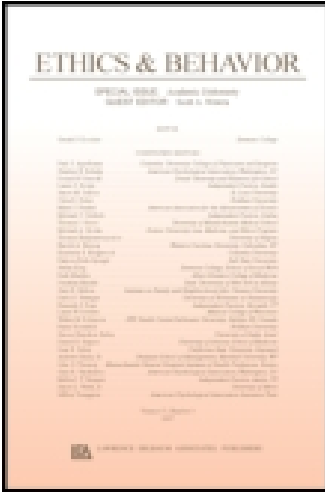


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On: 26 June 2015, At: 11:58

Publisher: Routledge

Informa Ltd Registered in England and Wales Registered Number: 1072954 Registered office: Mortimer House, 37-41 Mortimer Street, London W1T 3JH, UK



Ethics & Behavior

Publication details, including instructions for authors and subscription information:

<http://www.tandfonline.com/loi/heb20>

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Accepted author version posted online: 21 Aug 2014.



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To cite this article: Charmaine Thokoane (2015) Ethical Challenges for Piloting Sexual Health Programs for Youth in Hammanskraal, South Africa: Bridging the Gap Between Rights and Services, *Ethics & Behavior*, 25:2, 169-179, DOI: [10.1080/10508422.2014.954117](https://doi.org/10.1080/10508422.2014.954117)

To link to this article: <http://dx.doi.org/10.1080/10508422.2014.954117>

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Ethical Challenges for Piloting Sexual Health Programs for Youth in Hammanskraal, South Africa: Bridging the Gap Between Rights and Services

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This article describes challenges of conducting an HIV prevention program involving 40 male and female participants ages 12–18 in Hammanskraal, South Africa, aimed at increasing awareness and knowledge of laws protecting children’s sexual health rights and access to services through a culturally based “study circle” format. Challenges highlighted by the project included Institutional Review Board approval of youth consent procedures, cooperation and coordination with local policymakers, the need to modify presentation materials to youths’ comprehension levels, availability of youth-based sexual health service providers, and cultural ambiguity over parental involvement in youth health care decisions and laws pertaining to sexual relationships among minors.

Keywords: ethics, youth, sexual health, HIV/AIDS, research, rights, services, South Africa

Young people represent the majority of the population in South Africa, and they are also the most affected by the HIV epidemic (Shisana et al., 2014). Sexual and reproductive health programs targeted at young people provide a window of opportunity to address risky sexual practices that contribute to HIV infection at a stage when some youth begin engaging in sexual practices. In recent years South Africa has been active in developing laws to protect the sexual health and rights of citizens through community-centered interventions and consultations. The AIDS and Human Rights Research Unit, a collaboration between the Centre for the Study of AIDS and the Centre for Human Rights, has been running a community-based project from the Paralegal Advice Centre in Hammanskraal, a small rural town north of Pretoria, since 2004. The Unit promotes and supports research on issues arising from the intersection of HIV and AIDS, on one hand, and human rights, on the other hand. The Unit has reviewed legislation affecting children in the Southern African Development Community (SADC) region, is updating a review of human rights frameworks in selected countries in the SADC region for the United Nations Development Program, assisted the Gauteng Provincial Legislature to mainstream HIV and AIDS into its oversight function and has run research and advocacy projects on rights in four SADC countries.

The broad objectives of the community-based projects responding to South Africa’s sexual health rights initiatives were to reduce HIV- and AIDS-related stigma and discrimination through

training programs and awareness campaigns, as well as provide much needed paralegal services on cases related to human rights violations through mediation and referrals (Chetty, 2007). Even though the project had success, it mostly served the needs of the adults in the community. The Centre for the Study of AIDS and the Paralegal Advice Centre in Hammanskraal held a series of discussions with young people, project beneficiaries, governmental and nongovernmental partner organizations, staff, and volunteers of the project to identify ways in which a youth-based program could build on recommendations from the South African National Department of Health's (2011) report on *Sexual and Reproductive Health and Rights: Fulfilling our Commitments (2011-2021)*. The vision of the National Department of Health's report is for "all people in South Africa to be able to protect, promote, enjoy and express their sexual and reproductive health rights" (South African National Department of Health, 2011, p. ii). The conclusion from the discussions was that a rights-based peer intervention program needed to be piloted to better understand young people's challenges with regard to sexual and reproductive health rights. This pilot program would then be used to source for funding to improve the program and increase its reach in the community.

Community interventions need to be a collaborative effort between various stakeholders to achieve some success. Involving stakeholders in the planning phase of an intervention program is critical to ensure that the intervention is sensitive to the lived realities and risks faced by the intended population. This must include a comprehensive assessment of the behavioral and environmental influences on youth HIV risk and available community resources (Schaalma & Kaaya, 2008). Working with young people in their communities requires a population approach that takes into account the needs and concerns, not only of the young people but also of their parents/guardians. Enhancing health opportunities for engagement in government-sponsored programs also requires understanding and responding to the concerns of health care providers, ethics review board members, and government officials. This article describes lessons learned from efforts to increase youth engagement in sexual health programs in Hammanskraal, South Africa.

PROGRAM OVERVIEW

The aim of the pilot program was to increase awareness and knowledge of Sexual and Reproductive Health Rights and services among young people through focus group discussions and participatory peer group educational dialogues called study circles. In South Africa, peer education is considered an effective tool used in combination with other structural interventions to strengthen HIV prevention efforts for young people. As described by Bastien, Flisher, Mathews, and Klepp (2008) "peer education has the potential to effectively tailor prevention messages to suite the context and needs of the intended audience in a language they can relate to and generate community support and mobilization" (p. 186).

Forty youths were recruited from two partner organizations and divided into four groups according to their sex and age (male 12–14 years, female 12–14 years, male 15–18 years, female 15–18 years). Each group was assigned to a staff member from the Centre for the Study of AIDS, who was of the same sex as the group of participants. The staff members were trained HIV counselors and HIV peer educators. The first phase involved small-group discussions designed to gather information on youths' (a) understanding of HIV acquisition and transmission; (b) awareness of their rights under the Department of Health's Human Rights, *Sexual and Reproductive Health and Rights* Report; (c) knowledge about and challenges to accessing sexual health services

available to young people in the community. In the second phase the study circles workshop was then used as a platform and safe environment for the young people to discuss sensitive topics such as sex, relationships, and health rights and share ideas about how to overcome the challenges they face. The young people were then to meet monthly at their respective organizations after completing the workshop in order to initiate discussions with the rest of the young people from their organizations and immediate community. The focus group discussions and study circles were all conducted in the local language by Centre for the Study of AIDS staff members. The informed consent process included obtaining permission to record all discussions with appropriate guarantees of anonymity and confidentiality. The study was approved by the University of Pretoria's Faculty of Humanities Ethics Committee.

Study Circles

A study circle is a participatory and dynamic process that is based on the experience and contribution of the participants, called "members." It is a flexible learning opportunity and is completely removed from the formal educational system. The study circle method uses a small group of about six to 12 members. Such a group works together for a certain period on one or more problems or subjects under the guidance of a group leader/facilitator, who has been identified and accepted by the group members. The main difference between the study circle method and more conventional training methods is that teaching is not carried out in a "top-down" manner—from trainer to trainees—but rather learning depends on interaction among participants. The work within study circles is built around the participants' search for knowledge according to their own needs, issues, and interests. The members regularly meet and work according to a study plan that they often develop themselves. They generally meet once a week for about 2 to 3 hr, six to eight times in total depending on the topic(s).

The purpose of a study circle is to build on the knowledge of members; make them more aware about the need for change, and what changes are required; and actively involve members in bringing about change in their own communities. This is accomplished through a process in which participants in the study circle gain knowledge by sharing and exchanging ideas and experiences, undertaking research, reading, and raising awareness about issues in the community. Three components are essential to the successful implementation of a study circle: (a) experience and skills of the participants; (b) a study plan or study materials that have been produced specifically for the study circle, dealing with the issues that are important for the participants; and (c) a leader/facilitator who guides the work of the study circle. Although each study circle agrees to its own rules, participants of a study circle meet one or more times during a certain period (usually a week) and have "homework" between meetings to test ideas, to find necessary information.

A critical component of study circles are the principles of freedom and democracy. Participation is introduced as free and voluntary; individuals are not "pushed" to participate in a study circle. Usually there is a free, relaxing atmosphere instead of a very structured lesson typical of school-based teaching. Everyone has a right to express his or her opinion and be heard.

Ethical Challenges to Program Implementation

Exploration of adolescent sexual and reproductive health concerns is complex due to its close link to people's notions of morality. These notions are dependent in part upon South African

Law, inconsistencies among various acts under the law, and its interpretation by policymakers and health providers. It is also influenced by differences in community morals, both between and within local communities (Lie, 2008).

Laws Involving Informed Consent

The South African law considers children younger than 18 years old legal minors, with limited capacity to act independently without the assistance of an adult (Strode, Slack, & Essack, 2010). However laws have also been passed that allow children to make independent decisions about their sexual and reproductive health. According to the Children's Act 38 of 2005, children from the age of 12 may consent independently to medical treatment, HIV testing, contraceptives, and contraceptive advice if they are of sufficient maturity and have the mental capacity to understand the benefits, risks, and social and other implications involved (Parliament of South Africa, 2005). However, the Sexual Offences Act 32 of 2007 states that it is a criminal offence to have sexual intercourse if one is younger than age 16, even if it is consensual (Parliament of South Africa, 2007). If a child is found to be having sex, he or she should be reported to the police so that they can investigate the possibility of statutory rape. Furthermore, for a child younger than 18 to participate in any health research, consent from the parent/guardian is required; however, the person may consent independently to some of the processes in the research. For example, a 12-year-old would need consent to participate in HIV research but may consent independently to an HIV test if provided within a research context (Strode et al., 2010).

The first challenge to program implementation involved whether to classify the pilot program as treatment or research. This had particular implications for whether guardian permission would be required or waived for children younger than 18. Given the sensitive topics that were to be discussed, the Faculty of Humanities Research Ethics Committee, University of Pretoria, South Africa, ultimately decided that classification as research would provide more stringent protection of minors. This was supported by the fact that the effectiveness of the pilot intervention was unknown and designed to be assessed. Informed consent was thus obtained for the participants who were 18 years old, and child assent and permission from a parent or guardian was obtained for participants younger than 18.

We were pleased and surprised that 40 parents/guardians gave permission for their child's participation. For some parents of the youngest participants, permission was not as readily given based on concerns about the sexually sensitive nature of the issues that would be discussed and discomfort in the children raising questions at home that the parents did not feel they were able to discuss.

Designing Age-Appropriate Instructional Techniques

Educational material was developed for the program and was used during the first workshop. Using the study circle model, the material required active participation from the young people through group work and interaction with the facilitator. It became clear early in the workshop that the young people were finding it difficult to relate to the content and make sense of it. For example, when the young people were asked how HIV is transmitted, they were able to name the different modes of transmission (unprotected sex, mother to child, infected blood). However, when the process of transmission (infection occurs through access to bloodstream of uninfected

individual from an infected individual) was explained, they were unable to connect the modes of transmission with the process of transmission. The training material had to be adapted into active demonstrations and role-plays involving active participation of the youths.

To improve learning about transmission, the facilitators first explained to the participants that if someone is infected with HIV, then all their bodily fluids contain the virus, but some bodily fluids contain more of the virus than other. The bodily fluids containing more of the virus are blood, breast milk, vaginal fluids, and semen. The bodily fluids containing less of the virus are sweat, tears, saliva, mucus, and urine. The facilitators then explained that smaller quantities are required to be infected with bodily fluids with more of the virus compared to bodily fluids containing less of the virus. The facilitators demonstrated this by taking a tablespoon in one hand (this represented blood) and a 5-L bucket in the other hand (which represented saliva) to explain that the infection from a tablespoon of blood would be equivalent to infection from a bucket of saliva (this example was purely for explanation purposes and not intended as true comparison between infection from a teaspoon of blood and a bucket of saliva). The participants then acted out different scenes, using the props, to demonstrate scenarios in which infection might take place, for example, open cuts and wounds where infected blood might enter.

Parent–Child Communication

The most compelling role-play emerged when both facilitators and participants acted out a scenario between parents and their children regarding dating and sex. The participants assumed the role of parents and facilitators the role of children. The participants wanted the facilitators to experience the difficulty they face when discussing sex and relationships with their parents. The participants felt that the language, tone, and sometime blatant dismissal of the topic by parents and guardians made it near impossible for them to have open discussions. In one of the scenes a participant (in the role of a parent) confronted their child (played by facilitator) as the child walked into the house, accusing her of inappropriate behavior because a neighbor had seen her standing with a boy at the local market. The parent did not give the child any opportunity to explain the situation; instead the child was told not to be standing on street corners with boys because it meant you are loose/easy. The child was then told to go to her room. After the scene the participants asked the facilitators what they would do in that situation, because saying something to a parent could result in harsher punishment. The facilitators gave some suggestions such as waiting for the parent to cool off first and bringing the topic up at a later stage. It was during these role-plays that participants suggested that parents also need to have workshops so that they can learn to talk to their children about sex and relationships. The role-playing scenarios thus resulted in not only learning for the youth but increased program leaders' awareness of the need for information on parent–child communication that could improve the future implementation of these programs.

Confidence Building

It also became clear to the facilitators that confidence and self-esteem was a major issue among the young people, especially the young women. The training material thus had to be adapted to include sessions on self-awareness, identity, and confidence. For example, during one self-awareness activity the participants were asked to make a list of qualities they liked about

themselves, they were then asked to share with the rest of the group if they felt comfortable. Most of the participants were not comfortable sharing because they felt others would laugh at them. The facilitators then shared a list of qualities they liked about themselves to help put the participants at ease. The participants were then challenged to share at least one positive quality about themselves, and most of them shared. After the exercise the facilitators asked participants to say the qualities to themselves out loud in their own private space until they feel comfortable enough to share the entire list with someone else.

Time Constraints

Not surprisingly, implementation of the program took longer than expected due to delays in ethics committee review and approval, adaptations to the workshop material, and low attendance of the workshops from the young people due to family and school responsibilities. The workshop was intended to take place over a period of 3 months (January–March 2013) during the weekends, but it ended up occurring later in 2013.

DESIGNING FUTURE YOUTH SEXUAL HEALTH RIGHTS AND SERVICES PROGRAMS: WHAT WE LEARNED

In this section we provide further insight into the lessons we learned from discussions with youth. Although there were gender differences in some of the themes that emerged, in the majority of cases, knowledge and attitudes were relatively similar across age groups. The section begins with a description of youths knowledge and misconceptions regarding HIV/AIDS and their awareness of and attitudes toward sexual health services. The article then turns to their understanding of their legal rights and issues regarding parental/guardian permission for obtaining sexual health services. It concludes with what was learned about youths' attitudes toward sexual relationships.

HIV/AIDS Knowledge and Awareness of Youth Sexual Health Services

The focus group discussions and study circle discussions indicated that young people are curious about their sexual and reproductive health. They want information that helps them understand their own bodies and the changes it goes through; they also want to understand the bodies of the opposite sex. This correlates strongly with the findings from another study on adolescent sexual and reproductive health in South African townships (Vujovic, Struthers, Meyersfeld, Dlamini & Mabizela, 2014).

HIV Knowledge

As noted previously, although the young people had basic awareness and knowledge about HIV transmission, treatment, and prevention, youth in Hammanskraal are exposed to information about HIV/AIDS through community campaigns, the Internet, and government campaigns on television, billboards, and newspapers. Some schools invite volunteers and staff from the clinics to give health talks. Yet, as previously described, although youth are generally aware of HIV, they remain somewhat unclear about the mechanisms of transmission. The study circles provided an

opportunity for participants to fully understand how HIV is transmitted, what treatment does to the body, and how prevention is of vital importance. As previously stated, the demonstrations and role-plays helped participants fully grasp the concepts in HIV transmission. Through the study circle discussions, they were better able to connect their basic knowledge of HIV (modes of transmission) with the understanding of how HIV is actually transmitted and multiplies in the body. This helped the participants make better sense of the information they were exposed to through media campaigns and health talks at schools

Although the introduction of role-playing in the study circles helped to increase awareness, the focus groups indicated a need to better address the efficacy of current HIV treatments. For example, many youths understood that being HIV positive does not mean the end of life. As one female participant indicated, “HIV doesn’t kill if you take your medication.” Another male participant said, “I know you don’t die from HIV because you have options, take medicines, eat fruit, exercise and live a healthy lifestyle.” Some, like this youth, were more fatalistic: “It’s just an illness; we’re all going to die. . . . As long as I enjoy my life, people are always dying, and others are always being born.” In response to these comments, facilitators introduced a session in which participants were asked to think of their future—who they want to be and what they want to do with their lives. The facilitators then asked the participants how HIV would affect their dreams and futures. This helped the youth to realize how important it is for them to prevent HIV infection. This was a significant change from the responses of the participants during the focus group discussions when asked how they felt about HIV.

Concerns about HIV stigma were frequently mentioned; derogatory terms are sometimes used to refer to people who are HIV positive, for example, “He’s on the 3 o’clock bus” (the 3 is for the three-letter HIV acronym). A number of youths mentioned that older people in the community say that HIV will kill you, but they don’t believe it because they know people who are positive. They also noted that although some adults talk about their HIV status, many don’t. These comments suggested that more efforts need to be made to reduce HIV stigma among the adult population and to consider including adults who are openly living with HIV to study circle programs in the future.

Awareness of Sexual Health Services

Participants from all the groups were aware of the limited health services for youth in their community. As one male participant in the 12- to 14-year group stated, “I only know of three clinics where you can go if you are HIV positive.” However, whether they would actually utilize these clinics is most concerning because most expressed negative views regarding how they as youth would be treated at these sites. They were concerned that staff would question, “Why is this child asking so much about HIV and condoms? Is he having sex or is he HIV positive?” Some participants indicated that you need to be brave to go and ask for sexual health information at clinics and school because “you feel like people are going to talk about you,” “you don’t know if they are going to talk about your HIV status,” or “they ask you, ‘why are you having sex?’” The female respondents appeared more comfortable obtaining information from their local organizations because there are people in the organizations who are HIV positive and are more understanding. However, they also indicated that they were not always comfortable going to the clinics because they are afraid of the attitude from healthcare workers and they fear a lack of confidentiality. As one respondent said, “Before you know it people in your street will be knowing you went to the clinic and judging you.”

The issue of confidentiality was raised frequently in the study circles. Through role-playing exercises, it became clear that youths believed that in most cases their parents would find out if they went alone to a clinic. For example, in one of the role-plays, one of the participants (acting as a parent) told the other participant (acting as the child), “What were you doing at the clinic? Did you think I wouldn’t know? I know people who go to the clinic.” The participants reiterated that they did not want to deal with healthcare professionals who were going to make them feel bad.

Attitudes Toward Youth Sexual Rights and Guardian Oversight

To address the lack of knowledge on sexual and reproductive health rights identified in the focus group discussions, the facilitators started the topic off with general rights and responsibilities that the participants were aware of, such as the right to education, food, shelter, and health. The facilitators then briefly introduced the Children’s Act as a law designed to protect children in South Africa and to assist in making sexual health services more legally accessible to them. The participants were asked how they would feel if they could make sensitive decisions regarding their reproductive health without the consent of their parents. Some of the participants indicated that they would want their parents to be involved because their parents have more knowledge than they do; others indicated that waiving parental permission would make young people more reckless. Some study circle youth endorsed the right to independent consent for sexual health services because they are not able to discuss such matters with their parents. The sense facilitators got from the participants that even though there were laws that gave young people some independence regarding their sexual health, many youths do want to discuss issues on sex and relationships with their parents/guardians. We learned that more sessions need to be held with the young people on their sexual and reproductive health and rights, and the responsibility that comes with the rights.

South Africa’s history of liberation from apartheid ensured that schooling introduced students to the general concept of human rights. As one participant in the male 15 to 18 year group stated, “I have the right to education, food, safety, . . . right to say no to abuse.” By contrast, it was evident from the focus group discussions that the young people were not aware of laws in the Children’s Act and Sexual Offenses Act and consequently were uninformed with respect to their reproductive health rights. For example, the female participants in the 15–18 year group found it difficult to answer a question about their sexual health rights but did indicate they thought using contraceptives should be a decision they make without consent of a parent. In contrast, the female participants in the 12–14 year old group indicated that although they should make some health decisions independently, they needed to be taken care of by their parents because they are not able to support themselves. Male participants were more likely to voice support for youth sexual rights. When we asked a general sexual health rights question, male participants were likely to respond, “I have a right to be healthy.” Answers became more specific when questions were more direct. For example, when we asked, “If you decide to get circumcised, do you think that should be a right, or should your parents decide?” The response was, “I should have the right to decide for myself.” The young male participants also felt that men had a right in the reproductive health of women in relation to unplanned pregnancies. They strongly believed that the decision to terminate pregnancy should be decided by both partners involved. From these comments we realized that in the future the design of the youths sexual health rights and services programs will need to incorporate more specific questions and examples of youths’ legal rights as well as

include the socially sensitive and ethically critical issue of women's reproductive rights within the context of culturally entrenched gender roles and values.

Sexual Relationships

Respondents expressed the belief that the older generation valued relationships more than young people today. As evidenced in the following comments from male participants, some felt that the lasting relationships of the older generation were outdated: "Getting married now days is useless because the love doesn't last"; "I can take my friend's girlfriend anytime I want." The general sense was that youths did not need to take relationships too seriously because they were still young and needed to experiment. The female respondents mentioned that they found it difficult to raise issues they are facing with their partners in relationships. The female participants said they need advice on relationships from parents, especially their mother, but felt that their parents are not open to talking about relationships and sex. One issue that arose was the feeling among some girls that they needed to please their male partners. Female participants also noted that girls were treated differently from boys because "girls can fall pregnant," and that is a "burden to the parents." The facilitators felt that in the future, study circles should include more attention to discuss relationships as well as power and abuse in relationships.

Conclusion

The pilot project demonstrated that young people living in small rural towns of South Africa are in need of and responsive to age and culturally appropriate programs designed to enhance their knowledge about HIV/AIDS and their sexual reproductive rights and to discuss barriers to obtaining youth HIV services. Although the pilot project encountered a number of challenges, with age, gender, and educational adaptations, the culturally based study circle format is a promising approach toward reaching this underserved population. The focus group and study circle discussions highlight the fact that although the educational system is providing youth with a strong foundation in South Africa's human rights achievements, additional outreach is needed to introduce youth to their legal rights to sexual health services. The pilot also highlights the need to go beyond youths surface knowledge of HIV/AIDS transmission and acquisition to tease out and correct underlying misconceptions.

Establishing a trusting relationship with romantic partners is a critical component toward achieving youth sexual health. In that regard, more attention needs to be paid to the rather cavalier attitude that youth, at least in this pilot project, expressed regarding the transient nature of such relationships as well as differences in gender sexual behavior role expectations. Discomfort with discussing sexual and relationship issues with parents creates a critical gap in the informational and supportive resources that parents can provide. Thus, in the future, programs will need to incorporate information sessions with parents/guardians to guide them on how to talk about sexual and reproductive health issues with their children in a positive manner. This will require initial focus group discussions with parents to uncover their own sexual health informational needs and cultural attitudes toward health rights for youths in general. Sexual health rights specifically need to be appropriately integrated into a successful program.

As in other settings, HIV stigma is a significant barrier to accessing sexual health services for this population. Youths' comments suggest that they observe such attitudes among the adults in their lives, including healthcare providers. The issues raised by the young people regarding the dismissive and judgmental attitudes of healthcare workers are not new in South Africa. Sensitivity sessions with healthcare workers are an ongoing process facilitated by the Provincial Health Department and civil society organizations. The importance of creating youth-friendly services needs to be continually reiterated. Future programs will aim to familiarize providers with not only youth sexual health rights but age-appropriate communication techniques and services.

The challenges that were faced in this pilot program are both reflective of community-based programs in general and the challenges of enhancing youth sexual health rights and services in a fast-changing legal environment. Overall, the program has received positive reviews from the local organizations and the young people. On that basis, funding is being sourced from the local municipality to improve the program and increase its reach. Across study circles, participants expressed a desire for more opportunities to discuss sexual issues, relationships, personal challenges, and future hopes. The commitment of the Centre for the Study of AIDS staff and Hammanskraal community to this initiative will help ensure that youths' hopes are met.

ACKNOWLEDGMENTS

I acknowledge Centre for the Study of AIDS staff members (Lerato Lebona, Mpho Motiang, Tshepo Magudulela, Erens Malatji, Ray Lazarus, Mary Crewe), Haripe Community Stakeholder Forum, Phyllis Sibiya, Leratong Mission Centre, Perseverance Rural Development Centre.

FUNDING

This research was funded by the Fordham University HIV and Drug Abuse Prevention Research Ethics Training Institute/National Institutes of Drug Abuse (R25DA031608-01; Principal Investigator, Celia B. Fisher) and by The Santander Universities/Fordham Ethics and Society Scholarship Program.

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