

The Gerontologist Vol. 51, No. 3, 285–294 doi:10.1093/geront/gnq130 © The Author 2011. Published by Oxford University Press on behalf of The Gerontological Society of America.

All rights reserved. For permissions, please e-mail: journals.permissions@oup.com.

Advance Access publication on February 3, 2011

Theory and Practice in Participatory Research: Lessons from the Native Elder Care Study

R. Turner Goins, PhD,*,¹ Eva Marie Garroutte, PhD,² Susan Leading Fox, MSW,³ Sarah Dee Geiger, MS,⁴ and Spero M. Manson, PhD⁵

¹Center on Aging, Department of Community Medicine, West Virginia University, Morgantown.

²Department of Sociology, Boston College, Chestnut Hill, Massachusetts.

³Health and Medical Division, Eastern Band of Cherokee Indians, Cherokee, North Carolina.

⁴Department of Community Medicine, West Virginia University, Morgantown.

⁵Centers for American Indian and Alaska Native Health, School of Public Health, University of Colorado Denver, Aurora.

*Address correspondence to R. Turner Goins, PhD, Center on Aging, Department of Community Medicine, West Virginia University, PO Box 9127, Morgantown, WV 26506. E-mail: rgoins@hsc.wvu.edu

Received September 30, 2010; Accepted December 14, 2010 Decision Editor: William J. McAuley, PhD

Models for community-based participatory research (CBPR) urge academic investigators to collaborate with communities to identify and pursue research questions, processes, and outcomes valuable to both partners. The tribal participatory research (TPR) conceptual model suggests modifications to CBPR to fit the special needs of American Indian communities. This paper draws upon authors' collaboration with one American Indian tribe to recommend theoretical revision and practical strategies for conducting gerontological research in tribal communities. We rated the TPR model as a strong, specialized adaptation of participatory research principles. Although the need for some TPR mechanisms may vary, our experience recommends incorporating dissemination as a central TPR mechanism. Researchers and communities can expect well-crafted collaborative projects to generate particular types of positive project outcomes for both partners, but should prepare for both predictable and unique challenges.

Key Words: TPR, CBPR, Indians, North American, Aged, Minority health

Health disparities among older American Indians are well-documented. These include elevated prevalence and incidence of many chronic diseases and their risk factors, together with higher rates of disability and mortality compared with Whites (Denny, Holtzman, Goins, & Croft, 2005; Goins, Moss, Buchwald, & Guralnik, 2007; Hayward & Heron, 1999; Indian Health Service, 1997). Although more than 4.2 million American Indians live in the Unites States (U.S. Census Bureau, 2002) and the number of American Indians aged 65 years or older is projected to increase 3.5-fold between 2010 and 2050 from 410,000 to 1,395,000 (U.S. Census Bureau, 2008), we know virtually nothing about the aging process in this vulnerable population.

A wide range of factors can impede health research in American Indian communities. On the academic side, these often include lack of knowledge or appreciation of tribal needs, histories, and diversity. For example, tribes' post-colonial relationships with the federal government vary substantially, resulting in quite different arrays of social and health services. Then, too, their beliefs about illness often reflect concerns in regard to balance, harmony, and connectedness with nature (Hendrix & LeBeau, 2009; Smyer & Stenvig, 2007), rather than the biomedical assumptions underpinning most health research.

There are equally prominent obstacles from tribes' points of view, not the least of which is their skepticism that research will serve their needs. This wariness reflects a checkered history of interactions with researchers, whose insensitivity and selfinterests have long been a subject of comment in Indian Country (Deloria, 1991, 1995). The recent struggles of the Havasupai, a small tribe located in Arizona, are emblematic of this troubled relationship. Members had consented to donate genetic specimens to researchers from the University of Arizona for a study on diabetes, a disease devastating their population. Later, without seeking further consent, the researchers shared specimens with colleagues who used them in unrelated projects on schizophrenia, inbreeding, and population migration (Mello & Wolf, 2010; Smith-Morris, 2007). The Havasupai brought a lawsuit arguing that the additional use of their genetic data injured individuals' rights as research participants and offended tribal values. Although the court eventually found for the Havasupai, the case has underscored tribal worries about the value and safety of research in American Indian communities.

Conceptual models grounded in the principles of community-based participatory research (CBPR) have won increasing recognition for their potential to guide researchers in crafting scientifically meritorious projects that also correspond to the priori-

ties of disprivileged communities. An emerging model provides adaptations of participatory research tenets (Brydon-Miller, 1997) to the special needs of American Indian communities known as tribal participatory research (TPR) (Fisher & Ball, 2002, 2003, 2005). However, few published studies have considered the benefits and challenges of implementing CBPR principles with American Indian partners in light of practical experience. We know of only one other study that uses such experience to evaluate the promise of the TPR model for theory and application (Letiecq & Bailey, 2004). Accordingly, we draw lessons from our own Native Elder Care Study that gathered health data among older members of an American Indian tribe. We illustrate how each step of the research process can incorporate theoretical guidance from CBPR and TPR, while discussing practical challenges and their resolutions. On the basis of this experience, we offer refinements to the TPR model accompanied by strategies for collaborative gerontological work with American Indian communities.

Context

Participatory Research

The conceptual framework of participatory research goes by various names: "CBPR," "participatory action research," "community engagement," and "community-academic partnerships," among others. Although the design and measures for participatory research have not been standardized, there is general agreement on overarching principles. These principles, summarized in the top

Table 1. Elements of Community-Based Participatory Research (CBPR) and Tribal Participatory Research (TPR)

CBPR principles^a

Recognizes community as a unit

Builds on strengths and resources within the community

Facilitates collaborative partnerships in all phases of the research

Integrates knowledge and action for mutual benefit of all partners

Promotes co-learning and empowering process that attends to social inequalities

Involves a cyclical and iterative process

Addresses health from both positive and ecological perspectives

Disseminates findings and knowledge gained to all partners

TPR mechanisms^b

Tribal oversight (research code, council resolution, committee supervision)

Culturally specific assessment

Employing and training community members as staff

Neutral facilitation of meetings between community members and research staff

^aIsrael et al. (1998).

^bFisher and Ball (2002, 2003, 2005).

half of the Table 1, are laid out in a widely cited article arguing for participatory research as a meaningful "partnership" between researchers and communities (Israel, Schulz, Parker, & Becker, 1998).

Participatory research approaches have gained credibility in recent years and inspired related theoretical developments, including TPR. The TPR model shares a general ideology with CBPR. It draws selectively on participatory research principles and proposes four mechanisms (summarized in the lower portion of the Table 1) for translating into the special circumstances of research with American Indian tribes (Fisher & Ball, 2002, 2003, 2005).

The uniqueness of the research context with which TPR concerns itself is immediately suggested in its first mechanism. Specifying the "tribal oversight" mechanism reminds researchers of tribes' powerful legal-political status. Contrary to common belief, federally acknowledged Indian tribes are not simply ethnic groups that occupy an equal social status vis-à-vis research universities. Rather, tribes enjoy governmental powers that may in some instances exceed even those of state governments. The TPR model draws attention to tribes' increasingly common view that their prerogatives include the power to regulate research in ways that may surprise academics accustomed to various "academic freedoms." We proceed now to reflections on our own experience in the context of a specific research project that illustrates how both CBPR and TPR may translate into practice, discussing advantages and disadvantages associated with these choices and the theoretical insights suggested.

Study Implementation

We carried out the Native Elder Care Study with the Eastern Band of Cherokee Indians (EBCI), a tribe whose lands span five counties in western North Carolina. As a federally acknowledged tribe, the EBCI is considered a "nation-within-a-nation" by the U.S. federal government and exercises inherent sovereignty. EBCI thus maintains its own distinct government with executive, legislative, and judicial powers.

The project began from a position of strength in relation to CBPR principles three through five, which emphasize researchers' responsiveness to community-defined concerns from the inception. In the case of the Native Elder Care Study, tribal representatives initiated the research request by

approaching the principal investigator (PI; R. T. Goins), who was known to them from a previous collaboration, asking if she could conduct an elder needs assessment. These representatives described the project as a high priority originating from community concerns about the adequacy of elder services and indicated that the tribe hoped to use the data to inform local service planning. At this early phase of the collaborative process, the PI kept tribal leaders, who were not always familiar with the protracted nature of funding processes, informed of progress.

Tribal input helped us design the project with respect for CBPR principle seven, which encourages that it "addresses health from both positive and ecological perspectives," to the extent possible. On the one hand, given the nature of needs assessment, the project focused on a negative outcome—disability. At the same time, the study was viewed by tribal leaders as playing a positive role in the effort to improve services for its elders. Local leadership also encouraged us to locate the determinants of disability within an ecological model that considered the contribution of biomedical, social, economic, environmental, and cultural factors. Hence, our measurement strategy was broadened to focus on physical and mental health status, service use, social support, helping network characteristics, household income, perceived income adequacy, health insurance, built environment, and cultural dynamics.

Eventually, with federal funding secured, researchers were positioned to seek formal tribal approval for the project. Notably, a full collaborative partnership required us to observe these protocols even though the request had originated with the tribe. From our previous experience, we understood that in the case of the EBCI, the first principle of CBPR, namely "recognizes the community as a unit," implied approaching the tribe as a "nation" ordered by a full complement of governmental institutions. We understood from the first mechanism of TPR, "tribal oversight," that such institutions were appropriately approached according to formalized procedures of the tribe's own creation.

We interpreted commitment to participatory values to imply our willingness to answer to the tribe's research review procedures. In a move undertaken by many tribes in recent years, the EBCI created its own Institutional Review Board (IRB) in 1998 to address internal needs and to manage increasing external requests to conduct

research. However, this entity enjoys a much broader scope of jurisdiction and responsibility that most investigators assume based on past experience with more conventional IRBs. The EBCI IRB assures human participants' protections, protects tribal interests by reviewing research requests for cultural appropriateness and relevance, and secures tribal control of research data. EBCI has relied on a very particular set of questions to inform IRB decisions on projects. These include (a) Whose research is it?, (b) Whose interests does it serve?, (c) Who will benefit from it?, (d) Who designed the questions?, and (e) How will the results be disseminated? These questions are accompanied by a broader set of judgments about researchers themselves including (a) Is their spirit clear?, (b) Do they have a good heart?, (c) What other baggage are they carrying?, (d) Are they useful to us?, and (e) Can they actually do anything practical (Smith, 1999)?

Such criterion departs from those that most academic researchers expect will be applied to their work. Study proposals receiving tribal IRB approval are next presented to the Tribal Council, which must pass a formal resolution in favor of the work. In addition, when elder-related issues are involved, the tribe's Elder Council contributes its assessment of the proposed research. The criteria and multi-layered process of the review represent expectations characterizing the growing number of tribes to regulate research involving their citizens.

Our proposal to undertake the Native Elder Care Study was submitted and approved through the process described previously and subsequently by the IRB at the PI's university. We considered the tribal resolution, which described the potential project and outlined expectations incumbent upon the researcher, as embodying the "research code." The tribal IRB review and tribal resolution generated written records of the nature and scope of the research, divided responsibilities among partners, and established tribal ownership of the data. The formal review process also led to the Tribal Council appointing the tribe's Health and Medical Board as the authoritative committee to provide guidance throughout the project, giving additional insurance that the tribe's interests would be protected. Thus, our project reflected all elements of the TPR "tribal oversight" mechanism, which specifically urges a research code, a formal resolution from Tribal Council, and a tribally appointed review committee.

After receipt of funding, the PI met with tribal partners to discuss study implementation, with continuing attention to the collaborative emphasis of CBPR's principle three and the "iterative" processes of feedback and revision stipulated in principle six. We believed that collaboration and ongoing refinement implied that the investigator and the tribal leaders had to work hand-in-hand to ensure that the study would yield comprehensive information on the care needs of their elders. The PI committed to in-person meetings, e-mail exchanges, and telephone calls with officials including the tribe's Medical Director, IRB Chair, Health and Medical Division's Deputy, Administration Division's Deputy, Director of Community and Recreation Services, and a member of the Elder Council—over a period that spanned 16 months from receipt of funding to the beginning of data collection.

Discussions with the named tribal authorities covered sampling logistics, recruitment strategies, cultural and linguistic requirements for survey content, and staffing issues. These interactions contributed to the project's ability to realize CBPR's principle two, which urges researchers to "build on strengths and resources within the community." Doing so allowed the PI to benefit from the highly specialized institutional and cultural knowledge possessed by a number of tribal personnel representing a range of perspectives. For example, the member of the Elder Council worked with the PI in translating the survey into Cherokee.

Seeking tribal input led to suggestions, negotiations, and study design modifications. The original study, for instance, proposed surveying 400 local community-dwelling persons aged 65 years or older, equally divided between Cherokee tribal members and White participants. Tribal consultations, however, encouraged us to modify the inclusion criteria. Based on tribal leaders' reports that they had noticed a trend toward earlier onset of disability in their community—an observation supported by empirical evidence (Hayward & Heron, 1999)—we altered the threshold for study participation from age 65 to 55 years. Another revision reflected the tribe's desire to maximize the number of EBCI participants; in response, we eliminated the comparison sample of White elders to allow for fuller sampling within the tribe.

Similarly, iterative processes informed survey instrumentation. We interpreted reliance upon culturally sensitive methods and measures as consistent with CBPR's principle five, which encourages researchers to "attend to social inequalities" and TPR's mechanism two, which stipulates "culturally specific assessment." Accordingly, whenever possible we adopted measures previously validated among American Indian populations. Moreover, once drafted, our tribal partners reviewed the instrumentation, posed queries, and suggested revisions. For example, with respect to cognitive screening, this process led to replacing the Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975) with the Time and Change Test (Inouye, Robison, Froehlich, & Richardson, 1998). Our tribal partners preferred the latter's comparative brevity and less bias due to participants' socioeconomic characteristics. At the tribe's Health and Medical Deputy and the Medical Director request, we jointly developed questions about participants' interest in proposed tribal services thereby informing future planning processes. Yet a third example is the inclusion of questions about boarding school attendance, an experience that our tribal partners felt influences older members' physical and mental health as well as trust, and thus use of government-sponsored services.

The investigative team then used a cognitive interviewing approach to assess potential sources of response error in the draft survey (Willis, 1999). This process offered the PI insight into how tribal elders would likely interpret the questions and led to modifications of several items. We added, for instance, specific wording that described the appearance of elders' Medicare and Medicaid cards (e.g., "the red, white, and blue card") to help them determine if they were program participants. Elsewhere we modified one of the self-efficacy scale items (Jerusalem & Schwarzer, 1982) that originally stated "I can solve most problems if I invest the necessary effort" to read "I can solve most problems if I try hard enough." This revision was not only simply a matter of vocabulary but also a cultural difference in focus, from the problem (external) to self (internal). This iterative process of survey development briefly delayed implementation, yet ultimately contributed to improved measurement, thus favoring enhanced data validity and applicability.

Training and employing community members is CBPR's second principle and the third of the TPR model's mechanisms. Both approaches envision community members as preferred research staff because of their understanding of local environment, acceptance by other community members, and commitment to projects designed for their own

benefit. Accordingly, advertising in the tribal newspaper and by word of mouth, we aggressively recruited EBCI members as interviewers; ultimately, over half of the interviewer team (16 of 28) were tribal members. The remaining interviewers were local residents who were either American Indians from other tribes or White. All interviewers were provided an 8-hr human participant protection certification training augmented with information and discussion of cultural sensitivity and the local tribal community. We anticipated that tribal members would have more success in locating persons and securing interviews and be more likely to speak the Cherokee language if needed. The latter was an important consideration, given that the large majority of Cherokee tribal citizens aged 50 years or older is fluent Cherokee speakers (Kituwah Preservation and Education Program, 2006). Although tribal interviewers did not prove to elicit the higher survey response rate that other studies have found (e.g., Fisher & Ball, 2003), we remain convinced that such a hiring preference is worthwhile.

Data dissemination composed the final aspect of study implementation. Broad dissemination of information collected by research is generally viewed as critical in participatory frameworks (Israel et al., 1998). It is arguably the most important vehicle for CBPR principle eight, namely "disseminates findings and knowledge gained to all partners." Surprisingly, the TPR model fails to include this element. By contrast, our observations from the field encouraged us to make dissemination activities a central aspect of research. Tribal partners were eager for study updates; therefore we devised multiple media dissemination strategies. For example, because data collection occurred more than 25 months, we provided progress reports through a project newsletter mailed every three months to all research participants, tribal leaders, and interested community members. In addition, the PI gave periodic updates on preliminary results to the tribe's Deputy of the Health and Medical Division and made a joint presentation with her to the tribe's Health and Medical Board at the midpoint and conclusion of data collection and a third time in response to the appointment of several new Board members.

At the conclusion of the project, we compiled a final report with study findings. We then made oral presentations of findings to the tribe's Health and Medical Board and another to the Cherokee Hospital clinicians and staff. To ensure the findings were distributed effectively to the general

community, the project team scheduled additional presentations at the tribal senior centers and at several tribal community clubs. Finally, we arranged for the tribal newspaper to publish a story about the study and its findings and mailed a copy of the final research report, written in lay language, to all newsletter recipients.

Notably, although a fourth mechanism of TPR calls for "neutral facilitation of meetings between community members and research staff," we did not encounter any situations in which such thirdparty mediation seemed appropriate or necessary to us or to our tribal partners. However, as the PI and the Project Manager made presentations about the project to community clubs, Tribal Council, and the Health and Medical Board, they were accompanied either by the Health and Medical Deputy or by the Administration Division Deputy. As tribal members and leaders, their presence served as a visual sign of tribal approval of the project and collaboration and were also able to reassure community members of the benefit and applicability of the project. Although we appreciate the need for more structured use of a facilitator when contentious or intractable issues arise, our project, fortunately, was not greatly troubled by these.

Discussion

We designed and implemented the Native Elder Care Study with special attention to CBPR principles and TPR mechanisms. This research orientation allowed us to offer the project as an example of how these principles and mechanisms can be translated into practice. It also permitted an experience-based evaluation of the TPR model. Each CBPR principle was originally conceptualized on a continuum of implementation (Israel et al., 1998). Our experience confirmed the characterization of participatory principles as each representing continua rather than immutable directives. We found, in practice, that particular circumstances and tribal preference sometimes indicated strong reliance on a principle or mechanism but weak or no reliance on others.

Our efforts yielded many satisfying outcomes. Benefits to the "research community" from this strongly collaborative project included generating substantial data about the health needs of a vulnerable subpopulation. Although our knowledge base remains sparse compared with that available for other older racial and ethnic minorities, this

study has added to it in important ways. Yet, the benefits of the Native Elder Care Study extended beyond us to the participating "tribal community." Given strong partnership commitments among all actors throughout the life of the project, the research generated information that the tribe requested and subsequently has applied to its own purposes. The tribe has drawn on findings to prepare a successful federal grant application that will allow them to convert a wing in their nursing home into a dementia unit. It is anticipated that the EBCI will continue to use data for similar purposes. This proiect also provided tribal members an experience that afforded them new familiarity with the research process and new skills. For example, the project added to tribal clinicians' knowledge of measures for capturing elders' level of physical functioning and served as an impetus for geriatric assessments at the Cherokee Indian Hospital. The project's focus on elder health also stimulated discussion that expanded opportunities in the community at large. For instance, this work helped prompt the tribal newspaper to begin consistently providing a listing of elder-related events and resources.

Challenges

Although our TPR-guided project was successful overall, its analysis would be incomplete without discussion of eventualities that complicated the process. Although the tribal leaders and the investigative team had worked together before, the Native Elder Care Study was an important learning experience for both, and challenges arose from both the tribe's and the researcher's perspectives. Below, we discuss these challenges that are common to most participatory research efforts.

Time Issues.—Our project often required community leaders to make time for project presentations and updates. On some occasions, it also required them to commit the time of others, including tribal employees. Researcher should anticipate these time requests on community collaborators. Also, researchers need to be aware that their timetable may not coincide with the community's timetable. When the PI wanted to obtain permission to give a conference presentation of the study findings that included identifying the tribe, she did not obtain tribal permission in time. Thus, she used an alternative presentation that did not identify the community, which did not require special tribal approval. The biggest time-related challenge, however, was

the lengthy data collection process. The partners discussed and agreed to approaches to expedite data collection including training and hiring additional interviewers, dedicating additional investigative team members to scheduling and conducting interviews, and creating an incentive program to encourage interviewers to complete blocks of interviews.

Career Issues.—Whereas some challenges implicate all parties in a research collaboration, some apply uniquely to researchers. Chief among these are career issues. Researchers who undertake participatory research with Native communities commit to a range of responsibilities that exceeds the demands of other types of research, and they submit themselves to various processes of tribal review. Such activities can slow professional progress as measured by conventional markers (Nyden, 2003). Researchers need to anticipate this and determine if they are committed to this approach in spite of the time and associated career issues.

Personnel Issues. - Employee retention presented another challenge. Of 28 interviewers hired, 12 of them failed to begin work, whereas others did not work throughout the duration of the project. The 16 interviewers who began the project worked an average of eight months, each conducting approximately 32 interviews. Retention issues were, in turn, related to control of project inventory. Despite our control procedures required all interviewers to sign and assume responsibility for equipment, including replacement of lost items; one interviewer who quit unexpectedly did not return equipment. Its recovery resulted in a substantial lost time on the part of the investigative team and required support from the On-Site Project Coordinator, the Health and Medical Division Deputy, and the tribe's legal counsel.

Recommendations

Taken together, our experiences with the Native Elder Care Study shed light on theoretical and conceptual issues relevant to the principles of CBPR and to the TPR model they have inspired. First, we rated the TPR model as a strong, specialized adaptation of the principles of participatory research. We found TPR mechanisms one through three directly applicable to our work with EBCI and would expect them to have broad applicability with other Native communities as well as with

other racial and ethnic minority communities. Yet although we found it a useful guide to our project, we encourage future researchers seeking guidance from the TPR model to add an emphasis on "dissemination"—a principle of participatory research that is not represented among the mechanisms of the TPR model as currently formulated. Conversely, we propose that the importance of "neutral facilitation" will vary across projects, for example, by the sensitivity of the research questions and with the extent of partners' preexisting research relationships.

In addition to these recommendations for theoretical refinement, our experience with the Native Elder Care Study suggested practical strategies for successful research. To researchers contemplating projects in collaboration with tribal communities, we offer the following recommendations:

Prepare for Extensive Up-Front Work.—Each tribe is a sovereign nation with its own unique culture, history, language, needs, priorities, and standards for acceptable research. Researchers will benefit by learning as much as possible about such things before even approaching a community about research participation. Tribes are also internally diverse, meaning that researchers should anticipate that community leaders and members often do not agree in their identification of pressing issues, their ideas about how research might help the community, and their level of support for research activities. There is no substitute for early, personal interaction with stakeholders about the social environment and the range of perspectives it includes. A genuine effort on the part of the researcher to learn about local history, culture, and beliefs will be greatly appreciated by an American Indian community.

Strengthen Human Protections.—Our study received both tribal and university IRB approvals. Although EBCI has its own IRB, most tribes as well as non-Native communities do not. If a tribe does not maintain its own IRB, we recommend that researchers work with their university's IRB to determine if it has appropriate community representation. If not, the researcher may be able to request that a community representative is allowed to serve as a consultant for the project review. Alternatively, the PI and an IRB member can meet with community representatives about the study. Also, researchers may consider engaging

the tribally appointed review committee or a community advisory board not only to assist in developing the study but also in advising on the informed consent process (Strauss et al., 2001; Quinn, 2004).

Re-consider the Prerogatives of "Academic Freedom."-Whereas the academy has conventionally enshrined researchers' rights to free inquiry, individual data ownership, and unrestricted publication, tribes are now extending their authority into these spheres. Researchers partnering with tribes must decide if they are willing to cooperate with the research codes that a growing number of tribes have developed to regulate the collection and circulation of information about their members. The EBCI, for instance, requires that any presentations or publications that identify the tribe must receive their approval. Similarly, investigators should understand that meaningful collaboration implies relinquishing some control of study design.

Instill Project Transparency.—Given the damage some academic researchers have caused and the resulting wariness of tribes to partner with academic researchers, we recommend paying special attention to ensuring that all aspects of the project activities are transparent to tribal leaders and community members. We believe this to be especially true when examining a sensitive issue or involving a subgroup valued by the tribe. Elders are held in high esteem and tribal communities want to care for their elders in ways that preserve and promote their dignity and honor cultural traditions (Red Horse, 1980). During the Native Elder Care Study, EBCI Tribal Council members expressed several times in different venues a strong protective feeling of their elders. We believed project transparency would reassure these tribal leaders that the elders were being respected throughout the research process. Strategies we used included widely publicizing a local number to the On-Site Project Coordinator and a toll free number to the PI for anyone to use with questions or concerns about the project. Although considered dissemination, the multiple community-wide, Tribal Council, and Health and Medical Board meetings were also used to help communicate and provide project transparency.

Be Flexible.—A researcher's expectations of deadlines may not closely correspond to those of community partners. Subsequent tensions often

can be prevented by clear communication upfront about the timetable, including funding availability and speed of data collection, analysis, and dissemination. However, because every issue cannot be anticipated, flexibility is critical to successful collaboration. In our experience, being flexible was especially key to maintaining feelings of goodwill among all parties. To illustrate, the PI twice traveled to Cherokee to give scheduled presentations to the Health and Medical Board, only to discover both meetings had been precipitously cancelled. Voicing frustration or annoyance would have been counter-productive. Instead, we saw it as an opportunity to use the time to pursue other important activities such as meeting with community members or project staff. Also, related to the notion of flexibility is the importance of being aware that there can be cultural differences in temporal orientation between those of Western European descent and American Indians. White individuals often view time as linear and equivalent to money whereas American Indians often function on less rigid timetables (Deloria, 2003; Fixico, 2003).

Discuss Career Issues with Relevant Institutional Advisors.—Researchers should be aware of potential conflicts between a commitment to CBPR and the values of their academic environment. Before committing to collaborative projects, one should open discussions with relevant university colleagues on such issues as how his/her collaborative work fits into timelines for promotion and tenure. Resolving disagreements and ambiguities with administrators and department chairs will help minimize future surprises.

Plan Hiring Carefully.—Staffing plans should take into account local environments. Reservations and surrounding geographic areas often have high rates of poverty, a social condition that may render residents disproportionately vulnerable to negative outcomes such as illness, transportation crises, and personal or familial trauma. When hiring from vulnerable populations, projects will do well to hire more employees than needed to allow for attrition. They also should create flexible budgets to account for unanticipated expenses, such as repeatedly hiring and training new personnel. Staffing considerations are relevant as well to the academic side of the tribal—academic partnerships. Key skills include cultural sensitivity, cooperation,

communication, leadership, creative time management, and technical competence (Davis & Reid, 1999; Strickland, 2006). Prospective researchers should carefully consider if they and their research team possess such skills.

Conclusions

The Native Elder Care Study provided an opportunity to consider the promise of CBPR principles, and their particular contribution to the TPR model, for research in American Indian communities. Although the TPR model has not been adopted for research with other populations, its mechanisms could have broader application aside from American Indian communities. Our reflection on its protocols and processes in light of our own recent project inspired theoretical and practical recommendations. In its outcomes, the project generated relatively rare data and illustrated how scientifically meritorious research can be carried out with locally meaningful benefit to an American Indian community. It is commonly suggested that collaborative projects stimulate greater participation (e.g., Fisher & Ball, 2002, 2003; Viswanathan et al., 2004), and although it is not possible to measure this claim objectively, we believed it true of our own project.

Certainly we do not imply that participatory research is the only form of good research. Yet our experiences suggested that research that aids both the population of study and the scientific community is especially suited to accomplish the goals of public health, including the reduction of health disparities in vulnerable populations. Our intent is to share our experience to encourage and help others who may be interested in conducting research in the area of American Indian elder health, which may contribute to ameliorating health disparities. Although the processes of research collaborations differ from those to which most researchers are accustomed, the impact promises to be rewarding in ways not often evident in more conventional approaches to the scientific enterprise.

Funding

National Institute on Aging at National Institutes of Health (K01 AG022336 and K07 AG023641) and the University of Colorado Denver (HHS1242200400049C).

Acknowledgments

We would like to thank Drs. Dedra Buchwald and Carolyn Bergquist for comments on earlier drafts.

References

- Brydon-Miller, M. (1997). Participatory action research: Psychology and social change. *Journal of Social Issues*, 53, 657–666. doi:10.1111/j.1540-4560.1997.tb02454.x.
- Davis, S. M., & Reid, R. (1999). Practicing participatory research in American Indian communities. *American Journal of Clinical Nutrition*, 69, 755S–759S.
- Deloria, V. (1991). Commentary: Research, redskins, and reality. *American Indian Quarterly*, 15, 457.
- Deloria, V. (1995). Red earth, white lies. New York: Scribner.
- Deloria, V. (2003). God is red (3rd ed.). Golden, CO: Fulcrum.
- Denny, C. H., Holtzman, D., Goins, R. T., & Croft, J. B. (2005). Disparities in chronic disease risk factors and health status between American Indian/Alaska Native and White elders: Findings from a telephone survey, 2001 and 2002. American Journal of Public Health, 95, 825–827. doi:10.2105/AJPH.2004.043489.
- Fisher, P. A., & Ball, T. J. (2002). The Indian family wellness project: An application of the Tribal Participatory Research Model. *Prevention Science*, 3, 235–240. doi:10.1023/A:1019950818048.
- Fisher, P. A., & Ball, T. J. (2003). Tribal participatory research: Mechanisms of a collaborative model. *American Journal of Community Psychology*, 32, 207–216. doi:10.1023/B:AJCP.0000004742.39858.c5.
- Fisher, P. A., & Ball, T. J. (2005). Balancing empiricism and local cultural knowledge in design and prevention research. *Journal of Urban Health*, 82(Suppl. 3), iii44–iii55. doi:10.1093/jurban/jti063.
- Fixico, D. L. (2003). The American Indian mind in a linear world. New York: Routledge.
- Folstein, M. F., Folstein, S. E, & McHugh, P. R. (1975). Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatry Research*, 12(3), 189–198. doi:10.1016/0022-3956(75)90026-6.
- Froehlich, T. E., Robison, J. T., & Inouye, S. K. (1998). Screening for dementia in the outpatient setting: The Time and Change Test. *Journal* of the American Geriatrics Society, 46, 1506–1511.
- Goins, R. T., Moss, M. P., Buchwald, D., & Guralnik, J. (2007). Disability among older American Indians and Alaska Natives: An analysis of the 2000 Census public use microdata sample. *Gerontologist*, 47, 690– 696.
- Hayward, M. D., & Heron, M. (1999). Racial inequality in active life among adult Americans. *Demography*, 36, 77-91.
- Hendrix, L. R., & LeBeau, H. (2009). American Indian traditions and theologies. In Ethnogeriatrics Steering Committee of the American Geriatrics Society (Ed.), Doorway thoughts: Vol. 3. Cross-cultural health care for older adults (pp. 9–21). Sudbury, MA: Jones and Bartlett.
- Indian Health Service. (1997). *Indian health focus: Elders*. Washington, DC: U.S. Government Printing Office.
- Inouye, S. K., Robison, J. T., Froehlich, T. E., & Richardson, E. D. (1998).
 The time and change test: A simple screening test for dementia. *Journal of Gerontology: Medical Sciences*, 53A, M281–M286. doi:10.1093/gerona/53A.4.M281.
- Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*, 19, 173–202.
- Jerusalem, M., & Schwarzer, R. (1992). Self-efficacy as a resource factor in stress appraisal processes. In R. Schwarzer (Ed.), Selfefficacy: Thought control of action (pp. 195–213). Washington, DC: Hemisphere.
- Kituwah Preservation and Education Program. (2006). 2005 Cherokee language comprehensive survey. Cherokee, NC: Eastern Band of Cherokee Indians.
- Letiecq, B. L., & Bailey, S. J. (2004). Evaluating from the outside: Conducting cross-cultural evaluation research on an American Indian reservation. *Evaluation Review*, 28, 342–357. doi:10.1177/01938 41X04265185.
- Mello, M. M., & Wolf, L. E. (2010). The Havasupai Indian Tribe case: Lessons for research involving stored biologic samples. New England Journal of Medicine, 363, 204–207. doi:10.1056/NEJMp1005203.
- Nyden, P. (2003). Academic incentives for faculty participation in community-based participatory research. *Journal of General Internal Medicine*, 18, 576–585. doi:10.1046/j.1525-1497.2003.20350.x.
- Quinn, S. C. (2004). Protecting human subjects: The role of community advisory boards. American Journal of Public Health, 94, 918–922.
- Red Horse, J. G. (1980). American Indian elders: Unifiers of Indian families. *Social Casework*, 61, 490–493.

- Smith, L. T. (1999). Decolonizing methodologies: Research and indigenous peoples. New York: Zed Books.
- Smith-Morris, C. (2007). Autonomous individuals or self-determined communities? The changing ethics of research among Native Americans. Human Organization, 66, 327–336.
- Smyer, T., & Stenvig, T. E. (2007). Health care for American Indian elders: An overview of cultural influences and policy issues. *Home Health Care Management and Practice*, 20, 27–33. doi:10.1177/1084822307305380.
- Strauss, R. P., Sengupta, S., Quinn, S. C., Goeppinger, J., Spaulding, C., & Kegeles, S. M. (2001). The role of community advisory boards: Involving communities in the informed consent process. *American Journal of Public Health*, 91, 1938–1943.
- Strickland, C. J. (2006). Challenges in community-based participatory research implementation: Experiences in cancer prevention with

- Pacific Northwest American Indian tribes. Cancer Control, 13, 230-236.
- U.S. Census Bureau. (2002). The American Indian and Alaska Native population 2000: Census 2000 Brief. Washington, DC.
- U.S. Census Bureau. (2008). Projections of the American Indian and Alaska Native alone or in combination population by age and sex for the United States: 2010 to 2050. Statistical Abstract of the United States: 2008. Washington, DC.
- Viswanathan, M., Ammerman, A., Eng, E., Gartlehner, G., Lohr, K. N., Griffith, D., et al. (2004). *Community-based participatory research: Assessing the evidence*. (AHRQ Publication No. 04-E022-2). Rockville, MD: Agency for Healthcare Research and Quality.
- Willis, G. B. (1999). Cognitive interviewing: A "how to" guide. Research Triangle Park, NC: Research Triangle Institute.