Ourselfs, Our Bodies, Our Realities: An HIV Prevention Intervention for Women With Severe Mental Illness

Pamela Y. Collins, Pamela A. Geller, Sutherland Miller,
Patricia Toro, and Ezra S. Susser

ABSTRACT *This paper describes a 10-session behavioral intervention introducing female-initiated methods of human immunodeficiency virus (HIV) prevention to reduce vulnerability to HIV infection for women with severe mental illness. In a pilot test of the intervention, 35 women were randomly placed in the experimental intervention group or an HIV education control. Subjective norms, intentions to use, perceived efficacy, and attitudes toward the male condom, female condom, and a microbicide were assessed at baseline, postintervention, and 6-week follow-up. The participants in the treatment group reported a significantly more positive attitude toward the use of female condoms ($t = -2.12$, $P < .05$) at 6-week follow-up. Providing women with severe mental illness with choices of protective methods and the knowledge and skills to ensure proper use are among the many crucial ingredients in prevention of acquired immunodeficiency syndrome.*

KEYWORDS HIV/AIDS, Prevention, Severe Mental Illness, Sexuality, Women.

The acquired immunodeficiency syndrome (AIDS) epidemic threatens the lives of women with severe mental illness (SMI).^{*} Recent evidence suggests that AIDS is a leading cause of mortality among young women with psychotic illnesses in suburban New York State; these women acquired AIDS primarily through unsafe sex with HIV-infected men.¹ Rates of human immunodeficiency virus (HIV) infection among women with SMI approach those of men with SMI, greatly exceeding seroprevalence rates among women in the general US population.² Prevalence rates ranging from 5% to 9% have been reported among chronically mentally ill women in urban centers.^{3,4}

Drs. Collins and Susser are from the Department of Psychiatry, College of Physicians and Surgeons of Columbia University, the New York State Psychiatric Institute, and the Joseph L. Mailman School of Public Health of Columbia University; Dr. Geller is from the Department of Clinical and Health Psychology, Medical College of Pennsylvania, Hahnemann University; Dr. Miller is from the New York State Psychiatric Institute; and Dr. Toro is from the New York Presbyterian Hospital and the Weill Medical College of Cornell University.

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Correspondence: Dr. Pamela Collins, Assistant Professor of Clinical Psychiatry, 601 West 168th Street, Suite 32, New York, NY 10032. (E-mail: pyc1@columbia.edu)

^{*}Severe mental illness is used to indicate severe and persistent psychiatric illnesses, including schizophrenia, schizoaffective disorder, bipolar disorder, or major depression with psychotic features.

In this article, we present a behavioral intervention for HIV prevention that begins to address the needs of women with SMI, including the need for female-initiated barrier methods such as the female condom. This article describes (1) the context of HIV risk for women with SMI, (2) the HIV prevention curriculum “Ourselves, Our Bodies, Our Realities” for women with SMI, and (3) the results of a test of the intervention.

THE CONTEXT OF RISK

Behaviors that place women with SMI at risk for HIV infection include sex in exchange for money or goods, substance abuse, multiple sexual partners, sex with partners who use injection drugs, and inconsistent use of condoms.^{5–9} Long-term institutionalization does not protect these women entirely from sexual encounters and their inherent risk as sexual intercourse without condom use continues to occur in some institutional settings.¹⁰ Yet, these individual behaviors occur in a larger context that is essential to note. Among the contextual factors that influence the ability of women to reduce their risk of HIV infection, we highlight three: economic dependence, sexual violence, and the impact of severe and persistent psychiatric illness, such as schizophrenia, on cognitive functioning.

Economic Dependence

Most women with SMI living in urban environments are poverty-stricken. A severe and persistent mental illness all but ensures limited employment opportunity and economic dependence on government subsidies, family members, or partners.¹¹ For impoverished women with SMI, concerns for survival and financial stability may conflict with opportunities for risk-free sexuality.

Economic disadvantage carries the complexities of dependency. Women often depend on male partners for economic support of children, for shelter, and for food. Partnerships may emerge with the understanding that a woman and her children will be provided for in exchange for a sexual relationship. In such arrangements, women with SMI may not have the freedom to prioritize their safety in sexual relationships above material needs. Weinhardt et al.¹² report that women with SMI rated poverty and employment as greater life priorities than HIV prevention despite engaging in HIV-related risk behaviors.

Violence

Exposure to violence often accompanies inner-city urban life for impoverished women. Women with SMI, in particular, report high rates of violent victimization and rape.^{13–15} The review of the literature by Goodman et al.¹³ illustrates these patterns: A majority of women with SMI have experienced physical or sexual abuse in their lifetimes, and a large number of these women experience repeated victimization. Substance use combined with cognitive impairment secondary to SMI may further increase vulnerability to coercive and violent sexual encounters.^{7,13,15}

Violent environments limit options for sexual encounters that are free from the threat of physical and emotional harm, as well as sexually transmitted diseases like HIV.¹⁶ Under such circumstances, women may have little or no control over choice of sexual partners, timing, or location of sexual activity.¹⁶ Sexual assault, coercion, and rape in early life may also play a role in later risk for HIV and sexually transmitted diseases (STDs).¹³

Impact of Mental Illness

The psychiatric symptoms women with SMI experience also contribute to HIV-related risk.¹⁷ The data are scant on these issues, however, and only the results of cross-sectional studies are available. Cournos et al.⁵ noted that high-risk sexual behaviors were associated with more symptomatic psychotic illness and decreased functioning. Patients with positive symptoms may be more likely to have multiple sex partners; excitement symptoms appear to correspond to a greater likelihood of sexual activity in general, as well as a greater likelihood of trading sex.¹⁷ Psychiatric illness, including substance abuse, may also be associated with impulse control difficulties, along with a reduced ability to assess the danger of a situation or to act on the assessment.¹⁸

Cognitive impairments have long been recognized as a key symptom in schizophrenia; they affect an individual's ability to live in community settings and to acquire social skills.¹⁹ These include attentional difficulties, poor abstraction abilities, and/or memory impairment.

In the setting of a sexual encounter, an impaired ability to abstract, to inflect speech, to perceive affect and social cues from the partner, or to display affect will increase the difficulty of negotiating the interaction. Cognitive impairments can affect a woman's ability to attend to relevant information, to disregard irrelevant information, and to recall. As a result, cognitive functioning mediates a woman's ability to negotiate the subtleties of a sexual relationship.

OURSELVES, OUR BODIES, OUR REALITIES: DEVELOPMENT OF AN HIV PREVENTION INTERVENTION

Background

Clinicians and investigators have established that men and women with SMI are able to participate and benefit from HIV preventive behavioral interventions. As studies in psychiatric rehabilitation suggest, a focus on targeted skills, demonstration, and practice are important ingredients for behavioral interventions aimed at people with SMI.²⁰ However, interventions that target the needs of women with SMI remain few and far between. The pilot study of Weinhardt et al.²¹ of an assertiveness training intervention is the only published study of an HIV prevention intervention aimed specifically at women with SMI. In that study, women in the intervention group, who were taught to be sexually assertive, increased their assertiveness skills, HIV knowledge, and frequency of condom-protected intercourse.

Based on understanding gained from ethnographic research and clinical experience, Susser²² and Waterston²³ investigated approaches to HIV prevention among women with SMI. They found that interventions must be sensitive to the context in which women live and should take into account the daily activities of their lives.

In developing the *Ourselves, Our Bodies, Our Realities* curriculum, our objective was to present an intervention that appreciated the social context in which women live by taking into account the frequent victimization suffered by women with SMI, their living environments, their diminished power in sexual relationships, and the lack of safe alternatives during sexual encounters. We sought to integrate these issues with those concerns that are unique to women living with a severe mental illness: cognitive impairment and the attention, learning, and communication difficulties that accompany it.

Social Context

Ourselves, Our Bodies, Our Realities was adapted for women living in group residential settings by first taking into account typical daily activities. For example, many residences have a central lounge that allows residents a common area for smoking and watching television. Contemporary daytime television broadcasts sensational talk shows in which sexual behavior is discussed openly. A talk show format was adopted to facilitate discussion of sexual issues in a familiar and entertaining way, while remaining respectful of traumatic experiences participants may have endured. The curriculum utilized pertinent themes, such as women's relationships with their children and their relationships with men.

Addressing the Impact of Mental Illness

We developed a curriculum that could meet the needs of women with cognitive impairments. The talk show format provided an engaging program that, through its playfulness and encouragement of active participation, captured the women's attention. The prevention and safety messages are repetitive, and women receive them visually and aurally. The intervention begins with the basics: education about AIDS and education about the female body. We focus on skills training: skills to use the methods that we discuss and skills to communicate with others. We debated how much to focus on negotiation skills versus skills for condom use. Ultimately, we incorporated practice of communication skills into the role-playing activities, but the intervention sessions focus on teaching the women skills to use female-initiated methods. We believed that keeping the goals simple and skill oriented would facilitate learning and recall for the participants.

The Theme of Autonomy: Female-Initiated Methods

Female-initiated methods of HIV prevention, such as the female condom, are presented in the intervention. These methods provide women with some degree of autonomy in their encounters with men. Although they are not a substitute for communication skills and respectful relationships, they provide women with protective options in addition to the male condom. In situations in which women with SMI are unable to negotiate with their partners for male condom use, use of a female condom may offer a safe alternative.²⁴

The female condom is a contraceptive that is effective in reducing the risk of HIV transmission.²⁵ Although more costly than the male condom, women living in residential settings may be able to obtain them through the institution's formulary or via prescription covered by Medicaid. Insertion of the female condom requires skills already familiar to many women who have used diaphragms.

The female condom allows women to take the initiative in protecting themselves; yet, although it is female initiated, the condom is visible to the male partner and may require some degree of negotiation. We also introduced the use of microbicides in HIV prevention as an additional female-initiated measure that does not require negotiation or the partner's knowledge.

Ourselves, Our Bodies, Our Realities presents a hierarchical model of protection from STDs and HIV that is a modified version of the New York State hierarchical approach.²⁶ In the hierarchy, a male or female condom with a nonoxynol-9 microbicide confers the most protection, a male or female condom alone is second best, and finally, a nonoxynol-9 spermicide alone offers the least amount of protection a woman should use.

The presentation of a variety of methods raises the question of the safety of

each method. Barrier methods such as the male and female condoms are considered effective tools for prevention of STDs and HIV. In regard to microbicides, the data—and the Food and Drug Administration²⁷—have long supported a role for microbicides in STD prevention²⁸, and some studies have suggested that nonoxynol-9 is also effective against HIV^{29,30}, but there has been concern about biological safety. A study by Kriess et al.³¹ raised questions as to whether overuse of nonoxynol-9 might have a facilitative effect on HIV transmission. Later studies provided conflicting evidence in the role of nonoxynol-9 in HIV prevention, but suggested that it could be useful in STD prevention, and that it might be safe in lower doses.^{32,33} Since the time of the development and pilot testing of this curriculum, the preliminary results of a Joint United Nations Programme on HIV/AIDS (UNAIDS) study of nonoxynol-9 and condom use at three African sites have shown that the microbicide is not protective in vivo against HIV transmission and may be facilitative in a high-risk population.³⁴

The model of including microbicides among the HIV prevention options for women, however, is valuable. Presently, more than two dozen candidates for microbicides are in development. Although the message in subsequent administration of the curriculum will not emphasize nonoxynol-9, we are hopeful that acid-buffering agents, mucosal surface-attachment inhibitors, monoclonal antibodies, or compounds that prevent the fusion of HIV with vaginal mucosa cells currently under investigation will yield successful products for women in the near future.³⁵

Another safety concern that has been suggested, but only recently tested, regarding presentation of multiple preventive options has been that women offered an array of choices may opt for methods of HIV prevention that are less well established, and they may abandon options like the male condom.³⁶ For example, when presented with information about microbicide use, women might opt to use this less-proven method in lieu of a male condom.³⁷ This has been termed “migration from the male condom.” However, empirical evidence suggests otherwise, at least among populations other than commercial sex workers.^{36,38} In an empirical study in a large sexually transmitted infection (STI) clinic in Philadelphia, Pennsylvania, Latka and colleagues³⁸ have shown that fears of migration from the male condom may be unfounded.

Rationale and Theory

The theoretical foundation of the curriculum derives from social cognitive theory, with an emphasis on self-efficacy and skills training. This foundation was derived from two primary sources: (1) the psychiatric rehabilitation literature and (2) two components of behavioral change described by Bandura³⁹, an informational component (i.e., educating women about HIV transmission and their risk) and development of self protective skills and enhancement of self-efficacy through modeling and role play. Through group discussions, re-enactment of real-life situations, and repetition of safety messages, the women simultaneously instruct and learn from each other.

The group facilitators play the roles of a talk show host, Daphne Darling, and the panel expert, Professor Private Parts, throughout the curriculum. The women are invited to assume roles of their favorite celebrities in panel discussions about safe sexual practices, and others in the group play the participating talk show audience. Each session emphasizes the importance of advocating for safer sex by having the women rehearse and role-play teaching their friends and daughters the message of safe sex. Female condom and male condom use are demonstrated using pelvic

models and penile models. Women practice insertion of the female condoms on these models while familiarizing themselves with female anatomy.

Women are taught how to confront barriers to self-protection. Facilitators and group participants discuss the advantages and disadvantages of each contraceptive/HIV prevention method. The women list potential problems and generate potential solutions. As specific methods of protection are introduced, the women are guided through the procedures for proper use and are provided opportunities for practice and mastery of skills.

Content of the Curriculum

The intervention is a 10-session curriculum. At the time of the curriculum development, we experimented with delivery of the intervention in short time periods, believing that this schedule would be most feasible for use in inpatient and other clinical settings. To that end, the curriculum was administered over the course of 5 days. Two 50-minute sessions of *Ourselves, Our Bodies, Our Realities* were conducted each day, separated by a brief snack. Our subsequent experience with this curriculum does indicate that a weekly schedule may be more beneficial. Exner and colleagues⁴⁰ noted that there appears to be a “minimal dosage threshold i.e., number of sessions, necessary to evoke sexual risk reduction.” Effective interventions in their review lasted five or more sessions.

Sessions 1 and 2 introduce the women to the need to protect themselves from HIV and to the idea that methods of protection in addition to the male condom are available. Exercises in these sessions help women to assess their HIV risk, develop greater ease in discussing sexual issues, and review female sexual anatomy using a pelvic model and illustrations of external and internal genitalia.

In Session 1, through self-tests, visualization, and role play, women assess their personal risk for HIV infection and the risk of their partners. Exercises in Session 2 focus on sexual anatomy—learning to identify the uterus, ovaries, cervix, vagina—as well as linking the anatomy to its role in sexual intercourse. In one exercise, women divide into teams to see who can name the various parts of a woman’s anatomy and tell how these body parts may play a role in a range of romantic scenarios.

In the third session, the women learn the consequences of infection. An exercise in this session provides the women with a note card that describes a particular sexual behavior (e.g., hugging, kissing, or vaginal intercourse). They must determine what kinds of sexual behaviors are riskiest and rank themselves from highest risk to lowest risk according to the cards they hold.

Session 4 reviews traditional messages of male condom use, and the women identify pros and cons of this approach. Contraceptive methods that do not confer protection against HIV and STDs are distinguished from barrier methods of protection. The discomfort that some women have with using methods requiring vaginal insertion is also discussed. These concepts are reviewed in role-playing activities. Methods such as dental dams are also discussed, and the women are provided with instructions for making dental dams from latex gloves.

In the fifth session, the women establish criteria for what an effective female-initiated method should do. They are provided with samples of condoms and microbicide and are encouraged to familiarize themselves with these methods. A nonoxonyl-9 microbicide is introduced, and the women assess the advantages and potential disadvantages of this method.

The sixth session focuses on the female condom, and the participants discuss

why this is a viable alternative. The seventh session permits practice in insertion of the female condom on pelvic models. The women are encouraged to practice inserting the female condom, privately, between sessions. Session 8 reviews use of the male condom. Facilitators demonstrate the proper technique for using a male condom, and the women practice on models. Session 9 reinforces advantages of the female-initiated methods and discusses problems that may arise with either method. The intervention concludes in the 10th session with reinforcing messages about protecting oneself from HIV infection and a graduation ceremony.

In each session, the participants have opportunities for role play. Facilitators balance encouragement of participation with sensitivity to the varying levels of psychiatric symptomatology among the women in the group sessions. Those who choose to play celebrities on the show might discuss the risks of their glamorous lifestyles and stardom. Other women may be asked to role-play teaching a friend to use a female or male condom, a woman introducing her boyfriend to female-initiated methods, or a mother telling her daughter about options for HIV prevention.

Each session includes rehearsal of educating friends and daughters about the topics learned and concludes with an assignment that focuses on spreading the messages of safe sex. For example, at the end of each intervention session, women are instructed to teach one message they learned to a friend or relative outside the group. At the beginning of the following session, women report their experiences of teaching someone about safe sex.

By integrating these themes into an interactive intervention with a sound theoretical base, we have produced an engaging curriculum that provides opportunities for learning and self-expression. The focus on skills building, the use of multiple modes of presentation (oral, visual, tactile), the use of repetition and rehearsal, and the use of the talk show as an entertaining way to engage the participants enables this intervention to meet the needs of women who may be impaired cognitively.

TESTING THE INTERVENTION

There were 35 women who participated in a randomized trial to assess norms and attitudes toward female-initiated methods, as well as sexual risk behavior at baseline and 6 weeks after exposure to the intervention *Ourselves, Our Bodies, Our Realities* or a control intervention.

Methods

Participants Participants were female inpatients recruited from a large state psychiatric hospital north of New York City. The majority of women receiving treatment in this facility are diagnosed with chronic psychotic disorders such as schizophrenia, schizoaffective disorder, and bipolar disorder. All women in the psychiatric hospital referred by the unit chief were invited to meet in small groups on their wards with at least two members of the research team to discuss the purpose and nature of the study. Women who participated gave informed consent after being assessed for capacity.

Interviewers and Facilitators Research team interviewers were required to attend a sexual desensitization and interviewer training course sponsored by the HIV Center for Clinical and Behavioral Research at the New York State Psychiatric Institute.

Interviewers subsequently were trained to administer the assessment instruments. This training included audiotaped rehearsal of interviewing nonpatient volunteers with supervision by the HIV Center trainer. On completion of the course, participants received certification as sex research interviewers. Interviewers were blind to the treatment condition.

Intervention The 35 women were assigned randomly to one of two groups (N = 18 experimental group, N = 17 control group). Participants assigned to the experimental group participated in 10 sessions of *Ourselves, Our Bodies, Our Realities* conducted over the course of 5 days. Experimental groups were cofacilitated by one member of our research team and one clinical staff member of the psychiatric hospital that had been trained previously by our team.

Control Sessions The control group met for 1 day in two 1-hour sessions of an educational presentation on HIV risk reduction; the sessions were separated by a snack. The control group sessions were facilitated by a member of our research team. In these sessions, prevention of sexually transmitted diseases and HIV, contraceptive options, and female-initiated HIV prevention methods were discussed.

Instruments

Interviews Female members of our research team conducted interviews at three time points. The first interview was conducted immediately following the recruitment meeting, when possible, or within the next week. The second interview was conducted immediately following the final experimental or control group session. The third interview was conducted 6 weeks following the final group sessions. All interviews were conducted on the participants' wards, and women were paid in cash at the conclusion of each interview.

Demographics Participants were asked to report their age, ethnic group status, marital status, number of children, education, employment status, and history of homelessness, time in jail, psychiatric hospitalization, and drug treatment, among other variables.

Determinants of Behavior Determinants of sexual risk behavior were assessed using the Subjective Norms of Woman-Controlled Methods (SNOW-CM) (Geller PA. Use of female-controlled HIV prevention methods among women with mental illness: psychometric properties of a new instrument. Forthcoming.). The instrument includes a section for each of the three methods targeted by *Ourselves, Our Bodies, Our Realities: Advantage-24* (a nonoxynol-9 microbicide), the female condom, and the male condom. Each section assesses information regarding a participant's knowledge and experience with the method, attitude, subjective norms, perceived self-efficacy, and behavioral intentions. For example, the assessment of attitudes is comprised of two items that address the female condom, five items about Advantage 24, and one item on the male condom. For most questions, participants are asked to indicate how much they agree with a particular statement on a scale from 1 (strongly disagree) to 4 (strongly agree).

Sexual Behavior The Sexual Risk Behavior Assessment Schedule (SERBAS) adapted for use with women was used to assess sexual behavior in the past 3

months that may be related to HIV transmission, as well as any history of forced sexual activity.⁴¹

Results

The sample included 35 women who completed baseline/preintervention interviews. Of the 18 women randomly assigned to the experimental group, 14 completed the experimental sessions, 13 completed the postintervention interviews, and 13 completed the 6-week follow-up interview. Of the 17 women randomly assigned to the control group, 16 participated in the session, 10 completed the postintervention assessments, and 12 completed the 6-week follow-up interview.

Demographics The average age of the participants was 43.8 years ($SD = 10.1$); 51% were European-American, 31% were African-American, 11% were Hispanic/Latina, and 6% classified themselves as belonging to another ethnic group. The majority of the sample (60%) had never been married. Of the participants, 63% reported that they had at least one child. In terms of education, 57% of the sample held at least a high school diploma, with 29% also completing some college or trade school. Almost 43% of the sample, however, had not completed high school, with 11% reporting less than an eighth grade education. The majority of the participants (83%) were unemployed, while a portion (17%) were employed in some capacity through the hospital facility. There were 40% who had been homeless at some time in their lives, and 31.4% had been in jail at least one time. At least 83% of the participants reported that they had been admitted to a hospital for psychiatric or emotional problems at least once prior to the current occasion, and 20% reported a history of drug treatment. There were no notable differences between the experimental and control groups with respect to these factors.

Sexual Behavior Responses on the SERBAS revealed very limited sexual behavior at baseline, which included the 3 months prior to intervention. This is likely due to the fact that these women resided on locked hospital wards with limited access to situations amenable to sexual encounters. Responses on the SERBAS did reveal that 23% of the 35 participants interviewed at baseline reported a history of forced sexual activity at some time in their lives.

Subjective Norms and Attitudes Participants in the treatment group reported more positive feelings toward use of the female condom across all dimensions (attitudes, norms, self-efficacy, behavioral intentions) immediately postintervention, though this did not achieve significance. There were no notable differences between treatment and control groups with respect to the male condom and Advantage 24.

At the 6-week follow-up, trends were consistent across each dimension (attitudes, norms, self-efficacy, behavioral intentions) unless otherwise indicated in the text. The participants in the treatment group reported a significantly more positive attitude toward the use of female condoms ($t = -2.12$, $P < .05$) (Table). For male condoms, there was a trend in the same direction ($t = -.73$, $P < .1$). With respect to Advantage 24, the results did not follow the trend ($t = -.53$, n.s.).

Comments

The results suggest that women in the treatment group had more positive attitudes toward the female condom compared to the control group both postintervention (trend) and at the 6-week follow-up (statistically significant). Attitudes toward the

TABLE. Means (and standard deviations) for behavioral determinants for each method according to treatment group at 6-week follow-up^{*,†,‡}

	Treatment (N = 13)	Control (N = 12)
Advantage-24		
Attitude	12.27 (5.44)	13.56 (5.39)
Perceived efficacy	5.80 (1.75)	4.22 (2.22)
Subjective norm	5.70 (3.62)	5.89 (1.62)
Intentions to use	2.70 (1.16)	2.78 (1.20)
Female condom		
Attitude§	5.75 (1.82)	4.18 (1.72)
Perceived efficacy	2.17 (1.19)	2.00 (1.13)
Subjective norm	7.42 (3.20)	6.27 (3.17)
Intentions to use	2.75 (1.29)	2.00 (1.18)
Male condom		
Attitude	3.20 (1.03)	2.83 (1.27)
Subjective norm	4.40 (1.90)	3.83 (2.21)
Intentions to use	3.25 (1.14)	2.55 (1.37)

*The ranges for the behavioral determinant scales are as follows: Advantage-24 (attitudes = 5–20, perceived efficacy = 2–8, subjective norms = 3–12, intentions = 1–4); female condom (attitudes = 2–8, perceived efficacy = 1–4, subjective norms = 3–12, intentions = 1–4); male condom (attitudes = 1–4, subjective norms = 2–8, intentions = 1–4).

†A higher mean indicates a more favorable/positive attitude and the like.

‡Not every respondent answered every question; for this summary, “don’t know” responses were considered “missing.”

§The *t*-test revealed a significant difference between treatment groups for the 6-week follow-up for attitude toward the female condom ($P < .05$).

male condom remained positive at the 6-week follow-up despite the focus of the intervention on female-initiated methods. The results of the pilot study suggest that women with SMI presented with two female-initiated methods in addition to the male condom continue to have positive attitudes and intentions to use the male condom at the 6-week follow-up. This is consistent with studies that suggest that female-initiated methods presented as an alternative to the male condom contribute to greater safe sexual behavior, reducing the proportion of unprotected sex acts.^{36,38,42}

It is possible that we were not able to show positive attitude change for the microbicide Advantage-24 because it is not presented in the intervention as a definitive preventive agent for HIV. The lack of definitive studies at the time of the pilot trial on the efficacy of nonoxynol-9 products as virucidal agents *in vivo* prevented us from presenting this microbicide as anything other than an adjunct to a female or male condom. Research on microbicides for HIV prevention has not yet identified a product that can be presented as a primary method of prevention *in vivo*. Interventions with a broader range of objectives than HIV prevention alone (i.e., pregnancy prevention) may be better able to demonstrate a safe and effective use for these products.

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