

Unit 3 Chapter 21

The Use of Community-Based Participatory Research to Understand and Work with Vulnerable Populations

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Health disparities and lack of access to health care among some disadvantaged populations have received increasing attention and concern among healthcare providers and health policymakers (Minkler, Blackwell, Thompson, & Tamier, 2003; U.S. Department of Health and Human Services, 2000). As healthcare providers and policymakers have become more concerned about the health of vulnerable populations, more research has been developed to better understand their plight. The goal of these research studies is to develop effective interventions. These studies, however, often fail to present the perspective of those who are vulnerable, resulting in less than optimal interventions. The purpose of this chapter is to present an overview of community-based participatory research (CBPR) as an approach to learning about and working effectively with vulnerable populations.

Vulnerable populations encompass those groups with decreased access to care and increased risk for illness and accidents. In trying to intervene with various vulnerable populations, it is imperative that healthcare providers understand their perspectives rather than imposing on them what we believe to be their experiences. Without such understanding we may unwittingly exacerbate problems, and community members who are vulnerable may believe they are being given edicts, are disempowered, and have no voice in the solution to their problems. An example is the exclusion of women from clinical trials with the disastrous results that findings related to men were simply applied to women without scientific evidence for the clinical significance of these findings. Women as a population became vulnerable by virtue of being excluded from research. At this point the National Institutes of Health mandates the inclusion of women unless there is obvious rationale for excluding them. Such inclusion, however, does not guarantee that the perspectives and voices of women are included in the research. The issue of appropriate recognition of women's issues continues to be argued and debated (Parascandola, 2006).

Many researchers use open-ended approaches to understanding the experiences of others, including asking open-ended questions without imposing variables a priori. This approach yields important data that would not otherwise be generated. However, this research is done "on" the participants. CBPR takes a different approach. It actively

involves the participants as coresearchers. Clark and colleagues (2003) addressed the need for community members themselves to contribute to identifying the needs within their communities. This chapter presents an overview of this method and then describes why it is appropriate for working with vulnerable populations.

Overview of Community-Based Participatory Research

CBPR is an action-oriented research method that involves a team approach inclusive of all participants. “All” participants refers to the researchers and the “researched” as equal members of the research team, all with an important voice in the research. Rather than referring to the process of doing research “on” people, this approach refers to doing research “with” people. The “people” are those members of a community of interest, those who are most directly affected by the phenomenon being studied. The members of a community also work in tandem with the researchers, leading to a collegial research effort within an environment of collaboration rather than the traditional hierarchical environment. One important goal of CBPR is to empower those who have not been empowered (e.g., those who are vulnerable) by helping to eliminate oppressive situations and/or conditions contributing to marginalization and vulnerability.

CBPR engages community members as active participants in the research. An important aim of this research is to generate an understanding of the community members’ perspectives and needs so as to develop interventions that meet the needs of the community members. The concept of action is integral to CBPR (in fact, some refer to this kind of research as “participatory action research” or “action research”) because the overt goal of this research is to take constructive action. CBPR is most appropriate for addressing the needs of vulnerable populations because it encourages the direct and active involvement of the members of those populations. Such an approach seeks to mitigate inequalities and oppression among vulnerable groups.

In recent years CBPR has received increasing attention. Seymour-Rolls and Hughes (2000), Minkler et al. (2003), and Israel, Schulz, Parker, and Becker (1998) addressed the importance of this approach to research in better understanding the nuances and complexities in communities of interest. Olshansky and colleagues (2005) described how CBPR can be used to understand and alleviate health disparities. At the Eastern Nursing Research Society a research interest group was recently formed with a specific focus on CBPR, reflecting the increasing interest in this approach to research.

Israel and colleagues (1998) aptly described eight key principles of CBPR:

1. Recognizing that the community is the unit of study
2. Building on the strengths already present in the community
3. Continually facilitating collaboration and partnership in each phase of the research
4. Integrating knowledge and action (e.g., knowledge alone is not enough; it must be coupled with action for social change)

5. Promoting the alleviation of social inequality by colearning
6. Using an iterative process
7. Focusing on wellness and an ecological perspective of health
8. Partnering in the dissemination of research findings

This chapter uses the framework presented by Israel and colleagues. The next section presents an in-depth look at each of these principles, followed by a focus on the applicability of each to working with vulnerable populations.

Principles of CBPR: Applicability to Vulnerable Populations

1. *Recognizing that the community is the unit of study.* This principle addresses the central focus of CBPR: the community and the factors that influence the community must be understood and addressed to understand the issues of the individual within the community. The concept is consistent with the ecological framework that addresses social, political, economic, environmental, and sociological factors as part of the community context and contributing to the experience of individuals within the community. Although the experiences of each individual are important and each individual is unique, the focus is on the community in which the individual experiences situations and problems. Individual differences within communities are taken into account to develop a comprehensive understanding of the complexities within communities.
2. *Building on the strengths already present in the community.* This principle embraces the attitude that those within the community already have strengths despite the fact that they are vulnerable by virtue of unequal access to care and perhaps oppression by other dominant groups. In the spirit of empowerment it is important to learn from them how they view their strengths, how they would like to use their strengths to tackle the problems identified, and how they can improve on present strengths. It is imperative that the community members articulate these strengths and why they view them as strengths. Reciprocally, it is imperative that the members of the research team truly listen to and hear the community members' descriptions of how they cope with situations, how they have managed in the past, and what their views are in regard to how to continue to manage and move forward despite the vulnerabilities that they experience on a daily basis.

Focusing on strengths encourages empowerment among the members of the community. They believe they have something to offer rather than being told what they should do by the researchers or health professionals. In addition, the researchers can learn from the community participants. Rather than, as is traditionally done, imposing their views on the community participants, the researchers can begin to understand what works best for the community participants.

3. *Continually facilitating collaboration and partnership in each phase of the research.* Collaboration and partnership are signature aspects of CBPR. To develop a collaborative partnership with the members of a vulnerable community requires much planning (Kelly, 2005). It takes time to develop a true partnership with members of the community, particularly when there has been a lack of trust of researchers from an academic or other institution among vulnerable community members. Taking the time initially to develop trust, enabling the entrée of the traditional researcher into the community, is crucial to the success of the research. Strategies for achieving this trusting relationship include going into the community and conducting focus groups on site (as opposed to having the community members travel to the location of the researcher).

It is important that the researchers venture out of the “ivory tower.” Community members, likewise, need to know that they have an open invitation to the researcher’s location, but of overriding importance is for the researchers to enter the context of the community members. By doing so they strive to understand the context and to reverse the often stereotypical view of the ivory towers of academia. Gaining entrée into the community and developing trust among the community members is only the beginning of this collaboration and partnership. Community members are considered equal partners in the research. They have an active voice in determining the research question, in designing the research method, in contributing to the data collection and analysis, and in disseminating the research results. They work in partnership as equal members of the research team.

It is important to recognize the unique skills and contributions made by each member of the research team. The community members are the experts in the actual phenomenon under study. The traditional researchers are the experts in research methodology, including collection and analysis of data, and writing up or presenting research results. Therefore each member of the research team contributes based on his or her area of expertise, but all members of the research team are involved in all the steps of the research process to greater or lesser degrees.

Focus groups are commonly used in CBPR as a way to involve all members of the research team and to elicit perspectives from the various members of the research team. Focus groups are a way of facilitating discussion within an atmosphere of openness, where the goal is to hear the various perspectives and views of community members and the traditional research members. The focus group serves several purposes. It helps each member of the team to get to know one another and to hear each person’s perspectives and description of their experiences. It also helps the members to come together in a collaborative manner as they begin to understand each person’s experiences, focusing on the differences among them while also looking for and eventually being able to define commonalities. The focus group allows the members to more clearly define the research problem, the focus of the research, and to identify the goals and outcomes of the research.

4. *Integrating knowledge and action.* A crucial component of CBPR is action, in the form of developing and implementing interventions within the community that will help to alleviate the problems identified. CBPR is a form of research with the overt purpose of making social change to alleviate disparities, oppression, and other factors that lead to vulnerability. CBPR is true “translation research” because the translation into practice occurs in an immediate and ongoing fashion from the moment the research commences and throughout the entire process. By working closely and collaboratively with community members who desire constructive social change, the emphasis on action to achieve this constructive change is paramount in CBPR. This approach is germane to nursing education as nursing students are a strong voice for social change necessary to improve health disparities among vulnerable populations (Reimer-Kirkham, Van Hofwegen, & Hoe-Harwood, 2005).
5. *Promoting the alleviation of social inequality by colearning.* The principles discussed above contribute to alleviating social inequality. This principle is directly related to the principle of integrating knowledge and action. To alleviate social inequality it is imperative that constructive social change leads to social emancipation and alleviation of oppression. Such social change is truly constructive only if those less fortunate (those who are vulnerable) are empowered. Integrating this principle into CBPR reflects the complexity of this research approach. This research process includes developing collaborative partnerships, involving all members of the community actively in the research project, overtly seeking to make social change in a constructive manner, and doing all of this while empowering those less fortunate. In fact, without such empowerment the other aspects of the research will not be achieved. Lofman, Pelkonen, and Pietila (2004) aptly described the importance of the involvement of the community members to address unequal power relationships.
6. *Using an iterative process.* An iterative process is one in which each of the phases of a study are conducted in a circular, as opposed to a linear, fashion. Each phase is not a discrete part of the process. Each phase informs the next phase, and subsequent phases may lead to returning to previous phases to make changes based on continuous learning throughout the CBPR process. This iterative process is central to all qualitative research. CBPR uses qualitative research methods through focus groups, eliciting perspectives of informants in their own words, and approaching data in an interpretive manner. The research begins in an inductive manner as the research question is open ended, and the goal is to learn the perspectives of the members of the community without imposing preconceived variables. As the research continues certain variables that are generated through the research process receive greater focus based on continuing data to support these variables. In qualitative terms this is referred to as saturation of data (Strauss & Corbin, 1998). At this point data collection becomes more deductive, focused on

looking for further evidence of predetermined and emerging variables. Previous data are then reanalyzed with the explicit purpose of looking for data or evidence to support the existence of these variables. This iterative process involves going back and forth with data collection that influences data analysis, which then furthers data collection.

7. *Focusing on wellness and an ecological perspective of health.* CBPR proposes multiple and interacting factors within ones' social context that influence and are influenced by health. This ecological perspective embraces the notion that context is a key factor in understanding how to promote wellness. The context includes biological, psychological, environmental, social, and interpersonal factors. Health and wellness occur within this context. Using CBPR, the research team seeks to understand the factors in this ecological perspective. These factors are uncovered by open-ended questions and participant observation.
8. *Partnering in the dissemination of research findings.* As noted earlier, in CBPR all members of the research team are involved in all aspects of the research process, including the dissemination of research findings. Traditionally, the dissemination of research has consisted of researchers writing for publication or presenting at conferences. These publications and conferences have been refereed (i.e., reviewed by a panel of experts who are also researchers and scholarly peers). In CBPR those peer reviews continue, but research findings are also disseminated in magazines and meetings of the lay public. Those publications that are sent to peer-reviewed journals will, ideally, include the lay community members as coauthors. The research data and findings are "owned," in a sense, by all members of the research team, a key aspect of CBPR.

CBPR and Vulnerable Populations

Vulnerable populations often lack a voice in regard to what they need and to how these needs could best be met. It is more common for presumed "experts" from health care and other arenas to dictate solutions to vulnerable populations. This dominant attitude, although perhaps well meaning, is usually counterproductive. It keeps vulnerable populations in vulnerable positions. They continue to lack a voice. A CBPR approach seeks to address these limitations of the traditional approach to assisting vulnerable populations. CBPR aims to assist the vulnerable in attaining and maintaining a voice, to recognize those who are vulnerable as the true "experts" about the issues they are experiencing, and to ultimately assist them toward partnership in social change.

Implementing a CBPR Approach with Vulnerable Populations

Even after establishing the critical need for CBPR in alleviating inequalities and oppressions suffered by vulnerable groups, it remains difficult to implement such an approach. Many barriers exist, but one goal of nurses and other healthcare providers and researchers

is to work actively to overcome those barriers. This section presents strategies for implementing CBPR in research and healthcare settings.

In academic research settings there needs to be support for such an approach. The National Institutes of Health recognizes the need for CBPR, reflected in a recent call for research proposals incorporating CBPR. In educational settings, this approach should be included in research courses in undergraduate and graduate programs.

Academic researchers and healthcare clinicians should partner with one another to develop research programs that include community members. An ideal CBPR project would include academic researchers, clinicians, and community members. In addition, health policy experts and members of health insurance companies could also be included in such research. All these participants in the research process can contribute important perspectives. The research team is expanded to include the voices of the community members. The community members then have the opportunity to voice their concerns to these various members of the healthcare team.

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