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Tiffany D. Baffour Ph.D.  
*Winston-Salem State University*

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## Addressing Health and Social Disparities through Community-Based Participatory Research in Rural Communities: Challenges and Opportunities for Social Work

Tiffany D. Baffour  
Winston-Salem State University

**Abstract.** *Social workers can increase the translational ability of their research efforts to create sustainable community change in rural communities through the use of community-based participatory research (CBPR). CBPR is a congruent approach to social work values, representing a balance between research and community empowerment. This article focuses on methodological concerns in conceptualization, setting research goals, measurement, data collection, and dissemination of the findings. Recommendations for how interrelated areas of social work education, practice, research, and policy can address rural social and health disparities through CBPR are advanced.*

**Keywords:** community-based participatory research, social work profession, rural, research methodology, academic-community partnerships, social and health disparities

Social and health disparities experienced by underserved rural populations have deleterious consequences for individuals, families, and communities. Although rural residents make up approximately 25% of the United States population (United States Department of Agriculture [USDA] National Agricultural Library, 2008), they experience lack of parity with urban areas in poverty rates and access to critical health, mental health, substance abuse, and social service facilities. Thus, improving the economic and social conditions of rural residents has the ability to significantly enhance the well-being of a sizeable and critically underserved group. Community-based action research can be successfully integrated with policy analysis and community organizing to affect positive change in underserved communities (Reisch & Rivera, 1999).

Community-based participatory research (CBPR) is an umbrella term utilized to characterize an orientation to research that seeks to integrate participation, research, and social action. It is widely recognized as an appropriate and valid approach to working with diverse populations, types of communities, and target problems. The process has been recognized for its ability to improve outcomes for at-risk and underserved groups; it is appropriate for groups that have been difficult to research historically through other research methodologies (O'Toole, Aaron, Chin, Horowitz, & Tyson, 2003). CBPR highly values both social action and scientific advancement.

### Community-Based Participatory Research: An Overview

In a CBPR approach, scientists work collaboratively with community partners in various phases of research: definition of the problem, development of research questions, methods, ethical standards, and interpretations (Shepard, Northridge, Prakash, & Stover, 2002) and dissemination and publication of the research findings (deLemos, 2006). Concepts of full partnership and collaboration include shared decision making and responsibility, as well as the benefits and recognition of the research (Morford, Robinson, Mazzoni, Corbett, & Schaiberger, 2005).

To go beyond mobilizing the marginalized towards activating allies, this research approach to social change begins with a particular community concern and individual experiences, and uses qualitative and quantitative procedures to understand the associated and complex issues of inequality, injustice, and insecurity (Reitsma-Street, 2002, p. 69).

Recognizing the community as the unit of identity, CBPR builds on the strengths and social capital of the community by emphasizing the significance of community-defined social and health problems. The aim of CBPR is to have all participants benefit from their involvement; participation in the research process and its outcomes should be transformative for both academic and community partners. As social scientists engage community members, the participants join in a process of co-learning that can enhance collective professional and personal development.

There has been a consistent increase among academic and community-based organizations in developing an infrastructure for conducting CBPR as well as pursuing funding opportunities (Tandon et al., 2007). Through CBPR, philanthropic organizations have addressed social and health disparities in society. Many philanthropic and government organizations are increasingly providing financial support for research projects that are community *based* rather than community *placed* (Wallerstein, 2006). The National Institutes of Health (NIH) has issued several CBPR-based requests for funding (RFAs) that highlight the importance and value of community collaboration in the scientific community. Recognizing the potential that the social work profession has in contributing to CBPR, NIH offers workshops and RFAs, among other opportunities, to integrate the social work profession more effusively into its funding infrastructure.

Leung, Yen, and Minkler (2004) suggested that CBPR represents a shift in the power base away from sole ownership of the research process by scientists through the “deconstruction of power and democratization of knowledge” (p. 3). This is accomplished through an epistemological shift on the part of the scientific community and the acceptance of other ways of knowing, such as the indigenous knowledge of community members. This shift creates an environment in which communities have greater relevance and participation in the research process and research has significance for the affected communities. When scientists develop egalitarian relationships with communities, they have the ability not only to impact policy through evidence presented to the scientific community via journal publication or presentation, but to provide evidence, education, and programs directly to impacted communities about social problems. Findings of CBPR can be successfully communicated to community residents, media, and policymakers (Shepard et al., 2002). This can take place in the form of town meetings, local conferences, or workshops involving community partners, the media, and political leaders.

### **Congruence of Social Work Values with a CBPR Approach**

*Community* is widely recognized as a fundamental aspect of social work and is an important place to develop evidence about practice (Coulton, 2005). The focus of the social work profession is:

to pursue social change, particularly with and on behalf of vulnerable and oppressed individuals and groups of people. Social workers' social change efforts are focused primarily on issues of poverty, unemployment, discrimination, and other forms of social injustice. These activities seek to promote sensitivity to and knowledge about oppression and cultural and ethnic diversity. Social workers strive to ensure access to needed information, services, and resources; equality of opportunity; and meaningful participation in decision making for all people (National Association of Social Workers [NASW], 2008, p. 3).

Social work emphasizes ethical conduct, egalitarian relationships between clients and practitioners, and personal and community empowerment. Through its Code of Ethics, NASW asserts core values and ethical principals of the profession that encourage social workers to utilize their skills to pursue change efforts that promote social justice, to value the importance of human relationships, and to value the dignity of self-worth of all persons. Moreover, with its strong emphasis on cultural competence and work with underserved groups, social work is a desirable professional perspective in CBPR with increasingly diverse rural communities. Racial and ethnic minorities make up over 18% of non-metropolitan residents with Latinos and Asians comprising the fastest growing minority populations in rural areas (United States Department of Agriculture [USDA] Economic Research Service, 2008).

### **Addressing Challenges and Strengths of Rural Communities**

According to the United States Census Bureau, approximately one-fourth or 61.7 million people in the United States are classified as residing in rural areas (USDA National Agricultural Library: Rural Information Center, 2008). Collectively, rural communities are a powerful economic and political force. Rural communities have clear strengths as well as challenges. Rural communities have a distinctive culture, social independence, and close-knit community bonds. They are diverse in their needs and experiences.

Unique challenges in work with rural communities include fragmentation of network services and structure, geographic distance from large urban centers, lags in connectivity, and limited exposure to modern technology. In addition to challenges in infrastructure, a significant methodological challenge for researchers working in rural communities is defining rurality. Although definition is important for resource allocation, statistical accuracy, and the ability to replicate studies of rural areas, no central definition of *rurality* exists. This can be attributed to several factors, including competing descriptions of what it means to be a rural community. Rurality can be defined by remoteness, distance from urban resources, sparse settlement, or low population density (Ricketts, Johnson-Webb, & Taylor, 1998).

CBPR, as a philosophy and approach, has numerous strengths in work with rural communities. It offers community buy-in and participation in the process. CBPR seeks to utilize the indigenous knowledge of community members, technical assistance by universities, and capacity building in both communities and academic institutions (Strickland et al., 2003). Academicians may be able to effectively engage the community as collaborators in the research process through hiring community members to work as integral parts of the process via

community organizations or as direct employees of the university (Srinivasan & Collman, 2005). This can be attractive and beneficial to rural communities that lack economic resources to address social problems, while at the same time attracting bright and capable community members to remain in the community by providing them competitive salaries and benefit packages, as well as opportunities to further their education via face-to-face or virtual classrooms.

### **Academic-Community Linkages and Values**

Previous literature has asserted that academic and community linkages develop models for ongoing collaboration and communication between research partners (Currie et al., 2005). This is necessary in part due to differences in the goals and values of community and academic partners. Some academic research partners may feel a sense of urgency to publish findings of their work to meet specific milestones to earn tenure. Due to the participatory nature of CBPR, researchers engaging in this model must balance their needs for promotion and tenure with the time-consuming nature of collaboration. Academicians and community partners may have different goals for participation in the project, but both seek respectful recognition of their contributions and both wish their roles to be valued by others. Furthermore, Currie et al. (2005) asserted that CBPR can be methodologically rigorous while making unique contributions not available through other types of research.

The process of collaboration is a clear strength of the CBPR approach. For researchers, scientific rigor is critical to project success. Through the process of co-learning, community partners can appreciate the value of scientific rigor because its advances can significantly enhance community goals and provide the credibility necessary to facilitate change (Srinivasan & Collman, 2005). Researchers can gain a unique perspective into social problems through the eyes of those who are most passionate and impacted.

Strickland et al. (2003) identified trust, cooperation, and readiness for participation as potential challenges in engaging rural communities in CBPR. Community members often lack time, resources, or motivation to participate. There may be communication difficulties, such as researchers using technical language that is not understood by community participants or language barriers due to a significant number of non-English speaking community participants. Logistical barriers such as limited transportation, lack of stable home address, or working telephone can be hindrances to research participation. Having multiple venues for participants is critical so those with various levels of interest and motivation can experience appropriate levels of involvement.

Researchers from academic institutions must be aware of the historical role of their institutions in collaborating with communities. These institutions may have engaged communities in the research process but did not utilize an egalitarian approach to engagement, instead engaging communities without their input or full cooperation. This can cause a legacy of mistrust among community members (deLemos, 2006). Therefore, researchers may have to overcome barriers to relationships established by previous researchers working in the community.

## **Methodological Strengths and Challenges of CBPR in Rural Communities**

### **Conceptualization**

Community participation is usually fueled by the pressing need for social action and intervention to address social and health issues. Community participants are often interested in immediate change, perhaps even prior to the conclusion of the research project. The process of developing mutually defined goals and objectives with various community stakeholders is often time consuming. CBPR can be a successful approach in understanding the nuances of local and regional differences in rural problems, policies, and needs. For example, during the conceptualization phase, various questions must be addressed:

- What are the geographic boundaries of the “rural community” being studied?
- How do local cultural factors differ from one (rural) region to another, by what methods can we detect these differences, and how can we use such knowledge to target interventions to improve health? (Hartley, 2004, p. 1677)
- Who will be involved in problem definition?
- If there is an intervention component, who chooses and designs the intervention?
- Who will be hired and how much will they be paid?
- Will there be a control group?
- Who has ownership or control over the development of papers and presentations?
- Who decides how results will be interpreted and disseminated both locally and nationally?
- Who are the community partners/community leaders involved?
- How will infrastructure for the project be established and developed?

Those seeking to engage communities in research should enter the relationship with guidelines and documentation, such as a memorandum of understanding (MOU), to reduce potential conflicts. Simultaneously, those seeking to engage in CBPR must be open and flexible to changing agendas and expectations to accommodate the needs of community stakeholders. All stakeholders must work together to achieve appropriate balance between process and outcomes.

## Congruency in Research Goals

Researchers may encounter community partners who have a sole interest in community interventions and service projects and a lack of interest in scientific questions and processes. This may be a particular problem in rural communities that lack the infrastructure for health care, social services, or even transportation that are in place in larger urban or suburban communities. Scientists must be willing to give up some power over the research process. In this collaborative process, scientists will not have sole control over the establishment of research goals. Ideal community-academic partners will have a mutual interest in both research and social action.

## Measurement

Community stakeholders and researchers must come together to develop precise operational definitions of concepts to be employed in the research study. Academicians must embrace their role as educators to train community partners in how to conduct research. However, before beginning data collection, variables should be defined so that all parties are very clear about what is being measured and what is being observed. This may require bringing all parties together and educating community members about variable and sample selection. Widely accepted operational definitions from the academic literature may vary greatly from a laypersons' definition of the problem. Scientists must understand the culture of the community and how to phrase questions so that the desired concepts are understandable by all research participants. Researchers have the option of utilizing definitions commonly found in the literature or crafting new definitions based on community and scientific collaboration. Further, it is critical to define the boundaries of the rural area being studied utilizing either descriptive definitions developed by collaborative research partners or definitions developed by other organizations. Widely accepted definitions of rurality developed by The Office of Management and Budget and The Census Bureau are commonly utilized in decision making regarding rural health policy (Prouty Vanderboom & Madigan, 2007).

How variables are operationalized has a direct relationship to the findings. Decisions must be made about how to measure variables and the limitations of categorical or ordinal levels should be weighed. If a survey is utilized, questions must be addressed:

- How many questions are too many questions?
- What should be the target level of readability?
- Should a Likert-type scale be utilized? If so, will participants find this confusing?
- What type of sensitive information (e.g., income, sexual history, domestic violence, and medical history) should be included or excluded?

This is particularly critical to enhance participation among rural participants who may be familiar with those persons collecting the data. Pre-testing previously used scales and instruments on the target population prior to implementation are essential. Community partners can often provide valuable input regarding these issues prior to testing phases of the project.

Thinking through these issues in advance can reduce bias and address issues related to external and internal validity.

CBPR projects seek, as its primary goal, *sustainable* social transformation and community empowerment. Evaluation of community partnerships is critical to establishing best practices and developing documentable procedures that can be replicated by other researchers and community partners seeking collaboration. Therefore, CBPR projects must seek to collect data and measure satisfaction with the partnership and evaluate relationships between community partners such as academicians, community leaders, and research participants. Several studies (Anderson, 2000; Gibbon, Labonte, & Laverack, 2002; Rogers, Chamberlin, Langer Ellison, & Crean, 1997; Saegert & Winkel, 1996) have utilized scales to examine personal empowerment and/or community empowerment concepts. CBPR projects must also seek to evaluate and accurately document community transformation by evaluating community changes in local or state-wide policy (i.e. evaluating improvements to health or social care).

### **Data Collection**

This phase of the research project is arguably the most important. The setting is a critical aspect of data collection. Community partners can be helpful in developing a plan about where and how to collect data that takes into account where participants live, public transportation routes, and typical work schedules for the targeted group. These factors are particularly critical in rural areas where poor and underserved participants may lack access to transportation to attend or follow-up with the research study. A budget for data collection in rural areas should consider offering incentives such as child care, transportation, and meals to encourage participation.

Dependent on the goals of the research study and the design of the project, data collection for behavioral research may involve interviewing participants or administering questionnaires. Again, ingredients of community input and scientific rigor produce the best CBPR recipe.

- What is the best way to collect the data—in person, by mail, or by telephone?
- How can respondents be selected to produce the most representative sample?
- What time and place are best to reach the sample?
- Who should conduct the interviews?
- Will confidentiality or anonymity be a problem if rural community members collect the data? If so, one way to address this issue is to provide training and support for community members.

Once community members who will collect data have been trained regarding human subjects protocol and the importance of confidentiality, they can be asked to sign a confidentiality statement. This is critical among rural populations with close knit communities where those



involved in data collection may potentially know research participants. A successful strategy can include partnering community members with researchers or trained master's- or doctoral-level students to assist in explaining human subjects procedures and to ensure data is collected and stored appropriately.

In a CBPR model, recruitment is community focused (Cartwright & Allotey, 2006), thus enhancing possibilities for community buy-in and increased participation by research participants. Participants often participate in research studies with a great deal of trepidation, particularly in minority or rural communities. Mistrust is often fueled by a history of oppression and exploitation. Studies such as the Tuskegee Experiment have left a historical legacy of medical mistrust among ethnic minorities (Anderson Loftin, Barnett, Summers Bunn, & Sullivan, 2006; Scharff et al., 2010). In addition to a historical legacy of impropriety regarding medical ethics, researchers must also address general attitudes of mistrust expressed towards outsiders common in rural communities (Anderson Loftin et al., 2006). In their study of attitudes and beliefs about participation in medical research, Corbie-Smith, Thomas, Williams, and Moody-Ayers (1999) found that African Americans reported a mistrust of doctors, scientists, and the government in general. Further, participants expressed concerns about the ethical conduct of clinicians and investigators in their work with minority communities. Even when risks are explained, many people do not understand the purposes of risk and the purposes of human subjects' protocol. In addition to misperceptions about informed consent, African Americans have reported that signing a document meant relinquishing autonomy in the interests of legal protection of physicians (Corbie-Smith et al., 1999). In working with rural populations that may have issues with literacy, informed consent may require numerous revisions and pretesting.

Baffour, Jones, and Contreras (2006) described innovative techniques to recruit pregnant and parenting women for participation in a CBPR project aimed at reducing infant mortality and prematurity in a rural community. Indigenous community health workers, called Family Health Advocates, conducted informal outreach through personal contacts in churches and grocery stores, as well as door-to-door canvassing. Other social marketing techniques include organization newsletters, public service announcements, and attendance at community events and health fairs. Health fairs have been held at churches, schools, and community centers to attract program participants. Incentives such as child care and meals during focus groups, and pre- and post-test surveys were provided.

### **Data Analysis and Outcome Expectations**

Ongoing evaluation is an important part of a successful CBPR model. Part of a good evaluation model seeks to evaluate outcomes, including satisfaction with the partnership and identification of areas for improvement. Focus groups, surveys, or interviews can provide a venue for partners to communicate regarding their experiences concerning power distribution and control throughout the process. Community members should have an authentic role in the fruits of the research project: the findings. At the onset of the partnership, it is important for community-academic partners to agree regarding how findings will be disseminated and how authorship will be designated.

- How many publications will result from the findings?
- How will the responsibility of data analysis and the work of writing publications be distributed?
- What will be the role of community partners in writing for academic journals, report writing, and presentations at professional meetings and community forums?

Sharing preliminary findings with community members can provide opportunities to incorporate their interpretations into research reports or discern the need for further analysis (Cartwright & Allotey, 2006). This sharing can provide opportunities for all partners to “mentally digest” the results and decide how they can best be utilized to advance agendas of social action and scientific research. Findings can be shared with large community groups via agency or community consortiums, staff meetings, community forums, or partnership meetings. Sharing the findings of the study can be an important “next step” in determining additional possibilities regarding community needs for future research.

### **Implications for Social Work Education and Research**

Social workers in the academy have the ability to increase the translational ability of their research efforts to create sustainable community change through the use of CBPR. Academicians can help to build the infrastructure of local rural community organizations through consultation, field placements for baccalaureate and master’s-level students, and research internships for doctoral-level students. Social work students at all levels can significantly benefit from integrating an understanding of CBPR into their repertoire of skills. In a CBPR approach, researchers must utilize a tool kit of skills that are integrated into the social work curriculum. Social work has a significant advantage over other academic disciplines in that social workers receive significant hands-on and theoretical training in cultural competence, and communication and listening skills. This tool kit can assist social work researchers in the engagement and development of egalitarian partnerships with communities. It can be significantly enhanced by including more courses on community-based research methods, particularly at the doctoral level.

One of the goals at the forefront of social work education is for social workers to become effective consumers and producers of research. Thus, social workers utilize research to inform their practice and their practice to generate new research questions. Thus, communities can serve as effective laboratories for students, their field instructors, and practitioners to learn about real-world methodological challenges of conducting CBPR.

Social work researchers are uniquely positioned in academic institutions to form partnerships with other disciplines to build community capacity. Social workers must continue to collaborate with communities and with interdisciplinary colleagues on research that promotes a CBPR approach while simultaneously promoting evidence-based practice.

### **Implications for Social Work Practice and Policy**

Social work is in a unique position, due to its mission and values, to facilitate a collaborative social justice agenda through research and coordination of services. Social work can play a visible role in CBPR through the administration of both direct (case management, counseling) and indirect (administration, advocacy, lobbying, program design) services to underserved groups. Social workers who are engaged in CBPR should seek to develop partnerships with local organizations, companies, health departments, physicians, and health organizations to create a network that can promote sustainability for services after the conclusion of a research project. Social workers in multifaceted roles must utilize ways to make CBPR a relevant and appealing approach for those populations with whom they seek to work. One method of doing this is to offer services identified by community groups, advisory boards, or community participants. Town meetings, workshops, and retreats with community leaders and researchers can be used to elicit information throughout various stages of the research process. Previous researchers conducting CBPR have found town meetings to be an effective strategy to ensure that affected community stakeholders have a voice in identifying research priorities (O'Fallon, Wolfe, Brown, Dearth, & Olden, 2003).

CBPR must include holistic and comprehensive models of care. Community members' and organizations' interest and involvement in a research project may be part of a larger goal to improve community well-being and improve the quality of life for residents. As rural communities seek to address the needs of more diverse racial and ethnic groups, social work has an increasingly critical and multifaceted role. Social workers engaging in CBPR must not only seek to acknowledge the unique cultural perspectives that rural communities present but consider the physical, emotional, social, economic, and spiritual needs of the community. Accordingly, CBPR models must incorporate service components which include case management services that support holistic conceptualizations of care, such as oral health, HIV testing, support groups, housing assistance, utility assistance, and referrals for concrete services (e.g., health insurance, WIC, food stamps, and Social Security Insurance). One way to recruit project participants is to disseminate information about services being offered.

Social justice goals can be addressed in CBPR through action-research models that seek to teach advocacy skills to the target population. This can be accomplished by events and interventions designed to teach clients about policy and make an impact at state and local levels. Social workers serve a critical role in how social justice interventions are designed, implemented, and evaluated. CBPR has been a successful approach to address health disparities, particularly in rural areas, where gaps in service delivery are critical.

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### Author's Note

Address all correspondence to Dr. Tiffany D. Baffour, Associate Professor and Chair of Behavioral Sciences & Social Work, Winston-Salem State University, 108 Coltrane Hall, 601 S. Martin Luther King Jr., Winston-Salem, NC 27110, (336) 750-2627, [baffourt@wssu.edu](mailto:baffourt@wssu.edu).

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