



# Conducting Program Evaluation with Hispanics in Rural Settings: Ethical Issues and Evaluation Challenges

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## ABSTRACT

Conducting evaluations that are both valid and ethical is imperative for the support and sustainability of programs that address underserved and vulnerable populations. A key component is to have evaluators who are knowledgeable about relevant cultural issues and sensitive to population needs. Hispanics in rural settings are vulnerable for many reasons but especially because of language issues, differences in cultural beliefs and socioeconomic barriers. Additional factors, such as cultural proclivity to be deferential to authority figures and the possibility of having an undocumented alien status also are important issues for Hispanics living and working in rural communities. Because migrant farm workers comprise a large part of Hispanics living in rural areas, attention to the sensitive issues surrounding this population is paramount during program evaluations. This paper highlights ethical issues pertinent to program evaluations involving Hispanics residing in rural settings.

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## BACKGROUND

Providing health programs for underserved populations, such as Hispanics living in rural areas, is an emerging public health priority. Because Hispanics are considered vulnerable to exploitation,<sup>1</sup> the need to conduct valid and ethical evaluations is paramount to the support and sustainability of programs directed at this population. Program evaluation is “a collection of methods, skills and sensitivities necessary to determine whether a human service is needed and likely to be used, whether the service is sufficiently intensive to meet the unmet needs identified, whether the service is offered as planned, and whether the service actually does help people in need at a reasonable cost without unacceptable

side effects.”<sup>2(p.2)</sup> Accordingly, evaluators are responsible for ensuring that ethical issues specific to vulnerable populations are assessed and that the highest ethical standards are applied throughout the evaluation process. This paper discusses some of the leading ethical challenges that program evaluators face when carrying out their work with Hispanics in rural communities, including issues with informed consent, literacy and language barriers, cultural beliefs, migrant status, alien or undocumented status, and advocacy and evaluation roles.

## HISPANICS IN RURAL SETTINGS

Hispanics account for 25% of the population growth in nonmetropolitan areas.<sup>3</sup>

About half of U.S. Hispanics have settled in rural areas that are commonly dominated by non-Hispanic whites.<sup>3</sup> According to the U.S. Department of Agriculture,<sup>4</sup> about 34% of Hispanics are foreign-born, 53% have a high school education, 43% work in agriculture,

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construction, or manufacturing, and 26% live at the poverty level. The largest ethnic group to reside in rural areas is comprised of Mexicans, most of whom are migrant farmworkers.<sup>4</sup> Included in this group of farmworkers are 11.1 million undocumented migrants.<sup>5</sup> The majority of migrant workers arrive from economically depressed areas of Mexico in search of job opportunities or a higher quality of life.<sup>3,6</sup> Many have little formal education<sup>3</sup> and rate low in both English and Spanish literacy.<sup>6,7</sup> These factors limit employment opportunities, and therefore, result in less desirable or high-risk jobs such as working with hazardous chemicals or those with increased injury exposure.<sup>8</sup>

### VULNERABILITY TO EXPLOITATION IN PROGRAM EVALUATION

In general, Hispanics are considered a vulnerable population because of language barriers, socioeconomic barriers, education differences, documentation status and different cultural belief systems.<sup>6,9,10</sup> This generalization notwithstanding, Hispanics residing in rural settings are at an even greater disadvantage than urban Hispanics because of the increased likelihood of their lacking access to care, having undocumented alien status and being at enhanced risk for occupational exploitation.<sup>1,4,7,11,12</sup>

### ETHICAL CONSIDERATIONS

Phoenix<sup>13</sup> questioned whether current human protection programs were sufficient to protect the poorly educated, those with low social economic status and members of ethnic minority groups. The most common concerns included: (1) comprehension of the informed consent process with ethnic minorities with low or no English literacy, and (2) payment or remuneration that is not coercive. Although these points are valid ones to consider in program evaluations involving rural communities, there may be many other issues related to their vulnerability.

Whereas the examples that follow focus principally on Mexican migrant farmworkers, the ethical issues apply to most other vulnerable populations. However, the cultural issues strongly embedded with Mexican

farmworkers and other Hispanic migrants make these ethical issues especially relevant to these groups. The most notable issues involve trust, informed consent, literacy and language barriers, cultural-related issues, the migrant nature of many rural Hispanics, the role conflict of advocacy versus evaluation, and other evaluation concerns.

#### Trust

A fundamental value among Hispanics is trust (*confianza*).<sup>14,15</sup> An evaluator who is not indigenous to the culture might encounter resistance from program recipients if trust is not established prior to the evaluation.<sup>9,14</sup> This concern of trust may be explained, in part, by documentation status, the task of obtaining personal health information (especially from someone outside of the family), cultural deviance (i.e., behaviors that are against social norms or risky behaviors), and poverty.<sup>10</sup>

The use of gatekeepers, people who can provide access to a community, is one mechanism for establishing trust.<sup>6,7,16</sup> An evaluator holds the responsibility of ensuring that trust is maintained; thus, he or she must consider the risks that evaluation tasks may impose on work, immigration, or respect to the individual, family, or culture.

At times, the process to ensure trust among program recipients may interfere with the evaluation timeline or resources available for the evaluation. Nonetheless, it is an essential evaluation component to be undertaken. If trust is neglected, the fate or validity of the evaluation and participation in future evaluations by this population may be compromised. For instance, one of the end products of program evaluation is a written report. Forgoing culturally sensitive reporting of findings increases the risk of stigmatization of participants and their community. This lack of sensitivity not only harms the participants, but also discredits gatekeepers diminishing future opportunities for evaluation.

#### Informed Consent, Language and Literacy

Another ethical issue is that the informed consent process, including documentation

of consent, may not be well understood in a population with low literacy or with language barriers. The informed consent process is a means to inform program recipients of the purpose of the evaluation with some discussion of the evaluation process, risk, benefits and options. *"Informed consent is the process of communication between the researcher and the participant in which all information that could affect willingness to participate is made clear and agreement to participate is obtained. Written consent is the evidence that this communication process has been accomplished."*<sup>17</sup> Some authorities<sup>1</sup> argue whether "informed consent" is possible given its current structure in a population where limited English proficiency and low literacy are prevalent. Today's consent forms have morphed into complex and multiple-page documents containing medical and legal jargon that McDermott and Sarvela<sup>18(p. 48)</sup> state "might challenge even the most educated and literate of patients." Despite translation to Spanish or having an interpreter present, the content of the consent form, or the informed consent process, may still be misunderstood due to regional differences in the Spanish language (i.e., meaning variations of a particular word), cultural differences, or Spanish illiteracy.<sup>1</sup> Thus, evaluators must undertake all measures (e.g., pilot testing,<sup>18</sup> Brislin's seven-step translation process,<sup>19</sup> or use of health literacy tools from nationally accredited institutes) to ensure individuals understand the evaluation, including their options and measures to protect them from harm. Understanding the population's value and belief systems will further support these efforts, increasing the possibility of an informed decision.

Another ethical issue in the informed consent process is protection of participants' confidentiality. Most research institutions, hospitals, governmental agencies and other institutions mandate a signed consent form. At times, individuals are asked to provide identifiers such as phone numbers or social security numbers. This process may increase the participants' risk of being exposed by chance or as mandated by law. Furthermore, a signature may be interpreted as a binding



commitment to the study, which may lead to low accrual or anxiety among program recipients.<sup>1</sup> Moreover, there may be an inherent pressure to provide this information in fear of being identified as a person with questionable documentation to reside in the country; an ethical issue largely unique to Hispanics residing in rural U.S. settings. When working with a vulnerable population, evaluators may choose to waive the informed consent to protect individuals' identities. However, this choice can be risky as evaluators have no documentation that risks, benefits and options were explained in case adverse events occur.

### *Other Culture Issues*

According to Newman and Brown:<sup>20</sup> (p. 149) "Participants in more authoritarian cultures may be accustomed to acquiescing to requests for information coming from supposed official representatives. They may fear recriminations if they do not participate [in research or program evaluation]." Cooper et al.<sup>1</sup> noted this observation in their review of studies involving migrant farmworkers. In one study, a 100% participation rate was obtained. Further investigation demonstrated that the topic under investigation pertained to the participants' working environment. Consequently, participants felt an inherent pressure to be in the study because of a real or perceived threat to their job security. Similar reactions may also occur in different settings when a person of higher social class or an authority figure (e.g., physician, researcher wearing a white coat or smock, or another authoritative figure) requests participation in a study.

Another prevalent issue pertains to access to health care and low-income status. Rural settings are known to have limited resources for health care<sup>3</sup> and lack many of the most-needed services, such as low-cost health care or psychosocial support in their native language.<sup>6,21,22</sup> Hispanics in this setting are at significant disadvantage due to the lack of culturally-competent care, their low awareness of and access to services, or lack of insurance because of improper documentation status or limited job opportunities in settings that provide health insurance.<sup>3,15</sup> In

the face of limited resources, a solicitation to participate in a study may be misunderstood as a valuable opportunity to receive medical care.<sup>1</sup> Participation also may be driven by program recipients' economic state such as remuneration to meet economic needs. For instance, if monetary remuneration is purposely or unintentionally set high, it may unwillingly compel a low-income person to participate to meet a financial need. Consideration of these ongoing issues must be acknowledged in the program evaluation plan to ensure program participants are not coerced unwittingly.

### *Migrant Nature of Hispanics in Rural Settings*

Although Kandel and Cromartie<sup>3</sup> report an increased settlement in rural areas of the country, the high mobility of the population, especially among farmworkers, is still prevalent.<sup>6,11</sup> Applying a follow-up component to evaluation becomes challenging in a population with no permanent address or contact information. Furthermore, in certain situations, collecting contact information is not always feasible or recommended, as previously noted. Thus, evaluators may have to choose a less sophisticated evaluation design to ensure completion of data as set by stakeholders.<sup>2</sup>

### *Advocate versus Evaluator*

Another ethical issue encountered by evaluators is role conflict: evaluator versus advocate. For instance, programs offered to Hispanics in rural settings often are funded only temporarily or with other limitations. A stakeholder may request that an evaluation take place to encourage further funding.<sup>9</sup> However, evaluation findings may not support the stakeholder's intent.<sup>2</sup> Thus, the evaluator faces an ethical dilemma in choosing the evaluator role (e.g., reporting actual findings) versus the advocate role (e.g., promoting the strengths of a program and the needs being served). This decision is particularly important in settings where limited options are available. As an illustration, if a number of people do not have the economic or other resource means to obtain follow-up care upon the discovery of possible disease or injury (e.g., a suspi-

cious lump identified during a free mammography screening), it would be unethical to discontinue the only local program that provides this follow-up care at no cost to low-income individuals<sup>23</sup> because quotas outlined in the program objectives (i.e., provide care to 1,000 men and women) are not met. Discontinuing programs valued by the community may cause more harm than good and may discredit future evaluators. This consequence must be considered because beneficence and non-maleficence are vital and well-established components of research ethics.

### *Other Ethical Issues in Program Evaluation*

Other ethical issues common to program evaluations apply in the context of Hispanics residing in rural settings as well. These issues include the question of the external evaluator versus the internal evaluator, and participants' reactivity and the effect it has on the validity of the evaluation.<sup>2</sup> The debate of internal versus external evaluator revolves around issue bias, validity of results and cost (i.e., outside consulting versus using a staff member). The use of an internal evaluator may be criticized as being biased because he or she is highly vested in the program's performance.<sup>18</sup> Yet, this approach can increase the validity of the data due to a deeper understanding of the program and population dynamics<sup>2</sup> as well as program context.<sup>18</sup> Furthermore, program recipients may be more inclined to participate because the important element of trust is likely to have been established. Gaining an insider perspective of issues that affect programs with underserved Hispanics and trust are more challenging for an outsider evaluator. Nonetheless, outsider evaluators may identify issues or recommendations from an unbiased or dispassionate perspective, thereby introducing a perspective that can assist in improving program efforts.

Another ethical issue to consider is *reactivity*, e.g., when a participant responds or acts differently because of awareness of the researcher or the investigative setting. Several common examples of reactivity exist – i.e., researcher or observer effect, the



Hawthorne Effect, the John Henry Effect, social desirability response bias, and others.<sup>18</sup> If reactivity is not controlled, it can affect the validity of the evaluation. A partial solution to this concern is to establish trust, as noted previously. Participants may view the evaluator as a threat; and thus, feel intimidated to respond and express their views freely. Or, as discussed earlier, participants may not understand the question due to issues of literacy. Cultural differences may also affect the validity of response.<sup>1</sup> Whereas participants may think they comprehend what is being asked, they are inferring a different meaning; not that intended by the evaluator. One mechanism to resolve this misunderstanding is through thorough pilot testing of questions with program recipients.<sup>18</sup>

### AN EXAMPLE OF A STRATEGY TO ADDRESS ETHICAL CHALLENGES

A program currently operating in the Tampa Bay (Florida) Area is Catholic Charities' Catholic Mobile Medical Service (CMMS). It serves as a prime illustration of the need for sensitivity and cultural competence during program evaluation. Approximately 50% of CMMS's population served is comprised of migrants living in rural Hillsborough County (the large geographically and demographically diverse county that includes Tampa). Its patient population includes individuals with low literacy (Spanish and/or English), mixed documentation status, low income, and who are economically challenged. A previous evaluation conducted by the program staff revealed transportation deficits and cost of care as the major barriers to health services. The director of this program also reports that program participants do not seek health services, even when illness occurs, because of fear of losing their employment. For future evaluations with program participants, some considerations that should be undertaken to reduce participant burden and exploitation may include: (1) scheduling data collection in the evening or on the weekend at a convenient location; (2) discussing with the program director the goal for the evaluation and suggesting an evaluation that highlights

their assets and ways to improve their services; (3) sharing all translated data collection forms and the informed consents forms with program staff to assess comprehension; (4) discussing with the program director acceptable remuneration that is not coercive; (5) finding times to pilot test all data collection forms; and (6) considering the use of a trusted staff member to assist with data collection and participant recruitment.

### CONCLUSIONS

Evaluations of health-related programs can impact their eventual fate and outcomes. Most importantly, they can have a direct effect on the people the program serves. Given that Hispanics living in rural settings have certain vulnerabilities for exploitation; evaluators must strive for the highest ethical standards in all phases of program measurement and evaluation. Attention to the sensitive issues and cultural nuances that surround this population will support these efforts.

The discussion presented herein has the following implications for evaluation of health-related programs:

- A skilled evaluator with experience and training in cultural competence with Hispanics, especially those living in rural settings, is necessary for an ethical and efficacious evaluation.<sup>2</sup>
- Employing a skilled individual who is well-versed in program evaluation, including its technical capabilities and interpersonal and communication skills, should be a priority.
- Evaluators should confirm if remuneration is justified, especially with low-income communities. What an evaluator may think is a small or modest payment may actually be the compelling factor for participation.<sup>1</sup>
- The evaluator shares responsibility for gaining and maintaining the trust of the community and important gatekeepers. For example, in an evaluation of citrus worker health issues, Luque et al.<sup>7</sup> noted their disclosure to farmworkers during the evaluation to reassure them that they did not work for the citrus companies, and that neither community health workers nor other workers would

be penalized if they refused to participate in the project.

- Evaluators should always strive to use an informed consent process when possible. Situations may arise when a signed informed consent is not feasible. Moreover, recording a person's name may not be necessary. Finding creative ways to collect an informed consent form while protecting an individual's identity may be a viable option, such as using identifiers that only the participant would recognize.<sup>2</sup>

- Informed consent forms and all evaluation instruments should be linguistically and culturally relevant. Use of pilot-testing is a good means to confirm accuracy of language and meaning on forms. Some evaluators<sup>18</sup> argue for deliberate "cultural tailoring"<sup>24</sup> of questions or use of an extension of back-translation known as "decentering"<sup>25</sup> to assure relevance. Other avenues include using health literacy tools from nationally accredited institutes to improve readability of consent forms.

- Always strive to reduce participant burden – for example, providing evaluations at times when participants are at the program location or go to their homes. Evaluators must be cognizant of making evaluations convenient and allowing the flexibility to work around the participant's schedule.

- In reporting evaluation findings, consider the impact and ethical implication this reporting will have on the participants and programs. Even if evaluation findings conclude that a program is ineffective in some of its intended effects, it may have other values and attributes needed by participants.

Whereas this paper attempted to summarize the unique ethical issues with Hispanics residing in rural settings, the review was limited to literature mostly involving migrants or farmworkers. A comprehensive list of ethical guidelines for use by program evaluators working with ethnic minorities, specifically in rural settings, may be warranted. There is also a need to develop strategies to ensure that program recipients are well informed and understand the informed consent process and evaluation procedures. Finally, the sensitive nature of this population highlights the importance



of cultural competence training for evaluation staff.

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