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

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| — Methods — |

**Labyrinthine care pathways:**
- Layers of bureaucracy for refugees: allows for healthcare costs to be subsidised by aid organisations, 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.
- Circumstantial 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."

"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

| — Findings — |

**Challenges**
- Resource limitations: • Chronically underfunded healthcare system. • Reliant on international donations (in refugee camps). • Opioid limitations due to opioophobia and global distribution inequities.

**Opportunities**
- 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 HIV course” (WMMA), 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. It’s 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:
- “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**

**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 question: What does that mean to you?

| — Acknowledgements — |

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| — Publications to date — |

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