

# Health professionals' lived experiences of palliative care provision in humanitarian crisis

## Moral experiences confronting the suffering of patients who are dying or likely to die in settings of war, disaster, or epidemic.

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### Background

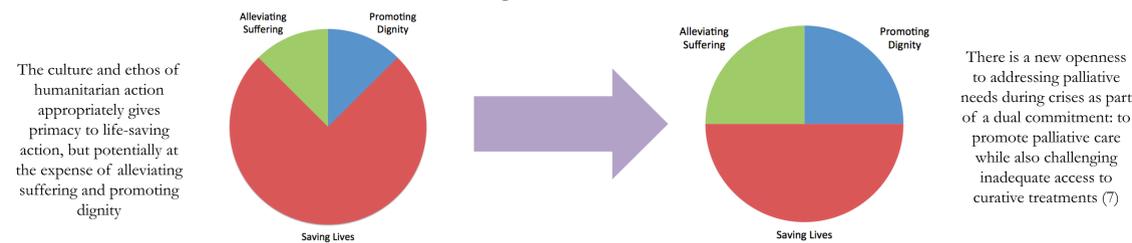
The toll in suffering and loss of life due to humanitarian crises is staggering (1). A range of international organizations and entities provide critical healthcare assistance. Situations often arise where curative care is unavailable, inappropriate, or unlikely to be successful:

- a woman with advanced renal failure on dialysis has been forced to flee to a refugee camp amidst an ongoing civil war
- a man with Ebola Virus Disease has been admitted to a treatment center at a time when case fatality rates exceed 60%
- a child has suffered a grievous crush injury during an earthquake and is triaged to not receive surgery because others have better chances of survival.

These individuals require compassionate care to control their symptoms and alleviate their suffering, while considering psychological, cultural, relational and spiritual dimensions of dying – they need palliative care.

The goals of humanitarian action are threefold: “to save lives, alleviate suffering and maintain human dignity” (3). Efforts to address suffering and uphold the dignity of individuals whose lives cannot be saved during a crisis have until recently received limited attention in humanitarian policy and practice. In the last few years, this has begun to change, with palliative care becoming a subject of discussion and reflection in many corners of the humanitarian sector (5,6,7).

#### Balancing Humanitarian Goals



To better understand challenges and opportunities for provision of palliative care in humanitarian crises, our team is undertaking research including an international survey, interviews with humanitarian policy-makers and health professionals, and four extended case studies in locales where a crisis has occurred or is occurring. Here we report our preliminary analysis related to the moral experiences of humanitarian health professionals and policy-makers.

### Methods

We conducted 24 semi-structured interviews exploring participants’ perceptions of, and experiences with, the provision of palliative care in humanitarian situations:

- 12 health care professionals who had participated in humanitarian responses in past 2 years (7 physicians, 5 nurses)
- 12 policy-maker roles within a humanitarian organization (11 health care professionals, 1 administrative professional)
- Worked with 19 different organization
- 20 of 24 from high income countries

#### Analysis:

- Interpretive description methodology (8)
- Inductive analysis using constant comparative techniques
- Moral experience as a conceptual framework to guide analysis (2,4):
  - The way people experience and act in the world is informed by their values: their understanding of what is right, just, good, and of what matters (and conversely, of what is wrong, unjust, or bad...).
  - Through their actions and interactions in their day-to-day life, people seek to actualize these values.

Our work explores care providers’ moral experiences:

- Through what ethical constructs do they make sense of the world?
- How do these understandings shape their experiences and their actions?
- Do they feel that their values were realized or thwarted?

We were interested in understanding the impact that being able, or unable, to provide what they felt was good palliative care had on participants.

### References

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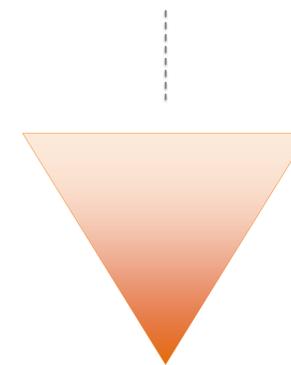
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### Findings

- engaging the humanity in the universal experience of facing dying and death
- non-abandonment / accompanying
- providing critical information to families
- involving families/community in care
- providing basic personal care and hygiene
- vital importance of human contact

#### Promoting Dignity

“And I think also it provides the patient with the sense of being cared for until the end. That you aren’t quote unquote a “lost cause,” or that you’ve been, again quote unquote, “abandoned.” But that your life still matters to the very end, however time you do have, and to live with as much comfort as possible until that time. So I think it possible and necessary, but it is a significant challenge” (P6)



#### Feeling the Weight of Responsibility

#### Acting to Ease Suffering

- essential humanitarian value to respond to most vulnerable
- treating physical and psychosocial pain and distress
- needing both medical and non-medical responses
- moral, psychological, and social consequences of responses

“... if you don’t provide something for pain, and you don’t do the little things then – then you’re losing a little bit of why you’re even there and the whole moral piece to it (...) - the humanitarian piece. Otherwise you’re just a bunch of medics running around in the field, trying to (...) stop the bleeding, but when – if you’re gonna be humanitarians, then you have to really look at that human piece, and there’s no better place than when you’re in – talking about palliative care, what is the human thing to do? Putting them behind the shed and forgetting about them is not the answer.” (P19)

- moral obligation to respond to suffering
- toll of failing to respond including distress, guilt, othering, disconnection
- motivation to advocate for organizational and systemic change
- deep satisfaction and positive impact of providing palliative care
- needing at times to recognize and accept limits
- acknowledging impact on providers and needs for support

“(...) the moral distress that I feel is rather than helping people, I frequently found myself in the process of prolonging their lives when they had no prospect of getting better. Or performing treatments that I knew I could do with less pain and better tolerability in a better setting, but was unable to do at that time. But my biggest issue that sort of continues to haunt me, I’d say was number one, how dressing changes are done, where the gauze tends to be ripped off, wounds scrubbed out and people held down and the dressings changed. And then also, I’ve literally watched hundreds of babies seize to death and it’s just a terrible...I mean, it’s not an existence right? And what their parents would do, would say, we’re just taking them home to die. But I didn’t have a way of keeping them comfortable, and letting them die in a warm, comfortable place and that really haunts me. (...) I kind of think, like I’m not religious at all. I’m atheist. I don’t believe in hell, but I kind of think there is a special place in hell for me.” (P22)

#### Prioritizing Care

- realities of limited human and material resources
- concern palliative care may divert scarce resources from care for others
- life and death choices of triage in emergencies
- harms of futile treatment
- minimum standards needed for pain management and personal care

“I think an increasing attention to this aspect of triage. I mean, to keep some resources first of all to be equipped with them (...) with opiates and (...) pain medication, and to keep some resource even some part of the of the staff, (...) of the team, to pay attention and to provide this basic care to people who will not be receiving (...) life-saving treatment: they will probably die, they may die, but at least they should die (...) in a respectful way, in a dignified way, and as much as possible without too much pain and with the presence of somebody” (P10)

#### Acknowledging Inequalities

- global inequities in health care compounded by crises
- broader social and political inequalities constraining all forms of response
- conditions are palliative in this context which would not be in others
- lack of palliative care in local health system beyond humanitarian action

“I think the added wrinkle in humanitarian contexts is sometimes there are patients who wouldn’t be palliative in another context, but because they become so, and that can be difficult. Well, in a context like Syria, where they wouldn’t have been palliative six years ago because there was a functioning healthcare system, and now there isn’t, and so that’s very difficult obviously. But, also for less experienced international staff who often have a really hard time with palliative care in a patient who, in their own context, would not be so, and that is sort of another side issue in how to support international staff who also maybe don’t agree with the decision to make someone palliative, don’t feel like we’re fighting hard enough, don’t feel like we’ve done enough for certain patients. And communication is key there as well.” (P23)

#### Navigating Cultural Perspectives

- cultural specificities of death and dying
- distances between expatriate, local provider, and recipient perspectives
- differing standards/acceptance of pain, distress, symptom management, and death
- awareness, humility, and local engagement required
- disruption of organizational culture/ethos of prioritizing life-saving

One participant recalls working in Ebola Treatment Units (ETUs) at the height of the 2014-5 epidemic: “...working with the ministry of health in developing (...) care around palliation and I think for clinical care that’s really important so palliation I think is huge (...) largely because how death is managed and how death is as a (...) social religious construct, is very different from what (...) foreigners might be used to or experienced. I think the- the pushback (...) wasn’t actually just in the ETUs, it was just in general you know so we were essentially taking away how death is (...) constructed, and worked around, (...) and how families (...) think- what they think is gonna happen to their loved ones and (...) first we’ve already taken them away, so they can’t see them die, they’re in ETUs, (...) there’s no- you know, there’s contact, but they, they’re not there when their family member dies and that’s a big thing already.” (P3)

#### Working Within Systemic Constraints

- limited access to medications especially opiates
- lack of awareness and skill in palliative care amongst providers
- lacking organizational awareness, policy, and protocols
- advocacy for change within organizations to improve training, access, and care

“The other case was a case of someone with (...) what we eventually presumed was metastatic disease, metastatic cancer, who had been in the hospital for weeks, whose family wanted to take him home because he was not getting better, and the (...) the physicians kept on treating, kept on treating, kept on looking for other reasons of what would be causing his illness (...) it was obvious from the get go that this man should have been allowed to go home with his family and die peacefully, but because I was so new to the team, it took me a while before I was comfortable voicing my opinion. And even then there was a lot of distress about allowing him to leave with his family and supplying the medication that would have been necessary for him to have a comfortable death. And there was no guideline to go to, no book to go to, no protocol to go to.” (P15)

### Discussion

Our findings from interviews with humanitarian healthcare providers involved in the provision of palliative care during humanitarian crises demonstrate they:

- feel humanitarian action and palliative care are compatible
- highly value commitments to address suffering and promote dignity in providing care to patients who are dying or likely to die during crises
- struggle to enact these commitments in the face of challenges specific to humanitarian crisis contexts
- experience moral distress from being unable to provide what they feel is appropriate palliative care
- may work, through formal or informal channels, to change the way their organization provides palliative care

Recommendations:

- Palliative care plays a crucial role in sustaining the core principles of humanitarian action
- It has been inadequately addressed previously, though there is a growing recognition of its contribution and potential
- Sustained advocacy and organizational change are necessary to ensure its effective inclusion
- It presents unique constraints and challenges; addressing these will require intentionality, adaptation, and compromise

Identified needs:

- context specific guidance (policy, guidelines, and clinical supports) to integrate palliative care effectively
- context specific training that includes the essential elements identified by providers, and access to ongoing mentorship and support
- Awareness of and engagement with cultural dimensions of suffering, dignity, dying and death: humanitarian organizational culture; expatriate and local medical culture; and host community culture