Practices and expectations for reporting ethical considerations in disaster research publications

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Dedication

To mom and dad

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Abstract

This thesis had two main objectives. The first is to analyze the state of ethical transparency in disaster research literature from 2003 to 2012. To achieve this, I present the results of a scoping review conducted of health-related disaster research publications in low-to-middle income countries (LMIC). I examine practices and norms related to the reporting of ethical considerations and research ethics methods in disaster research articles. Key questions underlying the inquiry include the following: How often do researchers mention obtaining informed consent and research ethics committee approval in their published work? How much detail do researchers provide regarding research ethics methods and challenges they faced while conducting research? How have these trends changed over the years? The second objective of my thesis is to examine norms and expectations regarding ethics reporting in disaster research literature, and to articulate why, and to what degree, ethical transparency should be expected in publications of disaster research. This objective is accomplished with a discussion of ethical transparency and how it assists with increasing reliability and credibility of disaster research findings.

Abrégé

Cette thèse avait deux objectifs principaux. Le premier est d'analyser l'état de la transparence éthique dans la littérature de recherche sur les catastrophes de 2003 à 2012. Pour y parvenir, je présente les résultats d'une revue de la portée des publications de recherche sur les catastrophes dans les pays à revenu faible à moyen. J'étudie les pratiques et les normes relatives à la déclaration des considérations éthiques et des méthodes d'éthique de la recherche dans les articles de recherche sur les catastrophes. Les questions clés qui sous-tendent l'enquête sont les suivantes: À quelle fréquence les chercheurs mentionnent-ils avoir obtenu le consentement éclairé et l'approbation du comité d'éthique de la recherche dans leurs travaux publiés? Dans quelle mesure les chercheurs fournissent-ils des détails sur les méthodes d'éthique de la recherche et les défis auxquels ils sont confrontés lorsqu'ils mènent des recherches? Comment ces tendances ont-elles changé au fil des ans? Le deuxième objectif de ma thèse est d'examiner les normes et les attentes en matière de rapports sur l'éthique dans la littérature sur les catastrophes et d'expliquer pourquoi et dans quelle mesure une transparence éthique devrait être attendue dans les publications de recherche sur les catastrophes. Cet objectif est atteint avec une discussion sur la transparence éthique et comment elle contribue à accroître la fiabilité et la crédibilité des résultats de la recherche en cas de catastrophe.

Chapter One: Introduction

1.1 Background

Nick in Nepal

Nick is a Canadian anthropologist conducting research in Nepal. His research objective is to understand how cash transfers improve the well-being and health status of individuals who receive them. Nick is working with Ana, a community leader, to find participants for the study. Nick is making significant progress on his work. He has gained the trust of local participants and has taken steps to protect their welfare, including by keeping their information confidential by storing study data on a password protected iPad. His research has also been reviewed and approved by both a Nepali and a Canadian research ethics committee (REC).

Three months after Nick's arrival, there is an earthquake with magnitude 5 on the Richter scale. The homes of many of the families he was working with are destroyed, people have been injured or reported missing, and most now lack access to food, shelter, healthcare, and clean water. Nick is unharmed, but the research he initially set out to do can no longer be continued due to the effects of the disaster. He speaks with his research team at home, and proposes to change research focus. Nick now wants to understand whether and how cash transfers improve the well-being of people affected by disaster. He rewrites his research protocol and sends it to the two RECs that originally approved his protocol. After one week, he still has not received a response from the Canadian REC. The local REC does not appear to be functioning as a result of the disaster. Nick is unsure what to do next. Should he wait and keep trying to contact the RECs? Should he seek approval from another source, such as the Ministry *of Health? Or should he go ahead with a modified version of his original protocol. Nick also considers other options, including volunteering to help with the disaster relief effort or to return home. He is unsure how to proceed.*

Though this case study is fictitious, it illustrates several ethical tensions that can arise for researchers in post-disaster settings. Ethical tensions arise in all types of research, but the emergent nature of sudden-onset disasters, combined with the chaotic and constantly evolving situation post-disaster, result in a distinctive set of ethical considerations that require careful deliberation. Researchers may plan and initiate research that is designed for a research setting. In some cases, like Nick's, research may already be underway when a disaster occurs. His situation is likely to give rise to many questions. Not only had he gained the trust of research participants, but he had begun to develop meaningful relationships with the community in which he was working.

Nick wonders: will he lose trust of people if he continues research at a time they need help? What are the implications on his job if he stops research to provide aid while his expenses and travel are paid for through his research funding? He has not been able to get in touch with his collaborator, Ana, and worries that she may be severely injured or dead. He is not able to get a flight back home right away as there is infrastructural damage at the airport. Nick is not familiar with how previous researchers have dealt with such ethical tensions in disaster research. Confused and worried and without many answers, one night on his iPad he decides to read through research ethics guidelines for insight on how he can approach the unfolding situation.

He starts with the online Tri-Council Policy Statement tutorial, from which he received a certificate of completion over a year ago. He reads through the section on preparedness plans for research in publically declared emergencies. This guideline focuses on the ethics review process, and not so much on the ethics methods of conducting research in disaster settings. In the Council for International Organizations of Medical Sciences' (CIOMS) 2016 guidelines, he finds guidance on disaster research emphasizing that "investigators must make every effort to ensure that the research is responsive to the health needs and the priorities of the population or community in which it is to be carried out; and that any intervention or product developed, or knowledge generated, will be made reasonably available for the benefit of that population or community" (1, Guideline 10). He refers to similar publications such as the guidelines made by the Working Group on Disaster Research Ethics (2) and recommendations by the Ethics Review Board of Médecins Sans Frontières (3).

Nick finds these texts helpful, yet wonders how previous researchers in disaster situations have put the guidelines to use. He remains uncertain how these guidelines can be put into action in a disaster situation. He thus turns his attention to articles in which researchers present findings of studies carried out during disasters. He hopes to find how other researchers have dealt with ethical tensions after earthquakes. Several papers are enlightening. For example, he finds an article that presents research on risk factors for posttraumatic stress disorder that was conducted after the Wenchuan earthquake in China during which the researchers also played the role of aid providers:

> More than 100 voluntary psychological assistants working at the Mianzhu City Working Station in June and July, 2008 received training by the authors of this study on communication and interviewing skills before commencing data collection. The psychological assistants recruited participants during routine visits to the temporary housing tents of the participants to provide psychological support […]. The psychological assistant was present during the whole data collection session to answer any queries from the participants. For those participants with elementary education or below, the questionnaires were administered by the psychological assistant through face-to-face interview (4, p.2).

Nick begins to wonder if he, too, could be both a researcher and provide humanitarian aid. Would this cause a potential conflict of interest? He finds little reassurance when he reads that the authors of the article have stated that they had no conflict of interest to declare. The authors also did not discuss how the psychological assistants in their study balanced the roles of being both researchers and aid providers without experiencing competing interests.

Nick decides to refer to another article, where the researchers implemented a rapid assessment survey to assess mortality and injuries after an earthquake in Gujarat, India (5). While the authors mention how challenging it was to get ethics approval when the research was reactive to a large-scale disaster, Nick fails to find a substantial discussion as to how the authors dealt with this challenge of not being able to obtain ethics approval.

Nick then finds a paper on infections and treatment of wounds in survivors of the 2004 Tsunami in Thailand (6). It states that their study protocol was exempt from an REC process because the investigation was part of the response to a public health emergency (6). Nick begins to wonder if providing cash transfers to earthquake survivors and observing implications of doing so would exempt him from seeking REC approval as it could be deemed a response to an emergency. He wonders if doing this would require informed consent of participants or approval from the government. He also realizes that the disaster situation may change overtime and begins to wonder how he would adjust to such changes so rapidly. However, he is unsure if this practice is indeed an accepted one, nor if it would apply to his situation specifically. He also notices that many authors reporting on research they conducted in disaster settings did not mention procedures related to research ethics (e.g. consent, REC review). Nick also wonders if he could publish the results of his research without mentioning any practices that some might consider 'unethical'. For example, if he is unable to obtain informed consent or unable to explain why some individuals got cash transfers over others, ought he to reveal this information even if doing so might negatively impact his career? Is accountability more important than his job as a researcher? Could he lose his job if he clearly explains what happened?

Nick is growing frustrated in his search to find answers, and with still no response from the Canadian REC, he begins to realize that there is little information about how to address ethical challenges in post-disaster research. He wonders why, as he sees just how ethically-fraught disaster situations can be…

Disaster research literature

Well-conducted research conducted during or in the aftermath of a natural disaster can generate knowledge about the health impact of these large-scale events (7,8). This can lead to important advances in planning and implementation of disaster relief, as well as better preparation for future disasters. Disaster research, however, poses a range of ethical challenges due to the unique features of these contexts: research protocols may be time-sensitive and require rapid REC approval to be implemented quickly; disasters may leave individuals traumatized and highly vulnerable, leading to concerns about exploitation or harm; research activities may hinder relief and aid efforts; and risks associated with research may change over time as post-disaster situations evolve (9-12). The researcher may also have questions about her role in the disaster setting. If she sees that her participant requires assistance, is it her duty to help? The lines between humanitarian aid worker and researcher may begin to blur and research participants could confuse research activities with relief operations (13).

Disaster research ethics is a growing field of inquiry and continues to expand as natural disasters are increasing globally (14). Several scholars have pointed to the need for greater transparency in reporting of research data in disaster settings. For example, in 2015 the World Health Organization released the *Ethics in epidemics, emergencies and disasters: Research, surveillance and patient care* manual. The training manual has two parts. The first part of the training manual discusses issues in research and surveillance, such as ethics oversight and publication ethics. The second part of the manual covers patient care, including triage, standards of care, and the professional duties of health care workers in emergencies. Calain (2015) outlines the need for confidentiality, risk minimization, permission, and availability and accessibility of the outcomes of the data analysis in research conducted in public health emergencies (15, p.142). The manual also makes clear that if ethics approval was not obtained prior to conducting the activity that led to data collection, then post-hoc ethics approval cannot be granted. The authors state that if they decide to publish such research, editors and publishers are taking moral responsibility regarding all ethical issues (15, p142).

The manual also introduces the concept of transparency in disaster research. Smith (2015) discusses how data transparency in the publication process might counteract publication bias, which occurs when the information published is systematically unrepresentative of the existing data (15, p.149). Smith also argues that transparency in the peer-review process should include reporting the names of peer-reviewers and publishing their comments, as well as making publications "open access" (15, p.150). While the manual touches on the importance of transparency of reporting research processes and data, the concept of ethical transparency is not discussed.

Transparency in publications of biomedical research has been described as the obligation of researchers to reveal their data, theory and/or methodology upon which their conclusions rest (16). The concept of ethical transparency is similar but extends transparency expectations in a new direction. It requires clear communication of how ethical standards were upheld when conducting research on humans. Ethical transparency lies at the intersection of research ethics and publication ethics, with the overall goal of transferring ethics knowledge across the research community and promoting accountability for decisions made and actions taken (16). In practice, ethical transparency requires researchers to report the features of a study that raised ethical challenges and how they responded to them. Ethical transparency is just one of the two principles that comprise the broader concept of 'ethics reporting'. Anderson, Eikjholt and Illes (2013) articulate two principles to guide ethics reporting: “1) transparency, i.e. reporting sufficient detail to enable readers to assess and reproduce the research ethics methods used, and 2) proportionality, i.e., providing detail at a level that is proportional to the ethical complexity and risk to participants” (17, p.844). But while ethical transparency and ethics reporting have been discussed for biomedical research, ethical transparency has received limited attention in the context of disaster research.

This thesis has two overall objectives. The first objective is to analyze the state of ethical transparency in the disaster research literature. To achieve this, I present the results of a scoping review that we conducted of health-related disaster research publications in low-to-middle income countries (LMIC) between the years 2003 and 2012. I examine practices and norms related to the reporting of ethical considerations in disaster research articles. Key questions underlying this inquiry include the following: How often do researchers mention obtaining informed consent and research ethics committee approval? How much detail do researchers provide about ethics methods and challenges they faced while conducting research? How have these trends changed over the years?[1] The second objective is to examine norms and expectations regarding ethics reporting in disaster research literature, and to articulate why, and to what degree, ethical transparency should be expected in publications of disaster research. This objective is accomplished with a discussion of ethical transparency and how it assists with increasing reliability and credibility of disaster research findings (17).

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[1] I will stress that in this thesis, I will not discuss *why* publication patterns emerge the way that they do. Instead, I present *what* the scoping review results reveals, and discuss the relevance of these findings for disaster research. This analysis provides a foundation for the work that I do in seeking to discuss what standards ought to guide ethics reporting in disaster research publications.

1.2 Personal Motivations

There are several experiences that inspired me to work on the topic of ethical transparency in disaster literature for my thesis. My interest in ethics was initially sparked during my undergraduate studies at Western University, where I had the opportunity to take courses in bioethics and very briefly learn about the challenges of applying ethical principles to the field of global health. During the last year of my undergraduate degree, I took a course on the philosophies of mental health with Louis Charland. I learned that I very much enjoyed the process of applying abstract concepts to help me see the world in new ways.

Uncertain of what I wanted to do after my undergraduate degree, I went on to work at a Toronto-based pharmaceutical contract research organization (CRO) where my role involved leading recruitment and marketing for multi-site clinical trials. During my time at the CRO I had the chance to work directly with research participants. This gave me the opportunity to speak to them informally about their experiences about being participants in research, their motivations to take part in research studies, and how they felt the process could be improved. It was during my time at the CRO, and through my conversations with participants, that I developed a keen interest in further learning about the ethics that guide research on human participants.

I applied to McGill University's biomedical ethics master's program in the hopes of figuring out exactly what area of research ethics I would like to focus on. After a conversation with Carolyn Ells about my research interests and interests in general, she connected me to Matthew Hunt's group focusing on disaster research ethics. Prior to joining the team full-time as a master's student, I had the opportunity to work for Matthew as a research assistant, where I began getting my hands dirty by assisting with the disaster research scoping review that would become a central component for my thesis research. During this time, I also had the chance to attend and publish a paper (18) on the 2014 Humanitarian Health Ethics workshop that brought together a multidisciplinary group from India, Switzerland, Haiti, the US, and Canada. The rich discussions during the workshop reminded me of my undergraduate courses in ethics during which a range of perspectives came together to discuss contentious issues in a thoughtful manner. It taught me just how many different ways there are to look at one issue, and how these issues can influence decision-making in various situations.

The field of bioethics is complex; this complexity is amplified when bioethical inquiry is directed toward urgent disaster situations. I became intrigued by both the complexity of disaster research ethics as a field of scholarly inquiry, as well feeling that this line of inquiry was needed to address the challenges of human-subject research in disaster settings. Most importantly, I saw the applicability of this work in the real world. Improving how disaster research is conducted can change the lives of the many people around the world who are impacted by the destructive nature of natural disasters. I hope that my work can make a contribution, even if a small one, in how we understand and regard natural disaster research and the ethical norms that guide it.

1.3 Structural Overview

This thesis is divided into five chapters. In chapter 2, *Overview of publication and research ethics*, I highlight how my thesis is situated at the intersection of research ethics, publication ethics, and disaster research. In it, I discuss the development of research ethics and publication ethics, leading up to the set of standards that guide research ethics today. In this brief historical sketch, I summarize several key documents that have contributed to current guidance in the area of research ethics, including the Nuremberg Code, the Declaration of Helsinki, and the Belmont Report. In the second part of the chapter, I review the development of publication ethics guidelines. Finally, I dial in my focus to report on the development and current state of a sub-field of research ethics, disaster research ethics. This chapter provides foundational knowledge leading up to chapters 3 and 4 which are the core of my thesis work.

Chapter 3 addresses the question: what does health-related disaster research literature tell us about ethics reporting? I discuss the methods that we used to conduct the scoping review and then present the results, divided into three main sections: informed consent, mention of REC approval, and conflict of interest. Though we analyzed the results of the scoping review in a variety of ways, I found that informed consent, REC approval, and conflict of interest revealed the most about the state of ethics reporting in disaster research literature. Along with graphs that illustrate how often these topics are presented in published disaster research articles, I include specific examples from the scoping review. In the discussion, I answer two main questions: 1) Do current publication ethics recommendations provide sufficient guidance for disaster research publications? and 2)

What should publication ethics guidelines for disaster research look like? I conclude this chapter with a discussion on the limitations of our review and future areas for research.

In Chapter 4, I conceptualize ethics reporting in disaster research publications. I start with a discussion of the implications of increasing ethical transparency in disaster publications. The chapter concludes with a discussion on the limitations and challenges of expecting greater ethical transparency in disaster research. I present an argument that more transparency of research ethics methods in disaster literature can result in both learning and internalization of the material, as well as holding researchers accountable for their actions in the field.

Finally, Chapter 5 summarizes the work of my thesis with a personal reflection of how my work ties together with an emphasis on potential future areas of work.

Chapter two: Literature Review

2.1 Introduction

Broadly, ethics refers to:

> A range of methods used to critically analyze, interpret and evaluate the variety of ways in which humans interact with each other. In the most general terms, ethics seeks to provide an account of how humans, as agents, assign and evaluate the worth of persons, organizations, their actions and their consequences. […] ethics engages in appraising the range of arguments offered to determine the rightness and wrongness of actions and policies, and reflects upon the praiseworthiness or blameworthiness of actors and organizations, and the justification for such judgments (19, p.19).

Drawing upon this definition, in this chapter I briefly review the topics of research ethics (section 2.2), publication ethics (section 2.3), and disaster research (section 2.4) in order to situate my analysis of ethics reporting in disaster research publications. Understanding these topics and how they interconnect provides foundational knowledge for understanding disaster research ethics, and setting up the analysis presented in Chapter 3 and Chapter 4 of my thesis (illustrated in Figure 1, 2.1).

Figure 1, 2.1: Interconnections among topics included in the literature review

2.2 Research Ethics

Research ethics encompasses analysis of ethical issues that arise when research involves human participants (20). There are three main objectives to research ethics: to protect human participants; to ensure research is conducted in a way that serves the interest of individuals and societies; and to examine specific research activities for their ethical soundness (20). The first and last objectives are concerned with looking at issues such as protection of confidentiality, the process of informed consent, and REC approval (20).

There is always a degree of risk involved whenever research is conducted with humans. In some circumstances, risks may be significant. Ethical analysis – by researchers, scholars, and RECs alike – throughout the research process helps reduce the risk of harm (both likelihood and magnitude) to research subjects (21). For example, RECs may conduct a risk-benefit analysis when analyzing a research protocol. A risk-benefit analysis is a decision-making process which enables researchers, REC members, and funders to assess whether a research project ought to be pursued at all and, if so, how it can be designed to make it less risky while maximizing benefits (21). To better understand the current state of research ethics, this section is broken into two sub-sections. First, I outline the development of research ethics over time. I then discuss current standards and research ethics guidelines, and their application to the conduct of research on humans.

2.2.1 The Development of Research Ethics

In the early 1900s, there was a lack of broadly accepted ethical standards regarding research on humans (22). Over the past century, many events have changed the way research on humans is conducted, and expectations for what constitutes ethical research. To illustrate how research ethics has evolved over time, I highlight three key developments related to the conduct of research with humans. Each of these developments occurred in response to events and played an important role in the refinement of research ethics rules and regulations. **Table 1, 2.2.1** presents an overview of these 3 key developments in the history of research ethics.

Document	Year	Description
Nuremberg Code	1946	First international document to outline voluntary participation and informed consent

The Declaration of Helsinki	1964	World Medical Association established recommendations for physicians who conduct biomedical research involving humans
The Belmont Report	1979	Publicity from Tuskegee Syphilis Study of 600 low-income African-American males led to articulation of general ethical principles and guidelines that assist in resolving the problems that arise in research involving humans

Table 1, 2.2.1: Three key developments in the field of Research Ethics

Nuremberg Code

The first key development in modern research ethics begins with the Nuremberg Trials, an incident that examined extremely unethical treatment of human participants in research (23). The Nuremberg Code was established in 1947 as a result of trials involving 23 German physicians charged with conducting torturous and murderous experiments on humans in heinous conditions during World War II (23). Most of the subjects of these experiments died or were left permanently disabled. The trials took place in Nuremberg, Germany and were led by judges from France, the Soviet Union, the United Kingdom and the United States. Many of the accused argued that their experiments were conducted at a time when there was no law that distinguished legal versus illegal experiments (23). When defense counsel asked one of the accused to reconcile the Hippocratic Oath that forbids physicians to “administer a poison to anyone even when asked to do so” (24, p.1438), referring to conducting fatal experimental interventions on humans, the accused replied, “I believe this Hippocratic commandment refers to the function of the physician as a therapist, not as an experimentalist, and what refers to the Hippocratic Oath is that he must have respect for life and the human rights of his experimental patient” (24, p1438). Though recognizing the value of the Hippocratic Oath, the judges realized there needed to be more done to protect humans in experiments. The Nuremberg Code was thus established as the first international document that outlined the rights of human subjects (24). The main elements are that voluntary consent of the human participant is absolutely essential, human subjects must be free to quit an experiment at any point in time, and researchers must stop an experiment at any point they feel that continuation would be dangerous for participants.

Declaration of Helsinki

The World Medical Association’s Declaration of Helsinki was first introduced in June 1964 (25). The primary goal of this document is to set an international ethical guideline for research involving human participants. The document was developed “as a statement of ethical principles for medical research involving human subjects, including research on identifiable human material and data” (25, p.2191). The Declaration of Helsinki was introduced in 1964 and linked the ten principles stated in the Nuremberg Code with the Declaration of Geneva, a statement of physicians’ ethical duties. A significant change from the Nuremberg Code was the Declaration’s guidelines for obtaining informed consent. The

Nuremberg code made consent “absolutely essential” whereas the Declaration asked doctors to obtain consent “if at all possible” and research without consent from the research participant him or herself, such as when consent is provided by a legal guardian[2], was thus possible (25, Article II.1).

Though the Declaration was created primarily to address physician researchers, the guidelines are the most influential document in research ethics (they are mentioned in several other guidelines such as the Committee on Publication Ethics or “COPE”) and may be used by anyone conducting research involving humans. Three key research ethics issues addressed in the Declaration of Helsinki include (26): research protocols should be reviewed by an independent committee prior to implementation; research should be conducted by scientifically qualified individuals; and risks should not outweigh the benefits. Since 1964, the Declaration has been revised and updated seven times, with the most recent revision being in 2013[3].

Belmont Report

The National Research Act – signed into law in July of 1974 – created the US National Commission for the Projection of Human Subjects of Biomedical and Behavioral Research (27). The Commission was created to develop guidelines for research that involves human subjects, and to oversee and regulate human experimentation in medicine.

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[2] A legal guardian refers to a person who is lawfully appointed with the obligation of taking care of another person who, because of age, understanding, or self-control is incapable of making his or her own decisions *(http://legal-dictionary.thefreedictionary.com/guardian)*

[3] In 1993, the Council for International Organizations of Medical Sciences (CIOMS) developed the International Ethical Guidelines for Biomedical Research Involving Human Subjects. Since 2002, this document has 21 guidelines (15 in the original document). The 2016 update has 25 guidelines regarding ethical justification and scientific validity of biomedical research involving human beings, informed consent, standards of external review, recruitment and compensation of participants, and more (28).

The development of the Commission was in part a response to the infamous Tuskegee syphilis study dating back to 1932 (and which ran until 1972) (27).

The Tuskegee Syphilis study began when the U.S. Public Health Service started working with the Tuskegee Institute to document the natural course of syphilis. The study was called "Tuskegee Study of Untreated Syphilis in the Negro Male" and involved 600 African-American men – 399 with syphilis, and 201 without the disease (27). Though initially the study was projected to last six months, it went on for 40 years, from 1932 to 1972 (27). The study was controversial and deemed unethical for several reasons. First, recruitment for the study was conducted via misleading advertisements. The study was advertised as a "*Last Chance to Receive Free Special Treatment"* (27). The participants, however, were not given a treatment and instead were recruited to participate in a spinal tap diagnostic. Second, the researchers recruited participants from low-socioeconomic backgrounds and did not seek their informed consent[4], nor were the participants informed about the purpose of the study[4]. Third, the researchers knowingly withheld penicillin treatment for syphilis after it became available in the 1940s following World War II. Participant well-being was overlooked for the sake of research results, and the participants were neither given the option to leave the study once treatment became available, nor were they offered treatment for their illness (29, p. 100).

Though no formal comprehensive paper of the study was published, there were several reports that were issued over the course of the study. The National Commission for Protection of Human Subjects was launched in the aftermath of the public scandal that

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[4] Informed consent involves telling participants about all aspects of an experiment that might reasonably influence their decision to participate (32).

erupted once the Tuskegee Syphilis Study came to national attention. The study inspired re-evaluation of ethics guidelines and the importance of emphasizing the value of human life over the pursuit of scientific research. The Commission was the first public national body to shape bioethics policy in the United States (30). The trials also emphasized the importance of an ongoing ethics review process throughout the course of an experiment, and the need for Institutional Review Boards (IRBs)[5] to review protocols prior to study implementation (31). The commission produced their Reports and Recommendations on many areas of research, including the Belmont Report.

The *Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research* was published in 1979 by the *National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research.* Today, the Belmont Report remains a reference for RECs to guide ethical decision-making. The report outlines three fundamental principles (33). The first principle, respect for persons, describes treating people as autonomous agents and acting towards them with courtesy and respect. It is linked to the practice of informed consent and prohibits deception. The second principle is beneficence and requires that benefits are maximized and risks minimized to the research subjects. The third principle, justice, is enacted when reasonable, non-exploitative and well-considered procedures are administered fairly.

The practice of informed consent was first operationalized by the Belmont Report, and linked to 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,

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[5] IRB is the United States terminology for REC.

benefits and alternatives to the research, and then obtaining documentation of permission to proceed" (34, p.86).

2.3 Publication Ethics

2.3.1 Introduction

Researchers have an obligation to make the results of research involving human-participants publicly available (35). Researchers are also accountable for the completeness and accuracy of the data and overall information they present to the public (35). Publication ethics refers to a set of rules of responsible conduct generally agreed upon by the academic community when publishing a scholarly paper (36). In the following section I present the development of publication ethics, and briefly touch on key transparency issues for global health and disaster research publications.

2.3.2 Publication Ethics Timeline

As noted above, the Declaration of Helsinki is an important reference document for researchers from all backgrounds. With respect to publication ethics, the latest version of the Declaration of Helsinki (35, paragraph 36) states:

> Researchers, authors, sponsors, editors and publishers all have ethical obligations with regard to the publication and dissemination of the results of research. Researchers have a duty to make publicly available the results of their research on human subjects and are accountable for the completeness and accuracy of their reports. All parties should adhere to accepted guidelines for ethical reporting. Negative and inconclusive as well as

> positive results must be published or otherwise made publicly available. Sources of funding, institutional affiliations and conflicts of interest must be declared in the publication. Reports of research not in accordance with the principles of this Declaration should not be accepted for publication.

Below I highlight other important developments in the history of publication ethics and discuss their relevance today (**Table 1, 2.3.2**).

Committee/Editors	**Year**	**Description**
Council of Science Editors	1957	A United States-based organization that supports the responsible and effective communication of science, adopting the slogan "CSE: Education, Ethics, and Evidence for Editors (E4)" in 2008.
International Committee of Medical Journal Editors	1978	A working group of general medical journal editors responsible for developing Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly Work in Medical Journals. In 1978, the ICMJE first developed the Uniform Requirements for Manuscripts

		(URMs).
World Association of Medical Editors	1995	A voluntary non-profit association of editors of peer-reviewed journals who seek to educate and foster a collaboration of medical journal editors.
Committee on Publication Ethics	1997	Committee provides advice to editors and publishers regarding publication ethics and in particular how to handle cases of research and publication misconduct.

Table 1, 2.3.2 Publication Ethics Timeline

The field of publication ethics dates back to the mid-nineteenth century when Charles Babbage – a British scientist – published an essay entitled *The Decline of Science in England* in 1830 (37). In this essay, Babbage discusses issues related to data fabrication, falsification, and manipulation (38) and asserts that research results can be manipulated even if it is in very subtle ways. Babbage gives the example of “cooked” data – a process which he defines as “an art of various forms, the object of which is to give to ordinary observations the appearance and character of those in the highest degree accuracy” (39, p. 191). Data can also be selectively published when doing so supports one’s expectations (40).

The topic of publication ethics particularly gained traction with the rise of the modern model of academic promotion. The phrase ‘publish or perish’ –used to describe the pressure in academia to continually publish work to further or sustain one’s career – was either first used in an academic context in 1927 or in 1942 (41, 42). Regardless of when the concept first gained prominence, publication ethics became an increasingly important topic to discuss alongside the steep rise of scientific publications and academic journals in the second half of the twentieth century. In 1957, the Council of Biology Editors (CBE) was established by the National Science Foundation and the American Institute of Biological Sciences as a United States-based non-profit organization (37). In 2000, it was renamed the Council of Science Editors (CSE). It publishes a style guide for scientific papers: “Scientific Style and Format: The CSE Manual for Authors, Editors, and Publishers” (43). The CSE manual provides online tools for manuscript preparation with a checklist instruction for authors to include in their published work. The CSE instructions to authors provides them with the details required by a journal for manuscript preparation and submission. These include research ethics methods such as identifying financial support, full-financial disclosure for all authors, permission to use pictures, and REC review. Though not as commonly used as some other style-guides such as those of the American Psychological Association and the American Medical Association, it was one of the first.

In 1978, the International Committee of Medical Journal Editors (ICMJE) first published the Uniform Requirements for Manuscripts Submitted to Biomedical Journals (URMs) (44). Their aim was “to review best practice and ethical standards in the conduct and reporting of research and other material published in medical journals, and to help authors, editors, and others involved in peer review and biomedical publishing create and distribute accurate, clear, reproducible, unbiased medical journal articles" (44). The URMs were initially published to standardize manuscript format across biomedical journals (44) but they have since been revised many times, with the latest version renamed "Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals" (44).

In 1995, a non-profit, voluntary global association of editors of peer-reviewed medical journals established the "World Association of Medical Editors" (WAME). WAME (pronounced "whammy") aims to "foster cooperation and communication among editors, improve editorial standards, promote professionalism in medical editing through education, self-criticism, and self-regulation, and encourage research on the principles and practice of medical editing" (45). WAME also developed an ethics committee to provide anonymous consultation for editors seeking advice on tough ethical issues related to academic publishing.

Also in 1995, the National Academy of Sciences in the US published a document entitled "On Being a Scientist: Responsible Conduct in Research". This was an updated version of a document entitled "On being a Scientist" published in 1989. Originally written for novice researchers, it aimed to describe the ethical foundations of scientific practice. It was revised in 1995, in part to respond to new US federal agencies policies for addressing ethical issues in science. The updated version incorporated new material from *Responsible Science: Ensuring the Integrity of the Research Process*, issued by the National Academies of Sciences and Engineering and the Institute of Medicine, as well as feedback from readers of the original booklet[7].

Two years after the development of WAME, the Committee on Publication Ethics (COPE) was established in 1997 by a small group of UK-based medical journal editors. COPE aims to provide support to both editors and publishers on all aspects of publication ethics, particularly how to handle research publication misconduct. COPE also funds research on publication ethics, puts out a quarterly newsletter and organizes seminars in the UK and US. Membership is open to editors of academic journals and to anyone interested in learning about various aspects of publication ethics, including how to address publication misconduct. The COPE now has over 10,000 members globally from a wide variety of academic disciplines and provides a set of standards which all COPE members are expected to follow (publicationethics.org). COPE is affiliated with the CSE, European Association of Science Editors, the International Society of Managing and Technical Editors, and the WAME.

In 1997, the COPE was founded and created *Guidelines on Good Publication Practice* – a set of guidelines for authors, editors, editorial board members, journal owners, and publishers. The guideline encourages academic honesty and is used both to inform publication ethics and prevent ethical misconduct. The guidelines are periodically updated. Currently, the topics outlined include: study design and ethical approval, data analysis, authorship, conflict of interest, peer-review, redundant publication, plagiarism, duties of editors, media relations, advertising, and dealing with misconduct.

In the next section, I highlight several main topics addressed in the *Guidelines on Good Publication Practices*: study design and ethical approval, conflict of interest, and authorship. These topics are particularly relevant to my analysis in chapter 3 of my thesis and so I have elected to review them in greater detail here. I structure the discussion of each topic below by presenting the norms for how each topic is to be addressed in scholarly publications, and discuss how it relates to the areas of disaster or global health research.

2.3.3 Ethical approval and informed consent

According to COPE, ‘good’ research includes studies that are well justified and planned, with appropriate study designs and which have been ethically approved (46). The guideline highlights the requirement of a formal and well-documented ethics approval from a recognized REC for studies involving humans, medical records or anonymized human tissues. Regardless of this definition of what constitutes ‘good’ research, many authors still fail to mention ethics approval in published research articles.

A review conducted by Klitzman et al. (2011) examined the frequency with which authors reported IRB or REC review in journal articles that described human HIV research conducted in four LMICs (47). They examined articles published in 2007 in Nigeria, India, Thailand, and Uganda. One third (32.1%) of the articles did not mention IRB approval. The likelihood that authors reported IRB or REC approval was increased when the article was published in a journal that had adopted the ICMJE guidelines. More about Klitzman et al.’s research on documentation of ethics approval and informed consent is discussed in Chapter 3 of this thesis.

2.3.4 Conflict of Interest

Generally, a Conflict of Interest (COI) occurs when personal interests conflict with professional obligations (48). COIs can exist both implicitly or explicitly, and regardless of their impact on decision making. *Obvious* COIs exist when a reasonable person can identify the partiality in professional decision making in a given context. In contrast, p*otential* COIs exist when there is the possibility of a COI. Most recently, critics have argued that there is no such concept as “potential COI”, as this “reflects the mistaken view that a COI exists only when bias or harm actually occurs” (49).

There are many examples of situations where a COI influences professional decision-making process. A primary example that is often discussed in the context of disaster research is when humanitarian aid is provided by organizations or individuals who are also conducting or sponsoring research projects. This situation has been described as an obvious COI (13). The main concern with COIs stems from the fact that they not only bias behaviour, but can also cause harm to research subjects (50). In the context of disaster research, participants may think they are agreeing to receive aid, rather than consenting to participate in research (13, 48). Individuals who are simultaneously involved in the conduct of research and the provision of humanitarian relief may also feel pulled between these responsibilities. For example, if mental health research to identify depression and post-traumatic stress disorder (PTSD) in disaster-affected individuals reveals that someone has PTSD, questions may arise about when and how an individual should shift between their dual roles as a mental health researcher and that of a mental health counsellor.

Declaring existing COIs in research publications is important for readers to understand biases that could have influenced research results (51). A majority of journals require that authors explicitly declare whether or not there is a COI, and if so, what it is. The COPE *Principles of Transparency and Best Practice in Scholarly Publishing (2014)* encourage journals to clearly outline policies for handling the potential COI of editors, authors, and reviewers (46). This expectation includes stating how the research was funded, the authors' affiliations, and any incentives that might have influenced peer review – such as gifting or personal relations.

There are two types of COIs that may occur in the context of public health research – financial and non-financial. For example, an obvious financial COI occurs when a community leader works in collaboration with public health researchers and may have financial interests that conflict with her or his responsibilities to the community, participants, or researchers (15, p.217). Non-financial COIs may result in research-related conflicts that are associated with local politics and non-government organizations (NGOs) (53). For example, if there is a research project going on in a community and some community leaders want to benefit from the research project to enhance their own reputations, they may try to please the investigators rather than provide support to advance the research endeavour (54). Since non-financial COIs are more difficult to spot and address, it has been suggested that priority should be given to the principles of accountability, integrity, and transparency during disaster and emergency research. If these principles are always at the forefront of research design and implementation, it may mitigate the risk of researchers being tempted to give priority to personal interests in the name of "emergency" (15).

To ensure transparency, some journals require authors to disclose all funding and financial support in their submitted manuscript. To add to this, journals may also require disclosing the role of the research funder, as well as the roles of all other parties contributing to designing the research, collecting data, and preparing a manuscript. A funding statement may reveal a COI if there are financial interests in the research outcome (55). For example, if a research is paid by a pharmaceutical company and the researchers work for the company, there may be a conflict of interest present between upholding duties to the company and duties as a researcher. Any contributions to the research process – such as involvement from NGOs, government, or community leaders – must also be mentioned in the publication. More detail on contributions is addressed in the following section on authorship.

2.3.5 Authorship

There is much discussion regarding authorship ethics in the academic community, specifically about plagiarism and ghost authorship (56). Plagiarism refers to "the act of representing as one's own original work the creative works of another, without appropriate acknowledgement of the author or source" (57). In this context, creative works include: written documents, published or unpublished work, computer software, interpretations, music, design, sounds, images, and ideas or frameworks gained through talking to another person. Various organizations, including the ICMJE, WAME, and COPE have discussed authorship and publication requirements for scientific manuscripts. While WAME and COPE give general guidance, the ICMJE has outlined specific authorship recommendations. ICMJE suggests that authorship credit should be based on: 1) substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; 2) drafting the article or revising it critically for important intellectual content; and 3) final approval of the version to be published (58). Authors should meet conditions 1, 2, and 3 to be listed as an author (58). The ICMJE also directs authors to acknowledge the involvement of contributors who do not meet the criteria for authorship. For example, those involved in providing purely technical help, writing assistance, or a department chair who gave only general support should be listed in an article's 'acknowledgements' section (59).

Although the ICMJE are often referred to as the leading standard in health research, including global health research, they do not adequately address all the complex issues that arise from collaborations in global health, including global disaster research, where contextual features influence how researchers contribute to a particular project (56). An example highlighted by Smith, Hunt and Master (2014) is how language abilities pose a significant barrier for North-South research collaborations in global health research (56). Since high-income country (HIC) researchers are more likely than low- to middle income country researchers (LMIC) to speak English, the latter may be at a disadvantage within a North-South global health partnership when writing or revising the article for English-language journals (ICMJE criterion 2) (56). While there is the option to publish in scientific journals that are not in English, these journals are less likely to be in international databases or receive the same international exposure (60, p.306). There is also the challenge of ranking authorship contributions in global health research publications. Smith, Hunt, Master (2014) mention that lack of guidance on authorship order could potentially "create confusion and lead to insufficient recognition of LMIC researchers. For example, LMIC researchers may be given reduced ranking on the author byline because their contributions to subject recruitment, data collection, administration and analysis are categorized as 'technical tasks' and may be considered of lesser value than drafting the manuscript" (59, p.4). The authors highlight this as ethically problematic as this scenario places LMIC researchers at a disadvantage. Lack of appropriate recognition of authorship may affect career prospects and access to research funds. Recommendations to address authorship publication issues in global health research include: " 1) to undertake research on research integrity (RRI) with a focus on authorship in global health research; 2) to increase awareness and understanding in the research community about authorship issues in the GHR context, and 3) to strengthen ethical guidance on authorship in GHR" (56).

2.4 Disaster Research

Disasters can be sorted into three groups: Natural disasters are events such as floods, earthquakes, tsunamis; human-related disasters include industrial and transportation accidents; and complex emergencies encompass a combination of natural and human causes. Major disasters may include features such as (25, 61): unexpected onset requiring[6] an immediate response; substantial damage to infrastructure; insecurity due to physical dangers, conflict and/or violence; a large number of casualties and challenges accessing survivors; and mass media coverage.

While the term disasters can be used to refer to all three of these categories, in this thesis when I discuss disasters I am strictly referring to natural disasters such as earthquakes and tsunamis (see Appendix 3 for a complete list). More specifically, the focus of this thesis is on natural disasters occurring in low-to-middle income countries (LMICs) (Appendix 4). I acknowledge, however, that disasters may occur in situations of political or social strife, and may lead to increased political instability and be described as complex

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[6] There are also slow-moving disasters such as droughts, and cyclical disasters (and therefore predictable) such as flooding.

emergencies. Disasters are increasing worldwide (62) and they are more likely to occur in LMICs (63). The increase in disasters is linked to increased meteorological disasters. Conducting research in LMIC disaster settings is challenging compared to high-income nations due to fewer resources being available for disaster preparedness and response, and underlying vulnerabilities which amplify the human consequences of disaster. It is difficult to predict how a disaster situation will change over time given the evolving situations of each setting (64).

Researchers face methodological, logistical, and ethical challenges after a disaster. Some issues are linked to situations of insecurity or safety concerns. For example, an increase in violent crime or an infectious disease outbreak after a flood can put a researcher's life in danger. Beyond physical harm, a researcher may also experience high levels of stress and even mental health issues in a post-disaster setting. It is critical that researchers are equipped with the right training and knowledge to address the challenges they may face while in the field to protect both research participants and themselves.

Though literature on disaster research is increasing, clarifying the ethics of disaster research remains challenging and is contested, in part due to the diverse and unpredictable nature of this area of study (12). One opportunity for advancing understanding of ethical challenges in post-disaster settings, and for better development of research ethics guidelines for disaster-specific situations, is to expand transparency in publications of disaster research.

2.5 Conclusion

At the outset of this chapter, I introduced a Venn diagram to illustrate the interconnections among topics that I discuss in the rest of the chapter. Disaster research publication ethics sits at the intersection of research ethics, disaster research, and publication ethics. In section 2.2 of this chapter, I outlined how research ethics guidelines have evolved significantly over the last century, often in response to significant historical events that motivated such developments. This section focused particularly on the Nuremberg Code (1946), Declaration of Helsinki (1964), and the Belmont Report (1979). While recognizing that these are not the only important historical developments to occur in research ethics, these were highlighted to provide context for the rest of this thesis.

In section 2.3, I discussed publication ethics. There are several international guidelines – such as the COPE, WAME, and ICMJE – which offer support and points of reference for authors on how to address in their publications topics such as ethical approval of research, conflict of interest and funding, and authorship. In section 2.4, I provided a brief summary of disaster research, presented a typology of 'disasters', and introduced some of the complexities of conducting research in these settings.

Several researchers have pointed to the challenges of applying ICMJE and other similar recommendations to global health research due to the emergent, interdisciplinary, and complex nature of such research, as well as structural inequalities for research production globally (59). The field of disaster research adds additional layers of complexity to expectations for reporting research ethics methods and ethical considerations in publications of disaster research. This added complexity is due to the time-sensitive and unpredictable nature of disaster settings. Gaining insight on disaster research publications and how ethics is discussed in these articles would be helpful to orient analysis and provide insight for the development of guidance for ethical transparency in disaster research publications.

Chapter 3: Reporting of ethics practices and considerations in disaster research publications from 2003 to 2012

3.1 Introduction

A disaster is a sudden and catastrophic event that causes extreme damage to the functioning of a society or community, and results in human, material, and economic loss (10, 65, 66). The impact of large-scale disasters exceeds a society's or community's ability to manage and rebuild using their own resources. Disasters can be classified as human-made (such as war or terrorism), natural (such as earthquakes or hurricanes), or complex emergencies involving both natural and human causes (10, p. 4).

Conducting high-quality research in disaster settings can generate knowledge about the impact of these situations, and thus, can lead to improvements in planning and implementation of disaster relief (67). Disaster research, however, can raise a unique set of ethical questions different from research that is conducted in controlled or non-emergent research settings. Some circumstances that are specific to disaster research include the following: risk associated with participation in research may change rapidly as post-disaster situations evolve; populations impacted by disaster may be distressed and vulnerable; research activities may impede relief efforts; protocols may need to be designed and implemented rapidly in the aftermath of a disaster; and potential participants may confuse research activities with humanitarian relief efforts (7-10).

General guidance on conducting research on human participants is available in international codes such as the Declaration of Helsinki and Council for International Organizations of Medical Sciences (35), and national policy documents such as the Canadian Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2). A critical discussion regarding research ethics in disaster settings followed after research conducted during the 2004 Indian Ocean Tsunami (68). Biological and blood samples were allegedly smuggled out of the region for research on neurobiological stress markers (69); researchers were accused of pressuring survivors to participate in research projects and answer questionnaires (70); and concerns were raised about potentially re-traumatizing survivors with several requests to participate in redundant studies, sometimes of culturally or contextually inappropriate interventions (71).

Until recently, it was uncommon to see mention of disaster research ethics in ethical guidelines or disaster research publications. For example, the 2006 *Handbook of Disaster Research* did not have a chapter on ethical issues, nor did it include a substantial discussion about concepts and practices such as informed consent and research ethics committee (REC) approval (72). The authors did acknowledge, however, that a chapter-length discussion on the topic of disaster research ethics was warranted (72), even though such a chapter was not included in the text. Recently, revisions of several major research ethics guidelines, such as the CIOMS (2016) and the TCPS-2 (2015), have introduced sections on disaster research or research during publically declared emergencies (73, 74). Groups such as the MSF Ethics Review Board have also published guidance documents for research ethics in emergent situations (75). However, despite progress in research ethics guidance, the topic of publication ethics in disaster research has received relatively little attention.

Research ethics methods are features of a study design that are undertaken for ethical reasons (76). For example, these features include actions taken to minimize harm or demonstrate respect for participants, such as obtaining informed consent or ensuring that study data remains confidential. The purpose of this chapter is to examine how ethics methods are reported and discussed in disaster research articles published between 2003 to 2012. After outlining the methodology we used to collect this data, I will present the results of this work to highlight trends in the reporting of ethics practices in disaster research publications. In the discussion following the results, I consider the fit of current publication ethics recommendations for disaster research, and how publication ethics guidelines could be refined to better address disaster research. I conclude this work with a discussion on limitations of this review and future areas for research.

3.2 Methodology

We[7] completed a scoping review following the five-step process developed by Arksey & O'Malley (2005) (76). Five out of six refinements for scoping studies that were proposed by Levac et al. (2010) were used to conduct the review of disaster literature (**Figure 1, 3.2**). We did not implement the sixth refinement of incorporating consultation with stakeholders.

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[7] The broader scoping review was conducted under a Canadian Institutes of Health Research disaster research ethics grant at McGill University.

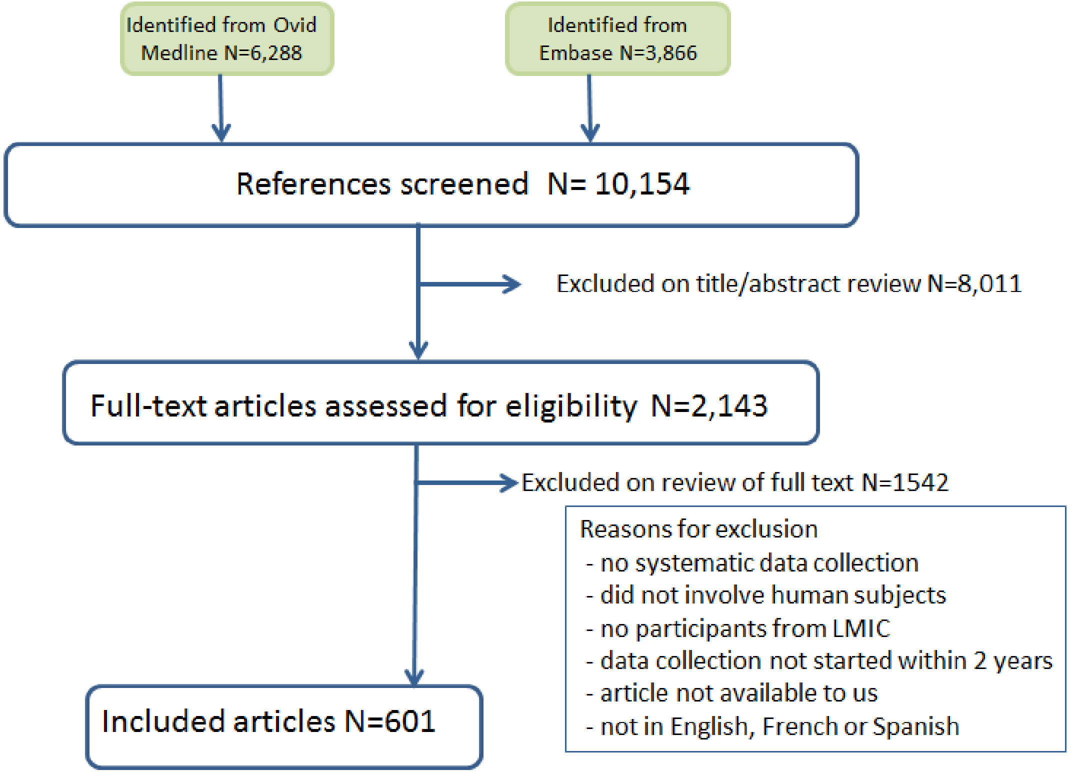

Figure 1, 3.2: Article selection process

The first step involved conducting a key-word search (Appendix 3) to generate a list of potentially relevant articles. In 2013, with the help of a librarian, we used Ovid Medline and Embase databases to generate a list of 10,154 citations. We focused on disasters resulting from natural hazards that took place in LMICs (excluding situations of war, epidemics and technological disasters). Climate-related and geophysical events listed in the National Library of Medicine's Medical Subject Headings (MESH) are provided in Appendix 1. We used the World Bank classification (as it stood in 2012) to define LMIC (Appendix 2).

Inclusion criteria for articles retained for review are:

1. The study was initiated during or within 2 years following a natural disaster;

2. The study was conducted in a LMIC;
3. The study involved living human participants (studies of human remains were excluded);
4. The study involved the systematic collection of data;
5. The article was published between 2003-2012;
6. The article was in English, French, or Spanish;
7. The full-text of the publication was retrievable through the McGill University Library Services or via its inter-library loan system.

Condensed publications and summaries such as abstracts and conference proceedings, and single case studies or case reports, were excluded.

Two reviewers independently assessed titles and abstracts. The full article was reviewed when an abstract was not available or when there was insufficient information in the abstract to determine if the study met the inclusion criteria. Disagreements between reviewers were resolved through discussion, with at least one other member of the research team present. Following these steps, 601 articles were deemed eligible and retained for further analysis.

The research team collectively established the data extraction scheme and the choice of variables. The format in which they were collected was refined as the scoping review progressed. Three data extractors participated in the coding of articles.

A total of twenty-six variables – including the type of disaster, REC approval, and whether informed consent was mentioned – were extracted for each article and entered into a Microsoft Access database. Using Microsoft Excel, we conducted univariate analyses of key descriptor variables and multivariate analyses to examine relationships between variables. The results presented in this chapter only include statistically significant relationships.

In this chapter, we present findings related to the reporting of informed consent, REC approval, and conflict of interest. In section 3.4, we highlight the findings and results of the scoping review. The results are followed by a discussion on what we learned about disaster research literature from conducting this research.

3.3 Results & Findings

3.3.1 Informed consent

Overall, there was a trend of increasing frequency of articles that reported whether or not informed consent was sought from study participants (**Figure 1, 3.3.1**). The year with the lowest percentage of articles (19%) that mentioned "informed consent" was 2004, whereas the year with the highest percentage of articles (47%) was 2011. In all years of the review, the number of articles that do not mention consent exceeds the number of articles that do. Across the 600 articles, less than half (42%) specifically address whether or not informed consent was sought. The articles that mentioned consent fall into three categories: 1) articles that mention consent was obtained; 2) articles that mention that consent was not obtained, and why; and 3) articles that mention why one form of consent was obtained over another (e.g. why verbal rather than written consent was obtained).

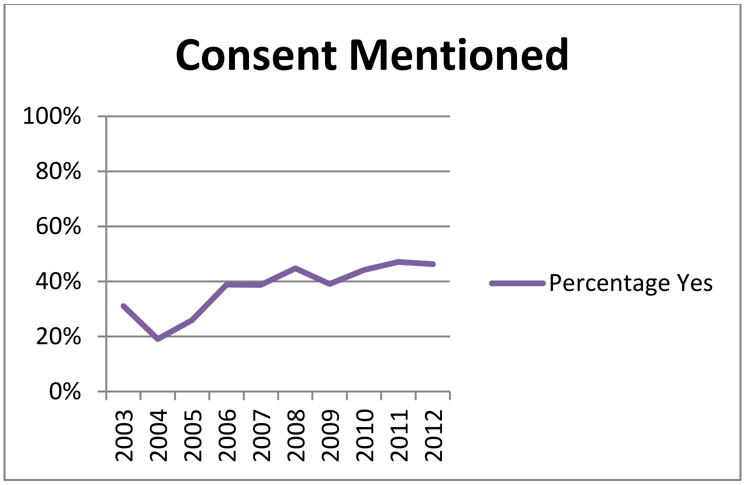

Figure 1, 3.3.1: Consent mentioned over time

Consent not mentioned

In some instances, ambiguous wording made it difficult to interpret if and how consent was obtained from participants. For example, several articles mentioned that participants were "invited to participate" without providing detail regarding how they were invited, what information was given about the study, and the context in which they agreed to take part in the study. An article which explored the influences of the Marmara earthquake on glycemic control and quality of life in people with type I diabetes stated that "the subjects responding to our invitation were informed about the procedure of the study individually" (78). The authors, however, do not provide any additional information about study participation and consent. Another example is of a psychology study assessing risk taking and risk aversion following the 2008 earthquake in China. The authors mention that "participants were paid a small fee (≈¥10) for each completed questionnaire" (79) and "participants were informed that they were participating in a study on decision making and were asked to indicate their decision choices on a paper-and-pencil questionnaire" (79). A third study used a survey to assess the mental health status of vulnerable tsunami-affected communities in Aceh, Indonesia. The article mentions that “no individuals refused participation in our study” (80) but does not provide further detail on the consent process.

Consent mentioned

Many articles included a simple sentence which stated that consent was obtained, without elaborating on the process. For example, an article by Telles et al. (2007) that explored whether or not yoga reduces symptoms of distress in tsunami survivors in the Andaman Islands simply stated that “all participants gave their consent to take part in the study” (81).

A few articles elaborated why obtaining consent was difficult in the context of disasters and how this was addressed in their project. An article discussing the mental health problems amongst survivors of the Yushu earthquake included the following description:

> Verbal informed consent was obtained from each participant prior to interviewing. Written informed consent was not collected individually based on two considerations. First, as a part of the psychological relief program, this investigation was expected to minimize as much as possible the disturbance to survivors who have just experienced earthquake trauma. According to volunteers and social workers, requiring local survivors to sign their name without adequate explanations is very difficult, and might increase their worry for participating in the investigation. Second, according to observations of investigators, relative to oral commitments, local participants might interpret written informed consent as distrust. A statement

> approving this investigating procedure and verbal consent was signed between investigators and local community cadres. The Ethics Committees approved this consent procedure (82).

Several articles also included cultural explanations for why written consent was not obtained. This was the case for an article that described risk factors of posttraumatic stress disorder among survivors of the Wenchuan earthquake in China. The authors state that "signing a consent form for research is not common in Mainland China and the study area. It would be very difficult to make the participants to understand that signing the forms has no other commitments and consequences besides the current research. We did not want to increase potential worries of the participants" (4, p.2). Therefore, the authors sought only verbal consent. Another example of cultural explanations impacting researchers' decisions about how consent was obtained was a description in a published article where the authors state that "after consultation with local team members, it was clear that verbal consent was more appropriate culturally than was written consent" (83). However, no details are provided on how this decision was made, and what the consultation involved.

3.3.2 REC Approval

The percent of articles that mentioned REC review increased between 2003 and 2012, with the peak occurring in 2011 (**Figure 1, 3.3.2**).

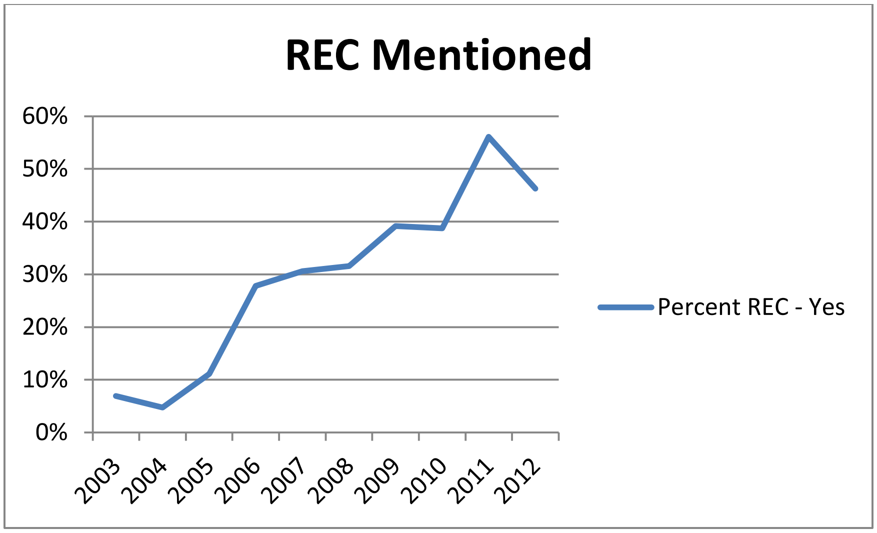

Figure 1, 3.3.2 Percentage of articles that mentioned REC

Across the time period of the review, 58% (n=349) articles did not mention REC approval, 37% (n=224) stated that REC approval was received, and 4% (n=28) explicitly stated that no approval was sought (Table 5.3.4). In some cases, ambiguous wording of REC approval made it challenging to discern why REC approval was not sought from one type of REC over another. For example, in an article by Chan & Kim (2010) investigating health outcomes of internally displaced population in settlement camps after the 2005 Pakistan earthquake, the authors stated that they obtained ethical approval from relief organizations, but did not explain why approval from a REC or from the local public health agency was not sought (84). In another study that interviewed participants to measure health effects of flooding in rural Bangladesh, the authors failed to mention whether consent was sought or not, even though their study was approved by three RECs (85). The researchers may have had a credible and justified approach to consent, but without mentioning what they did and why, readers will not know what approach they took.

The following relationships between statements about obtaining consent and REC approval can be observed. Over half (66%) of the articles that mention obtaining consent also mention obtaining REC approval (**Figure 2, 3.3.2**). Only 17% of articles that mention consent do so with no mention of obtaining REC approval. Over half the articles (78%) that do not mention consent also did not mention obtaining REC approval. The number of articles that explicitly stated not obtaining consent did not change much whether or not they mentioned REC approval. None of the articles that were REC approved but did not mention consent (or did mention consent but did not obtain it) provided details as to why this was the case.

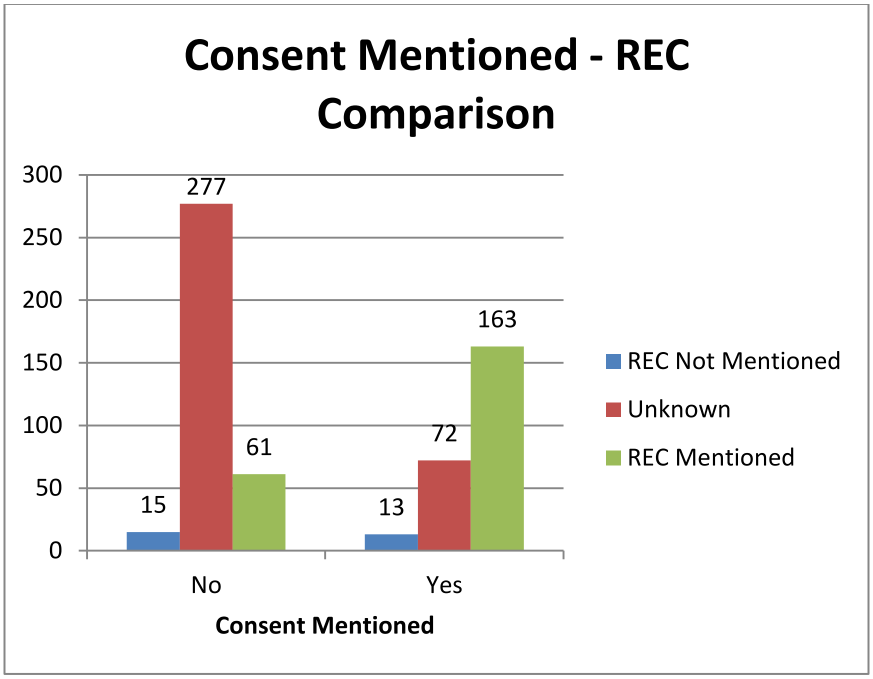

Figure 2, 3.3.2: Consent Obtained v REC Approval

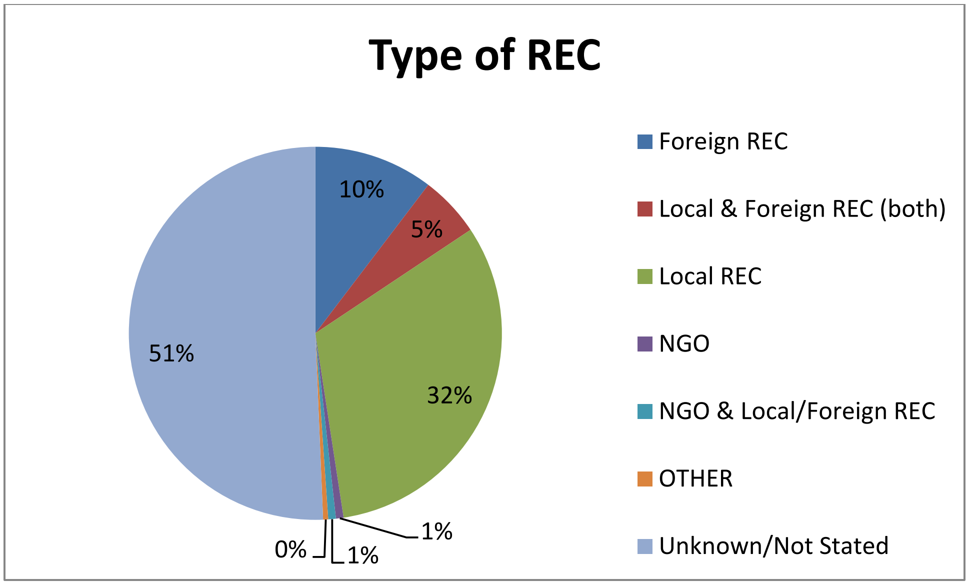

Figure 3, 3.3.2 Type of REC

3.3.3 Conflict of Interest

Over the time period of our review, authors were increasingly likely to identify whether they did or did not have a conflict of interest in relation to the research. All the articles in which authors declared having a potential COI detailed the source of the conflict, though these only occur in the last two years of the review (both 2011 and 2012). For example, an article investigating a disease outbreak in a Thai hospital declared that one of the authors was a consultant for the pharmaceutical company GlaxoSmithKline while "all other authors report no potential conflicts" (86).

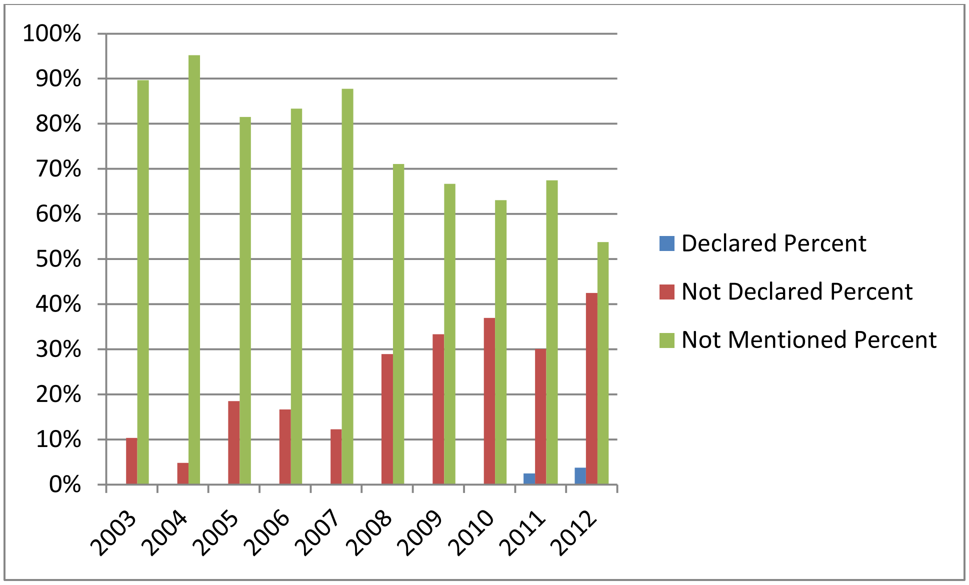

Figure 1, 3.3.3: COI Declared over time

For articles that listed a funding source, the authors were more likely to report a COI than not report a COI. This number, however, should be interpreted with caution since there were few such cases in the review (n=1 COI declared when funding not mentioned, n=5 COI mentioned when funding mentioned). The rest of the articles did not mention COI even when a funding statement was included. None of the articles that mentioned having a COI provided an explanation as to how they managed the COI beyond disclosing it.

3.4 Discussion

The purpose of presenting these findings is to examine how ethics methods are reported and discussed in disaster research articles published between 2003 to 2012. Other reviews conducted to explore transparency of research ethics methods in published literature in other fields have found different findings due to different search strategies and area of focus. For example, a review conducted by Klitzman et al (2011) investigated how often journal articles reporting on human HIV research in four developing world countries mentioned review by RECs (they refer to them as Institutional Review Boards) (47). They examined 221 articles published in 2007 from India, Nigeria, Thailand and Uganda and found that 32.1% (n=71) of articles did not mention REC approval. Our findings show that 28% (19/49 articles published that year) report REC approval in 2007. Klitzman and colleagues suggest that lack of reporting about REC approval could be attributed to some journals requiring mention of approval in only the cover letter upon submission, but not in the actual published article itself. Based on these findings, they recommend that journals should require more transparency about these practices in the published article, not just in the cover letter to the editors (47).

Another study conducted by Munung et al assessed the extent to which ethics approval and informed consent is mentioned in publications from Cameroon indexed in PubMed from 2005 to 2009 (87). The study reflects the state of research ethics review and informed consent in a developing country with minimal legislation governing health-related research. In this review, out of 219 full-length articles, they found that 58% (n=127) reported ethics approval, whereas 71% (n=155) reported informed consent. In our scoping review, between the years of 2005 to 2009, consent reporting increased from 26% (7 out of 27) to 46% (27 out of 69). The discrepancy in these findings may be explained by the fact that Munung et al's research search strategy led to the identification of research in international journals rather than national ones (87).

In another study, Rohwer et al developed a questionnaire and conducted in-depth interviews to document LMIC health researchers' views about authorship, redundant publication, plagiarism, and COI (88). They asked participants of the study whether these practices were common at their respective institutions. Forty per cent of the respondents indicated that their colleagues failed to declare conflict of interests in the past (88). They also found that researchers are uncertain what COI means and what constitutes a COI. Interviewees questioned whether or not declaring a COI was adequate, stating that mentioning COI did not always mean that the research was free from any external manipulation (89). Others speculated that researchers generally declared not having a COI even if they did have one. Respondents were confused about declaring personal relationships with friends, family, and spouses for scientific papers (88). Overall, the majority of respondents felt there was inadequate guidance on what to declare and when to declare it. In our scoping review, mentioning COI increased over the years, but with "not mentioned" still surpassing the number of articles that mentioned COI across the timeline of the review. Confusion about if and when to declare COI may explain this finding.

As demonstrated by our review, transparent reporting of research ethics methods in disaster research has been lacking– with many authors opting out of mentioning ethics methods entirely. Authors may face confusion about what is appropriate to report and when, or there may be an issue with lack of guidance on what to report and where to report it. When we analyzed our data to identify if there were differences in ethical transparency by type of disaster, author team nationality, and region of disaster, we found that these factors did not affect rates of reporting of ethics methods. One way to increase transparency of research ethics methods in disaster research publications is to update recommendations to address challenges that are specific to disaster research. For example, the COPE and ICMJE could update their recommendations to reflect existing and emerging disaster research guidelines that highlight the difficulties of conducting research in disaster settings. The updated 2016 CIOMS guidelines state that "the standard mechanism for ethical review will often be too time consuming to enable full research protocols to be prepared and reviewed at the outset of a disaster" (1, p.78). Authors may then discuss this in their final published work and describe briefly the challenges of going through traditional methods of review. While the CIOMS guidelines do not neglect or downplay the importance of a traditional REC review process, the guidelines do suggest that REC procedures should be developed to facilitate and accelerate the ethical review in a situation of crisis. For example, RECs may conduct an initial accelerated review of research protocols and then continue oversight of the studies as they are being conducted. The CIOMS guidelines also suggest that ideally, research in disasters should be planned well in advance (1). However, "pre-screening" generic protocols in advance should not substitute for the ethical review process of specific protocols in a disaster. While these guidelines are specific for disaster research, how this research should be reported in a publication is not well detailed in publication ethics guidelines such as the COPE and ICMJE. As documented in Rohwer et al.'s study, researchers may be confused about what it is they need to include in final publications. More robust requirements for authors should help with increasing transparent reporting of research ethics methods. The COPE and ICMJE may include a designated section specific to disaster research publication ethics. This would be following the same steps that research ethics guidelines have taken (such as the TCPS2) by highlighting that disaster research requires special consideration due to the nature of how research can unfold in disaster settings.

By explicitly discussing the particular challenges arising in disaster research (as with research during epidemics or war), within existing guidelines that were created for medical research, a standard is set for the level of transparency that authors should strive for. As a result of setting a standard of practice, overall quality of disaster research may increase across the field of disaster research. More transparency of ethics methods in disaster research publications also allows for learning and internalization of the material being presented to readers. This allows readers to better understand and critique the work as they are reading it. Furthermore, more transparent reporting of research ethics methods holds researchers accountable for their actions in the field. These concepts are further discussed in Chapter 4.

There are several limitations that are relevant to our scoping review. First, we searched only two databases – Ovid Medline and Embase. We selected these databases to reflect our focus on health-related disaster research. Additional databases from the humanities would have expanded our study's disciplinary scope and allowed us to identify additional articles for review. However, we chose to limit the review to two databases for feasibility as they already identified over 10000 articles. Second, due to budgetary reasons, we were not able to include articles in languages other than the ones understood by our research team. Thus, articles that were not in English, Spanish, or French (even when they had English abstracts) were excluded from our review.

A scoping review that included articles in other languages would likely reveal additional information regarding ethical considerations in disaster research literature. For example, several articles that were excluded from our review were written in Chinese script and Persian. The information provided by these articles would have provided further detail for our analysis, and given insight into how ethics is discussed in journals that have different national and linguistic characteristics. For future research, interviews with disaster researchers about the choices they made regarding what ethics methods to include in their published articles, and how much detail to provide about their practices and rationales for their decisions, may give insight on structural and personal factors that shape these decisions.

3.5 Conclusion

This scoping review aimed to examine how ethics procedures and ethical issues are reported in disaster research literature from 2003 to 2012. The results show that while the number of articles that mention informed consent, REC approval, and COI increased over this 10-year period, over half the articles still fail to mention ethics methods in disaster research literature. Factors for lack of transparent reporting may include insufficient journal requirements requiring mention of ethical standards. One suggestion is to update current publication guidelines, such as the COPE and ICMJE, with disaster research taken into consideration to provide clear guidance to researchers on when and how to include research ethics methods in publications. Another more general suggestion involves journals requiring authors to include research ethics methods in the body of the article and not just the cover letter to the editor. With more transparency of ethical methods in disaster research publications, readers will be able to further trust the ethical rigor of these studies and better understand the contexts in which they were conducted. It will also provide another opportunity to enhance accountability for the actions undertaken by disaster researchers and encourage high standards of ethical practice.

Chapter 4: Transparency in reporting of ethics methods and ethical considerations in disaster research publications

4.1 Chapter Overview

The purpose of this chapter is to present an argument for more transparent reporting of research ethics methods in disaster research publications. As discussed in Chapter 3, given the ethical complexities that can arise during disaster situations, it is important for researchers carefully consider what information about the ethics methods they employed in their research should be included in the scholarly publications that they produce. In the previous chapter, I presented a scoping review of how research ethics methods are reported and discussed in health-related disaster research literature from 2003 to 2012. In light of the review findings, I considered whether publication ethics recommendations provide sufficient guidance for disaster research publications. I argued that they do not and I proposed opportunities to revise the guidelines to better accommodate disaster research. This chapter continues that line of inquiry and here I develop a normative argument for the importance of ethical transparency in disaster research publications.

In this chapter I start with the core of my argument in section 4.2. In turn, I discuss the notions of learning, internalization and accountability as virtues of more transparency in disaster research publications. In section 4.3, I discuss key challenges and limitations to more transparent reporting of research ethics methods. Finally, in section 4.4, I conclude with a proposal for what ethical transparency in disaster research publications should look like.

4.2 A case for more ethical transparency

> _“Research ethics methods are features of a study design conceptualized and undertaken for ethical reasons” (17, p.843).

Researchers’ decisions regarding how research ethics methods are undertaken are likely to be influenced by the specific research context. For example, while obtaining written consent before collecting biological samples from research participants is common practice in medical settings, a team of researchers conducting a study on an infectious disease outbreak as a result of severe flooding explained their decisions in the following way: “written consent was not possible due to logistical limitations of multiple testing and survey site locations and the need for immediate data collection in the setting of the outbreak” (89, p2.). In this case, this description helps readers understand the rationale behind the researchers’ decision to seek verbal rather than written consent even though the researchers were conducting interviews and collecting biological samples. Another example of ethics procedures being influenced by the disaster context is a rapid assessment survey after the Gujarat earthquake in 2001. The authors of this study reported their rationale for not seeking REC review, stating that:

> [I]t was not practically feasible to approach any ethical body. As present study does not consist any kind of intervention or procedure that ethically cannot be approved.

> Planning committee decided to go with study without any ethical approval. Also due to time constraint and lack of facilities to approach any ethical committee considering emergency situation of earthquake; it was not practically feasible to approach any ethical body (5, p.489).

The authors, however, do not detail why it was not practically feasible to approach an ethical body. They also do not provide any reason for why they decided their study did not consist of any kind of intervention that needed ethical approval. Though approaching disaster-affected individuals with a survey may seem 'harmless' to the authors, the request to participate in research could re-traumatize participants, hinder humanitarian interventions, or a range of other challenges could arise. The reader is left to wonder if the researchers considered these issues, and if so, how they considered and rationalized them. The authors in this case failed to provide a reasonable account for why REC approval was not feasible. If time constraint was a major issue and the authors found the REC review process too slow or unattainable, why was ethics approval not sought from a local community member instead? Likewise, by providing an explanation for seeking verbal rather than written consent in the first study quoted above, this rationale becomes available for review and discussion.

The absence or opacity of research ethics methods in disaster publications makes it challenging for all readers – including researchers and REC members – to discern if what they are reading is something they can trust. The scoping review (Chapter 3) detailed how disaster research publications lack transparent reporting of research ethics methods. In one example, authors stated that "participants were informed that they were participating in a study on decision making" (79, p.106) without further detail or example of what this means and why no participants refused to participate. In cases such as these, the reader is left to imagine how the research occurred in the field and fill in knowledge gaps based on assumptions or questions, rather than evidence. The opacity makes it challenging for researchers who might take inspiration from these methods for their own work. If a rapid assessment survey were to be conducted after another earthquake, the research from Gujarat could serve as an example for how authors thought about REC approval and consent (5). However, with lack of adequate information about the rationales offered for their decisions, understanding of the work they conducted in the field proves to be difficult.

Learning

More transparency also allows REC members to learn from decisions and experiences of researchers in a given context. A critical step to conducting research involving humans is seeking ethics approval from a research ethics committee (90). Currently there is limited knowledge regarding how RECs understand and apply research ethics guidelines for disaster research protocols (91). To address this knowledge gap, Hunt et al. (2016) conducted a qualitative research study to investigate the experiences and perceptions of individual REC members who had participated in disaster research review. In their discussion, they note that few RECs have opportunities to develop knowledge related to the review of disaster research (67). The authors make suggestions to address this, including developing training materials that include ethics guidance on topics relevant to disaster research. Disasters ethics training would be used to support REC members seeking more information about disaster research. Greater ethical transparency in disaster publications could support these initiatives. It would contribute to the body of knowledge of how researchers address ethical considerations and enact ethics methods during disasters. Anderson et al (2013) describe this concept as “learning” (17). Learning will be promoted when readers have access to research ethics methods information in disaster research literature. This information will allow readers to better understand the challenges that disaster researchers face in the field. In turn, the research community will gain insight for orienting their own work if they were to conduct similar studies or experience similar challenges in the future.

Internalization

With more learning comes the second notion presented in Anderson et al’s work, which is that of “internalization” (17). Internalization entails considering research ethics methods, and offering clear descriptions of ethics procedures in peer-reviewed publications, as part of the research process. In other words, internalization moves away from the current standard where reporting of research ethics methods in disaster literature is an after-thought and only occasionally or thinly discussed (17). By incorporating the reporting of research ethics methods as a standard publication practice, ethics is treated as part of the scientific process rather than an addition. Doing so would normalize discussion of research ethics methods, and encourage more authors to discuss the work as it happened in the field.

Furthermore, by reporting research ethics methods succinctly in publications, authors enable other investigators engaged in similar work to learn from their methods and they increase the possibility that readers can understand how the research was conducted in the field. Clarity allows others to learn from the challenges and insights of previous researchers in disaster settings, and allows for a certain amount of 'replicability' of methods where appropriate. For example, after referring to disaster research articles from previous earthquakes of similar magnitude, a researcher may decide that conducting rapid assessment surveys post-disaster make obtaining REC approval challenging. He may then decide to seek pre-approval of the survey before an earthquake happens in order to speed the process. Transparency in previous work might present ideas and possible options which a researcher can use to inform himself about what others have done in similar circumstances. Transparency of research ethics methods does not tell researchers what is the right or wrong thing to do in a given context. Instead, this information can help him imagine possible options as he designs his protocol or thinks through decisions in the field.

Ethical accountability

In addition to learning and internalization of ethics methods, the third category of benefits of transparent reporting is ethical accountability. Anderson et al (2013) have briefly described what this looks like in the context of biomedical research:

> The methods used to address ethics issues are currently a black box: by failing to report on their treatment of the ethical dimensions of their work, biomedical scientists hide from view the care and concern they bring to these issues. By reporting on research ethics methods, scientists enable critical assessment and enhance the accountability of their research. By insisting on such reporting,

> journal editors enhance the ethical accountability of biomedical research as a whole (17, p.844).

Similarly, as discussed in Chapter 3, research ethics methods in disaster research publications are often absent or presented as in a "black box". Typically, much of the ethical decision-making that occurs in disaster research – such as decisions around informed consent, REC approval, funding and managing conflict of interests –is left out of published literature. If information on research ethics methods is lacking, it is difficult to hold researchers accountable for their actions as they played out in the field. Disaster research settings are not stable and controlled like clinical research settings. Research methods and processes may need to change as situations and circumstances develop in the field. Since RECs review research protocols *before* the research starts, there needs to be another social accountability function for research in emergent settings where situations can change (93).

To further explain this point, I present a short case:

> *A researcher is conducting a study to understand the experiences of physically disabled women living in displacement camps after a large-scale disaster. He interviews a woman in her late 30s and the interview is progressing well. He learns about her life before the earthquake and how it has changed since. He asks how she copes with her daily activities following the amputation of her arm due to a crush injury, and what medical resources could help her situation. She begins to cry, saying that it is not her physical disability that is making it difficult to cope, but*

> *rather, her environment. She reveals to him that she regularly witnesses sexual assault in the displacement camp, and feels unsafe every day.*

Guillemin and Gillam (2004) argue that conducting research ethically is much more than just research that has gained the approval of an REC (90). Since situations and circumstances can change in the field as the research is being conducted, and not all ethical challenges can be anticipated and planned for, researchers need to practice reflexivity. They link this notion with ethics and refer to reflexivity as "closely connected with the ethical practice of research and comes into play in the field, where [RECs] are not accessible" (90, p 273). In other words, reflexive research means that the researcher is consistently aware of their role in the research process and is alert to ethical issues that arise in research. This alertness "might include conscious consideration of a range of formal ethical positions and adoption of a particular ethical stance" (90, p 276). Therefore, it is not simply enough to note that research was REC approved. How a researcher has thought about ethical issues and adapted to issues as they arise is an important function of accountability that needs to be addressed in published work. What did the researcher in the case study do after the woman revealed that she feels unsafe and witnesses sexual assault? How did this change the course of his work? What if this is an experience that he heard about from many study participants? What are some other ethical tensions that arose as he conducted his research? He may need to make decisions that deviate from the steps he outlined in his original REC-approved research protocol. For example, he may refer her to counselling or he may work to ensure that safety measures are put in place in the shelter. Recording these steps in the final publication holds him accountable to his actions, and allows the reader to learn about the kind of situations that arise when conducting this type of work. An outcome of ethical accountability is that it will encourage researchers to think about their work using a disaster research ethics lens, not keeping ethics at the periphery of their decision-making processes or reserved to the process of research ethics committee review. How more transparency can be achieved in disaster research publications is not as simple as writing ‘more’, however. In the next section, I discuss transparency and how it relates to the principle of proportionality (17).

4.3 When and how should ethics methods be reported?

In very urgent or fragile situations, it will be difficult to seek local REC approval during a disaster. In some cases, researchers may need to identify other sources to provide approval for a study to proceed. For example, one group conducting research regarding water sanitation after a landslide in Uganda state:

> After the disaster, a technical committee was constituted to respond to this emergency. It included staff from the Ministry of Health (epidemiology unit), Office of the Prime Minister -Uganda, the Ministry of Relief, Disaster Preparedness and Refugees, and the Makerere University School of Public Health. Bearing in mind the urgency of the data and the operational nature of this work, it was decided that there was no need to subject the study to the Institutional Review Committee. However, this technical team reviewed the protocol and all the tools, gave comments and approved them. Besides, the purpose and objectives of the assessment were clearly explained to the Bududa district and Bulucheke Sub-

> country Administration, as well as the Technical health staff who included the District Health Officer (DHO). Permission to conduct the assessment was granted (92, p.5).

This is an example of how a succinct but informative paragraph on ethical challenges can lead to better understanding of research conditions for readers and hold the authors accountable for actions they undertook during the research.

Two principles should guide research ethics reporting. The first is what I have already discussed: the principle of transparency. Transparency involves providing sufficient detail to enable readers to assess and possibly recreate the research ethics methods used.

In **Table 4.1**, I highlight several examples of what transparent reporting in research involving humans in disaster settings could look like. I stress that these are just a few examples, as I do not mention other aspects of research ethics methods such as COI. This work, however, is derived from a similar table presented in Anderson et al. (2013) for transparent reporting of ethics methods in biomedical research. Below each recommendation, I highlight examples of questions that a researcher may consider addressing in her work (17). The list of examples is also not comprehensive, meaning that if there are other questions that an author feels are important to address, then she should do so. It is recommended that researchers use their best judgement when deciding which aspects of research ethics methods to include in their work. If, for example, researchers are working in the same site as humanitarian aid workers who are providing assistance, the researchers could discuss the steps they took to make sure participants knew they were not aid workers. They should also highlight how they ensured their research activities did not hinder the work of humanitarian aid workers. In contrast, if the researcher conducted her research in a setting where aid workers are not present, or only present on certain days, she need not highlight the steps taken to ensure that research activities not interfere with the work of humanitarian aid workers. That said, she still may need to highlight steps she took to ensure that participants knew she was a researcher and not an aid providers.

Table 4.1: Recommendations and examples of research ethics methods that could be included in disaster-research publications

1. Report the process of obtaining informed consent.

- Was consent obtained from every participant? If not, why is that the case and what is the rationale for this decision?

  How was consent obtained (written or oral)? If not obtained in writing, what is the rationale for this decision?
  Were any challenges experience in obtaining consent?

2. Steps taken to ensure ethics approval before conducting research.

- What steps were taken to ensure ethics approval?

If ethics approval from a particular REC was not possible, why was that so? What steps did they take to ensure oversight and gain approval for the study?

3. Explain the steps that were taken to minimize risks and burdens for study participants and third parties, as appropriate.

- What steps were taken to ensure that research activities did not interfere with the work of humanitarian aid workers?
- What steps were taken to protect data security and patient safety in

Table 4.1: Recommendations and examples of research ethics methods that could be included in disaster-research publications

insecure environments?

- Were any unanticipated risks identified as the study progressed?

4. Explain steps taken to maximize benefits for current participants and downstream beneficiaries of the research results.

- What are the potential benefits of this research for individuals and communities who will be affected by disasters in the future?
- What benefits might there be for research participants?

5. Document steps taken to address issues of justice and access.

- How were participants selected? Was recruitment targeted to certain groups or were some people excluded from the research? What is the rationale for these decisions?
- What services and benefits were participants provided after taking part in the study (e.g. access to psychosocial support/counsellors)?

These suggestions illustrate that better reporting of research ethics methods requires more than just proposing “more transparency”. This is why the second principle to guide research ethics reporting is proportionality (17). Proportionality involves providing detail proportionate to the ethical complexity and risks to participants in the research study (i.e. the more complex or more risky the study, the greater the expectations for transparency around ethical methods). Below I expand further on the principle of proportionality and how it can be used to address limitations and challenges of transparent reporting of ethics methods.

4.4 Limitations and challenges

Several arguments can be made against requiring greater transparency in disaster research literature. First and foremost, researchers may be concerned that increased transparency may jeopardize their credibility. If a researcher includes the process they used to obtain informed consent, for example, using only oral consent and not written consent, and a reader deems the chosen approach to be inadequate, or worse, unethical, the researcher's credibility may be at risk. Other more severe consequences may include loss of funding, loss of job, or legal implications. If an entire community of researchers deems a practice that the researcher has included in their publication as 'unethical', the researcher may be reprimanded by their institution or funding agency. To address these issues, I stress the importance of disaster research ethics training for all researchers with reference material and summary of key points being easily accessible and available when conducting the research. Researchers should be very familiar with research ethics practices prior to conducting work in disaster settings. A researcher should be able to reasonably justify why she made certain decisions using research ethics principles. If, for example, written consent was not possible, and only verbal consent was obtained, the researcher needs to be able to articulate why this decision was made. For example, a research team expressed that in their research:

> Verbal informed consent was obtained from each participant prior to interviewing. Written informed consent was not collected individually based on two considerations. First, as a part of the psychological relief program, this investigation was expected to minimize as much as possible the disturbance to survivors who have just experienced earthquake trauma. According to volunteers and social workers, requiring local survivors to sign their name without adequate explanations is very difficult, and might increase their worry for participating in the investigation. Second, according to observations of investigators, relative to oral commitments, local participants might interpret written informed consent as distrust (82, p.2).

This allows readers to understand and learn the justification of using research ethics methods that can be deemed less than ideal.

There is also the argument that transparency of some ethical methods could put participants at risk – perhaps revealing too much about their location or situation – and thus making known their identity. For example, if a researcher is conducting a research project on the spread of sexual practices and sexually transmitted infections post-disaster, revealing how participants were selected and from where they were selected (as suggested in Table 4.1) might stigmatize a certain area or community. Such a practice would go against the ethical principle of non-maleficence and doing no harm to research participants. It is important, therefore, to understand that transparency is not an "all or nothing" concept. It is to be used with discretion, meaning that if transparency on a particular aspect of the study might jeopardize the safety or privacy of participants, it ought not to be included in the final publication. For example, it is in the best interests of the participants not to specify that research participants of a study looking at STI transmission came from one particular community, area, or shelter post-disaster. Even if the name of the place is not mentioned, any revealing details familiar to locals may give away the community. Especially if only one such shelter or place exists.

Another example of ethical transparency and informed consent is discussion of participation rates. Thus, if a researcher is only able to obtain verbal consent but not written consent, and if the participation rate is 100%, the researcher ought to explain why verbal consent was selected, and also to address potential concerns regarding the participation rate. For example, she might respond to the following questions: What might have contributed to the fact that everyone who was approached agreed to participate in the research? And why was written consent not appropriate or feasible? Explaining why certain steps were taken over others helps readers understand the situation further and adds nuance that may be useful for RECs and researchers in the future, and contributes to the accountability for decisions that are made.

Another issue that critics of these proposals might bring up is that of word count and lack of space in publications. Discussing ethical methods in research takes away space that the researcher could have used for other aspects of research such as presenting study results. In this sense, devoting space to describe research ethics methods might be seen as 'weakening' the presentation of a research study. This is an important consideration when journals set tight word limits. Several proposals could help to overcome this hurdle. For example, the issue of space can be tackled by providing a transparency index – similar to an appendix, which does not contribute to the overall word count, but is referenced in the paper for the reader to consider at her own discretion. In online-only publications, external links (such as “active citations”) to another page where researchers discuss ethical considerations can also guide the reader to information beyond the pages of the research paper (16). These links can take the reader to a webpage with a more detailed account on research ethics methods, challenges the researchers faced in the field, and how the researcher may do things differently in the future.

It can also be argued that there is no guarantee that ethical transparency has the intended effects, such as contributing to accountability, further internalizing research ethics in the culture of disaster research, or assisting RECs with decision-making during disaster research protocol review. While this may be true, and while we do not know for certain what would happen with increased transparency of research ethics methods, I argue we also do not know that the opposite is true. In other words, we do not know if keeping things the way they are is necessarily better than the alternative that I have proposed here. We do know however, from the scoping review in Chapter 3, that currently many research ethics practices are not reported. With limited information of ethical considerations in disaster research literature, as evidenced in our scoping review, it is unconvincing to conclude that the current model of disaster research publications is necessarily the best one. Increased transparency of ethical considerations will assist us in identifying where researchers can improve, and how they can draw upon disaster research articles to gain insights for making better informed decisions for disaster research in the future.

4.5 Conclusion

Increasing transparency for research ethics methods in disaster research publications can enhance learning and internalization of research ethics into the field of disaster research. Having more information about how researchers address ethical aspects of disaster research will allow readers to better understand the research as it occurred in the field, and researchers and RECs can learn from the experiences of research teams that have conducted research in disaster settings. Secondly, transparency can allow for more accountability, including holding researchers responsible for how they conduct research in the field. Since disaster situations can change quickly and unpredictably, it is important for researchers to document how they adapted to emergent situations. Researchers should use judgment when deciding which aspects of research to include, and select which features of the research to discuss and in what detail, in a way that is proportionate to its ethical complexity and the risks for participants. For example, if revealing certain details or study procedures can put participants at risk, then researchers should not include this information. At the same time, researchers should ensure that readers are able to clearly follow their description of how ethical considerations were addressed in the research, and to understand how events unfolded in the field. I have proposed counter-arguments for possible objections to transparent reporting of research ethics methods. These include researchers being knowledgeable about research ethics practices prior to conducting research, the principle of proportionality, and the concept of including hyperlinked information about ethical methods in online research articles. Greater transparency of research ethics methods has the potential to teach us more about the field of disaster research, normalize the discussion of ethics in published literature, and hold researchers accountable for their actions.

Chapter 5: Conclusion

In chapter one, I highlighted the two objectives of this thesis. The first objective was to analyze and understand the current state of ethical transparency in disaster literature. After a literature review of current ethical guidelines in Chapter 2, I outlined the results of a scoping review in Chapter 3. The scoping review of disaster research publications in low-to-middle income countries (LMICs) between the years of 2003 and 2012 revealed that mentioning of research ethics methods in disaster research literature is still scarce, even with gradual improvement over the years. This could be due to lack of journal requirements that encourage reporting ethical standards, or other factors such as limited space, authors' fears of negative repercussions for being transparent, or confusion about what ought to be included in published articles.

The second objective was to develop and defend an account of what ethical transparency might require for disaster research publications. In Chapter 4, I proposed that transparent reporting of research ethics methods has three benefits. The first involves learning – allowing readers to learn about research ethics methods. The second involves greater internalization of research ethics within a field of research, in this case in disaster research. The third benefit involves ethical accountability. Ethical accountability ensures that authors and researchers are accountable for their actions as they occurred in the field, and can contribute to trust in the research process. I concluded chapter 4 with suggestions on how to increase ethical transparency in disaster research literature, highlighted some challenges and limitations to transparent reporting and stated how these can be overcome.

The number of disaster research guidelines has increased since 2003, with a peak in the number of documents being issued between 2008 and 2010 (93). Eight out of the 14 guidelines that Mezinska et al identified in a systematic qualitative review of ethical guidelines were issued in 2008 and 2010. The qualitative analysis of 14 guidelines revealed several themes: vulnerability and the REC review process as core themes; improved quality of informed consent (in six guidelines); conflicts of interest (four guidelines); and cultural sensitivity of researchers (five guidelines). Authors of guidelines post-2008 particularly emphasized the risks associated with conducting research in disasters and how it can diminish monitoring and control of research (9) and mentioned corresponding values (e.g. accountability and transparency) (94).

As mentioned, this thesis presented results of a scoping review that looked at health-related disaster research literature between the years of 2003 and 2012. But with more research ethics guidelines having been developed post-2008, an updated scoping review would be likely to offer further insight on the current state of research ethics methods in disaster research literature. This may give insight on the applicability of disaster research ethics guidelines being developed, and whether or not more practical suggestions are needed regarding how to weigh conflicting principles in disaster settings (95). Mezinska et al highlight the tension between generalized and specific approaches to guidance and suggest that more practical decision-making tools are essential. Even with recent developments in disaster research ethics guidelines, the evidence supporting guideline development is weak, and rather diverse and confusing (93). Most guidelines are based on “personal experiences, unique situations, or NGO practices. Empirical evidence is urgently needed to support the statements and requirements included in the research ethics guidelines” (93, p.10). Perhaps more transparent reporting of research ethics methods and ethical considerations in disaster research literature can provide that.

Appendix 1 – list of disasters included

animal infestation

ash fall

Avalanche

Blizzard

Cyclone

Drought

dust storm

Earthquake

Erosion

extreme cold

extreme heat

Fire

Flood

hail storm

heat wave

Hurricane

ice storm

insect infestation

Landslide

lava flow

Mudslide

plant disease

sand storm

snow storm

Thunderstorm

Tornado

tropical storm

Tsunami

Typhoon

Volcano

Wildfire

Appendix 2 – list of LMICs

Source: World Bank
http://data.worldbank.org/about/country-classifications/country-and-lending groups#Lower_middle_income

Low-income economies ($1,025 or less)		
Afghanistan	Gambia, The	Mozambique
Bangladesh	Guinea	Myanmar
Benin	Guinea-Bisau	Nepal
Burkina Faso	Haiti	Niger
Burundi	Kenya	Rwanda
Cambodia	Korea, Dem Rep.	Sierra Leone
Central African Republic	Kyrgyz Republic	Somalia
Chad	Liberia	Tajikistan
Comoros	Madagascar	Tanzania
Congo, Dem. Rep	Malawi	Togo
Eritrea	Mali	Uganda
Ethiopia	Mauritania	Zimbabwe

Lower-middle-income economies ($1,026 to $4,035)		
Albania	Indonesia	Samoa
Armenia	India	São Tomé and Principe
Belize	Iraq	Senegal
Bhutan	Kiribati	Solomon Islands
Bolivia	Kosovo	South Sudan
Cameroon	Lao PDR	Sri Lanka
Cape Verde	Lesotho	Sudan
Congo, Rep.	Marshall Islands	Swaziland
Côte d'Ivoire	Micronesia, Fed. Sts.	Syrian Arab Republic
Djibouti	Moldova	Timor-Leste
Egypt, Arab Rep.	Mongolia	Tonga
El Salvador	Morocco	Ukraine
Fiji	Nicaragua	Uzbekistan
Georgia	Nigeria	Vanuatu
Ghana	Pakistan	Vietnam
Guatemala	Papua New Guinea	West Bank and Gaza
Guyana	Paraguay	Yemen, Rep.
Honduras	Philippines	Zambia

Upper-middle-income economies ($4,036 to $12,475)		
Angola	Ecuador	Palau
Algeria	Gabon	Panama
American Samoa	Grenada	Peru
Antigua and Barbuda	Iran, Islamic Rep.	Romania
Argentina	Jamaica	Russian Federation
Azerbaijan	Jordan	Serbia
Belarus	Kazakhstan	Seychelles
Bosnia and Herzegovina	Latvia	South Africa
Botswana	Lebanon	St. Lucia
Brazil	Libya	St. Vincent & the Grenadines
Bulgaria	Lithuania	Suriname
Chile	Macedonia, FYR	Thailand
China	Malaysia	Tunisia
Colombia	Maldives	Turkey
Costa Rica	Mauritius	Turkmenistan
Cuba	Mexico	Tuvalu
Dominica	Montenegro	Uruguay
Dominican Republic	Namibia	Venezuela, RB

Appendix 3 – Search Strategy in Ovid

	CONCEPT 1		CONCEPT 2		CONCEPT 3
	Natural Disasters		Low & middle income countries		humans
1	ash fall*.mp.	45	Afghanistan*.mp.	209	adolescen*.tw.
2	avalanche*.mp.	46	Albania*.mp.	210	adult*.tw.
3	blizzard*.mp.	47	Algeria*.mp.	211	aid worker*.tw.
4	cyclon*.mp.	48	American Samoa*.mp.	212	amputee*.tw.
5	exp Disasters/	49	Angola*.mp.	213	assistant*.tw.
6	disaster*.mp.	50	Antigua*.mp.	214	aunt*.tw.
7	drought*.mp.	51	Argentin*.mp.	215	brother*.tw.
8	dust storm*.mp.	52	Armenia*.mp.	216	care giver*.tw.
9	duststorm*.mp.	53	Azerbaijan*.mp.	217	caregiver*.tw.
10	earthquake*.mp.	54	Bangladesh*.mp.	218	carer*.tw.
11	erosion*.mp.	55	Barbuda*.mp.	219	exp child/
12	extreme cold.mp.	56	Belarus*.mp.	220	child*.tw.
13	extreme heat.mp.	57	Belize*.mp.	221	clinician*.tw.
14	fire*.mp.	58	Benin*.mp.	222	community member*.tw.
15	flood*.mp.	59	Bhutan*.mp.	223	community network*.tw.
16	hail storm*.mp.	60	Bolivia*.mp.	224	companion*.tw.
17	hailstorm*.mp.	61	Bosnia*.mp.	225	coroner*.tw.
18	heat wave*.mp.	62	Botswan*.mp.	226	cousin*.tw.
19	heatwave*.mp.	63	Brazil*.mp.	227	daughter*.tw.
20	hurricane*.mp.	64	Bulgaria*.mp.	228	dentist*.tw.
21	ice storm*.mp.	65	Burkina*.mp.	229	displaced.tw.
22	insect infestation*.mp.	66	Burundi*.mp.	230	doctor*.tw.
23	land slide*.mp.	67	Byelarus*.mp.	231	donor*.tw.
24	landslide*.mp.	68	Cambodia*.mp.	232	exp family/
25	lava flow*.mp.	69	Cameroon*.mp.	233	families.tw.
26	mass casualty incident*.mp.	70	Cape Verde*.mp.	234	family.tw.
27	mud flow*.mp.	71	Central African Republic.mp.	235	father*.tw.
28	mud slide*.mp.	72	Chad*.mp.	236	female*.tw.
29	mudslide*.mp.	73	Chile*.mp.	237	fire fighter*.tw.
30	sand storm*.mp.	74	China*.mp.	238	firefighter*.tw.
31	sandstorm*.mp.	75	Chinese*.mp.	239	exp focus groups/
32	sink hole*.mp.	76	Colombia*.mp.	240	focus group*.tw.
33	sinkhole*.mp.	77	Comoros*.mp.	241	Foreign professional personn
34	snow storm*.mp.	78	Congo*.mp.	242	friend.tw.
35	snowstorm*.mp.	79	Costa Rica*.mp.	243	friends.tw.
36	thunderstorm*.mp.	80	Cote d?Ivoir*.mp.	244	grand father*.tw.
37	tornado*.mp.	81	Cuba*.mp.	245	grand mother*.tw.

38	tropical storm*.mp.	82	Democratic People's Republic of Korea.mp.	246	grand parent*.tw.
39	tsunami*.mp.	83	Democratic Republic of Congo.mp.	247	grandfather*.tw.
40	typhoon*.mp.	84	developing countr*.mp.	248	grandmother*.tw.
41	volcan*.mp.	85	Developing Countries/	249	grandparent*.tw.
42	wildfire*.mp.	86	developing nation*.mp.	250	guardian*.tw.
43	wildland fire*.mp.	87	Djibouti*.mp.	251	Homeless Persons/
44	or/1-43	88	Dominica*.mp.	252	homeless*.tw.
		89	Ecuador*.mp.	253	human*.tw.
		90	Egypt*.mp.	254	humanitarian adj2 worker*.t
		91	El Salvador*.mp.	255	Humans/
		92	Eritrea*.mp.	256	husband*.tw.
		93	Ethiopia*.mp.	257	individual*.tw.
		94	Fiji*.mp.	258	infant*.tw.
		95	Gabon*.mp.	259	inpatient*.tw.
		96	Gambia*.mp.	260	inspector*.tw.
		97	Gaza*.mp.	261	interview*.tw.
		98	Georgia*.mp.	262	investigator*.tw.
		99	Ghana*.mp.	263	male*.tw.
		100	Grenad*.mp.	264	medical examiner*.tw.
		101	Guatemala*.mp.	265	missionar*.tw.
		102	Guinea*.mp.	266	mother*.tw.
		103	Guyana*.mp.	267	nephew*.tw.
		104	Haiti*.mp.	268	next of kin.tw.
		105	Herzegovina*.mp.	269	niece*.tw.
		106	Hondura*.mp.	270	nurse*.tw.
		107	India*.mp.	271	offspring*.tw.
		108	Indonesia*.mp.	272	orphan*.tw.
		109	Iran*.mp.	273	outpatient*.tw.
		110	Iraq*.mp.	274	paramedic*.tw.
		111	Ivory Coast*.mp.	275	exp Patients/
		112	Jamaica*.mp.	276	parent*.tw.
		113	Jordan*.mp.	277	participant*.tw.
		114	Kazakhstan*.mp.	278	partner*.tw.
		115	Kenya*.mp.	279	patient*.tw.
		116	Kiribati*.mp.	280	people*.tw.
		117	Kosov*.mp.	281	person*.tw.
		118	Kyrgyz*.mp.	282	exp Persons/
		119	Lao*.mp.	283	pharmacist*.tw.
		120	Latvia*.mp.	284	physician*.tw.
		121	Leban*.mp.	285	planner*.tw.
		122	Lesoth*.mp.	286	refugee*.tw.
		123	less developed countr*.mp.	287	exp Refugees/

		124	less developed nation*.mp.	288	relief team*.tw.
		125	Liberia*.mp.	289	relief work/
		126	Libya*.mp.	290	research subject*.tw.
		127	Lithuania*.mp.	291	respond?nt*.tw.
		128	low income countr*.mp.	292	exp self-help group/
		129	low income nation*.mp.	293	self help group*.tw.
		130	Macedonia*.mp.	294	sibling*.tw.
		131	Madagasca*.mp.	295	sister*.tw.
		132	Malawi*.mp.	296	exp social support/
		133	Malaysia*.mp.	297	social support*.tw.
		134	Maldiv*.mp.	298	specialist*.tw.
		135	Mali.mp.	299	spouse*.tw.
		136	Marshall Island*.mp.	300	staff*.tw.
		137	Mauritania*.mp.	301	step father*.tw.
		138	Mauriti*.mp.	302	step mother*.tw.
		139	Mexic*.mp.	303	step parent*.tw.
		140	Micronesia*.mp.	304	stepfather*.tw.
		141	middle income countr*.mp.	305	stepmother*.tw.
		142	middle income nation*.mp.	306	stepparent*.tw.
		143	Moldov*.mp.	307	sufferer*.tw.
		144	Mongolia*.mp.	308	support group*.tw.
		145	Montenegr*.mp.	309	exp Survivors/
		146	Morocc*.mp.	310	survivor*.tw.
		147	Mozambiqu*.mp.	311	team*.tw.
		148	Myanmar*.mp.	312	therapist*.tw.
		149	Namibia*.mp.	313	uncle*.tw.
		150	Nepal*.mp.	314	victim*.tw.
		151	Nicaragua*.mp.	315	Voluntary Workers/
		152	Niger*.mp.	316	volunteer*.tw.
		153	North Korea*.mp.	317	wife.tw.
		154	Pakistan*.mp.	318	wives.tw.
		155	Palau*.mp.	319	woman*.tw.
		156	Panama*.mp.	320	women*.tw.
		157	Papua New Guinea*.mp.	321	worker*.tw.
		158	Paragua*.mp.	322	young adult*.tw.
		159	Peru*.mp.	323	or/209-322
		160	Philippin*.mp.	324	44 and 208 and 323
		161	Principe*.mp	325	limit 324 to yr="2003 -Curre
		162	Romania*.mp.		
		163	Russia*.mp.		
		164	Rwanda*.mp.		
		165	Samoa*.mp.		
		166	Sao Tome*.mp.		
		167	Senegal*.mp.		

		168	Serbia*.mp.		
		169	Seychelle*.mp.		
		170	Sierra Leone*.mp.		
		171	Solomon Island*.mp.		
		172	Somalia*.mp.		
		173	South Africa*.mp.		
		174	Sri Lanka*.mp.		
		175	St Lucia*.mp.		
		176	St Vincent*.mp.		
		177	Sudan*.mp.		
		178	Suriname*.mp.		
		179	Swaziland*.mp.		
		180	Syria*.mp.		
		181	Tajikistan*.mp.		
		182	Tanzania*.mp.		
		183	Thai*.mp.		
		184	third world*.mp.		
		185	Timor Leste*.mp.		
		186	Togo*.mp.		
		187	Tonga*.mp.		
		188	Tunisia*.mp.		
		189	Turk*.mp.		
		190	Turkmenistan*.mp.		
		191	Tuvalu*.mp.		
		192	Uganda*.mp.		
		193	Ukrain*.mp.		
		194	under developed countr*.mp.		
		195	under developed nation*.mp.		
		196	underdeveloped countr*.mp.		
		197	underdeveloped nation*.mp.		
		198	Urugua*.mp.		
		199	Uzbekistan*.mp.		
		200	Vanuatu*.mp.		
		201	Venezuela*.mp.		
		202	Vietnam*.mp.		
		203	West Bank*.mp.		
		204	Yemen*.mp.		
		205	Zair*.mp.		
		206	Zambia*.mp.		
		207	Zimbabwe*.mp.		
		208	or/45-207		

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