

Introduction

Building relationships with decision makers and developing teams that include local researchers in humanitarian crises is critical for cultural relevance and to promote the integrity of the research. This poster clarifies ethical and practical dimensions of the human engagement aspect of researching palliative care in humanitarian crisis contexts.

The crucial dimension of responsive and responsible research is but one feature of the research activities involved in a case study that forms part of a larger study entitled, *Aid when there is "nothing left to offer": A study of ethics & palliative care during international humanitarian action* (www.humanitarianhealthethics.net). The Jordan Case Study represents a recent and ongoing conflict crisis. Here is the story of how we enlisted and engaged decision-makers (government and UNHCR), program planners and local research institutions to better understand ethical and practical experiences, challenges, and possibilities of humanitarian organizations integrating palliative care into public health emergency responses.

Objective

Our study aims to clarify how humanitarian organizations and healthcare providers caring for people affected by a humanitarian crisis might best support ethically and contextually appropriate palliative care. We present lessons learned about the ethical and political particularities of researching palliative care in one particular case study: acute conflict/refugee situation in Jordan.

Applying concepts from R2HC and CCGHR partnership guidelines, our objectives include highlighting the importance of culture in all research roles, ensuring integrity of the research, and promoting participant voices, particularly those of vulnerable participants (e.g. refugees).

Methods

Study Design

Four case studies based on in-depth, semi-structured interviews thematically organized into: public health emergency (Guinea, Ebola), natural disasters (Philippines, Typhoon Haiyan), acute conflict (Jordan, refugees) and protracted conflict (Rwanda, refugees).

Research Ethics

Three case studies required support from local researchers and approvals from various levels of government. Local research ethics boards existed as national committees (Guinea, Rwanda), or UNHCR and local researchers' university (Jordan).

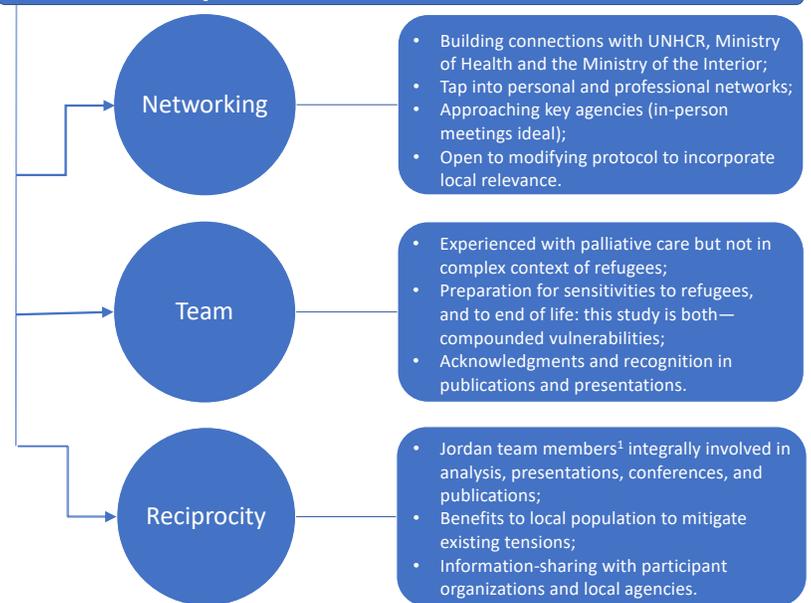
Other Considerations

Access to potential participants was achieved through a number of strategies: building relationships with decision-makers, agency leaders, and government personnel in each setting and professional networks (Jordan).

Results

- Findings include the importance of building relationships that are sensitive to multiple vulnerabilities and unequal power dynamics.
- Relationship-building created a space that facilitated adaptation of the study protocol so that local needs for equity were respected, required approvals were supported, and access to the study population was facilitated.
- Participant agencies are interested and asking for the final report and recommendations.
- Anticipated is information to guide service provision to refugees, palliative care practice for refugees and Jordanians, training, and support for the specific humanitarian context.
- Findings add to the larger study in highlighting the provision of palliative care, addressing moral distress when it cannot be provided, informing palliative care guidelines, training, and support for the specific humanitarian context.

Implementation Considerations



¹UNHCR staff, palliative care experts, and researchers.



From left to right: Mr. Suleiman Wahoush, Malek Alnajjar, Rou'eyh (Roya) Alnaser, Dr. Olive Wahoush (Canadian lead) and Dr. Wejdan Khater (Jordanian lead).

"Now I know why the training emphasized managing stress in response to participant stories..."

— Local research assistant following first interview

Conclusion

Lessons learned include:

- To be able to support local needs, inclusivity and adapt research protocols as needed.
- The selection, hiring and training of local team members essential to involve local lead.
- Training to build on palliative care to overlay with understanding of refugee experiences.
- Essential supports for research team: training interview, timely access to project/local lead for debrief discussions, identified agencies to refer refugees for supports.
- Integrally involve local team in collecting, reviewing and analysing participant information.
- Translating the understanding of the results for dissemination to broad audiences.

Acknowledgments

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- Takhliq Amir for her help with the preparation of this poster.

Resources

- 1) Research for Health in Humanitarian Crises. (ND). Partnerships. <http://www.elrha.org/r2hc/partnerships/>
- 2) Canadian Coalition for Global Health Research (2009). Partnership Assessment Toolkit. <http://www.ccghr.ca/resources/partnerships-and-networking/partnership-assessment-tool/>
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