Protracted Conflict/Refugee Case: Refugees in Rwanda

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Funding agency

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- R2HC is a programme within Elrha, Enhanced Learning and Research for Humanitarian Action:
  - “Improving humanitarian outcomes through partnership, research and innovation”
- The R2HC programme “aims to improve health outcomes by strengthening the evidence base for public health interventions in humanitarian crises.”
- The R2HC programme is the product of a strategic partnership between the UK Government (Department for International Development DFID) and the Wellcome Trust, with Elrha overseeing the programme’s execution and management.

Elrha: www.elrha.org
R2HC: http://www.elrha.org/r2hc/home/
Palliative Care in Humanitarian Crises

Justification for Case Study Selections
- Four cases 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.

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.

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.

Natural Disaster Array
- Case type: Natural disaster
- Specifics:
  - three locations: Nepal, Haiti, Indonesia
  - three disasters: earthquake, hurricane, tsunami
  - acute and chronic.
Rwandan context: Refugee situation

- Rwanda has been a generous host to refugees fleeing violence and persecution for nearly two decades.
- Rwanda is home to some 172,000 refugees
- There are 6 refugee camps in Rwanda:
  - The oldest, Gihembe, dates to 1997 and is in the North-West;
  - The youngest, Mahama, is only two years old and is in the Eastern Province.
- Gihembe is home to approximately 13,000 mainly Congolese refugees
- Mahama is the largest, and is home to approximately 50,000 mainly Burundian refugees.
The “UNHCR delivers primary healthcare for all refugees with [partner support] and ensures access to secondary and tertiary care [which is how most palliative care is provided] through support for national hospitals” (UNHCR 2017b).

Rwanda’s Minister for Disaster Management and Refugee Affairs (MIDIMAR), Seraphine Mukantabana stated, “The wellbeing we wish for all Rwandans is the same we wish for all refugees,” and so is the expectation of MIDIMAR and its international partners in terms of palliative care provision to refugees across Rwanda (Kalinda 2017).

Refugee patients, like Rwandan nationals, are expected to pay 10% of the total cost of hospital health services; the UNHCR and partners cover this cost for those who do not have the financial means.
One of the two new health centers opened in 2017 to improve medical services in the Mahama camp.

Picture: UNHCR

Occupied new mud brick shelters in Mahama refugee camp [Photo/UNHCR - Eugene Sibomana]
Methods and analysis

Semi-structured in-depth interviews:

- 3-5 local health care providers providing palliative or supportive end-of-life care to refugees in Rwanda (within camps or in local settings)
- 3-5 expatriate health care providers and/or policy decision-makers from international aid organizations providing palliative or supportive end-of-life care to refugees in Rwanda (within camps or in local settings)
- 3-5 patients who are or might have been eligible for palliative or supportive, and/or their family members

Our aim is breadth and diversity rather than representative sampling.

Analysis:

- Analysis with NVivo 10.0 qualitative data management software.
- Directed thematic and interpretive approaches.
- With an interest in informing future policies, we will also identify linkages between participants’ accounts and WHO principles of palliative care.
Recruitment and consent

- We will seek approvals from the Rwandan Ministry of Disaster Management and Refugee Affairs (MIDIMAR), from the United Nations High Commission for Refugees (UNHCR) which oversees the camps, and any local authorizing bodies as identified by the RNEC, MIDIMAR or UNHCR.
  - We anticipate that these agencies will further specify recruitment strategies.

- Our established local co-investigators (Drs. Philip Cotton, Emmanuel Musoni) and local collaborators (Drs. Christian Ntizimira and Pascal Bwambi) will assist with contacting local health care providers in-person, by email/text or by phone, to identify potential eligible participants at the camps.

- Participants—healthcare and aid organization professionals, and members of refugee communities—will be recruited and interviewed in their language of choice. We will hire local research assistants who speak local languages to assist with interviews and with translation where needed.
Protection of privacy & data protection

- Nvivo qualitative data management software will be used to organize all primary data,
- Study participants assigned participant ID number,
- Personal names, locations and dates will be removed at time of transcription; transcriptionists will have signed confidentiality agreements.
- Electronic audio files will be deleted and paper files with identifying information will be destroyed after 10 years. Transcripts, with all identifying information removed, will be archived and made available to other researchers via Scholars Portal Dataserve network through McMaster University (http://dataverse.scholarsportal.info/dvn/),
- De-identified transcripts will be shared between co-applicants at McGill, Western universities and at the University of Toronto,
- Data with identifiers will be transmitted between local field research sites and McMaster University through an encrypted, cloud storage service,
- Only research team members will have access to the raw data with the understanding that access to the audio files are limited to creating and verifying the transcript;
- Data will be transmitted by personal delivery between research team members, on password protected, encrypted USB memory device, or an encrypted, electronic file-sharing site such as Dropbox where all team members follow a two step authentication security process.
Research team in Canada

Principal Investigators:

- Lisa Schwartz, PhD, Arnold L. Johnson Chair in Health Care Ethics, Department of Health Research Methods, Evidence and Impact, McMaster University, Hamilton, ON, Canada
- Matthew Hunt, PhD, Associate Professor and Director of Research, School of Physical Occupation and Physiotherapy, McGill University, QC, Canada
- Coordinating lead for the Protracted Conflict/Refugee (Rwanda) case: Sonya de Laat, PhD, Postdoctoral Fellow in Humanitarian Healthcare Ethics
Local Principal Investigators, Rwanda:
• Dr. Emmanuel Musoni, Chief Resident, Department of Psychiatry, School of Pharmacy and Medicine, University of Rwanda
• Dr. Phillip Cotton, Vice Chancellor, University of Rwanda

Local collaborators, Rwanda:
• Dr. Christian Ntizimira, Medical Director at Kibagabaga Hospital in Kigali City, Rwanda, Coordinator of the first Pediatric Palliative Care Center in Rwanda, and Educator and Trainer of Palliative Care at the national level (http://www.ipcrc.net/news/christian-r-ntizimira-rwanda/).
• Dr. Pascal Bwimba, Chief Medical Officer at the Mahama camp.
  • (Paul Kenya, UNHCR director of the Mahama camp.)
Thank you!

If you have additional questions or would like to learn more about the Humanitarian Health Ethics research group, contact and visit us:

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