Cultural and Ethical Issues Concerning Research on American Indian Youth

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A study of American Indian youths illustrates competing pressures between research and ethics. A stakeholder–researcher team developed three plans to protect participants. The first allowed participants to skip potentially upsetting interview sections. The second called for participants flagged for abuse or suicidality to receive referrals, emergency 24-hr clinical backup, or both. The third, based on the community’s desire to promote service access, included giving participants a list of service resources. Interviewers gave referrals to participants flagged as having mild problems, and reported participants with serious problems to supervisors for clinical backup. Participants seldom chose to skip sections, so data integrity was not compromised. However, participants did have more problems than expected (e.g., 1 in 3 had thought about suicide, 1 in 5 had attempted suicide, and 1 in 4 reported abuse), so service agencies were not equipped to respond. Researchers must accept the competing pressures and find ethically appropriate compromises that will not undermine research integrity.

Keywords: adolescent research, ethics, consent, suicide, abuse

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Researchers must balance sensitivity to ethnicity and culture, ethical considerations, and research integrity. This article discusses these issues and uses a National Institute of Drug Abuse-funded study of American Indian youths to illustrate the basic dilemma in handling competing pressures between research demands and human participants or ethical demands. The difficulty lies in balancing two aims: (a) protecting child and adolescent research participants and their families from harm and (b) promoting opportunities for advancement of knowledge (Hoagwood, Jensen, & Fisher, 1996). For example, research requires the same responses each time from each person, and the design must avoid influencing the type of responses or interfering with the natural changes over time. The demands of ethics requires that the research never violate promises of confidentiality, do no harm in the interview, protect the person from harm, and protect anyone else from being harmed. However, there may be conflicts between these ethical demands (confidentiality and not ignoring someone in need) and research demands (not influencing responses or natural changes; King & Churchill, 2000). A critical question for all researchers involves how to handle ethical issues without destroying research integrity (Hoagwood, Jensen, & Leshner, 1997). In child research conducted with community-based samples in naturalistic settings, the ethics or research conflict may be exacerbated due to a number of factors, including the disparity of power between the adult researcher and the child participant, and the child’s potential inability to provide fully informed consent (Dorn, Susman, & Fletcher, 1995; Hoagwood et al., 1996; King & Churchill, 2000; Putnam, Liss, & Landsverk, 1996). Children’s vulnerability is greater than that of adults, because their lack of competence may lead to involuntary or nonvoluntary assent. In addition, the adult consenting may not necessarily have the child’s best interests at heart. In the case of institutionalized children or children who are in state custody, the legal consenting guardian may be far from the ideal protective caregiver. Research has an unfortunate history of abusing or exploiting children as research participants (Glantz, 1996). However, because research with children is critical, conducting such research in a manner that best demonstrates respect and caring for the children is imperative (Glantz, 1996; Koocher & Keith-Spiegel, 1990; Levine, 1995; Melton, 1992; Thompson, 1992). Researchers are bound legally and ethically to ensure that they place the welfare of participants first (Attkisson, Rosenblatt, & Hoagwood, 1996). There is no moral or ethical justification to conduct research that puts participants even at the most minimal risk without a counterbalancing of benefits (Osher & Telesford, 1996). There is little guidance in the research literature for resolving moral or ethical conflicts in research (King & Churchill, 2000). The major legal guidance for assuring appropriate protection is based on the ethical principles of the Belmont Report: respect for persons, confidentiality, and beneficence, and justice in distributing the benefits and burdens of research (The Belmont Report, 1979; Hoagwood et al., 1996; King & Churchill, 2000; Munir & Earls, 1992; National Institutes of Health [NIH], 1998).
Current literature on applied research ethics remains slim, (Blanck, Bellack, Rosnow, Rotheram-Borus, & Schooler, 1992; Hoagwood et al., 1996; Runyan, 2000). However, recommendations consistently include involving stakeholders and collaborators in research projects to avoid or resolve ethical issues (Attkisson et al., 1996). Sometimes stakeholder participation in research projects is limited to local institutional review board (IRB) reviews, although there may be more than one where there are multiple sites, agencies, populations of children, or institutions (Hoagwood et al., 1996). The literature on professional ethics in research also stresses fully informing and involving families in decisions, striving for cultural competence, and respecting the diversity and experiences of the family (Osher & Telesford, 1996). The language used in the research must be made accessible so that families are able to weigh the benefits and the disadvantages and decide, free of pressure, whether to participate (Putney & Gruskin, 2002).

Another potential conflict between research and participant protection occurs because the Child Abuse Prevention and Treatment Act states that professionals have the obligation to report suspected cases of child abuse or neglect (Kalichman, 1993; Myers, 1992). There is, however, considerable disagreement as to whether that regulation applies to researchers, or if certificates of confidentiality override mandated reporting statutes (Kotch, 2000; Steinberg, Pynoos, Goenjian, Sossanabadi, & Sherr, 1999). Mandated reporting statutes present a direct conflict between the duty to report and the research promise of confidentiality. Clear language informing of the necessity to breach confidentiality in this situation must be included within research materials and consent forms (Attkisson et al., 1996). Even children in child maltreatment research may provide new disclosures, identification of perpetrators, and additional information about their welfare (Putnam et al., 1996). Disclosure to authorities carries some consequences that may affect the youth: emotional distress, the risk of provoking further abuse for disclosing, intrusive investigations by the law enforcement officials, and separation from parents. An option is to encourage the youth, and possibly the family, to seek assistance and self-report the maltreatment. This is thought to empower the family to move forward in treatment, and assist the researcher to avoid violating confidentiality (Putnam et al., 1996). There is however, little data, anecdotal or empirical, about the effects, positive and negative of disclosure of maltreatment on the child or family (Singer, 1984).

The previously stated research, human participants, and ethics issues are even more poignant among American Indians (Marshall, 2001; Stubben, 2001). Unfortunately, they have a history of having been cheated by unscrupulous business and research arrangements. Goods or information have been taken from them while they received nothing in return (Doyle, 2001). Therefore, researchers, to obtain access to do research, must be trusted by the community. Part of that trust involves an understanding that the researcher sees the tribes’ and the tribal members’ best interests as primary (Beauvais, 1999; Norton & Manson, 1996; Weaver, 1997). The situation is further complicated because the physical areas of American Indian reservations constitute independent national entities for which tribal councils can
make their own laws. Nevertheless, they and all those on their lands are subject to the same laws that govern the rest of the United States.

The American Indian Multisector Help Inquiry (AIM-HI) Project is studying the needs and services of American Indian youth living in reservation or urban settings in a Southwestern state. We report the process of merging human participants concerns, issues of confidentiality, and research requirements with tribal and urban communal demands. We detail confidentiality issues when working within small close-knit communities, cultural sensitivity of standardized questions, and unique tribal requirements and reactions.

METHODS

This article is based on data and experiences from the AIM-HI, a NIDA-funded study of service use and drug-use information in two American Indian populations, one urban and one reservation-based. The representative samples are unique in that both are from a single, Southwestern state.

Sample

A sample of 401 youths (about 200 from each area) was interviewed in person in 2001. (They were followed yearly until 2004 to obtain ongoing information about service needs and use.) Youths, ages 12 to 19, were recruited through a two-stage method. First, a sample of 300 reservation-based and 300 urban-based youths was randomly selected from complete tribal enrollment and school district records, respectively. We used these lists to assure that the selection was representative of all the American Indian youths in both areas. Only one child per household was enrolled in the study.

Personnel from local American Indian educational and health services made the initial contact with the selected families to keep the records confidential. Tribal representatives notified tribal member families about AIM-HI, informed them of tribal support for the research, and encouraged their participation. Families were asked to return a fold-over, prestamped postcard signed by the youth and a guardian who either consented to or refused the research. Families who did not refuse were contacted directly for recruitment. Only six families or youths refused in each area.

In 2001, we contacted the randomly selected youths from each area and administered a brief interview tapping behavior and functioning: the Achenbach Youth Self Report (YSR; Achenbach, 1991), the child version of the Columbia Impairment Scale (CIS; Bird et al., 1993), and substance use questions from the Youth Risk Behavior survey (Centers for Disease Control [CDC], 1996, 1998).
Of the 300 youths in each area who participated in the brief interview, we randomly selected 150 in each area for the long interview. To enrich the sample with youths likely to need services, we added 50 youths who were not among the randomly selected 150 but who had scores at more than the borderline clinical cut point \((T > 63)\) for the YSR and greater than 15 for the CIS (Bird et al., 1993). This enriched the sample of youths in each area with an additional 50 youths most likely to need services.

**Interview Procedure**

Trained interviewers went to each youth’s home, explained the brief interview and the full study, obtained parent or guardian and youth consent (if not already signed), and administered the brief interview. Participants in the brief interview were offered a T-shirt with an AIM-HI logo designed by a local American Indian artist. If the youth met either random selection or high-need enrichment criteria, the interviewer then scheduled the long interview. Participants were paid an additional $25 for the long interview. Of those who completed the brief interview and were scheduled for the long interview, 2.7% refused or had a parent withdraw consent.

The interviewers were asked to sign confidentiality contracts and to decline to interview any child or family with whom they had personal contact. They then underwent training in physical abuse, suicidality, and stress reactions.

Prior to the interview, participants were given a consent form that specified that confidentiality would be broken if the youth indicated he or she or someone else might be in danger and that the youth would first be told that this was happening. IRB approval was obtained from the researchers’ university, the tribal council, and the urban school board. A certificate of confidentiality was also obtained from the NIH.

**Analyses**

All analyses were completed using SAS. Because the study deliberately enriched the sample with high-need participants after the random brief screening interview, the researchers weighted the data to reflect the percentages of disorders found in the general community sampled. To do this, two proportions were calculated based on the ratio of youths in the initial larger random sample \((n = 567)\) to those in the smaller oversampled high-need group \((n = 401)\): one for youths who met high-need criteria \((203/182)\) and one for those who did not meet high-need criteria \((364/219)\). This recreated a sample \(N\) equivalent to that in the original random sample and with the same balance of high-need youths. These weights were 1.7 for the youths who did not meet high-need oversampling criteria and 1.1 for the youths who did meet high-need criteria. The weights did not change the rates of the triggered items.
RESULTS

History of Planning
The AIM-HI Project was designed to research the service needs and service use of American Indian adolescents. As part of the original planning for this research, the researchers initiated a Research Implementation Team (RIT) composed of tribal elders, human service workers, council members, parents, and representative youths. Thus, the research process itself had a strong “consumer-driven” or stakeholder approach. The RIT directed the types of questions that they wanted included in the survey, as they were very aware of the problems in their community and anxious that information be obtained about particular problems. In many cases, the information they requested was much more sensitive than what the researchers originally planned. The initial RIT specifically requested detailed information about various kinds of physical and sexual abuse, HIV risk behaviors, and gay and lesbian activities, as well as the standard drug abuse and mental health issues. A mutually agreed-on research plan and associated instruments formed the basis of the research proposal sent to NIH. The RIT was involved in the development of the questionnaire. All of the questions were also piloted with groups of American Indian parents and youths in the respective areas.

Unfortunately, as is often the case, the lag time between the establishment of the RIT and the actual funding of the project was approximately 3 years. Although regular contact was maintained on a semiannual basis, the origin of the initial decisions had long faded from memory and commitment. When the researchers received funding notification, they informed all of the team members and thanked them for their help and support. Due to the time lag, new agency personnel, new members of the tribal council and new members of the urban parents group became involved with the questionnaire and began to raise many new concerns about the interview. They were not at all concerned with the questions usually mentioned in the human participants literature, such as abuse, neglect, suicidality, violence, or homicidality. However, they were very concerned that participants might become overwrought due to questions about parental problems, neighborhood violence, school violence, and life stressors. The new team members also expressed concerns about topics such as sexual behavior that had been initiated by the earlier RIT members. Finally, they were adamant about using the research contact as a service access point.

The research team repeatedly reassured the concerned members that they had never had youths experience stress reactions to the questions of concern and that usually youths enjoy the process of talking about themselves. However, the American Indian historically based distrust overwhelmed reassurances. Therefore, researchers and stakeholders compromised by incorporating three safety-valve plans into the interview. The first safety valve allowed for an easy opt-out of interview sections that the council members thought might be upsetting. A statement indicat-
ing that some people may wish to not answer these introduced these sections. The interviewer handed participants a paper copy of the questions with instructions to look it over before deciding whether they wanted to answer the section. If they did decide to answer the section, participants could respond on a computer, further masking their answers from the interviewers.

The second safety-valve plan addressed questions that required action, such as abuse or suicidality. Positive responses to questions triggered additional questions at the close of the interview. These questions led to referral for services, an abuse or neglect hotline report, or an emergency suicide intervention. The additional triggered questions and dialogue at the end of the interview reminded the participant of the earlier consent and explained the interviewer’s concern. The following actions were made available to interviewers: clarifying the youth’s risk level, telling the youth of any concerns, and telling the youth of the need to consult the supervisor (so as to not violate confidentiality without permission). In the case of abuse, the interviewer gave the youth the opportunity to disclose to a mandated reporter. For abuse and suicidality, the interviewer immediately informed the supervisor of any issues so that previously positioned clinical backup could be initiated. In both the urban and reservation areas, agencies had individual service providers on 24-hr call for the AIM-HI Project.

Our first concern in cases of child abuse was to protect the child from potential harm. We had to assure that the interviewer acted in a manner that was legally, ethically and morally upright. Of equal importance was protecting not only the child, but also the family and the tribe. Because of the extended family atmosphere in the tribal area on the reservation, breach of confidentiality could destroy the family, their reputation, their self-esteem, and their ability to live in physical proximity to the study. We grappled with a number of questions: Would reporting cause more harm than good? What was the severity and currency of the youth’s report of physical or sexual abuse? Was abuse likely to recur? Were we tapping into cultural or ethnic variations of discipline that would be interpreted as abuse only outside the community? Were relevant service providers and protective services already involved? Finally, if we reported, were services available?

The RIT and the researchers agreed on a plan to provide interviewers and field supervisors with extensive training in abuse reporting and to intimately involve protective services in the research protocol. The training acquainted interviewers with mandatory child abuse reporting laws and procedures for protecting themselves and the youth physically and legally. Training covered the potential consequences of acting as a mandated reporter. Training also dealt with interviewers’ concerns that reporting abuse might escalate it, that the foster situation in the community was inadequate, and that protective services had very strained resources with few services and a high caseload. Finally, training dealt with concerns that interviewers could place themselves in harm’s way, that the family would leave the study, or that the family might be harmed.
Reports of suicidality were critical for the RIT, as American Indian suicide rates are higher than rates in other communities (Office of Technology Assessment [OTA], 1990). In general, studies on U.S. youths have found that approximately 8% make an attempt at some time (although less than .1% succeed; CDC, 2004). Deaths due to suicide are 2 to 3 times more prevalent among American Indians aged 15–34 than among other ethnic groups (OTA, 1990), with suicide their second leading cause of death, and 23% making suicide attempts (Manson, Beals, Dick, & Duclos, 1989). Because American Indians have cultural prohibitions about revealing feelings, the RIT was concerned that if we overreacted, the child may deny feelings later, and thus get less, rather than more, help. However, it was clear that some action was required. If we ignored such situations, and a youth killed or harmed himself or herself, what value would any research contribution have as opposed to that unique life?

Concerns regarding suicidality included the danger of overreacting to nonlethal thoughts, violating confidentiality if parents or providers were brought in, and handling a crisis situation in the field so that an actively suicidal youth would not be left alone until help arrived. Positive responses to any of the suicidal questions triggered a set of additional questions at the end of the interview. The interviewers asked whether the suicidal feelings were current, whether there was access to lethal means, whether the youth was already involved in treatment, and whether a treatment provider or parent were involved with the youth. In the case of actively suicidal feelings, the interviewer stayed with the youth until a parent or provider was brought in. In each case, the interviewer first explained the necessity for breaking confidentiality based on their concerns for the youth (no youth objected). For both abuse and suicidality, incident reports for the supervisor were developed for each youth. These reports documented the flags, the youth’s response, and the interviewer’s actions.

A third safety-valve plan was instituted in response to the American Indian community’s desire to use the research as an entry point to services for any youth with problems. The historical research position has always been to not react to any responses in a structured interview (Ventura, Liberman, Green, Shaner, & Mintz, 1998). Interviewers have historically been trained that listening without reacting was itself helpful, and to not go beyond that. They are typically told that, if they did more, they might change the mental health and behavior of the respondent and compromise the goals of an epidemiological naturalistic study. However, there is real danger that not acting might place a child in future danger, or leave a child feeling hurt and unheard. Based on this consideration, and the desire of the community to use the research for enhancing services access, a plan was implemented to intervene in such a way as to avoid influencing any of participants’ future actions as much as possible. All participants were given lists of local services and hotline numbers so they could help themselves. In addition, for youths flagged as having mild problems, interviewers intervened more proactively by suggesting the youths
consult with a teacher, physician, social services provider, and so on, and encouraging them to get help from specific agencies on the service list. In the case of a participant with serious mental health or addiction problems, the supervisor was notified and clinical backup was initiated on behalf of the youth.

Results of Flagging System

The safety-valve plan that allowed participants to skip out of interview sections was seldom implemented, so it did not compromise the data integrity. Despite being given the choice to skip out of several different sections of the interview presumed by the RIT to be stressful, most did not skip any sections at all (94%). An additional 3% skipped only one, and 3% skipped two or more sections. Further, the results from a reaction question at the end of the interview helped reassure the local stakeholders, as greater than 85% of participants reported that the interview was interesting or helpful, and only one youth (.3%) reported that it was upsetting.

In other research conducted by the authors, very few teens self-reported abuse, so we expected rates of self-report to be low in this interview, despite the known higher rates for American Indians (Wallace, Calhoun, Powell, O’Neil, & James, 1996). For example, an unpublished 1995 survey of adolescents by the Native American Health Center in the same Southwestern area found 18% were physically abused and 12% were sexually abused. However, almost immediately on initiating the interviews, we began confronting reports of abuse. Some of the abuse perpetrators had worked with us in developing the research, which created additional problems. More than one-quarter of the participants answered questions in a way that triggered a flag for abuse. Of those, approximately a fifth had already been involved with protective services for the latest incident of abuse; 7% agreed to an immediate call (with the interviewer present) to protective services; but 25%, when asked to clarify the incident, described an incident that was clearly not reportable abuse. (Typically, that involved some kind of bullying or being picked on in the playground.) For almost half of participants reporting abuse, the last occurrence was more than a year previous, with about a quarter of those having been 10 or more years previous. One in five abused youths informed us that they had already received help for their abuse situation, and many of them were in a new family situation, with the abuser having left the home or been imprisoned.

Suicidality reports were also very high. A third of the youths reported feelings of suicidality, with about one in three having thought about it and one in five having attempted suicide. This was 2 to 3 times higher than in the authors’ other research (Stiffman, 1989; Stiffman & Cunningham, 1990), but consonant with the known high needs of the American Indian community (Wallace et al., 1996). A 1995 survey of adolescents by the Native American Health Center in the area found 20% had attempted suicide, and 10% wanted “to kill themselves.”
On further questioning after being flagged for suicidality, only 14% of the “suicidal” participants reported being suicidal currently. Only a few of those who were currently suicidal agreed to call someone for help (15%). None agreed to call a parent or a doctor, but some agreed to call a local agency or hotline. Almost 90% of the participants who were currently suicidal and refused to make a call, did make a verbal promise to the interviewer that they would not attempt suicide before AIM-HI arranged for help. In these cases, a report was given to the supervisor, who informed the 24-hr AIM-HI clinical backup at the local agency. In these cases, the interviewer stayed with the participant until a parent or provider came.

The question of reactions to the interview proved extremely important in relation to suicidality. In the year of the first interviews, the reservation area experienced four youth suicides. A rumor began that these youths were led to commit suicide by the stress of the interviews. The tribal council became concerned. It was extremely important for the future of our study that we had data proving that none of the suicides were AIM-HI participants, that suicidal participants got help, and that the interviews did not stress participants.

In all, 90% of participants had at least one kind of trigger raised that required directing the youth to services. This constituted an expensive burden to the interviewers, who had to discuss these issues with the youth and help recommend him or her to services. In each case, the interviewer first obtained the agreement of the participant to break confidentiality based on their concerns for the youth. Although the tribal council and the urban school system requested the flagging and service access system, problems occurred in providing services. In the reservation area, the tribal council mandated that these incident reports be turned over to Human Services. Human Services providers were supposed to screen these reports and provide services. This provision of services was at the specific request of Human Services and the tribal council, which funds them. However, the actual implementation was crippled by provider actions. Some providers felt that they could not offer services, even if the youth were in danger, without prior parental permission. They did not consider the research consent form to be adequate, although their agency representatives had shaped it. One of the providers breached confidentiality by revealing to a parent the presence and source of an incident report. The parent responded with a telephoned death threat to the research supervisor, who was also a tribal member, and to the interviewer.

CONCLUSIONS

We have presented the issues confronted by a single research project in illustration of more general ethical dilemmas that confront most field research projects. The problems we confronted and our solutions, or lack of them, will hopefully fill a needed gap in the research literature and serve as potential thought-provoking guides for other researchers.
We attempted to conduct our research on American Indian adolescents without neglecting the need to provide services to abused youths, suicidal youths, and those with more generic mental health and environmental problems. This process had a number of potential pitfalls in terms of maintaining research integrity, maintaining youth confidentiality, and upholding research obligations to the cooperating community. Because participants had more problems than initially expected, and the service agencies that asked for referrals were not equipped to follow through, additional levels of concern rose to the fore.

This individual research program has several limitations that might reduce generalizability to other research projects. Our American Indian sample is unique, it is limited to only two geographic areas, its services are limited, and the youth represent only one minority culture. The actual problems and solutions might vary widely with other groups, but we believe that the issues would largely be similar.

The conflicts between research and ethical demands confronted by the researchers and interviewers in the American Indian community were not necessarily different from issues confronted by other researchers in other communities. However, the pressure within the American Indian community to provide services and the concern about the sensitivity of the questions were different. This required creative balancing of the human participants and ethical issues in responding to need for services without compromising research integrity. The fact that such a high percentage of the participants responded positively to questions that required some kind of services put an additional strain on the project. Nevertheless, the researchers’ concern with protecting the integrity of the research was balanced against a general sense of satisfaction that the interviews did result in bringing a number of youths with problems to the attention of service providers. Also, all participants were exposed to the principle of beneficence in that they were provided a list of medical, psychiatric, or community health resources.

Of major import is the recognition that there are no easy answers to ethical issues within research. No matter the decision of the researcher, potential pitfalls remain for both the youthful participant and for the research project. Stakeholder involvement, supervisor attention, expert consultation, and provider availability are all needed to minimize dangers. Researchers must accept that they have to live with competing pressures as they find the most ethically appropriate actions that will not undermine their research integrity. Open communication by researchers through more articles and discussions concerning their internal ethical decisions and actions would help advance the state of the field.

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