**There is no time for these patients**: Ethics, obstacles and palliative care in humanitarian settings

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**Project:** Aid when there is "nothing left to offer": A study of ethics & palliative care during international humanitarian action

**Aims:** The overall 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.

**Context:**
- Here we present results from 1 of 4 case studies, this one focusing on refugees in Jordan
- Participants living with MS, colorectal cancer, breast cancer, lung fibrosis.
- Refugees' experiences navigating different mandates of over 280 NGOs providing various forms of support.

**Provider Perspectives**
Healthcare providers felt palliative care was important yet they lacked the resources to implement, i.e. pain meds, treatments

- "I have to take extra precautions, such as not to be exposed to extreme weather conditions either severe cold or hot weather. Now I am suffering here from hot weather. Sun is harmful for me. There is no electricity before 8 o'clock and I can't use the fan all day." (P5)
- "I can't afford to pay for my medicine; then they asked me to come next day for treatment. It's a long complicated procedure and routine which needs a lot of paperwork" (P5)

**Comparisons to Home**
Participants from middle income countries were accustomed to access to healthcare and specialist care

- "Food, water, and clothing that’s all, what I need." (P5)

**Expressions of Gratitude**
- Heartfelt
- Frequent
- Balanced with frustration

**Challenges**
- Sometimes labyrinthine system to access care
- Long waits and delays
- Geographically remote

- "They asked me to go to [name] organization to ask for help. They tried to help me, but not enough. A lady there tried to help me, she is very nice, but what can she do? ... They didn’t secure my medicine, although they are trying their best to help." (P5)

**What could help?**
- Access to basic necessities (clean water, nutritious food)
- Timely access to health services
- Childcare
- Reduced administrative barriers to accessing care & follow up
- Support for ADLs
- Contact with family to say their goodbyes

- "It’s a long time from when I requested to have a catheter to when I get it," (P5)
- "at [the] hospital they said that I should get money from [org] to be able to get the catheter bags enough for a month regularly, but now I am still waiting for [org] to do something, and that day I get very frustrated from their long waiting times and delays, I regret that I shouted at them." (P6)

**Discussion:**
1. Comparison of patient and provider perspectives tells a moving story. Where providers are focused on barriers to treatment, these things are significant for patients but overshadowed by simpler, more immediate needs such as access to basic necessities. 2. Silence around death/dying was noted, only one participant clearly indicated he understood he was dying. 3. Palliative care is acknowledged as important by international aid actors and basic palliative care training is provided to UNHCR medical staff, but palliative care considered outside main remit until broader donor community expresses interest.

**Recommendations:** Donors and agency leaders need to consider how to address the need for palliative care during emergencies. While pain management and treatment are significant, they should be considered an aspect of broader needs.

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**References:**
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