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Malicious Whites, Greedy Women, and Virtuous Volunteers
Negotiating Social Relations through Clinical Trial Narratives in South Africa

As clinical trial research increasingly permeates sub-Saharan Africa, tales of purposeful HIV infection, blood theft, and other harmful outcomes are widely reported by participants and community members. Examining responses to the Microbicide Development Programme 301—a randomized, double-blind, placebo-controlled microbicide trial—we investigate the ways in which these accounts embed medical research within postcolonial contexts. We explore three popular narratives circulating around the Johannesburg trial site: malicious whites killing participants and selling their blood, greedy women enrolling in the trial solely for financial gain, and virtuous volunteers attempting to ensure their health and aid others through trial participation. We argue that trial participants and community members transform medical research into a meaningful tool that alternately affirms, debates, and challenges contemporary social relations.

As an ever-increasing number of clinical trials are conducted throughout the developing world, relations between trials and their participants are being critically examined (Craddock 2004; Leger 2008; Petryna 2006). One locus around which these inquiries coalesce is narratives of harm. In sub-Saharan Africa, interactions with medical professionals and care have produced accounts of the malicious creation and spread of lethal diseases such as HIV, blood theft, clandestinely inflicted sterility, and the trade in, or theft of, body parts (Geissler 2005; Kaler 2009; Niehaus and Jonnson 2005; Renne 2008; Scheper-Hughes 1996). Although often dismissed by medical researchers as misunderstanding, myth, or urban legend, some medical and clinical trial programs have begun to include a public engagement or community participation component, intended to mitigate negative perceptions of the research process through the creation of more “accurate” understandings of clinical procedures (Fairhead et al. 2006; Vallely et al. 2007). Yet despite these initiatives, tales of deadly clinical trials and blood stealing have persisted. We argue that the understandings of patients, clinical trial participants, or community members are not simply the result of misinformation. These statements persist, in part, because medical narratives in sub-Saharan Africa reflect, negotiate, and contest contemporary concerns and anxieties.

Medical dialogues have been understood as commentaries, expressing inherent meanings and truths about existing relationships between medical practitioners and medical subjects (Briggs and Mantini-Briggs 2004; Landecker 2001; van der Geest 2005; Whyte et al. 2002). Anthropologists have looked to narrative accounts as a means of escaping the ubiquity of biomedical interpretation and empowering the perspectives and experiences of patients (Garro and Mattingly 2000; Hunt 2000; Kleinman 1988; Thomas 2008). Stories are expressive perlocutionary acts that can be employed strategically to simultaneously comment on the lived
world as well as an idealized one. As Ochs and Capps (1996:22) write, “Narratives situate narrators, protagonists, and listeners/readers at the nexus of morally organized, past, present, and possible experiences.” In so doing, narratives affirm, negotiate, and contest social relations and hierarchies. In line with these perspectives, tales of the manufacture of HIV or blood theft can be regarded as a form of everyday protest, a weapon of the weak that is capable of articulating complex accusations (Geissler 2005; Kaler 2009; Newton et al. 2009; White 2000; Youde 2007). This explanation seems particularly appropriate given the context of clinical trials, which are often portrayed as “foreign enterprises” that are managed by multinational pharmaceutical companies. In contrast, local communities and participants are depicted as relatively powerless given their low levels of income and education (Craddock 2004; Leger 2008; Petryna 2006).

Drawing from our research as members of the Johannesburg Social Science Unit of the Microbicide Development Programme 301 (MDP301)—a clinical trial designed to determine the efficacy of the microbicide PRO2000 in preventing vaginally acquired HIV infection—we argue that while clinical trial narratives do address the relationship between researchers and researched, tales of harm should not be reduced to a single sentiment or meaning. Although clinic staff, MDP301 participants, and community members reported and (in some instances) affirmed rumors that the trial was a tool through which malicious whites infected participants with HIV and sold their blood, these stories formed part of a larger series of complementary and contradictory narratives. As Treichler writes, “Diverse voices, then, represent not diverse account of reality but significant points of articulation for ongoing social and cultural struggles” (1999:126). Rather than presenting a single uncontested perspective, trial narratives became a vehicle through which gender, cash, social reproduction, morality, and medicine were articulated and negotiated.

Research Methods and Procedures

As anthropologists, our research was an official and integral component of the MDP301 and conducted through the trial apparatus. A multi-center, randomized, double-blind, placebo-controlled trial conducted from 2005–2009, the MDP301 enrolled a total of 9385 women at six research centers: Johannesburg (South Africa), Durban (South Africa), Mtubatuba (South Africa), Mwanza (Tanzania), Entebbe (Uganda), and Lusaka (Zambia). Although conducted in sub-Saharan Africa, the MDP301 was managed as a partnership between Imperial College London and the Clinical Trials Unit of the U.K. Medical Research Council. Like with many other clinical trials, the pharmaceuticals and financial support were provided by organizations in the economically prosperous north. PRO2000 was designed and produced by the United States-based Endo Pharmaceuticals, whereas the MDP received funding from the U.K. Department for International Development and the Medical Research Council.

Assembling resources from the developed world, the MDP301 was conducted in areas characterized by poverty, poor living conditions, and a lack of economic opportunities. The Johannesburg site enrolled 2,503 female residing in former townships of Soweto and Orange Farm, most of which were between the ages of 18 and 29 (69 percent), unemployed (66 percent), had not worked the previous year (70 percent), and had not completed secondary school (62 percent). To be eligible, women had to be 18 years and over, sexually active, HIV negative, and not pregnant. Urged to always wear condoms during intercourse regardless of gel use, participants were randomized to three trial arms: a placebo gel, a gel containing a
concentrate of 2 percent PRO2000, and a gel containing a concentrate of 0.5 percent PRO2000. During their 12-month enrollment, trial participants were asked to use a gel during sexual intercourse as well as visit a designated clinic once a month to receive gel supplies and condoms, return used and remaining unused gel applicators, have blood drawn for testing, undergo physical examinations, and participate in interviews with clinic staff. Cash remuneration was provided for all clinic visits.

The Social Science Unit of the MDP301 was responsible for gathering qualitative data from a sample small enough to allow detailed information to be collected for each participant but large enough to ensure that the results could be generalized to the entire trial (Pool et al. 2010a:5). The data presented here are drawn from 401 interviews with 179 female trial participants, 28 interviews with 18 male partners, 42 focus groups with male and female community members, and extensive participant–observation in the MDP clinic waiting room, in the local community, at participants’ homes, and at meetings between the community advisory group and the study team, and at various study activities such as road shows and recruitment drives. If randomly selected, participants were privately interviewed in the trial clinic, usually by an interviewer of the same sex, during their 4th, 24th, and 52nd weeks in the trial. Interview questions focused on acceptability of the microbicide gel and trial procedures, sexual behaviors and relationships with partners, and gel and condom use. Conducted at a community crèche in Orange Farm and a venue at the Chris Hani Baragwanath Hospital in Soweto, focus group discussions were used to gain a broader knowledge of rumors and awareness of the trial, vaginal cleansing practices, health and healing, sexual partnerships and HIV/AIDS. All interviews and focus groups were digitally recorded, transcribed, translated, incorporated into Nvivo, and coded. Ethnographic field notes were similarly added to the Nvivo database and coded.

Reviewing and analyzing the data collected, we identified three narratives regarding the MDP301 that equally pervaded Soweto and Orange Farm. The first, which we label “malicious whites,” portrays the MDP301 and its managers as exploiting and threatening the lives of black Africans through medical means—inflecting participants with HIV and selling their blood. The second, “greedy women,” casts trial participants as young, selfish, and promiscuous, misleading their partners and trial staff, willingly selling their blood, and placing their lives at risk as a means of accessing cash. The final narrative, “virtuous volunteers,” asserts that trial participants were selflessly contributing to the advancement of science. Although prevalent, these narratives were not universally endorsed, and it was difficult to precisely gauge the popularity of each. Some individuals made firm assertions, some speculated, and some reported the assertions and speculations of others. Consequently, we believe that the power of these tales lies in their articulation rather than their “truth.” Reviewing each in turn, we argue that trial narratives not only address the role of international clinical research and medical practice in South Africa, they also reflect other long-standing debates and insecurities regarding cash, gender, and social reproduction.

Malicious Whites

Throughout sub-Saharan Africa, tales of white malice suffuse many discussions of HIV/AIDS, prevention methods, and medical research. In South Africa, one widely recorded narrative contends that HIV was secretly and intentionally created by white people to eliminate the black population (Epstein 2008; Niehaus and Jonnson 2005; Stadler 2003). Organizations and
individuals thought to support white interests were especially implicated, such as the CIA or Wouter Basson, the former Director General of Health during the apartheid era. Condoms, as well as other HIV diagnostic and prevention technologies, were considered to be one way through which the virus was maliciously spread (McNeill 2009). Tales of white malice, purposeful infection, and the danger of HIV prevention technologies also suffused discussions of the MDP301. Reflecting a common sentiment, a 28-year-old participant stated, “There are people who are saying that . . . white people are trying to kill blacks through the study.” Two examples include stories that the gel contained AIDS or deadly worms. Marshaling evidence to corroborate these accusations, some participants and residents remarked that other microbicide trials had also put their participants at risk. Many had seen media reports regarding the Zambian Cellulose Sulphate trial, which was suspended after higher rates of HIV infection appeared among those using the product as compared to those randomized to the placebo. Several months after joining the trial, a 30-year-old participant reported, “My partner is supportive but since yesterday—after hearing that there were people who were using the gel and they became HIV positive—he started to panic saying, “You see that gel of yours!” He does not trust [the gel] anymore.”

Trial procedures such as financial reimbursements and blood draws were also subjects around which narratives of harm were structured. As stipulated by the Medicines Control Council of South Africa, all trial participants received R150 (US$21) per clinic visit. Over 12 months, a total of R1,800 (US$258) would be collected for clinical appointments alone. Trial staff stressed that these payments were reimbursements for travel expenses, not fees for participation. However, actual travel costs were far lower than the sums being distributed. This discrepancy led many to speculate about the “real” purpose of these payments. In some instances, reimbursements were said to be a “bribe” intended to discourage participants from complaining about any “side effects” that resulted from gel use. In others, monetary compensation was explicitly linked to the threat of death. When asked about community views of the MDP301 during a focus group discussion, one man volunteered:

> The people who stay next to me are scared because someone came here [to the MDP301 clinic]. I mean the time the research had just started and when they tested her they found that she is HIV positive. Then after three days she started to become very sick and then after that she died. So, people are scared because they said when you come here they tell you your status then give you R50 and the next day after drinking a cold drink that you bought with the money that they give you, you die.

Through discussions with people on the streets of Soweto and Orange Farm, we learned that some residents warned one another that any funds received as a result of trial participation would actually be used to “buy your coffin.” As one 41-year-old woman succinctly noted during an interview, “They say you will die for the sake of getting R150.”

Another persistent narrative concerned the sale of blood. Accounts of blood selling were so widespread in Soweto and Orange Farm that community members nicknamed the microbicide trial clinic “money for blood” (IsiZulu: imali ye gazi). Residents alleged that women enrolled in the trial received cash reimbursements as payment for blood that was drawn as a routine part of clinic visits. Although the informed consent process included an explanation of these procedures, many participants felt that the amount of blood taken for testing and storage was excessive and potentially dangerous. Rather than a resource that could
be easily replenished, blood was considered to be a substance that existed in limited quantities within the body. Once blood was depleted, health and well-being would be compromised. One 32-year-old woman commented, “Someone had told me that she knew someone who was participating in this study and they drew so much blood from her that she ended up weak.” A few participants also reported that nonparticipants asserted that trial blood draws would lead to death.

Not only was the health of trial participants in jeopardy as a result of the blood draws, the “payment” was thought to be inadequate. One older participant noted in an interview, “I have heard some women participating in the study saying that the money is too little because the blood taken in the clinic is too much.” We were told in other participant interviews that women received only “a little” money because the clinic staff were profiting from the sale of trial blood. As proof, one participant cited the expensive new cars that the clinic doctors drove through the poor township. Similar to the assertions of trial participants, residents also stated that R150 constituted only a small portion of the total funds that the clinic received. The bulk was thought to be appropriated by trial staff. In these narratives, the clinic was portrayed as endangering the lives of trial participants while simultaneously deriving profit from reselling their blood.

Postcolonial Relationships

Through medical interventions and clinical trial research, the “long conversation” between colonizers and colonized is continued (Jean Comaroff and John Comaroff 1991). From the introduction of colonial medicine and its portrayal of black bodies as fundamentally diseased, medical narratives have been suffused with social meaning (Jean Comaroff 1993; John Comaroff and Jean Comaroff 1992; Saethre and Stadler 2009; White 2000). For decades, the disenfranchisement and segregation of the black population in South Africa was justified through the language of public health (Jochelson 2001; Packard 1989; Phillips 1990). The HIV pandemic and contemporary medical interventions bear an uncanny family resemblance to previous circumstances. The AIDS pandemic began to attract attention in South Africa at the same time that the apartheid system was being dismantled. As township residents watched their family and friends succumb to the new disease, they did not, and do not, see white people sharing their experience. Similar to earlier public health measures, those spearheading education campaigns and interventions appeared to be wealthy, white, and (increasingly) foreign. The MDP301 was certainly an example of this trend.

Situated within a postcolonial context, narratives of white malice, contaminated pharmaceuticals, and blood selling are made much more meaningful and credible (Geissler 2005; Kaler 2009; Niehaus and Jonnson 2005). Tales of Wouter Basson or the CIA creating HIV as a biological weapon, reflect a suspicion resulting from a long history of white oppression in South Africa. Similarly, stories of “coffin money” and blood selling couple historical relationships with everyday observations to link cash with injurious and exploitative procedures. These narratives reconfigure the relationship between researchers and researched by constructing a counterepistemic community through which historical and contemporary relationships between “poor Africans” and “wealthy whites” can be expressed and critiqued. Bracketed by a continuing history of inequality, economic domination, and repressive public health, Soweto and Orange Farm residents express a genuine reality—black people are disproportionately suffering the effects of AIDS, clinical trials have been proven hazardous,
and trial doctors do drive expensive vehicles. Examining rumors of organ stealing, Scheper-Hughes writes, “The stories are told, remembered, and circulated because they are fundamentally, existentially true” (1996:9).

Participant responses to the MDP301 and other clinical trials are not “merely” critical commentaries on exploitation. They embody the deep personal, economic, and social anxieties that suffuse the postcolonial world. Since the apartheid era, South Africa has experienced a rise in “spiritual insecurities” (Ashforth 2005) and “occult economies” (Jean Comaroff and John Comaroff 1999, 2000), in which harmful magic is employed to achieve monetary benefit. Exemplifying this trend, witchcraft is an acute source of concern throughout the nation. Much more than a system of explanation, witchcraft represents a fundamental threat to the social and moral structure of society (White 2000). However, witchcraft is not the only means through which these concerns are given voice. Sharing many of the themes found in witchcraft accounts, tales of clinical trials and other medical interactions also provide a series of narratives through which spiritual insecurities are similarly negotiated.

Analogous to rumors concerning the MDP301, the immoral exchange of blood for wealth and the misfortune that results from it are recurring themes in witchcraft narratives. Witches are accused of deviously taking innocent people’s blood, giving it to witch familiars, and receiving cash in exchange (Bähre 2002). Although money is gained through these transactions, it is portrayed as “unproductive and sterile,” failing to benefit the wider society (Niehaus 2000:50). These illicit exchanges threaten the very fabric of family and sociality. While blood is considered a vital bodily fluid, it also embodies notions of personhood. Conceptualized as the comingling of a man’s white blood and a woman’s red blood, the transfer of fluids during sexual intercourse is essential to the constitution of individuals and their relationships to one another (Thornton 2008). These exchanges acquire social legitimacy through the payment of lobola, or bridewealth. Lobola is given for a woman’s “blood” or reproductive potential. In this way, blood and cash are necessary components to ensuring social continuity. If these transactions are perverted or hijacked—for instance when blood is stolen for profit—the foundation of society is put at risk.

Incorporating the MDP301, its staff, and medical procedures into long-standing narratives, spiritual anxieties permeated accounts of “coffin money,” blood selling, and contaminated gels. One participant’s male partner reported that his close friend, whom he had grown up with in a rural homeland, believed the trial was “white people’s witchcraft”: “He said white people are bewitching them; they have put other people’s sperm in the applicator and the woman inserts them inside her vagina so when a man have sex with the woman they do so on top of the other person’s sperms.” Other community members also noted the similarity between narratives of witches stealing blood and trial administrators selling blood.7 We were told that trial staff resembled witches “thirsty for their own child's blood,” and blood draws were proof that the trial staff engaged in witchcraft. These statements not only stress the oppression of Africans at the hand of foreign powers, they do so by invoking representations of an irreplaceable and priceless resource—lifeblood—without which health, self, and procreation would collapse (Stadler and Saethre 2010). As in narratives of illicit blood transaction, the alleged presence of foreign sperm in the gel endangers a legitimate exchange and undermines relatedness. Because wealth obtained at the expense of social reproduction can lead only to death, trial participants were said to buy their coffins.
Greedy Women

Although narratives of “money for blood” and “coffin money” portrayed women as victims of white malice, community residents expressed little sympathy for their plight. Depicting participants as greedy, deceitful, and licentious, trial membership was marshaled as evidence of moral weakness. The “real” reason that women joined the trial—risking their health and their lives in the process—was a selfish desire for “money all the time” and “fashionable clothes.” These trial participants were cast as lazy, young, self-centered, and untrustworthy—accessing cash without participating in the wage labor market, then concealing from their partners that they used gel and got reimbursed. Men and women of all ages made these statements. Many suggested that women accessing the trial for cash also engaged in sexual relations with numerous men.

Women charged with joining the trial solely as a means of obtaining cash were often accused of “dumping” their gels. Gel dumping was described by a 32-year-old participant as follows: “A person will go into the [bath]room for hours, squeezing the gel out so that they hand over an empty applicator. Then they lie and say they used it. They are not using the gel. They are only coming here for money.” Although none of the women we interviewed admitted to disposing of the gel, many stated that they had met or heard tales of gel dumpers. While sitting in the waiting room, one participant reported hearing another divulging that she had discarded the contents of five applicators. Whereas gel dumpers confided in other women, they attempted to conceal their actions from trial staff and their partners. In an effort to avoid discovery, some gel dumpers were thought to discard the gel in the “long grass” and other secluded locations. In one case, a participant described a woman who pretended to insert the gel in front of her partner as a means of concealing her dishonesty.

Similar to other narratives involving the insatiable desire for cash, accounts of gel dumpers implicated young, greedy, deceitful, promiscuous women. After participating in the trial for six months and commenting positively on the gel, one 36-year-old woman noted, “The majority of people dumping the gel are young people and those who did not disclose to their partners. They are only interested in money.” In one Orange Farm focus group discussion comprised of individuals not enrolled in the trial, a male noted that “[participants] come here because they want money”. A female responded that many of these women are not in monogamous relationships and dump their gels. She added, “It is not right because they are just playing with RHRU [the trial coordinators].” Gel dumping was also said to be “naughty” and fundamentally irresponsible because it endangered the scientific process. If the trial closed due to a lack of positive results, participants told us, it would be the fault of the gel dumpers.

Gendered Relationships

Trial narratives not only reflected notions about relationships between white researchers and black subjects, they also formed part of a larger conversation concerning gender in Orange Farm and Soweto. Stories of greedy women and gel dumpers mirrored widespread dialogues that cast young unmarried women as using men only as a means of accessing cash. Although these women were not referred to as “prostitutes” (magosha) because they did not “stand in the streets,” they were nevertheless accused of relentlessly pursuing money and, in the process, transforming love and relationships into a commodity. A female Orange Farmer noted:
When they see money they pretend as if they love meanwhile there is no love. . . . Yes, there is someone who has a boyfriend that has money and she loves him because he has money. There are people who are close to that person and they tell you that he has money and he can give you money. You find that she does not love the guy but she wants his money. She even says he is ugly but he has money.

While concealing their greed from partners, women confided in others. In Soweto, some women referred to their boyfriends as “ATMs” or “checkbooks” (Wojcicki 2002a:360). During a focus group discussion with women from Orange Farm, all four present condemned “selling your body” as immoral and stressed that it resulted in promiscuity and infidelity. Immediately after making these statements, the women contrasted this with lobola [bridewealth], which was “good” because it demonstrated that “your parents looked after you.”

Since the 1970s, sub-Saharan Africans have expressed concern over the growing independence of urban women and the link between sexual relationships and monetary ones. Accounts of women engaging in “transaction sex” have been increasingly documented by researchers (Harrison et al. 2001; Hunter 2002; Jewkes et al. 2003; Kaufman and Stavrou 2002). These narratives are often understood as a reflection of changing economic and gender relations (Cornwall 2002; Kaler 2006; Wojcicki 2002a, 2002b). As early as 1895, when the Kruger government introduced a £2 flat tax to be paid by all African males, cash was a tool to encourage migrant labor (Gilomee 2003:294). While mine workers took home cash to rural regions, family relationships were restructured as men were separated from their wives, children, herds, and land for extended periods. Just as crucial, lobola payments shifted from cattle to cash (Murray 1981). Although men possessing steady work were now afforded the opportunity to choose a wife without relying on the approval and resources of family members, those that did not faced an extended bachelorhood. Over the years the price of lobola rose alongside the cash economy, leading an increasing number of men to complain that taking a wife and starting a family were becoming ever more costly and prohibitive (Kaler 2006).

As men postponed matrimony, women obtained cash—in part—through transaction sex, which was often portrayed as the antithesis of lobola. Instead of remaining a virgin until the wedding night, the desire for cash was thought to motivate women to engage in premarital sex with a variety of partners. Once married, wives could be prompted to either deceive or divorce their husbands in the hopes of gaining greater resources from another man. Whereas lobola cemented procreative relationships, money gained from feigning love was thought to profit the individual rather than the collective. Women were said to purchase commodities for their sole use, such as fashionable clothes or perfumes. Associated exclusively with the female gender, these items did not, and could not, benefit the entire family. Money acquired via sex was often depicted as a threat to “traditional” gender and family relations. Consequently, statements condemning women for using sex to access cash were not confined to males. A force that is “expressive and transformative” (Cornwall 2002:971), commoditized relationships rearticulate and reshape gender and family interactions.

Given the convergence of female participants, sexual activity, and cash reimbursements, the MDP301 became incorporated into existing gender dialogues. Framed by a wider unease regarding women’s access to money via premarital sexual relationships, participation in the trial became a focus around which these notions were expressed. While older participants in stable sexual relationships were portrayed as honest and moral, young single participants were thought to be greedy, deceitful, and promiscuous—terms similar to those used to describe
women who sold their bodies to men. In these instances, the MDP301 seemed to assume the characteristics of an illicit male lover, who provided women with a clandestine income but could also be deceived. Greedy participants were accused of “playing with” RHRU, much like they did with their boyfriends. Instead of feigning love or hiding infidelity, trial participants cheated by dumping the gel, lying to clinic staff, and then boasting to friends. Interestingly, community members asserted that women dumped gel in the long grass, where illicit affairs are thought to be conducted. Dumping the gel, like engaging in transaction sex, was portrayed as benefiting the individual while harming the collective by placing the success of the trial at risk and threatening the development of a pharmaceutical that could conceivably benefit millions of African women. Through these accounts, the MDP301 was transformed into a vehicle for conveying local gender concerns regarding who should be having sex and for what reasons.

Virtuous Volunteers

Stories of malicious whites and greedy women led some community members to confront trial participants, who reported being taunted for selling their blood to the clinic, accused of enrolling in the study for remuneration, and attempting to infect others with HIV. Faced with these indictments, women taking part in the MDP301—as well as their male partners— reframed these discussions by highlighting their own agency and questioning the accuracy of popular narratives. Dismissing accounts of HIV-laden gels, bribes, and “coffin money,” participants claimed that these stories were the result of ignorance and misinformation. Despite news coverage of the Zambian Cellulose Sulphate trial and the concerns of her partner, the participant discussed earlier did not believe that the MDP301 was putting her health at risk. She commented, “You know when we talk like this we must know that the media lies sometimes or exaggerates things. They add inaccurate information to get people’s attention.” Similarly, the 32-year-old woman who had been told that blood draws led to ill health, enrolled in the MDP301 despite these tales because “the girl was lying.” Individuals outside the trial were repeatedly cast as basing their opinions on hearsay and supposition rather than fact and experience. The man who had equated the MDP301 with witchcraft was described as “an uncivilized person who does not believe in this science stuff.”

Whereas rumors of harm were rejected as uninformed and unfounded, nonparticipants were depicted as indolent, irresponsible, promiscuous, and jealous. A primary theme in these counternarratives was HIV status. An unwillingness to join the trial was equated with an unwillingness to be tested for HIV. As a result, non-enrolled women were sometimes referred to as “cowards,” “lazy,” and “not doing anything in their life or about their health.” Fear of HIV testing was also marshaled as proof that nonparticipants were promiscuous and, as a result, could not be trusted. After participating in the trial for only a month, a woman with a stable partner who encouraged her to use the gel commented, “Some say that the gel will infect women with HIV/AIDS because they are paying women who are using the gel. And I do not believe what they are saying because they know that they have multiple partners and that is why they say all these things.” In some instances, licentious, HIV-positive individuals were portrayed as envious of those women who were able to access resources by joining the trial.

Although trial participants criticized women who chose not to join the MDP301, they also condemned fellow participants who enrolled simply for financial benefit. We were told that it was “wrong” for women to “waste” the gel by dumping it. After spending a year in the
I have noticed that many of them joined the study because they like the reimbursement. And I tell them I joined the study without the knowledge of the reimbursement and I did it because I wanted to be part of the study. And some of them dump the gel because they only need the money that they get from the study.

A clear distinction was made between women who had joined the trial for the reimbursements and those that had not. We were told that for some the trial was “like a job” and others were “volunteering”. When we asked a focus group of seven participants in Soweto how they would respond if the cash payments were discontinued, one told us, “I did not come here for money; we are here for our safety.” This statement was echoed by others in the room. Declarations such as this were common in focus group discussions and in-depth interviews. Rather than being motivated by cash, women reported that they enrolled for the security of knowing their HIV status and receiving regular physical exams.

For the majority of “volunteers,” medical procedures were viewed as an important method through which their well-being was monitored. In these narratives, blood draws—although sometimes still a source of anxiety—were recast in positive terms. One participant commented, “Yesterday they took ten bottles of blood and I asked myself, ‘What are they are going to do with my blood?’ Then I told myself that maybe my blood was good—that was why they took ten bottles.” Because participants possessed “clean” or uninfected blood, some asserted that the trial donated their blood to health facilities and private individuals for transfusions. Blood collected in the clinic was “going to work for someone who is sick” and “helping people.” We were told that the reimbursements were intended to purchase food and other items that would nourish participants and replenish their blood. Instead of being used to buy luxury feminine items, reimbursements were conceived as an exchange that benefited those in need, rather than a payment in the strict sense. In this narrative, cash for blood was portrayed altruistically. In addition to aiding those who required clean blood, women asserted that their involvement in the MDP301 could potentially benefit people around the world. If the gel were found to be efficacious, it could prevent millions of other women from contracting HIV. During the Soweto focus group of seven women that was discussed in the previous paragraph, another participant added:

People talk too much about the gel because it’s not them using it. When they are testing the gel on us, it’s what we want. It is true when they say we are taking risks—so what. I am proud of what I am doing because I want to see if this gel works so it can help many people. That is why at the end I tell myself that I am a lifesaver and I feel good about it.

Rather than casting the motivations of all participants greedy and avaricious, women enrolled in the trial portrayed their motivations as selfless and moral.
Reciprocal Relationships

Accounts of virtuous volunteers challenged the notion that medical interventions and their participants posed a fundamental threat to society, while simultaneously addressing divisions and tensions between trial women and the local community. Whereas some residents depicted trial enrollment as an indicator of greed, deception, promiscuity, and immorality, participants invoked their HIV-negative status to contest these claims. Popular themes of malice, gender, and cash were reconfigured to portray nonparticipants as ignorant, jealous, malicious, and potentially HIV positive. When confronted by community members asserting that she would die “for the sake of getting R150,” the woman responded, “I tell them that I am better because I know my health and I am even aware of my HIV status.” These assertions functioned as a powerful declaration, particularly in a nation where AIDS sufferers are often stigmatized (Mills 2006; Petros et al. 2006; Robins 2006). Stressing that trial participation was contingent on remaining HIV negative, enrollees demonstrated their own health and morality, while calling into question that of others. As one young participant from Orange Farm commented, “We are different because if you join the study it means you are responsible about your life. So those ones who did not join the study, they do not care about their life.”

Although women asserted that some individuals enrolled in the trial for monetary rewards, these statements were contrasted with beliefs regarding “volunteers” and “lifesavers,” which portrayed the activities of trial participants as largely beneficial. Concerned for the collective good rather than individual profit, “volunteers” acknowledged that they were willing to take risks in an effort to contribute to the testing and development of AIDS prevention technologies. Similarly, blood sale was transformed from a dangerous and selfish act into a long-term productive relationship between the clinical trial and its enrollees. Stating that they purchased foodstuffs rather than fashionable clothes or perfumes, trial participants emphasized that reimbursements were used to potentially nurture an entire family. Like lobola, “donating” blood at the trial clinic was framed as an instance in which the exchange of cash for blood engendered legitimate bonds. Participants’ insistence that they were involved in a reciprocal relationship with the clinic—a cyclical flow of lifesaving blood for blood-renewing cash—transformed what some viewed as an amoral act of consumption into a model example of social and procreative relations. Instead of attacking the very basis of relatedness, women claimed to be engendering life, health, and personhood through their participation in the MDP301.

Standing in stark contrast to tales of malicious whites, those of virtuous volunteers significantly reframed the relationship between medical researchers and clinical trial participants. Rather than exploitative enterprises, clinical trials are depicted as ultimately constructive. Imparting a variety of resources to its participants, the MDP301 allowed women to assert claims regarding their probity and agency. By enrolling in the trial, women were able to monitor their health, access cash that was not controlled by men, and become valued contributors to medical research. Participants remarked that clinical trials made affluent, white, and foreign medical professionals dependent on poor black women (Saethre and Stadler 2010). The MDP301 allowed women to invert global relationships while simultaneously restructuring local narratives of gender, cash, and sex. Rather than a static enterprise, clinical trials can be imbued with a multiplicity of meanings, which are routinely disputed.
Conclusion

Although unanticipated by its inventors, microbicide technology itself encouraged community members to create signification. Introduced to support female autonomy in HIV prevention, microbicide gels were designed as a technology that could be used without the tacit knowledge of a sexual partner (Bell 2003; Mantell et al. 2006). In a setting where “HIV risk” is often equated with “multi-partner sex,” microbicides can appear to be a technology for promiscuous women. Not only do microbicides address sexual norms, their ability to be concealed also overtly restructures gender relations. Assuming that some women would choose to hide their use of a microbicide gel, the MDP301 did not require participants to inform their partners of their enrollment. Consequently, it is hardly surprising that the trial became a locus around which narratives of women’s agency were debated. Through the process of witnessing, discussing, and participating in the trial, residents of Orange Farm and Soweto fashioned the MDP301 into a tool through which ongoing social processes and insecurities were affirmed, debated, and contested. Although the MDP301 was successful in providing women with pharmaceuticals and reimbursements that could be concealed from men, in so doing, it ignited fears that gender relations and social reproduction would be fundamentally challenged. Considering that microbicide technology was developed to aid young unmarried women, it is ironic that the residents of Orange Farm and Soweto often equated sincere trial participation with stable sexual relationships and disclosure to partners. The different significations of microbicide gels—and medical technologies and interventions generally—highlight the importance of anthropological research within medical settings, particularly in regard to issues of recruitment, adherence, and acceptability.

Replicating discussions that cast medicine as authoritarian and controlling, there has been a tendency to view clinical trials as corporate enterprises that victimize their participants. Littlewood (2003:256) suggests many medical anthropologists have transformed the relationship between doctors and patients into that of colonialists and the Other. Much more than interpretations of medical procedures, narratives of malicious whites, greedy women, and virtuous volunteers speak to these ongoing debates. Rather than producing a single narrative with a single meaning, the MDP301 functioned as a wellspring of resources—conceptual and financial—which was exploited and manipulated. Employing common themes with shifting meanings, both participation and nonparticipation were a source of alternating criticism and power. We suggest that clinical trials should not be viewed simply, and unproblematically, as projects that are solely created and controlled by Western organizations or that medical narratives are invariably, and continually, structured around the reified dichotomies of doctor–patient, global–local, victimizer–victimized, and colonizer–Other. Although these themes were present in some MDP301 narratives, others focused on gender, witchcraft, morality, and marriage. Consequently, narrative analysis should encompass not only local views of the global but also local views of the local. Although funded by the British government to test a microbicide designed and produced in the United States, the MDP301 was imbued with signification, dynamically negotiated by community members, and, as a result, actively transformed into a local institution.

Notes

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1 For the purposes of this article, we use “narrative,” “story,” and “tale” as synonyms. We acknowledge that some researchers consider these distinct concepts, so that narrative refers to the representation of discourse and story refers to the events that the narrative relates (Garro and Mattingly 2000:12).

2 The results revealed that PRO2000 is safe but unable to prevent HIV infection (McCormack et al. 2010).

3 The protocol was approved by local and national ethics committees, in all participating countries and in the United Kingdom. In South Africa, permission to conduct the research was granted by the Witwatersrand University Human Research Ethics Committee (Reference 050108).

4 Approximately twenty kilometers separate the two communities. Soweto consists of 38 townships and 1.2 million inhabitants, while Orange Farm accommodates 170 thousand people. As Orange Farm was initially settled by individuals unable to afford a room or land in Soweto, the residents of both communities continue to enjoy a close relationship.

5 To protect the anonymity of participants, all identifying data were removed before being collated. For more information regarding the methods employed, see Pool et al. 2010a, 2010b.

6 Venous blood draws took place at regular intervals at least five times throughout the study; they were tested for HIV (8.5 milliliters), syphilis, and herpes simplex (5mls), while an additional 15 milliliters were collected for storage. The first 500 women had a further 15 milliliters of blood taken for full blood counts, liver function, kidney function, and clotting tests.

7 White (2000:18) notes that blood-selling rumors in East and Central Africa were derived from witchcraft beliefs.

8 Some women did conceal remuneration from their partners. While we have no quantitative figures, we believe that these women were in the minority.

9 As with other narratives, statements such as this one express idealized notions rather than strict realities. Although many participants reported using reimbursement to purchase a range of products and services that assisted their households, including food, basic household articles, children’s clothing, transport to seek work, and school fees, others did acquire luxury items for themselves.