

# Training for Research in Mental Health and HIV/AIDS Among Racial and Ethnic Minority Populations: Meeting the Needs of New Investigators

Margarita Alegría, PhD

My experiences as a mentor of young investigators, along with conversations with a diverse pool of mentees, led me to question the ability of conventional research methods, problem formulation, and instruments to address the unique challenges of studying racial and ethnic minorities.

Training of new investigators should prepare them to explore alternative research paradigms and atypical research strategies, such as community-based participatory research and Photovoice technique. Unconventional approaches to research may challenge common explanations for unmet needs, noncompliance with treatments, and poor service outcomes. Mentors may need to develop broader theoretical insights that will facilitate unconventional problem formulation.

The teaching of scientific research and mentoring of young investigators who study minority populations should evolve along with the changing research environment. (*Am J Public Health*. 2009;99:S26–S30. doi:10.2105/AJPH.2008.135996)

## IN RESPONSE TO GROWING

evidence of racial and ethnic disparities in health and treatment, the National Institutes of Health (NIH) has encouraged research on racial and ethnic minorities and other underrepresented groups and made a strong commitment to recruiting and training racially and ethnically diverse students. Over the past 15 years, mentoring has changed dramatically because a racially and ethnically diverse pool of students has entered predoctoral, doctoral, and postdoctoral programs and has begun to focus on understudied populations.<sup>1</sup> Through a series of mechanisms (including the Research Centers for Minority Institutions of the Center for Research Resources, the National Institute of Mental Health–National Institute on Drug Abuse Minority Supplements, the National Institute of Mental Health Family Research Consortium, and the Loan Repayment Program of the National Center on Minority Health and Health Disparities), these students have entered the research world with novel lines of inquiry and an admirable zest in tackling the colossal problems of HIV/AIDS and mental health, particularly among racial and ethnic minority groups. They have also brought forth profound questions about the nature of scientific research and created innovative approaches to data collection.

Training and mentoring this diverse pool of investigators present new challenges to traditional

programs. I aimed to describe problems posed by trainees who were examining understudied populations and to recommend to both trainers and funding agencies ways to address these concerns. As this dynamic generation of researchers enters the field, it is time to rethink old models of training to better fit their needs.

For more than 10 years, I have mentored undergraduate and graduate students engaged in mental health and substance abuse services research, psychiatry residents, and minority junior faculty. These trainees have diverse racial and ethnic backgrounds and come from various disciplines, including psychology, anthropology, sociology, social work, psychiatry, economics, and health policy. They participate in academic training programs geared toward the development of peer-reviewed research proposals and journal articles. Although these training programs are quite varied, they all follow a similar format; mentors provide advice and supervision in identifying research topics, developing appropriate methods, and conducting research. Mentors' interaction with mentees can be either prolonged (2 years in a postdoctoral fellowship) or of short duration (a week in a training workshop).

My experiences as a mentor for academic trainees investigating understudied populations have given me insight into the challenges they face as they embark on

their research. Their concerns about traditional research methods illustrate the shortcomings of traditional training models.

## CLASHES BETWEEN TRADITIONAL TRAINING AND NONTRADITIONAL STUDIES

### The Funding Dilemma

Mentees have described the socialization process that unfolds during research training. These young researchers are instructed in the “right questions” to ask and in the correct design of studies that seek to answer these questions, but they also challenge the assumptions they perceive are underlying the instructions: Are these the questions that are meaningful to the researcher and that will lead to important insights of use to the studied population, or are these simply the right questions because they will succeed in being funded?

One duty of a mentor is to teach trainees pragmatic skills—in topic formulation and research methods—that will enable them to persuade a funding agency to finance their projects. Therefore, training programs primarily focus on instructing trainees to ask the questions that will get their research funded. Unfortunately, young investigators sometimes ask questions most relevant to their areas of interest but find that funding agencies are reluctant to support their ideas. I have

observed this dilemma with increasing frequency among trainees who are struggling to apply standard research methods learned through training and mentoring programs to understudied populations.

### Applicability of Traditional Methods to Nontraditional Populations

Trainees have argued that although our research community advocates the importance of “thinking outside the box,” our research methods actually constrain creative ideas. For example, a randomized clinical trial (the classic gold standard for clinical research), in which some individuals receive an intervention and others do not, seemed immensely impractical to one trainee, given the scarce resources in the service setting in question to provide even the basic intervention. Moreover, including a comparison site that offered similar services was impracticable because no similar setting closely approximated the original site. Moreover, including a control group required declining to provide services to people who desperately needed them, which seemed morally wrong, even when the efficacy of the intervention had not been clearly demonstrated.

As a mentor, I was advocating a scientific research design and allocation of scarce resources to its implementation in a setting with a depleted infrastructure in which patients were not even receiving basic services. The trainee questioned whether there was something wrong with this logic. This is just 1 example of how traditional research methods, long considered to be the most appropriate by funding agencies and many members of the research community, may be impractical or even

ethically questionable for use in resource-poor service settings.

### A Need for New Study Designs and New Skills

Another consideration for research design with diverse racial and ethnic populations is the new set of skills needed to carry out recruitment. Anonymity is important to these respondents, some of whom are undocumented immigrants. They may be reluctant to provide contact information and may be concerned about who will have access to it. In many cases, respondents need to be reassured that they will not be contacted at their jobs. Establishing a trusting relationship is necessary, although it may increase the time needed to complete an interview and obtain informed consent. Yet training programs rarely teach how to develop trusting and sustainable relationships with hard-to-reach populations or how to adapt research recruitment protocols to fit community needs.

Mentees often grapple with such issues as the amount of time and effort required for screening many households to obtain, for example, an adequate sample of American Indian women or recent immigrants. They are concerned about whether funding agencies and review panels understand the need to collect data on large enough sample populations to facilitate exploring subgroup differences within Asian, Latino, and American Indian communities. They advocate conducting small qualitative studies to better formulate hypotheses when no relevant literature on the population of interest exists, but find funding for such projects elusive.

I have heard debates about what constitutes scientifically sound comparison groups. Is a non-Latino White sample always

needed or will comparisons across racial and ethnic minority groups satisfy reviewers? How should sample design account for heterogeneous populations? Why are non-Latino Whites considered to be a monolithic group that does not require subethnic identification? I have encountered all of these challenging questions, and many remain unanswered.

### Measurement Instruments for Diverse Populations

In addition to struggling with appropriate study designs, many of our mentees question the utility of standard measures and data collection techniques in assessing physical and mental health and HIV outcomes in diverse populations. For example, one mentee thought that a good way to capture how neighborhood violence is integrated in the lives of ethnic and racial minority youths was through a Photovoice technique in which youths were provided with disposable cameras to depict what they saw as neighborhood violence. Her pilot project was a great success; for example, it effectively showcased how youths viewed police in patrol cars as emblems of neighborhood violence.

For her mentor, the concern was that there might be no funding home for such a project. Although this innovative photo documentary method has been successfully used to elucidate underlying issues in marginalized populations in recent years,<sup>2,3</sup> these projects were more likely to be funded by small nonprofit organizations than by larger and more competitive funding mechanisms such as NIH grants. Therefore, I suggested that my mentee develop a “more research-y” project combining innovative methods with more-traditional methods, primarily because many funding agencies

appear to be unwilling to risk sponsoring a novel methodological approach undertaken by a new investigator. Although more recently I have seen a move to provide funds for new methods, most review committees remain unwilling to risk substituting novel approaches for the safe, familiar methods.

Instrumentation for assessing mental health and HIV/AIDS treatment and adherence to treatment is an issue trainees have repeatedly grappled with. They point out the lack of conceptual equivalence in the measures used for diverse populations and express reservations about how phenomena are conceptualized and how they are measured by standard instruments. Young investigators view standard measures as inadequate to account for the circumstances of ethnic and racial minorities, including living conditions, cognitive demands, and literacy levels. One mentee tried to use the self-administered version of the Beck Depression Inventory with Latina women who had limited education in an effort to replicate a similar study conducted with middle-class non-Latina White women. However, many of the Latina women could not understand the questions and answered yes out of fear of giving an incorrect answer. Another trainee queried why a scale assessing antidepressant medication adherence failed to evaluate whether losing sexual appetite was a side effect, a common deterrent for her patient population (comprising mainly African American and Latina women).

Mentees have also challenged HIV/AIDS treatment adherence assessments that assumed that people went without medications as a willful choice, rather than as their only alternative in the

navigational chaos of Medicaid and managed care. Why were current regulations for prescribing methadone and buprenorphine not considered as possible explanations for treatment non-compliance among drug users with HIV/AIDS? Why did study questionnaires fail to ask about the transportation and bureaucratic requirements involved in filling prescriptions? Why did they not inquire about the limited choice of treatment options available to the respondents?

Many trainees have observed patients who seemed to be so occupied with keeping their heads above water (finding money to pay bills, caring for sick children, and so on) and with social problems (history of childhood abuse, limited job opportunities, and so on) that all their energy was directed to making it to the next day rather than to their long-term treatment regimen. Trainees concluded that the planning required for medication management would be an unrealistic luxury for patients facing these daily struggles.

Another problem pinpointed by trainees is occupational categorization by the Bureau of Labor Statistics (which classifies jobs into broad categories based on the major occupational groups), which fits the experience of mainstream populations but not marginalized people. Although initially skeptical, I learned from focus groups and interviews with community members the truth of this observation. I was told about jobs never encompassed in the standard classification system, such as providing personal security, renting space for drug use and storage, selling firearms, valet parking, and cleaning car windows in street intersections.

These challenges in developing and implementing research with

ethnic and racial minorities are faced by older investigators as well as trainees, as I can testify. I tested an older version of the CAGE (Cut-Annoyed-Guilt-Eye Opener) questionnaire for its applicability to Spanish-speaking homeless participants in an HIV/AIDS study. During the cognitive debriefing process, one question, about whether the respondent ate too much salt, was received with laughter. These respondents wondered why an investigator would ask about too much salt intake when they were struggling just to get a meal. This experience illustrated the absurd assumptions made by instruments developed among mainstream populations and applied to persons with much different experiences.

In fact, many items in scales seem inappropriate for ethnic and racial minorities. For example, the Composite International Diagnostic Interview assessment of generalized anxiety disorders includes questions about tense, sore, or aching muscles. These symptoms are frequently present in Latino laborers for reasons that have nothing to do with anxiety. Likewise, the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*, considers a bereavement period of only 2 months to be normal, a standard considered by many trainees from other racial and ethnic groups to be unquestionably Anglo and not at all the norm in their communities.<sup>4</sup>

Although individual items or entire instruments have been altered and then revalidated successfully,<sup>5,6</sup> and instruments specific to ethnic and racial populations have been developed<sup>7,8</sup> to address concerns about comprehension and relevance, budgetary constraints in small grant mechanisms rarely permit such expenses or provide the time

frame to complete them. Moreover, trainees often lack the knowledge and skills to conduct this work.

Trainees are concerned about the typical strategies of research and their failure to incorporate indigenous ways of generating knowledge. Reliance on surveys and questionnaires ignores the evidence that other approaches to data collection, such as qualitative methods, are more effective among some understudied populations. Trainees have also asked whether randomized clinical trials are the only accurate mechanism for evaluating the effectiveness of interventions. For example, some have proposed videotaped interviews asking participants how they have changed or not changed as a result of the intervention. One trainee inquired why documentaries depicting the narratives and rituals of American Indian communities were not incorporated into interventions used to teach community members how to build resiliency in the face of hardship. Why does the research community ignore many culturally supported interventions<sup>9</sup> and the methods of community groups with extensive experience working with ethnic and racial minority populations? These strike me as legitimate questions because there is increasing agreement that translating research into practice is highly problematic.<sup>10</sup>

### Cultural Sensitivity

Trainees seek mentors who can speak their language and understand their world. They mean by this the language of oppression and injustice they and the members of their communities experience in their daily lives. For example, a mentee asked why measures addressing the receipt of HIV/AIDS services did not also

encompass the marginalization created as a result of poverty and complete destitution, which can be as widespread and devastating as HIV/AIDS. Why was so little attention paid to the quality of services and their failure to address the needs of this patient population? Indeed, I found that few service measures evaluated whether respondents hesitated to seek services because they feared being judged or disregarded for their poverty and social situation. Few studies assessed the quality of institutional services or evaluated whether the pool of service options was a reason that patients dropped out of care.

Some trainees see traditional problem formulation as perpetuating deficit models in minority communities. They ask why so few scales that measure substance use relapse include concepts of hope and spiritual resources as motivators for behavior change. These students want to know why social, political, and economic considerations are excluded in attempts to understand modifiable risk factors and behavior change. For example, some asked why studies of the risk for HIV/AIDS among transient populations have not considered limitations imposed on housing opportunities for racial and ethnic minorities by discriminatory lending practices and lenders' preferences for completely or predominantly White neighborhoods.

Why, students ask, are we not discussing social disorganization and lack of response by government institutions as forces that affect the well-being of minority populations, rather than focusing on respondents' failure to find health care and adhere to the demands of treatment? Few scales include institutional deficits as part of the explanatory models. Why

are we not inquiring about respondents' past experiences with coercive government mental health services to understand why HIV/AIDS patients are reluctant to seek mental health care? In other words, are we asking the right questions to understand the reasons why respondents may not seek HIV/AIDS and mental health care or comply with pharmacological treatments? Are we asking the right questions to understand modifiable risk factors, human motivation, and behavior change? Mentees are absolutely right in their critique of the organizational variables assessed in traditional research.

Finally, mentees also ask tough questions about whether they should seek to implement professional approaches to data collection on disease prevention, health promotion, and illness management or try alternative approaches that make use of community members. They assert that the very idea of sustainable interventions assumes that the communities and the funding system actually have the required resources. This appears ludicrous in the case of some rural or urban resource-poor settings that have an unstable pool of health care providers and are barely managing to offer basic services. Should researchers test procedures for reaching out to young women of color at risk for suicide when the waiting time for an appointment in nearby specialty settings is 3 to 6 months? Should we instead be training lay personnel to offer suicide prevention? What would be the risk of making that offer? Sustainability of services can seem to be a trivial concern to our trainees, when services in Spanish, Korean, or Chinese are not available and access to services has not even been established. Yet some funding

agencies' requests for applications now ask the applicant to demonstrate potential sustainability of the intervention once funding is gone.

Together, these concerns cast doubt on whether the usual concepts and methods taught through research training programs, which replicate mainstream views of illness, reasons for seeking help, and life conditions of research participants, are applicable to ethnic and racial minorities.

### RECOMMENDATIONS FOR IMPROVING MENTORING PROGRAMS

The questions my trainees ask and the challenges they identify show that research training should be adapted to the needs of racial and ethnic minority students and young investigators. Recently, researchers and practitioners have developed innovative research methods<sup>11,12</sup> and have combined community-based participatory research<sup>13,14</sup> and qualitative methods with traditional methods to successfully partner with underrepresented populations in research studies. Community-based participatory research is an especially powerful research perspective that allows investigators to create sustainable projects that more directly meet the needs of these communities.<sup>15</sup>

Training programs must also prepare trainees to modify or translate traditional study methods, instruments, and interventions to better fit the needs of diverse multicultural populations. Despite increased interest in studying racial and ethnic minorities, specific guidelines have yet to be formulated on how to integrate the contextual and cultural life circumstances of minorities into conceptualizing research problems

and putting the concepts into practice. Instead, the majority of mental health studies conducted to date continue to be based on assumptions of the universality of the American mainstream experience.<sup>16</sup> This is surprising in light of the substantial evidence that many measures appear to work differently for the various ethnic and racial groups.<sup>5,17</sup>

Training on how to translate research into interventions that will be effective among minority populations also requires providing models that will facilitate cultural adaptations of evidence-based treatments<sup>18</sup> or prevention programs.<sup>19</sup> The inadequacy of research to date on the effectiveness of evidence-based treatments for Asian and American Indian/Alaska Native populations,<sup>20</sup> among other groups, makes it impossible to guarantee the appropriateness of given interventions for specific ethnic and racial populations. Mentors should be helping trainees identify when and how treatments need to be adapted, modified, or completely redesigned to ensure a good match in a given community.<sup>21</sup>

Our experiences have helped us identify several strategies for improving mentoring programs. In a reversal of function, mentors could be mentored by the current pool of young investigators in learning how to consider alternative hypotheses that direct attention to life conditions, power differentials, and limited social and economic opportunities of disenfranchised minority populations. Training activities should be developed that allow the exploration of alternative research paradigms and atypical research strategies. Providing a cadre of mentors who can inspire trainees will encourage these novel scientific lines of inquiry. Research training may

benefit from new models and methods, including lessons learned in other fields, such as information systems, music, and the business sector.

Mentors should advise and train their mentees to critically examine and question the appropriateness of standard measures when they are examining health and mental health outcomes among racial and ethnic minority groups. Furthermore, they should be trained to always pilot test measures in their target population before using them in larger studies. Cognitive debriefing of a small sample of people who share the characteristics of the target population—to see if words are understood and if the measure has validity for that ethnic and racial group—is vital.<sup>16</sup>

Community-based participatory research can integrate meaningful questions for a given community. Theoretical models need to be developed to explain unmet needs, noncompliance with treatments, and poor service outcomes among disadvantaged racial and ethnic minority populations. This process requires community input and has the potential to help mentors provide training in problem formulation that is applicable to mentees' own lives and the communities they plan to study.

Exploration of alternative research paradigms also requires the expansion of current funding programs and the creation of new mechanisms to support the development and use of innovative research methods and data collection techniques for examining understudied populations. Focus groups with trainees might yield valuable suggestions for how research funding could be altered to fit new models of inquiry.

Finally, these recommendations are not applicable exclusively to trainees interested in the health of



racial and ethnic minority populations. Instead, efforts should be made to incorporate cultural competency training and basic information on racial and ethnic health disparities in all training programs nationwide.<sup>22</sup> Greater acknowledgment and understanding of these issues may lead to improved funding mechanisms and innovative study designs as this new wave of researchers and practitioners enters the field. ■

### About the Author

Margarita Alegria is with the Center for Multicultural Mental Health Research, Cambridge Health Alliance, Somerville, MA, and the Department of Psychiatry, Harvard Medical School, Boston, MA.

Requests for reprints should be sent to Margarita Alegria, Center for Multicultural Mental Health Research, Cambridge Health Alliance, and Harvard Medical School, 120 Beacon St, 4th floor, Somerville, MA 02143 (e-mail: malegria@charesearch.org).

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