Published in final edited form as:
Women Health. 2008 ; 47(1): 83–104. doi:10.1300/J013v47n01_05.

“You’ve Gotta Know the Community”: Minority Women Make Recommendations About Community-Focused Health Research

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Abstract

Objectives—To determine what ethnic and racial minority women recommend as the best approaches to participatory health research in their communities. To achieve this goal, this study focused on HIV prevention research.

Methods—In 2003, Seven African American and seven Latina women (ages 33 to 52), all members of an HIV Prevention Collaborative Board, participated in individual interviews, lasting about 90 minutes each. Participants discussed their involvement in participatory research, and made recommendations as to how health researchers might better engage their communities. Data were coded independently by two coders following standard procedure for content analysis.

Results—Women’s voices and expertise can help guide health-related research. This study shows that: (1) participatory HIV prevention research should be founded on trust and commitment, leading to social support; (2) research partners ought to come from diverse backgrounds and be knowledgeable about the community and willing to work on common objectives; and (3) collaborative partnerships ought to portray an image of strength and cohesion, and a clear articulation of the mission around a research project.

Implications—To develop meaningful health research, researchers need to establish long-term ongoing relationships with community collaborators, including minority women from diverse backgrounds. Researchers ought to take a holistic approach working with communities, and ought to consider their research interests vis-à-vis the community’s needs.

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Keywords

Minority women; Community-Based Participatory Research; health research; HIV prevention

INTRODUCTION

Community-Based Participatory Research (CBPR) for health can be conceptualized as an “orientation to research” (Minkler & Wallerstein, 2003, p. 4) that fosters close collaboration between university-based researchers and community partners, so that research questions and procedures can reflect the needs and priorities of residents in their communities—social systems characterized by the affective and personal bonding of its members who may not necessarily live in proximity to one another, but who share a common history (Longres, 2000; Netting, Kettner, & McMurtry, 2004).

Collaboration that encourages community partners to participate fully in the design and implementation of health research represents an opportunity for researchers to engage in ongoing relationship-building with those community partners that are inclined to engage in long-term commitments and to offer their experiences and expertise. In CBPR, intensive and ongoing collaboration between researchers and community partners is not only desired, but is necessary for advancing knowledge (Israel, Schulz, Parker, & Becker, 1998). Therefore, within this orientation, research questions ought to reflect that indigenous knowledge that has been subjugated in favor of more unitary and privileged types of knowledge (Foucault, 1980).

Although the need for indigenous knowledge has been explored elsewhere (Gutierrez & Lewis, 1999), little research is available that employs systematic collection of data from community partners about their recommendations for participatory health research. Researchers have much to learn from collaborators, especially from ethnic and racial minority women, a population at high risk for several health and mental health problems (LaVeist, 2005; Zierler & Krieger, 1997). Racial and ethnic minority women have historically experienced barriers to fully participating in research, to accessing care and to taking advantage of treatment options (Brown et al., 2001; Escobar-Chavez, Tortolero, Masse, Watson, & Fulton, 2002).

It is important that we elicit the opinion of research collaborators, because they can help to bring experiences, perspectives, and knowledge, and thus help researchers address the complexity of health problems we face today (Minkler, 2004). Women’s voices have been historically subjugated, and their perceptions dismissed as unscientific (Lorber, 1994). Nonetheless, the situated voices of minority women research collaborators can advance knowledge about their positions in their communities, while emphasizing researchers’ “responsibility to attend to the voice of those we study not only in terms of what they have to say about themselves but also what they have to say about us” (Crapanzano, 2004, pp. 4–5). Indeed, researchers can learn how best to assist communities in improving their health by listening to resident’s voices.

The present study therefore focused on a group of women who have collaborated in HIV prevention research for the past decade. We chose to focus on HIV research because this is the area of expertise of the authors and of the sample of women chosen for this study. However, the general principles used to develop this study, as well as the recommendations derived from the data, will be useful to researchers studying other myriad diseases.

Participatory HIV Prevention Research and Empowerment

Given minority people’s concerns about the exclusion of their voices from interpretations of sex- and drug-related data, planning close participation of community members is especially important in HIV prevention research (Stevenson & White, 1994). As rates of HIV infection rise in communities of color, especially among young women (Centers for Disease Control and Prevention, 2004), empowering those voices also becomes essential.

Empowerment in participatory health research relates to a conscious decision by researchers and their community partners to deconstruct power relations, and to address cultural, gender, racial, and class differences that might hinder both the processes and the outcomes of research (Ristock & Pennel, 1996). A community empowerment intervention seeks to affect community-wide change in health-related behaviors by organizing communities to define their health problems, identify the determinants of those problems, and engage in effective individual and collective action to change those determinants. The empowerment component ensures that community participants, particularly women of color, are empowered with the realization of their own capabilities to be researchers, become change agents and begin to induce desired changes within their communities (Beeker, Guenther-Grey, & Raj, 1998).

Approaching communities from an empowerment stance, researchers would consult and collaborate with individuals, groups and institutions based in the communities they study. Through ongoing social processes in the course of research, new knowledge can be built, oppressed voices can be revealed, and healthier communities can be developed (Rappaport, 1990).

The literature on community-based participatory and action research suggests that community residents can effectively contribute to the design and implementation of health research. Non-academic members of community-focused research teams have been involved in defining research questions, recruitment of research participants, and data collection and analyses, and thus can become agents of changes in their communities (Beeker, Guenther-Grey, & Raj, 1998; Giachello, Arrom, Davis et al., 2003). Investigators agree that researchers need to engage in ongoing relationship-building with communities (Israel, Schulz, Parker, & Becker, 1998) so as to derive mutual benefits (e.g., higher rates of participation) that may lead to more meaningful health research (Zambrana, 1996). This approach has been identified as an orientation that allows all partners to contribute their strengths, while sharing roles and responsibilities within research partnerships. It thus suggests that collaboration between researchers and community members can ultimately improve public health by pooling academic and local expertise, by enhancing relevance of research questions and results, by developing communityfriendly programs, and by increasing communities' power over research projects (Hall, 1992; Schensul, 1985; Wandersman, 2003).

Challenges in HIV Prevention Participatory Research

Myriad challenges may affect how researchers and community partners work on health problems. These challenges may include the selection of the issue on which the community wishes to tackle and the selection of team members, how to share research findings, and power struggles between insiders and outside allies (Fadem, Minkler, Perry, Blum, Moore, & Rogers, 2003). Even with effort on the part of both researchers and their partners, some of these challenges may not fully get resolved, and, on occasion, the collaboration may not work out. These challenges may be exacerbated in HIV prevention research because HIV transmission is associated with complex social problems that include poverty, profound stigma and discrimination. Providers in the HIV field have faced major organizational and service delivery challenges including the rapidly shifting needs of consumer populations, poor training and role confusion (Poindexter, Lane, & Boyer, 2002), consumers' fear around stigmatization (Breslin, 1999), and lack of trust in communities of color (Dalton, 1989; Pinto & McKay, 2006a, 2006b; Thomas & Quinn, 1991). These issues may impose understandable barriers (e.g., access, recruitment) for both services providers and researchers working with at risk populations.

The HIV pandemic has created a need for researchers to not only explore a wide range of sexual and drug-related behaviors, but also to interact with community members and health practitioners to design and conduct research. Indeed, known principles of CBPR teach us that researchers ought to acknowledge the diverse range of social norms, values, and behaviors of a particular community and to commit to exploring, discussing, and debating topics related to the manner in which individuals and groups conduct their lives (Reece & Dodge, 2004).

CBPR principles have played an important role in health research (see, for example, Minkler & Wallerstein, 2003; Pinto, Schmidt, Rodriguez, & Solano, 2006), and may be particularly suitable in HIV prevention research, a more overall controversial and sensitive issue, compared with other diseases (Morisky, Ang, Coly, & Tiglao, 2004). However, it also suggests that the dynamics in HIV prevention participatory research may differ from research on other diseases that are not as stigmatizing and ostracizing as HIV/AIDS.

The importance of working with community members to design, deliver, and evaluate preventive efforts has been stressed elsewhere (Hatch et al., 1993; Eccles, 1996; Farhall, Webster, Hocking et al., 1998). In our approach to participatory research, community collaborators may assume many roles, and giving advice and directing the focus of research are particularly significant. This approach allows researchers to enter into a relationship with community members, so as to learn how to learn from them, while deconstructing issues of cultural supremacy (Landry & MacLean, 1996). Partnerships that value these ideas have been characterized as being at a high level of collaboration (Hatch et al., 1993).

Working at this level of collaboration, the Collaborative HIV Prevention and Adolescent Mental Health Project–CHAMP Collaborative Board– has increased community input in many research projects and has increasingly helped to determine the leadership, design, implementation and evaluation of several projects, including a 12-session, family-based HIV prevention intervention, the CHAMP Family Program (Madison, McKay, Paikof et al., 2000). This program is family-focused and has been developed with community input (McKay, Pinto, Bannon, & Guillamo-Ramos, 2007). CHAMP provides individualized recruitment (e.g., home visits, phone calls), monetary incentives, and opportunities for learning about intervention research and for developing social networks and support. The program targets 4th and 5th grade youth (9 to 11 years of age) and their caretakers–ethnic minority women in communities with high rates of HIV infection. The program helps participants develop HIV-related protective behaviors.

In an attempt to understand best how to overcome these challenges, we sought to uncover the voices of minority women involved in participatory research by systematizing their recommendations on how researchers can best approach community-based research. Given the contextual characteristics of HIV transmission and the stigma attached to this disease, we also sought to determine the extent to which their recommendations follow known principles of CBPR. This study adds scarce data about community collaboration from the perspective of community residents, minority women, and not researchers whose perspectives on research collaboration are plentiful in the literature.

METHODS

We have asked respondents to provide recommendations for meaningful collaboration between researchers and communities, and have interpreted their voices from an empowerment framework aligned with the tenets of both feminism and community psychology (Maguire, 2001). Our methods draw on contemporary researchers who encourage methodologies that reflect paradigms of empowerment and participatory research (Lincoln & Guba, 2000).

Design and Procedures

The idea for this project arose from discussions during the CHAMP Board's biweekly meetings. Following a participatory orientation, the general procedures for this study were decided in these meetings, and Board members encouraged each other to participate in the interviews that would take place. To address potential interviewer biases, it was decided that no Board member would be interviewers for this project. Institutional Review Board approval was obtained for the study protocol, and informed consent was obtained from all study participants. At a later date, two interviewers, a Master's social work student and a social work PhD candidate, were identified for this project. After meeting Board members at one of their meetings, the interviewers contacted Board members to schedule individual interviews. All members agreed to participate. Since this study focused on female community collaborators, we present here only the data generated by Board women living in the community who represented 50% of the Board's membership.

Each interview was held at a time and place–at work or at home–that fit the participants' needs. Interviews were audio recorded, and ranged from 30 to 90 minutes. In each case, 15 to 20 minutes were set aside for participants' recommendations. Recordings of the interviews were subsequently transcribed by a professional.

Study Participants

The CHAMP Board oversees several research projects, from design of interventions to delivery and testing to dissemination of findings. The Board consists of urban, mostly ethnic and racial minority parents, public school educators and administrators, representatives from community-based agencies, and university-based researchers. Board members have been selected over time in a fashion similar to a snowball sampling. The first board members came from local school PTAs, community-based organizations, and from Columbia University. Board members nominated new members. Candidates were selected based on their record of involvement in their community, and their commitment to community-focused research. Once selected and nominated, candidates were voted on by the full board. Board members are involved in every step of the health research process, and they focus on developing their community's capacity for future empowerment and participatory prevention research. Moreover, this Board also helps to identify and pursue additional funding for HIV prevention research. (For more details on the process of establishing the Board and recruiting members, see McKay et al., 2007.)

For this study, we drew on data from 14 African American and Latina women Board members to explore their experiences with participatory research. These women were selected for this study because their knowledge was unique. They have collaborated on all phases of HIV prevention research–as participants in a family-based HIV prevention intervention trial, as facilitators of that intervention, and as members of the Collaborative HIV Prevention and Adolescent Mental Health Project (CHAMP), a collaborative board that oversees several HIV prevention research projects. Because each of these women had been participants in the CHAMP family-based intervention trial, they represented minority women who might be participants in health research.

The level of commitment these women have made places each in the role of key informant, and this is the main reason we draw recommendations from them. Among these 14 key informants, 7 were African American and 7 were Latinas. Their ages ranged from 33 to 52 years (Mean = 43.64; SD = 5.67). We are not providing more detailed demographic information so as to preserve confidentiality.

Instrument

Participatory research sensitizing concepts served as a framework for the interview protocol, and thus for analysis of the data. The interview comprised rapport-forming, demographic, descriptive, and analytic semi-structured questions about participatory HIV prevention research. Questions were followed by prompts for clarification when necessary (Fontana & Frey, 2000). Participants discussed their histories of involvement in participatory research as members of a Collaborative Board and provided advice to researchers about collaborating with minority communities. This paper draws on recommendations of all the women on the Board who lived in the community from which the Board was originated.

Interviewers took care to explore participants' advice, prompting only for clarification. The key prompt question for recommendations was "If you could teach a group of university students, faculty, and researchers about working and collaborating with communities, what would you say?" This prompt led to follow-up questions: (1) "What characterizes ideal collaborators?" (2) "What image community partners and university-based researchers should project on the community?" and (3) "How researchers ought to approach HIV prevention research?"

Analytic Approach

Analysis of recommendations was informed by ideas emerging from the full transcripts.

Data sampling—From a random sample of three transcripts (about 30% of the interviews), two coders identified first independently and then by consensus key units of analysis in the texts. These units consisted of grammatical segments (sentences and themes) and/or larger pieces of text.

Finding themes—Two independent coders, one whom was one of the interviewers, read the text of the interviews line-by-line, looking for opinions, ideas, and assumptions about HIV prevention research collaborations and collaborators. Several areas of recommendations emerged from the analyses of the two coders. Through co-coding and by consensus, the coders developed major themes (Silverman, 2000).

Building codes—Upon agreement around key themes, coders created a grid of codes that were applied to the remaining interviews. No theme was entered in the grid until the coders, through discussion, reached a consensus. Because we coded large pieces of text, and because we reached a consensus in choosing excerpts (themes and sub-themes), we came to 100% agreement, and thus we did not need to calculate intercoder reliability coefficients.

Marking text—All other transcripts were coded using the grid as a guide. By consensus, the coders added a few new categories, and reached agreement on the final scheme.

Data interpretation—The collection and analysis of the data, as well as the interpretation of the recommendations, followed the basic guidelines of content analysis (Charmaz, 2000; Patton, 2002). Moreover, we submitted our results for review and interpretation (Lincoln & Guba, 1985) by five members of the CHAMP Collaborative Board, four of whom participated as informants in the present study. They reviewed the manuscript to see how well our explanations fit the descriptions of themes that emerged from the data (Janesick, 2000). They read the manuscript independently, held a meeting to discuss it, and one of them reported back to the first author. They helped clarify key points in the manuscript while validating the way in which the results, specifically the interview excerpts, lent meaning to the themes explored.

RESULTS

Only themes and sub-themes that appeared in at least two-thirds of interviews were reported. We present excerpts that closely represent the opinions of the majority of women respondents. All participants spoke of at least two of the following themes: (1) key ingredients for working and maintaining collaborations; (2) personal qualities that characterize ideal research partners, and (3) how research partnerships ought to approach community health.

Key Ingredients for Meaningful Collaboration

Researchers ought to build relationships and trust—Respondents identified several elements that might enhance research collaboration, making the research more meaningful to both researchers and community partners. Respondents agreed that the foundation of collaboration should be relationship-building and development of trust between researchers and community members, before actual research takes place.

> First of all, I would tell [researchers], you know, when they are going into a community, the first thing, they would have to win over the community's trust . . . that's a big plus, you know, if you don't get their trust and for them to really trust you, you stand to have a battle ahead of you.

> I would say that [researchers] have to come to the community first, get involved, before they decide to do anything. Because I, as a member of the community, I would like, [for example] you, now, you came to interview me, maybe in the near future, if you want to work with the community, I'd be more open to you.

> A lot of times when [researchers] come just like that, people don't trust. [People] don't know where they come from, how they started. But it's good to start coming to the community little by little first, then you could come to work with the community, because a community likes to see people involved first before they bring any problems.

> [Researchers need to show] that they really care for the community, that they really love what they do for the community … because, when you come to the community you have to come as a … like you are part of the community.

Researchers ought to make long-term commitments—Long-term commitments among research partners were also discussed as key ingredients of meaningful collaboration. Commitment to one another and to the community seems to have inspired this group to collaborate with researchers. About their own commitment to research collaboration respondents said:

> [We] hold to [our] meetings and [we're] there at those meetings every single time they have one. That's how you know … they're committed. They have questions and information, and everything they do they give it out to you … the information. You need to know something, you call them up and they're there. And if they're not there, you leave a message. They'll call you. They make sure they call you back. So, I mean, I find that they are very committed in what they do.

> [We] are ready to work … we have open discussions. It feels, from time to time, like … people are not only committed, but they're so open … and honest. I really like the positive honesty. 'Cause if you're honest, then I can feel like I trust you. And that has a lot to do with it, being open, open-minded, and honest, and determined.

Characterizing Ideal Research Partners

Respondents gave opinions as to what they perceived as important qualities in both community collaborators and researchers. Their opinions on what makes an ideal community collaborator seem to stem from how they perceive themselves, and from their experiences working with community residents on the collaborative board.

Research partners ought to be diverse and knowledgeable—Participants reported that both researchers and community members ought to come from diverse backgrounds, and ought to be knowledgeable about the community and its needs.

> You have a lot of people from the Board with a lot of strengths, different types of strengths … we have doctors, we have professors, we have ordinary peoples, we have teachers, we have everything on the Board, so whatever you need is basically there … and you can get any question that you want answered.
>
> We have many cultures in this neighborhood … you can't just focus on one culture. [Collaboration] has to be a multicultural thing.
>
> I think that [collaborators] should bring their ideas, their educational background and their support to all of our communities, not just one community, but everyone.

Researchers ought to get involved with the community—Respondents also said that researchers needed to develop close relationships in the communities where they work. This can be accomplished by visiting the community, and by learning the demographic makeup of the community and its way of life.

> If [researchers] decide to work with one specific community, [they should] educate themselves about the community … visit the community. See, you know, the faces around the community. See what are their needs.
>
> Well, first thing to … the … you've gotta know your … the community well. You have to know what the community, the population's made up of. After you do your research you know who the people are, where their cultural backgrounds are, what makes them, what motivates them, what doesn't motivate them. Because then when you come out and you meet with people in the community and you can … tell them, "Yeah, I know about this. And I know about your foods, and I know about …" Then the people feel more relaxed. They feel like, "Oh, this person's really interested in me. They've taken out the time to know about my culture and about me."
>
> [Researchers] have to learn the different religious status of the people in the community because we have African, we have Jamaican, we have Hispanic, Mexican … and they all have different religions and different a way of living a life. So there's something that we have to learn their customs, and once we learn their customs, it will be easier to relate to them and to be able to talk to them.

Approaching Community-Based Health Research

Research partnerships ought to be well articulated—Respondents reflected on the image that collaborative research partnerships ought to present to the community they represent. Respondents said that all involved ought to articulate an image of strength, cohesion, expertise, and a clear mission. This would stress the purposes of research projects pursued by the partnership.

> First of all, we [collaborators] would have to advertise and let the people know who we are, our mission, you know, what we stand for, and how we can help the community.

> The way we are as one, that’s what we should project in our community.
>
> We’re strong … and we really try to live up to our mission statements.
>
> If you are making plans, have plans being realistic. You want the people to see that you’re realistic in your plan, you know that, that it’s real. That what you’re putting in paper is working. You gain their trust.
>
> Another thing is to be well versed in what you’re going out there to help the community with. Be out, be able to give real good information, not have half information. Like, if you’re out there to help the community, go well equipped with all the information … that you know the community you’re trying to reach.

Research partnerships ought to have a holistic approach to health problems— Although the women in the study came from a Collaborative Board that focused primarily on HIV prevention research, they agreed that community-researcher partnerships do not need to work exclusively on one health issue. Indeed, they noted that, once a partnership is formed around one issue, for example, HIV prevention, it can work to combat other health problems in the community.

> Well, I know that [the Board] is addressing the violence coming in, ’cause there’s a lot of violence around, especially with domestic violence. … Umm, the drugs … there’s a lot of drugs out there. And that’s an issue that where there’s drugs involved, alcohol, then there’s violence. [The Board] should try to get a little more involved in the drugs cause once there’s other drugs involved, alcohol, then there’s all that other stuff coming in … there’s sex, and there’s the violence.
>
> [Collaborative approaches] can help with other things like education. Like, there’s a lot of problems here with the reading level … and the math and stuff like that. If a program can be developed to help the community access some low cost or no cost tutoring for their kids, I’m pretty sure the parents would go for it.

Research partnerships ought to engage in myriad activities—Respondents in this study suggested the need for educational and social activities that would reflect a holistic view of community health. These may help convey the image the respondents described above.

> Well, they need, some kind of program for the kids in this area to get into something. To keep them off the streets, to keep them from getting into trouble. Something to, like, somewhere where they can learn as well as playing. They can get to learn, they can learn about safe sex, you know, and not to use drugs, and violence, like, have a place where they can go.
>
> Like, maybe, like fa … fairs . . ? *¿Una feria?* It’s, uh, is that when they put like tables with little brochures … sometimes people like get curious outdoors … like put a table, balloons, a group of people.
>
> Maybe there’s something that I’ve been doing for a while, and I say, “Oh, there’s a change!” Stay[ing] in a community or an environment for so long, you’re like, okay, let me find a change. What can I do to make it different? Instead of going to the park all the time by yourself, have the community go to a barbecue or a picnic, or, we all go probably to Great Adventures, or have it a communitybased thing, so people are more together.

These activities suggest bringing families and community members together to help combat myriad psychosocial and health problems. Recommendations also included activities such as after school programs, sports, health fairs, educational workshops, and training programs, in connection with HIV prevention research.

DISCUSSION

Results revealed key ingredients for meaningful research collaboration, elucidating that prior to initiation of community research projects, researchers' involvement with the community is essential. Mutual commitment appears to be an essential element of relationship-building and development of trust among community members and researchers. These findings appear in other studies, and are aligned with perspectives that articulate women's development of support systems to combat power differentials (Rosser & Miller, 2000; Schulz et al., 2003).

This study specifically adds to the literature data that demonstrate, from the voices of community residents, minority women, that meaningful health-research ought to be founded on trust and commitment, that researchers must be knowledgeable about the community with which they work, and that research partnerships ought to articulate a mission that reflects both community and researchers perspectives.

Reflecting assumptions of participatory research, respondents expressed a desire for researchers to make long-term commitments to the communities in which they work. Commitment can help create a solid foundation upon which meaningful research questions can be posed and collaboration could then be sustained overtime (Israel, Schulz, Parker, & Becker, 1998). Ongoing renewal of this commitment and trust-building could help maintain research partnerships over time.

Diversity appears to be an important issue to respondents who themselves represent diverse ethnic, racial, professional, and personal experiences. In order to establish meaningful health research in communities of color–those most at risk for health problems–researchers need to recognize that communities are not homogeneous systems of similar individuals contained in a geographic space. Combining diverse backgrounds, including researchers, may lead to research that is relevant to the community at large, and not discrete sectors that possess more power (McKay et al., 2007).

The recommendations made by participants call for researchers to establish personal relationships with community members, which may require a level of closeness difficult for researchers to achieve, given the demands of a career in health research. Nonetheless, both personal and cultural differences must be confronted before meaningful research can occur. Therefore, in collaborating with community partners, researchers should explore and practice values–trust, honesty, and open communication–that are integral parts of our day-to-day social interactions. Relationship-building can lead to the resolution of power imbalances, disagreements and frictions (Ochocka, Jansen, & Nelson, 2002).

Statements about the representation of collaborative research reveal how some of the key ingredients identified above–trust, togetherness, commitment–convey respondents' notions of cohesion and a clear mission as essential for approaching community health research. Moreover, they point to respondents' inclination to disseminate knowledge ("good information") in community-based outlets. Moreover, the idea about the multiple roles of collaboration, of working on different health problems at the same time, suggests a holistic approach to community health that reflects ecological models for both research and practice (Bronfenbrenner, 1990). This idea also suggests the need for bringing together all resources available in a community, in order to address agreedupon health problems.

The results also suggest that communities ought to help prioritize their needs and develop relevant programmatic responses for multiple health problems. However, little is known about how researchers, who may be experts in one particular area, can develop models of research that truly encompass communities' priorities in a more holistic fashion. Further research in this area is needed. Moreover, the social activities recommended by participants–after school programs, sports, health fairs, educational workshops, and training programs–could become spaces for community members to speak about health research and give programmatic responses to community needs. Moreover, these suggestions point to concepts of relationship-building and commitment among women explored here and elsewhere by other writers (Gilligan, 1982; Robbins, Szapocznik, & Tejeda, 2003; Schulz et al., 2003).

IMPLICATIONS FOR COLLABORATION IN HEALTH RESEARCH

Communities of color have begun to demand that research show greater sensitivity to communities' perceptions, needs, and unique circumstances (Green, 2001). Effective research requires researchers to attend to the social and cultural fabric of the community being studied and to understand the extent to which that fabric influences risk behaviors (Reece & Dodge, 2004). We found evidence, from the voices of minority women who were community research collaborators, that at the foundation of participatory research there should be trust and commitment. Research partners ought to come from diverse backgrounds, be knowledgeable about the communities with which they work, and be willing to work on agreed-upon health concerns. Collaborative partnerships ought to portray an image of strength and cohesion, and a clear articulation of the mission around their research projects.

The notion of relationship-building pervades all nine principles of CBPR, and has been amply explored in the participatory and action research literature. Researchers and community collaborators can use relationship-building to work through power differentials and issues of mistrust of research, and to come to terms with conflicting agendas and priorities (McKay, Pinto, Bannon et al., 2007; Schulz et al., 2003). Since HIV-related research requires the exploration of both sexual and drugrelated behaviors viewed as taboo, issues of trust might be even more prominent in this type of research.

The results clearly reflect, to differing degrees, all principles of CBPR thus far described in the participatory research literature (Israel, 1998; Minkler, 2003). These principles highlight that researchers ought to address health issues that are relevant to community residents, to establish study aims and methods driven by the needs of communities, to disseminate knowledge in academic and community-based media, and to develop programmatic responses to community needs. Nonetheless, in this study, respondents particularly recommended that researchers forge relationships with community partners so as to become part of their community. Given the history of misleading research (e.g., the Tuskegee Syphilis Study) and the possible misinterpretations of sexual and drug practices (e.g., deviant and promiscuous) in minority communities where we study HIV prevention (Stevenson & White, 1994; Wyatt, 1997), the notion of ongoing relationships between researchers and community needs to be further explored and integrated into the principles of CBPR.

Researchers would need to make their commitments early in the relationship, before a project actually starts, a notion that could also be articulated and integrated into the principles of CBPR. Also, because researchers come from different racial and ethnic backgrounds and draw on the values of their disciplines, combining diverse backgrounds may lead to research that is more relevant to community members and not only specific sectors of the community that possess more power or influence. This notion should be integrated into the principles of CBPR.

This study portrays the opinions of a small group of women community collaborators with experience in HIV prevention research. Because each of these women was a Board member, socially acceptable response bias could have occurred. However, because the present study did not focus on the specific works of the Board, this type of bias was probably minimal. By focusing on recommendations for health research in general, respondents were able to give their candid opinions without referring to any specific work of the CHAMP Board.

Generalization of their advice must be made only with caution, knowing that their recommendations may not be applicable to all types of research, or in all communities. As stressed in the literature, principles of CBPR ought not be adopted nor imposed on communities as a definitive set of values (Schulz et al., 2003). The same is true for the recommendations made by our participants, which also comprised a small and potentially non-representative sample, since the respondents were selected specifically for their unique knowledge. Because one of the interviewers was also one of the coders for the study, bias in coding and interpreting the results could have occurred. To address this issue, we used two independent coders and reported only themes and sub-themes that were independently coded by both coders and that appeared in at least two-thirds of interviews.

Nonetheless, the systematic collection of recommendations from minority women who have acted as community-based research partners advances knowledge by uncovering voices that have been excluded from research discourses and have been underrepresented even in participatory health research.

Acknowledgments

The authors would like to thank the CHAMP Collaborative Board, especially those board members who reviewed earlier drafts of this paper. This study was supported by grants from NIMH (R01 MH 63622) and the W. T. Grant Foundation. At the time of this study Rogério M. Pinto was a post-doctoral fellow supported by a training grant from NIMH (T32 MH19139, Behavioral Sciences Research in HIV Infection) at the HIV Center for Clinical and Behavioral Studies (P30 MH 43520). HIV Center's MOSAIC Program was supported by a grant from the Ford Foundation (Gender, Sexuality, and Health: Sexuality Research Training Program for Ethnic Minority Undergraduate Students).

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