

SAMHSA

**Disaster Technical Assistance Center
Supplemental Research Bulletin:
Challenges and Considerations in
Disaster Research**

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INTRODUCTION

Disaster research allows professionals in the field to advance existing preparedness, response, and recovery practices. It is important to study the impact of disasters on behavioral health to identify the emergence of psychopathology and to develop mental health interventions to prevent or mitigate the traumatic effect. However, this specific type of research comes with many ethical and methodological challenges that may dissuade or hinder its execution, such as funding and timing constraints, environmental concerns, risk for disaster survivors, and the public perception of conducting research during a time of distress (Knack et al., 2006). The primary dilemma faced by researchers is safely balancing the pursuit of answers to their questions with the serious and immediate needs of survivors (Benight et al., 2007).

This issue of SAMHSA Disaster Technical Assistance Center's *Supplemental Research Bulletin*, "Challenges and Considerations in Disaster Research," addresses the ethical and operational concerns in research design, participant recruitment, data collection, and data interpretation during disaster research. The purpose of this issue is for researchers to learn about and anticipate procedural challenges that can only be overcome by prior planning, including having a research team properly trained in and prepared for the unique aspects of disaster research (Lavin et al., 2012). The following challenges and considerations will be discussed in this issue:

- 1. Risk-benefit analysis**
- 2. Funding**
- 3. Institutional Review Board approval**
- 4. Participant recruitment**
- 5. Informed consent**
- 6. Emotional distress of participants**
- 7. Participant tracking**
- 8. Researcher safety and distress**
- 9. Cultural sensitivity**
- 10. Environmental factors**
- 11. Generalizability**
- 12. Disaster Response and Recovery Funding Opportunities Relevant to Behavioral Health**

Note: This issue identifies major concerns from recent investigations in this area. The recommendations presented do not reflect a complete review of experiences in the field or a comprehensive summary of solutions, but provide an overview of challenges and offer strategies for consideration.



RISK-BENEFIT ANALYSIS

A disaster event can impair a person's ability to prepare for, cope with, and recover from life stressors (Ferreira et al., 2015). There may also be additional risks for survivors participating in a research study. Researchers must be aware that some populations are more likely to experience greater risk as participants such as children, the elderly, those with past trauma or mental health diagnoses, and the socially and medically vulnerable. Therefore, researchers should carefully consider how their work could be structured to minimize potential risks to the participants (Fleischman et al., 2002; Knack et al., 2006; Lavin et al., 2012).

Collogan et al. (2004) discussed the numerous risks involved when participating in disaster research including "physical harm, inconvenience, legal action, economic hardship, psychological discomfort, loss of dignity, breach of confidentiality, and unwanted media attention" (p. 367). They believed that a research study should balance the potential risk of participation with protective measures meant to alleviate burden and distress. They suggested the recruitment of representatives from the affected community may promote greater safeguards for participants during the planning process. The risk-benefit ratio used should also consider the novelty of the research question and its necessity to the field. However, further research is needed to assess the risk and benefits of participating in disaster research, its effect on participants, and expectations about participation versus the reality of the experience.


Ferreira et al. (2015) discussed two theoretical principles that can guide disaster research with vulnerable populations: utilitarianism and social justice. A researcher's goal should be to help the greatest number of people as possible and contribute to the greater good. "The idea is that research is needed on disaster survivors, despite their status as a vulnerable population, so that services and programs can be refined for both future disasters and to streamline services for a current disaster" (p. 32).

The principle of social justice is incorporated into this research by providing vulnerable populations an opportunity to express their concerns, reveal and address inequities, and promote fair treatment in the current and future allocation of resources.

FUNDING

A major obstacle in disaster research is funding, in part because data are typically time sensitive. Richardson et al. (2009) found that the urgency of data collection combined with the chaotic disaster environment hindered many of the authors' ability to find and apply for research funding, which even led to some authors funding portions of the research activities themselves. Future disaster researchers are advised to search for funding opportunities and seek input on research design before a disaster strikes. However, sometimes funding opportunities do not become available until after the large-scale impact of the disaster is witnessed.

After Hurricane Katrina, a variety of governmental, nongovernmental, and academic agencies—such as the National Institutes of Health (NIH) and the National Science Foundation—funded studies assessing the disaster's impact through rapid response grants (Henderson et al., 2009; Richardson et al., 2009; Giarratano et al., 2014). When Hurricane Sandy hit in 2012, it became the 2nd costliest hurricane in U.S. history. In October 2013, the Centers for Disease Control and Prevention, along with the U.S. Department of Health and Human Services (HHS) Office of the Assistant Secretary for Preparedness and Response, and National Institute of Environmental Health Sciences awarded \$7.1 million in grants to support



research to aid the long-term recovery in areas hard hit by the storm. Funded under the Hurricane Sandy Recovery and Rebuilding Supplemental Appropriations Act of 2013, these grants are unprecedented and represent the first time HHS has funded research needed by local communities to support long-term disaster recovery efforts.

INSTITUTIONAL REVIEW BOARD APPROVAL

Federal law requires all human subject research to be reviewed and approved by an Institutional Review Board (IRB). IRBs are tasked with considering the overall burden to those participating in the research study and ensuring that safeguards are in place to combat it. Burden could occur because of the nature of preexisting factors, the exposure to a disaster event, participating directly in the research, or being asked to participate in multiple studies (Collogan et al., 2004). Lack of coordination among disaster researchers may lead to research redundancy and participant research burnout (Richardson et al., 2009; Barron Ausbrooks et al., 2009; Lavin et al., 2012). The National Institute of Mental Health advises coordination and collaboration among researchers and IRBs to minimize and stay sensitive to this burden on disaster survivors (NIH, 2007). For example, after the bombing of the Alfred P. Murrah Federal Building in Oklahoma City in 1995, the University of Oklahoma Health Sciences Center served as the single entity approving research involving the survivors to protect those affected, maximize knowledge gained, improve coordination, minimize burden on participants, and facilitate fair dissemination of clinical treatment to the population (North et al., 2002).


The process for IRB approval can take up to 6–8 weeks, which has significant implications in disaster research (Barron Ausbrooks et al., 2009). Benight et al. (2007) warned researchers not to get engrossed in the immediate needs and sense of urgency that happens after a disaster. Instead, before a disaster occurs, researchers should study and derive questions from previous research. Ferreira et al. (2015) advised researchers to begin the IRB application process as quickly as possible and to inform the IRB about an upcoming submission. Researchers can decrease IRB approval time by submitting protocols (instruments and proposed methodology) in advance of a disaster event.

PARTICIPANT RECRUITMENT

Knack et al. (2006) discussed the difficulty in participant recruitment during Hurricane Katrina. “In the days immediately following the hurricane, survivors could be found in most shelters and in many makeshift shelters such as churches and large stadiums. Reaching potential participants during the days immediately following the hurricane [was] unrealistic. For example, many survivors were without food, water, clothing, or toiletries” (p. 178).

It is not only ethical, but practical for researchers to allow for survivors’ basic needs to be met, as this may also facilitate greater willingness to participate in research studies (Ferreira et al., 2015). Compensation for research participation is a major ethical concern in disaster research because it could lead to intentional or unintentional coercion by the researcher (Knack et al., 2006). Lavin et al. (2012) recommended that disaster survivors should not be monetarily compensated, but instead, researchers could help connect them with information or refer them to resources.

Lessons learned from the 2005 tsunami in Southeast Asia and Hurricane Katrina reminded researchers of why it is necessary to understand and address the historical context of the affected community, as



those with limited resources were unable to evacuate and faced the greatest need (Benight et al., 2007). Underserved racial and ethnic minorities may be at greater risk of devastation after a disaster because of their lower levels of preparedness and limited recovery resources and access to aid relative to the majority population (Andrulis et al., 2007; Eisenman et al., 2007). Researchers should not take advantage of survivors' desperation or counteract any relief efforts in progress (Lavin et al., 2012; Collogan et al., 2004).

Knack et al. (2006) suggested that researchers could volunteer their time to assist in the relief efforts as an opportunity to help and build rapport with survivors. Securing research participants may involve persuading disaster survivors, and sometimes response workers as well, of the benefits of the study. Benight et al. (2007) advised researchers to pursue cooperative agreements or at least engage in dialogue with local entities such as government, nongovernmental organizations, or universities in the affected region. This practice provides an opportunity to address any ethical concerns, promotes the transfer of knowledge, and may assist the researcher in participant recruitment.

INFORMED CONSENT


The decisional capacity required for disaster survivors to participate in research studies varies depending on the nature of the research question, complexity of the choice, and the potential risks involved with participating. Collogan et al. (2004) believe it is inaccurate to assume that all disaster survivors have impaired decision-making capacity, especially when evidence has shown that those with acute stress disorder and posttraumatic stress disorder do not generally possess diminished capacity. Rosenstein (2004) noted that while most trauma survivors are capable of making informed, autonomous decisions, researchers should incorporate safeguards in the study to accommodate survivors' decision-making capacity or to remove impaired individuals from the study altogether.

Researchers can use screening tools or assessments such as the MacArthur Competence Assessment Tool for Clinical Research (McCAT-CR) in addition to behavioral observations to determine if an individual has cognitive impairments or may be susceptible to a negative reaction (Ferreira et al., 2015; Collogan et al., 2004). NIH (2007) also encourages the use of capacity assessment tools before participation is allowed and suggests the continued monitoring of capacity over time.

Another factor in ensuring voluntary and informed consent is the perception of research participation. Survivors may feel pressured to participate in disaster research because of the heightened sense of patriotism and civic duty after a disaster. There may also be a "therapeutic misconception" by the participants if they believe they are receiving clinical care when they are not (Collogan et al., 2004, p. 368). NIH advises researchers to seek consent in a safe and controlled setting to facilitate an informed decision-making process for potential participants. Those determined to be eligible for the study must be informed about the study's purpose, its methodology, genuine benefits, potential risks, and methods to ensure confidentiality before participating to adhere to ethical and IRB standards.

EMOTIONAL DISTRESS OF PARTICIPANTS

Participating in disaster research may be upsetting to survivors, but not as significantly upsetting as the disaster itself (Collogan et al., 2004). Legerski et al. (2010) conducted a review of the literature and believed there was no evidence to suggest that participating in trauma-focused research could cause



emotional distress. Some evidence showed that research participants preferred, and experienced lower levels of distress with, certain methodologies such as interviews and questionnaires compared to psychological assessment measures and other data collection procedures. Yet, any distress experienced by a participant during or after the study was not long term, and most did not regret participating. The authors did acknowledge the potential for self-selecting bias from those research participants that chose to be part of trauma studies.

As a safeguard, researchers can regularly consult with a mental health practitioner or be trained on how to address emotional distress, most often through referral to appropriate mental health services (Ferreira et al., 2015; NIH, 2007; Collogan et al., 2004).

PARTICIPANT TRACKING

Tracking research participants after a disaster event may be difficult because of limited access to communication devices and temporary living arrangements. This circumstance can lead to research bias because those individuals most able to return to the study, either through greater access or motivation, may not adequately represent the desired sample (Lavin et al., 2012). Lavin et al. (2012) advised researchers to have multiple contingency plans to address these logistical concerns.

Researchers need to have a plan for contacting participants when they move, either by ensuring the participant has the researcher's contact information or by securing relationships and lines of communication with governmental entities, the American Red Cross, or other disaster relief agencies before the disaster. However, to safeguard the survivors' privacy, researchers should ensure agencies request permission from survivors before sharing contact information (Knack et al., 2006).


RESEARCHER SAFETY AND DISTRESS

Lavin et al. (2012) discussed the impact disaster research has on researchers in the field: "What adversely impacts the [research] participant will also adversely impact the researcher so it is critical to be aware of what participants experience and plan in advance to be able to cope with such difficulties" (p. 7).

The researchers' physical safety also poses a serious concern in the chaotic setting of disasters (Henderson et al., 2009). Because most researchers are not trained responders, they should be prepared beforehand to work in an adverse environment so as to not be a burden during the disaster (Lavin et al., 2012). Knack et al. (2006) offered suggestions to promote researchers' safety, such as working in pairs or trios, and advising teams to collect data in shelters or university campuses instead of apartments or residences. Collogan et al. (2004) suggested researchers should train and support research staff who will be exposed to distressing topics discussed by research participants. Researchers may also consider using technology to study and deliver interventions to disaster survivors to circumvent this challenge. For example, Steinmetz et al. (2012) conducted and assessed a trial, self-help Internet intervention for survivors of Hurricane Ike to decrease negative reactions and increase coping skills.

CULTURAL SENSITIVITY

Mukherji et al. (2014) examined three research projects conducted after the 2001 Gujarat earthquake in India, 2011 Japan earthquake and tsunami, and the 2010 Haiti earthquake to assess fieldwork challenges in post-disaster settings. They emphasize that it is critical to understand participants' language and its



nuances for field interviews and translating research instruments. However, because of limited resources, onsite interpreters may be unavailable to assist. Researchers that have relationships with local agencies or institutions may seek assistance in locating a suitable translator. Having at least one colleague familiar with the affected areas leads to more culturally appropriate procedures in sample recruitment and instrument development (Henderson et al., 2009).

Varying literacy levels may affect survivors' ability to participate. Those with limited education may be unable to read or understand technical jargon relevant to informed consent or instructions for participation. The IRB requires all materials to be translated to the local language at a reading level that is acceptable to those participating. In addition, consent may need to be verbally recorded to accommodate individuals who cannot read or have difficulty understanding the material (Mukherji et al., 2014).

Knack et al. (2006) also discussed how diversity of the disaster survivors and the devastation they experience requires researchers to assess the appropriateness of measurements used and the interpretation of findings. The authors caution researchers against using instruments not validated for diverse samples in terms of language and culture. In addition, after a disaster, survivors may respond differently (i.e., with greater negativity) to questions than they normally would. The interpretation of research findings should account for this environmental factor to minimize response bias. In addition, researchers may enter situations that require sensitivity to gender, culture, power dynamics, and other biases. Maintaining awareness and respect for these differences could potentially prevent methodological and ethical issues within any study (Ferreira et al., 2015).

ENVIRONMENTAL FACTORS

While disasters provide a uniquely natural opportunity to study causation on a population level, their unpredictability restricts interpretation of the true nature of changes caused by the disaster unless pre-disaster information is available (Galea et al., 2008). Post-only designs limit researchers' ability to determine the degree to which disasters affect the behavioral health of survivors and communities. A post-disaster environment is also challenging because the location of the study is not known beforehand, so the study design is usually developed quickly and without comprehensive knowledge of the situation (Henderson et al., 2009). Disasters affect infrastructure and social systems, causing establishments such as hospitals, clinics, schools, local service agencies, businesses, and public transportation to become unstable. Interruptions in service may lead to problems if these resources are integral to research implementation. Giarratano et al. (2014) cautioned researchers to understand that there may be a "new normal" after a disaster, which can change service access and delivery for years. The authors also suggested researchers seek data from studies already in progress before a disaster for baseline data that can be quickly adapted to include new measurements to address the new research objectives.

GENERALIZABILITY

Knack et al. (2006) addressed the issue of data interpretation in disaster research. The authors cautioned the field about the possibility of overgeneralization because study results obtained in disaster situations may be context dependent and generalize only to similar events and populations. Researchers are advised to review existing literature to determine the generalizability of their findings. Replication of results provides greater clarity on generalizability.



CONCLUSION

The keys to addressing any of the challenges of conducting disaster research are foresight and preparation. Few researchers have sought to empirically tackle ethical or methodological considerations for this type of research, instead broaching the topic as anecdotes in their studies. It is important to account for the urgent nature of post-disaster settings because it can impede the ability to locate and pursue funding streams and force rapid research design and implementation. Ethical practices around informed consent, privacy, confidentiality, cultural sensitivity, and researcher and participant distress must be carefully considered and planned for, given the chaotic nature of post-disaster environments. Disaster research provides a unique opportunity to study behavioral health impact on large and diverse samples; however, generalizability of research findings must be rooted in the context of the situation and may not be broadly applied.



APPENDIX: DISASTER RESPONSE FUNDING OPPORTUNITIES RELEVANT TO BEHAVIORAL HEALTH

Following is a list of emergency response and recovery funding opportunities that may provide an opportunity for researchers to become involved in national, state, and local disaster response activities in the United States.

Crisis Counseling Assistance and Training Program (CCP)

U.S. Department of Homeland Security, Federal Emergency Management Agency (FEMA)

U.S. Department of Health and Human Services (HHS), Substance Abuse and Mental Health Services Administration (SAMHSA)

Website: <http://www.samhsa.gov/dtac/ccp>

Brief Description: The CCP is a supplemental assistance program administered through a partnership with FEMA and SAMHSA. The CCP supports short-term interventions that involve the counseling goals of assisting disaster survivors in understanding their current situation and reactions, mitigating stress, assisting survivors in reviewing their disaster recovery options, promoting the use or development of coping strategies, providing emotional support, and encouraging linkages with other individuals and agencies who may help survivors in their recovery process.

SAMHSA Emergency Response Grants (SERG)

HHS, SAMHSA

Contact SAMHSA's Emergency Coordinator; 240-276-2244 or terri.spear@SAMHSA.hhs.gov

Brief Description: SERG funding enables public entities to address mental health and substance abuse needs when existing resources are overwhelmed by an emergency and other resources are unavailable. The incident does not need to result in a presidentially declared disaster. Recently, SERG funded recovery activities in response to the Aurora theater shooting in Colorado.

Disaster Case Management

U.S. Department of Homeland Security, FEMA

HHS, Administration for Children and Families

Website: <http://www.acf.hhs.gov/programs/ohsepr/disaster-case-management>

Brief Description: The Disaster Case Management Program is a federally funded supplemental program administered by FEMA that is available after an Individual Assistance Presidential disaster declaration. Disaster Case Management provides relief to disaster survivors by connecting them with resources and services available from multiple agencies, including the development of individual recovery plans that incorporate sustainable assistance for the household's recovery.



Project School Emergency Response to Violence (SERV)

U.S. Department of Education, Office of Elementary and Secondary Education

Website: <http://www2.ed.gov/programs/dvppserv/index.html>

Brief Description: SERV from the U.S. Department of Education funds short-term and long-term education-related services for local educational agencies and institutions of higher education to help them recover from a violent or traumatic event in which the learning environment has been disrupted.

Disaster Assistance for State Units on Aging and Tribal Organizations in National Disasters Declared by the President

Administration on Aging, Administration for Community Living

Website: <http://www.grants.gov/web/grants/view-opportunity.html?oppld=279744>

Brief Description: Grants awarded under this announcement are to provide disaster reimbursement and assistance funds to those State Units on Aging and federally recognized tribal organizations who are currently receiving a grant under Title VI of the Older Americans Act. These funds only become available when the president declares a national disaster and may only be used in those areas designated in the disaster declaration issued.

Extension Service Post-Crisis Education and Assistance

U.S. Department of Agriculture, Cooperative State Research Education and Extension Service

Website: <http://articles.extension.org/disasters>

Brief Description: The agency's Extension Disaster Education Network provides post-crisis education and assistance to individuals, families, farm operators, small businesses, rural communities, and local leadership in the immediate aftermath of a disaster.

Crime Victim Compensation Grant Program

U.S. Department of Justice (DOJ), Office for Victims of Crime (OVC)

Website: <http://ojp.gov/ovc/grants/types.html#formulagrants>

Brief Description: Victims of Crime Act formula grants for crime victim compensation are awarded to every state, the District of Columbia, the U.S. Virgin Islands, and Puerto Rico. The grants supplement state funds that reimburse victims for out-of-pocket expenses resulting from the crime.

Antiterrorism Emergency Assistance Program

DOJ, OVC

Website: <http://ojp.gov/ovc/grants/types.html#antiterrorism>

Brief Description: The Antiterrorism Emergency Assistance Program offers assistance to victims of terrorism and mass violence by providing funding through crisis response grants, consequence management grants, criminal justice support grants, crime victims compensation grants, and training and technical assistance during the aftermath of a crisis. Federal funding is administered on a case-by-case



basis but is eligible to international, national, military, tribal, state, and local victim assistance and criminal justice agencies and other professional organizations.

Robin Hood Foundation

Website: <https://www.robinhood.org>

Brief Description: Robin Hood is New York’s largest poverty-fighting organization and since 1988 has focused on finding, funding, and creating programs and schools that generate meaningful results for families in New York’s poorest neighborhoods. After Hurricane Sandy in 2012, Robin Hood organized a relief fund for hundreds of organizations in New York, New Jersey, Long Island, and Connecticut to support communities in need. As of February 25, 2014, Robin Hood collected \$74.7 million in donation.



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