

## CHAPTER 9

*Ethical Issues in Research  
With Immigrants and Refugees*

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**ETHICAL ISSUES IN  
RESEARCH WITH  
IMMIGRANTS AND REFUGEES**

As is the case with much of social science, research on immigrants and refugees is not morally neutral. Immigration policies are hotly debated in our society. Supporters of immigration argue that immigrants benefit the country but may need special programs to assist them in their adjustment, whereas opponents suggest that immigrants drain resources that could be spent on other national priorities. Ethical issues are also involved in refugee admissions policies that may cause great suffering for those whose asylum claims may be denied, forcing them to return to their native country. Research on the experience and adaptation of immigrants and refugees is used to argue both sides of this debate, as illustrated in several articles in the journal *International Migration Review* (Abernethy, 1996; Carens, 1996; Gibney, 1996; Southeast Asian Resource Action Center [SEARAC], 2003) that considered the pros and cons of immigration policies. The uses of this research place great responsibility on the researchers who study these populations, as the findings of their studies may be

used to inform policies that have great impact on the lives of many people.

At the same time, defining ethical responsibilities for the researcher is complex when working with vulnerable populations and diverse cultures with distinctive and sometimes conflicting definitions of what is ethical. As a result, researchers confront ethical dilemmas that cannot be easily resolved with guidance from existing ethical principles and guidelines. The first type of ethical dilemmas may arise when researchers try to balance attention to humanitarian concerns with scientific rigor, such as when studying experiences of refugees in the midst of humanitarian crises (Leaning, 2001). Jacobsen and Landau (2003) describe the “dual imperative” faced by researchers who must balance their concerns about reducing suffering with their professional responsibility to produce research that meets the highest scientific standards. In order to address humanitarian concerns in such situations, researchers may compromise the research design and methodology. On the other hand, although ethical considerations must guide the research process, if studies make compromises with respect to the research design, findings will ultimately not be interpretable or useful to

the groups being studied. For example, studies that do not employ control groups in order to provide treatment to all who need it or omit important questions from questionnaires out of concern for the respondents' reactions may fail to yield valid data, and the research effort will have been in vain. As Jacobsen & Landau (2003) suggest, ensuring scientific rigor in research on vulnerable populations is an ethical responsibility of the researchers because of the importance of the issues and the need for valid data that can inform intervention efforts.

The second type of ethical dilemmas in research with refugees and immigrants involves balancing potential differences in the ways *ethical* behavior is defined by the culture of the researcher and the research community versus the culture of the research participants. There are situations when cultural norms with respect to what is ethical may be contradictory, making *ethical* behavior, as defined by one culture, unethical in the other, and vice versa. Existing ethical guidelines do not provide sufficient guidance to help the researcher determine how to reconcile such conflicting perspectives.

The complexity of these dilemmas means that researchers studying refugee and immigrant populations must develop a sophisticated understanding of the underlying issues so that they can negotiate creative solutions to resolve them. The purpose of this chapter is to highlight the problems and complexities in acting ethically while conducting research with immigrants and refugees and to offer some suggestions for solutions to such dilemmas. Throughout, the chapter illustrates the points made with examples from the author's experience with research in immigrant and refugee communities from the Soviet Union and Vietnam.

The chapter is organized as follows: First, a description of who are refugees and immigrants is offered to highlight the distinctive characteristics and needs of these populations

relative to other groups, such as ethnic minorities. Second, the chapter will outline ethical considerations and challenges that arise in conducting research with these groups. Inclusion of immigrants and refugees in research is highlighted as one critical ethical issue, and challenges faced by researchers who try to include these groups are discussed. Further, challenges involving ethical treatment of participants in research conducted across cultures are described. The chapter concludes with the suggestion that inclusion of cultural insiders on research teams is necessary to ensure that researchers act ethically. It is argued that because of the complexity of ethical considerations that arise in research with immigrant and refugee groups, broad ethical guidelines will never be sufficient to help resolve ethical dilemmas that arise in the course of research with culturally diverse and politically vulnerable populations. Rather, inclusion of cultural insiders on research teams can help create processes that can ensure discussion and negotiation of research approaches that result in ethical research.

#### WHO ARE THE IMMIGRANTS IN THE UNITED STATES?

*Immigrant* is a term used to describe foreign nationals who enter a country for purposes of permanent resettlement. In the United States, there are three broad categories of immigrants: (1) voluntary migrants who come to join relatives already settled in the United States or to fill particular jobs for which expertise may be lacking among U.S. nationals, (2) refugees and asylum seekers who enter the country to avoid persecution, and (3) and undocumented immigrants who enter the country illegally. It is currently thought that since the 1970s, the United States has been experiencing the largest migration wave in its history. Approximately

1 million immigrants enter the country for permanent resettlement each year, about 700,000 of them legally and an estimated 200,000 to 300,000 without legal documents, mostly from Mexico.

Among the legal immigrants, approximately 50,000 to 100,000 annually are refugees. The United Nations Convention Relating to the Status of Refugees (1951) defines *refugee* as a person who “owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion, is outside the country of his nationality, and is unable to or, owing to such fear, is unwilling to avail himself of the protection of that country” (United Nations High Commissioner for Refugees, 1951, Article 2). Unlike refugees, immigrants are seen as continuing to receive the protection of their government were they to return home; however, refugees flee because of the threat of persecution and cannot return safely to their homes. The distinction between refugees and immigrants can be vague and tied to United States foreign policy. Some groups, including refugees from Somalia, Vietnam, and Jews and Evangelical Christians from the former Soviet Union, qualify for refugee status in the United States “based on their membership in a protected category with a credible, but not necessarily individual, fear of persecution” (United States Department of State, 2002).

Refugees, immigrants, and undocumented immigrants confront unique challenges in resettlement that have implications for conducting ethical research. For example, undocumented immigrants may fear being identified and may thus shy away from participation in research studies, particularly if research might lead to their identification by authorities. Refugees who have been granted asylum, on the other hand, do have the benefits of legal status and protection, but may *feel* vulnerable, based on their prior experiences (Yu & Lieu, 1986).

One of the main features of the current migration wave is its diversity. Unlike prior waves in U.S. history, the vast majority of current arrivals are not European. Mexicans continue to represent the largest immigrant group entering the United States. With the fall of Saigon in 1975, a large influx of Vietnamese refugees began to arrive, soon joined by migrations from Cambodia and Laos. Other countries from which immigrants came to the United States in large numbers since the 1970s include the Philippines, China, Taiwan, Korea, as well as other countries throughout Asia and Latin America. Current immigrant and refugee arrivals represent a diverse group, coming from more countries than ever before, with larger populations, such as Mexican, and small groups, such as the Hmong, continuing to enter the country. In addition, relatives of refugees who had arrived in the late 20th century continue to come to United States for permanent resettlement.

Several aspects of the diversity of immigrant groups are worth noting. First, immigrant and refugee experiences may overlap, but are not synonymous with experiences of ethnic and racial minorities. For example, on entering the United States, immigrants from East Asia and Africa experience themselves as racial minorities in their new country. On the other hand, some immigrants from Europe who may have been ethnic minorities in their countries of origin, such as Jews or Irish, on entering the United States experience themselves as “White” and have the possibility of blending in with the majority. Thus although all immigrants may experience difficulties with discrimination, acculturation, and maintaining ties to their culture of origin, immigrants who are also racial minorities in the United States may experience additional discrimination and prejudice. On the other hand, White immigrants share many aspects of experience with non-White groups, yet may be overlooked amidst

concerns about addressing issues of minority groups.

Second, some of the immigrants have formed large ethnic enclaves whereas others have not. Some are members of groups that have large representation across different geographical locations in the United States, such as Mexican Americans who comprise the largest immigrant population across the United States and in many local communities. Other smaller groups have ethnic concentrations in specific regions, such as Polish immigrants in Chicago or Cuban immigrants in Miami. These immigrants have the option of settling within ethnic enclaves that maintain some infrastructure, including cultural institutions, events, agencies, and programs in the native language. This infrastructure provides opportunities to interact with others from similar backgrounds. On the other hand, other groups are relatively small, and even when small ethnic enclaves exist, they do not provide the types of resources that larger communities can sustain, such as native language television and radio programming, newspapers, or ethnic health service providers. The implication of these differences is that research with larger populations within ethnically concentrated communities confronts different issues than research with the smaller populations. Although public attention and often funding focuses on such larger groups, it is the smaller groups that may require greater resources in the context of fewer available experts who can address these issues.

Third, in addition to the complexity mentioned above, the current migration flow is continually changing, with new countries becoming sources of migration. This makes it difficult to anticipate the needs and characteristics of potential new migration waves and places researchers interested in these groups in the position of constantly confronting new languages, cultures, and circumstances. It is well known that, historically,

immigrants from Europe have been a progressively smaller proportion of immigrants, declining from over 90% in the decade between 1901 and 1910 to about 15% in the years between 1991 and 2000 (U.S. Citizenship and Immigration Services [USCIS], 2003); in the last few years, European migration decreased from 16.5% of all immigrants in 2001 to 14.3% in 2003 (USCIS, 2003). At the same time, migration from a variety of countries in Africa has been on the rise in recent years, increasing from 5% in 2001 to almost 7% of all immigrants in 2003. With refugee admissions in particular, countries of origin of migrants change depending on political situations throughout the world, with time-limited migration waves resulting from wars in Southeast Asia, the Balkans, and Africa. This dynamic quality of the migration flow means that it is difficult to anticipate the needs of the newly arrived groups, and resources are rarely available to assist with resettlement and guide research with newly arrived refugee populations.

Finally, refugee and immigrant groups are characterized by tremendous diversity within ethnic groups. There are differences with respect to socioeconomic status, religion, and political views. As illustrated in the next section, some immigrant populations have varied ethnic subgroups within them, marking important differences in backgrounds, reasons for migration, and hopes for life in the United States. Further, acculturation differences between those who arrived in earlier waves and newer arrivals can create important differences in attitudes, values, lifestyles, and (indeed) perceptions of ethical issues in research.

### *Immigrants From the Soviet Union and Vietnam in the United States*

Consider the case of Vietnamese and former Soviet émigrés, whose diversity and

complexity illustrate the points made above. Both groups entered the United States largely as refugees fleeing communist countries. The migration of both groups has spanned the decades from the 1970s to today, and both groups are extremely diverse with respect to length of residence in the United States, socioeconomic status, ethnicity, religion, and status as refugee or immigrant.

*Soviet migration.* With respect to migration from the Soviet Union, approximately 700,000 have come to the United States for permanent resettlement since the early 1970s (USCIS, 2003), with approximately 550,000 having entered the country with refugee status. Former Soviet émigrés are diverse in a variety of ways. The U.S. government granted refugee status to ethnic Jews who were seen as seeking freedom from discrimination in the former Soviet Union. In the United States, some former Soviet Jews have integrated into the American Jewish community and have adopted religious practices that they were not able to engage in within the atheist Soviet state. The majority, however, are predominantly secular, and many have not become active members of American Jewish communities (Gold, 1992; Markus & Schwartz, 1984; Simon & Simon, 1982a, 1982b). In addition to Jews, some Evangelical Christians fleeing antireligious policies of the Soviet Union were also granted refugee status by the United States. Although the majority of Jews are urban and highly educated, Evangelical Christians are more likely to have less formal education and come from more rural areas. Since the breakup of the Soviet Union in 1991, an additional influx of approximately 150,000 has entered the United States holding immigrant visas. Although some of these immigrants are ethnic Jews, most are from the dominant ethnic groups of the former Soviet republics and include Russians, Ukrainians, Armenians, and others.

*Vietnamese migration.* The Vietnamese migration to the United States also began in the 1970s, with over 1 million arriving since the fall of Saigon in 1975 (SEARAC, 2003; USCIS, 2003). Many fled their home country involuntarily due to war and may have spent months or years residing in camps without any idea of where they would resettle (Rumbaut, 1991); however, in later years, with improvement of relations with Vietnam, an increasing number have come for reunification with family members living in the United States. Thus, current migrants are increasingly entering with immigrant rather than refugee status. Vietnamese refugees and immigrants also differ in the ways they left their country. Some fled on boats, spending long years in refugee camps in Thailand and the Philippines. More recently, others have been able to take direct flights to the United States. Although some suffered severe trauma and persecution, such as former South Vietnamese military officers who may have spent years in communist “reeducation camps,” others were born into a country increasingly open and friendly to the United States.

As with the former Soviets, improvements in relations between the United States and Vietnam over the years have made it possible for some to come with immigrant rather than refugee status, further differentiating those who were resettled within the United States refugee resettlement program and those who arrived without such support. As with former Soviets, there are also important ethnic and religious distinctions among the Vietnamese. A large portion of the migrants are ethnic Chinese who were living in Vietnam but had maintained a distinctive language and culture. Many ethnic Chinese have assimilated into “Chinatowns” in the United States and have had a resettlement experience quite distinctive from other Vietnamese émigrés. Further, a large subset of the Vietnamese immigrants and refugees

are Catholics, whereas others are Buddhists. Finally, the Vietnamese migration has also been economically diverse, ranging from rural migrants with low educational levels to others such as former military officers who are well educated.

*Diversity and ethical issues.* This kind of complexity and diversity in today's migration wave is important to understand when considering ethical issues in research with these groups. The experience of immigrants and refugees may or may not overlap with that of ethnic minority groups and require particular attention. For example, many Vietnamese refugees have lived through experiences different from those of Asian Americans, such as war-related trauma, postwar communist repression, and traumatic experiences during flight from Vietnam. At the same time, they share some experiences with Asian Americans in the United States, particularly as they relate to discrimination as members of a racial minority group. Former Soviets, on the other hand, are White and, it would seem, have the opportunity to assimilate easily. Yet they experience problems in adaptation and acculturation, including discrimination (Birman & Trickett, 2001a), that suggest a similarity to issues faced by non-White immigrants. Because of this diversity and the marginality of refugee and immigrant groups, it is particularly important to articulate ethical considerations with these populations in their own right.

#### **INCLUSION OF IMMIGRANTS AND REFUGEES IN RESEARCH**

One of the implications of the diversity of immigrant groups is that they are often not included as participants in research; however, including diverse refugee and immigrant groups in research samples is an ethical issue. Without studies that include these populations,

policy remains uninformed about their experiences and the effectiveness of medical and psychological interventions unknown. For example, it is National Institutes of Health (NIH) policy that all grant applications explain the extent to which they are including women, children, and minorities in their research. This requirement was precipitated by recognition that historically, much of medical and mental health treatment efficacy research included only adult White males, with little known about whether these treatments would be effective with minorities, women, and children (Hohmann & Parron, 1996; U.S. Department of Health and Human Services, 2001).

Similar dangers exist with respect to diverse migrant groups. Failing to routinely include refugees and immigrants in research samples runs the risk of perpetuating health care services that may be ineffective or harmful to these groups. As pointed out above, some of the migrant groups are subsumed within the classification of ethnic and racial minorities in the United States, but many are not. In addition, the experiences of recent immigrants and refugees are distinct from those of U.S.-born minorities. In the absence of policies advocating for specific inclusion of refugee and immigrant groups in research samples, it is likely that we will continue to know little about these populations and run the risk of imposing policies and interventions developed for other populations on them without attention to their particular circumstances and needs; however, it can be extremely challenging to identify and include these groups in research projects.

#### *Challenges of Identifying Refugee and Immigrant Populations*

Researchers can confront many difficulties trying to identify members of particular refugee or immigrant populations within a local community in order to develop an



appropriate sampling frame. In most communities, there is an absence of specific data in many agency records that can be used to reliably identify populations of interest and select representative samples. For example, although statistics are kept on legal admissions to the United States, after immigrants and refugees are resettled, most institutions do not track immigrant status as a relevant demographic descriptor. Schools, for example, are not permitted to ask about immigrant status, making it difficult even to estimate the numbers of refugees versus immigrants attending schools in a particular district. Although data on racial/Hispanic make up of a school's students is readily available on most school Web sites, other information may only be obtained at the district or state level. Even then, only proxy variables, such as the language spoken in the child's home or the country of birth are available to deduce information on specifics of the immigrant or refugee background of the students. Refugees born in refugee camps outside their country of origin, or speaking languages that are common to several countries, are particularly difficult to identify through such data. For members of specific ethnic subgroups or African tribes, only information on country of birth or last residence may be available. Further, it is impossible from such information to distinguish immigrants from refugees arriving from the same country. Thus it may be impossible to identify members of particular ethnic groups or separate out students who come from war torn areas, and who may suffer from traumatic stress symptoms, from those whose parents came as economic immigrants and who do not need such services.

### *Sample Size*

In the social sciences, the incentive structure for publishing in mainstream journals

makes it important to collect relatively large and homogeneous samples in empirical work. In this context, variability with respect to culture is perceived as "noise" that makes it difficult to draw causal inferences from the data. Studies that include multiple ethnic subgroups must have sufficient participants in every cell to be able to conduct analyses that account for ethnocultural differences; however, the realities of most research projects prohibit such a focus and lead researchers either to concentrate on a single (generally larger) migrant group or to ignore specific cultural variation and use a broader category, such as Latino or Black to describe them. To reduce variability, studies either concentrate on collecting data from majority groups or oversample a preselected number of minority groups in order to gather enough of a sample size. As a result, populations that represent relatively small subgroups in the society either are not included in the majority of studies or are absorbed by larger categories. For example, Caribbean Blacks are grouped with African Americans, or European, first-generation immigrants are grouped with Anglo-Americans, although the phenomenology of their lives with respect to the research questions of interest may be quite distinct.

### *Public Health Interest*

A related issue is that research funding mechanisms encourage an emphasis on populations of public health interest. Such interest is understandably focused on larger groups within the country. Although this is a worthy goal, it may inadvertently discourage research efforts with less prevalent groups that may also experience a great many difficulties and have few resources. This perspective reinforces the unintended biases of such policies as those of NIH mentioned above to limit the inclusion of immigrants and refugees in research samples.

### *Within-Group Diversity*

Another consideration for researchers who are specifically interested in the migration experience is that the wide diversity within these migrant groups makes it difficult to even delimit the population of interest and thus determine sampling frames. We have struggled with this in our research with immigrants and refugees from among former Soviet and Vietnamese samples.

*Case 1: Soviet refugees.* With former Soviets, our sampling frame and definition of the population of interest has differed from study to study. In one research project for example, we were interested in how adolescents from the former Soviet Union were adapting to schools. The term *Russian* is frequently used to describe these adolescents by school administrators, resettlement organizations, and others, without always acknowledging that it may be inappropriate, given that many are ethnic Jews (and thus not considered Russian in the former Soviet Union) and others may be ethnic Ukrainians, Georgians, Byelorussian, and others; however, because all are Russian speaking and culturally Russian, this is the term used to designate them in the United States. The only way the county school system could identify these students was to give us a list of students whose native language was listed as Russian in the records (Birman, Trickett, & Buchanan, 2005). Our resulting sample was diverse; approximately 50% had arrived as refugees and 50% as immigrants. Further, approximately 50% (and 80% of those arriving with refugee status) identified themselves as Jews, but the rest did not. Consider the dilemma then of how to compare our findings with other studies with “this” population (however that is defined) in other locations. Would it be appropriate, for example, to compare our data with those of samples that are predominantly Jewish, or had refugee

status? If the composition of the Russian population is different on multiple dimensions in every community, how can our data, or data collected in any community, be generalized to other communities?

In a study in a different community, our sample of Russian students attending a public high school was approximately 80% Jewish, with 100% of the respondents having reported arriving as refugees (Birman & Trickett, 2001a; Birman, Trickett, & Vinokurov, 2002). In a third study (Birman & Trickett, 2001b; Trickett, Birman, & Persky, 2004), we purposely sampled only those who arrived with refugee status, because the goal of the study was to understand the resettlement experiences of refugees, and the funding for the study came from the state refugee resettlement office. Consider the difficulty, however, in determining what population(s) these three different studies generalize to. It is no wonder many researchers overlook such complexity and settle for studies of groups that are easier to define!

*Case 2: Vietnamese refugees.* Similar issues emerged with Vietnamese refugees (Birman, Trickett, & Persky, 2003). This study was also conducted with funding from the refugee resettlement office, and thus we concentrated on those who arrived as refugees, not immigrants; however, because of difficulties in accessing the community, we used a snowball method that initially targeted a Vietnamese Catholic church, a location where many gathered and it was easier to spread the word. We were conscious of the fact that our data might be biased toward Vietnamese Catholics, a segment of the Vietnamese population who often tend to come from higher socioeconomic strata. Further, although we asked respondents on questionnaires to indicate whether they were ethnic Chinese, we found that almost no respondents answered yes to that question,



although we knew that this is an important subsection of the Vietnamese community. We were not certain whether this bias in the sampling resulted from our overreliance on the Vietnamese church (ethnic Chinese are less likely to be Catholic), particular networks of our data collectors, or specific characteristics of the Maryland Vietnamese community. As was the case for other researchers of Vietnamese refugees elsewhere (Yu & Lieu, 1986), we could locate no data on the composition of the community with respect to these variables, making it impossible for us to assess the representativeness of our sample. Thus we have had to acknowledge that our sample is not pure and that any generalizations to Vietnamese refugees that we might draw from our study need to be made with all of these caveats.

### *Inclusion of Refugees and Immigrants in Research: Lessons Learned*

As researchers, we are trained to ask whether our samples are representative of the population we are studying. In the two examples offered, however, the question becomes how we even define our population of interest. Is our population of interest refugees, immigrants, or all émigrés from Soviet Union and Vietnam resettled; and are we interested in those resettled in Maryland, the entire United States, or the northeastern region of the country? Even if we can determine the boundaries of our population of interest, no statistics are available to allow us to confirm whether or not our samples fit the particular population profile. These types of problems plague most studies of refugee and immigrant groups that most often draw samples of convenience. Yet few published reports of such studies acknowledge the possible limitations of their sampling methods, leading readers to draw implications and inappropriately generalize to the entire ethnic

group rather than a subgroup that the study represents. The ethics of this are treacherous, particularly when research is used to inform policy.

Although some may argue that this set of considerations makes it practically impossible to include diverse refugee and immigrant samples in research, ethically we cannot turn away from the challenge of doing so. By pretending that ethnic Chinese from Vietnam are not an important subgroup of Asian Americans, for example, we do not take away the variability associated with their experience; it's still there and may be an important factor in our research findings. By removing them from such samples in order to simplify the research design, we may be acting unethically by excluding them from research and making their lived experience invisible.

Our experience suggests that the sampling strategy must be determined by the research questions being asked. In one case, the purpose of our study (Trickett et al., 2004) was to document the adaptation of refugees resettled by the Maryland state resettlement services, and we were specifically interested in those with that legal status because they made use of specialized services and the research project was in part designed to evaluate the impact of these services; however, our findings from this study cannot be used to generalize to the population of émigrés from the former Soviet Union, a broader and more diverse population. On the other hand, if we were interested in the ways in which immigrants and refugees from the former Soviet Union and Vietnam come together to form ethnic communities that transcend these legal distinctions, we would have needed a different sampling frame. This was our approach in studying adaptation of all Russian-speaking students in Montgomery County Schools, regardless of their legal status or whether or not they identified as Jews (Birman et al., 2005).

An ethical approach to research is to insist on including the diversity of immigrant and refugee populations in research and to include questions about the variety of within-group variations in the research protocol. Researchers need to define and describe the specific population of interest and the ways in which their sampling strategies are intended to capture its particular segments. Most important, researchers bear an ethical responsibility to clearly outline the limitations of their sampling strategy and caution others against generalizing inappropriately to other segments of the refugee or immigrant group. In this way, others can learn about these populations and appreciate the limitations of the findings.

#### **ETHICAL TREATMENT OF RESEARCH PARTICIPANTS IN RESEARCH ACROSS CULTURES**

When research projects are conducted across cultures, researchers need to tailor ethical guidelines for the responsible conduct of research to the ways in which ethical issues are viewed by the culture of the community being studied. Cultures different from that of the investigator may have different perceptions of what issues constitute ethical dilemmas. Lack of familiarity with participant cultures poses particular challenges with respect to assessing research risk/benefits, procedures to obtain informed consent, determining appropriate incentives in research and avoiding coercion, and maintaining confidentiality.

#### ***Challenges in Determining What Is Ethical***

Different cultures may have ethical codes that may be in direct contradiction to those of the culture of the researchers. For example, in many countries worldwide,

terminally ill patients are not told the truth about their medical condition, and doctors only reveal the seriousness of their health status to the family. This is done because of cultural assumptions that dying people would not want to know about their condition and that knowing may actually harm them by making them more likely to give in to depression, which can in turn worsen their health outcome (Levin & Sprung, 2003). On the other hand, in the individualistically oriented United States, the reverse is true. Doctors feel it is their duty to tell the truth to the patient, yet they are judicious about releasing information to others, even family members, unless the patient gives consent. Thus, if immigrants were involved in a research project, revealing to research participants that they have a terminal illness may be perceived as a right in one culture and an ethical violation in another.

When conducting research across cultures, most ethical guidelines (e.g. Tapp, Kelman, Triandis, Writsman, & Coelho, 1974) expect the researcher to act ethically according to the norms of both cultures involved. As illustrated in the example above, however, it may not be possible to honor both the culture of the researcher and the culture of the research participants. Our current ethical codes do not help us resolve such dilemmas. Researchers may feel that the only option to act ethically for them is to decide not to do the study. This, however, creates ethical dilemmas in their own right and can lead to exclusion of vulnerable populations from research.

#### ***Participant Rights***

Barry (1988, cited in Davidson, 1999) described a particularly challenging situation while attempting to conduct studies of HIV infection in Tanzania. The problems arose as a result of the Tanzanian government's insistence that blood samples drawn for other

purposes be used for research without the informed consent of the women who were to be tested and that donors not be informed of the blood test results. These research practices were deemed by the researchers to be in violation of the rights of donors and of regulations for research with human participants within the researchers' culture. Thus, the study did not proceed.

As Barry (cited in Davidson, 1999) points out, however, the ethical problems were not eliminated by the researchers' decision that the study should not proceed. "On the contrary, the researchers' insistence that the host culture apply ethical standards as stringent as those applied to research carried out within the developed country had the same public health outcomes that were associated with anonymous serum sampling and nondisclosure" (Barry, 1988, p. 1085, cited in Davidson, 1999). Specifically, there was no health promotion or medical treatment of persons testing HIV positive that could have resulted from conducting this research project. Further, the women who had HIV would have been no worse off had the research been conducted; they would not have been harmed by the study, and with or without the study, they would not learn about their HIV status. Negotiation of a long-term research and education plan might have contributed to prevention of HIV in the country, and collaboration with the Tanzanian government may have, over time, led to the researchers convincing them to follow Western-style research procedures. Thus ethical research practices involve attempting to negotiate a reasonable solution before deciding not to conduct the research project at all.

### *Informed Consent Procedures*

Informed consent is a complex process when administered by researchers from one culture to research participants from another. The intent of informed consent procedures is

to fully disclose to research participants all relevant aspects of the research study. The benefit of this process is to educate the research participants that laws and regulations govern the research process, holding the researchers accountable. On the other hand, some informed consent procedures can be so cumbersome that they may make it nearly impossible to engage refugees and immigrants as research participants.

*Benefits of informed consent procedures.* Informed consent procedures conducted by research teams can help educate the communities they study and prevent unethical practices. In our experience, some of the organizations that refugees encounter do not follow the kinds of ethical standards that university researchers are bound by. Thus, refugees may have had experiences that lead them to distrust researchers, questionnaires, and any assurances of confidentiality. Our research team was once contacted by someone who had participated in one of our research projects and had thus spoken to us about issues of informed consent. She was calling because she was concerned that her elderly relative was being asked to complete questionnaires on personal matters as part of a special recreational program at a social service agency; however, there was no explanation or consent form for the survey provided, and the surveys were not anonymous. Her experience participating in our research project led her to question procedures of this organization and raise awareness among others in the community about research ethics. Thus, carefully conducted informed consent procedures can have benefits beyond assuring the rights of participants in a particular research project.

*Challenges resulting from informed consent procedures.* In practice, however, informed consent procedures can also discourage members of communities from participating in

research projects for a variety of reasons. The need to sign informed consent forms takes away the possibility of anonymous participation and may create great fears about loss of confidentiality. Further, the increasingly stringent expectations about complexity of consent forms on the part of university internal review boards may inadvertently create as many problems as they solve. Informed consent forms often resemble the kinds of small-print, lengthy, and legal-sounding documents and statements that consumers are frequently asked to sign in our society. They can leave the reader confused and worried that by signing, they may be giving up their rights to object or withdraw. Studies have shown that research participants perceive the informed consent process as intended to protect the researcher rather than the participant (Howard-Jones, 1982). Moreover, complex and legalistic consent forms can prove nearly impossible to translate into multiple languages, particularly for immigrants and refugees who have low levels of literacy in their own language.

For example, Yu & Lieu (1986) described great difficulties in obtaining signed informed consent from Vietnamese refugees whom they were surveying, even when they were perfectly willing to participate in the study. The prospective participants' fears stemmed from their perceptions of the threat of communism, as they believed that Vietnamese communist spies may come after them after learning that they willingly signed such a document. Subsequent to obtaining informed consent, these researchers report that one refugee discontinued the interview and asked for the form back so that she could destroy it, and another had 3 sleepless nights following the interview, fearing possible repercussions that might result from signing the form.

*Informed consent: Lessons learned.* In our research, we've learned that the informed

consent process needs to be an important part of the research project, requiring budgeting of sufficient time and resources. Informed consent procedures need to be carefully crafted and may sometimes require extensive discussions with the research participants who may have no context within which to understand the purposes or process of research. We have tried to take an informal approach and explain our research in nontechnical ways, to the extent possible. These procedures have been extremely labor-intensive and time-consuming but have yielded excellent response rates.

For example, in our studies with Vietnamese and former Soviet émigrés, we sent out a letter, in English and in Russian/Vietnamese, to explain the reasons for the project. In this letter, we carefully explained our personal and professional interests in the project, revealing to research participants that some of us on the research team are ourselves from immigrant/refugee backgrounds and have a personal investment in collecting information on the migration experience. Bilingual and bicultural research assistants followed up the letter with a phone call and arranged for a time to meet with the prospective participants in their homes. The informed consent process was then explained during this meeting. Our explanations included describing the reason for the stringent rules and need for signatures and the professional sanctions that exist for the investigators if confidentiality is breached or approved procedures are violated.

It is interesting to note that in one case a woman who had refused to participate called the university IRB coordinator to explain that she did not want to participate in the study. Our sense was that she was checking to see if our project was legitimate. We were delighted that she did so because she learned that indeed, the phone numbers on the consent form did lead her to a high-level administrator in the university whose job it was to

hold us accountable. We hoped that she would share her experiences with others in the community and that this would help us earn the community's trust.

In general, we've come to view participants challenging the informed consent procedures or refusing to participate as opportunities to learn about their concerns and improve our procedures. In the former Soviet community, for example, on several occasions participants who had been contacted by mail or phone called me to complain about the study and expressed strong feelings that we had no right to ask that their children be taken out of class to complete questionnaires. They did not trust that we were acting independently of the state agencies that fund refugee services.

In these situations, we've insisted on assuring them that they had every right not to participate, but when possible we also provided extensive explanations of our project and mailed a blank questionnaire to ask for their feedback. In other cases, we've contacted those who refused to participate, not to persuade them to change their minds but to ask them to help us understand why. These conversations have been extremely instructive, and we've adapted our procedures based on this feedback. In almost every case, we've found that people we contacted were extremely appreciative of being asked about their opinions and input, and in several instances these conversations ended in offers to help us recruit more participants for the study. These conversations have also served as a reminder of the importance of allowing the time and space in our interaction with potential research participants to explore their reservations and concerns and reassure them about our procedures. Thus, there is a need for researchers to treat informed consent as a critical process in its own right. The informed consent process needs to be a dialogue that can reassure the participants and provide opportunities for the

research team to learn about and address participant concerns unanticipated by the research protocol.

### *Defining Incentives and Coercion in Culturally Diverse Situations*

Another particularly complicated issue in research with immigrants and refugees involves cultural differences in determining what may constitute coercion. These issues require particular attention when, as is most often the case, power differentials exist between the researchers and the research participants. For example, when the research participants are undocumented aliens, they may want to avoid participation in research projects but may also not fully trust that they are free to decline participation. Refugees who are being held in refugee camps constitute a particularly vulnerable group, as their rights are substantially restricted, and to some extent they are a "captive" population. Thus, what constitutes voluntary participation in research projects, particularly when they are sponsored by powerful organizations, is not always clear (Fisher et al., 2002). In our own work with Vietnamese and former Soviet refugees, we have had several instances of differences with the communities with respect to what constitutes coercion. Two specific examples are offered below.

*Case 1: Involvement of religious community leaders.* In our research with the Vietnamese community, we collaborated with Mr. Nguyen (a fictitious name), a master's level psychologist of Vietnamese background, to identify the sample, translate and adapt measures, structure and coordinate data collection, and supervise the bilingual/bicultural research assistants who collected the data. We felt that he was an ideal choice because he had extensive training in psychology, firsthand knowledge and understanding of the Vietnamese language and culture, and was a

leader commanding respect from the local community. We had discussed at length various procedures, including informed consent and ethical practices in conducting the study, and, in retrospect, we assumed that because of his master's level training in psychology and experience conducting his own research project for that degree, Mr. Nguyen's understanding of ethical concerns would be similar to ours. We were surprised to learn, however, that his perception of what was coercive differed from our more American or Western views.

We were planning to set up data collection in a Vietnamese church when Mr. Nguyen called us with what he thought was great news, that the priest was happy to help us with our project and was willing to describe and endorse this project during the services. In addition, Mr. Nguyen was particularly pleased that the priest was going to recommend that the \$15 stipend that our research project was giving families in return for their participation be donated by the families to the church. Mr. Nguyen thought this was a great idea. He had been concerned in the past that many families were uncomfortable taking the money in return for participation, but he thought that this was a very palatable option for them. There would be no embarrassment involved in accepting the money, and they would feel that it would be a great honor to be able to do this for their church. Our own ethnocentric reaction was one of surprise that Mr. Nguyen, despite his level of training in psychology and some experience with research, did not perceive this procedure as unethical.

Mr. Nguyen was, in turn, surprised to learn that our perception of this arrangement was that it would be coercive and unethical. Our concern was that parishioners would feel that the priest's endorsement of the project meant that he expected them to become involved; and the suggestion to donate to the church the money that we were giving them for their

participation seemed to take away their rights for reimbursement in return for their participation. After some discussions, Mr. Nguyen immediately assured us that he would ask the priest not to speak to the congregation at all, and we continued with a more limited snowball data collection procedure.

Although we considered negotiating with the priest some other noncoercive process that would take advantage of his endorsement of our project, we were also humbled by our realization that we were outsiders to the church and community and would have little control over, or firsthand knowledge of, what actually would take place in the church. Because our lack of language facility made it impossible for us to participate in this process, because we were sure that other misunderstandings may take place, and because we were conducting the project from out of state, we decided not to risk colluding in potentially unethical behavior and chose a different participant recruitment strategy altogether. Under different circumstances, however, and with more time and resources, we might have considered working out an alternative process with the priest.

*Case 2: Involvement of community organizations.* The second situation occurred within the former Soviet immigrant community. Mrs. Katz (not her real name), a woman active in the community, agreed to help us with collecting data from former Soviet elderly. Mrs. Katz lived in a subsidized housing building with many other former Soviet elderly. She invited us to the party room in her building where she said that she would gather the Russian-speaking elderly. The incentive for research participation was \$10 a person, which is a substantial sum of money for the refugee elderly, most of whom live on Supplemental Security Income (SSI). Thus, when she told us that she could gather as many as 50 people one evening, we were not surprised and collected the questionnaire



data. Subsequently, we received a call from someone else in the Russian community who had heard that an elderly woman was very upset because she was denied the opportunity to participate in a research study and earn \$10. On further investigation, it turned out that Mrs. Katz was the president of a community association in her building. We also learned that Mrs. Katz charged a membership fee of \$7 to belong to her association. Apparently, she made the announcement in her building about the research project and said that this would be an opportunity for the participants to earn \$10; however, only association members would be allowed to participate. Those who were not association members had to join the association but could use part of the money from the \$10 research incentive to join at the time of the data collection. The woman who had complained did not want to join the association and was denied the opportunity to participate in our research project.

We were horrified to learn of this and proceeded to make every attempt to rectify the situation. We called Mrs. Katz and had a long discussion with her about the problem that she had created for us. Our efforts to protect the confidentiality of the research participants created a further problem because we did not have a list of names and contact information of those who participated. Although we obtained signed consent forms that we could use to decipher the participant names, we had promised them that their participation was confidential, and contacting them after the data collection, we thought, would ruin that trust. Mrs. Katz promised to call everyone who joined the association that evening (she told us there were very few) and offer to return the association fees. She also contacted the two people to whom she had denied the opportunity to participate, and we were able to include them in the study.

Although we felt confident that Mrs. Katz had acted unethically according to our

standards (and were upset that she had not been truthful with us), from her perspective she took the opportunity to do something positive for her community: Create an association that would serve as an advocate for the members and garner resources on their behalf. Here, we learned the importance of extensive discussion about ethics with community organizations who help us in the research process. In retrospect, we had jumped on the opportunity to collect a large amount of data too quickly, and we should have looked into Mrs. Katz's background with others in the community who would have probably alerted us to the existence of her community organization.

### *Confidentiality*

Issues of confidentiality can also pose difficulties in conducting research with immigrants and refugees. First, some communities are small, and members of the research team need to guard against inadvertently revealing information that they became privy to as a result of the study (Fisher et al., 2002). Having members of the community collect data can, in fact, be problematic because respondents may feel that fellow immigrants will not honor their promises of confidentiality. In Russian culture, for example, the word *privacy* doesn't exist, and many are unlikely to believe that professional ethics will truly prevent a researcher from gossiping. This is why it is a helpful strategy to explain to former Soviet émigrés that sanctions exist against the researcher when confidentiality is violated. Some researchers (e.g. Jacobsen & Landau, 2003) suggest that, to guard against this, research assistants collecting data must be proficient in the language of the refugees, but not from the same culture or community.

On the other hand, relationships within the ethnic community can be a great asset in the research. Ironically, it was through community gossip networks that we learned about

the ethical violation involving data collection using Mrs. Katz. In our experience, working with an ethnic community over a long period of time provides multiple opportunities to demonstrate to others that we will not reveal information that was provided to us by participants as part of the data collection. Thus, in the long term, trust can be earned.

*Case 1: Receipts for research compensation.* Even when it is possible to develop an excellent reputation and community trust, other obstacles can emerge. In our study with former Soviets, we reimbursed families for their participation. The simplest process to do this was to pay cash for participation; checks would take some time to cut, and we did not want to risk the possibility that they would arrive late or not at all, which would violate the participants' trust; however, in return for the cash, the university required not only signed receipts from participants but also their Social Security numbers. Research participants were extremely uncomfortable with this process and felt that it completely undermined our assurances of confidentiality. They were concerned that because the study was being funded by the state office of refugee resettlement, we were interested in tracking private information about them by using their Social Security number. Former Soviet émigrés have good reason not to trust bureaucratic procedures, and we took their concerns seriously. In the end, we were able to convince the university to reconsider the rule, and they waved the Social Security number requirement. Nonetheless, this experience again reminded us of how much care needs to be taken to assure and protect confidentiality in these situations.

### ***Ethical Treatment of Research Participants: Lessons Learned***

It is perhaps an understatement that conducting research with people from different

cultures, with different norms and definitions of ethical behavior, different experiences with research, and lack of trust of government organizations that fund research is tremendously challenging. The importance of ensuring protection of participant rights, guarding confidentiality, avoiding coercion, and creating extensive informed consent procedures cannot be overstated. These activities are labor-intensive and costly procedures and require a constant willingness to learn about and resolve unanticipated barriers and concerns. They must also be informed by a true understanding of the culture and community of the participants. The processes that are required to assure ethical treatment of research participants from diverse immigrant and refugee groups are in many ways identical to those required to successfully recruit these participants into research. Many have noted (e.g. Miranda, Azocar, Organista, Muñoz, & Lieberman, 1996) that minorities and immigrants are often reluctant to participate in research projects. We have viewed the process of ensuring that we engage in ethical research practices and the process of recruiting research participants as one and the same. The most important strategy in this process involves working with cultural insiders on the research team to ensure that understanding of the community and the culture informs the ways in which these aspects of the study are designed and implemented. This is the most important lesson learned, and the subject of the next section.

### **INCLUSION OF CULTURAL INSIDERS ON RESEARCH TEAMS**

The ethical dilemmas described above arise out of cultural differences and power differentials between the investigators and research participants. The Tapp Report (Tapp et al., 1974), a landmark attempt to provide guidelines for ethical conduct of cross-cultural

research, was developed by cross-cultural psychologists, primarily from the United States, but with extensive input from international colleagues and involvement of the American Psychological Association, the International Association for Cross-Cultural Psychology, and other organizations. Although it has been criticized more recently (Davidson, 1999) for being overly idealistic, the report represents the most comprehensive effort to date to provide ethical guidance to psychologists working in cross cultural situations. The advisory principles outlined in the report are directly relevant to research with immigrants and refugees.

The report outlines principles of responsibility within three broad areas: (a) to individuals and communities studied; (b) to collaborators and colleagues in the host community, and (c) to the scientific community to ensure scientific standards. The first and third sets of principles are echoed in the discussion above, as they involve the importance of attending to ethical treatment of research participants, maintaining scientific rigor in research design, and reporting of research findings with candor. The second area mentioned by the Tapp Report, however, is the focus of the remainder of this chapter and concerns the ways in which researchers must involve cultural insiders, or collaborators, from the host community in the research process.

The underlying assumption of the Tapp Report is that cross-cultural research can be conducted ethically *only when done in collaboration and partnership with members of the cultural communities being studied*. Thus, it is not enough for the investigator to develop cultural sensitivity and knowledge about the group of interest. Rather, ethical research cannot be conducted across cultures without involvement of members of the community being studied. In this vein, the Tapp Report suggests that involvement of members of the community on the research

team must be collegial and is most effective when the ethnic collaborators are professional peers to the principle investigator and thus also highly trained researchers. The Tapp Report cautions about the potential for exploitive relationships and goes even further to suggest that investigators are responsible for ensuring that involvement in the research project must be professionally beneficial for the cultural collaborators.

The notion that it is important to include members of the community being studied is generally accepted by most researchers and not new (Fisher et al., 2002); however, on closer inspection, the need to include cultural insiders on research teams raises several questions that have not yet been sufficiently explored in our field, particularly with respect to immigrant and refugee groups. The first question is who is qualified to be a true cultural insider and represent an immigrant community on the research team; the second is in what capacity does this cultural insider need to join the team.

I have conducted the research program on émigrés from the former Soviet Union described above as a cultural insider, having come to the United States as a Soviet Jewish refugee; however, I was an outsider to the Vietnamese community. My perspective on insiders and outsiders on research teams is shaped by these experiences. Seeing firsthand the relative advantages I had as a cultural insider, I have become convinced of the importance of seeking out ways to involve cultural insiders, to the extent possible, in the research enterprise.

### *Defining Cultural Insiders*

I use the term *cultural insiders* to refer to persons who have knowledge of the language and familiarity with the culture of a particular group through their membership in that group. Although insiders in general have shared lived experience with persons whose

lives they study (Bartunek, Foster-Fishman, & Keys, 1996; Bartunek & Louis, 1996; Chaitin, 2003; Griffith, 1998; Staples, 2000), *cultural* insiders have the additional advantage over outsiders because they have facility with the language and culture that allows them access to the cultural community, which can be extremely difficult to gain even by sensitive and knowledgeable outsiders.

*Partial insiders.* To some extent, a true cultural insider is an abstraction. The prior discussion of the complexity of defining the refugee and immigrant group may raise the question of whether it is possible to be a cultural insider at all. Social class, extent of acculturation, and religious and other differences can make people who are seemingly united by language and culture only *partial* insiders to each other's world in some situations (Griffith, 1998). In my case, for example, although I speak Russian and am familiar with Russian culture, I came as a Jewish refugee and may be perceived as an outsider by non-Jews. Many have written about the extent to which anyone is both an insider and an outsider when working within any community (Chaitin, 2003; Griffith, 1998). On the other hand, in immigrant and refugee communities, native knowledge of the language and culture creates a different degree and level of access than that available to sensitive and caring outsiders.

*The insider identity.* In the research context, the definition of who constitutes an insider rests on the extent to which the researcher identifies with the culture or community being studied. With a sense of identity, insiders experience the findings of the research as reflecting on them directly. Even in situations when members of my research team were only partial insiders in the former Soviet community, doors to participants' homes and community organizations were opened to us

when we were able to explain to them the ways the research touched on our lives personally. Further, not only did they understand that our study was designed to learn about *their* perspectives, but they also trusted that we had enough understanding of their experience to know what questions to ask to uncover the issues that concerned them the most. Most important, the participants understood that the bicultural members of the research team identified with the émigré community they were studying. As a result, the ways in which our study would portray members of the community would reflect on those of us on the research team who were Russian as well.

*The cultural insider continuum.* We have also found that it is useful to think of cultural insiders along a continuum. No one person can represent the entire community, as there are differences in perspectives and experiences within any community. Thus it is necessary to have a spectrum of community members involved with a research project. Our Vietnamese project may have benefited from involvement of multiple persons of Mr. Nguyen's stature who may have represented different segments of the émigré community. Access to multiple gatekeepers may have provided us with a better appreciation of differences within the community and forced us to be more sensitive to differences and peculiarities of various religious and other organizations and their leaders. In my case, I have been fortunate in working with other cultural insiders from the Soviet Union on shared research projects, people whose experience of migration and acculturation differed from mine. Through this work, we have found that although we shared a common language, country, and culture of origin, acculturation differences among us created an "acculturation chain" of experience, with people forming "links" between

divergent perspectives of those who are more or less acculturated than others. Without such links, more acculturated persons may not fully understand the cultural perspectives of those who are newly arrived. Yet through these links, such group discussions among people at different places in their acculturation process can be very helpful when trying to understand cultural phenomena, design questions, or interpret findings. In this way, multiple perspectives on what constitutes ethical behavior or how to translate Western research practices into the immigrant culture can be discussed and alternative solutions determined.

This image of the acculturation chain can also be useful for outsiders working with an immigrant community. For example, in coming to know the Vietnamese community, we found it useful to begin our interviews with community members who were closer to us on the acculturation chain, that is, those who were more acculturated. Because they shared some cultural assumptions with us, they could explain to us the perspectives of those who were farther away from us along the acculturation continuum. Other members of the community on the researcher team can then serve as further links to different experiences that may be less accessible to those who are more acculturated.

*Social networks.* Another invaluable asset available to cultural insiders are the social networks within the ethnic community. Our research has confirmed the importance of ethnic social networks for both former Soviet and Vietnamese refugees, particularly adults. In fact, we have found that adults in both groups continue to have over 80% of their social contacts with members of their own ethnic group, even after many years in the United States (Trickett et al., 2004). Immigrant networks are also interesting because members of particular local communities within the

countries of origin are scattered across the United States in the process of resettlement. This phenomenon creates multiple and overlapping ethnic networks, as immigrants and refugees come to know others from their ethnic group who live near them in the United States but also maintain contact with close family and friends elsewhere in the country. The interwoven nature of immigrant networks makes them potentially broader, and membership in them can help provide tremendous access to multiple segments of the population. At the same time, it makes protection of confidentiality even more imperative.

Our ethnic social networks played a critical role in our experience with Mrs. Katz, described above. First, without insider status and personal connections (Mrs. Katz was the mother of a friend's friend), we would not have had access to these research participants, or at least it would have been difficult to earn their trust. Mrs. Katz made data collection on a large scale possible for us. At the same time, without social networks in the community, word would not have reached us that the ethical problem had occurred. It was through an acquaintance that I heard about what happened, who had heard it from someone else. Further, without insight into the culture, we might have become outraged and accused this important community member of egregious ethical violations when, in fact, she was acting in ways she felt were ethical. We learned to ask many questions about how data collection opportunities are being set up in future work to avoid such situations. On the other hand, although I have no reason to assume that anything unethical took place, I hate to think about what kinds of things we might be unaware of in our Vietnamese project. As an outsider to the Vietnamese community, I know that I am unlikely to hear what people in the community may be saying about our research project.



### *The Role of Cultural Insiders on Research Teams*

Although there are many good reasons to include cultural insiders on a research team, the challenge remains how to do it in ways that result in their knowledge and experience truly reflecting on the research process. As the Tapp Report suggests, the best way to collaborate with cultural insiders is with professional colleagues who are themselves from the culture that we are studying. Yet the relative absence of scholars from many of the immigrant/refugee communities that we study can make that impossible. This suggests that one long-term solution to the problem of how to conduct ethical and competent research in immigrant and refugee communities is to encourage professional training opportunities for members of refugee and immigrant groups. As noted earlier, professional organizations need to acknowledge the importance of special efforts to recruit and retain in training programs not only minority group members but also members of refugee and immigrant communities who may or may not be from underrepresented minority groups in the United States. Only such specialized attention to training can create a corps of professionals who can be knowledgeable about particular immigrant groups and about the general issues that concern immigrant and refugee research.

When such collaboration is not possible, however, the task of the researcher becomes more complicated. Typically, researchers believe that they can include the insider perspectives on the research team by hiring members of the group being studied at different levels of the research project. In our Vietnamese study, we did just that. We had several highly qualified consultants who were well respected within the Vietnamese community assist us with every step of the process, including measure selection and translation, developing the sampling and data

collection procedures, and interpreting the findings. We were also very fortunate to work with Mr. Nguyen who was trained within our field and oversaw all aspects of the data collection process. We have no reason to doubt that the interviewers that we hired to collect the data were sensitive to the research process and knowledgeable about the community. At the same time, in the end, there are countless ways in which we, those responsible for the design and implementation of the study, remain outsiders to the research process and the resulting data. This suggests to me that more is required in order to assure the true involvement of cultural insiders in the research process.

Unfortunately, existing structures, such as grant mechanisms, do not provide adequate opportunities to do that. In fact, most grants require that there be only one principal investigator (PI), making it difficult for researchers to collaborate with each other, much less with community members. The only solution seems to be for researchers to carefully attend to these issues as they unfold in the research process, to be cognizant of their own limitations, to be constantly vigilant about issues in the communities they study, and to ensure that cultural insiders feel free to voice their concerns and explain their perspectives throughout the research process.

### **THE FUTURE OF RESEARCH ETHICS INVOLVING IMMIGRANTS AND REFUGEES**

This chapter has outlined a large set of complexities in carrying out ethical research with immigrants and refugees. Reviewing the long list of issues and problems, one might conclude that it is much simpler not to do research with these groups! Yet as argued in this paper, this would not be an ethical stance. Rather, researchers must acknowledge



and embrace the complexity of all groups in our society and include them in research projects.

A major theme of this chapter has been the notion that the level of complexity involved in doing research with diverse and vulnerable groups precludes the possibility that any code of ethics can fully anticipate and successfully resolve the multiple ethical dilemmas that arise in the course of doing this work. Researchers must be familiar with the ethical issues and concerns of the immigrant cultures. In addition, researchers must devote sufficient time and resources to engaging in a lengthy process of recruiting participants into the research project, obtaining truly informed consent, and assuring ethical treatment of participants.

We have learned to never underestimate possible differences in the ways that our perceptions of ethical issues differ from those of

the community members. Only ongoing communication can unearth such differences and prevent potential ethical violations. Without such efforts, the researcher can remain naive about ongoing ethical issues; yet the fact that the researcher is unaware of an ethical violation does not mean that it isn't occurring.

Finally, such a process can only be successful if multiple cultural insiders are active and influential members of the research team. Further, it would be valuable for the field to learn more from the experiences of cultural insiders on the research teams, those persons who've been hired by researchers to help inform the research process. Perhaps insight into their experience can help us restructure the ways in which we organize the research process so as to ensure that they can help us, cultural outsiders, conduct ethical research in their communities.

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