Chapter 1
Disaster Bioethics: An Introduction

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1.1 Disasters

Most disasters are characterised by sudden onset, overwhelming needs and in-sufficient resources. Recent examples have revealed their devastation graphically, including the 2011 Great East Japan earthquake and tsunami, the 2010 and 2011 flooding in Pakistan, the 2010 earthquake in Haiti, Hurricane Katrina in the US in 2005, and the 2004 Indian Ocean tsunami.

While large-scale disasters receive widespread attention, smaller disasters occur regularly, averaging one per day. According to the United Nations International Strategy for Disaster Reduction (UNISDR), 2010 was the deadliest year for disasters in decades: 373 natural disasters killed 300,000 people, impacted 200 million more, and cost over US$100 billion (UNISDR 2011a). Foremost amongst the deadliest of these disasters were the Haitian earthquake that killed over 222,000 people and a heat wave that killed 56,000 people in Russia. Subsequently, 2011 was the costliest year ever for damages from disasters, estimated at between US$350 and 380 billion, largely due to the Japanese earthquake (McClean 2012).

The increased impact of disasters has happened for a number of reasons. Foremost among these are climate change and increased urbanisation involving poor planning and bad building practices (IFRC 2010). Although low- and middle-income countries suffer the greatest loss of life from disasters, high-income countries experience the greatest disaster-related economic losses. Thus, while the impact of disasters varies by country, it is consistently highly significant. As a result, disaster preparedness and risk reduction are top priorities for the United Nations (UN) and many other organisations.

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Disasters are defined in various ways, as will be apparent in the chapters of this book. While the specific details vary, a number of common characteristics are recognised by various sources. Foremost among these are that local, and often national, capacity to respond is overwhelmed which creates immense logistical problems as well as leading to a host of ethical dilemmas. The World Medical Association (WMA) highlights a number of features common to disasters (WMA 2006):

- Sudden, unexpected onset requiring prompt response
- Massive damage to materials, infrastructure, and the environment
- Large numbers of human casualties, with difficulties accessing survivors
- Complications to relief efforts from weather, pollution, infection and psychological factors
- Insecurity due to physical dangers, conflict or violence
- Broad media attention.

Disasters are usually categorised into one of three groups: natural disasters (such as floods, earthquakes, or mudslides), human-related disasters (such as industrial and transportation accidents, as well as disasters due to war or terrorism), or complex emergencies, which involve natural and human causes. These classifications point to some of the major general causes of disasters. However, such classifications can be arbitrary, especially as both natural and human-related factors are involved in most disasters.

1.2   Disaster Bioethics

Disasters involve many complex issues. There is a growing realisation that amongst these, ethical issues are frequently involved. In October 2011, at the second meeting of the European Forum for Disaster Risk Reduction (EFDRR 2011), the Council of Europe committed itself to a new framework for disaster risk reduction. In this, ethics was held to be crucial to putting people first in disaster risk reduction. The first recommendation was to address the ethical aspects of disaster risk reduction through the application of ethical principles. However, specific details were not provided about the ethical framework to be used, or how the ethical issues could, or should, be addressed.

Ethics is a vast subject, broadly covering issues of right and wrong in human behaviour, attitudes, character and policy. This book will not attempt to provide a theoretical foundation for ethics or disaster bioethics. Such work is only beginning, and much philosophical reflection remains to occur in this area (Zack 2010). This book is a contribution to the field of applied ethics. Rather than propose one particular approach to resolving ethical issues in disasters, this book seeks to draw attention to the many ethical issues. Our aim is that ethicists and disaster responders will see the need to apply various ethical frameworks and approaches to the ethical issues in disasters. Different chapters show how this already has been attempted. One conclusion already arising is that much contemporary western bioethics has important

limitations when applied in disaster settings (Karadag and Hakan 2012). One of the reasons for this is the way resources (and people) are completely overwhelmed in disasters. Another is that contemporary bioethics is very focused on individuals and individual rights, while disasters lead to a greater focus on the rights and care of populations. As such, disaster bioethics addresses issues raised within public health ethics, itself a fledging field of bioethics (Lee et al. 2012).

Widespread agreement exists that ethical issues occur throughout disaster management and response (Jensen 1997). High-level statements on disaster ethics exist. The International Federation of Red Cross and Red Crescent Societies (IFRC) has a Code of Conduct for disaster responders (IFRC 1994), which is reprinted by permission in Appendix I. In 2006 the World Medical Association issued a *Statement on medical ethics in the event of disasters* (WMA 2006), which is reprinted by permission in Appendix II.

However, such statements can be seen as highly aspirational and would require further exploration to permit practical application. After all, numerous ethical decisions must be made in disaster preparation, and also during responses. But these decisions are highly complex, involve much uncertainty and risk, and in disasters are made in the midst of chaotic and often dangerous situations. Often the decisions involve trying to choose the 'lesser evil', rather than finding an ideal solution (Magone et al. 2011). Such difficulties create challenges for those seeking to address ethical issues in disasters.

For example, in the immediate aftermath of disasters, healthcare professionals may have to decide who they accept into care and who they must turn away. Such triage decisions are difficult, especially knowing that in other circumstances they could probably help the injured survive. Once in care, decisions must be made about how best to treat patients, especially knowing that follow-up care may be inadequate, if not non-existent. Further triage decisions must be made when considering whether treatment should be withdrawn from existing patients to care for potential patients (Eyal and Firth 2012). Using medical criteria to make triage decisions is one thing, but other factors lead to complications. Pressure can be brought to bear to take care of certain people because they have powerful connections, or to give others lower priority for non-medical reasons.

Other ethical dilemmas arise when professionals are asked to practice in ways they know they are not credentialed for 'at home.' Disagreements arise between personnel, as they do in all areas of practice, but they seem accentuated by the environment. Local customs and practices may appear to go against evidence-based practice, creating dilemmas over what should be done or recommended. Different approaches may seem warranted on the ground, but be contrary to 'head office' guidelines. Organisations may have commitments and obligations to governments and donors that appear to conflict with meeting the needs of people in the locally affected community. When armed conflict is added on top of these, dilemmas are further intensified.

Disaster bioethics is a field of recent interest that falls within the broader area of applied ethics. While ethical dilemmas have existed throughout the history of humanitarian relief, they have rarely been examined in detail (Magone et al. 2011). Some

qualitative research has identified ethical dilemmas facing healthcare responders and disaster researchers. These situations can lead to moral distress, which sometimes incapacitates responders, hinders them returning to the field, or leads to long-term psychological problems (Alexander and Klein 2009). In spite of these challenges, healthcare responders are provided little training or guidance for the ethical dilemmas they face (Schwartz et al. 2010).

Disaster bioethics examines issues of moral conduct, questions of right and wrong, as encountered by individuals and organisations as they respond to the needs of people impacted by disasters. Many of these questions arise in the context of healthcare needs and provision. In addition, because these needs lead to research on how best to intervene, disaster bioethics also studies the ethical issues arising from conducting research in disaster settings. Disaster research covers a wide variety of study types, ranging from surveys asking people about their experiences and needs, to randomised controlled trials of medical interventions. Various types of studies raise different ethical issues, with some people questioning whether certain types of research should not be conducted at all during disasters. They would argue that the focus, at least during the acute phase, should be exclusively on search and rescue, and taking care of survivors.

However, decisions are made at all stages of disaster relief about what interventions or strategies to adopt. Disaster relief agencies and those developing policies for disaster risk reduction are increasingly called upon to make evidence-based decisions. Yet the available evidence is far from ideal. The Hyogo Framework for Action (HFA) is the UNISDR's plan for disaster risk reduction that details the work necessary to reduce losses from disasters. Its 2011 mid-term review noted that '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 2011b, p. 46). Hence, more research is needed to understand disasters and the best ways to reduce their risks and improve responses.

As with any research involving human subjects and participants, intricate ethical issues arise in disaster research. However, it might be especially challenging to uphold strict ethical standards in the circumstances that surround and arise from a disaster. Previous reviews of disaster responses have identified unethical research practices (Sumathipala and Siribaddana 2005) and in a small number of cases, international controversy has arisen. In other cases, participants in disaster research have not been treated respectfully, leaving them with a negative view of research (Pittaway et al. 2010). It is imperative that ethical principles be upheld in all disaster research. Ethical lapses in this area can hamper efforts to conduct further important research that might benefit both those affected by the immediate disaster and those affected by future disasters.

Disaster research in general can be justified ethically given that it may provide results that benefit future victims of disasters. However, each individual study needs to be ethically justified and demonstrate that it will be carried out to the highest possible ethical standards. Yet no internationally agreed guidelines or ethics codes exist for research in disaster settings. A working group set up after the 2004 Indian

Ocean Tsunami has developed draft guidelines for disaster research (Sumathipala et al. 2010). Médecins Sans Frontières (MSF) has developed processes to ethically review their disaster research projects (Schopper et al. 2009). However, much further work is needed to examine the ethical complexities involved in disaster research, including how to address the urgency of disaster research, the vulnerability of disaster survivors, and issues of informed consent. Several of these issues are explored in Part II of this book.

1.3 Chapter Outline

This book is divided into two parts. The first examines some of the ethical issues in responding to healthcare needs during disasters. The second examines research ethics in disaster settings. The chapters are developed from presentations given in 2011 at a symposium at the Brocher Foundation in Geneva, Switzerland.[1] The presentations and discussions highlighted many of the complex ethical dilemmas faced during disasters, and the need for further scholarly work and policy-development in this area. This book does not attempt to address all the ethical issues in disasters, nor does it provide the final word on the topics addressed. Instead, it aims to stimulate further discussion and debate on these important ethical issues.

Part I examines the ethical issues in providing health care during disasters. Henk Ten Have examines disaster bioethics from a macro-ethical perspective. He analyses ethical questions associated with the current framework of disaster relief and humanitarian aid. He examines the language used to describe disasters, and questions the legitimacy of distinguishing natural from man-made disasters. Such language has important ethical implications as it suggests certain views of human causation and responsibility. This chapter also examines recent changes in the use of military resources in disaster relief. The moral reasoning behind humanitarian action points to certain moral responsibilities: to protect populations, save lives, and relieve suffering. Ten Have argues that instead of the language of needs and compassion, humanitarianism would be better served by the language of human rights and dignity.

Healthcare professionals who have provided humanitarian health aid after disasters were interviewed by Lisa Schwartz and colleagues. Their chapter discusses some of the insights gained about the ethical challenges faced by these professionals. The interviews show how clinical decision-making in disaster contexts is complicated by factors such as resource scarcity, security conflicts and disparate cultural expectations. Because of the ethical challenges in responding to patients, professionals perceived that they were unable to provide appropriate standards of care, which

had profound impact on the healthcare professionals, leading to stress and burn-out. The authors conclude that training and other resources are needed to help disaster responders develop skills for managing moral dilemmas before they enter the field. The chapter proposes strategies, both theoretical and practical that may help prepare humanitarian healthcare providers to manage ethical conflicts that threaten to interfere with care.

One of the ethical dilemmas faced by healthcare professionals is the requirement to decide which of the injured to treat and not treat, or treat differently. Such triage decisions are a source of significant moral distress for healthcare professions. Michael Barilan and colleagues give an outline for triage in mass-casualty disasters. They make a distinction between three types of disasters: those impacting well-ordered societies, those that wreak havoc on the infrastructure of the society, and 'double disasters' that ravage societies whose infrastructure had already been substantially deficient because of poverty. Three schemes of triage are also examined. Each is shown to be ethically justifiable, though with each being more applicable to particular disaster scenarios. They explain their preference for the third approach that combines elements of the first two.

Many disasters involve international assistance and bring together different cultures that might otherwise have limited or difficult interactions. In his chapter, Athula Sumathipala addresses some of the ethical issues that arise in disasters because of cultural differences. Drawing on his direct experience of the response to the 2004 Tsunami in Sri Lanka, Sumathipala explores such ethical dilemmas, particularly when pre-existing cultural conflicts exist in a disaster-impacted region. The chapter proposes a number of ethical responsibilities for disaster responders in their approach to cultural differences and conflicts during disasters.

Joseph Scanlon examines ethical issues in communications during health emergencies and pandemics. Drawing from historical examples of disasters, he identifies several principles for effective and ethical communication during disasters. Planning and training are essential for effective communications to ensure responses are not made ad hoc. During a major health disaster, communications should be handled by all who have relevant and credible backgrounds, not just the healthcare community. Most elements of crisis communications can and should be anticipated in prior planning. The messages themselves should be consistent and be repeated. The information should be accurate, positive and show concern and empathy. All channels of communication should be used. Scanlon points out that communications about ethical controversies arising during disasters has received little attention. He concludes with some suggestions about how these could be addressed appropriately.

The final chapter in the first part of the book examines issues of evidence and healthcare needs during disasters. Aasim Ahmad and colleagues examine how evidence-based practice has developed within medicine, and is increasingly called for to guide humanitarian responses. They note that basing humanitarian responses on evidence-based principles is challenging and has met with resistance. However, they defend the view that generating and using evidence in disasters is ethically justified. They cite a number of myths about disasters and disaster responses, which have been overturned as better evidence is made available from disaster research. At

the same time, the studies needed to develop an evidence base raise challenges for research ethics, which is the focus of Part II of the book.

The second part begins with an examination of the harms and benefits of disaster research. Evelyne Shuster argues that conducting research on people after disasters is a luxury. People should not be used merely as means to achieve other people's goals. Shuster acknowledges that many types of research can be conducted after disasters, and her focus is on clinical research that puts subjects at risk of physical harm. She claims that such research is difficult to justify in the immediate aftermath of a disaster, although it may be ethically acceptable during the recovery phase. Researchers may believe that new treatments must be tested to improve current practices and reduce the risk of harm in future disasters. However, Shuster argues that in disaster contexts combining medical care with medical research complicates the validity of informed consent and compromises the risk-benefit calculation. The risks of eroding particular moral values in the pursuit of scientific progress make such progress not worth having.

George Annas examines a recent trend that emphasises the benefit of medical research for future patients and society in general. According to Annas, this takes the emphasis off the rights of research subjects, especially regarding informed consent and the right to withdraw. Recent revelations about US medical research in Guatemala in the 1940s provide another example of medical necessity being used to over-rule human rights, with unethical results. Annas notes that the pressures and urgency of conducting disaster research could likewise lead to calls to conduct such research without consent. Ethical violations have occurred in US-sponsored research conducted in response to health disasters in Africa. If subjects' consent cannot be obtained for disaster research, Annas holds that such research should not be done. Disasters are opportunities to help victims, and should not be used as opportunities to exploit victims by doing research on them without their consent. He argues that ample opportunities exist to conduct ethically sound research without resorting to research without consent.

The next chapter explores the ethical issues involved in setting disaster research priorities. Virginia Murray and Anthony Kessel describe the difficulties and complexities involved in setting priorities for disaster research. However, overcoming these challenges is vital both to produce credible evidence for disaster risk reduction and planning, and to facilitate improved responses to humanitarian and health catastrophes. They note that little has been written on how to set disaster research priorities, and even less on the relevant ethical issues. Identifying the priorities depends partly on the systems that exist within countries, regions and international organisations. They describe three broad approaches to setting disaster research priorities and explore each critically, examining their advantages and disadvantages. They conclude by identifying the ethical issues involved in each approach and make recommendations for future planning.

Survivors of disasters are sometimes viewed as a vulnerable population when considered as research subjects. Ruth Macklin notes that being vulnerable does not, in and of itself, raise the level of risk in a research study. However, vulnerable subjects deserve additional protections, even in less risky research. Ethical guidelines often note the need for additional safeguards for vulnerable subjects, but rarely specify

what such protections should be. Different types of disasters may call for different safeguards depending on the type of disaster, proximity in time to the disaster, the severity of injury or trauma, and other factors. The types of safeguards needed for vulnerable subjects in research conducted during or after a disaster will depend on contextual factors that cannot be specified in advance. Macklin describes a 'layers' approach to vulnerability that provides guidance on protections for the rights and welfare of subjects. A cardinal ethical principle is that research should never interfere with or delay medical care or other aid being provided to treat or prevent further harm to disaster victims.

Doris Schopper notes increased awareness of the need to have clear guidance for ethical review of disaster research, and that internationally accepted guidelines are lacking. General research ethics guidelines provide some direction, but are not specifically targeted at disaster research. She examines in depth the Ethics Review Board (ERB) of Médecins Sans Frontières (MSF), of which she is a member. Its governance is based on that of other research ethics guidelines. A specific procedure for pre-approval of a generic research protocol has been developed, allowing expedited approval of the finalised protocol once a disaster occurs. Schopper examines other ethical issues that can arise in disaster research, including the importance of involving the local community in disaster research, the dual use of tissue samples collected during disasters, and addressing misconceptions that research subjects may have about what it is that they are agreeing to participate in. Schopper concludes that an internationally recognised body urgently needs to develop international guidance for ethical oversight of disaster research.

South Africa has experienced few natural disasters, but has seen some man-made disasters. Keymanthri Moodley analyses South Africa's experience with HIV/AIDS and drug resistant tuberculosis as a public health disaster. While not having a sudden onset, it has created many opportunities for disaster research. When disasters occur in resource depleted settings, escalated vulnerability ensues. Moodley describes how a research ethics regulatory infrastructure and guidelines evolved rapidly in South Africa. She examines the ethical dilemmas that arose in the context of HIV/AIDS research and how these issues were addressed in ethical guidelines. She also describes how approaches to research ethics review in disaster settings are to be incorporated into South African research ethics guidelines currently under revision.

The book concludes with reprints of the 1994 IFRC *Code of Conduct* for disaster responders and the 2006 World Medical Association *Statement on medical ethics in the event of disasters*. We are grateful for permission from these organisations to reprint these statements.

As editors, we appreciate the thought and reflection that each of the contributors have put into their chapters. We offer this volume as a stimulus for further discussion. We invite interested readers to engage with these issues and contribute to the development of this new field. Our hearts and prayers go out to those hit by disasters and to the many men and women who go to their aid. Our hope is that by providing clearer ethical reflection and guidance their lives will, in some small way, be improved. Disaster bioethics is ultimately about promoting good ethical norms when nothing else seems normal. Disasters may destroy many things, but they should not

destroy human dignity. *Disaster Bioethics* aims to identify ethical means to promote human dignity in the midst of disasters.

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