"ETHICS IS PART OF THAT AS WELL": HUMANITARIAN HEALTHCARE POLICY

"ETHICS IS PART OF THAT AS WELL": NAVIGATING THE LANDSCAPE OF HUMANITARIAN HEALTHCARE POLICY

A Thesis Submitted to the School of Graduate Studies in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy

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DOCTOR OF PHILOSOPHY (2017)

McMaster University

(Health Policy)

Hamilton, Ontario

TITLE: "ETHICS IS PART OF THAT AS WELL": NAVIGATING THE LANDSCAPE OF HUMANITARIAN HEALTHCARE POLICY

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NUMBER OF PAGES: x, 138

Lay Abstract

In the past decade, there has been an increase in the need for international humanitarian aid response. The realities of humanitarian aid work can differ from the expectations that inform policy, and this gap can lead to tensions for humanitarian healthcare workers. Qualitative methods were used to understand how policy in humanitarian healthcare organizations is conceptualized and used; the factors affecting its creation, implementation, and evaluation; and, the tensions arising from policy. A better understanding of how policy contributes to these tensions will help policy makers and humanitarian healthcare workers better prepare for some of the difficult situations they encounter in the course of their work, as well as ensure the best care for communities affected by humanitarian crises.

Abstract

In the past decade, there has been a rise in the need for global humanitarian assistance with natural disasters and complex emergencies increasing in severity. Ethical tensions are extensive in humanitarian situations, as aid workers find themselves in unfamiliar and unstable contexts making difficult decisions about right and wrong courses of action. These ethical tensions have repercussions for the people targeted for care and result in moral distress of aid workers. In this dissertation, I seek to highlight new ways of understanding how aid agency policies and agendas contribute to these ethical tensions and clarify their development, implementation, and evaluation in humanitarian settings. In order to understand the policy landscape and provide greater conceptual clarity, the first study in this dissertation identifies and explores the characteristics of policy. The analysis uncovers multiple interpretations of policy and related concepts such as code, guideline, and strategy. In the second study, through a series of semi-structured interviews with individuals working within international humanitarian healthcare organizations (organizational members), a qualitative descriptive analysis reveals how policy is developed, implemented, and evaluated. Findings demonstrate that the realities of humanitarian aid work can differ from the expectations that inform policy, with various social and political factors affecting the policy process. The third study unpacks the ethical tensions arising from policies through an interpretive descriptive approach, with three main themes identified: tensions related to institutional memory loss; clashing

departmental priorities; and social norms and expectations. Results from all three studies help establish a common policy language; identify influences shaping policy development, implementation, and evaluation; and, shed light on the ethical tensions shaped by policy. Together, these findings may be used to help identify new ways to improve policy processes and resolve or better anticipate some of the ethical tensions aid workers may encounter in the course of their work, thereby diminishing moral distress and ultimately benefiting communities that are targeted for care.

Acknowledgements

This thesis represents the culmination of a rich and rewarding experience as a graduate student. Without the financial support of McMaster University and the Canadian Institutes of Health Research, this dissertation would not have been possible.

I wish to offer my most profound gratitude to my supervisor, Dr. Lisa Schwartz, for believing in me and setting the bar to heights she knew I was capable of achieving. I will always revere her depth of knowledge and calming demeanor no matter how busy her day. She has been tremendously inspirational in influencing my academic achievements and I am esteemed to have worked under her supervision.

For their attentiveness and timely guidance of an ever-evolving work, I wish to thank Drs. Julia Abelson and Lydia Kapiriri for serving as my committee members. I am also deeply grateful to each interviewee who generously shared their time and whose stories contributed so meaningfully to my dissertation; truly, it was a great privilege. Thank you to my research team for their input and guidance on various aspects of my undertakings. I would like to extend my sincere appreciation to Dez Szeredi and Bonnie Walsh Szeredi for their support as friends and mentors - thank you for always keeping me afloat in rough seas. Many thanks to my colleagues and the CHEPA staff (most notably Lydia and Terry).

Words cannot express how thankful I am to my mother, whose support knows no boundaries. She helped me believe in myself at my most difficult times and taught me to never give up. I dedicate this thesis to my loving grandparents who followed my every achievement with exceptional pride.

To everyone who helped me along the way, directly or indirectly – thank you for extending your hand to me on this journey.

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Abbreviations

HHEAT Humanitarian Health Ethics Analysis Tool
HiREB Hamilton Integrated Research Ethics Board
ICRC International Committee of the Red Cross

ID Interpretive description

IHL International humanitarian law

INGO International non-governmental organization

JPO Joint Policy of Operations
MSF Médecins Sans Frontières
NGO Non-governmental organization

OM Organizational member

PPHO Principles and Policies of Humanitarian Operations SCHR Steering Committee for Humanitarian Response

UHT Ultra-high temperature

Declaration of Academic Achievement

This thesis is comprised of three original works (chapters 2-4) as well as an introduction and conclusion (chapters 1 and 5). I am the lead author of the three studies and I conceived each chapter in collaboration with my supervisor (Dr. Lisa Schwartz) and my current supervisory committee (Dr. Julia Abelson and Dr. Lydia Kapiriri). Additionally, I performed all data collection and analysis for each chapter. I drafted all chapters and have incorporated comments and suggested revisions from my supervisor and supervisory committee.

Chapter 1 – Introduction

This doctoral dissertation follows a "sandwich" thesis format. It consists of an introductory chapter, followed by a series of three qualitative studies to be submitted as articles for publication in scholarly journals, and a concluding chapter. This introductory chapter will begin with a reflection on the current humanitarian landscape and the complexities aid agency policies and agendas can create for humanitarian healthcare ethics. It will also briefly outline the research objectives and methods used for each of the qualitative studies.

In the past decade, the need for international aid response has expanded, as the scope and complexity of natural disasters and armed conflict has risen. Funding requests of inter-agencies increased by 600% between 2004-2014, while in the same amount of time the number of people targeted for assistance more than doubled (OCHA, 2015). In the past three years, the scope of forced displacement due to conflict and starvation has grown to crisis proportions (UNHCR, 2017). According to Leaning and Guha-Sapir (2013), approximately 217 million people are affected by natural disasters every year, while 300 million people globally are surrounded by an atmosphere of violence and insecurity. In 2013, protracted, conflict-driven emergencies (rather than natural disasters) tested the limits of the humanitarian community: the crisis in Syria and surrounding region left 2.5 million refugees and 6.8 million people inside Syria in need of assistance by the end of the year (OCHA, 2015). In difficult and

dangerous conflict zones, attacks on humanitarian action also occur, and there has been a disturbing trend of attacks targeting healthcare structures. Recently, the international medical humanitarian organization Doctors Without Borders/Médecins Sans Frontières (MSF) suffered the biggest loss of life for their organization in an airstrike when their hospital was attacked in late 2015 in Kunduz, Afghanistan (MSF, 2015). Since then, the aid organization has suffered from a deluge of further attacks: three people in an MSF-supported hospital were killed in southern Syria in February 2016 (MSF, 2016a), and in the latest incident, 11 people lost their lives in an airstrike on a Yemeni hospital in August 2016 (Dehghan, 2016). To date, almost 100 MSF or MSF-supported medical facilities have been bombed (MSF CRASH, 2017). In many settings, disaster and conflict go hand in hand and the acute and longer-term effects of these events on large populations constitute humanitarian crises (Leaning and Guha-Sapir, 2013).

Hugo Slim, a pioneer and leading authority in the field of humanitarian studies, describes the essence of the moral goal of humanitarian healthcare practice as "bringing care to those who need it most" (Slim, 2012). Slim further says it is about preservation of the person in dignity, and essential flourishing. The person is the end in humanitarian ethics, which means it does not have a great project of political progress; however, the humanitarian agenda can never completely leave the political arena. For example, a controversial element of humanitarian aid emerges where interventions are strategically used as part of foreign relations policy by governments to win hearts and minds of the populace

(Feldbaum et al., 2010; Yim at al., 2009). Others have highlighted another concern of the political dimension of humanitarianism: a tendency to "obscure its own politics as a consequence of its self-representation as a pure morality, embodied in the ethical act of responding to emergencies" (Nolan and Mikami, 2012, p. 62). Consequently, a paradox of humanitarianism is that humanitarian agencies might themselves inadvertently sustain conflict, with emergencies becoming a more or less permanent aspect of contemporary reality and prolonging suffering. For example, MSF withdrew from Rwandan refugee camps in Zaire because aid intended for refugees actually strengthened those responsible for perpetrating the genocide (Terry, 2002). Perhaps most importantly, ethical challenges arising in humanitarian response are a result of the political failures and economic injustices in our world and are an inherent part of this work, which presents the fundamental problem of how to act justly in an unjust world (Dwyer, 2003). Katy Long (2014), lecturer in International Development at the University of Edinburgh, reminds us that humanitarianism does not exist in a vacuum, and while aid is a moral act it is still one that has "both political causes and political consequences: it is a deliberate choice" (p. 4). Not surprisingly, the idea of an ethics of humanitarian healthcare practice is gaining momentum.

Ethics is identified in humanitarian literature as a field of study based on philosophical and critical reasoning (MSF, 2016b). This does not mean it is only reserved for academic philosophers: even the most common interactions

between people and day-to-day decisions in life necessarily involve ethics. Ethics may hold different meanings for different people. Some may think of ethics as aspirational, striving for higher values like respect for autonomy, dignity, and rights. Others may view ethics as codes or rules to dictate our behavior. Senior Lecturer in Ethics, Decision-Making & Evidence at Dublin City University, Ireland, Dr. Donal O'Mathuna states ethics "also includes the emotional and motivational aspects of decision-making" (O'Mathuna, 2016). In the context of humanitarianism, one aid organization portrays ethics as about "deliberating and discussing the issues that we face in a non-ideal world. Ethics in humanitarianism is about acknowledging the troubling issues that keep our fieldworkers awake at night, questioning whether they did the right thing" (MSF, 2016b). Regardless of how it is spun, it is likely to involve notions of right and wrong and the disconnect between how things ought to be and how things are. This disconnect plays out in humanitarian aid work, and is a primary source of tension, conflict, and distress (MSF, 2016).

Just as there are a variety of ways to understand ethics, "ethical challenge" can also be approached from different angles. It too involves notions of right and wrong, where perhaps the right thing to do is not clear, or perhaps it is clear but you cannot do anything about it, or you have to compromise and do the "least wrong" thing (Schwartz et al., 2010). Being forced into unethical choices in extreme situations can lead to moral distress. There may be circumstances in which all options are morally problematic: whatever is chosen,

something of moral significance will be lost. While those taking the decision may feel the choice is justified, it may not feel just because the situation itself is so unjust. And, unlike operational challenges that respond to technocratic fixes, ethical challenges can hide in the dark and might be unrecognized in everyday practice (Clarinval and Biller-Andorno, 2014); they may not be easily defined and discussed, and can poison team morale and functioning in the field (MSF, 2016b).

Numerous studies have indicated that guidance is needed to help practitioners act ethically in the context of humanitarian healthcare practice (Clarinval and Biller-Andorno, 2014; Elit et al., 2011; Hunt, 2009; Hunt, 2011; Schwartz et al., 2010; Sinding et al., 2010). Medical disruptions due to natural disaster and human action can impact practitioner responsibilities as questions regarding how to balance conflicting obligations take on a different meaning (House et al., 2015). As Clarinval and Biller-Andorno (2014) suggest, ethical issues may go undetected because managers overseeing humanitarian operations are unlikely to be trained in ethics. Particularly, short-term volunteers may be less equipped for working in low-resource settings, and more vulnerable to stress responses in difficult ethical situations (Ripp et al., 2012 as cited in Asgary and Junck, 2013). Between 15% and 33% of humanitarian workers cite depression, anxiety, exhaustion or post-traumatic stress disorder symptoms upon return (Cardozo and Salama, 2002; Ehrenreich, 2006; Eriksson et al., 2001; Holtz et al., 2002).

The role of policy in ethics and humanitarian aid

A study by Schwartz et al. (2010) found the source of ethical challenges experienced by humanitarian healthcare practitioners was described by four themes: resource scarcity; historical, political, social, and commercial structures; professional norms; and, aid agency policies and agendas. The findings of this interview-based study helped systematize an understanding of the ethical challenges associated with humanitarian healthcare work and pointed towards new ways of thinking about healthcare ethics in the context of humanitarian aid.

Because little empirical data has been collected about the policy dimensions of ethical issues (as opposed to greater discussion related to standard of care and resource allocation issues, for example), I have elected to focus on developing this theme arising from the study conducted by Schwartz et al. (2010). Respondents in this study reported challenges that arose due to what they perceived to be disparities between policies written at a distance, and the realities they faced providing patient care in trying circumstances. A recent paper published by Tipper (2016) of the Humanitarian Practice Network supports these findings, stating challenges can come from internal policies that seem out of touch with the daily reality of those working on the frontline of humanitarian response. Previous studies have not detailed the dynamics and processes by which policies of aid organizations shape ethical issues. Deepening our understanding of how policies of aid organizations shape or relate to ethical issues experienced by clinicians in the field could contribute to improved policy

development, implementation, and evaluation within humanitarian aid organizations. It is also our intention to ensure better ethical care and, where appropriate, help alleviate unnecessary moral suffering that is a consequence of ethical challenges in international disaster or conflict response. This work is a vital step toward indicating novel and distinct areas for discussion in humanitarian healthcare ethics, which is a new area of analysis examining the ethical dimensions of healthcare provision and public health activities during international responses to situations of humanitarian crisis (Hunt et al., 2014).

Research questions and objectives

The main purpose of my dissertation is to illuminate and understand how policies of humanitarian healthcare organizations shape ethical dilemmas experienced by clinicians in the field, and to explore what can be done to improve policy clarity and success in order to advance responses to ethical challenges or avoid them altogether where possible. The dissertation is guided by the following research questions: i) What is the relationship between scholarly notions of policy, and the ways in which it is used in aid organizations?; ii) In the context of humanitarian healthcare organizations, how do policies originate, how are they implemented, and how are they evaluated?; and, iii) What are the ethical tensions that arise from aid agency policies and agendas or that trigger the need for policy development? The dissertation is organized around three main objectives carried out through three qualitative studies:

- To promote clarification of the concept of policy as it is understood from a scholarly standpoint, and to reflect on how humanitarian healthcare organizations use and apply policy
- ii) To better understand how policies are socially and institutionally constructed, implemented, and evaluated in humanitarian healthcare organizations
- iii) To explore how policies and ethics inform each other in order to better understand where tensions arise and how policy in humanitarian healthcare organizations can be improved in this regard

Overview of the dissertation

This thesis has three interlinking but discrete components. The first component (Chapter 2) is theoretically driven and consists of an evolutionary concept analysis (Rodgers, 2000) intended to improve the conceptual clarity of policy in humanitarian healthcare organizations. Undertaking a concept analysis provides the foundation and clarity necessary to enhance the continuing cycle of concept development, and allows for reflection on how humanitarian aid agencies talk about policy and how it is used. Given the rather extensive history and theory of policy in contemporary political science, Chapter 2 is prefaced around this wider context, followed by a comprehensive review of the humanitarian literature to understand what constitutes policy. The search includes the primary literature (journal articles); secondary literature (books, chapters, textbooks); and, grey

literature, and was supplemented by "snowball" methods (scanning reference lists of key texts, key informant interviews, and being alert to serendipitous discovery). Analysis is conducted to identify the evolution, key attributes, related concepts, antecedents, examples, and consequences of humanitarian policy.

With this understanding, Chapter 3 explores how policy in the context of humanitarian healthcare organizations is socially constructed, implemented, and evaluated, drawing on evidence generated through interviews conducted with organizational members from five aid organizations who have agreed to support this avenue of study. We could not speak to every kind of humanitarian nongovernmental organization (NGO) and therefore for practical reasons, we focused on those that are delivering medical care. It is possible, however, some of the learnings could extend to other contexts. A qualitative descriptive approach (Sandelowski, 2000) is used to guide data collection and analysis. Semistructured, conversational-style interviews are conducted with individuals who have experience in – or are currently involved in – the development, implementation, or evaluation of policy related to humanitarian crises. Within the context of this research, we will take "humanitarian crisis" to mean those situations requiring rapid response in the form of medical care due to natural disasters and armed conflict in low- and middle-income countries. We acknowledge that the definition of a humanitarian crisis does not lend itself readily to an agreed upon definition; however, accepted understandings about what a humanitarian crisis is include the Humanitarian Coalition's definition: an

event or series of events that represents a critical threat to the health, safety, security or wellbeing of a community or other large group of people, usually over a wide area (Humanitarian Coalition, n.d.). Interviewees are identified through investigator contacts, organization regional mailing lists and groups, social media, and snowball sampling techniques to capture a diversity of experts from a variety of levels and units, including: directors; managers; program advisors; and, medical advisors. Sampling concludes when the research question and objective have reached saturation, while recognizing that study findings are intended to produce a better understanding of policy development, implementation, and evaluation in humanitarian healthcare organizations and are by no means exhaustive.

In the final component (Chapter 4), we seek to understand how ethics and policies inform each other. Drawing on the dataset from Chapter 3 and informed by the conceptual theory from Chapter 2, this chapter applies interpretive description (Thorne, 2008) to drill down and explore themes around the types of ethical situations encountered in humanitarian healthcare policy and practice, and how policy responds to these challenges or raises new ethical dimensions.

The concluding chapter brings together the three chapters into a coherent narrative by reflecting on the relevance of the findings, as well as how the dissertation makes a significant contribution to the field of health policy and humanitarian healthcare policy and practice. Given the increasingly complex nature of the humanitarian sector, the importance of this analysis for enhancing

policy development by considering the ethical dimensions of humanitarian healthcare practice is warranted. Doing so will help policy makers and field workers resolve or better anticipate some of the ethical tensions they may encounter in the course of their work, thereby diminishing moral distress and ultimately benefiting communities towards which care is directed.

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Chapter 2 – Conceptualizing policy in humanitarian healthcare organizations: Toward a common language

Abstract

There is a lot of ambiguity around defining policy, and the terms that are used to communicate the concept can be confusing. Policy is part of a family of similar concepts, with interpretations differing widely. Such flexibility has given rise to different terms that are used interchangeably with policy, including code, guideline, and strategy. This has important implications for how non-governmental organizations – such as humanitarian healthcare organizations – operationalize the concept, and a common language is necessary for understanding and applying it in various contexts. When the space for interpretation is large, this can lead to confusion, frustration, and ethical challenges for the doctors, nurses, and other healthcare workers who implement policies in the field.

In this theoretically driven paper, we offer a conceptual analysis of policy to promote clarification of the term, by exploring the humanitarian literature to understand what constitutes policy. We also seek to understand how the concept of policy is used and applied in humanitarian healthcare organizations. Thematic analysis was employed to help describe the major aspects of the concept.

Clarification of the concept will provide better understanding of how policies are understood and applied in humanitarian healthcare organizations, and help inform improved policy development in this regard. Uncovering the multiple meanings of policy will also shed light on the common ground that exists, in order

to resolve problems of misunderstanding, ambiguity, confusion, and moral distress in the field. This analysis may contribute to a better understanding of healthcare provider interactions with policies in other contexts, including in Canada.

Introduction

According to Rodgers (1989), concepts are integral to the development of knowledge. They encourage the organization of experience and facilitate communication among individuals. When the definition of a concept is not clear, the ability of the concept to assist in fundamental tasks is greatly impaired (Rodgers, 1989). Assert Tofthagen and Fagerstrøm (2010), "When a concept is defined, it to a greater degree becomes possible to describe the phenomenon and its characteristic manner in relation to the distinctive nature of the discipline" (p. 22). Within the genre of policy research, Ball (1993) states "defining 'policy' is difficult because frequently analysts fail to define conceptually what they mean by policy. The meaning of theory is taken for granted" (p.10).

Humanitarian healthcare response often occurs in relatively unstable and complex environments overwhelmed by poverty and increasingly where political conflict complicates security, communication, and resource availability. Although the work life of a healthcare professional is almost entirely governed by written procedures, in the humanitarian context there may or may not be countrywide or clinic specific policies for managing health issues, contributing to confusion,

misunderstanding, and moral distress. According to Hunt et al. (2012), NGOs are responsible for supporting their staff through the establishment of clear and defensible policies for a range of situations, including security protocols, lines of accountability, and decision-making and program mandates. Clarification of the concept of policy is an important first step to understanding how policies are developed and applied in the context of humanitarian aid organizations, and in helping inform improved policy development in this regard.

What constitutes policy, exactly? There is a lot of fuzziness around defining policy both conceptually among scholars as well as practically in the way NGOs operationalize the concept. In spite of numerous attempts at definition, the concept of policy continues to be open to a variety of ambiguous and individualized interpretations. Rather than clear definitions of policy, we find a mutating vocabulary of terms and concepts. Thus, the importance of advancing conceptual clarity about the term policy is recognized through the difficulty of gaining a common understanding of what is meant by policy. This is especially true of humanitarian NGOs such as emergency medical aid organizations who despite a strong sense of core values, often lack clear policy orientation. Policies may be more implicit than explicit, and rely on individuals' interpretation of them in decision-making settings (M. McHarg, personal communication, May 10, 2013). Moreover, knowledge of acceptable actions representative of an organization's values may develop over a long period of enculturation and

experience. This can make training on the use and interpretation of policies complex (M. McHarg, personal communication, May 10, 2013).

What is the family of ideas called policy? This question is relevant to humanitarianism because of the importance of policy as it relates to behavior. Humanitarianism, as Barnett and Veiss (2008) explain, is constantly being reshaped:

"The meaning of humanitarianism has expanded and increasingly includes what were once considered distinctive features of social action . . . a general ethic of moral caretaking and the reduction of suffering . . . it is an orienting feature of global social life that is used to justify, legitimate, and galvanize action." (p. 29)

The term is open to varied interpretations and, as such, implementation. This is due to the many underlying motivating factors of different humanitarian NGOs, which are based on a set of core values that form the foundation for the individual policies of an organization. Humanitarianism could also be extended to other fields such as: helping a friend with their homework, helping a neighbor with a task, being active in the community in improving it, or choosing a career that is heavily focused on helping individuals, organizations, governments or industries to help improve the overall wellbeing of society. This variation on the notion of humanitarianism offers a starting insight as to how and why policies regarding humanitarian aid vary so widely. Within the context of this research, we will take humanitarianism to mean the humanitarian desire to alleviate suffering of others

(Redfield, 2005). Despite a strong sense of core values, these organizations often lack clear policy orientation. Additionally, many humanitarian healthcare organizations not only provide medical care to patients but also organize healthcare for entire population groups, calling for greater attention to policy and organizational ethics. Moreover, knowledge of acceptable actions representative of an organization's values may develop over a long period of enculturation and experience, which makes training on the use and interpretation of policies complex. Routine, practical information alone is insufficient for humanitarian healthcare organizations seeking how-to guidance in relation to their actions, and for purposes of accountability.

Aim

The aim of this concept analysis is to promote clarification of the term 'policy' as it is understood in the field of humanitarian studies and in aid organizations by asking 'What is the relationship between scholarly notions of policy, and the ways in which policy is used in aid organizations?'

Methods

Rodgers' (2000) evolutionary concept analysis framework was used to guide this concept analysis and identify the features associated with policy. This method of inquiry follows a rigorous, inductive approach for the analysis of concepts and it was chosen for its applicability to concepts that continue to

evolve or change. Allowing for the likelihood of change rather than viewing concepts as being characterized by fixed sets of necessary conditions, this method of analysis is primarily a means of identification, not imposing any strict criteria on a concept, but having the ability to view what is common in its existing use. Given the many contexts that humanitarian aid organizations operate in, the evolutionary perspective recognizes that concepts change over time and across situations relative to associated contextual factors (Burchum, 2002), making Rodgers' evolutionary concept analysis an appropriate method to achieve our objective.

There are several primary activities involved in the evolutionary method of concept analysis. These are:

- Identify the concept of interest and associated expressions (including related and surrogate terms - terms used interchangeably to express the same or a similar idea)
- Identify and select an appropriate realm (setting and sample) for data collection
- 3) Collect data relevant to identify relevant aspects of the concept
 - a. the attributes of the concept (which constitute a real definition of the concept); and
 - the contextual basis of the concept antecedent (situation preceding an instance of the concept) and consequential (what happens after an instance of the policy has been set) occurrences

- 4) Analyze data regarding the above characteristics of the concept
- 5) Identify an exemplar of the concept, if appropriate
- 6) Identify implications, hypotheses for further development of the concept
 An in-depth literature search was conducted using key words, titles, or abstracts
 that included the concept of interest. The literature search traversed several
 domains to enable examination of variations and similarities of the concept of
 'policy'. Development, disaster, ethics, and, nursing literature was searched, and
 because undertaking an understanding of the notion of policy in humanitarian
 contexts by necessity draws on wider and varied contexts, traditional policy
 studies, critical legal studies, and philosophy literature was reviewed and
 incorporated into this paper as appropriate. The choice of texts included primary
 literature (journal articles); secondary literature (books, chapters, textbooks); and,
 grey literature (unpublished literature, dissertations, reports).

Electronic searches were conducted in Web of Science (Science Citation Index (SCI-EXPANDED), Social Sciences Citation Index (SSCI), Arts & Humanities Citation Index (A&HCI), Conference Proceedings Citation Index – Science (CPCI-S), Conference Proceedings Citation Index – Social Science & Humanities (CPCI-SSH)) and ProQuest (Applied Social Sciences Index and Abstracts (ASSIA), BioOne Abstracts & Indexes, British Humanities Index (BHI), Canadian Research Index, CBCA Reference & Current Events, Dissertations & Theses @ McMaster University, ebrary® e-books, ERIC, Linguistics and Language Behavior Abstracts (LLBA), MLA International Bibliography, PAIS

International, Periodicals Archive Online, Philosopher's Index, ProQuest
Dissertations & Theses: UK & Ireland, ProQuest Dissertations & Theses A&I,
ProQuest Nursing & Allied Health Source, ProQuest Political Science, PsycINFO,
Social Services Abstracts, Sociological Abstracts, Worldwide Political Science
Abstracts).

A research librarian was consulted prior to conducting the search. The search strategy included the following terms: policy, protocol, guideline, statement, non-governmental, humanitarian aid, scholarly, concept, and origin. The key words used to search the electronic databases and journals were selected for their potential to maximize inclusion of potentially relevant literature. The search strategy for Web of Science included policy or protocol or guideline or statement AND concept or origin AND non-governmental or humanitarian aid or scholarly. ProQuest included all(policy OR guideline OR statement OR protocol) AND all((origin OR concept)) AND all((non-governmental OR humanitarian aid)).

Given that formal protocol-driven search strategies of complex and heterogeneous evidence may fail to identify important evidence, the search strategy was supplemented in several ways: by "snowball" methods such as scanning reference lists of key texts, personal communication with experts in the field, and simply being alert to serendipitous discovery (Greenhalgh and Peacock, 2005). Select humanitarian-focused journals, identified from a literature review of humanitarian policy (The Research Council of Norway, 2011) were also searched. These included the International Journal of Voluntary and Non-profit

Organizations (VOLUNTAS), International Organization, Millennium, Public Health Ethics, Disasters, Humanity, and Prehospital and Disaster Medicine. The search terms used for VOLUNTAS, International Organization, Disasters, and Prehospital and Disaster Medicine were: policy or guideline or protocol and humanitarian aid or non-governmental; for Public Health Ethics: policy or guideline or protocol or standard and concept and humanitarian aid or non-governmental; and lastly, Millennium and Humanity: policy or guideline.

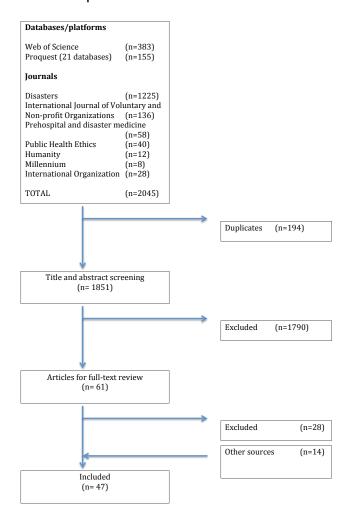
Seminal texts from the policy studies literature were purposively selected to enhance the analysis, which were identified through a reference list of core readings retrieved from 35 US and Canadian health policy course syllabi (Abelson et al, 2008).

We applied the following inclusion criteria. Texts were included in the sample if the text: (a) was published in English between 1980 and 2014, and (b) helped to clarify the concept of policy by delineating relevant aspects of the concept: evolution, attributes, related concepts, antecedents, examples, and consequences.

A process of inductive thematic analysis was used to identify major themes emerging from the literature. Phrases, themes, and passages from the literature were recorded onto coding sheets in Microsoft Excel and were analyzed relevant to each aspect of the concept until a coherent system of categories emerged. Word labels were then selected to provide clear descriptions of each

aspect of the concept. The resultant data set consisted of 47 documents. Figure 1 illustrates the results of the literature search:

Figure 1. Flowchart of literature review process



Findings

Policy has a rather extensive history in contemporary political science, dating back to at least the early 1950s (Hale, 1988). This wider or borrowed context – the "cannon of literature" – defines the foundations of policy. We will begin by presenting the findings around this wider context, followed by the

evolution, attributes, related concepts, antecedents, examples, and consequences of policy as found in the humanitarian literature.

The foundations of policy.

Policy is a basket of ideas; while its ambiguity and vagueness had been established prior to conducting this study, we found a range of uses and interpretations of the concept. Actual definitions of policy were provided in some cases. The Oxford English Dictionary defines policy as a "principle or course of action adopted or proposed as desirable, advantageous, or expedient" ("Policy", 2014). The cannon of policy literature also describes it as a course of action (Walt, 1994; Wilson, 1989); the rational attempt to attain objectives (Stone, 1989); and, instruments or tools to tackle issues of concern (Pal, 2001), manifesting themselves in a range of practices over time (Boychuk, 1999). One author suggests that the way to unpack policy is to see it as a social practice – a practice of power (Levinson et al., 2009). Official rules are generally referred to as laws (Stone, 1988), and law is the substance of policy and policy-making (Lax, 2011). According to Hale (1988), "it is a broader term even than law, involving the legal command to do something ... what really distinguishes between a policy and law is that a 'policy' is something that an administrative agency can conceive of immaculately ... policy in this sense is also better than law: more flexible, more comprehensive. 'Policy' can therefore serve as a catch-all..." (p. 436). One author referred to policy as both "intentions and actual results" (Milakovich and

Gordon, 1978, p. 355). Policy may be documented and codified, or it may not exist in writing (Levinson et al, 2009). The language of policy may also be vague; policy documents are often of a vague and consensual nature (Pahl as cited in Deas et al., 2013). This definition offered by Ball (1994) illustrates the complex nature of policy: "Policy is both text and action, words and deeds; it is what is enacted as well as what is intended. Policies are always incomplete insofar as they relate to or map on to the 'wild profusion' of local practice" (p. 10) (or, more accurately, a dynamic environment that is in constant flux with the local practice). A working definition developed by Abelson and Giacomini (2003) describes policy as "decisions, commitments, or goal-oriented behaviours that are undertaken systematically, and to some degree always collectively". Building on this definition, Prus (2003) adds:

Regardless of the formality with which policy is expressed, the comprehensiveness of its scope, its duration, or the precision with which policy is articulated, policy denotes a sense of direction to which people may attend in some collective fashion. Thus, even though group positions on particular matters need not be well articulated, highly sustained, or have a singular emphasis, some sense of policy or notions of direction, rules and procedures is essential if people are to coordinate activities, cooperate with one another, and develop meaningful routines of interchange. (p. 17)

To summarize this knowledge in a working definition, we will understand policy to be the following:

- 1. a collection of traits including adaptable, flexible, and broad; and
- 2. a label which supports the practice of these traits, and is applied to thoughts and principles which guide the overall activities of an organization
 Policies may exist implicitly or explicitly within a given context. Given what we know about policy, we will now apply it to the context of humanitarian policy development.

Evolution of policy in humanitarian aid organizations.

The Red Cross and Red Crescent Fundamental Humanitarian Principles – humanity, impartiality, neutrality, independence, voluntary service, unity, and universality – proclaimed in 1965, affect humanitarian vision and governance, and influence most humanitarian work around which humanitarian identity is created (ICRC, 1986). The Red Cross and Red Crescent Movement is an international humanitarian movement consisting of several organizations that are legally independent from each other and united by common principles (ICRC, n.d.). While humanitarian principles have their closest historical connection with an organization's policies and standards (Hunt, 2011), principles are abstract and distinct from practice, and there is a lack of clear understanding about what principles imply in terms of organizational policy and practice (Leader, 1998). Indeed, there are significant tensions and conflict among different actors about

how principles should be perceived and applied in practice (Dany, 2014). For example, Oxfam had written policies, but at one time lacked a statement of the fundamental principles (Buchanan-Smith, 2003). Neutrality is one of the fundamental humanitarian principles, but as Hilhorst (2005) noted, it is not

a panacea for humanitarian policy, providing clear directions for aid . . . there are indicators that humanitarian aid is losing credibility on the ground . . . a stronger policy of neutrality may help to overcome the problem, but this is not likely to happen in the short term. (p. 358)

What is clear is that NGOs are values-based organizations: dependent on values for their identity, their legitimacy and by extension, survival (Jakimow, 2010). According to Stoddard (2006), NGO humanitarian agencies are regarded as "autonomous—and increasingly influential—non-state actors in pursuit of their own value-driven agendas" (p. xi). Ford et al. (2010) suggest that institutional mandates are the starting point for any decision about how, where, and when to intervene in humanitarian contexts. It is policy that binds people to its mandates (Levinson et al., 2009), but ultimately mandates are self-endowed and therefore revisable (Ford, 2010). International bodies, such as the International Committee of the Red Cross (ICRC), have legally recognized mandates (most notably, the Geneva Conventions, which form the core of international humanitarian law (IHL) (Tong, 2004). Other NGOs use international legal instruments as points of reference for their activity, are not bound by IHL, and talk in terms of a mandate

(Tong, 2004). As Janssens (2005) cautions about the realities of the humanitarian sector,

the more complex the world gets the more dogmatically we have to cling to our principles, self-set policies and norms . . . When it gets misty outside we feel comfortable inside the box. (p. 182)

Attempts at new approaches often fail because innovation involves changing traditional methodologies and constructed realities supported by these institutions (Walkup, 1997). Instead of trying to control on-the-ground realities to fit the policies and capacities of organizations, organizations might try to better anticipate what is coming, and adjust to new challenges. Evolving is a matter of losing things and gaining new ones, but it does not necessarily imply giving up principles.

Attributes of policy in the humanitarian context.

Rodgers asserts, "a concept is considered to be an abstraction that is expressed in some form, either discursive or non-discursive. Through socialization and repeated public interaction, a concept becomes associated with a particular set of attributes that constitute the definition of the concept" (1994, p. 24). The four attributes defining policy identified in this analysis are dynamic, normative, flexible, and informal. Rodgers' approach to concept development follows a dispositional view of concepts, which addresses the "meaning of concepts in use, and by those who use them" (Baldwin, 1998). Given the many

different countries and situations in which humanitarian organizations operate, context matters

The literature review identified some consensus on how policy is defined in the humanitarian context. Four major themes emerged:

Dynamic. Analysis of the humanitarian literature resulted in the description of the concept of policy as a process (Black, 2003): an ongoing process, not a one or two-time event (Burkle et al., 2009). In addition, the humanitarian literature also described policy as an outcome (Christoplos, 1999). In some cases, policies need to adapt to changing environments. The humanitarian landscape is complex and it keeps changing, giving rise to new challenges (Tong, 2004), requiring policies to continually adapt and keep in line. As Buchanan-Smith (2003) expressed, "policy aims for continuity or change of a practice" (p. 3). And it is this continuity of purpose that gives rise to innovation (Boychuk, 1999). In some sense, innovation represents continuity with the past; it is based on the sum of long-term experience. Policies are meant to be revisited on a regular basis: even the language of mid-term policies, on which an annual plan is based (Heyse, 2013), reflects the temporary, fluid nature of policies in humanitarian organizations.

Normative. Similar to the general policy literature, the humanitarian literature also draws parallels between rules, law, and policy. As Forsythe (2005) explains, "law is not just a technical language and set of rules but is also codified policy preferences" (p. 172). Unofficial rules, such as moral rules and principles,

also act to coordinate behavior (Stone, 1988). And within the humanitarian system, there are two broad uses of humanitarian principles (Leader, 1998). The first is a set of moral principles that are expressed in great detail in IHL, and the second is intended to guide activities of humanitarian organizations. The latter are known as the principles of humanitarian action, such as neutrality and impartiality. The principles that guide humanitarian action belong to flexible social norms, and because they are contested through practices and discursive interventions, their meaning is able to change, which opens up a space for the politicization of humanitarian aid (Dany, 2014). When humanitarian aid organizations such as the ICRC help develop IHL, they participate in an international legislative process. The Statutes of the ICRC specify that the organization works for the faithful application of IHL in armed conflicts and to acknowledge any complaints based on alleged breaches of that law, as well as for the understanding and dissemination of knowledge of IHL (ICRC, 2013). As Slim (2003) suggests, humanitarian aid is necessarily political because "it is a political project in a political world" (p. 1).

Flexible. Rules cannot be perfectly tailored to individual circumstances and therefore stifle creative responses to new situations (Stone, 1988). This is relevant to humanitarian policy development because, as Christoplos (1999) emphasized, "complex emergencies do not lend themselves to clear, explicit rules and to set-piece enforcement procedures" (p.133). As one author

acknowledged, sometimes a contextual adaptation for the best possible outcome must be made (Tong, 2004).

Informal. Similar to the traditional policy studies literature, the humanitarian literature illustrates the informal nature of policy. This accounts for variability in the structure of policies, for example, Schneiker (2013) found that some humanitarian agencies included specific security strategies in their security policies, whereas in others it implicitly existed, but was not considered a strategy. In addition, ambiguities in technical guidance were observed, as for example in a Red Cross policy on the use of artificial milks, which refers to 'non-fresh' milk or milk products. In this case, it was not clear whether the policy provisions applied to ultra-high temperature (UHT) milk, "an ultra high temperature treated liquid, has a prolonged shelf life and is usually packaged in cartons" (Seal et al., 2001, p. 147). Explicit mention of UHT milk would help clarify if and when there is a role for this product in emergency situations, and if so, the safeguards that should be in place during its use to ensure safe artificial feeding of infants (Seal et al., 2001). Uncertainties of language could structure some of these issues. And this may be further complicated, for example, when policies written by someone whose mother tongue is not the one the policy is written in, or awkward translations, which may be an issue for international humanitarian aid organizations.

Related concepts.

A variety of related terms were used interchangeably to communicate the concept of policy, with no clear defining line. These included: 1) code; 2) guideline; and, 3) strategy. For example, codes—including the Code of Conduct for the International Red Cross Movement and International NGOs in Disaster Relief (i.e., the Code of Conduct or "Code")—are regarded as sets of tools (Hilhorst, 2005), as well as a collection of flexible policy guidelines (Christoplos, 1999). In this sense, the concept of code and policy share a similar feature in that both have been described as a tool. Code thus resembles policy in a significant way, yet could also be used effectively to refer to an assemblage of policy guidelines.

Several authors also referred to guidelines. For example, Black (1994) referred to a formal environmental policy, and in the following sentence stated "in no case was it clear that such guidelines were directed towards specific problems expected in refugee-affected areas..." (p. 111). Black (2003) also gave examples of two key sets of ethical guidelines for humanitarian intervention: the Joint Policy of Operations (JPO), and Principles and Policies of Humanitarian Operations (PPHO). Lastly, another author referred to infant feeding guidelines in complex political emergencies as "policy guidelines" (Leyenaar, 2004, p. 6).

Strategy was used interchangeably with policy. One author first made reference to a 'repatriation strategy', only later in the paper to refer to it as the 'repatriation policy' (Borton, 1996).

Antecedents.

Antecedents help clarify the contextual basis of policy. Phenomena or events preceding the concept of policy included 1) feedback and evaluation from the field; 2) epistemic communities; and, 3) the manner in which situations were framed and described. For example, conclusions and recommendations of regional workshops and training seminars, where lessons from the field were shared, were at times incorporated into standard agency policy and have also lead to constructive changes in policies (Noel, 1981). It has also been suggested that epistemic communities (defined as a network of professionals with shared sets of normative and principled beliefs, shared causal beliefs, a consensual knowledge base, and a common policy enterprise (Hass, 2007)), an entity familiar to policy studies, can be applied to humanitarian aid organizations to move them in the direction of coordination to adopt common policy positions (Bollettino, 2008). Lastly, the way in which an issue is framed carries importance in humanitarian communities as it does for so many policy areas. Paulmann (2013) observed that the manner in which situations were framed and described (for example, in terms of ethics or human rights) affected the kind of humanitarian policies that could be implemented at a particular time.

Examples of the varieties of policies from the humanitarian context.

How is policy used and applied in aid organizations? Policies are used to delineate acceptable behaviours and processes to enable responses for affected

populations and support aid workers. Examples of policies identified in the humanitarian literature included whistle-blower policies (which establish channels for staff to report corruption safely) and zero-tolerance policies (Maxwell et al., 2012). It was noted that their employment within aid agencies is in the early stages and effectiveness has not yet been evaluated. Moreover, staff in field offices is often unaware of their existence, while local partners and beneficiaries face barriers to accessing them. Interestingly, one author found that among German aid agencies, responses to security issues generally are treated as secret policy (Schneiker, 2013).

Policies of aid agencies prohibiting treatment of people with certain conditions under specific circumstances (also known as vertical programs), or policies requiring only people with specific diagnoses are treated, were found to create ethical dilemmas in humanitarian aid work (Schwartz et al., 2010). A desire to provide care came into conflict with the values that the policies were intended to promote and preserve. As Tronto (1993) suggests, caring will always give rise to moral dilemmas because the needs for care are limitless, and in meeting some needs, other needs inevitably go unmet.

Other examples included reactive policies – such as those offered by the Sphere strategy (which aims to improve the effectiveness and accountability of NGOs) – which would be designed to respond appropriately to an acute emergency, versus proactive, long-term policies, which focus on enabling populations to reach their maximum potential (McDougal and Beard, 2011). Many

NGO policy initiatives to improve quality and accountability – including the Sphere strategy – fall into the fundamental and emergent type of decision regimes (Lindquist as cited in Buchanan-Smith, 2003). In a fundamental decision, the core principles of the policy base are open to scrutiny, all policymakers and actors potentially affected by a significant change are involved in decision processes, and the type of information sought probes underlying assumptions and requires data of significant scope (Lindquist, 2001). The greatest demand for, and receptivity to, research comes in anticipation of fundamental policy decisions, or following sharp regime shifts. Policy based on research, knowledge, and experience is also known as evidence-informed policy (Slob and Staman, 2012). The preference is for the evidence to be scientific in nature, which suggests that the evidence was obtained in a proper, methodological way. Core beliefs and values may be relinquished when careful studies or compelling anecdotal evidence is presented (Lindquist, 2001). There is also the possibility of an emergent decision regime, which is characterized by a small number of actors but shares similarly with the fundamental decision regime a broad vision for the policy base (Lindquist, 2001).

A 2007 Edition of Doctors Without Borders/Médecins Sans Frontières (MSF) Volunteer's Handbook contained various peripheral policies such as stress management policy; accommodation policy in the field; transport policy; per diem policy; policy for break and holiday in the field; and, training policy.

Consequences.

Several consequences of policy, or situations that follow an instance of the concept, were identified in the humanitarian literature. These were: 1) failure or inadequate implementation; 2) irreproducibility; 3) psychological and motivational effects; and, 4) ethical issues.

With respect to failure or inadequate implementation, one author cited the weak institutionalization of policies as an underlying reason behind the failure of translating infant-feeding policies in emergencies into practice (Borrel et al., 2001). Young (1986) described the development of aid agency policy on the use of high nutrition biscuits in emergency relief. While the biscuits were freely available on demand to recognized operating agencies, with few exceptions, technical information and advice on the use of biscuits in the field was not readily available. Another author spoke of disconnect between policies developed at agency headquarters and their execution by field offices, which led to incomplete implementation (Maxwell et al., 2012). Further, because most personnel are hired on short-term contracts, their employment vulnerability discourages questioning of authoritative decisions or policies that they know will be problematic in implementation (Walkup, 1997).

In other cases, in practical terms, policy was irreproducible (Dudley, 1988). Reconstruction in the wake of the March 1987 earthquake in Ecuador led to the construction of several houses using sand stabilization. There was no sand available in the area so it had to be brought in; and, in addition to agencies not

wanting to fund transport, there were very few and poor tracks close to the houses, such that the sand would need to be carried by people or mules. Only a few of the most accessible houses with sand added to clay were built before the policy was abandoned. The opportunity for learning from these sorts of errors include changed practices and approaches in preparing for and responding to disasters, ultimately leading to saved lives and resources.

Emergency aid can also have other unintended effects. In the Republic of Croatia, shelter programmes for refugees and displaced persons relied on centrally prepared and pre-cooked meals. While this policy was cost-effective, it removed from the inhabitants control over one of the most basic and familiar processes of life, giving rise to serious psychological and motivational effects on refugees (Ellis and Barakat, 1996). Lastly, drawing on psycho-analytical theory, Erica Burman (as cited in Slim, 1994) argued that western concepts of childhood (which are often implicit in much emergency policy and practice) often stand at odds with the reality of children's lives in other societies. As such, western fantasies about an ideal childhood state act, albeit unintentionally, to separate children from their communities.

Schwartz and colleagues (2010), who have been pioneering empirical research on humanitarian ethics, found that humanitarian healthcare practitioners described aid agency policies and agendas as origins of ethical challenges in the field. Another author found that there was confusion, frustration, and sometimes

tension between sections in the field as a result of lack of clear, common policies for national staff (Mommsen, 2005).

Discussion

The results of this analysis provide a foundation for gathering new data and support the need for the descriptive and interpretive analyses: they promote and give direction to additional inquiry, and provide the foundation and clarity necessary to enhance the continuing evolution of the development of the concept of policy. Literature analysis of policy led us to a variety of different meanings. Many of the conceptual features of the broader, scholarly notions of policy are present in this analysis. For example, scholarly notions of policy describe it as a principle; similarly, policies of humanitarian aid organizations share a connection to principles. In both cases, the language of policy may be vague, and it is a very dynamic concept.

Related concepts such as 'guideline', 'strategy', and 'code' are frequently used loosely, even interchangeably, in the humanitarian literature; however, guideline and strategy refer more appropriately to how policy is implemented. The boundaries between these concepts may be unclear because it has been suggested that policy implementation is an activity that is not separable from policy formulation; rather, policy is made in the implementation stage (Stephenson, 1985). While they may compliment each other, the concepts that are used for the understanding of policy can be confusing, undermining the

effectiveness of the various ways of characterizing unique aspects of policy. Moreover, they can lead to confusion, frustration, and ethical challenges for the doctors, nurses, and other healthcare workers who implement policies in the field. The concept of policy is hard to define, which makes its use problematic. There are many different political and cultural origins and typologies of aid organizations (Tong, 2004), but a common language would be helpful for trying to understand policy in its context and thus make it operational.

While there are parallels in law and traditional policy studies of the family of concepts that get used as policy in aid organizations, NGOs do not have legally recognized mandates and subsequently the lines between these concepts are muddied. While humanitarian work follows international guidelines offered through Sphere, the Code of Conduct, and the Core Humanitarian Standard (CHS Alliance, 2017), statements that are meant to span organizations and be of general use can be problematic. The language in which guidance is formulated can have a significant bearing on how the user views it (Hurwitz, 1995). For example, while signatory includes a commitment to adhere to humanitarian principles, the Code of Conduct does not provide clear, proactive regulation with respect to the provision of humanitarian aid (Hilhorst, 2005). It is not regulatory because of its cautious language (e.g., 'we shall endeavor'), a reminder that humanitarians have limited controls over the humanitarian space and basically depend on other participants. This language makes such documents comprehensive and appropriate, but less useful for aid organizations seeking

guidance in relation to their actions and for purposes of accountability (Hilhorst 2005): there should be no platitudes when there are moral things at stake.

Consequently, humanitarian principles can become easily sidelined, despite the best intentions of the individuals and organizations that cherish and support them (Thompson, 2015). While policies may be based on experience, principles, values, and IHL, this may not be appropriately expressed, which raises difficult challenges for principled action at the operational and policy levels. For example, as Calain (2012) highlights,

... a moral principle common to medical humanitarian organizations appears to be their explicit or implicit commitment to universal distributive justice. This leaves it open for individual organizations to rely on additional and distinct moral principles, notably to ground the allocation of their resources. (p. 63)

Moreover, that humanitarian principles can have different meanings for different actors because they belong to flexible social norms makes operationalization of the principles in policies and practice all the more difficult. The Steering Committee for Humanitarian Response (SCHR) (an alliance of seven NGO networks and the Red Cross Movement), conducted work to determine if it was objectively possible to measure the principle of impartiality. They chose this principle because it is core to the humanitarian endeavor. It was observed that when there is a policy framework in place, the chances were that strategic

decision and operational decision-making would more systematically examine the question of impartiality than it would otherwise (Halff, 2015).

Antecedents of policy were factors related to situations in the field, and value-related factors. Consequences of policy in the humanitarian context suggested that policy was not always associated with a favorable outcome.

Therefore, understanding its antecedents and consequences could lead to higher promotion of the importance and application of policy in humanitarian situations.

It is important to note here the purpose and parties affected by certain policies. For example, MSF Volunteer's Handbook, loaded with routine information, addresses most of the major, practical issues or obstacles that are likely to arise in a mission, but it is less useful in supplying on-the-ground guidance vis-à-vis policies. It is insufficient for those seeking how-to guidance in relation to their actions, and for purposes of accountability. These human resources policies are directed toward volunteers, while others are intended to guide clinical practice, field operations, and so on.

The humanitarian community has had an inherent weakness in promoting humanitarian action into a collaborative endeavor to develop policy (Burkle et al., 2009). Saunders (2004) also notes that there are limited connections between field, research and policy units. In meeting rooms, a reality is created which is not necessarily reflected on the ground. The individuals who create policies are substantially removed from the context of the activities referenced by particular policies, yet this process ought to include everyone from management to program

staff and the end users of the policies. A potentially useful mechanism is the Humanitarian Action Summit. As an academically-based format, it is one initiative focused on areas in which solutions to problems in management, practice, and policy have been slow, non-existent, or poorly defined (Burkle et al., 2009). Further, the mission of the Humanitarian Encyclopedia – a new initiative led by Professor Doris Schopper of the Geneva Centre for Education and Research in Humanitarian Action (CERAH) – aims to understand commonalities and differences between concepts used in the humanitarian sector so that language of humanitarian actors can be translatable across organizations (CERAH, 2017).

Limitations

This study has several limitations. There are no firm rules in concept analysis, and it is not a concrete tool for writing a well-formed definition.

Considering the philosophical basis of the evolutionary approach to analysis, the results do not provide a definitive answer to the question of what policy is. Policy relies on context, and it is a multidimensional concept.

Conclusions

This study attempts to bring perspective and better understanding of humanitarian healthcare provider interactions with policies, by highlighting the relationship between scholarly notions of policy and the ways in which policy is used in humanitarian aid organizations. The results of this analysis indicate that

there is still a need to better understand policy in a way that could help inform how aid organizations are using this concept. Such an understanding would enable improved policy development in this regard, and the identification and dissemination of best practice of policy development and application that is crucial in a sector as complex as the humanitarian sector.

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Chapter 3 – "We learn as we walk": Policy development, implementation, and evaluation in humanitarian healthcare organizations

Abstract

Healthcare professionals working in humanitarian contexts such as conflict and natural disasters are at the forefront of some of the worst scenes imaginable, and can feel unprepared to respond effectively. Humanitarian healthcare workers face a stressful environment that can have a significant impact on their emotional and mental health. As a consequence, humanitarian healthcare organizations are responsible for supporting their workers through the establishment of clear policies for a range of different situations. Policies are intended to be wide reaching, and beyond supporting healthcare worker wellbeing to mitigate moral distress, they also aim to improve care to patients and increase efficiency. This study provides evidence to inform policy development, implementation, and evaluation, generated through 14 semi-structured interviews conducted with organizational members in diverse roles from international humanitarian healthcare organizations. The findings from this research have some important implications for the way such organizations conceptualize and contextualize policy to provide assistance to people affected by humanitarian crises. Informed by both normative and practical considerations, policy takes different forms and interpretations, and there is variability in its application. The absence of policy can lead to moral distress of field workers, yet may also produce favorable conditions amidst chaos. The international humanitarian community continues to

evolve, but large gaps remain in understanding the development, implementation and evaluation of policies.

Introduction

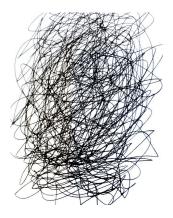
Humanitarian action presents itself as primarily an ethical pursuit: as Hugo Slim (2014) states, it is a "compassionate response to extreme and particular forms of suffering arising from organized human violence and natural disaster" (p. 1). Despite this, a wide range of ethical challenges is associated with the international response to humanitarian crises, highlighting the nature of a domain with depth and complexity in its operations. As Schwartz et al. (2012) note, there are both similar and distinct aspects of clinical work in humanitarian contexts compared to home contexts. Technical questions can quickly mutate into major ethical dilemmas due to heightened security issues, greater needs, scarcer health resources, and prominent population health considerations. Left unaddressed, these issues can take an emotional and psychological toll on field workers that has been described as moral distress (Kälvemark et al., 2004).

In 2012, an expert meeting with participants from a variety of disciplinary and organizational backgrounds was held in Hamilton, Ontario, Canada to discuss the development of applications for ethics in humanitarian healthcare practice (Hunt et al., 2014). A priority research area identified from this meeting was the impact of policies on humanitarian health ethics. Policies may function to increase or decrease ethical uncertainty or ethical challenges and have an

important influence on the ethics of humanitarian healthcare work (Hunt et al., 2014). This finding has been validated in earlier research, involving interviews with expatriate healthcare professionals, which identified ethical challenges in humanitarian health work arising from the mandates, agendas, organizational policies, and actions of aid agencies (Schwartz et al., 2010). Respondents in this study also reported challenges that arose due to what they perceived to be disparities between policies, written at a distance, and the realities they faced providing patient care in trying circumstances. For example, respondents described situations in which their agencies had policies prohibiting the treatment of people with certain conditions under specific circumstances, or policies requiring that only people with specific diagnoses be treated. While respondents understood the rationale of the policies, their application created conflict and was morally difficult to implement. Additionally, in a recent poll in which 75 anthropologists discussed their experiences in medical humanitarianism, 12.3% identified policy as an area of concern for humanitarian ethics and governance, while many called for a pathway to create "meaningful, flexible, sustainable, effective, and ethical policies" (Abramowitz et al., 2014).

Policymaking is a complex, decision-centric process as described in Chapter 2 of this thesis. Ben Holt (2015), UK Digital Lead and International Strategic Advisor at the international medical organization Médecins Sans Frontières (MSF), captures the complexity of the organization's international structure and decision-making in this graphic:

Figure 1. MSF's international structure and decision-making explained



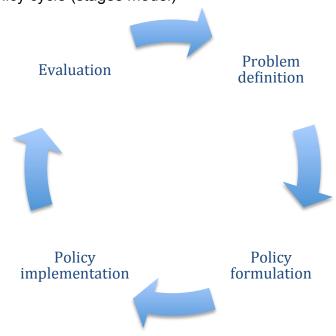
Little empirical data has been collected about the policy dimensions of ethical challenges experienced by healthcare providers in international crises. Given the highly complex and fragmented nature of the humanitarian sector, this study attempts to clarify and document policy development, implementation, and evaluation processes to better identify the social and institutional architecture of humanitarian policy and practice, and to understand how these dynamics unfold in the field. The results of this research are intended to inform and improve policy development, implementation, and evaluation in humanitarian healthcare organizations, to support more optimal circumstances for the delivery of care.

Aim

The aim of this qualitative descriptive study is to better understand how policies are socially and institutionally constructed, implemented, and evaluated

in humanitarian healthcare organizations. The policy cycle below is a stages model, integral to policy analysis since its establishment in the 1950s, and will be used to understand this process (Pal, 2009). Problem definition is part of the framework but is presented elsewhere in Chapter 4 of this thesis. This paper focuses on policy formulation, implementation, and evaluation:

Figure 2. The policy cycle (stages model)



Methods

Approach.

In order to understand how policies are created, how they are implemented, and how they are evaluated in the context of humanitarian aid organizations, we used qualitative description for this study (Sandelowski, 2000).

While inquiry entails description and description entails interpretation, we did not go as far into the interpretive aspect, in order to stay close to the data and obtain minimally theorized answers to questions of special relevance to practitioners and policy makers (Sandelowski, 2000).

Recruitment and Sample of Respondents.

The study was reviewed by the Hamilton Integrated Research Ethics Board (HiREB) and the Institutional Review Board of the Faculty of Medicine, McGill University. We sought to interview organizational members (OMs) from Canadian offices of humanitarian non-governmental organizations (NGOs) as well as from international offices. In order to gain a broad insight into how policies originate, and how they are implemented and evaluated, we included OMs from a variety of levels and units in the organizations. Interviewees held roles that spanned from directors to managers, and medical advisors to program advisors. Information about the study (see Appendices A-D) was distributed through investigator contacts, organization regional mailing lists and groups, and social media. In addition to purposive sampling, a snowball approach was also undertaken, whereby people who took part in the study were asked to identify others who may be interested in taking part, and, if they were willing, to facilitate our connection with additional possible participants. Snowball sampling ensured diversity and variety, and when we reached the point where those who had taken part in the study were identifying the same people, we were confident data

saturation had been achieved. Interviews with 14 organizational respondents (six female, eight male) allowed us to explore the questions and objectives guiding our study through a range of positional perspectives. Collectively, interviewees represented five different organizations with humanitarian health care experience in 33 countries.

Interviews.

Interviews were conducted between February 2014 and November 2015. Individual interviews were employed, as they are well suited for exploring personal narratives and the more complex, subtle, or emotionally laden details of decisions and experiences. An interview guide was created to help focus the interviews without imposing too much structure (Appendix E), and was piloted on one respondent prior to data collection. In semi-structured, conversational-style interviews, respondents involved in the development, implementation, or evaluation of policy related to work in resource-poor settings and areas of disaster and conflict were asked to identify what means and strategies factored into the decisions around policy development, implementation, and revision. Interviews were audio-recorded with respondents' consent and transcribed verbatim. Interview lengths ranged from 25 – 133 minutes, with the average interview length being 57 minutes by Skype and telephone.

Analysis of interviews.

Data from interviews was coded to explore understandings of policy development, implementation, and evaluation revealed in interviews with OMs of humanitarian healthcare organizations. All collected data were managed using NVivo software. In order to preserve participants' confidentiality and reduce the possibility that they would be identified, interviewees' names, names of organizations mentioned, and personal names in the stories were removed when the recordings were transcribed. Data were first coded in order to sort and organize information into a manageable form, and then relationships and patterns were identified between individual interviews. To minimize researcher bias in coding, initial coding was developed by the principal investigator (LG), and the wider research team (LS, MH, JP) was involved in the analytic process when preliminary results were presented at an annual team retreat on November 27th 2015, and again at a team teleconference on May 3rd, 2016, further reducing the subjective element.

Findings

We asked respondents to offer an overview of policy development, implementation, and evaluation. Respondents were asked a general set of questions about what means and strategies factor into the decisions around policy development, implementation, and evaluation. Below, we present findings drawn from respondents' stories.

What is policy?

In describing how policy is developed, several participants offered their understanding of the meaning of policy. As in the humanitarian literature in Chapter 2 of this thesis, participants reported varying interpretations of policy. Stated one participant, "It's kind of an overriding guidance, and a reference, and a benchmark for many" (Advisor, Health Policy and Practice, Organization 1). It was described as a document of guidance for conflict resolution, particularly when people disagree on a fundamental value or when there is a misunderstanding and "not a catalogue of what we want or do not want to do" (Senior Researcher, Organization 1). Policy was also described as coming up with the vision and outline of the way things are supposed to look and the objectives of activity, and defining the principles and commitment of an organization. Policy was also viewed as putting in place provisions for people to be briefed and directed for the possibility to face difficult situations. The identification of ethical issues in the field was important for guiding policymaking. As one interviewee expressed:

"I think that actually a huge number of policies are created because of ethical challenges that we face and I think much more than we even realize ... there are so many ethical dilemmas and ethical challenges in humanitarian assistance that we are constantly reacting because we can't predict what those challenges are going to be. How does that translate for the doctor who's standing in his health clinic and dealing with people

face-to-face every day, which I am not doing. I don't have to face the father of the child who died because we were not able to put an IV in because we were not doing IV treatments. I don't have to face them, he does. So I think in any of our policy making which involves very fundamental, ethical questions we always have to make that reference back to what does it mean to stand on the ground and be there and deal with the grieving parents." (International Board Member, Organization 1)

As in Chapter 2 of this thesis, policy was not necessarily equated with a written document, but was also described as a tool, highlighting metaphorical terminology and the diverse forms policy takes. One respondent described policy as an advocacy tool, focused in this example on helping push for treatment:

"The field had to diagnose the patients with HIV and wanted to treat HIV. And the headquarters, whatever, said no you can't because we have to discuss it with the UN and dah, dah, and finally having this HIV policy helped us push and get treatment to the field for our patients. So there are numerous stories like that to tell and I do think that policies are very powerful tools, not on a daily basis, they're almost not on our minds on a daily basis but when you need them it's good to have, to be able to go back to them." (Manager, Organization 1)

Policy, however, was felt to lack clarity: the how-to component (for example, how to implement a particular program at a particular place or time) is often missing from medical policies. Other participants reported more practical, specific

documents known as "public health protocols" or "standard operating procedures" outline the how-to: how to respond to a public health crisis and current practices around this. Given the many contexts organizations operate in, one participant noted,

"The policy needs to be flexible enough to change according to context and according to the technology that is in place. But they shouldn't be as broad as that finally they don't say anything, or they don't prioritize anything. So it's quite a difficult exercise." (Medical Director, Organization 1)

Another participant cautioned against the dangers of adapting to the local context:

"I think standard and policy are very, very closely related ... When people say, well we can't really expect buildings to be physically accessible, another good example. We'll do it good enough for Afghanistan. And that will often mean filling in a staircase with cement, which is at such a high angle that it is actually dangerous instead of doing it at a proper 6% grade it ends up being at a 40% grade. And you can't get up that independently and even if someone is pulling you up if they let go and you feel you could be further injured, and it's not an independent process, you lose your dignity entirely. To do it to an international standard shows respect for the fact that there's a reason why it's been adopted as an international standard. To describe locally a policy that says what we've done is, except

it's really hard because it's a conflict zone or it's really hard because we don't have enough budget in this poor country, I think really short changes people in those settings and it also like I said, lowers expectations tremendously." (Manager, Organization 2)

Policy development.

Some participants described various building blocks of policy. Policy was described as being formed around needs, and ensuring access: access to doctors but also diagnosis, treatment, and follow-up care. Values such as the core principles of humanitarianism (humanity, impartiality, neutrality, and independence) were very often described as a reference in policies and in reflections about the needs of suffering people affected by conflict, which in turn inform policy development:

"So the value here is to put people at the center of decisions and the process of reflection, based on the needs and our perception, and based on that we will define a policy and a response." (Senior Researcher, Organization 1)

As one participant expressed, "these values are a bible of UN agencies in Syria" (Assistant Representative, Organization 3). And while they may not always be explicitly stated, they are "taken into consideration so they are part of the policy, an implicit part of the policy" (Medical Director, Organization 1). These principles also emerge in international humanitarian law (IHL), and in normative documents.

Normative documents, which outline principles as well as the directions organizations want to go, were described by one participant as "always the ground where policies start" (Manager, Organization 1). The Code of Conduct is one such document outlining principles for organizations involved in humanitarian activity, and was mentioned as being a constant reference in action and very often referred to in policy documents. One participant (Senior Medical Advisor, Organization 4) identified "doctrines", which express the main principles—for example, for developing assistance such as medical assistance, sanitation, or nutrition—as the basis for policy.

Socially-based policy.

Policy development is a social process within an organization. It was felt by some that policy was based on opportunities and biased information, with ethics principles not being the main driver of policy at the macro level. Some policies are brought onto the policy agenda as a consequence of political choice, based on the strength and influence of the director who writes them. Referring to the social and political elements of policymaking, one respondent stated,

"I think they [policies] change mostly as the personality of the director changes ... It's a social process within an organization ... it's a bargaining process in the end." (Senior Researcher, Organization 1)

Expanding on this:

"You always have an individual factor, you know; some heads of delegation like to do this, others like to do that. At the end, it's not necessarily the, you know, the policy in reference to the certain level of needs that is taken into consideration." (Senior Researcher, Organization 1)

Another respondent also described policymaking as a normative process:

[People just] "want to do what they want to do, what they think is best, not what is indicated by the situation on the ground based on an objective set of measurements..." (Manager, Organization 2)

Institutional, structural, or organizational policy development was described by one respondent as a very 'heavy' process – requiring a lot of thinking – in larger organizations. Having people engaged in the process and their understanding of it was considered important:

"I think it's the only way to get to your goal. Because if people don't understand the process and they don't feel comfortable with it then they're not going to engage with it ... If you get them engaged throughout the process then you get to your goal very, very easily." (International Board Member, Organization 1)

Evidence-based policy.

One participant who managed clinical services in hospitals said he learned very early on that evidence is needed to justify why you do or do not do

something, or why you would introduce something new. It was noted that in some cases, evidence does inform policy; however, the formulation of evidence-informed policies could take some time because, in the case of one organization, it would involve a technical group with the knowledge and expertise to support the evidence that makes up the content of the policy. The same interviewee noted that although evidence-informed policy can take time to reach consensus and get finalized, protocol development cycles are much shorter, more dynamic and amenable to change based on new evidence that emerges through practice. However, there may also be instances where evidence from the field is lacking. In the case of the 2014-2015 Ebola Crisis in West Africa, evidence from the field was lacking for policy development, and decisions were made in the moment for the best possible outcome. As one interviewee questioned,

"Are we there to stop the epidemic or are we there to treat individual patients? What kind of treatment are we going to give a national staff as opposed to an international staff? You see these are things, as I say it to you my skin crawls and I could start crying because I don't feel, we had to make decisions and I don't feel comfortable with them but they were the best decisions we could make at the time given the circumstances."

(International Board Member, Organization 1)

Another interviewee discussed the inability to offer even basic palliative care, highlighting the need for the development of policies that integrate palliative care services across the continuum of care:

"I mean we could give our, we could give to our patients so little and there was so much in transmission that because we didn't really have a policy, we just had this idea that the organization goes toward patient-centered approach that we were caught in this dilemma of should we put all our investment in Ebola treatment centres and forget about early detection, surveillance, community awareness so that we try to save as much as possible knowing that the elements that we had for saving those patients was almost zero." (Medical Director, Organization 1)

As shown by respondents, policy development – or lack thereof – was influenced by a number of factors.

Policy implementation.

Policy implementation was examined from the perspective of medical advisors, programme advisors, heads of project units, and directors of operations. Once policy is developed, how does it translate into practice? "Strategies", "guidelines", and "programs" were terms described by several participants as the "doing" link between policies and operational activities: the way by which policies are implemented and what actually happens on the ground (Senior Medical Advisor, Organization 4; Director of Operations, Organization 5). There was an identified gap in this process. While policy comes up with the vision of the way things are supposed to look, participants distinguished between accepting policy and implementing it, which can make implementation problematic:

"What we have to fight for in fact is the fact that it is written down, how to make that really translate into bigger numbers [of people applying it] in the field." (Head of Medical Unit, Organization 1)

While one participant expressed that practitioners are aware of policy and follow it (some felt ethically compelled to stick by policies), there is dialogue between policy and practice whereby policy can be influenced and challenged by practice. Discretion is important:

"Professional discretion is important and at the field level, hospital level, clinic level, you know the patient side, discretion will be used as well."

(Advisor, Health Policy and Practice, Organization 1).

One respondent described practices in place that were not written down as policy, and the discussion that took place when an ethical dilemma arose and there were no identified pathways to get to a solution:

"And that was usually through dialogue, it was us talking through what the consequences might be and weighing what our options were and the likelihood that we would succeed if we implemented this approach, this tactic." (Manager, Organization 2)

He described openness among his team even though they had very different perspectives on things, and they took equal responsibility for the decisions they proposed to headquarters. Often, these were approaches for how to handle different kinds of corruption.

"We had to come up with ways to describe it and options for our headquarters to choose among with our suggestion, choose A please or choose B, do not choose C whatever you do." (Manager, Organization 2)

Unwritten or 'unofficial' policy was shown to positively influence conditions on the ground and in some instances to address the challenges associated with implementing official policies perceived to be ethically untenable. This respondent described a cost-share system he created as unwritten policy at a hospital outpatient department in Afghanistan. He contrasts his experience in a New York hospital with that of one in Bamiyan:

"The policy at the time of municipal hospitals – because there was significant financial pressure on the municipal system – we had a three-part system called deflect, defer, deny. And this was an official policy that we were to try and get people not to use our facility ... we had so many patients who had no means of payment ... So when I confronted the chief financial officer at our facility and said, 'I have a really hard time with my position as a manager at a hospital denying people care, telling them to go to a different facility, asking them to come back in a month', he said, 'That's just the way the world works.' So this was something that happened again in Afghanistan ... And how to then respond when you have 400 people in a day, 50 of them, easily, would come to the office at the hospital and say, 'I actually don't have any money at all, we have no money in our family, there is no money for us to pay.' And what would be

equivalent to you and me of a few cents, they didn't even have that to pay to get the small clinic card so that they could then get free immunization ... We created a co-pay, a cost share system and we asked people who could pay to pay extra, because some people did have money. So that then built up a slush fund ... It wasn't an official policy ... It's the same thing in New York where the front desk of the hospital were actually turning people away before they even got to the finance office to plead poverty. But in New York we had an official policy on how to deal with it. In Afghanistan, I had more leverage, because I controlled my own little universe there to come up with a tactic to overcome that problem."

(Manager, Organization 2)

Implementation of policy regarding certain controversial subjects can also be challenged by wider community perception and cultural practice. One example given was a policy on abortion. In many cultures and religions, termination of pregnancy is something that is not accepted; therefore, even when it is offered as part of the core reproductive health package, women may fear the religious consideration and principles of their community or leaders:

"And so the implementation of the policy seems to be problematic and I think one of the reasons is fear. Fear of perceptions of others, fear that certain communities might totally not agree, which might be true but might also be totally untrue because it has not been verified, it's purely perception." (Manager, Organization 1)

Another respondent echoed similar concerns around access to safe abortion care:

"So there's also certain context, where even though the policy is there we could do it but either the religion, either the ethnicity, either the context, the internal arrangement are not able to do so. So even though the policy is there we're not necessarily all the time coming to it because we need that flexibility." (Medical Director, Organization 1)

The examples provided by respondents demonstrated that generally, when confronted with reality, policy stumbled.

Policy evaluation.

Perceived challenges in policy evaluation arose due to the difficulties of linking field results to policies, as well as measuring quality. Management issues, how evaluation was triggered, and the various approaches that different organizations used to review and revise policies were also described.

Many respondents expressed the difficulty of linking results from the field to policies. One participant described a results based management project taking place in house, the aim of which is to get an overview of results from the field:

"And of course the day we have that, we can link the results to the policies.

But, I don't have any examples to give you. I think a lot of the work we do,
and others too, is we learn while we walk. We need to learn about the
paths we had. And, I think this is kind of a gene we have in the

humanitarian field. You know, we become more clever, so we do things that are better adapted to the reality, but we tend also, we tend to have a basic disease which is the lack of memory." (Medical Advisor, Organization 4)

Another interviewee stated that quality was very difficult to measure:

"We are very bad at trying to see if the policy was the right one, whether the policy obtained what it was meant to obtain. So today it's much more, as the policy highlights priorities then we will come with data that show us quantity. As the policy goes beyond that and speaks a lot of quality, and for that aspect we are very bad at measuring that. So in quantity, for example again, if we give priority to vaccination we can perfectly well see the trend in vaccines and vaccine campaign implementation and we can say that the policy has been successful. But then if we go into what the impact of that vaccination is generally inside the policy, we're much less strong to defend it." (Medical Director, Organization 1)

Other policies, such as safe abortion care, were not only problematic to implement, but also difficult to measure (e.g., how and where it is performed, and how many women have had access to it) due to the sensitivity surrounding the intervention:

"We've only succeeded to monitor that in one project. Because it is a sensitive issue and in some countries we don't want to write it down, in some countries we had codes for it. So it's extremely, it's not only a

problem for implementation but also a matter of how do you measure this activity? In other activities it's much easier, it's much easier to count the number of deliveries during emergencies or how many patients we had put on tuberculosis treatment, how many patients were on HIV care, etc. So we do track it by our data collection system; but as always the data that comes out is only as good as the data that goes in. So we are struggling still in some fields but I think we have made vast improvements compared to 10 years ago." (Head of Medical Unit, Organization 1)

While one respondent of an international organization indicated that programs are evaluated, the evaluation of policies would be seen as threatening higher management:

"I don't think there is a process during the lifetime of one policy of checks and balances, so we have this ethical issue, which is a consequence of political choices." (Senior Researcher, Organization 1)

Similarly, it was felt that bureaucracy and political insecurities hindered opportunities for on-the-ground evaluations:

"I think that people in policy positions like me who are trying to guide organizations, we have to make an effort to talk to people and we have to spend a good portion of our time talking to people on the ground saying 'What do you think? How are you feeling about this? Where are we on this? Is this right or wrong?' But that requires a lot of things inside to be

able to do that; it's not easy for an operational centre to allow me to make that contact." (International Board Member, Organization 1)

Another respondent from the same organization, indicating that their organization does engage in evaluation, provided a counterexample:

"We evaluate things often, we're evaluating our projects in line with our policies or our policies in line with the direction things are moving, where the need is ... I can't tell you how often things might be revised but it doesn't take too much to trigger a revision. So for instance if things, if evidence based research has emerged that would be a trigger for revising policies." (Clinical Health Psychologist, Organization 1)

One respondent described a formal process of engaging in reflection in order to revise policies:

"So this is a new development which is actually a space where we open a file, an ethical issue, a difficult decision to make, or a difficult case that we encounter in the field in operations. So this reflection is fed by operations, and we open a shared reflection in this group in order to perhaps, yeah, based on existing doctrines and policies and standard procedure, to see to what extent these policies are still adapted or still meets the needs raised by a particular new situation, and if there is a need to revise the policy, if this is the case, then we would effectively work on that. That would not necessarily be the work of this group, but the role of the group is really to enlighten a decision and to inform the people in charge of responding to a

particular situation, or what would be a good possible way to respond."

(Senior Medical Advisor, Organization 4)

Similarly, discussions with other sections within an organization to talk about the work they are doing, how they are doing it, and trying to harmonize in some ways, was another approach to revising and finessing policies. With new experiences and new practices that come out of projects, they can add to their policies:

"I think a lot of policies are sketched out skeletally in the beginning and shored up with more with experience. I think if anything, if anything we live policy before we get it down on paper, which is probably where we're different from development agencies." (Clinical Health Psychologist, Organization 1)

Advances in technology can also trigger revision of policies:

"The neonatal policy at the beginning was whenever a premature baby of less than 700 grams, we are not going to readmit that person, that baby because the chances of that baby surviving are almost zero and because the possibility of disabilities are extremely high that will at the end be a burden to the family. Now with the technology today we cannot apply that policy everywhere and we have been seeing in the Middle East that babies that are premature, that are 700 grams or less, still with the technology that we have can survive. So we had to review first to make it

broader and try not to exclude scenarios where that policy could be counterproductive." (Medical Director, Organization 1)

Discussion

While a precise and unanimous definition of policy did not emerge from this study – one of the chief findings – policy in humanitarian aid organizations was found to be informed by both normative and practical considerations: built heavily around humanitarian principles and values; needs; and, access. As Slim and Bradley (2011) explain, humanitarian principles might be expected to clarify policy and operational tensions at field level, but in practice, principles seem more manipulated than respected. For example, it is largely unknown how humanitarian aid organizations apply humanitarian principles, and while donors rhetorically espouse them, "in practice, donor aid flows are not impartial and needs-based but gravitate towards geo-political conflicts and counterinsurgency support..." (Slim and Bradley, p. 17). The political concerns of donors as well as those of local armed groups can also influence humanitarian aid organizations, and this has been shown to compromise their independence (Haver, 2016).

That humanitarian aid should be allocated on the basis of need alone is a central tenant of traditional humanitarianism; for example, MSF states it "provides care on the basis of need alone" (as cited in Rubenstein, 2015) and the Code of Conduct for The International Red Cross and Red Crescent Movement of NGOs in Disaster Relief states "aid priorities are calculated on the basis of need alone"

(as cited in Rubenstein, 2015). Rubenstein (2015), in her book on the political ethics of humanitarian NGOs, asserts further that when examined in a broader context, proponents of the need principle do not actually mean it literally, and the concept is often used interchangeably with the far less demanding requirement of impartiality. For example, the principle of impartiality forms the basis of the Code of Conduct quote cited above. In its entirety, it reads: "Aid is given regardless of the race, creed or nationality of the recipients and without adverse distinction of any kind. Aid priorities are calculated on the basis of need alone" (as cited in Rubenstein, 2015). The need principle lacks clarity and leaves the door open to interpretation, giving one a sense that it is a bit arbitrary. Given that principles were perceived by respondents to be important drivers of policies, it is not difficult to see how policies could also lack clarity. Other ethical approaches – beyond humanitarian principles – are necessary for sufficiently addressing complex issues in humanitarian healthcare policy and practice.

Policy was viewed as a document of guidance, and also had a symbolic value in being described as an advocacy tool to help bring treatment to the field. The case of unwritten policies is an interesting one: on the one hand, the absence of explicit policies may serve to expose something that is functionally useful, and positively influence conditions on the ground in the midst of chaos. This was illustrated by a respondent in Afghanistan who described the development of unwritten policy in response to existing, official policy (i.e., denying people access to care) that was untenable for the people on the ground

to live by and implement. On the other hand, one might also imagine scenarios where policy guidance not designed in advance could lead to moral distress, and raise problems with transparency and accountability when not democratically agreed upon or produced. Despite the best intentions of policy, the findings of this study reinforce those of other papers published in this area. Similar to findings of Schwartz et al. (2010), some respondents of this study noted that aid agencies are always acting in relation to multiple imperatives, with concerns that the needs of patients were not always a driving force in decision-making. An authority on humanitarian ethics, Hugo Slim (2014) notes:

"This variety of motivations across the humanitarian sector is significant because it means that while the profession presents itself as a primarily ethical pursuit it is also strongly influenced by other personal incentives that drive humanitarian individuals and create an accusation of vested interests that are embedded within its institutions." (p. 14)

Expanding upon this, there are decisions that need to be made based on the values of institutions, which must also accommodate interests. Often, there are competing factors at play (individual and political, knowledge and evidence) and sometimes there is more than one approach to solve a problem, but a decision must be made on the best way to tackle it. It may emerge that alternative decisions were also as right, and it is important to acknowledge this when one decision wins over others. Rubenstein (2015) argues that while need should play a role in large-scale decisions about resource use (decisions typically

made at headquarters about where to work, which groups to assist, and themes or issues to address), the need principle should be rejected because it is a poor representation of egalitarian, democratic, justice-based, and humanitarian norms. Instead, she offers that exercising the ethics of resistance – a form of political judgement which focuses on overall consequences, but has expansive understanding of what consequences matter – publically, and in dialogue with others, is what it means to make decisions about resource use in a way that is consistent with the aforementioned norms.

There was a clear disconnect identified between policy development and implementation: how things ought to be and how things are. There was a necessary pragmatism in the implementation of policy. Policy is translated into practice to differing degrees, and respondents of this study spoke of an individual factor that comes into play in applying policy, as well as the need for discretionary application of policy. This suggests – and indeed some examples given by respondents seem to imply – that there are often individuals rather than groups on the front lines implementing policy, which gives them additional autonomy that groups working as a collective would not have. Additionally, given the many environments in which aid organizations operate, several respondents expressed a desire for policy to facilitate the context. Indeed, while many countries face similar issues, what works in one setting may not work in another.

Contextualizing, however, acknowledges weaknesses in the system, and if taken too far may even result in a wrong application of the policy. Adjusting

written policies in view of national contexts would also be difficult, given the number of places aid organizations work in. A consultant on humanitarian action, Raymond Apthorpe (2012) cautions: "Too much attributed to the importance of context may result, in effect, only in obscuring its lesser due" (p. 1547). On the other hand, it would also be detrimental to have a policy so broad and open to interpretation that it is difficult to apply. This may make a case for the situational formulation of policies as clinicians work; however, this too raises concerns. Understanding how the global and local context interact with each other, and what is shareable, is important. Having the end-user engaged in the policy development process, and engaging in meaningful consultation with beneficiaries of aid to understand their morals and principles, may mitigate some of these aforementioned issues.

While several respondents indicated their organizations engaged in some form of policy evaluation, including ethics reflection and discussion, others pointed to the difficulties of measuring policy effectiveness and learning from past paths. As the 2014-2105 Ebola Crisis in West Africa saw mistakes of past public health emergencies repeated, Smith and Upshur (2015) question why cumulative ethics knowledge and reflection on values and guidance generated following previous outbreaks continues not to inform efforts in global outbreak management, and fails to be translated into policy and practice. On aid effectiveness, Apthorpe (2012) suggests:

"So when, over time, as is inevitable, one orthodoxy is succeeded by

another, the way they cope with the failure of their earlier absolute truth is interesting; mostly, this happens simply by forgetting whatever is known about the past as soon as possible. International aid is often said to be unaware of its past and for that reason besides sticky organizational learning issues condemned to repeat itself." (p.1548)

Instead of revising and updating existing policies through evaluation processes, re-inventing the policy wheel often becomes necessary. Apthorpe (2012) further elaborates that a consultant hired to carry out an aid evaluation will in the best cases be tasked with verifying an aid programme's track record, and validating the policy blueprint behind (or in front of) it. Undoubtedly, there is a need for better institutional memory of humanitarian healthcare organizations.

Limitations

This study had several limitations. Firstly, we drew on a relatively small number of interviews; however, we were not attempting generalizations but rather identifying rich and detailed insights from a diverse set of people with in-depth experience in policy development, implementation, and evaluation in aid organizations. Secondly, findings are illustrative examples based on perceptions of interviewees and await further expansion. Lastly, as our attempt was not to identify organizations, specificity of results was sacrificed in order to reduce the risk of deductive disclosure and to protect the identities of the individuals who participated in our research.

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Chapter 4 – Ethical challenges at the intersection of policy and practice in humanitarian contexts

Abstract

This study explores international humanitarian healthcare organizational members' accounts of ethical challenges at the intersection of policy and practice during disaster and conflict response. In analyzing participants' narratives, three key themes were identified from the interviews, which were participant perceptions of tensions related to 1) institutional memory loss; 2) priorities within different departments of humanitarian healthcare organizations; and, 3) social norms and expectations of humanitarian healthcare organizations and local communities. This paper illuminates these stories and promotes further exploration of developing the capacity to judge the correct means for achieving good ends in humanitarian practice.

Introduction

Recognition of the profound, moral challenges inherent in humanitarian action has only recently started to gain traction, despite ethical elements being ever-present in humanitarian work. Several researchers and academics have argued that humanitarian agencies generally pay insufficient attention to the ethical dilemmas of decisions, including risks to affected populations (Slim, 2014a; Stoddard et al., 2016; Terry, 2016). It is not entirely surprising, as humanitarianism is defined by "action, not consequences, and especially by action directly delivered through human contact on-site" (Fassin and Pandolfi,

2010, p. 52). This implies the emphasis is on speed of action, as opposed to reflection. Indeed, humanitarian healthcare organizations have justified continuing to provide assistance in worsening security situations by focusing on technical issues of relief provision, with less consideration for competing ethical issues (Mills, 2015). In a systematic review of qualitative evidence examining aid workers' experiences of ethical preparedness in disaster contexts, Johnstone and Turale (2014) found ethical issues may be characterized as personal issues, or overlooked altogether. Moreover, when disputed or challenged, outcomes of difficult ethical decisions in medical humanitarianism tend to be interpreted as issues of professional negligence, reflecting a very narrow understanding of ethics (Calain, 2015).

Very importantly, when not properly addressed, ethical challenges can also cause hardship for beneficiaries. Illustrative examples of ethical dilemmas in specific contexts include infectious disease outbreaks, such as the 2014 Ebola Virus Disease outbreak. The questions of who received treatment, and who was treated first, were among the toughest of challenges (CBC News, 2014; Kass, 2014). Additionally, whether or not it was permissible to distribute experimental drugs and vaccines in response to the outbreak was another ethical concern — what if the new intervention didn't work? Or, worse: what if the intervention harmed, killed, or expedited the virus and its spread? (Schwartz, 2014).

In violent contexts, ethical dilemmas in decision-making include those arising from risk management, such as acceptable levels of risk for staff and

working in environments where hospital facilities and local populations are targeted (MSF, 2016). For example, the international medical organization, Médecins Sans Frontières/Doctors Without Borders made the difficult decision to evacuate teams after they deemed the area not safe enough, following the death of 19 patients and one MSF staff member when an airstrike hit a hospital in Yemen (MSF Canada, 2016). The tension between the duty of care health practitioners traditionally owe to patients, and the duty of care the nongovernmental organization (NGO) owes to its health practitioners and local staff, was apparent. Clarifying when it is morally acceptable for national staff to face higher risks than international staff is also part of a related discussion. For example, in Afghanistan, one international non-governmental organization (INGO) made the decision – unprecedented for the organization – to evacuate national staff and their families when anti-government forces occupied the province and they were directly threatened (Haver, 2016). As illustrated by both cases, ad-hoc decisions to evacuate staff members reveal the need for policy development on this issue.

Not surprisingly, given the different contexts in which humanitarian healthcare organizations work, the ethical challenges experienced by humanitarian workers are also distinct (Schwartz et al., 2012). Usual sources of ethical guidance, such as biomedical ethics or professional codes of conduct, do not sufficiently address or capture the full complexity of humanitarian situations where ethical challenges arise. As such, different frameworks and tools have

recently been developed to assist humanitarian aid workers in their decisionmaking process (Clarinval and Biller-Andorno, 2014; Fraser et al., 2015). Understanding the ethics on which an organization bases its action could mean a "substantial improvement of our perception of humanitarian aid and, most importantly, could have the potential of transforming the nature of criticism into a constructive one" (Patrichi, 2015). A developing focus of attention in this area is humanitarian ethics – a distinct and nascent field of inquiry and practice, intersecting with bioethics, public health ethics, and global ethics (MSF, 2016). While it may not provide a single "right" answer, it could improve the ability of the humanitarian community in understanding reasons, values, choices, and in helping explain why certain decisions have been made. This may lead to clearer policies and decision-making, and reduced moral distress. Creating a safe space for deliberation through ethics support could have far-reaching effects, including improved institutional memory of ethical issues so that mistakes are not repeated (Pringle, 2016). In turn, this may lead to better outcomes for beneficiaries and fieldworkers.

Researchers have just begun to understand the range of ways in which humanitarian healthcare organizations' policies can shape ethical dilemmas in the field (Hunt et al., 2014; Schwartz et al., 2012). There is a need to examine links between policy development and ethical issues in field projects, and how best to vet new policies before they are developed and implemented in order to identify potential ethical implications (Hunt et al., 2014). This study lays out some

of the ethical tensions that affect the profession by identifying ethical challenges that arise from aid agency policies and practices, or that trigger the need for improved policy development.

Aim

The aim of this interpretive description study is to explore how policies and ethics inform each other in order to better understand where problems arise and how policy and practice in humanitarian healthcare organizations can be improved in this regard. We seek to understand the ethical challenges around humanitarian aid agency policies. Did ethics help to define the problem? Did ethical issues inform the policy formulation or did a policy raise new ethical dimensions?

Methods

Approach.

We used interpretive description (ID) methodology for this study (Thorne, 2008). ID is a newer qualitative research methodology aligned with a constructivist paradigm that was originally developed in nursing science as an approach to answering clinically relevant and practice-oriented research questions. Given our research focus on firsthand experience and applied practice, ID methodology is suitably aligned with the study objectives. ID extends qualitative description into the interpretive domain and draws upon aspects of

Grounded Theory (Glaser and Strauss, 1967) and Naturalistic Inquiry (Lincoln and Guba, 1985). These origins and sources of inspiration are part of the trajectory of ID. Indeed, Sandelowski (2000) notes qualitative work is not the product of any "pure" use of a method, but from the use of methods that are textured, toned, and hued. We prioritize understanding to go beyond description and more deeply into the interpretive aspect of ID in order to unpack problems and ethical issues in humanitarian aid, while staying true to the aim of ID: to "create a qualitative description that can be characterized as interpretive" (Hunt, 2009, p. 1290).

Recruitment and Sample of Respondents.

We sought to interview organizational members (OMs) from Canadian offices of humanitarian NGOs as well as from international offices. In order to gain a broad insight into how problems are identified, we included OMs from a variety of levels and units in the organizations. Interviewees held roles that spanned from directors to managers, and medical advisors to program advisors. Information about the study (see Appendices A-D) was distributed through investigator contacts, organization regional mailing lists and groups, and social media. In addition to purposive sampling, a snowball approach was also undertaken, whereby people who took part in the study were asked to identify others who may be interested in taking part, and, if they were willing, to facilitate our connection with additional possible participants. Snowball sampling ensured

diversity and variety, and when we reached the point where the same people were being identified by those who had taken part in the study, we were confident data saturation had been achieved. Interviews with 14 OMs (six female, eight male) allowed us to explore the questions and objectives guiding our study through a range of positional perspectives. Collectively, interviewees represented five different organizations, with humanitarian health care experience in 33 countries. The study was reviewed by the Hamilton Integrated Research Ethics Board (HiREB) and the Institutional Review Board of the Faculty of Medicine, McGill University.

Interviews.

Interviews were conducted between February 2014 and November 2015. Individual interviews were employed, as they are well suited for exploring personal narratives and the more complex, subtle, or emotionally laden details of decisions and experiences. An interview guide was created to help focus the interviews without imposing too much structure (Appendix E), and was piloted prior to data collection. In semi-structured, conversational-style interviews, respondents involved in the development, implementation, or evaluation of policy related to work in resource-poor settings and areas of disaster and conflict were asked to identify stories of ethical challenges they faced – the types of ethical situations encountered, and how policy responded to these challenges or raised new ethical dimensions. Interviews were audio-recorded with respondents'

consent and transcribed verbatim. Interview lengths ranged from 25 – 133 minutes, with the average interview length being 57 minutes by Skype and telephone.

Analysis of Interviews.

A thematic analytic approach informed by ID was used to explore understandings of ethical dilemmas revealed in interviews with organizational members of humanitarian healthcare organizations. All collected data were managed using NVivo software. In order to preserve participants' confidentiality and reduce the possibility that they would be identified, interviewees' names, names of organizations mentioned, and personal names in the stories were removed when the recordings were transcribed. Data were first coded by generating succinct labels in order to sort and organize information into a manageable form. Codes were then examined to identify broader patterns of meaning and potential themes between individual interviews. Initial coding was developed by the principal investigator (LG), and the wider research team (LS, MH, JP) was involved in the analytic process when preliminary results were presented at an annual team retreat on November 27th 2015, and again at team teleconferences on May 3rd, 2016 and September 20th, 2016, further reducing the subjective element.

Literature references helped identify key areas for deeper analysis, as well as the need to explore implicit content generated in Chapter 3 of this thesis that

deserved further reading and connection with the theoretical literature. This background knowledge provides valuable foregrounding of the phenomenon being studied. As Hunt (2009) notes, ID should be located within the existing knowledge so that research findings can be created on the basis of connections to the work of others in the field. Themes were refined and checked against the dataset to determine if they answered the research questions. A descriptive label was assigned to each theme, and the scope of each theme was determined. As the qualitative analysis involved interpretive description, attention extended beyond description to interpreting meaning and significance for humanitarian actors. The analysis was an iterative process, and the structure of the findings took shape gradually, through testing alternative linkages, new vantage points, and diverse interpretations (Thorne, Reimer Kirkham & O'Flynn-Magee, 2004).

Findings

We identified three main thematic areas for humanitarian practice, which can best be framed as tensions. These themes are not exhaustive, but represent an aspect of our interpretation that revolves around three tensions evident in the data: 1) Unaware of its past: understood as a tension within humanitarian healthcare organizations to be nimble, responsive, and sufficiently structured while at the same time not feeling bogged down with the past; 2) Clashing departmental priorities: tension between operational choices versus on-theground realities; and, 3) Social norms and expectations: tension between

organizational vision and community vision, for example perceptions of vulnerability. Below, we unpack the themes in more detail.

Three tensions.

Unaware of its past.

The repercussions of institutional memory loss of humanitarian healthcare organizations were apparent, and respondents reported that it was difficult to learn from past experiences. According to Marilyn McHarg (at the time Director General of MSF Canada) in an interview on CBC Radio Metro Morning, Jan 25, 2010), an estimated 50% of health workers who travel with MSF will not return to do a second mission. There may be a variety of reasons for this high attrition rate (Schwartz et al., 2010), and when fieldworkers do not return, ethical issues and past paths can be forgotten. For example, one respondent said, "Analyzing difficult dilemmas is also to learn from mistakes, but because of the rapid turnover of people in the field, and also in other places, it makes this memory issue quite challenging (Medical Advisor, Organization 4).

Another respondent agreed with this observation, and reinforced why peoplebased institutional knowledge is so critical to organizational effectiveness:

"So if the next nasty outbreak comes and some of us that were involved are still there and have something to say, I'm sure the lessons learned will be taken into account. But if it takes too much time it will be forgotten and the same mistakes will be made again." (Manager, Organization 1)

Organizations spend a lot of time developing knowledge and capability. The ability for this knowledge to be translated into policy suffers when, over time, institutional memory moves away or is forgotten when employees leave the organization:

"There are significant challenges, there is significant lack of policy, there is significant lack of debate, it has been overlooked, not intentionally. I think there's a lot of burden on people providing services, there is a lack of support, people get burned out, there's high turnover. The survival and getting to the immediate need of the population is obviously the first thing that people focus on and there's no time for reflection, well if there is there's no mechanism, perhaps there's no expertise. So overall, I can tell you we are doing poorly in terms of having policies; and it's not just policies, it's having strategies, ideas how we can support an ethical approach in a particular humanitarian situation." (Board of Directors Member, Organization 1)

On the one hand, while nimbleness and responsiveness are important in the face of an emergency, one respondent pointed out that ethical decisions and policy formulation cannot be rushed:

"What I think the best thing we can do is not to try to make final ethical policies in the middle of a crisis. We have to look back afterwards. Now is the time to look back at Ebola, even though if we don't know if it's finished or not or where it is, we have to be very careful. But now is the time to

look back and say how we should have dealt with that, how would we have better dealt with that, how would we have involved the field? So I think that ethics, it's one of those things I push a lot, my thing is you cannot rush ethical decisions, do not rush them. You have to take the time, you have to let it float around in your head ... you have to do that, otherwise you're not doing it justice." (International Board Member, Organization 1)

Similarly, another responded added:

"A lot of policies are significantly debated to the point I can say sometimes they cause nausea. Though time consuming, I guess in the long run it's just more likely to be reflective of the movement rather than just a group of individuals." (Board of Directors Member, Organization 1)

As shown by respondents, there is tension created when humanitarian healthcare organizations fail to retain and transfer institutional memory, which has repercussions for ethical decision-making and policy development. Moreover, because these processes require time and reflection, this makes the preservation of institutional memory all the more important.

Clashing departmental priorities.

Medical and operations departments are meant to compliment each other, but there is a substantial split between the two and it was identified as a primary source of tension in humanitarian healthcare organizations. Quality of care was

prioritized by medical departments and was perceived as put in opposition to providing efficacious and widely impactful care, valued more by operations departments. Explained one respondent,

"You have on one side the medical department that says we need to ensure minimum of quality in our program even if we are in humanitarian settings. And you have the people from the operations who think we need to display that we are ready to act and be present anytime and anywhere, even if there is some tradeoff to quality." (Senior Researcher, Organization 1)

Tensions about tradeoffs are evident in how priorities are weighted differently between departments, and the role that policy plays in these debates, another respondent replied:

"It's much more about how many people did you treat, how many refugees do you have, did you provide enough food items, did you have mass vaccination campaigns. Whereas in the medical department we use policies to say, 'Hang on, we have agreed to have a TB policy in emergencies, we have an HIV policy that also spells out in emergencies we want to provide HIV care. So those policies provide us to be able to have an argument and to go to operations ... there is not conflict, but the priorities are weighted differently, let's put it that way. To have this healthy kind of push-pull conversation and push for equal care for particularly vulnerable populations." (Head of Medical Unit, Organization 1)

Operational choices defined project parameters, and were framed by this respondent as imposing limits, clashing with perceived needs from the field:

"I'm not sure you can call it a disconnection, I think it's an active choice ... to put limitations and restrictions. 'No you cannot have the IV infusion because it's not needed. No you cannot treat the person who is 42 years old. No you cannot have this type of diagnostic test done.' And then when you're in the field, that's very different. It's easy from an office. But it's very difficult to live it when you're in the field." (Manager, Organization 1)

The same respondent used the following analogy to illuminate the difficult realities fieldworkers face on the ground:

"It's just easier. I think it's like in the army. In the army, you have a General or an Admiral that pushed on a button – that's very easy. But for the military to actually go in – I think that's much more difficult." (Manager, Organization 1)

Several respondents viewed establishing a space for dialogue and reflection as critical. Expressed one respondent:

"I don't think that there's one space, I think it's an ongoing space and I think that as a policy decision it is critical ... We've lost that very fluid, ongoing dialogue in the field. The field has become like another place of the headquarters ... We have to make the effort to talk to people and we have to spend a good proportion of our time talking to people on the ground saying, 'What do you think, how are you feeling about this, where

are we on this, is this right or wrong?' But that requires a lot of things inside to be able to do that, it's not easy for an operational centre to allow me to make that contact. So our bureaucracy and our insecurities inside the organization can also affect a lot of ethical decision-making."

(International Board Member, Organization 1)

Social norms and expectations.

Tension between organizational vision and local community vision arose in the desire to respond to the most vulnerable. The following quote demonstrates an ethical issue raised when a humanitarian healthcare organization's priorities came up against local community values, which favored the elderly because of their social benefit as a repository of knowledge:

"And also you would want to save more life years. So that means the most vulnerable being many times the children and the pregnant women of course. And also if you save a child, you would save more life years. But for some, this is not acceptable; this is a real ethical issue. For example, a nutrition crisis where you would put all the focus on the under five and the old people are not saved because nobody cares, that can be a real issue for the local population because for them, they can make a child easily, they can replace a child easily but an old person they cannot replace as easily, because it takes a lot of time in becoming old and old people are like a library for them." (Manager, Organization 1)

Another respondent shared a similar story of the ethical issues arising when organizations place too much focus on younger people, neglecting the elderly:

"We show up in places where we start a program for children but we completely forget the elderly because our value is that well children are important because they are innocent and all of those things and it's true. But I tell you I've been in the communities that people show up to me and they wanted their elderly 65, or probably more, with multiple medical conditions to do whatever I can to keep them alive. And they basically tell you, 'If my two or three kids are going to die I don't care, because that person – that elder – is the glue that keeps the community together, is the history, is what makes them that tribe'." (Board of Directors Member, Organization 1)

Turning to a different example, a proposed policy for HIV-infected children in nutrition programs raised new ethical dimensions for this particularly vulnerable group, highlighting the need for sensitivity to what makes someone vulnerable to stigma:

"We have a proposal for children in nutrition programs that are severely malnourished and have higher than average rates of HIV infection. But families are often dealing with an intense stigma, including a stigma that may exist just by having malnourished children. And so the idea of introducing HIV testing in a systematic way raises an ethical question of how well can we protect people's privacy, will they have confidential

counseling space, will they have counseling? We're talking about children who are vulnerable, families who are vulnerable, and so we have to find the right balance." (Clinical Health Psychologist, Organization 1)

In addition to vulnerability, this theme is about social and contextual norms, and beliefs, that a newcomer to the setting – no matter how experienced in other settings – cannot fully grasp. It requires openness to new possibilities:

"He had been a very powerful commander and he was my age. His second wife was having a very complicated delivery and she needed blood and he refused, he absolutely refused. And the ethical dilemma was there, because we had just had a series of staff members – all who had been the same blood type – already give blood. You know you can only give so much in a period of time, otherwise you do face a health consequence. Well this woman, she needed several units of blood; she was not going to survive otherwise and he refused and he actually assaulted our staff and left. He came back with armed men and threatened the whole hospital staff because we were trying to pressure him to give up his blood. And this was for his own relative, not a stranger. And his explanation was, 'If God will take her, I will have a new wife.' Oh my God, I mean I had heard stories like that before but I had never been told directly to my face that this was his solution, she was replaceable. And I struggled with that because she did die." (Manager, Organization 2)

As demonstrated by these examples, honoring humanitarian healthcare organizations' values, personal values, and local communities' values in setting policies and priorities – and managing this tension – is a challenge.

Discussion

Participants shared a wealth of complex viewpoints about tensions that arise between policy and practice in humanitarian healthcare settings. While this paper cannot show saturation of the types of ethical challenges facing humanitarian healthcare organizations, it is a move to bring stories forward and formalize and capture histories so we can learn from them. For various reasons identified by participants, such as high staff turnover and the complex nature of conflicts and disasters in different countries, building institutional memory to improve humanitarian aid and implement lessons has been a longstanding challenge. Nearly a decade ago, it was considered to be an almost universal weakness of NGOs: their often limited capacity to build upon a long past and continuously improve the quality of what they do (Fowler, 1997). Despite a long history of carrying out humanitarian response around the globe, humanitarian decisions today are still made based on limited past experience for information – to some extent justified by the urgent nature of humanitarian action (ALNAP, 2016; Tafere, 2014).

Humanitarianism exists as part of larger global structures, and making challenges visible is part of addressing the problems facing the humanitarian

system. Macro-level issues – global crises in humanitarianism – are perhaps most widely known; however, as shown by participants of this study, the smaller day-to-day decisions on the ground may cause greater distress overall because of their prevalence, yet may not be appropriately identified or acknowledged. Meso-level issues within different departments of organizations also created friction: "being there" sometimes occurring for its own sake, even if it meant a tangible and measurable result was minimal. As Slim (2014b) indicates, most moral problems in humanitarian work arise because the ideals and principles presented in formal codes and commitments do not align with the context and capability of humanitarian operations, which are never ideal. For example, the "do no harm" principle is sometimes imperfect; it may only be possible to do the least harm, with something of moral significance being sacrificed. Recently, MSF refused a million free pneumonia vaccines from the pharmaceutical corporation Pfizer in a stand against the extremely high cost of many vaccines (Hamblin, 2016). Pfizer disagreed with MSF about how to do the least harm, asking "Is policy really more important than the opportunity to vaccinate and protect vulnerable people in emergency settings?" Because MSF's priority is to vaccinate as many children as possible in the long term, they chose the less imperfect option that will yield the greatest good, even though this meant many children might not receive the donated vaccine. As this example highlights, because of the tragic choice, even the most virtuous organizations will end up entangled in situations in which doing the morally right thing is impossible (Tessman, 2017).

Organizational and policy responses.

Organizations and their policies could play a key role by creating conditions that reduce the risk of moral distress for fieldworkers. Creating the conditions to reduce moral distress in fieldworkers could also reduce hardship for those they strive to serve, which is and ought to be their primary goal. Predeparture training has been identified by fieldworkers as relevant, given the acuity and time-sensitive nature of decision-making in the field (Fraser et al., 2015; Hunt et al., 2012). As expressed by participants in our study, the best decisions could not be made in the present because of forgotten past paths. Even if a small number of fieldworkers do not return due to experiences of frustration, moral distress or disillusionment related to ethical challenges they encounter, then it is possible that ethics-related preparation and support could enable some to sustain their humanitarian health work and promote more healthy, effective workers. Therefore, pre-departure training may lead to better institutional memory and mitigate ethical dilemmas experienced by fieldworkers on the ground, by introducing processes and procedures to staff and building skills.1

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¹ The Canadian Disaster and Humanitarian Response Training Program is one such pre-departure training course, which includes an in-class component, as well as a three-day simulation exercise that involves understanding of cultural context, war, natural disaster, and other challenges typically experienced by humanitarian responders. Courses of this nature aim to provide participants with the skills all humanitarians should possess before working in a disaster situation, for the benefit of fieldworkers and recipients of aid.

In the spirit of creating a culture of learning, and preserving institutional memory, there are several initiatives currently underway in the humanitarian community. One such initiative is Admitting Failure (www.admittingfailure.com). With the goal of sharing information and encouraging honest and open dialogue, it is described as "a space to publically acknowledge that something didn't work in order to ensure that the mistake isn't repeated." Similarly, MSF Analysis (msf-analysis.org) is a platform created by the Analysis and Advocacy Unit of MSF's Operational Centre in Brussels with the aim of promoting reflection and stimulating debate on both MSF's operations and the wider humanitarian arena. Recognizing that consideration must be given beforehand in order to respond in the face of an emergency, the significance of moral space is now being acknowledged within the humanitarian sector. As Fassin and Pandolfi (2010) suggest, "time rarely stops long enough for a true dilemma to be posed and ultimately resolved" (p. 281).

Recently, a motion initiative was put forward to MSF's Board in April 2016 requesting commitment to reflections, discussions, and concrete measures to promote ethics dialogue in order to improve humanitarian action and reduce moral distress (MSF, 2016). It calls for ethics to be integrated into the culture of the organization. It is not intended as another layer of bureaucracy – a concern expressed by one participant in this study – but rather as a support that will formalize the way ethical issues are identified and remembered so that mistakes are not repeated. This engagement – directed reflection and debate – is critical to

resolving ethical issues. Indeed, if recurrent sources of tragic choices can be identified, there is a possibility of establishing an effective feedback loop.

Importantly, ethics cannot become a stand-alone subject: previous research has shown that the word "ethics" may discourage usage of a Humanitarian Health Ethics Analysis Tool (HHEAT) designed to support fieldworkers seeking guidance in the field (Fraser et al., 2015). Indeed, for organizations not accustomed to hearing problems raised in these terms, an "ethical" problem can immediately take on dramatic importance and lead "unnecessarily into a predicament of extreme options" (Slim, 2014a, p. 7).

Improved dialogue may also mitigate dysfunctions between operations and medical departments of humanitarian healthcare organizations. Former head of the French section of MSF, Fiona Terry, made the controversial claim that humanitarian healthcare organizations act as though the initial decision to supply aid satisfies any need for ethical discussion and are often blind to the moral quandaries of aid (Terry, 2002). Participants in this study echoed these sentiments. While it is likely both departments value the same factors, they felt a sense of being pulled toward certain factors in favour of the others. Rather than fuelling personal conflicts of opinion, controversies could be elevated into meaningful debates about humanitarian medicine and its limits – including dialogue on managing the implications of policies, where relevant. For example, this may include understanding the ethical underpinnings of policies developed within an organization, and the moral implications for those living policy

applications. As well, novel ethical challenges raised by successful dialogue may be better anticipated and addressed.

Building on the previous thought, there is a need for improved dialogue not only within humanitarian healthcare organizations, but also between organizations and the local communities they assist. Questions of equity, and the role of local communities in setting priorities, fuel the current subject. Understanding how to adapt the principles that inform policy to local contexts so that communities can understand them in their own terms is critical to deliberations as well as the likelihood that communities will support policies. For example, previous research conducted by MSF described community members' bewilderment about the organization's set priorities for vertical programs that met one need, but not others they believed to be more important (Abu-Sada, 2012). As demonstrated by participant narratives in our study, in a desire to respond to the most vulnerable, the priorities of humanitarian healthcare organizations were also at odds with community perceptions and cultural practices, and did not reflect well local needs and values. This is not entirely surprising, as the current humanitarian system's organizations are mainly exogenous and come from outside affected countries, rather than being endogenously built from within societies facing conflict or disaster (Slim, 2014b). It would be useful to investigate the role local organizations play, and whether or not they have input into international organizations' policies, as they may have an understanding of both the local context as well as policies of international organizations.

It is often not possible to share resources all around so that everyone benefits, yet perhaps the most important underlying issue is that choices should not have to be made between individuals and groups. Ethical issues arising from circumstances in which decisions to prioritize care and allocate scarce resources between individuals are frequently experienced by clinicians as inescapable tragic choices (de Waal, 2010). This may be an indication that tragic choices dominate now, and require more examination to help avoid, resolve, or manage and live with them. In the event – which is always the case – that clinicians will need to make these decisions, explicit and consistent guidance could mitigate distress. Again, the need to make such decisions is largely due to a range of external features – global structures – and decisions taking place outside of humanitarian healthcare, related to how the world is organized (Hunt et al., 2012). Still, promoting engagement and discussion for reflection on these topics will help support fieldworkers through the development of clear policies for making well-considered and morally defensible decisions, and most importantly, better serve those in need.

Limitations

This study had several limitations. Firstly, we drew on a relatively small number of interviews; however, 14 interviews allowed for sufficient development of themes, and we were not attempting generalizations. Rather, our aim was to identify rich and detailed insights from a diverse set of people with in-depth experience in policy development, implementation, and evaluation in aid

organizations. Secondly, the three thematic areas we identified are illustrative examples based on perceptions of interviewees and await further expansion. We did not include a formal policy analysis – that is, it did not analyze and evaluate any particular aid organization policy or procedure. Rather, it was largely about the subjective experience of the policy end-user, and how his or her perception of policy – living and working in the policy shadow – interacted with ethical challenges. Therefore, it can be challenging to determine what perceptions collected reflect reality. Lastly, as our attempt was not to identify organizations, specificity of results was sacrificed in order to reduce the risk of deductive disclosure and to protect the identities of the individuals who participated in our research.

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Chapter 5 - Conclusion

My doctoral thesis set out to shed light on how policies of humanitarian healthcare organizations shape ethical dilemmas experienced by clinicians in the field, and to explore what can be done to improve policy clarity and success in order to advance responses to ethical challenges or avoid them altogether where possible. Given the potentially far-reaching effects of policy, the resources dedicated to policy processes, and the pivotal role humanitarian healthcare organizations play in disaster and conflict response, it seems reasonable to examine how policy is conceptualized and used in humanitarian healthcare organizations, as well as how it is developed, implemented, and evaluated. Therefore, this thesis is guided by the following research questions: i) What is the relationship between scholarly notions of policy, and the ways in which it is used in aid organizations?; ii) In the context of humanitarian healthcare organizations, how do policies originate, how are they implemented, and how are they evaluated?; and, iii) What are the ethical tensions that arise from aid agency policies and agendas or that trigger the need for policy development? These research questions are addressed through three qualitative studies organized around three main objectives:

To promote clarification of the concept of policy as it is understood from a scholarly standpoint, and to reflect on how humanitarian healthcare organizations use and apply policy

- ii) To better understand how policies are socially and institutionally constructed, implemented, and evaluated in humanitarian healthcare organizations
- iii) To explore how policies and ethics inform each other in order to better understand where tensions arise and how policy in humanitarian healthcare organizations can be improved in this regard

In this concluding chapter, I will summarize the key contributions of my dissertation research and reflect on their implications for organizational members of humanitarian healthcare groups and the populations they aim to help. I will also discuss the thesis' major substantive, methodological, and disciplinary contributions to the field. Following this, I consider the strengths and limitations of the thesis, and provide recommendations for future research.

The many faces of policy in humanitarian healthcare organizations

In Chapter 2, we begin by showing that defining precisely what is meant by policy is no easy matter, and a lack of clarity exists. There is a need to unpack the various concepts that get lumped into policy. What counts as policy reminds us, uneasily, of Humpy Dumpty's notorious remark in Lewis Carroll's (1934) *Through the Looking-Glass*:

"When I use a word,' Humpty Dumpty said, in rather a scornful tone, 'it means just what I choose it to mean—neither more nor less.' 'The

question is,' said Alice, 'whether you *can* make words mean so many different things.' 'The question is,' said Humpty Dumpty, 'which is to be master—that's all." (p. 205)

One can draw parallels between the above quote and the problem of how policy is conceptualized in humanitarian healthcare organizations. Determining a set of defining characteristics of policy is complicated by the understanding that people's viewpoints, and interpretations of instances of policy, may differ widely and are not static occurrences; instead, they are subject to modification as people consider and redefine instances of policy. My dissertation identifies core features of policy as a concept and represents an original contribution to the literature by showing how policy in a humanitarian context maps on to traditional notions of policy in academic literature. The results provide a foundation for additional development of the concept of policy through the identification of areas of ambiguity.

Articulating policy in ways that are relevant and useful to an extraordinary variety of humanitarian emergency situations highlights the important reality of context, which plays a critical role in determining how to operationalize many aspects of policy. Evidently, there is no single correct or universally agreed upon conceptualization or definition of policy that would apply to all contexts. It is sufficiently broad so as to capture a range of contexts. Instead of viewing policy as absolute and a hard and fast rule-set, it may have to be the exception that proves the rule: it may be useful to consider if policy ought to be put in place and

followed in a way that is adaptable for each given context. Policies can have an interpretive aspect that is helpful in the context; they are malleable.

Beyond conceptualization: Policy development, implementation, and evaluation

The results of Chapter 3 help us understand how policy is developed, implemented, and evaluated in humanitarian healthcare organizations. Through in-depth interviews with organizational members, we communicate and raise awareness of policy processes and bring a new perspective through respondents' narratives.

Policies that document correct procedures are needed for reference, dissemination, and quality control, and were considered as either supportive, hindering, or noticeably absent. Interviewees appreciated the important role of policy; however, even well formulated policies were considered to have their limits. For example, policies can help decision-making in the field, but each field is different, requiring further contextualization of the policy on the ground. The policy outline may be prescribed, but lesser information than is perhaps necessary is provided as to how to carry it out. This may lead to varied and erroneous application of policies in some contexts, and it can also require a lot from staff who do not have the skills, experience, or time necessary to develop appropriate or best practices.

While policy is necessary, it is not sufficient, and this analysis highlights the opportunities and limitations of policy – what it can and cannot do. As well, policies are designed as if they are not operator dependent, but they are: minimal involvement of fieldworkers to relate policies to the varied conditions and situations on the ground warrants the need for discussion and reflection to encourage the drive for a stronger evaluation of what works (reflecting a policy's headquarters-to-field validity), in order to better inform policies and develop them. Given the time and resources dedicated to policymaking, the importance of evaluation to informing policy and practice is key.

What exactly policies are asking users to do or accomplish, who will use policies, and where and when policies will be used ought to inform the development process. When developed so precisely, however, one wonders if a policy could apply in any other situation than the one for which it is developed. Practical deliberation and the application of prudential reasoning may allow users to go back and forth between contexts and realities with expansive policies that must be applied in different contexts.

Revealing the interaction between policy and ethical challenge

The results of Chapter 4 reveal something more than description can do.

They lay out some of the ethical tensions that affect the profession by identifying ethical challenges that arise from aid agency policies and practices, or that trigger the need for improved policy development. Policies may mitigate or alleviate

ethical challenges, but they may also be the source. It is important for humanitarians to identify and discuss ethical challenges and problems, to ensure responses to emergencies are not disconnected or lead to negative impacts.

Stepping back to reflect on past paths, known principles of good priority setting, and better involvement of communities to help harmonize priority setting, are important first steps that can lead to positive changes in policy and practice.

Study contributions

The work presented in this thesis consists of substantive contributions that provide a better theoretical and empirical understanding of policy and its applications; methodological contributions providing a range of approaches that can be adopted by others for developing a better understanding of how to support policy development, implementation, evaluation in humanitarian healthcare organizations; and, disciplinary contributions.

Substantive disciplinary contributions.

The original studies that make up this thesis contribute to the field of humanitarian research and study efforts that aim to support a clearer understanding of policy and ethics in humanitarian healthcare organizations. The work in Chapter 2 provides theoretical insights into understanding the ideas and concepts that make up policy. These insights may be useful for promoting a mutual understanding of the concept of policy in humanitarian contexts, which

can be meaningful for knowledge development and ultimately practice, and may also assist in identifying strengths and weaknesses in how humanitarian actors conceive the role of policy. Chapter 3 and 4 offer some insights by describing tensions arising from policies, although we do not yet know all of the features of policies that can help and strengthen circumstances and responses of humanitarian direction. Well-developed concepts are essential to building the scientific research base in this area. We offer a working definition of policy in Chapter 2, understood to be:

- 1. a collection of traits including adaptable, flexible, and broad; and
- 2. a label which supports the practice of these traits, and is applied to thoughts and principles which guide the overall activities of an organization
 This could be used as a starting point based on a rigorous conceptual analysis, which could go on to further examination and testing through its application.

Chapter 3 provides a detailed overview of how policy is developed, implemented, and evaluated in humanitarian healthcare organizations. It highlights how a combination of factors shapes these processes. Stories shared by organizational members of humanitarian healthcare organizations are useful to those involved in similar activities and who wish to consider how these factors might influence their own work. These responses will help future policymakers understand the matters at hand and inform policy processes in this regard.

Lastly, Chapter 4 yields novel output in the three thematic tensions presented. It also provides application implications that description alone cannot

achieve, and reflects variations on traditional methodological choices that intend to expose readers to the experiential reality of those working in humanitarian contexts and to inform the interpretive understanding of the larger social, historical, and cultural context within which practice occurs. Our focus on the experiences of organizational members complements published work in this field, and generates new insights that shape new inquiries as well as applications of evidence to practice.

Methodological contributions.

Chapters 2-4 contribute to the development of methodological approaches for undertaking work focused on understanding policy in humanitarian healthcare organizations. Chapter 2 uses an evolutionary concept analysis to generate findings that provide new conceptualizations of policy in humanitarian healthcare organizations, and establishes a clear application of this methodological approach for scholars undertaking similar analyses in the future.

Chapter 3 uses qualitative description to detail the phenomenon of policy development, implementation, and evaluation in humanitarian healthcare organizations, which, to our knowledge, has not been carried out as original research before now. The findings from this study may also provide working hypotheses or key categories for future theory-based research.

Finally, in Chapter 4, we enriched our analysis of interview data by extending qualitative description into the interpretive realm, realizing something

from a higher order of analysis that needed to be captured. From a methodological perspective, interpretive description facilitated exploration of the nature of ethical issues in humanitarian healthcare organizations by elucidating the interaction between ethical challenges and policies. Novel thematic categories generated from this study offer insights for exploring new avenues of inquiry related to humanitarian action.

We struggled with what interpretive description means in terms of data collection and analysis, as these approaches can vary. For example, multiple data collection strategies are often used in interpretive description to avoid a naïve overemphasis on interview data (Thorne et al., 2004). Therefore, we used sub-methodologies: a concept analysis informed by a critical review of the state of knowledge by way of a literature review formed the basis for constructing the dissertation, followed by qualitative description of interview data. Since interpretive description assumes investigators are rarely satisfied with description alone and are always exploring meanings and explanations that may yield application implications (Thorne et al., 2004), we delved into an interpretive account of our interview data to guide and inform disciplinary thought in some manner. Further guidance of analytic development in the validity of the approach for interpretive description would be welcomed.

Strengths and limitations

Together, the three studies presented in this thesis have several strengths. First, by focusing on an area with relatively sparse research about how policy is conceptualized and used in humanitarian healthcare organizations, and by drawing on humanitarian as well as political science literature, I have taken important initial steps toward to developing this area of research and providing a unique and potentially important contribution to the field. This multidisciplinary perspective also provides a comprehensive understanding of the factors that shape policy use and conceptualization in humanitarian healthcare organizations. While the findings of this thesis will be relevant to those who support policy processes in such organizations, the study concepts and approaches will also be of interest to scholars in political science, philosophy, and health policy.

Another strength is the triangulation of different methods to help establish credibility and external validity of findings. While Chapters 2-4 occurred in distinct steps that can stand alone, each relies on the other and the interpretive description approach helps draw the studies together. For example, the conceptual analysis presented in Chapter 2, which includes a thorough literature review, provides a foundation for gathering new data and supported the need for the descriptive and interpretive analyses. In Chapter 3, empirical evidence generated by interviews yields a direct and simple description of policy development, implementation, and evaluation. Chapter 4 relies on the knowledge generated in the previous chapters to culminate in a higher order analysis that enriches qualitative description by extending it into the interpretive realm, by re-

exploring interview data to draw out nuances. In developing Chapter 4, I met with my thesis supervisor and research team – comprised of qualitative research experts – to review the process of data analysis and discuss potential identified patterns. As Thorne et al. (2004) note, expert guidance to novice researchers facilitates the interpretive process by helping the researcher work through earlier assumptions and make sense of the emerging concepts and themes. Marck et al. (2010) suggest the rigor of study interpretations is also strengthened with contributions from these experts. Including verbatim quotes, along with interpretation, also helps the reader see how conclusions were drawn.

This dissertation has several limitations. For Chapters 3 and 4, we draw on a relatively small number of interviews; however, we achieved an appropriate sample size for the aim of the study, and we were not attempting generalizations. The findings we describe may be applicable to similar populations in similar contexts, and are illustrative examples that await further expansion. This analysis was also based on the perceptions of interviewed organizational members, and while in no way does this diminish the value of feedback for humanitarianism, perceptions are just that: perceptions, and detailed accounts of participants' experiences (Nouvet et al., 2016). We have not been able to collect empirical data that corroborates the feelings respondents expressed. Instead, we have their perceptions of ethical challenges and these are important as they describe the frustrations, problems faced, and ways forward.

This thesis did not include a formal policy analysis – that is, it did not analyze and evaluate any particular aid organization policy or procedure. Rather, it was largely about the subjective experience of the policy end-user, and how his or her perception of policy – living and working in the policy shadow – interacted with ethical challenges. Therefore, it can be challenging to determine what perceptions collected reflect reality. Lastly, as our attempt was not to identify organizations, specificity of results was sacrificed in order to reduce the risk of deductive disclosure and to protect the identities of the individuals who participated in our research.

Future research

While this thesis addressed numerous gaps in the research literature, it also identified important areas awaiting further exploration. For example, findings from Chapter 2 are a preliminary attempt at conceptualizing policy in humanitarian healthcare organizations. They may be used as a point of departure for other similar investigations to understand different ways of working with a certain concept, and in identifying commonalities and differences in order to better coordinate work within the humanitarian sector.

Ethics at the core of humanitarian practice needs to be emphasized.

Integrating ethics into organizational culture could assist policy makers in developing better policies and humanitarian healthcare workers in making choices, and in helping explain why certain decisions have been made, in order

to mitigate moral distress. It would be interesting to determine if these decisions are linked in any way to policy development.

As this thesis demonstrates, what happens in humanitarian healthcare organizations sometimes occurs organically and strategically, manifesting as unwritten policy and hidden knowledge. A simultaneous qualitative study was taking place exploring the perceptions of healthcare providers and other field workers, and the ethical challenges around organization policy. A manuscript produced from this project, led by colleague Dr. John Pringle (2017), found that unwritten policy may be perceived positively or negatively, depending on the outcome. Similarly, feelings toward a written policy may be positive if the policy was perceived as helpful in navigating ethical perils or protecting from moral distress. Conversely, feelings may be negative if the written policy was perceived as exacerbating a bad situation or impeding ethical decision-making. It seems fair to add that there are no policy solutions to humanitarian problems, and as Pringle (2017) notes, ethical challenges stem from broader political and ideological failures resulting in inhumane conditions that necessitate humanitarian response. Policy it seems, at best, can only anticipate and mitigate ethical challenges. Research that aims to gain additional insights from other relevant fields in order to revise or strengthen these ideas of the interaction between policy and ethical challenge would be welcome.

To conclude on a point of reflection, there is a movie called 'Metro Manila'.

It is the story of protagonists Oscar and Mai, an honest and loving couple who

decide to move their young family from a remote province to Manila in hopes of finding better work. Nothing could prepare them for the harsh reality they encounter there, and Oscar and Mai make desperate sacrifices. Oscar accepts a position as a security guard, and constantly weighs his desire to do what is right versus the obligation he feels he owes to his mentor and boss who, by the very nature of the job, exposes him to the dark side of crime and corruption inherent in the position. The film mirrors perhaps an aspect of the harsh realities faced by practitioners implementing policies in the field: what options exist sometimes come at great personal cost. Policy continues to emerge, grow, change, and evolve, and an uncertain and fast changing world poses challenges for policy in humanitarian healthcare organizations. There is growing recognition that flexible and adaptable approaches to policy are needed in an increasingly complex world, and the future will be strongly formed by the insightfulness of those learning as they walk, navigating amidst familiar and new paths.

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Appendix A

EMAIL SCRIPT

Dear [insert name],

My name is Leigh-Anne Gillespie and I am from the Health Policy PhD Program at McMaster University. I belong to the humanitarian healthcare ethics (hhe) research group with Drs. Lisa Schwartz and Matthew Hunt, http://humanitarianhealthethics.net/. I would like to let you know about a research study regarding ethical issues arising from health-related humanitarian aid that may be of interest to you or your colleagues.

Because of your involvement in humanitarian aid work, you were identified as a potential participant, and/or an individual who could forward this information to potential participants.

We are interested in interviewing 1) individuals with experience in writing, implementing, or evaluating policies in acute humanitarian emergencies, or 2) individuals with experience as part of a humanitarian healthcare team during acute humanitarian emergencies, to learn more about these experiences. Participation would involve a 45-90 minute interview by phone, Skype, or in person. Some of the questions include:

- (1) What are types of ethical challenges that occur in resource poor settings and areas of disaster and conflict?
- (2) How have healthcare providers responded to these challenges?
- (3) What role if any have policies played in these challenges?
- (4) What kinds of preparations/resources have been helpful, or would be helpful, in supporting healthcare providers in dealing with these ethical challenges?

If you have any questions or would like to participate in our research study, please review the attached information and contact:

Policy personnel – Leigh–Anne Gillespie (gilleslb@mcmaster.ca)

Healthcare fieldwork – John Pringle (john.pringle@mcgill.ca)

For more information on our program of research, please visit http://humanitarianhealthethics.net/. We look forward to hearing from you.

Sincerely,

Leigh-Anne Gillespie

Ph.D. (cand.), Health Policy McMaster University

Email: gilleslb@mcmaster.ca

Dr. Lisa Schwartz (Principal Investigator) McMaster University 1-905-525-9140 ext. 22987;

Email: schwar@mcmaster.ca

Dr. Matthew Hunt (Principal Investigator) McGill University 1-514-398-4400 ext. 00289;

Email: matthew.hunt@mcgill.ca

Appendix B

LETTER OF INTRODUCTION TO PROSPECTIVE INTERVIEWEES

April 7, 2014

Hamilton Integrated

APR 1 4 2014

Research Ethics Board



Dear Sir or Madam,

We would like to let you know about a research study we are currently carrying out that may be of interest to your organization. We ask you to share this information with others for possible participation. The title of the interdisciplinary, qualitative study is *Ethics and humanitarian healthcare practice and policy (EHHPP) during acute crisis response in low or middle-income countries*. Our objective is to better understand the ethical issues arising from health-related international humanitarian aid programs in settings of disaster, conflict, or complex emergencies. This is a follow up study to a previous project described in Schwartz L, Sinding C, Hunt M, Elit, L, Redwood-Campbell, L, Adelson, N, Luther, L, Ranford, J, de Laat, S. "Ethics in humanitarian aid work: Learning from the narratives of humanitarian health workers". *AJOB Primary Research*. 2010;1(3):45-54. You can access this paper at https://www.humanitarianhealthethics.net/index.php?option=com_content&view=article&id=80&Itemid=259.

The current study aims to capture and compare the views of two groups:

- Members of international humanitarian healthcare teams responding in acute crises (e.g., healthcare professionals, water and sanitation specialists, logisticians, etc.); and
- Individuals with experience or currently involved in the writing, implementation or evaluation
 of policies related to healthcare provision in acute crises (e.g., directors, policy makers, human
 resource managers, senior medical advisors, field level administrators, etc.).

Individual, open-ended interviews will be employed, as they are well suited for exploring narratives and the more complex nature of decisions and experiences.

Funded by the Canadian Institutes of Health Research (CIHR), this study has been reviewed and approved by the Hamilton Integrated Research Ethics Board (HiREB) and the Institutional Review Board of the Faculty of Medicine, McGill University.

If you or other prospective participants have questions, would like additional information, or are interested in participating, please contact Sonya de Laat at <u>delaat@mcmaster.ca</u> or 905-525-9140 ext. 28604. You may also visit our website for further information on this study and on humanitarian healthcare ethics more generally: http://humanitarianhealthethics.net/. A poster for circulating and advertising within your organization is enclosed.

Sincerely,

Dr Lisa Schwartz (Principal Investigator) McMaster University 1-905-525-9140 ext. 22987; email: schwar@mcmaster.ca

Dr Matthew Hunt (Principal Investigator) McGill University 1-514-398-4400 ext. 00289; email: matthew.hunt@mcgill.ca







Appendix C

RECRUITMENT POSTER





A New Study!

Ethics in Humanitarian Healthcare Practice and Policy During Acute Crisis Response in Lower and Middle Income Countries

 To better understand ethical issues arising from health-related humanitarian aid in settings of disaster, conflict, or complex emergencies.

Interviews will be conducted by phone, by Skype, or in person at a time convenient for you, and will take approximately 45-90 minutes.

Confidentiality: All personal information will be removed from the data. Participants will receive a small honorarium.

We seek participants for interviews!

- Policy personnel: Individuals with experience in writing, implementing or evaluating policies in acute humanitarian emergencies.
- Healthcare fieldwork: Individuals with experience as part of the humanitarian healthcare team during acute humanitarian emergencies.

For more information please contact:

<u>Policy personnel</u>: Leigh-Anne Gillespie (gilleslb@mcmaster.ca) <u>Health care fieldwork</u>: John Pringle (john.pringle@mcgill.ca)









Appendix D

LETTER OF INFORMATION/CONSENT FORM FOR INTERVIEW **PARTICIPANTS**







Letter of Information /Consent for Policy Personnel Ethics in Humanitarian Healthcare Practice & Policy **During Acute Crisis Response in Lower and Middle Income Countries**

Investigators:

Dr. Lisa Schwartz (Principal Investigator) McMaster University (905) 525-9140 ext. 22987 email: schwar@mcmaster.ca

Dr. Matthew Hunt (Principal Investigator) McGill University (514) 398-4400 ext. 00289 email: matthew.hunt@mcgill.ca

Research Sponsor: Canadian Institutes of Health Research (CIHR)

Purpose of the Study

In this study, we want to better understand the ethical issues arising in health-related international humanitarian aid programs in settings of disaster or conflict.

What is involved in the Research?

If you are an individual with experience in – or currently involved in – writing, implementing or evaluating policies in acute crises such as disasters, conflicts, or complex emergencies, then we are interested in interviewing you. If you participate in our study, an experienced interviewer will interview you about your thoughts and experiences regarding this line of policy work. Interviews are also being conducted with individuals who have experience in humanitarian healthcare fieldwork during acute crises. These individuals are being asked about the ethical challenges they encountered in their line of work, and any relations to policy.

The interviewer will encourage you to speak in depth and detail about situations you found ethically difficult, to discuss your responses to the situation (if a response was possible or required) and how you came to that response. The interview will be conducted by phone, by Skype, or in person at a time convenient for you, and will last for approximately 45-90 minutes. With your permission the interview will be audiotaped. You may be asked if you are willing to participate in a follow up interview, to clarify what you have said earlier, and to comment on our emerging ideas about what we are learning. If you consent, the second interview will last approximately 1/2 hour, and will also be audiotaped.

Version date: 07/04/14

Protocol date: 05/22/12

1 of 4

Potential Harms, Risks or Discomforts:

Despite our attempts at confidentiality, it is possible that the narratives you recount might still identify you. This may have negative personal and professional repercussions. We will attempt to mitigate these harms to the extent outlined in the 'Confidentiality' section below.

It is possible that it will be uncomfortable or upsetting to talk about ethically difficult situations you encountered. The interviewer will not rush or pressure you. You do not need to speak of any situation that is too upsetting or disclose anything that you wish to keep private. If you wish to take a break, you are welcome to. If you wish to end the interview, you are welcome to do that as well. The interviewer will have information about support resources you may choose to access following the interview.

Potential Benefits:

We hope with this research to provide resources and guidance to policy makers and individual health workers struggling through ethically challenging situations. These resources may not benefit you directly. However we will make them available through publications and presentations, and they may be of use to you and your colleagues.

Payment or Reimbursement:

You will receive a gift certificate of \$25 for your participation in the interview.

Confidentiality:

Your interview will be digitally audio-recorded so that it can be re-reviewed and transcribed (written down word-for-word). Informed consent forms and audio-recordings will be kept under lock and key in the Principal Investigators' offices. Electronic copies of transcripts and digital audio-recordings will be password protected on research team computers. Only researchers involved with this study will hear the recordings or read whole transcripts. Recordings and transcripts will be retained for a minimum of ten years after the study results are published.

During data collection and analysis, we will use an ID number instead of your real name. Only the Principal Investigators, Interviewer and Research Ethics Board (REB) would be able to link your ID number with your real name. Your name, names of any organizations you mention, and personal names in the stories you tell will also be removed when the recordings are transcribed and will be replaced by placeholders. Demographic information about study participants will only be presented in an aggregated form. To the best of our ability, we will not make public personally identifying information about you unless required by law. If the results of the study are published, your name and the name of your organization will not be used and your identity will not be released or published without your specific consent to the disclosure.

However, despite our efforts, anonymity cannot be absolutely guaranteed as there is the possibility that specific stories that are included in the study findings, even once names are removed, might be recognized by others and associated with you or with your organization. You are free to ask that any particular story or revelation not be included in the study data.

2 of 4

Version date: 07/04/14 Protocol date: 05/22/12

Participation:

Your participation in this study is voluntary. It is your choice whether or not to participate. If you decide not to participate in this study, there is no consequence to you. If you do decide to participate, you may decline to answer any interview questions. If you decide to participate but change your mind later, you may do so without explanation or penalty. You may withdraw from the study up until the time that data analysis is completed. The approximate date for data analysis completion is the autumn of 2015.

Information About the Study Results: A final report from the study will be available on the McMaster Ethics in Health Care website http://fhs.mcmaster.ca/ethics/.

Information about Participating as a Study Subject: If you have questions or require more information about the study itself, please contact Dr. Lisa Schwartz at (905) 525-9140 ext. 22987 or Dr. Matthew Hunt at (514) 398-4400 ext. 00289.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB) and the Institutional Review Board of the Faculty of Medicine, McGill University. The REB 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 questions about your rights as a research participant, please call The Office of the Chair, HiREB at 905.521.2100 x 42013 or Ilde Lepore, Senior Ethics Administrator, Faculty of Medicine IRB at (514) 398-8302 (at McGill University).

Version date: 07/04/14 Protocol date: 05/22/12 3 of 4

CONSENT

Email:

I have read the information presented in the Letter of Information about this study entitled "Ethics in Humanitarian Healthcare Practice & Policy During Acute Crisis Response in Lower and Middle Income Countries" being conducted by Dr. Lisa Schwartz of McMaster University and Dr. Matthew Hunt of McGill University. I have had the opportunity to ask questions about my involvement in this study, and to receive any additional details I wanted to know about the study. I understand that I may withdraw from the study at any time, if I so choose, as explained in the Letter of Information. I agree to participate in this study. I have been given a copy of this Consent Form.

1. I agree that the interview can be audio recorded.

If yes, where would you like the results sent:

2. I would like to receive a summary of the study's results. Yes

Mailing address:		Research Ethics Board
the request. Yes	bout future research and I understand No	I that I can always decline
Please contact me at:		
Name of Participant	Date (yyyy-m	m-dd)
	A Consent: The sest that I have explained the nature and the study participant, and I have answer	
Name of Person Obtaining Informed Co	nsent (print) Signature of Person Obtaining Informed	Consent Date (yyyy-mm-dd)
Version date: 07/04/14	Protocol date: 05/22/12	4 of 4

Hamilton Integrated

APR 1 4 2014

Appendix E

INTERVIEW GUIDE FOR QUALITATIVE INTERVIEWS OF PERSONNEL INVOLVED IN POLICY, REGARDING ETHICAL DILEMMAS DURING ACUTE CRISIS RESPONSE

PRE-INTERVIEW BRIEFING

Before we start and before I start recording, I'm just going to go through a quick overview of the research project and the interview process.

The purpose of this research project is to collect stories of ethical challenges faced by policy personnel involved in the development, implementation or evaluation of policy related to work in resource-poor settings and areas of disaster and conflict. We would like to investigate the types of ethical situations encountered, how policy responds to these challenges, and what means and strategies factor into the decisions around their development, implementation and revision.

There are a variety of ways to understand "ethical challenge". "Ethical challenge" involves notions of right and wrong, where perhaps the right thing to do isn't clear, or perhaps it is clear but you can't do anything about it, or you have to compromise or do the wrong thing. Maybe it didn't seem like an ethical challenge at the time, but you felt uncomfortable about it afterward: those thoughts that come back to you at night and maybe disturb your sleep. Do you understand what we mean by "ethical challenge", and is this how you understand "ethical challenge"?

We would also like to ask for your permission to audio-record this interview. Your responses, identifying information, and other names mentioned – including the names of organizations – will be kept confidential as explained in your Consent Form. If information from this study is published or presented in any manner, your name will not be used. You may also request that a particular story or revelation not be included in the study data. Your participation in this study is completely voluntary and you may withdraw from the interview at any time. Please let me know if there are any questions you find too sensitive to answer. I will gladly move on to the next question.

Please feel free to look over this consent form and ask any questions that you may have. (Have consent form available with main points highlighted)

The interview will take about 45 minutes to an hour and a half. Do you have any questions before we begin? Then with your permission, I will start recording.

MAIN RESEARCH QUESTIONS

- (5) What are types of ethical challenges that occur in resource poor settings and areas of disaster and conflict?
- (6) How have healthcare providers responded to these challenges?
- (7) What role if any have policies played in these challenges?
- (8) What kinds of preparations/resources have been helpful, or would be helpful, in supporting policy personnel in dealing with these ethical challenges?

Length: 45 min – 90 minutes

*** Priority questions

INTERVIEW QUESTIONS

- 1. Do you consider yourself as speaking on behalf of your organization or as individual?
 - Are you authorized to speak on behalf of the organization?
 - 2. Can you give me a brief overview of the humanitarian relief work you have done?
 - Probe for:
 - Locations and durations
 - ii. Duties
 - iii. Contexts
 - iv. Organizations
 - If there are many examples, direct participant to focus on acute crisis settings during the interview
- 3. We are interested in knowing how policies are formed, implemented, and evaluated in this organization.
 - What are some examples of policies in this organization?
 - How are policies formed in this organization?
 - Are values such as the expressed core values of the organization deliberately considered/invoked when policies are being formed? If so, how? Are there any external documents that inform this process (e.g., Sphere, World Medical Association statements)?
 - What are some of the key policies (written or unwritten) in your organization that you believe raise ethical issues or are responsive to ethical issues experienced by health professionals in the field?

- How are policies formed/revised in this organization in response to ethical concerns?
- 4. Can you describe a situation(s) where policies or a lack thereof caused an ethical challenge in the field?

An ethical challenge may look like:

- Ethics has to do with our ideas about right and wrong
- We are thinking about situations where for instance when the right thing to do isn't clear or the right thing to do is clear but you can't do anything about it, or there is a sense that it is wrong but you have to do it.
- When right and wrong bump up against each other.
- The ethically preferred response is unclear
- The ethically preferred response is clear but cannot be enacted
- The actor must choose between equally acceptable responses to a situation
- The actor must choose between equally unacceptable responses to a situation
- Afterwards I felt very uncomfortable about it
- I knew it was wrong
- Knowing what I ought to do, but couldn't do anything about it
- a) What was your role in addressing this issue? How was it addressed by the organization?
- b) Did this situation lead to a new policy or revision of the exiting policy?
- c) Are you satisfied with the policy that emerged, is it effective (was it implemented/operationalized on the ground according to the original vision, was the policy fully translated into practice)? Do you think the policy addressed the issue? What could have happened differently?
- d) How are policies (is this policy) evaluated?
- 5. How are the ethical challenges faced in these disaster response situations similar to or different from ethical challenges in healthcare practice in [country of origin]? What accounts for these differences? Are there factors beyond the fact that a disaster has occurred?
- 6. How are ethics addressed within your organization? Is ethical discussion a component of the practices and culture of the organization?

7. How are health professionals trained or supported for ethical challenges in your organization?

Debrief

This brings us to the end of my questions. Before we finish, is there anything you would like to add or clarify about what we discussed today?

Thank you. I am now stopping the recording.

We would appreciate it if you could provide us with the names of two other healthcare workers who you know have done humanitarian relief work in the last 6 months. (Ask if they could either provide the name/contact information or, if they are uncomfortable with releasing this information, agree to contact these people on our behalf).

Thank you very much for your time. We have learned a lot from your stories and appreciate gaining your perspective on these topics.

[END]