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# “We do what we can”: Palliative care in two refugee camps in Rwanda

Humanitarian teams often operate in high mortality settings, raising crucial questions about care for the incurable and the dying, their families, and their communities. The Humanitarian Heath Ethics (hhe) research group conducted a study aiming to better understand ethical and practical experiences, challenges, and possibilities of integrating palliative care into humanitarian crisis response.

This research snapshot reflects the results of a case study on the provision of palliative care in two protracted conflict-induced refugee camps in Rwanda. The qualitative study identified ethically and contextually relevant interventions including public education, caregiver training, integration of services, and small things (e.g., infrastructure modifications) that are low cost but of high impact.

> “Palliative care as I understand it is also counselling; it’s very important along with medicines.”
> – Camp healthcare provider

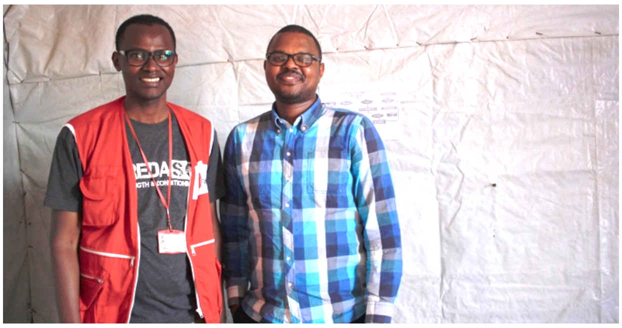

Figure 1. Study lead in Rwanda, Dr. Emmanuel Musoni (right) with key collaborator Dr. Pascal Bwimba (left).

## Background

Rwanda has been a generous host to refugees fleeing violence and persecution for almost two decades. Of the approximately 172,000 refugees currently residing in Rwanda, around 21% have severe medical conditions, 19.5% have disabilities, and 9.7% are older persons at risk (UNHCR 2017). Despite having a national palliative care strategy in place since 2011, such care is not an official offering in refugee camps in Rwanda in terms of budgeting or clinic organization. Nevertheless, palliative care and symptom management are being provided by local healthcare providers, volunteers and family members who “do what [they] can” to address the needs of those facing serious health-related suffering.

> “We are created equal, we have to respect the human being …”
> —Camp healthcare provider

## How the research was conducted

Semi-structured interviews were conducted with:

- 7 local and international healthcare providers working in refugee healthcare settings; and
- 10 refugees who are living with a life-limiting or terminal illness and/or their family members.
- Several of the conditions contributing to participant’s sympotoms and needs for palliation included illness and injury that are treatable in higher resource settings.
- **Major research assumption:** Palliative care is an approach that improves quality of life through prevention and relief of physical, emotional and spiritual suffering associated with serious illness or injury; it should never be a substitute for quality preventative or curative care.

## Key findings

- Focusing on living and remaining hopeful dominated refugee participants' narratives.
- **Pain relief** was a major concern, as were existential issues such as **anxiety** of dying in a foreign land and leaving family members.
- Refugees identified **obstacles to a sense of wellbeing**: trauma from causes of displacement; disruptions and **distress** from taking on new identities & roles (i.e., as refugees, ill person, primary caregiver); **time delays** in diagnosis & treatment; **distance** from family and other comforts; **stigmatization** associated with their illness; and material **barriers** (e.g., infrastructure, distance, finances, nutrition, childcare, etc.).
- Healthcare providers caring for refugees with life-limiting illnesses were unanimous in their commitment to offer palliative care, seeing it as a **moral duty to care** for fellow human beings, and a professional responsibility as care providers.

## Implications for humanitarian practitioners and policymakers

- **Public education** could help address stigma and illness assumptions, to normalize talk about death and dying, and to increase learning about palliative care.
- **Essential palliative care training** for various healthcare providers and family caregivers could help them in addressing palliative needs
- **Centralizing information sharing and simplifying referral administration** could reduce delays in accessing essential care.
- **Integrating palliative care** within broader medical and social services could be more cost effective as well as holistic.
- **More globally, greater efforts are needed to remove barriers to accessing essential medications in order to reduce suffering and support refugees facing serious life-limiting illnesses.**

## Recommendations for future research

- Organizational ethics and policy research on impacts of humanitarian palliative care practices.
- Developmental research for public education.
- Explore moral and practical experiences of community palliative care workers & informal caregivers who fill the gap in addressing

## About the study team

The Humanitarian Health Ethics research group is a multidisciplinary team of researchers and practitioners collaborating since 2009 with the aim of helping to clarify the ethical issues that are present in humanitarian healthcare practice.

The Rwanda case study was led by Drs. Sonya de Laat and Emmanuel Musoni.

The Principal Investigators of the larger study are Drs. Lisa Schwartz and Matthew Hunt.

## Keywords

Palliative care, end-of-life care, humanitarian response, refugee camps, ethical practices

## Articles and further reading

Project page on Elrha website:
https://www.elrha.org/project/ethics-palliative-care-international-humanitarian-action/

Moral experiences of humanitarian health professionals caring for patients who are dying or likely to die in a humanitarian crisis:
https://jhumanitarianaction.springeropen.com/articles/10.1186/s41018-018-0040-9

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www.elrha.org/programme/r2hc