4

COMMUNITY-BASED PARTICIPATORY RESEARCH AND OCCUPATIONAL HEALTH DISPARITIES: PESTICIDE EXPOSURE AMONG IMMIGRANT FARMWORKERS

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Community-based participatory research (CBPR) has become a widely accepted approach to involve minority and vulnerable communities in health research (Arcury, Quandt, & Dearry, 2001; Brody et al., 2009; Kreuter, Kegler, Joseph, Redwood, & Hooker, 2012; Quandt, Arcury, Austin, & Cabrera, 2001; Rhodes et al., 2012; Viswanathan et al., 2004). CBPR is a format that allows research to address the actual health concerns of minority and vulnerable communities, involves community members in all components of the research process to improve the quality and relevance of the research and

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to grow the skills of community members, and returns information from the research to the community in a format that individuals can use to improve and protect their health and leaders can use to improve policy. However, with a few exceptions, CBPR has not been used to address occupational health disparities.

Communities are social groups with shared identities, experiences, and histories, even if the social groups are not limited to a geographic locale. Occupational groups often fit this definition of community, and CBPR is an appropriate approach for research and intervention. For example, CBPR has been used for research on the occupational health of farmworkers (Coronado et al., 2011; Farquhar, Shadbeh, Samples, Ventura, & Goff, 2008; Flocks, Kelley, Economos, & McCauley, 2012; Samples et al., 2009) and with immigrant Latino and African American poultry processing workers (Lipscomb, Epling, Pompeii, & Dement, 2007; Marín et al., 2009; Quandt et al., 2006). It also has been used in the design, implementation, and evaluation of a safety-training program for Latino day laborers (Williams, Ochsner, Marshall, Kimmel, & Martino, 2010). Each of these occupational groups is a vulnerable population.

The goal of this chapter is to introduce the use of CBPR in conducting research with minority and vulnerable occupational communities. We begin by defining CBPR and discussing its characteristics and by providing conceptual and operational models of CBPR as translational science. We present a specific CBPR project, PACE3: Community Participatory Approach to Measuring Farmworker Pesticide Exposures, focused on the occupational health (pesticide exposure) of migrant and seasonal farmworkers in North Carolina to illustrate the conceptual and operational models of CBPR. We conclude with a discussion of issues to consider when developing a CBPR project that addresses occupational health disparities.

COMMUNITY-BASED PARTICIPATORY RESEARCH

Several dimensions of applying CBPR to occupational health require specification. These include defining CBPR and listing its elements; providing conceptual and operational models of CBPR as translational science; and explaining how CBPR is appropriate in addressing occupational health disparities in vulnerable populations.

Definition and Elements

CBPR is the process by which trained health scientists and community members collaborate in a joint process to critically investigate and change the environment, both physical and social, in an effort to improve people's health

(Arcury et al., 2001). CBPR is an approach to research that maintains rigorous methods while transforming the power dynamics and barriers between the researcher and the researched by emphasizing coeducation, power sharing, and knowledge sharing (Israel, Schulz, Parker, & Becker, 1998; Minkler, 2004). It has four major elements. First, it includes the participation of the people being studied. In the purest case, community members would be involved in delineating the topic that the research addresses; it is a topic that is important to the community. They would participate in the design of the research and the implementation of data collection. They would direct the analysis and reporting of study results. Second, CBPR uses the personal experiences and perceptions of community members as data. The systematic documentation of these personal experiences and perceptions often uses textual (in-depth individual interviews, focus groups) as well as statistical (e.g., survey interviews) methods. Third, the CBPR has a focus on empowerment and capacity building in which the community gains control and sovereignty as a result of their participation. Finally, a product of the research must be action by community and academic members to change the conditions causing the problems. This action may be political in working with elected officials and government workers to change policy, it may be community organizing to increase community-member involvement in implementing solutions, it may be implementing programs to provide community members with information or training, or it may be legal action or litigation to force changes on recalcitrant entities or gain remuneration for community members.

Israel et al. (2005) presented a set of principles for CBPR that are useful to consider when establishing community collaboration. They define *community* as a unit of identity reinforced through social interaction and characterized by shared values. Foremost among their principles is the understanding that CBPR requires a long-term commitment that must transcend a specific research project or research grant and that CBPR should grow through an iterative process. For example, our work with farmworkers in North Carolina began in 1995, and it has expanded for almost 2 decades to include activities beyond research. Maintaining a long-term commitment reflects two other principles: Collaborative activities should build on community resources and relationships, and they should establish equal partnerships. Collaborative programs developing from a long-term commitment should address locally relevant health problems and balance research and action. The results gained through these collaborative programs should promote reciprocal transfer of skills, with the results of these programs being actively disseminated to all partners. We add another principle to this list: CBPR conducted with vulnerable communities is a political process in which the collaborative program is addressing the needs of the vulnerable communities in the face of powerful and opposing political forces.

Conceptual and Operational Models of CBPR as Translational Science

Translational science rests on two processes. The first is making current empirically based health information available to health care providers, public health practitioners, and community members in a format that they can readily use to improve medical care, public health practice, and health self-management. The second process is providing health scientists with information that describes the real-world needs of health care providers, public health practitioners, and community members to help the scientists focus their research.

Translational science is at the heart of our conceptual model of CBPR (see Figure 4.1). This model begins with identifying community needs. Numerous processes can be used in identifying community needs. Community-based organizations, community advisory boards, and exploratory research can all present scientists with information documenting the health issues important to a community. For example, in our research on farmworker pesticide exposure, health care providers, community advocacy organizations, and farmworker community organizations all indicated that farmworkers were exposed to pesticides at work but that little information was available to document how they were exposed, the health implications of this exposure, or how to reduce this exposure.

This model proceeds to conducting research that addresses the community-identified needs. The design of the research will vary depending on the questions being asked. However, in all cases, rigorous scientific methods must be applied in this research. CBPR with vulnerable populations is always a political process; therefore, the research must be of the highest caliber to withstand the scrutiny of the politically powerful. Community members and stakeholders will be involved to different degrees with different parts of the research.

The results of the research must be "translated" or made available to the different stakeholders in a format so that each stakeholder group (audience)

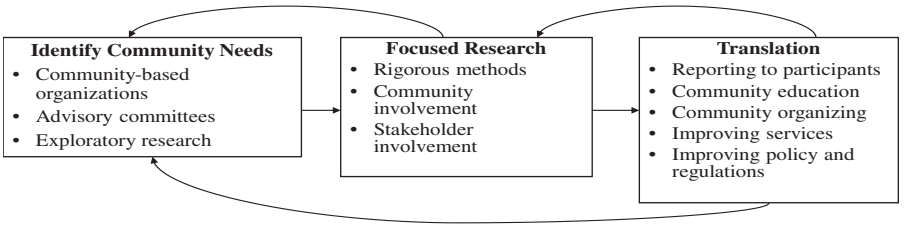

Figure 4.1. Conceptual model: Community-based participatory research (CBPR) as translational science.

can understand and use the results. This translation can be in the form of providing participants with their study results (e.g., laboratory results indicating level of exposure to a toxicant, medical diagnoses) and how they can use these study results to improve health. It can be used for community education and community organizing by providing information to all members of an affected community that they can use to improve their community. It can be used to inform the provision of services to a community or to change policies or regulations that improve the health of the community.

Connecting the three elements of the model are feedback loops. The model is not linear. Discussions of policy (translation) can inform the need for new research, as can gaps in community education. Similarly, issues related to services can be reflected in community needs. New research results can also be used in identifying community needs.

The multimode, multidomain operational model of CBPR is proactive in developing active participation from all community segments to identify community needs, conduct research, and translate research results (Arcury, Austin, Quandt, & Saavedra, 1999; see Figure 4.2). All community project participation is reflected in four domains: (a) consultation, which involves helping to delineate what should be done; (b) strategic planning,

	Community participation domains			
Examples of community participation modes	Consultation (What we should do)	Strategic planning (How we should do it)	Implementation (Do it)	Translation (Tell what we found)
Academic–CBO partnership				
Community advisory committees				
Health care provider advisory committees				
Partnership with service organizations				
Community meetings				
Training community members				
Training students				

Figure 4.2. Operational model: Multimode multidomain community-based participatory research (CBPR) model. CBO = community-based organization. From "Enhancing Community Participation in a Public Health Project: Farmworkers and Agricultural Chemicals in North Carolina," by T. A. Arcury, C. K. Austin, S. A. Quandt, and R. Saavedra, 1999, *Health Education & Behavior*, *26*, p. 570. Copyright 1999 by Sage Publications. Adapted with permission.

which involves deciding how it should be done; (c) implementation, which involves completing the tasks to actually do it; and (d) dissemination, which involves sharing what was accomplished with other community residents and policymakers. We have learned that the members of vulnerable communities, because they have limited immediate economic resources, are often limited in participating even when they understand the long-term benefits of participating. If they have the opportunity for an immediate economic reward that allows them to feed their families, this takes precedent over long-term community gain. It is easier for a person with an outside income to be a volunteer; for those with a limited income or limited work opportunities, volunteering is often difficult. Therefore, this operational model allows community members to use the modes of participation in which they are comfortable within the four domains. For example, individual community members may only have the time to serve on an advisory committee involved in consultation and strategic planning that meets once per month or to attend an annual community meeting at which consultation is provided. Other community members might have the time to be active members of community-based organizations and become community investigators active in all domains of participation. Students from the community who are at all levels of education can become involved in projects and help with the implementation and translation domains. Finally, community members may be hired as project data collectors who are trained by the project and gain skills that help them with future employment.

CBPR With Vulnerable Populations

CBPR is appropriate for research and interventions addressing occupational health disparities experienced by vulnerable communities. CBPR provides a framework for conducting translational health research in vulnerable communities that allows community members the opportunity to participate in a manner that fits their situation. Through CBPR, the trust needed for environmental health research is established between community members and academic investigators. CBPR requires scientists and community members to share power, share resources, invest time, and invest effort. However, structural and cultural barriers often limit sharing power, resources, time, and effort. For example, granting agencies generally recognize one organization (most often the academic partner) as the primary grant recipient, which gives that organization control of resources. Those with more education and regular, secure employment (again, usually the representatives of the academic partner) often are seen as having more prestige and power. At the same time, community organizations can be unwilling to share the power they have in the form of community access and knowledge. The investment of time and effort requires academic partners to spend time at community venues and

events; it requires community partners to learn about how research is conducted and data are interpreted.

Farmworkers are an excellent example of a vulnerable population for which CBPR is appropriate. Farmworkers experience great occupational and environmental hazards, including the physical environment (e.g., sun, heat, dust), wild plants (e.g., poison ivy) and animals (e.g., snakes), sharp tools, mechanized equipment, chemicals (e.g., pesticides, fertilizers, fuels), noise, and substandard housing (Arcury, Grzywacz, Sidebottom, & Wiggins, 2013; Arcury & Quandt, 2009). At the same time, farmworkers have little power because they are immigrants, are often unauthorized, have low incomes, have little formal education, and often do not speak English. They have limited control over the way in which their work is organized (Grzywacz et al., 2013). They have limited access to health care (Arcury & Quandt, 2007; Frank, Liebman, Ryder, Weir, & Arcury, 2013). Current occupational safety policy and regulations often exempt agriculture (Liebman et al., 2013). Therefore, research is needed to document the occupational health hazards that farmworkers face for the development of appropriate safety technology, training, and policy. Research is also required because the politically powerful deny that farmworkers experience heightened occupational health and injury risk, and refuse to consider further enforcement of existing regulations or implementation of new, stronger regulations. At the same time, the politically powerful seek to limit research so that the data needed for showing the need for greater safety technology, safety training, and safety policy are not available.

PACE3: A CBPR PROJECT ADDRESSING PESTICIDE EXPOSURE AMONG LATINO FARMWORKERS

In light of these factors, we developed and implemented PACE3: Community Participatory Approach to Measuring Farmworker Pesticide Exposures as a CBPR project to document the exposure of farmworkers to pesticides in the workplace. PACE3 was built over 10 years of community collaboration. In 1995, we began an association with the North Carolina Farmworker Health Alliance (which has since disbanded) to produce an unsuccessful proposal for research to document farmworker pesticide exposure. In 1996, we submitted a second proposal with the North Carolina Farmworkers Project (Benson, NC), which was funded; we initiated PACE1 (Reducing Farmworkers' Exposure to Agricultural Chemical, Grant No. R24 ES08739) in 1997. In 1999, we submitted another proposal in collaboration with the North Carolina Farmworkers Project, which was funded (PACE2: La Familia: Reducing Farmworker Pesticide Exposure, Grant No. R01 ES08739). Currently we are involved in PACE4: CBPR on

Pesticide Exposure & Neurological Outcomes for Latinos; PACE4 will take the partnership through 21 years.

PACE3 began in 2006 and was based on the ongoing primary partnership between Wake Forest School of Medicine and the North Carolina Farmworkers Project. The executive director of the North Carolina Farmworkers Project was a project coinvestigator. Other partners participating in data collection included Greene County Health Care, Inc., and Columbus County Community Health Center. Student Action with Farmworkers and the Farmworker Advocacy Network collaborated in the project design and in the translation of results. PACE3 included a farmworker advisory committee that met in Benson, and a health care provider advisory committee that met in Raleigh. The PACE3 structure included both informal community meetings and the work of undergraduate students (including Student Action with Farmworker interns) and graduate students.

PACE3 addressed each of the four domains of community collaboration and participation described in Figure 4.2: consultation, strategic planning, implementation, and translation. *Consultation* was based on the long-term associations of the project partners that had been initiated in 1995. This consultation reflected the continuing concerns of all parties in the exposure of farmworkers to pesticides, the limited regulations that were in place to protect farmworkers from this exposure and the limited enforcement of these regulations (Arcury, Quandt, Austin, Preisser, & Cabrera, 1999), and the lack of knowledge about pesticide exposure among farmworkers and their beliefs about this exposure (Quandt, Arcury, Austin, & Saavedra, 1998; Rao et al., 2006). At the same time, farmworker service and advocacy organization demands for greater pesticide regulation and enforcement were met with resistance from state and national regulatory agencies because of the lack of data clearly documenting that farmworkers were exposed to pesticides.

The partners were involved in the *strategic planning* that led to the grant application for which funds for PACE3 were obtained. These partners included the North Carolina Farmworkers Project and Student Action with Farmworkers, as well as Wake Forest School of Medicine. Strategic plans included specifying the specific aims and hypotheses, and designing procedures for selecting and recruiting participants and collecting data.

The farmworker and health care provider advisory committees and the community partners (North Carolina Farmworkers Project; Greene County Health Care, Inc.; Columbus County Community Health Center; and Student Action with Farmworker) all participated in the *implementation* of PACE3. Participation in implementation included input on the design of the data collection protocol, recruiting and hiring data collectors, providing lists of farmworker camps and the directions to these camps, introducing data collectors to farmworkers in the camps, and participating in data collection.

PACE3 data collection was largely completed in 2007, but some additional data collection for ancillary studies was completed in 2008. The 2007 data collection design included contact with farmworkers at four points at 1-month intervals across the agricultural season (June through September). Data collection involved four components. At each contact the participants completed an interviewer administered questions that took about 45 minutes to complete at the first contact and 25 minutes to complete at the second through fourth contacts. At each contact they provide a first morning void urine sample that was processed to measure urinary pesticide metabolites and metals. At each contact they provided a finger stick blood sample that was analyzed for cholinesterase activity. (Cholinesterase is a family of enzymes critical to proper neurological function; the organophosphorus and carbamate insecticides work by binding with cholinesterase and disrupting neurological function.) At the first contact, they provided a saliva sample that was used for genetic analysis. Ancillary studies in 2008 involved three contacts at 1-month intervals with a subsample of participants who completed an interview and a finger stick blood sample at each contact, and an eye test and a venous blood draw at one contact.

We had great success in recruiting and maintaining participation of farmworkers because of the collaboration of our community partners. Farmworkers were recruited in 44 camps in 11 counties in 2007. A total of 287 farmworkers participated, with 50 completing only the first contact, 14 completing two contacts, 27 completing three contacts, and 196 completing all four contacts. The participation rate was 95.7%, and we had a total of 939 data points. In 2008, 122 farmworkers were recontacted and agreed to participate for a set of ancillary studies.

The primary findings of this project focused on farmworker pesticide exposure (Arcury et al., 2009, 2010). Analyses showed that biomarkers (urinary pesticide metabolites) for several different pesticides were common among all farmworkers. The presence of metabolites varied across the agricultural season; farmworkers were exposed to multiple pesticides, and they were exposed to individual pesticides multiple times. Farmworker pesticide exposure had implications for health, with cholinesterase depression being associated with the number of organophosphorus and carbamate pesticide metabolites detected in urine samples (Quandt, Chen, et al., 2010).

We found that field and camp sanitation requirements that would reduce pesticide exposure were widely ignored (Vallejos et al., 2011; Whalley et al., 2009). For example, one in five of the farmworkers reported not having received required pesticide safety training (EPA Worker Protection Standard: Final Rule, 1994), and an equal number reported not understanding the training that they received. One third of the farmworkers reported having no access to water for hand washing available at work, and one half reported not having soap or towels for hand washing available at work. One in five

farmworkers reported that they lived in camps in which there were more than 30 residents present for each working washing machine or washtub. The number of substandard housing conditions increased across the agricultural season.

We also worked with our community partners to address several other issues of farmworker health. We found that farmworkers have high levels of arsenic and lead in their systems (Quandt, Jones, et al., 2010), they had poor vision and high rates of eye injuries (Quandt, Schulz, Talton, Verma, & Arcury, 2012), and because they are often separated from their families for 6 months of the year as a condition of their employment, they had limited knowledge of sexually transmitted disease (Rhodes et al., 2010). Other analysis investigated the genetics of pesticide metabolism and cholinesterase depression among farmworkers (Howard et al., 2010).

Four audiences were the foci for the *translation* of PACE 3 results: the actual study participants, the general farmworker community, advocates and policymakers, and environmental and occupational health scientists. Translation of study results differed for each of these audiences. The community advisory committees and community partners participated in the translation by helping to delineate the messages for each audience as well as the formats in which messages were to be delivered. Students also participated in translation.

Three approaches were taken in the translation of study results for participants. First, we prepared materials describing the pesticide urinary metabolites detected in each participant to provide these results to the participants in a manner that they could use. It is difficult to translate these results because they are complicated (results include data for 23 different metabolites with measures indicating if the metabolite was present in a urine sample in an amount above the laboratory limit of detection and the amount of the metabolite in μg/liter) and because the actual health effects of any amount of pesticide exposure is not known. Our approach was based on our earlier work in which we reported this information to the members of farmworkers families, indicated our lack of knowledge of the health implications, and provided them with safety information to reduce exposure to pesticides (Quandt et al., 2004). Second, we prepared materials describing the levels of pesticides found for all members who lived in a camp. Finally, we prepared an educational program on pesticide safety for all camp residents. Results were reported to camp residents by a member of the project team who was fluent in Spanish.

The study results were translated into a community education program on pesticide safety that was delivered to farmworker camps (Lane, Vallejos, Marín, Quandt, & Arcury, 2008). Community partners were trained to deliver the education program, which used a flipchart to present information

on pesticide safety behaviors at work and at home, with brochures based on the flipchart left in the camps. Community partners also suggested that we reach a wider audience with pesticide safety using radio announcements. We developed five different radio announcements that were played for 10 weeks in 1-week rotations on two Spanish language radio stations (Lane et al., 2009). The foci of the radio announcements were as follows: (a) farmworkers should bathe immediately after work to remove pesticide residues; (b) employers are required to provide pesticide safety training to farmworkers in a language they can understand; (c) it is important for farmworkers to wash their hands during the work day to keep pesticides from entering the body, and employers are required to provide hand-washing facilities at the worksite; (d) farmworkers should store and wash their work clothes separately from other clothes to prevent contaminating nonwork clothes with pesticide residues; and (e) farmworkers should wear long sleeves, pants, and closed shoes while working to decrease exposure to pesticides. Two versions of the radio announcements were prepared, one for North Carolina with state-specific information and a general one for the United States that did not have contact information for North Carolina agencies.

The translation of PACE3 results for advocates and policymakers began with the development of policy briefs. These two-page documents summarized results reported in peer-reviewed journal articles, noted the policy implications of the results, and presented recommendations for achieving policy changes. Three policy briefs were developed from PACE3 results: Biomarkers of Farmworker Pesticide Exposure in North Carolina, Meeting the Requirements for Occupational Safety and Sanitation for Migrant Farmworkers in North Carolina, and Housing Conditions in Temporary Labor Camps for Migrant Farmworkers in North Carolina (Arcury et al., in press). Development of the policy briefs was undertaken as a collaboration of the academic investigators and the community investigators. Investigators also made presentations of study results in forums attended by advocates and policymakers, including the Governor's Pesticide Task Force in Raleigh, North Carolina (2008); 22nd East Coast Migrant Stream Forum (2009); 19th Annual Midwest Stream Farmworker Health Forum (2009); National Institute for Farm Safety (2010); and National Occupational Research Agenda (NORA) Symposium (2011).

The translation of PACE3 results to health scientists followed the traditional frameworks. Numerous presentations were made at professional conferences by PACE3 investigators and staff members. Investigators and staff members have written 23 peer-reviewed journal articles and one book chapter (not counting this chapter) that have been published or accepted for publication. An edited volume (Arcury & Quandt, 2009) draws heavily from the investigators' PACE3 experiences. Community partners were

included as coauthors of PACE3 materials when it was appropriate given the requirements for coauthorship. For example, Leonardo Galván, project coordinator with the NC Farmworkers Project, was a coauthor on nine PACE3 peer-reviewed articles, and Melinda Wiggins, coinvestigator from Student Action with Farmworkers, wrote a chapter in the edited volume. The inclusion of community investigators as coauthors acknowledges their contributions to the research.

PACE3 resulted in other forms of health science translation. On the basis of study results and discussions with community partners, PACE3 provided a framework for four ancillary studies not included in the original study protocol. These ancillary studies addressed farmworker biological burden of heavy metals, farmworker cholinesterase depression, farmworker eye health and eye injuries, farmworker knowledge of sexually transmitted infection, and the genetics of pesticide metabolism. Four new research projects are based on PACE3 results. These include studies of the effects of pesticide exposure on neurological and cognitive outcomes (CBPR on Pesticide Exposure and Neurological Outcomes for Latinos: PACE4, Grant No. R01 ES008739; and Pesticide Exposure and Age-Related Changes in Cognitive Function, Grant No. R21 ES019720); a collaborative project directed at improving health science communication with community partners (A CBPR Approach to Biomedical & Behavioral Health Communication with Farmworkers, Grant No. R03 ES017364); and research on scientific integrity in CBPR research (Scientific Integrity in Community-Based Participatory Research, Grant No. R21 ES020967). Several additional project applications are planned. Finally, PACE3 promoted increased collaboration of the academic investigators with investigators at other institutions, including Virginia Tech, Duke University, and East Carolina University.

Summary

PACE3 was the product of a long-term commitment of community and academic partners working in collaboration to reduce pesticide exposure and improve health among farmworkers. It addresses a concern of farmworkers and farmworker service providers and advocates. The project recruited a large number of farmworkers and maintained their participation over several months; those participating in an ancillary study remained involved for over a year. Participants completed a diverse set of data collection activities that were often time consuming and unpleasant, in that they included participants' providing saliva, urine, and blood samples. The results have been communicated to a number of audiences—including farmworker participants, farmworker communities, advocates and policymakers, and scientists. The results were used to develop educational programs for farmworkers that have been

used across North Carolina and the United States. The PACE3 partners continue to use study results to influence policy.

A variety of community members were involved in each of the domains of consultation, strategic planning, implementation, and translation. Community participation was structured so that individual involvement reflected the time and resources that community members could provide. Members of the community-based organizations had the greatest involvement, as they were paid for their time. Farmworkers who participated as members of an advisory committee had a smaller commitment, but they were provided a small honorarium and a meal for each meeting. The commitment of farmworkers who participated in community forums was very limited. Members of farmworker advocacy organizations had varying time commitments, but they were professionals committed to ensuring safety for farmworkers.

QUESTIONS TO CONSIDER WHEN DEVELOPING CBPR PROJECTS

CBPR should not be undertaken without considering its implications for community members and professional investigators. CBPR requires significant commitment from the community and professional investigators. If a CBPR partnership is successful, it can result in real and permanent change that reduces occupational risk and provides workers with health sovereignty and improved health. If a CBPR partnership fails, it can result in further harm to vulnerable workers, it can alienate potential allies, and it can harm the career of a professional investigator—particularly a junior investigator. In their review of CBPR projects for the Agency for Health Care Research and Quality, Viswanathan and colleagues (2004) provided a list of issues that should be considered in developing a CBPR partnership. This list provides a foundation for a set of five questions that community and professional investigators should consider in forming a CBPR collaboration.

Question 1: Are the Topic and Population Appropriate for CBPR?

Incorporating worker communities in the research and intervention process can benefit most projects. However, not all research in occupational health and safety requires the use of a CBPR approach. For example, much laboratory engineering research can be accomplished without the participation of worker communities. A number of organizations, such as unions, can facilitate CBPR research. However, CBPR research is most appropriate for occupational health and safety research when it is conducted with vulnerable worker communities, and these generally are not represented by organized

labor. When worker communities are "hidden," lack trust in outsiders, and are drawn from marginalized populations, CBPR projects can provide the access needed to conduct valid and reliable research.

Ancillary to this main question are two additional considerations: (a) who needs the research, and (b) whether the partnership is driven by common need or by the requirements of a funding agency. If the community does not perceive the research to be needed, then the research is not needed by the community, or if the research is initiated by a professional researcher without community involvement, then a CBPR approach is not appropriate. For example, should an investigator wish to examine the health of a group of workers exposed to a chemical in the work place, a CBPR approach may not be appropriate if the workers or their advocates are not concerned about this exposure. The research itself may be extremely important, but the professional investigator may need to use approaches other than CBPR for it. Funding agencies that have become interested in CBPR to improve health equity have required that research applications use a CBPR approach. This can result in professional investigators convincing a community organization to participate in research when this research falls outside the organization's mission. The result of such partnerships is generally frustration for both the community organization and the investigator.

Question 2: Are Appropriate Community and Professional Partners Available?

Not all communities have the types of organizations present that can participate in a CBPR project. Occupational communities, particularly those composed of vulnerable workers, often have no "corporate" organizations representing them, such as unions, workers' centers, or advocacy and service organizations. Some communities lack any degree of formal organization; therefore, even knowing with whom to initiate a conversation is difficult.

Worker organizations involved in CBPR will be more successful if they have a volunteer or paid staff that is from the community they serve. Community staff members ensure that the organization reflects the actual needs and views held by community members. They should have a mission that is compatible with the goals of the research. For example, our research with farmworkers has included different community partners based on the topic being addressed. Toxic Free North Carolina has a mission to address pesticide exposure and has been a strong partner for our pesticide research. Student Action with Farmworkers has a mission to support the interaction of college students with farmworkers, and we have worked with them on educational programs. Finally, community organizations should have the resources to engage in a research project. Even organizations with paid staff

often do not have the time to participate in a CBPR project and still perform their regular duties. Grant funding may not provide sufficient resources with continuity for the organization to expand its staff.

Many professional investigators are not trained or equipped to do CBPR. They do not have the temperament for CBPR. Academic investigators are often naïve about the actual commitment needed for CBPR; for example, they may not understand that community participation requires foregoing travel on fall, holiday, and spring breaks to work with the community, or they do not understand that communities do not work on a semester system and the work cannot be put on hold for summer travel, writing, or teaching. Work on CBPR projects often requires effort at times when community members are working, such as evenings and weekends.

Question 3: What Is the Structure of the Partnership?

Community and professional investigators need to consider how they structure a CBPR project to ensure it is successful. Issues include the types and number of staff members that are needed, who hires the staff members, and who is hired to staff the project. The first two issues are best addressed through collaboration in which the community and professional investigators together decide on the staffing needs of a project when the project is being designed and jointly select these staff members. For example, in designing our projects with farmworkers, the community and professional investigators designed the project together and together selected the project managers, data collectors, and community educators needed for the project. This is generally an iterative process in which the design suggests the staffing, which the investigators discuss in light of the funds that are available. Often the design and the staffing are revised to fit within the project's funding limits.

Who is hired by the project can be a cause of disagreement. Projects can provide employment for individuals from vulnerable communities with few opportunities. Projects need individuals with the skills required to collect data and present information to the community. Organizations want the members of their communities to benefit from the employment and career development opportunities that a project can offer; professional investigators are equally concerned about training their students. These issues are best addressed when the project is being designed. It is important to note that CBPR projects should include sufficient time and resources to provide training for community and student staff members.

The involvement of community members as investigators and staff requires that training be provided so all team members have a basic understanding of project design and research integrity. Professional investigators often move forward with project design based on years of training and

experience. Similarly, their understanding of the need for research integrity (maintaining a protocol, IRB requirements and human subject protection, reporting results in an appropriate format) is part of professional training. Although this knowledge is taken for granted with professional investigators, it is often unfamiliar to community investigators. These issues came to light in PACE1, our first project with farmworkers. We planned a community lay health advisor program to train farmworkers about pesticide safety with an intervention group in the first year and a control group that would receive the delayed intervention in the next year (Arcury et al., 2000). However, at our first lay health advisors' training, we found representatives from control group camps. On asking our community partner about this obvious protocol violation, they stated that the training we were providing was valuable and that all farmworkers should receive it! We had not adequately provided the community investigators with an understanding of why it was important to have a control group.

Question 4: Who Has Power?

Power is not typically discussed in the province for research administration. However, power is often at the core of CBPR. CBPR is frequently undertaken because a group is vulnerable—it lacks power. Power in CBPR reflects several domains. It includes who controls the money for a project. Whether the community or professional organization receives the grant (is the prime contractor) can influence how power is shared. Often grant-reporting requirements make it difficult for a community organization to administer a federal grant; professional organizations, like universities, have entire departments dedicated to fulfilling these reporting requirements, whereas the director of a nonprofit organization may need to spend weekends completing these reports. Most nonprofit organizations do not have a negotiated overhead or indirect cost rate that provides the professional organizations with the resources to meet funder reporting requirements. When a community organization is not the primary recipient of a grant, having a subcontract with a budget can help equalize power between community and professional investigators.

Other constituents of power include ownership of data collected by a CBPR project and control of reporting of study results (who controls authorship). Data ownership provides power to the professional investigator in driving the research program, whereas data ownership by the community organization helps the organization control the release and publication of results in a manner that reflects its policy needs. Trust is important for data ownership and authorship. One approach to data ownership and publication is reaching agreement on common purposes for data. Professional investigators value

publishing results in the peer-reviewed literature (Quandt, Arcury, & Pell, 2001). However, article authorship may not be valued by community investigators. All the investigators must agree on the requirement of authorship, with the requirements for community investigator authorship reflecting differences with the professional investigators in education and experience. Our experience is that we must often convince community investigators that they should be coauthors of peer-reviewed articles even if they do not value them. Authorship is important for community members in recognizing their contributions and ownership of the project results; community ownership of project results gives credibility to community investigators and can shield professional investigators from legal attack. We also work with community representatives to develop documents, such as policy briefs, that meet community and advocate needs. We have developed policy briefs and refrained from releasing them until a time when community members felt the briefs would have the greatest effect in the legislative process.

Results that could have adverse effects for the community must be considered in any plan for data ownership and release. Research might achieve negative results, that is, results that do not support or disprove the causes of occupational illness or injury proffered by the community. For example, community members may believe that worker cancers are the result of exposure to a common work chemical, but epidemiological and mechanistic research shows that this is not the case. Research may also document negative community characteristics, such as the fact that many immigrant workers lack proper documentation or that the use of sex workers leads to high rates of sexual transmitted infections among immigrant workers. Community and professional investigators need to agree about how to release these results at the start of a project, as ethics require that negative results be reported and that the community be protected.

Processes to equalize power and to make all partners responsible for a project are important for CBPR investigators. These processes should demystify research by including all partners in the strategic planning, implementation, and translation of a project. They also require that projects be designed to include resources that build community capacity (e.g., workshops, especially scientific writing workshops). Professional investigators must be committed to the partnership, ensuring that the community investigators can initiate research (frame the research questions); that community organizations receive some of the funds; and that benefits accrue to community members through the provision of information, employment, and skill development. Community members must also recognize that their knowledge of the community and their access to community members for CBPR projects constitute power, and they must be willing to share this power with the professional investigators.

Question 5: How Will Results Be Translated?

The entire exercise of CBPR with vulnerable worker communities is a sham without the translation of results to a format that provides workers greater health and safety. Therefore, translation needs to be at the core when CBPR partnerships are established and projects are designed. From its inception, we endeavored in PACE3 to translate study results to all potential audiences. We provided individual results to farmworker participants and used project results to provide useable information to all farmworkers through the creation of educational materials. Our goal is always health sovereignty, the state in which individual workers can control their own health. Providing individual results to farmworkers remains difficult, as the actual health risks from long-term exposure to low levels of pesticides are not entirely understood. We provided study results to health and service providers so that they could improve their practice. We also worked with advocates so that our science could be used to improve the policy and regulations that could reduce farmworker exposure to pesticides. Finally, we wrote our results so that other occupational health scientists could use them to further the empirical basis of protecting worker health and safety.

CBPR projects are ethically bound to translate their results, and they should endeavor to translate their results to formats that can be used by diverse audiences. They need to include the idea of translation at the stage when they are identifying community needs. They must also endeavor to improve translation methods and share these improved translation methods. New technologies are becoming available every day, and even the most vulnerable populations are gaining access to these technologies. In 2006, we argued that telephone lines should be provided for migrant farmworker camps in an effort to improve worker mental health (Grzywacz et al., 2006). In 2012, we found that almost all farmworkers owned or had access to cell phones. These new media provide greater opportunities to communicate information to vulnerable workers that they can use to protect their health.

POSTSCRIPT

We began our efforts to collaborate with farmworkers to improve occupational health in 1995. When we began this work we had no experience in CBPR. We have made impressive mistakes, but we have also had impressive success during the almost 2 decades of work. We have learned a great deal about farmworkers and those who advocate for farmworkers; farmworkers and their advocates have learned a great deal about research and its benefits.

The work required to establish, implement, and maintain a community-engaged approach to addressing the health of vulnerable worker populations, such as CBPR, can be daunting. However, the personal rewards and achievements in improving worker health can also be extraordinary. Community and professional investigators who select a community-engaged approach should not begin this process blindly. Nor should they shy from it because of the long hours and potential for failure (when she learned about our first CBPR project, PACE1, Sister Evelyn Mattern, a long-time farmworker advocate, exclaimed that the project was brave as we had such great potential to fail!). However, they should be realistic about the political nature of this work with vulnerable communities.

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