

Examining the ethics and practicalities of palliative care in emergencies

Since the Ebola outbreak of 2014–2016, there has been increasing attention on the need for palliative care in emergency settings, but a lack of evidence and practical guidance has hampered humanitarian practitioners' efforts to provide it in different contexts. This study, 'Ethics and palliative care during international humanitarian action', led by McMaster University, Canada, between 2016 and 2018, examined the ethical and practical experiences, challenges and possibilities of humanitarian organisations integrating palliative care into their emergency responses.

The study findings have influenced new World Health Organization (WHO) guidelines on integrating palliative care into humanitarian responses and new palliative care standards in the fourth edition of the Sphere Handbook, both published in 2018. Given the high profile of these sources, this represents a significant contribution to supporting practitioners implementing palliative care in emergency settings. Médecins Sans Frontières (MSF) in Spain has also reported changes to its strategic plans and internal guidelines for field staff.

Title: Ethics and Palliative Care During International Humanitarian Action

Location: Guinea, Jordan and Rwanda (among various other locations that experienced natural disasters)

Study type: Mixed methods (literature review, surveys, interviews)

IMPACTS

- Influenced WHO guidance and recommendations on integrating palliative care into humanitarian response
- Influenced development of new Sphere Standards on palliative care
- Influenced organisational dialogue and internal guidelines of MSF (Spain) on palliative care

RESEARCH IMPACT LEARNING

- Early engagement with humanitarian actors to ensure research and outputs are relevant to them
- Importance of engaging WHO and Sphere to broaden influence on global standards.

BACKGROUND



Demands on healthcare during a humanitarian crisis typically outweigh resources, often leaving people with incurable illnesses and those who are dying with little to no end-of-life, or palliative, care. But palliative care is important not only for the patient but also for their families, by preventing and relieving suffering.

The Ebola outbreak in 2014 in West Africa highlighted the stark lack of available treatments for people at the end of life, with MSF reporting significant demand from field teams for training in palliative care. This humanitarian crisis triggered increased global attention on palliative care in emergencies, and in 2016 a WHO working group focusing on palliative care was established.

Despite this attention, without evidence and practical guidance, providing palliative care remained a significant challenge, particularly when considering the wide range of humanitarian contexts, from disasters to protracted conflicts, for which such care may be very different.

THE STUDY



The mixed-method study set out to examine the ethical and practical experiences, challenges and possibilities of humanitarian organisations integrating palliative care into their emergency responses. It looked at how existing standards could be adapted to enable the delivery of better care, and the ethical complexities of doing so. It aimed to support the integration of palliative care into all humanitarian responses, via inclusion in standards and guidelines. Study questions and objectives were developed in consultation with humanitarian organisations and members of affected communities.

A literature review was first conducted to understand the available evidence for palliative care provision in emergency settings, in terms of needs, practices, barriers, recommendations and ethics.

The study then explored four distinct crisis settings, retrospectively: the 2014–2016 Ebola outbreak in Guinea, disasters in various locations (eg, 2004 tsunami in Sri Lanka, 2015 earthquake in Nepal), the displacement of Syrian refugees in Jordan, and a protracted refugee setting in Rwanda. Data were collected using an organisation-based survey, sent to organisations such as MSF, to investigate to what extent humanitarian organisations enable their staff to provide palliative care. Semi-structured key informant interviews with local and international humanitarian organisations that provide care were undertaken to better understand the views and experiences of humanitarian staff. Where possible, people living with a terminal or life-limiting illness and members of their families were also interviewed.

FINDINGS



The study found a scarcity of data and a lack of consensus on the ethics of providing palliative care in humanitarian responses, suggesting that more research, training and open discussions are needed.

The organisation-based survey and key informant interviews found that humanitarian responders were driven to provide palliative care by values such as compassion and justice. Themes that were reported included easing suffering, upholding dignity and prioritising this type of care. In terms of providing palliative care, patients and healthcare providers across all contexts overwhelmingly spoke of the crucial importance of low-cost and non-specialised care such as helping patients and their families with ordinary tasks of living, and accompanying a person in their final hours.

The study found that working towards improving local and global health systems was of utmost importance, with this requiring advocacy for equity, justice and rights to health and healthcare. The findings highlighted that palliative care in humanitarian contexts should never diminish attempts to offer curative care.



Camp 22, Cox's Bazaar, Bangladesh.
Credit: Rachel Yantzi

COMMUNICATIONS AND ENGAGEMENT



Strong relationships between the study team and influential experts, particularly at the WHO and MSF, were important to the study's success. Dr Marie-Charlotte Bouesseau, WHO's lead on palliative care, was on the study's advisory board, opening up her networks for vital further engagement, securing WHO buy-in, and maximising impact opportunities. Early engagement with the Palliative Care in Humanitarian Aid Situations and Emergencies (PallCHASE) group including Dr Joan Marston and Dr Farzana Khan, an informal network that helps to meet the palliative needs of people affected by humanitarian disasters and mass casualty incidents, was important for knowledge sharing. Early engagement with humanitarian operational organisations, and Sphere, were undertaken to inform the research objectives and survey questions and open avenues for engagement with the surveys and interviews.

Professor Lisa Schwartz from McMaster University, one of the study's Principal Investigators, holds a position on the MSF ethics review board. This was important for fostering engagement opportunities for the study findings, for example when training MSF medical coordinators. The study team presented findings at a 2018 MSF Scientific Day, for both MSF and external staff, in London, UK, sparking an engaged discussion on the provision of palliative care in humanitarian settings. They also later presented findings at a similar meeting in New Delhi, India.

International events were held to disseminate the study findings. Workshops in Geneva, Switzerland, convened experts from ALNAP, MSF, International Committee of the Red Cross, Sphere, the UN High Commissioner for Refugees (UNHCR) and WHO and provided an opportunity to understand the relevance of the study findings in different humanitarian contexts.

In addition to the aforementioned literature review, peer-reviewed articles were published on moral experiences in the *Journal of International Humanitarian Action* and on obstacles to palliative care inclusion in *Conflict and Health*. An overview paper of the full study was published in *PLOS Global Public Health* and a comment piece in *The Lancet*.

UPTAKE AND IMPACT



The 2014 World Health Assembly Resolution 67.19 on Palliative Care had already included its integration in humanitarian response. Then in 2018, the WHO published guidance on integrating palliative care into humanitarian responses, with recommendations that reflect and cite the key findings from the study. A chapter was authored by Professor Schwartz. Three WHO booklets on the integration of palliative care in humanitarian contexts have since been published. Given WHO's reputation and influence, it can be inferred from inclusion in these materials that the study has indirectly influenced humanitarian practice.

The fourth edition of the *Sphere Handbook*, published in 2018, also contains new palliative care standards authored by Professor Schwartz, Dr Elysée Nouvet and other members of the Humanitarian Health Ethics (HHE) team. These reflect and cite the study's key findings. As this handbook is considered to be the gold standard for humanitarian practice, incorporation of the study's findings represents a significant contribution to supporting practitioners implementing palliative care in emergency settings.

Professor Schwartz and HHE team member Dr Kevin Bezanson contributed to *A Field Manual for Palliative Care in Humanitarian Crises* published by Oxford University Press. The study findings also influenced the palliative care practices of MSF's Operational Centre in Barcelona-Athens (OCBA). In 2021 OCBA produced internal guidelines for field staff, which included integrating palliative care into their interventions. The guidelines cited the study findings, and their palliative care specialist Kathryn Richardson confirmed that the study was important in pushing palliative care forwards in the humanitarian sector. According to a key informant, palliative care is now reflected in MSF's Strategic Plan 2020–2024, and MSF's growing interest in palliative care is indicated in a blog written by Dr Amin Lamrous, Palliative Care Specialist, MSF.

“[We took] lots of inspiration from the Schwartz study in terms of defining the ethical framework used for end-of-life care and defining goals for success”

– Dr Amin Lamrous, Palliative Care Specialist, MSF

This has influenced an MSF-led study to explore staff experiences of providing palliative care and how MSF palliative care guidelines have been applied in paediatric care in refugee camps in Cox's Bazar, Bangladesh. A PhD student and HHE member conducted the research while working as nurse manager with MSF in 2021.

Finally, palliative care delivery organisation the Fasiuddin Khan Research Foundation reported that it was partially influenced by the study when conducting a needs assessment to support Rohingya refugees in Bangladesh. A set of minimum standards for palliative care for Rohingya refugees was subsequently developed to inform the health sector Minimum Service Package with input from the research team. The Health Sector Coordinator, Cox's Bazar (WHO) confirmed the indirect influence of the study on the development of the standards.

RESEARCH IMPACT LEARNING



IMPORTANCE OF EARLY ENGAGEMENT

This is crucial to adapt study tools/research questions to ensure relevance of findings and outputs for humanitarian actors. This study reflects a high priority for humanitarian health delivery organisations and the approach shows consideration and concern for patients and families, and an increasing focus of the sector on taking care of its own staff, leading to relevant and applicable findings. This awareness was borne out of early engagement and ongoing dialogue.

IMPORTANCE OF ENGAGING WHO AND SPHERE TO BROADEN INFLUENCE ON GLOBAL STANDARDS

This is key because these bodies offer high-level recognition, as well as translation into operational use.

Training and discussion are also essential, as is advocacy to improve awareness of palliative care and the resources required to support communities with dignity.

PARTNERS

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McMaster University; McGill University ; Le Comité National d'Éthique pour la Recherche en Santé (CNERES); Jordan University of Science and Technology

ABOUT ELRHA

Elrha is a global organisation that finds solutions to complex humanitarian problems through research and innovation. This study was funded by Elrha's Research for Health in Humanitarian Crises (R2HC) Programme which aims to improve health outcomes by strengthening the evidence base for public health interventions in humanitarian crises.

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R2HC captures detailed case studies through a process that triangulates and validates evidence on uptake and impact. The case study methodology and full version of this summary case study are available on request.



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