



CHAPTER SIX



Using a CBPR Approach to Develop an Interviewer Training Manual with Members of the Apsáalooke Nation

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This chapter will focus on how a community-based participatory research (CBPR) approach was used to develop and implement an interviewer training manual for a preintervention survey (see Chapter Five for a more detailed discussion of the development of a community survey using a CBPR process). The project Messengers for Health (MFH), conducted on the Apsáalooke Reservation, uses a lay health advisor approach to decrease cervical cancer screening barriers, increase knowledge regarding screening and prevention of cervical cancer, and increase Apsáalooke women's participation in cervical cancer screening. We describe the CBPR process used to modify interviewer training protocols, developed for use with non-Native groups, to increase the cultural acceptability of this approach and the accuracy of the data gathered from women on the Apsáalooke Reservation. Both the cultural acceptability and the accuracy and reliability of survey data are essential for the development of effective efforts to reduce the high rates of cancer of the cervix among Native American women of the Northern Plains.

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COMMUNITY SETTING

The Fort Laramie Treaty established the Apsáalooke Reservation in 1851. Originally 38 million acres, the reservation has been eroded by treaty changes, and now stands at approximately 2.25 million acres. Apsáalooke means “children of the large beaked bird,” and this name was communicated in sign language by flapping one’s hands to resemble a bird’s wings in flight. White explorers and traders misinterpreted the sign as referring to the crow, and used that word in reference to the Apsáalooke. Apsáalooke community members asked the research team to use the term Apsáalooke during this project, although use of the term Crow is ubiquitous on the reservation.

Apsáalooke traditions remain very strong and are part of the Apsáalooke way of life today. Among women who completed the MFH survey, 80 percent reported speaking Apsáalooke at home. In the Apsáalooke culture, one’s clan, immediate family, and extended family are very close and these ties are extremely important. For example, a cousin is tantamount to one’s brother or sister, an aunt is analogous to one’s mother, and an uncle to one’s father. So, if one’s mother were to pass away, other women in the family would take her place as one’s mother. These strong clan and family ties form the basis for the information networks of communication and support that lie at the core of the MFH project (Lowie, 1935).

As shown in Table 6.1, Native Americans from the Northern Plains, where the Apsáalooke Reservation resides, have significantly higher rates of cervical cancer mortality than women in other regions of the United States. Native American women of the Northern Plains have the highest rate of cancer of the cervix across all regions and races of the United States (Espey, 2003).

Table 6.1. Indian Health Service (IHS) Age-Adjusted Cervical Cancer Mortality Rates, by Region, 1994–1998

U.S. all races	2.6
All IHS regions	3.7*
Alaska	1.5
East	4.3*
Northern Plains	4.7*
Pacific Coast	2.4
Southwest	3.9*

Note: Rates are mortality per 100,000 population per year, adjusted to the 2000 U.S. population.

*Denotes a rate significantly higher than the overall U.S. rate.

Source: Data are from Espey, 2003.

CBPR PARTNERSHIP BACKGROUND

Alma Knows His Gun McCormick, Apsáalooke tribal member and project coordinator for MFH, and Suzanne Christopher, faculty member at Montana State University and principal investigator on this study, began meeting early in 1996 while working through the Montana Department of Public Health and Human Services on the CDC-funded Breast and Cervical Health Project. Alma informed Suzanne of her desire to provide cancer education and outreach on the Apsáalooke Reservation and Suzanne shared with Alma her interest in writing a proposal for a collaborative grant for a cancer project with the Apsáalooke Nation. MFH evolved as a result of more than five years of meetings among Alma, Suzanne, and selected members of the tribe (most of whom later became members of the project's advisory board).

Most CBPR projects include working with existing community-based organizations (CBOs). Reservations typically have few formalized CBOs. However, comparable organized bodies have decision-making and leadership capabilities in these tribal communities. On the Apsáalooke Reservation, these groups include the Crow Tribal Legislature, the Tobacco Society, and the Crow Tribal Health Board. In addition, tribal members also recognize many individuals as being in positions of leadership. Examples are leaders of traditional groups or organizations (such as sacred societies), those who have been given the right to lead traditional ceremonies (such as the sun dance, the sweat lodge, or Peyote meetings), leaders of tribal clans, individuals who do traditional healing, and elders. Hence Native American community partners involved in this project represented a variety of groups and individuals in a number of leadership positions. In addition, Native American Cancer Research (NACR), an American Indian CBO that works with tribal organizations throughout the North American continent and has conducted multiple studies on cancer prevention and control (Burhansstipanov, 1999; Burhansstipanov, Dignan, Wound, Tenney, & Vigil, 2000; Burhansstipanov, Gilbert, LaMarca, & Krebs, 2002; Orians et al., 2004) provided technical assistance to the project on an as-needed basis.

Partners for the project included the project coordinator, the principal investigator and staff from Montana State University-Bozeman (including students who were members of the Apsáalooke Nation and other Native American tribes), members of the advisory board, and individuals in leadership roles in the community. (All these partners are hereinafter referred to as the *research team* or, more simply, the *team*). The advisory board included individuals who helped with planning the grant, cancer survivors, tribal elders and leaders, and women who worked with or were interested in women's health. (See Chapter Two for additional discussion of the development of community partnerships.)

DEVELOPMENT OF INTERVIEWER TRAINING MANUAL

Before an interviewer training manual could be developed, a survey instrument had to be designed that was culturally, geographically, and scientifically relevant to the Apsáalooke community. The goal of the survey interviews was to gather accurate and comprehensive information to guide the development of a culturally competent, community-driven educational intervention. The survey development process included, but was not limited to the advisory board's reviewing community-driven priorities and question phrasing, expert (scientific and cultural) panel reviews, and multiple meetings to discuss the phrasing and concepts behind the phrasing. This process required one year, and the final tool included 120 items. (See Chapter Five for a description of the development of a survey instrument within the context of a community-based participatory research partnership.)

Although the team was able to locate multiple survey instruments used with Native communities, it was able to procure only one detailed interviewer training manual developed for use with Native communities. The team determined that that manual was not culturally acceptable for the Apsáalooke community (because it was almost identical to other manuals developed for use with non-Indian populations). Thus the team used a manual developed for non-Indians as a template, revising this template line by line, discussing the appropriateness of the content, and making changes to increase the cultural acceptability of the manual to the local community.

Although every part of the manual had significant changes from the template, we will focus our discussion here on six areas:

- The goals of survey research
- Recruitment and enrollment
- The manner of the interviewer
- Beginning the interview
- Language use
- Dissemination and use of survey findings

Goals of Survey Research

The goals of most survey research are to “produce accurate statistics” (Fowler & Mangione, 1990, p. 12) and “to ensure as far as possible that ‘bias’ factors do not have an effect on the data collected” (Salazar, 1990, p. 569). Although collecting valid data was a key component of this study as well, when the team first discussed the survey, Apsáalooke team members suggested that having respect for the women interviewed and for the community was a primary goal.

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As we demonstrate in the remainder of this section (and in discussing beginning the interview), these goals are in fact inseparable: the ability to collect accurate and valid data is dependent on demonstrating respect for the women interviewed.

The Apsáalooke members of the research team called attention to their long and repeated experiences with previous research and the ways in which it was disrespectful—by, for example, failing to invite Native Americans to be involved with research taking place in their community or by not giving community members access to data collected from them. Thus the team needed to implement procedures that would address earlier cultural affronts to the community and poor research ethics, such as community members' providing information to researchers who were never heard from again. It would be essential for all participants in this study to view their participation as voluntary and as contributing to their community rather than to the researcher's career, promotion, or salary. The team felt strongly that community members, regardless of their direct participation in the survey process, should be assured that the information shared in interviews would

- Remain confidential
- Be brought to the community (for example, findings would be made anonymous and then shared locally prior to release of information outside of the community)
- Be used to directly help improve Apsáalooke women's health

Apsáalooke women who worked with the training manual wanted these points spelled out in the manual to avoid problems of past research with Native Americans. These concerns and practices are not typical of those addressed in the interviewer training manuals that the team reviewed in this process. The research team believed that specifying and implementing such guidelines would increase the likelihood that the project would be perceived as trustworthy and would subsequently result in the women welcoming the interviewers into their homes and feeling comfortable sharing information.

Recruitment and Enrollment

Much of the interviewer training literature mentioned addressing the process of persuading potential participants to agree to the interview. For example, Suskie (1996) suggested that interviewers remain neutral at all times except during this interaction. He stated that "it is then and only then that we use our powers of persuasion to get a prospective respondent to agree to an interview" (p. 168).

When looking over the template manual, tribal members stated that such tactics would be detrimental to this study because it is neither appropriate nor acceptable in the Apsáalooke culture to coerce or push someone into doing

something. In Apsáalooke, the term *iisáatchuche*, which translates as “bold face” or “hard face,” is used to describe someone who is being blunt, not taking no for an answer, being bold, or not respecting others. Persons who act that way are being disrespectful and inconsiderate; thinking of themselves rather than thinking of others. Another term that describes someone like this is *baaiilutchichihletuk*. The elders pass on to the younger generations that this is not an appropriate manner in which to behave. Hence the research team concluded that interviewers should not be trained to behave this way, and team members changed the original version of the interviewer training manual to a new version that stated “do not try to persuade her [the potential participant] to complete the interview.”

The revised interviewer training manual discussed approaching a potential study participant through a respectful and open dialogue. The team concurred that women were more likely to want to participate in the study if they fully understood that the purpose of the interview and survey results were to provide information for subsequent interventions in the local community (that is, the team sought understanding rather than coercion). Elders emphasized that the words we speak are sacred. They said that people should speak to each other using kind words. There is an Apsáalooke term, *baaleéliaitchebaaluúsuuk*, that means it is easy to speak good words. Thus the team determined that a person would be more willing to respond to something said to them when kind and good words were used.

This method differs from the stronger methods suggested in some literature, such as prodding (Suskie, 1996, p. 168). Given the atmosphere of distrust already existing around research, the interviewers were coached not do any type of prodding. With interviewers trained to use open and respectful dialogue when approaching women to participate in the study, only 2 of the 103 women approached declined, yielding a response rate of 98 percent.

Manner of the Interviewer

The usual advice in the interviewer training literature was to encourage the interviewer to be neutral, distant, and businesslike (Gillham, 2000; Sapsford, 1999; Suskie, 1996). For example, Salazar (1990) states that “one of the greatest challenges of interviewing is combining some important human qualities such as kindness, sensitivity, and concern with a general sense of detachment” (p. 569). This recommended manner assumes a cultural homogeneity that does not exist in the United States (Christopher, Christopher, & Dunnagan, 2000; Taylor, 1989). For instance, Voss and colleagues (1999) drew out distinctions between the white and the Lakota cultures and stated that “often, what is viewed as good, healthy, and confident behavior in the dominant [non-Native] culture is based on a high valuation of the individual. This is in direct contradiction to the traditional Lakota valuation of tribalism” (p. 293). In tribalism,

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the emphasis is on the extended family and kin over the individual. This more collectivistic view also fits with the Apsáalooke worldview and affects interactions between individuals, including interactions during survey interviewing.

When conducting focus groups to develop interview methods for a survey with Native Hawaiians, Banner and his colleagues (1995) found “negative reactions to the standard neutral voice tone and lack of interviewer responsiveness to respondent answers” (p. 450). They altered their methods to reflect Hawaiian cultural norms, and interviewers were encouraged to use their normal speech patterns and rhythms. Likewise, the MFH research team made changes from its template to encourage the interviewers to feel relaxed during the interview and to display a compassionate attitude and interest in the women that were consonant with the Apsáalooke culture. The team’s manual stated that “sincerity and interest in the woman’s feelings and family will help establish rapport.”

Beginning the Interview

Another change that came about through the team’s collaborative work on the manual affected beginning the interview. The team’s training manual discussed proceeding with the interview at a pace that was comfortable to both the interviewer and the participant. This might mean taking time before the interview started to make sure that the participant was comfortable and familiar with the interview process and to describe what would happen with the information she shared. A common and important Apsáalooke custom is that when two people come together they introduce themselves by stating the family they belong to and where they come from geographically. Most interview guides however discourage the practice of disclosing personal information. As Fowler and Mangione (1990) state, “[a]lthough an interviewer may volunteer information or explanation, this behavior is only to prepare for the question asking event” (p. 9). However, team members stated that such disclosure is culturally expected and required for a trusting conversation or interview to follow.

The team’s training manual said that interviews conducted with Native people on reservations and in tribal community settings (including urban Indian clinics) may be preceded with a visit, a snack, and a cup of coffee or tea. Although some non-Native procedures (Suskie, 1996) admonished against such practices, others acknowledged that they may be sometimes appropriate. However, the research team recognized that an interview is a social situation and in a social situation giving and accepting food is a traditional way of welcoming someone and revealing a family’s generosity and is an important part of the Apsáalooke culture. The serving of a plate of food when a person comes to a home for a visit or to a gathering is common; to ask if someone is hungry before offering food is impolite. This giving of substance happens at clan meetings, after going into the sweat lodge, and at any time where people come together.

It is disrespectful to turn down a participant's offer of hospitality, and if an interviewer does refuse it, the subsequent interview is typically incomplete and includes misinformation. As one Native woman said, "If they don't trust me enough to visit with me and to eat my food, why should I trust them with my personal knowledge? I told them all kinds of wild stories. They didn't deserve the truth" (NACR, 1996).

Language Use

Crazy Bull (1997c) has stated that "language is the medium for the transmission of culture" (p. 21). Regarding language, the usual advice given is that "the research interview should be conducted in the respondent's preferred language" (Keats, 2000, p. 82). As stated previously, 80 percent of the women interviewed for this study stated that they spoke the Apsáalooke language at home. It is the preferred language for many Apsáalooke people. This language is mainly oral; most people who speak Apsáalooke are not able to read or write it with the same proficiency. Native American culture has often been carried on orally rather than through writing (Hodge, Fredericks, & Rodriguez, 1996). The team did not find any literature on training interviewers or conducting interviews in a language that is predominately oral. The usual advice given is that "[i]f the study population does not speak the primary language of the interviewer, which is usually English, then data collection instruments must be translated" (McGraw, McKinlay, Crawford, Costa, & Cohen, 1992, p. 283).

Because the Apsáalooke language is predominantly oral, the research team decided that it would not be practical or workable to translate the interview into Apsáalooke and have the interviewers read the script. It would also not be culturally acceptable to ask the participants to speak only in English. The team's training manual therefore noted that it might be necessary for the interviewers to translate the questions from English into Apsáalooke. It added that such interpreting would not only help the participants to better understand certain questions but would also allow them to feel more comfortable and would provide a means of more effective communication for both the interviewer and the participant. It asked the interviewers to conduct the interview in the language preferred by the participant, and this usually meant alternating between Apsáalooke and English. During the interviewer training, the interviewers practiced conducting the interview in this manner. It appeared to be comfortable and natural for the interviewers, as tribal members often speak in this manner in everyday conversation. The project coordinator, a fluent Apsáalooke speaker, observed the interviewers practicing and the interviews were conducted without hesitation and with mutual understanding between those playing the roles of questioner and respondent. Some researchers are uncomfortable with real-time translation and clarification of items during survey administration and feel that the exact wording of a question and its various possible responses

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should be retained (Keats, 2000; Suskie, 1996). We understand that the direct translation may have subtle variations from interviewer to interviewer, but believe that the MFH method yielded the best results. After the interviews were completed the interviewers stated that using this method, they could go through the interview with the assurance that the participant was clear about what was being asked and that using the Apsáalooke language allowed the participants to feel at ease, feel free to answer personal questions, and feel that they were not being judged.

Another point about language concerns the words used to describe the interviewers, participants, and their work. This language is often mechanistic. For example, Groves and McGonagle (2001) discuss the “displayed behavior” of the participants, other authors discuss what participants say as “an utterance” (Schmidt & Conaway, 1999), and other literature refers to the interviewer as a “research instrument” instead of as a person (Gillham, 2000). Although those who use mainstream English language may be accustomed to the strategic, instrumental, and detached connotations of this discourse, it is crucial for those working cross-culturally to realize that such language is characteristic of a particular cultural outlook, namely that of “utilitarian individualism” (Bellah, Madsen, Sullivan, Swindler, & Tipton, 1985; Taylor, 1989). This technique was discarded by the team as culturally disrespectful to the Apsáalooke. Some survey research literature also suggested ways of dealing with “inadequate or irrelevant” responses. Schmidt and Conaway (1999) state that the “response may be incomplete, or an answer may be irrelevant to the question. Some responses are so poorly organized that they are difficult to follow. Sometimes inaccurate information is given” (p. 42). Weisburg, Krosnick, and Bowen (1996) mention replies that are unclear, vague, or “off the track.” Fowler and Mangione (1990) discuss “probing inadequate answers” (p. 37) and what to do if what the respondent says is “not a complete and adequate answer” (p. 33). Seeing this advice in the template training manual, one Apsáalooke woman working on the training manual stated that there was no such thing as an inadequate or irrelevant response and that whatever the participants had to offer was valid and informative. Burhansstipanov (1999) encourages interviewers to listen carefully to the stories the respondent tells because they will frequently provide answers to subsequent interview questions and the stories usually help clarify the responses. The training manual developed by the team discussed how to probe to receive answers that fit the closed-ended question responses.

The team also added to the manual the point that if the woman is talking about other things, the interviewer needs to be patient and courteous. This is another example of looking at the women who were sharing information in a respectful manner and is consistent with Apsáalooke cultural practices. Long (1983) noted that among the Apsáalooke people, “[o]ne does not correct

others or indicate that the other's perceptions are incorrect. Tolerance of others is highly valued, and is practiced through silence and nonintrusive behavior" (p. 124). The training manual included some neutral probes that interviewers could use without appearing to judge an offered response when that response did not fit the question. For example, the template training manual advised the interviewer to say, "What do you mean?" This was felt to be too negative a response, and alternatives were given such as, "Could you tell me a little more about . . . ?" or, "I'm not sure I understand what you mean." The team's manual also advised interviewers to write any additional information given in the interview on the side of the questionnaire form, in order to include all responses.

Dissemination and Use of Survey Findings

Most research projects consider dissemination and use of survey findings a task to be addressed during the latter portion of a study. The team did not see this issue addressed in any of the literature on interviewer training. However, dissemination and use of findings was an important component of the interviewer training manual for MFH. The team added this material because a common and valid complaint in Indian Country is that communities rarely receive survey findings, nor do they receive benefits from surveys done in their communities. Due to this history, there is resistance to taking part in contemporary surveys.

The interviewers received information on how previous research had been conducted and how this project would be different in the ways in which findings from this study would be used and shared with the community. The training manual specified how MFH planned to continuously update the community on the progress of the project. These plans included holding multiple community meetings to share results of the survey and developing easy-to-understand handouts on the survey results that would be widely distributed. The manual also stated that the survey information would be used to help all Apsáalooke women to be healthier and specifically that survey findings were going to be used to determine

- The focus of training of the lay health advisors
- The information that would be emphasized by the lay health advisors in educating women in the community
- The nature and focus of the educational materials provided to the community

Use and dissemination of survey findings was part of the information given by interviewers to potential participants.

THE INTERVIEWERS

As has been true for other successful surveys conducted with Native populations, hiring and training local community members to conduct the survey demonstrated respect for the community and increased the accuracy of the data. Some researchers (Singleton & Straits, 2002) suggest that race matching is of limited utility and that few studies have found any association between interviewer demographics and the answers obtained from participants. Other survey experts recommend cultural awareness of the acceptability of matching or not matching on race (Keats, 2000) as well as on gender.

Apsáalooke team members contended that the only way to receive honest and accurate information would be to hire Apsáalooke interviewers. The trust essential for Apsáalooke women to discuss personal health issues would not exist with nontribal interviewers. Further, they considered it important that the interviewers be female and speak Apsáalooke. Cross-gender taboos would prohibit male interviewers from being successful in this situation, and those working on the manual stated that many community members felt more comfortable talking in Apsáalooke than in English. Likewise, there are subtleties of nonverbal communication (such as individuals' proximity to one another and eye contact) that required the interviewers to be intimately familiar with the culture. Thus the team decided that Apsáalooke women living in and known by the community, who practiced typical Apsáalooke cultural behaviors and norms, would be selected as interviewers.

The interviewers were recruited by a professor at Little Big Horn College (LBHC), a tribal college on the reservation. The interviewers came from all areas of the reservation and ranged in age from the late twenties through the late fifties. The interviewer training took place over the course of one day at LBHC, with a follow-up meeting one week later to discuss progress, questions, and concerns. The training covered the following topics: the purpose and focus of the study, confidentiality and privacy protocols, cervical health and cervical cancer, roles and responsibilities of the interviewer, and interviewing procedures and techniques. Interviewers were trained to conduct interviews in a standardized manner, for example, not varying the order of the questions. The interviewers also practiced role playing the interview. Interviewers were paid with project funds at rates agreed to by the study team, and support and supervision were provided by the project coordinator. To ensure confidentiality interviewers signed a confidentiality statement. The statement read:

I (insert name) agree to keep the identity of all persons in the study and any information on these persons that I gain access to as a result of this study completely confidential. I will maintain confidentiality in order to protect the rights and well-being of the women participating in this study. By doing so, I agree to

never discuss any information on the women participating in this study with anyone but this research team (including significant others, family, friends, other interviewers, or other women being interviewed), nor will I allow anyone who is not a member of this research team to view interviews, study files, or data.

LESSONS LEARNED AND IMPLICATIONS FOR PRACTICE

In this chapter we have discussed various lessons learned in the process of using a CBPR approach to develop an Apsáalooke-specific interviewer training manual. Specifically, we have described a history of inequality, manifest in disrespectful interactions and in the community's inability to access, influence, or make use of information generated through research to improve health in the community. We have described several specific ways that this history of disrespect and inequality shapes current perspectives and responses to research, and the implications for training survey interviewers to collect information to improve the cervical health of women on the Apsáalooke Reservation. In this section we summarize the lessons learned and their implications for public health research and interventions.

Both historical events and the cultural values of the specific population need to be taken into account in determining the content of the interviewer training manual and in the process of creating the manual. To be successful at integrating these implications researchers must be prepared to spend a considerable amount of time and energy with and in the community of concern. In this process a broad range of historical events should be taken into consideration, including those that have involved research, researchers, governmental agencies and employees, and health care institutions. For example, community members shared with the MFH team stories of researchers who gathered personal and sensitive information from them never to be heard from again. They did not know what happened to the information or how it was used, and they doubted that the information was used to directly help the community.

Others have described additional research indiscretions that potential researchers need to be aware of as they conduct research with Native Americans. These include (Alfred, 1999; Ambler, 1997; Christopher, in press; Deloria, Foehner, & Scinta, 1999; Deloria, 1969, 1980, 1991; Dixon & Roubideaux, 2001; Freeman, 1993; Red Horse, Johnson, & Weiner, 1989; Smith, 1999; Trafzer & Weiner, 2001; Trimble, 1977).

- Grouping all tribes together
- Failure to invite Native American individuals and communities to be involved with research taking part in their own communities

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- Failure to inform Native communities of study findings or to allow access to data collected from them
- Research that does not benefit Native American communities
- Research that reinforces stereotypes and emphasizes negative behaviors
- Research that blames individuals or communities as the cause of problems rather than identifying historical events and inequalities that shape these challenges
- Researchers who place their own interests ahead of those of the people they are working with

Because of this history, many Native communities, including the Apsáalooke community, are wary about participating in studies of a community's health. The research team took this history into account when developing the interviewer training manual. The team's manual addressed these issues up front and discussed how team members were aware of this history and were actively working to establish a different precedent. The interviewers were instructed to discuss these issues with potential respondents. If this had not been a part of the interviewer training manual, women might not have been interested in taking part in the interview, might have shared information just to get the interview completed, might have participated but not in a manner of open disclosure, might have provided inaccurate information, or might have felt uncomfortable or disturbed by the interaction and subsequently less open to future interviews (Ambler, 1997; Trimble, 1977). Other important recommendations for working successfully with Native American individuals and communities have been spelled out and include working honestly and cooperatively with communities, working from a standpoint of respect, spending time with communities, working with tribal colleges, and ensuring that Native communities are involved in all stages of the research endeavor (Banner et al., 1995; Crazy Bull, 1997a; Davis & Reid, 1999; Harrison, 2001; Kritek et al., 2002; Macaulay, 1994, Marín et al., 1995; Mihesuah, 1993; Nason, 1996; Stubben, 2001; Swisher, 1993; Weaver, 1997, 1999).

It is also necessary to gain an understanding of cultural values, including appropriate and inappropriate ways of behaving during interactions, with particular attention to behaviors that signal disrespect. For example, a part of the Apsáalooke culture is that a person will not always look another person in the eye during a conversation. It would have been inappropriate to put in the manual that the interviewer should look the respondent in the eye during the interview as is typically recommended in the literature. It is also important to understand how cultural values around the survey topic area may affect

survey interactions. For example, the team's manual included a discussion of how the words *cancer*, *breast*, and *cervical* or *cervix* may bring about feelings of discomfort among some women. Traditionally, the use of certain words has been taboo, and the word *cancer* has had negative associations. For example, there is no specific word in the Apsáalooke language for cancer. The phrase used to describe it translates as "dreadful, awful disease." These topics were dealt with directly in the manual. It stated: "Because of outreach education that has been done in this area of health, women are responding better to the use of these words and people are understanding that not all people who are diagnosed with cancer will die. Now we have Crow cancer survivors. We want women to feel comfortable to use these words because it's important for women's health and we hope that this interview will help to overcome some barriers to using these words."

Without the CBPR approach, the manual would have been unlikely to have addressed the cultural nuances referred to throughout this chapter. Because thousands of surveys have been implemented in Indian Country, the team was surprised to learn that no culturally appropriate interviewer manuals were available to use as a template (the one that had been used with Native communities had few cultural modifications). The manual described here is available from the first author upon request.

Like other CBPR projects and products, the development of this manual required several years for the researchers to become acquainted with the community, learn how to work within the community, and gain trust from community members. This was accomplished through frequent team meetings in community settings for more than five years before funding was received. Additionally, the principal investigator read many books about the Apsáalooke Nation, attended cultural and community events, and talked with tribal members to learn about the culture. This demonstrated to the community that the university members were committed to helping and were not just interested in furthering their own careers.

Time was also required for the tribal leaders and key members of the community to become members of the research team. The team collaboratively developed drafts of the manual that were reviewed and revised by tribal leaders and lay members of the community. These meetings and discussions revealed patterns of tribal communication among the Apsáalooke that were incorporated into the manual. As a result, this knowledge about tribal communication was used in a way that could potentially facilitate trust and respect between the interviewer and the study participant. Such information required considerable time to uncover, not because of deliberate attempts to hide information but because for the local community, as for all of us, this type of information is typically implicit and not immediately accessible to conscious awareness and reporting.

CONCLUSION

The historical legacy of interactions between Native communities and government officials, health researchers, and health workers has impeded the success of research intended to improve health. Individuals working with Native communities “are likely to be confronted with some of the grief and anger over losses and injustices of the past. They will be better able to deal with these confrontations if they have gained some insight into the events that caused the pain” (Harrison, 2001, p. 9).

We close by quoting from Cheryl Crazy Bull’s (1997b) eloquent explanation of a culturally respectful research process. This process is in line with a CBPR approach and was an inspiration for us in developing a training manual respectful of the Apsáalooke community and culture.

As we seek our own understanding of tribal research and scholarship, we must remember the people of the community are the source of our profound understanding of tribal life, values, and rituals. We must hear their voices and participate in their stories and ritual in order to attain the wisdom we seek. As we explore the world of scholarship, the everyday people and everyday rituals must form the foundation for the lodges we build [p. 16].

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