UCLA
American Indian Culture and Research Journal

Title
"It Is Not Just Diabetes": Engaging Ethnographic Voices to Develop Culturally Appropriate Health Promotion Efforts

Permalink
https://escholarship.org/uc/item/3fc1w2k8

Journal
American Indian Culture and Research Journal , 38(1)

ISSN
0161-6463

Authors
Weiner, Diane
Canales, Mary

Publication Date
2014

DOI
10.17953

"It Is Not Just Diabetes": Engaging Ethnographic Voices to Develop Culturally Appropriate Health Promotion Efforts

Diane Weiner and Mary K. Canales

Anthropologists generally agree that health is a product shaped by cultural perspectives, strategies, and social relations. The unequal distribution of social, economic, and cultural capital affects the health risks of individuals and communities and impacts the abilities of these individuals and groups to create and sustain changes.[1] Abel tells us that cultural capital is expressed through behaviors, perceptions, skills, and knowledge as well as the ability to engage valued institutions and resources through these skills.[2] Bourdieu identifies these resources as forms of capital and identifies social capital as "the sum of actual and potential resources that can be mobilized through membership in social networks."[3] Shim observes that cultural health capital might be a useful framework for examining how health inequities develop, are articulated, and are reproduced.[4] Within this context, narratives created by Northeastern Native American community members and Native and non-Native researchers

---

The late Diane Weiner was an assistant professor at Boston University's School of Medicine graduate program in Medical Anthropology and Cross-Cultural Practice and in the Behavioral Sciences program at the School of Public Health. This special issue is dedicated to her and highlights some of her research contributions to improving the health of American Indians. Mary K. Canales is a professor in the Department of Nursing at the University of Wisconsin-Eau Claire and has been lead author on several papers from these studies conducted with northeastern tribes and other vulnerable and underserved populations. Her research focuses on multigenerational perspectives on health and biomedicine.

are used to demonstrate the dynamism of ethnography and community-based participatory research (CBPR) as tools to elicit and apply cultural capital.

A review of CBPR in the context of health promotion programs provides an opportunity to demonstrate the ways cultural capital is shaped and in turn shapes health interventions. While the researchers focused on developing cancer education programs, Native participants and community members continually integrated their concerns and issues associated with diabetes into discussions and, ultimately, into educational programming. Data from Natives in the Northeast are integrated throughout the paper to highlight the varying influences of cultural capital.

We also examine cultural capital within the context of ethnography, CBPR, and holism. Ethnography is an effective way to elicit information about the health-relevant cultural capital of indigenous people. As a method, CBPR provides a context to "apply" cultural capital in the research arena while holism, as a practice, provides an excellent exemplar of how cultural capital is manifested in the day-to-day lives of Native Americans from the Northeastern United States whose tribal perspectives and experiences have been less visible in the published literature.[5]

Sample Population: Northeastern Native American Tribes

The ethnographic data reported throughout the paper were collected primarily in Connecticut and Rhode Island during a five year period (2007–2012).[6, 7] In addition to the nine state- and federally recognized Native American tribes and communities distributed across Connecticut, Rhode Island, and Massachusetts, there are Native Americans in this region whose tribal affiliation is not situated within one of these states. These varied affiliations created a very diverse tribal network for us to draw upon. For example, according to the 2010 Census, the total Native American population in Connecticut is approximately 31,000 (alone or in combination with one or more races), with marked differences in places of residence, languages, religions, cultures, health beliefs, economic status, and occupational and social resources.[8]

In this region of the northeastern United States where the CBPR projects were conducted, the Connecticut tribally managed local health facility provides direct primary medical care and behavioral services to federally recognized Natives and to eligible Natives enrolled in a historic state-recognized tribe. Because employment and housing opportunities attract Natives from throughout the United States, the clientele is tribally and ethnically diverse. An additional tribal health facility on a neighboring reservation provides referrals to primary and specialty care services for their tribal members and spouses.

This program also administers contract health services and similarly managed clinics in neighboring states. Access to care, whether through tribally managed services or through other systems in this and neighboring states, is reportedly contingent on enrollment status, insurance access, transportation, trust of providers, programs, and technologies.[9]

Native Americans in the Northeast region experience numerous and substantial health, education, and social disparities. Limited state and regional data reveal that compared to the general state population, a greater number of the region's Natives are habitual smokers, are overweight, and suffer from higher rates of chronic illnesses than the general state population. For example, data from a 2007–2009 Massachusetts Behavioral Risk Factor Surveillance System (BRFSS) study revealed that 34 percent of Natives are obese as compared to 22 percent of all state residents. Moreover, Natives from Massachusetts have a diabetes prevalence rate of 12 percent while the state prevalence rate among non-Natives is 7 percent.[10]

To add to the limited health data available for northeastern Native Americans, a survey was conducted with 204 Natives (2007–2008) in Connecticut.[11] Results indicated that 13 percent of the sample had received a diagnosis of cancer during their life, 55 percent reported smoking 100 or more cigarettes per week at some point in their lifetime, and 38 percent stated that smoking is allowed in their homes.[12] Although regional smoking prevalence data on eastern Indian tribes are unavailable, these data were consistent with data from another northeastern state, Maine, where the smoking rate among Native Americans was reported as 43.9 percent,[13] as well as 2007–2008 BRFSS data, which reported higher smoking rates for Connecticut Native Americans (34.4 percent compared to 15.3 percent among Connecticut non-Hispanic whites).[14]

This survey, part of a two-year cancer education project, was designed, piloted, revised, and conducted jointly by researchers and community members. It was part of several parallel efforts that engaged local voices to establish culturally competent community-based health education programs.[15] Examination of research-based health programs, developed and managed from 2006 onwards in this region of the Northeast, illuminates how community voices and cultural strengths shape and reshape health education programs. Of particular importance to this discussion was the observation that programs designed to ostensibly address issues of cancer prevention, screening, and survivorship actually were and continue to be infiltrated by the interaction of this condition with diabetes prevention, care, and survival. Exemplars from study participants interviewed during the five-year period are integrated throughout the paper to reinforce these researcher observations.

DIABETES, CANCER, AND NATIVE HEALTH

Data suggest that approximately 30 percent of Native Americans, ages 55 and older, have type 2 diabetes,[16] while the age-adjusted prevalence of diagnosed diabetes is approximately 20 percent per 1000 among Native American women.[17] Data from the 2000–2006 BRFSS indicate that 12.4 percent of American Indian/Alaska Native respondents as compared to 6 percent of non-Hispanic Whites reported having ever been "told they have diabetes" (excluding during pregnancy).[18] Although these rates are significant, they are underestimations and often do not include Native peoples who choose not to identify themselves as Native American due to a host of reasons including perceived discrimination.[19]

Although Native Americans with diabetes have increased contact with the biomedical system, they are screened for cancer at lower rates. For example, approximately 48 percent of Native males ages 50–75 years old had a prostate specific antigen (PSA) test compared to 58 percent of non-Hispanic white male cohorts,[20] while Native women reported lower mammography use than non-Hispanic white women.[21] These trends impact cancer diagnosis and staging. For example, an examination of invasive and in situ female breast cancer in the Northeast from 1999–2004 indicates that among Native women, 64.1 percent were diagnosed at an early stage, 32 percent were diagnosed at late stage, and 3.9 percent of cases were diagnosed at an unknown stage.[22] In contrast among Non-Hispanic white women, almost 70 percent of cases were diagnosed at early stages, 25.3 percent were diagnosed at a late stage, and 5.3 percent were diagnosed at an unknown stage.[23] Although differences in incidence rates[24] among Native Americans exist in general, cancer survival for colon,[25] breast,[26] and other cancers among this population is relatively poor compared to survival rates for the same cancers among other racial/ethnic groups in the United States.[27]

From a biomedical perspective, co-morbidities of diabetes, obesity, and hyperinsulinemia all disproportionately affect Native women and are related to increased risk for breast cancer[28] and for proximal[29] and distal colorectal cancers.[30] The likelihood of Native women being obese is 29.4 percent compared to 20.3 percent for non-Hispanic white women and 5.8 percent for Asian women,[31] with extreme obesity more common among Native women.[32] Similar to certain cancers, biomedical risk factors for type 2 diabetes are metabolic syndrome, hyperinsulinemia, obesity, poor diet, lack of physical activity, and a genetic predisposition (family history).[33] These associations are critical for health education and demand a shift of focus from fractured programming that addresses a particular disease to a holistic model of health promotion and education.

METHODOLOGY: TOOLS OF THE TRADE TO ELICIT CULTURAL CAPITAL

One way to develop a holistic model is to reveal, examine, and maneuver cultural health capital embedded in a community. Although anthropologists and other researchers have used a variety of mechanisms to understand the cultural aspects of the "tool kit of resources" employed to create and perform health behaviors, community-based participatory research (CBPR) seems particularly useful to analyze the means by which cultural health capital is expressed through health interactions. In a discussion of social capital and health inequities and the need for collaboration, Lynn Morgan asserted that, "As experts in 'the local,' it is up to [anthropologists] to point out the effects of institutionalized stratification and discrimination that keep certain people excluded from civil society, or community participation, or barred from access to social capital, even as others are encouraged to participate."[34] We contend that, while anthropologists focus on the local, community-based participatory research enables researchers, advocates, and partners to contribute their analyses of the local in order to assess and act upon broader meanings and representations of health.

Community-based Participatory Research (CBPR)

More than twenty-five years ago Susan Guyette wrote:

> The concept of community-based research has its roots in the idea of self-determination. It is research, largely descriptive, that comes from within the community. It may include outsiders, but in a cooperative and sharing relationship that is sensitive to the viewpoints of both insiders and outsiders. Community-based research can be an invaluable tool in community development, as a means of documenting needs and testing solutions.[35]

This orientation espoused by Guyette was inspired by the self-determination rhetoric of the 1970s, including the Indian Self-Determination and Education Assistance Act of 1975.[36] Guyette's definition of community-based participatory research (CBPR) appears to have many, but not all, of its roots in popular education movements, liberation theory, critical consciousness, and decolonization processes of the 1960s and 1970s.[37, 38] Freire argued that as people engage one another in a larger social context, how they think and ascribe meanings about their social world changes, their relationships to each other strengthen, and their abilities to reflect on their own values and choices are impacted.[39] Meanings are made and revised through the creative processes of participatory co-learning and problem solving. In an anthropological context, it becomes imperative to understand the ideas, behaviors, and "the worlds" of the distinct participants of CBPR in order for anthropologists to aid in the process of making all participants visible, vocal, and present.

Anthropologists also problem-solve, and for this reason, one can see applied anthropologists who engage broadly the processes of art and science to uniquely enhance CBPR.[40] Barbara Rylko-Bauer and colleagues stress the "discipline's goal of pragmatic engagement" that requires a willingness to take stands on pressing human issues, to be ethically and politically *subjective* while methodologically *objective*, and to accept advocacy as part of a disciplinary framework that already values theory and research excellence.[41] Finally, "pragmatic engagement requires a willingness to not only shape public discourse but also offer evidence-based solutions to social problems."[42]

This engagement advocates a willingness to be shaped by local discourses and partners to enhance and establish local solutions to problems within historical and sociocultural contexts.[43] Furthermore, Suzanne Heurtin-Roberts notes that applied anthropology acknowledges, extrapolates, and struggles with "power differentials and economic forces inherent" in social structures and organizations that contribute to health conditions and to distinctions between and among CBPR participants.[44] Researchers such as Anja Krumiech and colleagues and Maghboeba Mosavel and colleagues also agree.[45]

When CBPR approaches are combined with applied anthropology, it enhances the abilities of individual or group participants to identify a problem and to creatively develop and implement culturally relevant, comprehensible, and effective interventions.[46] Rather than attempt to "fix" deficit knowledge, this approach embraces and wrestles with contextualized knowledge, experiences, and strategies. The ideals of CBPR may imply additional effort on the part of participants to achieve desired goals, but it is fundamentally about who has the right to speak, analyze, and act.[47] Use of CBPR involves long-term commitments, trust, and passion to enable change, whether at the system or individual levels. Indeed, CBPR projects are often an outgrowth of dedicated people working—often for decades—at local, regional, and federal levels. These programs address health conditions such as diabetes and all its complexities: the social, cultural, physical, spiritual, and emotional. In delineating CBPR, CDC uses the W. K. Kellogg Foundation Community Health Scholars program's definition, which states: "CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities."[48]

With this perspective and that of Guyette in mind, one can examine the motivations, inspirations, challenges, and pitfalls that emerge in designing, implementing, and evaluating CBPR that involves Native Americans, type 2 diabetes, and cancer.[49] To provide a context for this topic, we provide a case study from a completed research project.

From 2006–2008 the coauthors of this article served as the anthropologist and nurse researcher for several community-based participatory studies, including the "Families Together, Native American Intergenerational Cancer Survivorship Project" which brought together the multidisciplinary approaches of epidemiology, medical anthropology, nursing, health education, and medicine with several tribes in Connecticut.[50] In addition to the coauthors, core project staff included a project director who is also a licensed professional counselor, an epidemiologist, and seven Native American community educators. The primary objective of the project was to develop and evaluate a culturally appropriate community participatory cancer survivorship education program with local Native Americans.

Prior to beginning the research, we created an advisory board composed of tribal representatives, cancer survivors, and a government tribal liaison. The advisory board members guided research staff in their work and served as liaisons to their tribal communities. The involvement of the advisory board is consistent with CBPR principles and reflects the research team's effort to include community representation in all phases of the project, including problem identification, data analysis, curriculum development and evaluation, as well as publications and presentations. The advisory board also was valuable in assisting the project team to recruit Native Americans to the education sessions.

We conducted six group interviews across the state with sixty-three Native Americans, eighteen years of age and older, about cancer coping strategies and health education needs. Additionally, seventeen cancer survivors participated in formal individual interviews. Participants were recruited through flyers posted in tribal buildings, advisory board members, Native cancer survivors, university connections with Native American Studies programs, and word of mouth. The project team also partnered with the Applied Anthropology program of a local college in which five students conducted a field study resulting in a report on how tribal leaders view cancer and cancer information. The students' report was distributed to college faculty, our project team, and the host tribe. These qualitative data were complemented by a quantitative analysis, conducted by the research team's epidemiologist, of the cancer incidence and mortality among Native Americans recorded in the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program during the time period 1990–2005. We incorporated all of these data as we developed four curriculum modules related to health promotion and cancer.

Each module followed a similar format agreed upon during community educator trainings with Native American facilitators. Unique content was written for each topic and quotes from the qualitative data and data collected from the epidemiologic analysis were integrated throughout the content section; these data allowed us to connect the information to local Natives' experiences. We also included group activities to provide more interaction between the program facilitators and participants. During a formal individual interview, one participant, an adult child of a breast cancer survivor, suggested we design the modules to be "very basic" at their core with the ability to delve into detailed matters when requested. Charley, the research participant who offered this advice, explained:

> So education should be very basic. . . . What can I ask?
> What should I ask?
> What should I not ask?
> Is it ok to be angry?
> Is it ok to be mad about cancer with God, Creator?
> Should I feel guilty about that?
> Is it ok to shriek at the doctor? . . . Are the needles necessary?
> Is there a stranger who walks in the door, why am I seeing a stranger, when I see another doctor?
> The physical is one thing, the emotional is another. What about my nurse?
> Can my family be angry? What do I tell them? What do I explain to them?
> What about diet? . . . And in my terrors, will the doctor be upset with me? Am I neurotic? Am I making too many phone calls to learn more about my diagnosis and care? Will they be sympathetic? Empathetic? If they explain to me, I'll be in such terror I may not understand or remember they explained it to me already.

We completed three trainings and a dry run with a group of Native American cancer survivor community educators recruited from the advisory board membership, participants in group or individual interviews, and by word of mouth. The trainings were led by project team members and included introductions, review of videos, discussion of curriculum topics, logistics of the sessions, and participant recruitment.

Evaluation of this project was multipronged, encompassing: (1) community educator evaluation of the trainings and their role in presenting the survivorship education program; (2) education session participant evaluation; and (3) formative evaluation. Utilizing multiple forms of evaluation allowed us to capture evidence of cultural capital in several forms. For example, community educators' evaluations indicated that, overall, they gained knowledge that enhanced their own learning as well as facilitation skills that increased their confidence and ability to engage a wider audience.

The advisory board members who wished to emphasize a holistic, and perhaps a more secular, slant to community-based education named the program "Wellness and Cancer Prevention Circle" education sessions. In addition, the use of a Modified Talking Circle format enabled community educators to communicate directly with participants as well as provide support to others.[51,52] Evaluation data from one community educator explained this effect: "The Circle was more relaxing because it was . . . more Native—we shared more experiences and knowledge and just spoke more, as in community gatherings." In regard to the trainings, community educators asserted that additional trainings would enhance their skills and provide more opportunities for bonding as a group. In their evaluations of the training, they identified future programming needs, such as nutrition, "because [patients] won't sit with a doctor and get a diet." These perspectives from tribal members are the foundation for disrupting inequities in cancer education. Indeed, these ideas aided in the development and implementation of local cancer education and wellness programs from 2009–2012 and grant proposals connecting cancer and diabetes education from 2011–2013.

Education session evaluation data were collected from participants via a feedback form that was completed at the end of each education session. A blunder that researchers made while writing the grant was to employ pre- and post-tests as evaluation tools. The research team and the funding agency were informed by the advisory board members that pre- and post-test evaluations were culturally inappropriate and would not be completed by the majority of participants. Clearly a conflict with biomedical cultural capital and the academically oriented researchers required a critical revision of ideas. The advisory board members also questioned the use of the collected data and requested that project team members contact the funding agency directly and determine how data would be used. The trust issues that surfaced during these discussions were clearly related to long-standing negative perceptions of research and the historical trauma associated with research practices experienced by Native Americans.

With the aid of advisory board members, project team members developed a draft of a post-event feedback form, and the community educators provided edits. This approach was in direct response to the ideas of the advisory board members. The associated funding agency was contacted and after a few conversations they agreed to this change in forms and the partial shift to rebalance power. The strength of the advisory board and cancer survivor facilitators' cultural capital was evident during this process and demonstrated to the project team that although participatory in nature, there were clearly power struggles within this CBPR project. Members of the research team realized they had made a cultural gaffe and relied on the views of community members to bolster the justification for changes. The outside researchers apologized to advisory board members and explained the researchers' error to funders.

During the study period we conducted nine educational programs, collecting fifty-two evaluations (52/69=75 percent response rate). Excerpts from evaluation data are provided to highlight participants' overall response to the CBPR programming. In general, participants described the cancer education program as an opportunity for "physical, spiritual, and mental healing" as well as education. Participants also identified topics for future programming, including cancer prevention as a whole and the "big three: diet, exercise, [and] medical exams." Interactive exercises and "having specific topics to cover along with an open session" (or talking circle) were also requested for future sessions. In terms of the format itself, participants evaluated it as "very supportive and talking together means so much." Formative evaluation of the project included: quarterly advisory board meetings, where each objective of the project was reviewed and discussed; monthly review of the project time-line, with communication via e-mail to team members of how each objective was being met; and weekly teleconference calls between research team members to assess progress, review previous and upcoming education sessions, and plan for advisory board meetings and presentations.

Cultural capital was employed by researchers, community advocates, and advisory board members at a variety of levels. Ethnographic data represented the experiences, choices, ideas, and knowledge of interview participants, as well as the communicative styles of interview participants. This "tool kit" of cultural capital served as the foundation for the implementation of modified talking circles. Concurrently, the structure and associated processes of these talking circles illustrated another use of cultural capital. Success is reflected by continued external funding, ongoing participation in educational programs and events, and requests for programs by Native individuals and members of neighboring, but not-as-yet partner tribes.

Perhaps our greatest success was achieved when the project team and advisory board members agreed to host a winter intertribal social as an honoring ceremony for a community elder who is known as a health advocate, cancer survivor, and leader in the cancer prevention and education movement in Connecticut and Rhode Island. More than one hundred guests as well as invited drum groups joined the project team to sing, dance, celebrate, and honor this remarkable woman. To our joy, additional drum groups arrived and requested to perform. During the event, team members were able to discuss health promotion with the entire group as well as individuals. For an extended period of time, community members, especially elders, continued to share with the project team how important this cancer education program is to their communities and reinforced that it must continue.

These strategies illustrate the ways cultural capital is made and enacted: empowered individuals employing local methods to redistribute health capital.

Although these specific examples were from a cancer education program designed for and by Native Americans, the processes are applicable for those developing and implementing diabetes education programs. The key to harnessing and enacting cultural capital is for researchers to recognize and trust the capabilities of Native American communities and include members in all aspects of the process.

Ethnography

Community-based participatory research requires critical ethnographic methods, often with an emphasis on individual and group interviews, participant observations, informal conversations, oral histories, and community strategy meetings.[53] These form the foundation for the development, implementation, and evaluation of education programs that rely on the viewpoints and voices of insiders and outsiders. In this way, ethnography contributes to multidisciplinary CBPR, a tool for leveling power differentials, even if a "perfect balance of power can never be achieved" between partners and stakeholders. Such an orientation also provides an opportunity to elicit cultural capital.[54]

Native-based health education programming often reflects community-based initiatives linked to the institutionalized production of knowledge about diabetes or other health diseases created by funding agencies and grant mechanisms. Holistic strategies may center on ways to alleviate multiple health crises, or comorbidities, rather than on a single, medicalized issue such as diabetes, cancer, or obesity prevention. For researchers, the agenda is often shaped by a particular research topic. The use of ethnography to collect and assess formative and in-depth research data allows the researcher, participants, and other team members to engage a mélange of voices into a dialogue with the "agenda." In our experience, stories and ideas about type 2 diabetes frequently leaped to the forefront of the conversation about health between Native community members and researchers. Ethnography is one way that distinct types of evidence and styles of expressing such data might be shared in a culturally appropriate manner for different partners.[55] This approach is also a way to explicate and extricate cultural capital as a means to help close health inequities.

An example from our work illuminates these interconnections. During one of our research projects, Jennifer, a Northeast Native nurse, was interviewed by the first author. Jennifer shared a story about a Native man who was a patient. Her goal was to teach the author, a researcher, about ways community members interact to achieve and protect health. She articulated details about the ways members of her tribal social network use cultural capital in order to alleviate health problems.

> There was one elder there with diabetes and he wasn't sticking to his diet and no matter what the Indian health nurse said, he took foods, he wasn't going to eat certain foods. It was a lot of work for him and it took a lot of work, you know, one-on-one, you know talking to him and he would only talk to the Indian nurses so that we carry the same history, and for whatever reason. So . . . that's what I see, that our people do better when they deal with their own people and people they know because people they know—maybe it's a trust issue where they were not told the truth about a lot of things and this carries over to health issues also.

Later in the interview, Jennifer discussed her work in a non-Native hospital, stating:

> Sometimes [Native patients] would be resistant to treatment, but all you had to do is give them that contact and talk to them and you know . . . our people are very, very private, and they are used to doing their own thing, their own way, but usually if you do something they're familiar with, they know. Then you're able to at least reach them because your experience is their experiences, and they know this. And I think they feel that one of their own can relate to how they feel.

Jennifer's thoughts provoke a consideration of cultural capital. Her perceptions, skills, and behaviors are mobilized to enact and portray trust based on shared culture.[56] In this context, her Native cultural capital appears to have had more authority than biomedical cultural capital.[57] However, biomedicine is not neglected; rather the two different forms of cultural capital (Native and biomedical) appear to both compete with and complement one another. Jennifer illustrates her points with a focus on topics and resources that are meaningful to members of her social network: diabetes, trust, and resistance.

To reframe entrenched ideas of negative distribution of resources, one might consider cultural health capital as a way to investigate how Native perceptions, skills, and strategies are shared as strengths and assets. It is through an ethnographic approach that culturally relevant questions may arise, such as: What are the sociocultural factors and resources that enable and enhance a more equitable distribution of health-relevant cultural capital? How might the behaviors, skills, and knowledge of distinct members who participate in social networks disrupt health inequities? In what ways can resistance to a singular focus on health promotion and education be shifted to a local, more holistic stance?

We contend that ethnographically-based program approaches in cross-cultural settings tend to be relatively flexible, humorous, and "egoless" and give researchers, participants, and partners a way to facilitate the extrapolation and translation of all aspects of culturally relevant health capital within a specific sociohistorical framework in order to construct and enact health programs.[58,59] Victor C. de Munck writes that ethnographic research is either problem-oriented or holistic, although this divide is "fuzzy."[60] De Munck asserts that problem-oriented ethnography tends to be conducted in less time than holistic ethnography and centers on a specific dilemma or issue.[61] Lines of separation may become very blurry with CBPR projects that focus on health and social change. The ethnographer and a tribal health committee, for example, may initiate an outline for a diabetes project based on a call for projects by a funding agency, yet community strategy meetings and ethnographic research may reveal a concern about hypertension or a local health condition that is neither named nor recognized by funders or administrators.

By combining problem-oriented and holistic ethnographies, the ethnographer may be turned on her head a bit; for example, she is funded to examine biomedical or public health-named issues of diabetes care or education approaches while at the same time eliciting stories and ideas infused with information about pain, stress, and their multiple complex connections. Although separating biomedical disease categories may facilitate a response to particular research agendas or funding mechanisms, such an artificial separation may inadvertently obscure community-based needs and interests.

By using a variety of ethnographic approaches, the authors were able to retain a more holistic approach towards data collection and thus limit the effects of a biomedical approach that separates cancer from all other disease states or life processes. We incorporated data collected from informal interviews, semi-structured interviews, surveys, informal conversations, observations, participant observations, group editorial or strategy meetings, and group interviews in our efforts to examine and connect the ideas and perspectives of multiple people.

Similar to the goal of focus-group interviews, the goal of group interviews is to obtain insights about a particular subject through group interactions.[62] Unlike focus groups however, consensus on matters is generally not a goal and researchers assume that participants may know each other.[63,64] Indeed introductions to these group interviews usually include questions of belonging. In a hypothetical example, Jill might introduce herself, and other participants might ask, "Who are your parents? Is your cousin Mike the one who moved to Boston?" The links appear to create a sense of social and historical connectedness. Such connections can shape interviews, as these communicative cues and styles are often shared by the participants. These participants may make references to events, people, places, and histories known to each other yet unfamiliar to or unknown to the researcher.

The group interviews reveal behaviors and perceptions and illuminate the wording, style, and context associated with these strategies and associated explications. The development of local interventions embraces these ideas and communication approaches. For example, individuals may offer advice to one another based on personal, family, or community experiences. In some cases, familiarity enables participants to reveal what might be deemed embarrassing matters due to comfort levels. In the Northeast, teasing among group interview participants is an acceptable response that implies trust, endearment, and support among speakers. The teaser is basically questioning the speaker's original statement while encouraging the speaker to keep talking and to explain himself because the teaser can be trusted to understand the perspective of the speaker.

Because connectedness manifests itself in a variety of ways, interpretation of its impact on group interactions may sometimes be lost to the researchers. Long-term research relationships are therefore essential to enhance the ability of researchers to understand group dynamics. Furthermore, when researchers include community members in the research process, the latter may be adept at explaining relationships between participants as well as interpreting underlying interactions, values, and cultural symbols. Moreover, this inclusive technique considers local connectedness as a community asset and as a pathway for the expansion of health, social, and research relationships.

This approach enhances the ability of community members to teach outsider researchers the intricate social and biological connections between individuals of distinct reservations and communities in order to understand and implement social networks to provide support or prevention education for individuals with chronic conditions. For example, the prevalence of conditions that may be biologically inherited might be explained by a community epidemiological discussion in which the people diagnosed with an ailment from four different reservations and seemingly distinct family lines are noted and biologically connected. This type of communication elicits critical health capital in terms of skills and knowledge that might be used to develop culturally appropriate education for community members and their health professionals.

The next ethnographic research study example provides insight into how individual voices can come together through ethnographic inquiries to strengthen their collective cultural capital. In 2009, the "Wellness & Cancer Prevention Circle" education sessions were expanded to a neighboring state. Since 2010, researchers, program managers, and a cadre of community advocates, most of whom had been advisory board members or community educators since 2006, were funded to implement culturally appropriate community-participatory breast cancer education programs. The goal of these efforts was to increase access to cancer prevention and detection resources among Native Americans in a single state and a neighboring reservation in another state. Each education session had a theme and an associated education module, based on ideas from feedback forms, with information about topics such as family history, stress, and diet incorporated into session discussions. In a 2011 community cancer-education training session in which the first author was present, advocates and educators made a group decision to include diabetes-education information in all future cancer prevention and wellness sessions, especially during presentations about potential cancer risks and treatment approaches.

Through 2009, the advisory board, the research data, and the researchers influenced the planning of programs. Community educators managed and steered the education session activities. Although there has been some attrition and change amongst board members, researchers, and educators, we have all matured. This maturity has realigned not only who implements activities, but also who designs and reviews them. Data continue to drive our agendas as do the ideas and growing public speaking and education skills of Native American community educators.

Nevertheless, this orientation is also shaped by the nature of funding. For example, since 2010 programs focused mainly on breast-cancer-specific health promotion activities because funding was secured from a breast cancer organization. Fiscal circumstances therefore impact holism. Although the projects serve men and women, the overwhelming majority of participants are women because breast cancer is generally perceived as a woman's issue. The topical focus, as a result of funding streams, is breast cancer, but nonetheless ethnographic data, evaluation data, and general feedback resist such pigeonholing in myriad ways. For example, participants at an event might ask a question about environmental pollutants and general health or local access to herbal resources. Or a husband may share how his wife managed chemotherapy in light of her diabetes and what changes she needed to make in her diet during this cancer treatment period.

Through participant observations of education events, strategy meetings, and individual interviews we began to notice an underlying discourse: in the midst of our concentration on cancer, we were also having dialogues about diabetes. Consider this story told by one community educator to other members of the project team and participants at a cancer education event. The educator, a cancer survivor with diabetes, prepared for a colonoscopy by ingesting the prescribed laxative and apparently passed out. Arriving at the hospital the next day for her procedure somewhat bruised, the patient and her doctors decided that her blood sugar had drastically changed due to her fasting and cleansing for the colonoscopy. The following week, she publicly declared that she is reluctant to have another colonoscopy. However, she also explained to others that she did not "realize you could drink clear liquids" and this might have prevented her medical dilemma. Reflecting upon the event, this woman stated, "I didn't read the fine print" on the cleansing directions, "but if the doctor knows you're diabetic, he should explain things; the doctors should specify what a person can consume, and a patient has to remember to ask—it was my stupidity." As an advocate for and teacher about cancer detection and survivorship, this woman's body demonstrated the negative impact of separating prevention strategies for cancer and diabetes.

Planning meetings between researchers, advisory board members, and community participants as well as conversations between researchers and tribal leaders reveal concerns about diabetes and overall wellness. Biomedical and public health advocates and educators, lay individuals, and tribal health leaders delineate general lifestyle risks and connections between diabetes and cancer. Although framed by different situational contexts— education sessions, strategy meetings, conversations, or interviews—diabetes and cancer are still conceived of as distinct, yet interacting medicalized conditions.

A final ethnographic research study example illustrates how cultural capital can be integrated into a single intervention to address two diseases that are, in the conventional biomedical world, rarely considered together. Information generated through evaluations, strategy meetings, and advisory board meetings since 2008 led to the development of a CBPR intervention to test the effects of an early-detection program for increasing breast and colon cancer-screening participation among Northeastern Native women diagnosed with, or at risk for, diabetes. For example, strategy meetings were conducted in which community members were asked to comment upon health concerns and ideas for continued research. Participants often emphasized a desire to focus on diabetes, diet, exercise, environmental pollutants, and cancer. Feedback forms from five years of cancer education programming reiterate such concerns. These forms include both open-ended queries and checklists about preferred topics for future education sessions. The checklists are based on the feedback form responses from prior years, thus creating a continuing referral process.

The proposed project will be unique in its effort to address behavioral strategies and concerns associated with diabetes and cancer. It will address health conditions in a community-designated manner and respond to the concerns of people in a relatively holistic manner. Suzanne, who participated in an individual interview, exemplifies these interconnections:

> I [need to] get my health in order. I currently have kidney stones, HBP [high blood pressure], always worried about my cancer coming back, I have diabetes. My pressure is up now and [the doctors] give another pill. I wasn't exercising, my sister

> was ill and passed—I was exercising for a year [but due to illness and death of sister] I didn't exercise for several months so my pressure is back up.

The proposed project includes and relies upon the ethnographic perspectives of project participants, partners, and researchers. It also builds on questions that emerged when researchers, community advocates, program participants, and tribal health leaders examined the data and each other. Prior studies in the Northeast might be viewed as formative studies in which all of us attempted to integrate ethnographic data and practices into processes of CBPR.[65] Moreover, this idea refocuses the singular, individually oriented approach of health promotion and education efforts toward a community-driven, family-oriented holistic perspective.

LESSONS LEARNED

So what do these examples illustrate in terms of creating and implementing CBPR interventions centered on Native American health and on diabetes in particular? How can ethnographic methods enhance the joint ability of researchers and communities to establish projects focused on chronic illnesses that continue to disproportionately affect Native Americans? The following information about holism, trust, research queries, and education materials are critical seeds for the development and sustenance of ethnographically focused health education programs.

Holism: A Form of Cultural Capital

Although it is common for people to experience co-occurring chronic illnesses such as cancer and diabetes, it is uncommon to hear reports from individuals who have received simultaneous care for these chronic diseases. During our years working with tribes in the Northeast, we often heard participants share their frustrations with how medical providers separated their bodies into distinct diseases rather than treating them holistically. Northeastern Native perspectives stress holism and social, spiritual, emotional, and physical identities that encapsulate histories of bodily changes. This outlook addresses overall healing rather than parceling problems conventionally categorized as comorbidities.

A holistic approach shaped by local cultures, histories, and ways of knowing engages local vocabularies, categories, and styles of talk and of action. Following this path, ethnography appears to be a natural orientation to incorporate and express distinct perspectives and approaches to alleviate diabetes or other chronic health problems. Future research that investigates these conditions from a holistic perspective may be able to examine the impact such a holistic orientation has on improved individual health as well as improved health outcomes overall.

Researchers and Partners

Ethnography offers a variety of benefits for the development, implementation, and evaluation of education programs. Perhaps the most complicated issue involves the determination of how, about whom, and for what ends knowledge is explicated. In order to develop pertinent goals and objectives, develop useful research questions, obtain beneficial data collection and analysis, and generate knowledge and action, we must ponder the question: with whom do we need to think and work? The assemblage of a project team may take many forms, based on institutional, fiscal, political, social, cultural, and emotional demands.

Identifying project team members and partners may be tricky. The steadfast guideline is to start slowly, be patient, and get to know one another. Furthermore, acknowledging strengths, skills, and weaknesses is essential. Individuals with distinct skills and experience should be able to fortify the project by means of the identification and demarcation of roles and duties. Some people are superlative data collectors; other people understand participant recruitment. Formal education may be an asset, but one of the most effective participant recruiters we ever worked with never finished high school. This individual relied on her passion, compassion, and concern for her Native community and Native health care in general to invite individuals and families to participate in the research and educational interventions. She also activated social networks, whose seemingly hundreds of members invited people associated with additional social networks to participate in programs. In a pre-Facebook era, these Native individuals maneuvered intergenerational social ties of blood, marriage, and friendship that bound rural, suburban, and urban people. In the eight years we have worked together, we never witnessed anyone refusing participation when requested by this woman. Her use of cultural capital encouraged social network members to partake in presentations, community forums, and strategy meetings in which health knowledge was redistributed among those present.

Our formal advisory board defined the protocols and processes of the projects. These individuals invoked cultural capital—personal experiences and the views of tribal partners—in order for researchers to explicate community assets, needs, concerns, and constraints. These partnerships also enabled discussions between distinct parties and individuals about ideal aspirations and realistic goals and activities. For instance, researchers might plan to invite fifty women to a ten-week diabetes education session between May and July;

advisory board members may explain that forty of these women have children, nieces, nephews, godchildren, and grandchildren graduating from primary, middle, and high school in June, and have events and parties to attend so that the education session must be rescheduled. Seemingly mundane matters about scheduling may also reveal information about social obligations and health. The simple act of revamping a schedule may demonstrate mutual respect and trust and assist partnership expansion with other communities, academics, participants, politicians, administrators, and the like.

Much like friendships, partnerships and associations ebb and flow; they are often circumscribed by local, regional, and national interests, economics, and politics as much as by social values.[66] Furthermore, individual personalities shape partnerships. For example, charismatic and relatively socially energetic community educators or advisory board members have initiated contact with a variety of additional partners, whereas other individuals may be less prone to do so. Moreover, those individuals who invoke cultural history and values may sway the design of local protocols and procedures while persons less familiar with such valued discourse might defer to those more prone to do so. In some contexts, elders or patient survivors have the opportunity to access authority as their experience-based wisdom is recognized.

Learning to read cultural cues can be confusing and awkward at times due in part to distinct communication patterns. Simple methods including the development, review, and agreement upon communication protocols and guidelines for particular advisory boards, projects, or partnerships can facilitate productive and equitable information sharing and decision-making. Discussions or written documents that outline specific communication processes for distinct contexts may be necessary. Such approaches are particularly important for cross-cultural partners.

Trust

The issue of trust between researchers and Native community members has been raised by innumerable community-based participatory researchers.[67] A key aspect of the entire process of health education is, as Charley, a Native community educator, explained one day in 2009, about trust and learning to read one another: trust among community educators, trust between educators and researchers, and trust between the project team and the community participants. Charley was concerned that as the initial community educator core team remains active in projects and additional individuals joined the educators, we must all gaze inwards, contemplate, and discuss the particular dynamics of our culture of learning and teaching.

In the spring of 2010 researchers and educators focused on this matter of trust and respect during a facilitator training. Since then we have expanded project team interactions to reflect both as individuals and as a team on personal and collective matters of education and communication. For example, we have created hand signals for each other if we think one of the community educators or researchers is talking too tangentially to the topic and the participants seem confused. Even though some of us are still shy with this approach, project team members tease each other and laugh publicly and openly at ourselves (perhaps the latter is a more common cultural trait in the Northeast than in other locales). These details reflect the expansion of trust among team members.

Furthermore, evidence suggests that community members are starting to trust that our program is a resource for comprehensible and useful information. For example, community members are requesting assistance from individuals associated with the cancer education program or requesting education circle sessions for their community. Trust is based on overcoming personal bias (an existential process when cultures are involved) and necessitates acknowledging both one's biases and the value of one another's cultural capital.

In an ideal world everyone gets along and agrees to disagree. In actuality, compassionate, determined, and flexible individuals who share the long-term goals of the project or overall problem resolution should lead the overall team. All CBPR projects have leaders. Not everybody understands all research approaches and analytic methods, and although some people are particularly adept at organizing individuals and groups to act, others may not be. Our projects suggest that issues of intellectual, educational, racial/ethnic, gender, age, or cultural privilege clearly exist. The twist is to acknowledge differences and identify ways to use them as part of a constructive process and practice. A doctoral adviser of the first author once told her to treat potential partners and participants as she would want them to treat her mother. This sound suggestion has rarely failed and, when used skillfully, can assuage some imbalances of power.

Research Questions

Another key element of CBPR for diabetes and other health education programs involves the focus of the project. It is critical to establish feasible research questions. These are questions that recognize passions and biases: financial, labor, and other resources; and time constraints. The researchers have to collaboratively delineate the "big picture" questions and priorities. For those of us who become excited about many different issues, David Fetterman's admonition is imperative: the decision is not what research questions should be included, but what shall be rejected.[68] Collaboration may enhance the ability to trim questions and priorities, especially if one or more members of the team is willing to say "stop" or "wait until the next project" to address certain topics.

Collaboration may also expand questions exponentially. Our teams have found two approaches to be quite successful. The first method is to ensure that a designated driver or two have the willingness and capacity to rein in others through ways that are socially acceptable to the group—generally by teasing or declaring "no." The other system is to list every question and concern team members have and hold one or two group editorial meetings to whittle down queries and ideas. Gathering team members for such purposes must include individuals' justifications and explanations as to why a question is proposed, always keeping in mind the importance of the question or topic to the individual, the community, academics, policy makers, or health care professionals at local or more global scales. The act of specifying a problem will also facilitate a discussion of associated variables and factors for study, such as, "does gender matter?"[69] "what impact does geography have on access to health resources?" and "how might we understand spirituality and its impact on diabetes strategies?"

Ethnography and Education Materials

Once general research questions are formulated, ethnographic data collection and analysis remains favored for the construction of community-specific education materials. As with the development of a theoretical stance, data must be continuously interrogated to provide a relevant foundation for educational tools. Ethnography aids project team members to infiltrate project education materials with local knowledge, terminologies, categories, styles, and grammars as well as to elicit cultural capital.

When writing education-session module outlines or other curricula, we as the researchers relied on ethnographic data. For example, with the initial research study (2006–2008), three distinct researchers coded the chunks of data of different participants line by line, categorized data by themes, and then listed the information by topic. The authors did the bulk of the writing, incorporating ethnographic data and verbal styles with research from public health, nursing, and medicine. One of us would draft a module on a topic and the other would comment, edit, and embellish the information. To illustrate particular points, we added interview narratives. Sometimes we forged a number of responses into a composite sentence or paragraph. Some descriptions were authored by a single individual and barely edited. Once drafted, modules were reviewed by other project team members and Native community educators commented upon and revised them.

For example, in a 2007 education module section that focused on the relationships between "little daily activity, weight and hormonal conditions" and "cancer, diabetes, and heart disease," we included an excerpt from a participant in a group interview, who stated:

> You've got to set an example as mother or adult, as leader of family. Getting back to the basics, I think it all starts with basic nutrition. . . . Learning nutritional values of food. They feed kids ramen; the worst thing, [it is] so convenience oriented, [not] home style.

With different projects, modules and other materials are refined based on community feedback in distinct forms. Some community educators use the education modules as guides; other educators distribute the modules to community members as resources. There were occasions during education sessions when modules sat in a pile and were neglected because participants requested assistance with a seemingly different matter, such as resource navigation, as opposed to the scheduled session on healthy diet.

This flexible approach towards learning moves beyond tailored messages and serves to create meaningful, efficacious, and appropriate education.[70] For example, stories about direct health experiences seem to be the preferred mode of learning in this region. These stories are important forms of cultural capital whereby individual and communal knowledge is valued and validated by speakers and listeners.[71] Furthermore, the acquisition and use of such knowledge is a way to convert cultural capital in order to decrease disparities in health education.[72] Sharing stories as part of education sessions encouraged narrators to create, interpret, and strategize problems that were comprehensible to listeners who could potentially translate the information into action. This approach seems especially cherished by individuals from relatively small Native communities who historically have received health education materials developed for or by geographically different Native organizations or non-Native ethnic minority groups.

CONCLUDING REMARKS

In this article we have described a few of the approaches used to include ethnography as a foundation for the design, implementation, and evaluation of Native community-based health education programs that include the application of cultural capital. Ethnography has its own peculiar disciplinary problems such that, although often viewed as a powerful research tool, its practitioners rarely wield policy or fiscal power. Discussing health care decisions, Margaret Lock and Vinh-Kim Nguyen assert that "the reasons for the choices that people make can only be fully appreciated in light of local histories and current conditions," with choices about medical services and technologies tending to be based upon pragmatism.[73] Our projects and the collaboration and cooperation between researchers, Native community members, and associated partners replicate this strategy of the pragmatic use of cultural capital to alleviate health problems.

One way to empower researchers and participants may be to look across categories, disciplines, and diseases and focus on local notions of health, such as holism, rather than on the reductionist approach of allopathic medicine. Ethnography facilitates holism. Researchers and community partners must creatively listen to, analyze, translate, and engage distinct health knowledge. They will do well to also be attuned to local, regional, national, and perhaps international health "champions," networks, and resources. Change, even at the micro level, will be linked to advocacy with communities, rather than for them.[74]

During the past few decades we also learned that family-centered programs administered by trustworthy, respectful, self-critical, and mindful individuals enhance the production, utilization, and incorporation of social capital. Use of CBPR offers participants, researchers, and advisers the opportunity to translate social capital and culturally relevant health capital into programs that are more effective and viable. A comprehensive approach is itself culturally appropriate as it fits within the worldview of most Native peoples who perceive that events such as disease or ill health do not occur in isolation. Solutions to the problem of health inequities also need a comprehensive, holistic approach. Within this context, one of the critical components of effective health promotion programming is recognition of cultural capital as both a knowledge framework from which to build upon and a source of new knowledge for future generations.

Acknowledgments

We greatly appreciate funds received from Spirit of Eagles Community Grant (2005–2006 and 2009, Weiner, PI); The Lance Armstrong Foundation Evolution Grant (2006–2008, Samos, PI); National Cancer Institute CIS Partnership Grant (2006–2008, Weiner, PI); and Susan G. Komen for the Cure Connecticut Affiliate Grants (2010–2012, Weiner, PI). We especially thank all the community members in the Northeast who contributed their time, passion, and commitment to these projects. Markos Samos, Nina Wampler, Lori Arviso Alvord, and Linda Burhansstipanov are among the researchers and health educators who made this particular work possible and fruitful. Laurette McGuire, Christine Romero, Deborah Wingard, Bruce Finke, Crystal Roberts, Mark Wallace, and community members in California helped lay the

foundation for efforts in the Northeast. We appreciate the editorial assistance of Lance Laird, Juliet McMullin, Rob Weiner, Jennie Joe, and Rob Young, and the manuscript preparation assistance of Rosa Canales.

NOTES

1. Thomas Abel, "Cultural Capital in Health Promotion," in *Health and Modernity: The Role of Theory in Health Promotion*, ed. David V. McQueen, , Ilona Kickbusch, Louise Potvin, and Jürgen M. Pelikan (New York: Springer, 2007), 43–73.

2. Ibid, 45.

3. Pierre Bourdieu, "The Forms of Capital," in *The Handbook of Theory of Research for the Sociology of Education*, ed. J. E. Richardson (Westport, CT: Greenwood Press, 1986), 243.

4. Janet K. Shim, "Cultural Health Capital: A Theoretical Approach to Understanding Health Care Interactions and the Dynamics of Unequal Treatment," *Journal of Health and Social Behavior* 51, no. 1 (2010): 1–15.

5. It is important to note the language variations we used throughout this paper to describe the target population. In the Northeast, tribal members, research participants, and eventually the researchers used the terms Native Americans, American Indian, and Natives interchangeably. When working with diverse Native populations from various tribes, we encountered the many ways they referred to themselves. "Natives" captures these variations, while "Native American" was commonly used by Northeastern tribal members with "American Indian" more often used in the literature and by government agencies to describe the population. We therefore employ the term that most appropriately matches the context.

6. Mary K. Canales, Diane Weiner, Markos Samos, and Nina S. Wampler, "Multi-Generational Perspectives on Health, Cancer, and Biomedicine: Northeastern Native American Perspectives Shaped by Mistrust," *Journal of Health Care for the Poor and Underserved* 22, no. 3 (2011): 894–911, doi: 10.1353/20110096.

7. At the request of the respective tribal governments, data are presented in aggregate by state or region rather than as tribal-specific.

8. Tina Norris, Paul L. Vines, and Elizabeth M. Hoeffel, *The American Indian and Alaska Native Populations: 2010* (Washington: US Census Bureau, January 2012), http://www.census.gov/prod/cen2010/briefs/c2010br-10.pdf.

9. Canales, et al., "Multigenerational Perspectives," 897.

10. Massachusetts Department of Public Health, "Health Survey Program, Bureau of Health Information, Statistics, Research and Evaluation," in *Health Status of American Indians in Massachusetts, 2001–2009* (2010), http://www.mass.gov/eohhs/docs/dph/behavioral-risk/health-status-american-indians-ma.pdf.

11. These unpublished data were collected through a federally funded research study: Diane Weiner, "Is CIS Reaching CT Native Americans? Understanding Cancer Information Seeking," National Cancer Institute/Cancer Information Service [R21 CA 126321 01] (2006), http://fundedresearch.cancer.gov/nciportfolio/search/details?action=abstract&grantNum=1R21CA126321-01&grantID=7226086&grtSCDC=FY%202006&absID=7226086&absSCDC=CURRENT.

12. Ibid.

13. Maine Center for Disease Control and Prevention, "Native Americans, American Indians, Alaskan Natives and Tobacco Fact Sheet," *Office of the Department of Health and Human Services*

(2008), http://www.tobaccofreemaine.org/explore_facts/documents/25-809%20NativeAmerFacts.pdf.

14. Centers for Disease Control and Prevention, "Smoking & Tobacco Use: State Highlights Connecticut," (February 2011): http://www.cdc.gov/tobacco/data_statistics/state_data/state_highlights/ 2010/states/connecticut/index.htm.

15. Canales, et al., "Multigenerational Perspectives," 898.

16. Kelly J. Acton, Nilka R. Burrows, Jing Wang, and Linda Geiss, "Diabetes Prevalence Among American Indians and Alaska Natives and the Overall Population—United States, 1994–2002," *Morbidity and Mortality Weekly Report* 52, no. 30 (2003): 702–04.

17. Kelly J. Acton, Nilka R. Burrows, Linda Geiss, and Jing Wang, "Diagnosed Diabetes Among American Indians and Alaska Natives Aged < 35 years—United States, 1994–2004," *Morbidity and Mortality Weekly Report* 55, no. 44 (2006): 1201–03.

18. C. Brooke Steele, Cheryll J. Cardinez, Lisa C. Richardson, and Lillian Tom-Orme, "Surveillance for Health Behaviors of American Indians and Alaska Natives—Findings from the Behavioral Risk Factor Surveillance System, 2000–2006," supplement, *Cancer* 113, no. 5 (2008): 1131–41, doi: 10.1002/23727.

19. Patrick Johansson, Clemma Jacobsen, and Dedra Buchwald, "Perceived Discrimination in Health Care among American Indians/Alaska Natives," *Ethnicity and Disease* 16, no. 4 (2006): 766–71.

20. Charles L. Wiggins, David K. Espey, Phyllis A. Wingo, and Judith S. Kaur, "Cancer Among American Indians and Alaska Natives in the United States, 1999–2004," supplement, *Cancer* 113, no. 5 (2008): 1142–52, doi: 10.1002/23734.

21. For relevant breast cancer statistics see: Lisa C. Richardson, Sun Hee Rim, and Marcus Plescia, "Vital Signs: Breast Cancer Screening Among Women Aged 50–74 Years—United States, 2008," *Morbidity and Mortality Weekly report* 59, no. 26 (2010): 813–16; Phyllis A. Wingo, Jessica King, Judith Swan, and Steven S. Coughlin, "Breast Cancer Incidence Among American Indian and Alaska Native Women: US, 1999–2004," supplement, *Cancer* 113, no. 5 (2008): 1191–1202, doi: 10.1002/23725.

22. David K. Espey, Xiao-Cheng Wu, Judith Swan, and Charles Wiggins, "Annual Report to the Nation on the Status of Cancer, 1975–2004, Featuring Cancer in American Indians and Alaska Natives," *Cancer* 110, no. 10 (2007): 2119–52, doi: 10.1002/23044.

23. Wingo, et al., "Breast Cancer Incidence."

24. Espey, et al., "Annual Report."

25. For colorectal statistics see: Limin X. Clegg, Frederick P. Li, Benjamin F. Hankey, and Kenneth Chu, "Cancer Survival Among US Whites and Minorities: A SEER (Surveillance, Epidemiology, and End Results) Program Population-Based Study," *Archives of Internal Medicine* 162, no. 17 (2002): 1985–93, doi:10.1001/162.17.1985; Cristina Cueto, Sean Szeja, Betsy C. Wertheim, and Evan S. Ong, "Disparities in Treatment and Survival of White and Native American Patients with Colorectal Cancer: A SEER Analysis," *Journal of American College of Surgeons* 213, no. 4 (2011): 469–74, doi:10.1016/2011.05.026.

26. For staging disparities see: Christopher Li, Kathleen Malone, and Janet Darling, "Differences in Breast Cancer Stage, Treatment, and Survival by Race and Ethnicity," *Archives Internal Medicine* 163, (2003): 49–56, doi:10.1001/163.1.49; Nina S. Wampler, Timothy Lash, Rebecca A. Silliman, and Timothy C. Heeren, "Breast Cancer Survival of American Indian/Alaska Native Women, 1973–1996," *Soz Praventivmed* 50, no. 4 (2005): 230–37; Siew Loon Ooi, Maria E. Martinez, and Christopher I. Li, "Disparities in Breast Cancer Characteristics and Outcomes by Race/Ethnicity," *Breast Cancer Research and Treatment* 127, no. 3 (2011): 729–38, doi: 10.1007/s10549-010-1191-6.

27. Data from these studies tend to analyze information from distinct groups and time periods and thus may not be comparable.

28. For research examining breast cancer and diabetes see: Karin B. Michels, Caren G. Solomon, Frank B. Hu, and Bernard A. Rosner, "Type 2 Diabetes and Subsequent Incidence of Breast Cancer in the Nurses' Health Study," *Diabetes Care* 26, no. 6 (2003): 1752–58, http://care.diabetesjournals.org/ content/26/6/1752.full.pdf+html; Pamela. J. Goodwin, "Insulin in the Adjuvant Breast Cancer Setting: A Novel Therapeutic Target for Lifestyle and Pharmacologic Intervention?" *Journal of Clinical Oncology* 26, no. 6 (2008): 833–34, doi: 10.1200/JCO.2007.14.7132; Susanna C. Larsson, Christos Manzoros, and Alicja Wolk, "Diabetes Mellitus and Risk of Breast Cancer: A Meta-Analysis," *International Journal of Cancer* 121, (2007): 856–62, doi: 10.1002/22717; Antonio Nicolucci, "Epidemiological Aspects of Neoplasms in Diabetes," *Acta Diabetologica* 47, (2010): 87–95; Marc Gunter, Donald R. Hoover, Herbert Yu, and Sylvia Wassertheil-Smoller, "Insulin, Insulin-Like Growth Factor-I, and Risk of Breast Cancer in Postmenopausal Women," *Journal of National Cancer Institute* 101 (2009): 48–60, doi:10.1093/415.

29. For research examining colorectal cancer in general and diabetes see: Susanna C. Larsson, Nicola Orsini, and Alicja Wolk, "Diabetes Mellitus and Risk of Colorectal Cancer: A Meta-Analysis," *Journal of National Cancer Institute* 97, no. 22 (2005): 1679–87, doi:10.1093/dji375; Paul J. Limburg , Kristin E. Anderson, Trista W. Johnson, and David R. Jacobs, "Diabetes Mellitus and Subsite-Specific Colorectal Cancer Risks in the Iowa Women's Health Study," *Cancer Epidemiology, Biomarkers and Prevention* 14, no. 1 (2005): 133–37.

30. For research examining site-specific colorectal cancer and diabetes see: Alessandra Tavani, Silvia Francheschi, Fabio Levi, and Renato Talamini, "Diabetes Mellitus and Subsite-Specific Colorectal Cancer Risks in the Iowa Women's Health Study," *Cancer Epidemiology, Biomarkers and Prevention* 14, no. 9 (2005): 227, doi:10.1158/1055–9965.EPI-05-0331; Sung-Wook Oh, Young-Ho Kim, Yong Sung Choi, and Dong Kyung Chang, "The Comparison of the Risk Factors and Clinical Manifestations of Proximal and Distal Colorectal Cancer," *Diseases of the Colon and Rectum* 51, no. 1 (2008): 56–61, doi: 10.1007/s10350-007-9083-5.

31. Patricia M. Barnes, Patricia Adams, and Eve Powell-Griner, *Health Characteristics of the American Indian and Alaska Native Adult Population: United States, 1999–2003*, Advance Data from Vital and Health Statistics, no. 356 (Hyattsville, MD: National Center for Health Statistics, 2005).

32. Charlton Wilson, Susan Gilliland, Kelly Moore, and Kelly Acton, "The Epidemic of Extreme Obesity Among American Indian and Alaska Native Adults with Diabetes," *Preventing Chronic Disease: Public Health Research, Practice, and Policy* 4, no. 1 (January 2007), http://www.cdc.gov/pcd/issues/2007/jan/06_0025.htm.

33. National Institutes of Health, *Diabetes in American Indians and Alaska Natives* (Washington, DC: Department of Health and Human Services, 2002).

34. Lynn Morgan, "Community Participation in Health: Perpetual Allure, Persistent Challenge," *Health Policy and Planning* 16, no. 3 (2001): 226, doi:10.1093/16.3.221.

35. Susan Guyette, *Community Based Research Handbook for Native Americans* (Los Angeles: American Indian Studies Center, University of California, Los Angeles, 1983): xvi.

36. Ibid.

37. For discussion of CBPR and action research see: Kurt Lewin, "Action Research and Minority Problems," *Journal of Social Issues* 2, no. 4 (1946): 34–46; Kurt Lewin, *Resolving Social Conflicts* (New York: Harper & Row, 1948).

38. For discussion of CBPR and social, critical movements see: Frantz Fanon, *The Wretched of the Earth* (New York, NY: Grove Press, 1963); Paulo Freire, *Pedagogy of the Oppressed, 30th Anniversary Edition*, trans. Myra Bergman Ramos (New York: Continuum, 2000).

39. Freire, *Pedagogy*.

40. Erve Chambers, "In Both Possibilities: Anthropology on the Margins," *Human Organization* 68, no. 4 (2009): 374–79.

41. Barbara Rylko-Bauer, Marjorie Kagawa-Singer, and John Van Willigen, "Reclaiming Applied Anthropology: Its Past, Present, and Future," *American Anthropologist* 108, no. 1 (2006): 178.

42. Ibid, 186.

43. For further discussion see: Bill Genat, "Building Emergent Situated Knowledges in Participatory Action Research," *Action Research* 7, no. 1 (2009): 101–15, doi:10.1177/1476750308099600; Marjorie Kagawa-Singer, "Where is Culture in Cultural Tailoring?" in *Confronting Cancer: Metaphors, Advocacy, and Anthropology*, ed. Juliet McMullin and Diane Weiner (Santa Fe: School for Advanced Research, 2009), 207–30.

44. Suzanne Heurtin-Roberts, "Self and Other in Cancer Health Disparities: Negotiating Power and Boundaries in US Society," in *Confronting Cancer*, 187.

45. For further discussion of applied anthropology in these contexts see: Anja Krumiech, Wies Weijts, Priscilla Reddy, and Anne Meijer-Weitz, "The Benefits of Anthropological Approaches for Health Promotion Research and Practice," *Health Education Research* 16, no. 2 (2001): 121–30, doi:10.1093/16.2.121; Maghboeba Mosavel, Christian Simon, Debbie van Stade, and Mara Buchbinder, "Community-Based Participatory Research (CBPR) in South Africa: Engaging Multiple Constituents to Shape the Research Question," *Social Science and Medicine* 61, no. 12 (2005): 257–66.

46. For further discussion of applied anthropology and CBPR see: ibid.; Juliet McMullin, Momi Bone, Jane Ka'ala Pang, Victor Kaiwi Pang, and Archana McEligot, "Native Hawaiian Voices: Enhancing the Role of Cultural Values in Community Based Participatory Research," special issue, *Californian Journal of Health Promotion*, no. 8 (2010): 52–62.

47. For further discussion of challenges associated with CBPR see: Heurtin-Roberts, "Self and Other;" Budd L. Hall, "From Margins to Center? The Development and Purpose of Participatory Action Research," *The American Sociologist* 23, no. 4 (1992): 15–28.

48. Zubaida Faridi, Jo Anne Grunbaum, Barbara S. Gray, and Adele Franks, "Community-Based Participatory Research: Necessary Next Steps," *Preventing Chronic Disease: Public Health Research, Practice, and Policy* 4, no. 3 [serial online] (July 2007), http://www.cdc.gov/pcd/issues/2007/jul/06_0182.htm.

49. Guyette, *Community-based Research*.

50. The authors were part of a research team funded through a non-profit organization: Markos Samos, "Families Together: The Connecticut Native American Intergenerational Cancer Survivor Education Project," *Lance Armstrong Foundation Evolution Grant* (2006).

51. Talking Circles is an Indian Health Service (IHS) Best Practice method based on Native spirituality, traditions, and communication practices. For further discussion see: Indian Health Service Division of Diabetes Treatment and Prevention, *Indian Health Diabetes Best Practice: Community Advocacy for Diabetes Prevention and Control* (Albuquerque: Revised April 2011). http://www.ihs.gov/MedicalPrograms/ Diabetes/HomeDocs/Tools/BestPractices/2011_BP_Comm_Screen_508c.pdf.

52. Felicia S. Hodge, Larri Fredricks, and Beverly Rodriquez, "American Indian Women's Talking Circle: A Cervical Cancer Screening and Prevention Project," supplement, *Cancer* 78, no. 7 (1996): 1592–97.

53. The inclusion of the term *critical* rests in part on the definition of "critical indigenous pedagogy" by Norman K. Denzin and Yvonna S. Lincoln, who argue that all inquiry is both political and moral and employs methods for social justice and "critical qualitative research." Norman K. Denzin, and Yvonna S. Lincoln, "Introduction," in *Handbook of Critical and Indigenous Methodologies*, ed. Norman K. Denzin, Yvonna S. Lincoln, and Linda T. Smith (Los Angeles: Sage Publications, 2008), 2.

54. For a discussion of CBPR and balance of power see: Margaret Cargo, Treena Delormier, Lucie Levesque, and Kahente Horn-Miller, "Can the Democratic Ideal of Participatory Research be Achieved? An Inside Look at an Academic-Indigenous Partnership" *Health Education Research* 23, no. 5 (2008): 904–14; Nina B. Wallerstein and Bonnie Duran, "Using Community-Based Participatory Research to Address Health Disparities," *Health Promotion Practice* 7, no. 3 (2006): 312–23.

55. Denzin and Lincoln, *Handbook of Critical*, 2.

56. Canales, et al., "Multigenerational Perspectives," 907.

57. Victor C. de Munck, *Research Design and Methods for Studying Cultures* (Lanham, MD: Alta Mira Press, 2009).

58. Chambers, "In Both Possibilities," 374.

59. Shim, "Cultural Health Capital."

60. de Munck, *Research Design and Methods*, 15.

61. Ibid.

62. For discussions on group interviews see: Jenny Kitzinger, "Introducing Group Interviews," *British Medical Journal* 311, (1995): 299–302; Maria J. Mayan, *Essentials of Qualitative Inquiry* (Walnut Creek, CA: Left Coast Press, 2009).

63. Michael Q. Patton, *Qualitative Research and Evaluation Methods*, 3rd ed. (Thousand Oaks, CA: Sage Publications, 2002).

64. For discussions on focus group interviews see: Richard A. Krueger, *Focus Group Interviews: A Practical Guide for Applied Research*, 2nd ed. (Thousand Oaks, CA: Sage Publications, 1994); Amy Vastine, Joel Gittelsohn, Becky Ethelbah, and Jean Anliker, "Formative Research and Stakeholder Participation in Intervention Development," *American Journal of Health Behavior* 29, no. 1 (2005): 57–69, doi:10.5993/29.1.5.

65. Nicolette Teufel-Shone, Thomas Siyuja, Helen Watahomigie, and Sandra Irwin, "Community-Based Participatory Research: Conducting a Formative Assessment of Factors that Influence Youth Wellness in the Hualapai Community," *American Journal of Public Health* 9, (2006): 1623–28, doi: 10.2105/2004.054254.

66. Rogerio M. Pinto, Clecy N. T. Schmidt, Paulo S. O. Rodriguez, and Renata Solano, "Using Principles of Participatory Research: Groundwork for a Collaboration in Brazil," *International Social Work* 50, no. 1 (2007): 53–65, doi:10.1177/0020872807071482.

67. For discussion of CBPR and Native health programming see: Linda Burhansstipanov, Suzanne Christopher, and Ann Schumacher, "Lessons Learned from Community-Based Participatory Research in Indian Country," supplement, *Cancer, Culture, and Literacy* 12, no. 2 (2005): 70–76; Patricia Cochran, Catherine Marshall, Carmen Garcia-Downing, and Elizabeth Kendall, "Indigenous Ways of Knowing: Implications for Participatory Research and Community," *American Journal of Public Health* 98, no. 1 (2008): 22–27, doi: 10.2105/2006.093641.

68. David Fetterman, *Ethnography* (Thousand Oaks, CA: Sage Publications, 1998).

69. Mosavel, et al., "Community-based Participatory Research"; deMunck, *Research Design and Methods*, 59.

70. Kagawa-Singer, "Where Is Culture."

71. Shim, "Cultural Health Capital," 3.

72. For a discussion of cultural capital and health disparities see: Shim, "Cultural Health Capital"; Pierre Bourdieu, *Distinction: a Social Critique of the Judgment of Taste* (Cambridge, MA: Harvard University Press, 1984).

73. Margaret Lock and Vinh-Kim Nguyen, *An Anthropology of Biomedicine* (West Sussex: Wiley-Blackwell, 2010), 63.

74. Freire, *Pedagogy of the Oppressed*.