Moral experiences of humanitarian health care professionals caring for patients who are dying or likely to die in a humanitarian crisis

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Background

- Humanitarian healthcare aims to save and safeguard the lives of people caught up in situations of crisis.
- The overriding imperative of saving lives in humanitarian healthcare has often left limited room for addressing suffering and dignity, especially for individuals who are dying.[1]
- Despite increased attention, there is little information about palliative care interventions carried out as part of humanitarian response to crises.[2]

Objective

Using the concept of moral experience as an analytic lens, this study analyzed participants' experiences of values that they held to be important being realized or thwarted as they responded to the needs of patients who were dying or likely to die in a humanitarian crises.

Methods

Guided by interpretive description methodology, this inquiry was undertaken within a constructivist paradigm in which human experience is understood as subjective, local, socially and experientially based, and as culturally and historically specific.[3,4]

Recruitment	• Recruited 24 participants through 4 approaches [social media, professional networks, survey, snowball sampling]
Participants	• From 19 aid organizations: expatriate humanitarian healthcare workers & policymakers
Interviews	• Two versions of interview guide based on feedback from humanitarian health professionals and policymakers

The following case scenarios demonstrate the difficulty of ethical decision-making in humanitarian situations where curative care is often unavailable, inappropriate, or unlikely to be successful:

Epidemics

A woman is admitted to an Ebola Treatment Center with a high fever, diarrhea, nausea and dizziness. Her condition is deteriorating rapidly. Strict infection control procedures are in place, leaving her with minimal contact with care providers and none with her family. At this stage of the outbreak, the case fatality rate is over 50%. Resources are limited, and given the progression of the patient's symptoms, her prognosis is dire.

Natural Disasters

72 hours ago, a small city experienced a powerful earthquake. Thousands were killed, but many are still injured. A rapid deployment field hospital has just been set up in a soccer stadium. A doctor and a nurse are assigned to triage the hundreds of individuals waiting outside. One of them is a young man with a severe crush injury. He is triaged as unsalvageable. He says he is thirsty and in severe pain. He appears confused.

Active Conflicts

In an internally displaced persons' camp surrounded by an active civil war, a patient arrives at the medical tent with her son. Previously on dialysis, she has end-stage renal disease. A camp physician estimates that with the medications available at the camp, she is likely to live for several more months, over which time her symptoms will gradually increase until her kidneys fail completely.

What are the moral experiences of humanitarian health professionals as they respond to the needs of individuals who are dying or likely to die during a humanitarian crisis?

Essential humanitarian value to respond to most vulnerable; treating physical and psychosocial pain and distress; needing both medical and non-medical responses; considering the 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…" (P19) • "…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" (P1)
Engaging one's humanity in the universal experience of facing dying and death; providing critical information to families; involving families/community in care; upholding privacy and respecting traditions; considering the vital importance of human contact.	• "What is the human thing to do? Putting [dying individuals] behind the shed and forgetting about them is not the answer." (P19) • "It provides the patient with the sense of being cared for until the end. That you aren't a 'lost cause,' or that you've been, 'abandoned.' But that your life still matters to the very end… to live with as much comfort as possible" (P6)
Realities of scarce resources; concern palliative care may divert scarce resources from care for others; harms of futile treatment; minimum standards needed for pain management and personal care to address suffering of dying patients even during triage situations.	• "…in a big mass casualty event or a really, really, busy complex conflict, the amount of time that people are able to give to palliative patients is going to be limited. And I think that, unfortunately, that's a reasonable decision"(P21) • "Patients who simply need decent care for dying—you need, you are obliged to calculate and provide resources to accommodate those patients…" (P14)
Limited access to medications; lack of provider awareness and skill in palliative care; lacking organizational awareness, policy, and protocols; advocacy for change within organizations to improve training, access, and care.	• "…from a human compassion perspective, some things that people die of are painful and uncomfortable. And we have the tools to limit that discomfort and we should use them." (P23) • "Advocate … for palliative care in humanitarian crises to be a basic human right…It should be a human right and the norm." (P1)
Moral obligation to respond to suffering; toll of failing to respond including distress, guilt, disconnection; motivation to advocate for organizational and systemic change; deep satisfaction and positive impact of providing palliative care; needing to recognize and accept limits; acknowledging impact on providers and needs for support.	• "A little girl, I think about the age of nine, and who called me, 'Uncle can you hold my hand,' and because I knew that we could sit down and talk to them, so—which I did, and once I held her hand, she died…and so, for—for many, many months, even when I came [home], I could still feel that touch…I could still feel—hear that voice." (P20)

Discussion

Our findings illuminate humanitarian healthcare providers' experiences and perceptions:

- feeling humanitarian action and palliative care are compatible, and describing not providing such care to individuals as ethically wrong;
- highly valuing commitments to address suffering and promote dignity in the provision of care to patients who are dying or likely to die during crises;
- struggling to enact these commitments in the face of challenges specific to humanitarian crisis contexts;
- experiencing moral distress when 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.

Distinct yet connected are the commitments to justice and compassion that inspire/underlie/inform the identified themes. These five components shed light on why and how individuals engaged in humanitarian healthcare crises experience the needs for palliative care provision as morally important—and sometimes haunting—experiences.

Identified needs

- Context-specific guidance (policy, guidelines, and clinical supports) to integrate palliative care effectively.
- Context-specific training that includes 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.

Recommendations

- Palliative care plays a crucial role in sustaining the core principles of humanitarian action.
- Sustained advocacy and organizational change are necessary to ensure its effective inclusion.
- Training and preparation in the area of palliative care is needed in humanitarian settings.
- Addressing the unique constraints and challenges of palliative care provision in such crises will require intentionality, adaptation, and compromise.

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