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Field Research with Underserved Minorities: The Ideal and the Real

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ABSTRACT The realities of doing field research with high-risk, minority, or indigenous populations may be quite different than the guidelines presented in research training. There are overlapping and competing demands created by cultural and research imperatives. A National Institute on Drug Abuse (NIDA)-funded study of American Indian youth illustrates competing pressures between research objectives and cultural sensitivity. This account of the problems that were confronted and the attempts made to resolve them will hopefully fill a needed gap in the research literature and serve as a thought-provoking example for other researchers. This study built cross-cultural bridges. Researchers worked as a team with stakeholders to modify the instruments and methods to achieve cultural appropriateness. The researchers agreed to the communities' demands for increased service access and rights of refusal for all publications and presentations. Data indicate that these compromises did not substantially harm the first year of data collection completeness or the well-being of the youth. To the contrary, it enhanced the ability to disseminate results to those community leaders with the most vested interests. The conflicts between ideal research requirements and cultural demands confronted by the researchers and interviewers in the American Indian community were not necessarily different from issues faced by researchers in other communities. Of major import is the recognition that there are no easy answers to such issues within research.

KEYWORDS Adolescent research, American Indian, Cultural sensitivity, Underserved minorities.

INTRODUCTION

Researchers are increasingly aware of the need to be sensitive to ethnicity and culture. Promoting opportunities for advancement of knowledge¹ and maintaining cultural sensitivity may not always be compatible. For example, the value of knowledge advancement in the sciences is predicated upon a linear incremental world view, whereas some cultures have a circular spiritual mode of understanding the world.² Although current literature on applied research concerning bridging cultural divides remains slim, recommendations for research consistently include involving stakeholders

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Because of community confidentiality, the names of the community leaders who contributed to this paper cannot be published.

and collaborators in research projects.³ Recommendations also stress striving for cultural competence, respecting diversity and experiences,⁴ and making the language used in the research accessible.⁵ A study of American Indian youth illustrates the dilemma caused by competing pressures between research guidelines and cultural preferences, needs, and values.

Research, as taught in schools, involves several key imperatives: (1) obtaining the same responses each time from each person when a measure is assumed to be static; (2) not influencing the type of responses;⁶ (3) not interfering in natural changes that an individual makes over time; (4) not violating promises of confidentiality; and (5) using standardized normed instruments. In contrast, cultural concerns may put pressure on the researcher to adapt those research demands to be culturally syntonic. The phrasing of questions on standardized instruments may need to be adapted to a particular culture. For example, various cultures may have unique family or helper configurations. Also, many cultural groups have a fear of being presented in a negative light. Unfortunately, research, particularly mental health and addictions research, typically looks at behavioral and community problems rather than strengths. Various cultural groups may differ in their valuing of the importance of research or confidentiality.^{7,8} Finally, the issue of confidentiality within a particular minority cultural group, especially if that cultural group is a small close-knit community, may be quite different than confidentiality issues for majority groups. For example, in a small group everyone might know who participated in a survey, and if the criterion for such participation is a behavior problem, that would become known.

Issues of bridging cultural gaps in research are especially pertinent when doing research with American Indians. 9-11 They have a history of having been "cheated" by unscrupulous business and research arrangements. 12 To obtain access to do research with American Indians, researchers must bridge the cultural gap to become trusted by the community. Bridging cultural differences involves understanding the tribes and the tribal members' best interests and accepting them. 13-15 Also, because American Indian reservations constitute independent national entities for which tribes can make their own laws, reservations might have separate regulations regarding protective services or internal review board procedures. Researchers must abide by both the national US and the tribal laws.

There are at least two theories that might help the researcher navigate the bridging of the ideal and real when doing research in different cultural situations. One is the cultural literature, ¹⁶ and the other is social exchange theory. ¹⁷

Cultural Literature

The cultural literature helps the researcher understand potential problems that must be navigated in doing research. Field research is typically done either in an agency or in culturally diverse populations. If it is done in an agency, there are academic versus practice cultural divides in values, time constraints, and interests. If it is done in culturally diverse populations, there are racial, ethnic, social, economic, and cultural issues to be addressed.

The literature is extremely sparse about how to bridge cultural divides. Over the history of research there have been changing attitudes toward cultural differences. Early cross-cultural research was marked by a universalistic approach in which commonalities between various cultures were sought. Later, research took a pluralistic approach drawn from cultural anthropology. In that approach, researchers attempted to look at each culture in its own terms and as an integrated whole.

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More recently, the approach towards bridging cultural divides in research has focused on cultural constructionism. That is, it is characterized by an openness to interchange and more egalitarian participation in the achievement of research outcomes.¹⁹

The literature provides some information about bridging cultural divides between different ethnic or racial groups, but does not address the research arena. To some, bridging that divide means exiting one's own "culture bubble." Once exited, one can genuinely encounter others. To do this, one must develop cultural fluency. This consists of fluency in language, and in strategies that take the meanings of other cultures into account. To bridge cultures, one needs collaboration, genuineness, sensitivity, humility, and congruence. One must build, in the other culture, acceptance, respect, trust, and friendship, which together foster interracial unity. If

Bridging cultural gaps is important in research, because we know that minority cultures differ enough from the dominant culture that the meanings of much research is not comparable. For example, the meanings of measures may not be comparable among different cultures, context may be nonequivalent, and there may be differences in how to interpret questions, as well as how to filter and express the responses. Recently, researchers have raised questions about the conceptual equivalence of many standardized assessments, particularly with American Indian populations. For example, in American Indian communities the family is a complex web of relationships with little distinction between immediate and extended family. In the conceptual equivalence of many standardized assessments, particularly with American Indian populations.

Social Exchange Theory

Social exchange theory does not deal directly with research in different cultures, yet its principles apply to bridging gaps. The theory simply emphasizes minimizing participants' costs and maximizing rewards. In research, rewards may be maximized through direct financial benefits, such as third party contracts for overhead to cooperating sites, hiring staff from that agency or population, salaries or travel expenses for participants, assuming costs of existing service programs from communities (if service programs are being studied), or buying supplies and equipment for the research project and then turning it over to the community after the study.²² There may also be indirect financial benefits for participants, such as access to libraries, computers, consultation, staff supplementation, and staff training programs. Finally, there may be social, intellectual, and intervention benefits. Many cultural groups are very concerned with the problems in their communities and anxious to have information that can advance their health and social services programs. They may benefit from having researchers provide information that would then direct their policies and programs. Finally, individual participants may find that helping their community obtain information is personally rewarding.

To minimize costs to participants, research must be compatible with the normal operations, perspectives, and priorities of the culture and must examine questions relevant to the culture. Researchers may need to reframe their professional priorities to address the community's priorities. For example, the researcher might be interested in testing service access theories, whereas the community may be interested in delineating needs for services. It is important to uncover potential incompatibilities in both style and substance in the planning stage to reduce apparent costs for the community. Finally, intrusions and disruptions in daily life that may be created by the research process must be minimized.

This article outlines the process of adapting ideal research requirements with cultural issues in a study of American Indian youth and presents data on the results of the field research process, after it was adapted to bridge the researchers' and the communities' differing perspectives.

METHODS

The processes of bridging cultures described here is based on data and experiences from the American Indian Multisector Help Inquiry (AIM-HI), a National Institute on Drug Abuse(NIDA)-funded study of service use and drug-use information in two southwestern American Indian populations, one urban and one reservation-based.

Sample

Two hundred five reservation and 196 urban youth were interviewed in person in 2001. At that first of four yearly interviews, the youth averaged 15.4 years of age, and 56% were female. Youth were recruited from the reservation by using tribal enrollment rosters and from the urban area by using school district records. They and their families were first contacted by community leaders. Eligible youth were between 12 and 18 years old, with only one per family recruited by personnel from the respective local American Indian educational and health services and by tribal representatives. Further details of the recruiting methods, and procedures can be found elsewhere, as this article deals with the research processes rather than results. 9,23,24

Interview Procedure

After community representatives obtained initial agreements to participate, trained interviewers went to the youth's homes and explained that they would first give a brief interview and then ask some participants to continue into a full study. The interviewers obtained parent/guardian and youth's consent (if not already signed) and administered the brief interview. If the youth met selection criteria, ^{23,24} the interviewer then scheduled a long interview.

The consent form specified that confidentiality would be broken if the youth indicated that he/she or someone else might be in danger "of harming oneself or another or of being harmed" and that the youth would first be told that this was happening. The researchers' university, the tribal council, and the urban school board granted Institutional Review Board approval and National Institutes of Health (NIH) granted a Certificate of Confidentiality.

RESULTS

Cross-Cultural Collaboration

The AIM-HI project was designed to research the service needs and service use of American Indian adolescents. The researchers (one of whom is American Indian) initiated a Research Implementation Team (RIT) composed of tribal elders, human service workers, council members, parents, and representative youth from the participating American Indian communities, giving the research process a strong "community-driven" approach. The RIT detailed the problems in their communities that the research should address. The initial RIT members specifically requested sensitive, detailed information about various kinds of physical and sexual abuse, HIV-risk

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behaviors, and gay and lesbian activities, as well as the standard drug abuse and mental health issues. The field methods and instruments were mutually agreed upon by the RIT team and other parent groups. The questions were also piloted with groups of American Indian parents and youth in the participating communities.

The Principal Investigator (PI) maintained regular contact with the communities over a 3-year period until the AIM-HI application received funding. For example, the PI provided consultations (gratis) to one of the communities on a disability survey that was initiated by them.²⁵ By the time the AIM-HI study received funding, there were new agency personnel, new members of the tribal council, and new members of the urban parents group. They became involved and began to raise many new concerns. The new team members decided that they would use the research as a means to identify and refer youth who might benefit from preventive services.

Community Desires and Demands

However, they expressed concern about sensitive topics, such as sexual behavior, which had been initiated by the earlier RIT members. They indicated that certain sections of the instrument contained topics not normally discussed in their American Indian culture. For example, these new RIT members believed that the youth would become disturbed if they were asked questions about life stressors, family problems, sexuality, conduct problems, stressful events, traumatic experiences, neighborhood and school environments, and mistreatment. To address this concern, the researchers devised a method that allowed youth respondents to "skip out" of a number of sections prior to being asked the questions. The youth was given a copy of the questions and asked if they would be willing to respond to them. When a response was in the affirmative, the youth was given the option to complete the interview section personally on the computer or to continue with the standard interview method. This represented an enormous research risk because the youth could skip out of seven sections, which could have crippled the project with missing data.

The communities did not want to be portrayed as communities of problems with no strengths. Thus, special attention was paid to the instruments, the analyses, and the presentations to emphasize strengths of the communities and of the individual participants, the culture, the families, the neighborhoods, and the schools (Stiffman AR, Brown E, Freedenthal S *et al*, unpublished data, 2004). Open-ended questions about strengths were included in each topical area of the interview to present a more balanced view.

Cultural Adaptations to Instruments

Despite the push by "ideal" research not to modify standardized instruments, we found it necessary to make such modifications to adapt them to the American Indian culture. For example, in the substance use sections of the Diagnostic Interview Schedule (DIS),²⁶ questions were added to clarify whether tobacco and hallucinogens were used only for traditional ceremonies.²⁷ The Services Assessment for Children and Adolescents was also modified to include service providers who were culturally sanctioned,^{28,29} such as healers, elders, and traditional medicine people.

Specific adaptations were made to the instrument based on pilot studies that showed that the youth were unable to respond as needed to some specific instruments. For example, the Oetting and Beauvais Cultural Identification Scale,³⁰ asks about identification with American Indian culture, White culture, and any other culture. The youth became confused and could only answer the questions for their

identification with American Indian culture. Thus, despite some evidence in the literature that bicultural identification is important, we modified the instrument to include only American Indian cultural identification.

One of the major adaptations occurred in the substance abuse section of the DIS.²⁶ The RIT objected very strongly to the length of the instrument and the repetition of the symptom questions for each illicit substance used. They wanted the symptoms to be asked only for a generic category of "any illicit substances". With these modifications, the instrument was pilot tested. The modifications to the DIS meant that it no longer accurately provided diagnostic categories for particular types of illicit drugs. That opened the possibility that youth who barely met the number of criterion symptoms for diagnosis would be diagnosed without being dependent on any particular drug. They could theoretically meet one criterion for one substance and two criteria for another. The communities' requested change also necessitated modification in the way the data were analyzed. Most of our analyses regarding substance use are based on the number of dependence and abuse symptoms and the types and quantities of substances used, rather than diagnosis. Because the study was primarily a service use study rather than an epidemiological study, this switch was acceptable within the framework of the overall research goals. The data did reveal that for the eighteen youth meeting only minimal criteria for diagnosis, sixteen had clearly identifiable substances that they abused, with eight using only one illicit substance, and the other eight using only one regularly. Thus, over-identification of dependence was not a major issue despite the changes in the instrument.

Cultural Adaptations in Fieldwork Procedures

A number of adaptations were also made to the fieldwork procedures. The communities wanted to receive direct benefits from the research. They proposed that monies received from the grant should go back to the communities involved in the project. To accommodate this request, community members were hired as field supervisors and as interviewers. Their selection was based on their knowledge of the communities and the respect accorded to them by the communities. The RIT explained that, within the American Indian culture, self-disclosure is tantamount to giving part of oneself to the study; thus participants' compensation should parallel the importance of that action. Youth participants' compensation was made quite generous (\$25 in Wave One to \$40 by Wave Four).

Pay schedules for staff had to accommodate economic exigencies of these community workers. The American Indian interviewers threatened to quit unless they were paid within days of completing their assignments. To accommodate them, special arrangements had to be made through the researcher's university. In addition, payment was based on the number of interviews completed to emphasize the task orientation needed in this work. To reinforce their desire to stay in the interviewer pool and complete more interviews, interviewers received bonuses for every five or ten interviews they completed.

Some of the restrictions on NIH-funded projects are not conducive to bridging cultural disparities, particularly with American Indian communities. For example, food is an important part of all gatherings for American Indians. NIH does not allow research grant funds to be spent for food. Thus, payment for culturally necessary social amenities, such as food or token gifts at the RIT meetings or presentations was made from other sources.

Also, some customary academic behavioral styles may not be culturally appropriate. The American Indian Co-Investigator cautioned the PI that approaching an

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issue directly, as trained in academia to do, is considered inappropriate. One does not present a suggested solution; one asks questions and allows the solution to rise to the fore after discussion.

Information Dissemination Adaptations

The community insisted on the right to review and/or edit all publications and presentations. Theoretically, they could refuse to allow publications of certain data if it portrayed them negatively or they felt the interpretation was inaccurate. The research team agreed to continually consult with community officials and provide all presentations or papers for their review before submission. No papers are submitted for publication until requested changes are made and approval is obtained from the communities' representatives. The communities' representatives have been very cooperative and helpful in assuring that data interpretations are accurate and presented with sensitivity. The communities also requested and received ongoing study results for policy and service planning. The research team conducted staff training at community agencies, gave regular reports to the tribal council and the various agencies, and provided frequency books and charts for each wave of data collection. Along with the frequency books and charts, the research team held inperson yearly training in reading frequency tables. In addition, the researchers responded to direct questions from the communities about the charts. This process has enabled the communities to greatly accelerate translation of the research into programs, policies, and practice.

DISCUSSION

Using the Research as a Springboard to Services for the Subjects

As stated above, the communities wanted to provide services to those youth who were identified in the interview as having problems. Increased service access for these participants was viewed as an important direct benefit for the community. There are some important "ideal to real" issues when one intervenes in the need for care in a longitudinal research study. By intervening, it is possible that researchers might change the mental health condition and behavior of the participant, which might compromise the goals of a naturalistic study. However, the researchers decided that in a service study such as AIM-HI, as long as they tracked the services used by the youth and how they got there (whether through the research itself or through another path), such intervention would not critically impair the research goals.

The desire to provide services based on responses in an interview raises a number of questions. The primary question concerns the appropriate time to intervene. In two situations there is a clear legal or ethical need to intervene; for example, child abuse and suicidality. In child abuse, legally, one must make a hotline call when informed about abuse. However, because of system response capacity, protective services departments are not able to spend time investigating many reports if those reports are not accurate or serious. Also, when dealing with abuse within a minority culture that is small and relatively self-contained, a number of issues are raised. Because of the extended family atmosphere in the tribal or reservation area (and perhaps in any small community), an abuse report could destroy the family, its reputation, self-esteem, and ability to live in physical proximity to the study.

Although the law does not mention any of these factors, it is extremely important to make sure that this is weighed against the possibility of making a trivial report. Similarly, when a youth reveals suicidal thoughts or behavior, action must be taken. Imminent self-harm, of course, needs immediate attention whereas suicidal thoughts merit a referral for help.

For other noncritical risk factors there is no legal or ethical imperative on part of the researcher to react in any way, but the community wanted to use the interview as a means of identifying potentially needy youth and provide preventive mental health or social services. This brought a number of cultural disparity issues to the fore. For example, although the researchers' primary focus was on knowledge development, the community's primary focus service was on service enhancement.

To respond to both the required legal and optional community calls for action, the concluding questions of the interview triaged for services. Positive answers to questions about generic risk problems, child abuse, or suicidality were flagged. The interviewer then reminded the youth that the consent form said that if the youth revealed that he or she was in danger of being harmed the interviewer would discuss it and make sure that the youth got help. The interviewer repeated the youth's earlier responses and asked clarifying questions that would lead in the direction of either nonintervention or intervention. Based upon advice and training from the local protective services and human services agencies, referral to protective services was made only if the abuse had not yet been treated or taken care of by protective services. It was not brought to the attention of protective services, however, if the abusing individual had left the household or the state or was in jail. It was also not brought to the attention of protective services if further examination of the abuse incident, as often was the case, showed that it was simply a physical fight on school grounds with a peer instead of an in-family or adult-child issue. However, in both the hotlined and non-hotlined cases, the community wanted a report to be brought to the attention of the Human Services agencies for further follow-up to help the youth.

A similar series of triaging questions were asked for youth who mentioned any degree of suicidality. Once it was ascertained that the youth was suicidal at that time, immediate action was taken by having the youth call a 24-hour hotline. The interviewer stayed with the youth until a responsible individual whom the youth selected, such as a parent, guardian, or provider arrived. If the youth was not currently suicidal, the interviewer made sure that the youth contacted a provider and/ or a parent while they were still with the youth

Youth with noncritical problems were provided a list of available resources within the community and encouraged to review it and make appropriate calls. A surprisingly high percentage of the youth (90%) had a problem that required directing the youth to services. The provision of service information was at the specific request of the tribal Human Services Agency and of the tribal council who funds them. However, the sheer number of youth needing services was a severe challenge to the agency and the individual providers. In all cases where some intervention was discussed with the youth (which was only and always because the youth had revealed some problems), an incident report form was filed with the supervisor documenting the problems, the youth's responses to a discussion with the interviewer, and what action was taken or recommended.

Data on the Research Modifications

AIM-HI's data show that the compromises made in design did not adversely effect the research in the first wave of data collection or the researchers' ability to do iii64 STIFFMAN ET AL.

follow-up interviews (86% of the youth participated in a Wave Four interview 3 years later). The plan that allowed youth to "skip out" of interview sections was seldom implemented, so it did not compromise the data integrity at Wave One. Of the 6% of youth who opted to skip, half of them skipped only one section. About one third of the youth who did not "skip out" chose to use the computer to respond privately. Data collection recently ended for Wave Four. Future analyses will investigate whether the protective mechanisms implemented earlier were related to incomplete data at later interviews.

A final interview question about reactions to the interview proved extremely important to the continuation of the research project. The reservation area experienced four youth suicides in the first year of the study. A rumor began that these youths committed suicide because of the stress of the interview. The tribal council became concerned. However, analysis of the data showed that none of the youths who committed suicide had been AIM-HI participants, and further, participants who were suicidal were given referrals. Analysis of the final question revealed that the interviews were not stressful to participants. More then 85% of youth reported that the interview was "interesting" or "helpful", and only one youth reported it to be "upsetting."

CONCLUSIONS

The problems confronted in this study in bridging the research/cultural disparities gap will hopefully serve as potential thought-provoking examples for other researchers. The conflicts between research and cultural demands confronted by the researchers and interviewers in the American Indian community were not necessarily different from issues confronted by other researchers in other underserved minority communities. However, the pressure within these American Indian communities to provide services, and the concern about the sensitivity of the questions, were different, as was the history of exploitation and the cultural legacy of mistrust. These differences required creative balancing of cultural imperatives without compromising research integrity. Ultimately, this balancing accelerated the end goal of all research, to translate research into practice or action.

This study has several limitations that might reduce generalizability to other research projects and other cultures. The American Indian sample is limited to only two geographic areas, and the youth represent only one racial/ethnic culture. The actual problems and solutions might vary widely among other racial/ethnic groups, although research concerns may be quite similar.

What was learned in this process? First, cultural divides are difficult to bridge. One cannot expect to be able to drop one's own cultural patterns or thoroughly integrate those of others. What can be achieved is best outlined by social exchange theory. One can learn what others' perspectives and priorities are, and find creative compromises that are compatible with each participating party's priorities and provide benefits to each. There are no easy answers to balancing cultural and research perspectives. Continuous cross-cultural involvement is needed to minimize misunderstandings and disappointments. Researchers should share their experiences and try to assess the impact that culturally sensitive modifications make on research outcomes so that more effective modes of bridging cultural divides can be developed.

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