



“Dying alone is hard
anywhere in the world”

Palliative care in natural disaster response

A Report for Humanitarian Practitioners and Policymakers

Natural Disaster Team:

Rachel Yantzi, Takhliq Amir, Sonya de Laat, Carrie Bernard, Laurie Elit,
Corinne Schuster-Wallace & Lynda Redwood-Campbell

Report Authors:

Takhliq Amir & Rachel Yantzi

Principal Investigators:

Lisa Schwartz & Matthew Hunt

Sub-Study Leads:

Sonya de Laat & Emmanuel Musoni (Rwanda)
Elysée Nouvet & Pathé Diallo (Guinea)
Olive Wahoush (Jordan)
Rachel Yantzi (Natural Disasters & Bangladesh)



@humethnet

Find Us: www.humanitarianhealthethics.net

Contact Us: yantzir@mcmaster.ca, schwar@mcmaster.ca, matthew.hunt@mcgill.ca

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• **Graphic Design:** Isis A. Harvey | harvey.isis@yahoo.com



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Introduction

Humanitarian aid organizations and healthcare providers (HCPs) increasingly recognize the importance of palliative care in humanitarian crisis as a means of fulfilling the humanitarian commitment to relieve suffering and uphold dignity.¹ Unfortunately, given the overwhelming need for healthcare resources in many humanitarian responses, efforts to save lives often overshadow the needs of those who cannot be saved.² This was highlighted during the West African Ebola crisis, where healthcare providers were faced with a devastating illness with a high mortality rate and limited treatment options.

In response to the emerging recognition of the need for palliative care, the Humanitarian Health Ethics Research Group undertook a program of research in order to understand the ethical dimensions of palliative care during humanitarian action. Here, we present key findings of the sub-study focused on **natural disaster settings** that was part of this larger program of research. Through this series of reports, we hope to present the perspectives of those engaged in humanitarian healthcare firsthand – as patients, host community members, policymakers, and local and international healthcare providers – in order to clarify how humanitarian organizations and humanitarian healthcare providers might best support ethically and contextually-appropriate palliative care in a range of humanitarian crises.

Key Findings

- Participants described palliative care **as a key component of comprehensive humanitarian healthcare** involving companionship and psychosocial support for patients and their families, dignity in death and dying, and the management of pain and other distressing symptoms.
- **Barriers to the provision of palliative care in natural disaster settings** included damage to health structures; inadequate resources; disrupted supply chains; the invisibility of patients with palliative needs; differences in local cultural norms; the prioritization of acute needs; and challenges of mobility and access to care.
- Despite existing limitations, respondents agreed that humanitarian aid organizations have **an ethical obligation** to provide palliative care.
- Integration of palliative care may play a role in **alleviating distress** among disaster responders, particularly those from affected communities.
- Participants emphasized that palliative care must be **integrated into disaster planning** from the beginning; otherwise, it is likely to be neglected during a crisis.
- There was a clear consensus concerning the need for palliative care **training and protocols to guide practice** in natural disaster settings.

Palliative care “improves the quality of life of patients and their families facing [problems] associated with life-threatening illness, through the prevention and relief of suffering.”³

Overall Study

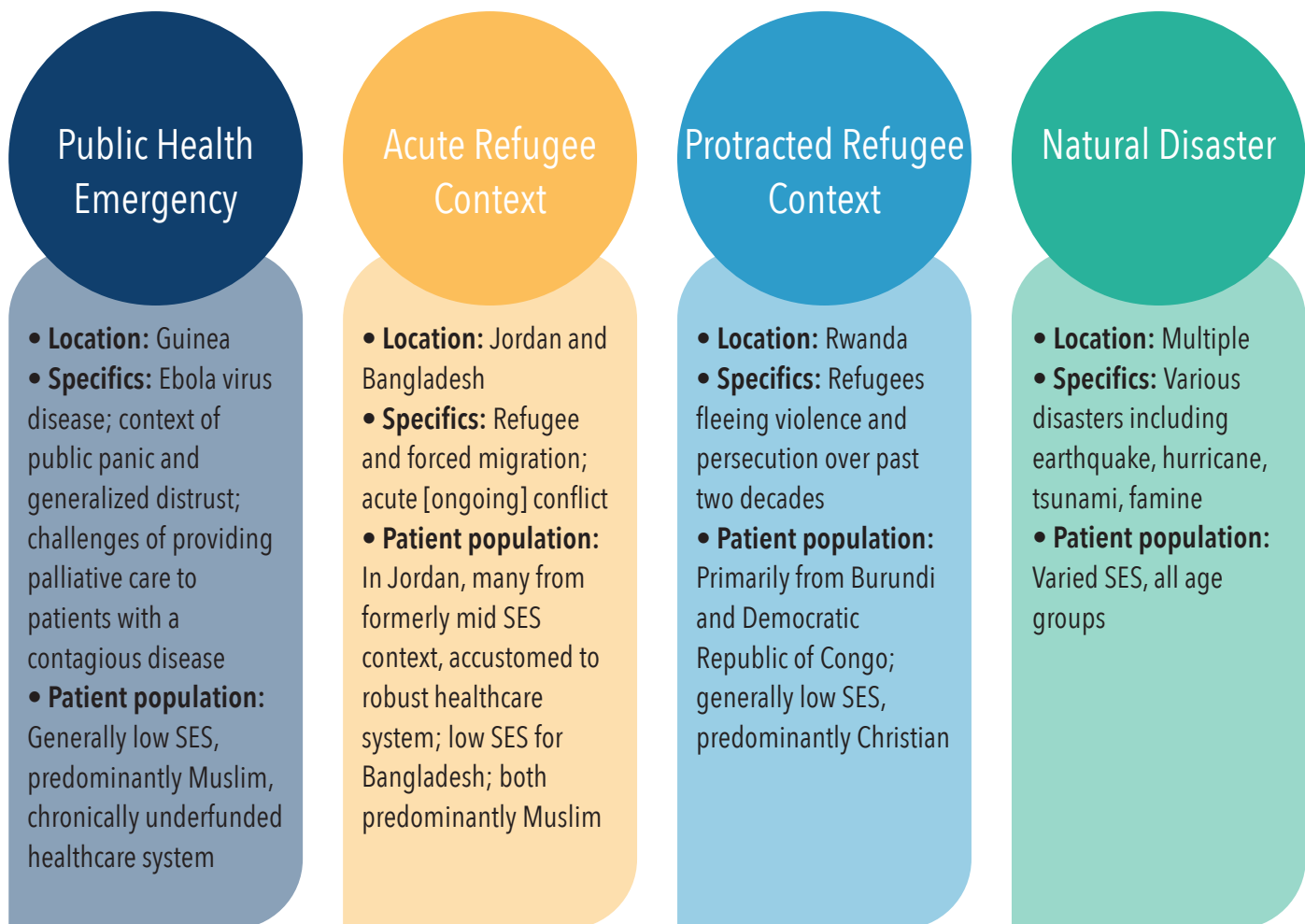
Aid when there is "nothing left to offer": A study of ethics & palliative care during international humanitarian action is a program of research focused on palliative care in humanitarian crises that involved a literature review, organizational survey, key informant interviews, and the following in-depth sub-studies:

- public health emergency
- protracted refugee context
- acute refugee context
- **natural disasters**

The goal of the program of research was to **clarify the ethical and practical dimensions of providing palliative care in humanitarian crisis contexts**, and to **inform policy and practice**. Sub-studies were identified through stakeholder meetings and key informant interviews, and are further described in the diagram below.

"To me, palliative care is about acceptance of and creating dignity and a real patient-centered approach to, to when medical treatment is no longer lifesaving, to when it's futile."

- International nurse, earthquake



Background: The Context of Natural Disasters

According to the World Health Organization (WHO), a natural disaster is “an act of nature of such magnitude as to create a catastrophic situation in which the day-to-day patterns of life are suddenly disrupted and people are plunged into helplessness and suffering, and, as a result, need food, clothing, shelter, medical and nursing care and other necessities of life, and protection against unfavourable environmental actors and conditions.”⁴ While we use the term “natural disasters” in this report, it is widely recognized that the impacts of natural disasters such as earthquakes and tsunamis are shaped by human activity, degrees of vulnerability of certain communities, and action or inaction to mitigate natural hazards.⁵ The annual death rate due to natural disasters is around 90,000 people worldwide, with approximately 160 million others also affected.⁶ Over the last 10 years, 95% of the nearly two billion people affected by natural disasters were affected by a weather-related event.⁷



Infrastructure damage caused by the earthquake in Haiti in 2010. Photo credit: Matthew Hunt

Like conflict settings and public health emergencies, natural disasters can overwhelm the capacity of health systems to meet the needs of the general population. This constitutes a humanitarian crisis, wherein the health and well-being of large groups of people are threatened due to factors such as lack of access to care, infrastructure damage, and resource scarcity. In recent years, many nations, including Haiti, Nepal, Pakistan, India, and Japan have experienced significant losses of life and devastation to infrastructure due to natural disasters.

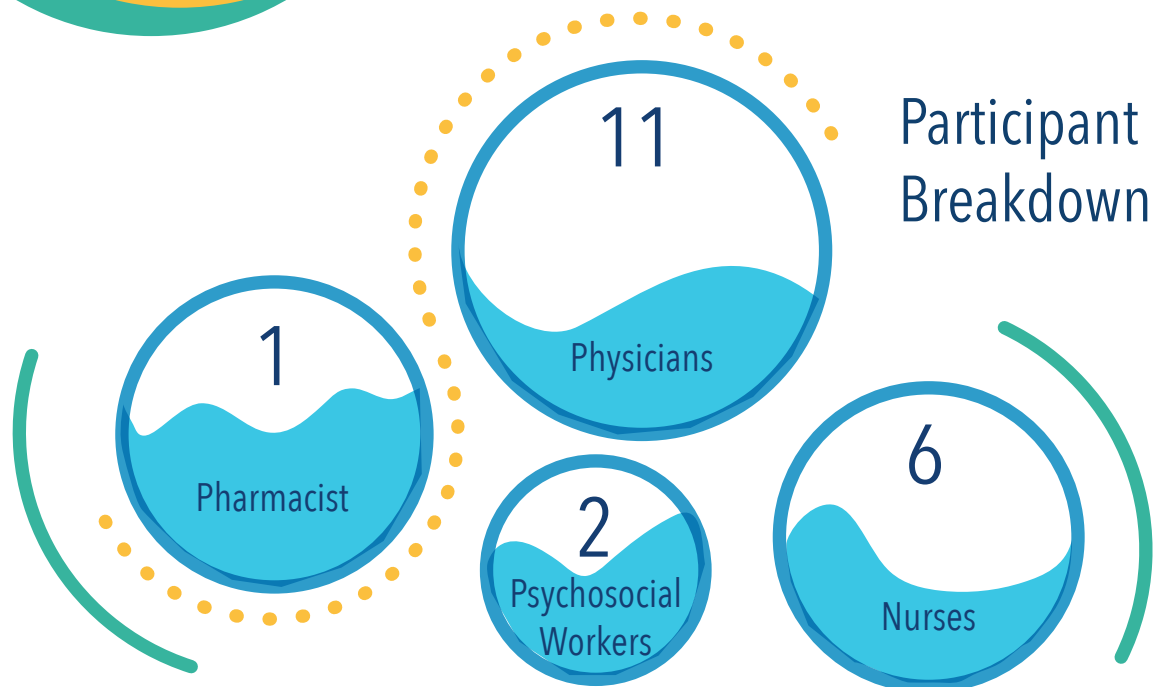
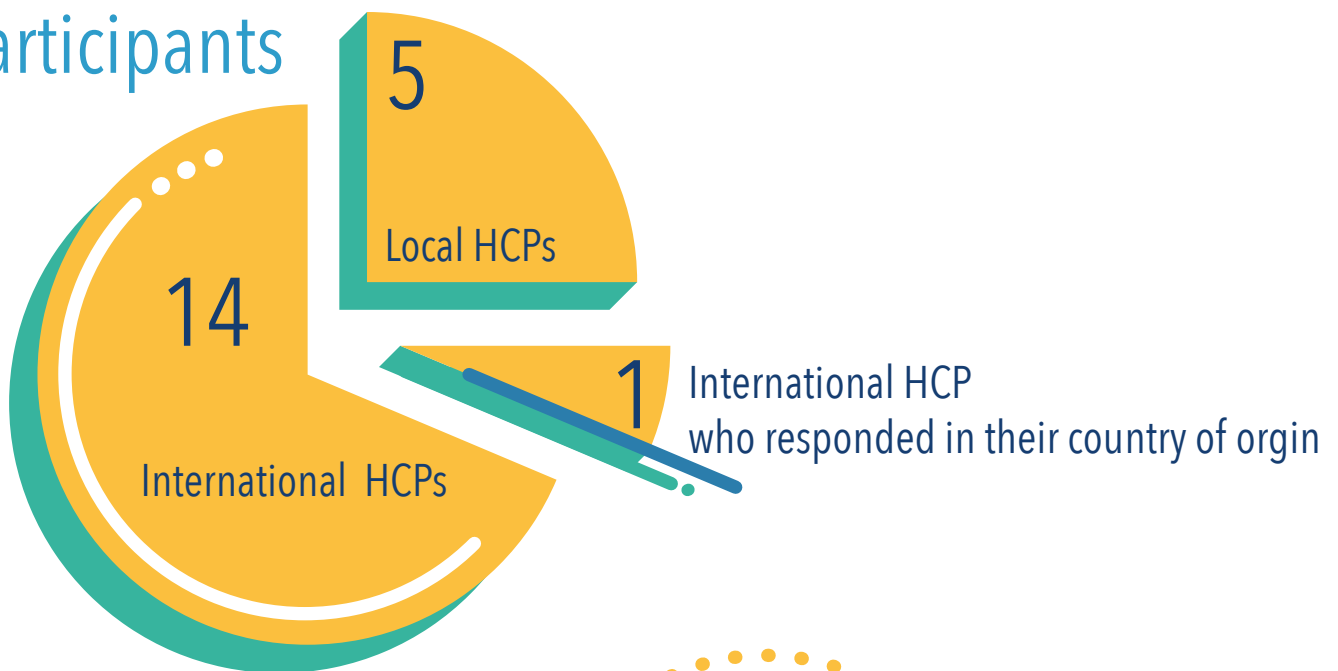
For this sub-study, we included natural disasters that often strike without warning (earthquakes, landslides, and flash floods); those with a short warning time frame (tsunamis, hurricanes, typhoons and flooding); and protracted or foreseeable disasters (famine). The relationship between conflict and natural disasters was also explored. Natural disasters, including famine, can exacerbate conditions in regions experiencing conflict, and are often a factor in the development or escalation of violence. Likewise, ongoing conflict in disaster-affected countries can further limit or hinder disaster response. This perpetuates a continuous cycle of poverty and instability for such countries, and constrains the possibilities for disaster preparedness and response by local and international care providers.

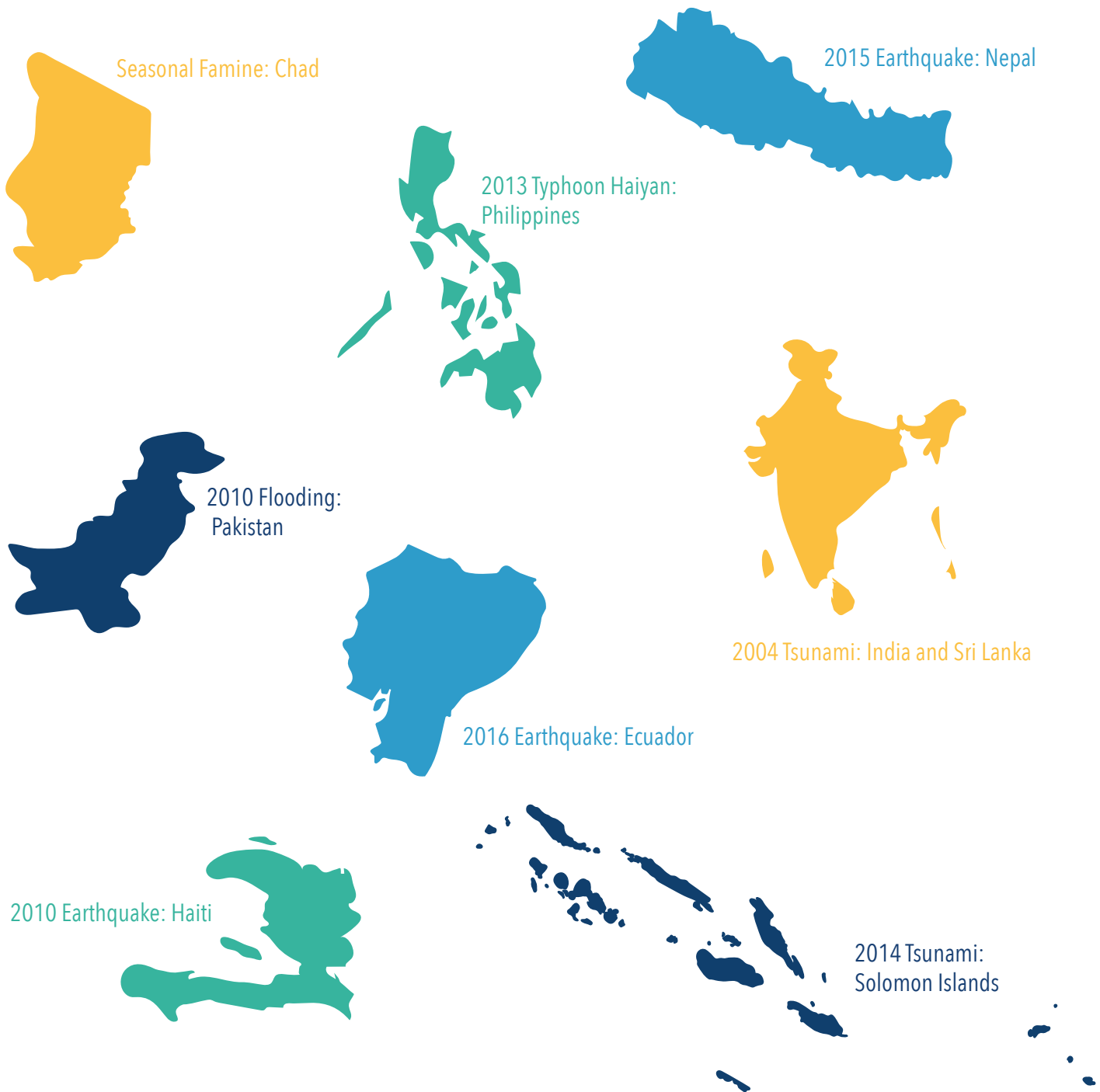
How the Study was Conducted

In-depth, semi-structured interviews were conducted with international and local HCPs who had responded to a variety of natural disasters.

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Participants





Semi-structured interviews explored:

- What does palliative care mean to you?
- How has your experience in [natural disaster context] impacted your thinking of palliative care?
- How important is it to pay attention to palliative care needs during natural disaster response?
- How can palliative care be integrated into natural disasters response?
- Do you think providing palliative care should be an ethical obligation for humanitarian organizations?

Research Findings

"Holding the hand of someone who's dying and letting that one go peacefully. But to that person, that will be what he's leaving this world with. Someone who cares."

- International physician, earthquake

"Let's say the person cannot leave the bed, so normally you have to clean the patient every day and take care of that patient every day... So palliative care is the same thing like cleaning the patient."

- Local physician, earthquake

"He didn't have any family with him, I remember that; I remember us all being very sad about that, and um, and we were like his family, and he was with us for a while ... And even when he did pass, we were able to organize like a little funeral for him and like a box and cover it with payne [cloth] and made sure he had a proper burial. So I think that was also just for us as, you know, his companions in end of life."

- International nurse, earthquake

"If I'm imagining it being a family member of mine who's been in a disaster and to know if like their last moment was something that was at least human or tender and compassionate, and someone who just, you know, spent a few moments to recognize that this is a life."

- International nurse, earthquake

"I mean I see it, I see a good death and a dignified death and a comfortable death and a calm death as being the best outcome for actually an awful lot of people, for everyone. It's what we all want at the end of the day; nobody wants to die in a state of panic or stress or fear. So I think when you get down to it, it's about providing everybody with the death that you would want."

- International nurse, earthquake

What does palliative care look like during natural disaster response?

Physical Touch

Personal Care & Activities of Daily Life

Care for the Body & Burial

Accompaniment, Psychosocial & Spiritual Care

Dignity

Pain & Symptom Management

Involvement & Care of Loved Ones

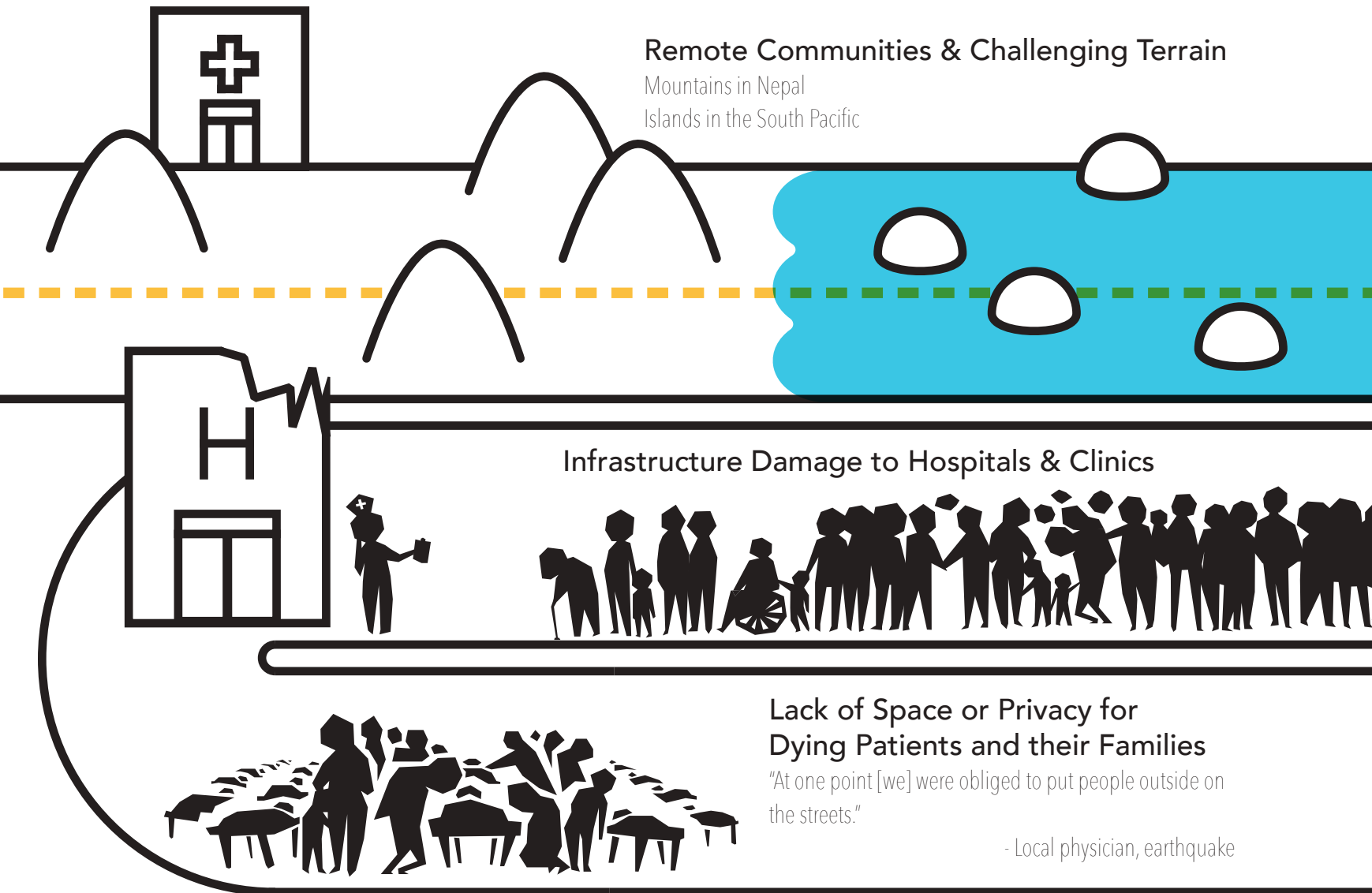
"Palliative care for me is very much focused on creating a situation that is bearable for patients which means that he will have, as little as possible, problems with pain, problems with nausea, problems with discomfort."

- International advanced practice nurse, multiple disasters

"... you look at the person as a whole and involving the family, and people, yeah, in their illness. To involve the people that they love and bring them joy and comfort, and also for the family, to help them grieve and see that they survive beyond the patient."

- International nurse, earthquake

What barriers hinder efforts to bring palliative care to the people who need it the most during a natural disaster?



All of these factors, including the challenging terrain, infrastructure damage (both transportation-related and institutional), overwhelming need compared to inadequate resources, as well as the lack of space and privacy, impede efforts by humanitarian healthcare providers to bring palliative care to those who would benefit from it during a natural disaster. Three overarching factors were identified that complicate efforts to implement palliative care effectively:

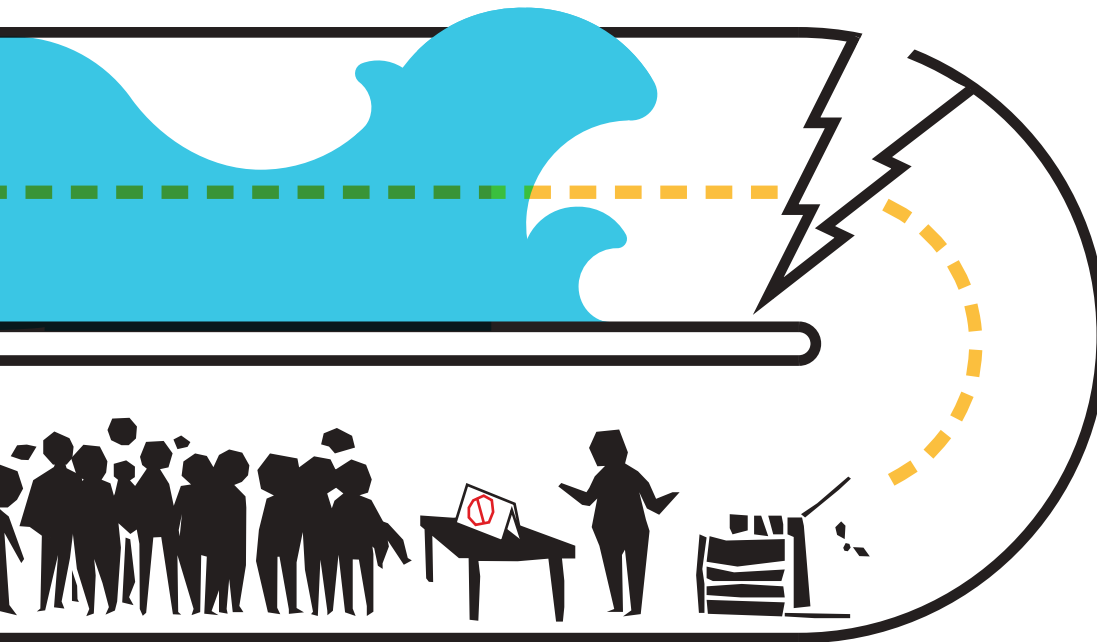
1. Lack of Familiarity with Cultural Practices around Death & Dying

Due to the time-sensitive nature of emergency response, many international HCPs were unaware of local cultural norms and healthcare practices. Language barriers, as well as a lack of understanding around cultural beliefs about use of pain medication and death and dying, can hinder relationships between international and local HCPs, patients and families. As one participant described, "I think one of the major [challenges] is cultural. Not having the cultural knowledge necessary to accompany people in different cultures..." (International psychosocial worker, multiple disasters).

Obstacles on the path to palliative care

Destruction of Transportation Infrastructure

Flooding of roads
Landslides



Overwhelming Need

+

Inadequate Resources

=

Complex Triage Decisions

"You were kind of putting all your energy and resources into saving those that were going to be saved and then people that were really truly about to die they were not really given much attention."

- International physician, earthquake



Invisibility of Patients with Palliative Care Needs

"So I think if we think about palliative care you know we cannot just think about those who need to reach the hospital... we need to, to think more globally."

- International nurse, earthquake & tsunami

2. Trauma & Loss

Many participants described trauma as a result of the disaster and loss or separation from family to be pervasive influences on the health of the local population. In particular, several participants discussed the important role of family members and other relatives in bringing the needs of the patient to the attention of the providers. As one participant stated, *"Especially in natural disasters, people have lost ... a lot, and like family and belongings and you know, they're probably at the most vulnerable part or time of their life, and so to be able to provide that ... it's almost*

like to slow down and to be able to make sure that you're giving each person, each individual the care that they deserve..." (International nurse, earthquake).

3. Wounded Healers

Local healthcare providers were often personally impacted by trauma and loss. Many continued to provide care while living in tents in their neighbours' yards, or while waiting to hear if family members had survived. The inability to relieve patient suffering was seen as exacerbating the trauma of the disaster event.

Why is it Important to Include Palliative Care in Disaster Response?

- Respondents agreed that humanitarian aid organizations have an ethical obligation to provide palliative care and suggested that it should be more of an “attention point.” Ethical justifications included: respect for the human right to dignity in death and dying; health equity; and the humanitarian commitment to relieve suffering.
- Many felt that the capacity to provide comprehensive palliative care, as well as the degree of moral obligation to provide it, increased as time passed after the initial disaster event.
- It was suggested that in disaster settings, the local community often have “lost ... their footing and sense of community.” Thus, it becomes the role of international aid organizations to act “like a headlamp”, and to provide a “path” with the understanding that “once they’re back on it they don’t need it or us anymore” (International psychosocial worker, multiple disasters). Participants felt palliative care would be best provided by or in partnership with local care providers due to their cultural understanding and pre-existing trust with local communities, as well as the possibilities for the sustained response and continuity of care following the departure of international care providers.

“I think the palliative aspect... for the immediately dying person in the disaster is of utmost importance ... To me it’s as valuable if you want to treat people equally, it’s as valuable as treating someone who’s going to survive ... When do you stop caring for someone? Even in death you care for them. So while they’re dying it’s even more crucial because that person is more vulnerable.”

- International physician, earthquake

“Well it’s suffering, it’s unnecessary suffering. And whether that’s physical, mental or emotional. That’s part of our mandate, we want to alleviate suffering ... Let’s do that better.”

- International advanced practice nurse, multiple disasters

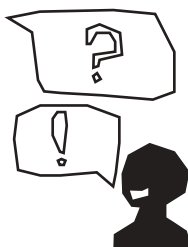
Actionable Recommendations



Disaster planning. It was emphasized that unless palliative care is integrated into healthcare planning for disasters from the beginning, it will continue to be neglected in crisis settings. Improved awareness regarding the role of palliative care, including its purpose in reducing the suffering of those with life-threatening illness, will help the public to realize its importance in care provision. Disaster planning should include how and when specific palliative care interventions will be incorporated, as well as a clear delegation of responsibility. In particular, it is important to decide ahead of time who will be responsible to care for dying patients during triage situations to ensure they are not abandoned.

"...And so by not having a plan you end up not really being able to accomplish what you set out to accomplish. And I think the same thing goes as well for palliative care."

- International physician, earthquake



Sensitivity to cultural differences. Humanitarian HCPs should receive cultural sensitivity training to understand local norms and beliefs regarding healthcare, illness, death and dying. This can be challenging during sudden onset natural disasters; however, one participant suggested that international care providers should engage in early conversations with local community members or caregivers to better understand "how can [they] best better serve this population" (International physician, earthquake). Psychosocial workers may have a particular role in rapidly assessing local beliefs and practices around death and dying and communicating this information to the team.

"...And also tolerance for families because some have large families and culturally they all want to be there, so I think we should have space for that. It's a very temporary thing, usually lasts two, three hours and then they're gone, but we should have that space."

- International psychosocial worker, multiple disasters



Emotional support for responders. Several participants stressed the importance of providing emotional support for responders, many of whom deal with the moral distress of making difficult decisions as they provide care to an overwhelming number of patients. Local humanitarian healthcare providers may be coping with trauma associated with the disaster event itself and the loss of loved ones. Facilitating their ability to relieve patient suffering was described as an important way to prevent trauma-related stress among responders.

"Immediately after the earthquake their healthcare system and the national staff was just so incapacitated because there were so many themselves who had perished and then they had to take care of their own families ... They're also just trying to take care of themselves and grieve themselves..."

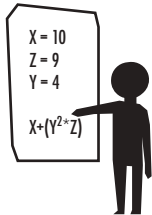
- International nurse, earthquake



Minimum levels of support. Participants recognized that comprehensive palliative care may not be feasible in certain natural disaster contexts, but certain minimum standards were described, including: shelter, space, and privacy; awareness of and sensitivity to cultural norms and needs; accompaniment, respect and dignity in death and dying; access to pain medication; and the involvement of family and community.

"In other words, you can be in a hut getting some palliative care and dying with all the dignity as someone who is in a palace is dying with dignity in his own way. So the death of a queen and the death of a peasant may be equitable."

- International physician, earthquake



Training and protocols. Training is needed for HCPs and other professionals regarding the appropriate provision of palliative care in natural disaster settings. This should be accompanied by the development of standard palliative care protocols so that all local and international HCPs working in these settings provide a similar level of care.

"I would say our training package needs to be two things simultaneously, the medical care and the psychosocial emotional tensions side of things."

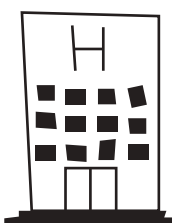
- International nurse, earthquake



Local empowerment. Local healthcare providers were described as the true "first responders" following a natural disaster. In fact, the majority of deaths during a natural disaster occur in the first few days, often before the arrival of large international organizations. Efforts to incorporate palliative care must build on the capacities of local responders.

"... you know when you start rebuilding the sense of community, that's when people start feeling their personal power again."

- International psychosocial worker, multiple disasters



Local health systems strengthening. There is a need for local governments to focus on the integration of palliative care within the health system, including the development of palliative care centres and departments. If palliative care is inaccessible in a community, this will only be exacerbated in the event of a natural disaster. An important aspect of improving access to symptom relief is ensuring access to opioids and other medications.

"I don't think the government has done a lot in terms of palliative care so there are hospitals I know of, like public non-profit hospitals providing palliative care to adult and pediatric patients, but as far as I know the whole domain of palliative care is left behind."

- Local physician, earthquake

Innovative Solutions

Dedicated spaces for dying patients and grieving families during mass casualty events

"You had to create a little bubble the best you can."

- International psychosocial worker, multiple disasters

Expanding the role of psychosocial workers to rapidly assess local practices around death and dying

"It's something I try to get the first days [in] the field ... I would sit down and get some of the information, what do you usually do, how do you do it, what's appropriate, what's not? And I get that, I get that knowledge. And I think to take it one step further, I recommend it in my end of mission that that knowledge be given by the psychosocial delegate to the team."

- International psychosocial worker, multiple disasters

Leveraging community supports

"So I guess the palliative care in her case was let's get the community to help her...So we made a plan... that every day the women would go and see her twice a day."

- International psychosocial worker, multiple disasters

Finding small creative solutions in situations of resource constraints

"It was compressing on his airway and the beds we had available were just beds; you couldn't move the head of the bed, so then we had made this wooden triangle so we could lift it up just so he could breathe easier while sleeping."

- International nurse, earthquake

Implications for Humanitarian Practitioners & Policymakers

- Palliative care should be incorporated into disaster planning.
- Individuals living with severe chronic disease or at the end-of-life may not present to health facilities or be visible during a disaster; response teams should take active measures to ensure access to palliative care for these populations.
- Even when comprehensive palliative care is not possible, basic palliative care strategies should be implemented during a disaster response.



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