Chapter 7 Evidence and Healthcare Needs During Disasters

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7.1 Introduction

Disasters cause much damage and inflict much human suffering. They lead to severe imbalances between human needs and the resources immediately available to meet those needs (Wang 2009). Disasters come in many different types. The Centre for Research on the Epidemiology of Disasters (CRED) maintains a publicly accessible database called the Emergency Events Database (EM-DAT). This categorises disasters into one of three groups: natural disasters (e.g. floods, earthquakes, mudslides), technological disasters (e.g. industrial accidents, transport accidents), or combinations of these in what are called complex emergencies (CRED 2011). Disasters can also be conflict-related (due to, for example, war or terrorism), and these may or may not be considered separately.

The lack of standard definitions has led to much variability in the data available on disasters in different databases (Kar-Purkayasha et al. 2011). This leads to varying estimates of the precise impacts and costs of disasters. Such databases are the result of considerable effort and resources, and they contain large amounts of data. Even with their limitations, such databases provide a general sense of the disaster trends. According to CRED, the number of natural disasters is increasing steadily, with 2010 being the deadliest year in decades: 373 natural disasters killed almost 300,000 people, impacted over 200 million more, and cost over US\$100 billion (CRED 2011). Foremost amongst these, the Haiti earthquake killed over 222,000 people and a heat wave in Russia killed about 56,000 people; the costliest disaster in 2010 was an earthquake in Chile estimated to have caused US\$30 billion in damages.

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D. P. O'Mathúna Dublin City University, Dublin, Ireland At the same time, some positive developments are occurring. According to the 2011 Global Assessment Report on Disaster Risk Reduction, the risk of death due to weather-related disasters is decreasing globally, except for those who live in the poorest countries (United Nations 2011). However, the economic cost of disasters is increasing in all parts of the world. The forecast does not look good. One assessment found that climate-related disasters (which make up 98 % of all disasters) will affect about 375 million people annually by 2015, an increase of 50 % over recent averages (Ganeshan and Diamond 2009). The financial loss from Japan's 2011 earthquake and tsunami alone was estimated at more than US\$300 billion (CNN 2011).

As the frequency of natural disasters increases, their impact is especially significant in lower income countries. Ironically, as countries begin to experience economic growth, their exposure to economic loss from disasters increases more rapidly (United Nations 2011). Underlying factors that contribute to these additional risks are poverty, bad urban planning and management, and ecosystem decline. The impact of a disaster on ecology, health, and economics largely depends on the type of disaster and the underlying characteristics of the community, the geo-political state of the region, and the population's vulnerability and capacity to respond. New evidence is showing that disasters have a particularly negative impact on children and displaced persons, yet these are rarely taken into account (United Nations 2011).

Despite the growing knowledge about disaster prevention and disaster risk reduction, dealing with disasters and their aftermath has always been difficult, even in regions with financially sound and well established systems, as was seen with Hurricane Katrina. This is because the nature and magnitude of disasters is highly variable and the conditions and needs are usually not known accurately in the immediate aftermath of a disaster.

Disasters result in what have been called the 6 Ds: destruction, death, disease/disorders, displacement, disappearance, and disarray (Sumathipala et al. 2010). Most of these have implications for the healthcare needs of those affected by disasters. Responses to those needs, like all healthcare decisions, should be based on high-quality rigorous research and evidence. Unfortunately, current decision-makers in disaster situations are often without the high quality research and sound evidence they would like to have. More generally, 'much of the existing operational research related to emergencies and disasters lacks consistency, is of poor reliability and validity and is of limited use for establishing baselines, defining standards, making comparisons or tracking trends' (UNISDR 2011, p. 46). All this points to the importance of generating evidence to guide healthcare workers and policy-makers. This leads to questions concerning what evidence is needed, how it should be generated and the ethical issues involved in conducting research to produce such evidence.

7.2 Evidence-based Practice

Evidence can be defined as various observations, facts or organised bodies of information offered to support or justify inferences or beliefs provided to support various conclusions or judgements (Bradt 2009a). Evidence-based medicine (EBM) has developed since the early 1990s in response to concerns about the way clinical decisions were made prior to then. EBM is defined as 'The conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence-based medicine requires the integration of individual clinical expertise with the best available external clinical evidence from systematic research and our patient's unique values and circumstances' (Bradt 2009a, p. 299). Prior to this, it had been assumed that informed intuition, unsystematic observations from clinical experience, pathophysiological rationale, and traditional medical training were sufficient for clinical decision-making (Bradt 2009a). In what has been described as a Kuhnian 'paradigm shift', EBM developed, stressing the examination of evidence from clinical research (Kuhn 1970).

Given the heterogeneity of modern health care systems, it is naïve to expect a univocal definition of evidence. Although EBM arose from clinical epidemiology, a quantitative discipline, quantitative approaches alone will not be sufficient to assess the strength of all forms of evidence relevant to EBM. Critics of EBM describe it as representative of narrow reductionism that inappropriately relies on epidemiology and statistics, while ignoring clinical judgment and experience. Evidence within EBM is ranked hierarchically, with highest place given to systematic reviews and randomised controlled trials (Bradt 2009a). While qualitative methods either are not included in such hierarchies or are given lower priority, this arises because of the types of questions addressed by each research methodology. EBM focuses on questions of effectiveness and safety of interventions, for which a randomised controlled trial (RCT) is best suited.

Such an approach does not mean that qualitative methodologies are not appreciated to address other questions. At the very least, values, preferences and experiences of individuals and communities must be incorporated into clinical decision-making. It is certainly not enough to have quantitative evidence alone to measure the strength of evidence, but individual preferences and contextual dimensions must be taken into account. Attention to the narrative context of clinical care explains the extent to which values and experiences are seen as relevant evidence, but more importantly underscores the significance of how evidence is collected and interpreted (Greenhalgh 1997). Thus, it is not that EBM per se is problematic, but rather that the importance of carefully choosing one's clinical question may be overlooked. This then impacts how decisions are made about what type of evidence is most applicable and needed.

The changes promoted by EBM have taken decades to materialise. The role of evidence-based practice in humanitarian relief of disasters is only now being developed, and faces a number of challenges. Within EBM, external evidence takes higher priority over expert opinion, yet within disaster relief settings, expert opinion continues to reign supreme (Bradt 2009b). Within disaster relief, local and context-specific knowledge remains important but needs to be combined with 'global' evidence (Kayabu and Clarke 2013).

Humanitarian responses should be based on needs, and evidence plays an important role in identifying needs accurately and showing how needs can best be met, especially with limited resources. But the acute crisis of a disaster can leave needs assessment and evidence accumulation as lower priorities. 'Without appropriate evidence, allocation is based on estimates and professional judgement, and needs assessments in practice play a minor part in determining allocations' (Willitts-King 2006, p. 26). A vicious cycle can be set up where the lack of evidence makes evidence-based decisions impossible, leading to a lack of incentives to develop the needed evidence.

7.2.1 Evidence-based Guidelines

When evidence is lacking in any healthcare arena, decision-making guidelines tend to be less helpful. For example, analysis of various medical guidelines has found that developers use a puzzling variety of systems to rate the quality of evidence underlying their recommendations. 'Some are facile, some confused, and others sophisticated but complex' (Guyatt et al. 2008b, p. 995).

To address this situation and improve clinical decision-making, formal systems have been developed to grade the quality of evidence available and the strength of recommendation possible. While these have been developed primarily to assist in normal medical situations, these can be usefully applied in disaster settings. A variety of systems and tools have been developed, with the GRADE approach (Grading of Recommendations Assessment, Development and Evaluation) being one which is increasingly being adopted by organisations worldwide (Guyatt et al. 2008a). The GRADE system is explicit, comprehensive, transparent and pragmatic in its approach. It has similarities to other grading systems, but seeks to incorporate all of the advantages available in other systems. It is beyond the scope of this chapter to examine the GRADE approach extensively, but some of its key factors will be mentioned.

Central to the GRADE approach is making a distinction between rating the quality of evidence and grading the strength of recommendations (Guyatt et al. 2008a). Quality of evidence refers to the types of studies conducted to address a research question and relates to the level of confidence we can have in the current estimate of effect. For example, in addressing whether or not an intervention is effective, RCTs provide the highest quality evidence and anecdotal reports provide low quality evidence, also called a high risk of bias.

Strength of recommendation differs significantly from the quality of evidence, although the terms are sometimes used interchangeably. If the two are not clearly distinguished, confusion can result (Guyatt et al. 2008a). A strong recommendation may be given if high quality evidence consistently supports a particular intervention. Sometimes lower quality evidence (say, observational studies) can support a strong recommendation if the beneficial effect is consistently large and adverse effects minimal. At the same time, high quality evidence may lead to a weak recommendation if, for example, the desirable and undesirable effects are relatively balanced, or if the evidence shows that different interventions are similarly effective (Jaeschke et al. 2008). In such cases, even if high quality evidence exists, choosing whether or not to use an intervention, or picking between interventions, will need to rely more on cultural or individual values.

Another factor is how well a specific research study has been designed and conducted. While RCTs will normally be high-quality evidence, their quality can be reduced by study design limitations (lack of blinding, subjective outcomes, etc.), inconsistent results across different studies, indirectness of evidence, imprecision (primarily due to small sample sizes) or publication bias (Guyatt et al. 2008b). Lower quality studies may have their quality increased if large magnitude effects are consistently found, if all plausible biases would reduce the demonstrated effect, or if a dose-response gradient is visible (Guyatt et al. 2008b).

Because of the importance of using evidence to guide disaster responses, many organisations are recognising the need to evaluate guidelines along the lines of those suggested by GRADE. For example, the World Bank has described four general models of research methodology for conducting impact evaluation of interventions in humanitarian settings (World Bank undated; Independent Evaluation Group 2009).

- Randomised evaluation. Groups or locations are randomly assigned to receive different interventions or controls. Outcome measures are collected or other observations gathered to assess the impact of the interventions.
- 2. Quasi-experimental design where the intervention group is matched to a control group by non-random methods. Statistical methods are used to ensure the groups are as similar as possible.
- 3. Ex-post comparison of intervention group with a non-equivalent control group. Evaluation occurs after the project has started and multivariate analysis is used to control for differences between the groups.
- 4. Non-experimental approaches using surveys and case studies to collect information on perceptions of interventions' impact.

The World Bank regards only Types 1 and 2 as rigorous because 'they are the most reliable for establishing causality—the relationship between a specific intervention and actual impacts—and for estimating the magnitude of impact attributable to the intervention. They are able to distinguish the impacts of the intervention from the influence of other, external factors' or confounders (World Bank undated, p. 3). While these methods are the most reliable for certain questions, the World Bank also notes that qualitative studies remain valuable, with mixed method approaches having many advantages.

7.3 Evidence and Disasters

Having discussed the complex issues of evidence and evidence-based approaches in general, the role of evidence for decision-making in disaster settings will be examined more closely. Currently most disaster relief operations are based on evidence that not too infrequently is of questionable accuracy and low quality. Although rigorous approaches to evaluation are necessary to provide the best guidance during disasters, 'the limited corpus of rigorous studies is notable' (Bradt 2009b, p. 488). As a result, decision-making in disaster management is largely dependent on expert opinion, eminence-based decisions or non-rigorous studies (Bradt 2009b).

In such situations, well-meaning healthcare professionals do the best they can, but can make decisions that do not have good outcomes. The first author of this chapter witnessed this after a recent earthquake in Pakistan.

A 4 year old girl child was brought to the children's hospital in Islamabad 3 weeks after the devastating earthquake that hit the northern areas of Pakistan in early October 2005. She had an amputated right arm, with disarticulated elbow joint and a jutting humerus, without any muscle cover. It so transpired that the initial surgery was performed in a makeshift camp by the surgeons of an international aid organization. Not one of the doctors involved was a qualified surgeon. (Loff et al. 2007, p. 265)

To avoid such well-intentioned, but non-evidence based decision-making, other surgical teams undertook research after the same earthquake to provide evidence that could be applied to future disaster relief efforts after earthquakes (Rajpura et al. 2010). By involving international and local medical expertise, evidence about how best to treat complex fractures was developed to save as many limbs as possible while promoting optimal patient care.

Little is documented during disaster relief, which hinders learning from past experience. When data is collected, it is usually not standardised, leading to much variability in the available databases. Research reports have contained insufficient detail, revealed shortcomings in study methodology, and raised concerns about high risk of bias. All this, in spite of 'an ethical imperative to ensure that all data collected is of good quality, and is useful and relevant to as many users as possible' (Kar-Purkayasha et al. 2011, p. 10). The resulting challenges are being tackled by a number of initiatives, including the Cochrane Collaboration's Evidence Aid, the US National Library of Medicine's Disaster Information Management Research Center, the World Association for Disaster and Emergency Medicine (WADEM) and the UK Wellcome Trust.

Systematic reviews of randomised double-blind placebo-controlled studies provide the highest quality evidence for interventions and can lead to the strongest recommendations, but these are practically non-existent for disaster situations—and sometimes ethically impossible to conduct. However, they are widely recognised as crucial to developing evidence-based disaster response (Kayabu and Clarke 2013). When available, they can contribute to developing globally accepted standards for performance and accountability during disaster relief operations. In addition, while accreditation standards for those responding to disasters are not generally available, a register for disaster healthcare professionals was recently established in the UK (Redmond 2011).

7.4 Evidence and Ethics in Disasters

The underlying motivations for generating and using evidence in disaster settings is ethical. The primary objective in disaster relief, as in all humanitarian assistance, is to do the most good for as many people as possible (Bradt 2009b). In the immediate aftermath of a disaster, this involves saving lives and alleviating suffering. However, myths and fallacies about health risks and health needs during disasters exist in both

public perceptions and the views of some responders (Wang 2009). Good quality evidence is needed to identify the best ways to help people after disasters.

For example, panic is believed to be widespread after a disaster, yet evidence shows that most survivors do not panic. Instead, empirical research has for long shown that survivors remain calm and play crucial roles as the first responders to help rescue people and treat their injuries (Quarantelli 1975). Although external disaster response teams play important roles, empirical research in China, Mexico and the US has found that more than 80 % of disaster survivors are located and rescued by other survivors (Wang 2009). This has important implications for disaster preparedness training and planning, highlighting the importance of conducting research immediately after disasters.

For example, to address the trauma associated with disasters, different psychological interventions have been used widely. Rather than assuming that any intervention by a caring, competent counsellor is helpful, research is identifying which interventions are effective and for which people. A systematic review of research on psychological debriefing to prevent post-traumatic stress disorder (PTSD) has shown that it is generally not effective (Rose et al. 2002). On the other hand, for those exhibiting PTSD symptoms, cognitive behavioural therapy (CBT) can be safe and effective (Kar 2011). However, up to 50 % of those treated do not respond to CBT for a variety of reasons.

Another important ethical principle is to avoid harm. Disaster responses must be examined with a long-term perspective, not just short-term. Thus, an evaluation of the response to the 2004 Indian Ocean Tsunami has found that the influx of foreign aid undermined local disaster relief efforts and, in places, set back local organisational infrastructural (Cosgrave 2007). Such outcomes were surely unintended, but 'good intentions do not excuse bad outcomes' (Bradt 2009b, p. 483). High quality evidence can help identify why these harms resulted and how they can be avoided with different interventions. Another finding is that local communities did much to save lives in the immediate aftermath of the Tsunami. This highlights the importance of investing in disaster risk reduction and preparedness as an effective means of reducing future harms (Cosgrave 2007). The importance of local communities has often been overlooked, but now there is good quality evidence to support their importance.

One of the central ethical principles of humanitarian assistance is that resources should be provided according to need (Willitts-King 2006). One of the reasons for this approach is to minimise the provision of resources according to bias or prejudice, such as when one group receives more or less aid because of race, religion, gender, age, social class or other non-relevant attribute. If aid is not provided according to need, further harm can occur to those with the greater needs who do not receive sufficient aid. In addition, needs-based assistance is a just way of distributing scare resources.

Providing aid according to need necessitates prior understanding of people's needs. However, accurate data on people's needs is often limited, especially in the immediate aftermath of disasters. A number of international humanitarian initiatives have found serious deficits in the information available on health needs requiring humanitarian assistance and a lack of standardised approaches to collecting such data (Bradt 2009b).

Conducting needs assessments in disaster settings is challenging, and points to the importance of awareness of pre-disaster health resources and infrastructure. Once again, the overall value of the evidence from needs assessments provides some ethical justification for carrying out such studies. At the same time, many ethical challenges exist for such research in disaster settings. Collecting accurate data is pivotal, but difficult during a disaster. A balance must be maintained between the immediate needs of individuals and the long-term needs of the population at large.

While evidence is both vital and scarce in disaster relief settings, evidence and knowledge are not the main limiting factors to effective humanitarian responses. 'Rather, it was (the lack) of political and organizational will to act on that knowledge, and to deploy the necessary resources to tackle problems using the best available solutions' (Bradt 2009b, p. 482). Such issues go to the underlying moral motivations of those involved in disaster relief, which go beyond the focus of this chapter.

7.5 Ethical Challenges in Disaster Research

Evidence-based practice, as shown by the examples given above, demonstrates the need for, and value of, disaster research. However, how such research is conducted raises a number of different ethical issues. A number of these will be addressed in depth in Part II of this book, so they will be mentioned only briefly here. Such ethical issues in disaster research range from the difficulty in assessing benefits and risks (Chap. 8), the quality or lack thereof of truly 'informed' consent (Chap. 9), the vulnerability of participants (Chap. 11), appropriate standards of care, and the 'philanthropic' misconception, to the paucity of ethical guidelines for disaster situations and the difficulties for members of research ethics committees to review complicated protocols urgently and thoroughly (Chap. 12).

7.5.1 Ethical Guidelines

Ethical guidelines for research (both national and international) can contribute to the appropriate conduct of research in disaster situations. However, specific guidelines for disaster research are lacking. One such set of guidelines was developed by the Working Group on Disaster Research and Ethics (WGDRE) which was formed in response to the 2004 Indian Ocean tsunami (Sumathipala et al. 2010). These guidelines are intended to supplement, not replace, existing research ethics guidelines by highlighting ethical issues of particular importance in disaster settings. They articulate twelve general principles, which are briefly summarised below.

- 1. All research in disaster situations should be relevant to those affected by disasters and impossible to conduct in non-disaster situations.
- 2. Informed consent for research is mandatory. While prior, free and voluntary informed consent is difficult to attain in normal circumstances, it is particularly challenging in disaster situations. Informed consent for medical or scientific

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research is a 'non-derogable right' and therefore cannot be exempted if individuals have the capacity (UN Commission on Human Rights 1984). Research teams should identify potential barriers to informed consent and make every effort to overcome them. Inducement of any kind must be avoided and no attempt made to disguise research as humanitarian aid or part thereof. Efforts must be made to avoid the so-called 'philanthropic misconception' (Ahmad and Mahmud 2010). This is a specific instance of the therapeutic misconception where research subjects believe their participation in a study is equivalent to clinical care and confuse the researcher with a care giver. Disaster victims may similarly confuse research participation with humanitarian aid.

- 3. Community consultation and participation should be encouraged at all stages of the research process. At the same time, collective community agreements should not substitute for individual informed consent.
- 4. Research participants should be selected for scientific reasons related to the research project. The research should not put extra burdens on those who are already traumatized or the local infrastructure.
- 5. Extra care should be taken to protect the privacy, confidentiality and dignity of survivors.
- 6. While disaster survivors may not be defined legally as a vulnerable population (Levine 2004), their heightened vulnerability should lead to additional efforts to minimise risks from the research.
- 7. Institutions sponsoring disaster research should recognise their ethical obligations and help coordinate research with disaster relief.
- 8. The highest standards of professional competence and scientific rigour should be maintained within the research team.
- 9. The research should provide direct or indirect benefits to those researched, the disaster-affected community or future disaster victims. The local community should be consulted regarded those benefits.
- 10. The research results should be disseminated widely and transparently after peerreview, and used to influence policy.
- 11. Independent, multidisciplinary and pluralist ethics committees should review all research proposals. Representatives from the disaster-affected community should be included. Novel arrangements and different stages of review may need to be developed.
- 12. International collaborative research must be based on mutual respect and partnership, involving various organisations and the local community.

7.6 Conclusion

Much further work needs to be done on generating evidence for disaster situations, working to ensure decisions made in disaster planning and responses are evidencebased, and ensuring that research is conducted to the highest ethical standards. The WGDRE guidelines provide an important foundation for the development of international guidelines for disaster research (Sumathipala et al. 2010). Standards of care in disaster situations have been defined in different ways, making it challenging to see to what standards healthcare providers and researchers should be held accountable (Altevogt et al. 2009; Annas 2010). Given this lack of clarity, review by a research ethics committee is particularly important. However, ethical review of disaster research is challenging given the urgency of review, the devastation and complexity in the research setting, and the importance of training all committee members. Some frameworks for ethics committees have been proposed, but further work is needed in this area (Schopper et al. 2009; Tansey et al. 2011). Disaster bioethics is a complex and multi-faceted field of study, with much challenging analysis and discussion remaining to be done.

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