Ethics in humanitarian research: Insights on the experience of researchers

by

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August 2015

A thesis submitted to McGill University
in partial fulfillment of the requirements of the degree of
Master of Science in Experimental Medicine (Bioethics)

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ABSTRACT

This thesis takes the consensus around the need for more data collection in humanitarian settings as a point of departure, and goes on to address the lack of knowledge about the experience of the actors involved in data collection activities in such settings.

To address the identified knowledge gap, I begin with a conceptual analysis of the intersections between data collection, relationships and moral experience in humanitarian settings broadly defined. In particular, I look at how the greater emphasis now being placed on the accountability of aid organisations has resulted in the notion of ‘impact’ becoming increasingly central to the way they are assessed. I focus on the potential implications of the resulting appetite for data collection for both the kind of relationships made possible with host populations and on the moral experience of humanitarian researchers.

I follow this discussion with an empirical investigation that explores the experience of researchers who have conducted studies in post-disaster settings. I show that the (perceived) red-tape of the research ethics apparatus weighs on post-disaster researchers, many of whom describe mechanisms to bypass ethics oversight. At the same time, the researchers interviewed recognise that post-disaster research is fraught with thorny ethical issues, including concerns about compensation offered to study participants.

Overall, the premise guiding this work is that the experience of those collecting data matters for both intrinsic and instrumental reasons, such as the protection of study participants. For this reason, I conclude by promoting approaches that might address the needs of post-disaster researchers in a manner that seeks to ensure due ethical oversight while addressing researchers’ concerns for efficiency. These approaches include real-time responsiveness and the creation of moral space.
Ce mémoire part du consensus qui existe autour de la nécessité d’intensifier la collecte de données lors des crises humanitaires et progresse vers une remédiation du manque de connaissances disponibles sur l’expérience des acteurs impliqués dans ces activités de collecte de données.

Pour combler le déficit de connaissances identifié, je commence par une analyse conceptuelle de l’intersection, dans les situations humanitaires (ici définies au sens large), entre les activités de collecte de données, les relations humaines et l’expérience morale des individus. Plus spécifiquement, j’investigue comment l’accent aujourd’hui mis sur le principe d’*accountability* (ou d’obligation de reddition de compte) des organisations charitables a mené à l’importance grandissante de la notion « d’impact » dans l’évaluation de ces organisations et, conséquemment, à un plus grand appétit pour la collecte de données. Je me penche sur les conséquences potentielles de cet appétit à la fois pour les relations avec les populations d’accueil et pour l’expérience morale des chercheurs humanitaires.

Je fais suivre cette discussion conceptuelle d’une étude empirique qui explore l’expérience de chercheurs qui ont mené des études dans des endroits touchés par des catastrophes naturelles. Je montre que la lourdeur (perçue) de l’appareil d’éthique de la recherche pèse sur ces chercheurs, lesquels décrivent d’ailleurs des mécanismes d’évitement. Ceci dit, il faut noter que les chercheurs interviewés reconnaissent que les études faites à la suite d’une catastrophe naturelle se heurtent à des questions éthiques épineuses telles que l’indemnisation aux participants.

Dans l’ensemble, la prémisse guidant mon travail est que l’expérience de ceux qui participent à des activités de collecte de données mérite notre attention pour des raisons intrinsèques et instrumentales. Ces dernières incluent par exemple la protection des sujets humains. Pour cette raison, je conclus mon exploration du sujet en faisant la promotion d’approches qui pourraient permettre de répondre aux besoins des chercheurs œuvrant dans des lieux affectés par une catastrophe naturelle, et ce, d’une manière qui à vise à la fois à assurer le suivi éthique et à prendre en compte le souci d’efficacité exprimé par les chercheurs. Les approches présentées
incluent la notion de *real-time responsiveness* (réactivité en temps réel) et de *moral space* (espace moral).
Pour Arthur, dont j’ai les souliers,
Pour Renée-Johanne, qui ne connait pas sa valeur,
Pour Mélissa, *habichuela mágica*,
Pour Simone, qui pose les yeux sur un monde qui a besoin de son émerveillement.

Quatre générations, même inspiration.
ACKNOWLEDGMENTS

A few years ago, I drafted a commentary with Sunita Bandewar from the McLaughlin-Rotman Centre for Global Health and Michael Dunn from the Ethox Centre on the issue of responsiveness in bioethics. The commentary, written in response to a call for papers from the Hastings Center Report on the future of bioethics, identified five aspects we believed were essential for the field to be truly responsive. First, we argued that bioethics needed to broaden “the range of interactions with stakeholders, with a particular focus on social scientists, practitioners who work in oft-ignored environments, and patients and users receiving services within such environments.” Second, we believed bioethics needed to engage more closely with stakeholders “on their own terms.” Third, we suggested that bioethicists needed to adapt to emerging needs “by developing new skills and research methods.” Fourth, we identified the need to find “innovative ways to maximize limited resources to build ethics capacity and deliver services.” Finally, we argued that bioethics as a field needed to become better at “focusing on temporally-relevant issues while anticipating needs.” I realise in hindsight that the topic and approach chosen for this thesis were very much influenced by the five criteria we set up.

This is but one example of how I have (both intellectually and emotionally) deeply benefited from a tremendously generous network of bioethicists since my interest for the field blossomed while taking a course at the University of Toronto eight years ago. Without the mentorship of individuals such as Sunita, Shawn Winsor, Frank Wagner, Jim Lavery, and Solly Benatar, I would never have embarked on this enthralling journey in the first place.

Putting a close to this thesis has a funny sensation to it; it feels like putting a close to much more than a simple 80-page paper. This, I think, can be explained by the numerous detours I took during the MSc process. I was fortunate to have the opportunity to dabble in a number of projects throughout the course of my studies. These past three years have been so much more than just about writing a Master’s thesis, and distinguishing between the various related pieces is difficult. For instance, summer funding from the Faculty of Medicine at McGill University sparked a collaboration with Andreas Reis from the World Health Organization that lasted for two years and that culminated in the publication of a training manual on research ethics in public health.
emergencies that was piloted during the recent large scale outbreak of Ebola Virus Disease in West Africa. This collaboration allowed me explore another facet of the topic I discuss in this thesis, and it allowed me to contribute actively to the development of training material on research ethics—an activity I argue for in a subsequent chapter.

If some of my dispersion during these three years did not help with keeping tight deadlines, it did open up my horizons. It has also meant being able to accomplish dreams (e.g., collaborating with the WHO), continuing to work on issues that I hold dear (tuberculosis research), and working with people that inspire me. I will long cherish the détours I took on the journey to completion. They are part of the well-rounded graduate training I think I have received.

I am acutely aware of the privileged position in which I have been throughout this project. The flexibility of taking a less straight route towards completion was made possible by the incredible support—financial and otherwise—I received from a number of sources. Among them, the Fonds de recherche du Québec, the Fondation Desjardins and the Association francophone pour le savoir, the Canadian Institutes for Health Research, the Centre de recherche en éthique, the Centre de recherche interdisciplinaire en réadaptation du Montréal métropolitain, and various initiatives at McGill University. Travel grants from McGill University further allowed me to present my work in Istanbul, Mexico City, and Cape Town. Such opportunities will have lasting impacts on my career in bioethics, and I wish to thank those whose vision has made them possible.

I was also fortunate enough to be offered a full-time position with the Advisory Committee on Research Ethics at the International Development Research Centre (IDRC) just as data from my interviews were trickling in. I am grateful for Dominique Charron and Thierry Balde, my mentors there, for the flexibility and understanding when came the time to put the final touch to this thesis, as well as for the opportunity to continue exploring the issue of research ethics in crises through fieldwork in Burkina Faso. Although data from this fieldwork is not presented here, it has further strengthened my conviction that research ethics in crises is a topic that needs further attention.
Throughout these past three years, there are a number of people whose encouragements has helped me keep my eyes on the finish line. First among them is Renée-Johanne: her loving support is the one thing I could never doubt. Jean-Claude, with his eyes brightening up every time I mention the university, Sylvie, who always found the right words to cheer me up, and Guy, by providing an inspiring writing environment, played important roles when it mattered most. Marie-Joëlle and Nicky for their part always managed to provide the right types of conversations to keep me stimulated.

To those who encouraged me to do a direct passage to the PhD, thank you for your trust. Choosing not to pursue this option was a difficult one; this project easily could have been turned into a full-fledged dissertation. More than that, researchers working in post-disaster settings actually deserve the kind of attention that only doctoral work could offer. For this reason, my participants not only have my deepest thanks for their contribution to this project, but also my apologies for any shortcoming in the analysis or the representation of their voices.

Matthew Hunt has been a wonderful supervisor. His dedication, availability, and interest for my project and academic success make him the kind of supervisor I would wish to any graduate student. His encouragements to explore career-enhancing activities right from the start of my program have played no small part in helping me secure external funding for my project. His memory of texts continues to fascinate me; it was, more than once, very helpful throughout this endeavour. I am grateful to him for his unwavering support, and for always being present when I needed a tap on the shoulder. Matthew was there at every step of the project, helping me design the study, refine the data collection process, question (and re-question) my analyses, and point out those passages that read like they were written en français.

In addition to Matthew’s expert eye, I also received editing assistance from Richard Cooper and Mélissa Gélinas. Member of Matthew’s research lab (Evelyne Durocher, Véronique Fraser, Ali Okhowat, Catherine Olivier, John Pringle, Cathy Tansey, etc.) and of his Canadian Institutes of Health Research grant EOG 123679 (James Anderson, Anant Bhan, Lisa Eckenwiler, Lisa Schwartz) have also provided helpful comments on drafts of my study protocol, conference presentations, early analyses, and portions of the text.
Finally, during my journey, I saw my partner blossom as she undertook graduate studies of her own. I am surrounded by people who motivate me to stride to aim higher, but Mélissa is an inspiration in the deepest sense of the term. Plus, her *doussage* keeps me sane.
CHAPTER 1: INTRODUCTION

1.1 Background
When the 2015 Nepal earthquake struck, I was in Cape Town, South Africa, attending a workshop on the conduct of health research in disaster settings. Humanitarian practitioners and coordinators alike were sharing thoughts and experiences on the challenges of conducting humanitarian research. Suddenly, a loud alarm went off: a smartphone with an app keeping track of disasters occurring as a result of natural hazards alerted us to the first of what would be multiple earthquakes in Nepal. Unsurprisingly, many attendees’ attention was immediately pulled away from the workshop: frantically typing emails, they set off to start coordinating the relief efforts that would rapidly take shape. Over the span of the two-day workshop, it became clear that the catastrophe that had hit Nepal would require months of reconstruction efforts. But help was also needed right away. To participate in the much-needed relief effort, teams across the world promptly began to hop on planes and depart for Kathmandu.

The World Health Organization (WHO) defines “humanitarian assistance” as the operations that “are intended to respond to the immediate need to save lives, limit extraordinary suffering, prevent further injury to the population or damage to the society.” (1) The number of settings that can be described as needing humanitarian assistance is extremely diversified. Public health emergencies, such as the one unleashed by the spread of the Ebola virus in West Africa in 2014-2015, clearly create humanitarian settings. Financial crises can also lead to the creation of humanitarian settings, as ongoing concerns in South Sudan suggest (2). At other times, it is multiple factors such as “large scale displacement, civil conflict, food insecurity, high food prices, endemic poverty, diminishing resources (water and hydrocarbons) and influxes of refugees and migrants” that combine to create “complex storms” that lead to large-scale humanitarian crises (3). In such cases, whole countries can find themselves in the midst of a humanitarian crisis. For instance, at the time of writing, close to 80% of the Yemeni population is finding itself in need of humanitarian assistance (4).

Personal preparation to respond to a humanitarian crisis requires reliable data about both the challenges that one can expect and the best means to face them. As Gerdin et al suggest,
“Healthcare providers in disasters need readily accessible, reliable, up-to-date information on interventions that might be considered in the context of disasters.” (5) In addition, it is crucial not only to hone clinical skills (6), but also to anticipate ethical challenges that may be far more common than in relief workers’ normal clinical settings in their home countries (7)—such as having to decide what to do when one observes the delivery of substandard care (8). But despite the collective accumulation of experience since Henry Dunant’s publication in 1862 of the influential *Un souvenir de Solferino*—a book that led to the creation of the Red Cross movement, there is still a general feeling that there is a high level of unpredictability to humanitarian crises. This uncertainty not only complicates pre-departure preparation, but also on-the-ground operations. As trauma psychologist David Chesire explains, “The painful truth is that it is impossible to be fully prepared for what to expect in a disaster situation.” (9)

While many might agree that to be fully prepared to respond to a humanitarian crisis would be an impossible task,¹ paradoxically, we seem less inclined to be generous with the relief system as a whole. Critics, for example, do not shy away from making stinging comments about the preparedness of the relief system. From the 2004 Indian Ocean Tsunami to Hurricane Katrina and the 2010 Haiti Earthquake, none of the major disasters that have marked the global psyche over the past decade have escaped scrutiny. News stories have been filled with images and stories about the suffering of victims and the inability of the relief system to respond adequately. In the media, the coverage of disasters now seems to follow a predictable progression: from sensationalist recording of the number of people affected, to coverage of charity appeals, to criticising of the relief efforts. The cycle is not necessarily long: only a few days after an earthquake struck Nepal in 2015, articles problematizing the response were already appearing (10).

Members of the relief system and humanitarian research scientists alike have internalised these critiques, and many have in fact been active critics themselves (11). It is indeed well recognised that “the humanitarian system is by nature self-critical, with a tendency to emphasise its failures and shortcomings.” (12) A recent example of this can be found in the writings of the Director of

¹ This, of course, is not to say that it would be excusable for individuals to rush to crisis-affected areas and not invest time in personal preparation, as is sometimes seen after a disaster takes place.
the Center for Refugee and Disaster Response at the Johns Hopkins Bloomberg School of Public Health, Thomas Kirsch:

Research provides some well-documented evidence that many international health-oriented responses are poorly targeted and may be influenced by objectives that play well on the home front rather than what’s needed on the ground. (13)

For many critics, an important means to address the inefficiency, ineffectiveness, or illegitimacy of the humanitarian system is to conduct more data collection. For instance, Zachariah and colleagues (2010) emphasise that research could play a key role in improving relief. More recently, the large-scale outbreak of Ebola virus disease (EVD) in West Africa played a determining role in raising awareness about the importance of conducting research in the midst of public health emergencies (14). In response, stakeholders at various levels (ranging from international organisations to ethics committees) tackled the issue of study designs for trials on therapeutics for EVD (15).

The creation of the funding mechanism Research for Health in Humanitarian Crises (R2HC) (http://www.elrha.org/r2hc/home/) also testifies to the belief in greater data collection activities in humanitarian settings. The director of ELRHA, which hosts the R2HC initiative, has gone on record to explain that

The earthquake in Nepal throws a spotlight on the increasing need to support people facing humanitarian crises. We must urgently find efficient solutions to save the most number of lives. Research which underpins solutions in a crisis situation is critical to make humanitarian responses most effective. (16)

This thesis takes this broad consensus around the need for more data collection in humanitarian settings as a point of departure, and goes on to address the lack of knowledge about the experience of the actors collecting data in such settings. To address the identified knowledge gap, I begin with a conceptual analysis of the intersections between data collection, relationships and moral experience in humanitarian settings broadly defined. I follow this discussion with an empirical investigation that explores the experience of researchers who have conducted studies in
post-disaster settings specifically, seeking to identify approaches that might ensure due ethical oversight while addressing researchers’ needs.

1.2 Personal motivations
One of the first times I pondered the intriguing world of being a health researcher was during fieldwork I conducted during my undergraduate studies at the University of Toronto. In the context of a series of case studies on the community engagement component of several projects funded by the Bill & Melinda Gates Foundation’s Grand Challenges for Global Health initiative, I travelled to Mexico with a colleague to interview individuals who had participated in studies conducted by the Consorcio mexicano contra la tuberculosis [Mexican consortium against tuberculosis]. Over the course of this fieldwork, I was deeply moved to see the relationships that had blossomed between many participants and the research team. Treatment for tuberculosis is long and, in settings where resources are constrained, particularly fastidious. The side effect of the chemotherapy can be debilitating—particularly when second line drugs are involved. It was clear that the research team I visited had become very close to their participants, who spoke fondly of the research initiative. This researcher-participant relationship ran much deeper than what reading about health research had led me to envisage as possible. As my colleague and I continued to interview participants, it became clear to us that part of the success of the medical treatment was that the relationship nurtured by the researchers facilitated optimism and adherence to treatment among participants.

The literature on the so-called ‘art’ component of medicine has long been replete with stories of the importance for the physician to demonstrate caring qualities. Meanwhile, the literature on international research ethics I was reading at the time of my undergraduate degree was focused on determining whether lower standards of care were acceptable in some settings, and whether informed consent needed to be documented with a written signature. Rare were discussions of the more ‘artful’ aspects of being global health researchers. Mostly, the concern seemed to be about what mechanisms needed to be put in place to ensure researchers did not exploit participants. This sort of detached, cold discourse about global health research contrasted sharply with researchers’ emotional investment I had witnessed in Mexico. Data collection activities, it
seemed to me, should not only be thought of as something that researchers robotically partook in, but also as something they *experienced*.

Not surprisingly, by the end of my undergraduate studies, my reflection on the above had led me to become very curious about how research ethics was portrayed in professional research circles. Before taking the graduate studies plunge, I thus enrolled in a one-year training course in clinical research, and excitedly set out to observe how an upcoming cohort of clinical research associates was being trained on research ethics.

That year yielded interesting insights. Even more than in the academic setting, research ethics was not so much presented as a mindset, but rather as a tedious, treacherous barrier—in this case, to a long, successful, and, most importantly, lucrative career in drug development. One misstep, and your prospects in Big Pharma could be over. The implicit threat took a particularly realistic turn when we were asked to make presentations on research ethics scandals after having taken a series of multiple answer tests on the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. Of course, where ethics is reduced to a multiple-answer test, there can be little art to being a researcher…

After this experience, it was clear to me that how the research ethics apparatus is portrayed can be a source of moral anxiety for stakeholders involved in research activities. In fact, through the sort of socialisation that was taking place throughout that year, I almost came to share the dread and angst that was seemingly being instilled in my classmates. What pressure the research ethics apparatus can be portrayed to impose on researchers! In hindsight, Hugo Slim’s warning that bureaucratisation can “deter and undervalue the leaders, pragmatists and risk-takers who are so important to effective and innovative humanitarian work” (17) appears perfectly applicable to research ethics in the clinical research setting. Research ethics suddenly started to appear to many of us in the program as potentially stifling innovation and good research. Sadly, this view continues to be perpetuated. As I was finalising this thesis, Steven Pinker, professor of psychology at Harvard University, caused a commotion in bioethics circles by writing in the *Boston Globe* that
the primary moral goal for today’s bioethics can be summarized in a single sentence. Get out of the way. A truly ethical bioethics should not bog down research in red tape, moratoria, or threats of prosecution based on nebulous but sweeping principles such as “dignity,” “sacredness,” or “social justice.” Nor should it thwart research that has likely benefits now or in the near future by sowing panic about speculative harms in the distant future. (18)

When I began to develop plans to undertake graduate studies, I was inspired by then-recent writings, such as those of Adriana Petryna (19,20), that detailed how the off-shoring of clinical trials meant that considerable clinical research resources were diverted to middle- and low-income settings for the conduct of trials. My initial thoughts were to investigate whether it would be ethically feasible to increase the number of trials held in humanitarian settings as a way to increase accessibility to medical resources among highly vulnerable populations. Of course, this vulnerability—and associated fears of exploitation and coercion—is a determining factor of why many might recoil at the thought of conducting full-blown trials during humanitarian crises. Certainly, Hans Jonas gives indications in his famous essay on human experimentation that he would have frowned upon such a proposal:

one should look for additional subjects where a maximum of identification, understanding, and spontaneity can be expected—that is, among the most highly motivated, the most highly educated, and the least “captive” members of the community. From this naturally scarce resource, a descending order of permissibility leads to greater abundance and ease of supply, whose use should become proportionately more hesitant as the exculpating criteria are relaxed. An inversion of normal “market” behavior is demanded here—namely, to accept the lowest quotation last (and excused only by the greatest pressure of need), to pay the highest price first. (21)

However, as I thought back to some of the tuberculosis researchers I had met in Mexico I had no doubt that it would be possible to find researchers who would demonstrate both the sensitivity and empathy that would be necessary to work with populations affected by humanitarian crisis in the context of a clinical trial. In other words, I thought that Jonas’ insistence on using an inverted
market behaviour might be misguided. My guiding premise was that research could instead be used to help participants become less “captive” members of a community.

But I kept coming back to this issue of emotional investment, and I wondered about the toll that working with humanitarian populations might take on researchers. There are many first-hand accounts of the distress healthcare professionals feel when they work in settings that are under-resourced or in turmoil—James Orbinski’s work being a well-known example (22)—and formal investigations of the phenomenon can be found in the literature (6). However, it is much harder to come across discussions of the experience of researchers. This thesis is my contribution to this needed body of knowledge.

At the core of my interest for the moral experience of researchers is a more fundamental question about what it means to be a researcher. By its nature, this thesis can be but a small indent in this wider topic of interest.

1.3 Intrinsic and instrumental considerations

The premise of the work that follows is that the experience of researchers matters for both intrinsic reasons, as well as for more instrumental ones. Intrinsically, being responsive to the experience of fellow human beings is important, for “empathy, sensitivity, and responsiveness to particular others may often be better guides to what we ought to do than are highly abstract rules and universal principles” (23).

It is, however, important to be mindful that the notion of ‘responsiveness’ opens the door to the “is-ought problem” that British philosopher David Hume first described. In the case at hand, if individuals involved in data collection in humanitarian settings were to describe certain aspects of the research ethics apparatus (e.g., expectation that protocols will be submitted for review to research ethics committees (RECs)) as being problematic, does it necessarily mean that the oversight system should be changed? Taken to the extreme, if researchers were to say that they would prefer that the ethics oversight apparatus be done away with entirely, should steps actually be taken to dismantle it? Hunt and Carnevale acknowledge this challenge of doing empirical research in bioethics: “research that identifies how individuals act in particular circumstances,
what they believe about a particular moral issue or how they experience an ethically significant situation does not necessarily provide an epistemological footing to critique or support social practices or beliefs.” (24)

This is where turning to more instrumental reasons to justify being responsive to the experience of individuals offers leverage. Instrumentally, we should be mindful of researchers’ experience because it could directly influence the way they go about conducting research. In other words, how researchers experience research might impact the way participants and their data are treated. Instrumental reasons give us a simple way out of the thorny is-ought problem: since protecting research participants is the founding tenet of research ethics, the research ethics community ought to be responsive to the experience of researchers if it is shown to jeopardise participants’ well-being.

1.4 A note on the distinction between practice and research
At this point, it might be worthwhile to say a few words about the diversity of data collection activities with human subjects. Outside of the humanitarian field, commentators have tried for several decades to distinguish between data collection activities that should be considered health research from those that should be considered practice. As things currently stand, the distinction tends to have important implications in terms of responsibilities and obligations towards communities and human subjects. Data collection projects that are deemed to fit within the category of ‘research’ are typically required to go through a formal process of ethics review by a qualified REC. Conversely, data collection projects understood as part of practice (e.g., evaluations to ensure program quality) tend to be exempt from research ethics oversight. The influential Belmont Report described research as an activity permitting to draw conclusions and create generalisable knowledge (25). But it is becoming less controversial to hold both that the conceptual distinction between data collection for practice vs. research is more complex than first meets the eye (26), and that the possibility of drawing a distinction at the level of individual projects can prove particularly elusive.²

The need to distinguish between types of data collection activities can furthermore be challenged on the grounds of relevance. Historically, the importance given to the oversight of research activities comes from the desire to protect individuals from harms associated with unduly dangerous, ill-conceived, or problematic research protocols. Yet, it is questionable whether the distinction adequately serves the protection and well-being of communities as some data collection initiatives that do not fit the description of ‘research’ can pose substantial risks. Not surprisingly then, approaches that blur the boundaries between biomedical practice and research (27) and between public health practice and research (28) are emerging. For example, Faden and colleagues have proposed a framework that seeks to make learning in healthcare settings easier by increasing the ease with which data collection activities that do not undermine the interests or rights of patients can be conducted (27).

In the humanitarian context, where urgency is commonly combined with destruction or deficiency of local infrastructure, the distinction between data collection for practice vs. research is no less ambiguous. Data collection in the humanitarian realm currently spans several spheres of activity and ranges from university-sponsored studies to so-called operational research conducted by non-governmental organizations, and from independent monitoring and evaluation to public health surveillance. The existing humanitarian ethics literature generally falls short of drawing sharp research vs. practice distinctions amongst these diverse data collection activities. For instance, Banatvala and Zwi describe a number of questions they believe should be investigated without explicitly dissociating research from evaluation, evidence gathering, and other similar terms. For them, it appears sufficient to say that “New initiatives in evaluation, and in operational and policy research, require an interdisciplinary, transparent, and process oriented approach” (29). This lack of precision is not surprising: as observed in more traditional clinical settings, it can be difficult to distinguish conceptually between various types of knowledge creation activities (30). Looking at the techniques used to collect data is also not, in itself, a useful indicator to separate between humanitarian data collection for practice vs. research. Orbinski’s vivid description of a survey of Rwandan refugees that allowed Médecins sans Frontières to ascertain that 80% of family members had perished within a few months (22) might well have used the same techniques—and generated similar risks—to projects that others
would have had to submit for research ethics approval before initiating data collection because they were explicitly done for research purposes.

The activities that allow humanitarian organisations to bear witness are not always fully consistent with the scientific approach. Take, for example, the advocacy undertones of témoignage, a concept coined by Médecins sans Frontières that refers to the act of witnessing and speaking out about the suffering one sees, as opposed to remaining silent. The advocacy undertones of témoignage may be counter to more ‘objective’ research methods. Yet, in so far as humanitarian organisations produce new knowledge through the survey and documentation of unbearable situations, they may come close to approximating what more traditional researchers do. In general, humanitarian witnesses share similarities to researchers for they, too, can “testify not on the basis of what they have lived through, but on the basis of what they have seen” (31). Testifying is essentially what researchers do when they report results from social science inquiries and from randomised trials. Whether as practitioners or researchers, humanitarians do not directly experience, but can choose to communicate, the stakeholders’ experience that is the centre of their attention. Humanitarian research and humanitarian practice can look remarkably similar under such circumstances—even if, whereas researchers generally choose to do so through peer-reviewed publications or reports, practitioners might prefer working under the auspices of témoignage.

Hence, theoretical and pragmatic considerations suggest that it might be more useful to think of humanitarian human subject research and humanitarian practice as being on a spectrum, with some activities—such as needs assessment—difficult to categorise as either one or the other. This is consistent with the recommendation of the 2009 technical consultation on Research Ethics in International Epidemic Response organised by the World Health Organization, which suggested that ethical oversight be tied to risks, rather than a contested delineation between research and practice (32). Using a risk-based approach avoids the ‘sorting problem,’ while providing a mechanism to protect individuals from potential harms linked to data collection.

3 It is important to note that the term témoignage is not shared by all organisations committed to a similar ideal of reporting on the experience of affected communities, and that the stance is expressly rejected by some humanitarian organisations.
activities—no matter where or how they occur. In addition, a risk-based approach opens the door for a more consistent approach to ethics oversight.

My thesis reflects some of the tensions related to the research distinction that exist in the literature. In the first part, I do not make clear distinctions between the kinds of data collection activities involving human beings that some might feel more comfortable categorising as part of practice vs. research. Personally, I tend to side with those arguing that projects involving data collection with human subjects should be judged based on their risk profile, as opposed to the ultimate purpose (e.g., generalizable knowledge, scientific publication). As will become apparent, what is of particular interest to me is the type of relationships that can be nurtured in a context of data collection, as opposed to the conceptual distinction between research and practice. As such, in the second chapter, I adopt the broader terms data collection and data collectors, as opposed to research and researchers, which imply a narrower set of activities (25). And when I speak of humanitarian data collection, I refer to those activities that occur in humanitarian settings, rather than those with an explicit ‘humanitarian’ aim, i.e. one that seeks “to save lives and alleviate suffering of a crisis-affected population.” (33) In the second part of the thesis (Chapter 4), I use the term ‘research’ more specifically for reasons that will become clear, but that essentially revolve around strategies for the recruitment of participants rather than a philosophical endorsement of the distinction between data collection for research vs. practice.

1.5 Structure overview
My thesis follows an article-based structure. Two manuscripts (Chapter 2 and Chapter 4) are the core of the work, and they are brought together by introductory (Chapter 1), bridging (Chapter 3), and concluding (Chapter 5) chapters. Following the introduction, I begin with a conceptual analysis of the intersections between data collection, relationships, and data collectors’ moral experience in humanitarian settings, broadly defined (Chapter 2). I then present findings from an empirical study I conducted with researchers who worked in post-disaster settings specifically (Chapter 4), before drawing concluding remarks.

Chapter 2 explores some of the conceptual implications of the push to improve the effectiveness and efficiency of humanitarian aid through the conduct of data collection activities. With greater
emphasis being placed on the accountability of aid organisations, the notion of ‘impact’ is becoming increasingly pivotal to the way humanitarian actors are expected to address issues of need and scarcity. Data collection in the humanitarian realm already spans several data collection activities, and I focus on the potential implications of this race to collect data on both the kind of relationships made possible with host populations and on the moral experience of humanitarian researchers. I draw in particular from the work of Didier Fassin (31) to identify and analyze some of the potentially troubling aspects of the humanitarian researcher-participant relationship. This chapter is written for a journal whose audience has a broad understanding of the humanitarian arena.

Chapter 3 bridges the two core manuscripts by explaining the move away from the broader field of ‘humanitarian data collection’ discussed in the first manuscript to a focus on research conducted following a ‘natural’ disaster (e.g., earthquake, tsunami) in the second manuscript (Chapter 4).

In Chapter 4, I present a study that I conducted based on interviews with researchers who had experience working in post-disaster settings (see Appendix 1 for the informed consent form). Findings from this study help shed light on the challenges post-disaster researchers face, and whether they have the resources needed to cope with them. Drawing upon this analysis, I propose that alternative approaches to current ways of thinking about research ethics oversight might be particularly fruitful in post-disaster settings. This chapter caters specifically to the research ethics community interested in empirical approaches to bioethics research.

Finally, I briefly conclude in Chapter 5 with a personal reflection that brings together the various elements of the thesis and its process and that points to future areas of work.
CHAPTER 2: DATA COLLECTION IN HUMANITARIAN CONTEXTS: THE NEED TO EXPLORE RELATIONSHIPS AND MORAL EXPERIENCE

2.1 Abstract
There is a generalised push to improve the effectiveness, efficiency, and legitimacy of humanitarian aid. Consequently, the way humanitarian organisations’ performance is assessed is changing. In particular, the notion of ‘impact’ is becoming pivotal to the way humanitarian actors are expected to respond to issues of need and scarcity. In what follows, I explore factors that might affect the moral experience of those involved in data collection, as well as the types of relationships they can engage in. The premise is that moral experience and relationships matter in humanitarian settings, for they can have significant impacts on the ability of those who collect data to protect their participants and promote their well-being. To explore the issue of relationships, I draw from observers of the humanitarian world such as Didier Fassin (31).

2.2 The quest for data in humanitarian settings
An analysis of historical trends suggests that the contemporary interest for data collection in the humanitarian field parallels the rapid expansion of the discourse on accountability. Though analyses show that the trend towards increased use of evidence in the humanitarian field began long before the 1990s, (34,35) formal oversight mechanisms, which can include social audits and accreditation (36), have only been developed and widely applied in the past decade (see, for instance, the Disaster Accountability Project, which was founded in 2007).

The creation of the Sphere guidelines,4 along with learning initiatives such as ALNAP (http://www.alnap.org/) and ELRHA (http://www.elrha.org/), reflects well the evolving expectations placed on humanitarian actors to ensure high standards are met in the planning and implementation of their programs. Quantitative measures such as the administrative cost ratio (the money spent on administrative activities, including fundraising, divided by the total expenses of the entire organization) have become increasingly important considerations in recent

4 The Sphere Handbook is the most widely known set of principles and minimum standards against which a humanitarian response can be evaluated. It is the result of the Sphere Project, an initiative that fosters dialogue between humanitarian agencies (http://www.sphereproject.org/).
years. However, an alternative approach focusing on the extent to which organisations are seen as delivering legitimate aid to affected communities is gaining traction (17). While it is open to debate how effectiveness, efficiency, and legitimacy of humanitarian interventions are to be evaluated, one thing is clear: doing so requires some form of data collection involving human subjects.

Data collection activities are now at the forefront of discussions within the humanitarian community (37–40). For instance, the 2016 World Humanitarian Summit, an initiative of the United Nations Secretary General, will focus on providing “an opportunity for scholars, practitioners and policymakers to propose innovative research- and evidence-based alternatives to conventional approaches to improving humanitarian effectiveness” because the “rise of managerial culture, with its focus on efficiency, accountability, performance and results, has also compelled humanitarian agencies to give more importance to evaluation of their activities and measurement of outcomes.” (http://www.humanitarian-quest.org/about/) Beyond making evaluation of individual organisations possible, data collection in humanitarian settings is also seen as essential by many commentators for improving the delivery of assistance more generally (41). In fact, some have gone so far as suggesting that “it may be unethical not to generate knowledge intended to evaluate or improve delivery of services in such contexts” (42). For de Waal, data collection and the generation of evidence to guide practice can also serve the morally important role of helping avoid some of the “escapable cruelties of the humanitarian predicament” that arise from technical failings and the lack of professionalization (43).

Since data and evidence are becoming central to humanitarians’ ability to live up to public expectations, many organisations have increased their capacity to collect data—directly or through partnerships (17). Of course, all observers do not gladly share in the enthusiasm. Slim, for example, cautions against the implications of trying to introduce “deeply unrealistic measures and systems of quality, improvement and accountability into agencies and contexts which simply cannot absorb them, handle them or benefit from them” (17).

But not all data collection in humanitarian settings is done with the explicitly humanitarian aim of saving lives and alleviating suffering of a crisis-affected population (44). In some cases, it
might fit more broadly within the purview of academic and/or health research (45). Consequently, data collection can be, and often is, conducted independently of humanitarian organisations.

Not surprisingly then, the peer-reviewed literature related to humanitarian aid has experienced a massive expansion in recent years (46). A look at absolute numbers confirms the publication boom: a search of the PubMed database reveals that an annual average of 1,000 articles about human research and disasters alone were published in English between 2005 and 2011 (46). Suggestive of this trend, the number of peer-reviewed articles published by the international humanitarian organization Médecins Sans Frontières increased by a factor of 10 between 2000 and 2008 (42). Yet simply looking at published outputs is sure to vastly underestimate the number of data collection activities conducted in humanitarian settings. As Zachariah and colleagues explain, “there is rarely necessity or reward for publishing the results of research studies” for those who engage in humanitarian operational research (47). More than this, some of this type of data collection does not qualify as research *per se* and, consequently, may not be eligible for publication in some peer-reviewed journals. Consequently, it is difficult to have a clear picture of data collection in humanitarian settings. Answers to the following questions remain elusive: Who conducts data collection activities?; What are these activities?; What types of relationship do they foster?; and, importantly, What is the moral experience of those who conduct them? In what follows, I focus specifically on two of those questions, looking at issues of moral experience and relationships associated with humanitarian data collection activities.

2.3 Moral experience of humanitarian ‘data collectors’

The appetite for discussions of humanitarian research ethics is clear: in a poll conducted with 75 anthropologists, 40% of respondents identified research ethics in humanitarian settings as an “area of key concern” (48). Already, a number of ethical analyses of humanitarian research have been proposed (44,49–51). However, discussions have mainly focused on elucidating how traditional research ethics concerns should be operationalised (51,52). More importantly, there continues to be a lack of attention paid to activities not expressly classified as human subject research, but that nonetheless involve data collection from humans.
It is concerning that direct engagement with individuals collecting data in humanitarian settings—formal researchers and others—to assess the relevance of trying to operationalise traditional research ethics concerns appears to have been all but inexistent to date. This is especially concerning given that there are reasons to believe that the concerns of data collectors active in humanitarian settings could differ significantly from those working in more traditional settings. Black discusses this possibility by suggesting that humanitarian researchers may be concerned about their data falling into the hands of belligerent parties, for instance (53). Although Black’s work is sensitive to concerns that might be researcher-specific, it is not based on the kind of empirical investigation that would be necessary to elicit the actual concerns of those collecting data in humanitarian settings.

To date, few empirical studies have been conducted on the perspectives of researchers regarding ethics guidelines and the ethics review process in general (54), let alone in the context of humanitarian research. Even less is known about the involvement of non-researchers (e.g., consultants conducting interviews) with those same resources. This is an important gap, particularly since the perspectives of communities and of research ethics committee (REC) members have been increasingly studied (55) and that we know that tensions exist between the three main groups of stakeholders involved in research, i.e. the researchers, the ‘researched’, and the individuals ensuring ethical oversight (56). Qualitative assessments of the perspective of the stakeholders involved in the research process suggest that they can teach valuable insights about ethics guidelines. For example, Hyder et al’s (54) work shows that research ethics guidelines developed and sponsored by North American institutions might not be fully responsive to the needs of researchers working in low-resource settings. One area that is particularly understudied is the issue of moral experience of researchers and other data collectors in humanitarian settings.

Hunt and Carnevale define moral experience as encompassing “a person’s sense that values that he or she deems important are being realised or thwarted” as a result of an encounter (24). Moral experience, then, is “centred on what matters most to individuals” (24); it arises not only under distressing circumstances, but in many aspects of daily life. For example, a situation that is understood as being fair or equitable also counts as a moral experience. In that sense, it is
different from some analogue phenomena more often discussed in the literature, such as moral distress and moral residue (57).

Moral experience is an experiential phenomenon that is contextualised, i.e. that is “best understood from the subjective perspective of the person living the phenomenon within his or her local social context” (58). Importantly, the conceptualization of moral experience is underpinned by hermeneutical conceptions of the human sciences and of human agency (59). In the words of Hunt and Carnevale, the language of moral experience, then, is that of spectra rather than absolutes: spectra of right and wrong, good and bad, just and unjust (24). For Kleinman, the shaping of the moral experience happens through the interaction of three phenomena: cultural meanings, social experience, and subjectivity (i.e. inner emotions and sense of self) (60). In other words, large-scale forces shape moral experience by impinging and transforming what matters most for ordinary people.

Humanitarian situations are a clear example of circumstances that might lead to a ‘re-ordering’ of one’s life. Individuals traveling from abroad to collect data in such settings, though they may be less affected by the direct event, may well find themselves in situations where cultural meanings are changed, where their experience of the social world is channeled through power imbalances, and where their emotional stability may be disturbed. Experienced humanitarian aid workers often describe deeply unsettling situations (22). If such situations are difficult to handle for care providers, who might at least rely on their skills to offer some level of comfort, what of those collecting data who have little to offer in terms of immediate relief? Surely the lack of resources and skills to respond to the witnessed calls for help might create profound emotional distress.

However, as described above, moral experience is not only about those extreme events, but is also to be found in the mundane day-to-day of data collection. For instance, there might be circumstances where researchers deviate from expected practices and then struggle to live with the outcome. Orbinski reveals that healthcare professionals do, for instance when they find themselves rejecting the cold logic of triage: “It made no rational sense to spend so much time away from the clinic treating one patient when there were so many. I don’t know why I did, but I
Although data on the issue is sparser for individuals involved in data collection than for humanitarian professions, it is not difficult to imagine the former similarly having to make decisions difficult to rationalise post hoc (61)—or that, at the very least, cannot “be taken for granted.” (62)

For researchers, an additional source of moral experience may be the expectations they face from the research ethics system, study participants, and society at large. Prior to the recent launch by ELRHA’s R2HC program of *An Ethical Framework for the development and review of health research proposals involving humanitarian contexts* (63), no ethics guidelines had been specifically developed for the conduct of research in humanitarian settings. Researchers—and other data collectors curious about the issue—were therefore limited to draw on a number of resources for general ethics guidance. For example, they might have turned to their professional code of ethics (e.g. Canadian Code of Ethics for Registered Nurses) or referred to general research ethics guidelines (e.g. Declaration of Helsinki). In addition, ethics guidelines targeted at the practice of humanitarianism already existed, including the Code of Conduct for the International Red Cross and Red Crescent Movement and NGOs in Disaster Relief, the Joint Policy of Operations, and the Principles and Policies of Humanitarian Operations (53). It is unclear, however, to what extent these various documents set up helpful or contradictory expectations.

Finally, the politicisation of humanitarian data collection could also be a factor affecting the moral experience of those involved in it. An example of such politicisation is offered by Orbinski when he describes the control over research ethics approval by the Rwandan government as a political tactic (22).

### 2.4 Relationships in humanitarian data collection

Beyond issues of moral experience, the rise of data collection in humanitarian settings raises questions about the relationship between the person collecting data and the host communities. Part of the worry is that the shared vocabulary and circumstances of humanitarian aid workers and data collectors might lead to the reproduction of several forms of relationship that have been identified as sources of concern by commentators such as Fassin (31) and Barnett (34).
A first concern revolves around power. For Fassin, “a relation of domination and a relation of assistance (...) is constitutive of all humanitarian government” (31). This unequal relationship is constructed independently of the goodwill of the ‘rescuers.’ Means of resistance, on the other hand, are limited for those who are ‘helped.’ Indeed, “the very gesture that appears to grant them recognition reduces them to what they are not—and often refuse to be—by reifying their condition of victimhood while ignoring their history and muting their words” (31). In appraising humanitarian relationships, Fassin further suggests that “the founding inequality of the humanitarian gesture resides in this asymmetry of lives” (31). The asymmetry he describes is that between a life that is passively sacrificeable due to uncontrollable exposure to danger and that of a life that might be sacrificed as a result of a deliberate choice. The first describes the life of the ‘victim’, while the second describes that of the humanitarian worker who has willed her presence into the field.

This analysis can be extended to the individual collecting data in humanitarian settings, especially in cases where she works independently. In such cases, the humanitarian ‘researcher’ might have even more of a choice with regards to the extent to which she is exposed to risk, further exacerbating the cruelty of the relationship. In this case, cruelty is to be understood in its Artaudian meaning, namely that “cruelty is a matter of neither sadism nor bloodshed, at least not in any exclusive way (...) The word ‘cruelty’ must be taken in a broad sense, and not in the rapacious physical sense that it is customarily given (...).” De Waal similarly sees an act of cruelty when a physician “must look into the eyes of a man or woman in the most desperate need of his or her expertise, and withhold that help.” (43) The researcher who has the liberty to leave when risk spikes up, but who must leave behind her research participants to fend for themselves, finds herself in a relationship of Artaudian cruelty. True, some see in the result of data collection the promise of less cruel relationships. For instance, de Waal believes that in due time “operational research will further upgrade the capacity and quality of relief response, so that more of the escapable cruelties of the humanitarian predicament can be avoided.” (43) But for now, the Artaudian cruelty of the data collector-participant relationship seems inescapable in humanitarian settings. Even témoignage, the form of advocacy Médecins sans Frontières is well-known for, seems to fall short of recalibrating the cruelty of the relationship, for humanitarians engaging in the practice simply speak in place of aid recipients from mostly protected spaces.
Nonetheless, individuals carrying out data collection activities might be thought to be in a better position than care providers to establish a respectful relationship with victims of humanitarian crises. After all, the very nature of their work is to put on display the experience of the participants from whom they collect data. In other words, even though there might be a cruel aspect to the disparity between the situation of one who collects data and one who offers them, one might anticipate that the relationship could be an opportunity for the voiceless to be heard.

Sadly, this conceptualisation of the work of humanitarian data collectors has clear limitations. Dillon suggests that “respect involves deference, in the most basic sense of yielding: self-absorption and egocentric concerns give way to consideration of the object, one’s motives or feelings submit to the object’s reality, one is disposed to act in obedience to the object’s demands.” (64) Yet, more often than not, those collecting data are ultimately the ones imposing their research agenda on host communities and participants. The extent to which “one’s motives or feelings submit to the object’s reality” when collecting data is thus often debatable. Even in cases when humanitarian data collectors may wish to commit to more participatory approaches, they may find themselves constrained by inflexible funding mechanisms and other constraints—realities faced by parties interested in participatory approaches outside of the humanitarian realm too (65). Rare exceptions to this may include data collection as part of social audits, which Hilhorst describes as “an accountability mechanism that adopts a stakeholder approach in order to assess the performance of an organisation in relation to its aims and those of its stakeholders.” (36) In general then, it appears that a blanket assumption that data collection in humanitarian settings necessarily favours relationships that are more respectful than those nurtured through the provision of humanitarian aid would be ill-founded.

An aspect of the relationship related to the issue of respect that must be explored is that of ‘display.’ Fassin would like us to “take the measure of this exaltation of misfortune, the exaggeration of the figures, the exhibition of horror, the staging of suffering, the catastrophization of the social world” (31). I would contend that these activities, except hopefully for the exaggeration of figures, are at the core of what most humanitarian data collection activities are about. In a sense, humanitarian data collection ought to exhibit the horror of complex emergencies and disasters, for only by doing so can it legitimise its existence. Those
who collect data in humanitarian settings find themselves in a conflict of interest similar to that of all other researchers: the more their subject of inquiry can attract the sympathy or concern of the public and funders, the better their chances of being able to pursue their research programme. This conflict of interest might be echoed in the grant applications researchers file, where they are incentivised, by the nature of the evaluation process, to cast the issue they are interested in studying in a way that will appeal to funders—and, increasingly, the public too, as the use of video presentations in high-stake competitions such as Canada’s “Stars in Global Health” program demonstrates. Whereas this conflict of interest may be shared by all researchers, those working on humanitarian topics should reflect on whether there is something particularly distasteful in their case because the ways in which they frame the object of their inquiry are telling of the power dynamics found in the relationship. The mounting critiques targeting organisations that prominently feature shocking pictures in their appeal for donations and annual reports (66) should, by analogy, prompt an analysis of how data collectors portray participants in humanitarian settings. A discourse analysis of grant applications and publications could help shed light on this issue.

At the same time, data collection might be instrumental in recasting ‘victims’ in such a way that helps resist the temptation to reduce their condition to “their bare physical existence” (31). Indeed, the data collection process is not necessarily consistent with what has been the humanitarians’ tendency to focus solely on survival as a result of the irreducible urgency of humanitarian situations. In contrast, those individuals mandated to carry out data collection activities might have (relatively) more flexibility to consider ‘victims’ more holistically since the same time and resource constraints need not necessarily apply to them. Researchers might indeed have a greater chance to ‘get personal’ with individuals affected by humanitarian crises than care providers. They might, for example, have the opportunity to learn about the life history of participants while their counterparts are tasked with maximising the number of patients seen. In other words, humanitarian circumstances might make it possible to invert two important relationships encountered under more normal circumstances: that of the impersonal researcher-subject dyad and that of the care-centred practitioner-patient dyad.

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While this may appear promising, Barnett also offers a warning about humanitarian relationships that data collectors active in such settings should carefully heed (34). Barnett believes that we are more likely to overlook matters of consent if we feel responsible for the welfare of others and if we are convinced of our capacity to improve their lives (34). Grounding the humanitarian discourse in notions of vulnerability can suggest “a need for protection, for which adults must be responsible” (34). This infantilisation of persons affected by disasters or complex emergencies is one that those involved in data collection could easily fall prey to—by foregoing informed consent or local research ethics review, for instance.

The discussion above suggests that there are some circumstances shared by those collecting data and providing care in humanitarian settings. Thus, at least some of the concerns expressed by Fassin and Barnett (31,34) about humanitarian relationships, summarised above, might be replicated in the context of data collection.

In addition to Fassin and Barnett’s critiques, further aspects of the relationships fostered by data collection in humanitarian settings could be found to be in need of being problematized. For example, the issue of ‘philanthropic misconception’ has been raised among bioethics circles. Philanthropic misconceptions refer to the misconceptions that are “likely to exist among beneficiaries of philanthropy or humanitarian aid when these agencies conduct or sponsor research projects.” (67) In such cases, research participants “may start believing that the aim of such researchers is primarily human welfare and the best interests of individuals instead of research.” (67) The phenomenon of philanthropic misconception is one example of factors not shared with the provision of humanitarian aid that could have serious implications for the way relationships between those collecting data in humanitarian settings and those offering those data might be construed.

2.5 Conclusion
Data collection in humanitarian settings promises important improvements in the delivery of humanitarian aid. But as I have sought to suggest here, the trend towards increased data collection might also have concerning repercussions on the types of relationships that emerge between those involved in the process (both data collectors and informants), as well as on the
moral experience of those parties. For this reason, in future empirical inquiries, particular attention should be paid to the moral experience of humanitarian data collectors. After all, it is bound to be tied, in part, to the kind of relationships researchers are able to develop with host communities and research participants. Ultimately, answers to questions such as: Who conducts data collection activities?; What are these activities?; What types of relationship do they foster?; and, importantly, What is the moral experience of those who conduct them? will help us get a better grasp of what ethics resources researchers need to best ensure both the well-being of participants and the integrity of the scientific enterprise. In the meantime, caution is warranted, not least because, as Siriwardhana explains, “Populations in humanitarian settings present opportunities for unscrupulous researchers to conduct unethical and exploitative research, in the guise of humanitarian aid.” (68)
CHAPTER 3: FROM ‘HUMANITARIAN’ TO ‘POST-DISASTER’ RESEARCH – A LINKING STATEMENT

In the previous chapter, I sought to draw attention to the fact that there is limited knowledge of two important aspects of data collection in humanitarian settings: the moral experience of those collecting data and the ways they can relate to those whose data they are collecting (i.e. the types of relationships they can engage in). These aspects seem likely to be closely interrelated, but these linkages have yet to be investigated. In the next chapter (Chapter 4), I describe an attempt to start remedying part of the identified knowledge gap. Specifically, I present results from an exploratory study that focused on experiences of individuals—both established researchers and students—who conducted studies in post-disaster settings. The timeliness of the study I conducted was reaffirmed by Siriwardhana in a recent article pointing out that “experiences of researchers gained in specific contexts, especially while conducting research among vulnerable populations in cross-cultural settings, are rarely shared.” (68)

At this point, it is important to note that the angle of analysis that I take in Chapter 4 is different than the one I adopted in Chapter 2. In what follows, I bridge the two core manuscripts by explaining why I move away from talking about “humanitarian data collection” generally to talking about human-subject research conducted following a ‘natural’ disaster (e.g., earthquake, tsunami) specifically and why I do not use the term ‘moral experience’ in Chapter 4.

In Chapter 2, I suggested that greater attention should be paid to the “moral experience” of individuals involved in data collection. I defined moral experience using the work of Hunt and Carnevale (24). The empirical study I describe in Chapter 4 uses less specific terms than “moral experience.” Rather, in this component of my thesis I investigate the “experience of research ethics” and researchers’ “ethical experience.” Getting at a fuller understanding of the moral experience of post-disaster researchers would arguably have required more in-depth data collection than was feasible in the context of this study. Without more immersive and prolonged data collection, it is difficult to envisage being able to study “an individual’s sense that meaningful values are being enacted or impeded.” (24) In other words, “to draw out and examine diverse aspects of daily life that were understood as morally significant by the individuals
involved” (24) would have required a hermeneutical approach to data collection that was not fully attainable in the context of this thesis. Specifically, I had to balance the methods that would have been necessary to get at the nuanced and rich phenomenon described as moral experience against the desire to recruit a geographically dispersed sample, which required the use of approaches to data collection less suited to hermeneutical engagement (e.g., phone interviews).

Chapter 4 also has a narrower focus than Chapter 2 in regards to the type of setting under discussion. In Chapter 2, I set my discussion of data collection within the whole range of humanitarian contexts—disasters, conflicts, epidemics. In contrast, the next chapter focuses on the experience of post-disaster researchers, where disaster specifically refers to disasters associated with natural hazards.

I chose this set of humanitarian situations for my empirical inquiry for a number of reasons, including methodological concerns. While discussions of “humanitarian settings” can conjure up vivid images, there is in fact surprisingly little consensus on how to define humanitarianism (34). Disasters, contrarily to humanitarian crises, tend to be more easily definable. For instance, the International Disaster Database (http://www.emdat.be/) defines a disaster as an event that leads to at least one of the following four criteria: 1) 10 or more individuals are reported killed; 2) 100 or more people are reported as affected, 3) a declaration of a state of emergency is made; or 4) a call for international assistance is issued. The United Nations Office for Disaster Reduction’s definition is less specific, but nonetheless corresponds to instances that can easily be agreed on: a disaster is a “serious disruption of the functioning of a community or a society causing widespread human, material, economic or environmental losses which exceed the ability of the affected community or society to cope using its own resources.” (69)

A further, if controversial, categorisation of disasters can be made by drawing a distinction between disasters that are natural vs. manmade. The World Health Organization however notes that the use of the term “natural disaster” has been falling out of use:

In the 2005 Secretary-General Report “Relief to Development”, the expression “natural disasters” was purposely not used, as it conveys the mistaken assumption that disasters occurring as a result of natural hazards are wholly “natural”, and
therefore inevitable and outside human control. Instead, it is widely recognized that such disasters are the result of the way individuals and societies relate to threats originating from natural hazards. The nature and scale of threats inherent in hazards vary. The risks and potential for disasters associated with natural hazards are largely shaped by prevailing levels of vulnerability and measures taken to prevent, mitigate and prepare for disasters. Thus, disasters are, to a great extent, determined by human action, or lack thereof. The expression “disasters associated with natural hazards” should therefore be used, in line with the Hyogo Framework for Action adopted at the World Conference on Disaster Reduction held in January 2005 in Kobe (Hyogo, Japan). Natural Hazards comprise phenomena such as earthquakes; volcanic activity; landslides; tsunamis; tropical cyclones and other severe storms; tornadoes and high winds; river floods and coastal flooding; wildfires and associated haze; drought; sand/dust storm; infestations. (1)

Since ‘humanitarian research’ is broader in scope and includes study circumstances that can be vastly different—and possibly much more complex—than those brought about by a physical disaster, a sampling strategy focused on eliciting the diversity of experience would likely have resulted in a sample size that was less feasible in the context of my Master’s thesis. Given the diversity of causes and consequences of humanitarian crises, conducting empirical studies with ‘humanitarian researchers’ also gives rise to the challenge of setting inclusion and exclusion criteria that are logistically and analytically viable. I chose to address this challenge by focusing on a more constrained sample of humanitarian situations.

My interest to focus on research in post-disaster settings was also based on considerations that extended beyond sampling concerns. First, as I mention in Chapter 2, it has so far been harder for researchers to come across research ethics resources developed for settings affected by disasters. Whereas writing on the ethics of humanitarian research with refugees and in conflict settings goes back at least a decade, post-disaster research had received little attention until recently. Although this has begun to change (70), only a fraction of the individuals who can claim to have experience with the conduct of post-disaster research are likely to have had access to these resources recently developed. Consequently, I anticipated that post-disaster researchers, in
contrast to some other subsets of humanitarian researchers (e.g., researchers active in conflict areas) would offer no mainstream definition to questions about what they thought were the kind of expectations the research ethics apparatus and society had of them. As guidance on the ethics of post-disaster research becomes increasingly available, the discourse of post-disaster researchers might gradually change to echo these new resources—indeed, future empirical studies could evaluate how discourses evolve. But at the time I conducted the study, tailored ethics guidance for post-disaster researchers had not existed long enough to have been used by any of the respondents.

Second, it may also be that a wider spectrum of research projects and research experience is viable in post-disaster settings than in situations where conflict is ongoing. For example, as the study described in Chapter 4 reveals, post-disaster research seems to be particularly accessible to novice researchers. This might contrast with research in more violent humanitarian settings, where inexperience could be a dire liability—both for researchers and participants. With regards to making it possible for a wider spectrum of study topics, it is easy to imagine how navigating the political terrain to conduct research in conflict-affected settings might constrain the breadth of research topics deemed feasible. In addition, conducting research in conflict-affected areas might be like dancing through a field of landmines: not only does the support from outside states shift, but alliances between tribes and fighting parties are also ever changing—often following the money and the weapons (22). In the face of such instability, researchers might be less willing to engage in certain types of research that require long-term engagement. In other words, researchers in post-disaster settings might have more latitude to conduct diverse studies than those working in conflict-affected areas. This, in turn, made it possible for me to conduct a study that looked at the experience of researchers across a variety of fields under circumstances more clearly defined (e.g., post-disaster) than would have been implied by the term ‘humanitarian setting.’

In reality, whether or not post-disaster settings truly favour a larger breadth of investigations than conflict-affected settings remains to be empirically verified. But at the very least, I thought that the fact that post-disaster research might be less prone to the kind of politicisation that has been witnessed in humanitarian research in conflict-affected areas (62) would make it possible to
uncover challenges and ethical issues that would not otherwise have surfaced in brief interviews. In other words, I was concerned that researchers who were active in settings where violence and conflicts were prevalent might be more inclined to talk about those issues than those “aspects of moral experience that are played out in seemingly mundane and everyday settings.” (24) My intuition was that it would be easier to draw out those aspects from post-disaster researchers. At the same time, I anticipated that post-disaster settings could magnify the issues researchers might face daily in the conduct of research, making it easier to elicit reflections from the participants than if I had focused on a more traditional setting (e.g., tertiary care-based research). Again, the need for comparative studies to test out these intuitions is clear. For now, the data from the exploratory study I present in the next chapter illuminates the ethical experiences of researchers who conduct studies in post-disaster settings.
CHAPTER 4: POST-DISASTER RESEARCH AND ETHICS: AN EXPLORATORY STUDY OF RESEARCHERS’ EXPERIENCES

4.1 Introduction

A few days after the 2015 Nepalese earthquake, Thomas Kirsch from the Johns Hopkins Center for Refugee and Disaster Response published an opinion piece in the Washington Post stating that “We have too little data to know how to help countries like Nepal recover from natural disasters” (71). Kirsch argued that, to this day, there is a paucity of evidence to guide the response to public health emergencies. Kirsch is not alone in his belief that research conducted during humanitarian crises could lead to improvements in relief efforts and a better understanding of how these crises impact populations; an increasingly vocal movement of stakeholders is making a similar case (72). Shaikh and Musani even believe that “1% of all resources allocated for emergency preparedness and response must be earmarked for research capacity and strengthening for applied research in priority areas.” (73)

The concern to gather evidence on medical responses to disasters dates back at least to the 1988 Osaka Declaration on Disaster Medicine, which alluded to the importance of “formulat[ing] study programs for disaster relief medicine” (as reproduced in (63)). Major catastrophes since the turn of the millennium, such as the 2004 Indian Ocean Tsunami and Hurricane Katrina, have led to even more explicit encouragements. Most recently, the Sendai Framework for Disaster Risk Reduction 2015-2030, which was discussed during the sixty-ninth session of the General Assembly of the United Nations, promotes greater “scientific research on disaster risk patterns, causes and effect.”

As these calls for more research in disaster settings are heeded, it will be important to work towards addressing the disparity in attention that various disasters have received to date. In particular, results from literature reviews suggest that the lack of research on disasters is especially flagrant when they occur in low- and middle-income countries (74) and that locally-initiated projects are heavily underrepresented. Specifically, it has been found that while most disasters and deaths from disasters occur in low- and middle-income countries, only one percent
of published disaster research articles are about disasters in these countries (75). Of this one percent, four-fifths are authored by researchers from high-resource countries (75). This disparity aside, the growing interest in post-disaster research is clear. As a result, members of the bioethics community have begun to explore the implications of conducting post-disaster research (76) and how the heterogeneity of post-disaster research should relate to the way it is ethically appraised (44).

However, a perspective that is still mostly missing from the literature on the ethics of post-disaster research is that of researchers active in those settings. In fact, even beyond disasters, very few studies have been conducted with researchers to better understand their experiences (54,77–79). Of these studies, the ones focusing on the distinctive ethical features of so-called “sensitive research”⁶ (79,80) might be the most relevant for discussions of the ethics of post-disaster research. Some of the ethical features of post-disaster and sensitive research indeed tend to be shared, such as the heightened vulnerability of research subjects and researchers, the uncertain safety of the research team, and the challenges related to distinguishing practice from research.

Complementing these more generic explorations of researchers’ perspectives, a few first-person accounts of post-disaster researchers’ experience have promisingly begun to emerge over the last few years (61,81,82). These accounts include descriptions of some of the ethical challenges faced in the field. For example, Mukherji and colleagues discuss four categories of ethical concerns that arose in the course of their fieldwork: 1) the risk and benefit of participation for the disaster survivor, 2) the ability of the participant to make decisions, 3) the importance of informed consent, and 4) the oft-discussed helicopter researcher trap (81).⁷ For their part, Browne and Peek discuss specific situations (e.g., offering a balcony to a participant) that raised ethical concerns when they conducted research after the passage of Hurricane Katrina along the Gulf Coast of the United States of America in 2005 (61). These first-person accounts offer valuable

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⁶ Topics of so-called sensitive research might include: drug and alcohol abuse, homelessness, violence, sexual behaviours, or suicide.

⁷ The term ‘helicopter research’ refers to the type of research in which researchers fly into (literally or figuratively) a host community to collect data and immediately leave after without ever following up with the community to communicate research results, etc.
insights into the ethical experience of conducting post-disaster research—both in low- and middle-income countries and in high-income ones, and, as such, they are a welcome addition to the literature. However, there continues to be no third-party-initiated empirical work exploring post-disaster researchers’ perspectives.

Expanding the available data on the lived experience of post-disaster researchers, particularly in low-resource settings, could provide important guidance for efforts to ensure that the continued refinement of the research ethics system is responsive to the experiences of researchers. Such responsiveness is important not only for intrinsic reasons (23), but also for instrumental ones. It is easy to imagine that working in stressful and dangerous situations with limited targeted training (most researchers are not explicitly trained to conduct research in post-disaster settings) prior to departure and with little support affects one’s ethical experience. Considering the primary purpose of research ethics, i.e. the protection of participants, attention to and consideration for the experiences of post-disaster researchers is instrumentally important: it could directly influence the way they go about conducting research, which, in turn, might have implications for the wellbeing of research participants. For instance, an overly negative experience (e.g., emotional burnout) could decrease researchers’ ability and/or willingness to take the measures needed to ensure that the protection of participants’ data is not jeopardised.

In other research areas, steps have been taken towards making portions of the research ethics system more in line with a conceptualisation of ethicists as mediators who are available to support researchers when they struggle with ethical concerns. The creation of various research ethics consulting services is a clear indicator of this trend (83–87). But the accessibility of such services to post-disaster researchers remains limited. It cannot be ruled out that a possibility for why this is so is that, beyond the obvious logistical challenge, providing tailored ethics support to post-disaster researchers would require that those providing this service have a reasonably well-grounded understanding of researchers’ realities and needs.

With these considerations in mind, I conducted an empirical study to better understand the ethical experience of post-disaster researchers working in low-resource settings. Here, ‘ethical experience’ is understood as comprising the ethical issues faced by researchers, their perceptions
and responses to explicit and implicit expectations of research stakeholders (e.g., participants, funders, and society), and the ways their experiences of post-disaster research is shaped by the requirements of research ethics (e.g., ethics oversight requirements).

4.2 Methods

4.2.1 Study design

This exploratory study is part of a larger research programme on disaster research ethics.\textsuperscript{8} The study’s design was guided by interpretive description (88), by previous studies on the ethical experience of humanitarian healthcare workers (8,58,89), and by conceptual work on moral experience (24,60). Interpretive description is of greatest use when a research project involves description and interpretation of a phenomenon from the perspective of those who actively live it (90). As such, interpretive description seeks to contribute directly to our understanding of how people experience certain phenomena (90). The constructivist underpinning of interpretive description acknowledges the constructed and contextual nature of human phenomena, while also recognising that realities can be shared (90). A crucial departure from other qualitative description approaches is the commitment to transformative impact that is inherent in interpretive description (91).

The goal of the study was to illuminate the ethical experiences of researchers conducting research in post-disaster settings and the extent to which researchers find existing resources helpful for working through the moral uncertainty they may face (e.g., how to prevent therapeutic misconception). Overall, the study was inspired by the desire to help contribute to the empirical foundation needed for the development of research ethics resources responsive to the needs of post-disaster researchers. It is the commitment to bring about changes responsive to the phenomenon one observes in the course of data collection that is intrinsic to the method that originally drove the choice of interpretive description as a methodological framework for the study.

\textsuperscript{8} Canadian Institutes of Health Research, grant EOG 123679, \textit{Investigation of the ethics of disaster research in low resource settings}, 2012-2015, http://humanitarianhealthethics.net/.
The primary source of data for this project was interviews with researchers who had conducted studies in post-disaster situations. The interviews consisted of open-ended, semi-structured questions focusing on the respondents’ experiences conducting post-disaster research. Emphasis was put on the perceptions and practices of the researchers regarding the research ethics apparatus (e.g., adherence to the requirement for informed consent).

Interviews were conducted in French or English, at the preference of the participants, and they lasted between approximately 40 and 75 minutes. They were conducted in person, by phone, or over Voice over Internet Protocol (Skype). The interviews were audio-recorded and transcribed verbatim by professional transcriptionists. The transcripts were reviewed for accuracy by the main researcher by listening to the original audio file.

4.2.2 Study sample and recruitment
To be eligible to participate in this exploratory study, prospective respondents had to have conducted at least one study in a post-disaster setting that included data collection with human subjects. In addition, the study had to 1) have been based on a research question related to the natural disaster, 2) have been initiated within two years of an event that caused major and prolonged disruption, and 3) have included data collection in a country not related to the group of high-income economies (according to the World Bank classification, http://data.worldbank.org/about/country-and-lending-groups). A preliminary database of potential participants was made using the list of authors of research articles identified as part of a scoping review being conducted by the investigators of the Canadian Institutes of Health Research grant EOG 123679. To be included in this study as a “researcher,” potential participants did not need to have a terminal degree or hold an appointment as an independent investigator at a university; they only needed to have been involved in data collection activities (i.e. they could be a student, research assistant, principal investigator, etc.).

Recruitment emails were sent to prospective participants using the contact information provided in the publications that were collected in the scoping review. These emails included a brief introduction to the study as well as a copy of the consent form. A follow-up email was sent to
participants who had neither declined nor accepted the original invitation to participate in the study. Approximately 5% of the total number of individuals to whom an email was sent agreed to take part in this study. Factors explaining this low enrolment rate possibly include the fact that some email addresses might no longer be active, that English was not a language in which all prospective respondents would have been comfortable corresponding, and that many individuals might simply delete cold emails of this nature. In total, ten interviews were conducted with post-disaster researchers over a period of three months. Of these, only nine were used for the analysis, as the tenth interview was excluded due to a significant language barrier between the interviewer and interviewee.

Due to the low response rate, the sample was one of convenience, as opposed to a purposive sample as originally planned. However, consistent with the intended purposive sampling approach, the demographics and background of the self-selecting respondents were varied. Respondents’ backgrounds ranged from current graduate students (n=2) to a researcher with more than 30 years of experience. The fields of epidemiology, psychology, medicine, nursing, maternal health, and nutrition were represented. Only two respondents conducted their respective study in their country of origin. Although the recruitment strategy sought participants with experience with a wide range of natural hazards, self-selection resulted in all respondents but one having worked in earthquake- or tsunami-affected regions. The ninth respondent conducted a study after a major flood. None of the participants, when queried about the status of their projects, reported a study that was terminated prior to planned completion.

4.2.3 Analysis
Data analysis sought to identify themes and patterns across participants’ responses while accounting for variations between them (88,92). To do so, verbatim transcripts of the interviews were loaded in NVivo 10, where data units were coded using a constant comparative process. Coding was done using labels that answered questions such as “What is happening here?”, and memos were used to keep track of the analytical process. A progressive and mixed inductive-deductive analysis led to the refinement (renaming, collating) of the roughly 350 different nodes that were first used (including in vivo nodes) until they could be aggregated into a set of main...
categories. Patterns and linkages within and across the transcripts were sought and, through further analysis and aggregation, developed into themes that reflected ideas or concepts that communicated core aspects of the phenomenon of interest. The mixed inductive-deductive analytical approach that I used made it possible to group similar experiences together, while also accounting for differences between respondents. In this chapter, I present five themes that provide insight into the study’s sub-questions, as well as a sixth one that puts the other five in context.

In the results section below, quotes have been ‘cleaned’ for ease of reading. Ellipsis points without brackets indicate a pause, a hesitation, or an incomplete thought from a respondent. Ellipsis points surrounded by brackets indicate that a portion of the original transcript has been omitted from the quote.

4.2.4 Research ethics
The protocol was reviewed and approved by the Institutional Review Board of the Faculty of Medicine at McGill University. In terms of compensation, participants could elect for an anonymous $20 CAN donation to be made to the Canadian chapters of either Médecins sans Frontière or the Red Cross on their behalf.

4.3 Results
The first theme describes characteristics that are specific to disaster research and how these relate to the motivations of disaster researchers. The second theme reports key logistical, personal, and social challenges experienced by the respondents. Third, the issue of compensation to study participants, an important source of concern for all interviewees, is discussed in detail. Beliefs about and struggles related to compensations were closely tied to the fourth theme: researchers’ impressions of research ethics oversight. The fifth theme explores the challenge researchers face when trying to be reflective about their practices. The sixth theme relates to respondents’ perceptions of resources to guide post-disaster research.
4.3.1 Foregrounding post-disaster research and the post-disaster researcher identity

The first distinctive characteristic of post-disaster research described by respondents is the chaotic nature of its context. Respondents attributed this chaotic nature to different factors. Beyond the disaster itself, some suggested that it was associated with the complexity of the relief system, with its cluster system\(^9\) and innumerable institutions and organisations: “one of the things that I think is actually most complex about the post-disaster situation is understanding the administrative and procedural kind of setup of how services and funding are provided” (P205).

Due to the chaotic nature of post-disaster research, respondents found it difficult to maintain the same level of control over their studies compared to other contexts of research: “if I compare this study to my other studies, you’ve got less control over the situation, which is quite hard sometimes” (P201). This respondent noted that, “You just kind of have to go with the flow” (P201). This lack of control can be particularly salient for individuals who wish to combine research activities with a mission to provide care, as expressed by a respondent who had no input into where he would be sent within the host country: “They told us when we first got there, the first evening in [name of city], they called us and said: Voilà, this is where you’ll be stationed” (P202).

A second defining characteristic of research in post-disaster settings is that it is normally “bound” by the event itself, where the notion of being bound is linked both to the social value of the project and its temporality. As one respondent explained,

“Stuff that you do after a disaster is usually related to the disaster situation or to the conditions of the people who are affected. So you’re not going to do an evaluation of exercise in young children in a post-disaster situation because it’s not going to be related to it realistically in the context of their normal life. On the other hand, you might do an evaluation of (...) newborn health services in a disaster situation because, obviously, that has immediate relevance to provision of

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\(^9\) The cluster system is a system of coordination during humanitarian crises between humanitarian organisations, national and local authorities, as well as civil society. Each cluster represents one of the main sectors of humanitarian action (e.g., shelter, food security, logistics, education). Clusters are put in place when numerous actors within a given sector are active in a setting and national authorities cannot ensure full coordination themselves. The cluster system then provides a clear point of contact for each sector and designates accountable parties to ensure that appropriate assistance is provided.
services (…) as well as to what other interventions you might decide to implement.” (P204)

The third characteristic that is distinctive about disaster research is the small window of opportunity to conduct meaningful studies. Once this window of opportunity to complete data collection has passed, the value or even the feasibility of the study may become nil. In the words of one of the researchers, when you are in this line of work, “You don’t have weeks to sit around and mull” (P206). This sense of urgency was heightened by the perception of rampant competition between teams involved in data collection:

“You could see the competitiveness of the whole humanitarian industry and I’m afraid to say it is an industry—a multi-billion-dollar-a-year industry—where getting there first really matters, whether you’re in a non-governmental organisation, or U.N. organisation, or an academic institution. We were there first. We got the data out first. We got the first paper published.” (P206)

To describe post-disaster researchers as opportunistic would not reflect the empathy and commitment to social improvement that permeated the responses of the interviewees. At the same time, the trajectory of the respondents was often accidental, and their identity as post-disaster researchers transient. This was particularly clear when respondents contrasted their work in post-disaster settings with other work: “the anthropologist in me is always, like, a little bit appalled at the kind of quick and dirty methodologies that we have to use. But that’s the reality of the work” (P205).

The accidental trajectory of post-disaster researchers especially came to light in the responses of individuals who had been students at the time of conducting their study. In such cases, their decision to become involved in post-disaster research appeared to be largely driven by external factors, such as the timing of the event. A respondent reported that “when I started my Master’s I wasn’t even really doing disaster studies. And then after the [event], I switched” (P206). Another respondent described the decision to conduct a disaster study in the following manner:

“I think I just talked to some people, and someone came up with the idea to do… because I was interested in PTSD, to do research, well, in areas that were affected by
Two other students described similar experiences of being led into post-disaster by opportunities identified by their supervisors or mentors rather than by interest alone. Among more established researchers, it also did not appear that specialisation in post-disaster research was the norm. While some of the respondents had also conducted studies in humanitarian situations (e.g., prolonged conflicts), none had made a career out of post-disaster research. One respondent explained how specialisation would in fact be difficult from a career perspective: “I didn’t go on to study disaster. (…) It would have been really interesting. I’m still really interested in it. But I guess it’s harder to find funding usually, and you never know when there’s a disaster, of course” (P201).

If external factors played a determining role in the respondents’ pursuit of post-disaster research, personal motivations were not inconsequential. In this area, respondents demonstrated greater variability. Most of the researchers interviewed conducted studies in countries from which they did not originate. For the two respondents working in their own country, a nationalistic thread ran through their discourse: “You’re curious, and then even more as a national citizen, you want to help your people and help your society” (P203). Conversely, for many of the foreign researchers, scientific curiosity and thirst for knowledge seemed to combine with the exoticism of conducting studies abroad: “I was quite eager to go abroad just for the experience because I wanted to do some research abroad” (P201).

But personal motivations did not only boil down to nationalistic responses or the desire for foreign exposure. Empathy also played a key role. For one respondent, it seemed like there was no alternative but to conduct this type of study, for “It’s insane the opportunity of research, and the impact that we can do after” (P203). This sentiment was shared by others: “I just remember being just so saddened by the disaster and really wanting to do something. (…) I remember sitting in our apartment that morning and seeing the destruction of the [disaster] and just knowing that I was going to switch [my project]” (P208). In this latter case, witnessing the
impact of a natural hazard was so emotionally moving to the respondent that he felt compelled to change the nature of the empirical work he had planned for his graduate studies.

Despite being driven by ambitious goals, respondents had reasonable expectations regarding their potential contribution. Researchers who were not care providers generally saw their role as one that could help make the relief system more efficient and effective, while making it possible not to divert human resources away from the main relief activities. By conducting studies, respondents thought they might be freeing up care providers, who they suggested might otherwise have been tasked with doing data collection themselves. In the words of one respondent, research “gives me some tools to help provide practitioners how to do their jobs better and not overwhelm them with turning what is mostly a program intervention into a research project” (P206). But for this to work as intended, this respondent also acknowledged that a researcher’s presence needed to be justified before entering a study site: “if you choose to get on the ground then make sure you’ve got a good, clear, articulate reason that’s been vetted with some other parties, stakeholders; that yes, you’re needed, your time on the ground is valuable and you’re not going to be kind of sucking up too much oxygen from the rest of the enterprise” (P206).

4.3.2 “We had to compromise many times”: The multi-faceted challenges of post-disaster research

Respondents raised a number of concerns about the validity of the data they were able to collect in the midst of the chaos ensuing from a natural catastrophe. For one, applying strict inclusion and exclusion criteria can be challenging, even for non-medical research. Similarly, working with individuals who have little previous research experience poses an important challenge. For example, while working with interpreters can be challenging in any type of research, the respondents were particularly concerned about their ability to find competent translation services after a disaster. When asked about the most valuable lesson from his first study, a respondent suggested, “I would definitely make sure that I’ve got good interpreters and try to validate my questionnaires in the other language before I go there.” The same respondent explained that using untrained interpreters “just leaves you a little bit of question, like you just don’t know. You’re not really able to know how valid all the questions were” (P201). The chaos that ensues
from disasters makes it particularly difficult to identify trained and reliable collaborators on the ground.

Research fatigue\(^{10}\) is another challenge post-disaster researchers face. A respondent reported: “In some ways some disaster victims were really willing to share and to talk but [over time] became less willing (…) because I think there was just such a huge inundation of aid workers and foreigners that people had a more difficult time getting people to talk and share” (P208). Partly explaining this threat is the lack of coordination between various research teams, unanimously described by respondents as the norm in the settings in which they worked. “It was often very difficult to kind of unpack who was working where,” (P205) said one of the respondents, emphasising that navigating the aid response (for example, to ensure proper referral) was possibly more difficult than the actual recruitment of participants and collection of data.

Other logistical challenges were brought to the fore during interviews with participants. These ranged, broadly, from insufficient resources to be able to reach sample size (e.g., lack of research personnel, lack of funds to defray transportation costs) to issues of travel restrictions and lack of time to sort through all of the proper logistics of international travel (e.g., obtaining visa, making childcare arrangements). Needing to adjust their methodology and research questions to fit the available timeframe raised uncomfortable concerns about whether they might have to “cut corners” (P205). For one of the respondents, achieving the right balance between integration of research and aid was also a thorny issue: “I think that part of the ethical dilemma … how much research can a program absorb without feeling as though their program interests are subservient to the research questions” (P206).

At a more social level, the presence of media was also described as adding a layer of complexity, one with which many researchers may not be used to dealing, but which can make research on certain topics much more difficult. Although none of the respondents had to deal with vocal opposition to the conduct of their studies, a few also brought up this possibility as one that post-

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\(^{10}\) Research fatigue is described as “a demonstration of reluctance toward continuing engagement with an existing project, or a refusal to engage with any further research [attributed to] previous or continuing involvement with research” (116).
disaster researchers should be prepared to encounter: “you want to be sure that you can go forward with the work, even in the face of what might be possible opposition, hum, but that’s not to say you could just ignore those local concerns because sometimes there may be very real concerns” (P206).

At the more human level, respondents highlighted the lack of a supporting community of post-disaster researchers. Finding colleagues or collaborators can be a difficult endeavour. “I didn’t find anybody who did research like I did” (P207), suggested a student, echoing the concerns of other researchers struggling with the lack of interest in disaster-oriented studies among their academic colleagues. This lack of a strong network of post-disaster researchers was also evident when respondents spoke of their isolation in the field: “it was really just something that we just totally organized ourselves, and we just went” (P201). For researcher-students active in post-disaster settings, isolation was further illustrated when they described the absence of contact with their supervisors for extended periods of time.

The difficulty of combining roles and responsibilities was also discussed by respondents. For local researchers, getting away from regular responsibilities—for example at their home institutions—might be more difficult than for researchers travelling abroad, who were more disconnected from their other roles. However, respondents also described challenges combining roles and responsibilities when they played a role in the provision of clinical care in addition to conducting a study.

Although improving one’s adaptability might be key to improving one’s experience as a post-disaster researcher, the role that sympathy and empathy bears on the respondents’ experiences may be more nuanced. One challenge that was expressed by a couple of respondents was the difficulty of dealing with the disparity of resources or opportunities between themselves and their study participants. Summarising these concerns, a respondent spoke of the “sickly feeling for seeing the poverty of someone and taking their time and not addressing it” (P208). The same respondent further elaborated on this issue of disparity, explaining that “it’s such a stark inequality and it’s impossible to hide (...) I think any kind of guise that people try to I guess portray… any kind of similarity between the researcher and researched, it just… it breaks down
immediately as soon as you encounter the person. It’s just so hyper visible.” (P208) The challenge of dealing with profound disparity was closely related to the struggle around compensation to study participants.

4.3.3 “I’m a human being in front of another human being”: Wrestling with compensation to participants

In general, respondents did not appear to share a common sense of whether or not compensation to participants in post-disaster research should be encouraged. In some instances, respondents hinted at the possibility that an ill-planned provision of compensation could be an invitation to conflicts between community members or between researchers and participants.

In a telling moment, a respondent who was not providing any compensation to participants described his provision of transportation for a woman in labour, emphasising why this specific instance of ‘benefit’ to a participant had been acceptable. Criteria mentioned included the fact that the event was a crisis, that it was public, and that the request had come from community members, as opposed to from the participant directly.

“I didn’t consider this compensation or anything, but I mean immediately, I had transportation, and I transported her to a hospital, and I felt that there’s the ethical line that we aren’t able to provide compensation, and then there’s an immediate crisis that I, as a human being, can actually provide direct relief without compromising or hopefully without creating more of an ethical crisis.” (P205)

But the distinction between direct relief and compensation for participation is not always limpid in the field, and it might be difficult for researchers themselves to draw the line. For instance, one respondent spoke of the provision of food to hungry participants as a form of ‘compensation’ that could help build and sustain relationships.

There was among respondents an acute awareness that compensatory practices can come dangerously close to crossing a moral line: “the ethical question is how to make sure that you’re not, hum, you’re not creating what’s called a perverse incentive” (P206). Respondents explained
that they were alarmed by this potential for a ‘perverse incentive’ because of the likelihood that it would “screw up our data because people are poor, and they will do and say anything for money” (P201). In other words, questions were raised around the possibility for potential participants to be tempted to “perform” in order to be enrolled in a study. A few respondents thus hinted that researchers ought to exercise a degree of scepticism towards their study participants’ responses:

“I think in the sudden onset… well, any kind of situation where you’re dealing with people with quite serious needs, I think the question often arises… We look at this so it’s often called the social desirability bias, you know, somebody saying what do you want me to say here? Do you want me to describe terrible human rights violations because that’ll make you happy about, you know, you’re doing the right thing and focusing on these huge problems? Sure, I’ll tell you more about human rights violations or do you want me to be starving? I’ll be starving. You want me to, you know, have my rights violated? I’ll be that.” (P206)

However, issues of participant performance and social desirability can emerge even when no direct compensation is offered. Respondents with more open attitudes towards the use of compensation therefore suggested that compensating should thus come down to an issue of fairness (“Largely either these people were completely unemployed, because everything that they had had been destroyed, or they were dependent on fishing, or agricultural livelihoods, which I felt like I was taking them away from by doing the interview” (P208)) or pragmatism: “if you want to get good response rates you may have to pay to some degree, as it were, what the market demands” (P206).

A respondent reported that determining the right level and form of compensation requires investigative work: “you do have to do the research to say what’s an appropriate level of compensation that doesn’t over compensate.” (P206) One way to “do the research” to ascertain the correct amount of compensation is to find local collaborators, mentors, or other key informants: “they definitely helped me talk through the sort of change from gift giving to compensation and instructed me on how much to give and all of that stuff” (P208).
But even when this sort of investigative work is undertaken, the intricacies of compensating can remain:

“One thing I kind of didn’t mention, but it’s a huge… it really influenced whether or not I compensated people, was you can encounter gigantic class disparity. So in some contexts, for the poorer populations it was very appropriate to compensate people for the time that they spent. In other contexts, even if it was a higher peasant for example, wealthier, I mean… wealthy by no means, but wealthier, it would be very rude to compensate them with cash. It would be much more appropriate to give them a gift. If you still went through and offered them cash […] there can be pride in that.” (P208)

Likewise, one respondent brought up the prospect that participants could ask for very high compensations, for example in cases where the population from which one could recruit was relatively small or when the participants had almost become ‘professional’ research participants. The question, in that case, becomes: “do you not do the interviews because you think it’s somehow become a kind of an occupation [or] you just accept that as the going rate to get an interview?” (P206) For this respondent, the answer to the question remained unclear.

When participants felt that they ought not to compensate—or could not for lack of funds—but wished that they had been able to do so, distressing situations could be experienced: “it’s just like a personal thing. It has nothing to do with policy, I guess. But it feels a bit… I feel bad just leaving there again without leaving them anything or just couldn’t do a lot for them” (P201).

Respondents who felt this sort of moral unease for not providing compensation described mechanisms to alleviate their discomfort. Among these was being transparent from the start about what they could and could not offer to prospective participants. In two cases, respondents made sure that discussions with prospective participants emphasised that no compensation would be provided in exchange for participation. Another described a more drastic measure. Uncomfortable not providing compensation, he chose to offer compensation to study participants even though this action had not been included in the original protocol that was approved by his research ethics committee (REC). Aside from this researcher, the other respondents appear to
have followed what they thought were the rules—even if that resulted in experiencing a form of moral distress.

While the uncertainty around compensation was clearly a taxing one, respondents were strongly opposed to the idea of developing guidelines surrounding compensation for research participants in post-disasters settings: “The problem is the rigidity of that. I think it needs to be like: go to the culture, spend some time, see what the appropriate compensation would be and then adhere to that. So it really needs to be an open question” (P208). To some extent, this wariness of external control over compensatory practices was reflected in respondents’ overall approach to research ethics oversight.

4.3.4 “I just don’t say anything, you know?”: Forms of resistance to research ethics oversight

Concerns around whether all individuals affected by a disaster are necessarily vulnerable, and how this should impact the research ethics oversight of post-disaster research, were raised by respondents. One summarised his view by suggesting that “in this situation, even though, statutorily, they wouldn’t be one of the groups of highly vulnerable groups, it required the same level of concern because it was a post-disaster setting” (P205). Respondents highlighted how the vulnerability of the populations they sampled had sometimes emerged suddenly (“They were immediately landless and homeless” (P208)), as when business owners lost everything overnight.

In spite of the recognition of the acute situations in which many of their prospective participants found themselves, most of the respondents seemed ambivalent about the existing research ethics apparatus—or what they understand it to be—and several respondents either did not go through a research ethics committee at all or did so only in a post hoc fashion. Those who did go through a more conventional process said that they mostly “don’t think it was particularly helpful.” That is not to say that all the respondents who had interacted with the research ethics apparatus doubted the usefulness of oversight. A respondent indeed suggested that research should in fact come second to the honouring of the “imperatives for humanitarian response” and only when “the ethics of the research being conducted are also well established... well vetted and established” (P206).
When respondents who had not sought approval before the initiation of data collection were probed, they emphasised issues of feasibility and usefulness, rather than suggesting, for example, that they had determined that regulations did not require the study to go through research ethics review. The concern around feasibility was mostly about the turnaround time of research ethics committees. The unique urgency of requests from post-disaster researchers also appeared to play a key role in the decision whether or not to apply for a research ethics review. For one respondent, it boiled down to pragmatism: “I think it’s also a very practical decision in a way that we just didn’t have the time to do it because before that time, we didn’t even know whether [the idea] was going to succeed or not. So it’s only at the last moment that we found a place where we could actually go, so, you know, there wasn’t even time for ethical approval” (P201).

For respondents whose projects had either evolved following the initiation of an aid response or faced important constraints (e.g., in the time limits of a school degree), the issue of feasibility was particularly acute. In contrast, for researchers involved in studies that might have political implications, it might not have been so much the issue of feasibility as concerns about the usefulness of the review that led them to bypass the local research ethics system. A respondent explained that research ethics oversight might pose a particular challenge to researchers who seek to document human rights abuses or corruption. Speaking from experience, the respondent suggested that researchers and organisations working in such areas may struggle to find the right balance between compliance with the local research ethics apparatus and the concern that their projects could be politicised.

Some responses about why post-disaster researchers had not sought approval before the initiation of data collection also hinted at possible misconceptions about research ethics requirements. For instance, one respondent suggested that since his organisation did not receive any government funding, there was no requirement for them to submit protocols to ethics committees. Another respondent who was a student explained that his supervisor did not “make me go to that” on the basis that he was not receiving funding. A third respondent suggested that conducting research in a country different from that of his home institution meant that he could not submit to his home REC. A fourth respondent reported that he did not seek research ethics review because he was not affiliated with an academic institution and did not have a grant. The requirements of research
ethics review appeared particularly challenging for novice researchers, as reflected by a respondent reporting that with more experience he was now much more rigorous in submitting protocols to research ethics committees than he was for his first study, which had been in a post-disaster setting.

As mentioned in the previous section, respondents who had no choice but to go through an REC before leaving (because they were affiliated with a university, for instance), but who disagreed or felt uncomfortable with the recommendations made or the institutional policies found ways to circumvent them:

“we were largely encouraged not to compensate participants financially and to give them gifts [but] when I got to the field, I realised almost immediately that that was insufficient and seemed condescending and so I immediately tacked on a financial piece as well, even though (laughs) I wasn’t really meant to. I just did it.” (P208)

For respondents with a more clinical background, a similar sense of autonomy was asserted by invoking what is sometimes a fine line between clinical practice and research. One student explained that it had been suggested to him that initiating the collection of data as part of clinical care and framing it as a “pilot test” before seeking a review by an REC was acceptable.

An additional motivation to submit protocols to RECs was the implementation of editorial policies by academic journals. Two respondents described going through a post hoc process of ethics review. This was partly motivated by the desire to publish results in peer-reviewed publications. In one case, although the respondent had been able to present findings at international conferences, he needed to be able to tick the box indicating that it had been reviewed by a research ethics committee for the manuscript to go to press.

4.3.5 “You just fly in and out”: Struggling to reflect on perceived expectations

Most respondents appeared to share the impression that the expectations from various stakeholders (society at large, universities, etc.) were no different from those for other types of research. Yet seldom did the respondents find it easy to identify these expectations. At one extreme, when asked about them, a respondent simply stated, “Nothing, and from nobody”
(P203). When probed about more diffuse expectations, the same respondent’s response seemed slightly derisive: “What is expected from society from a disaster researcher? I think they’re not even aware of it” (P203). Another respondent echoed this sentiment by suggesting that expectations were mostly self-imposed, and that expectations from academia focused on mundane, uninspiring aspects such as report writing: “I think the worst (…) for me was just the expectations I had of myself. That my research would contribute to something and it didn’t, or I felt like it didn’t. Hum, otherwise, I mean I fulfilled the university’s expectations. I fulfilled the expectations of my funders. I wrote the reports” (P208).

Similarly, respondents frequently alluded to perceived expectations regarding the validity of their study by emphasising the ways through which it might have been jeopardised. In regard to the conduct of research, a respondent suggested that it is imperative for post-disaster research to be conducted in “as efficient a way as possible so that we don’t take up any more space than we need” (P206). The focus of the respondents’ framing of expectations as being primarily methodological in nature also carried over into discussions of the development of relationships with aid organisations. For example, one respondent described feeling that the aid organisations might have expectations that are too high regarding the capacity of small research-oriented organisations to “provide an evidence base for the work that they’re doing” (P205).

Respondents’ summaries of participants’ and gate-keepers’ expectations primarily revolved around the more tangible issue of compensation or direct aid. In some cases, those expectations were not only perceived, but very concretely articulated by host communities:

“we had one experience, like one orphanage just said ‘Unless you give us all this… you are not going to come and see the patients or you can’t come and treat them, or you can’t go near them…’ because most of them had lack of food. They had lack of services. So they said unless you give us all these aspects you can’t see the kids. You can’t treat them or anything and you can’t even collect data for your research… nothing.’” (P207)

The collected data also point to the fact that the respondents worried about being able to meet some of the requirements found in most research ethics guidelines, particularly getting informed
consent and ensuring privacy, even though they expressed such concern without pointing to specific research ethics guidelines or text. Rather, some of the responses focused on the difficulty of obtaining truly informed consents in disaster settings, suggesting some internalisation of the expectations set out by the research ethics system. The issue of informed consent and privacy aside, respondents volunteered few expectations that could easily be associated with ethics or that obviously carried moral weight for them.

4.3.6 Reflections on the conduct and oversight of future post-disaster research

Each respondent was asked about whether there were resources that, if developed or made available, would make it easier for researchers to carry out post-disaster research. In contrast to respondents from academic settings, respondents affiliated with larger organisations (e.g., international non-governmental organisations) expressed their impression that several resources were already available (mostly internally) and that it was also possible to learn from the experience of colleagues. Resources otherwise mentioned by respondents as highly desirable included 1) the mapping of the main stakeholders (e.g., aid organisations) in a study area, 2) the mapping of all ongoing research efforts in a study area, 3) an up-to-date list of funding opportunities for post-disaster research, 4) the contact information of competent local interpreters, 5) an accessible synthesis of existing data on a given topic, and 6) a platform to facilitate collaborations between researchers and NGOs.

If respondents differed with regards to the type of resources they thought would be useful, they were unanimously sceptical about the development of resources that would provide specific guidance for research practices such as compensation. On the other hand, one area in which respondents identified an area of need was for tailored ethics training specific to post-disaster research. Opinions on what should be covered in such training programs—and whether they should be mandatory—varied, but how to get proper informed consent in post-disaster settings—and models on how this should be done—were generally presented as desirable.

Although respondents were sceptical about the formalisation of research ethics guidance for post-disaster research, they themselves did not shy away from making normative statements about its conduct. One area of relative agreement seemed to be that disaster response teams
should be more involved in the conduct of research. For one of the respondents whose collection of data had been particularly ad hoc, it was clear that projects should be “A thousand times more structured. The study’s structure should already be in place before leaving, so that it is possible to know where each donated cent should be allocated” (P202). The same participant further emphasised that it would be important to keep things “simple,” given the ease with which data can be lost in the field—for example because of power outages or lack of storage space.

There was variation amongst the respondents with respect to the topics and methods perceived to be acceptable for post-disaster research. For example, one respondent was adamant that post-disaster research should be about improving the organisation of the relief response and that it should seek to address issues related to the cluster system specifically. Addressing those issues would in fact be “the only way we can really help” (P202). Others were more flexible in regard to the type of research that would be acceptable, while still setting limits that emphasised that post-disaster research should have social value. Finally, respondents were also cautious about further burdening participants, suggesting, “Each question has to sort of earn its place as opposed to, well, ‘We’ll put that in because there might be something there for us down the road’” (P206).

4.4 Discussion
This study sought to generate information on the experience of post-disaster researchers working in low-resource settings, with an emphasis on the ethical issues with which they struggled throughout the course of their work. The study shows that post-disaster researchers’ experience can vary significantly, from generally positive to mildly traumatising. Given the small sample size of this study, additional data must be collected before definitive conclusions can be made, but comparison between participants seems to suggest that factors that influenced the participants’ experience included previous familiarity with doing post-disaster research, seniority, and personal characteristics, such as the ability to cope with the disparities witnessed in the course of the research.

Not surprisingly, the study revealed clear examples of moral distress and moral residue amongst respondents (57,93), including significant concerns around issues of compensation. Although
unsurprising given the realities of working in post-disaster settings, the presence of moral
distress and moral residue is concerning considering the documented impacts they have on
wellbeing and job satisfaction in other domains, including healthcare provision (94). But
respondents were unanimously ambivalent about the benefits of developing stricter or
prescriptive guidelines for disaster research ethics and of increasing the stringency of research
ethics oversight mechanisms.

When initiating this study, I assumed that the experience of post-disaster research would be
shaped by the requirements of research ethics. For example, I expected that the increasing
expectations (in research ethics) that benefits should be shared with research participants post-
study (95) might weigh heavily on researchers. Similarly, I was uncertain whether post-disaster
researchers’ plans to conduct specific studies might be impeded by the sluggishness of the ethics
review process (77). The experiences of my respondents suggest, instead, that some post-disaster
studies may not be conducted in ways that are fully in line with expectations set out in many
research ethics guidelines and journal publication policies.

An example of a deviation from those expectations is the decision not to submit protocol
amendments to the overseeing REC when changes are made to the way the study is being
conducted. Another example (described by two respondents) was situations in which post hoc
ethics approval was sought as a means to enable researchers to publish research based on data
that had been collected as part of clinical practice. Guidance around post hoc approvals is at
times unclear, but, in general, post hoc approvals are strongly discouraged. Post hoc research
ethics approval is particularly problematic if the research ethics system is to be understood as
one that exists to encourage reflective consideration of ethical issues that emerge throughout the
lifecycle of a project. Not only does post hoc review represent a missed opportunity to engage in
ethical reflection as ethics issues emerge, but it may also encourage masking of ethical concerns
that surfaced during the course of a research study. If the motivation to obtain post hoc approval
is publication in a scholarly journal, will researchers choose to reveal issues that they think might
delay publication?
Factors that may explain why studies might not always be in line with expectations of research ethics include that some researchers might not expend much effort to investigate research ethics regulations in the first place, in particular when it comes to research ethics regulations in the countries where they will conduct research. This may be a result of misinformation or the lack of time to prepare adequately. Indeed, the study shows that the respondents had mostly embarked on post-disaster research because an opportunity had arisen and they felt motivated or even compelled—either for altruistic or personal motives—to put their skills to use in these contexts. Consequently, they may have lacked awareness of the research ethics apparatus. Second, some independent researchers have insufficient information about or access to alternatives to university-based RECs, or they are unable to afford the high fees of some of the private RECs. Based on this study’s sample, the same might be true for aid workers who start conducting research later in their careers: they may not be sufficiently knowledgeable about research ethics oversight to follow its conventions.

Third, lack of adequate mentorship might also play a significant role. As Shankar and Simmons explain, “The current [research ethics] system relies on knowledge diffusion to work effectively. This means that new or inexperienced researchers learn how to navigate the ethical oversight system from more experienced researchers.” (96) From this perspective, the limited guidance from supervisors that was received by the respondents who were students might have contributed to their becoming disconnected from, or even defiant towards, aspects of the research ethics system.

Fourth, practices such as not submitting protocol amendments for approval might be a form of resistance by which researchers sceptical of the value of the current research ethics system might regain some sense of autonomy over their project. Admittedly, this study provides limited data supporting this hypothesis; additional and more in-depth interviews with researchers are needed to confirm it.

These four factors are particularly concerning given the range of ethical concerns experienced by respondents. These ethical issues, many of which resemble issues encountered in other contexts of research, are rendered more complex and challenging by the socio-environmental
circumstances that emerge after a disaster. This observation was clearly reflected by the respondents when they discussed the issue of compensation. Although concerns related to compensation are at the fore of many discussions of the ethics of international research (97), this study supports O’Mathúna’s intuition that concerns related to compensation may be magnified in post-disaster settings (76).

I suspect that when researchers describe relying on ‘upfront transparency’ about what they will be able to offer to prospective participants in terms of compensation, they displace some responsibility onto the principle of informed consent. In other words, they assuage their moral unease by suggesting that participants’ consent to receive a given level of compensation legitimises the level offered. It is questionable, however, if this coping mechanism is truly in the interests of prospective research participants, considering the ongoing debate about the extent to which consent can be truly informed (98), particularly in the context of post-disaster research (49). This study therefore brings additional evidence that there is a clear power imbalance between those who can choose what to offer in terms of compensation and those on the receiving end. In light of this observation, the assertiveness with which respondents declared that having specific guidelines about compensation would have been unlikely to help them cope with the moral concern associated with compensation is concerning: it raises a clear is-ought problem that the research ethics community will have to work through.

Another example of ethical issues discussed by post-disaster researchers is the necessity of making compromises in the course of studies. Needless to say, post-disaster researchers are not alone in having to make compromises when conducting studies; all data collection involves a balance between what is ideal and what is feasible. Of interest is the fact that many of the respondents did not expressly acknowledge feeling a different type of pressure or higher expectations when conducting post-disaster research. Thus, it is not fully clear whether the moral stress stemming from being constrained by social, personal, and logistical challenges in post-disaster research is actually more salient and/or if it is linked to other factors than those that contribute to the moral angst experienced by researchers who work in less disrupted environments.
These ethical issues do not seem to be the only reason why post-disaster researchers lack a feeling of attachment to the notion of “post-disaster research”—a situation illustrated by the fact that only a few respondents reported actively keeping track of studies similar to their own. For the respondents in this study, the lack of engagement with post-disaster research as a field appears to be linked to the fact that taking part in post-disaster research resulted from an unplanned opportunity that presented itself—particularly in the course of an undergraduate or graduate degree. For researchers working in their home countries, post-disaster studies were seen as an opportunity to participate in relief efforts, even when their personal training or interests were not directly in line with their post-disaster project. For others, a deep-seated interest in working with vulnerable populations brought them to conduct studies with individuals affected by a disaster. Unfortunately, it is likely that the lack of long-term interest or involvement in post-disaster research makes it much harder to take full advantage of collective experiences to improve resources for post-disaster researchers. Respondents who had had access to resources about methods, for example, accessed them through the organisations with which they worked. Further investigation of the relationship between the lack of accessibility of certain resources (e.g., previous research protocols) and the absence of a stable community of post-disaster researchers would be beneficial.

A related aspect that should be of concern to both researchers and the research ethics community is the lack of real-time information about research that is undertaken in post-disaster settings, an issue alluded to by respondents when they lamented the lack of coordination across research teams. Redundancy of research for purposes other than validating results is wasteful and can be detrimental to host communities, which may experience a form of ‘assessment fatigue’ (99). Facilitating coordination and limiting redundancy should not be overly taxing. For example, an online registry of disaster-related research could be established for any given event. The appetite for this sort of resource seems clear. In the midst of the 2014-2015 outbreak of Ebola virus disease in West Africa, anthropologists from across the world were prompted to create a mailing list over which Ebola-related resources and requests for collaboration were broadly disseminated. This sort of initiative could go a long way towards addressing the fact that the students interviewed lamented the absence of a close-knit community of post-disaster researchers.
A more identifiable community of post-disaster researchers could also facilitate ongoing reflectivity about post-disaster research ethics. If the description of the medical sphere as an ‘art’ as well as a ‘science’ has become ever more entrenched in both the popular culture and the ways in which medical students are taught, exposure to a similar notion seems far more limited among aspiring researchers. For instance, beyond disciplines such as sociology and anthropology, researchers working with human subjects have been less inclined to put on paper their reflections about their praxis (78) compared to individuals directly involved in patient care. While memoirs of physicians describing the situations that kept them up at night throughout their careers form a whole genre, equivalent works by researchers are much harder to come across. Similarly, the discourse surrounding the research ethics apparatus might not be conducive to training researchers to engage in reflective praxis. After all, is the research ethics system not often presented to researchers in training as only a hoop they have to jump through before getting started on the real work?

In this sense, the concept of “moral space” is relevant to post-disaster research. Urban Walker describes moral spaces as those spaces “where a sound and shared process of deliberation and negotiation can go on” (100). Writing about the idea of moral spaces in the clinical context, Urban Walker describes the clinical ethicist as “neither a virtuoso of moral theory nor a moral virtuoso, but is one among other participants (...) recruited to the distinctly human and humanizing task of keeping moral community and traditions alive and meaningful” (100). She is a mediator, someone who actively participates in a deliberation with the primary goal of achieving a fruitful resolution. Extended to the research ethics apparatus as a whole, Urban Walker’s model implies that ethics oversight should be designed in such a way that it favours an “inclusive process of moral negotiation within the constraints” (100) of a given situation.

Although Urban Walker’s discussion focuses on justifying the need for moral spaces in tertiary care settings, her argument holds well for post-disaster research. Indeed, issues of balkanization (in this case, between humanitarian actors), poor institutional memory, fleeting contacts between individuals, and time constraints—common in tertiary care (100)—are likewise defining characteristics of post-disaster research.
Promisingly, promoting moral space furthermore addresses the main concern expressed by the interviewed researchers about the need for flexibility. One approach to nurturing moral space in the post-disaster context is real-time responsiveness (RTR), an approach that has been recently described (101). Real-time responsiveness is a guiding principle and practice that encourages ongoing and critical engagement between the various stakeholders of research, such as researchers themselves and research ethics committee members, throughout the lifecycle of a research project. Consequently, under a RTR paradigm, support to address post-disaster researchers’ moral concerns can be offered as they arise (101).

It is no secret that there is growing recognition that the research ethics apparatus by and large continues not to be structured in such a way that it can provide the resources needed to nurture moral spaces throughout the lifecycle of studies. A telling example of this is the fact that oversight of study projects by RECs is usually limited to a yearly renewal of the ethics approval. Obtaining this renewal does not normally require the sort of open deliberation about the ethical issues of a project that Urban Walker has in mind. In fact, as this study shows, the normal REC process can appear so stifling to researchers that they resist or circumvent it. Discussions of approaches such as real-time responsiveness are a direct and promising response to this growing realisation.

4.5 Study limitations
A number of limitations in this exploratory study are worth noting, including the modest sample size and self-selection of respondents (confirmed by the low response rate). Furthermore, the approach used to recruit participants (i.e. through identification of published authors) might introduce biases. For one, considering the time-to-publication of many studies, it is entirely possible that the context of disaster research may have shifted in that time in regards to expectations around ethics review. Considering that there is usually a lag of several months to a few years prior to publication following data collection, all of the participants talked about experiences that they had up to 9 years ago. Therefore, the zeitgeist and practices might have evolved since the studies discussed were conducted.
The recruitment method may also have constrained the range of reported experiences. For instance, a researcher whose planned post-disaster studies never came to be published would not have been identified as a potential respondent. In addition, the small sample size means that a limited number of all possible scenarios were represented. One can imagine, for example, that the factors that deter researchers from pursuing ethics review might include practical aspects related to non-functioning structures in countries experiencing disasters. However, this situation was not explicitly identified in the current study. Although identifying more individuals with more diverse experiences could have yielded additional insights for the study as a whole, the recruitment strategy seems to have not be conducive to doing so. However, in spite of this limitation, the fact that there does not seem to be established networks of post-disaster researchers made recruitment through identification of published authors the method I preferred to opt for.

Another constraining aspect of the recruitment method is the frequent lack of availability of contact information of co-authors. In practice, the corresponding author in multi-national teams tends to be a senior member based at an institution in the Global North. Hence, even if for recruitment purposes the role of the participant (e.g., principal investigator, data collector, etc.) in conducting research did not matter as long as the participant was present in the field during the research project, recruiting research team members who were not principal investigators proved challenging. Consequently, the breadth of “researcher” experience documented here is necessarily narrower than what is experienced by the full spectrum of individuals involved in post-disaster research.

Divergent views exist regarding who should wear the label of “researcher.” For instance, the Canadian Institutes of Health Research draw an important distinction between the terms “researchers” and “independent researchers”. Whereas the former is understood as anyone who carries out research activities, the latter implies possession of a formal academic or research appointment. In the context of this study, recruitment was opened to individuals who were

\[\text{I am grateful to the external examiner for bringing this point to my attention.}\]

\[\text{See the Glossary of Funding-Related terms prepared by the Canadian Institutes of Health Research:}\]

http://www.cihr-irsc.gc.ca/e/34190.html
involved in data collection activities that resulted in a publication in an academic journal, irrespective of academic appointments or perceived differences between types of data collection activities (“research” vs. quality improvement) and/or scientific review of the project prior to its initiation. In other words, the use of the term “researcher” reflects engagement in particular activities, rather than an implicit description of professional status.\textsuperscript{13} Evidently, this approach raises the issue of heterogeneity, particularly in terms of how the results might be more reflective of the interviewed trainees’ supervision than the actual state of research ethics in the post-disaster context. Students’ dual roles as trainees and individuals involved in data collection, along with the presence (or absence) of effective supervision might shape their experiences of ethics while conducting post-disaster research in a way that is substantially different from “independent researchers.” Future research involving larger samples might allow for a more refined analysis of the student vs. seasoned researchers distinction.

Another limitation relates to the conduct of data collection due to the geographic spread of respondents across the globe. As Deakin and Wakefield have suggested, more research is needed to understand how new information technologies might affect the process and outcome of data collection \textsuperscript{(102)}. In this study, disembodied interviews (using either Skype or telephones) were the primary method of data collection. Although disembodied interviews offer greater flexibility to respondents in terms of scheduling, they also make it much more difficult to ensure that respondents find themselves in a place that is free from distractions at the time of interview. In other words, “finding the ideal time and space to conduct the interview relies upon the interviewee choosing a suitable location” \textsuperscript{(102)}. Furthermore, in voice-only interviews, visual cues that can help build rapport, such as body language, are absent. The extent to which this is problematic is debated \textsuperscript{(102)}. For example, it has been suggested that online interviews might in fact be an effective medium to ask participants to reflect on sensitive or embarrassing experiences \textsuperscript{(103)}. In the case of this research project, frequent disconnects of the calls and the need to ask participants to repeat portions of their answers due to fluctuating quality of the internet or telephone connection seemed to make reliance on phone and Skype more a deterrent to candid discussions than an encouragement. Another observation was that the more ‘senior’

\textsuperscript{13} I am grateful to the external examiner for bringing this point to my attention.
researchers seemed more reluctant to share specific anecdotes, and they appeared to have a better sense of the ‘correct’ (or expected) responses they should provide. Perhaps face-to-face interviews would have enabled the creation of a more trusting rapport that would have promoted more candid responses.

Discussing the issue of perceived “expectations” was also a challenge. In a few cases, non-native speakers of English struggled to understand what the term represented, and additional explanation and examples needed to be provided. This may have led to less spontaneous answers. Given the overall difficulty of getting post-disaster researchers to talk about the expectations they feel society, participants, and the research ethics apparatus have of them, additional thought must be given to how to elicit this data more productively in future studies. Reassuringly, it was possible to elicit stories about both rewarding and less positive experiences, and some respondents openly disclosed that they may not always have fully followed research ethics conventions. This suggests that, in spite of the constraints such as self-selection bias and limitations related to participant recruitment, it was possible to access a broad spectrum of experiences.

4.6 Research agenda

This study represents a first step towards better understanding the ethical experiences of researchers who work in post-disaster, low-resource settings. Given the important limitations of this study, alternative approaches to recruitment should be explored in the future. Alternative study designs, such as the cross-sectional online survey used by Sullivan et al (104), seem to offer better recruitment rates among similar populations and in the pursuit of similar research topics. Future studies with larger samples would allow for comparison across different groups of post-disaster researchers (e.g., years of experience, location of home institution vs. location of study, students vs. independent researchers) and the themes raised in this exploratory study. For example, it would be helpful to identify if there is a sub-group of researchers that especially struggle with the issue of compensation. To achieve a larger, more diverse sample of individuals with more recent experiences in the field, modes of recruitment that do not solely rely on the published literature should be pursued.
Already, additional empirical studies in the area of post-disaster research ethics are underway. Indeed, a number of major funding agencies and programmes, including the Canadian Institutes of Health Research, the European COST program, and The Johns Hopkins University (105), are funding research programmes in the area. These empirical studies will shed additional light on the field of post-disaster research and include the perspective of research ethics committee members. Studies investigating the experience of researchers working in specific research domains (e.g., mental health) may add additional nuances to the more general study described here.

Pursuing studies investigating the phenomenology of being a researcher will provide valuable insight into researchers’ lived experiences—both in post-disaster settings specifically, and in other settings too. Too little is known about the experiences of researchers, and many questions remain about what it means to be a researcher. Self-reflective pieces, like those of Jafari et al (80), offer important glimpses into the issue, but further empirical work building on the study presented here would provide important additional insights.

Finally, one area in which data continues to be missing is whether harm and/or risk to research participants can be linked to the lack of responsiveness to researchers’ needs by the research ethics apparatus. The study data hint at the fact that some practices among post-disaster researchers, such as bypassing research ethics oversight and using unqualified translators, might increase the risks to participants—or, at least, might reduce the opportunities to assess risk adequately. Future research could evaluate the relationship between these phenomena. If links were established, this would provide a strong incentive to pay closer attention to the responsiveness of the research ethics apparatus to the needs and moral experience of post-disaster researchers.

4.7 Educational implications
The results of this exploratory study can help inform the development of training resources, such as pre-departure modules focusing on the more common ethical challenges post-disaster researchers face in the course of their work. In particular, training on how to obtain informed consent in post-disaster settings is a need clearly identified by researchers. The study also hints at
the importance of thinking through an educational model that would support young researchers interested in specialising in post-disaster research.

As regards the development of guidance on ethical concerns such as compensation, the study suggests that it is likely that efforts to systematise practices would meet with initial pushback from researchers. Two measures, however, can be taken immediately. First, post-disaster researchers can be encouraged to engage more systematically in discussions with individuals familiar with the research setting to determine locally sensitive practices when it comes to issues such as benefit sharing, community engagement, and compensation to study participants. Second, post-disaster researchers can be asked to be more systematic in documenting both the ethical issues they face and their attempts at resolving them. This need not be done only in published articles. For example, the creation of an open access database documenting the benefits or compensations offered to participants across studies would be a helpful step. These two measures would not require disproportionate amounts of resources on the part of researchers yet could go a long way towards improving transparency and fairness in post-disaster research.

More broadly, this study shows that there is a clear opportunity to engage in more open dialogue around what it means to be a post-disaster researcher, and what expectations various stakeholders—from funders to participants—can legitimately have of the post-disaster research enterprise. This conclusion is supported by the difficulty post-disaster researchers had in expressing the expectations they felt they had to live up to. In addition to fostering dialogue about the issue, the research oversight apparatus should encourage post-disaster researchers to reflect carefully about their perceived expectations before departing for the field, as those perceptions are likely to influence the way they will respond to the logistical, personal, and social challenges that await them.

4.8 Conclusion

Until recently, little was known empirically about post-disaster research as a field. But with the spreading conviction that post-disaster research is crucial to improve the effectiveness and efficiency of disaster responses, there has been an increased interest in mapping the field. However, until now, attention to the way post-disaster researchers experience ethics in the course
of their work has been lacking. Interviews with researchers who conducted post-disaster studies reveal that they face a number of logistical, personal, and social challenges, and that those challenges affect their overall ethical experience. Struggles around how best to compensate participants—if at all—and how to obtain informed consent are ethical issues post-disaster researchers grapple with. In addition, post-disaster researchers seem unclear which research ethics conventions should apply to their projects. This can be explained by a lack of accessibility of information on research ethics, but also by the reluctance of researchers to engage too closely with the research ethics system, often seen as a barrier rather than an enhancer of post-disaster research. No specific examples were brought up during interviews of harms to participants that could be attributed to an overly negative experience of post-disaster researchers, but additional data collection to explore this issue more specifically is needed.

Overall, it is clear that additional efforts could be undertaken to better prepare researchers for some of the defining challenges of post-disaster research. Unfortunately, the current setup of research ethics oversight is not designed to be responsive to the specific needs of post-disaster researchers. For training to be useful, the capacity to apprehend precisely what is involved in researchers’ work must be improved, for example by building on the data from this study and from the first-person accounts that are slowly emerging. In addition, the research ethics apparatus must evolve so as to be in a better position to provide moral spaces for researchers during their post-disaster fieldwork. This could be done by adopting the practice of real-time responsiveness (101).
CHAPTER 5: CONCLUSION

In a blog post published on February 26, 2015, the Chair of the Presidential Commission for the Study of Bioethical Issues, Amy Gutmann, stated that the recent large-scale outbreak of Ebola Virus Disease in West Africa was highlighting “major inadequacies in our ability to respond to global public health emergencies.” (106) Importantly, the Commission added that the outbreak was teaching us that “public health preparedness requires ethics preparedness.” (106)

I take ethics preparedness for humanitarian crises to imply that infrastructures are in place to respond to ethical concerns that arise in such settings—from issues of triage to that of relationships between researchers and participants. From the perspective of research ethics, this implies that research ethics committees and research ethics consultants would need to have a sufficiently thorough understanding of the context to advise and guide individuals embarking on data collection activities involving human subjects throughout the lifecycle of those activities. It also means that, prospectively, training would be available for those embarking on such activities.

With this thesis, I have sought to contribute to the movement towards ethics preparedness for humanitarian crises by calling for the research ethics community to be more responsive to the moral experience of post-disaster researchers and by suggesting that more attention be paid to the issue of relationships. The overall contribution of the thesis to ethics preparedness is, admittedly, more limited than I had originally hoped. For instance, the conduct of the study described in Chapter 4 was driven by the desire to provide the empirical foundation for the development of ethics guidelines that would be more responsive to the needs of post-disaster researchers. However, as noted in the bridging section (Chapter 3), I elected not to undertake an investigation of the nuanced and rich phenomenon described as moral experience in exchange for a more geographically dispersed sample, which implied using approaches to data collection less well suited to a full exploration of moral experience (e.g., phone interviews). Thus, in the end, what this study provides are modest insights that might help guide future efforts to develop resources and guidelines, but that will need to be further strengthened (as I described in the “Research agenda” section of Chapter 4). The exploratory nature of my study means that it also falls short of Siriwardhana’s wish for a “coherent post-research strategy to debrief the researcher.
experience, especially the ethical aspects of research implementation” (68). I hope, however, that the study helps nurture the kind of enthusiasm for the experience of researchers that will be needed if Siriwardhana’s vision of a systematised approach to debriefing is to be realized.

The other manuscript included in this thesis, found in the second chapter, also seeks to encourage reflection on and engagement with a topic that has been underexplored to date. In the chapter, I drew upon discussions by noted anthropologist Didier Fassin to suggest some patterns that we might expect to see emerge in the relationships between data collectors and host communities and participants in humanitarian settings. In my opinion, understanding this dynamic is essential (clinical ethics has looked at the issue of relationships for several decades (107)), but has been a neglected aspect of scholarship on the ethics of humanitarian research. My discussion in Chapter 2 was therefore an early attempt to draw attention to some issues in those relationships that might be troubling, such as the issue of display. It is important to reemphasise that my concern for relationships in the context of data collection in humanitarian settings does not only stem from its link with the moral experience of researchers. Yes, relationships are one factor that can influence their moral experience. But relationships have importance in their own right, for they have direct implications on the well-being of participants—the primary concern of research ethics.

Before definitive conclusions about relationships in humanitarian data collection can be drawn and recommendations made on this issue, more empirical work is needed. For instance, to identify best practices, it would be important to elicit local opinions on the type of relationship that ensues when emphasis is put on data collection in humanitarian contexts. Researchers conducting empirical work related to the relationships between data collectors and participants would benefit from engaging with the “perception movement” that appears to be emerging in the humanitarian world (108). The perception approach draws from field surveys with local stakeholders (e.g., religious and political authorities) to identify trends in perceptions about humanitarian action and, as such, can serve as a useful model for social scientists interested in the issue of relationships in humanitarian research.

Efforts should also ultimately be deployed to draw connections between the types of relationships that data collection in humanitarian settings foster and the moral experience of data
collectors. In hindsight, I realise that the design of my study was not fully conducive to bridging the theory gap between moral experience and relationships. Originally, I had anticipated that the researcher-participant relationship would feature much more prominently in the answers of my respondents than it did. Consequently, the study presented in Chapter 4 can only serve a modest role in suggesting that this is an area worth of further exploration, and that a more explicit emphasis at the level of study design might be needed to gather relevant data on the topic. As suggested throughout this thesis, we should not continue to remain blind to the moral experience of data collectors, especially in humanitarian settings. A careful exploration of how moral experience is linked to the types of relationships fostered by disaster research will help to identify mechanisms that can promote the well-being of both participants and data collectors.

To those who would object that the protection of data collectors has not traditionally been seen as falling within the purview of the research ethics mandate (109), I answer that this view is shortsighted. While empirical data on the issue is lacking, I have a deep-seated intuition that the moral experience of data collectors has direct implications on the way human subjects and their data are treated. This intuition seems to be shared by commentators such as Siriwardhana:

Contemporary research processes are complicated and extremely demanding due to the interplay of funding regulations, deliverables, ethical approval and career issues, to name a few, thus increasing the chances of unsound ethical practices and damaging researcher integrity. (68)

Furthermore, anecdotal first-person accounts, such as those previously mentioned by Browne and Peek, also hint at the connectedness of moral experience and relationships between researchers and participants involved in post-disaster research (61).

In taking interest in moral experience and relationships, this thesis has not paid close attention to the unintended consequences that data collection in humanitarian settings might bring about at a more meta-level. The lack of attention to structural issues has been a failure of much of bioethics scholarship—one that a few authors have rightly lamented (110–113). Thus, in these closing remarks, I wish to at least allude to two concerns that come to mind when thinking through the implications of the appetite for increased data collection in humanitarian settings.
First is the concept of depoliticisation, to which Fassin draws attention by showing how the language of humanitarianism tends to individualise broader and more structural issues (31). He suggests that whereas humanitarians should want to talk of inequality, domination, injustice, and violence, they instead often speak of exclusion, misfortune, and trauma—concepts that put emphasis on victims, rather than structural perpetrators. Of concern is that the depoliticising nature of the humanitarian vocabulary aligns well with the operationalization of many research programmes, which require large numbers of identifiable subjects. Conducting data collection on the number of individuals suffering from trauma is far more manageable than trying to understand the phenomenology of violence in any given context. This recasting of important concepts away from structural issues is convenient for those who need a large sample, for it makes it possible to extend the number of ‘victims’ considerably (31) and, with it, the number of potential research participants. There is thus a risk that data collectors in humanitarian settings do not question the categories that humanitarian actors presently tend to use but that are problematized by observers such as Fassin. One redeeming factor, however, is worth noting. It is raised by Anderson, who explains that for “policymakers as well as the general public, statistics are meaningless until they are reinscribed within a story, which however removed from the original context, nevertheless forms a discursive whole, the textual embodiment of disaster. In other words, for raw data to be put into practice and policy, it must be shaped into a narrative” (35). If we are to accept the view that all narratives are intrinsically political, then, provided Anderson’s suggestion is accurate, it might be that the depoliticisation Fassin speaks of occurs at the level of data collection, but not consistently throughout the whole lifecycle of a study (which necessarily includes some sort of dissemination of findings).

Anderson’s writing does, however, raise the specter of a phenomenon we might worry about. Anderson describes collectivisation as the process whereby social differences are levelled off for a brief period following a disaster (35). For Anderson, in the face of destruction caused by natural hazards, material and social barriers between various groups fall apart, even if only for a brief period. During this process of collectivisation, marginalised segments of the population make political gains that must be taken into account. It is unclear, however, what impact data collection might have on this process. Studies that essentialise individuals to their biological identity as participants—such as ones where the data collected are biological samples—might
not counter the process of collectivisation. In such studies, previous socio-economic status might matter little, and participants are not reminded of such status. But there are a number of ways by which data collection might have the opposite effect, quickly bringing back to the fore the social differences that were for a brief moment rendered invisible. For example, some studies tie in socio-economic considerations that might remind participants of the social order that existed before a disaster struck. In essence, it is important that data collectors active in humanitarian settings remain conscious of the potential implications their presence might have on the social dynamics of host communities. This is not a novel suggestion: researchers have been increasingly encouraged to do so over the past several years (114). But what Anderson shows is that there are social processes that might be unique to the post-disaster or humanitarian setting, and the impact researchers might have on these processes will deserve further attention.

Fortunately, there are good reasons to believe that interest to discuss research ethics in the context of humanitarian and post-disaster settings is on the rise. For example, since I began work on this thesis, a few important resources have been published on the ethics of research in humanitarian settings. In Chapter 2, I briefly mentioned R2HC’s framework (63). This framework offers “a set of relevant questions that researchers developing protocols, and those conducting ethical reviews of such protocols, might utilize.” (63) This approach is not unlike what the research ethics committee of Médecins sans Frontières has recently published (115). In the case of Médecins sans Frontières’ framework, the approach is described as putting greater emphasis on “a conversation about ethical issues, rather than impos[ing] quasi-legalistic rules.” (115) According to the authors,

- the use of questions should aid deliberation by anyone using the framework.
- Formulating the content of the framework in terms of questions very deliberately ‘frames’ the discussion about research ethics. It provides an open and flexible approach, rather than seeking to articulate a number of general statements. (115)

The move of the Médecins sans Frontières research ethics committee towards deliberation around ethical concerns related to research conducted in humanitarian settings reflects the spirit of real-time responsiveness (101), an approach I introduced in Chapter 4. Like real-time
responsiveness, the framework put forth by Médecins sans Frontières seeks to encourage ongoing reflection and communication. As its proponents explain:

we have come to understand that research ethics should be seen as an iterative evolving process. Our experience shows that ethics review can be a constructive learning process, and a time of reflection and critical debate. We think research ethics review should take this format. This, of course, differs from the ordinary perception of institutional ethics review as legalistic, formulaic and at times obstructive. (115)

This sort of thinking is very much in line with Urban Walker’s notion of moral space that I also briefly explored in Chapter 4 (100), and that I argue should be expanded beyond the tertiary clinical care setting all the way to humanitarian data collection. This sort of approach makes it clear that paying attention to the moral experience of researchers is crucial. How would it be possible to live up to the “special responsibility as ethicist to foster and nurture a collective and collaborative moral process” (100) without understanding the perspective of the parties involved?

At this point, data are lacking on the extent to which these new approaches will be welcomed by those collecting data in humanitarian settings. The authors of the Médecins sans Frontières framework recognise that it will be important that the impact of this new approach to appraising humanitarian research be assessed. Similarly, the utility of R2HC’s framework in shepherding the conduct of data collection activities in humanitarian settings remains to be established. It is, however, a noteworthy development, considering that “there is a dearth of practical resources to support researchers and RECs to tackle [ethical] concerns, with current bioethical models lacking the ability to address complex issues present in these settings.” (68) Thus, the extent to which both of these new frameworks are responsive to the needs of researchers and contribute positively to their moral experience should be expressly tracked. Doing so is particularly important considering the quote by Siriwardhana cited earlier about the potential implications of complicated contemporary processes on researchers’ integrity.

Related to this, I also note that it would be interesting to study whether post-disaster researchers’ discourse changes to echo the dissemination of new resources on the ethics of post-disaster
research, such as the R2HC and the Médecins sans Frontières framework. One of the findings of my study is that terms that have become familiar in clinical ethics and that are central to many discussions of the experience of caregivers, such as “moral distress” (57) and “moral residue” (93), did not spontaneously arise in the context of the interviews conducted with post-disaster researchers. This sort of observation suggests that post-disaster researchers are yet to internalise the language of bioethics. It will be interesting to see if their discourse changes with the dissemination of resources targeting them specifically. Empirical studies exploring this would help us get a better sense of the uptake of this kind of resources over time.

Finally, at a personal level, this project has also helped me mature as a researcher, helping me better identify comfort zones and refine areas of interest. Methodologically speaking, one of the main observations I take home is that the challenges of using phone interviews to exchange meaningfully with respondents about conceptual questions that require self-reflection are far greater than I had anticipated. Thus, in spite of recent enthusiasm for disembodied approaches to the collection of data (102), I remain doubtful that they are conducive to discussions of moral experience.

Finally, in addition to emphasising the importance for the research ethics community to preoccupy itself with understanding the experience and needs of post-disaster researchers, this thesis has also played an important role in cultivating my interest for the study of the phenomenon of being a researcher—an interest I noted in my introductory remarks. Truthfully, much remains to be done before the phenomenology of being a researcher is revealed. But this thesis has taught me valuable lessons about how I might go about exploring further this phenomenon in the future.
APPENDIX 1: INFORMED CONSENT FORM
INFORMED CONSENT FORM

Investigating researchers’ experience of ethics in post-disaster research

Title of study
Investigating researchers’ experience of ethics in post-disaster research

Student researcher
Renaud Boulanger, BA (Hons)
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Principal investigator
Matthew Hunt, PhD
(+1) 514-398-4400 ext. 00289
matthew.hunt@mcgill.ca

Institution
McGill University, Montréal, Canada

Research sponsor
Fonds de recherche du Québec - FRQS

Study purpose
The primary objective of this project is to better understand the experience of post-disaster researchers working in low-resource settings, with a specific emphasis on research ethics.

Procedures involved in the study
You will be interviewed about experiences related to ethics (that is, those experiences that you see as implicating your values) in the context of post-disaster research. The interviewer will encourage you to speak in detail about topics such as your experience as a researcher, your perspectives on available research ethics guidelines, the expectations you feel you faced in your work, and the resources that you found useful (e.g.: toolkits, training) or that you think would be useful for other researchers.

The interview will be conducted by phone, by Voice over Internet Protocol (VoIP, e.g.: Skype), or in person at a time convenient for you. It will last approximately one hour, probably between 45 and 90 minutes.

With your permission, the interview will be audio-recorded.

You may be asked if you are willing to participate in a follow up interview and/or to comment on our preliminary results before they are published. Should you agree to participate in a second interview, this follow-up interview can be expected to last approximately 30 minutes (half hour). It will also be audio-recorded if you agree.
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Potential harms, risks or discomforts
It is possible that it will be uncomfortable or upsetting to talk about ethically difficult situations you encountered while conducting research. The interviewer will not rush or pressure you. You do not need to speak of any situation that you find upsetting, and you do not need to disclose anything that you wish to keep private.

At any time, if you wish to take a break or end the interview, you will be welcome to do so.

Potential benefits
We hope that the findings from the study will contribute to the development of recommendations for disaster research ethics guidelines that are tailored and responsive to the realities of disaster research, and that take into consideration the perspectives of researchers working in such circumstances.

The study is part of a broader research program looking at the area of ethics and humanitarian health assistance; findings are expected to help advance our knowledge in this area. In particular, one of our aims is to produce a tool that will assist in clarifying, identifying, and addressing some of the ethical issues arising in disaster research. Such a tool, as well as other publications, presentations, or reports developed as a result of this study, may be of use to you and your colleagues and will be made available upon request.

Payment or reimbursement
You will not receive financial compensation for your participation in the interview. However, an anonymous CAN$20 donation to either the Canadian chapter of Médecins Sans Frontières or the International Committee of the Red Cross can be made on your behalf if you so wish (your personal information will not be used for the donation).

Confidentiality
Efforts will be made to ensure your confidentiality. Your name, that of any organizations or research ethics board you mention, researchers you name, or details pertaining to a specific protocol, will be anonymised in transcripts. Transcripts will only be reviewed by other members of the study team after names have been changed.

You are free to ask that any particular anecdote or experience not be included in the study data.

Digital copies of the audio recordings and of verbatim transcripts will be encrypted on the student’s laptop for the duration of the study, after which they will be deleted. The digital versions of the transcripts will be password-protected and encrypted. Informed consent forms, audio recordings (on encrypted USB flash drives), digital verbatim transcripts (on encrypted USB flash drives), and the code-key will be secured in separate locked filing cabinet within the principal investigator’s offices (Matthew Hunt).

Unless required by law or regulatory oversight, we will not share with anyone without your permission any personally identifying information about you or your organisation.

Participant’s initials: ____________________________
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or information that explicitly identifies specific researchers or research studies that you were involved with. For example, if information from this study is published or presented at academic meetings, your name, that of your organisation, and other identifying information will not be used.

Please note that in spite of the efforts outlined above, we cannot guarantee absolute confidentiality of your identity.

A risk to confidentiality comes from the recruitment strategy. Since it will be disclosed in the study findings that a number of potential participants were identified because they published their findings in scholarly journals, third parties could attempt to guess your identity. However, given that hundreds of authors meet the inclusion criteria of this search strategy, this threat to the confidentiality of your identity is very limited.

Participation
Your participation in the study is voluntary. If you decide to participate, you can decide to stop at any time, even after the signing of the consent form or part-way through the interview. If you decide to stop participating, there will be no consequences to you.

Information about study results
A summary of the findings of this project will be provided to you if you wish to receive them. Additional information will be available through publications, presentations, and reports that will be made available on the Humanitarian Health Care Ethics website (www.humanitarianhealthethics.net). You can opt to receive updates about dissemination initiatives if you so wish.

Information about participating as a study subject
If you have questions or require more information about the study itself, please contact the Principal Investigator, Dr. Matthew Hunt, by telephone at (+1) 514-398-4400 ext. 00289 or by email at matthew.hunt@mcgill.ca

This study has been reviewed by the McGill University Faculty of Medicine Institutional Review Board. The Institutional Review Board is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them.

If you have any question about your rights as a research participant that you do not feel can be answered by the Principal Investigator, please contact Ilde Lepore, Senior Ethics Administrator, by telephone at (+1) 514-398-8302 or by email at ilde.lepore@mcgill.ca

Participant’s initials: ____________________________

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INFORMED CONSENT FORM

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CONSENT
I have read the information presented in the information letter about a study being conducted by Mr. Renaud Boulanger under the supervision of Dr. Matthew Hunt of McGill University, Canada.

I have had the opportunity to ask questions about my involvement in this study, and to receive any additional details about the study I desired.

I agree to participate in this study, but I understand that I may withdraw from the study at any time, if I choose to do so.

I will not have waived any of my rights by signing this consent form.

I have been given a copy of this form.

1. I agree that the interview can be audio recorded. YES □ NO □

2. I would like to receive study-related results and updates. YES □ NO □
   by email:
   by regular mail:

3. At this point, I agree to be contacted for a short follow-up interview, but I know that I can always decline the request at a later time. YES □ NO □
   Please contact me at:

4. I wish for a CAN$20 donation to be made on my behalf. MSF □ ICRC □ NO □

5. Signature of participant:

6. Name of participant:

7. Date (DD/MMM/YYYY):

Person Obtaining Informed Consent:
My signature below signifies that I have explained the nature and purpose of the study and the risks involved to the study participant, and I have answered all questions to the best of my ability.

__________________________  ______________________________     __________________________
Name of Person Obtaining Informed Consent (Print)  Signature of Person Obtaining Informed Consent  Date (DD/MMM/YYYY)

Participant’s initials: __________________________

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