs].”

Such statements became powerful assertions of moral character. Similarly, pregnancy urine tests taken during the trial could reveal the ‘truth’ about a woman’s behavior, unless she was shrewd enough to conceal it. Nomsa (26) criticized women for trying to cheat the clinical trial and equated this to “trying to cover up their sins,” accusing them of “being after money.” She was shocked to hear some trial participants even swapped their urine to avoid being found to be pregnant.

Ironically, women's lies to create the impression of moral behavior was at risk of being undermined by biomedical testing. The HIV test in particular had the power and the potential to reveal underlying moral character—infidelity and 'bad behavior,' something of which the women were acutely aware. The stakes are huge because of what HIV could reveal to others about one's behavior in relationships and the health implications of acquiring HIV. Women also regarded the HIV test as a means to detect the truth about adherence.

Accounts of dishonesty and nonadherence took on a new significance when in September and November 2011 two arms of the trial (the tenofovir tablet and gel, respectively) were discontinued due to 'futility,' meaning that there was no prospect of success even if the trial continued. Women randomized to those arms were exited from the trial, while those who were randomized to the Truvada tablet or the oral placebo remained. Exited women expressed their reactions to the discontinuation of the two arms, interpreting this as evidence that women had been nonadherent but had lied about adherence. Akhona (20 years), said: "... and she would lie and say that she does take them. You see these are the problems we come across. I think it is something that is making [the results] not to be specific."

Trial participants were not unaware of the significance of their individual adherence for the trial results overall. They were constantly reminded through their interactions with clinic staff and during adherence counseling sessions of the importance of using the trial products as instructed, and that the success of the trial depended on this. The ultimate power of the 'adherence lie,' then, rested in its ability to draw the whole process—and its complex network of researchers, funders, health professionals, administrators, and participants—to a grinding halt.

Conclusions

As anthropologists embedded in the trial, our positions as 'insiders' created an opportunity to observe and participate, providing insights into the relatively secretive world of clinical trial research. Yet, our association with the clinical trial colored our interactions with participants who sought to maintain their status as 'perfect adherers.' In our analysis, we have adopted an interpretive approach that seeks to understand the meaning of our informants' statements in the context of their everyday lives.

Recognizing that medical matters such as adherence to medication often mirror social issues, Crandon-Malamud wrote: "medical dialogue reflects, involves, and contributes to the construction of political, economic, ideological, and social relations" (1997:87). The lie may be understood "as context dependent and under perpetual construction" (van Dongen and Fainzang 2002:91). Ultimately, VOICE was more than a clinical trial to test the effectiveness of HIV prevention technologies. It became an opportunity for women to assert credibility, to perform a respectable reputation in the face of anticipated moral judgment. In the context of relentless unemployment and financial insecurity, and in the uncertain, transient spaces of migration, women could forge new moral subjectivities. They did so with a keen awareness of the gendered moral scripts that continue to be embraced by local AIDS discourses. Trial participants sought to (re)define themselves as virtuous women, using the apparatus of the

trial to do so. Reputations were managed and promiscuity scripts rejected, as women crafted an image of themselves as responsible agents looking toward a better future. Crucially, this rested on a performance of being the ‘perfect trial participant.’ That women were able to define themselves in these ways attests to the power of the biomedical clinical trial to establish moral order. Yet ultimately blood tests in the VOICE trial exposed the lie of nonadherence, and identified participants as ‘liars.’ Reactions to the unmasking of the lie revealed a view of young African women as deceitful and unreliable, undermining the science of HIV prevention.

To understand these reactions, one needs to unpack the complex relationships that unfold between designers of new medical technologies, the funders, researchers and users, and the technologies themselves. Catherine Montgomery (2012) observed that the transnational development and testing of vaginal microbicides is a political process that has entailed a particular construction of gendered subjects. Combined with the image of HIV as having ‘a woman’s face,’ and the emergence of sub-Saharan Africa as the epicenter of the epidemic, the logic of microbicide development hinged on particular images of black African women and men. Where women were biologically more vulnerable to HIV, powerless to negotiate safer sex and therefore in need of saving, men were “promiscuous, uncaring and irresponsible” (p. 931). In other words, “by framing women’s lack of social power as a medically-unmet need in the HIV arena, it became possible to provide a pharmaceutical solution to empower women—a vaginal microbicide” (p. 928). It was hoped that women could use this product to protect themselves from infection, ideally without the knowledge of their male partners, who were anticipated to be uncooperative—just as they were in the negotiation of condom use.

The construction of African women as passive but responsible meant that they were also perceived to be more adherent than men when it came to using HIV prevention technologies (Cornell et al. 2012), an impression supported by clinical evidence (Nachege et al. 2006). Herein lies a clue to understanding why the response to evidence of women’s nonadherence in the VOICE trial was so incredulous and damning. In failing to adhere to required dosage instructions, and then apparently constructing an untruth to cover it up, women were acting contrary to this dominant image of the powerless African victim. They were also actively sabotaging research that could one day potentially save their lives, giving rise to a perplexing conundrum: Why would women deliberately undo the means to their own empowerment?

The moral narratives implied by these criticisms is not unique; it resonates with public health discourses of ‘irresponsible’ patients who do not take antiretroviral medication, and therefore deny worthy others (Biehl 2006). In a similar vein, there is a popular local discourse that suspects young women of deliberately becoming pregnant in order to benefit from state child support (Macgregor 2006), and even intentionally exposing themselves to HIV to access state disability grants (Leclerc-Madlala 2006). These rhetorics of blame speak to current gendered and generational concerns regarding political apathy, self-enrichment, and rampant materialism. They also echo much older discourses about poor, single women on welfare in many parts of the world, which frame them as “grasping and irresponsible” (Fraser and Gordon 1994).

It is largely through the medium of medical tests that the process of creating moral order in the trial is given authority and rendered credible. The assumed reliability of the pharmacokinetic tests carried out in VOICE—as in any other clinical trial—reveals much about how science is understood to accurately capture reality. This is the unquestioned ‘truth’ revealed by the medical test, coupled with the view of the body itself as a signifier of truth, awaiting interpretation of its signs. If women’s bodies were the sites where efficacy of an experimental product was to be proven (in itself a test for ‘truth’), it follows that the same bodies would be able to expose the ‘truth’ about women’s behavior during the trial.

Why was the evidence from blood so irrefutable against women’s words? What is it about blood or the blood sample that bestows such power upon it? Janet Carsten’s (2013) ethnography of pathology laboratories illustrated the capacity of blood “to accrue layers of meaning” (p. 132). “Discourses about ‘scientific’ blood testing,” she argued, “may ... be enfolded into understandings about the ways in which blood has a particular power to reveal the truth about the person” (p. 132). Trialists and trial participants alike endorsed and embraced this image of blood and blood tests, but for the latter, this endorsement appeared to have been only partial. For some women, blood tests held the power to expose infidelity (their own but also their partners’), but also lent credence to a vision of themselves as virtuous, HIV free, and healthy. Tests to reveal drug levels, by contrast, appeared not to have been taken as seriously. It is possible that some women did not fully believe that nonadherence would actually be exposed, or that the desire to please the counselors and researchers with whom they had interacted during the trial effectively trumped the risk involved in having their ‘lie’ exposed and the morality of their choices questioned. Indeed, some women confirmed this, explaining that they had lied about adherence because they had not wanted to disappoint the trial staff who had exhibited compassion and care for the trial women.

While some critics saw the adherence lie as a deliberate act of ‘elaborate deception,’ this interpretation is ultimately too simplistic. A focus on individual motives of self-interest or ‘altruism’ fails to recognize the inherently political nature of trial participation and the multilayered and competing subjectivities that it may engender. In practice, women could not maintain the image of the ‘perfect’ adherer they had worked so hard to craft; they could not meet the rigid requirements of compliance—not even when product taking became mentally ‘ingrained,’ automatic acts.

Despite these contradictions, it was possible for trial participants to *both* endorse aspects of the moral order of the trial while simultaneously contesting and rejecting other aspects of the trial. There were positive benefits to being associated with the trial: the opportunity to craft a reputation as virtuous, proximity to potential sources of employment, and concrete health benefits. Furthermore, many participants did not imagine they would be ‘found out’ if they lied, while others had doubts about the very intentions and actions of the researchers, and of the drugs they were testing.

The broader socioeconomic context of the participants’ lives help to explain why trial participation appealed to them, why the moral narrative presented by the trial was so compelling, and why they used it to craft their reputations in particular ways (as sexually

virtuous, healthy, HIV negative, perfectly adherent to biomedical requirements). Moreover, what is relevant about women's socioeconomic context is not only poverty, migration and social inequality, but also the influence of a profoundly stubborn AIDS stigma and of gendered scripts that define female and male sexualities in particularly restrictive ways.

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