A Field Manual for Palliative Care in Humanitarian Crises

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Chapter:

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Introduction

In focusing on the psychosocial and spiritual needs of patients, families and communities, we are guided by a trauma-informed approach. Trauma is defined as “an event or series of events . . . that is experienced as physically or emotionally harmful or life threatening and has the potential to have lasting adverse effects on mental, physical, social, emotional, or spiritual well-being.”[1] Clinicians begin by attending to people’s survival needs for acute medical care, food, water, shelter, and security, including symptom management. Only when those are addressed can aid workers attend to the other dimensions of people’s experience. Employing best practices, aid organizations would ideally deploy trained colleagues in psychosocial and spiritual support and collaborate with local experts to meet people’s multidimensional needs.

Applying Cultural Humility to Unconscious Beliefs and Biases

There is no way to separate a humanitarian crisis from the cultural context in which it occurs. Unconscious and unavoidable cultural assumptions govern how we see the world and shape how we offer care. These beliefs include how we view suffering, death, and dying; how the circumstances surrounding a death affect grief and bereavement; how people construct meaning from their losses; and whether the decision-making model is individual or collectivist.[2,3] As a foundational principle, we assert that cultural self-awareness, cultural humility,[4] and cultural curiosity[5] are essential to providing effective care, whether in the clinic or in a disaster zone.

Core Areas of Concern for Culturally Effective Palliative Care

The most significant contributor to culturally effective palliative care in humanitarian crises is communication. During a crisis it may be challenging to establish trust within the context of great emergency. Following are some common cultural conundrums in humanitarian crises and methods to approach them with humility.

- ***Nonverbal communication***: Observe other patients and providers to assess how they respond to vocalization, eye contact, physical contact, gestures, and body language.
- ***Decision-making***: Ask individuals how they wish to be involved in decision-making. They may wish to share this role with family, religious leaders, or other community stakeholders.
- ***Discussing death, dying, and prognosis***: Ask how individuals or families would like illness discussed; honor preferences for information; address hopes and worries (e.g., “We are also hoping for X, and we worry about Y.”).

- ***Cultural differences in physical examinations***: Whenever possible, honor cultural preferences for gender of provider for intimate examinations; preserve privacy; cover sensitive body areas, genitals, hair, and face; acknowledge limitations in emergencies.
- ***Cultural views of diagnosis and medications***: Explore cultural narratives for diseases, diagnoses, treatments, and the role of healthcare providers; align with beliefs and integrate Western medical interventions with existing practices as feasible.
- ***End-of-life rituals and burial practices***: Ask questions; express curiosity and the desire to care for loved ones appropriately. Concerns may include who can touch the body, confessional deathbed prayers, funerary practices, and burial clothing.
- ***Safety in funerary and burial practices***: Work directly with community members to ensure both culturally respectful and medically safe compromises when practices may pose a health or infectious concern.
- ***Cultural perspectives on suffering***: Apply curiosity and humility without judgment in acknowledging the cultural continuum of grief from reserved to verbally and physically overt.

Mapping the Psychosocial and Spiritual Terrain of Palliative Care in Humanitarian Crises

Common psychosocial and spiritual responses include the following:

- Dysregulated emotional behavior such as rage, terror, and profound grief
- Questioning why one has survived when others have not
- Losing coherence or meaning in one’s world
- Losing one’s future dreams and hopes
- Confronting one’s fragility and mortality
- Fight, flight, and freeze reactions; diminished cognitive processing
- Activation of historical trauma, intrusive thoughts or images

Individuals’ vulnerability in the face of crises will vary depending on what coping strategies and supports they have available, their access to safety after a crisis, and the meaning a person attributes to the event. In a protracted humanitarian crisis such as multiyear conflicts, ongoing human rights abuses, and destruction of entire communities, the psychological sequelae may be far more difficult to address and resolve, given the continued trauma.

Factors that can exacerbate psychological morbidity include the following[6]:

- High perceived threat to life, loss of control over outcomes, and an inability to predict whether the threat is ongoing, reoccurring, or contained
- Extensive personal loss—for example, family members, home, safety, functional capacities, usual roles
- Crisis is human-caused (e.g., terrorism, massacre), sudden, shocking, and associated with massive injuries and loss of life
- People are exposed to grotesque circumstances or corpses, especially of children
- Extensive loss of the social and communal safety net

Protective Factors in Stress Resilience and Recovery

Not everyone exposed to traumatic experiences goes on to display long-term psychological morbidity. Rather, it is estimated that approximately 75% of a group enduring a humanitarian crisis display what is termed "psychosocial resilience."[7,8] The remaining 25% run a significant risk of developing psychological distress that does not resolve. It is crucial to direct scarce mental health resources toward those patients who manifest the most severe symptoms.[9]

Psychological First Aid (PFA)

There is growing empirical evidence to support interventional practices and programs in the immediate and mid-term periods following disaster and mass violence. The principles undergirding such interventions are to promote a sense of safety, calm, self- and collective efficacy, connectedness, and hope.[10]

At the time of the actual crisis, *if* it is time limited, "psychological first aid" (PFA) has emerged as a response strategy endorsed by the World Health Organization. Core actions of PFA include the following[9,11]:

- ***Contact and engagement***: Approach survivors who require assistance in a nonintrusive, compassionate, and helpful manner.
- ***Safety and comfort***: Ensure immediate and ongoing safety and attend to physical and emotional comfort needs.
- ***Stabilization*:** Calm emotionally overwhelmed or disoriented survivors, and help them to become better oriented to their surroundings.
- ***Information gathering***: Listen to people's stories and identify immediate needs and concerns so as to customize PFA interventions.

• ***Connection with social supports***: Establish contact with support persons including family members, friends, and community organizations, agencies, and networks.

• ***Information on coping***: Provide information about stress reactions and coping. Normalize emotional responses (e.g., shock, numbing, and/or intense feelings) and the adjustment process (e.g., there is no one "right" way to respond; there is no one "right" timeline for recovery).

Grief and Bereavement During Humanitarian Crises

Because of the high probability of multiple losses in crises, it is helpful to assess which are most pronounced for those one is serving, in order to triage care. Loss can appear in any of the following domains: loss of identity and customary roles, loss of bodily functions, loss of relationships, and material loss. The process of grief and bereavement is a long-term task with an individually and culturally variable timeline. Experts in the field have identified tasks of grief including accepting the reality of the loss, experiencing the emotional pain of grief, and finding an enduring connection with the deceased.[12]

Special Circumstances of Grief: Disappearance of Loved Ones and Uncertainty

Humanitarian crises can result in unique forms of loss, including the disappearance of loved ones and prolonged uncertainty. Disappearance is one of the most challenging losses to process because of its ambiguity,[13] as victims repeatedly vacillate between hope and despair. Losing individuals complicates decision-making, especially for children who would otherwise turn to those individuals for assistance. If the bodies of loved ones cannot be found or identified, certain rituals meant to honor the deceased and affirm a connection between the living and the dead—such as cleansing the body or keeping vigil—are thwarted. Even when the deceased's body is located, preferred multiday funerary rituals may not be feasible given displaced communities.

Spiritual Care in the Midst of Humanitarian Crises

Spiritual care practices in palliative care include helping individuals face and overcome fears and find hope and meaning; attending to existential suffering; addressing feelings of punishment, guilt, unfairness, and remorse; assisting when people need to confess or reconcile; and offering grief support and death preparation assistance. All of these interventions can be facilitated by a skilled listener expressing *human kindness and compassion* as a form of first aid. *Being available for connection, demonstrating acceptance, caring, and concern, with respect and attention to dignity, is the primary spiritual intervention in humanitarian crises.* Studies involving people affected by Louisiana floods

in 2016,[14] Hurricanes Katrina and Rita in 2005, the 2010 Deepwater Horizon oil spill,[15] and a 4-year drought in Botswana[16] indicate that perceived spiritual support promotes adaptation responses and can have a protective effect on post-disaster resilience.[17]

For aid organizations to enact best practices in providing comprehensive care, we recommend integrating spiritual care into the long-term strategy of the organization. To this end, it is critical to advocate for spiritual specialists within humanitarian organizations, as well as to partner with local spiritual leaders and faith-specific liaisons.[18]

As a disaster spiritual caregiver, there are several principles of SFA that can help guide specific responses[19]:

- ***Stabilization and introduction***: Build rapport and allow for assessment.
- ***Acknowledgment***: Listen actively to the person in crisis.
- ***Facilitating understanding***: Validate and normalize survivors' experiences by allowing them to express their reactions. Offer basic information about stress.
- ***Encouraging adaptive coping***: Identify past positive effective coping strategies for survivors and promote their use.
- ***Referral***: Serve as a "bridge" to resources; help to access local community spiritual and religious leaders and religious rituals. In response to hearing, "Why did God allow this to happen?" you might respond, "You're asking a very profound question. I think you might benefit from speaking with someone who can help you explore what is happening. Would you like me to arrange for that person to visit you?"

Disasters and other humanitarian crises compel us to confront forces that are beyond our mastery. They accentuate our fragility, mortality, and smallness in uncomfortable and distressing ways. What is asked of us is to stand with survivors in mutual vulnerability and authentically convey a simple yet hopeful message: "You are not alone. You matter to us. We are here for you."

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