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

June 22 2021

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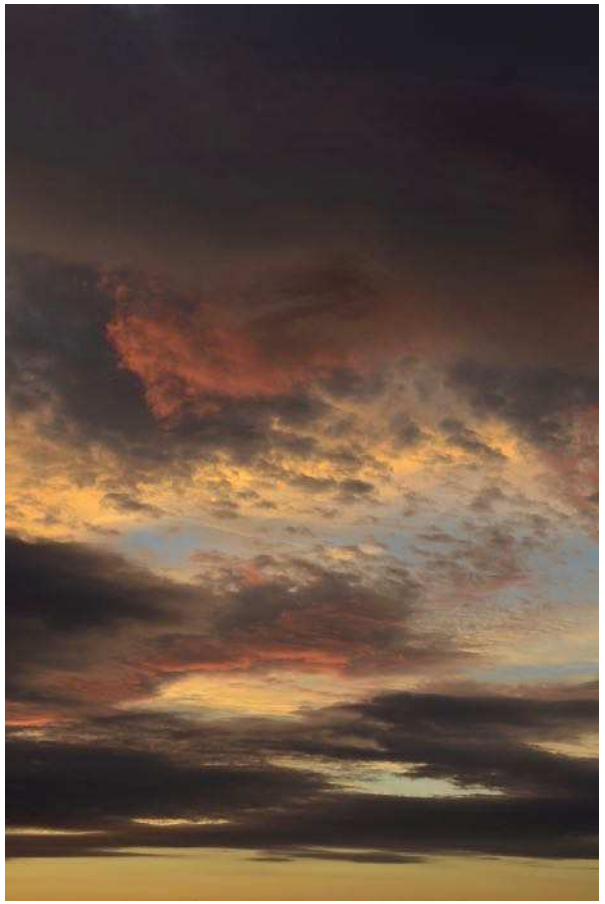
A word about “palliative care”



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

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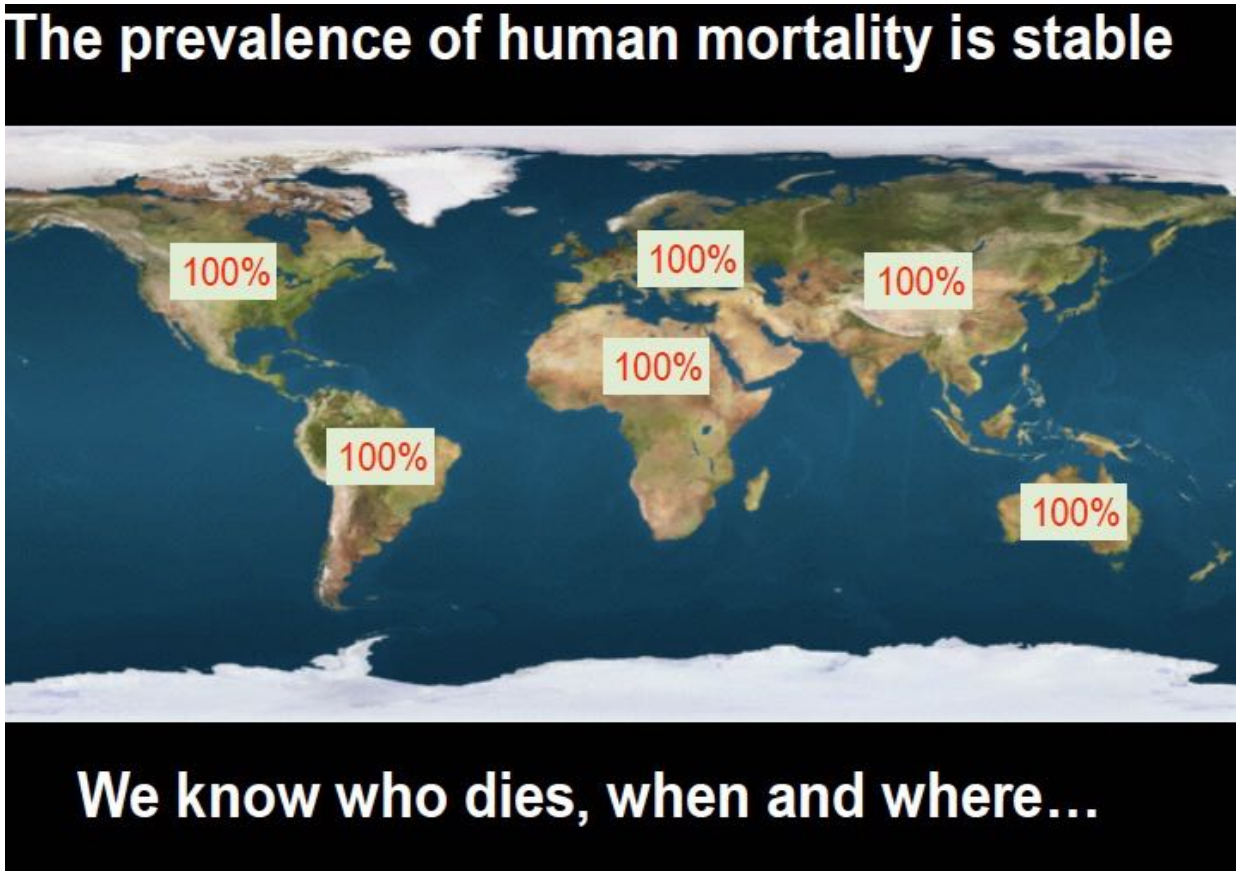
Why Palliative Care in Humanitarian Crises?



Credit: Dr.Alejandro (Alex) Jadad

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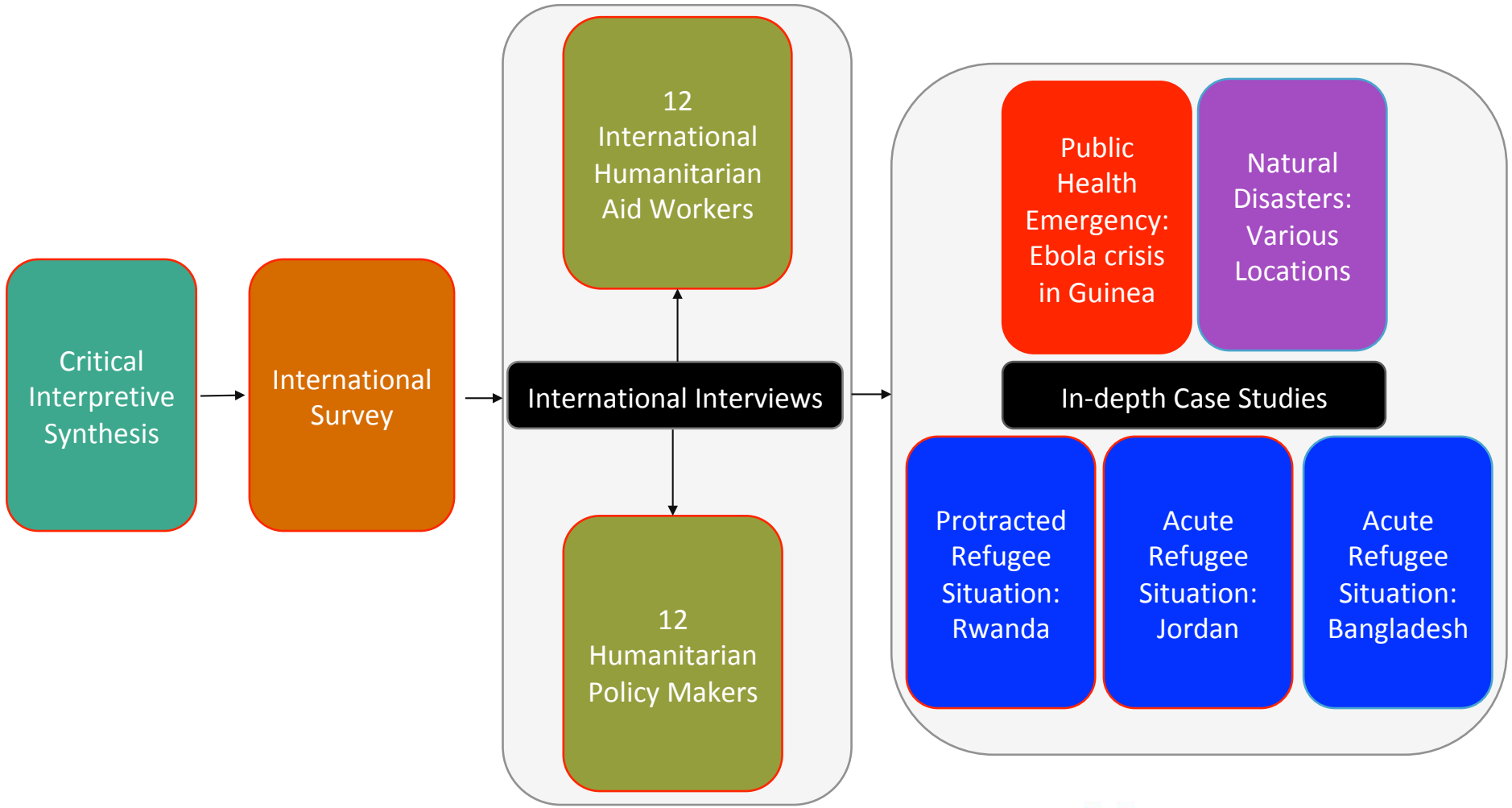
Study Components Overview



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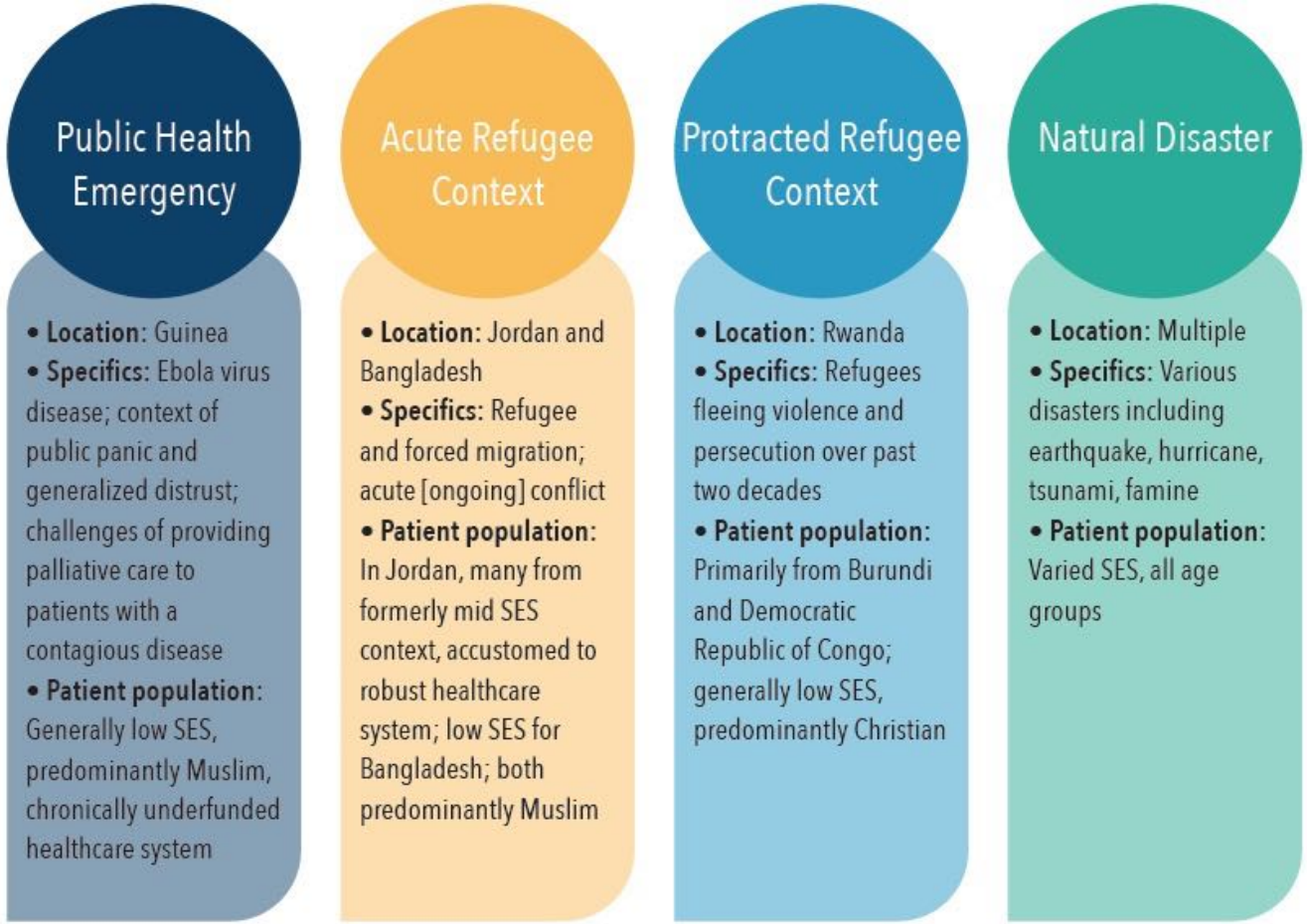
Crises Types & Study Sites



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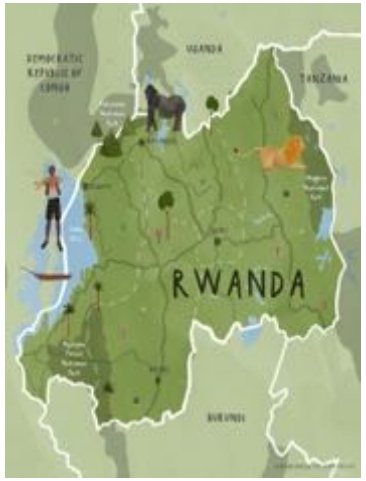
Study Recruitment



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

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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]

McGill University

McMaster University

UKaid from the British people

r2hc Research for health in humanitarian crises | elrha

Western University · Canada

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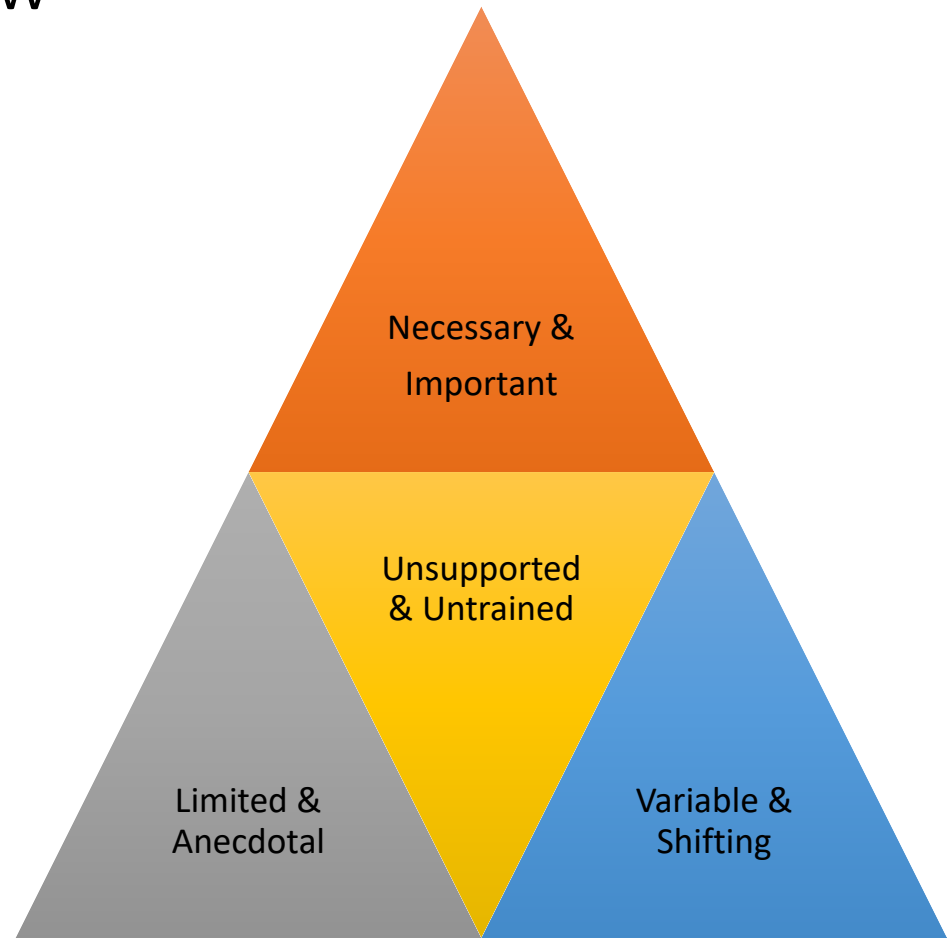
wellcome trust

Context:
Literature Review



Nouvet et al. Journal of International Humanitarian Action (2018) 3:5
https://doi.org/10.1186/s41018-018-0033-8

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Moral Experiences:
Humanitarian Healthcare Workers & Policy Makers

Photo: Kevin Bezanson

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

Hunt et al. Journal of International Humanitarian Action (2018) 3:12
https://doi.org/10.1186/s41018-018-0040-9

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Obstacles:
Humanitarian Healthcare Workers & Policy Makers

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

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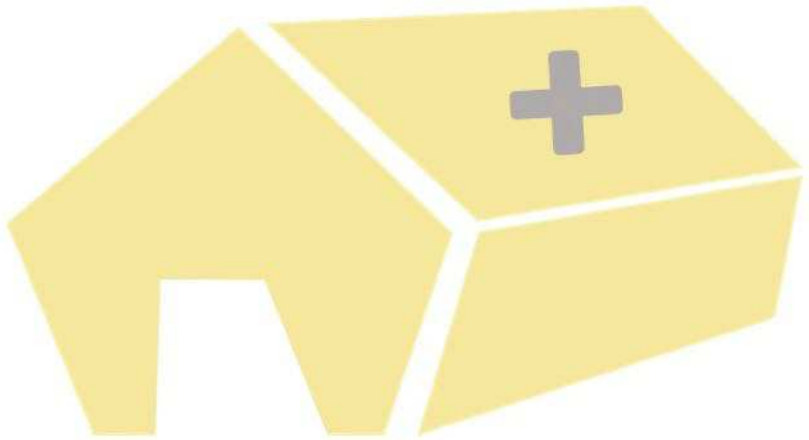
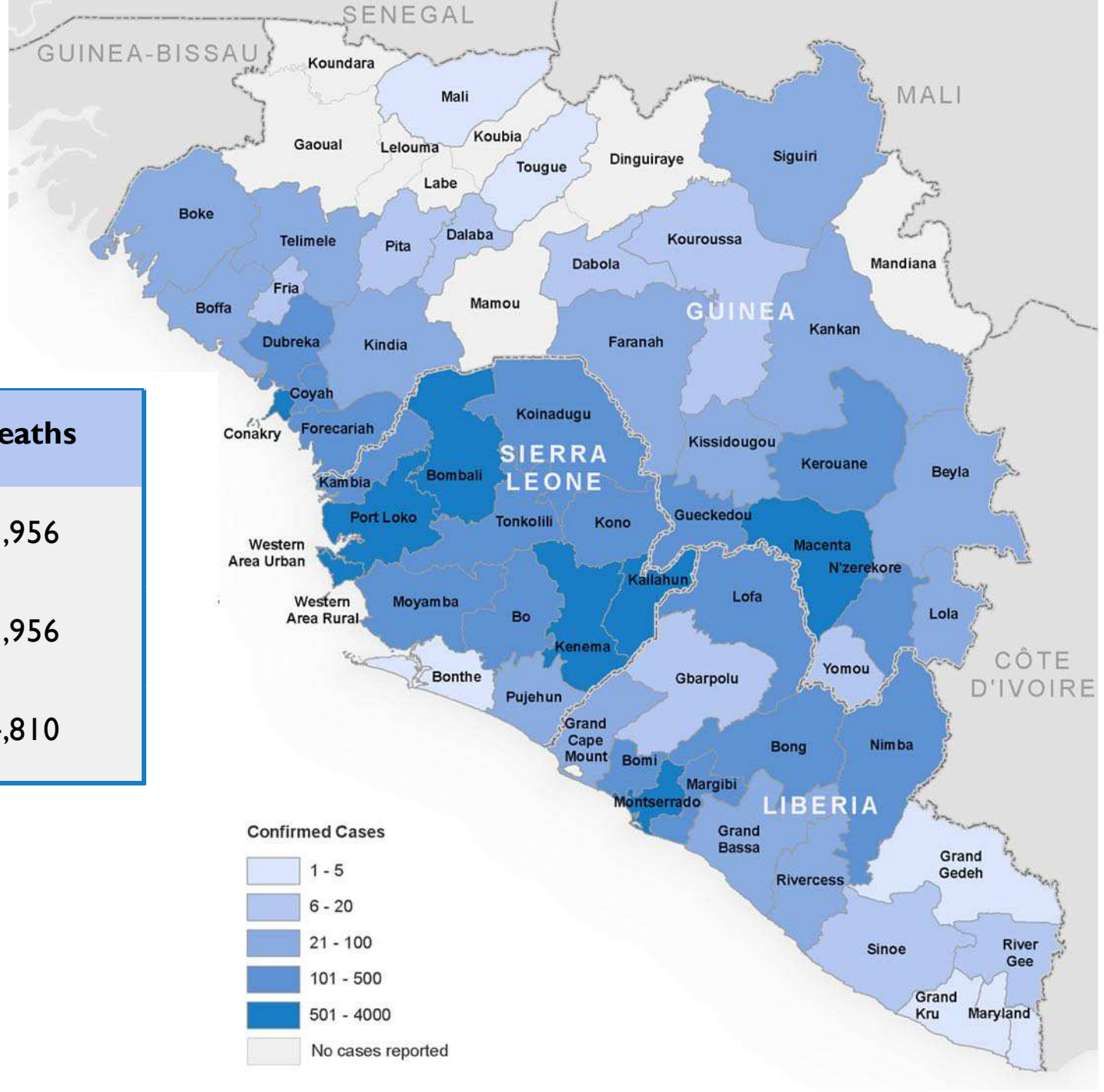
CASE STUDY in FOCUS:

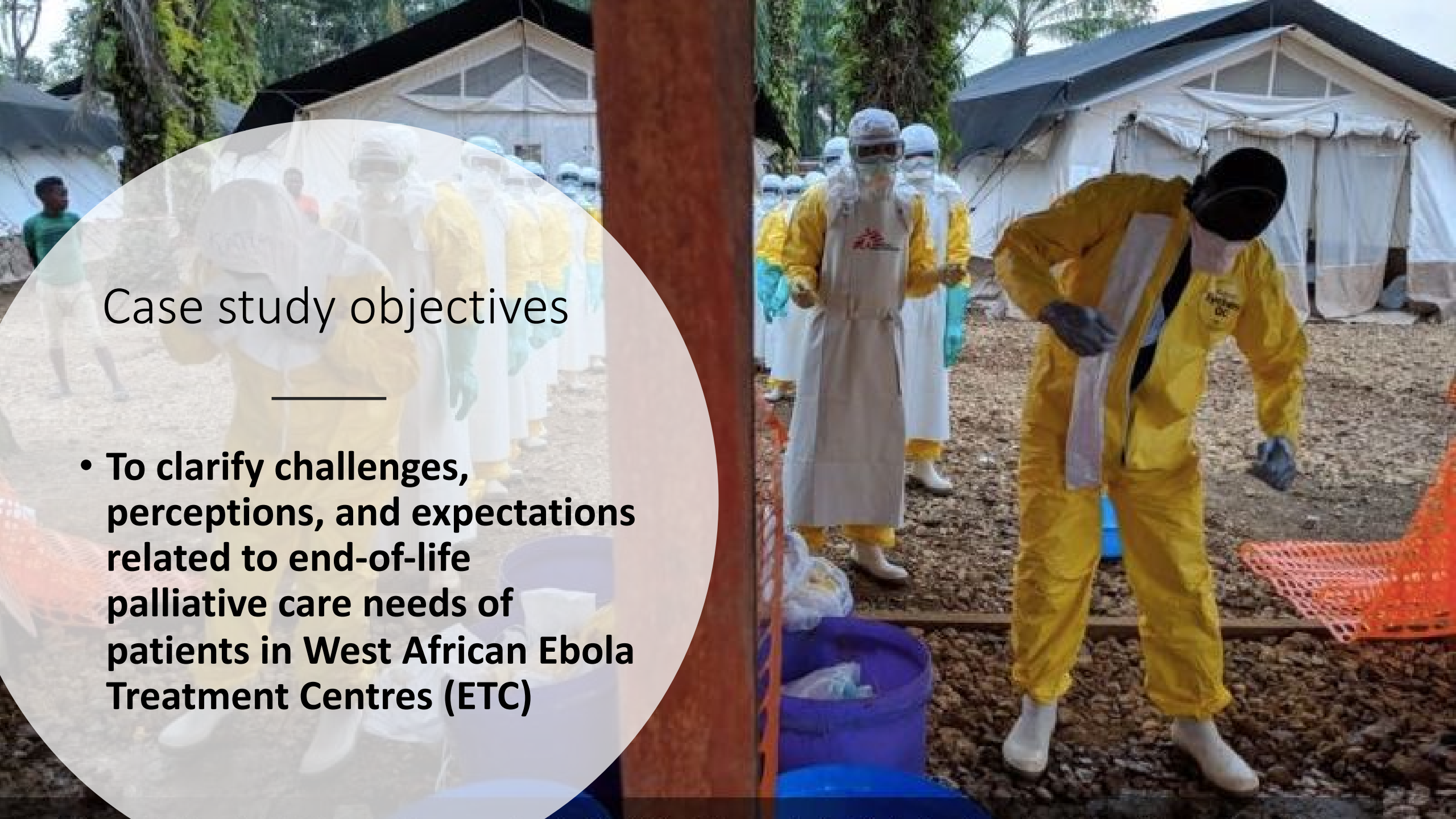
PALLIATIVE CARE DURING THE 2013-16 EBOLA EPIDEMIC IN GUINEA



Nouvet et al. Dying in Honor: experiences of end-of-life palliative care during the 2013-2016 Ebola outbreak in Guinea. **Journal of International Humanitarian Action** 2021.

	Reported cases	Deaths
Guinea	3,814	3,956
Liberia	10,678	3,956
Sierra Leone	14,124	4,810





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)**

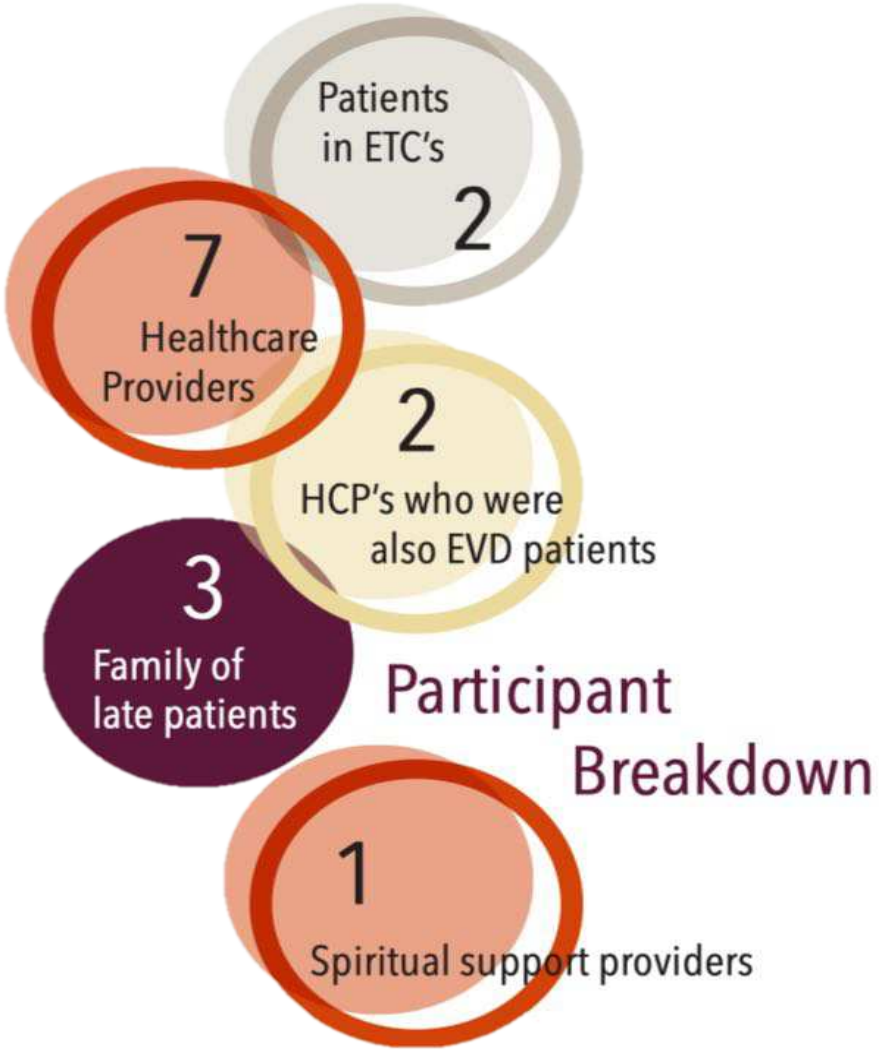
STUDY METHODS

- 15 semi-structured interviews

APRIL - - - - JULY 2018

Interview Length:

21 - 140 minutes



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

BBC https://www.bbc.com/news/in-pictures-28086185

“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.”

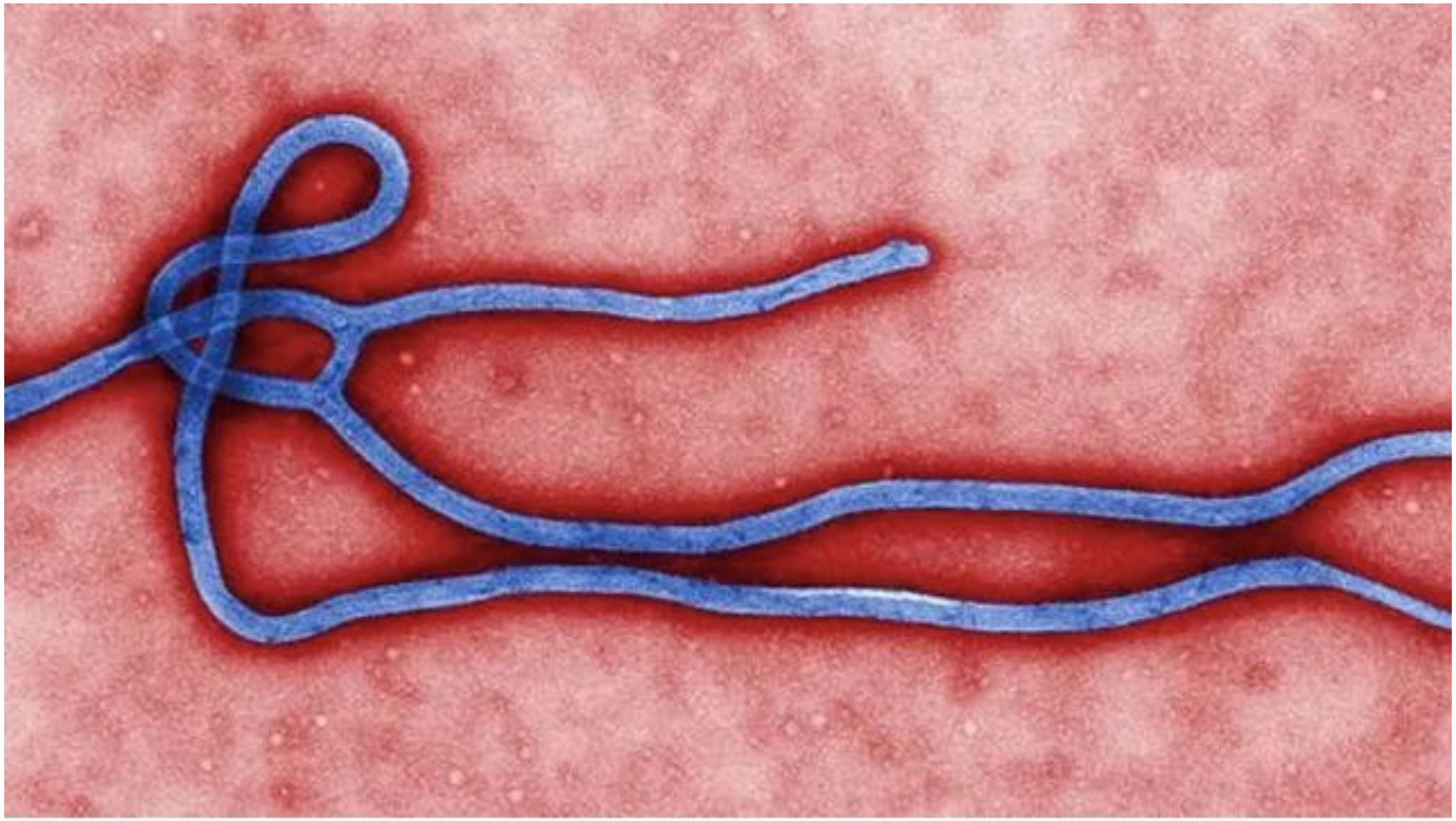
(Participant 4, patient/survivor)

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)

Dying in honor

“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)

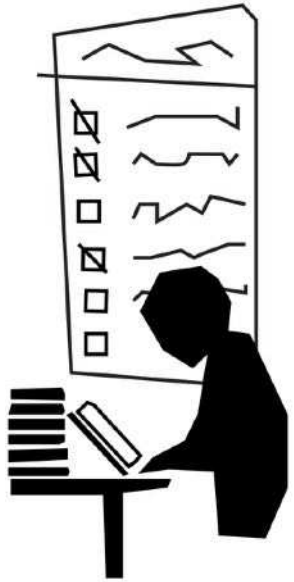
"We are sons of the country. If we don't respect [those customs], it can act against us also."
(Participant 12, national HCP)

SYLVAIN CHERKAOUI/COSMOS/MSF

The World Health Organization (WHO) has called for "drastic action" to contain the Ebola outbreak in West Africa

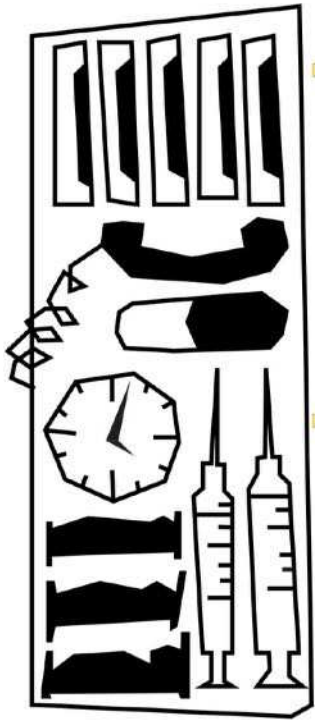
RECOMMENDATIONS – patient centered

- 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



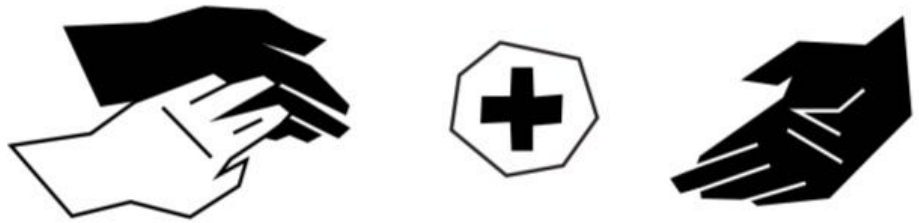
RECOMMENDATIONS – policy centred

- 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

VS

DIFFERENCES

- Mode of transmission and transmissibility
- Mortality extent and age distribution
- Types of symptoms in severe disease

COVID-19 AND EVD PALLIATIVE CARE

SIMILARITIES

- Racial and social disadvantage impacts risk of infection and outcome
- Importance of accompaniment/ non-abandonment
- Importance of connection with families and loved ones

VS

DIFFERENCES

- Massive variation in response capacity and resources between settings
- Worldwide pandemic versus regionally localized
- Response primarily by local health systems/providers, not international humanitarian organizations

Thank you!

Questions? Comments? Want to collaborate?:

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