

THE BOSTON HAITIAN HIV PREVENTION COALITION FORMATIVE EVALUATION: A PARTICIPATORY APPROACH TO COMMUNITY SELF-ASSESSMENT

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INTRODUCTION

This paper presents the findings of the Metropolitan Boston Haitian HIV Prevention Coalition community survey. The coalition comprises a group of service providers serving the Haitian community. The major goal of the coalition is to design, implement, and evaluate a unique community-driven strategy to reduce HIV infection within the Greater Boston Haitian community. The intervention targets Haitian women, men, youth, couples, new immigrants, and Haitians living with HIV, and the survey is one element of the HIV/AIDS preventive education evaluation design. The survey data include Haitian demographic characteristics, HIV/AIDS knowledge and sources of knowledge, health beliefs and attitudes, HIV risk behaviors, and perceptions of HIV risk.

The community-based participatory strategy used in designing and implementing the survey is based on the "community of inquiry" concept.¹ The community of inquiry approach differs from other participatory approaches to evaluations in that it involves more than simply involving people in the process; a community is formed, bonded by a shared commitment to the evaluation. This paper details the community of inquiry approach to the evaluation of the HIV prevention intervention, the survey findings, and how the survey data is being used to improve the efficacy of the intervention.

METHODS

Data collection was divided into 2 stages. During the first stage, a com-

munity of inquiry was created through weekly meetings, in which valid, reliable data could be collected. The community of inquiry included service providers, consumers, other stakeholders, and the evaluators. The first step in creating the community of inquiry was to create a risk-free environment in which to build trust. Core operating values to guide the evaluation process were established. During the first weekly meetings, conflicting values were discussed and negotiated, to ensure that values concerning research are shared within the community. These values formed the building blocks used to establish rules and procedures, and to define roles and responsibilities in conducting the research. The second step included identifying the process and outcome measurement criteria, and designing the evaluation. The third step included identifying data sources, how and when data were to be collected, and assigning responsibilities for specific data collection tasks.

Data collection procedures were implemented during Stage 2. A sampling frame was constructed from households listed in the residential telephone directories for the targeted cities. The first step in the sampling process was identifying the telephone exchanges with high concentrations of Haitians, based on the residential patterns reported by human service agencies serving the Haitian community. From the sampling frame, a random sampling procedure was used to select 3,500 Haitian households. Of this sample, 2,719 households responded to the survey, representing a 78% response rate. According to the 2000 US Census, 31,192 individuals who live in the target cities identify themselves as being of Haitian ancestry. Based on these data, 8.71% of the Hai-

This article describes the application of participatory evaluation principles and methods to designing and conducting a community survey of the metropolitan Boston Haitian population. The findings of the evaluation baseline community survey of 2,719 Haitians are described, including an overview of the population characteristics and the prevailing HIV prevention knowledge, attitudes, and practices. The participatory evaluation approach was effective in building evaluation capacity, and provided a reliable data source with which to fine-tune the prevention intervention, and increase its efficacy in reducing HIV transmission. (*Ethn Dis.* 2004;14[suppl 1]: S1-20-S1-26)

Key Words: Action Research, Haitian Community Health, Health Disparities, HIV Prevention Intervention, Immigrant Health, Participatory Evaluation

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tian population residing in the target cities was included in the survey sample.

The survey was conducted by telephone, using a questionnaire schedule. One adult per household was interviewed. Qualifying questions were used to identify an appropriate adult to respond to the survey. Each household in the study was assigned a tracking code. A telephone survey script was used to acquire oral informed consent. Respondents were provided the option of conducting the interviews in Haitian Creole or English. More than 90% of the interviews were conducted in Haitian Creole.

One month prior to commencing data collection, the Center for Community Health, Education and Research (CCHER), the coalition's lead agency, conducted an intensive radio information campaign to inform the Haitian community that the survey would be forthcoming, and to solicit the community's participation. Information about the survey and its importance was presented on radio stations that provide programming in Haitian Creole. The radio audience had the opportunity to call in and ask questions about the survey. Individuals requesting additional information were invited to contact CCHER to discuss the survey in more detail. The radio audience was encouraged to inform their neighbors, friends, and family about the upcoming survey. Information about the survey was also distributed to churches and businesses in the Haitian community. Due to this concentrated outreach effort, by the time the first respondent was contacted, the community was ready to participate.

Completion of the survey took 30 to 45 minutes. A telephone bank was installed at CCHER to conduct the survey. The College of Public and Community Service at the University of Massachusetts, Boston, oversaw the project, and was the technical advisor throughout the data collection and processing. To ensure consistency in data collection, the College of Public and

Community Service developed guidelines and tracking procedures. The day-to-day management of data collection was delegated to the CCHER project coordinator and 2 assistants. Interviewers were recruited from the Haitian community, and trained by the College of Public and Community Service. All interviewers were Haitian, and spoke both English and Haitian Creole.

RESULTS

Demographic data were gathered to identify the population's age, gender, sexual orientation, marital status, and length of residency. These data are presented in Table 1. The demographic data show that Haitians in this region are a stable, middle-aged, first-generation immigrant population. Ninety-seven percent were born outside the United States; the mean age of the population is 41 years; and the mean length of US residency is 12.8 years. Almost one third of the Haitian population is single, or not in a partnership relationship. There is an almost 2 to 1 ratio of single women to men. Although the population describes itself as heterosexual, when asked the gender of their sexual partners, responses revealed that same gender sexual activity does occur. Table 3 shows that 8% of the respondents had engaged in same-sex sexual activity.

The survey included measures of health beliefs about the origin of HIV and responses to ill health in general. The findings reveal that 87% of Haitians believe that HIV is caused by unprotected sex between a man and a woman. Seventy-seven percent believe that HIV transmission occurs as a result of irresponsible personal behavior. If confronted with a serious disease, such as HIV, 98% of Haitians reported that they would seek medical treatment from a medical professional. Fifty-three percent of the Haitians reported that, in addition to going to a medical doctor, they would pray for healing. Overall,

Table 1. Haitian population characteristics (N=2,719)

Age	
<20	5%
20-29	17%
30-39	27%
40-49	26%
50-64	17%
>64	8%
Gender	
Male	38%
Female	62%
Sexual orientation	
Bisexual	0%
Homosexual	0%
Heterosexual	84%
Unidentified	16%
Marital status/living arrangement	
Married	60%
Living with partner	6%
Separated	3%
Divorced	5%
Widowed	6%
Never married	20%
Place of birth	
Born in the United States	3%
Not born in the United States	97%
Years lived in the United States	
<1	3%
1-5	21%
6-10	20%
11-15	20%
16-20	20%
>20	16%
Language preference	
French	2%
Haitian Creole	71%
English	7%
Distribution within metropolitan region	
Outside Boston	42%
City of Boston	58%

63% of Haitians reported that religion is very important to them in making healthcare decisions. In contrast to stereotypes, fewer than 1% of the Haitians identified a voodoo priest as a source of help for overcoming illness.

Descriptive measures of knowledge included personal perception of knowledge level, sources of knowledge, and objective measures of knowledge. Table 2 shows that only 58% of Haitians reported knowing a lot about HIV/AIDS.

Table 2. Sources of knowledge and HIV knowledge (N=2,719)

Source of information about HIV/AIDS	
Radio	77%
TV	75%
Doctor/clinic	61%
Magazine	51%
Family/friend	48%
Newspaper	43%
Billboards	42%
Work	35%
School	33%
Flyers	23%
Other	14%
Adequacy of the amount of HIV information	
Too much	2%
Not enough	62%
Right amount	14%
Don't know	23%
Accuracy of HIV information	
Always	58%
Sometimes	18%
Never	1%
Don't know	23%
Based upon knowledge, prediction of change in HIV transmission within 5 years	
Increase greatly	14%
Increase somewhat	16%
Stay the same	3%
Decrease greatly	21%
Decrease somewhat	5%
Don't know	41%
Individual rating of personal knowledge about HIV	
Lot	58%
Some	23%
A little	12%
Nothing	7%
Correct responses to objective knowledge questions	
Modes of person-to-person HIV transmission	93%
Behaviors that places one at risk of exposure to HIV	87%
Ways to prevent HIV transmission	92%
Effectiveness of HIV Treatment	88%

However, the objective data demonstrate that Haitians are more knowledgeable about HIV/AIDS than they perceive themselves to be. Baseline objective measures of knowledge revealed that 93% are knowledgeable about the sources and modes of HIV transmission. Eighty-seven percent of the respondents

were aware of the behaviors that place one at risk of becoming HIV infected. Ninety-two percent were aware of self-protective behaviors that prevent the spread of HIV. Forty-one percent were aware that, if properly treated, HIV-infected people can live a long time without developing AIDS.

Within the Haitian community, the four major sources of information about HIV/AIDS in rank order are radio, 77%; television, 75%; doctors' offices and clinics, 61%; and magazines, 51%. Sixty-two percent believed that an insufficient amount of information about HIV is provided to the Haitian community. Fifty-eight percent believed that the information provided to the Haitian community is always accurate. Eighteen percent believed that information is sometimes accurate, and 23% did not know if information is accurate.

Findings from the objective data presented in Table 2 revealed that Haitians have a high level of knowledge about HIV; however, the indicators of risk presented in Table 3 show that Haitians are engaged in risky sexual behaviors. To quantify the level of risk perception in the Haitian community, the survey included questions about sexual practices, perception of risk, and changes in practices to prevent risk. Indicators of risk included number of partners, knowledge of partners' sexual history, and condom use. Table 3 shows that the population is sexually active, and that the never-married individuals are more sexually active than the other groups, with the exception of married individuals, and individuals cohabiting as conjugal partners. Of the individuals who identify themselves as not being married or living with a partner, widowed individuals reported less sexual activity, compared to never-married and separated individuals. While individuals more than 64 years of age are not as sexually active as those in other age groups, more than one fourth reported being sexually active within the last 5 years.

Individuals who are under 30 years

Table 3. HIV risk behaviors (N=2,719)

Population sexually active	73%
Sexual activity by age	
<20	40%
20-29	73%
30-39	89%
50-64	65%
>64	27%
Sexual activity by marital status	
Yes	
Married	88%
Partner	84%
Separated	41%
Divorced	46%
Widowed	13%
Never married	54%
Gender of sexual partner	
Male/female	95%
Male/male	3%
Female/female	5%
Number of sexual partners	
1 Partner	88%
2 Partners	6%
3 Partners	2%
>3 Partners	4%
Knowledge about partners' sexual history	
Lot	73%
Little	16%
Nothing	10%
Refused to answer	1%
Knowledge about partners' drug use	
Lot	4%
Little	1%
Nothing	12%
Refused to answer	1%
No drug use	82%
Frequency of condom use	
Always	19%
Sometimes	30%
Never	47%
Refused to answer	4%

of age reported having more sexual partners than individuals over 30 years of age, with those in the group 20-29 years of age reporting the highest number of partners. Seventy-three percent of the respondents reported knowing a lot about their partners' sexual history, and 82% reported that their partners do not use drugs. Forty-seven percent of the respondents reported never using condoms, 30% reported using condoms sometimes, and 19% reported always using condoms. By gender, 24% of the

Table 4. Perception of personal HIV risk (N=2,719)

Perception of personal risk					
Great risk	4%				
Some risk	18%				
No risk	44%				
Don't know	35%				
Refused to answer	0%				
Perception of personal risk by gender					
	Female	Male			
Great risk	2%	2%			
Some risk	16%	20%			
No risk	41%	50%			
Don't know	40%	28%			
Refused to answer	1%	1%			
Perception of risk by condom use					
	Perception of Risk				
	At Great Risk	At Some Risk	No Risk	Don't Know	Refused
Frequency of condom use					
Always	26%	19%	19%	19%	17%
Sometimes	33%	35%	27%	30%	21%
Never	41%	43%	51%	47%	8%
Refused	0%	3%	3%	4%	54%
Changes in personal lifestyle due to HIV threat					
A lot	21%				
Some	18%				
None	61%				
Refused to answer	1%				
Types of changes in lifestyle due to HIV threat					
Fewer sexual partners	38%				
More knowledge about sexual partners	42%				
Always use condoms	32%				

males, and 13% of the females, reported always using condoms. Forty-one percent of the males, and 52% of the females, reported never using condoms. Frequency of condom use was highest among individuals under 30 years of age.

The data presented in Table 4 show that most Haitians did not perceive themselves to be at risk for contracting HIV, and that there has been little change in Haitian lifestyles aimed at reducing the risk for HIV transmission. Of the individuals who perceived themselves to be at no risk, 90% reported having only one sexual partner. Twenty-seven percent of the individuals who perceived themselves to be at some risk for contracting HIV reported having 2 or more partners within the last 5 years. Of those individuals who did not know whether they were at risk for becoming

HIV-infected, 14% reported having 2 or more partners. By gender, 50% of the males, and 41% of the females, perceived themselves not to be at risk for contracting HIV. Forty percent of the females, and 28% of the males, did not know if they were at risk for contracting HIV. By age, the group less than 20 years old contained the highest percentage of individuals who did not know if they were at risk for contracting HIV. However, condom use was highest among this age group.

Eighty-four percent of the individuals who reported never using condoms when having sex perceived themselves to be at great, or some, risk for contracting HIV, with 47% of these individuals reporting not knowing whether they were at risk for contracting HIV. Fifty-three percent of the Haitians reported not making any changes in their lifestyles

based on knowledge about HIV transmission in the Haitian community. Of those individuals who reported making changes in their lifestyles, 38% had fewer partners, 42% knew more about their partners' sexual history, and 32% always used condoms when having sex.

DISCUSSION

The community of inquiry approach to evaluation provided an opportunity to create a community-based research culture, which builds trust and respect for research as a tool to learn. One of the by-products of engaging in a deliberate community-building process is that the community took great pride in its role in the survey, and was eager to learn from the survey results. The evaluator learned new skills in conducting

cross-cultural evaluations that embrace both ethnic cultural differences, and differences in professional ethos and practices. Feedback from the participants demonstrates that participation had the following results:

1. The service providers have a better understanding of the function of evaluation as a tool to improve their work.
2. The evaluator has a greater understanding of the Haitian culture and its impact on how research is conducted and how findings are interpreted.
3. There is collective pride in the Haitian community, and a feeling of ownership in the survey results.
4. The evaluator has learned how to negotiate terms and condition that will ensure the data collection methods comply with evaluation principles and standards within the context of the community.

Some of the benefits of moving beyond the process to developing a mutually shared mindset about evaluation that bonds a group of stakeholders are:

1. The community, as a full participant in all aspects of the process, takes ownership of the evaluation, and responsibility for using the results.
2. Tensions about the intent of the evaluation and how findings will be used are resolved, alleviating sabotage and other tactics designed to prevent the evaluator from acquiring valid information.
3. Trust is based on a shared understanding of the evaluation process and its benefits to the community, which helps service providers to transcend their fears of being judged.
4. The inclusion of a broad array of stakeholders in defining measures of success increases the legitimacy of the findings.
5. The community's legitimization of findings increases the likelihood that the findings are used to improve practice.

Unfortunately, since the completion of the community survey, the community has changed. There have been staff turnovers in the provider agencies, and some of the other stakeholders no longer participate in the process due to changing interests. Changes in the composition of the community membership have produced conflict, and a level of distrust has developed within the community. Consequently, many of the old games of sabotage, conflict-of-interest issues, and lack of commitment to data collection, have surfaced. The service providers who were part of the survey community of inquiry are taking the leadership to revitalize the community. The lesson learned is that the community of inquiry is continuously evolving. The diversity of values requires that the community continue to transform itself to resolve conflicts.

There are 4 major findings with implications for improving the efficacy of the community-wide HIV intervention strategy:

1. The gender distribution of the population, and its sexual orientation, have implications for intervention coverage improvements and strategy changes.
2. The role of religion in making healthcare decisions has implications for provider training and institutional changes.
3. Behavioral risk taking, despite high levels of knowledge, has implications for intervention strategy changes.
4. Risk behavior, perceived risk, and lifestyle changes data have implications for intervention strategy changes.

The gender distribution of an almost 2 to 1 ratio of single men to women has implications for HIV-prevention strategies targeted to meet the needs of women. In a male dominant culture, such as the Haitian culture, single women who are emotionally and economically dependent upon their male partners are not empowered to make self-

protective decisions about sexual practices.²⁻⁴ The impact of this phenomenon on the Boston Haitian community is evident in AIDS Surveillance reports, which show that increases in AIDS among women and children highlight the course of the HIV epidemic in the Haitian community.⁵

The imbalances of power in sexual relationships, and the increase in HIV infections among women, suggest that controlling the spread of HIV requires changes in social norms at the community level. Community norms that sanction practices such as men having multiple sexual partners, men's refusal to use condoms, and male domination in decisions about sexual practices, contribute to the increase in HIV-infected females. Shared understanding of these practices must be examined. Also, shared meanings attached to specific behaviors must be examined, such as whether asking a partner to use condoms suggests distrust of one's partner, or the infidelity of the partner requesting condom use. A female's insistence upon the use of a condom when having sex is considered to be a challenge to the male partner's power in the sexual relationship. A male's perceptions of challenges to his power can lead to physical abuse of a female. Therefore, the Haitian community's HIV-prevention strategy must target changing the shared understandings and meanings that define gender roles and power relationships in sexual relationships.

Another population characteristic with implications for HIV-prevention planning is underscored by the fact that none of the respondents identified themselves as homosexual. There may be several reasons for this omission. One reason is that sexual orientation is not a topic discussed in the Haitian community. This finding also relates to the relevance of community social norms in designing prevention strategies. Due to shared meanings that make homosexuality socially unacceptable in the Haitian community, the homosexual population

is not likely to self identify. A concentrated effort must be made to reach this population to ensure that it receives HIV-preventive education, and that HIV-infected individuals receive treatment.

The emphasis the community places on religion has implications for designing health services that support this value. Medical professionals serving the Haitian community must be culturally sensitive to religious beliefs, and, instead of attempting to invalidate individual beliefs, they should provide medical treatment as another source to use to maintain or restore health. Previous studies of HIV prevention in the Haitian community affirm the importance of cultural competence in Haitians' utilization of HIV services and their subsequent compliance with treatment.^{6,7}

The finding that high knowledge levels have not translated into behavioral changes to prevent the transmission of HIV in the Haitian community is consistent with results from earlier HIV research. AIDS research confirms that information and education are necessary, but not sufficient, conditions for behavioral change.^{8,9} Service providers must be cognizant that increasing public knowledge does not automatically translate into self-protective behavior. Bandura pointed out that one of the failures of education as a prevention strategy is that individuals are not provided training to develop competencies required to change behavior.¹⁰ The Haitian community-wide HIV prevention intervention needs to be adjusted to extend the preventive education model to include the behavioral means, resources, and social supports required to change behavior, and to sustain behavioral change.

The finding that the adult Haitian population is sexually active, with sexual activity occurring between men and women, is consistent with the Commonwealth of Massachusetts, Department of Public Health AIDS Surveillance data. The Commonwealth data identified heterosexual sexual contact as

the primary mode of HIV transmission within the Haitian population.⁵ Because the primary mode of HIV transmission in the Haitian community is through heterosexual sex, occasional sex with partners outside a monogamous relationship, especially those who are bisexual or inject drugs, expands the range of potential risk.

Due to the high probability of response bias in self-reported risk behavior, it is difficult to determine the level of risk in the Haitian community. In their study of self-reported behavior, Forsyth and Carey observed that respondents tend to over-report prescribed behaviors, such as condom use and self efficacy, and to under-report proscribed behaviors, such as the number of sexual partners and engaging in unprotected sex.¹¹ Studies of HIV prevention also show that most people do not know how to discuss the subject of sexual history with sexual partners, and when they do, most partners do not reveal the truth about their sexual history.¹² Therefore, one can assume that risk behavior in the Haitian community is more common than the survey data reveals. Based upon this assumption, the findings provide an even stronger argument for adjusting the intervention to include developing competencies necessary to actualize changes in behavior to reduce risk.

The finding that most people have not changed their lifestyles due to the threat of the HIV epidemic is consistent with the population's overall perception that it is not at risk for contracting HIV. This finding is supported by psychosocial theories that identify perception of the susceptibility to, and severity of, a disease to be determinants of risk behavior.¹³ In the case of prevention, individual behavior is tempered by the individual's estimation of personal harm. Individuals who do not perceive themselves to be at risk for personal harm are not likely to engage in self-protective sexual practices. The reality is that the disparity between the HIV infection

rates for the Haitian and the non-Haitian populations is not likely to diminish if Haitians do not change their sexual practices.

Overall, the findings suggest that the Haitian community needs to fine-tune its intervention. The integration of social cognitive learning and social constructionist theories provides a framework for broad-based community transformation. Bandura's social cognitive model of behavioral change focuses on the interrelationships between individual behavior, knowledge, skills, action, and beliefs in self-efficacy, and the interaction between the individual and the social environment.¹⁴ Several elements of the social cognitive model are applicable to the HIV prevention in the Haitian community.

First, the social cognitive model provides a framework for linking individual cognitive processing to reciprocal interaction between the individual and the environment. Second, although the model focuses on individual behavioral change, it acknowledges that preventing HIV requires not only changing one's behavior, but also changing the behavior of another person. Bandura notes that changing the behavior of another requires a higher level of belief in one's ability to change sexual behavior. To address this problem emphasis is placed on self-efficacy as a requisite condition for behavioral change. Bandura suggests that community-wide HIV prevention interventions should develop competencies in negotiating protective sexual practices, and should focus on activities that build self-confidence in one's ability to take self-protective actions. Third, the social cognitive model stresses sustaining behavior as an important element in the strategy to reduce the spread of disease. In the absence of community support, the individual is likely to relapse into former practices.

Social constructionist theory provides a useful framework for designing interventions targeted to changing social norms to support behavioral changes.

Social constructionist theorists postulate that community-level changes will occur when there is a critical mass of strategically placed "change agents" to introduce new understandings and meanings regarding sexual relations and self-protective behaviors.¹⁵ Based upon this theoretical construct, the HIV prevention strategy should introduce information to the Haitian community that can be used to create new shared understandings and meanings regarding sexual practices, and associated consequences. The HIV-prevention intervention participants will become the change agents to transform sexual practices in the Haitian community. These change agents will be equipped with the new knowledge, competencies, and self-confidence to change behavior. Through these change agents, new gender roles and new rules concerning sexual relations will become shared values, resulting in the adoption of self-protective sexual practices. Self-protective sexual practices will become a community norm when a significant proportion of the Haitian population adopts these values. The new community norm will lead to a reduction in the HIV transmission rate within the Haitian population, thus reducing the HIV infection rate disparity between the Haitian and non-Haitian populations in the Commonwealth of Massachusetts.

Using social cognitive learning and social constructionist theories as a guide, the community-wide intervention must incorporate training to develop competencies in negotiating self-protective sexual practices, and should focus on activities that build confidence in one's ability to take self-protective actions. To ensure that individual behavioral changes are sustained, the community must transform community norms to reinforce behavioral changes; ie, the com-

munity's long-term goal must be social change, derived from the transformation of shared understandings and meanings that prescribe and proscribe sexual behavior.

CONCLUSION

The survey findings were used to make changes in the intervention design to increase the likelihood of attaining the goal of reducing HIV transmission rates in the Haitian community. Changes in the intervention design include:

1. The inclusion of domestic violence as a topic in the preventive education targeted to men.
2. Recruitment efforts are targeted to men who have sex with men, a subgroup that was under-represented among intervention participants.
3. Emphasis is placed on skills to negotiate self-protective sexual behavior, and the development of assertiveness training across all targeted groups.
4. Launching a media campaign utilizing billboards and posters throughout the community, designed to effect changes in community norms.

This survey is the Greater Boston Haitian community's first effort to gather comprehensive public health data. The survey served as a catalyst for bringing the Haitian community together to reduce HIV transmission rates. In addition, the community increased its capacity to engage in community-based systematic inquiry, and to use evidence-based information to improve its practice.

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