Dying in the Margins: Palliative Care, Humanitarian Crises and the Intersection of Global and Local Health Systems

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Acknowledgements:

• Good father, 71 years old
• Leader
• Exhausted by the long trip for treatment; local system requires all patients coming from Great Lakes Region of Africa to the sole care centre at Kigali to be deep screened in the hospital courtyard if they arrive the right before the time limit.

• Mother of 2 children aged 26 and 28
• “I don’t have much hope, we were in Darfur and I could only get treatment for 2 years for fear of deportation.
Now in Rwanda, I cook for my [cousin’s] children.
I bought some food for him and够 of his medications. Whatever was available; I sent it to him in the food and to buy food for the family; to have his time cleaned.

• Woman turned psycho-socio agent (AMH)

“People have told him that his illness (leukemia) is worse than HIV/AIDS; you will die soon, so why disrespect him, and they are taking his things”

Considerations:

Many of our participants in Guinea, Jordan and Rwanda commented on the importance of accompaniment—a sense of not being abandoned—as being more important almost even to painkillers. Healthcare providers recognized what patient-participants described: that global equity is needed in screening, treatment and symptom management. Local health system improvements would also lead to better palliative care for those further pushed to the margins in humanitarian crises. Public health education is also needed to dispel myths around certain illnesses, dying, death talk and palliative care. Palliative care is being done in various adhoc, informal ways—because some people cannot be saved. Evidence & evaluation of priorities and impacts on physical & mental health are of ongoing importance.

Findings:

Health system limitations are amplified in humanitarian crises.

Curative care capacity constraints disproportionately impact refugees and others made vulnerable by their social position; they are often the first to face the health system’s limitation:

• Curative care or screening options are already limited for local nationals; refugees, marginalised, poorer people or those unfamiliar with navigating the local culture, let alone a health system, are less likely to access timely care, resulting in premature palliative needs;
• Palliative care should never be considered a replacement for the need to continually improve the local health system;
• Access to opioids or other pain treatment more restricted due to limited stocks during non-crisis times, or due to lack of funds on the part of refugees or those cut off from banks;
• Removed from family supports and community comforts, limitations in health systems come into relief in terms of:
  • Mobility: reaching treatment centres or pharmacies more difficult if infrastructure lacking or no funds for childcare;
  • Electricity: some participants said they could cope with pain if they had access to lights or fans;
• Lack of public health education leads to nearly impossible conversations around end-of-life planning and leads to stigmas to do with illnesses, the dying process, or palliative care as “giving up.”
• Contacting family members to say final goodbyes.

Care providers:

“...So for me, the big part of palliative care is the patient...the beautiful way we see our human beings, equality, non-discrimination, 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 issue, equality, non discriminative, quick response, empowering families ...

Patient participants:

On lack of comprehensive care:

• “what I know, that I am very sick, living in a tent and I have no support, but God! I am praying to God, and feeling anxiety and pain... Everybody should help, but there is nothing like that, they only come and take photos and never come back.”
  — Jordan (REFCOM2)

On missing health system limitations:

“…In Darfur, they say it is better if you die. I don’t know why, even... I don’t know if I have something, but they did not even know what. Certainly, they had heard rumors of leukaemia, leukemia... And that word was said to be an incurable disease, when you heard it you were devastated.”
  — Survivor turned psychosocial agent (AMH)

On delays:

“Are they waiting for me to die until they realise they need to help me?”
  — Jordan (RefCam)

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Publications to date:


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