Invited Commentary

Trauma-informed palliative care for humanitarian crises

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Abstract

Healthcare triage during humanitarian crises requires attention to saving lives and prevention of suffering at end of life. The prevalence of life-threatening experiences during humanitarian crises needs a trauma-informed palliative care approach, attending to the trauma-related psychosocial needs of patients, caregivers, and health care providers to support healing. This commentary includes research and practice literature that builds on and complements themes from an International Psychosocial Oncology Society Palliative Care Special Interest Group initiative. During humanitarian crises, palliative care experts contribute to mobilizing and training host country health care providers and volunteers who reciprocally promote cultural sensitivity for patients and their caregivers in all aspects of death and dying. Future directions require assessing how best to integrate trauma-informed principles into early and later responses to humanitarian crises. Culturally sensitive research partnerships with patients and caregivers must account for hierarchy and flexibility in research design and knowledge construction.

Keywords: trauma-informed care, humanitarian crises, compassionate communities, cultural sensitivity, healthcare providers, palliative care, trauma-informed palliative care, patient expertise

1. Introduction

The numerous humanitarian crises worldwide highlight that health care triage requires innovation to save lives and provide palliative care to relieve suffering.[1,2] During humanitarian crises, trauma (the direct or indirect exposure to life-threatening events, serious injury, and sexual violence)[3] is prevalent.[4] The multiple crisis-related stressors involving chaos, infrastructure loss, and displacement[5] call for a trauma-informed palliative care (TIPC) approach.[6] TIPC recognizes trauma exposure is ubiquitous and may result in adverse short-term or long-term physical and mental health consequences among patients, caregivers and health care providers. TIPC incorporates this understanding into palliative care policy, practice, and procedures, with an emphasis on avoiding retraumatization.

In October 2022, the authors organized an International Psychosocial Oncology Society (IPOS) Palliative Care Special Interest Group webinar[5] to illustrate the benefits of TIPC during and in the aftermath of humanitarian crises. Experts in TIPC conveyed their lived experiences in the Ukraine, Bangladesh, and Rwanda. We summarize and connect related research and practice literature to the webinar's main themes, current challenges and opportunities for increasing accessibility to TIPC, and recommendations.

2. Palliative care in humanitarian crises

Sphere, an initiative created by humanitarian nongovernmental organizations (NGOs), sets standards that include palliative care to enhance the quality and accountability of humanitarian responses.[7] Palliative care is the prevention and relief of suffering from life-threatening illnesses and injuries among people of all ages and their families.[8] During humanitarian emergencies, individuals requiring palliative care include those with pre-existing life-limiting diseases (eg, HIV infection), advanced health

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J. M. de Groot holds the following grants: (co-PI Alberta Cancer Foundation, 2020-current) Carole May Yates Memorial Endowment (PI, 2023-2024), Office of Health Medical Education and Scholarship, Equity, Diversity & Inclusion Grant (PI, 2023-2025), CPSA Healthier Albertan Grant, An innovative model of equitable cancer care, Indigenous Cancer Patient Multi-disciplinary rounds (project member, 2023-2026).

All authors contributed to the writing of the commentary and agree with the final version. J. M. de Groot co-conceptualized the commentary and took a lead role in writing the manuscript. D. C. Fehon coconceptualized the commentary and led the review and editing of the manuscript.

J of Psychosocial Oncology Research and Practice (2024) 6:2

Received: 22 December 2023 / Received in final form: 25 March 2024 / Accepted: 9 April 2024

http://dx.doi.org/10.1097/OR9.0000000000000132

conditions with limited access to treatment (eg, cancer), premature births, and conditions generated by the emergency itself (eg, severe injuries, burns, and malnutrition).

Integrating palliative care into humanitarian responses has an ethical rationale: *doing good* by honoring dignity, *justice* in resource allocation, *autonomy* by respecting preferences and traditions, and *doing no harm* by reducing moral distress for health care providers.[9]

To address the inequities in access to pain relief worldwide, the *Lancet Commission on Palliative Care and Pain Relief* outlined an affordable, effective, and essential package of palliative and pain relief interventions to help alleviate serious health-related suffering.[10] The dire need for sufficient analgesic medications when trauma is ubiquitous is buttressed by the bidirectional model of pain and post-traumatic symptoms (PTS).[11,12] Appropriate pain relief during early resuscitation and treatment of serious injuries helps prevent PTS.[13] Conversely, pain interference, the extent of physical, social, and mental activities reduction due to pain, increases PTS risk among patients receiving palliative care for advanced cancer.[14] Thus, affordable pain management is essential to TIPC during humanitarian crises.[7]

3. Trauma-informed palliative care

Trauma-informed care (TIC), as defined by the *Substance Abuse and Mental Health Services Association (SAMHSA)*,[15] is increasingly integrated and evaluated within health care.[16] In this model, trauma includes adverse childhood experiences, discrimination and racism and exposure to life-threatening events. A foundational assumption is that trauma is pervasively present. This assumption is integrated into policy, practice, and procedures and emphasizes avoidance of retraumatization. TIC recognizes that patients and health care workers may have experienced previous trauma or vicarious trauma[15] and identifies six core principles to support healing without focusing on the trauma type. These principles subsume 1) safety, 2) trustworthiness and transparency, 3) peer support, 4) collaboration and mutuality, 5) empowerment, and 6) attending to historical, cultural, and gendered contexts. We assert that TIPC is essential to support patients with life-limiting illnesses during humanitarian crises when morbidity and mortality are high and resources limited.

Psychological first aid (PFA)[17] should be available to people exposed to traumatic humanitarian events. Sphere standards emphasize that PFA is a basic, humane, and supportive response to suffering. PFA includes listening carefully, assessing and ensuring basic needs are met, encouraging social support, and protecting from further harm.[7,18] Community leaders, health care workers, and others involved in the humanitarian response can provide PFA to people in distress.

TIPC also endorses patient expertise regarding their bodies, values, preferred types of care, and choice of individual or relational decision-making. Host country health care workers, community leaders, and volunteers may support incorporating cultural, historical, and gender issues into care plans. Humanitarian organizations and their workers must seek to become aware of and reduce biases in providing care. In this regard, cultural understanding and responses to death and dying are important considerations.[19]

TIPC recognizes the importance of responding to the needs of health care providers whose resources are stretched and who experience secondary traumatic stress[20] after treating horrific wounds,[21] hearing about others' trauma,[20] or experiencing moral injury due to ethical conflicts.[22] For example, health care providers' concerns in Ukraine often resonate with patients' concerns about where to live and of personal safety. Practices to reduce traumatization may enhance staff effectiveness and morale. A RISE (Resilience, Inspiration, Storytelling and Empathy) program supported storytelling guided by a trauma-informed response for meaning-making among a global health providers group during the pandemic.[23]

4. Cultural sensitivity and trauma

Attending to cultural contexts supports the principles of safety, collaboration, mutuality, and patient and family empowerment. Culture informs TIPC through understanding of beliefs about pain, death and dying, and desire for types and amount of information.[19] Cultural sensitivity requires avoidance of "othering" or stereotypical reductionism.[19] In crisis situations involving human displacement, loss of life, and societal infrastructure, culturally sensitive care becomes crucial for preserving the identity of patients and caregivers.[19]

Health care workers and families may support a TIPC approach while adhering to cultural or religious norms, even when prognosis is not disclosed.[24] Location of death and speaking and hearing one's own language are important considerations.

5. The role of community in humanitarian crises

Community engagement is essential to humanitarian responses. Reconnecting as a community helps heal fractured communities and address the uncertainty of new refugee identities in the context of chaos and trauma. The arts can serve as a potent means of healing, reuniting communities, preserving culture, and uplifting health care providers. For example, Ukrainian choir members who sang in train stations[25] helped displaced individuals preserve a sense of identity and community.

Compassionate community initiatives complement medical care by supporting holistic well-being through offering practical resources for individuals facing end of life.[26,27] The compassionate communities concept considers public health is everyone's responsibility, including end-of-life care.[26,28] Outcomes include empowering patients to be educators and community members to gain greater comfort with death and dying.[26] During humanitarian crises, palliative care clinicians contribute to mobilization, training, and support of host and displaced communities.[29] This includes training local palliative care volunteers and helping to create social connections and resilience in the face of death and dying.[29]

Longer-term humanitarian responses are necessary for continuously displaced refugees. To enhance provision of palliative care for Rohingya refugees in Bangladesh, Project ECHO (Extension for community health outcomes) for palliative care facilitates virtual training and continuous mentoring for nurses, health care assistants, and physicians.[29,30] PallCHASE (Palliative care in humanitarian aid situations and emergencies https://pallchase.org/) offers online training and resources for health care providers working in humanitarian emergencies.[31] Within multidecade Rwandan refugee camps, a refugee network initiated a palliative support program for individuals who have lost loved ones.[24] Presence, nonabandonment, and advocacy are important social elements of holistic palliative care in the face of separation from one's country.[24] As community health workers use existing skills,

they may preserve or reinstate self-worth by conferring supportive palliative care.

6. Future directions

Given widespread human suffering, particularly in the context of ongoing and traumatic humanitarian crises, we emphasize TIPC is a necessary psychosocial consideration for humanitarian and refugee efforts. TIPC is a new concept within the field of palliative care. Consistency of terminology about trauma and compounded trauma is required. Work is needed to describe and define the elements of a trauma-informed approach during humanitarian crises initially and over the long term. Similarly, research into how TIPC principles may best be integrated and implemented is crucial. Qualitative research and case reports may be valuable to describe exemplar programs using culturally informed TIPC approaches.

To explore the benefits of TIPC within humanitarian crises requires culturally sensitive research partnerships attending to hierarchy and flexibility in the research codesign.[32] Patients and/or caregivers may contribute to research codesign or be involved as research subjects with appropriate informed consent to support knowledge construction and ensure their voices are heard.[33] Qualitative and mixed methods research may capture rich data regarding the power of TIPC.

Integration of TIPC into policy and practice requires committing education and funding to mobilize community resources.[34] In resource-rich countries, opportunities have increased for medical and psychosocial learners to train for work in global health settings. For effective humanitarian responses, standardization of TIPC competencies across different specialties and the capacity to train others is required. Examining and addressing ethical considerations in supporting trainees to work during humanitarian emergencies is vital.

Qualitative research may usefully define benefits and limits of compassionate community engagement during humanitarian crises and explore their role in articulating implicit knowledge to enhance TIPC and contribute to collective moral resilience.[35] It will be useful to identify best practices for bidirectional learning between palliative clinicians, host country health care workers, volunteers, and the patients they serve. Finally, best TIPC practices must support emotional well-being and prevent moral distress among host and international health care providers and volunteers.

Acknowledgements

This article includes themes from a webinar held on October 4, 2022 and hosted by the International Psychosocial Oncology Society (IPOS) Palliative Care Special Interest Group, Education Subcommittee. We sincerely thank Drs. Megan Doherty (Canada), Oleksander Wolf (Ukraine), Sonya de Laat (Canada), and Jessi Humphreys (USA) for their valuable presentations, wisdom, and discussion. Special thanks to IPOS for hosting the webinar.

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