Health professionals’ lived experiences of palliative care provision in humanitarian crises  

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 amid 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 manage 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” (2). 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).

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 religious, national and international organizations

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

Analysis

- Interpretive descriptive methodology (8)
- Inductive analysis using constant comparative techniques
- Moral experience as a conceptual framework to guide analysis (2,4)

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?

Findings

- Engagement in the human universal experience of facing death and dying
- Non-abandonment / accompanying
- Providing critical information to families
- Involving families/community in care
- Providing basic personal care and hygiene
- Vital importance of human contact

“...and I think also it provides the patient with the sense of being cared for until the end. That you aren’t quite imperishable a ‘best course’ or that you’re been, again quite imperishable. ‘Shudderingly, broken, and yet systemic change time you do have, and to live with such comfort as possible until that time. So I think it’s possible and necessary, but it’s a significant challenge” (9)

- Moral obligation to respond to suffering
- Tolly of failing to respond including distress, guilt, othering, disconnection

“...I think this applied similarly to the concept of ‘tolly of failing to respond’...it was a struggle for the last two weeks of his life to have enough pain and nausea remediation in a hospice setting, but we were unable to do that at the time...we felt very keenly then the absence of meaningful treatment, actually, and that’s the way we approached the problem, all of the time” (10)

- Deep satisfaction and positive impact of providing palliative care
- Needing to times to recognize and accept limits

“...and I think this is particularly important for everyone who is working in this field...to keep with as much comfort as possible until that time. So I think it’s possible and necessary, but it’s a significant challenge” (9)

- Acknowledging impact on providers and needs for support

“...the moral distress that I feel is so much less helping people...I frequently found myself in the position of predicting how long they had left to live and helping them to prepare” (11)

‘Putting...a little bit of...I don’t see these people as just a bunch of numbers running around in the field...trying to...” I think the finding...is that...we’re going to have to deal, somewhere, with these kinds of experiences. And this, they are, I’m told, extremely extensive. And what other people would do, they would...we’re just taking them home to die...But I don’t have a year of keeping them comfortable, and that’s not what they actually...they’re...not kept. It’s...I don’t think I heard...It’s not a kind of thing that’s a special place to be fault in” (11)

Feeling the Weight of Responsibility

- 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

“...Until people begin to understand the aspects of triage they have to make choices that are difficult for all of us to be equipped with (that (...with hope...with (....pain medicine, and to keep some resources even accessable for the (...of the (...of our policy and intention to provide this huge care to people who will not be receiving (...life-sustaining treatment...they probably die, first, and...to really, so that when we die in a meaningful way, and actually as possible without too much pain and with the presence of somebody)” (11)

Prioritizing Care

- Life and death choices of triage in emergencies
- Harms of futile treatment
- Minimum standards needed for pain management and personal care

Navigating Cultural Perspectives

- Cultural specificities of death and dying
- Distances between expatriate, local provider, and recipient perspectives
- Offering standardized response, symptom management, and death awareness, homeliness, and local engagement required
- Disruption of organizational culture/ethos of prioritizing life-saving

“...on a 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?

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
- High value commitments to address suffering and promoting dignity in provider to patients who are dying or likely to die during crises
- Struggling in implementing these commitments in the face of challenges to humanitarian crises
- 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

Acknowledgements

- Global inequities in health care compounded by crises
- Broaden social and political inequalities constraining all forms of response
- Facilitate meaningful palliative care for our patients
- More resources to reach our patients
- Advocacy for change within organizations to improve training, access, and care

Working Within Systematic Constraints

- “The other main reason is because of (....with (....moral distress from being unable to provide what they feel is appropriate palliative care
- Lack of awareness and skill in palliative care amongst providers
- Lack of organizational awareness, policy, and protocols
- Advocacy for change within organizations to improve training, access, and care

References