

Conducting Research in Diverse, Minority, and Marginalized Communities

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There are several reasons why disaster research among racial/ethnically diverse and marginalized communities is indicated. First, and most fundamentally, few postdisaster samples have included sufficient numbers of members of ethnic and marginalized communities, and thus few studies have been able to examine disaster effects across and within these groups.

Second, there is reason to suspect that prevalence of exposure to predisaster trauma may be higher than average within economically disadvantaged urban environments (Breslau et al., 1998; Selner-O'Hagan, Kindlon, Buka, Raudenbush & Earls, 1998) and, if so, these communities may have a greater prevalence of predisaster trauma-related psychopathology. Knowledge of the epidemiology of trauma and posttraumatic stress disorder (PTSD) within specific minority populations is limited by the shortcomings of most previous studies. For example, in the National Comorbidity Survey (Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995), the Hispanic, Asian, and Native American samples were small in size, heterogeneous in terms of national origin, and limited to English-speaking persons (see Norris & Alegria, 2005).

Third, it can be hypothesized that minority and marginalized communities are at greater risk following disaster than other groups and therefore need greater research attention (Norris & Alegria, 2005). The relative impact of race, female gender, exposure levels, preexisting psychiatric disorders, family history, childhood trauma, exposure to violence, race-related stressors, lack of support, and under-utilization of mental health services has yet to be

systematically examined (Breslau, 2002; Vernberg, LaGreca, Silverman, & Prinstein, 1996). A host of factors including racism and discrimination may render ethnic minority individuals more prone to negative outcomes resulting from disasters. The examination of race-related stressors that include social and economic effects of racial prejudice or stigmatization as well as bicultural identification (Jones, Brazel, Peskind, Morelli & Raskind, 2000; Loo, 2003) may be essential to the discovery of linkages between risk factors and symptom expression. In our program of research investigating the impact of fire, we have highlighted the need to study further the influence of gender, race, socio-economic status, social support, parent's reactions, and coping on African Americans functioning following trauma exposure (Jones & Ollendick, 2002).

Fourth, the question of whether expression of certain psychiatric disorders is the same across ethnic/racial groups has yet to be adequately addressed (Breslau et al., 1998; Kessler et al., 1995). This question can only be answered through systematic investigations targeting members of minority and marginalized communities by trauma researchers. For example, in a study by Perilla, Norris, and Lavizzo (2002) following Hurricane Andrew, culture was found to have an effect on the types of symptoms minority groups displayed. African Americans tended to express distress in terms of arousal, while Spanish-speaking Latinos were more likely to express distress in terms of intrusive thoughts. Consistent with this, African Americans have higher levels of cardiovascular reactivity in response to a wide assortment of behavioral stressors (Anderson, McNeily, & Myers, 1992; Parker & Jones, 1999). Lawson (2000) likewise suggested that PTSD symptom expression in African Americans might be different than in other racial groups and may result in misdiagnosis.

Fifth, treatment efficacy among these minority groups remains under-researched. The dearth of outcome studies including clinical trials, psychotherapy, and cognitive behavior

therapy has been embarrassingly great (Zoellner, Feeny, Fitzgibbons & Foa, 1999). Issues related to the retention of ethnic minorities in therapy have yet to be systematically examined (Rosenheck & Fontana, 1995).

Recognizing the importance of conducting research in these populations, we aimed in this chapter to identify (a) barriers to research among minority/marginalized communities and (b) solutions to facilitate the conduct of research with these populations following disasters.

Barriers to Research in Minority/Marginalized Communities

Mistrust

Perhaps one of the greatest barriers for researchers is the lack of trust. When asking a group of minorities why they did not participate in research, Roberson (1994) documented the three most frequent responses: fear, mistrust, and a lack of knowledge about scientific research. African Americans' fear and mistrust of researchers has been well documented. Gamble (1993) noted that, as early as the 1920's, African Americans avoided entering hospitals for fear of being used as test subjects. It is not unreasonable to suggest that African Americans' reluctance to participate in the white medical/scientific community's research programs may be a product of the historical relationship between them and Whites in the United States (in particular, the social and medical abuse that has been visited upon African American populations; Shavers-Hornaday, Lynch, Burmeister, & Torner, 1997). The horrific impact of the Tuskegee Study where infected African Americans were neither informed of their disease status nor treated (King, 1992) remains a constant reminder to this community of potential abuses of science. In a survey of 220 African Americans, Million-Underwood, Sanders, and Davis (1993) found that 57% of respondents were either (a) of the opinion that scientific research was unethical in the United States or (b) wary of scientific research although they required more information to make a definitive judgment.

Bonham (2002) also documented forms of distrust with other minority and marginalized populations. For instance, undocumented Latino immigrants reported fear of deportation and, therefore, were naturally wary of strangers who approached them to provide information on a given issue (Marín & Marín, 1991). A related reason Latinos may be wary of research is the fact that they are frequently targeted by unscrupulous business organizations (Marín & Marín, 1991).

Mistrust is also evident in the domain of treatment and impedes successful recruitment of minorities to research. For example, Corbie-Smith, Thomas, and St. George (2002) found that African Americans had a greater distrust of research than Whites even when controlling for social class. Mistrust of physicians, cultural misunderstandings, misdiagnoses of illnesses, and financial constraints collectively contribute to mistrust on part of the minority groups (Boulware, Cooper, Ratner, LaVeist & Powe, 2003; Johnson, Saha, Arbelaez, Beach & Cooper, 2004).

Access

There are several barriers to access for researchers interested in working with minority or marginalized populations. These populations may not be familiar with the research process and may have limited time to talk to researchers. Additionally, the array of social, demographic, and geographic barriers also prohibit racial and ethnic minorities from receiving needed attention following disasters.

Culture and Linguistics

The third major barrier relates to culture and linguistics. Disaster researchers' lack of attention to issues related to these constructs has left huge gaps in their knowledge base and ability to work effectively with marginalized populations. Researchers' inability to address issues related to culture is a major hindrance to progress in this area. For example, their lack of understanding and appreciation of constructs of thoughts, communications, actions, customs,

beliefs, values, and institutions of those represented in marginalized, minority and underserved groups seriously jeopardizes their access to these groups. Without careful consideration to culture, our research paradigms, data collection methods, and interpretation of findings will continue to be significantly flawed. The interpretation of variables including gender, social support, coping, family environment, and family composition must all be examined through “cultural lenses” if valid conclusions are to be drawn.

Language has also proven to be a major barrier for non-English speaking individuals to mental health research and care. Language refers to words, syntax, and local idiomatic expressions as well as symbols and concepts shared by the cultural group (Jones et al., 2001). For example, a major obstacle for Hispanic and Asian Americans is the absence of bilingual mental health workers. Nearly 1 out of 2 Asians Americans has difficulty accessing mental health treatment because they do not speak English or cannot find services that meet their language needs (U.S. Department of Health and Human Services, 2001a). This shortcoming is certainly mirrored in many disaster research efforts.

Consequences of linguistic problems have resulted in misdiagnosis and poor quality of treatment (Norris & Alegria, 2005). Frequently, immigrants who have trouble communicating in English are more likely not to receive care (Norris & Alegria, 2005). Additionally, many instruments used in assessment rely on an understanding of the English language, which makes it impossible for a non-English speaking individual to participate in research activities. Consequently, there is a strong need to devise appropriate instruments for Latinos and others (Perilla et al., 2002). Furthermore, understanding the meaning of body language, gestures, postures and inflections within a minority group may increase rapport.

Summary of Barriers

These challenges present major obstacles to research, among minority and marginalized communities, including recruitment of study participants and enrollment of participants into treatment research. Solutions to overcome these obstacles are becoming of even greater importance in light of the fact that the United States is becoming more ethnically and racially diverse than ever before (Betancourt, Green, & Carrillo, 2002). However, there are potential solutions that can help researchers overcome these barriers, as discussed in the following section.

Solutions

In light of the fact that there exists no empirically validated model that spells out guidelines for addressing issues related to mistrust, access, and culture/language in disaster research, we are proposing such a model entitled: “Cultural Competence Model for Accessing Minority and Marginalized Communities Affected by Disaster” (Figure 1). This working model is based on the “dose-response” notion whereby the greater the impact of the disaster, the greater the likelihood of more negative outcomes. This model is similar to our model used in our exploration of child and adult survivors of residential fire (see Jones & Ollendick, 2002). In this model, the relationships between the “Event” and the “Outcomes” are influenced (mediated or moderated) by the availability of resources (i.e., trust, access, and cultural/linguistic capabilities) to address challenges that have long plagued minority communities. With reference to the third step in the model, “Resources,” we hypothesize that the extent to which such resources are afforded by the culturally competent approach, the greater the likelihood that challenges will be lessened. Consequently, “Outcomes” at the Acute, Data Analytic and Recovery phases will be more desirable.

FIGURE 1 HERE

A major predictor of success within this model is a culturally competent perspective. Betancourt et al. (2002, p. V) defined cultural competence as “the ability of systems to provide care to patients with diverse values, beliefs, and behaviors, including tailoring delivery to meet patients’ social, cultural, and linguistic needs.” We strongly suggest that a cultural competence perspective serve as the lens through which disaster-related initiatives are conceptualized and implemented. If disaster researchers are serious about learning more about the nature and course of the impact of disaster on minorities and marginalized communities, it is essential that such a framework be adopted. We feel that its adoption and implementation will lessen the negative impact of the obstacles of mistrust, barriers to access, and cultural and linguistic challenges. Solutions for each challenge will be presented in turn.

Mistrust

From the perspective of our model, the following three suggestions are presented which may assist in remedying issues resulting from mistrust. First of all, the reader is directed to the list of recommendations in Table 1 for a list of very practical suggestions including assessing and discussing levels of distrust, involving community gate keepers, and articulation of the research project’s benefit to community members. Secondly, it is important to recognize the fact that there is a problem. As researchers and mental health professionals, we can ill afford to continue to deny the fact that negative practices with reference to minorities exist. While there is indeed a role to play on the part of minorities (e.g., voicing problems resulting from disaster and seeking help), the bulk of the responsibility is on the part of the mental health professional. After all, our mission is to assist and help those who fall prey to the vicissitudes of disasters.

TABLE 1 HERE

Third, it is paramount that the reader recognizes that maximal participation of minority and marginalized groups in research efforts will be forthcoming in instances where meaningful relationships have been forged and are operative prior to the event. No matter how rudimentary or firmly established these relationships might be, their presence is essential to ensure success in times of crisis. During and after disasters, individuals are most likely to turn to trusted and enduring support systems where previous successes have been demonstrated. The prerequisite for any type of meaningful entry into communities is the development of relationships.

For this purpose, it is useful to consider the conceptual framework for the National Academic Centers of Excellence for Youth Violence Prevention (ACE), which offers the following suggestions. First, the establishment of a participatory process consisting of diverse local, state, and national stakeholders was recommended. Having key representatives of minority and disadvantaged populations at the table during the early planning phases of projects is imperative and is also an important element of the cultural competence model. Secondly, the requirements of relationship building and careful planning are also key components of this model and are essential prerequisites for successful ventures with minority communities.

Another essential component of this model is building capacity. Requiring researchers to work hand in hand with a variety of individuals within a given community, ranging from laypersons to professionals, is a major component for relationship building. For example, from the initial stages of forming consensus on “the plan of action,” to the actual obtainment of data following disaster, researchers should openly and consistently solicit input from community partners. The openness of the researcher to receive input from the targeted group, at any point in the process, should have an important impact on communities’ acceptance of various aspects of the project. A culturally competent team, sensitive to the unique needs of a given community,

should play a major role in the training, mentoring and provision of technical assistance to community participants. Once the data are collected and analyzed, input from these community partners in the interpretation of findings as well as their translation into practice and policy should be obtained.

Given that cultural sensitivity is a sine qua non of these types of efforts, a second example is in order. Israel, Schulz, Parker, and Becker (1998) described a collaborative approach to community-based research in which studies are conducted in community settings utilizing input and active participation of actual community members in the research process. Israel et al. (1998) cited multiple features and benefits to community-based research approaches. These research designs build on the strengths and pre-established networks already in place within the community. Additionally, a collaborative partnership is facilitated between researchers and community members, thereby increasing ownership and control of the studies being conducted. Another benefit of community-based research designs is that they involve partnerships of individuals with a diverse array of skills. This wide selection of different skills is often quite valuable at solving the complex problems addressed by community-based research designs. When formed and implemented correctly, collaborative community-based research designs can be an effective way to work with individuals in minority and marginalized communities.

Access

A number of very practical suggestions are provided in Table 1. Readily adaptable strategies targeting a variety of practical issues include using publicity campaigns to recruit participants, use of door to door recruitment, and providing transportation to research sites as well as incentives for participation. An additional course of action is the use of educational efforts to enhance potential participants' involvement in the research study. Information

regarding the research process, as well as the relative benefits of data collection to community members, is a vital step in gaining access to these communities. The need for individuals to become aware of the relative merits of sharing their experiences during the disaster as well as their resulting fears and needs (both psychological physical) is of vital importance. Both the recovery, on the part of survivors, and knowledge to be gained by the research can be facilitated.

A fairly successful strategy was implemented in our National Institutes of Mental Health (NIMH) funded project designed to assess the impact of residential fire. In light of the fact that African Americans are among those most at risk to experience injury and death resulting from fires, access to this was group was essential. Therefore, to gain the acceptance of churches and/or church members we incorporated a religious component within our protocol to capture “culturally sanctioned ways of coping.” More specifically, a measure of religious coping was administered where questions pertaining to the role of prayer, attending church, and looking to religious leaders in times of crises were examined. When approaching various religious organizations, we were able to inform them of the inclusion of these questions, with the goal of determining the relative role of such religious practices on their recovery. Given that we found this practice to be particularly helpful, we strongly advocate for the inclusion of instruments that tap culturally specific modes of dealing with disasters.

The extent to which the researcher’s goals overlap with those of community members may do much to enhance participation. Addressing the age-old questions of “what’s in it for me?” up front and in a straightforward manner is likely to enhance participation even in the face of historical challenges. For instance, if parents are informed that disasters have been found to interfere with academic performances of some children, they may be open to finding out how their child’s academic performance might have been affected. Consequently, their willingness to

participate might be greatly enhanced. If intervention strategies are promised following assessment, this may be an even greater reinforcer for those whose children might benefit.

In communities where such elaborate cultural competent systems are yet to be established, a similar approach can be taken whereby disaster studies may be endorsed by, and carried out in, culturally sanctioned entities. For example, in several investigations designed to assess the impact of fire-related trauma on children and their families, we found a great resource within the culture of the Red Cross. That is, after informing Red Cross officials of our work and its potential to develop a knowledge base regarding the psychosocial impact of disaster on families, they not only embraced several of our projects, but also provided actual sites where we were able to recruit and interview participants. The essential point here is that conceptualizing existing cultures as resources can provide another means of gaining access to minority communities. We should add that this strategy is particularly applicable to situations where relationship were not previously established. The leveraging of existing entities within communities may be the most effective route to pursue.

Culture/Linguistics

Table 1 provides several suggestions to address issues related culture/linguistic challenges in research. These challenges are similar to those faced by practitioners. The U.S. Department of Health and Human Services' (HHS) Office of Minority Health (OMH) established a set of fourteen standards to ensure that all people receive equitable and effective health care. (U.S. Department of Health and Human Services, 2001b, 2001c). Gleaning from the standards proposed, we feel that the following recommendations would aid research teams interfacing with minority communities: (a) ensure that all participants are treated respectfully in a manner compatible with one's culture, health beliefs and practices, and preferred language; (b)

include, retain, and promote individual representatives of the traumatized community on the research team; (c) ensure that all members of the research team receive ongoing education and training in culturally and linguistically appropriate service delivery or research; (d) offer and provide language assistance capabilities, including bilingual members and interpreter services to all participants with limited English proficiency, at no cost; (e) develop, implement, and routinely assess a written strategic plan outlining goals, policies, and systems of accountability to engage culturally and linguistically appropriate research; (f) use culturally and linguistically appropriate measures and assess participants' satisfaction with such measures; and (g) establish collaborative partnerships with traumatized communities where individuals representative of these communities are involved in the designing and implementing of research initiatives.

In summary, if research participants of color are to be ensured culturally and linguistically appropriate inclusion, it is incumbent upon the research team to systematically implement the above recommendations. Furthermore, interviewers need to understand the meaning of body language, gestures, postures and inflections within minority group as to enhance the overall effectiveness of the interview process.

Summary

Challenges of conducting research in minority and marginalized communities include mistrust on the part of minorities toward researchers as well as the mental health system, the lack of access, and cultural and linguistic issues. These barriers are best addressed through the adoption of attitudes, behaviors, and processes embedded within culturally competent approaches. The benefits of a culturally competent framework to the trauma researcher are enormous. The wealth of resources resulting from relationship building, engagement of indigenous professionals, paraprofessionals and community leaders, sensitivity in the training,

mentoring and provision of technical assistance to participants and “openness” of the researcher to receive input from the community are certain to enhance the quantity and quality of interaction between the traumatized communities and researchers. It is hoped that this union will do much both to enhance our knowledge of the impact of disasters on these groups and to enable mental health professionals to better assist them during the recovery process.

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Table 1

Recommendations for Overcoming Barriers in the Conduct of Research with Minority and Marginalized Communities

Mistrust/Beliefs

- Assess & discuss levels of mistrust.
- Find community gatekeepers and request their involvement.
- Interact with leaders & members of target community.
- Build rapport by establishing bonds with members of the community.
- Include representatives from the target groups as part of the research team.
- Use People of Color and individuals from marginalized communities as role models.
- Understand current needs & realities of target group.
- Recognize and respect differing cultural beliefs and practices.
- Recognize the importance of churches and other community organizations as legitimate support systems.
- Contact people personally when possible.
- Articulate the fact that the program will benefit the target group.
- Demonstrate how the benefits will outweigh risks.
- Ensure research will be conducted ethically.
- Assure all data are confidential & will be used for research only.
- Use culturally sensitive instruments.

Barriers to Access

- Find study sites proximate to communities/convenient location.
- Use publicity campaigns directed at minorities.
- Use door-to-door subject recruitment.
- Develop convenient hours of operation.
- Provide/find transportation services to research/treatment sites or reimbursement for transportation costs.
- Provide financial assistance, fee waivers, & incentives.

Culture/Linguistics

- Develop, implement, and assess specific plans that outline goals, policies, and systems of accountability when engaging in culturally and linguistically appropriate services.
 - Train all research team members in culturally and linguistically appropriate service delivery and research methods.
 - Appropriately translate and interpret research materials and measures when research participants are not comfortable with the English language.
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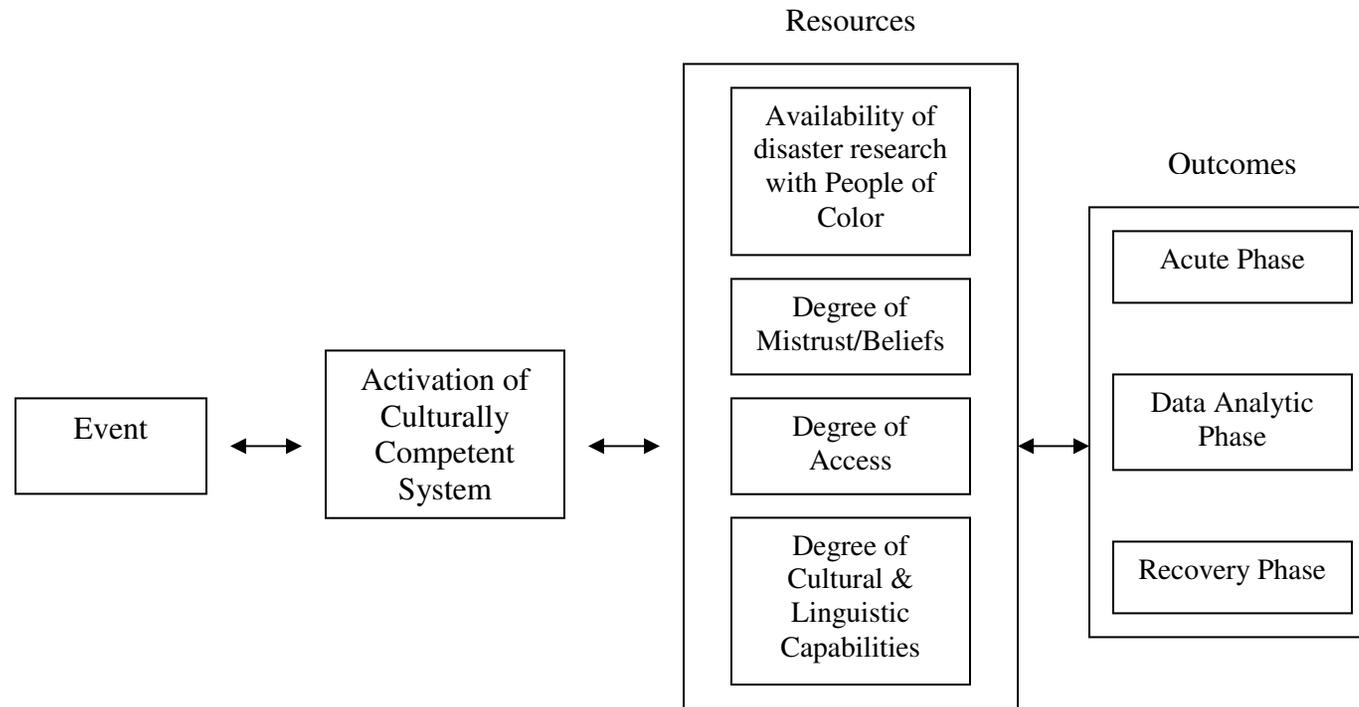


Figure 1. Cultural competence model for accessing minority and marginalized communities affected by disaster.