

Ethical Considerations for Conducting Disaster Research with Vulnerable Populations

Regardt J. Ferreira, Ph.D.

Tulane School of Social Work, Tulane University, New Orleans

Research Fellow, Department of Social Work, University of the Free State, South Africa

rferrei@tulane.edu

Fredrick Buttell, Ph.D.

Tulane School of Social Work, Tulane University, New Orleans

buttell@tulane.edu

Sandra B. Ferreira, Ph.D.

Department of Social Work, University of the Free State, South Africa

ferreirs@ufs.ac.za

Journal of Social Work Values and Ethics, Volume 12, Number 1 (2015)

Copyright 2015, ASWB

This text may be freely shared among individuals, but it may not be republished in any medium without express written consent from the authors and advance notification of ASWB

Abstract

Worldwide there has been a significant increase in disasters the past decades, particularly in the United States. Due to the increased frequency of disasters, the field of disaster research has seen a corresponding increase in empirical studies involving human subjects. A large number of these studies include vulnerable populations. Study of these populations requires additional precautionary disaster research practices in order to align with ethical standards for research. This article has a dual purpose: Part I provides a better understanding of the vulnerability of populations associated with disaster research; Part II offers a framework for best practices in conducting disaster research with vulnerable populations.

Keywords: ethics, disasters, disaster research, research methodology, vulnerable populations

1. Introduction

Communities worldwide are affected by an increasing number of natural and technological (man-made) disasters (Myers & Wee, 2005). Over the past three decades, there has been a rapid increase in the number of disasters occurring worldwide, affecting communities, households and individuals. It is estimated that there is a disaster occurring, somewhere in the world, every day (Norris, Galea, Friedman, & Watson, 2006). This is particularly troubling given the rapid worldwide increase in disaster fatalities (Mileti, 1999; Wisner, Blaike, Cannon, & Davis, 2003; Baez, de la Fuente, & Santos, 2010; North, Oliver, & Pandya, 2012).

With this increased frequency of disasters worldwide, there has been a concomitant increase in interest in disaster research involving human subjects (Baez et al., 2010; Legerski, & Bunnell, 2010; Pfefferbaum et al., 2013). Humans have

suffered and endured disaster throughout history, but the scientific study of response to disaster is in many regards still in its infancy stages. Rigorous inquiry has been limited and is confounded by the chaos and extreme disruption inherent in disasters (Gulliver, Zimering, Carpenter, Giardina, & Farrar, 2014). Much of this existing research has been devoted to identifying why disasters occur and how they affect people. Disasters of epic proportions, such as the South East Asia Tsunami in 2004, the Haiti Earthquake in 2010, and Typhoon Haiyan in 2013, have caused the deaths of hundreds of thousands of people and catastrophically disrupted the lives of millions more. The United States is no stranger to disasters. The past 20 years are remembered for major disasters such as Hurricane Andrew in 1992, the 9/11 terrorist attacks in 2001, Hurricane Katrina in 2005 and Hurricane (or “Superstorm”) Sandy in 2012. These disasters have the distinction of negatively affecting the psychological and psychosocial well-being of first responders and those personally affected for a considerable time post-disaster. Current statistics indicate that there has been a significant increase in climate-related disasters (Henghuber, 2010; Guha-Sapir, Vos, Below, & Ponserre, 2011; Smith & Katz, 2013), which is a trend likely to continue.

Certainly, the issues of ethics and legal rights in disasters have been raised in the past by researchers (e.g., Soliman, 2010), but disaster research is a multidisciplinary field. This interdisciplinarity results in many different academic fields and professions being involved in conducting disaster related research. Unlike social work, which is a field of professional practice, not all of the allied professions can rely on an established code of ethics to guide this research with vulnerable populations. We believe that there should be adherence to an ethical standard of practice when conducting disaster research, and we propose the implementation of a universal code of ethics when conducting disaster research with vulnerable populations.

This article has two purposes. In Part I we aim to provide for a better understanding of

disaster-exposed populations that will make disaster researchers more aware of potential ethical concerns that may arise in their research with them. We highlight how the decision-making capacities of these populations differ significantly from those in other types of research involving human subjects (Stallings, 2002; Rosenstein, 2004). In Part II we propose best practices for conducting disaster research that are informed by the principles identified in Part I. Both parts are influenced by the perspectives of the authors. Two are social workers actively involved in disaster research, and the third is a social worker who serves as the chair of the IRB at Tulane University, a Carnegie I, research-intensive university.

2. Part I

2.1 Defining the target research population

People subjected to disasters, and thus available to be exposed to disaster research, tend to be more vulnerable than other types of research populations. Disasters affect a broad group of people. Depending on the focus of a particular study, the research participants could range from individuals who experienced primary exposure to a disaster (e.g., disaster survivors and first-line responders) to those who experienced secondary exposure (e.g., health care providers, mental health specialists, community rebuilders, or volunteers). The concept of vulnerability has become extremely elastic, capable of covering almost any person, group, or situation. This, in part, creates confusion among the research community as to how vulnerable populations exposed to a disaster differ from other potentially vulnerable populations (Levine, 2004).

Vulnerability as a concept in disaster research has its founding roots in biomedical research. The meaning of vulnerability within biomedical research embraces the restrictions of an individual’s or group’s capacity for judgment and the potential for coercion among populations that are closely or figuratively “captive.” Vulnerability arises when people might have the decision-making capacity, but there is a lack of power and

resources to make a truly voluntary decision. Importantly, current federal Human Research Protection policies have no specific category for disaster victims. The disaster literature offers a number of different definitions for vulnerable populations. Vulnerability can be described as the characteristics of a person or a group and their situation that affect their capacity to anticipate, cope with, resist and recover from the impact of a natural or man-made hazard, defined as an extreme natural event or process (Wisner et al., 2003). More broadly, vulnerability is a combination of factors that influence the extent to which livelihood, property and other assets are at risk, as a result of a discrete and identifiable event in nature or society. Vulnerability is thus the term that is used to describe different factors that may adversely affect people's capacity to deal with the specific disaster. Factors such as gender, age, disability, health status and other contextual life stressors affect vulnerability and shape people's ability to cope and survive in a disaster context (The Sphere Project, 2011; Wisner et al., 2003; Gillespie & Danso, 2010).

In the post-World War II era and through the late 1970s there was a shadow cast on research practices involving human subjects. The US government convened a commission in 1978 to investigate research practices involving human subjects. As a result of the findings, the Belmont Report was created and is still regarded as the ethical basis for the regulatory structure used to protect human subjects and particular vulnerable populations (U.S. National Commission, 1979; Collogan, Tuma, Dolan-Sewell, Borja, and Fleischman, 2004). The way the report defines vulnerable populations is that they are constituted by groups that might "bear unequal burdens in research" due to their "ready availability" in settings where research is conducted, "such as prisons, hospitals, and institutions." The report concluded that because of their vulnerability these groups required extra protections in the review process (Levine, 2004).

The Code of Federal Regulations developed in 1978 establishes protections for particular groups in research, namely children, prisoners, pregnant women and fetuses. The Code makes

reference to other populations who may have impaired abilities to make voluntary and willing decisions about their participation in research. These populations are those who are cognitively impaired or suffering from a mental disorder and those who are economically or educationally disadvantaged. The Code requires that if these vulnerable populations are included in research, some restrictions must apply. This may force an Institutional Review Board to impose procedural safeguards to protect the interests of the human subjects (Collogan et al., 2004; Rubin and Babbie, 2011).

Although not mentioned in the Code, participants in disaster research might be regarded as people who have limited decision-making capabilities (Soliman, 2010). This can be attributed to the psychological impact of being subjected to a disaster. The stressors of a disaster or traumatic event can cause a wide range of physical, behavioral, cognitive and emotional symptoms that can affect social interactions among the exposed disaster population (Norris et al. 2002; Myers & Wee, 2005; Newman, Risch, & Kassam-Adams, 2006; Barron Ausbrooks, Barrett & Martinez-Cosio, 2009). In essence, a disaster might turn otherwise healthy people into a vulnerable population. For example, in a review of studies on disasters and their particular impact on the mental health of the people experiencing them, Norris et al. (2002) found that 74% of human subjects experienced post-traumatic stress and one-third of the studies identified individuals who showed symptoms of depression.

Rosenstein (2004) states that the extent to which vulnerable populations are able to make capacitated and voluntary decisions to enroll in research should be taken into account when conducting research with vulnerable populations. Evidence suggests that extra precaution should be taken when including disaster-affected populations for research (Stallings, 2002; Barron Ausbrooks et al., 2009). There should be adherence to some form of ethical guidelines for inclusion when recruiting participants. Perhaps the largest ethical dilemma that arises is whether human subjects are "mentally fit enough" to be included in post-disaster research.

2.2 Ethical analysis: Incorporating utilitarianism and social justice

There are two complementary theories that both organize and underlie our ideas about research with vulnerable populations post-disaster: utilitarianism and social justice. The notion of utilitarianism emphasizes that any endeavor should strive to achieve the greatest amount of benefit for the greatest number of people (Freeman, 2000). Equally important is the idea that the moral worth of any action is solely determined by its resulting outcome. With the implementation of the ethical concept of utilitarianism in disaster research, it is essential that researchers should not only act in pursuit of their own goals (e.g., accomplishing their research objectives), but should consider the impact of their actions on the people they study. In brief, this is a “greater good” argument. The emphasis is thus on the results and end product achieved with the research. The results from the research should be seen as being beneficial for the greatest number of people possible (Freeman, 2000; Etkin & Davis, 2007). Translating the concept of utilitarianism into a disaster research setting allows researchers to conduct research with what we have argued thus far is the definition of a vulnerable population. Incorporating safeguards to protect victims of disasters allows for them to be studied. 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. Thus, research in one setting can serve both to improve the response in that situation and to improve aid in future disasters, and thus contribute to the greater good.

The second ethical principle applicable to disaster research is social justice. The needs of socially marginalized groups can be captured and addressed with social justice practices incorporated into disaster research (Soliman & Rogge, 2002). When conducting disaster research, the concept of social justice will allow for the identification and fair treatment of disenfranchised groups. The idea is to prevent their status as a marginalized

group from carrying over into both disaster-related research and service provision in ways that would further their oppression. For example, some groups during Hurricane Katrina did not receive evacuation orders in the wake of the greatest disaster in the history of the United States. Deploying the concept of social justice can ensure that all groups exposed to a disaster situation are considered for inclusion. Disaster research incorporating social justice practices may help address inequalities in society. Employing social justice practices when conducting research with vulnerable populations can help ensure that people’s rights are not overlooked as was the case with Hurricane Katrina. Social justice embodies the “equality principle,” which allows for each person in a society to have an equal right to the same amount of liberty as everyone else (Freeman, 2000; Sheng, 2004). Equality is necessary when conducting disaster research to ensure the inclusion of a wider spectrum of the population. Equality will limit bias toward certain groups in disaster research and ensure that marginalized groups are represented in research that may dictate both allocation of resources and future disaster services.

3. Part II – Ethical Recommendations for Conducting Disaster Research

When aiming to incorporate research ethics into disaster research practices with vulnerable populations, it is essential to consider ethical research recommendations. The complex nature of disaster situations creates the need for the inclusion of additional precautionary ethical recommendations. The New York Academy of Medicine and the US National Institute of Mental Health have identified four key recommendations for conducting disaster research (Sumathipala & Siribaddana, 2005). The recommendations are based on input from mental health practitioners, trauma researchers, public health officials, ethicists, representatives of institutional review boards, loved ones of victims and emergency personnel from the Oklahoma City and the World Trade center attacks in 2001. The four areas of critical importance identified are:

- Decisional capacity of potential participants that has been affected by a disaster or terrorist attack to be included in the research study,
- The vulnerability of research participants,
- Risks and benefits of participating in the intended research,
- Informed consent from participants.

Unfortunately, these recommendations are so broad as to not be terribly prescriptive, and they mimic existing institutional review board (IRB) requirements. The remainder of this article attempts to go further by providing practical advice for conducting research with vulnerable populations post-disaster. The seven recommendations listed below are for conducting ethical disaster research with vulnerable disaster populations. The recommendations are based on an extensive literature review, practice experience, and the perspective of the IRB.

3.1 Recommendation One: Time-frame—When is a good time to start and end a disaster research study?

3.1.1 *When to enter the field?*

There is no set time to start conducting post-disaster research (Norris, Galea, Friedman and Watson, 2006). Instead, there are a series of questions one must ask about balancing the goals of the research with the situation of those affected. For instance, many argue that starting too soon with research can be problematic, since many research participants are frequently focused primarily on their physical wellbeing (Stallings, 2002). People may experience different symptoms on wholly different time frames. What takes hours after a disaster for some may take days for others. These symptoms can range from shock and disbelief to experiencing powerful emotions including fear, anger and grief. It is fair to say that most people experience some form of post-traumatic

symptoms (Boyd Webb, 2004; Myers & Wee, 2005; Roberts, 2005; North et al., 2012; Davidson, Price, McCauley & Ruggiero, 2013).

According to the DSM-IV definition, it takes two weeks to diagnose major depression and four weeks to diagnose Post-Traumatic Stress Disorder (PTSD) (Roberts, 2005). The disaster researcher intending to conduct immediate research could face the issue of adding an extra psychological burden and stress to participants (Norris et al., 2006). If research must commence immediately post-disaster, we suggest that whenever possible researchers use research methods that are either unobtrusive (if possible) or non-invasive on the research participant and his or her well-being. Regardless of when it begins, researchers should be prepared to sacrifice some degree of methodological integrity once they are in the field (Stallings, 2002).

There are advantages to starting research just after a disaster has occurred. Studies carried out some time after the disaster may fail to identify some portions of the population who had symptoms of PTSD or who have fled the disaster area. Inclusion of participants in a research study that was initiated immediately after a disaster could ensure the identification of PTSD symptoms where those starting later may miss some cases. Another good reason to conduct an empirical investigation just after a disaster has occurred would be the ability of participants to answer foretelling questions more easily. However, some evidence suggests that successful studies can start well after a disaster (e.g., Norris et al., 2006). What these studies gave up in terms of evidence about the acute impact phase, was compensated for by the specificity of their measures and the information they provided about the lingering, long-term effects of the disaster. Personal experiences with disaster research by the authors indicate that survey studies that begin 12–18 months after a disaster have a very low response rate. However, within that same 12–18 month time period, focus groups have proven to be both very well-received by the participants and well-attended. The data gathered from focus groups during this phase have proven richer than

survey data, perhaps because focus groups provide a vehicle for participants to reflect on their personal growth and resilience, and to articulate their disaster-experience narrative. Regardless, as Norris et al. (2006) state, there is no single right time to begin a study, but the timing of the study must match the questions and vice versa. We argue that the physical and emotional wellbeing of the research participant should have top priority.

3.1.2 When to end the study?

There is also no clear consensus as to when a research investigation should end, since there is no commonly agreed-upon timeframe among disaster researchers as to the duration of post-disaster trauma. Instead, the feasibility of completing the study should be taken into account (Norris et al., 2006; Stallings, 2002). Factors having an impact on the timeline of a study might differ from disaster to disaster. Factors can include but are not limited to the severity of the disaster, the willingness of the local community to participate in the research, and accessibility to the disaster site. A rule of thumb is necessary to determine time points that represent the critical period (2-6 months), intermediate period (12-18 months) and long-term period (2-3 years). Only rarely have there been reports from studies continuing long afterwards (Stallings, 2002; Norris et al., 2006).

3.2 Recommendation Two: Adhering to federal regulations governing research

When conducting disaster research, it is necessary to adhere to federal regulations governing research, to ensure that ethical standards for research with human subjects are being upheld. Federal regulations provide a framework for the protection of human subjects participating in disaster research. The federal regulation referred to is "The Common Rule-45 CFR 46, subpart A" (Jastone, 2006). The regulations and additional subparts B through D define standards for the ethical conduct of research including the process for proposal review through institutional review

boards (IRBs) for research involving human participants (Norris et al., 2006).

Based on our experience, there are two recommendations here that may save researchers a lot of time and stress. First, one should inform the IRB about the upcoming submission of a disaster-related research proposal. This action allows the IRB to begin to identify appropriate reviewers for the submission and greatly reduces the review time. A related point is to begin to consider the IRB application as early as possible in the research process. Our experience has been that both junior and seasoned researchers have a tendency to think about the IRB as an afterthought. Consequently, they put less time into the IRB application than they do the development of the research protocol or grant, and the IRB application becomes sub-par. This delays the approval of the application, because there are routinely a number of revisions and re-submissions required. This is a particularly important issue when dealing with time-sensitive events like disaster research. Second, one should approach the IRB for assistance with the application. At our university, upon request, an IRB staff member will work with researchers to help compile their applications. For example, our university uses an online application system (i.e., IRBNet) that involves a 38-page application process for the main body (Part II), and requires multiple parts to be submitted (in some cases, up to 57 pages, depending on the various subparts that need to be addressed). If researchers are not experienced IRB applicants, having a staff member assist them can be invaluable in terms of time, revisions and likelihood of quick approval.

3.3 Recommendation Three: Screening method for including participants

3.3.1 Decision-making capacity of participants

The disaster researcher should determine the decision-making capacity of the research participants before commencing disaster research. There should be a screening method for including participants (Levine, 2004; Newman et al., 2006).

Possible screening methods can consist of paper-based screening tools or assessments, and behavioral observations of prospective participants. Incorporating such a process will help the researcher to determine which potential participants might have cognitive impairments or be at particular risk for a serious mental health outcome. Disaster researchers should undergo training to identify emotional problems in subjects, and if needed refer the participants to a mental health practitioner assigned to the population (North, Pfefferbaum, & Tucker, 2002). Consultation with mental health practitioners by the disaster researcher can also have positive outcomes for participants.

3.3.2 *Determining participant vulnerability*

It is necessary to identify the characteristics of disaster-exposed research participants (Soliman and Rogge, 2002). This, in turn, will allow the disaster researcher to determine the level of vulnerability of the research participants. Aligning with the principles of the Belmont Report and making sound judgments on vulnerable populations in the face of a disaster will allow the researcher to make ethical decisions regarding the inclusion of participants in the research study. It is important to note that defining vulnerability post-disaster should not be tied to a demographic characteristic of an individual or group membership. Disaster victims frequently suffer from psychological and emotional distress bearing signs of acute anxiety, depression, posttraumatic stress, and severe forms of grief (Boyd Webb, 2004; Myers & Wee, 2005; Roberts, 2005; Newman et al., 2006; North et al., 2012). These emotional factors, combined with the additional stresses of the possibility of permanent dislocation, social disruption, strains on family life and financial implications, concerns about the environment, and ecological stress, can cause participants to be more vulnerable and hamper their ability to make informed decisions (Norris et al., 2006). Disaster researchers should combine and incorporate elements of the Belmont Report, ethical judgment, and knowledge concerning symptoms experienced by disaster participants when deciding whether participants could be deemed vulnerable.

In other words, researchers should cast a wide net when defining “vulnerability,” to ensure that they protect the interests of those recently affected by a traumatic event and do not add to their burden by including them in a research project. Thus, by erring on the side of caution, researchers can conduct research that is ethical in nature.

3.3.3 *Determining risks and benefits of the proposed study*

Limited empirical evidence is available on the risks and benefits of participant-focused disaster research (Norris et al., 2006). IRBs will be able to identify the associated risks and benefits for participants. There are clearly risks and benefits associated with participation in disaster research (Newman et al., 2006). According to Rubin and Babbie (2011), it can be difficult in some instances to judge whether the long-term good to be derived from a study will eventually outweigh the damage done by the ethically questionable practices that may be required for adequate scientific validity. Benefits of disaster research, according to Norris et al. (2006), include but are not limited to enhanced awareness of material resources, medical and mental health services, empowerment, learning and insight, altruism, kinship with others, experiencing a feeling of satisfaction or value after participating, and favorable attention from the investigators.

Associated risks that might be faced by the disaster researcher include but are not limited to physical harm, legal action, inconvenience for the participants, economic hardship, psychological discomfort, loss of dignity for the participants, breach of confidentiality and exposure, unwanted media attention, social media exposure, and over exposure to disaster research (Norris et al., 2006). A relatively unknown risk is the use of social media platforms in disaster research. There has been a significant increase in research usage of social media and disasters (Palen, Starbird, Vieweg, & Hughes, 2010; Murthy & Longwell, 2012). Social media pose potential risks for the researcher and study participants. It is the task of the researcher to ensure that extra precaution is taken when working with social media formats (e.g., Facebook, Twitter

etc.). De-identification of participants should be considered at all times and the use of photography of participants should be avoided if possible. The use of social media during disasters has unpredictable outcomes (Lindsay, 2011). The incorrect use of social media, such as inaccurate posting of information or not de-identifying participants in a way consistent with the research protocol could lead to both potential harm and over exposure for vulnerable participants.

Another potential risk that might surface with disaster research involving human participants is emotional distress (Norris et al., 2006 and Myers and Wee, 2005; Newman et al., 2006; Legerski & Bunnell, 2010). It is essential that the disaster researcher be able to assess the mental health status of participants. Since disaster research involves remembering events, the emotional distress can cause retraumatization. Norris et al. (2006) argue, however, that the use of the term “retraumatization” can be misleading within the context of disaster research, and may lead to over-exaggeration of the risk involved in study participation. Disaster studies with diverse populations have found that the majority of participants have indicated that disaster research can be beneficial (Boscarino et al., 2004; Newman et al., 2006). Precautions should be taken in assessing the risk-benefit ratio of a research protocol, which will ensure that there is not an over- or underestimated risk involved for the participant in the research. Here, it is essential for the disaster researcher to work in close collaboration with the overseeing IRB, to ensure that risks and benefits are accurately depicted in the proposal and are not detrimental to the well-being of the research participants.

3.3.3.4 Respecting gender and cultural norms and traditions

Disaster researchers will encounter situations where they are faced with gender challenges and cultural situations that could hinder the methodological quality of a study and thus hinder the validity of the findings (Rubin and Babbie, 2011). It is crucial for the disaster researcher to be sensitive towards gender, cultural differences, bias, and

dynamics of the research population. Prioritizing the social work concept of “respect” will ensure that ethical standards with vulnerable populations are maintained during the research process. For example, when a tsunami struck on December 26, 2004, the rim countries of the Indian Ocean experienced an influx of researchers (Sumathipala & Siribaddana, 2005). Local cultural norms and customs of the affected populations were disregarded in the process of providing counseling services and conducting research. During the recovery phase of the tsunami, there were reports of aid agencies conducting research on vulnerable populations without the necessary protocols. Vulnerable populations affected by the tsunami were not properly informed as to why they were participating in research, and informed consent was not alone regarded as a protective measure for participants (Sumathipala & Siribaddana, 2005).

3.4 Recommendation Four: Incorporating a professional code of ethics into one’s research

As social workers conducting disaster research, the authors of this article rely on the fundamentals of the National Association of Social Workers (NASW) Code of Ethics. Section 5.02 on Evaluation and Research should be incorporated by the disaster researcher to ensure that the proposed research is ethical in nature and does not infringe on the rights of participants. Incorporating the NASW code of ethics into research does not end with Section 5.02, but should also incorporate Section 4.01 as set forth by the NASW (Rubin and Babbie, 2011): “Social workers should critically examine and keep current with emerging knowledge relevant to social work. Social workers should routinely review the professional literature. ... Social workers should practice on recognized knowledge, including empirically based knowledge, relevant to social work and ethics” (National Association of Social Workers).

3.5 Recommendation Five: Gaining informed consent from participants

An integral part of conducting research with human subjects is to gain informed consent from research participants in the study (Sumathipala et al., 2011; Jastone, 2006; Newman et al., 2006). Voluntary informed consent is the cornerstone of research ethics. All forms of research should be viewed as optional, and the refusal to participate should be respected. Informed consent plays a pivotal role in research ethics. Participation in research disrupts the human subjects' normal activities (Rubin and Babbie, 2011). Disaster research might disrupt human subjects even further, simply by asking them to participate in research. After some publicized research scandals in the 1960s and 1970s, public awareness increased of the risks of research and the motives of researchers conducting research. Informed consent was first operationalized by the Belmont Report, which stipulated the principle of respect for persons in research. Informed consent is a broad process that includes informing the potential participant of the procedures, potential risks, benefits and alternatives to the research, and then obtaining documentation of permission to proceed (Norris et al., 2006). Rubin and Babbie (2011) state that, in theory, informed consent might sound easy to apply, but it is not always the case in practice settings. For example, it has been our experience that many researchers are interested in capturing phenomena that people experience in disasters but that they may be reluctant to discuss (e.g., increase in intimate partner violence post-disaster), making truly informed consent difficult to obtain. On these occasions, it is imperative that researchers rely on their utilitarian perspective and prioritize participant rights ahead of their research agenda.

It is thus the duty of the disaster researcher to ensure that truly informed consent is obtained from research participants (Stallings, 2002; Barron Ausbrooks et al., 2009). This can be done by requesting that participants sign a consent form before they participate in the research study. The

consent form presented to potential research subjects should provide a brief description of the features of the study that might affect their decision to participate, particularly regarding the methodology of the study, potential harm, and the anonymity or confidentiality of their responses. IRBs require consent forms to be comprehensive and be implemented in all research involving human subjects. Separate consent forms are required for the inclusion of children as research participants. The consent form should be on the reading level of participants.

3.6 Recommendation Six: Maintaining anonymity or confidentiality

Subject privacy and confidentiality are important in all forms of research, but in the case of disaster research these concerns may be even more pronounced, since participants might be in a heightened state of vulnerability (Barron Ausbrooks et al., 2009). When conducting survey research, the clearest concern is the protection of participants' identities, which relates to their interests and wellbeing. If there were to be an unintentional disclosure of some sort that would cause injury to the wellbeing of participants, it would be a breach of research ethics. Either anonymity or confidentiality can be regarded as the norm to protect participants. In terms of federal regulations, anonymity refers to data that cannot be linked back to the research subject, even by the researcher. In this way it is "de-identified." Confidentiality means that the researcher knows the identity of the subjects and can link them back to their responses (e.g., this can be important in measuring changes in an attribute between pre and post-test), but works hard to protect their privacy by using codes rather than names to link subjects back to their responses. In our view, anonymity is preferable in disaster-related research, since the researcher does not want to exacerbate the stress that subjects are already experiencing post-disaster. The disaster researcher should ensure that either anonymity or confidentiality is upheld among all members of the research team.

3.7 Recommendation Seven: Providing assistance to research participants

The researcher has to be sensitive regarding possible negative emotions experienced by some individuals during post-disaster research. In order to address emotional distress, clinical care referral to a social worker or psychologist working in the area of disaster mental health could address possible emotional distress symptoms (Newman et al., 2006). Disaster researchers should also be familiar with disaster-related practices concerning disaster aid and shelter. Research participants could feel a sense of belonging if some of their questions and concerns could be answered by the disaster researcher in the wake of a disaster. Also, researchers should disseminate a resource sheet to participants that tells them what services are available and how to access them.

4. Conclusion

With the increase in disasters worldwide there will continue to be an increase in research with vulnerable populations exposed to disaster. As a field, social work can lead this emerging field by demonstrating how to conduct ethical research with vulnerable populations following a disaster. The recommendations we make here will help ensure that the stigma and controversy surrounding disaster related research is limited. By limiting controversy associated with disaster research, scholars from different disciplines can conduct research that is welcomed by the community affected by the disaster, and that advances our knowledge about how to be more effective helpers in future disasters.

References

- Baez, J., de la Fuente, A., & Santos, I. (2010). Do natural disasters affect human capital? An assessment based on existing empirical evidence. *IZA Discussion Paper No. 5164*. Bonn, Germany: The Institute for the Study of Labor. Retrieved from <http://ftp.iza.org/dp5164.pdf>
- Barron Ausbrooks, C. Y., Barrett, E. J., & Martinez-Cosio, M. (2009). Ethical issues in Disaster Research: Lessons from Hurricane Katrina. *Journal of Population Research and Policy Review*, 28(1), 93-106.
- Boscarino, J. A., Figley, C. R., Adams, R. E., Galea, S., Resnick, H., Fleischman, A. R., . . . Gold, J. (2004). Adverse reactions associated with studying persons recently exposed to mass urban disaster. *Journal of Nervous and Mental Disease*, 192, 515-524.
- Boyd Webb, N. (2004). *Mass trauma and violence: Helping families and children cope*. New York: Guilford Press.
- Collogan, L. K., Tuma, F., Dolan-Sewell, R., Borja, S., & Fleischmann, A. R. (2004). Ethical issues pertaining to research in the aftermath of a disaster. *Journal of Traumatic Stress*, 17(5), 363-372.
- Davidson, T. M., Price, M., McCauley, J. L., & Ruggiero, K. J. (2013). Disaster impacts across cultural groups: Comparison of Whites, African Americans, and Latinos. *American Journal of Community Psychology*, 52(1-2), 97-105.
- Etkin, D., & Davis, I. (2007). The search for principles of disaster management (Working Paper). Retrieved from <http://www.training.fema.gov/EMIWeb/edu/emprinciples.asp>
- Freeman, S. (2000). *Ethics: An introduction to philosophy and practice*. Belmont, CA: Wadsworth.
- Gillespie, D. F., & Danso, K. (2010). *Disaster concepts and issues: A guide for social work education and practice*. Alexandria, VA: Council on Social Work Education Press.
- Guha-Sapir, D., Vos, F., Below, R., & Ponserre, S. (2011). Annual disaster statistical review 2010: The numbers and trends. Retrieved from http://www.cred.be/sites/default/files/ADSR_2010.pdf
- Gulliver, S. B., Zimering, R., Carpenter, G. S., Giardina, A., & Farrar, J. (2014). The psychological consequences of disaster. In O. Paige & J. P. Read (Eds.), *Trauma and substance abuse: Causes, consequences, and treatment of comorbid disorders* (2nd ed.), 125-141. Washington, DC: American Psychological Association.

- Henghuber, G. (2010). Two months to Cancun climate summit: Large number of weather extremes as strong indication of climate change. Press Release. Munich, Germany: Munich RE. Retrieved from <http://www.munichre.com/en/media-relations/publications/press-releases/2010/2010-09-27-press-release/index.html>
- Jastone, L.O. (2006). *Federal protection for human research subjects: An analysis of the common rule and its interactions with FDA and the HIPAA privacy rule*. New York, NY: Novinka Books.
- Legerski, J. P., & Bunnell, S. L. (2010). The risks, benefits, and ethics of trauma-focused research participation. *Ethics and Behavior*, 20(6), 429-442.
- Levine, C. (2004). The concept of vulnerability in disaster research. *Journal of Traumatic Stress*, 17(5), 395-402.
- Lindsay, B. R. (2011). Social media and disasters: Current uses, future options, and policy considerations. *CRS Report No. R41987*. Retrieved from <https://www.fas.org/sgp/crs/homesec/R41987.pdf>
- Mileti, D. S. (1999). *Disasters by design: A Reassessment of natural hazards in the United States*. Washington, D.C.: Joseph Henry Press.
- Murthy, D., & Longwell, S. (2012). Twitter and disasters: The uses of Twitter during the 2010 Pakistan floods. *Information, Communication and Society*, 16(6), 837-855.
- Myers, D., & Wee D. F. (2005). *Disaster mental health services: A primer for practitioners*. New York, NY: Routledge.
- National Association of Social Workers. (2008). *NASW code of ethics*. Washington, D.C.: National Association of Social Workers Press. Retrieved from <http://www.socialworkers.org>
- Newman, E., Risch, E., & Kassam-Adams, N. (2006). Ethical issues in trauma related research: A review. *Journal of Empirical Research Ethics*, 1(3), 29-46.
- Norris, F., Galea, S., Friedman, M., & Watson, P. (2006). *Methods for disaster mental health research*. New York, NY: Guilford Press.
- North, C. S., Pfefferbaum, B., & Tucker, P. (2002). Ethical and methodological issues in academic mental health research in populations affected by disasters: The Oklahoma City experience relevant to September 11, 2001. *CNS Spectrums*, 7(8), 580-584.
- North, C. S., Oliver, J & Pandya, A. (2012). Examining a comprehensive model of disaster-related posttraumatic stress disorder in systematically studied survivors of 10 disasters. *American Journal of Public Health*, 102(10), 40-48.
- Palen, L., Starbird, K., Vieweg, S. & Hughes, A. (2010). Twitter-based information distribution during the 2009 Red River Valley flood threat. *Bulletin of the American Society for Information Science and Technology*, 36(5), 13-17.
- Pfefferbaum, B., Weems, C. F., Scott, B. G., Nitiéma, P., Noffsinger, M. A., Pfefferbaum, R. L., ... Chakraborty, A. (2013). Research methods in child disaster studies: A review of studies generated by the September 11, 2001, Terrorist Attacks; the 2004 Indian Ocean Tsunami; and Hurricane Katrina. *Child Youth Care Forum*, 42, 285-337.
- Rosenstein, D. (2004). Decision-making capacity and disaster research. *Journal of Traumatic Stress*, 17(5), 373-381.
- Roberts, A. R. (2005). *Crisis intervention handbook, Assessment, treatment, and research* (3rd ed.). New York, NY: Oxford University Press.
- Rubin, A., & Babbie, E. R. (2011). *Research methods for social work* (7th ed.). Belmont, CA: Wadsworth.
- Sheng, C.L. (2004). *A Defense of utilitarianism*. Lanham, MD: University Press of America.
- Smith, A. B., & Katz, R. W. (2013). US billion-dollar weather and climate disasters: Data sources, trends, accuracy and biases. *Natural Hazards*, 2013, 67(2), 387-410.
- Soliman, H. H. (2010). Ethical considerations in disasters: A social work framework. In D. F. Gillespie & K. Danso (Eds.), *Disaster*

- concepts and issues: A guide for social work education and practice*. Alexandria, VA: CSWE Press.
- Soliman, H. H., & Rogge, M. E. (2002). Ethical considerations in disaster services: A social work perspective. *Electronic Journal of Social Work, 1 (1)*, 1-21.
- The Sphere Project. (2011). *Humanitarian charter and minimum standards in humanitarian response*. Oxford: Oxfam Publishing. Retrieved from <http://www.sphereproject.org/silo/files/the-sphere-handbook.zip>
- Stallings, R. A. (2002). *Methods of disaster research*. Bloomington, IN: Xlibris.
- Sumathipala, A., & Siribaddana, S. (2005). Research and clinical ethics after the tsunami: Sri Lanka. *Lancet, 366*, 1418-1420.
- Sumathipala, A., Jafarey, A., De Castro, L., Ahmad, A., Marcer, D., Srinivasan, S., ..., Siribaddana, S. (2011). The Draft statement/guidelines for disaster research. *Global Health Trials*. Retrieved from <https://globalhealthtrials.tghn.org/articles/draft-statementguidelines-disaster-research/>
- U.S. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1979). The Belmont Report: Ethical guidelines for the protection of human subjects of research. *DHEW Publication No. (OS) 78-0012*. Washington, DC: U.S. Government Printing Office. Retrieved from http://videocast.nih.gov/pdf/ohrp_appendix_belmont_report_vol_2.pdf
- Wisner, B., Blaikie, P., Cannon, T., and Davis, I. (2003). *At risk: Natural hazards, people's vulnerability and disasters* (2nd ed.). London, Routledge.