Life, death, and isolation: Reflections on palliative care from Ebola to COVID-19

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A word about “palliative care”

Palliative care improves the quality of life of patients and that of their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual.

https://www.who.int/news-room/fact-sheets/detail/palliative-care
Why Palliative Care in Humanitarian Crises?

Credit: Dr. Alejandro (Alex) Jadad
Study Components Overview

- Critical Interpretive Synthesis
- International Survey
- International Humanitarian Aid Workers
- 12 Humanitarian Policy Makers
- International Interviews
- Public Health Emergency: Ebola crisis in Guinea
- Natural Disasters: Various Locations
- In-depth Case Studies
  - Protracted Refugee Situation: Rwanda
  - Acute Refugee Situation: Jordan
  - Acute Refugee Situation: Bangladesh
Crises Types & Study Sites

Public Health Emergency
- Location: Guinea
- Specifics: Ebola virus disease; context of public panic and generalized distrust; challenges of providing palliative care to patients with a contagious disease
- Patient population: Generally low SES, predominantly Muslim, chronically underfunded healthcare system

Acute Refugee Context
- Location: Jordan and Bangladesh
- Specifics: Refugee and forced migration; acute/ongoing conflict
- Patient population: In Jordan, many from formerly mid SES context, accustomed to robust healthcare system; low SES for Bangladesh; both predominantly Muslim

Protracted Refugee Context
- Location: Rwanda
- Specifics: Refugees fleeing violence and persecution over past two decades
- Patient population: Primarily from Burundi and Democratic Republic of Congo; generally low SES, predominantly Christian

Natural Disaster
- Location: Multiple
- Specifics: Various disasters including earthquake, hurricane, tsunami, famine
- Patient population: Varied SES, all age groups
Study Recruitment

Guinea
- 2 survivors
- 6 local HCPs
- 2 local HCP/survivors
- 1 religious leader
- 3 family members
- 2 international HCPs

Jordan
- 8 Refugees
- 5 Jordanian Nationals
- 2 local HCPs
- 1 international HCP

Rwanda
- 10 refugees in two camps
- 6 local HCPs
- 1 agency representative

Bangladesh
- 1 local palliative care physician
- 2 lay health workers

Natural Disasters
- Nepal, India, Chad, Haiti, Philippines, Ecuador, Solomon Is.
- 14 Int’l HCPs
- 6 local HCPs
Funders & Team:

Co-Principal Investigators – Lisa Schwartz\(^1\) and Matthew Hunt\(^2\)

**HHE Leads:** PhD; Sonya de Laat, PhD; Elysée Nouvet, PhD; Olive Wahoush RN; Rachel Yantzi RN, MPH;

**Local Site Leads / Team:** Weyden Kahter PhD\(^6\); Malek Alnajar\(^7\); Ibraheem Abu Siam, RN, CNS; Assoc. Public Health Officer; Emmanuel Musoni, MD; Pathé Diallo, MD

**HHE Team:** Ani Chénier, MA\(^2\); Kevin Bezanson, MD, MPH\(^3\); Carrie Bernard MD\(^5\); Gautham Krishnaraj PhD\(^1\); Lynda Redwood Campbell MD\(^1\); Laurie Elit MD\(^1\)
Context:
Literature Review

https://doi.org/10.1186/s41018-018-0033-8

Necessary & Important

Limited & Anecdotal

Unsupported & Untrained

Variable & Shifting
Moral Experiences:
Humanitarian Healthcare Workers & Policy Makers

“I kind of think there is a special place in hell for me.”

Photo: Kevin Bezanson

https://doi.org/10.1186/s41018-018-0040-9
Obstacles:
Humanitarian Healthcare Workers & Policy Makers

Hunt et al. Conflict and Health (2020) 14:70
https://doi.org/10.1186/s13031-020-00314-9
CASE STUDY in FOCUS:

PALLIATIVE CARE DURING THE 2013-16 EBOLA EPIDEMIC IN GUINEA

### Reported cases & Deaths

<table>
<thead>
<tr>
<th>Country</th>
<th>Cases</th>
<th>Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guinea</td>
<td>3,814</td>
<td>3,956</td>
</tr>
<tr>
<td>Liberia</td>
<td>10,678</td>
<td>3,956</td>
</tr>
<tr>
<td>Sierra Leone</td>
<td>14,124</td>
<td>4,810</td>
</tr>
</tbody>
</table>

![Map of West Africa showing cases and deaths](image-url)
Case study objectives

• To clarify challenges, perceptions, and expectations related to end-of-life palliative care needs of patients in West African Ebola Treatment Centres (ETC)
• 15 semi-structured interviews

APRIL - - - - JULY 2018

Interview Length:
21 - 140 minutes

Participant Breakdown
1. Spiritual support providers
2. HCP's who were also EVD patients
3. Family of late patients
7. Healthcare Providers
2. Patients in ETC’s
Interviews conducted by

Sékou Kouyaté

1978-Dec. 16 2020
Limitations

- Recruitment through networks
- Ebola still feared & stigmatized
- Interviews in capital (Conakry)
- No perspectives from the deceased
“I still see the death before me, like that. I don’t even see you. I see myself in the centre, like that. I see myself with the deceased patients. I see myself with friends who passed.”

— Participant 6, physician
Care in a context of generalized and overwhelming loss and risk

• Rapid succession of death during time of interviews

• Many faced the very real risk of death for themselves, friends, family

• Social death through association with disease if they survived

“Every day they wrapped the dead. All they did was wrap the dead, only wrapping, only wrapping, only wrapping. He! The ETC door would not close. The rooms were stuck together, and we saw everything through the door.”

– Participant 5, patient/survivor
“The people suffering were hitting the [plexiglass] windows, the tent, to be heard.”

(Participant 9, family of deceased)
“From the moment I entered, I saw only death. My mind was focused entirely on death. Because when you enter even, it is the smell of death and suffering people. You see people screaming and lamenting their suffering, gravely ill without help. No one coming to see them. That is what frightened me... There were a lot of people in the room. Too many people. Too many cries. You know if someone is critically ill, those sounds hurt them.”

(Participant 4, patient/survivor)
Limited patient-healthcare provider contact
“We called the doctors to tell them to come. That there was someone already on the floor. On the floor after stumbling around. But, well, you know, the doctors, when you call for help, it takes at least 5 to 10 minutes for them to come in. Because there is the PPE. They need to put it on and carefully. But the time it took for them to come the guy was dead.”

(Participant 2, patient/survivor and local HCP)
Prognostic uncertainty & commitment to saving lives
Distrust & fear

“There was the case of a woman who didn’t take her drugs. When the doctors would give her the drugs, she would take them in her hands and do as though she was taking them. Then, after the doctors would leave, she would dispose of them. I told her, ‘If you don’t take those capsules you will die.’ She did not listen, and she died a few days after.”

(Participant 4, patient/survivor)
Factors contributing to the alleviation of dying patients’ suffering
Connecting patients with their families outside the ETC
Limited truth-telling
“What you have done there, it’s serious. And it’s serious because, your words can really affect this young one. Your words can morally crush this young one.”

(Participant 14, physician)
He said to me, ‘tell me the truth.’

...Eh!!! His numbers were very low. I knew he was going to die, but what day? I didn’t know. So, if he pushes me to tell the truth, you see? And so, I just stayed there tapping [taps his fingers together]. I couldn’t say it. I couldn’t find words to say it.”

(Participant 6, local HCP)
Accompaniment

“We cannot do anything against death. We can stay next to [the patient]. Then, administer the treatment, until death. But especially stay at their side.”

(Participant 11, local HCP)
“It’s no good. Listen, everyone who died in that period was put in a bag. It’s not everyone who had Ebola! My sister said that the dead were not washed, and they were put in bags, regardless of how they died.”

(Participant 10, family of deceased)
“to die in honor is to die surrounded by those who love you. To have the opportunity to ask them for forgiveness if you have wronged them. To accept their apologies if they have hurt you. To be able to say to yourself, yes, even if I must die, still I am ready. I feel close to my loved ones.”

(Participant 2, HCP & patient/survivor)
“We are sons of the country. If we don’t respect [those customs], it can act against us also.”
(Participant 12, national HCP)
RECOMMENDATIONS – patient centered

• Examine and adapt the spatial architecture

• Facilitate contact between patients & families however possible

• Plan for accompaniment of patients dying and at risk of dying

• Attend to cultural-specific needs and patient preferences
RECOMMENDATIONS – policy centred

• Explicit integration of palliative with treatment-focused, supportive care

• Ensure palliative medications and supplies are available

• Prioritize hiring of local HCPs and their roles in guiding contextually appropriate care

• Increase HCP numbers where possible
RECOMMENDATIONS – provider centred

• Enhance palliative care staff training and support where needed

• Acknowledge and support fellow patients as caregivers

• Provide intentional psychosocial supports to HCPs / caregivers

• Explicitly discuss as team harm vs. benefits of ‘truth’ telling to patients
COVID-19 AND EVD PALLIATIVE CARE

SIMILARITIES

• Role of PPE in caregiving limiting nature of possible interactions

• Prognostic uncertainty and rapid changes in patient condition

• Need for BOTH full supportive care with limited targeted therapy AND palliation of symptoms and preparation for possible death

DIFFERENCES

• Mode of transmission and transmissibility

• Mortality extent and age distribution

• Types of symptoms in severe disease
<table>
<thead>
<tr>
<th>SIMILARITIES</th>
<th>DIFFERENCES</th>
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<tbody>
<tr>
<td>• Racial and social disadvantage impacts risk of infection and outcome</td>
<td>• Massive variation in response capacity and resources between settings</td>
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<tr>
<td>• Importance of accompaniment/non-abandonment</td>
<td>• Worldwide pandemic versus regionally localized</td>
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<tr>
<td>• Importance of connection with families and loved ones</td>
<td>• Response primarily by local health systems/providers, not international humanitarian organizations</td>
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Thank you!

Questions? Comments? Want to collaborate?:
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