Integration of a Participatory Research Strategy into a Rural Health Survey

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The Glades Health Survey, a population-based survey of tuberculosis and HIV infection, provides a model for building community-research partnerships with local health departments in ethnically diverse communities. The survey was initiated without broad community participation; a year and a half of organizing established community leadership of the project. Essential factors in the success of the project included a shared objective, direct confrontation of fears about research, inclusion of all socioeconomic and racial/ethnic groups, and community participation in performing the research. These activities led to establishment of a community-based organization that received funding for HIV counseling and testing and HIV prevention case management.

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Tuberculosis (TB) increased dramatically in the United States between 1985 and 1993, reversing a long-standing downward trend in incidence. Despite recent successes in combating this resurgence, TB is still a substantial public health problem in some areas of the country. Tuberculosis is traditionally considered to be an urban disease, but in rural western Palm Beach County, an area known locally as "the Glades," TB rates in the early 1990s exceeded 70 cases per 100,000 inhabitants. This rate was higher than that in most urban areas of the United States.¹

Sexually transmitted diseases have also been important public health issues in rural south Florida for many years.^{2,3} One such disease, HIV, increases the risk of TB.⁴⁻⁶ To determine the prevalence of active and latent TB among residents of the Glades, to investigate the relationship between TB and HIV, and to define optimal intervention strategies to control TB and HIV, a team of investigators was formed in early 1993. This team included representa-

tives from the Palm Beach County Health Department, the Florida Department of Health, the United States Centers for Disease Control and Prevention (CDC), Emory University, and Dartmouth Medical School.

BACKGROUND

Research Site

The location of the Glades, a largely agricultural area, is shown in Figure 1. The population in the 2000 census was 34,759 persons (15% white, 50% African American, 25% Hispanic, and 10% Haitian).⁷

In 1985, the CDC conducted a population-based survey in the Glades² that dispelled the notion of mosquito transmission of HIV. The study received nationwide publicity and Belle Glade became known as "the AIDS capital of the world."⁸ This characterization had practical consequences for community residents: checks from Belle Glade banks were not accepted in some neighboring coastal cities, high school football teams refused to play in the area, and local businesses suffered economic losses. The experience of being shunned by persons from outside the area was very much on the minds of residents when the proposal was made to community groups to conduct another survey in the Glades examining TB as well as HIV.

Developing the Research Project

The research project, the Glades Health Survey, was initially proposed in October 1994. In December 1995, a pilot study to evaluate the randomization process, the availability of study participants, and the reliability of the questionnaire was completed. The pilot indicated a likely 50% participation rate, a rate inadequate to obtain reliable results. Interviews indicated that distrust of the local health department, primarily around the issue of confidentiality, was an important reason for the low participation rate; similar distrust has been reported in other communities.^{9,10}

The director of the Glades Branch of the Health Department and other residents urged the researchers to engage the community and convince local leaders to take ownership of the survey. The idea of a survey was presented to the community in early 1996 at a meeting of a local group, Planned Approach to Community Health (PATCH), a local umbrella organization of 25 representatives from political and public and private health-related enterprises.^{11,12} PATCH formed a "TB study committee" to clarify the issues and challenges posed by the survey, and assess the level of community support. The TB study

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During the period of the initiation of the Glades Health Survey, Dr. Stratford was with the University of Florida, Gainesville, Fla; Mr. Abbott was director of the Palm Beach County Health Department Branch, Belle Glade, Fla; and Dr. Horsburgh was with Emory University, Atlanta, Ga.

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The western portion (shaded) of Palm Beach County in the State of Florida, United States is a rural, agricultural community known as "the Glades".

FIGURE 1. The "Glades" area of Florida, site of the Glades Health Survey.

committee decided that the survey should be performed by a local nongovernmental organization, and formed the Glades Health Survey Board (GHSB) to undertake the task. The TB study committee solicited nominations for membership, with the goal of achieving a board that represented the institutional, ethnic and geographic diversity of the Glades.

The creation of the GHSB during 1996 and 1997 culminated in broad-based, active community leadership of the research activities. Researchers and community advocates confronted several serious issues, including concerns about confidentiality of information, the potential for negative publicity for the community, and who would exercise fiscal and administrative control. Ultimately, a consensus was reached among major community groups and organizations that the opportunity to improve local health conditions (and to take credit for this improvement) outweighed the risk of further negative publicity.

The resulting GHSB comprised 19 members: 11 men and 8 women, 10 African Americans, 6 whites, 2 Hispanics, and 1 Haitian. Ten resided in Belle Glade, 4 in Pahokee, 3 in South Bay, and 2 in other areas. Five board members worked at social service organizations, 3 were pastors, 2 were city officials, 2 were health department employees, and 1 was a physician. The board selected staff from and representative of the local population, and a PATCH member and longtime community leader to be the Executive Director of the survey. A local 501.c.3 organization, Neighbors Organized for Adequate Housing (NOAH), was selected as the fiscal agent for the survey.

Survey Description

In order to assess population-based rates of TB and HIV infection, a random survey of Glades' households was

performed. The project was reviewed and approved by the Institutional Review Boards of the CDC, the State of Florida, Emory University, and Dartmouth College. Residents who agreed to participate gave informed consent, were interviewed using a standardized questionnaire, were skin tested for TB, and had blood drawn for HIV serology. Survey participants who had untreated medical conditions were referred for clinical care.

During the 3-year period of the survey (1998–2000), the GHSB and the survey staff were active in publicizing the survey and its aim of improving health in the community. Announcements were placed in the local press; physicians answered questions about the survey on local talk radio shows; pastors discussed the survey from the pulpit; and presentations were made to Lions, Rotary and other community group meetings. A brochure was prepared and booths were set up at local festivals and fairs that distributed the brochure and refrigerator magnets with the survey logo. These and other efforts were made to assure that Glades residents would be informed about the survey, so that, if selected to participate, they would agree. Messages included the rationale for the survey, the importance of participation to overall community health, and information about the signs, symptoms and availability of treatment for TB and HIV.

RESULTS

Participation

One resident at each of 609 residences was randomly selected to participate. The survey completed enrollment with an overall participation rate of 516/609 (85%); 447/609 (73%) persons received tuberculin skin testing and HIV testing. Participation rates were equal in all racial and ethnic groups. A convenience sample of 210 additional HIV-infected persons also was enrolled as a comparison group.

Tuberculosis and HIV

Three persons were diagnosed with active tuberculosis; of the 657 persons who received tuberculin skin tests, 163 (25%) were positive, 140 received chest radiographs and 57 were offered treatment for latent tuberculosis. As can be seen in Table 1, the number of tuberculosis cases in the Glades community declined over the period of the survey at a faster rate than in the urban portion of Palm

Table 1. Tuberculosis Cases in Palm Beach County, Florida, 1998–2001

Year	Glades, n (%)	Not Glades, n (%)	N
1998	17 (20)	67 (80)	84
1999	21 (20)	85 (80)	106
2000	6 (8)	70 (92)	76
2001	13 (16)	66 (84)	79

Beach County. However, this trend was not statistically significant (χ^2 for trend, $P = .19$). Seven (1.6%) of the 447 persons in the random survey who were tested for HIV antibody were positive.

DISCUSSION

The Glades Health Survey provided an accurate estimate of the scope of TB and HIV infection in the Glades and led to the treatment of 67 persons for these infections. Several factors were important in making the survey successful. First, the project was focused on public health issues that were immediate and important to the community. Second, community mobilization was able to address prevailing fears about research, and to build community support for and confidence in the project. Third, all socioeconomic and racial/ethnic groups were represented in the process of creating the Survey Board and performing the survey. Lastly, community management of the project allowed residents to be recognized for taking the lead in addressing important local public health issues.

Had the community's earlier research experience not been so negative, the process of community mobilization might have taken less time and energy. However, building trust and establishing an effective working relationship with a community is inherently time consuming; it also is fundamental to good participatory research practice.¹³⁻¹⁶ The process is a reciprocal one in which both parties educate each other about their needs and expectations from the research. Attention is focused on elucidating information to direct interventions, improve professional practice, and lead to improved local health outcomes.

The results of the survey enabled the GHSB to define intervention strategies to reduce the burden of TB and HIV in the community. The GHSB reorganized in 2000 as a nonprofit corporation, Glades Health Initiative, Inc. (GHI). GHI received funding from CDC for an HIV counseling and testing program that includes street outreach in high-risk neighborhoods, and from the Florida Department of Health for HIV prevention case management of uninfected persons. GHI is also collaborating with other local organizations to increase access to treatment for persons in the Glades with sickle cell disease and for children with asthma. Research reports are reviewed by the GHI and the collaborating agencies and then are submitted for publication in scientific journals. GHI (to which one of the researchers continues to serve as scientific advisor) and the

Glades community are determining the direction of future research efforts and publications.

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