Community-Based Participatory Research: An Introduction for the Clinician Researcher

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Chapter Overview

Despite the strides that have been made in overall health status in the United States, not all communities are benefiting equally from current medical and health advances. In fact, many of the complex health problems that persist in the United States have proven to be ill suited for traditional "outside expert" approaches to health research, health improvement, and intervention development and implementation. To decrease the growing gaps in health status among vulnerable communities such as minority (e.g., racial/ethnic, sexual orientation) and economically disadvantaged communities, alternative approaches to health research, health promotion, and disease prevention are being explored and promoted. Community-based participatory research (CBPR) is an approach to research designed to promote community health through the establishment and maintenance of community partnerships. Rather than a clinician researcher coming into a community "knowing" what is best for a community, a partnership approach to research benefits community partners, community-based organizations (CBOs), and researchers alike.

A partnership approach promotes health and aids in disease prevention because, among its strengths, it creates bridges between communities and researchers; incorporates local knowledge and local theory based on the lived experience of members of the communities involved; ensures the development of appropriate research design and methods; and lends itself to the development of culturally relevant measurement design and instrumentation. Partnerships enhance both the quality of data collected and the validity of findings and their interpretation.

In this chapter we define and describe the advantages and processes of CBPR. We also describe why CBPR is an appropriate approach to research within the historical context of the physician assistant (PA) profession. We then introduce four research methods and describe how a CBPR approach may be applied and incorporated. Finally, we offer a case example of the application of CBPR in an ongoing research study.

Introduction: Community-Based Participatory Research Defined

Emerging evidence suggests that through a process of partnership that includes lay community members,
community representatives, and clinician researchers, advances in health and reductions in health disparities can occur as health promotion and disease prevention approaches, strategies, and efforts increase in authenticity. To truly understand community health, community members participate in the research process to guide the study and intervention design, ensure the accuracy of measurement, and support the interpretation of results. However, partnership is not easy; clinician researchers must establish and maintain trusting, authentic co-learning partnerships with community members if partnerships are to function well and improvements in health are to occur within communities, especially the most vulnerable among them.

CBPR is an approach to health and research intended to increase the value of studies for both community members and researchers. CBPR is a collaborative research approach that is designed to ensure and structure participation by communities affected by the issue being studied, by representatives of organizations, and by researchers in all aspects of the research process (Box 8-1).

CBPR emphasizes co-learning and the reciprocal transfer of expertise, decision-making power, and the ownership of the processes and products of research. This approach involves a strong partnership in which all parties (e.g., lay community members, CBO representatives, health department representatives, and researchers) participate and share control over all phases of the research process. These research phases typically include:

- Identifying research questions;
- Assessing community strengths, assets, and challenges;
- Defining priorities;
- Developing research and data collection methodologies;
- Collecting and analyzing data;
- Interpreting findings;
- Disseminating of findings; and
- Applying the results to address community concerns through action or intervention.

While participation of the affected community in all research steps is critical to CBPR, another hallmark of CBPR is the transformation of findings into action. The accumulation of knowledge is important for the progression of science and understanding; however, the priority for most community members and CBO and health department representatives is the application of findings to improve the health status of community members, including friends, neighbors, families, consumers, patients, and clients. Furthermore, growing concern exists that the pendulum has swung too far toward "research for research sake" without the application of new knowledge to effect change to improve the health outcomes of populations and community members. Actions may include individual-level change interventions, community-level interventions, and policy advocacy and change interventions.

CBPR relies on community participation to ensure that the research questions asked are important not only to the clinician researcher for accumulation of knowledge, but also to the community members themselves. CBPR helps to ensure that the methods used are reasonable and authentic to existing community structures and experiences, and as noninvasive as possible. Finally, the increased validity of findings from CBPR yields more effective actions or interventions in health care because of its base in community participation.

Table 8-1 illustrates the advantages of using a CBPR approach, as summarized from the literature.

### Research Paradigms

All research approaches, including the design of a study and the methods selected, reflect a specific research paradigm. Research paradigms are defined as a set of basic beliefs about the nature of reality that can be studied and understood. These basic beliefs are accepted simply on faith, and, however well argued, no way exists to establish their ultimate truth. The positivist and post-positivist research paradigms, for example, hold that a single reality on how things really are and really work exists to be studied and understood. The positivist research paradigm posits that this single reality can be fully captured; this paradigm is reflected in experimental research designs and methods, which are used most often in the basic sciences. The post-positivist research paradigm, in contrast, holds that this single reality can only be approximated and is reflected in quasi-experimental research designs and methods, used most often in the social and behavioral health sciences. Both experimental and quasi-experimental methods require objective detachment between researchers and participants so that any influence in either direction (i.e., threats to validity) on what is being studied can be eliminated or reduced.
Table 8–1
Advantages of Community-Based Participatory Research

- Enhances data relevance, usefulness, and use
- Improves the quality and validity of the research by engaging local knowledge and local theory based on the lived experiences of the people involved
- Recognizes the limitations of the concept of value-free science and encourages a self-reflective, engaged, and self-critical role of researchers
- Recognizes that knowledge is power, and thus knowledge gained can be used by all partners involved to direct resources and influence policies that will benefit the community
- Overcomes the fragmentation and separation of the individual from his culture and context
- Aims to increase health and well-being of communities involved, both directly through examining and addressing identified needs and indirectly through increasing power, control and skills
- Joins partners with diverse skills, knowledge, expertise, and sensitivities to address complex issues
- Strengthens the research, program, and problem-solving capacity of partners
- Creates theory grounded in social experience, and creates better informed and more effective practice guided by such theories
- Increases the possibility of overcoming the understandable distrust of research on the part of communities that historically have been the subjects of such research
- Has the potential to bridge “cultural gaps”
- Involves communities that have been marginalized on the basis of, for example, race, ethnicity, class, gender, and sexual orientation in examining the impact of marginalization and attempting to reduce or eliminate it

CBPR is often aligned with a constructivist research paradigm, which holds that multiple realities exist to be studied and understood. Each reality is an intangible construction; rooted in people’s experiences with everyday life, with how they remember and make sense of them. Individual constructions of reality are assumed to be more or less “informed,” rather than more or less “true,” because they are always alterable. This means that as researchers and participants encounter and consider different perspectives, they will alter their own views. The result is a consensus construction of reality that is mutually formed by variations in preceding constructions (including those of the researchers), and that can move both participants and researchers toward communicating about action, intervention, and change. The methods of constructivist research require researchers and participants to be interactively linked so that the consensus construction of reality is literally created as the study proceeds. Researchers using a CBPR approach, therefore, are cast in the dual roles of participant and facilitator.

Physician Assistants and CBPR

Initially developed for the deployment of well-trained ex-military corpsmen into rural primary care practices to utilize their unique training and experiences from their service, the PA profession was designed to improve the health and well-being of vulnerable communities that faced the interrelated challenges of a dramatic undersupply of physicians and an increase in health-care costs. This commitment to community health and the provision of services to those communities that often fall through health-care cracks aligns itself well with CBPR. Creatively working to improve the health and well-being of vulnerable communities that initially were rural, PA clinician researchers are well positioned to take on increasingly more community-based and participatory approaches to scientific inquiry and discovery to positively affect the health and well-being of minority (e.g., racial/ethnic, sexual orientation) and economically disadvantaged communities to reduce health disparities.

Common Research Methods

Successful use of CBPR relies on various partnership principles and values that include:

- Building and maintaining trust between community members and researchers;
- Establishing formal and informal partnership networks and structures;
- Committing to transparent processes and clear and open communication;
- Agreeing on the values, goals, and objectives of the research;
- Building research upon each partner’s strengths and assets;
- Balancing power and sharing resources;
- Sharing credit for the accomplishments of the research; and
- Disseminating findings to research audiences, community members, and policy makers.

Often, the clinician researcher feels that she or he must make decisions on behalf of the community.
is a natural inclination given the years spent in school, in training programs, or in the field. The clinician researcher may be motivated to apply and use her or his resources for the benefit of the community. After all, the clinician researcher is armed with intellectual resources, training and experience in the reduction of bias and the traditional approaches to increase validity with the hope of increasing generalizability, and perhaps financial resources or, at the minimum, increased access to financial resources, among other tools. Thus, the clinician researcher may forget that community members and representatives from CBOs have perspectives that will be useful for inclusion during the research process.

It has been said that for community members “the textbook of life is living.” With this axiom in mind, clinician researchers must recognize that community members have a perspective that can greatly enhance all phases of the research process. Community members have firsthand knowledge of the health issue of concern. They contribute to identifying and understanding the most salient health needs of their community, giving context to epidemiological data and building theory about needs, challenges, and potential solutions that may not have occurred to or be easily understood by outsiders. Each of these points can strengthen research and intervention design through the interpretation of data and the evaluation and revision of intervention strategies.

Although their training and experiences may or may have not been learned in formal educational or training programs, representatives from CBOs and local agencies who are on the frontlines also may have an understanding of the community that is also not readily available or apparent to the clinician researcher. These individuals may include service providers, educators, providers of medical and mental health services, and counselors. They know systems and may have a wealth of experiences providing services to community members on the frontlines or at the grassroots level. However, their perspectives may lack detail and they may miss insights that have not been well discovered or explored.

Many clinician researchers might conclude that they themselves are on the frontlines in their capacity as clinicians; yet they may truly know very little about the lived experiences of their patients or clients, especially once patients or clients leave the clinician’s office. To illustrate; having access to care and medications does not ensure that a patient will adhere to prescribed medication regimens for diabetes management. Patients and clients (and providers themselves) live in complex social contexts that cannot be easily understood or teased apart by outsiders. Thus, although representatives from CBOs or community agencies such as the health department have useful knowledge, experiences, and theories, alone their insight is insufficient.

CBPR can be infused into any research methodology; however, the following section highlights four research methods and briefly describes how CBPR can be applied. These methods include action-oriented community diagnosis (AOCD), focus groups, photovoice, and in-depth interviews. Although this discussion is not meant to be exhaustive, it is intended to serve as an initial “starting point” for clinician researchers who want to understand and explore the use of CBPR.

**Action-Oriented Community Diagnosis**

The purpose of AOCD is to understand the health status, the collective dynamics and functions of relationships within a community, and the interactions between community members and broader structures that can impede or promote the conditions and skills required to assist community members in making decisions and taking action for social change and health status improvement. AOCD can be a critical first step in program planning, intervention, and evaluation because it provides the foundation for:

- The establishment of baseline data from which objectives, intended outcomes, and measures of change can be derived;
- The selection of intervention methods and delivery that are most appropriate based on the community’s structure, including formal and informal power dynamics and community assets and strengths; and
- A collaborative relationship between professionals and communities, who can begin “closing the gap between what we do not know and what we ought to know.”

AOCD may serve as a process for needs assessment but actually goes beyond traditional interpretations of needs assessment. While needs assessment is defined as a systematic examination and appraisal of the type, depth, and scope of needs for the purpose of setting priorities, AOCD also identifies and explores community assets on which intervention can be based. CBPR utilizes a strengths-based approach to research to identify both the needs and challenges faced by communities, and just as importantly, the assets and strengths within the community. To forego the identification of community assets and strengths is to use a deficits-based approach that may miss key information vital to understanding the community’s reality and lived experience and the strengths and resources on which intervention strategies can be based (Box 8–2).

Like all research methods that adhere to a CBPR approach, AOCD begins with the establishment of a working collaborative relationship with community members. Representatives from the community, CBOs,
and clinician researchers come together to determine a research plan. Usually existing community-specific data are reviewed. These may include epidemiological data usually available from public health departments at the local or state levels as well as other reports and resources available from local CBOs such as faith-based service providers and other agencies.

A windshield tour of the community is an important initial step in the AOCD process. If the community consists of a geographical location, a clinician researcher will explore the community guided by community members to gain an appreciation of the community’s geography, size, physical characteristics, and important community venues (e.g., a corner store where people gather or a house of worship). This windshield tour is meant to be an introduction to the community and its context through simple observation and community member guidance and commentary. If the community is less geographically defined such as a community of elderly shut-ins, for example, a windshield tour may include the agencies and organizations that visit and offer support to these community members. A windshield tour for a virtual community might include exploring the chat rooms, list serves, bulletin boards, and newsgroups visited and used by the community and visiting sites that are advertised on popup and pop-under screens.

After the windshield tour and throughout AOCD, clinician researchers document their experiences using field notes. Frequently kept in various study methodologies and often informal, field notes are documentation of details about the community that are interesting or noteworthy and when combined with other data might well prove to be important. Field notes may serve several purposes including:

1. Providing the clinician researcher the opportunity to document first impressions about a community;
2. Assisting the clinician researcher to remember experiences encountered in the field;
3. Recording names of individuals and places that may prove key in the execution of the AOCD process; and
4. Documenting unusual characteristics within a community.

Field notes also allow the clinician researcher to track her or his own perspectives, impressions, feelings, and frustrations during the AOCD research process. Field notes can be simply reflective writings while the research “event,” such as a windshield tour, is still fresh in the mind of the clinician researcher. It is wise to keep field notes of all research efforts because field notes serve as a documentation source for decisions made that affect the research process and subsequent data interpretation.

Because clinician researchers tend to be very different from the communities they study, clinician researchers need to gain an emic or insider’s perspective on how people live and the issues facing the community. An insider’s perspective is privileged knowledge that only members of a particular community have. Outsiders can guess and hypothesize, but those assumptions are not value free and may not be accurate or complete. Because no researcher can completely remove her- or himself from the research, an emic perspective provides the clinician researcher insight into the perspectives of community members. For example, a homeless individual understands aspects of the lived experience of homelessness better than any outsider. Members from a disabled community can provide insights that may not be understood or correctly interpreted by an outsider.

Furthermore, one’s social position in a community affects the “truth” of the experience of community life. For example, all African-American gay men do not share a truth; in fact, among other influences, perception of truth is affected by the position within the community. Thus, AOCD allows for distinctions and differences to emerge that may be lost through other approaches. This is a challenge for clinician researchers who must work with community members to merge emic and etic data, the clinician researcher helps the

| BOX 8-2 |

**Needs Assessment**

Needs assessment is the systematic examination and appraisal of the type, depth, and scope of needs for the purpose of setting priorities. It is the process of identifying and measuring gaps between what is and what ought to be.
community disseminate the findings. AOCD relies on a community forum to present to influential advocates the findings of a research process. This forum highlights issues, may propose solutions, and allows the community to dialogue with influential advocates who are supporters, but who may also benefit from increased awareness and greater understanding of the situation. The forum is an opportunity to initiate dialogue and for participants to come together during a facilitated discussion to explore potential action or intervention. Without the forum, AOCD merely explores root causes, but does not move to improving health status of the community. Dissemination of findings within the community and movement toward action are important steps in CBPR and AOCD.

AOCD requires the involvement of both insiders and outsiders to ensure the collection of accurate (defined as reliable and valid) data and the correct interpretation of these data. AOCD might include understanding both the emic and etic perspectives of uninsured families within a cultural and geographic community. This understanding may lead to action and, perhaps, policy changes that reduce barriers or increase access. For example, Latina women may have little access to public health department services if their local health department does not have translation capacity. Coming together during a forum educates providers on the ramification of the deficiency and sparks new ideas and innovative approaches to solving problems. AOCD allows for solutions to emerge based on the compilation of realities that come from various perspectives. No one group or sector is responsible for change; rather, direction and change come from a negotiated process. The exchange of perspectives and ideas allows insiders and outsiders to see community health from fresh perspectives and builds partnerships that are stronger and can move forward in directions that positively affect health.

Often emic and etic perspectives are explored and interpreted through the use of qualitative methods. A research partnership may choose to conduct focus groups, photovoice, or qualitative interviews—methodologies that also are outlined within this chapter and the chapter on qualitative research. More quantitative methods may be less useful during the early stages of AOCD because they may not allow for sufficient flexibility and exploration of perspectives. They may, however, provide important data in less exploratory or developmental research.

FOCUS GROUPS

As a qualitative methodology, focus groups provide the opportunity to investigate more fully participant responses and a reaction related to an issue and allow new areas of inquiry to emerge. The methodology can reveal key nuances and perspectives that clinician researchers may not be able to foresee. In brief, focus groups usually are comprised of six to ten participants who are guided through a set of general predetermined open-ended questions outlined in a focus group moderator’s guide. The guide may be based in a behavioral theory or may allow for theory to explain phenomena to be developed based on the findings, much like a grounded theory approach to research. Either way, the guide should be agreed on by the partners. Not only should the research objectives be mutually agreed on, but in addition the selection of focus groups as a methodology and the line of inquiry delineated in the guide should reflect the most meaningful approach and language as agreed on by the research partners.

After an introduction to the focus group process (once of course informed consent to participate has been obtained) and a review of the ground rules (e.g., speaking one at a time, respecting various opinions, maintaining confidentiality), the participants, who sit in an informal circle, respond to open-ended questions. Group interaction is an explicit component of this methodology. Instead of the clinician researcher asking each person to respond to a question in turn, participants are encouraged to talk to one another, asking questions, exchanging anecdotes, and commenting on one another’s experiences and perspectives. The moderator must be skilled and experienced in soliciting discussion from all participants in a group, reminding participants that there are no wrong answers, affirming all opinions, and probing for detail. Probing for detail, whether through examples, clarification, or further exploration, is key to successful qualitative data collection, especially when using focus groups. In most cases, qualitative research requires the clinician researcher to allow the design to emerge more fully during the project’s evolution, thus, all potential questions cannot be predicted. The moderator’s guide is meant to serve as an outline, but the moderator must facilitate the discussion beyond what is written within the guide. The moderator may need to probe into a perspective to develop and understand it more fully. However, the moderator must be skilled at keeping the discussion on track. If the discussion deviates from the purpose of the focus group, the moderator must be able to bring the discussion back to the purpose of the focus group.

Furthermore, besides a moderator, successful focus groups most often involve at least one note taker who documents participant speaking order and body language and facial expression that cannot be captured by audio-recording, but may provide important insight during the data analysis and interpretation phases. Because anonymity may be desired, names of participants are not used. Rather, participants may be assigned numbers that are added to the focus group transcript in
order to track which focus group participant is saying what. It may not be important to know the name of a participant; however, it may be important to attribute certain quotations to certain participants. Perhaps only one participant has a certain perspective about a topic that she or he continues to reiterate. When analyzing the transcripts, it may be important to recognize this and “weigh” the findings accordingly.

The note taker also documents nonverbal communication. If a participant is noticeably uncomfortable with a discussion topic or the focus group discussion, but does not assert her or his unease or disagreement, such observations should be noted by the note taker. Overall, the note taker is documenting what is going on during the focus group session that may be missed by the audio-recorder and by the moderator who is leading the session.

When applying a CBPR approach to focus group research, the research question, moderator’s guide, and recruitment methods must be developed and agreed on by the research partners. Data analysis and interpretation should be completed in partnership to allow community participation.

PHOTOVOICE

Photovoice is a qualitative method of inquiry that:

1. Enables participants to record and reflect on their personal and community strengths and concerns;
2. Promotes critical dialogue and knowledge about personal and community issues through group discussions and photographs;
3. Provides a forum for the presentation of the lived experience of participants through the images, language, and contexts defined by participants themselves.22

As a CBPR method, photovoice improves quality and validity of research by drawing on local knowledge, developing local theory, and progressing toward action, hallmarks of CBPR. Photovoice engages participants in the following procedure:

- Attending an informational training session to receive a disposable camera, and determine the topic for their first photo-assignment;
- Recording through photography each photo-assignment;
- Sharing and discussing their photographs from each photo-assignment during photo-discussion sessions; and
- Organizing a forum to present their photographic and thematic data to local policy makers and service providers identified by participants as potential collaborators and advocates for change.

Photo-discussions typically begin with a review and discussion of themes that emerged from the analysis of previous sessions followed by a “show and tell” activity that allows each participant to share her or his photographs and explains how the photographs relate to the photo-assignment. These discussions follow a Paulo Freirian-based23 model of root-cause questioning and discussion known by the acronym SHOWED.24 At the conclusion of each photo-discussion, the group develops a new photo-assignment by asking, “Given what we have learned so far, what should we explore next?” (Box 8-3).

The photo-discussion data are analyzed like other qualitative data, through exploring, formulating, and interpreting themes. The participants share these themes with local community leaders, service providers, and policy makers. These photographs serve as the medium through which issues are discussed to raise awareness among a core group of allies, mobilize these allies, and plan for change.

Photovoice transitions from knowledge, or raised consciousness around issues and assets, to direct community action. Although a relatively new methodology, photovoice has been found to be a flexible method both in terms of the issues it has been employed to explore and address and the geographically and culturally diverse groups with which it has been employed. It has been applied in partnership with a number of communities including Latino youth in the rural southeast21; Chinese women in the Yunnan Province, China25,26; homeless men and women in Michigan, USA26,27; youth peer educators in Cape Town, South Africa28; urban lay health advisors;2 and public health department leaders and constituents.29

IN-DEPTH INTERVIEWS

Individual in-depth interviews are another common data collection methodology. Simply, these interviews
are unstructured, semistructured, or structured depending on the research goals. Unstructured interviews are characterized by questions that emerge during the interview process. The research partners may have general topic areas or categories, but the questions are asked as they are formulated in the natural course of the discussion. There is no predetermined wording of questions. This style is more conversational and increases the salience and relevance of questions. A problem with unstructured interviews is that different information is collected from different individuals based on different questions. Less systematic and comprehensive resulting in data analysis challenges, unstructured interviews may be useful for initial exploration or case studies.

Semistructured interviews by definition provide more structure for the interviewer. Topics and issues to be explored and discussed are specified in advance, often in outline form. Semistructured and structured interviews require an Interview Guide that leads the interview process. Leading a semistructured interview, the interviewer decides the order and sequence of the questions during the course of the interview. The interviewer may probe for detail and develop questions and their wording during the interview process. Data collection using this approach is more systematic than an unstructured approach. Because semistructured interviews remain conversational and situational, gaps in data can be explored and closed. However, important and salient topics may be inadvertently omitted as interviews go in directions that jeopardize comparability among interviews and the data collected.

Structured interviews are often well defined prior to the interview. The sequence and exact wording of questions are determined in advance. All interviewees are asked the same basic questions in the same order and manner. Structured interview questions may be open-ended, closed-ended, or may comprise a combination of question type. Open-ended questions tend to provide more exploratory, developmental, and contextual data. Data from open-ended questions tend to be more descriptive. For example, an open-ended question that was asked of health-care providers who worked in an undocumented Latino community in western North Carolina was: "If you could envision an answer to meeting the health-care needs of the local Latino community, what would that vision be?" Answers were descriptive and complex, providing not only ideas about how to meet health-care needs in the short and long term but also providing further information about what health-care needs existed in this community and root-cause explanations.

Closed-ended questions are characterized by response options that are fixed. Participants choose among a list of fixed responses. An example of a closed-ended question from a structured interview that was implemented among Latino men was: "Some men report having sex with other men for a variety of reasons; have you ever heard of a male friend having sex, including oral or anal sex, with another man?" The response options were: "yes," "no," and "refused to answer."

Closed-ended response options simplify data collection and analysis because many questions can be asked in a shorter period of time and responses can be easily aggregated and compared. The disadvantage, however, is that participants must fit their experiences and feelings into predetermined categories. This may distort the true experiences and feelings of the participants by limiting their response choices.

Conventionally, closed-ended interviews collect data on a topic by asking individuals questions to generate statistics on the group or groups within a community or population that those individuals represent. Closed-ended interviews do not tend to be formative or exploratory; rather they ask questions about a variety of factors that influence, measure, or are affected by health. For example, population-based closed-ended interviews may document and follow health status. Or, closed-ended interviews may provide local data and a baseline for evaluation of intervention efforts. Once a local CBPR research project has evolved and developed a research intervention to effect change (e.g., individual behavior change, community change, or policy change), interviews comparing baseline data to intervention implementation or post-intervention follow-up may provide information on how well the intervention is working.

When applying a CBPR approach to research, the research question, measurement method (e.g., interview, questionnaire), and items or questions to be included must be agreed on by the partnership. Furthermore, recruitment and administration must be decided. Questions that the research partnership will want to answer include:

1. How will participants be recruited?
2. What type of compensation will be provided?
3. Who will administer the interview or questionnaire?
4. Will interviewers be used or will the questionnaire be self-administered?

Clinician researchers may think she or he knows the best way to recruit interviewees and administer a questionnaire. However, community partners may provide great insight that may increase recruitment and response rates as well as honesty. What seems scientifically sound to the researcher (e.g., reducing bias and threats to validity) may inhibit responses.
Qualitative and Quantitative Data Analysis

Analyzing and interpreting any type of dataset, whether qualitative or quantitative, using a CBPR approach is challenging. Ensuring the participation of all partners in the process can be daunting. Clinician researchers may have a variety of data analysis software to choose from that community partners may not have the time or energy to learn and apply. Thus, creative ways to examine data may be necessary. During qualitative data analysis, community partners may review and provide perceptions on potential themes through their detailed reading and rereading of the transcripts separately. The clinician researcher may choose to analyze the data using a software program to code and retrieve non-numeric data (e.g., Nvivo™, ATLAS.ti,™ Ethnograph,™ NUD*IST™). Coming together, the research partners compare broad categories, resolve discrepancies, and begin the process of interpreting the findings through the development of themes. Themes based in qualitative data are most often directional. Themes can be described as potential assertions that can be tested later through subsequent research. Examples of themes developed using qualitative analysis include: (1) While participants realized the importance of condoms for disease prevention, attitudes about condoms were negative. Or, (2) Undocumented Latinos felt that they have no right to access public health care. Quotations are usually abstracted from the qualitative transcripts to illustrate the themes.

Quantitative data analysis poses similar challenges. How can community members who lack quantitative data analysis skills or software training participate in this phase? Clinician researchers should communicate and solicit feedback with the partnership throughout the process, keeping the partners up to date on statistical approaches, decisions, and rationales. Furthermore, clinician researchers should not assume that partners do not want to be engaged in the analysis process. After all, CBPR promotes knowledge gain and skill development on all sides. As mutual co-learners, the clinician researcher is learning about the partners, and the partners are learning as well; this learning may include learning data analysis skills.

Because it may be difficult to ensure participation of community partners, getting a commitment from one, two, or three partnership members who are from the community may be key to the data analysis. The whole research partnership may choose not to participate in all phases of the research process, but establishing guidelines that ensures community member representation in each phase of the process is key.

In this section only a few research methods were described. However, it is important to note that a clinician researcher need not give up traditional research methods, but may infuse a CBPR approach into any research method.

How to Get Started with CBPR

Beginning the exciting work of CBPR requires a clear understanding of partnership principles and values, as outlined earlier in this chapter. Below, we outline some pivotal tasks in the clinician researcher’s effort to engage in CBPR.

Network, Network, Network

A first task in the CBPR process requires the development of a network with other individuals with a similar health area of interest or concern. A relatively easy and helpful initial contact for a clinician researcher may be a local public health department. Providers and educators within health departments around the country are likely to have connections with community agencies working with those affected by and committed to a variety of health concerns. A clinician, administrator, nutritionist, intern, health educator, and/or epidemiologist within the public health department might already be working with established local health coalitions or community groups. Dialoguing with these potential partners represents a good solid start in this process well worth the effort. A simple review of a public health department Web site or a telephone call to the health department may offer initial guidance and contacts, and an informational interview with a health department staff member will begin the networking process essential throughout CBPR. As a clinician researcher, “casting a wide net” facilitates networking contacts to identify overlapping health concerns and resources including talent that may support the research process synergistically. Networking also initiates the establishment of trust that is key to success in CBPR.

The clinician researcher must understand the local communities and work in collaboration and not through confrontation with local stakeholders. Stakeholders typically are individuals who are affected by the health issue and those who will be part of the research as well as affected by the research and subsequent change. Stakeholders may include community members experiencing the problem, service providers, and community leaders, among others.

In addition to contacting and networking with a local public health department, making connections with those health-care providers in the community who are
working with individuals and community members affected by overlapping health and research priorities may provide access to potential partnerships. The clinician researcher benefits from thinking broadly about those individuals providing care, for example, nutritionists, exercise physiologists, physical therapists, mental health providers, and so forth. Furthermore, becoming familiar with other local CBOs, community agencies, and service providers and making contact with representatives from a variety of organizations will yield helpful results. The clinician researcher may find partnerships for CBPR within the local school system, within clinical settings, clubs and service agencies, and/or retirement communities, just to name a few more possibilities.

**Build Trust**

Once commonalities have been identified, the clinician researcher will begin a process of trust building. Trust building is especially important as communities have felt exploited as “living laboratories” for universities and medical centers. Often communities are inundated by research projects that test hypotheses, but do not benefit the community itself. Communities may be apprehensive about committing to a partnership, and the clinician researcher may have to overcome a history of research that had not been initiated and conducted in a respectful manner. A positive relationship is built by working hand-in-hand with community members. A clinical researcher may choose to spend some up front time volunteering with a CBO and serving on local health coalitions. This serves several purposes. First, it advances a genuine and mutually respectful relationship between key community leaders whom the clinician researcher may need and want to have on board as partners in the research. It also may open other doors for the clinician researcher; the clinician researcher may be unfamiliar with all the players and may use the opportunity to identify informal community leaders who may be committed to a health issue and may be interested in the research. Third, it allows the clinician researcher the opportunity to understand community structure, decision-making processes, and levels of influences through their role as a participant observer. Finally, community service allows community members to interact with the clinician researcher in a setting that is not focused on any one agenda. By selecting the right place to volunteer and thus “being seen,” the clinical researcher may build community trust by association. If a Latino-serving CBO is well respected by the local Latino community, for example, the clinician researcher will gain more immediate community favor, and thus participation, by spending time there. Such volunteer work not only builds trust, but also begins to offer emic and etic community perspectives to the researcher.

Building trust includes building relationships. Relationships between community members, CBO representatives, and clinician researchers may involve informal “working” meetings that allow partners to get to know one another. Community events such as street fairs, church gatherings, and forums as well as parties and celebrations are ideal places for community members, CBO representatives, and clinician researchers to come together. These types of opportunities show commitment to the community and allow for community members, CBO representatives, and clinician researchers to know one another better. This improves trust and communication, which improve the research process.

**Maintain Relationships**

Key to trust building is relationship maintenance. While it may be easy to feel that one has built trust, one must remember that partnerships cannot be taken for granted. When things are being done “behind the scenes,” gaps in the research process may exist and the clinician researcher must be present within the community. For example, getting a research protocol approved by an Institutional Review Board (IRB) or Ethics Committee may require a delay in the research process, and the clinician researcher will want to touch base with partnership members to provide informal status reports. This is important because the clinician researcher does not want to lose community interest, motivation, or momentum. Community members do not necessarily understand the confusing steps that universities, research institutions, and funders require. Time should be spent in dialogue explaining these steps and their rationales.

**Negotiate Partnerships**

Subsequent tasks in the CBPR process include bringing key community members and CBO representatives together. This may be easy if an existing community health coalition exists. The coalition can determine whether a health issue is of interest or not. If a health issue is not a focus and yet data suggest that it contributes profoundly to morbidity and mortality of the community that the coalition serves or represents, the clinician researcher has to walk the fine line between asserting what she or he perceives to be “important information” and staying true to the priorities of the community. Exploring community priorities and perspectives may yield important insight or even areas of overlap. It may require creatively thinking or thinking “outside of the box.” The clinician researcher may pro-
vide data and increase awareness affirming her or his agenda or she or he may decide that the community-prioritized agenda is important and an opportunity to build trust and relationships. Nothing can impede or destroy trust between a clinician researcher and the community members and representatives than going into a community to “fix” something without asking community members what they prioritize. After all, community members are not inanimate objects to be “fixed”; they are potential partners. CBPR requires the clinician researcher to be flexible, and no place is this flexibility more evident than in adaptations related to community priorities. A clinician researcher may be required to take on other priorities as identified by the community in the spirit of partnership.

The clinician researcher may begin with a community-health coalition or may need to identify and build a network of community members and CBO representatives. Through this network, the foundation of a partnership may be established. Although growth may occur throughout, this network may evolve into a partnership through the hard work of those involved.

A Case Study: HoMBReS: Hombres Manteniendo Bienestar y Relaciones Saludables

HoMBReS, an acronym for “Hombres Manteniendo Bienestar y Relaciones Saludables” (Men Maintaining Wellness and Healthy Relationships), is an ongoing intervention research project in rural North Carolina that was initiated through a partnership of lay community members; CBO representatives; and university clinicians, practitioners, and researchers. A community health coalition known as Chatham Communities In Action (CCIA) was formed in 1991 as part of the North Carolina Community-Based Public Health Initiative (CBPHI). Because of the rapidly growing Latino community in North Carolina and their early success in diabetes prevention within the African American community, CCIA, with expanding Latino membership, chose to explore Latino health concerns within their local community. A subgroup of CCIA members met with university researchers to develop a plan to explore the health-care priorities of the Latino community.

The research partnership, which initially was comprised of current members of CCIA, came together first to determine how to further develop and expand the research partnership to include more Latino representation. Local Latino-serving CBOs and interested individuals who were not involved with CCIA were invited to participate in the process. This inclusion required time to build trust and clarify goals. These added members included representatives from the Liga Hispana de Fútbol de North Carolina (LHFNC; North Carolina Hispanic Soccer League), a local Latino tienda (grocery store), and a farm worker advocacy group. LHFNC is a nine-county Latino soccer league of more than 1600 adult men. The League president along with various other interested League members became involved in the research partnership. The research partners continued to build trust among themselves as research partners through personal relationships, genuineness, respect, and “being there.” CCIA representatives and the researcher spent many dinners meeting with League representatives. While CCIA had a history of working with the university, these relationships could not be assumed or taken for granted. Building and maintaining trust and communication always play a paramount role in CBPR.

The expanded research partnership gained consensus on the research aims. This process involved answering two equally important questions. First, the research partners had to ask themselves: “What do we want to know?” Second, the partners had to ask themselves: “Why do we want to know it?” This distinction is important because a CBPR approach recognizes that knowledge for knowledge sake (i.e., the accumulation of scientific knowledge) is important, but the immediate application of knowledge to affect the health and well-being of the participating community is equally important. The researchers had many curiosities and theories they wanted to explore, but the research partners kept the focus on the practical use of knowledge gain.

In this study, the research partnership chose to explore health concerns of Latino men primarily because the majority of Latinos newly arrived to the United States are male, especially in rural North Carolina. The research partnership had to come to agreement on the research and recruitment design and the roles and contributions of the partners. They decided to use focus groups to explore health priorities. The partnership created, reviewed, revised, and approved the focus group moderator’s guide. The League president recruited focus group participants and two partnership members served as the focus group moderator and the note taker. The note taker was the university researcher who was fluent in Spanish. A Latino-serving CBO hosted the focus groups. Five focus groups were completed.

The first stage of data analysis involved members of a subgroup from the research partnership sorting the focus group transcripts into broad content categories. After the initial sorting process was complete, the analysis team came together to compare broad categories and begin the process of interpreting the findings into conceptual domains. Once themes were created, they were presented to the research partnership and other community members.
including LHFNC members for number checking and interpretation. This was done by writing themes on flip charts, after which they were presented to the research partners and representatives from the soccer league and reviewed, discussed, and revised. Several iterations of this process were completed.

Findings were disseminated through community and national presentations, report writing, and manuscript development. Because action is a key component of CBPR, the findings also were used for funding proposals and intervention design. All partners had equal access to the findings. For example, CBO representatives used findings for grant preparation, and community members used the findings to advocate for Latino men’s health. It was through the initial focus groups that sexually transmitted diseases (STDs) and human immunodeficiency virus (HIV) infection were identified as priorities by members of LHFNC as well as the potential use of the social network of the League to develop, implement, and evaluate a lay advisor as an intervention.

The HoMBReS intervention study was funded by the Centers for Disease Control and Prevention (CDC). The goal of this CBPR study is to reduce the risk of STD/HIV infection among Latino men through the development, implementation, and evaluation of a lay health advisor intervention. In brief, HoMBReS is a three-year quasi-experimental research study with five interrelated objectives:

1. Develop and implement a lay health advisor intervention to reduce STD/HIV risk behaviors among members of the soccer league.
2. Evaluate the efficacy of the intervention by comparing soccer league members in the intervention to those in the delayed-intervention comparison group using self-reported sexual risk behaviors and utilization of STD/HIV counseling, testing, and treatment services;
3. Evaluate the changes experienced by the lay health advisors by being trained and serving as lay health advisors;
4. Assess the feasibility of engaging a soccer league in implementing a lay health advisor intervention designed to reduce STD/HIV transmission among Latino men;
5. Assess the feasibility of collecting biomarker data (i.e., urine for chlamydia and gonorrhea testing) from soccer league members, comparing those who have lay health advisors and those who do not.

The lay health advisors, known as “navegantes” (“navigators”), are trained to provide STD/HIV prevention education and prevention information and service and resource referral to their teammates. They serve as: (1) sources of STD/HIV information and referral; (2) opinion leaders to change risky behavioral norms resulting from culturally infused male gender socialization; and (3) community activists to work with organizations such as the local public health department to better address the needs and priorities of Latino men in culturally relevant approaches.

This project has been successful in the recruitment and training of a strong cadre of navegantes because of the initial “buy in” of the LHFNC. Without their history of interest, support, and involvement, the idea for STD/HIV primary prevention and the use of team members as lay health advisors would not necessarily have been considered. Had it been considered, the risks would have been higher because buy in would not have been garnered. Less knowledge about whether men would want to participate in a 16-hour, theory-based training and what that training should include would have left more opportunity for misjudgment on the part of the researcher. Instead, the partnership approach has ensured that fewer problems are incurred and when unavoidable roadblocks do occur, creative solutions that have a higher potential for success can be explored because more perspectives and options can be considered.

**Discussion**

It has been asserted that ensuring the health of the public will require clinicians, researchers, and agencies to join forces with organizations of both community insiders and outsiders to generate new understandings of health status, explore health status predictors and measures, and uncover innovative ways to effect change in the health status within vulnerable communities. While this may seem logical, the process of partnership requires time to establish trusted relationships, create a research infrastructure, and develop a history of partnership. The investment of time to build these trusted relationships is essential for successful CBPR; however, this effort is well worth the expense in time, energy, and resources if true changes in health status are to occur.

While no road map exists to conduct CBPR, it is important to note that often individuals, including researchers and community members, who are unfamiliar with CBPR confused community placed with community based. Community-placed efforts simply imply that clinicians, practitioners, and researchers leave the traditional institutions such as the hospital or medical center and go into the community to do their work. However, community-based efforts are more than going outside physical walls of these traditional institutions. CBPR requires partnering with communities and basing efforts in the reality and structures preferred by the community.

Health research through community partnership is a viable mechanism for health promotion and disease
prevention because CBPR improves the quality of research, increases community capacity, and advances positive health outcomes by

1. Bringing community members into a study as partners, not just as subjects;
2. Using the knowledge of the community to understand health problems and design meaningful interventions;
3. Connecting community members directly with how research is done and how it is used;
4. Providing immediate benefits from the results of the research to the community that participated in the study.

CBPR can be infused into any research design. In this chapter, four methodologies were briefly presented and one case study was described. Clinician researchers who are exploring the use of CBPR in their own research and practice should remember two important issues. First, key to using a CBPR approach is the inclusion of lay community members, CBO representatives, health department and other agency staff, and university personnel, including students and faculty researchers. Together these partners must share control over all phases of the research process, including: community assessment, issue definition, development of research methodology, data collection and analysis, interpretation of data, dissemination of findings, and application of the results to address community concerns. CBPR recognizes that lay community members themselves are the experts in understanding and interpreting their own lives.

Second, CBPR is committed to movement toward action or intervention. This action may be loosely defined, including: community organizing and mobilization; the development of new and authentic community member and agency partnerships with concrete tasks; and measurable plans for action with assigned responsibilities and defined timelines. The actions may be focused on immediate changes to improve health-related conditions, such as changes in a clinical practice protocol that increases adherence to an AIDS medication, policies that increase access to community mental health services, or even improved lighting on an outdoor neighborhood running/walking track to encourage utilization. Furthermore, actions may be focused on long-term changes in social determinants of health, such as improved racial equality in administrative and political representation through community mobilization and organization.

CBPR not only may be an effective tool to addressing the complex health problems facing vulnerable communities but it is also considered to be a just and democratic approach to research; as has been noted by community members, “Nothing about me, without me,” implies that community members have a right to participate in all aspects of the research endeavor. While CBPR is a challenging approach to research, CBPR offers the clinician researcher the opportunity to participate in a co-learning process of sharing resources, knowledge, skills, and attributes to increase the quality and validity of research. Increased quality and validity thus yield more effective interventions and improved health outcomes.

References


Section Resources

Besides the references cited within this chapter, supplemental resources are listed below.

CBPR


Creating Partnerships, Improving Health: Community-Based Participatory Research: http://www.ahrq.gov/research/cbprrole.htm

Photovoice

Photovoice: http://www.photovoice.org/


Health Disparities


Qualitative Research


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