

Autonomous Individuals or Self-Determined Communities? The Changing Ethics of Research among Native Americans

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Ethnographic and biological research among tribal communities demands that a researcher successfully navigate not only the social environment but also the political, legal, and biomedical perspectives that compete in today's ethics battleground. Health researchers are, therefore, increasingly drawn into the complex arenas of tribal identity, self-determination, and governance. This brief discussion reflects upon almost a decade of research among indigenous groups in the American Southwest, spanning some of the region's most hostile and unwelcoming years toward outsiders since the Pueblo Revolt. I focus upon the concept in biomedical ethics of individual autonomy, a powerful but inadequate concept for treatment of tribal decision-making and community self-determination. Incompatible with culture mores of strong family, community, and group decision-making, the principle of autonomy serves as an acculturative agent within medical research and treatment. Alternative approaches to consent, and to ethics more broadly, are called for.

Key words: ethnics, health research, Native Americans, tribal identity, individual autonomy

Introduction

Native American communities offer a perspective on research ethics in pluralistic medical societies that may be unsurpassed for instructive power. This is because many indigenous communities struggle not only with chronic and behavioral health epidemics that demand medical research and effective interventions, but with the slippery slope toward assimilation that a reliance upon Euro-American forms of research can help produce (e.g., Taussig 1980). These struggles accentuate the links between the communal and the individual experiences of such events as chronic disease, poverty, or the loss of farming as a way of life. A respectful and responsive ethics is, therefore, not a static set of responses to a given research project,

but an evolving process that emerges from collaborative, non-imperialist relationships between communities and their would-be researchers.

This discussion of research ethics reviews two well-trodden topics in both health and social scientific literatures—those of individual autonomy and indigenous self-determination. Autonomy is not only a fundamental legal right and obligation of citizens but one of the four principles of the hegemonic Principalist Approach in bioethics. Indigenous self-determination is likewise a familiar concept to scholars and advocates working among Native Americans, as it is the driving ideology behind current federal policy toward tribes (e.g., Canby 1988).

But in the ideological battleground of tribal research, autonomy and self-determination move into opposition; that is, the individualism of one clashes with the communalism of the other. It is this opposition that makes Indian Country such a compelling and instructive case study in research ethics. Responding to Everett's (2006) challenge that we consider the changing ethics of health research among Native Americans, I suggest a role for anthropologists in de-centering the autonomy principle that drives so much in our ethical debates. In particular, I will suggest that since individual autonomy is an imperfect concept for the protection of Native American rights in research, then researcher insistence on this rubric at the expense of communal forms of consent contributes to acculturative pressures of which anthropologists must be aware.

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Background

An alternative to Western biomedico-legal ethics is relevant for all cross-cultural health research, but is particularly timely for work in Indian Country where contemporary political and epidemiological circumstances requires it. First, US tribal communities are gathering momentum in what has been called an "era of self-determination," made apparent to novices by a review of the previous era names: "Removal," "Assimilation," "Allotment," "Reorganization" (Canby 1988). This relatively new phase in which tribes could determine, for themselves, more of their legal, economic, and social directions draws on the Self-Determination Act of 1974. But recent advances in tribal management of their own budgets and governance would not have been possible without the capacity-building years of the Nixon and Johnson administrations. In 1968, Johnson sent a message to Congress articulating his support for Indian self-determination and, through his "War on Poverty," created programs on reservations which would build Indian skills and self-governance capacity. The War on Poverty provided the first opportunities for tribes themselves to self-govern, to budget and spend, to build, and most importantly, to assess and respond to their successes and failures. One of the most important economic changes during this period has been the rejection of the grant concept of support from the federal government in favor of contract-based support. A Public Law (PL93-638) was passed to, effectively, take many programs away from the Bureau of Indian Affairs (BIA) while maintaining US legal and moral support for these services (e.g., health, education, etc.). This meant a transfer of much responsibility and control for tribal health services away from the Indian Health Service (IHS) to the tribes. Under PL93-638, many tribes do write "contracts" for BIA funds, allowing them more freedom to design and administer tribal programs. But, of course, tribal funds remain vulnerable to political attitudes and the changing federal priorities of each new administration. Nevertheless, the new capacity, growth, and directions of tribes are a direct result of their relatively new autonomy and these changes are having bold impacts in 21st century health research.

A second reason to look to tribes for models of research ethics is for what they teach about sustainability and the new face of "development" in which power relations between funding source and recipient are more equalized. This era of self-determination has produced more than slow, incremental improvements in tribes' abilities to govern themselves and to manage healthy economies. Recent years have been witness to signs of decreasing tribal tolerance for unwelcome outside advice and intervention. I saw these signs years ago at the Gila River Indian Community, when tribal council members made good-natured jokes about their liberal use of "consultants." But feelings of frustration with a dependency on *outside* expert consultants has grown over time. As one of the most scrutinized and surveilled communities in the world, with data flowing from multiple simultaneous research catheters, the Gila River and other tribes are in the middle

of a growing conflict over definitions of ethical conduct in research. Biomedicine has had a large and steady presence in the Gila River Indian Community, to which the Indian Health Service deployed some of its first clinicians, and because of which the National Institute of Diabetes, Digestive and Kidney Disorders (NIDDKD) was established in nearby Phoenix four decades ago. But the long-standing relationship of tribes to these biomedical institutions has produced a complicated rapport between long time (sometimes lifelong) researchers and the still-afflicted Pima.

Creating Autonomous Individuals

Just as tribal autonomy has only in recent decades evolved into local control of governance and budgeting, so too are notions of autonomy central to contemporary debates of research ethics in Indian Country. I will echo some long-standing criticisms by other anthropologists, sociologists, and many medical ethicists, that the individualistic approach to autonomy is a Euro-American value and cannot be ethically applied in Indian Country (see Everett 2006; Sargent and Smith-Morris 2006). Contemporary Euro/American, industrial society bases much of its ethical system on a philosophical tradition that valorizes the individual actor, and the autonomy and rationality of that individual's decision-making strategies and actions. Assuming that these are shared values, some contemporary bioethicists apply such terms as right and wrong, benefit and harm, risk and hope in precise and formal ways (Wax 1991). Among the assumptions produced by this system are:

- The reification of Truth as an abstract and universal proposition, arrived at only through the establishment of facts and a corresponding suspicion of traditional wisdom;
- An alliance of science with legal and biomedical paradigms, producing a tripartite social and ideological force;
- A de-emphasis of the group, family, or collective in favor of individuals and individualism; and
- An attitude toward time that is linear, progressive, and future-focused.

Most commonly critiqued by anthropologists are notions about the autonomy of any given individual (Marshall 1992; Marshall and Koenig 2004; Rapp 1999) and biomedicine's complete pre-occupation with a focal "patient" and the single suffering individual (Good 1994; Gordon 1988; Jordan and Irwin 1992). These assumptions are increasingly inappropriate in health care, where patients frequently come from cultural backgrounds different from their doctors. In a comprehensive review of literature on cultural factors to informed consent, Marshall writes, "Beliefs about personhood, individual autonomy, and decisional capacity are embedded within the social and cultural patterns of family ties and community obligations" (Marshall 2001:C-8).

Upon presentation at a biomedical clinic for services, patients are presumed to have adopted a myriad of beliefs, values and practices requisite for success in that treatment

modality. Fadiman's *The Spirit Catches You and You Fall Down* has been a widely popular case study of these processes. Several cases from Native American communities illustrate not only their differing perspectives but also point to the ways in which dominant principles erode Native views and practices. Among Native Americans exists a view of community membership not as accidental or immaterial, but as permanent, indelible, and automatic (Wax 1991). Ranae Womack's clinic-based surveys among adults in two northern Minnesota reservations addressed patient autonomy in an explicit way. Her research revealed that only 85 percent of respondents felt "the patient should be the primary decision maker regarding daily self-care of diabetes" (Womack 1995:85); and it is worth considering a sampling bias to enrollees in a hospital-based diabetes clinic. These patients might show greater willingness to participate in biomedical models of care than those who avoid such clinics. Gender was also a significant influence on Womack's results. And finally, in response to Womack's questions about the degree to which diabetes has a negative impact on their lives, "female patients with a high school or higher level of education were more likely to feel that diabetes has a negative impact on their lives." This correlation suggests a pairing of years-in-school with attitudes toward autonomy in an acculturative process (Womack 1995:82).

Rock has written provocatively about the presumptions in biomedical diagnoses and interventions for diabetes (Rock 2003). She suggests that intervention strategies assume not only good mental health of its enrollees but also an attitude toward time and planning. She states that prevention and intervention strategies "imply planning" and "routinely presume stable mental health...[which is predicated upon the] capacity to plan for the future.... [N]ot all people in sound mental health place equal emphasis on planning for the future. Indeed, the conception of the future varies cross-culturally. (Rock 2003:151-152). To "succeed" in treatment, then, patients must adopt these notions of future and attitudes toward making and following a plan.

My own work among pregnant Pima women has described how bodily clues about illness and disease undergo change in exposure to new medico-cultural experiences (Smith-Morris 2005). "Whether or not a particular behavior or experience is viewed by members of a society as a sign or symptom of illness depends on cultural values, social norms, and culturally shared rules of interpretation" (Mishler 1981:141). For many pregnant Pima women, no bodily clues to diabetes exist; they have no experience of illness. These pregnant women were relatively young (average age=25) and, therefore, had less hypertension, less use of insulin, and less of all the co-morbid conditions of diabetes than older Pimas. So what Pima women experience as a healthy pregnancy was often redefined by their health care providers as symptomless disease, an unhealthy pregnancy. Indeed, a diagnosis of gestational diabetes reconceptualizes pregnancy and diabetes as antagonistic states, the combination of which creates a *life-long* period of vulnerability to diabetes for both the mother and child. Not surprisingly, this unhealthy and risk-laden view of pregnancy is unpopular and confusing.

Consider also the following ideas reviewed in greater detail by Michielutte et al.: that health among Native Americans reflects a balance with nature and illness a disturbance of that balance, both physically and spiritually; that Native Americans orient themselves to the present, rather than the future; that some Native Americans are reluctant to dwell on death or bad things, which may encourage them to come true (for a review of literature on these and other subjects, see Michielutte et al 1994). Marshall's large body of work on cross-cultural bioethics offers an encyclopedic reference for more such cases (Marshall 1992; Marshall 2001; Marshall 2004; Marshall and Koenig 1996; Marshall and Koenig 2004). In particular, she has provided useful data and researcher narratives about the difficulties of obtaining informed consent in cross-cultural research settings (Marshall 2001). An informed consent form is both tool and symbol of the ideological assumptions listed above. A standard form extols the risks and benefits of the research, its methods, goals and purpose in detailed, clear-to-distraction, and authoritatively concise language. It can be completed in the absence of any rapport between professional and patient, and while its signing may produce some legal meaning, the form itself fails those who can sign their name but not (1) understand the ultimate consequences of, (2) safely question, (3) respectfully challenge, or (4) successfully negotiate an alternative to that document.

Patients whose cultural or family context renders them unable or unwilling to make decisions about their own care are one such group. These patients falter within a biomedical system that requires not only individual decision-making but also a fair degree of compliance and a certain attitude toward medical knowledge including, for example, a future planning or a forthright naming of disease (i.e., delivering the diagnosis) that may conjure them into existence.

The Ethics of Consent

The most influential research tool for conveying and acknowledging autonomy—whether it be the autonomy of individuals or the autonomy of tribes—is informed consent. Yet the ethics of consent are intimately related to the historic moment in which research and treatment are being proposed. Despite assertions that the Principalist Approach to bioethics is a universal paradigm—appealing to a 'common morality' shared by all thoughtful people (Beauchamp and Childress 2001)—the principle of autonomy is neither universal nor necessarily moral.

The Four Principles approach in bioethics, made famous by Beauchamp and Childress in the five editions of their class text on biomedical ethics, is the hallmark of the discipline. Although much critiqued by ethicists from diverse standpoints and by anthropologists (for example, physician-anthropologists Kleinman and Helman argue against assuming the relevance of Euro-centric premises in clinical practice), these principles continue as implicit, if not explicit, premises underlying analysis of ethical issues and decision making in clinical settings (Helman 2000; Kleinman 1980). The culturally

Euro-American reification of the Individual is so fundamental to the four principles as to limit its utility for communication in ethical conflicts, even though the US legal system rests on the concept of individual rights. Beachamp and Childress respond to attacks leveled against the Autonomy Principle by insisting on the individual's *right* to choose the form and content of care, stating, "Even if the patient delegates [their decision-making] right to someone else, the choice to delegate is itself autonomous" (Beauchamp and Childress 2001:61-62). Native and other patients who choose to refuse information about their health, or who direct that others will make decisions for them, have limited capacity to so choose within biomedical settings where individualism is assumed. Individual decision-making has become an *obligation* in the lived world of health care because of procedures and clinic milieus that preempt more creative strategies.

More creative solutions will not ignore the need to protect individuals from harm—and for guidelines in this arena, we might turn to the somewhat less culturally-bound Universal Declaration of Human Rights (e.g., Farmer 2003; Handwerker 1997). But an ethical approach to research among Native Americans will not ignore the additional burden of community protection that the researcher adopts. Thus, in addition to any necessary individual consent (or documentation of individual choice to delegate another decision-maker), researchers must establish a route by which community consent and protection occurs. Carolyn Sargent and I have proposed (Sargent and Smith-Morris 2006) *simultaneous* attention to the individual *and* cultural factors in questions of autonomy, patient rights, and decision making processes in health care. Following Marshall and Koenig, we do not "dispute the relevance of abstract principles in bioethics" or of the need for *both* individual and communal decision-making about health research, but as anthropologists we remain concerned with "the everyday practices derived from these principles, practices that often fall short of realizing [their] normative [or acculturative] intent" (Marshall and Koenig 2004:253).

Hudson and Taylor-Henley have suggested their own "four principles" for research with Native Americans. These principles are aimed at communal consent and protection.

- elder input;
- the use of traditional language
- immediate benefit to the community;
- and First Nations control which means that "the research is not just about understanding a particular set of phenomena in a frozen point in time; it is about attempting to be a catalyst for the sort of change identified by the participants" (Hudson and Taylor-Henley 2001).

Applying the Hudson and Taylor-Henley principles to research consent requires one to consider the very long life (through publication and through re-use/re-interpretation) of data. Indeed, one must recognize that the consent researchers seek is *eternal* consent and demands of the subject a degree of *passivity* toward the interpreted findings. Some tribes are choosing not to accept these conditions.

Even where the scientific method no longer grants unlimited access and authority over information, creativity and respect may still succeed. Dongoske (1996) described one creative solution to a complicated research question. In 1991, the Hopi Tribe's Cultural Resources Advisory Task Team (CRATT) was petitioned by a University Office of Contract Archaeology for permission to conduct nondestructive laboratory analysis of skeletal remains from two sites within the geographic area of Hopi affiliation. The unique feature of the remains (representing at least 14 individuals) was the presence of green bone fractures, impact marks, cut marks, and burning, and the scattering of these remains on the floor and bench in a kiva. Under the terms of consultation outlined in NAGPRA, the Hopi CRATT has responded to hundreds of requests for consultation. But this case required some form of conciliatory gesture and assurance of protection toward the spirits of the deceased. An agreement over the requested laboratory analysis was reached using a four-month time limit for reburial. This solution worked "because the number four is sacred and significant to the Hopi people and the premise was that if the spirits of these fragmented remains became aware of the four in the allowed time period, they would recognize the Hopi involvement and find the analysis non-threatening" (Dongoske 1996:294).

Piquemal (2001) has called for the *negotiation, renegotiation, and final confirmation* of an original consent, a potentially cumbersome process but one that offers legitimate regard and protection for communal rights. Through these many windows, communities (and individuals within them) can reassess their place in the research and the meaning of their participation as the research comes to completion and to publication.

In the final analysis, however, much rests on the researcher to build trust, to establish clear and oft-used lines of communication with individual subjects and with community decision-making bodies, and to be responsive to their needs. Kaufert offers this compelling summary:

Guidelines developed by First Nations and other indigenous organisations...place primary emphases on the importance of trust, reciprocity, respect for local knowledge and commitment to continuity in the research relationship. The researchers' creditability as a scientist is important to this relationship, but so also is their respect for local knowledge, their capacity to work in a collaborative manner and their cultural sensitivity... a relationship which will not only last over time, but be fully participatory at all stages of the research process. [Kaufert 1999:46-47]

Complementary Communal and Individual Consents

The need for consent to research in Indian Country has long posed the ethical question of "consent—from whom?"...

One can plausibly argue that cultural knowledge is the property of individuals that they have the right to communicate

or withhold as they please; one can also plausibly argue that the release of such knowledge should be controlled by a communal body. If one refers to local tradition, then the set of norms that respects personal autonomy and that does not approve of intervening in the decisions of others would conduce toward a judgment that each individual must retain the privilege of sharing or withholding knowledge. Yet kindred traditions instruct that others in the group may suffer if sacred knowledge were to be handled faultily or revealed to the wrong persons; and this would imply that only the community, as a whole, or those instructed to speak for it could grant consent. [Wax 1991:447]

Considerations of autonomy in tribal contexts only five to ten years ago could not have predicted the 21st century political and social milieu in tribes concerning research, and the remarkable transformations that have occurred to tribal processes of research review, approval, and monitoring. Questions left unanswered in the past are now, of necessity, built into increasingly legalistic research proposals that address not only consent but also such things as ownership of data, destruction of blood and tissue samples, pre-publication manuscript review, reporting of research results within the research community, responsiveness to community input, and increasing complexity and specificity vis-à-vis benefit to the community (for example, see Adler 2005; Kempf 1996).

There is now a dual consent process in many native communities—consent at the community level, either from a tribal governing body or IRB, and consent from each individual enrolled in the research. Research rarely proceeds without both forms of consent, but the former process—communal consent—is a new process to most tribes and remains vulnerable to the acculturative impacts of western models and guides. Through their participation in the biomedical community, Native American patients are influenced and assumed to adopt notions of individualism. Likewise, tribes can unwittingly promote bioethical and biomedical paradigms that are contrary to valued traditions and mores within the community.

It is tribal governing bodies, and not individual research participants, who tend to drive changes of this magnitude. As consent procedures and forms have grown in length and complexity, the role of the tribal governing body in the research review and approval process is likewise augmented. Few opportunities still exist for researchers to (ethically or in many cases legally) enter and conduct research an indigenous community without the approval of tribal governance. This is true regardless of scale or topic, and a body of case law is beginning to grow that will spell out sanctions for such infractions.

The Changing Ethics of Health Research in Indian Country

A final but important complication to the ethics of health research in Indian Country is the promise of cures and health care innovations inherent in the research enterprise. As tribal communities live through generations of epidemic

levels of disease burden (particularly metabolic disorders associated with colonial processes and capitalist incorporation), then the cultural, economic, political, and even biological mechanisms of the disease become somewhat convoluted (for example, see Benyshek, Martin, and Johnston 2001). In many native communities, it is a convoluted created by the failure of long-term, expensive, invasive clinical and biological research to produce a decisive cure. If disease rates reach endemic status, a new degree of skepticism is bred among those at risk. This is certainly the case for diabetes in the Gila River Indian Community (e.g., Kozak 1997; Smith-Morris 2006b). After almost forty years of intensive biomedical research into their epidemic of diabetes, Pimas have suggested to me that the research is (a) never going to produce a cure or reasonable control mechanisms, (b) a somehow fake or exploitive scheme by outsiders, or (c) targets benefits for non-Pima and non-Indian sufferers, rather than the community-specific needs of the Pima themselves. This community milieu of doubt, if not mistrust, is an important dilemma for researchers to address, not only because of the implications for disease prevention but because of the underlying hegemonic force and related acculturative pressure that research carries with it (Smith-Morris 2006a). A milieu in which researchers are declined permission to work on a reservation, or moratoriums placed on all or most research within a tribe, exacerbates the already tragic epidemic. And this is certainly an ethical dilemma.

Consider a lawsuit filed two years ago by the Havasupai tribe. Not only does this case raise obvious questions about research ethics, but it has become somewhat emblematic of tribal capacity for self-determination. The suit involves a \$50 million claim against a university and its Board of Directors, as well as the three professor/researchers (Shaffer 2004). The suit claims that blood samples collected for an approved research project had been subsequently used for other unrelated studies. Although it was the anthropologists who “blew the whistle” on the subsequent research (Parezo 2004), the Havasupai sued over a lack of oversight by the university’s Institutional Review Board in violation of federal law. Noteworthy is the fact that two lawsuits were originally filed, one brought by many of the research participants on their own behalf, and the other by the tribe itself. Approval of and consent to research has thus become very serious and very controversial in Native America. And one crucial question that this case raises is whether and when tribes may over-ride individual preferences vis-à-vis research participation. How tribes make these decisions will have an enduring impact on the character and survival of communal ways of life.

Repeated through myriad encounters across decades, it is not hard to see the role of individual-focused medical care in the larger transformations of community attitudes toward the individual as a decision-making unit. Helman notes that biomedicine’s focus on the individual patient, or even the individual organ, ignores wider issues that render consensus decision-making difficult to achieve (Helman 2000). Research and health care processes in Indian Country that categorically

preclude or make difficult the types of negotiations common among Native Americans (i.e., consensus, family-based decision-making) cannot help but have acculturative effects.

These acculturative forces are veiled in attractive language about individual choice and control. Capitalist markets and consumer culture thrive on this individualism. Marshall and Koenig suggest that “bioethics practices that celebrate only autonomy, with its emphasis on choice, and downplay social and economic constraints on individual agency, are out of touch with health-care realities in the U.S., as well as globally. The changed discourse—doctor becomes provider and patient becomes consumer—reflects fundamental, systemic problems characteristic of market-driven medicine” (Marshall and Koenig 2004). Some ethicists have openly labeled these processes “imperialist” (Angell 1988; Newton 1990). The acculturative effects of individualized medicine are, therefore, only part of larger economic processes.

Recommendations

If we are to address and avoid the unwanted acculturative characteristics of our research practices, anthropologists must offer their vigilance and perspectives to tribes, and must promote reasonable and fitting alternatives. Below are several recommendations to address the acculturative characteristics mentioned so far. Although the emphasis is here on strategies for obtaining (and retaining) communal consent, there remains a clear and unquestionable need to simultaneously respect individual decision-making and rights.

Tribal Research Review Committees. A first step for some tribes will be the formation, if one does not already exist, of a community group whose function it is to oversee research within the legal and geographic bounds of the tribal territory. In recent years, several tribes have created institutional review boards (IRBs) modeled after the US Department of Health & Human Services regulations. The regulations address such things as the quality of the research design, protections for individuals’ privacy, risks and benefits to individuals of participation, informed individual consent, and monitoring of the data collection (Services 1981). While this is a convenient and praiseworthy model, it is based on the same principle of individual autonomy that anthropologists have critiqued for years. Despite their obligation to comply with DHHS regulations, tribes can exercise some creativity in the composition and activities of their IRBs.

Rules of IRB membership, while respecting the federal demand for diversity, non-discrimination, and technical/scientific expertise, may also reflect the unique characteristics of each tribal community. The role of elders, war captains, healers, or matriarchs, for example, can and should be acknowledged and represented appropriately in the membership. The membership need not, for example, be limited to elected tribal council members or to Indian Health Service employees, as sometimes occurs by accident or design. Since committee membership must also reflect professional expertise capable of reviewing a range of study designs, each committee will

strike its own balance between local perspectives (themselves diverse) and those of professionals. Marshall writes,

The strong value placed on promoting scientific research among most IRB representatives may outweigh the concerns of a community representative. Moreover, lay members may experience psychological pressure to reach consensus and therefore they may be inclined to accept the arguments of a “professional.” [Marshall 2001:C-5]

Tribal IRBs have a distinct opportunity for striking a balance that better reflects the values and priorities of the community. Anthropologists can help ensure their tribal hosts know of these opportunities and are poised to take advantage of them.

IRB Statements of Purpose. The IRB statement of purpose is both a document and a planning process that should reflect the values of the community vis-à-vis health research. This statement (whether oral or written) helps guide the actions of the IRB committee members, but also promotes within the community a specified set of values surrounding research.

Of greatest interest in the present discussion is the degree to which individual informed consent is prioritized over group processes of consent in research. The IRB should state and widely publicize¹ its goals for community oversight of research, such as the protection of both individuals and communities, emphasis on certain goals for the community, and any preferences or restrictions on types or modalities of research. In developing this statement of purpose, the IRB will identify the scope of its protective function and authority, and will create a process by which community members can express their own multivalent ideas about research. In short, rather than adopt federal guidelines for these activities, tribes should carefully consider the distinctive ideas, beliefs, and events that might be threatened by an unexamined adoption of western bioethics and legal prescriptions for research. Ethnographic methods will be particularly useful and effective in these efforts.

Review of Research Applications. Once a broad purpose of the IRB has been considered and agreed upon, specific strategies for achieving that purpose can be discovered or created. These will include publicizing the role and contact information of the IRB, along with information about the application process, forms, permissions, or other supporting materials necessary to successfully navigate the process. Few professional researchers will attempt research in a native community without contacting the tribal governance, and some academic and institutional IRBs may require evidence of tribal permission. Yet tribes have begun to consider whether those external IRBs fully recognize their own, internal ethics and principles.

Tribes (as a whole) and tribal authors and speakers have articulated some of these cultural differences since the colonial era. But it is rare for tribes to publish guidelines for researchers about the cultural issues that warrant special sensitivity, protection, or behavior. Researchers discover

these issues in discussions with IRB members, as part of the researcher's background investigations (i.e., as they prepare their application), or after research has begun. A more proactive approach is for researchers to evaluate the assumptions behind their research questions and methods, and to engage in ample conversation about ethical issues before finalizing a proposal. The methods of participatory action research will be helpful in this regard and many others.

Participatory action research (PAR)—described by Israel (2003) as not a method, but an orientation—has helped scores of researchers in recent decades to align themselves properly with tribal goals of self-determination. Although an in-depth review of PAR is not possible in this article, a brief list of some key concepts will portray the relevance of this “best practice” in research. PAR facilitates collaborative, equitable partnerships in all phases of the work, from design through implementation and follow-up; PAR promotes co-learning and capacity building among researchers and communities that are considered partners in the process; and PAR facilitates the development of intelligent and flexible systems of research through a cyclical and iterative process. I have discussed elsewhere (Smith-Morris 2006a) how PAR is suited for work in tribal communities, by acknowledging the heterogeneity of tribal communities, allowing for tribal influence on (though not complete ownership of) research goals, and producing greater validity in research because the methods are informed and often *performed* by local residents.

One article cannot begin to address all the exigencies behind tribal review of research applications. The PAR model offers an orientation that can guide researchers through those exigencies in ways that allow scientific rigor without compromising community self-determination.

Ongoing Review and Supervision of Research. Once permission for research has been granted, the relationship of the IRB to the researcher will change. In some circumstances, the supervisory role of the IRB will be distant and passive; other IRBs may elect a more engaged and active role. Since the application review process is just one aspect of an ongoing relationship, IRBs and researchers should be informed and prepared for the ongoing review and supervision that will follow.

Tribal expectations regarding ongoing review and supervision of research should be made clear during the application approval phase. An approved research proposal gives the researcher his/her instructions and reference manual. The approved document contains the research methods, sampling techniques and locations, instructions for recruitment of and communication with participants, and details about the use of community members as project employees, just to name a few. Tribes should likewise view the approved proposal—typically a written document and not a verbal contract—as an opportunity to spell out its expectations and constraints for the research.

Additional topics that warrant dialogue between researcher and community, if not also explicit attention in a written research proposal, include: permission to publish

findings and/or tribal review of manuscripts before publication; allowances for future use of data in other projects; storage of data; ongoing maintenance of confidentiality; and long-term contact information should the researcher's host institution change. DHHS-model IRBs tend to have specific requirements (e.g., phrasing in a consent form or proposal that addresses these issues) that may be useful to tribes as a guide in determining their own specifications.

The IRB may request periodic and final research reports. In addition to selecting a meaningful frequency, time, and place for these reports, the IRB should recommend the most effective ways for communicating information among community residents. For example, reports at regular but poorly attended community meetings may meet the letter but not the spirit of reporting requirements. Creative strategies for disseminating research results should be encouraged by tribal leadership, especially for under-educated or geographically isolated members.

The final report should, according to the PAR model, facilitate open dialogue about the researcher's adherence to the proposal, conclusions, and recommendations. The final report can include appendices of raw or analyzed data, as negotiated during the proposal application process. Inclusion of raw or partially modified data (e.g., transcribed interviews) allow the tribe to make further use of gathered evidence. This strategy is particularly useful for ethnographic data which help tribal governing bodies hear from, know, and respond to the expressions of community members. This strategy may be less relevant for other forms of data. Nevertheless, the final report can be treated as one of the “benefits to community,” not only because it returns the interpreted findings to the community members, but because it recognizes a shared ownership in the results and a mutual interest in the interpretive process.

Community Benefits. Researchers should be clear about tribal expectations for direct and indirect community benefits of the research. These may include the hiring of community members on the research team, the provision of interventions to address identified health problems, or the dissemination of findings and trainings within the reservation. Collaborative research strategies require substantial effort and some costs, and should not be underestimated in their benefit to the community. However, some community members will have greater or different expectations about what researchers can bring to the tribe. The arrival of a research team in a remote or poor tribal community may prompt high community expectations for change, development, health, or financial investment. While research funding typically limits these various benefits to a small sample of the population, researchers can offer targeted dissemination of findings or other advocacy efforts that would partially respond to these community expectations.

The Tribe-to-Researcher Relationship. Finally, tribes can be more direct about the rights and responsibilities they bestow upon individuals (and their institutions) who come into a research relationship with the community. Contact with

the specific tribe's governing body is a reasonable starting place for researchers wishing to open negotiations about a future research relationship. In determining the *other* appropriate points-of-contact for tribes, researchers should be mindful of the diversity within and between communities. Tribal approval processes are organic and mutable, making a cardinal rule for the researcher in Indian Country to first develop informal connections within the community, using these to understand its political and cultural tides. Demonstration of one's interest in and dedication to the community as a whole, not just to the topic of research or the limited time span of a funded grant period, is an important testimony to one's acknowledgement of the research-to-community *relationship*. Ideally, the tribal approval process becomes a secondary endorsement of the researcher after some degree of public recognition and endorsement have occurred.²

Risks of PAR. Within these recommendations are several ideas that would be considered risky or too burdensome for some researchers or some projects. I acknowledge that certain research strategies and forms of data are inherently less "participatory" than others. However, with the balance of power and knowledge being tipped toward researchers for so long, tribes have been exploring their new authority under Self-Determination. Rather than proceed under the assumption that scientific research will retain its privileged status within, protections from, and access to tribal communities, researchers would benefit from a more proactive approach. This article attempts to broaden our discussion of these approaches, particularly PAR strategies, at the risk of facilitating a reduction in researcher control of the process. For example, tribal review of manuscripts prior to publication can be time-consuming and burdensome. Researchers will be especially concerned that "negative" findings or interpretations will be restricted in some way. In this case, as in most worrisome cases, the intent of my recommendations is not to produce tribal dominance over or exploitation of researchers. It is simply to ensure that assumptions be discussed, and that a mutually agreeable plan be developed. Several of the changes within these recommendations will be difficult to operationalize, such as the insurance of ongoing consent or effective dissemination of findings within the community. Here too, researchers and tribes are called to more of the creative solutions discussed above, rather than habit or culturally-inappropriate models.

Conclusion

Ethical health research is a difficult and shifting concept in any cross-cultural setting. Their longstanding patterns of medical pluralism notwithstanding, Native Americans continue to negotiate both their health and identity through these cross-cultural research settings in contexts of stark power differences. Because of their ideological, cultural, and economic dominance in the US, biomedical providers and researchers can often operate without questioning their ethical assumptions. In Indian Country, this is increasingly

rare. The appearances of tribal resistance to these hegemonic ethical ideas—the principal of autonomy being one, the notion of eternal consent another—are demonstrations of and reactions to this power differential. The ethical character of research will continue to change as the limits of tribal self-determination become clearer.

Participatory research may not be appropriate for all research questions. But it does expose the tension between scientific advancement of knowledge and tribal self-determination. Scientific rigor cannot be discouraged, but researchers must get beyond the assumptions of a hegemonic Euro-American ethics, in which consent for research demands so much loss of control by tribes and individuals. Far from colluding with practices that marginalize and objectify native research "subjects," our research should challenge the authoritative knowledge that produces such unequal power relations between clinicians and patients, non-native researchers and native research participants, archaeologists and tribal councils (Davis-Floyd and Sargent 1997; Jordan 1997). Creative solutions will demonstrate interactional cooperation and accommodation so necessary to truly collaborative work.

Notes

¹Publication of tribal values and goals regarding research among its members should reach all enrolled members, regardless of whether they live on or off the reservation. Attention to this geographic dispersion of tribal members will necessarily raise new discussions about the "reach" of research review committees, the identity politics of tribe member residence, and the role that research review can play in non-reservation member lives.

²For a description of my own process of approval-seeking in the Gila River Indian Community, and an anecdote about the importance of relationship-building, please see chapter two.

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