Dying in the Margins:
Palliative Care, Humanitarian Crises and the Intersection of Global and Local Health Systems

Sonya de Laat [1], Matthew Hunt [1], Elysée Nouvet [2], Olive Wahoush [1], Kevin Bezanson [3], Carrie Bernard [4], Lynda Redwood-Campbell [1], Laurie Elit [1], Wejdan Khater [5], Oumou Bah Sow [6], 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:


hhe humanitarian healthcare ethics reflecting on ethical practice

Palliative Care in Humanitarian Crises

Justification for Case Study Selections
- Four cases studies were identified through stakeholder meetings and key informant interviews;
- Each represents a different type of reoccurring or continuing humanitarian emergency situations;
- Variability in refugee situations calls for comparative study.

Guinea
Case type: Public health emergency
Specifics
- Ebola virus disease;
- context of public panic and generalized distrust;
- challenges and perceived challenges of palliative care w/ highly contagious disease;
- Context: Low SES, predominantly Muslim, historically weak health care system.

Natural Disaster Array
Case type: natural disaster
Specifics
- three locations: Nepal, Haiti, Indonesia
- three disasters: earthquake, hurricane, tsunami
- acute and chronic

Jordan
Case type: refugee camp, acute
Specifics:
- refugee and forced migration;
- acute (ongoing) conflict;
- patient population: many formerly mid-SES, accustomed to robust healthcare system;
- dying away from homeland / in exile / displaced

Rwanda
Case type: refugee camp, protracted
Specifics:
- long-term refugee camp (20+ years)
- socio-cultural and clinical complexities of dying and death in post genocide context
- protracted, recurrent conflict
- predominantly low SES, low literacy, predominantly Christian context

- Qualitative, constructivist
- In-depth, open-ended interviews
- NVivo qualitative data management software
- Constant comparative, thematic analysis
- Interpretive description (Sally Thorne 2016); continually asking the data "What is going on here?", "why is this here?", "what is missing?"

Findings:

Health system *limitations are amplified* in humanitarian crises.

Curative care capacity constraints disproportionately impact refugees and others made vulnerable by their social position; they are often the first to face the health system's limitation:

- Curative care or screening options are already limited for local nationals; refugees, marginalized, poorer people or those unfamiliar with navigating the local culture, let alone a health system, are less likely to access timely care, resulting in premature palliative needs;
- Palliative care should never be considered a replacement for the need to continually improve the local health system;
- Access to opioids or other pain treatment more restricted due to limited stocks during non-crisis times, or due to lack of funds on the part of refugees or others cut off from banks;
- Removed from family supports and community comforts, limitations in health systems come into relief in terms of:
  - Mobility: reaching treatment centres or pharmacies more difficult if infrastructure lacking or no funds for childcare;
  - Electricity: some participants said they could cope with pain if they had access to lights or fans;
  - Lack of public health education leads to nearly impossible conversations around end-of-life planning and leads to stigmas to do with illnesses, the dying process, or palliative care as "giving up;"
  - Contacting family members to say final goodbyes.

Patient participants:

- Grandfather, 71 years old
- Leukemia
- Exhausted by the long trip for treatment: local system requires **all patients** coming from Great Lakes Region of Africa to the **sole cancer care Centre of Excellence** to sleep overnight in the hospital courtyard if they arrive the night before their treatment.

PCR-RefCam-04

On lack of comprehensive care:

"…what I know, that I am very sick, living in a tent and I have no support, but God! I am Praying to God, and feeling anxiety and pain…Everybody should help, but there is nothing like that, they only come and take photos and never come back."

— Jordan (REFCOM1)

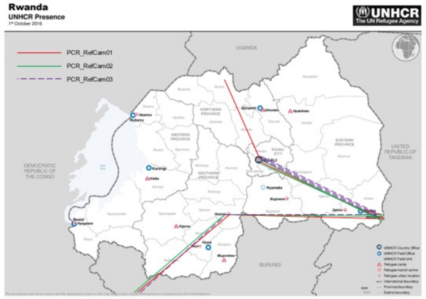

Figure 1: Travel routes from 3 refugees to access (combined) curative and palliative treatment in Rwanda.

On existing health system limitations:

"We were greeted in dusty rooms, no chairs, no bed, absolutely nothing. All that was there, the stuff that we used for Cholera patients. From there we went, were put. There was no water, absolutely nothing. And the doctors at the time were not coming in to say we're going to do something, but they did not even know what. Certainly, they had heard rumors of 'Ebola, Ebola'… And that Ebola was said to be an incurable disease, when you had it you were destined to die."

—Survivor turned psychosocial agent (GPALL02a)

PCR-RefCam-03

- Mother of 2 school-aged children
- Ocular blast injury sustained during civil unrest in Burundi
- Unable to access treatment for 2 years fear of detainment.
- Now in Rwanda, amp dust & cooking smoke causes chronic infections
- Travels weekly from camp to capital (5hrs each direction) by bus & on foot with help of husband, to have eyes cleaned.

PCR-RefCam-01

- 32 years-old, widow
- Mother of 4 children
- Breast cancer
- Access to Cancer Centre is free, but delays in refugee-specific paperwork has meant her cancer returned
- Childcare & bureaucracy are her major concerns.

Care providers:

"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)

"Ebola doesn't have a specific treatment. So, we can only rely on palliative care. Um. I think that there is an importance that was given to this kind of care, 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."

—Guinean healthcare provider (GPALL01)

"People have told him that his illness [leukemia] is worse than HIV/AIDS, you will die soon, so why disrespect him, and they are taking his things"

-Rwanda PCR-RefCam05

On delays:

"Are they waiting for me to die until they realize they need to help me?"

-Jordan (RefCam5)

Considerations:

Many of our participants in Guinea, Jordan and Rwanda commented on the importance of ***accompaniment***—a sense of not being abandoned—as being more important almost even to painkillers.

Healthcare providers recognized what patient-participants described: that global equity is needed in screening, treatment and symptom management. Local health system improvements would also lead to better palliative care for those further pushed to the margins in humanitarian crises. Public health education is also needed to dispel myths around certain illnesses, dying, death talk and palliative care.

Palliative care is being done in various *adhoc,* informal ways—because some people cannot be saved. Evidence & evaluation of priorities and impacts on physical & mental health are of ongoing importance.

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, LJ.,. (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/

Abstract ID: 3989

Follow us: www.humanitarianhealthethics.net **Twitter:** @HumEthNet

Contact us: delaat@mcmaster.ca; schwar@mcmaster.ca; matthew.hunt@mcgill.ca