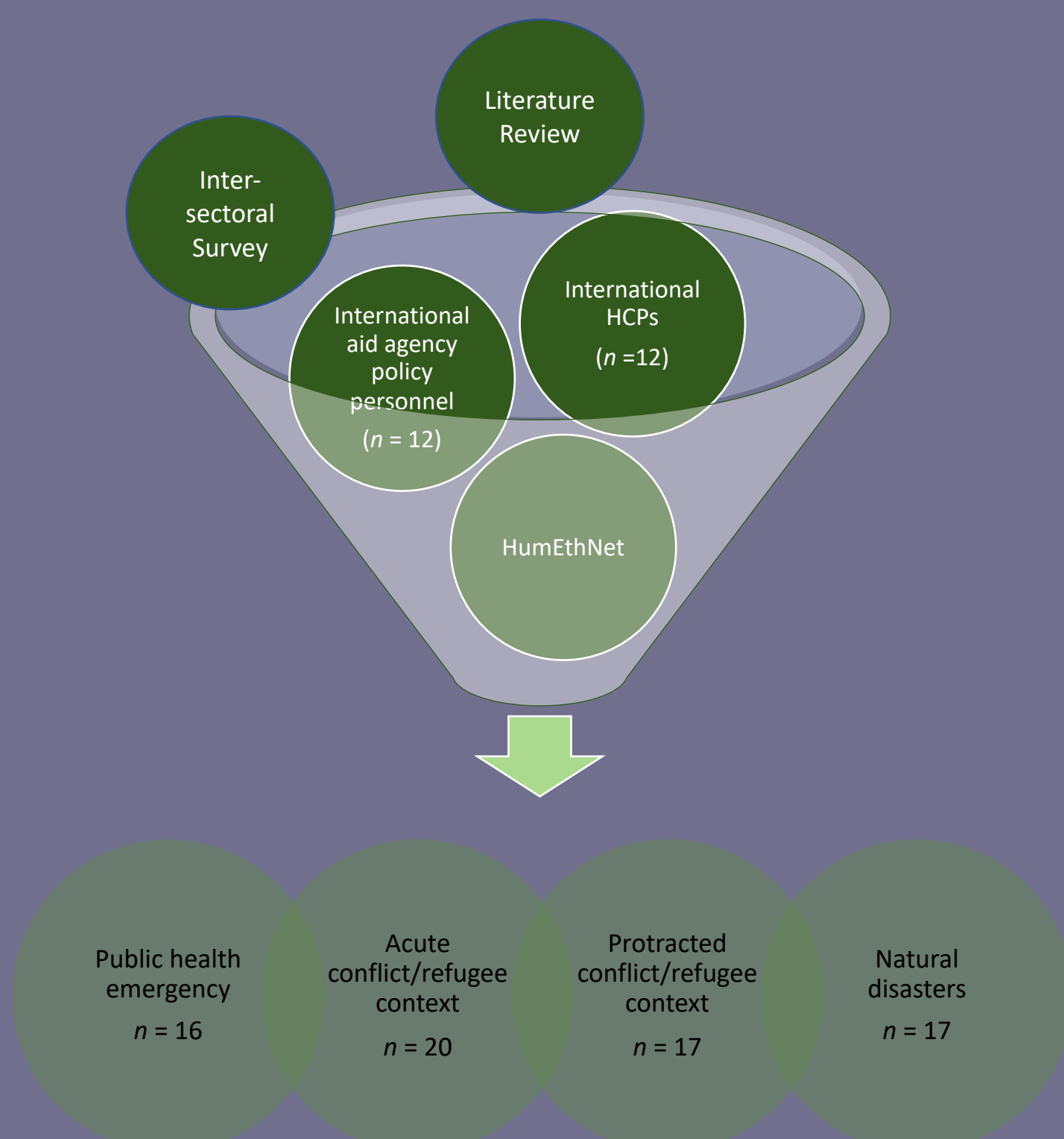


Opportunities and Challenges When It Appears There is “nothing left to offer”: Results from a qualitative study on palliative care in humanitarian crisis settings

Sonya de Laat ¹, Matthew Hunt ¹, Elysée Nouvet ², Lynda Redwood-Campbell ¹, Laurie Elit ¹, Carrie Bernard ⁴, Kevin Bezanson ³, Olive Wahoush ¹, Oumou Bah Sow ⁶, Wejdan Khater ⁵, Emmanuel Musoni ⁷, Rachel Yantzi ¹, Ani Chénier ¹, Lisa Schwartz ¹
McMaster University ¹, Western University ², Lakehead & Laurentian Universities, Thunder Bay Regional Health Sciences Centre ³, University of Toronto ⁴, Jordan University of Science and Technology ⁵, University of Guinea ⁶, University of Rwanda ⁷

— Methods —

— Findings —



Methodology & Analysis

- Qualitative, constructivist design.
- In-depth, open-ended interviews.
- Analysis conducted using NVivo qualitative data management software.
- Constant comparative, thematic analysis done concurrently with data collection.
- Interpretive description (Sally Thorne 2016), continually asking the data: “What is going on here?”, “Why is this here?”, “What is missing?”

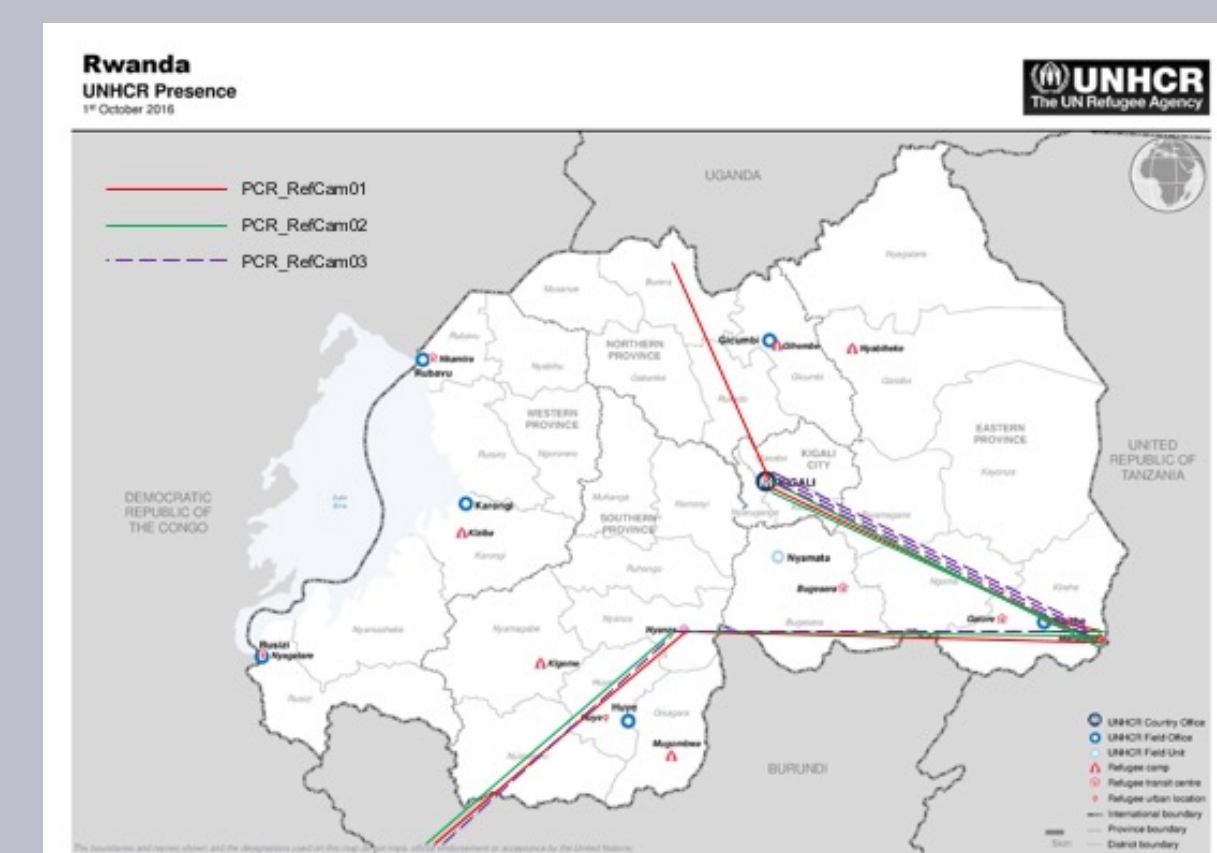


Figure 1: Travel routes from 3 refugees to access (combined) curative and palliative treatment in Rwanda.

Resource limitations:

- Chronically underfunded healthcare system.
- Reliant on international donations (in refugee camps).
- Opioid limitations due to opiophobia and global distribution inequities.

Social identities:

- Being ill often brings social disadvantage; this is amplified when the disease itself is stigmatized: Ebola virus disease, cancer, HIV/AIDS. This can lead to isolation, treatment avoidance, and stress/anxiety.
- Being identified as a refugee can also limit care access: where care is prioritized for nationals.

Challenges

Labyrinthine care pathways:

- Layers of bureaucracy for refugees; allows for healthcare costs to be subsidized by aid organizations, but results in delayed diagnosis and treatment.
- Travel distances to comprehensive healthcare facilities are great; transportation is circuitous or laborious for refugees reliant on NGO assistance.
- Difficulties accessing healthcare facilities are amplified during a public health or natural disaster crisis when such facilities are overwhelmed or damaged/destroyed.
- Circuitous discussions around dying and death as cultural norm.

“...they prescribed a drug for me. I went to the pharmacy, they said, ‘we don’t have it get a replacement prescription.’ The Dr gave me an alternative prescription & I returned. They said, ‘we don’t have this, go look elsewhere.’ I went to another pharmacy, they didn’t have it. I threw away the prescription.”

– Refugee living in a camp, Jordan

“People have told him that his illness [leukemia] is worse than HIV/AIDS: ‘you will die soon.’ So they disrespect him, and they are taking his things”

–Local Provider (5) Rwanda

Opportunities



Grandfather, 71 years old, Leukemia

32 years-old, widow Mother of 4 children Breast cancer

Always something to offer:

- “Small things” in the form of fans to manage sweating (from pain), a light to break the long, dark nights, or for someone to bring water or clear the trash.
- Accompaniment and non-abandonment.
- Minimally trained community health workers (in refugee camp settings) or lay psychosocial support workers (in public health and natural disaster settings).

Palliative care as just *good care*:

- As “a component of comprehensive care throughout the life course” (WMA), palliative care encourages patient-centered care, communication and support to (and by) the patient’s family, and respect for social, cultural, spiritual expectations around severe illness/injury, dying, death and bereavement.

“Ebola doesn’t have a specific treatment. So, we can only rely on palliative care. Um... I think there was an importance that was given to this care from the start. But this importance should be reinforced. I think there needs to be more importance given; attribute a very big importance to this type of care because *it’s the only care that could save patients’ lives.*”

– Local Provider (1), Guinea

Reinforces sense of humanity:

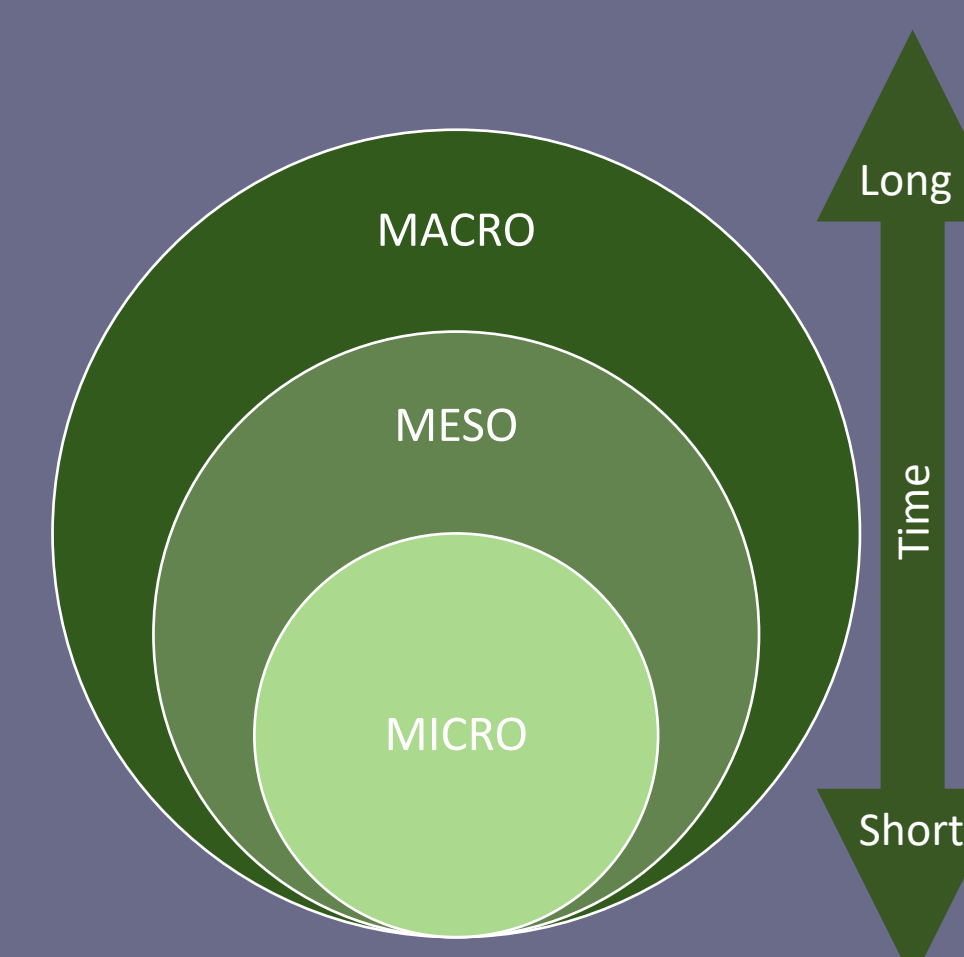
“So for me, the big part of palliative care is the values, the beautiful way we see human beings, equality, non discriminative, quick response, empowering families and patients, giving them the ability to make decisions, communication, seeing them, understanding that they are part of a whole system; it’s not addressing one patient it’s a whole family. So for me this is palliative care.”

— Palliative care consultant, Jordan (NATPRO1)

— Conclusions & considerations for future directions —

Conclusions:

- Lifesaving is and should remain the priority of humanitarian healthcare, but the reality is that not all lives can be saved.
- Palliative care is *good care* and endemic to humanitarian healthcare’s mandate to *reduce suffering*.
- Health system limitations are *amplified* in humanitarian crises.
- Palliative care should never be considered a replacement for the need to continually improve the local health system.
- Even amidst conditions of extreme deprivation, *there is always something to offer*.



Recommendations:

- Healthcare providers recognized what patient-participants described: that global equity is needed in screening, treatment and symptom management.
- Palliative care is being done in various *ad hoc*, informal ways—because some people cannot be saved. Evidence & evaluation of priorities and impacts on physical & mental health are of ongoing importance.
- Local health system improvements, including integrative palliative care training, would also lead to better palliative care for those further pushed to the margins in humanitarian crises.
- Public health education is needed to dispel myths around certain illnesses, dying, death talk and palliative care.
- Small and low-cost options were recommended such as fans or lights and **accompaniment**—a sense of not being abandoned.

Acknowledgements:

We would greatly like to thank those who participated in our study “Aid When There is ‘Nothing Left to Offer,’” particularly those participants who were ill or whose family members were ill. We also want to thank our collaborators & supporters in Guinea, Jordan, Rwanda and elsewhere, and our funders (ELRHA-R2HC) and to you for your reflections & feedback.

Publications to date:

Hunt M, Chénier A, Bezanson K, Nouvet E, Bernard C, de Laat S, Krishnaraj G, L Schwartz L. (2018). **Moral experiences of humanitarian health professionals caring for patients who are dying or likely to die in a humanitarian crisis.** *Journal of International Humanitarian Action*. 3: 12.
Nouvet, E., Sivaram, M., de Laat, S., Sanger, S., Banfield, L., Favila Escobio Rodriguez, P., and Schwartz, L.J., (2018). **Palliative care in humanitarian crises: a review of the literature.** *Journal of International Humanitarian Action*(2018) 3:5, 1-14.
Hunt, M, Bernard, C, Bezanson, K (2017). **Making Space for Palliative Care in Humanitarian Action: Reflections on Obstacles to the Integration of Palliative Care Approaches in Humanitarian Healthcare.** www.elrha.org/r2hc-blog/