

M.Sc. Thesis - Gautham Krishnaraj; McMaster University - Global Health
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HUMANITARIAN POLICY-MAKER PERSPECTIVES ON PALLIATIVE CARE
By Gautham Krishnaraj, B.Sc. (Microbiology & Immunology)
A Thesis Submitted to the School of Graduate Studies in Partial Fulfilment of the
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McMaster University MASTER OF SCIENCE (2017) Hamilton, Ontario (Global Health)

TITLE: HUMANITARIAN POLICY-MAKER PERSPECTIVES ON PALLIATIVE CARE

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#### **ABSTRACT:**

**Background:** In the face of overwhelming need and increasingly scarce resources, the humanitarian charge of "saving lives and alleviating suffering" is often reduced to simply saving lives. In 2014, World Health Assembly Resolution 67.19 called for the strengthening of palliative care as a key component of comprehensive care. However, even when palliative care is the only available option (ie. 2014-2015 Ebola Crisis), there is little evidence showing it is available in the field. More research is needed to understand this dissonance between policy and practice, and to ensure that humanitarians are providing ethical and contextually appropriate care.

**Methodology:** Twelve individual, in-depth, semi-structured interviews were conducted in English and French with humanitarian healthcare policy makers from North America, Europe, and the Middle East, average 10+ years of experience representing various international organizations. Interviews were transcribed and coded using NVivo11 and an interpretive description framework.

Findings: Participant comments suggested the existence of an institutionalized rescue culture, characterized by the fear of failure, equating of death with failure of the humanitarian healthcare professional, and a resultant systemic devaluation of palliative-type care in disaster contexts. The indoctrination of this culture may begin as early as medical school, and manifests clearly in the lack of consistent nomenclature and awareness of palliative care, treatment of palliative-triaged individuals, and resources

allocated to palliative care in humanitarian contexts. Palliative care provision is a moral obligation as a final bastion of the human right to dignity and to health.

**Discussion & Conclusion:** In order for palliative care to be integrated into the humanitarian mandate, a significant cultural shift must first take place. The findings of this thesis and the larger Humanitarian Health Ethics study will provide key guidance for the adoption and adaptation of policies that help humanitarians maintain the dignity of individuals in their most vulnerable moments.

#### ACKNOWLEDGMENTS

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#### LIST OF ABBREVIATIONS AND SYMBOLS:

HCP - Humanitarian Health Care Provider

WPCA - World Palliative Care Alliance

ICRC - International Committee of the Red Cross

MSF - Médecins Sans Frontieres - Doctors Without Borders

MdM - Médecins du Monde

UN - United Nations

WHO - World Health Organization

WFP - World Food Programme

UNICEF - United Nations Children's Fund

UNHCR - The United Nations High Commissioner for Refugees

OCHA - Office for the Coordination of Humanitarian Affairs

IASC - Inter-Agency Standing Committee

WMA - World Medical Association

ICN - International Council for Nurses

IFP - International Federation of Pharmacologists

ICMM - International Committee for Military Medicine

PPE - Personal Protective Equipment

IHL - International Humanitarian Law

## THESIS TOPIC SELECTION & DECLARATION OF ACADEMIC ACHIEVEMENT

The topic for this thesis arose from working with the Humanitarian Health Ethics (HHE) Research Group at McMaster University. In 2016, HHE was awarded an Enhancing Learning & Research for Humanitarian Assistance (ELRHA) Research for Health in Humanitarian Crises (R2HC) grant to investigate the Ethics of Palliative Care Provision in Humanitarian Contexts. Through consultation with Drs Lisa Schwartz (Supervisor and Co-PI), Matthew Hunt (Committee Member and Co-PI), and Elysee Nouvet (Committee Member and Co-I), I was able to carve out a significant piece of the larger R2HC-funded study to focus on for my thesis. The focus on rescue culture arose from the data, and I am responsible for the interpretive analysis presented in the following thesis.

All content presented in this document was written and completed by Gautham Krishnaraj, acknowledging the contributions of Drs. Lisa Schwartz, Matthew Hunt, Elysee Nouvet, and members of the Humanitarian Health Ethics Research Group, who developed research documents (letter of information and consent, interview guide, codebook etc), conducted interviews, and guided my analysis.

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#### **Chapter One: Introduction**

"I solemnly pledge to consecrate my life to the service of humanity"

(World Medical Association Declaration of Geneva, 1948)

Known as the "Modern Hippocratic Oath", the World Medical Association's (WMA) Declaration of Geneva is a document of great medical gravitas. According to the World Health Organization (WHO), the WMA is the recognized authority for physicians to speak on international affairs, and to promote of the highest standards of medical care. Above is the first pledge that is made upon entering into the medical profession, calling for a lifelong dedication to serving and preserving humanity. The first documented use of the word "humanitarian" occurred over 100 years prior to the Declaration of Geneva, to describe an attitude of trust in humanity, but slowly adapted to reference anything that "intended to benefit humanity" (Brauman, 2012). Using this definition, it could be argued that every physician, regardless of time spent 'in the field', is charged with being a 'humanitarian' from the moment they first picked up the stethoscope. While the term 'humanitarian' remains a contested one, most would agree that its usage should, and does, extend far beyond the role of the physician. The modern humanitarian roster would be severely lacking without the services of nurses, engineers, lawyers, journalists, and many other key professionals who play a critical part in delivering holistic, integrated, and effective humanitarian response. However, in recognition of the key responsibilities and abundance of physicians in the decision making roles of humanitarian organizations, I

believe that the World Medical Association's policies can serve as an appropriate entry point into this thesis.

# 1.1 The World Medical Association (WMA) & The Ebola Crisis in West Africa World Medical Association Policies Involving Palliative Care

Following the Declaration of Geneva, the WMA and its associated National Medical Associations (NMAs) have adopted a number of policy documents (Statements, Declarations, Codes, and Resolutions) to guide and set international norms for medical care in times of peace and unrest. Many of these documents provide the basis for discourse on medical ethics, end-of-life issues, and healthcare in disaster contexts. The first of the relevant documents was the WMA International Code of Medical Ethics, which was adopted at the 3rd World Medical Assembly, and amended at the 22nd (1968), 35th (1983), and 57th (2006) General Assemblies. Here, enshrined among many other charges of the physician, is the call to be dedicated to providing medical service with compassion and respect for human dignity.

This reference to medical care as a preserver of dignity also appears in the WMA Statement on Medical Ethics in the Event of Disasters, which was adopted at the 46th General Assembly (1994) and revised at the 57th (2006). The Statement goes beyond the aforementioned Code of Medical Ethics, specifically stating that patients who cannot be cured must be shown "compassion and respect for their dignity" and that "the dignity of survivors *and* their families must be respected". In this Statement, there is also extensive

discourse surrounding the ethics of triage as it is applied in disaster contexts; the WMA asserts that it is ethical for physicians to not persist in "wasteful" therapeutic efforts when resources are scarce. However, the WMA also states individuals deemed "beyond emergency care" must receive dignified care, which includes the administration of "appropriate pain relief and sedation", which are key (but not the only) elements of palliative care. Determining what is "wasteful" and what is "dignified" becomes a matter of subjective and professional opinions, and it must be recognized that dignity is a complex and thoroughly debated topic in and of itself.

Because the Statement on Medical Ethics in the Event of Disasters uses a functional definition of disasters that explicitly "excludes situations arising from conflicts and wars, whether international or internal", the WMA adopted a set of Ethical Principles of Health Care in Times of Armed Conflict and Other Emergencies at the 65th General Assembly in 2014. It is important to note that this set of principles were created through ICRC consultations with the WMA, the International Council of Nurses (ICN), International Pharmaceutical Federation (IFP), and International Committee of Military Medicine (ICMM). Here too (and perhaps as a consequence of a larger diversity of health professionals being consulted), there is an emphasis of the obligation to provide dignified and holistic care, stating:

"the primary task of health care personnel is to preserve human physical and mental health and to alleviate suffering. They shall provide the necessary care with humanity, while respecting the dignity of the person concerned, with no discrimination of any kind, whether in times of peace or armed conflict and/or other emergencies".

Interestingly, the Principles also call on health-care personnel to "make their best efforts to ensure respect for the privacy of the wounded, sick, *and deceased*" [italics not in original] (WMA, 2014). Once again, the care of individuals who cannot be saved is foregrounded as a critical responsibility of the health care professional, indicating that the alleviation of suffering remains important even in Armed Conflict/Emergency contexts.

The first of the WMA's Ethical Principles of Health Care in Times of Armed Conflict and Other Emergencies posits that "Ethical principles of health care do not change in times of armed conflict and other emergencies and are the same as the ethical principles of health care in times of peace" (WMA, 2014). As such, it is valuable to briefly look at the WMA Declaration of Venice on Terminal Illness (Adopted 35th WMA in 1983, revised at the 57th in 2006), the WMA Declaration on Euthanasia (Adopted by 39th WMA in 1987, reaffirmed at 170th WMA in 2005, and 200th in 2015), the WMA Statement on Physician-Assisted Suicide (Adopted by 44th WMA in 1992, revised by 170th WMA in 2005, and reaffirmed by 200th WMA in 2015), and the WMA Declaration on End-Of-Life Medical Care (Adopted by 62nd WMA in 2011) for more specific discourse on end-of-life in peacetime settings. First, it is important to highlight that all four documents explicitly condemn Euthanasia as ethically unacceptable, regardless of context. The Declaration on Euthanasia clarifies that this does not include the physician allowing "death to take its natural course", which is deemed ethically acceptable. The

Declaration of Venice reiterates that "the duty of physicians is to heal, and where possible, to relieve suffering", while recognizing that end-of-life care has "historically not received the attention it deserves" (WMA, 1983). Physicians are called upon in the Declaration on End-Of-Life Medical Care to "adopt an attitude to suffering that is compassionate and humane, and act with empathy" and states that failure to do so constitutes an unacceptable "abandonment of the patient" in need. The Declaration goes on to state that "receiving appropriate end-of-life care must not be considered a privilege, but a true right, independent of age or any other associated factors" (WMA, 2011).

Despite the clear and consistent assertion throughout the WMA policies that end-of-life care is a vital part of the physician's responsibility as a preserver of dignity and humanity, there is reason to believe that the realities of practice may not reflect these aspirational policies.

Sentinel Case: The 2014 Ebola Crisis in West Africa

In 2014, the Ebola Crisis in West Africa challenged international humanitarian response mechanisms, as there was no vaccine or cure for this viral pathogen which had a 95% mortality rate in some regions (WMA, 2014). The logical assumption would be that with such strong policy precedence, end of life/palliative care would be presented as the immediate response priority by the WMA. However, this was not the case. The 2014 WMA Resolution on the Ebola Viral Disease adopted at the 65th General Assembly in Durban, South Africa, contained no mentions of palliative care, psychosocial efforts,

bereavement/grief support, or engagement with families and communities. In the face of an international crisis where the alleviation of suffering was the only available measure, the WMA called for all things except palliative care. There were appeals for greater international cooperation, increased research capacity, and more robust personal protective equipment (PPE) protocols, but not a single indication was made to the importance of preserving the dignity and humanity of those who would inevitably die from the disease. The Ebola Crisis therefore serves as the sentinel case for this thesis, showing that even when palliative care is all that can be offered, it is still far removed from the realities of humanitarian practice.

The lack of palliative response to the Ebola crisis may be indicative of the existence of structural, cultural and/or personal barriers inhibiting the integration of end-of-life care into the humanitarian healthcare agenda. The objective of this thesis and the larger study within which it is embedded is to delve deeper into the realities of end-of-life care in disaster contexts, to better understand the experiences, barriers, and potential future directions of palliative care provision in humanitarian response. This will be done through a brief history and literature review, which will provide the theoretical background for a presentation of key informant interview findings. These interviews will have common themes abstracted, from which recommendations and implications will be highlighted for discussion, and future research and actions will be suggested.

#### 1.2 Thesis Structure

Chapter One is intended to serve as an entry point to the discussion of palliative care in humanitarian contexts, focusing on the World Medical Association and the 2014 Ebola Crisis in West Africa. Chapter Two will examine the historical foundations of humanitarianism through the establishment of what are arguably the three largest actors in the sector, followed by a review of relevant literature and the gaps that exist, concluding with the research questions that guided this thesis study. Chapter Three will discuss the methodology and analytical framework that was used for the collection, analysis and presentation of the study data. Chapter Four will then present the findings, followed by Chapter Five which will discuss the limitations, implications, future directions and conclusions drawn from this research study. References can be found in Chapter Six.

#### 1.3 Definitions

There are a few functional definitions that must be provided in order to set the stage for the remainder of this thesis. First, the terms supportive care, end-of-life care and non-curative care will be used interchangeably with palliative care throughout this thesis; and the definition of palliative care will be the one employed by the WHO:

Palliative Care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WPCA, 2014)

Furthermore, for the purposes of this thesis, I will use the definition of Humanitarian Assistance/Action that is presented in the WHO-published ReliefWeb Glossary of Humanitarian Terms, which begins as follows; "Aid that seeks, to save lives and alleviate suffering of a crisis-affected population" (WHO 2008). I will define Crisis as synonymous with Emergency, which is defined in the ReliefWeb Glossary as "A sudden and usually unforeseen event that calls for immediate measures to minimize its adverse consequences" (WHO 2008). I will specifically define a Humanitarian Healthcare Crisis as a situation in which a sudden, unpremeditated event has overcome, damaged, or destroyed the existing healthcare system (state or non-state), requiring the intervention and support of international organizations for the provision of basic medical care. This definition is adapted from ReliefWeb Glossary definition of 'Disaster' as a "serious disruption of the functioning of a community or a society causing widespread human, material, economic or environmental losses which exceed the ability of the affected community or society to cope using its own resources (WHO 2008).

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#### **Chapter Two: Background**

This chapter will provide background drawn from the literature pertaining to the provision of palliative care in humanitarian contexts with the aim of of providing a thorough representation of palliative care provision as it is currently understood in humanitarian contexts. This background is divided into four sections; first, the history of humanitarian healthcare, and the current scope of the sector. Second, a discussion on the concept of triage, followed by a look at the potential influence of the utilitarian foundations of triage on instantiating a cure vs care dualism in medicine. Finally, recommendations for the integration of palliative care into humanitarian healthcare are drawn from the literature, highlighting the need for the present study.

#### 2.1 Historical Foundations of Humanitarian Healthcare

"Palliative Care [has been] in the DNA of humanitarian action from the beginning" (PALL10)

The history of classical humanitarian healthcare is often described through the history of three organizations, The International Committee of the Red Cross (ICRC), the United Nations (UN) and its affiliated agencies, and Médecins Sans Frontières/Doctors Without Borders (MSF) (Braumann, 2012). Founded in 1863, 1945 and 1971 respectively, each organization may be seen as a response to immense suffering in the wake of three important conflicts: the Battle of Solferino, World War Two, and the

Biafran War. A brief exploration of these three histories highlights the role of alleviating of pain and suffering, and protecting human rights, throughout the foundations of modern humanitarianism.

#### 2.1.1 The Battle of Solferino and The International Committee of the Red Cross

The Battle of Solferino was a critical battle in the Second Italian War of Independence, and was a decisive victory for the allied Napoleonic Army. However, it was the Swiss businessman Henri Dunant, who truly immortalized Solferino in the collective consciousness as the birthplace of the International Red Cross Red Crescent Societies. Dunant was passing through Castiglione della Pieve on June 24th, the day that the Battle of Solferino was fought, and was wholly overcome by the immense pain and suffering that he witnessed. Lacking the training to assist in medical service, Dunant dedicated himself to "find a way in which such suffering could somehow be prevented, or at least ameliorated, in future wars" (Dunant [1862], pg 9). In his 1862 seminal text, "A Memory of Solferino", Dunant captured, in unblinking detail, the valour, victory, defeat, and death of the battlefield. His most vivid descriptions however, centre on the sights, sounds, and smells of *suffering* in the seventy-two hours post conflict; "Oh, the agony and suffering during those days, the twenty-fifth, twenty-sixth and twenty-seventh of June" (Dunant [1862], pg. 60). Aside from the consistent reference to the immense suffering surrounding him, there are clear depictions of what can only be referred to as palliative services being provided in the form of spiritual support, fluid resuscitation, and

dignity for the dead; "In the thickest of the fight, Napoleon's chaplain, the Abbe Laine, went from one field hospital to the next bringing consolation and sympathy to the dying" (Dunant [1862], pg 31), "canteen women [...] went among the wounded men, lifting their heads and giving them drink as they cried piteously for water" (Dunant [1862], pg 32), "soldiers were detailed to identify and bury the dead" (Dunant [1862], pg 48).

Dunant's aim with the publication of "A Memory of Solferino" was for it to serve as a call to action, "in time of peace and quiet, to form relief societies for the purpose of having care given to the wounded in wartime by zealous, devoted, and thoroughly qualified volunteers" (Dunant [1862], pg 115). The national societies were to be dormant in peacetime and governed by men of honourable reputation and high esteem within their communities. He followed this plea with an acknowledgement of the 'divine' and 'inevitable' nature of war, and made an appeal to the humane and Christian ideals of Europeans. Drawing on historical Christian anecdotes of Archbishops, Nuns, and Priests who dedicated themselves to caring for the plague-stricken, he claims that "there [would be] nothing chimerical in counting upon such sacrifice" (Dunant [1862], pg 118) from "the good people of Europe."

In 1863, Dunant and a council of three men hosted a conference in Geneva with representatives of 16 nations, which culminated in a recommendation that governments support and protect the formation of national relief societies. This was followed by the 1864 Geneva Convention for the Amelioration of the Condition of the Wounded in

Armies in the Field, formalized the 1863 recommendations, and stated that neutrality and impartiality (care without distinction of nationality) was a crucial principle for the undertaking (Dunant [1862], pg 131). The importance of impartiality and principled humanitarian care remained at the core of the Red Cross as it grew, Dunant was awarded the first Nobel Peace Prize in 1901, and by World War One, 38 Red Cross National Societies were engaging in the alleviation of global suffering. However, it was only in 1965, at the 20th International Conferences of the Red Cross, that the Fundamental Principles of the International Red Cross and Red Crescent Societies were proclaimed. They were as follows; Humanity, Impartiality, Neutrality, Independence, Voluntary Service, Universality, and Unity. Humanity was presented, and persists, as the chief endeavour of the Red Cross, is an unwavering dedication "to prevent and alleviate human suffering wherever it may be found" (ICRC, 1965).

While the ICRC was founded as an organization to be dormant in peacetime (although they now engage in a diversity of domestic, non-conflict activities), another organization was soon to be envisioned as a keeper of the peace; the United Nations.

#### 2.1.2 World War Two and The United Nations

Recognizing the invaluable work of the League of Nations (1920-1946) as a forerunner to the United Nations, there are few global issues that exist today without the involvement or expectation of involvement of the United Nations. Starting with the Declaration of St. James Palace (1941) and followed by the Declaration of the United

Nations (1942), Moscow & Tehran Conferences (1943), Dumbarton Oaks (1944), and ultimately the adoption of the UN Charter at the San Francisco Conference (1945), the UN has become the major international organization for norm-setting and cooperation (Gareis, 2012).

Born of an official co-operation aligning states opposing Hitlerism and requiring a declaration of war on the Axis, the United Nations grew into the peacekeeping entity it is heralded for today over the years. Now, with 193 Member States and 34 "Programmes, Funds, Specialized Agencies, Other Entities and Related Organizations (United Nations, 2016), a full exploration of the United Nations would require volumes upon volumes of writing. Many, if not all, of these entities are involved or implicated in humanitarian response; the World Food Programme (WFP), the United Nations Children's Fund (UNICEF), UN Women, The United Nations High Commissioner for Refugees (UNHCR), The United Nations Office for the Coordination of Humanitarian Affairs (UNOCHA) etc. Coordinated through the Inter-Agency Standing Committee (IASC), the roles of these organizations are immense. However for the purposes of this thesis, I will focus briefly on the United Nations World Health Organization (WHO) and the right to health as presented in several UN Declarations.

The WHO was formally established as the health agency of the United Nations in 1948, although its first constitution was drafted in 1946 (Lee, 2008). In the preamble of this first constitution was an articulation of the right to health as a fundamental necessity of dignified human existence, with health being defined as "a state of complete physical,"

mental, and social well-being and not merely the absence of disease or infirmity" (United Nations, 2008). This was reaffirmed by article 25 of 1948 Universal Declaration of Human Rights (adequate standard of living) and the 1966 International Covenant on Economic, Social and Cultural Rights (ICESCR), and the roles of primary health care specifically was highlighted in the Declaration of Alma-Ata in 1978 United Nations, 2008). The inalienable rights to health and dignity are to be maintained even in times of conflict and strife, and infringements of these rights may be seen as an offense of International Humanitarian Law (IHL) which prohibits causing "superfluous injury or unnecessary suffering" (ICRC, 2004). If we accept palliative care as the alleviation of suffering in all its forms, then it is clear that this type of care brings a person closer to the UN definition of health, protects their dignity through the fulfilment of the right to health, and responds to infractions of IHL<sup>1</sup>.

In 2002, the WHO refined its official definition of Palliative Care to be "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (WPCA, 2014). In 2014, at the 67th World Health Assembly (the highest governing body of the WHO), recognized that "palliative care, when indicated, is fundamental to improving the quality of life, well-

<sup>&</sup>lt;sup>1</sup> If the violation takes place in a conflict context, and the suffering is seen to be disproportionate to the necessary means of armed conflict (ICRC, 2004)

being, comfort and human dignity for individuals" and urged member states "to develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems" (WHA 67.19, 2014). That same year, the Worldwide Palliative Care Alliance (WPCA) in conjunction with the WHO, released a report entitled The Global Atlas of Palliative Care, which elucidated an international lack of palliation services. It highlighted the complex relationship between curative and palliative care, noting the modern medical bias to curative care, the medicalization of death, and recommended that palliative care should be provided in peacetime and disaster contexts, regardless of the availability of curative care (WPCA, 2014). Based on these policies and statements, it can be said that palliative care is a human right, and its absence in the face of overwhelming need in humanitarian contexts is a significant cause for concern.

#### 2.1.3 The Biafran War and Médecins Sans Frontières/Doctors Without Borders

One organization with a particular bias towards emergency-type medical and surgical intervention is Médecins Sans Frontières (MSF). MSF was created by a group of French Red Cross doctors who felt a lack of responsiveness during their involvement in the Biafran Secession War (1967-1970). The lack was not in terms of medical capacity, but rather with regards to the politics of emergency medical aid. These doctors felt that it was necessary to reveal to the general population the atrocities of genocide to which they were witness, publicly denouncing the Nigerian forces. This represented an infraction of

the gag order that was a necessary precondition for the Red Cross to maintain neutrality while providing their services, and marked a deviation from the international norms of providing humanitarian assistance (Brauman, 2012). The MSF Charter states an observance of "neutrality and impartiality in the name of universal medical ethics and the right to humanitarian assistance" noting that impartiality and neutrality are not synonymous with silence, and reserving the right to speak out publicly in situations of unacceptable suffering or extreme need (MSF, 2011).

This tendency for "speaking out", alongside a fiercely independent mentality, an intense focus on immediate emergency phase response, and the stereotypical coffee-alcohol-tobacco diet led to the development of the "humanitarian cowboy" reputation that lingers to this day (Redfield, 2012). While some claim that MSF is simply following in the footsteps of the fledgling ICRC circa 1865 (Brauman, 2012), others believe that these actions and attitudes represent a shift from "classical" humanitarianism, coining terms such as "post-modern humanitarianism" or "neo-humanitarianism", in which reverence for, and practice of, the old ideas and principles are dead (Smillie, 2012). In focusing on the critical medical needs during the immediate phase of disaster response, MSF has aligned with the "saving lives" ideal, abandoning (to some degree) the "alleviation of suffering". While MSF does not represent the humanitarian sector on whole, they are one of the largest, most vocal and most well known humanitarian organizations in the world, providing assistance in over 69 countries, and mobilizing over 1.4 Billion USD in funds in 2015 alone (MSF, 2015). Their role in influencing humanitarian practice and the

adoption of palliative care should therefore not be ignored, and they may be a powerful ally if convinced of the importance of palliative care provision in humanitarian health care crisis contexts.

#### 2.1.4 Modern Humanitarian Healthcare - An Insurmountable Need?

Despite the impressive mobilization of funds and resources by MSF and many other organizations, this amount is only meeting a small fraction of the global humanitarian need. In late 2016, the United Nations Office for the Coordination of Humanitarian Affairs put forth a record high global appeal for 22.2 Billion USD in funding for the upcoming year (OCHA, 2016). Coming on the heels of a turbulent 2016, where only 52% of the UN appealed 20.1B USD was donated, these funds will be necessary to serve the estimated 128.6 million people in need in 2017 (OCHA, 2016). Protracted conflicts mutated into decade long struggles, frequent and severe natural disasters exacerbated by climate change, and increased pandemic potential facilitated by mass migration and population crises are just a few examples of the increasingly complex humanitarian environment of today.

The provision of palliative care should not be limited to any one of these settings, as needs exist at all levels of care independent of time (point during the response) or prognostic limitations (WPCA, 2014). For the purposes of this thesis however, I will focus on palliative care in response acute humanitarian healthcare crises, whereby a sudden, unpremeditated event (such as an earthquake, disease outbreak, or sudden armed

conflict) has overcome, damaged, or destroyed the state healthcare system, requiring the intervention of international organizations such as the UN, ICRC and MSF. In these situations of acute humanitarian health care crises, patients do not arrive in steady streams; rather, they are more akin to a raging river with pulses of even greater suffering and need. Resources and capacity are often overwhelmed, and the majority of efforts are focused on 'stopping the bleeding'. In order to manage these high volumes of patients, physicians and healthcare professionals have long relied on the concept of triage to allocate human and medical resources.

#### 2.2 Triage - The Tool of Choice

The first documented usage of "triage" is attributed to Jean-Dominique Larrey, Chief Surgeon for the French Emperor Napoleon Bonaparte's Imperial Guard in the 1700's. The word triage stems from the French verb "trier" meaning "to sort, classify or prioritize", and was used to rationally prioritize the treatment of wounded soldiers according to the severity of injuries and maximal efficiency of medical resources rather than rank or status (O'Laughlin & Hick, 2008; Christian et al., 2011). Utilitarian rationalization is clearly evident, and the prioritization conflict of chief utilitarian medical goods (life, reduction of morbidity/disability, and alleviation of suffering) in austere settings means that certain ethical challenges are intrinsically woven into triage as a concept within the disaster context (Barilan et al., 2014). It was nevertheless adopted with great fervour by military doctors around the world, manifesting in the casualty clearing

stations of WWI, and now commonly seen in prehospital, disaster, emergency department, intensive care units, transplant list, and battlefield contexts, albeit with significant adaptations for high and low resources settings (Kipnis, 2013; Repine et al., 2005). It is worth noting that triage in resource rich contexts (where the primary resource being allocated is the time of the healthcare professional) is different from triage in disaster contexts (where human, financial, and medical resources are all being allocated specifically.) There remainder of this discussion will focus on disaster triage.

Guided by the utilitarian aim of "doing the most good for the most individuals" (Jeng et al., 2014; McCollough, 2010), modern triage systems are believed to be more effective than clinical judgement alone. Building on this, Biddison and colleagues (2014) have claimed that even the systems based on limited evidence are ethically preferable to inconsistent, subjective clinical decision making alone. These triage systems should be dynamic and responsive to changing resource shortfalls and availabilities (Christian et al., 2014, Devereaux et al., 2008). In less austere settings, triage remains consistent with its foundational principles: seeking to best allocate the time of medical professionals (the scarce resource in this context), to the cases needing it most urgently. Misallocation of resources (be they time, opioids or beds), has been referred to as under- or over- triage (Repine et al., 2005). Some teams may choose to integrate what Einav and colleagues (2014) refer to as a "reverse triage" strategy, whereby the primary identification looks for patients that can be safely and ethically *discharged*, increasing the receiving capacity of Emergency Rooms (ERs) and Intensive Care Units (ICUs).

Christian and colleagues (2010) break modern triage systems down into three levels; primary (pre-hospital by paramedics), secondary (hospital by surgeons/emergency physicians), and tertiary (Intensive Care Unit/operating room by intensivists or surgeons). When possible/available, senior medical professionals may be identified as triage officers for/by their respective teams, and this individual is then responsible for the fates of patients, acting as "a gatekeeper, restricting access to precious limited medical personnel and resources" (Repine et al., 2005). In Mass Casualty/Disaster Events, this individual should be someone who is practiced in making similar triage decisions in non-austere emergency contexts on a daily basis (Einav et al., 2014).

Upon patient arrival at the health facility, the triage officer assigns a code based on the severity of their cases. These codes can be arrived at through a number of scoring systems including the Sequential Organ Failure Assessment (SOFA) Score, 6-point pneumonia severity score, Sacco Triage Method and other institution or department-specific rule-based system (Matzo et al., 2009). The codes may differ slightly but for the most part they align with the Simple Triage and Rapid Treatment (START) system; Green (Minimal), Yellow (Delayed), Red (Immediate), and Black (Expectant). Individuals assigned a Green Code minor injury and are generally ambulatory. The are known as the "walking wounded" and their treatment is lowest priority. Individuals assigned a Yellow Code are injured and require treatment, but are not expected to significantly worsen or die if treatment is delayed by a few hours. Red Coded individuals have a good chance of survival if provided with minimal time and moderate interventions immediately. Finally,

individuals assigned a Black Code are expected to die (or presumed dead) because of extreme injuries that are fatal in the face of lacking resources (human, medical supplies, etc). In more advanced adaptations of the START system, there may be White Codes (dismiss immediately) and/or a distinction between the dead and the untreatable dying (Black & Grey Codes) (Bogucki & Jubanyik 2009; Christian et al., 2010; Jeng et al., 2014; Kipnis, 2013; Matzo et al., 2009).

A recurrent theme found in the literature is the belief that patients receiving a Black/Grey/Blue (expectant) Code should not be removed from the ward/hospital, but rather be given all possible measures of support, comfort, communication with family, and pain/symptom management - which are all key elements of palliative care (Christian et al., 2014; Devereaux et al., 2014; Jeng et al., 2014; Repine et al., 2005; Zoraster et al., 2007). There is also general agreement within the literature that the hastening of death (euthanasia) is ethically unacceptable for Black Code/Expectant patients (Deveraux et al., 2008; WMA, 1987; WMA, 1982; WMA, 2011).

Patients should be informed of their diagnosis/code, of their right to discuss any concerns, and of their right to seek support (curative or non-curative) from the appropriate and available medical personnel regardless of their code (Biddison et al., 2014). Caro and colleagues (2011) assert that even people who are Black/expectant Codes have the right to "CARE" (Comfort, Assistance, Relief of Symptoms, Explanation). This right to be informed and supported is a manifestation of two major medical philosophy principles, fidelity and autonomy, which in addition to veracity, justice and beneficence, form the

ethical foundations of triage decision making and discourse (Repine et al., 2005). Autonomy refers to freedom of choice, moral position and right to participate in one's own care, and fidelity refers to the invaluable and foundational trust that underlies every patient-physician interaction. Fidelity is the trust that the physician will be entirely dedicated to each individual patient, which is difficult to maintain in triage situations; in these contexts, fidelity is dependent on the patient recognizing and understanding their place in the overall medical need, and establishing an even deeper trust in the physician's dedication to their care (Repine et al., 2005; McCollough 2010). This trust is easily lost, and very difficult to restore (Downar et al., 2010). Veracity is a patient's expectation to be told the truth (part of informed consent, which is pillar of Autonomy). Finally, in Rawlsian theory, Justice is Fairness (Repine et al., 2005; McCollough 2010), and part of Fairness is the recognition by both patient and physician that the assignment to curative or palliative care should be adaptive to changing circumstances, allowing for periodic reassessment (Caro et al., 2011).

While each of the aforementioned ethical principles are under some degree of stress in disaster triage contexts, beneficence is perhaps the most central, and most challenging aspect of triage. Beneficence is present in the highest charge of medicine, the Hippocratic Oath, which calls physicians to "do no harm" (non-maleficence); however, triage shifts this towards "do the most good for the most people". This simple shift in language is indicative of underlying ethical tensions, whereby beneficence for the whole group and beneficence for the individual may be placed at odds, requiring physicians

rationing care to violate (to some degree) the principle of beneficence towards the individual (Repine et al., 2005). Furthermore, "do the most good for the most people" seems to conflict with the utilitarian perspective, due to the lack of clarity on what "good" is defined as. When faced with an enormous amount of incurable suffering and a handful of saveable cases, resources allocated through a utilitarian schema would be directed to alleviating suffering as the "greatest good", assigning little or no resources to saving the few lives that can be saved (Barilan et al., 2011). This however is not the reality, as the alleviation of suffering in the form of palliative care would rarely prevail as priority over the presence of even a single curable patient.

# 2.3 Curing Vs. Caring = Worthwhile Vs. Wasteful in Humanitarian Contexts?

One of the main challenges of triage being guided by the principle "do the most good for the most people" is that "most good" is subjective and relative to the population, patient, and physician. Most Western medical professionals and systems have come to equate "good" with "lives saved", and this is undeniably well intentioned (Yang et al., 2010). However, it has shifted the focus of care in emergency situations towards one extreme, neglecting *en masse* the needs of those who fall under the category of those who cannot be saved. This "Cure vs Care" dilemma has been long debated in the medical profession; in 1978, John Fry summarized in a simple, nine-row table what the differences were believed to be. Curing took place in the hospital and dealt with the body and disease - it was biological, physical, clinical, scientific, and "first-class". Caring,

according to Fry, was "artistic, pastoral, emotional, behavioural and social" dealing with "person, soul and community" and therefore, "second-class". The ideology of caring being less valuable that curing pervades medical culture to this day, but is often expressed in less explicit terms, citing responsibility, efficiency and utilitarian philosophies as justification. One such example is Abbasi and colleagues (2013), who cite the 'duty' of giving the maximum services to the maximum people as reason to claim that they "should not waste time on time-consuming procedures" when more lives can be saved elsewhere.

This language of "wasting" time on non-recoverable or time-consuming patients can be seen throughout the literature, case studies and field reports of humanitarian health care professionals. Huffman (2011) refers to the case of a surgeon during the 2010 Haitian earthquake response who found it "unpalatable" to give a bed to a moribund patient and was "aghast" at the idea of a tent for the dying near a medevac site. Kipnis (2013) uses language similar to Abassi and colleagues, claiming that "Life-saving resources allocated to [green and black tagged patients] are, arguably, wasted; green tagged patients don't need them, and black tagged patients are less likely to benefit from them". In this situation, it is difficult to disagree without knowing the nature of the resources, and how "benefit" is defined. If the author is referring to something that is dual-use for life-saving and supportive care (such as Morphine), black tagged patients needs will always be ignored as in competition with life-saving efforts (Bogucki & Jubanyik 2009). Indeed, Powell and colleagues (2017) state that expectant patients are often neglected because they are perceived as diverting resources from "salvageable" patients, and that using

resources on unsurvivable injuries is "unreasonable". They go on to claim that Palliative Care in disaster triage contexts, "tends to be relegated to the domain of the unfeasible or impossible, allowing preventable suffering to occur". The ethical challenge underlying this perceived "waste" is once again the incommensurable nature of "three chief utilitarian medical goods (life, reduction of morbidity and disability, and alleviation of suffering)" (Barilan et al., 2010).

In some cases, medical professionals not only see these efforts as a waste, but they refuse to engage in them, and take their curative efforts to the extreme. Dillon (2015) recalls the case of an Ebola patient who had spent 12 days in the hospital, and declared palliative on the twelfth day. Instead of providing comfort and support, six physicians attended to the patient, starting a new treatment regime, antibiotics, and stopping other medications. The patient died on day 15, having been provided little comfort or palliation.

It is hard to deny that it is much more difficult to "write off" a dying person in a disaster than to do so in a drill or discussion (Burnstein 2009), and many professionals have noted a sense of helplessness when lives could not be saved (DeJong et al., 2010). However, taking 'good intentions' to extreme lengths can result in infringement on the principles of beneficence and patient autonomy, and has been deemed ethically unacceptable. Furthermore, the envisioning of healthcare professionals as strictly curative/life saving actors has built unrealistic expectations which ultimately exert a negative influence on their mental health and safety. Aryal and colleagues (2015) give an example from the Nepali context, suggesting the "creation of realistic expectations would

diminish violence against physicians, healthcare teams, and hospitals in the face of unsuccessful outcomes". This suggestion comes as a response to the observations made by Magar (2013) where relatives of Nepali patients who have died tend to blame the physician (citing negligence etc), with situations often escalating to the point of aggression.

The creation of realistic expectations will benefit from a "philosophical shift to embrace the goal of care for all, moving beyond the more circumscribed goal of saving as many lives as possible" (Gibson, 2014). While austere settings lack the resources to provide optimal care for all, the "vital secondary goal of minimizing suffering" does not need to be seen as in competition with the primary goal of saving lives (Matzo et al., 2009). Venticinque and colleagues (2008) believe that with the right mix of people, resourcefulness and well-honed critical care skills, the care for critically ill patients in disaster contexts can be significantly improved. The impacts of this shift in focus may even extend beyond the expectant/black-tagged/critically ill, improving the outcomes for infection (Fowler et al., 2014). Simply put, the failure to meet lifesaving needs does not allow for other needs such as pain relief and comfort to be forsaken by personnel not able to engage in life saving operations (Caro et al., 2011).

# 2.4 Recommendations from the Literature

Emergency medicine & humanitarian literature present an array of recommendations for the improvement of palliative services in disaster contexts. There is

widespread agreement that palliative care should be provided to those with incurable ailments, or those whose likelihood of improvement lands them lower on the priority list for curative efforts during humanitarian crisis (Biddison et al., 2014; Goodman & Black 2015; Marston, deLima & Powell 2015; Powell et al., 2017; Smith & Aloudat 2017; Young et al., 2016). It is believed that engaging in the alleviation of suffering can give a source of "meaning amidst chaos and misery", especially if clear ethical decision-making frameworks are developed for clarity in "impossible situations" (Goodman & Black, 2015). Within such frameworks, there is a strong consensus that the hastening of death, or euthanasia, should not be considered in any context, and is ethically unacceptable (Biddison et al., 2010, Downar et al., 2010, WMA, 1983; WMA, 1987; WMA, 2011). There is a clear distinction made between the hastening of death, and withdrawing/ withholding care. Health professionals who are engaged in disaster response should be informed of this distinction, as the latter two actions are ethically admissible, and indeed recommended, in certain contexts (Biddison et al., 2010). The withdrawal of care is reflective of the dynamic nature of disasters, where resources become scarce (or available), and needs grow (or diminish), requiring medical decisions to be adaptable (Caro et al., 2011). In both cases however, the patient having care withdrawn/withheld must be provided with appropriate palliative services including psychological and spiritual support (Antomarria et al., 2011; Deveraux et al., 2008). There is also mention of the need to provide psychological and spiritual support to the clinicians who are faced with these difficult decisions in disaster contexts (Antomarria et al., 2011).

There is considerable dialogue recommending on-site or "just-in-time" training for a number of individuals to increase the palliative care capacity in disaster and surge contexts (Burkle, 2006). Asagary & Jacobson (2013) recommend that medical personnel working in refugee contexts should receive on-site training to improve the general quality of service and use of resources. Downar and colleagues (2010) arrive at the same recommendation of on-site basic palliative training for medical personnel, referencing experiences during the H1N1 outbreaks in North America. In the Nepali context, Aryal and colleagues (2015) suggest that that intensivists in particular should be the target of palliative training to increase understanding and willingness to refer patients to palliative services, with the hopes of setting more realistic expectations and reducing violence directed at physicians following poor clinical outcomes (as discussed in the prior section). Just-in-time training may even be extended to the lay-public and families, as comfort care can be provided with less medical knowledge, and engagement of the lay public could greatly increase palliative capacity (Cherny 2010; Frahm & Gibson, 2011)

There are a number of demographics that may also benefit from ethical decision making and end-of-life care training that does not take place in the "just-in-time" context. It is recommended that all professional disaster responders, humanitarians, and hospital staff involved in disaster management should have basic training for competency end-of-life care (Matzo et al., 2009, Powell et al., 2017, Rosoff 2010). More specifically, Smith & Aloudat (2017) suggest that specialists, surgeons, paediatricians and generalists require

appreciation of palliative care interventions to deliver optimal care, and that resources must be allocated to the sensitization training for these staff.

Frahm & Gibson (2011) point out that existing nursing homes and hospice care institutions should be trained for the changing needs of their patients, and the general population, when disasters strike. This network of hospice, nursing homes, and palliative wards could and should be integrated into existing response structures as a key stakeholder/asset (Gibson, 2014). Perhaps the most aspirational recommendation comes from Downing (2014), who suggest that all professionals should be taught about palliative care during their undergraduate medical education, to ensure some level of competency. In addition to all of the above mentioned training recommendations, Downar and colleagues (2010) recommend that telemedicine be developed for consultations and second opinions.

With regards to resources, Biddison and colleagues (2014) suggest that it is ethically inadmissible to hold reserves during a disaster. In preparation for these disasters, earmarking of critical medical supplies specific to palliative care should be maintained so that palliative efforts are not in competition with curative efforts (Rosoff, 2010). These may include opioids, haloperidol, scopolamine, anxiety medications, and paediatric-specific treatments (Downar et al., 2010; Rosoff, 2010). Cherny (2007) recommends that returned and unused palliative medications can be checked and added back to stockpiles for disbursement to patients in austere contexts, and reports successful implementation of this strategy with cytotoxics, analgesics and antiemetics in conflict areas of Jerusalem.

When stocks of narcotic pain medications are depleted, Young and colleagues (2016) recommend the use of non-narcotic adjuncts, cannabis (wherever legal), and local herbal remedies to minimize pain for burn patients.

In Dunant's Memory of Solferino (1862), he recalls soldiers being tasked with identification and burial of bodies, and the standing WHO definition of Palliative Care (2002) includes the psychosocial support of families, which certainly extends past the moment of death. Building on this precedence, Biddison and colleagues (2014) state that international disaster responders should also be able demonstrate culturally and religiously appropriate respect for the dead, be willing to work with local providers to ensure both safety and sensitivity, and be able to provide grief and bereavement support. Where possible, it is recommended that palliative care takes place in comfortable/private spaces, if possible in separate wards (Downar et al., 2010), where attention is paid to emotional, spiritual and cultural needs (Young et al., 2016).

In order to give the necessary support for all of the above mentioned training and resource management to occur, a supportive policy environment must be created (Powell et al., 2017). Efforts may be targeted through human rights mechanisms including challenging the signatories of ICESCR for compliance with core obligations, including increasing access to essential medicines such as opioids which are blocked in some nations (Gwyther 2009; Smith & Aloudat 2017). These legal bans are often fueled by state government's fears of doctor-driven addiction and increase in drug-crime, however,

the government and elite are often able to access these cheap and powerful pain medications in their own times of need (McNeil Jr., 2007).

## 2.5 Summary & Research Questions

This chapter has shown that elements of palliative care manifest in the foundations in humanitarian health care, and have the support of modern international human rights and humanitarian law. However, in the face of overwhelming global need, and a longstanding cure-care dualism reinforced by the underlying utilitarian principles of triage, palliative care has come to be neglected by humanitarians who have come to associate it with wasteful and unreasonable allocation of scarce resources in already austere circumstances. The literature and international policy environment recognize the ethical value and importance of palliative care, and contain several calls to action for the implementation of trainings and standards for physical, psychosocial and spiritual care.

Despite having historical precedence, a significant amount of support in the academic literature, and a supportive international policy environment, palliative care has yet to see any critical mass of organizations shifting to integrate it into their packages of care. This represents a fundamental disconnect between rhetoric, policy, and action. There is limited-to-no explicit discourse on how or why palliative care may have been excised from its foundational role in humanitarianism. In addition to this, there are few descriptions of humanitarian healthcare policy makers' (as field-based practitioners with leadership and policy influence) experiences of the need for, or challenges faced,

providing palliative care in humanitarian contexts. This thesis will seek to explore and address these gaps by asking the following research questions:

- What are humanitarian healthcare policy maker's experiences of supporting the provision of ethically and contextually appropriate palliative care in humanitarian contexts?
- How can existing standards, policies, and protocols be adapted to improve the provision of ethically and contextually appropriate palliative care in humanitarian contexts?

It should be noted that these research questions, adopted from the larger Humanitarian Health Ethics Research Group study which this thesis seeks to inform, were used to guide the initial inquiry rather than serve as explicit questions to be answered. The second question in particular was not the focus of my findings/discussion, but will be addressed more fully in the larger study.

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# **Chapter Three: Research Methodology**

This chapter will focus on study design, methodology, analytical framework, ethical issues, limitations, and concerns of rigour specific to this thesis. This clarification is necessary as the data set informing this thesis is part of a larger study on Palliative Care in Humanitarian Contexts led by Drs. Lisa Schwartz & Matthew Hunt. This larger, concurrent, mixed-methods study is funded by an Enhancing Learning and Research for Humanitarian Action (ELRHA) Research in Humanitarian Health Care (R2HC) grant. Included in the larger study are another subset of 12 interviews with humanitarian healthcare providers (HCPs), a comprehensive literature review, a globally disseminated survey (available in English, French, and Arabic), and a series of case studies. The design and initiation of this larger study predates the inception of this thesis, and several methodological choices were determined in the original protocols set prior to my involvement with the Humanitarian Health Ethics Research Group. All letters (recruitment, information, consent), advertisements, ethics, interview guides, and surveys used in this thesis were designed, and granted approval, for the larger study, and can be found in the appendices of this paper.

# 3.1 Study Design

#### 3.1.1 Qualitative Inquiry

Highly interdisciplinary fields of research face several challenges when it comes to identifying the "right" methodological approach. Global Health, for example, exists at

the nexus of international medical, sociological, and political systems (Koplan et al., 2009) with a wide array of key stakeholders to be considered. Within Global Health, humanitarian healthcare engages with these systems at their point of peak duress, or when they are in a state of transient dysfunction in the aftermath of a disaster (natural, man-made, disease, conflict etc.) (Norris et al., 2008). These complex disaster contexts are not always conducive to traditional, randomized control trial-style research programs. Here, the more inductive and open-ended approach characteristic of qualitative inquiry affords a flexibility to the researcher that enables them to gain a more holistic understanding of the disaster context (Philips, 2014). While the research informing this thesis did not take place directly in a humanitarian crisis, the flexibility and openness of qualitative inquiry aligned well with the questions I sought to answer. This flexibility, as a hallmark of a naturalistic approach to inquiry, allows the researcher to adapt the study as it develops (Lincoln & Guba, 1985; Patton, 2002). The naturalistic approach allowed me to shift my focus onto the many manifestations of what I have called "rescue culture" in humanitarian response as they pertained to the provision of palliative care, leading to a more detailed and specific analysis of the findings.

Philips (2014) claims that there are four stages of qualitative disaster research; preparedness, response, recovery, and mitigation. This thesis aligns mostly closely with the goals of mitigation research; specifically, how communities, organizations, and governments can enact policies to better protect and serve people in disasters (Philips, 2014). While I did not explicitly collect data during the response phase, several

individuals did deliver their interviews from the field, while others interviewed from their respective home bases. However, as we solicited reflections on the response phase from all participants, I was able to capture valuable insight into current practices and decision making processes that may inform future policies on humanitarian palliative care provision.

# 3.1.2 Interpretive Description

In consultation with my thesis committee, it was decided that Interpretive

Description would be the qualitative research framework that I would use to guide this
thesis study. This was determined from both the research objectives and questions, as well
as the desire to remain consistent with the larger study that this thesis will inform.

Interpretive Description is an approach to qualitative inquiry that was conceived by Dr. Sally Thorne and colleagues as a response to the need for creating grounded knowledge in nursing and allied health research (Thorne, 2008). Thorne and colleagues recognized that researchers in this field felt restricted by a requisite need to locate oneself within particular theoretical traditions, leading to "hollow allegiances" (Thorne, Reimer Kirkham, Macdonald- Emes, 1997) and the mixing-and-matching of elements from multiple research traditions to best fit their needs (Thorne, 1991). In effect, they felt compelled to compromise theoretical rigour and potentially undermine the credibility of their studies in order to fulfill their pragmatic obligations to produce "useable" knowledge (Thorne, 2016).

This tension is reflected and addressed in what Thorne (2008) refers to as the required "integrity of purpose" for Interpretive Description studies; a real practice goal, whereby research translates into practically applied changes in ground-level decision making. The purpose of this study was to describe humanitarian healthcare policymakers' experiences of guiding palliative care provision in humanitarian contexts, and to use these experiences to suggest ways in which existing policies could be adapted (or new ones be adopted) to improve the delivery of this type of care. The research questions directly reflect this purpose: what are humanitarian healthcare policy maker's experiences of supporting the provision of ethically and contextually appropriate palliative care in humanitarian contexts, and how can existing standards, policies, and protocols be adapted to improve the provision of ethically and contextually appropriate palliative care in humanitarian contexts? The link between the underlying philosophies of care, the value in (and meaning of) the experiences of humanitarian healthcare policy makers, and the desired impact on future practice clearly align this study with the Interpretive Description approach.

Thorne is transparent in her recognition that Interpretive Description is not a completely novel approach to inquiry, but rather "a way of naming and referencing the kind of well-founded logic that clinical researchers had [already] been coming up with in the health domain" (Thorne, 2008). Interpretive Description aligns with a naturalistic and constructivist approach to inquiry (Sandelowski, 2000), meaning that it strives to present the phenomenon as if it were not under study (without being influenced by the presence

of the researcher) and that it recognizes a value in attempting to understand and develop subjective meaning from the lived experiences of individuals (Creswell 2007). Interpretive Description requires a deep respect for, and knowledge of, its philosophical and theoretical underpinnings in Grounded Theory (sociology), Phenomenology (philosophy), and Ethnography (Anthropology) in order to carefully consider and understand the reasons for deviating from each of the aforementioned methods (Thorne, 2008). Consistent deviations made by researchers within a specific discipline may be indicative of a need for new methodologies; indeed, this was how Interpretive Description came to be (Hunt, 2009). In many ways, Interpretive Description is a perfect manifestation of the methodological *connoisseurship* that Sparkes & Smith (2009) identify as a hallmark of quality in qualitative research. Interpretive Description researchers often draw upon participant observation and interviews (key methods of Ethnography), engage in constant comparative analysis (characteristic of Grounded Theory), and highlight the significance of subjective reality (a foundational understanding of Phenomenology, Grounded Theory and Ethnography). Using these foundational elements, the researcher then moves past qualitative description and into the realm of interpretation in order to achieve a more accurate depiction of the underlying meaning in participant experiences of a phenomenon (Thorne, 2008). Strong justification of methodological deviations must be made by the researcher to defend against critiques of what is known as "methodological slurring" (Baker, Wuest & Stern, 1992).

Much to the chagrin of those whom Thorne (2008) refers to as "neophyte researchers" (including myself), Interpretive Description does not provide a prescriptive cookbook of methodological decisions. Instead, it provides a flexible way of thinking while navigating the variety of social science research tools. Hunt (2009) identifies this as a potential limitation of early Interpretive Description; as a newer, lesser known methodology, the flexibility of choice and lack of preexisting literature examples from which guidance may be drawn left some researchers uncertain if they have achieved appropriate depth of interpretation. Since its inception however, Interpretive Description has attracted support and visibility from within and beyond its intended audience of nurses and allied health researchers (Stevenson et al., 2015; Abdul-Razzak et al., 2014; Clark, Spence & Holt, 2011). Thorne's publication of a comprehensive (2008, updated 2016) edition on the methodology answer many of the questions and challenges earlier scholars may have faced, but one is also left impression that Thorne leaves some critical decisions embedded in the methodology itself, as a critical step of the thinking that she hopes future scholars of Interpretive Description will engage in. I believe that there is an immense value in the experiences of humanitarian healthcare policy makers, and that the participants in this study have provided a rich professional narrative with significant implications for the future of palliative care provision in humanitarian contexts.

# 3.1.3 Study Population

For the purposes of this thesis, the study population of 'humanitarian healthcare policy makers' will be defined as expatriate (working in the field, outside of own nation) health professionals (nurse, physician, health programs manager etc) who hold a higher level of decision making responsibility and policy influence within their organization. Participants were given the option of self-identifying areas of involvement within the humanitarian sector: active front-line humanitarian response, management of humanitarian response, development of protocols and policies for humanitarian response. The participants selected for the "Policy Maker" group had to self-identify as either 'management' and/or 'development', however the majority checked off all three areas of involvement. This is not unusual, as humanitarian healthcare policy makers are often individuals who have accumulated several years of field based experience, have worked with multiple organizations, continue to engage in field-based disaster response. Indeed, all twelve of the study participants were, or had recently (<3 years) been, active as frontline responders in the field, and could cross identify as a humanitarian healthcare provider and humanitarian healthcare policy maker. Furthermore, all but one of the study participants had been engaged in the humanitarian sector for greater than 10 years, and the mode number of years of humanitarian involvement was 20+ years (n=5). I chose to focus on this uniquely experienced group of participants based on their increased likelihood of being able to provide a nuanced and informed perspective of past, current, and potential future directions of palliative care provision in humanitarian healthcare.

Participants who did not self-identify as policy makers were assigned to the "Humanitarian Healthcare Provider (HCP)" group of the larger study, which will also look at the experiences of patients, families, and other key stakeholders.

## 3.1.4 Sampling Strategy

The sampling strategy has a significant impact on the data that is collected, and can ultimately determine who, and what, the data represents (Thorne, 2008). It was initially believed (by the Co-Investigators of the larger study that this thesis is nested under) that a purposeful sampling strategy would be the best way to recruit the desired quantity and variety of participants. Purposeful sampling is used in qualitative inquiry to capture the in-depth experiences of individuals who are engaged in the phenomenon being studied (Palinkas et al., 2015). The 'snowballing' effect is sparked through asking of key informants (or initial interviewees) questions such as "who knows a lot about ...." in order to identify other potential study participants (Patton, 2001). In order to avoid only capturing similar perspectives, initial interviewees for this study were asked if they knew of anyone who may have positive *or* negative opinions/experiences of palliative care in humanitarian contexts.

It quickly became clear that despite our efforts to avoid a homogeneous population, the initial interviewees reflected a bias to our own network of similar organizational and cultural backgrounds. Thus, we further stratified our sampling approach to focus on appropriate participant variety (Palinkas et al. 2015). Stratified

purposeful sampling is employed when enough is known about how a phenomenon manifests, allowing for researchers to select for participants with key characteristics in the interest of increasing the credibility of the findings (Patton, 2001). Many authors have observed that the phenomena of death, dying, and end-of-life care differ greatly between various organizational, geographic, and cultural spaces (Irish, Lundqvist & Nelson, 2014; Bullock 2011; Bulow, 2007; Kemp, 2005), and so we actively sought to increase the organizational, geographic and cultural diversity of our sample. We paid particular attention to the inclusion of faith-based and non-faith based organizations. This was in recognition of the significant role that faith-based aid plays (the World Council of Churches alone mobilizes over 1 Billion USD/year (Ferris, 2005), and the more clearly defined end-of-life expectations that such organizations may have. Beyond the financial influence of faith-based aid, religion and spirituality are a major factor in the personal palliative care needs of individuals around the world, and therefore are an important component of ethical and contextually appropriate provision of palliative care provision.

It should be noted that recruitment was facilitated by great interest in the study topic. The initial goal was to recruit 10-12 individuals who identified (or were identified) as humanitarian healthcare policy makers, and this goal was easily reached with many participants readily self-identifying or being receptive to referrals by colleagues.

Participant demographic data including gender, primary professional role in humanitarian healthcare, years of experience, and geographic details were collected and are presented in Appendix G.

Despite having enough interest to have included more than 12 participants, it was decided (through conversations with my thesis committee and precedence of previous theses submitted to McMaster Global Health) that 12 interviews would provide enough data to inform a robust analytical structure, and was realistic within the pragmatic limitations of this Masters Program. Furthermore, these 12 interviews were done (by Drs Elysee Nouvet & Sonya de Laat) in conjunction with 12 non-policy-maker, humanitarian healthcare providers, as outlined in the original protocol of the larger study. Keeping within the tradition of Interpretive Description, I do not seek to claim that I have reached "saturation" with my population of 12 policy maker interviews. Thorne (2008) explains that claiming saturation after any number of participants in a qualitative study imposes certain epistemological beliefs, namely, that there is an empirically true theory that has been reached, and that no further variation will emerge from additional data collection. This is not reflective of the epistemological underpinnings of Interpretive Description, which approaches the topic of saturation through the recognition that there will always be more to study, and that transparent claims of what the data represents are the best way to progress. This thesis therefore claims only to represent the experiences of 12 humanitarian healthcare policy makers, stitched together along a common, "professional narrative" surrounding the provision of ethical, contextually appropriate palliative care in humanitarian contexts.

#### 3.2 Data Collection

#### 3.2.1 Ethics

This research was approved by the Hamilton Health Sciences/McMaster

University Faculty of Health Sciences Research Ethics Board on 13 December 2016, and
by the McGill University Integrated Research Ethics Board on 23 August 2016 (See

Appendix E). Recruitment and interviews began after this date.

#### 3.2.2 Recruitment

Initial contact with participants was made via email (Recruitment Email Template Appendix B), which included a link to a 10-minute survey being done for the larger study (this data was not seen or presented in this thesis), the Letter of Information and Consent, and the participant demographic survey. If a participant agreed to be interviewed, they would respond via email with the completed Letter of Information and Consent,

Demographic Survey, their phone number, Skype<sup>TM</sup> Username, and availabilities for a 60-75 minute interview over a two week period. Both phone and Skype<sup>TM</sup> were used interchangeably as the video function was turned off to improve connection and voice quality - two interviews switched from Skype<sup>TM</sup> to phone part way through due to connection issues. Two participants failed to return the Letter & Survey on time, but verbally confirmed that they had read both documents and provided verbal recorded consent prior to being interviewed, and sent signed documents following the interview. At the end of the interview, participants were asked if they would like to refer any colleagues

to the study, and if the researchers may contact them again in the following weeks to clarify or expand upon any ideas presented during the interview. While all participants agreed, no follow up calls were necessary.

## 3.2.3 Consent & Language of Interviews

Letters of Information and Consent based on templates provided by the Hamilton Health Sciences/McMaster University Faculty of Health Sciences Research Ethics Board, and were provided to all participants in English or French. Participants did however have the option of being interviewed in French (by Dr. Elysee Nouvet), and one participant chose to do so. This interview was transcribed verbatim and not translated, as I was capable and comfortable conducting analysis in both English and French.

# 3.2.4 Individual, In-Depth, Semi-Structured Interviews

Interviews are also the most common method of inquiry used in qualitative disaster research (Philips, 2014). The purpose of the qualitative research interview is to contribute to a body of knowledge based on the concept that life experiences hold meaning and value. More specifically, the individual, in-depth, semi-structured interview is the most common method of qualitative inquiry when the data set is not being supplemented by observational data, and are widely used by healthcare researchers in general (DiCicco-Bloom & Crabtree, 2006).

This thesis was informed by a series of twelve semi-structured, individual interviews of humanitarian health care policy makers/leaders. The interviews were conducted by Drs Elysee Nouvet and Sonya de Laat, using an interview guide that was developed in an iterative process by the members of the Humanitarian Health Ethics Research Group (Drs Lisa Schwartz, Matthew Hunt, Elysee Nouvet, Sonya de Laat, Lynda Redwood-Campbell, Carrie Bernard, Kevin Bezanson, and myself) in consultation with international colleagues. Having many perspectives contribute to the production of a robust guide was a particularly valuable process. The core guide reflects the original research objectives of the study ("What does palliative care mean to you?", "Have you seen or participated in palliative care done well in a humanitarian context? What did it look like?") as well as integrating probing, open-ended questions for topics that developed during the course of the interview. After each of the first four interviews, minor alterations to the language or focus of the guide were made based on developing themes and concepts, but none of the changes represented a significant enough deviation from the original guide to merit resubmission to the ethics board.

The interviews lasted 60-75 minutes on average, and were conducted by two experienced qualitative researchers (Drs Elysee Nouvet & Sonya de Laat), in either English (n=11) or French (n=1) via phone or audio-only Skype<sup>TM</sup>. It was agreed upon through discussions with my thesis committee that Drs Nouvet and de Laat should conduct the interviews, in the interest of minimizing interviewer variability (Blomgren et al., 2006). This was important, as the interviews informing this thesis represent one of

two subsets of key informants to the larger study on Palliative Care in Humanitarian Contexts being led by Drs Schwartz & Hunt. Furthermore, as I entered this thesis as what Thorne (2008) refers to as a "neophyte qualitative researcher", it was agreed that the more significant learning opportunity would come through creating field notes, shadowing (n=6), transcribing (n=8), and summarizing (n=12) the interviews as part of the data immersion process (Saldana, 2015). Field notes (or 'memos') were anonymized using the same code as the interviews (PALL#), and were used as a method of creating an "audit trail" of observations, developments in my thinking, and new questions (Thorne, 2008). With regards to the transcription process, Thorne (2008) suggests that there may be something lost in the trend of employing professional transcriptionists, whereby the process of slow reading and attention to the "words and sounds and silent spaces rather than [storyline]" can uncover deeper nuances and understanding of the data. I found the process of transcribing to be incredibly useful in familiarizing myself with the data, as well as providing an opportunity to hear rather than read the interviews that I was not able to shadow.

While shadowing and transcribing the interviews, I was able to identify several key stages and elements of the interview process. Each interview began with a restatement of the study purpose, an offer for clarification on any details of the Letter of Information and Consent, and review of the demographic details provided beforehand. Following these formalities, there was a clear process of developing rapport (DiCicco-Bloom & Crabtree, 2006); initial questions centred around the patient's current

occupation, experience, mutual contacts etc. This was followed by introductory questions and probes, which then moved into questions eliciting personal anecdotes and challenges. For example, Following interview PALL\_08 on November 16, 2016, I recorded in my field notes "clear and consistent shift in the tone and openness of the interviewees that occurs approx. 10-15 mins into the interview". This is a common trajectory of qualitative interviews, whereby 'superficial' discussions are a necessary step towards to deepening relationships and richer conversation (Field & Morse, 1985).

Immediately after each interview, the interviewer completed an Interview Report (Appendix G), and the interview recording was transcribed as soon as possible. The transcript was then reviewed and cross-checked with the recording, with all names and organizational affiliations redacted. All recordings, demographic surveys, signed letters of consent, and transcripts, were kept in password protected folders. All transfers were made person-to-person using a USB key, in order to avoid non-secure online transfer of data.

Anonymized transcripts were then transferred to the NVivo11 (Mac) Qualitative Systems Research (QSR) data management software for analysis.

## 3.2.5 Limitations of Individual, In-Depth, Semi-Structured Interviews

When interviews are the sole source of data, the researchers must remain cognizant of the inherent biases introduced by the question guide, the interviewer-interviewee dynamics, and recall bias if soliciting personal anecdotes as a source of information (Yin, 2014). Furthermore, interviews often require more human resources

(interview time, transcription, review, coding) than other methods of qualitative inquiry, which may impose certain restrictions on population size, diversity and duration/depth of inquiry (DiCicco-Bloom & Crabtree, 2009). We sought to minimize these limitations by being as flexible as possible to accommodate the participant's time zone/schedule, recruiting for geographic diversity, and having a flexible upper limit of the study population. In order to make these accommodations and remain logistically feasible as a project, interviews had to be done by phone or Skype.

While virtual/phone interviews are growing in popularity, some researchers maintain a bias against them, citing perceived loss of nonverbal cues, ability to build rapport, and ability to preserve confidentiality as reasons for preferring in-person interviews (Novick, 2008). DiCicco-Bloom & Crabtree (2009) also identify increased technical issues with recordings, and interview privacy, as the interviewer cannot control the interviewee's environment from a distance. Some of the steps taken to address the limitations include; having two high-quality voice recorders for each session, italicizing text for particular *emphasis or emotion*, names and introductions being cut from interview recordings, and the aforementioned methods of secure transfer of recordings and demographic data etc.

#### 3.3 Analysis

Finalized transcripts were uploaded to NVivo11 and assigned attributes based on the corresponding participant demographic survey (gender, age, years of experience, profession, geographic spread of involvement etc). Transcripts were then coded and analyzed based on the three stage process depicted in Figure 1 and described in further detail below.

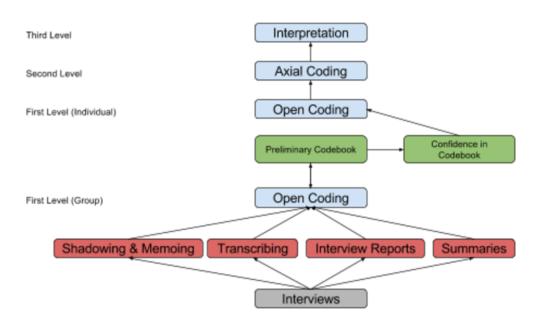


Figure 1. Analytical structure created with Drs. Matthew Hunt & Elysee Nouvet.

Coding is a central tenet of many methods of textual qualitative inquiry, and involves assigning a phrase, sentence, or passage to a "node" in hopes of capturing similar ideas across the data set. Nodes are structured in the "codebook" (Appendix F) which presents and defines the ideas being captured from the data set, and consists of the nodes, their definition, and any necessary inclusion-exclusion criteria. Interpretive Description allows the researcher relative flexibility when coding (compared to line-by-

line coding strategies), but it does draw upon other elements of Grounded Theory coding theory, including the three level structure that will be described below (Thorne, 2008; Glaser & Strauss, 2009).

## 3.3.1 First Level (Open) Coding & Confidence in the Codebook

Open Coding is the first step in the coding process, and involves "fracturing the data" from a large, monolithic transcript into smaller, more manageable parts that may reveal initial similarities, differences, and key ideas (Thorne, 2008). Examples of questions to guide Level 1 coding include: *What is happening here? What is this about?* The preliminary codebook was developed using the researcher's field notes, interview summaries, and group (Drs Elysee Nouvet, Matthew Hunt, Lisa Schwartz, Carrie Bernard, and Kevin Bezanson) coding of the first three interviews (PALL\_01, PALL\_04, PALL\_08) in an iterative process. This concluded with Dr. Hunt and myself using the preliminary codebook to code sections of PALL\_08, and comparing our code assignments.

Once the preliminary codebook was developed, I alone coded PALL\_10, and circulated my coding of this transcript to the aforementioned group of researchers. The group reviewed my coding, provided comments and confirmed that my coding (and the codebook) adequately captured relevant themes and ideas. This process was seen as a critical step in establishing 'confidence' in the codebook, and in me as an independent researcher, after which I was able to code the remaining eight interviews independently.

The various perspectives (biomedical, philosophical, anthropological, sociological) provided by the group resulted in the production of a more robust codebook and helped guard against integrating personal or disciplinary biases.

## 3.3.2 Second Level (Axial) Coding

Axial coding aims to rebuild the data set from the fragments created in open coding, restructuring and organizing the data such that initial relationships between nodes become more clearly visible (Thorne, 2016). This is generally done through the aggregation of nodes into categories, but it should be noted that some nodes may relate to multiple categories, or be prominent enough to be considered categories in themselves. Examples of questions that guided the axial coding process included: What are the possible patterns/linkages here? What explains these patterns? Can they be described in terms of contexts, causes and consequences? Axial coding can be done in NVivo or other softwares, however I found the more tactile process of using a whiteboard or cue cards on a cork board (as suggested by Dr. Hunt) to be an easier way of arranging and rearranging codes, facilitating the exploration of several possible organizational structures.

# 3.3.3 Third Level (Interpretive Themes) Coding

In pure Grounded Theory studies, third level coding is referred to as selective coding, and is where a conceptual framework is built using the categories developed through axial coding, in the interest of generating a new grounded theory (Thorne, 2008;

Strauss, 1995). Interpretive Description allows for some deviation from the structure at this point, and for the purposes of this thesis, third level coding is where major themes based on patterns and linkages in the data are created. These themes should reflect/answer the initial research questions, and represent a shift from description into interpretation by asking questions such as: What are the major elements of the phenomenon of humanitarian palliative care as it is currently practiced? and What is missing, hidden, unaccounted for with regards to humanitarian palliative care? When I arrived at this stage in the coding process, there were some clear overarching elements that were being discussed by participants. The interview guide ensured the themes of current realities of practice, barriers faced, and recommendations for the future, but discussions of triage and culture consistently arose from participant comments. Focusing on these two elements allowed for an even deeper level of analysis, whereby a common element is drawn from all participants; in this case, it distilled down to the narrative of "rescue culture" in humanitarian response, which will be presented and discussed at length in the following chapters.

## 3.4 Rigour

Interpretive Description was designed in response to the need for a way to generate grounded knowledge for the allied health sciences. Part of the specific need of the allied health sciences was the ability to recognize the importance of abstract theorizing and pragmatic obligations of an applied discipline; Thorne (2008) asks

researchers to constantly consider why the research is being done (Worthiness), who/what the research claims to represent (Credibility), and the practical significance for advancing knowledge (Significance). These bracketed characteristics represented by Thorne's call to quality represent three of eight "big tent" criteria for excellent qualitative research presented by Tracy (2010). Tracy presents a model for Quality that does not seek to be prescriptive (akin to Thorne's approach to Interpretive Description as a whole) in a criteriological way, but rather flexible and relative to the researchers means (methods and practices). Without downplaying the importance of the five other criteria that Tracy presents (rigour, sincerity, resonance, meaningful coherence and ethical), I will therefore focus the discussion of my methodological rigour/integrity on the three big tent criteria for Quality that are highlighted by Thorne.

Tracy (2010) suggests that Worthiness can often be determined by the relevance, interest, and timeliness of the research. The World Health Assembly Resolution 67.19 (Agenda Item 15.5) calling for the strengthening of palliative care as a component of comprehensive care offered throughout the life course (WHA, 2014) suggests that the topic is at the forefront of the humanitarian consciousness and confirms the timeliness of this research study. Relevance and interest were also confirmed by the fact that all twelve study participants indicated that they would like to assist beyond the interview (disseminate survey, receive and disseminate final publication etc.), and there were more potential interviewees identified than was possible to include within the scope of this Master's thesis.

The credibility of a study can be marked by thick description, multi-vocality, triangulation/crystallization, and member reflections (Tracy, 2010). Hunt (2009) indicates that thick description is one of the hallmarks of a strong interpretive description study, and the aforementioned coding structure outlines how a thick description of the interview data lays the foundation upon which any interpretation occurs. In presenting direct, contextualized quotes of personal anecdotes from the field, I seek to introduce an element of multi-vocality to the findings. Triangulation with multiple data sources and data collection methods is a commonly recommended method of validating findings (Creswell, 2007). While this thesis is informed solely by a set of twelve semi-structured interviews, the larger study under which it falls is a concurrent mixed methods study that is projected to include a comprehensive literature review, two interview populations, three case studies, and a globally disseminated survey Within this thesis, source and investigator triangulation (Denzin, 1978) were employed, whereby multiple sources from the data were used to corroborate any interpretation, and confidence was developed in both the codebook and the interpreter (myself) through an iterative coding process with an experienced, interdisciplinary team of researchers.

Lastly, the Significance of a research contribution can be judged by asking questions such as "Does the study extend knowledge/improve practice/empower [individuals]" (Tracy, 2010). Interpretive Description has a call to practical significance placed squarely at its core, heeding what Thorne (2008) refers to as the "practical obligations" of applied health sciences research. It is my hope that this research will have

an element of catalytic validity, inspiring humanitarians to shift the culture, while simultaneously creating a space for that wisdom and transformation to occur (Lather, 1986; Tracy 2007). This research also aspires to what Tracy (2010) defines as heuristic significance, attained through influencing of a variety of audiences including policy makers, participants, and the lay public to engage in change. The dissemination of this research will not be limited to the organizations involved in its production (as participants or through funding), and will seek to inform culturally appropriate changes in the way death and dying are dealt with in humanitarian contexts.

## 3.5 Reflexivity

A foundational element of qualitative inquiry is the explicit acknowledgement of the researcher as an "instrument" of the research process (Thorne, 2016), which in many ways rejects the long-held, quantitatively-rooted notion that the superior researcher is objective and invisible. If we are to recognize the researcher as an instrument of research, we must identify and disclose the strengths and limitations of the researcher, as we would with any other method or instrument of inquiry. This process is what is referred to as reflexivity. According to Finlay and Gough (2003), reflexivity is a constant process of thoughtful, self-aware analysis of intersubjective dynamics, critical self-reflection, and positioning of oneself in the research and research process. Wilkinson (1988) suggests that reflexivity can more simply be broken down into personal (background, motivations),

functional (adherence to methodological tradition), and disciplinary (specific disciplinary knowledge and biases) elements.

My thesis seeks to describe humanitarian healthcare policy makers' experiences and perceptions of providing ethical, contextually appropriate palliative care in humanitarian contexts. While I have not worked in the field as a humanitarian healthcare professional, I do acknowledge that my knowledge of this sector exceeds that of a lay audience, and that I have established a significant personal network of international humanitarian healthcare leaders who have influenced my perspective of the current state and potential future directions of the sector. My experience stems from 4 years of collaboration with the McGill Humanitarian Studies Initiative (now Humanitarian U), and related collaborations with the Canadian Consortium for Humanitarian Training, the Harvard Humanitarian Initiative, and the International Medical Corps. Two of the twelve participants were personal colleagues from past projects, however, given that I was not the interviewer, I believe that my personal connection to the participant was limited in its impact on the data collection (interview) process.

As a neophyte qualitative researcher, my theoretical knowledge base was significantly influenced by my thesis committee (Drs. Schwartz, Nouvet & Hunt) and my qualitative methods professor, Dr. Meredith Griffin. As I immersed myself in the literature of qualitative inquiry and the theoretical traditions relevant to my research (as well as potential alternative approaches), my committee was always receptive to questions, and considering their implications not only with regards to my thesis but the

larger study it informs as well. Sometimes my questions were more theory-based ("Which elements of Grounded Theory and Phenomenology do we integrate into Interpretive

Description and why?") while others were more methodological ("Are later interviewees having a significantly different experience than the initial interviewees? Are there significant differences between the two interviewers styles?"). These questions were captured in my field notes/memos (a practice recommended to me by Dr Matthew Hunt), which now serve as both an 'audit trail' and a reflexive log, documenting the trajectory of my thinking and increasing comfort with the methods and theoretical underpinnings of the qualitative inquiry over the course of this thesis study.

## 3.6 Summary

This chapter began with an introduction to qualitative inquiry and the theoretical traditions drawn upon by Interpretive Description. This was followed by a discussion and rationalization of the methodological choices made within the analytical framework of Interpretive Description. It then provided an in-depth look at the strengths and limitations of the sampling method, instruments of inquiry (interviews), strategies for ensuring rigour, and continuous, critical reflexivity was engaged in throughout the research process.

M.Sc. Thesis - Gautham Krishnaraj; McMaster University - Global Health

# **Chapter Four: Findings**

This chapter will begin with a brief description of the population demographic data and an introduction to the codebook, followed by the presentation of Rescue Culture as the major interpretive finding, and as the lens through which the remainder of the findings will be examined. These findings will be presented in an order that mimics the proceedings of a typical interview, first establishing participant definitions of key terms, followed by discussion of field-based experiences and perceived barriers, and concluding with participant with recommendations for policy, protocol and practice development.

### 4.1 Demographic Data

<u>Table 1.</u> Showing some of the key participant data collected through the pre-interview demographic survey sheet that was given alongside the letter of information and consent. This can be found in Appendix I. The Participant Codes range from 1-24 as codes were assigned for the larger study, which also included 12 Health Care Providers (24 total).

Participant Code	Gender (M/F/-)	Primary Profession	Home Region	Involved in Delivery/ Development /Management	Years
PALL01	F	Physician	N. America	Y/Y/Y	20+
PALL04	M	Physician	N. America	Y/Y/Y	20+
PALL07	F	Nurse	N. America	Y/N/Y	11-15
PALL08	M	Physician	Europe	Y/Y/Y	20+
PALL09	F	PT/OT	N. America	Y/N/Y	16-20
PALL10	M	Physician	Europe	Y/Y/Y	20+
PALL12	F	Physician	N. America	Y/Y/Y	16-20
PALL14	M	Physician	Europe	Y/Y/Y	16-20
PALL15	F	Physician	N. America	Y/Y/Y	20+
PALL16	M	Physician	Middle East	Y/Y/Y	6-10
PALL18	F	Physician	N. America	Y/Y/Y	20+
PALL24	M	Physician	Middle East	N/Y/Y	16-20

One of the strengths of the study population is the geographic diversity that is represented both in terms of participant home regions and regions engaged in humanitarian action. Participants came from the North American, European, Middle East North Africa (MENA) regions, with a significant North American bias. There was representation from leadership at all levels of humanitarian healthcare organization; the World Health Organization and United Nations, Médecins Sans Frontières, Médecins du Monde, Handicap International, EMMS International, Canadian Red Cross, and the United States National Disaster Medical System (NDMS). Participants drew on field-based experiences from many major humanitarian contexts including: Palestine, Sierra Leone, Nigeria, Haiti, Nepal, Syria, Libya, Yemen, Turkey, Lebanon, South Sudan, Ukraine, India, and Malawi.

There was an equal representation of males and females (6:6) (options to not identify/identify as other were given), and a significantly higher representation of physicians over other professions (10:2). There were no policy makers interviewed who did not come from a health professional background, which is consistent with the realities of this position, but also a potential limitation/source of bias in the data. All of the participants marked that they had involvement in the management of humanitarian healthcare provision, ten of the twelve had involvement in the development of organizational policies and protocols, and eleven of the twelve had field based experience in the provision of humanitarian healthcare. Eleven of the twelve participants had been

involved in the humanitarian sector for over 10 years, with the mode value being 20+ years (n=5).

#### 4.2 Codebook

All nodes coded for and their definitions can be found in Appendix F. From this point forward for the remainder of this chapter, all terms that are capitalized and placed in quotations (ie. "Funding") without being attributed as a quote, are representative of a "node". The term "node" comes from the analytical software NVivo and refers to the tag used to capture a common idea presented in the text during primary (open) coding. For more information on the coding process and structure, refer to Chapter 2, Methodology.

# 4.3 The Underlying Narrative: Palliative Care Conflicts with Humanitarian Rescue Culture

As previously mentioned, a key element that differentiates Interpretive

Descriptive studies from Grounded Theory/Qualitative Descriptive studies is the drawing out of a professional narrative that seeks to inform applied decision-making structures

(Thorne, 2008). Arriving at this narrative was an iterative process which began with the stated research questions of the larger Humanitarian Health Ethics Research Group study;

What are humanitarian healthcare policy maker's experiences of supporting the provision of ethically and contextually appropriate palliative care in humanitarian contexts, and

how can existing standards, policies, and protocols be adapted to improve the provision of ethically and contextually appropriate palliative care in humanitarian contexts?

After the primary [nodes], secondary [categories], and tertiary [themes] coding was completed, there was one node that stood out, as it was consistently double or triple coded with other ideas, throughout all facets of the discussion, ranging from how humanitarian action was defined, to personal experiences in the field, perceived barriers, and even recommendations for the future. The node was first entitled "Aggressive Care/ Rescue Complex" and was inspired by the concept of 'l'acharnement therapeutique'", presented by the first interviewee, PALL01. The full quote from PALL01 was as follows:

• "...we know that generally decisions, you have not a lot of time to make, but an ethical committee to review all the ethical issues and to make decisions on palliative care with family representatives, community representatives, or traditionally learned representatives, or cultural... to integrate cultural issues. Because it's really very complicated because, again, our doctors – and that, I can give you very practical examples – they explain that one time the child is admitted to the hospital, they feel the obligation to do all that is possible, even excessive care or l'acharnement therapeutique – I don't know how to, to say that in English. [...] So they never stop with the aggressive resuscitation because they say that the parents should see that they are doing the maximum." (PALL01)

The passage captures many complex structures interacting; the need for ethical decision making in triaging of patients, the need for cultural responsiveness, the vulnerability of pediatric populations and the increased pressure on healthcare professionals to save them, the visibility of palliative care and the expectations/ impressions that result. These topics will all be discussed at further length in this chapter.

The passage concludes by stating that the humanitarian physicians feel an obligation to do all that is possible to save a patient, but that they take this obligation too far, and end up engaging in what the participant identifies as "excessive" or "aggressive" therapies. These "excessive" actions carried out by individuals who have an exclusive focus on saving lives, ignoring the importance of providing comfort and alleviating suffering appeared throughout the data set, and in much of the anecdotal/case evidence presented in the literature. This exclusive focus on saving lives is somewhat represented by the "humanitarian cowboy" image of MSF (Brauman, 2012), and in the rhetoric of many other individuals and organizations.

Recognizing the potential importance of this theme, I sought to further nuance and define the node, looking for ideas similar to a "rescue complex" within and beyond the humanitarian literature. This brought me to Barnett's (2011) "New Paternalism" of the Liberal Humanitarian Age, Cole's (2012) "White Saviour Industrial Complex" (Bex & Craps, 2016), Goldwort's (1993) "Messiah Complex" and most importantly, the "ritual of rescue" in US hospitals as described by Chapple (2010). These complexes refer to paternalistic behaviour, thinly veiled neocolonial motivations, and a grandiose sense of obligation to "save" others respectively, which all align to some degree with the rhetoric I sought to capture under the "aggressive care/rescue complex" node. It is worth emphasizing that the intent was not to 'pathologize' the humanitarians' behaviour, nor to equate it directly to the Complexes as they are commonly defined (Goldwort's Messiah Complex in particular is a psychosis common to individuals living with schizophrenia).

The shift from individual "rescue complex" to "culture" was inspired by Kroeber & Kluckhorn's (1952) definition of culture which claims that culture is captured in the behavioural patterns, explicit or implicit, of a human group (in this case, humanitarians). This led to the following working definition in the codebook: "Rescue Culture: Comments that point to an ingrained saviour complex within the humanitarian, and the humanitarian sector, repeated to the point of becoming a "culture" of curative efforts that go beyond what may be appropriate". Throughout the remainder of this chapter, I have boldfaced all of the interviewee comments that reflect humanitarian rescue culture in rhetoric or action, to support my claim that it is a behavioural pattern to the point of meriting the use of the term 'culture'.

# 4.4 Lack of Consistent Nomenclature for Palliative Care & Humanitarian Action "For me, it is nonsense that humanitarianism is not palliative care. For me, it's the same care." (PALL 04)

The first place where save-cure rhetoric and rescue culture were apparent was in participants personal definitions of humanitarian action and palliative care (nodes: "Definitions of Palliative Care" & "Definitions of Humanitarian Action"). The data immediately exposed discrepancies in terminology, giving rise to the "Purpose of Humanitarian Action" and "Language of Palliative Care" and nodes, the latter of which sought to capture all the different terms and phrases that were used seemingly interchangeably by participants to refer to a relatively common set of practices. A separate

node for "Limits of Humanitarian Response" arose from the fact that most participants had a tendency to define humanitarian action not only by what they believed it was, but also by what they believed it was not:

• "We have to fix limitations. And again, bon, limitations are very difficult to accept: for expatriates – because they want to do everything – for nationals – because they want to do everything also, but for other reasons." (PALL01)

As seen above, Participant PALL01 believed that these limitations were important to outline not only for others, but for the humanitarians themselves, as a type of restriction on their ambition to "do everything". This desire to do everything has led to a plethora of definitions of what constitutes "Humanitarian Action" both in the literature and the interviewee responses.

#### 4.4.1 No Single Definition of Humanitarian Action

As illustrated by the statements below, definitions of humanitarian action vary; to some it is strictly life-saving, and to others, it is best defined as the provision of compassionate care:

- "I think of humanitarian healthcare as being a meaningful resource area, providing care on a compassionate-type basis, so, to me, it's not just disasters" (PALL12)
- "people who were formatted in 70's and 80's, saw humanitarian forces as uniquely life-saving operations" (PALL14)

In addition, PALL01 defined humanitarian action as existing within the realm of emergencies and post-emergency crises:

• "It is when you are in a really international emergency or crisis, or if you are in post-emergency crisis..." (PALL01)

While all twelve interviews (100%) had at least one reference to "emergencies" over the course of discussion, some of those participants believed that humanitarian action was far from restricted to emergencies and included more protracted contexts and entrenched issues such as gender inequity within the humanitarian mandate:

• "Particularly in rural India[...] I would describe some of the conditions as a humanitarian crisis [...] the gender inequalities [are] actually quite startling, so that's me saying there's a humanitarian crisis that needs to be addressed" [PALL08].

This topic of acute and extended humanitarian response arose in a number of interviews, and was particularly interesting to capture ("Acute vs. Extended Response") due to the linkages that participants made between the phase of response in which an NGO engaged, and the "appropriateness" of certain types of care. PALL07 for example believed that their NGO, by sheer length of deployment, would have more exposure to palliative needs than organizations such as MSF, ICRC or MdM, who depoy for shorter terms and therefore focus on acute needs:

- "[International NGO] tends to deploy for longer [...] the fact that we do deploy for up to four months, we'll see a lot more of those [palliative] patients come through than somebody only deployed for the first two weeks" (PALL07)
- "Medecins Sans Frontieres [MSF], Red Cross [ICRC] and Medecins du Monde [MdM] would, to me, be more in a position for that acute care" (PALL12)

Participants PALL12 and PALL15 held contrary beliefs, stating palliative needs are actually critical in the acute phase of humanitarian response, as people will be dying in a matter of days:

- "I think [the palliative approach] needs to be embedded in those acute responders, the emergency responders, the ones that are responding within the [first] 72hrs... there needs to be a palliative care expert embedded within those surgical teams" (PALL12)
- "I think that the difference in South Sudan is that we need some acute, we need some help with acute management of palliation I guess is the way to put it. You're not expecting that person to go home and be looked after by his family for three more months ... [he] is probably going to die within a few days" (PALL15)

The quotes above show that the participant's determination of the appropriateness of palliative care is often linked with their definition of humanitarian response, and the phases of humanitarian response. There was a clear binary of "acute" and "extended" phases, and participants readily identified organizations that they believed to be exclusively focused on each phase. The effect of this binary assignment of engagement was a "we can't, but they should" tone with regards to by whom and when palliative care should be provided.

# 4.4.2 Palliative Care is a broad term, and may be provided under many names

As evidenced by the quotes below, there was relatively consistent, albeit broad, understanding/definition of palliative care among the participants. It includes medical, physical, emotional, psychosocial and spiritual care, requires few pharmacological resources, and depends on compassionate recognition of and action to preserve human dignity in the face of suffering:

- "It encompasses everything in the WHO model... its the care that would be their medical, physical, emotional, psychosocial, spiritual care" (PALL08)
- "if we follow the WHO definition, it is about life in disease, not only the dying" (PALL14)
- "With ten medications, you can practice palliative medicine, pharmacologically speaking. But it is everything else. It is the communication, the relationship building, the dignity, it is all of those things." (PALL04)
- "...its providing dignity, and comfort, to those who are dealing with terminal illness, or in chronic pain..." (PALL07)
- "its having access to appropriate hydration, nutrition, stimulation in terms of a comforting and supporting and loving environment and having staff that recognize the importance of just basic medical care in terms of management of pain, management of skin integrity, nutrition as appropriate" (PALL12)
- "when things are not solvable, [we have to] alleviate suffering and pain of the patient [...] at least decrease the level of this pain or severity of the symptoms, and at least also, I think it's increasing the life expectancy" (PALL16)

The WHO's definition of palliative care (presented in Section 0.3) was only explicitly referenced in 3/12 of the interviews (25%), but most participants referenced the key elements including: pain management (100%), psychosocial support (100%), treatment of physical symptoms such as dehydration (50%) and ensuring comfort (58%). There was however, a clear lack of consistency in the use of, and at times purposeful avoidance of, the term "palliative care". This was further explored through the creation of a specific "Language of Palliative Care" node, which included statements such as the following:

- "We never speak about palliative care [...] we speak about comfort care. That is the same for us. But comfort care, sometime, bon, palliative care, but like I told you, it's not known and poorly perceived." (PALL01)
- "Q: [Palliative Care] is really under the label of 'quality of life and rehabilitation'?
  - A: Yes.
  - Q: Palliative care is not a term really used within policy documents or training?
  - A: Yes, exactly." (PALL09)
- "The whole term Palliative Care, even palliative care organizations really struggle with it because people associate it with end of life is imminent, and they're trying to move towards symptom management as their approach, [...] So I'm not a palliative care doctor or expert so I don't know what they prefer their services to be called now, when I give education and training in this area, I don't call it Palliative care, I don't even necessarily call it end of life care, I call it management of progressive diseases. [...] There is that negative connotation of 'I'm going to consult palliative care' people go 'oh why do you think I'm dying now?'" (PALL12)

There are a number of interesting and valuable observations to be made from the statements above. Between these five participants alone, the terms "comfort care", "end of life care", "dignified care", "management of progressive disease", "symptom management" and "quality of life and rehabilitation" are apparently all accepted and understood ways of communicating that "palliative care" is being provided. PALL01 & PALL12 explicitly stated that there are negative connotations of the term "palliative" from both responders and patients, due to its connection to the imminence of death.

Perhaps most interestingly, PALL08 suggested that this poor reception extends all the way to donors, necessitating the nesting of palliative efforts under "poverty reduction" activities:

• "I think we need to be innovative in terms of how we get funding for it (palliative care) - we've been successful with it under poverty reduction" (PALL08)

This negative connotation and poor perception reinforced the idea that palliative care faces stigma and prejudice within the medical sector and greater population. This led to the coding of "Stigma and Prejudice" which is best captured by the following statement made by PALL14:

• "The most important thing I believe is the stigma and prejudice that should be fought at the level of general public, but most importantly among medical workers - it's incredibly stigmatized and nobody understands what it does mean, palliative care, and basically it's not taught in the universities and medical institutes and thus it (death) is regarded as [an] enemy, and you have to fight this enemy, let's say if this person has a non-curable condition, then they will

fight until the end. Making non-comfortable 10 times, 15 times chemotherapy, you know, killing the patient by chemotherapy when there is no chance for cure, but they will do this. And you know, this is awful." (PALL14)

In exposing the stigma, fear, and avoidance of the term "Palliative Care", these participants are presenting key examples of how a Rescue Culture has influenced their approach to providing care. While some stated that they have gone on to provide Palliative Care under other names, others shared stories of colleagues who have internalized the stigma surrounding palliation, avoiding it to the point of "killing the patient by chemotherapy" in one instance.

# 4.5 Experiences of Providing Palliative Care

After establishing an understanding of what humanitarian action and palliative care meant to the participants individually, it was possible to move forward in the interview towards a discussion of their specific experiences of palliative care provision in the field.

# 4.5.1 Triage is where care begins for some, and where it ends for others

When the interviewers solicited participant's personal experiences of addressing, or witnessing palliative care needs in humanitarian contexts, discussions often began with the process of triage. As presented in the literature, triage is the entry point into the

humanitarian health care system, and is where some individuals have the misfortune of receiving a "black tag" (expectant/incurable/dead):

- "People get so caught up in how do I handle a crush injury and you know, I think that then, it should just the part of the language that follows through, so in an acute crisis, where they're using tags of people who should wait to be seen, the walking wounded, people who need to be emergency seen and the people who are tagged maybe you're not going to be able to save them" (PALL18)
- "Most often we are obliged when [there] is a lot of emergency, like we said, we have a triage system. So: a lot of red that are all the vital emergencies. We are obliged to make a black list. And for very long these ones on the black list, they were not really properly assisted because the objective was life-saving." (PALL01)

We immediately see the foregrounding of *exclusively* life-saving objective, a key element of Rescue Culture. Black tagged patients are not assisted because it is believed that they "will not benefit" from the attention, as explained by participant PALL07:

• "the focus on the early days is a lot on life-saving surgery and so on, so you have to triage accordingly, who can you help, who can you save, and who-who won't benefit from immediate intervention." (PALL07)

This of course reflects a very limited definition of the term "benefit", which does not consider the alleviation of pain, suffering, or the upholding of human dignity in the absence of a curative outcome to be a "benefit". PALL08 seemed to suggest that this focus on saveable cases may have to do with the immediacy of triage, and that palliative needs were out in the community, rather than in front of you:

• "I guess in a post earthquake situation, there may be, it depends how good your triage is in terms of the casualties, or people who have been left homeless, I mean the priority is to deal with what's in front of you rather than palliative care needs assessments or a palliative care assessment of a community that you've went to." (PALL08)

This "out of sight, out of mind" approach to triage may be required to focus on the task at hand, however the idea that palliative needs were not in front of the person conducting triage is not true. Participants PALL10, 12, and 14 identified that despite a necessary focus on saving lives and the use of triage to determine who has a chance of survival, there is an ethical obligation to provide some type of care to those who are assigned a "black tag":

- "[is it triage English?] Yeah. And typically even in the in the textbook you would say that a first obligation was say to the life you would be able to save, and how to, you know to differentiate in terms of possibility to save people and to for example to operate and to- to give a treatment, and very little if any attention was paid to people who were not in a situation where you would have a capacity to save a life, and you would forget about their needs to have at least a minimum of palliative care, minimum pain relief, et cetera." (PALL10)
- "If you're in one of those disaster situations and you have patient triage who looks like they're not going to survive, they're not going to be the ones selected to go to surgery but there needs to be somewhere, it's only ethical that we provide appropriate care for that patient" (PALL12)
- "We always put triage those patients and go for those with good chances of survival, those who doubtful chances for survival or no chances, they were kind of put an IV line, still of course we would inject morphine, intramuscularly, and then there is no attention because there is no time for these patients." (PALL14)

PALL10 and 14 go beyond stating an ethical obligation and begin to identify hydration and pain relief (through morphine, as an example) as key palliative therapies that can be provided. This however, does not seem to be the norm, and black-tagged patients are often forgotten, or actively under-prioritized, in the fray of triage.

4.5.2 Key Populations With Palliative Care Needs: Chronic Care, Displaced, Elderly & Youth

Four key demographics that were prominently featured in participant comments when discussing instances where the palliative needs of a population were not met: "Cancer & Chronic Disease Patients", "Displaced Persons", "Elderly Persons", and "Paediatric Populations". The majority of the interviewees spoke to the palliative needs of one of these four groups as the particularly memorable instances of "involvement in palliative care being provided well" or "situations where the palliative care needs were not met". Some of the comments regarding each of the four populations that captured the unique challenges and suffering (or support) of the demographic include:

#### Cancer & Chronic Disease Patients:

• "There was a guy I met who was a head teacher and he was dying of lung cancer, and had a very big property and large extended family and a courtyard and everything. You could see how the family were visibly moved that somebody was

<sup>&</sup>lt;sup>2</sup> Quotes from Interview Guide, Found in Appendix D

interested in this relative, this member who was dying and us being interested in [helping] them. ... People said "we were surprised you would want to come and help us" ... they are the people who would be forgotten in any other situation, because everybody is rushing out to save lives, and straighten the health system or health centre and responding to the emergency, everything is about saving lives, and I get that. But, it's not either or, I think it needs to be either/and, you also need to be caring for the people who aren't going to recover, and who are going to have ongoing issues." (PALL08)

In the quote above, we see a clear reference to affected population's internalization of humanitarian rescue culture. The statement "we were surprised you would want to come and help us" demonstrates that there is a clear expectation of what humanitarians are there to do - save lives.

#### **Displaced Persons:**

• "We have a problem of electricity, we don't have enough electricity to provide light for all people because the refugees are using electricity without paying the bill, and now we don't have electricity, we have half the time electricity, half the time you must be on a generator. We don't have enough water; drinking water, or water for the daily use, because it is, it is not for this population. We cannot have circulation on the roads, because half the refugees brought their car, they are using their car in the country, and if you add one million cars more in a small country, we cannot move now in the cities. [When such basic challenges are present], it becomes almost, not urgent to talk about somehow palliative care for refugees or to talk about, some special cases, this becomes very less urgent than the whole situation we are living." (PALL24)

This passage from PALL24 presents an interesting point, as the participant demonstrates a strong understanding of the local context, and outlines several of the basic

needs of life for displaced persons; drinking water, electricity, ability to move. They then use the lack of these things as a partial justification for the lack of palliative care, suggesting that it is a luxury, something special and not as fundamental of a need.

# **Elderly Persons:**

• "It was some ten years ago, it was in one hospital in Diinsoor, this was kind of elderly person, it was kind of - I don't remember honestly the diagnosis, it was kind of TB but treatment was incurable state, was not responding to variable medication, all it was, I don't remember. I just remember how this person was carried by his son and daughter in law, and their grandchildren, it was, he was really really well accommodated and supported. I think it was great psychological support and emotional, so we were really all to accompany the person and he was discharged I think, and they were supporting him at home - the relatives. But for [Major Humanitarian Organization], it evidently was not a priority." (PALL14)

In PALL14's comments regarding an elderly person with palliative care needs, we were presented with a glimpse of quality care in terms of psychological and emotional support being provided by the family. The passage ends with a blunt reference to the fact that providing this type of non-curative care was not seen as a priority of the humanitarian organization running the hospital, again demonstrating the exclusively curative efforts characteristic of a rescue culture. It should be noted however that the presence of a supportive family environment may have fed into the humanitarian organization's decision to discharge, and that further context was not given.

Paediatric Palliative Care:

• "A lot of kids that we see in the hospitals with parents who want to go home with them, and for reasons that we culturally find incredible, it makes sense that they need to put their other eight children ahead of this incredibly sick child who we think if only could stay in the hospital for a couple or more weeks we might be able to make him better - we don't know, we might not be able to, this child might die no matter what we do - how do we allow ourselves to be comfortable with the fact that this is not our child, this is their child." (PALL15)

PALL15 was one of many participants who discussed paediatric palliative care needs. The vulnerability of youth may be one of many reasons why their suffering leaves the greatest mental impact on humanitarians. PALL15 discusses the challenges of uncertainty in austere settings, and concludes with a statement that fully displays the struggle to not be engulfed in the paternalistic, neo-colonial tendencies of humanitarian rescue culture. Through acknowledging the need to be comfortable with the decisions made by patients and their families, this participant begins to identify what ethical and contextually appropriate palliative care may look like.

# 4.5.3 Palliative Care is best when integrated as an Approach

Once a patient has been assigned to receive palliative care (this assignment is not guaranteed, and many "black tagged/expectant" patients are not offered anything at all), what should that care look like? Through analyzing the limited participant experiences of palliative care being done "well", it was evident that palliative care was a holistic approach that begins with the comfort and acceptance of patient decisions presented by PALL15 above, as well as PALL09 in the following passage:

• "They told them, you know, "we have all of the information, the clinical information, for the moment with the means available to tell you that if we take off the machine in 3 days, then we know that, probably, he will be deceased." And then the discussion with the family started around, of course, finding economic means to extend it beyond these two or three days or whatever. So, let's say there was a sort of social negotiation that was going on that could buy time for the family to decide on this." (PALL09)

The above passage was also coded with "Engaging Family & Local Communities", which was identified by many participants as a valuable element of good palliative practice. PALL14 expanded upon this understanding and social negotiation, suggesting that in order to provide good palliative care that was contextually appropriate, humanitarians should actually "learn" from the locals:

• "I was witnessing this in Somalia. Somalia there is a big respect for the elderly people and they will do anything to accommodate the elders - they will even though they were lacking access to narcotic analgesics, at least all the other problems they were components of palliative care, were quite well applied, but it's by local community, without participation from major associations like MSF, so we have to learn from local people how they do accompany the dying people." (PALL14)

Once again, we see that palliative care was provided well (with limited pharmacological supplies) by local communities, but ignored by major humanitarian organizations. When humanitarians engage families, learn from locals, strive to understand and be comfortable with the decisions of patients and families, and meet palliative needs, they challenge the values of rescue culture. In the passages below,

PALL14 advocates for the importance of human touch, empathy, and non-curative support, which PALL18 demonstrated an instance where she provided those things, against the opinions of her colleagues, and found that she was providing the best possible care for that individual:

- "There is a lack of human touch and kind of emotional empathy or psychological support, this is just out of their understanding, this is important." (PALL14)
- "She said to me, thank you for taking care of me, and then she said do pray with me. And I'm not particularly religious and there were people there that said to me that they would not have done that because they feel it's not their role as a provider to do that, and I think these kinds of things [are a] really good discussion, because I got on my knees and we held hands and she said a prayer. And it was, I felt that was the best thing I could have ever done for her, and I basically said, I'm with you." (PALL18)

PALL18's comments simultaneously present rescue culture's influence on humanitarian perceptions of their role ("it's not their role to do that"), and challenges this belief at its core. In stating that this simple, caring gesture was the "best" thing they could provide, they directly contradict the assertion that care is always "second class" compared to curative actions (Fry, 1978). Throughout these comments, it becomes clear that palliative care is not a specific action or set of actions, but rather an approach marked by empathy and compassion for those who are suffering. This approach is also captured in the question presented by PALL07 in the final line of the following passage:

• "I think it is part of ethical- ethical medical care and I mean why not, you know I think in whatever measure it can be done in the context we are in I think those steps should be taken. You know if you can't admit a person because it's just not feasible, well, how can you get them home and make sure they're comfortable at home, you know? So it's just looking at every situation on its own to see well what can we do?" (PALLO7)

The simple shift in focus from what the humanitarian can't do (save this life), to what they can do (alleviate this suffering), may be a liberating and powerful shift in approach, replacing the fixation on death, with a focus on the life before death.

#### 4.6 Barriers to Providing Ethical & Contextually Appropriate Palliative Care

While most participants were able to identify an instance in which at least one element of the patient's palliative needs were provided for, several explicitly responded with a "no" when asked if they had ever seen or engaged in palliative care done well.

Some of this may be due to a difference in understanding of the term "palliative care"; in one case, a participant repeatedly denied any experience providing palliative care, despite the fact that many of her anecdotes illustrated key the provision of palliative care.

Miscommunications aside, every participant was able to identify at least one major barrier to the provision of palliative care in humanitarian contexts, which almost always pointed back to rescue culture, and the general prioritization of cure over care.

## 4.6.1 Material and Ideological Barriers

One of the first and most common barriers that was presented by the interview participants was the lack of human resources and physical resources, as PALL08 describes below:

• "So in an emergency context, as you know, even the capacity of (Major Humanitarian NGO) - that has the larger capacity in emergency, we have strong limitations because of money, materials, and most often, it's human skill, human resources" (PALL08)

There was a particular honing in on the lack of access to pain medication, and more specifically on the need for opioids and narcotics, such as morphine. The reasons for this lack of availability vary, but in many African countries it is due to legal restrictions, as described by PALL01 below:

• "And first, the first cause is because opioids, so morphine, opiacés, [...] are absolutely not authorized in most of west African and central African countries. So even for us, if we want to use morphine, to get the authorization for importation is very, very, very, complicated [...] There is no authorization in most of the country to use morphine. They are totally afraid to use it. There have the perception, the belief that morphine will kill because [of] side effects" (PALL01)

While these shortages in human and medical resources is important to acknowledge and address, they may also be seen as symptoms of larger, more systemic barriers, which include the lack of political prioritization of palliative needs following a humanitarian crisis highlighted by participant PALL15. As shown in the quote below, they stated that the focus of this "country building" stage in the aftermath of crisis is rife with

political instability and therefore political will is directed at initiatives with the greatest impact. Once again, this is understood to mean basic necessities of food, water, and shelter, but the maintenance of human dignity and alleviation of suffering through palliative care, is not considered "impactful":

• "I think it's like everything else, it (Palliative Care) has never been top of people's [political] agendas, they've been - they had a civil war after, they only stopped seven years ago, so there's been kind of all that country building, and there's a lot of political instability, and so the focus has been on what has the biggest impact." (PALL15)

PALL08's comments (below) suggest that the lack of political support itself is a superficial symptom of a deeper and more widespread lack of understanding of what palliative care is, and who can (and who should provide it), and how much need there really is. This is consistent with PALL01's comments which highlighted the lack of understanding specific to the effects of morphine as a key palliative pain relief medication.

Furthermore, the human tendency to fear what cannot be understood or controlled, often results in the development of taboos and stigmatization of topics and practices within communities. "When we talk about palliative care, it's true it's a taboo" was the observation made by participant PALL09, who went on to claim that a lack of knowledge and transparent discourse has inhibited the development of best practices and bolstered the taboo surrounding end-of-life care.

The lack of understanding hypothesis is also consistent and with the findings presented earlier in this chapter, which showed that there is no consistent understanding or definition of palliative care even among humanitarians. PALL08 suggests that general training programs may be a way forward:

• "We need to make sure that there is awareness - and I think that comes back to even for the health workers and relief workers that are involved in whatever the humanitarian crisis is, I think there needs to be some means of how they can identify that actually there is a palliative care need - they don't need to be the people that provide it, but they at least should have that general training to understand to understand what the general palliative care needs might be even if they can't provide specialist palliative care" (PALL08)

PALL16 (below) agreed with the idea that general training for palliative care 'should be considered in any health facility", but also demonstrate underlying paternalistic rhetoric (and thus, the influence of rescue culture) in stating "we have to help them":

• "I think it should be considered in any health facility if the human resources and tools are available, because in the end, those are the patients and they are considered as, really burden for themselves and their families and the society, and we have to help them. Otherwise, they are, the society is already in a crisis, and one patient won't be considered as a burden for one or two or three families inside. So taking care of such patients is not for making life easier for self only, its for family and sons and - actually the impact is important, is greater than treating one person. But again, the price to handle, it should be a balance where we can handle some palliative procedure, regarding the HR, that this is available, and the cost. But it should be considered when those things are available." (PALL16)

PALL16 goes on to note that the impact of taking care of palliative patients is not only directly alleviating the suffering of the individual, but also that of the many individuals surround that person. The quote also introduces another major barrier, that was consistently alluded to by participants; funding.

#### 4.6.2 Funding & Metrics

One of the challenges of providing any service that is dependant on donor dollars is the question of impact; how is the money being spent, and how can we see the impact that is being made? Throughout this chapter, I have highlighted several instances of "impact" being defined as saving lives. Smillie (2012) believes that we have entered an era of "new-humanitarianism" where old ideas, principles and norms are moribund, and this definition of impact (and the metrics of success that go along with it) may be seen as a reflection of that fundamental deviation from the old principles. While the number of lives saved is an easily understood, quantifiable, and compelling indicator, the reduction of suffering at end of life is inherently subjective and abstract. Comparing the suffering of an elderly cancer patient to the suffering of a middle-aged trauma patient would be impossible to compare objectively. Participant PALL14 personally struggled with communicating the value of what she calls "dignified care", arriving at the conclusion that mathematics rather than human attitudes are what incites action in the population;

• "you [can] try to explain why it's important to provide care, dignified care for dying people and it falls on a deaf ear, but **once they understand that it's a threat** 

to the rest of the population, they start to act. So you see for me it illustrates actually the mathematics rather than a human attitude."

As long as donor dollars are dedicated to strictly quantifiable indicators and firmly focused on saving lives, humanitarian organizations will orient their efforts accordingly. Despite this reality, some providers are finding alternative ways to integrate the alleviation of suffering and provision of comfort and care into "humanitarian action in a calculating world" (Smillie & Minear, 2004). Participant PALL08, for example, indicated that their organization has a clear palliative mandate (~33-50% of programming), has had to use "innovative" ways of raising funds, including "poverty reduction". While this is represents an inspiring dedication to the palliative cause, it also fosters a culture of organizational opacity through potentially false representation of programming. By challenging the rescue culture and removing its impact on the funding and metrics of success in humanitarianism, these providers will be empowered and encouraged to make their valuable work more widely known.

# 4.7 Palliative Care as a Moral Obligation & Human Right

Despite these significant institutional barriers, humanitarian professionals are seeking out ways to provide palliative services to those in need, under whatever name or guise necessary. This may be because of what they believe is at stake when considering the role of palliative care in humanitarian contexts. Here is where the policy-maker role

was particularly valuable to have, as participants were able to draw upon moral and philosophical convictions informed by long-term humanitarian engagement. As participant PALL10 eloquently expressed, the existence of institutional barriers should not deter action, and can almost be seen as markers of progress in the evolution of the sector;

• "A few years ago even in the issue of chronic disease was considered as a limit, as beyond the limits of what we do, and now we do that. [...] So a few years ago people would say oh we never do that, it's not part of the mandate, it's not part of what we do. So probably the same thing will happen, yes we have limits now, but probably as soon as you raise the issue of palliative care [and] people understand how important it is, they understand that you cannot ignore this dimension, and if they accept that then – yeah, you will have a lot of developments, and the limits will be pushed behind what we have now." (PALL10)

While there was some disagreement amongst the participants as to which humanitarian organizations could/should conceivably integrate palliative care into their mandate, there was consensus that Palliative Care was something that should be integrated somewhere, somehow, based on the following moral and human rights-oriented arguments:

• "We should advocate that, again, for palliative care in humanitarian crises to be a basic human right. Because it should be. Obligation, I don't like. Because I saw your question... Because people should not feel obliged. It should be the norm. It should be a human right and the norm. And again, it's as I told you. The big difference, in the past, it was absolutely not accepted. But to me, not giving palliative care and pain treatment is exactly like non-assistance to persons in danger or like accepting torture. Because some pains are like torture." (PALL01)

• "It has to do with the way, let's say, of respecting the individual rights of any individual that needs help in emergencies. I think there are minimum standards for humanitarian aid that have been discussed at the Istanbul summit, I think, last year, and where they say that in emergencies, there should be a set of basic rights that people have when they are living in conflicts and in emergencies. And, of course, the right to have access to palliative care, should be also a right ingrained within these basic rights." (PALL09)

If we are able to assert that palliative care is indeed a human right, established through the right to dignity and the right to health, then it stands to reason that any care provided in the absence of a palliative approach is not care at all. PALL08 stated this strongly, pointing back to triage as an important element of the humanitarian response mechanism where palliative considerations should be made:

• "...you're not caring for people if you don't [provide palliative care]. And that's the reality - what do you do? You're then, you, in my view - you then de-facto, there's an opportunity cost, which is an ethical issue that if you're not dealing with palliative care, you're not going to identify those needs and it comes back to the way you triage, and you think well, they're going to be dead in the next few weeks, let's just leave them and go and focus on somebody we can save" (PALL08)

PALL18 went further, stating that their personal reasoning for engaging in disaster response work was the very protection of dignity through the provision of quality care:

• "I do disaster response work [because] I really want to be part of providing dignified, quality care to people who have been severely traumatized. And I think that everything, I see everything, I do through the lens of the trauma they have experienced." (PALL18)

PALL18 is likely not alone in their dedication to this compassionate type of care, and this central motivation must be fostered within the ranks of humanitarian responders. Rescue culture however contradicts this compassion, reducing patients to a calculus, which an attitude that may result from a flawed/lacking education system.

#### 4.8 There is a need for education at all levels

Based on the statements above, which speak to the moral imperative to provide palliative care on the basis of upholding fundamental human rights, it is clear that the participants supported the integration of palliative care into humanitarian healthcare response. They also recognized the existence of several immediate, mid-level, and systemic barriers ranging from access to pain medications, to lack of general awareness of the importance of palliative care. In response to these challenges, participant shared several recommendations, in addition to responding to the direct solicitation of recommendations for minimum standards should be set (if the participant agreed that palliative care should be provided). Among the recommendations that arose more organically from the data was "Improved Education" at all levels: "Formational" (ie Medical or Nursing School), "Professional" (ie specialized diploma programs), and "Organizational" (i.e internal education programs).

• "I think it's more important to have education and training around health care professionals locally, the recognition of roles and strategies they can use. I mean

in a lot of countries you don't have multiple levels of different specialists, you have basic community based health workers but teaching them some of the basics around palliative and care, but it needs to be done within the local context in collaboration with local experts as appropriate. Like not a one-size fits all." (PALL12)

• "I think NGO, we teach and train, but WHO should really push ministry of health to review the curriculum of medical and nursing schools." (PALL01)

Participant PALL08 further highlighted the need for improvement in medical curricula, identifying medical school as an initial process through which palliative care is devalued:

• "[UK Professor], I don't know if you've heard of him, he was one of the kind of leading lights of the hospice movement in the UK and has a historical perspective and I was talking to him about threats to palliative care as a speciality and somebody was saying that they speak to medical students on the first day of their training in first year about palliative care, and they're very passionate, and they're very engaged and enthused about it and then you talk to the same students five years later before they graduate and none of them are interested because the system has almost removed that feeling, the fire that got them to medicine in the first place, the kind of medicalization of their training has tarnished that in a way, taken the varnish off" (PALL08)

According to this statement, the "medicalization" of training is what is to blame for students graduating from medical school with less zeal and compassion than when they entered. This "medicalization" may be interpreted as the indoctrination of a strict focus on saving lives, seeing patients as a success or failure on their part as physicians based on their clinical outcome. This is not to say that healthcare professefionals should adopt a *laissez-faire* attitude to death, but rather that they should recognize it as a normal

part of the life course, and be trained to ease this phase in a patient's life. In doing so, they may retain the very elements of care that drew them to medical practice in the first place.

This fear of failure and perception of death as a failure extends past physicians, and can be seen in the actions of many other humanitarian healthcare professionals.

#### 4.9 Summary

This chapter presented research findings with a special focus on behavioural and rhetorical patterns reflective of a humanitarian rescue culture. Among the findings was the exposure of a lack in consistent nomenclature for referring to non-curative efforts. Some participants identified this as a symptom of the stigma and prejudice surrounding the term "palliative care", associating it, and death, with failure on the part of the physician. There is also a lack of clarity on the actual practices that could be qualified as palliative care, with many participants alluding to practices that would actually fall under curative therapeutic interventions. Beyond these questions of nomenclature, there were several common experiences of palliative care provision, and the personal, cultural, and systemic barriers that exist. Funding, resources, and a lack of understanding were all recurrent themes. Despite these barriers, there was general consensus within the study population that there is a moral obligation to provide palliative care as part of preserving the dignity and rights of individuals.

Throughout the participants' comments, there was a reflection of a deeply-rooted focus on saving lives, often to the point of excessive, aggressive care. This "rescue

culture" will be discussed further in the the next chapter, and some suggestions for the realignment of humanitarian culture with the foundational humanitarian objective of alleviating suffering will be presented.

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# **Chapter Five: Discussion**

This chapter will focus on the roots of humanitarian "rescue culture", as well as how and why the culture may reorient itself with the foundational principles of humanitarianism through the inclusion of palliative care. This will be followed by explanation of some of the key indicators that show why now may be the right time for palliative discourse to occur in humanitarian context. The chapter will close with a presentation of limitations, future directions and conclusions drawn from this thesis study.

#### 5.1 Rescue Culture, Fear of Failure, and Death

Minor adaptations were made to the coding definition of rescue culture to arrive at the following definition, which will be used for the remainder of the discussion. The definition of palliative care as it is used in this definition, aligns with the holistic WHO definition that was used throughout this thesis.

**Rescue Culture:** A pattern of behaviours and actions carried out by humanitarian actors reflecting an systemic prioritization of saving lives, exemplified by the lack of palliative care provision even when faced with no contextually appropriate curative options, and/or engagement in "excessive/aggressive" cure-oriented therapies.

In the 2014 text "Rethinking Canadian Aid", Ian Smillie wrote with unblinking honesty that "failure is endemic in the development business [...] yet the aid establishment

is incapable of saying this or admitting to failure". Failure is not exclusive to development projects; humanitarian responses are equally subject to mistakes, mishaps and shortfalls. What were the UN instigated cholera outbreak during the 2010 Haitian earthquake response (Piarroux 2011), or the 2011 Somali Famine Response (Seal & Bailey, 2013) if not failures of catastrophic proportions? It is difficult to accept, of course, because failure within the context of humanitarian healthcare is almost always a matter of life and death. As participant PALL14 stated, death is regarded as the humanitarian healthcare professional's enemy, and they feel that it is their obligation to fight this enemy until the end. The fight for life and will to live is a basic human instinct, however, in the case of non-curable conditions in austere contexts, PALL14 seems to suggest that there may need to be a more nuanced relationship between the patient, humanitarian, and death. If /when humanitarians reach this point and stop viewing death as an enemy, a fight, and/or a failure on their part, the patient may have a more comforting end of life experience. Participant PALL01 discussed the challenge of convincing a colleague to stop resuscitating a patient who had undergone severe haemorrhaging ("...he never agrees that he should not resuscitate this patient"). Eliminating this fear of death as a failure of the physician does not mean "giving up" on patients that can be saved, but rather providing them with more appropriate care that addresses their needs instead of aggressively pursuing a low-chance curative option. This will in turn set more realistic external expectations, hopefully eliminating any future occurrences of the violence against

physicians, teams, and hospitals in the face of unsuccessful outcomes presented by Aryal and colleagues (2015), as discussed in Chapter 1.

It can therefore be justifiably posited that addressing the fear of failure and equating of death with failure will instigate a shift in behaviour, away from the negative ideologies of rescue culture, and towards the foundational humanitarian priority of alleviating suffering.

#### 5.2 Shifting the Culture

The aforementioned definition of culture from Kroeber & Kluckhorn (1952) continues beyond the simple recognition of behavioural patterns to state that "the essential core of culture consists of traditional ideas and their attached values", and that "culture systems may be considered products of action, or as conditional elements of future action". From the literature presented in Chapter 1, and the moral arguments presented by participants in Chapter 3, it is evident that the alleviation of suffering and the attached values of preserving dignity and human rights are at the essential core of humanitarian culture. The actions and circumstances of humanitarian response have deviated from this core, towards the "rescue culture" that was defined and exemplified in the previous chapter. This point is worth emphasizing; humanitarian actions must be seen in context, and their dedication to saving lives is both necessary and valuable. Rescue culture exceeds what is deemed professionally acceptable, causing further suffering through "aggressive" curative therapies when palliation should be prioritized, and is not

part of the humanitarian core. Returning to Kroeber & Kluckhorn, they state that the essential core may also be an element used to guide future action, and participants of this study clearly believed that palliative care was (and remains) a part of the essential core, and therefore could (and should) be re-integrated into humanitarian culture.

There were many commonalities between the recommendations found in the literature and those provided by the study participants. The observation made by participant PALL18, who believed that we should not only strive for the inclusion of palliative specialists amidst the ranks of humanitarian response units, but also for a baseline appreciation and engagement of all humanitarian healthcare providers in a generalized palliative approach, was a particularly valuable one. They believed that waiting for the integration of palliative specialists into team structures, policies and protocols would provide an easy-way-out of providing these services in the absence of these specialized individuals. This suggestion for generalized training, if carried out, would create a new normative pattern of practice across all members of the group, which may actually be seen as a shift back to the "essential core" of humanitarian culture. Smith & Aloudat's (2017) proposal for a shift away from the false dualism of "cure or care" would also be addressed by PALL18's suggestion of a generalized palliative approach, fostering a culture of "either/and" instead of "either/or" (PALL08).

This generalized shift in approach must begin from the entry point to humanitarian healthcare (triage), and extend well past the death of the patient. Triage was discussed at length by literature sources and study participants as a key area for policy/protocol

adaptation to shift away from rescue culture and towards a palliative approach. Triage is the point at which the save-only ideology of rescue culture manifests most clearly, in the way that terminal patients (black-tag/expected/unsalvageable) are treated. Rather than being triaged *into* a category of care (as the previously identified definition of triage would connote), patients who will die within the given context seem to be triaged out of care. They are relegated to back rooms and hospital hallways, are given no time or attention despite their extreme pain and suffering, and often treated as if they are already dead (Orbinski, 2009). Reorienting the triage structure away from triaging out and back to triaging in is a simple step, rooted in values-based shift, and requiring little change to the practices involving other "tags". As participant PALL04 stated, palliative care is not complicated; "With ten medications, you can practice palliative medicine, pharmacologically speaking. But it is everything else. It is the communication, the relationship building, the dignity, it is all of those things." The challenge therefore lies in changing the ways humanitarian healthcare professionals approach and view the dying. away from fear and cold-calculus, and towards dignity and compassion.

#### 5.3 Why Now?

In her discussion of the process of interpretive description, Thorne (2008) makes an important point about interviewing as a qualitative method. First, she recognizes that interviews capitalize on subjective knowledge, but more specifically on subjective knowledge that we are capable of articulating in words. What and how we articulate, and

what is inarticulable, is a definitive feature of human groups. In her words, "we are far more likely to reference conceptualizations that are familiar to us than to try and construct new ones" (Thorne, 2008 pg 128). When what we can verbalize dictates what we think about, and what we think about shapes what we are comfortable sharing, the interview process becomes limited in its capacity to uncover experiences that are new and lack the reference-able conceptualizations necessary to facilitate discussion.

While some may see this as a limitation, it can also be taken as an indicator of the readiness of a group or sector for discourse, and ultimately, change. Participant PALL09 was able to place the source of the stigma surrounding palliative care on this very absence of discourse;

• "that's the taboo around it; that there is not enough exchange of information around it because people are afraid that what they are doing is not correct, or there is a lot of space for improvement to do it. And that's, I think, is the first barrier for the moment in getting the subject more discussed." (PALL09)

There are a number of signs that the humanitarian sector, particularly in Canada, is ripe for discussion of this important topic. Firstly, there is a significant amount of discourse that already exists on palliative care in the literature, some of which was captured in the background chapter of this thesis. Secondly, within the Canadian context (as a major "donor" or "volunteer" country), the general public has been fiercely engaged in discussion on the ethics of end-of-life with a particular focus medically assisted dying and Bill C-14. Other countries, such as the Netherlands, have long standing policies surrounding these topics. The foregrounding of this topic in the collective consciousness

of the general population by the media presents an opportunity to discuss end-of-life beyond our borders. The dignity that we expect until and beyond our dying breath is also an expectation of those who face their final moments in disaster contexts. While euthanasia of patients in humanitarian contexts is considered ethically inadmissible, the blatant ignorance of palliative patients needs remains an under-discussed as an ethical infraction of the human right to health and dignity.

We have also seen several champions arise for the integration of palliative care in humanitarian response, including Joan Marston and the newly formed Palliative Care in Humanitarian Aid Situations and Emergencies (PALCHASE) Initiative. Several study participants have pointed to Medecins du Monde as pioneers in the humanitarian palliative care space (PALL01/04/10/12), and MdM continues to advocate for non-curative humanitarian efforts globally. Finally, the World Health Assembly Resolution 67.19 indicating that palliative care should be an integral part of the continuum of care was an important recognition on the international level that discourse and action were needed.

Through the joint efforts of these individuals and initiatives, palliative care has been begun to surface in the humanitarian consciousness, which in turn equipped our study participants with the necessary tools to articulate their subjective experiences with common conceptualizations. The very richness of the commentary and interest in contributing to the study can be seen as an indicator of the fact that now may be the right time for this conversation to turn into action. As PALL09 suggested;

• "when it is more discussable, then we will see better the impact of it [...] the people that were doing it before in secret, they will come out and also speak out to say, "okay, it is not a taboo anymore, so we really need this help and we really need to improve it".

Engaging these new voices and valuing their opinions on how to improve practice will be equally important in the future.

#### 5.4 Limitations

This study provided several key insights into humanitarian healthcare policy maker's experiences of providing palliative care in disaster contexts. While the study was richly informed by a number of extremely experienced humanitarian professionals and interviews were carried out by practiced qualitative researchers, there are a number of limitations that must be addressed. The demographic table (Section 3.1) reveals that there is a significant bias towards North American physicians. This may not be an issue, however the desired demographic was "humanitarian healthcare policy makers" and the lack of non-healthcare oriented policy makers (legal professionals, diplomats, etc) is a clear limitation of the findings. This is particularly relevant given that foundational barrier of rescue culture has direct links and roots in medical culture, which may have featured more prominently due to this homogenous sample population. It would be valuable to explore what non-healthcare humanitarian professionals (program managers, logisticians, engineers etc) believe with regards to the role of palliative care, particularly those who approach the issue from international human rights and international humanitarian law

backgrounds. These individuals may have focused more on the politico-legal barriers, and been able to speak more to the policy levers that may need to be engaged in order to reintegrate palliative care into the humanitarian mandate.

Looking at the study sample as a whole, it also becomes evident that there were no participants that were explicitly against the provision of palliative care in humanitarian contexts. Some participants readily identified organizations other than their own as the ideal actors to carry out the care, effectively dismissing themselves from engaging in the dialogue of a "palliative approach" but even these participants recognized the value of this type of care. This represents a significant limitation of this study, and it was addressed in part through soliciting participants comments on responses from their peers. Here we were able to capture a more realistic representation of the diversity of beliefs; participants discussed their attempts to convince colleagues from older generations, senior-level United Nations bureaucrats, and field-based national staff to see the value of palliative care, but were often unsuccessful. It would have been extremely valuable to have been able to capture the opinions of these individuals, as they are often the ones who have the rescue culture most deeply ingrained and, in the case of the bureaucrats, are the the ones who are able to effect international minimum standards recommendations and changes. This bias may be attributable to the stratified purposeful sampling strategy which, despite our efforts to reach beyond our network (asking colleagues questions such as "Is there anyone you know of who would might not agree with us?"), led to a sample that was homogenous in this way.

It was originally believed that 10-15 participants would provide sufficient data for analysis, and remain within the scope of Master's level research (based on the precedence of previous MSc Global Health Theses). After the 12th interview, many major themes had been presented by the participants to a point that was determined to be sufficient to fuel the interpretive process. Deciding on a stopping point is often difficult in interpretive descriptive studies, with Thorne (2008) explicitly reminding researchers that claims of "saturation" are often maladapted relics of qualitative researchers striving for legitimacy in an empiricist, quantitatively-oriented system. However, it is necessary to recognize the limitations of a relatively small sample size (n=12); consultations and further qualitative studies with a far more vast network of humanitarians and policy makers will be required before any substantial policy, protocol, or standard can be set.

## 5.5 Next Steps: The Larger Humanitarian Health Ethics Research Group Study

The limitations of this study are in part addressed by the next steps of the larger R2HC-funded Humanitarian Health Ethics Research Group study that this thesis is nested under. The analysis of the policy-maker subset is the first completed focus population; a number of humanitarian healthcare providers (HCPs), patients, and families were also interviewed, and the analysis of these interviews is anticipated in the next few months, followed by a cross comparison of major themes from policy maker and HCP interviews. There is also an exploration of key humanitarian contexts in the form of three major case studies (Infectious Disease/Public Health Emergency - Ebola in West Africa, Displaced

Persons - Palestinian, Syrian, and Afghan Refugees in Jordan, and Natural Disaster - location TBD) that is underway. Finally, a short survey (in English, French & Arabic) is being disseminated globally through the Humanitarian Health Ethics network and at several major conferences in North America, Europe, and Africa. Through this much larger, mixed-methods study, we hope to arrive at a more nuanced global perspective of palliative care's role in humanitarian response, and engage key stakeholders with recommendations based on these findings.

It will be particularly interesting to see if the rescue culture rhetoric arises in the interviews done with humanitarian healthcare providers (HCP), patients, and families. There were some indicators within the humanitarian healthcare policy maker (HCPM) interviews that patients affected by humanitarian healthcare crisis had internalized ideas of what the humanitarian is there to do; namely, to save and cure. It will also be valuable to focus on the differences between the various case studies in terms of the types of care that are provided by and expected of humanitarian healthcare providers. Finally, the difference between HCP and HCPM perspectives on the development of minimum standards will be of particular value moving forward. The HCPs would be the individuals most likely to need, and use, these minimum standards and policies as points of guidance while in the field. Although the policy makers continue to engage in field based response, their ideas and actions are much more likely to have been influenced and determined by years of experience within the sector and their respective organizations, possibly making them less amenable to newly imposed standards.

# 5.6 Knowledge Translation

This study has benefitted from a comprehensive knowledge translation strategy that has allowed the Humanitarian Health Ethics Team to engage with stakeholders from very early on in the research process. I personally presented an overview of the research as part of the McMaster University Three-Minute Thesis Competition, in which I placed 2nd overall and received the Dean's Award for Excellence in Communicating Research. The video of this presentation is available online at: https://www.youtube.com/watch? v=VO7hQQ40kLQ. In April 2017, as I neared the end of the data collection and had preliminary coding and codebook structure completed, I was invited by Dr. Calvin Ho and the National University of Singapore Bioethics Unit to present at their monthly Journal Club. I provided a 20 minute presentation which was followed by 40 minutes of questions from approximately 10-12 members of the NUS Bioethics team, ranging from PhD students to full professors. Their comments were extremely valuable and helped guide my thinking as I continued the analytic interpretive process. Following this, Drs Lisa Schwartz and Matthew Hunt provided a joint session at the Canadian Bioethics Society Conference in Montreal, Canada, focusing on the larger study under which this thesis is nested. I was able to attend and discuss the research progress with audience members as well as members of the Humanitarian Health Ethics Research Group at length during this Conference as well. Drs Schwartz, Hunt and Nouvet also presented the study at the International Committee on Military Medicine (ICMM) and the World Association for Disaster and Emergency Medicine (WADEM) Congresses, which I was

unable to attend. Lastly, Dr. Schwartz was invited to present at the MSF Canada Annual Clinical Education Day, which was focused on palliative care and pain management, and Dr. Schwartz addressed both of these topics in her presentations.

As one of the key differentiating factors between Interpretive Description and other qualitative methods is Interpretive Descriptions acute awareness and responsiveness to the pragmatic needs of allied health science researchers (Thorne, 2008). As such, any knowledge translation strategy for an Interpretive Descriptive study should tie back closely to the practitioners, aiming to help guide and inform decision making structures. As previously discussed, the humanitarian sector seems ready to receive and discuss this topic, as indicated by WHA Resolution 67.19 on palliative care as part of life course support, as well as the 2017 MSF Canada's Clinical Day Focus theme. The Humanitarian Health Ethics Research Group has close ties to MSF, WHO and SPHERE Standards, and three members of the Research Group hold board positions on the Ethics Review Board for MSF. Therefore, the end product (publication, recommendations for minimum standards, etc) of the larger study which this thesis informs will be disseminated to top decision makers and key stakeholders worldwide through direct, formal channels and personal contacts. Finally, all participants requested to be sent the findings/final publication once available. Given the fact that the study population consisted of influential members within their respective organizations, this interest and dissemination will be a key part of the knowledge translation strategy.

#### 5.7 Conclusions

This study fills several gaps in the existing body of literature, and is closely aligned with the needs identified by the sector, and by the participants in this study. In 2014, Hunt and colleagues published "A Research Agenda for Humanitarian Health Ethics" which identified five priority topic areas. The first area, "Experiences and perceptions of humanitarian health ethics" is explicitly addressed by this research, with a more specific focus on addressing the experiences of a particular group, namely humanitarian healthcare policymakers. While capturing their experiences of providing palliative care in humanitarian contexts would have been a valuable contribution in and of itself, the interpretive element of this study led me to an exploration of "rescue culture" within humanitarianism as a possible root cause for the apparent disconnect between humanitarian palliative care rhetoric ("save lives and alleviate suffering") and practice ("save lives"). This, as it turns out, aligns closely with a sub-topic within the fifth priority area of "Theoretical Frameworks & Ethics Lenses", namely "culture, asymmetries & humanitarian ethics". In this case, the asymmetry is not as clear cut as the North-South/ Decision Making-Practice issue that Hunt and colleagues identify, but rather a more fundamental dissonance between what humanitarians say they want to do and believe in, and what they are able to do and are funded for.

Beyond the "Agenda" set forth by Hunt and colleagues, there have been numerous calls from key individuals and stakeholder groups for the inclusion of palliative care into humanitarian practice (Biddison et al., 2014; Goodman & Black 2015; Marston, deLima

& Powell 2015; Powell et al., 2017; Smith & Aloudat 2017; Young et al., 2016). This study supports these calls for action, policies, protocols and standards, but recognizes that there is a necessary discourse and philosophical shift (or rather, return to fundamental principles) regarding the purpose and priorities of humanitarianism that must occur first. This discourse and philosophical shift could happen concurrently at all levels. Young health professionals could be educated on the value of palliative care in local and international contexts, maintaining the dedication to humanity that they exhibit on day one of medical school (PALL08). At the same time, field-based practitioners can be given access to "just-in-time" training on how to adopt a generalized palliative approach removing the immediate need for palliative specialists in the field (PALL18). Meanwhile, policy makers and organizational leaders can be engaged in the development of evidencebased standards, guiding the way to a re-imagining of the humanitarian healthcare experience from triage to toe-tag. The resultant reintegration of a palliative approach into the humanitarian mandate and culture will ensure the dignity of the individual up to and beyond the moment of death, and bring comfort to both patient and provider through the knowledge that there is always something left to offer.

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## **Chapter 6: References**

Abbasi, M., & Salehnia, M. H. (2013). Disaster medical assistance teams after earthquakes in Iran: propose a localized model. *Iranian Red Crescent Medical Journal*, *15*(9), 829-35.

Abdul-Razzak, A., You, J., Sherifali, D., Simon, J., & Brazil, K. (2014). 'Conditional candour' and 'knowing me': an interpretive description study on patient preferences for physician behaviours during end-of-life communication. *BMJ open*, *4*(10), e005653.

Ager A, & Iacavou M. (2014). The co-construction of medical humanitarianism: Analysis of personal, organizationally condoned narratives from an agency website. *Social Science & Medicine*, 120:430e-438.

Antommaria, A. H. M., Powell, T., Miller, J. E., Christian, M. D., & Task Force for Pediatric Emergency Mass Critical Care. (2011). Ethical issues in pediatric emergency mass critical care. *Pediatric Critical Care Medicine*, *12*(6), S163-S168.

Aryal, D., Acharya, S. P., Shrestha, G. S., Goffi, A., & Hawryluck, L. (2015). Nepal after the disaster. Insider points of view for the future of critical care medicine.

Asgary, R., & Jacobson, K. (2013). Comprehensive On-site Medical and Public Health Training for Local Medical Practitioners in a Refugee Setting. *Disaster medicine and public health preparedness*, 7(01), 82-88.

Baker, C., Wuest, J., & Stern, P. N. (1992). Method slurring: the grounded theory/phenomenology example. *Journal of advanced nursing*, *17*(11), 1355-1360.

Barilan YM., Brusa M., Halperin., 2014. Chapter 4: Triage in Disaster Medicine: Ethical Strategies in Various Scenarios. Disaster Bioethics: Normative Issues When Nothing is Normal, Public Health Ethics Analysis. 49-63.

Barnett, M. (2011). *Empire of humanity: A history of humanitarianism*. Cornell University Press.

Bex, S., & Craps, S. (2016). Humanitarianism, Testimony, and the White Savior Industrial Complex: What Is the What versus Kony 2012. *Cultural Critique*, *92*(1), 32-56.

Biddison, L. D., Berkowitz, K. A., Courtney, B., De Jong, C. M. J., Devereaux, A. V., Kissoon, N., ... & Powell, T. (2014). Ethical considerations: care of the critically ill and injured during pandemics and disasters: CHEST consensus statement. *CHEST Journal*, *146*, e145S-e155S.

Blomgren, K. J., Sundström, A., Steineck, G., & Wiholm, B. E. (2006). Interviewer variability–quality aspects in a case–control study. *European journal of epidemiology*, *21*(4), 267-277.

Bogucki, S., & Jubanyik, K. (2009). Triage, rationing, and palliative care in disaster planning. *Biosecurity and bioterrorism: biodefense strategy, practice, and science*, 7(2), 221-224.

Brauman, R. (2012). Humanitarian Medicine. Speaking Out Collection. Crash/Fondation Medecins Sans Frontieres.

Bullock, K. (2011). The influence of culture on end-of-life decision making. *Journal of Social Work in End-of-Life & Palliative Care*, 7(1), 83-98.

Bülow, H. H., Sprung, C. L., Reinhart, K., Prayag, S., Du, B., Armaganidis, A., ... & Levy, M. M. (2008). The world's major religions' points of viewon end-of-life decisions in the intensive care unit. *Intensive care medicine*, *34*(3), 423-430.

Burkle, F. M. (2006). Population-based triage management in response to surge-capacity requirements during a large-scale bioevent disaster. *Academic Emergency Medicine*, *13*(11), 1118-1129.

Burstein, J. L. (2009). Mostly dead: can science help with disaster triage? *Annals of Emergency Medicine*, 54(3); 431.

Caro, J. J., DeRenzo, E. G., Coleman, C. N., Weinstock, D. M., & Knebel, A. R. (2011). Resource allocation after a nuclear detonation incident: unaltered standards of ethical decision making. *Disaster medicine and public health preparedness*, *5*(S1), S46-S53.

Chan, E. Y. Y. (2017). *Public health humanitarian responses to natural disasters*. Taylor & Francis.

Chapple, H. S. (2010). No place for dying: Hospitals and the ideology of rescue. Left Coast Press.

Cherny, N. I. (2007). Palliative care in situations of conflict: lessons from Jerusalem. *American Journal of Hospice and Palliative Medicine*, *23*(6), 469-474.

Christian, M. D., Joynt, G. M., Hick, J. L., Colvin, J., Danis, M., & Sprung, C. L. (2010). Critical care triage. *Intensive care medicine*, *36*(1), 55-64.

Christian, M. D., Toltzis, P., Kanter, R. K., Burkle Jr, F. M., Vernon, D. D., Kissoon, N., & Task Force for Pediatric Emergency Mass Critical Care. (2011). Treatment and triage recommendations for pediatric emergency mass critical care. *Pediatric Critical Care Medicine*, *12*(6), S109-S119.

Clark, M. I., Spence, J. C., & Holt, N. L. (2011). In the shoes of young adolescent girls: Understanding physical activity experiences through interpretive description. *Qualitative Research in Sport, Exercise and Health*, *3*(2), 193-210.

Cole, T. (2012). The White-Saviour Industrial Complex. *The Atlantic*. Online.

Creswell, J. W., & Clark, V. L. P. (2007). Designing and conducting mixed methods research. 1st Edition, Sage Publishing.

De Jong, M. J., Benner, R., Benner, P., Richard, M. L., Kenny, D. J., Kelley, P., ... & Debisette, A. T. (2010). Mass casualty care in an expeditionary environment: developing local knowledge and expertise in context. *Journal of Trauma Nursing*, *17*(1), 45-58.

Denzin, N. K. (1978). The research act: A theoretical introduction to research methods. *New Brunswick, NJ: Aldine Transaction*.

Devereaux, A. V., Dichter, J. R., Christian, M. D., Dubler, N. N., Sandrock, C. E., Hick, J. L., ... & Braner, D. A. (2008). Definitive care for the critically ill during a disaster: a framework for allocation of scarce resources in mass critical care: from a Task Force for Mass Critical Care summit meeting, January 26–27, 2007, Chicago, IL. *CHEST Journal*, *133*(5\_suppl), 51S-66S.

Dhillon, P., McCarthy, S., Gibbs, M., & Sue, K. (2015). Palliative care conundrums in an Ebola treatment centre. *BMJ Case Reports*, *2015*, bcr2015211384.

DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical education*, 40(4), 314-321.

Downar, J., Seccareccia, D., & Associated Medical Services Inc. Educational Fellows in Care at the End of Life. (2010). Palliating a pandemic: "all patients must be cared for". *Journal of pain and symptom management*, 39(2), 291-295.

Downing, J. (Ed.). (2014). Palliative nursing and the Ebola crisis. *International Journal of Palliative Nursing*, 20(12), 275.

Dunant, H. (1862) *A Memory of Solferino*. International Committee of the Red Cross. Geneva.

Einav, S., Hick, J. L., Hanfling, D., Erstad, B. L., Toner, E. S., Branson, R. D., ... & Christian, M. D. (2014). Surge capacity logistics: care of the critically ill and injured during pandemics and disasters: CHEST consensus statement. *CHEST Journal*, *146*(4\_suppl), e17S-e43S.

Ferris, E. (2005). Faith-based and secular humanitarian organizations. *International review of the Red Cross*, 87(858), 311-325.

Field, P. A., & Morse, J. M. (1985). Nursing research: the application of qualitative methods. *Beckenham: Croom Helm*.

Finlay, L., & Gough, B. (Eds.). (2008). *Reflexivity: A practical guide for researchers in health and social sciences*. John Wiley & Sons.

Fowler, R. A., Fletcher, T., Fischer, W. A., Lamontagne, F., Jacob, S., Brett-Major, D. & Ferri, M. (2014). Caring for critically ill patients with Ebola virus disease. Perspectives from West Africa. *American journal of respiratory and critical care medicine*, 190(7), 733-737.

Frahm, K. A., Brown, L. M., & Gibson, M. (2012). The importance of end-of-life care in nursing home settings is not diminished by a disaster. *OMEGA-Journal of Death and Dying*, 64(2), 143-155.

Fry, J. (1978). Chapter 7: Cure and Care. *A new approach to medicine: principles and priorities in health care*. Springer Science & Business Media.

Gareis, S. B. (2012). The United Nations. Palgrave Macmillan.

Gibson, M. (2014). Seniors, Disaster Mortality, and End-of-Life Care. In *Disaster Preparedness for Seniors* (pp. 73-87). Springer New York.

Glaser, B. G., & Strauss, A. L. (2009). *The discovery of grounded theory: Strategies for qualitative research*. Transaction publishers.

Goldwert, M. (1993). The messiah-complex in schizophrenia. *Psychological reports*, 73(1), 331-335.

Goodman, A., & Black, L. (2015). The Challenge of allocating scarce medical resources during a disaster in a low income country: a case study from the 2010 Haitian earthquake. *Palliat Med Hosp Care Open J*, *1*(1), 24-29.

Gwyther, L., Brennan, F., & Harding, R. (2009). Advancing palliative care as a human right. *Journal of pain and symptom management*, 38(5), 767-774.

Huffman, J. L. (2011). Surgical palliative care in Haiti. *Surgical Clinics of North America*, 91(2), 445-457.

Hunt, M. R. (2009). Strengths and challenges in the use of interpretive description: reflections arising from a study of the moral experience of health professionals in humanitarian work. *Qualitative health research*, 19(9), 1284-1292.

Hunt, M., Schwartz, L., Pringle, J., Boulanger, R., Nouvet, E., & O'Mathúna, D. (2014). A research agenda for humanitarian health ethics. *PLoS currents*, 6.

International Committee of the Red Cross, ICRC (1965). The Fundamental Principles of the International Red Cross and Red Crescent Movement. Oct 31, 1986. Vienna.

International Committee of the Red Cross, ICRC (2004). What is International Humanitarian Law. Advisory Service on International Humanitarian law.

Irish, D. P., Lundquist, K. F., & Nelsen, V. J. (2014). *Ethnic variations in dying, death and grief: Diversity in universality*. Taylor & Francis.

Jeng, J., Gibran, N., & Peck, M. (2014). Burn care in disaster and other austere settings. *Surgical Clinics of North America*, *94*(4), 893-907.

Kemp, C. (2005, February). Cultural issues in palliative care. In *Seminars in oncology nursing* (Vol. 21, No. 1, pp. 44-52). WB Saunders.

Kipnis, K. (2013). Disasters, Catastrophes, and Worse. *Cambridge quarterly of healthcare ethics*, 22(3), 297.

Kroeber, A. L., & Kluckhohn, C. (1952). Culture: A critical review of concepts and definitions. *Papers. Peabody Museum of Archaeology & Ethnology, Harvard University*.

Lather, P. (1986). Issues of validity in openly ideological research: Between a rock and a soft place. *Interchange*, 17(4), 63-84.

Lee, K. (2008). The World Health Organization (WHO). Routledge.

Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry (Vol. 75). Sage.

Magar, A. (2013), Violence against doctors in Nepal. JNMA J Nepal Med Assoc 2013;52:I-II.

Marston, J., De Lima, L., & Powell, R. A. (2015). Palliative care in complex humanitarian crisis responses. *The Lancet*, *386*(10007), 1940.

Matzo, M., Wilkinson, A., Lynn, J., Gatto, M., & Phillips, S. (2009). Palliative care considerations in mass casualty events with scarce resources. *Biosecurity and Bioterrorism: Biodefense Strategy, Practice, and Science*, 7(2), 199-210.

McCullough, L. B. (2009). Taking seriously the" what then?" question: an ethical framework for the responsible management of medical disasters. *The Journal of clinical ethics*, 21(4), 321-327.

McNeil Jr., D.G. (2007). Drugs Banned, Many of the World's Poor Suffer in Pain. New York Times. September 10, 2007. Online: <a href="http://www.nytimes.com/2007/09/10/health/10pain.html">http://www.nytimes.com/2007/09/10/health/10pain.html</a>

MSF (2011). Charter and Principles - About MSF. <a href="http://www.msf.org/en/msf-charter-and-principles">http://www.msf.org/en/msf-charter-and-principles</a>

MSF (2015). Annual International Activity Report 2015. 2nd Edition. <a href="http://www.msf.org/sites/msf.org/files/international">http://www.msf.org/sites/msf.org/files/international</a> activity report 2015 en 2nd ed 0.pdf

Norris, F. H., Stevens, S. P., Pfefferbaum, B., Wyche, K. F., & Pfefferbaum, R. L. (2008). Community resilience as a metaphor, theory, set of capacities, and strategy for disaster readiness. *American journal of community psychology*, *41*(1-2), 127-150.

Novick, G. (2008). Is there a bias against telephone interviews in qualitative research?. *Research in nursing & health*, *31*(4), 391-398.

OCHA (2016). Global Humanitarian Overview 2017. United Nations Office for the Coordination of Humanitarian Affairs. <a href="http://interactive.unocha.org/publication/2017">http://interactive.unocha.org/publication/2017</a> appeal/#p=5

O'Laughlin, D., & Hick, J. L. (2008). Ethical issues in resource triage. *Respiratory care*, 53(2), 190-200.

Orbinski, J. (2009). An imperfect offering: Humanitarian action in the twenty-first century. Doubleday Canada.

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health and Mental Health Services Research*, 42(5), 533-544.

Phillips, B. D. (2014). *Qualitative disaster research*. Oxford University Press, USA.

Piarroux, R., Barrais, R., Faucher, B., Haus, R., Piarroux, M., Gaudart, J., ... & Raoult, D. (2011). Understanding the cholera epidemic, Haiti. *Emerging infectious diseases*, *17*(7), 1161.

Pou, A. M. (2013). *Ethical and Legal Challenges in Disaster Medicine: Are You Ready?*. National Emergency Training Center.

Powell, R. A., Schwartz, L., Nouvet, E., Sutton, B., Petrova, M., Marston, J., ... & Radbruch, L. (2017). Palliative care in humanitarian crises: always something to offer. *The Lancet*, *389*(10078), 1498-1499.

Redfield, P. (2012). The unbearable lightness of ex-pats: double binds of humanitarian mobility. *Cultural Anthropology*, *27*(2), 358-382.

Repine, T. B., Lisagor, P., & Cohen, D. J. (2005). The dynamics and ethics of triage: rationing care in hard times. *Military medicine*, 170(6), 505.

Rosoff, P. M. (2009). Should palliative care be a necessity or a luxury during an overwhelming health catastrophe? *The Journal of clinical ethics*, 21(4), 312-320.

Saldaña, J. (2015). The coding manual for qualitative researchers. Sage.

Seal, A., & Bailey, R. (2013). The 2011 Famine in Somalia: lessons learnt from a failed response?. *Conflict and health*, 7(1), 22.

Smillie, I., & Minear, L. (2004). *The charity of nations: humanitarian action in a calculating world.* Bloomfield, CT: Kumarian Press.

Smillie, I. (2012). Chapter Two: The Emperor's Old Clothes - The Self Created Siege of Humanitarian Action. *The golden fleece: Manipulation and independence in humanitarian action* (pp. 1-13). A. Donini (Ed.). Sterling, VA: Kumarian Press.

Smillie, I. (2014). Humane internationalism and the malaise of Canadian aid policy. *Rethinking Canadian Aid*, Black, D. R. (Eds) 17.

Smith, J., & Aloudat, T. (2017). Palliative care in humanitarian medicine. Palliative Medicine. Vol 31(2) 99-101.

Sparkes, A. C., & Smith, B. (2009). Judging the quality of qualitative inquiry: Criteriology and relativism in action. *Psychology of sport and exercise*, *10*(5), 491-497.

Spencer-Oatey, H. (2012) What is culture? A compilation of quotations. GlobalPAD Core Concepts. Available at GlobalPAD Open House.

Stevenson, K. N., Jack, S. M., O'Mara, L., & LeGris, J. (2015). Registered nurses' experiences of patient violence on acute care psychiatric inpatient units: an interpretive descriptive study. *BMC nursing*, *14*(1), 35.

Thorne, S. E. (1991). Methodological orthodoxy in qualitative nursing research: Analysis of the issues. *Qualitative Health Research*, *I*(2), 178-199.

Thorne, S., Kirkham, S. R., & MacDonald-Emes, J. (1997). Focus on qualitative methods. Interpretive description: a noncategorical qualitative alternative for developing nursing knowledge. *Research in nursing & health*, 20(2), 169-177.

Thorne, S., Kirkham, S. R., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International journal of qualitative methods*, *3*(1), 1-11.

Thorne, S. (2008). *Interpretive description: Qualitative research for applied practice* (Vol. 1). Routledge.

Thorne, S. (2016). *Interpretive description: Qualitative research for applied practice* (Vol. 2). Routledge.

Tracy, S. J. (2007). Taking the plunge: A contextual approach to problem-based research. *Communication Monographs*, 74(1), 106-111.

Tracy, S. J. (2010). Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. *Qualitative inquiry*, 16(10), 837-851.

United Nations General Assembly. (1948). Universal Declaration of Human Rights. Paris.

United Nations (2008). Fact Sheet No. 31- The Right to Health. Geneva.

United Nations (2016). History of the United Nations. Web. <a href="http://www.un.org/en/sections/history/history-united-nations/index.html">http://www.un.org/en/sections/history/history-united-nations/index.html</a>

World Health Assembly (WHA) (2014). Resolution 67.19 - Strengthening of palliative care as a component of comprehensive care throughout the life course. Sixty-Seventh Session of the World Health Assembly. Geneva.

World Health Organization (WHO) (2008). ReliefWeb Glossary of Humanitarian Terms. Online. <a href="http://www.who.int/hac/about/reliefweb-aug2008.pdf">http://www.who.int/hac/about/reliefweb-aug2008.pdf</a>

World Medical Association (1940). International Code of Medical Ethics.

World Medical Association (1994). Statement on Medical Ethics in the Event of Disasters.

World Medical Association (2014). Ethical Principles of Health Care in Times of Armed Conflict and Other Emergencies.

World Medical Association, WMA (1983). Declaration of Venice on Terminal Illness.

World Medical Association, WMA (1987). Declaration on Euthanasia.

World Medical Association, WMA (1992). Statement on Physician-Assisted Suicide.

World Medical Association, WMA (2011). Declaration on End-Of-Life Medical Care.

World Medical Association, WMA (2014). Resolution on Ebola Viral Disease.

World Medical Association, WMA (2007). Statement on the Ethics of Telemedicine.

Worldwide Palliative Care Alliance (WPCA) (2014). The Global Atlas of Palliative Care. Worldwide Palliative Care Alliance.

Yang, Y. N., Xiao, L. D., Cheng, H. Y., Zhu, J. C., & Arbon, P. (2010). Chinese nurses' experience in the Wenchuan earthquake relief. *International nursing review*, *57*(2), 217-223.

Yin, R. K. (2013). Case study research: Design and methods. Sage publications.

Young, A. W., Graves, C., Kowalske, K. J., Perry, D. A., Ryan, C. M., Sheridan, R. L., ... & Palmieri, T. (2017). Guideline for burn care under austere conditions: Special care topics. *Journal of Burn Care & Research*, *38*(2), e497-e509.

Zoraster, R., Vanholder, R., & Sever, M. S. (2006). Disaster management of chronic dialysis patients. *American journal of disaster medicine*, *2*(2), 96-106.

## **Appendix A: Contact Letter Template**



<u>Subject:</u> Invitation to participate in an interview-based research study relating ethics & palliative care during international humanitarian action.

#### Dear NAME,

You are being invited to participate in an interview-based research study led by Professor Lisa Schwartz, PhD, at McMaster University, and Matthew Hunt, PhD, at McGill University. The study is about experiences and/or expertise related to palliative care needs in public health emergencies and humanitarian crisis situations. The name of this interview-based study you are being invited to participate in here is: 'Aid when there is "nothing left to offer": A study of ethics & palliative care during international humanitarian action.'

Palliative or supportive care that strives to support rather than cure patients is a growing concern worldwide. There are circumstances in humanitarian crises where palliative care may be the most appropriate form of care to provide to patients, but there has been no concerted reflection or research on the need, possibilities, and challenges of humanitarian organizations providing such care to patients in a range of humanitarian emergencies. The goal of this study is to clarify from the perspective of those engaged in humanitarian healthcare first-hand (as patients, host community members, policy-makers, local and expatriate healthcare providers) how humanitarian organizations and humanitarian healthcare providers might best support ethically and contextually appropriate palliative care in a range of humanitarian crises.

The researchers anticipate that with your participation, the study will provide the necessary information with which to develop effective and practical ethical practice. With the findings, the researchers aim to encourage aid organizations to consider integrating palliative care in their programs and how best to do so. The introduction of palliative care training and resources into humanitarian healthcare toolkits can help shift attitudes and expectations, better prepare humanitarian HCPs to meet the clinical needs of the dying, and ease certain kinds of moral distress. Ultimately the goal is to improve end-of-life experiences for patients and HCPs in humanitarian settings.

In order to decide whether or not you want to be a part of the current research

study you will be asked to take part in an interview with a researcher experienced in sensitive issues. The interview is purely voluntary, and will last approximately 60-120 minutes. The interview will be conducted at your preferred location and in your preferred format. It can be conducted in person, over Skype or telephone.

Please note that your responses, identifying information, and other names mentioned would be kept confidential and anonymous. Word-for-word transcripts made from the interviews will not contain any information that will readily identify you or your family members. All personal names, names of doctors and hospitals and geographic places will be removed. Your healthcare providers will not see your specific responses. Only the major lines of thought that emerge from the interviews will be used to describe important ideas that come out of the interviews.

Enclosed is a sheet with detailed information about the research study. Please take your time to make your decision. Feel free to discuss it with colleagues, the research investigators, or anyone else you choose.

If you are interested in participating, you may contact the research coordinator, NAME, or the research team leader, Lisa Schwartz, listed below. Alternatively, you can respond to the research coordinator will be following-up to this letter within two weeks.

Thank you in advance for your time and consideration.

Sincerely,

#### Lisa Schwartz, PhD

#### **General Contact Information:**

To Participate in the Research:

Professor Lisa Schwartz, PhD Arnold L. Johnson Chair in Health Care Ethics McMaster University 905-525-9140 ext 22987; schwar@mcmaster.ca NAME

**CONTACT INFO** 

This study has been reviewed and approved by the Hamilton Integrated Research Ethics Board and McGill Integrated Research Board.





## **Appendix B: Email/Phone Contact Template**

1. Hello. Could I speak with...[name of potential participant]?

If yes: *continue to 2*.

If no: "What would be the best time to reach [potential participant]? Thank you very much."

2. My name is [research coordinator/assistant]. I am calling from McMaster University to invite you to participate in an interview-based research study. The study refers to your interest/involvement in palliative and supportive care in humanitarian situations. Is this a good time to talk?

If yes: *continue to 3*.

If no: "What would be the best time for me to call back? Thank you very much."

3. You are being invited to talk about your experiences and/or expertise related to palliative care needs in public health emergencies and humanitarian crisis situations.

Palliative or supportive care that strives to support rather than cure patients is a growing concern worldwide. There are circumstances in humanitarian crises where palliative care may be the most appropriate form of care to provide to patients, but there has been no concerted reflection or research on the need, possibilities, and challenges of humanitarian organizations providing such care to patients in a range of humanitarian emergencies. The goal of this study is to clarify from the perspective of those engaged in humanitarian health care first-hand (as patients, host community members, policy-makers, local and expatriate healthcare providers) how humanitarian organizations and humanitarian healthcare providers might best support ethically and contextually appropriate palliative care in a range of humanitarian crises.

The researchers anticipate that with your participation, the study will provide the necessary information with which to develop effective and practical ethical practice.

If you volunteer to participate in this study, we will ask you to take part in an interview with a researcher experienced in sensitive issues. The interview will last approximately 60-120 minutes. The interview will be conducted at your preferred location and in your preferred format. It can be conducted in person, over Skype or telephone. By all means take your time in making your decision. Feel free to discuss it with your colleagues or the investigators. This invitation can also be sent to you though the mail or email if you would like to have a document to refer to as you make your decision.

Please note that your responses, identifying information, and other names mentioned would be help confidential and anonymous from the transcripts that will be made of the interview. Only the major lines of thought that emerge from the interviews will be used to describe important ideas that come out of the interviews.

Does this sound like something you would like to participate in? Can I provide you with more information that can be of help to you in your decision?

If yes: Arrange a time. Inform them that they will receive a reminder call 24hrs before their scheduled interview. [Provide contact information in case they have to reschedule.] Thank you very much for your time.

If no: "Is it the nature of the study or the timing that is leading you to answer no?" If 'timing' is the response: "Would you reconsider if we were to contact you again in say two-weeks time?" Thank you very much for your time!

## Appendix C: Letter of Information and Consent







#### **Title of Study:**

'Aid when there is "nothing left to offer": A study of ethics & palliative care during international humanitarian action'

## **Locally Responsible Investigator and Co- Principal Investigator:**

Dr. Lisa Schwartz Professor of Clinical Epidemiology and Biostatistics, 1200 Main St. W., Hamilton, Ontario L8N 3Z5 Email: schwar@mcmaster.ca

Tel: (905) 521-2100 Ext 22987

#### **Co-Principal Investigator:**

Dr. Matthew Hunt, School of Physical and Occupational Therapy, McGill University 3654 prom Sir-William-Osler, Montreal, QC, H3G 1Y5

Email: matthew.hunt@mcgill.ca Tel: (514) 389-4400 ext. 00289\_\_\_\_\_

## Co-Investigator(s), Department/Hospital/Institution:

Dr. Elysée Nouvet, CE&B, McMaster University

Dr. Lynda Redwood-Campbell, Family Medicine, McMaster University

Dr. Lorraine Elit, Oncology, McMaster University

Dr. Carrie Bernard, Family Medicine, McMaster University/University of Toronto

Dr. Kevin Bezanson, Family Medicine, University of Toronto

Dr. Ross Upshur, Public Health, University of Toronto

Leigh-Anne Gillespie, PhD student, McMaster University

**Sponsor:** Enhanced Learning & Research for Humanitarian Assistance (ELRHA)'s program in Research for Health in Humanitarian Crises (R2HC)

We are inviting you to participate in an interview-based research study led by Professor Lisa Schwartz, PhD, because of your experiences and/or expertise related to palliative care needs in public health emergencies and humanitarian crisis situations.

In order to decide whether or not you want to be a part of this research study, you should

understand what is involved and the potential risks and benefits. This form gives detailed information about the research study, which will be discussed with you. Once you understand the study, if you wish to participate, you will be asked to sign this form. You will be given a copy of this form for your records. Please take your time to make your decision. Feel free to discuss it with your colleagues, the research investigators, or anyone you think would help you in your decision. You are completely free to accept or refuse to participate in this study. If you choose to participate, you can withdraw from the study at any time without providing an explanation.

#### WHY IS THIS RESEARCH BEING DONE?

Palliative or supportive care that strives to support rather than cure patients is a growing concern worldwide. There are circumstances in humanitarian crises where palliative care may be the most appropriate form of care to provide to patients, but there has been no concerted reflection or research on the need, possibilities, and challenges of humanitarian organizations providing such care to patients in a range of humanitarian emergencies.

The goal of this study is to clarify from the perspective of those engaged in humanitarian health care first-hand (as patients, host community members, policy-makers, local and expatriate healthcare providers) how humanitarian organizations and humanitarian healthcare providers might best support ethically and contextually appropriate palliative care in a range of humanitarian crises.

With the findings, the researchers aim to encourage aid organizations to consider integrating palliative care in their programs and how best to do so. The introduction of palliative care training and resources into humanitarian healthcare toolkits can help shift attitudes and expectations, better prepare humanitarian HCPs to meet the clinical needs of the dying, and ease certain kinds of moral distress. Ultimately the goal is to improve end-of-life experiences for patients, family, community members, and healthcare providers in humanitarian settings.

#### WHAT IS THE PURPOSE OF THIS STUDY?

- · To develop evidence clarifying ethical and practical possibilities, challenges, and consequences of palliative needs during public health emergencies.
- · To inform realistic, context-sensitive guidance, education, and practices for the provision of palliative care during public health emergencies.
- · To develop a baseline of current palliative care provisions for clinical and psychosocial care in humanitarian action against which progress can be measured.

#### WHAT WILL MY RESPONSIBILITIES BE IF I TAKE PART IN THE STUDY?

If you volunteer to participate in this study, we will ask you to participate in a semistructured interview conducted by one of the research team members that will last approximately 60-120 minutes. The interview will be conducted at your preferred location and in your preferred format. It can be conducted in person, over Skype or telephone. You will be asked to comment on do questions that relate to the following:

- · How can humanitarian organizations best support ethically and contextually appropriate palliative care in humanitarian crises?
- · What are the ethical complexities of doing so?
- · How can existing standards be adapted to support delivery of ethically and contextually appropriate palliative care in humanitarian action?

## WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

There is a possibility that participants, when retelling past events, may become emotional. There is also the chance that due to the specifics of a story being retold, a participant's identity may be revealed.

If you choose to take part in this study, you will be told about any new information which might affect your willingness to continue to participate in this research.

#### **HOW MANY PEOPLE WILL BE IN THIS STUDY?**

We anticipate interviewing approximately 66 individuals.

## WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR FOR SOCIETY?

We cannot promise any personal benefits to you from your participation in this study. We anticipate our study will provide the necessary empirical information with which to develop effective and practical ethical practice. We aim to encourage aid organizations to consider integrating palliative care in their programs and how best to do so. The introduction of palliative care training and resources into humanitarian healthcare toolkits can help shift attitudes and expectations, better prepare humanitarian HCPs to meet the clinical needs of the dying, and ease certain kinds of moral distress. Ultimately the goal is to improve end-of-life experiences for patients and HCPs in humanitarian settings.

# IF I DO NOT WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

It is important for you to know that you can choose not to take part in the study.

#### WHAT INFORMATION WILL BE KEPT PRIVATE?

We will be gathering your name, email address, and/or telephone number as well as organizational affiliation where applicable. This data will not be shared with anyone except with your consent or as required by law. All personal information such as your name, email or real address (where applicable), phone number, will be removed from the data and will be replaced with a number. A list linking the number with your name will be kept in a secure place, separate from your file. The data, with identifying information removed will be securely stored in a locked office or in a password-protected file on a password protected computer. Electronic audio files will be deleted and paper files with identifying information will be destroyed after 10 years. Transcripts, with all identifying information removed, will be archived and made available to other researchers via Scholars Portal Dataserve network through McMaster University (http://dataverse.scholarsportal.info/dvn/).

If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published without your specific consent to the disclosure.

## **CAN PARTICIPATION IN THE STUDY END EARLY?**

If you volunteer to be in this study, you may withdraw at any time. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

#### WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

You will not be paid to participate in the study.

## **WILL THERE BE ANY COSTS?**

Your participation in this research project will involve no additional costs to you other than your time.

#### WHAT HAPPENS IF I HAVE A RESEARCH-RELATED INJURY?

If you are injured as a direct result of taking part in this study, all necessary medical treatment will be made available to you at no cost. Financial compensation for such things as lost wages, disability or discomfort due to this type of injury is not routinely available. However, if you sign this consent form it does not mean that you waive any legal rights you may have under the law, nor does it mean that you are releasing the investigator(s), institution(s) and/or sponsor(s) from their legal and professional responsibilities.

#### IF I HAVE ANY OUESTIONS OR PROBLEMS, WHOM CAN I CALL?

If you have any questions about the research now or later, or if you think you have a research-related injury, please contact:

Dr. Lisa Schwartz Professor of Clinical Epidemiology and Biostatistics, 1200 Main St W, Hamilton, Ontario, L8N 3Z5 Tel: (905) 521-2100 Ext 22987

Email: schwar@mcmaster.ca

If you have any questions about your *rights as a research participant*, please call the Office of the Chair, Hamilton Integrated Research Ethics Board at 905.521.2100 x 42013.

#### **CONSENT STATEMENT**

#### **Participant:**

I have read the preceding information thoroughly. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.

#### Person obtaining consent:

I have discussed this study in detail with the participant. I believe the participant understands what is involved in this study, and understands that s/he can withdraw from the study at any time. I am committed to honor what has been agreed upon in this consent

form, and to give a signed copy of this consent form to the participant.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB).

The HIREB 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, Hamilton Integrated Research Ethics Board at 905.521.2100 x 42013.

## **Appendix D: Interview Guide**

**For participants:** Organizational Representatives, local and international HCPs, Community Pall Care Workers with experience providing palliative and supportive care in public health and humanitarian emergencies

**Total participant time required:** 60 minutes

**Break:** As many as necessary

The goal of this interview is to explore your experiences related to palliative care needs in public health emergencies and humanitarian crisis situations.

## Main research questions (50-80 minutes; *Probes in Italics*)

- 1. To begin, can you please provide your title and a description of your role within this organization (or, for local HCPs, in relation to humanitarian crisis response)?
  - a. How long have you been working in this capacity?
  - b. How has your title and role changed in that time with the organization?
  - c. Is the current organization with which you are working faith-based?
  - d. Have you worked in other organizations?
- 2. OPTION A: What does palliative care mean to you? What does palliative care encompass in your view? (*Note for interviewer*: If very specific or narrow, interviewer will clarify for them our focus on patients/families with incurable/ untreatable conditions facing likely death in the short to medium term)

OPTION B: When did you start thinking about the issue of palliative care in humanitarian emergencies? What drew your attention to this subject?

- a. What training if any have you received in palliative care?
- 3. Would you say (x organization for which currently working) responds to palliative care needs (or provides palliative care) as part of its humanitarian response? *If so, could you please describe how it does so?* 
  - a. Does your organization have in place policies or services to support care for patients with chronic illnesses who are beyond cure (e.g. life limiting illnesses, cancer)?
  - b. How does this compare to other humanitarian organizations with which you've worked?
- 4. Have you seen or participated in palliative care done well within a humanitarian

#### context?

- a. If so, what did that look like? Who was involved? What elements were key to making it work well?
- b. Was there a standard way in which that organization or health centre managed such patients, or was it somewhat exceptional?
- 5. Can you recall a situation or situations you have lived in which the palliative care needs of one or more patients was not well met in your eyes?
  - a. Palliative care involves providing physical, psychological, social, spiritual, even legal support to palliative patients and their families: what sort of support do you feel was lacking for the patient and their family in that situation you just described?
  - b. Did you get a sense of whether or not what happened aligned with the local staff's expectations of what was possible and what should be done?
  - c. How do you think things could have or should have happened differently?
  - d. Probe as necessary to clarify barriers or facilitators to the situation unfolding the way it did.
  - e. How well equipped did you feel the team was in responding to the suffering you encountered in this situation?
  - f. What do you think could have helped in this scenario for the patients/families' palliative care needs to be met more effectively?
- 6. Should providing palliative care during humanitarian emergencies be considered an ethical obligation for all humanitarian organizations? Why do you think it should or should not?
- 7. Do you think palliative care will be integrated more explicitly into humanitarian healthcare in the near future? (What makes you say/think that?)
  - a. What will that look like?
- 8. Do you see any challenges to integrating palliative care more fully into humanitarian healthcare?
  - -Probe in relation to political, economic and social forces or barriers
  - -Probe in relation to humanitarian and local cultural values or practices as barriers
  - -What do you think might help overcome those challenges?
- 9. In your view, is there a strict minimum (of supports/interventions) that should be provided by humanitarian response teams to palliative care patients and/or their families?

- a. Probe to clarify any minimums that are unclear and to understand why these elements of care are fundamental in the eyes of the participant.
- b. Is this a strict minimum for all humanitarian emergency contexts and all patients beyond cure wounded, critically ill, with cancer?
- c. In your opinion, what if any barriers exist at present that may hinder this minimum being introduced and upheld?
- 10. Some might argue that palliative care is not the responsibility of international humanitarian responders: that it is best done locally. Who do you think is best positioned to deliver this care: international NGOs, national governments, or local community-based organizations?
- 11. How important is it that we pay more attention to palliative care needs in humanitarian crises? Is this a major issue in your view? What is at stake? Why should humanitarian workers support this and why should the general population support this initiative?
- 12. Are there any limits to what humanitarian organizations can or should do for patients who cannot be rescued, in your view, in the context of a public health emergency or disaster setting? REPHRASE OPTION: What do you think the limits are for PC in humanitarian emergencies?
- 13. (If time allows) Have you noted changes over time in your organization or colleagues' attitudes towards palliative care needs in humanitarian emergencies? If recent, probe as to why there is this noticeable change.
  - a. What do you think has contributed to these changes?
- 14. You have mentioned x as a key challenge(s) for the provision of palliative care in humanitarian contexts. What is the most urgent issue that needs to be addressed towards improving palliative care in humanitarian response?
  - a. What do you think needs to happen for this to change?
  - b. IF PARTICIPANT TIME ALLOWS: Are there other factors that you see as needing to change to improve palliative care response?

## 15. (If time allows)

Are there any specific supports or resources currently being developed in your organization, or that you would like to see developed in your organization, connected to palliative care delivery in humanitarian settings?

a. Are there any other types of training, resources and supports your organization provides or is planning related to the delivery of palliative care that you would like to mention? *Probe for how and when (and why-in* 

- relation to what event) they were developed developed, how they were implemented and received.
- b. Have the resources designated for palliative care needs been evaluated or amended since their introduction? How so?
- c. Would these strategies for responding to patients' palliative care needs, in your view, translate well across humanitarian settings? REPHRASE: How appropriate are they / would they be in other cultural and organizational contexts?

#### **Debriefing**

Is there anything else that you would like to say about anything discussed today? Would it be alright if we contact you at a later date to clarify or elaborate on any statements you have provided?

Thank you very much for your time. At any point if you would like to revisit your participation in this study, do not hesitate to contact us. We have learned a lot from your story and appreciate gaining your perspective on these topic.

School of Physical and Occupational Therapy

Montreal, Quebec H3G 1Y5 3654 Sir William Osler

IRB Study Number A10-B54-16B

Aid when there is "nothing left to offer": a study of ethics and palliative care during international humanitarian action

# **Appendix E: Ethics Approvals**

Roberta Palmour, PhD

institutional Review Board A10-B54-16B



Project Title: Aid when there is "nothin roject Number: 1855

13 December 2016

Document Name	Document Date	Document Version
EPC-IHA_Protocol_4May	04May2016	Version 2
EPC-BIA_InterviewConsent_Sluly_CLEAN	05/3/4/2016	12
EPC-IIIA, SurveyParticipation, Study, CLEAN	05/3/4/2016	2
EPC-IHA Poster 4May	04May/2016	Version I
EPC-IHA_TelephoneContact_Transcript_4May	04May/2016	Version I
EPC-BIA Invitation Fernal Study CLEAN	05/3/4/2016	12
EPC-BIA_Invisation_Leterhead_Stuly_CLEAN	05/3ul/2016	22
EPC-BLA, SurveyInvitation_Email_Shily_CLEAN	05/3/4/2016	2
EPC-IHA InterviewGuidel Professionals 4May	04May/2016	Version I
EPC-IHA InterviewGuide2 CommunityMembers 4May	04May/2016	Version I
EPC-IHA Sample Survey 4May	04May2016	Version I
EPC-BIA DataTransmission_EncryptionProtocol_4May	04May/2016	Version 1

On 12 December 2016, at a meeting of the Institutional Review Board, the following received a full

Board review and approval:

Palliative care during international

humanitarian action global survey, IRB dated December

Dear Dr. Hunt,

of 12 months from the take of the HREB meeting on larse 21, 2016. Continuation and the continuation of the continuation to the continuation to the continuation to the continuation to the continuation of the

PLEASE QUOTE THE ABOVE REFERENCED PROJECT NUMBER ON ALL FUTURE CORRESPONDENCE

Dr. Mark Isrnan, MD, PhD Chair, Hamilton Integrated Re

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# Appendix F: Codebook

Theme	Category	Node	Definition
	What is Humanitarian Action	Definitions of Humanitarian Action	Participant Definitions of Humanitarian Action.
		Purpose of Humanitarian Action	Reference to the humanitarian sector's prioritization of certain actions or elements of care over others
Definitions and Questions of		Limits of Humanitarian Response	Recognition or perception of limits of humanitarian response as a whole
Nomenclature	What is Palliative Care	Definitions of Palliative Care	Participant Definitions of Palliative Care
		Language of Palliative Care	References to palliative care elements by other names - end of life care, supportive care, comfort care etc and references to challenges associated with certain language
Experiences of Providing Palliative Care	Triage	Triage	References to the triage process and its' outcomes, ethics, decision making etc.
	Key Populations	Elderly Persons	References to Elderly Persons requiring Palliative Care in Humanitarian Contexts
		Cancer & Chronic Disease Patients	References to Cancer and/or Chronic Disease Patients requiring Palliative Care in Humanitarian Contexts
		Paediatric Palliative Care	References to Paediatric Palliative Care in Humanitarian Contexts
		Displaced Persons	References to Palliative Care provision for displaced (internationally or internally) persons in Humanitarian Contexts
	Elements of Ethical and Contextually Appropriate Palliative Care	Empathy & Attitudes of Care	Reference to attitude of healthcare providers, empathy or lack thereof etc.
		Engaging Family & Communities	References to role of family, extended family, and community in the provision of contextually appropriate Palliative Care
		Learning from Locals (Customs & Culture)	Reference to culture and customs of a local population and how that knowledge can be integrated into the provision of ethically and contextually appropriate palliative care

Theme	Category	Node	Definition
	Elements of Ethical and Contextually Appropriate Palliative Care	Faith & Religion	Any reference to faith and/or religion on the provision (or lack thereof) or palliative care
Experiences of Providing Palliative Care		Fluid Resuscitation	References to IV/Fluid resuscitation
T amative date		Pain Management	References to providing Pain Alleviation
		Psychosocial Support	References to the provision of Psychosocial Support
Barriers to Providing Ethical and Contextually Appropriate Palliative Care	Polito-Legal	Politico-Legal	References to legal issues, international humanitarian law, human rights law, or political interference (regional, provincial, rebel, federal) with palliative care provision
	Resources	Funding	References to funding, cash flow, donors, earmarked funding
		Resources (Human)	References to scarcity of human resources or personal (or person-hours) to provide palliative care
		Resources (Medical)	Reference to lack of medical infrastructure and equipment to provide palliative care in humanitarian contexts excluding access to opioids and pain medication
		Resources (Narcotics & Opioids)	References to difficulty or scarcity of access to appropriate pain medication and alternatives that may be used in providing palliative care in humanitarian contexts, double coded with politico-legal if federal ban on access/usage
	Lack of Awareness	Lack of Awareness (Affected Populations)	This refers to humanitarians perceived awareness (or lack thereof) of local populations surrounding palliative care ("didn't get it" "awareness" "understanding" "unaware")
		Lack of Awareness (Responders)	This refers to awareness (or lack thereof) among humanitarian responders (National or Expatriate) surrounding palliative care; "didn't get it" "awareness" "understanding"
		Stigma & Prejudice	Reference to the stigmas and prejudices (domestic and international) surrounding palliative care, excluding specific references to culture and customs surrounding death and dying

Theme	Category	Node	Definition
What is at Stake	What is at Stake	Moral Arguments	WHY integrate palliative care into humanitarian action? (or Ethical imperatives or Convictions): grouping together statements about why, in participant's view or in views by which they abide (and excluding views they have heard and with which they disagree), palliative care has a place in humanitarian healthcare
		Dignity & Human Rights	Reference to Palliative Care as a human right, right to dignity, preserving dignity etc.
Recommend -ations	Improved Education	Formational	References to need for change at formational training level (medical, nursing degrees etc) to better integrate/emphasize palliative care, and references to participants own formational training
		Organizational	References to organization specific training for palliative care in humanitarian contexts (existing or recommended)
		Professional	References to secondary degrees/diplomas/ certificates that should be created and or changed, and references to participants own additional training
	Sustainability	Sustainability	Any reference to the durability/sustainability of a program or element of humanitarian response beyond
		Health Systems Strengthening	Reference to collaboration and capacity building to strengthen health systems within the local contexts of humanitarian events
		Working with National Staff	References to importance of/impact of/reliance on working with National Staff and local organizations/systems
	Minimum Standards	Minimum Standards	Reference to, or suggestions for potential or existing minimum standards
Rescue Culture	Rescue Culture	Rescue Culture	Somments that point to an ingrained saviour complex within the humanitarian, and the humanitarian sector, repeated to the point of becoming a "culture" of curative efforts that go beyond what may be appropriate Inspired by PALL01 - "l'acharnement therapeutique
Treasure Chest	Treasure Chest	Treasure Chest	Short quotes of particular eloquence, importance, or impact, for potential feature in the analysis/reporting

Appendix G: Interview Report Template	
Participant Code: PALL_	
Date:	
LENGTH:	
INTERVIEWER: REPORT COMPLETED BY:	
TRAINEE:	
Basic Participant Info:	
1. Describe any research pertinent exchanges before or after the interview with t participant:	this
2. Summarize points made or events describe that struck you as important or relevant in the context of this study:	
3. What if any were methodological challenges or suggestions you have for the conduct of future interviews based on this one ?	