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Increasing the Relevance of Research to Underserved Communities: Lessons Learned from a Retreat to Engage Community Health Workers with Researchers

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Increasing the Relevance of Research to Underserved Communities: Lessons Learned from a Retreat to Engage Community Health Workers with Researchers

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Abstract: **Summary.** This article presents information on a community retreat developed to seek input from community health workers (CHWs) to increase the relevance of our research to underserved communities in Oregon. Retreats facilitating dialogue between researchers and CHWs could yield important insight to enhance the significance of research for communities.

Key words: Community health workers, community engagement, health policy, health insurance, underserved.

There are many benefits to collaborating with community members at all stages of research.[1–3] Collaborations can increase the relevance of research questions; provide an insider perspective; increase community interest and support; overcome distrust of research; facilitate researchers' access to communities and community resources; and create more useful, translatable outcomes for specific communities.[2,3] We held a community retreat to seek input from community health workers (CHWs) in the first year of a health policy research project. We sought to obtain feedback about whether our proposed research questions were relevant to the underserved communities most affected by the policies being investigated. This paper presents methodology used to carry out a retreat with CHWs, the impact of the retreat on our research, and lessons learned from the process.

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The Research Project

We received funding to study how changes in families' public health insurance coverage affect children's receipt of health care. The study evaluates two Oregon state policy changes. The first occurred in 2003, when the Oregon Health Plan (OHP), a national model for Medicaid innovation,[4–6] implemented cost-containment policies that resulted in loss of coverage for thousands of adults.[6–9] The second took place in 2008, when the OHP implemented an insurance *lottery* that allowed a randomly selected group of qualifying adults to obtain coverage.[10] Our study will analyze a dataset that links OHP administrative data with electronic health record data from a network of more than 100 community health centers in Oregon. To ensure our questions were relevant to the families and communities represented in this dataset, we engaged CHWs to provide their perspectives on our research questions.

The Community Retreat

The retreat used popular education and cooperative learning methodology. Popular education methods aim to create settings in which people who have historically lacked power can expand their knowledge and use it to eliminate social inequities; these methods can effectively engage community members and enhance power.[11] Participatory methods such as those used in popular education have been utilized previously to engage community stakeholders in setting research agendas.[12,13] As with popular education, cooperative learning seeks to equalize power, balance participation, foster interdependence, and help participants develop collaboration skills.[14]

Participants

Community health workers are community members who participate in training so they can promote health in their own communities.[15,16] Community health workers' expertise is based on their life experiences rather than on formal education;[17] they combine first-hand knowledge of community strengths and needs with knowledge of the health and social service system.[18,19] In their recognized roles as liaisons and advocates,[18] CHWs frequently speak on behalf of the communities they represent; therefore, they are well suited to act as key informants in research projects. Community health workers' potential to inform research has gained acceptance; for example, a number of recent studies included CHWs in community-based participatory research projects,[20–24] and a few explicitly explored CHWs' roles as researchers.[25–28] We report on a model that, to our knowledge, has not been used previously to engage CHWs in a research project—a community retreat. We hypothesized that this novel method could be effective for engaging CHWs in the early stages of our health policy research project.

We sought to include CHWs who were knowledgeable about public health insurance, but did not work directly for state assistance programs. Members of the research team with expertise in community-based research and existing relationships with several community groups conducted outreach through e-mail and phone calls to culturally diverse organizations working with underserved families. Thirteen CHWs attended the retreat from four organizations that serve communities that utilize the OHP. Specifically, one organization serves a low-income, multi-ethnic community composed of immigrants and U.S.-born members; one serves multi-ethnic immigrants and refugees; two serve the Latino/Latina community. All CHWs were employed at the represented organizations and worked directly with people from the communities their organization serves; all CHWs who work with speakers of other languages were bilingual. Five members of the research team organized, attended, and facilitated the event. Participants were compensated for their time. The community retreat project and consent process were approved by the Oregon Health & Science University Institutional Review Board.

Set-up and Introductions

The retreat was a half-day event held January 2010 at one of the participating community organizations. In keeping with popular education methods, the room was arranged in a semi-circle, allowing all participants to see one another and all written information, most of which was presented on a flip chart. The research team welcomed the CHWs, facilitated introductions, shared the agenda and objectives for the retreat, and introduced popular education methodology, which was familiar to most.

One of the research team members led the group in a *dinámica*, a social learning game used to develop trust so that participants feel more comfortable sharing their thoughts. All participants were given oral and written information about the project and what would be expected of them during the retreat; consent to participate was obtained.

Research Project Orientation

We presented background on the research team's previous work, the current research project, and reasons for conducting it. This orientation included information on differences between primary and secondary data, how each can facilitate research, and how data on access to and utilization of insurance and health care services can be obtained from primary data (i.e., household surveys, interviews) and secondary data (e.g., electronic medical records, health insurance claims). We also gave specifics regarding the secondary data sources we will use in our project, including health insurance administrative claims and electronic health record data, and asked for feedback regarding these data sources and their relevance for the project being proposed. We discussed how research questions can be asked of secondary data sources and gave examples of research questions that the team has answered in past studies.

Some of the CHWs were unclear about the nature of research questions and assumed that the proposed questions would be posed directly to people in a survey or interview; we failed to make clear how the research questions would be answered. The use of traditional and formal presentation styles to describe the research project and secondary data sources may have limited the CHWs' ability to contribute.

Cooperative Learning Activity

Following introduction activities and background presentations, retreat participants were divided into four groups, each composed of CHWs from different organiza-

Box 1.

PROPOSED RESEARCH QUESTIONS PRESENTED TO THE GROUP FOR FEEDBACK

Oregon Questions

1. How have changes in the Oregon Health Plan (OHP) affected children's ability to get health insurance? To get health care?
2. Does parent's insurance coverage affect children's ability to get health insurance? To get health care?
3. When parents lose OHP coverage, how are children affected?
4. When parents gain OHP coverage, how are children affected?
5. How is care different when children have insurance versus when they do not have insurance?
6. What can we do to make things better?

National Questions

1. What types of insurance coverage do US families have?
2. How have these types of family coverage changed? How might they change in the future?
3. How does each family member's insurance status affect children's health insurance and healthcare?

tions. In each group, the following roles were assigned: *facilitator, recorder, timekeeper, reporter,* and *observer.* The groups were given background information, a summary of our research project aims, and a list of our proposed research questions (Box 1). Each group's *facilitator* then used a series of questions to spark discussion (Box 2). These questions were designed to explore the CHWs' opinions about the relevance of the proposed research questions to the community members they serve and to provide opportunities to formulate additional questions. The *recorder* for each group summarized key responses. The *timekeeper* reminded the group of the time remaining. Each group discussion lasted about 60 minutes.

After a short break, the large group reconvened, and the *reporter* from each small group presented their group's key responses. After each group presented their summaries, the *observer* shared insights about the group process and further discussion was invited.

Retreat Data Collection and Analysis

The data collected during the retreat included flip chart notes and digital recordings of the group discussion that occurred during the cooperative learning activities. We also had contextual notes taken by a medical anthropologist (external to the research

Box 2.

COOPERATIVE LEARNING ACTIVITY INSTRUCTIONS INCLUDING RETREAT QUESTIONS FOR DISCUSSION

Instructions given to the groups: please reflect on the following two questions in your groups. The recorder can take notes on all your responses. Then, please identify 3 key responses to each question. The recorder can write those key responses on flip chart paper to share with the larger group. We would also like to collect this sheet with your group's notes. Thank you!

1. What do you think about the proposed questions that the researcher and her colleagues are asking using this data? Are they interesting? Do they have any cultural implications or limitations?
2. What are some additional questions that are of interest to you that we might be able to answer using this data?

team) who observed the event. After the retreat, each research team member reviewed the data collected and identified themes and lessons learned.

Impact of the Retreat on Our Research Project

The engagement of CHWs, using the methods described above, yielded results that greatly strengthened our research. See Box 3 for specific quotations from participants regarding our proposed research questions, the impact their responses had on our research, as well as additional questions the CHWs were interested in.

Lessons Learned from Conducting the Retreat

1. *Involve the community at the start of the project.* Community health workers were engaged in the retreat and energetically discussed the research and its potential implications and limitations. Participants appreciated being consulted at the beginning of the research project, rather than after the research had already been completed. Many models of engaging community members only include them in dissemination of findings at the end of the project.
2. *Include participants when planning a retreat.* Our experience was similar to that of other researchers who reported community members should be engaged in determining the nature of their involvement to increase their influence on the research project.[29] Including CHWs in the planning would have likely increased their understanding of the retreat's purpose, a problem identified in a previous study that used focus groups to gain input on research design.[30] Including CHWs in the retreat planning could have also minimized confusion during the formal presentation.

Box 3

THEMES AND REPRESENTATIVE QUOTATIONS OF THE FEEDBACK PROVIDED BY COMMUNITY RETREAT PARTICIPANTS

Theme	**Representative Quotation**	**Implications**
The research questions are important	“We need to remember that it [health insurance] is a public health issue, and the health of each of us affects the health of all.” “People need to understand how the [health] insurance programs work . . .”	We feel validated and reaffirmed in our work and will continue with renewed dedication.
The research questions were not specific enough	“Questions need more clarification and need to be more specific. They are too broad and have too many meanings.” “Research questions need to be better described.”	We should have provided more explanation in advance when engaging community members; use popular education to better explain the nature of research questions.
The research questions did not take culture into account	“Income and legal status are factors that need to be considered throughout all of the questions.” “[The research questions] focus on the traditional family, which is too narrow of a definition, in addition they don’t distinguish between gender, generation, sexual orientation, etc.”	We will expand the definition of family.
Additional Questions of Interest		
How the OHP system works	“How are OHP policy changes communicated?” “If everyone who is eligible for OHP receives OHP, will there be enough practitioners to see them?”	We will think about these questions when designing future studies.
Ensure all groups are represented in the data	“What communities are not represented in the data?”	We will look closely at race/ethnicity variables.
Assess the short and long term effects of health insurance changes on the health and social status of the entire family	“How does parental loss of insurance affect the well-being of the children including . . . all the other social issues that come into play in the family?” “Beyond children, how do state health care policies affect adults, seniors, and men specifically, as well as the community as a whole?” “Are there any protective factors for obtaining and keeping insurance for everyone in the family?”	We will investigate the impact of losing or gaining health insurance beyond access to health services to include information regarding receipt of other social services.

3. *Frame the research.* It is important to spend as much time as possible describing the purpose of the research project and its relevance to the communities served by CHWs. We should have provided CHWs with the goals and expectations of the retreat, as well as a written summary of the research that will be discussed prior to the event.
4. *Consistently use a participatory approach.* We used formal presentation techniques (i.e., a didactic slide presentation) to describe our proposed research project. Popular education would have been more effective. Participants were trying to follow the researchers' presentation, but their attention frequently wandered. In contrast, during the segments of the retreat utilizing popular education, participants were more engaged. Evidence strongly suggests that popular and participatory approaches to education promote acquisition, retention, and application of the knowledge gained.[12,13]
5. *Provide information on actionable next steps.* Retreat participants were interested in continued participation in the research project, as well as information about how their involvement would affect and shape the proposed research questions. Past studies have also reported that community members in leadership roles were interested in informing research. In particular, community members wanted an account of how the research would address specific health needs and affect the constituents they serve.[31–33] One study that used focus groups to assess research priorities found that patients were especially focused on outcomes.[34] These findings were similar to ours; the CHWs were interested in practical next steps that would affect the populations with which they work. One participant offered an idea for a potential intervention to improve Oregon's public health insurance coverage application process: "*The State should subcontract with communities that have already established networks to help people apply and how that works since the current system is not meeting people's needs.*" Another participant wanted to increase public health insurance enrollment through education; he suggested our academic institution hold a *how-to* workshop. We recommend anticipating questions about continued involvement and being prepared to discuss next steps. A few ideas include: planning additional retreats or other avenues for engagement throughout the study, facilitating ongoing communication with retreat participants, or carving out time during the retreat to develop a strategy to continue working together toward relevant outcomes.

Limitations

Several limitations apply to this model for engaging CHWs at the start of a research study. Not all of the research team members had experience with popular education or cooperative learning methodologies, likely limiting use of these techniques. Our team benefited from prior relationships between some of the researchers and participating community organizations, which enabled us to easily recruit CHW participants; research teams may not always have established relationships with community members. While CHWs are often asked to speak for the communities they serve, there is a possibility that the feedback we received was only relevant to the CHWs and not representative of other community members.

Conclusions

Engaging CHWs at the beginning of a research study can help ensure research questions are relevant to communities. The model of a half-day community retreat presented in this paper can be easily replicated and could become invaluable to the research process. It will be useful to heed the lessons learned to ensure the success of future community involvement in research development.

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