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Using Community-Based Participatory Research to Prevent HIV Disparities: Assumptions and Opportunities Identified by The Latino Partnership

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Abstract

Background—HIV disproportionately affects vulnerable populations in the United States (US), including recently arrived immigrant Latinos. However, the current arsenal of effective approaches to increase adherence to risk-reduction strategies and treatment within Latino populations remains insufficient.

Methods—Our community-based participatory research (CBPR) partnership blends multiple perspectives of community members, organizational representatives, local business leaders, and academic researchers to explore and intervene on HIV risk within Latino populations. We used CBPR to develop, implement, and evaluate two interventions that were found to be efficacious.

Results—We identified seven assumptions of CBPR as an approach to research, including more authentic study designs, stronger measurement, and improved quality of knowledge gained; increased community capacity to tackle other health disparities; the need to focus on community priorities; increased participation and retention rates; more successful interventions; reduced generalizability; and increased sustainability.

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Conclusions—Despite the advancement of CBPR as an approach to research, key assumptions remain. Further research is needed to compare CBPR to other more traditional approaches to research. Such research would move us from assuming the value of CBPR to identifying its actual value in health disparity reduction. After all, communities carrying disproportionate burden of HIV, including immigrant Latino communities, deserve the best science possible.

Keywords

CBPR; HIV prevention; Latinos

Introduction

Latinos in the United States (US) are disproportionately affected by HIV and sexually transmitted diseases (STDs). Latinos have the second highest rate of AIDS diagnoses of all racial and ethnic groups, accounting for nearly 20% of the total number of new AIDS cases reported each year; this is three times the rate of new cases among non-Latino whites.¹ Rates of gonorrhea, chlamydia, and syphilis are two to four times higher among Latinos than among non-Latino whites.² Many southeastern states in the US, including North Carolina (NC), consistently lead the nation in reported cases of AIDS, gonorrhea, chlamydia, and syphilis.¹⁻³ HIV incidence rates in NC are 40% higher than the national rate, and HIV and STD infection rates for Latinos in the state are three and four times that of non-Latino whites.⁴

Our team of community members, including lay members of the immigrant Latino community; organizational representatives from AIDS service organizations (ASOs), health departments, and Latino-serving community-based organizations (CBOs); local business leaders (e.g., tienda [grocer] and cantina [bar] owners and staff, Spanish-language media); and academic researchers has been engaged in research to explore HIV risk and a broad range of intervention approaches to meet the priorities and needs, and build on the assets, of recently arrived immigrant Latinos.⁵ We initially focused on adult heterosexually active Latino men in NC; however, based on the trust gained within the Latino community and expanding community needs and priorities, our research has expanded to identify and address the HIV prevention and sexual and reproductive health priorities of Latino men who have sex with men (MSM) and Latina women. Simply, our research is conducted in partnership with the Latino community and follows a systematic process that begins with formative research and moves to action, including intervention development, implementation, and evaluation. This approach is known as community-based participatory research (CBPR), which is designed to harness the multiple perspectives and strengths of community members, organizational representatives, business leaders, and academic researchers.^{5,6}

We briefly present how our partnership, known as The Latino Partnership, defines and applies CBPR to understand the context of HIV risk and develop and test interventions to reduce risk among immigrant Latinos. We also outline key characteristics of CBPR that have emerged from our research with Latino communities and assumptions of CBPR that

our partnership has identified to provide direction for future research in applying CBPR approaches within HIV prevention.

Community-Based Participatory Research (CBPR)

Many interventions designed to reduced health disparities, including disparities in HIV infection, have not been as successful during efficacy trials or translation and dissemination as hoped. Traditional “outside-experts” (e.g., researchers) may have limited appreciation of how contexts and individuals interact.^{7,8} Thus, understanding and intervening on the complex behavioral, situational, and environmental factors that influence HIV risk may benefit from the multiple perspectives, experiences, and expertise of community members, organizational representatives, business leaders, and academic researchers. Blending the lived experiences of community members, the experiences of organizational representatives based in service provision, and sound science has the potential to develop deeper and more informed understandings of phenomena and produce more relevant and more likely successful and impactful interventions designed to promote community health and reduce health disparities.^{5-7,9} CBPR recognizes that an outsider (e.g., researcher), can work best with community partners, who themselves are experts. CBPR is a collaborative research approach designed to ensure and establish structures for participation by communities (including those community members affected by the issues being studied); representatives of CBOs, health departments, and local businesses; and academic researchers in all aspects of the research process to improve health and wellbeing through multilevel action, including individual, group, community, policy, and social change. CBPR emphasizes co-learning; reciprocal transfer of expertise; sharing of decision-making power; and mutual ownership of the processes and products of research.^{5,8}

CBPR is not a methodology; it is an approach to research. Common values underlying CBPR that members of our partnership have identified include: (1) participation of lay community members, organizational representatives, local business leaders, and academic researchers throughout all phases of the research process; (2) agreement among partners on the goals and aims of the research; (3) ongoing commitment, cooperation, and negotiation among partners to work towards and meet agreed-upon goals; (4) transparent processes with clear and open communication within the partnership; (5) multidirectional exchange of information and learning among partners; (6) multi-directional capacity development among partners; (7) a focus on community empowerment and an assets orientation to health promotion and disease prevention; (8) ongoing reflection among partners to ensure inclusion and ongoing adherence to values, partnership principles, and goals and aims; (9) conflict among partners as a catalyst to improve research processes and outcomes; (10) shared power and resources among partners; and (11) the movement of research to community change and improved health.

CBPR and HIV Prevention among Immigrant Latino Communities

Our partnership has successfully used CBPR throughout all phases of the research process, e.g., assessment and prioritization; problem definition; methodology selection; data collection, analysis, and interpretation; dissemination of findings; and application of the

results (action). We abide by principles of partnership (published previously¹⁰) that are designed to ensure that trust is built and maintained; all voices are heard and validated; and decisions are made based on the insights of all partners. For example, Latino community members and representatives from CBOs provide insights into the priorities and needs of the Latino community and guidance into research question formulation, research design, data collection and instrumentation, intervention development and content, and dissemination, including intervention manual development and manuscript preparation. Their role is not limited to establishing priorities, providing the formative data that guides intervention content, or serving on community advisory boards; rather, they are actively involved throughout the entire research process as co-researchers.

Adhering to CBPR values, principles, and approaches, our partnership has developed multiple HIV prevention interventions designed for Latino communities. Two of these interventions have been found to successfully increase condom use and HIV testing among heterosexual Latino men: (1) *Hombres Manteniendo Bienestar y Relaciones Saludables (HoMBReS)*, a lay health advisor intervention that harnesses the strengths of community-based soccer teams to promote social support among Latino men,¹¹ and (2) *HoMBReS-2* a two-session peer-led small-group intervention.¹² Both of these interventions were based on community priorities; were designed by CBPR partnership members representing Latino men, representatives from AIDS service organizations (ASOs) and Latino-serving organizations, business leaders, and academic researchers.

Assumptions of CBPR

Despite the promise of CBPR and our partnership's successes, there remain assumptions associated with the rationale and perceived benefits of CBPR as an approach to research. Through the process of developing, implementing, and evaluating the *HoMBReS* and *HoMBReS-2* interventions, our partnership has identified seven assumptions associated with CBPR that deserve further research. These assumptions are outlined in Table 1.

First, CBPR is based on the premise that study designs are more authentic, measurement is stronger, and knowledge is improved through the inclusion of multiple perspectives of partners. The inclusion of a variety of perspectives might yield better study designs and measurement and more informed understanding of health-related phenomenon, but it is not certain whether CBPR is uniquely key to this process or whether carefully designed studies that are based on thorough preliminary research could yield a comparable understanding of health-related phenomenon. We do not know, for example, whether our interventions required a CBPR approach throughout the process, from formative data collection through intervention evaluation, to be successful.

Second, we often assume that the involvement of community members as co-researchers in CBPR studies will result in capacity development that is transferable to solve other health-related problems that communities face. Communities that face HIV-related health disparities, for example, also tend to be affected by other health disparities. Unfortunately, there has been little empirical data to support the idea that interventions developed using CBPR approaches to address one health disparity, such as HIV infection rates, will build

skills that will be harnessed to change another, such as diabetes. Our partnership has identified ways in which partnership has built member capacity (e.g., grant writing, budgeting, public speaking, and advocacy skills); however, we have not been able to link these skills to changes in health besides HIV. In fact, making these linkages would require a long-term research (and funding) investment given the time needed to effect distal outcomes.

Next, the identification of community priorities is a key step in CBPR. However, academic researchers must be honest about where their interests and skills overlap and complement community priorities. Academic researchers should not necessarily focus on community priorities without regard to the epidemiologic data; in fact, community members and organizational representatives may rely on academic researchers to provide that epidemiologic data and thereby provide a context for various perspectives. Thus, multi-directional education and ongoing negotiation among all partners are warranted to establish priorities.

Fourth, it is widely assumed that CBPR increases study participation and retention rates. Our own studies have had high participation rates (i.e., 95%) and retention rates ranging from 81% at 18 months¹¹ to 98% at three-month follow-up.¹² We attribute our success to our CBPR approach that includes nurturing relationships and trust building; however, we also take a variety of well-established steps designed to ensure participation and retention (e.g., increased compensation for data collection assessments longitudinally, provision of laminated wallet-sized cards that include toll-free telephone numbers to stay in contact and report contact changes). Thus, teasing out the contributions of CBPR from established and carefully implemented techniques known to increase participation and ensure retention needs exploration.

It is also assumed that CBPR results in more successful interventions. Although many members within our partnership agree, it is not clear whether the process of CBPR yields more successful interventions or whether key individuals or research teams yield success. In our research, project staff (e.g., data collectors and interventionists) come from the Latino community itself; they are very closely connected to community members. It may be that the interventions are more successful because of CBPR or it may be that these community members do what it takes to make the interventions meaningful for participants as they implement it; the interventionist and the intervention may not be easily separated.

Furthermore, it is assumed that the precise tailoring of an intervention to a specific community or even geographic location may limit its generalizability and applicability in other communities. Our partnership has been careful to ensure that the two efficacious interventions that we developed for Latino men may be used in other communities after certain adaptations are made. For example, these interventions include a DVD scene that shows a Latino man going through the process of being HIV tested in local health departments. He role models dealing with the challenges that one faces in NC health departments: a security guard at the front door, limited Spanish-language interpreters, etc. This scene is key to the intervention, serving to demystify the testing process, role model how challenges can be successfully overcome, and trigger discussion about testing.

However, for this DVD scene to be meaningful in other communities, it needs to be adapted. Thus, our partnership tried to strike a balance between precise tailoring and generalizability.

Finally, CBPR has been linked to increased sustainability. Some interventions may not warrant sustainability (e.g. interventions that do not produce desired results); however, it has been suggested that some successful or promising interventions may be sustained by the community. For example, after an intervention has been found effective, an ASO, CBO, or health department may adopt the intervention as a program within its scope of work. However, in our own experiences with *HoMBReS* and *HoMBReS-2*, sustainability has not occurred. It has been only through further funded CBPR that we have been able to design new studies to examine impact of *HoMBReS* by comparing rural versus urban communities, longer-term intervention effects, or the adaptation of the intervention for other populations (i.e., Latino MSM and Latina women).

Discussion and Conclusions

The question underlying the use of CBPR, in general, and in HIV prevention, specifically, is: how can we separate the impact of CBPR from the other variables that may influence outcomes. For example, what roles do the investigators' training, previous experiences, skills, and philosophical perspectives have on the success of the research study? What roles do the research team's training, previous experiences, skills, and philosophical perspectives have on the success of the research study? It may be that the conceptualization of CBPR as a partnership approach to research obscures the other variables that are important to the success of the research. For example, members of our partnership work well together because members are committed to HIV prevention and have key complementary abilities and skills that help to ensure the success of our interventions rather than because we established structures for participation by members throughout the research process. Because we want to make a difference in the HIV epidemic within the local Latino community, our partnership is committed to working together to blend perspectives and expertise.

Our partnership has been able to combine authentic partnership with solid research to improve health outcomes among immigrant Latinos. However, we contend that we cannot confuse assumptions about CBPR and its effects with what is known empirically. Further research is needed to test these assumptions. A possible first step could be a meta-analysis describing differences in the processes and outcomes associated with traditional versus CBPR-designed randomized controlled trials (RCTs). These comparisons could guide future exploration of, for example, differences in recruitment and retention strategies; staff and community commitment and involvement; and innovativeness and cultural congruence of intervention strategies, activities, and materials. In addition, a more in-depth process evaluation could examine the roles of CBPR partners (e.g., backgrounds, motivations, commitment, and personal identification with CBPR studies), involved in developing trials that use CBPR. This would be important to discover important cogs in the process and inform the potential added value of CBPR. Of course, the ultimate test of CBPR would be to compare communities that used CBPR and communities that took a more traditional approach to reduce HIV disparities and follow the process and outcomes longitudinally.

Of course, these types of studies explore only the utilitarian aspects of CBPR; they do not touch on ethical considerations. Because CBPR allows for shared power and knowledge creation, it may be a more ethical approach to research, preventing researchers from having a monopoly over knowledge.¹³ Philosophical considerations balancing power and knowledge generation also should be explored.

Our partnership is committed to CBPR as an approach to HIV prevention. However, just as we are committed to thinking critically and creatively about assumptions we have about what will and will not be effective in immigrant Latino communities and what is meaningful in these communities, we are committed to thinking critically and creatively about CBPR to move the science of CBPR forward. CBPR has come far and still has far to go. It is an important step in the process to think more creatively about HIV prevention and other health outcomes important to our communities and partners.

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Table 1

Assumptions of CBPR that Deserve Exploration

1	Study designs are more authentic, measurement is stronger, and thus knowledge is improved
2	Community members increase capacity from their participating as researchers
3	CBPR must focus on the priorities of community members
4	Study participation and retention rates increase
5	Interventions are more successful
6	Tailoring reduces generalizability
7	Sustainability increases

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