

SILENCING THE SELF  
ACROSS CULTURES  
DEPRESSION AND GENDER IN  
THE SOCIAL WORLD

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## The Itinerant Researcher: Ethical and Methodological Issues in Conducting Cross-Cultural Mental Health Research

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I had this feeling of being violated and betrayed, then I went into shock, and then I got angry. . . and then I went into denial. I thought, 'oh well they don't know who I am. I was just a research subject.' After I participated in the study, I had no idea or didn't even realize what all it was going to entail in the future. And then I come to find out that all the results have been 'shared' through journal articles and publications. The realization for me was 'Oh my god, I've been abused and violated because I had no idea that they would talk about us like that. Now we've been labeled like we're just a bunch of people walking around with diseases on reservations.'

Anonymous Native American research participant (Casillas, 2006)

The unsettling and disturbing quote speaks to the core theme of this chapter—the responsible and ethical conduct of research, especially with historically disempowered and disenfranchised ethnocultural populations<sup>1</sup>—and the untoward effects that researchers can have on their respondents. In the past two decades, there has been a dramatic increase in mental health research conducted among ethnic, racial, and cultural groups in many parts of the world. As interest has increased, so have concerns of many cultural communities about research in general and the presence of researchers in their communities. The rising community concerns accompanied with the emergence of community-based research review committees present extraordinary complexities for researchers that are only beginning to be fully and seriously acknowledged at methodological, procedural, and conceptual levels. The most important challenge, however, is

the actual responsible conduct of researchers while they are in the field and the relationship they establish with their participants (Fisher, 1999; Mohatt & Thomas, 2005; Norton & Manson, 1996).

The responsible cross-cultural study of mental health issues needs to acknowledge and address the challenges that are at the core of this juncture. In recent decades, the mental health field has witnessed a significant increase in scholarly research and position papers on ethnocultural similarities and differences in the expression and diagnosis of syndromes and illnesses. For example, Parker, Gladstone, and Chee (2001) summarized the literature on depression among Chinese communities and concluded that “the interpretation of the literature is complicated by the considerable heterogeneity among people described as ‘the Chinese’ and by numerous factors affecting collection of data, including issues of illness definition, sampling, and case finding; differences in help-seeking behavior; idiomatic expression of emotional distress; and the stigma of mental illness” (p. 857). In a similar vein and drawing from ethnographic interviews with European Americans, African Americans, and Puerto Ricans, Alverson and colleagues (2007) concluded that “appreciating an ethnocultural background and being alert to how it may inform individual clients’ illness discourse might sensitize clinicians to the myriad qualitatively different ways that individuals understand and cope with mental illness and relate to the mental health system” (p. 1545). Both statements capture the range of intricacies associated with this field of inquiry and pose complex ethical issues.

The study of depression in women, the theme of this book, provides yet another layer of complexity. While popular and epidemiological knowledge suggest that women experience higher rates of depression (American Psychiatric Association, 1994), Colla, Buka, Harrington, and Murphy (2006) point out that depression rates differ significantly across cultural groups and postulate that social changes—including modernization, westernization, and development—may account for those differences. Reid (2002) highlights the importance of addressing the intersection of gender and culture in research. She argues that for many years, multicultural and cultural research often ignored the impact of gender and sexism within their agendas. As a consequence, the resulting discourse and research were interpreted from the dominant, male-centric perspective. Similarly, within the feminist literature, as long as the emphasis was on gender alone, the dominant ethnic/race was assumed (Reid, 2002). These statements stress the significance of the cross-cultural examination of depression in women: By focusing on the intersections of gender and culture, the voices of women within their communities are privileged over the male-centric, dominant-culture discourses. Research in this area needs to embrace the standard of “principled cultural sensitivity” (Fisher et al., 2002; Trickett & Birman, 1989; Trimble & Fisher, 2005; Trickett, Kelly, & Vincent, 1985) advocated throughout this chapter by not reproducing the historically oppressive discourses and methods that contribute to these women’s experiences.

Thus, the purpose of this chapter is to raise points to encourage ethical decision making for research on depression with women from ethnocultural populations that reflect the unique historical and socio-political-cultural realities within racial and ethnic communities. A secondary objective is to highlight the connection between irresponsible research and cultural incompetence. Through the description of a real-life example, this chapter will address the epistemological, ethical, and methodological challenges that responsible researchers confront when engaging disempowered and disenfranchised persons in research with ethnocultural populations.

The need for this chapter is multifold: It emerges from the increasing distrust ethnocultural communities express toward researchers. Countless community members are intolerant and unforgiving of past research efforts for a variety of legitimate reasons; many of their suspicions and concerns derive from the cultural incompetence and insensitivity of researchers. Ideally, researchers studying different ethnocultural groups either belong to or incorporate people in their teams who belong to the culture they are studying. Herein lies one of this book's unique contributions: Each study is written by researchers who are from, and almost all of whom live in, the culture they are studying. This was not too common in cross-cultural research in the past, and is still not common enough now. Researchers should be prepared to collaborate with the communities, share results that have practical value, engage in conversations about theories and methods, and accept the conditions imposed by the communities in gaining access to respondents. Additionally, researchers must be aware of scientific, social, and political factors governing definitions of gender, race, ethnicity, and culture; understand within-group differences; and become familiar with skills in constructing culturally valid assessment instruments.

### Facets of Principled Cultural Sensitivity

There are three ethical dimensions of multiculturally sensitive research: (1) applying a cultural perspective to the evaluation of research risk and benefits, (2) developing and implementing culturally respectful informed consent procedures and culturally appropriate confidentiality and disclosure policies, and (3) engaging in community and participant consultation with a standard of "principled cultural sensitivity." The concept of principled cultural sensitivity was introduced to the field of community psychology as a core component of the *ecology of lives* approach to field-based research collaboration by Trickett, Kelly, and Vincent (1985) and Trickett and Birman (1989). Briefly stated, the community psychologists maintain that principled cultural sensitivity is based on respect for those for whom research and interventions are intended and prohibits interventions that violate cultural norms. The principal goal of ecology of lives research and intervention is community development: The

studies are constructed in such a way that they become a resource to the community. Unless one cares and is knowledgeable about how lives are led at the community level, such a goal would be difficult if not impossible to achieve. Additionally, the perspective emphasizes the importance of culture as a historical and contemporary aspect of the framework within which individuals appraise their situation and their options. Research from this approach underscores the community context as the stage within which individual behavior occurs (Trickett & Birman, 1989; Trickett et al., 1985).

### *An Unfortunate Example*

Not long ago, a graduate student approached one of us with a serious concern about the contents of a recently published journal article that presented a psychiatric analysis of four women from her village.<sup>2</sup> The article was passed along to her by one of her classmates, who also had questions about its contents and ethical implications. The article presented a case for a unique culturally bound syndrome that closely resembled typical symptoms of depression; descriptions of the symptoms and corresponding behaviors were cast in the framework of the villagers' cultural worldviews and their historical experiences with colonialism. Although the student acknowledged the accuracy of a few of the cultural interpretations and the descriptions of the effects of colonialism on her people, she was deeply concerned that the researchers had presented enough information so that anyone familiar with the village could easily identify the respondents. Moreover, she was angry about the fact that the researchers misinterpreted the women's behavior and symptoms. She strongly maintained that the researchers failed to recognize that the behavior was completely congruent with the way her people typically express the effects of having taken on too many community and family responsibilities. From her cultural perspective, the four women were not depressed but rather were expressing their need for a time-out from domestic responsibilities. The student acknowledged that depression-like behaviors such as prolonged weeping, sadness, restlessness, loss of energy, and feelings of guilt occurred in her village when one lost a member of their extended family or loved one; the experiences are usually shared among many village members at the time of loss and in fact are expected to occur.

She sent a copy of the article to the elders in her village and asked them to comment on it as well as provide her information about the researchers. It didn't take long for her to hear back from one of the elders, who also happened to be the father of one of the women. He was deeply upset with the article's tone, inaccuracies, misrepresentations of the cultural ways of the village, and the fact that the villagers he talked to about the article were able to identify the four women. He went on to say that he wanted the student to write a letter to the authors on behalf of the village counsel and elders essentially berating and admonishing them for their mistakes as well as their whole approach to the sensitive topic. The student complied with their request, sending the letter back to the elders for their review

and comment. The lengthy, somewhat jarring and direct letter eventually was sent to the authors; they never responded or acknowledged receipt of the letter. Following additional instructions from the elders, she sent the authors another letter a few months later telling them that they and any researchers from their university were no longer welcome in the village; copies were sent to the authors' departmental chair and the university's president. The president responded with a polite note indicating she would check into the complaint; the student never heard back from the university president, the chair, or any of the recipients of the letter.

This unfortunate incident illustrates several key points concerning the culturally appropriate conduct of Western research with women from ethnocultural communities, and serves as ample evidence for why more and more communities are wary of "outside" researchers who appear to place their professional and academic interests above the needs of their host communities. These outside researchers create a swarm of problems for the participants, villages, neighborhoods, and communities, and leave them to struggle with the consequences alone. This once popular and widely used safari-scholar approach to research is fading from acceptance, and one-stop data mining by these itinerant researchers is no longer acceptable. More than ever, ethnocultural community members demand that research occur in their communities under their direction and control. Researchers should be prepared to collaborate with communities, share results that have practical value, engage in conversations and discussions about theoretical concepts and methods, and accept the conditions imposed by the community in gaining access to information and respondents (Fisher et al., 2002; Trimble & Fisher, 2005).

Based on the basic principles of ecosystems and ecology of lives perspectives, the psychiatric researchers or itinerant interlopers did not fully comprehend the host community's cultural-specific lifeways and thoughtways and their influence on daily life. A background search on their credentials and research experiences suggests that they had little experience in working with ethnocultural communities of any kind, as the bulk of their research occurred in psychiatric clinics in their city and surrounding suburbs. The researchers were introduced to a village elder who was a relative from a nearby village; hence, their three-week sojourn was their first visit to the community. In effect, their research orientation was an itinerant one where context didn't seem to matter to them.

Sections of the publication indicate that the researchers had little knowledge of the history of the village, including its struggles with colonialism, missionaries, the presence of miners and loggers, and the nature of the village's relationship with government agencies, including the politics associated with their relationship with the village. Moreover, some of the article's historical statements and descriptions of their linguistic and cultural background were incorrect and misleading. In addition, the gender dynamics within the village were not researched or described, and there was a complete lack of awareness about the gender and power relations between the researchers and the women interviewed. It is no surprise, then, that

this research on women from this village had the effect of further disempowering and pathologizing them, thus reproducing the oppressive gender and racial dynamics from the researchers' culture.

Finally, this case incident will provide other examples of the researchers' gender and culturally insensitive improprieties and blunders in subsequent sections of the chapter. But there is one incident that bears mention as it serves to reinforce the point that the researchers' interests were self-serving and that explorations into the deep cultural meaning of the villagers' lifeways and thoughtways were not valued. The researchers were observing one of their participants one afternoon as she responded to a series of psychological tests, and from all indications, she appeared to be acting out classic depression symptoms. Hoping to get a construct or term in the village's indigenous language that captures a description of a culturally bound syndrome, one of the researchers turned to a nearby villager—a man, not a woman—and asked him if there were words or phrases they had in their language to describe her illness or sickness. The man thought for a moment and then told them what it was; the researchers had him repeat the phrase while they tape-recorded it and wrote it down phonetically. The researchers used the phrase in their journal article as an example of an exotic culturally bound syndrome that was frequently used by the villagers to describe depression. Unfortunately, the researchers never asked for a literal translation of the phrase; otherwise, they might not have reported it: the villager's phrase translates to mean "she's not being herself today."

### Roots of the Itinerant Research Orientation

Anti-oppressive research involves making explicit the political practices of creating knowledge. It means making a commitment to the people you are working with personally and professionally in order to mutually foster conditions for social justice and research. It is about paying attention to, and shifting, how power relations work in and through the processes of doing research. (Potts & Brown, 2005, p. 255)

To avoid replicating the abuses of the itinerant researcher approach, it is crucial to examine the epistemological assumptions that underlie the ethical behaviors and methodological choices in research. The itinerant researcher is guided by the assumptions and traditions of the Western positivist paradigm in modern science, what Linda Smith (2005) calls the Western "discourse of discovery." The researcher objectifies the subjects of research; research participants become this exotic object that the researcher travels to visit and, once in their presence, submits to examination via various instruments. The itinerant research orientation assumes that the results and the "truth" to be obtained will appear because of the methodology used, regardless of the subjective qualities of the researcher and his or her relation to the participants and community. Researchers who work from this approach reproduce the patterns of oppression and exploitation that these ethnocultural communities have endured both throughout their history and currently.

Morin (1984) enumerates 13 principles that correspond to the paradigm of simplification from which conventional, Western science approaches its objects of inquiry. These include the principles of disjunction, reductionism, and one-dimensionality; the elimination of what is historical and contextual; and the incapacity to concede autonomy to the objects of inquiry (Morin, 1984). We examine these principles and assumptions to illustrate ethical and responsible research with ethnocultural populations.

## Decontextualized Knowledge

The principle of disjunction privileges objectivity over subjectivity. In order to objectively observe, research entrenched in this paradigm assumes that the isolation of the object of inquiry from its surroundings or context is necessary. The paradigm of simplification also presupposes that the knowledge of the object is equal to the knowledge of its parts (reductionism). As a result, the interactions between the parts and the interactions between the object of inquiry and its context are obliterated, making the knowledge derived from it one-dimensional. Martín-Baró and Blanco Abarca (1998) refer to this principle as the partialization (“parcialización”) of human experience within positivist science, denoting both how it pertains to only a part of the phenomena studied and how it manifests as a bias privileging only certain parts and dimensions. Barnhardt and Kawagley (2005), in their discussion of indigenous knowledge systems, have also characterized Western science and education as privileging compartmentalized and decontextualized knowledge. This approach often clashes with the worldview of the communities that the research and knowledge are trying to describe.

The researcher who assumes the conventional, Western scientific approach strives to be detached and removed from the object of study and from the results of his or her study. This detachment starkly contrasts with one of the aforementioned requirements of principled cultural sensitivity: *caring* how lives are lived at the community level. From this perspective, a detached researcher is not a culturally competent researcher.

### *Elimination of History*

Martín-Baró and Blanco Abarca’s (1998) psychosocial approach, particularly their writings about the psychology of liberation, critiques what they call Western science’s ahistorical reductionism. When mental health researchers fail to acknowledge and consider the his(her)stories of the relationships between many ethnocultural populations and biomedical research, their attempts at earning the communities’ trust are likely to be perceived as deceitful and insincere. The legacies of the Tuskegee study in the African American community, the early oral contraceptive trials in Puerto Rico, and the large-scale coerced sterilization of Native



American and Puerto Rican women, among many others, have served to highlight the role of research as a tool of colonization and oppression (Smith, 2005). Any research done within ethnocultural and historically oppressed communities starts where the last one left off. Part of acknowledging the communities' histories often includes repairing relationships and making amends for past abuses.

### *Autonomy and Self-Determination of Participants*

If researchers consider expertise to be lodged primarily with other PhDs who have been socialized in the language and logic of our theories and methods, to what extent does social research align itself primarily with dominant discourses, ignoring the expertise of those who suffer most? (Fine, 2006, p. 95)

The dominant white culture is killing us slowly with its ignorance. By taking away our self-determination, it has made us weak and empty. (Anzaldúa, 1999, p. 108)

Itinerant researchers are not concerned with the importance of self-determination in the communities they study. For many ethnocultural and indigenous scholars, recognizing autonomy in the populations they are researching includes questioning Western science's epistemic privilege: that is, the primacy of the knowledge gathered by "scientific means" over all other ways of acquiring and producing knowledge. In many cases, this questioning translates into "centering the margins" (Hill, Muñoz, & Correia, 2007): addressing the communities' issues from a framework of "self determination, decolonization, and social justice" (Smith, 1999, p. 4). To work from this paradigm, the researcher must privilege the validity of the knowledge of ethnocultural populations.

Within mental health research, centering the research agenda from a framework of self-determination entails recognizing a community's right to have control over how psychological health and maladjustment are defined, assessed, and addressed within their own contexts (Hill, 2005). In addition, responsible informed consent procedures need to promote the autonomy and self-determination of these communities: Informed consent should safeguard the populations under study from exploitation (Snyder & Barnett, 2006). In our case example, the women were not aware that their information would be shared and disclosed (i.e., published); this puts into question the validity of the informed consent procedures of the study. Moreover, the itinerant researchers imposed their own perceptions and judgments on what constituted pathology in the women of the tribe; the only intent of addressing the community's knowledge about the women's situation was to fit it into the researchers' particular perspective.

## **Ethical Challenges in Cross-Cultural Research**

The growing intensity of grievances of people from countless ethnocultural communities worldwide captured the attention of researchers and their respective

professional associations. Flowing largely from the scandalous accounts of the infamous Tuskegee Syphilis Study, the U.S. government—principally through what now is the National Institutes of Health—advocated and enacted strict ethical research guidelines. In the 1979 Belmont Report, the principles of autonomy, beneficence, and justice were identified as the moral ideals to which all research ethics should aspire. These principles formed the basis of federal regulations and scientific codes of conduct that require investigators to design studies that protect against harm by adequately minimizing research risks, maximizing potential research benefits, protecting confidentiality, and ensuring that participation is voluntary (Fisher et al., 2002; Mohatt & Thomas, 2005; U.S. Department of Health and Human Services, 2001).

The American Psychological Association's (APA) *Ethical Principles of Psychologists and Code of Conduct* (APA, 1992) and the *Guidelines on multicultural education, training, research, practice, and organizational change for psychologists* (APA, 2002) direct psychologists to conduct research ethically and competently. The APA's *Guidelines for Research in Ethnic Minority Communities* (Council of National Psychological Associations for the Advancement of Ethnic Minority Interests, 2000) stress the importance of involving community members in the design, implementation, analysis, and interpretation of all research. Additionally, in the APA's *Guidelines on Multicultural Education, Training, Research, Practice, and Organizational Change for Psychologists*, "[c]ulturally sensitive psychological researchers are encouraged to recognize the importance of conducting culture-centered and ethical psychological research among persons from ethnic, linguistic, and racial minority backgrounds" (APA, 2002, p. 40).

Responding to the clarion call for a stance on ethical research principles from their membership, in 2002, the International Union of Psychological Science (IUPsyS) convened an ad hoc committee to identify, develop, and submit a universal declaration of ethical guidelines. The committee was directed to identify principles and values that would provide a common moral framework for psychologists worldwide and would guide the development of distinctive standards appropriate for different cultural groups and their settings. In 2005, the committee acknowledged an exceptionally important standard when they stated:

Respect for the dignity and worth of human beings is expressed in different ways in different communities and cultures. It is important to acknowledge and respect such differences. On the other hand, it also is important that all communities and cultures adhere to moral values that respect and protect their members both individually and collectively.... The continuity of lives and cultures over time connects people today with the cultures of past generations and the need to nurture future generations. As such, respect for the dignity and worth of all human beings also includes moral consideration of and respect for cultural communities. (Universal Declaration of Ethical Principles for Psychologists, n.d.)

The emphasis of the Universal Declaration of Ethical Principles for Psychologists<sup>3</sup> on morality is in keeping with the fundamental ethical principle that one “should do no harm” when it comes to the conduct of research of any kind. Framing ethical principles and guidelines to include “moral considerations” is an indispensable condition for guiding research ventures.

The voices of Canada’s Aboriginal people guided the publication and release of “a set of principles to assist in developing ethical codes for the conduct of research internal to the Aboriginal community or with external partners” (Castellano, 2004, p. 98). Eight principles are laid out calling for the appropriate and enforceable protection of Aboriginal people’s interest in research ventures, highlighting the rights of Aboriginal people as the true owners of the information they provide for researchers and the researchers’ obligation to consider in their research plans the Aboriginal people’s struggles for self-determination. Similarly, in a document titled *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*, released by Australia’s National Health and Medical Research Council (2003) and written in collaboration with Aboriginal and Torres Island representatives, the authors point out that “[t]he construction of ethical relationships between Aboriginal and Torres Strait Islander Peoples on the one hand and the research community on the other must take into account the principles and values of Aboriginal and Torres Strait Islander cultures” (p. 3). The report goes on to describe a variety of ways Australia’s Aboriginal and Torres Strait Island people can work collaboratively with academic researchers to achieve mutual goals.

### *Evaluating Research Risks and Benefits from a Cultural Perspective*

The general rules of scientific conduct embodied in professional codes of conduct provide critical yet incomplete guidance for identifying and resolving the complex ethical challenges inherent in research involving ethnocultural populations. Investigators engaged in the critical task of generating information on which psychological services, public opinion, and policies for ethnocultural groups will be based are thus faced with the formidable responsibility of ensuring their procedures are scientifically sound, culturally valid, and morally just.

Modern Western science promotes a science of alienation. In this form of science, both researcher and participant are alienated from the product of the study. The quest for answers often does not produce immediate applicable results but joins the larger body of knowledge for future development and use. In graduate school, we are encouraged to study a lofty or new area and concentrate on publishing the results in journal articles that will be accessible to the academic and scientific community; typically, this does not make results available or applicable to the studied communities. This lack of immediacy and

applicability of the studies' results to the communities is often antithetical to the quest for knowledge in other cultures and worldviews.

Ethics in psychology, both in the clinical and research practices, should be anchored by liberating practices (Martín-Baró & Blanco Abarca, 1998; Smith, 2005). As researchers, if we are not part of the community that we are to research, a commitment to liberating praxis means being aware of your positions of power in relation to the community; knowing the history of the community and its struggles and dynamics of oppression; contributing to and respecting the right to self-determination; and striving to not reproduce the oppressive and exploitative patterns that the community has experienced in its history.

Amalio Blanco Abarca (in the prologue to Martín-Baró & Blanco Abarca, 1998) highlights the "commitment with the well-being" of the disempowered and disenfranchised communities that is inherent to Martín-Baró's psychosocial approach. This commitment goes beyond the principle of beneficence: Doing "good" within psychology entails a commitment to being personally and socially self-reflective and self-aware (committed to *concientization*) and to incorporate these reflections in our theoretical, clinical, and research practices.

### *Moral Persuasions and Value Orientations*

Close compliance with professional ethical principles and standards begins with the personal moral persuasion of researchers: It requires them to reflect on their actions and their corresponding cognitive-emotional foundation. The assessment of morality can be construed as a rational process; thus, the assessment of whether or not one's research approach "will do no harm" should lead to logical decisions in favor of protecting the rights of study participants. Unfortunately, some researchers take a more self-serving approach where their needs, aspirations, and desires overshadow those of their host communities. This approach—likely rationalized by the researcher—is the foremost reason for the problems ethnocultural communities have had historically and continue to experience with outside researchers. Self-serving researchers may believe they can mask their selfish intentions, but they may be deceiving themselves to believe they will go unnoticed. The prominent cultural anthropologist Ward Goodenough reminds us:

The principle that underlies problems of ethics is respecting the humanity of others as one would have others respect one's own. If field [researchers] genuinely feel such respect for others, they are not likely to get into serious trouble. But if they do not feel such respect, then no matter how scrupulously they follow the letter of the written codes of professional ethics, or follow the recommended procedures of field (research) manuals, they will betray themselves all along the line in the little things. (1980, p. 52)

Echoing Trimble and Mohatt, we take pause to ask, "what does it mean to be an ethical person when conducting research with [women from] ethnocultural communities?" (Trimble & Mohatt, 2005, p. 327). In addition to the personal

challenges to researchers that these authors' question summons, communities also will want to know what kind of person they will be working with. If researchers don't closely follow and live by a set of principled virtuous ethics such as prudence, integrity, respectfulness, benevolence, and reverence (Trimble & Mohatt, 2005), at some point they will slowly alienate their hosts and may be asked to leave. Furthermore, it is vital that researchers become aware of their own gender dynamics and how they are reproduced in the research process and in interactions with women from ethnocultural communities.

### Methodological Challenges

Alvidrez and Areán (2002) highlight the importance of doing research that results in improved accessibility and quality of services (i.e., effectiveness research) when engaging in mental health research with ethnocultural populations that have limited access to health and mental health services. One of the ways to improve the quality of services is by culturally adapting interventions to make them more acceptable, to improve their fit with ethnocultural groups, and to increase their utility in real-world settings. For example, in preparation for launching efficacy<sup>4</sup> and effectiveness<sup>5</sup> studies with Puerto Rican adolescents, a framework was developed (Bernal, Bonilla, & Bellido, 1995; Bernal & Sáez-Santiago, 2006) to culturally adapt or culturally center evidence-based interventions. The framework serves as a methodological tool and includes eight elements or dimensions that must be considered in the adaptation process in order to augment the ecological validity of an intervention (i.e., language, persons, metaphors, content, concepts, goals, methods, and context). The assumption is that an intervention is likely to be more effective when it is congruent with the culture and context of the person. Yet, how ethnicity and culture play a role in the treatment process and how interventions may need to be adapted to meet the needs of diverse individuals is still a challenge for the field (Bernal, 2006). It is also a challenge to develop evidence-based, culturally centered interventions (Bernal & Sáez-Santiago, 2006) beyond the one-size-fits-all approach (Bernal Jiménez-Chaffy, & Domenech Rodriguez, 2009).

As an example of how the gap between passive "subjects" and distant "experimenters" can be bridged—moving us more toward a science of intervention that is participatory and culturally informed—participants in two initial efficacy trials of cognitive-behavioral therapy and interpersonal psychotherapy with depressed adolescents (Rosselló & Bernal, 1999; Rosselló, Bernal, & Rivera-Medina, 2008) were invited to focus groups to learn about their experiences. Former participants and their parents became consultants to the investigators: The adolescents offered suggestions on making manual-based interventions more flexible and the parents (primarily mothers) asked for tools for dealing with their children's depression. As a result, treatments were

modified and a psychoeducational intervention for parents was designed, which was presented to other groups of parents for feedback on its relevance, feasibility, and utility.

Engaging ethnocultural populations from principled cultural sensitivity is akin to promoting community ownership of the entire research endeavor and, ultimately, to respecting members' autonomy and right to self-determination. From its very beginning, during the identification of the issues to be studied, throughout the recruitment process, the informed consent procedures, the study implementation, the ongoing monitoring of ethical and cultural issues, and the interpretation and application of the results for the sustainable benefit of the community, responsible researchers must privilege and honor the communities' priorities to foster and repair the trust that has historically been betrayed by the itinerant approach (Alvidrez & Areán, 2002). Alvidrez and Areán advocate for having a presence in the community prior to the study and maintaining it after data collection to ensure a beneficial impact to the population. This presence is marked by the building and nurturing of relationships with the community characterized by respect; recognition of the communities' values, needs, and priorities; and sustained involvement (Smith, 2005). Researchers must be reliable, innovative, committed to the work, and trusted and respected by the community, and must represent a source of help (Nama & Swartz, 2002).

### *Culturally Respectful and Responsible Informed Consent Procedures*

For an informed consent procedure to be valid, participants need to be able to understand the information provided, give consent freely and voluntarily, and be competent to give consent (Barnett, Wise, Johnson-Greene, & Bucky, 2007; Gross, 2001). When doing research with ethnocultural populations, the first two conditions present important ethical considerations. Itinerant researchers forget that our notion of "science" and "research" is bound by culture. Therefore, in order to responsibly request informed consent, it is of utmost importance to reveal the assumptions within this process that we often take for granted. This includes how and who to ask for consent, how to explain and distinguish research from treatment, and the power dynamics involved in the intersections of culture, gender, educational level, and socioeconomic status.

In our first example, the actions and conduct of the itinerant interlopers violated at least one of the ethical and moral principles embedded in their professional association and in the village's codes and standards for virtuous behavior. The ethics codes of the psychiatric and psychological associations highlight the important of safeguarding confidentiality in both research and practice as "[c]onfidentiality is essential to psychiatric treatment" (American Psychiatric Association, 2006, p. 7). The four women described in our unfortunate example were given pseudonyms to protect their anonymity; however, most

of the villagers knew their true identities, and it also turns out that frequent visitors to the village knew the four women by name after they read the article. Clearly, the researchers did not comprehend the meaning of anonymity from the villager's worldview; otherwise, this lamentable incident could have been prevented. As a result, the professional membership of the researchers to the American Psychiatric Association was jeopardized after an ethical complaint was filed by an anonymous member.

In addition to the ethical obligation, the researchers were obliged to collect informed consent forms from all participants as required by U.S. federal guidelines and institutional review boards (Berg, Appelbaum, Lidz, & Parker, 2001; Faden & Beauchamp, 1986). Regrettably, the participants in our example had little or no idea what a human subjects consent form was or meant. Nonetheless, because the researchers were doctors, participants unwittingly signed them without fully understanding the reason behind the request. Thus, informed consent was not truly obtained. Commitment to the well-being of a community needs to include the will and resources to carry out ethical and scientifically sound research; this includes regarding informed consent as a process, not an outcome, and going to great lengths to obtain it. This is an enterprise that may take more time and resources than what is commonly perceived (Adams et al., 2007).

Typically, problems arise when community participants are invited to participate in a study where they may be giving away certain rights and responsibilities that may not be known at the study's outset; in effect, when they sign a consent form, they may not fully comprehend the binding implication of their signature. For example, after learning that blood samples were being used for purposes other than what was stated in consent forms, the Havasupai Tribe of Arizona filed a \$52 million lawsuit against Arizona State University and the Arizona Board of Regents (Hendricks, 2004).<sup>6</sup> In retrospect, in our case example, villagers and the study participants had no idea the researchers were going to publish analytic case studies of those who were ostensibly experiencing depression. Similarly, the Havasupai participants had no idea their blood samples would be for anything else but to study the correlates of diabetes. Instead, they were used in studies related to inbreeding, schizophrenia, and human migration theories (Hendricks, 2004).

Even when the possibility of using the data collected in further studies is clearly outlined and discussed during the informed consent process, the history of exploitative research practices and the lack of immediate benefits for the community can make participants weary and suspicious (Molyneux, Wassenaar, Peshu, & Marsh, 2005). Disempowered and disenfranchised communities are asked for a leap of faith in favor of the researchers. Despite histories of exploitation, misinterpretation, and data mining in their communities by itinerant researchers, they are asked to trust and give of themselves without knowing how their participation will be used in the future. These situations

represent instances of biocolonialism. Hawthorne (2007) contends that “colonial theft [has been] extended to human anatomy” (p. 318) to the extent that biological material from ethnocultural groups is being used without their knowledge and consent for the academic and/or economic profit of itinerant researchers and/or other institutions (i.e., DNA racial profiling) and in the absence of any gain for the ethnocultural communities.

There are various language issues that are relevant to ethical informed consent procedures. In composing consent forms for use in field research, researchers often use unfamiliar scientific jargon and odd sentence and paragraph construction; these, along with a lack of understanding of what happens if they refuse to sign, contribute to a lack of informed consent (Trimble & Fisher, 2005). In addition, most consent forms have been verified to be an average of three grades higher than the reading level of the typical study participant (Brainard, 2003). The conduct of ethical research demands that informed consent procedures be presented in language that is understandable, which may require having additional versions of consent forms in the participants’ native language. Nevertheless, when consent forms are translated into other languages, the English meaning of terms and sentences does not always accurately translate into words and sentences found and used in the language of the participants. Some researchers have experienced interpretation difficulties with participants who are not literate or whose reading comprehension levels are too low to understand consent forms (Gostin, 1995).

A similar dilemma occurs when participants mistakenly believe that signing an informed consent form terminates their right to withdraw from a study or question procedures or postexperimental reaction (Fisher, 2002). Interestingly, in our example only 3 of the 20 village participants who signed the consent form had a high school diploma. Although all participants were bilingual and could read the consent forms (in English), 16 of them preferred to use their native language in conversations. None complained about signing the consent form, but the majority felt it wasn’t necessary because they didn’t believe the doctors would intentionally harm them.

Cultural values and norms involving self and other public avowal can present problems for research institutions and professional associations concerning the maintenance of anonymity and confidentiality in research studies. Self and other public avowal—public declaration of one’s name, family background, kin relationships, and tribal or village affiliation—is important to numerous American Indians and Alaska Natives. Mohatt and Thomas (2005) recount a circumstance involving confidentiality and consent forms in which the worldviews of the local university’s institutional review board (IRB) and the potential participants from Alaska Native villages clashed. The IRB denied the request for approval of the study’s research methods and consent forms because the potential participants were asked whether they wanted to be publicly identified and have the accounts of their experiences with sobriety published with their names included. After the



research team informed certain village Native elders about the IRB decision as well as the possibility of purging the raw data after five years, the elders protested, stating “that they could not imagine why they would tell their story if it would not be shared with others and would be destroyed” (Mohatt & Thomas, 2005, p. 104). The research team provided information to the IRB members about the village’s values and norms concerning personal name and family acknowledgment as well as the complaints from the elders. After much debate, the IRB agreed to the use of multiple consent forms that provided the participants various levels of confidentiality to choose from.

### *Informed Consent of Treatment Research in Ethnocultural Populations*

The challenges and issues regarding informed consent in research with ethnocultural populations apply both to discovery-oriented research and hypothesis-testing research (Bernal & Scharrón-del Río, 2001). Nevertheless, hypothesis-testing research, such as efficacy and effectiveness research for interventions, incorporates yet another level of informed consent: treatment. Ethical codes include informed consent stipulations for both research and treatment; however, for participants in underserved communities, the distinctions between these two may not seem clear-cut.

Within treatment research, additional issues regarding the process of signing for consent arise. While Western science assumes that informed consent is an individual decision, collectivist cultures may favor group or family decision-making processes (Kaljevic & VandeCreek, 2006; Shaibu, 2007). Moreover, if the potential participant is a woman, she may need to consult with her husband or other men in her family (Molyneux et al., 2005; Shaibu, 2007).

In their article about community voices and informed consent in developing countries, Molyneux and colleagues (2005) described the discussion groups facilitated with community members in a rural part of Kenya where a large biomedical research unit was based. These authors report that while some participants were not concerned about the signing of the consent forms, others (in particular, those who had declined to participate in research) had mixed feelings and views about this process. In cultures where oral traditions are highly valued, researchers insisting on the act of signing for written consent (which privileges the written word over the spoken word) can make the participants “suspicious” (Shaibu, 2007). According to Alvidrez and Areán (2002), the misuse of research to justify oppression and discrimination against ethnic and cultural minorities along with the exploitation suffered by these groups under the pretext of research fuel their distrust toward research endeavors. Moreover, their histories of oppression and exploitation often undermine their ability to attribute “benign or beneficent motives” to researchers (Alvidrez & Areán, 2002, p. 104). These instances highlight the cultural clash of values and practices that can take place between the

ethnocultural communities and the inflexible application of Western research institutional practices. When IRB expectations and policies are intended to be acritically applied to research with ethnocultural communities, the research ethics invoked are “much more about institutional and professional regulations and codes of conduct than it is about the needs, aspirations, or worldviews of ‘marginalized and vulnerable’ communities” (Smith, 2005, p. 96).

If research takes place within a clinical setting or involves providing treatment or resources in a severely underserved community, potential research participants may worry about the repercussions of refusing consent (Molyneux et al., 2005). Participants may worry that their future care will be of lesser quality, that they will be labeled as difficult or problematic, and that their relationship with the clinics and service providers will be damaged. The fear of losing access to the few available treatment resources may seem like opening the door to life-threatening repercussions.

An indispensable part of informed consent is that the person becomes a research participant voluntarily and freely (Snyder & Barnett, 2006). For a severely underserved population, the choice of participation may entitle choosing the research treatment versus no treatment; this is not much of a choice. The ethical and responsible researcher needs to be aware of the inequities and disparities (in access to and availability of quality care) that characterize the community’s health system when conducting research with women from underserved groups (Alvidrez & Areán, 2002).

Barnett and colleagues (2007) note that court rulings have dictated that in addition to including the risks and benefits associated with participation in a treatment study, potential participants must be informed of the risks associated with refusing treatment and offered “reasonably available alternatives” —with their respective risks and benefits—during the informed consent procedure. Therefore, in order for informed consent to be valid and fully voluntary, participants must have another option for treatment. In severely underserved groups, other options for treatment may be scarce or nonexistent.

The issue of the “reasonably available” treatment option goes to the heart of ethical issues in designing both efficacy and effectiveness research. Randomized clinical trials are the gold standard for demonstrating causality. To establish efficacy, the ideal is to have a no treatment, placebo, or control group to increase the likelihood of detecting a treatment effect. The ethical ideal would lead one to design studies in which all treatment conditions include effective treatments, or in the case of a no treatment condition, reasonable treatment options are available so that the decision to participate is fully voluntary. We offer two examples from the third author’s experience.

In a study of intergenerational family therapy with methadone maintenance patients in the San Francisco Bay Area, predominantly ethnocultural patients were randomized to either a manual-based family therapy or to didactic family psychoeducation. The investigators believed that the design itself was both

ethical and more rigorous than having opted for a no-treatment control. However, there were consequences to this decision: A treatment effect could not be demonstrated convincingly since both conditions appeared to be beneficial in various measures of outcome. At the time, the criterion for publication was having demonstrated an effect and thus the outcome paper was never actually published.

In a second study that focused on psychological treatments for depressed adolescents (Rosselló & Bernal, 1999), the issue of design and ethics was revisited. Here the investigators opted for contrasting two treatments that had empirical support in the field: cognitive-behavioral therapy and interpersonal psychotherapy. Although the use of a no-treatment control group was scientifically justified (there was no evidence on the efficacy of these interventions in Puerto Rico), it was clear to the investigators that there were no “reasonable available” treatment options for adolescents, particularly poor adolescents.<sup>7</sup> Given the earlier experience without a no-treatment control group, the research team opted for explaining to potential participants that they had a 33% chance of not getting treatment for three months, but made a commitment to offer the treatment of choice after the waiting period. There are consequences to this option: The costs of the study increase and there can be no meaningful comparisons at the subsequent follow-up between treatment and control conditions. In sum, there are always trade-offs in considering designs that are responsive to both ethics and culture. Ethical issues of ensuring reasonably available treatment options to ethnocultural groups have important implications for the design of studies when treatment is not available and when what is available is unreasonable.

### **Ethical and Responsible Mental Health Research with Ethnocultural Populations**

Kim, Park, and Park (2000) identify three approaches to cross-cultural research: universalist, contextual, and integrationist. The universalist approach, from which the itinerant researcher operates, represents the traditional epistemology of psychology and science, where the goal is to discover existing universal truths. Within this approach, the influence of culture is minimized, ignored, and often pathologized. The contextual approach, on the other hand, emphasizes the importance of understanding the participants from their own frame of reference. Kim, Park, and Park (2000) suggest that indigenous psychologies emerged as a “worldwide reaction” to the pressing need to decry the universalist assumptions and the effects of research from this perspective: “Although existing psychological theories and concepts are assumed to be objective, value free, and universal, in reality they are deeply

enmeshed with Euro-American values. . . . As such, they can be characterized as imposed ethics or pseudoethics, not true universals" (p. 64).

The integrationist approach proposes the integration of the knowledge and methods produced by both the "cross-cultural testing of psychological theories" and the indigenous psychologies (Kim et al., 2000). While there is no given formula or model to guide this integration (Hill, Pace, & Robbins, in press), research efforts from this approach must reflect a commitment to the autonomy and self-determination of the involved communities. Integrationist researchers must engage ethnocultural groups from a standard of principled cultural sensitivity. Martín-Baró and Blanco Abarca (1998) call for a revision of the assumptions and principles that guide our psychological methods and concepts. This revision, they advocate, should proceed from a place of commitment to action that reflects the needs and priorities of disenfranchised communities, and not from the comforts of our offices in the ivory tower. Research among disempowered communities should not be a mere academic exercise, but responsive to the immediacy of communities' realities and needs.

If in the process of doing research the participants and/or the community feel alienated, enraged, estranged, victimized, exploited, and misunderstood, who is the research serving? How can we genuinely advocate for doing research in communities if the process is victimizing in itself and the results and benefits of engaging in such exercise will not be immediately available for them? As such, our research with women from ethnocultural populations should not reproduce the patterns of exploitation and oppression based on race, gender, and/or culture that have historically existed. Let us recognize research as an intervention in itself, one that will have various effects in the participants and the community in which it is done.

## Notes

1. An ethnocultural community is a group of people that share similarities stemming from their ethnic, racial, and/or cultural background. Throughout this chapter, we use the term "ethnocultural communities" to refer to nondominant groups that have been historically marginalized.
2. All descriptions and narratives concerning the case example are factual. To protect the anonymity of the village and the women, the sequence of events has been modified and some incidents have been condensed. This case example, its ethical implications, and the effects of the itinerant researchers' transgressions on the women and their community have not been published elsewhere prior to this chapter.
3. This Universal Declaration represents a collaborative effort of the IUPsyS, the International Association of Applied Psychology (IAAP), and the International Association for Cross-Cultural Psychology (IACCP).
4. An efficacy study aims to determine whether an intervention can cause significant benefits in a controlled environment (experimental conditions) (Nelson & Steele,

2006); an example of this kind of study is a randomized clinical trial, in which an intervention group is compared to a control group.

5. An effectiveness study assesses whether an intervention will work and provide benefits in actual clinical or real-life settings (Nelson & Steele, 2006).
6. A Maricopa Arizona County Superior Court judge dismissed the case in May 2007 on a legal technicality.
7. The waiting period to get an appointment in the public mental health system was about four months and the available treatment was almost exclusively pharmacological.

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