

Trust and Collaboration in the Prevention of Sexually Transmitted Diseases

JAMES C. THOMAS, MPH, PhD^a
EUGENIA ENG, DRPH^a
JO ANNE EARP, ScD^a
HATTIE ELLIS, MEd^b

SYNOPSIS

High rates of sexually transmitted diseases (STDs) are sustained in communities by a relatively small group of people, referred to as the core of transmission. Definitions of the core vary but inevitably include people who are socially marginalized and who distrust people in authority, such as public health practitioners and university researchers. Having an effect on a marginalized group usually depends on effective collaboration with people they trust. Researchers from the University of North Carolina School of Public Health developed a trust-based collaboration with community members of a rural county in North Carolina to implement an STD prevention program that, in turn, relied on trust in local social networks.

As part of the STD prevention demonstration project, the research team established a community resource group made up of local African Americans who helped design, implement, and evaluate the intervention. The group identified 21 women to whom others in the community turned for advice on sex and STDs. These women were trained as lay health advisors to disseminate information and skills for preventing STDs among their social networks. Through face-to-face structured interviews before and after the intervention, the authors measured improvements in STD treatment and prevention behaviors.

The proportion of people practicing each of the targeted behaviors improved during the evaluation period. In addition to disseminating information through their own social networks, the lay health advisors demonstrated new skills and a desire to interact with local care providers to influence the provision of care for STDs for low-income African Americans in this county. Each participant in the collaboration played a role in establishing or building upon trust with others. These trusting relationships were critical for empowering a marginalized group at high risk for STDs.

^aSchool of Public Health, University of North Carolina, Chapel Hill, NC

^bBeddington High School, Step County, NC

Address correspondence to: James C. Thomas, MPH, PhD, Dept. of Epidemiology, Univ. of North Carolina School of Public Health, 2104-B McGavran-Greenberg Hall, CB #7435, Chapel Hill, NC 27599; tel. 919-966-7434; fax 919-966-2089; e-mail <jim.thomas@unc.edu>.

The authors thank Jadis Robinson and Charlotte Williams for their roles as community outreach specialists in the project; the members of the STEP Project community resource group; Darrah Degnan, who served as project coordinator; and Tammy Carlton, who served as field coordinator for the neighborhood surveys. This project was supported by National Institute of Allergy and Infectious Disease (Grant U01-AI31496), with supplemental funds from the HIV/STD Control Branch of the North Carolina Department of Environment, Health, and Natural Resources.

© 2001 Association of Schools of Public Health

Health disparities in sexually transmitted diseases (STDs) are large, with a small proportion of the community bearing most of the burden. This subpopulation has been termed the core of transmission. Definitions of the core vary. They include people repeatedly infected, people who infect more than one other person, prostitutes, and people who reside in a particular geographic area.¹

Preventing infections and transmission among the core is viewed as a strategic way to limit infection of the entire community.² But people in the core, however it is defined, are often marginalized in society on the basis of factors such as race and class and/or because of their infections. Marginalization breeds distrust of people in the establishment and engenders a lack of cooperation with their interventions. This vicious cycle creates a formidable barrier to health care providers who wish to target the core for disease reduction.

The administration of hepatitis B vaccine provides an example. Initially, the national vaccination strategy focused on people most at risk, including users of illegal injection drugs. High vaccination coverage could not be achieved among marginalized populations, however, so care providers changed to a strategy of vaccinating everyone in childhood.^{3,4}

Unfortunately, hepatitis B is the only sexually transmissible infection that can be prevented through a childhood vaccine; other STDs must be treated once they are acquired. To do so, health care providers must confront the challenge of establishing interventions to effectively reach the core, as defined for their purposes.

In describing the application of their theory of diffusion to HIV prevention, Dearing, Meyer, and Rogers highlight the special circumstances of introducing innovations to socially marginalized groups (such as some low-income African American communities) to reduce socially stigmatizing problems (such as AIDS).⁵ Because of distrust of people outside their group, such as professional health care providers, people in marginalized groups are more likely to adopt new ideas and skills learned from people they know, who are more like themselves, and whom they therefore trust. The influence of outside opinion leaders is displaced by marginalized groups' need for trust and interpersonal familiarity.

Lay health advisor (LHA) programs are an intervention model premised on trusting relationships. LHAs are people who are recognized as natural helpers by their peers and are trusted to provide reliable and confidential advice. In many settings they work as volunteers rather than as paid representatives of an

institution. Because their primary allegiance is to their social networks, they maintain credibility and effectiveness within marginalized subpopulations. Unlike peer advisor and outreach workers, who often interact with people they don't know, the lay health advisors trained in this project interacted within established relationships.

From 1995 to 1999, researchers from the University of North Carolina School of Public Health collaborated with community members of a rural county in eastern North Carolina. Together, the two groups implemented an LHA program to alter behaviors affecting the transmission of STDs among poor African American women living in a cluster of contiguous neighborhoods with high rates of syphilis and gonorrhea. The collaboration was called the Sexually Transmitted Epidemic Prevention (STEP) Project. For consistency with previous publications, the county in which the project operated is referred to as Step County.

The project was based on theories of diffusion and empowerment. The ability to achieve these goals, in turn, depended on the development of trusting relationships between researchers and community members. In this paper we describe how these trusting collaborations were developed. To set the context, we briefly mention aspects of the project that are reported in more detail elsewhere.⁶⁻¹⁰

SETTING

Step County lies in the rural tobacco-growing area of eastern North Carolina. In 1990, the county's population was about 67,000, of whom 38% were African American.¹¹ The central town of the county, where the LHA program was implemented, had a population of 37,000.

Although not officially segregated today, the county ranks very high in residential isolation—15 standard deviations above the state mean⁶—a de facto measure of segregation. Poor African American neighborhoods cluster almost entirely on one side of the railroad tracks that transect the town. In 1993, the reported rate of gonorrhea infection in these neighborhoods was 1,746 cases per 100,000 person-years (based on 516 cases)—a rate equal to those in large U.S. cities with the highest rates that year.⁷

During observational research conducted in 1991–1995, the researchers sought out community residents who could inform and advise them about the community. They began by asking staff in the health department and representatives of other community service agencies for the names of influential local African Americans. Once identified, these people then

informed the researchers of other, less-recognized people who could also provide key perspectives on community life. Eventually about a dozen people were identified, ranging from a professor at a local college to a low-income male cross-dresser.

It was readily apparent that several of these people would not be comfortable in the presence of the others. Thus, rather than convene these lay advisors as a group, the researchers met with them individually. The advisors informed the researchers about the community's dynamics and history and helped identify potential interventions based on their firsthand knowledge.

At the conclusion of the preliminary research period, the community advisory group was reconstituted for the purpose of designing the intervention. Some of the people left their advisory role because they felt they had less to offer at that point in the project; others with links to various community organizations were identified as new advisors.

This group was actively engaged in all aspects of the intervention: design, implementation, and evaluation. Because the resources they brought to the effort went beyond advice, they were referred to as the community resource group (CRG). This group was more homogenous than the earlier advisors and thus did meet together. Meetings between the CRG and the university researchers were held every two to three months, usually at lunch time on a week day. Lunch was provided by the researchers, and meeting rooms were provided by local agencies.

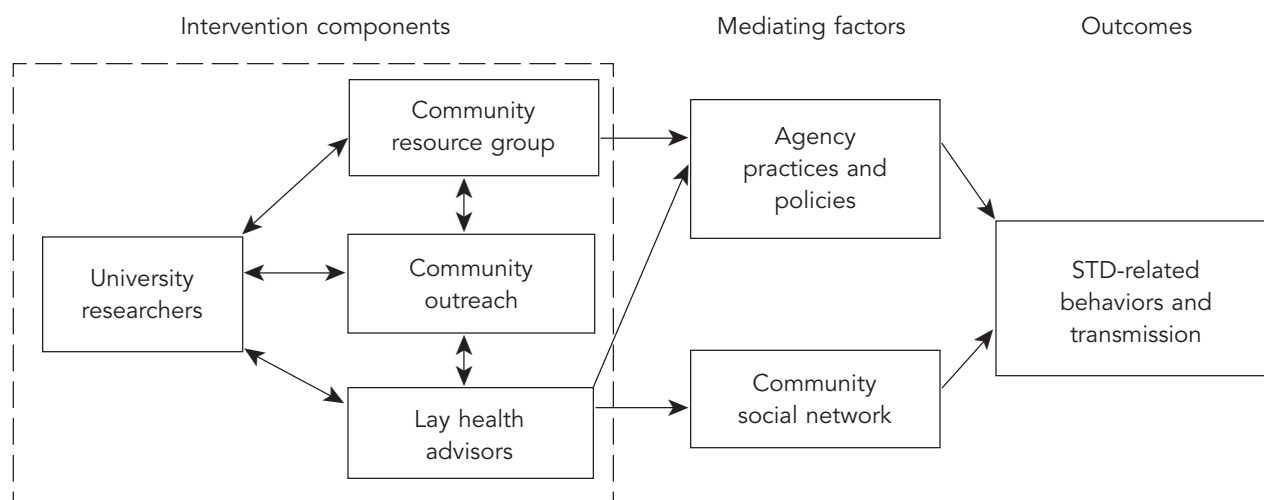
The researchers and the CRG sought to base the

intervention on community strengths, not community liabilities. During the years of observational study, the researchers had identified a strong social network among poor African American women. This network may have formed, in part, because many of the women were single mothers and relied on each other for help. Because of this naturally occurring social network, and because the collaborators wished to effect changes in sensitive behaviors among a socially disenfranchised group, the CRG and researchers chose to disseminate information, attitudes, and skills through existing trust-based relationships.⁸

The behaviors we sought to influence were seeking care for known or potential STDs and using condoms with main sexual partners. The intervention was also intended to empower poor African American community residents to communicate their concerns about STD prevention and treatment in discussions within their own social networks and with local health care agencies. The relations among the component parts of the intervention are diagrammed in the Figure.

The university staff member who served as the connecting point for the many elements of the intervention was stationed in Step County and designated a Community Outreach Specialist. She maintained contact with the members of the CRG, the researchers, the LHAs, the staff of the local health care agencies, and others in the community. Two women served sequentially in this role. The first was an African American woman who lived outside Step County but who was well integrated into the community, where her

Figure. Conceptual model of the lay health advisor intervention



children attended pre-school and day care. She was the Community Outreach Specialist for all but one year of the project. For the last year of the project, the Community Outreach Specialist was an African American woman who lived in Step County. She worked half time for the health department as a health educator and half time for the STEP Project.

The CRG together with the university researchers identified desired characteristics of LHAs. Those criteria included being an African American woman who was trusted and sought out for advice about relationships, sex, and STDs. Each of the CRG members then wrote down the names of people who they felt met the criteria. The Community Outreach Specialist contacted women named by more than one CRG member to confirm their "fit" for the role and to explain the project. Although the LHAs were not reimbursed, all 21 women who were asked to become advisors accepted. They included single parents living in public housing; lay ministers; students at a vocational school; and employees of a community clinic, a factory, the Department of Social Services, and the local health department.

LHA training was conducted by a University of North Carolina graduate student and the Community Outreach Specialist. Over a five-week period, 15 hours of training were provided, most of it on Saturdays to accommodate the LHAs with jobs. The training modules were designed with much input from the CRG. The training style employed popular education methodology¹² and focused on information about STD prevention, when to use STD services, negotiating condom use, and listening and advising skills.

Several sessions were led by representatives from the local health care agencies. For example, a nurse from the county STD clinic spoke about the clinic and answered questions. Conveying information was only a secondary objective of the sessions involving local care providers, however. The primary objectives were to enable the care providers to become familiar with the LHAs and become invested in their project, and to enable the LHAs to get to know some of the people working in the agencies. The hope was that acquainting the two groups with each other would decrease barriers, allowing the LHAs to communicate their needs and desires to the agencies.

EVALUATION

We evaluated the first 18 months of LHA activity. The time period was chosen solely as a function of the project's funding duration. The outcome evaluation

consisted principally of standardized face-to-face interviews with African American women ages 18 to 34 living in neighborhoods in which the incidence of STDs was high. These interviews were conducted both before and after the intervention. The baseline and follow-up questionnaires included items pertaining to the frequency of the targeted behaviors; attitudes toward the behaviors, including future intentions; peer norms and barriers to the behaviors; variation in sexual behaviors with different partner types; drug use; and sociodemographics. The follow-up questionnaire also included questions about interactions with acquaintances who talked with them about STD treatment or prevention. Photographs of the LHAs and a few other women (as controls) were shown to the respondents, who were asked if they had spoken with any of them about STDs.

The process evaluation included interviews with the LHAs about their project-related activities, field notes written by the university researchers, and an activity log maintained by the Community Outreach Specialist. In addition to evaluating the effect of the LHA intervention, we evaluated our selection of LHAs. We conducted semi-structured interviews with 17 LHAs and six project staff, seeking information about the consonance between the desired criteria for an ideal LHA as specified by the project staff and the LHAs' self-descriptions of their activities, beliefs, and attitudes.

Results of the STEP Project have been reported elsewhere.¹⁰ The focus here is on the trusting nature of the collaboration between the researchers and the community members, without which results could not have been achieved. The success of the intervention stemmed from having selected effective LHAs—women who could disseminate information among people who distrusted outsiders—and empowering them to act in new ways to benefit their community.

Through our interactions with the LHAs and by observing their activities, their social connections and influence in the targeted population, and the behavior changes described below, we felt we had identified and trained appropriate women as LHAs. We attributed this selection success largely to the role of the CRG in identifying women who met the study criteria for natural helpers. Three components of the process of identifying potential LHAs used by the CRG were critical: an exercise to clarify the types of people who would make good LHAs, the preliminary selection of women named by at least two CRG members, and screening interviews by the Community Outreach Specialist with all candidates to determine whether they were comfortable talking about sexual behaviors and condom use.¹²

The LHAs' effectiveness in disseminating information, attitudes, and skills was assessed through their activity level, the proportion of people with whom they interacted in the community, and changes in the targeted behaviors.

In a series of 45 interviews with the LHAs during the first six months of the intervention, we learned that the LHAs had had 139 helping encounters the previous week. As the diffusion of innovation model intended, the vast majority (84%) of these encounters were with friends, relatives, or co-workers. In 77% of the interviews, the LHA reported having had at least one conversation in the past week regarding STD prevention.⁸

The household surveys indicated that the number of households with an eligible respondent was 450 at baseline and 512 at follow-up. Of these, 217 (48%) at baseline and 258 (50%) at follow-up agreed to an interview. The respondents in the two samples were similar in self-reported age, age at first sexual experience, and church attendance. Similar proportions of both samples had been raised in Step County.

After 18 months of the intervention, 18% of African American women ages 18–34 identified an LHA from a page of photos as someone who had spoken to them about STDs within the last year. One third (32%) of respondents to the follow-up questionnaire reported having talked to a female acquaintance or another woman “like yourself” about STDs in the previous three months. These may have been LHAs or women who were disseminating information they had received from the LHAs; we were not able to determine the exact source with our research methods.⁹

Each of the three targeted behaviors improved during the 18-month intervention period that we evaluated. Consistent condom use increased 23%. Seeking care for an STD within three days of symptoms increased 60%. Seeking screening for an STD among those who suspected exposure increased 26%.⁹

Evidence of empowerment among the LHAs was seen in the new opportunities they created for their community to talk about STD prevention. With local agencies, they planned and co-hosted a health revival at a local church, an AIDS vigil, and a father-son basketball tournament. A few LHAs attended board meetings of the local health institutions for the first time. Some LHAs also accompanied acquaintances to the health department STD clinic, an activity they had not engaged in before being trained by staff from the health department. For its part, the health department indicated that it valued the LHAs by inviting them to participate in some outreach activities and advising them on literature distributed in their clinic.

IMPLICATIONS

Researchers are ranked among those with high status and authority in American society. A key challenge this presents to those aiming to decrease STD transmission is the need to transcend defenses erected out of distrust among those feeling marginal with respect to status and authority. This intervention was based on the assumption that a successful program required meaningful collaboration between community members and university researchers. Each of the intervention contributors—the CRG, the LHAs, the Community Outreach Specialist, and the university researchers—played a critical role.

The CRG was key in both legitimizing the intervention and making it effective. The members of the CRG held key gatekeeper positions in Step County's African American community. These people were both recognized and trusted as leaders among poor African Americans and experienced in working with whites in positions of authority. Because they were willing to develop trusting relationships with university researchers, CRG members were able to influence the direction and implementation of the intervention as well as identify people who fit the intervention model. The researchers could not have found these people on their own. Moreover, the women who were eventually trained as LHAs trusted the intervention because they were nominated by members of the CRG whom they knew. Indeed, some of the CRG members even took part in the LHA training. The CRG, then, was critical in bringing to the intervention representatives of the people most affected by the negative social forces at work in the community.

The LHAs carried the intervention even deeper into the community. Like the CRG members, they were trusted members of the community, and the people who trusted them were their relatives, friends, and co-workers, the very people for whom the intervention was designed. Because it was the LHAs who disseminated information, attitudes, and skills about STDs and care-seeking among people they knew, the message they communicated was much more likely to be heard, believed, and put into practice than it would have been had it been spoken by a stranger or an agency outreach worker who could have been seen as representing the power structure.

The intervention also overcame distrust by empowering the LHAs. Because of the new relationships that developed with staff in the local agencies, the LHAs found a new interest in and ability to approach the staff in their workplaces, sometimes by escorting a friend to the clinic, sometimes by participating in a

community event with clinic staff. The LHAs also enabled the community to begin talking in an informed way about STDs, including AIDS, and the attitudes and behaviors that facilitate transmission.

The Community Outreach Specialists, who also held a key gatekeeper position, facilitated the training and work of the LHAs and the interactions with the CRG. Unlike the researchers, they spent every working day in Step County. Although they were employed by the university, they were regarded as community members. To the community, they represented the most tangible investment in the community that the university made. To the researchers, they were proxy representatives of the community, able to inform the researchers of local news and rumors, strengths, and opportunities. It helped immeasurably that both Community Outreach Specialists were African American and naturally gregarious.

The Community Outreach Specialists would not have played the role they did in Step County if the researchers had not obtained funding to hire them and place them there. The researchers not only had the ability to obtain a grant, but they had the theoretical knowledge to design the conceptually sound process that the intervention followed as well as the methodological knowledge that informed the evaluation process.

The researchers were able to mirror the dissemination work of the LHAs by sharing the data obtained from the project—data that were more theoretical and shared with a different social network from the LHAs'. The researchers had the necessary credentials and skills to reach this important network through presentations and publications. The LHAs also had something to offer to this network of professionals. For example, one of the LHAs told her story in a plenary

Table. Contribution by the Community Research Group and by researchers in the design, implementation, and evaluation of the intervention to influence STD-related behaviors

<i>Phase of study</i>	<i>Contribution by Community Resource Group</i>	<i>Contribution by researchers</i>
Design		
Understanding the problem	Information about the local setting; provided advice on data collection.	Theory and experience with data collection and analysis; collected data to inform the intervention.
Identifying an appropriate intervention	Insights into what would be feasible and well received in the community.	Theory and experience with interventions.
Implementation		
Accessing those most at risk	Identified potential lay health advisors.	Helped identify characteristics of those most at risk.
Credibility with community members	Personal relationships with community members. Participated in lay health advisor training.	Prestige of the university. Conducted lay health advisor training.
Interactions with agencies	Knew people on staff at various agencies.	Able to make statements and suggestions to agencies that local residents could not make.
Maintaining the intervention	Provided advice on interacting with local agencies to gain their support for lay health advisors' work.	Obtained funding for the community outreach specialist.
Evaluation		
Household survey	Provided guidance to researchers on interactions with households during survey.	Collected and analyzed data.

session of a national conference.¹³ Following that session, many of the conference participants commented on the power of the LHA's presentation and presence.

The researchers also had an audience in Step County. Because of their affiliation with a university held in high regard in the county and because the principal investigator was a white man, he could gain entry to many of the (often white male) circles of power in Step County, bringing messages that would be less likely to be heard if spoken by a resident. These included messages about the importance of listening to those in Step County who were most affected by STDs and allowing them to help shape the public health policies and practices of the local agencies.

Each of the intervention actors was critical (see Table). Without any one of them, the intervention would not have been effective; indeed, it might not have occurred at all. The intervention not only achieved changes in targeted behaviors, it changed some aspects of the social dynamics in Step County that underlie the high rates of STDs, such as the interactions between some poor African Americans and the STD clinic staff.

Can this model be replicated elsewhere? This project was implemented in only one community. It was a demonstration project showing that such a model can work. Our results do not provide enough information to judge whether it will work elsewhere. Our experience suggests, however, that some aspects of the model could be replicated and other aspects might be inappropriate in other communities.

The aspect we believe is most important is the collaboration among the various actors. When the goal is to implement and have accepted a theory-based community intervention or the goal is to thoroughly evaluate a community intervention, a collaborative relationship between researchers and community members is indispensable. Our model using LHAs and a Community Outreach Specialist is also one of very few that has been shown to be effective in transcending age-old social barriers.

Using this collaborative approach, we were able to effectively address some of the needs and at least partly overcome some of the social barriers that underlie the disproportionately high rates of STDs among African Americans in this community. The intervention succeeded in increasing condom use, earlier care seeking for STD symptoms, and screening for STDs. In other communities with high STD rates, the reasons behind the rates may be different from those found in Step County. For example, higher rates of STDs in a particular community might be attributed to a greater number of commercial sex workers; in this case, the

desired qualities of a LHA would likely be different, and some of the messages and skills they disseminate might be different from those in our project. But the answer to the question of how to adjust the intervention to fit the needs of the community resides with the community advisors (or the community resource group). If advisors are in touch with the community and not just those community members most immediately accessed by researchers, they can provide invaluable advice about the design and implementation of the intervention. In turn, the ability to receive such advice depends on establishing a relationship between the researchers and the community advisors that is truly collaborative and characterized by mutual trust. Without a collaborative relationship of this nature, the distrust so often found among socially marginalized groups for research projects that take place in their communities will continue to undermine STD prevention programs.

REFERENCES

1. Thomas JC, Tucker M. The development and use of the concept of a sexually transmitted disease core. *J Infect Dis* 1995;174(Suppl 2):S134-43.
2. Over M, Piot P. Health sector priorities review: HIV infection and sexually transmitted diseases. In: Jamison DT, Mosley WH, editors. *Disease control priorities in developing countries*. New York: Oxford Press for the World Bank; 1993. p. 455-527.
3. Protection against viral hepatitis: recommendations of the Immunization Practices Advisory Committee (ACIP). *MMWR Morb Mortal Wkly Rep CDC Surveill Summ* 1990;39(2):1-76.
4. Hepatitis B virus: a comprehensive strategy for eliminating transmission in the United States through universal childhood vaccination; recommendations of the Immunization Practices Advisory Committee (ACIP). *MMWR Morb Mortal Wkly Rep* 1991;40(RR-13):1-25.
5. Dearing JW, Meyer G, Rogers EM. Diffusion theory and HIV risk behavior change. In: DiClemente RJ, Peterson JL, editors. *Preventing AIDS: theories and methods of behavior interventions*. New York: Plenum Press; 1994. p. 79-93.
6. Thomas JC, Thomas K. Things ain't what they ought to be: social forces underlying high rates of sexually transmitted diseases in a rural North Carolina county. *Soc Sci Med* 1999;49:1075-84.
7. Thomas JC, Schoenbach VJ, Eng G, McDonald MA. Rural gonorrhea in the southeastern United States: a neglected epidemic? *Am J Epidemiol* 1996;143:269-77.
8. Thomas JC, Eng E, Clark M, Robinson J, Blumenthal C. Lay health advisors: sexually transmitted disease prevention through community involvement. *Am J Public Health* 1998;88:1252-3.

9. Thomas JC, Earp JA, Eng E. Evaluation and lessons learned from a lay health advisor program to prevent sexually transmitted diseases. *Int J STD AIDS* 2000;11: 812-8.
10. Blumenthal C, Eng E, Thomas JC. STEP sisters, sex, and STDs: a process evaluation of the recruitment of lay health advisors. *Am J Health Promot* 1999;14:4-6.
11. Census Bureau (US). County and city data book. Washington: Government Printing Office; 1994.
12. Freire P. *Pedagogy of the oppressed*. New York: Seabury Press; 1970.
13. Leaning J, Eng E, Davis E. STD prevention as a human rights obligation: the challenge to public health researchers and policy makers. Presented at the National STD Prevention Conference; 1998; Dallas.