



“Dying in Honor”

Supporting end-of-life palliative care during the 2013-16 Ebola outbreak in Guinea

A Case Report for Humanitarian Practitioners and Policymakers

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Introduction

The West Africa Ebola Virus Disease (EVD) outbreak represented a turning point in the humanitarian healthcare consciousness of palliative care. The extremely high mortality rate of EVD was one most humanitarian healthcare providers had never experienced. It underlined the absolute necessity that humanitarian healthcare providers, even if maintaining a primary goal of saving lives, prepare for the provision of end-of-life palliative care. The goal of this study was to document and deepen understanding of experiences and expectations related to end-of-life palliative care for patients infected with EVD in West African Ebola Treatment Centers during the 2013-2016 outbreak. This research was conducted in the context of a larger study titled *"Aid when there is 'nothing left to offer': A study of ethics & palliative care during international humanitarian action."* Despite growing acknowledgment that palliative care must be considered within humanitarian healthcare, there has been limited research on its integration within international humanitarian healthcare responses. The study *"Aid when there is 'nothing left to offer'"* was developed in response to this knowledge gap.

Documenting and learning from lived experiences of end-of-life palliative care during the West African EVD epidemic is an ethical imperative. Reflecting on various barriers of identifying and responding to palliative care needs in Ebola Treatment Centres can provide motivation and guidance for such future needs. While based on one case study in Guinea, we anticipate findings can inform preparedness for a range of high mortality public health emergencies and contexts where the seriously ill must be cared for in isolation centres due to high risks of infection.

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual¹

Overall Study

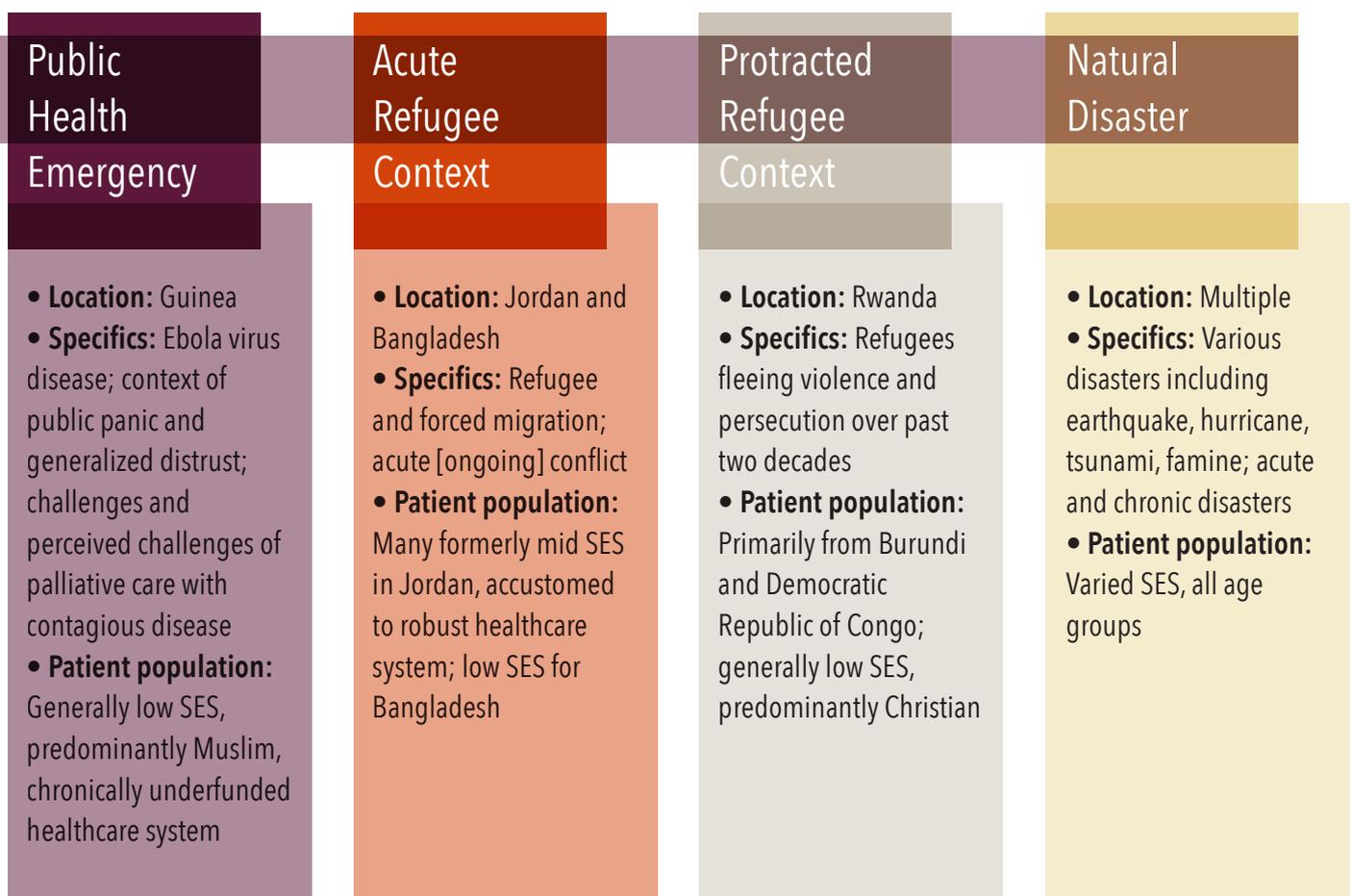
Aid when there is "nothing left to offer": A study of ethics & palliative care during international humanitarian action is a qualitative study of palliative care in humanitarian crisis that involved a literature review, organizational survey, key informant interviews, and four main cases studies:

- **public health emergency**
- **protracted refugee context**
- acute refugee context
- natural disasters

Study Methods:

This qualitative study is part of a larger project on palliative care in humanitarian contexts. It consisted of 15 in-depth semi-structured interviews with individuals impacted by EVD in a Guinean Ebola Treatment Centre during the West Africa epidemic: either as patients in an ETC (N=2); healthcare providers (N=7); healthcare providers who were also EVD patients at one point (N=3); family relations who visited patients who died in the ETC (N=2); or, providers of spiritual support to patients and family (N=1). Analysis was supported by NVivo 11 software, was team-based, and applied an interpretive descriptive approach.

The goal of the overall study is to **clarify the ethical and practical dimensions of providing palliative care in humanitarian crisis contexts**, and to **inform policy and practice**. Case studies were identified through stakeholder meetings and key informant interviews, and are further described in the diagram below.



Background: The West Africa EVD Epidemic

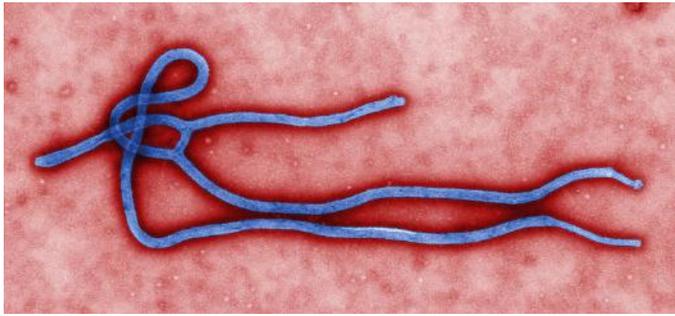
The West Africa Ebola outbreak resulted in 28,652 infections and 11,325 deaths, and was concentrated in three countries: Guinea, Liberia, and Sierra Leone.² None of these countries had previously experienced cases of the disease on their territory. All were quickly overwhelmed, as a result of a combination of structural and social conditions that rendered it difficult to mobilize affected populations' support for infection control, and healthcare facilities' abilities to care for the sick. These conditions included: underfunded health facilities; a lack of protective equipment or ability to isolate patients; as well as few healthcare providers with past experience managing this highly infectious and fatal level four pathogen.

In August 2014, the World Health Organization declared Ebola a public health emergency of international concern.³ Several international humanitarian organizations, including Médecins Sans Frontières, the Red Cross, ALIMA, Partners in Health, and the World Health Organization, joined forces with national responders to contain the crisis. The international humanitarian healthcare response included: building and equipping Ebola Treatment Centres (ETCs); funding additional healthcare team positions for patient and ETC management; mobilizing and bringing in non-national (expatriate) healthcare providers and technical support for the ETCs; as well as training local and expatriate ETC staff in infection control and patient treatment protocols designed specifically for the level four pathogen.



*Disease detective in Liberia 2014
[Photo/ John Saindon/CDC] - no changes made*

Even with the increased capacity to manage infections and care for patients, EVD implied unique challenges for the treatment of patients. EVD is a level four pathogen. It is extremely infectious, requiring full head to toe protective gear for healthcare providers aiming to treat patients, and removal of the infected from their homes for treatment in Ebola Treatment centers (isolation centres). The disease generally progresses rapidly. Its symptoms include vomiting, diarrhea, pain, fever, breathlessness, and, bleeding from orifices, are terrifying.² Mortality rates for those infected by EVD are extremely high. At their lowest, as reported in extremely well-resourced healthcare centres in Europe and the United States, these stand on average at 20%.⁴ The average mortality rate for the West Africa EVD outbreak ranged from 40-70%.²



The Ebola virus
[Photo/ Cynthia Goldsmith /CDC] - no changes made



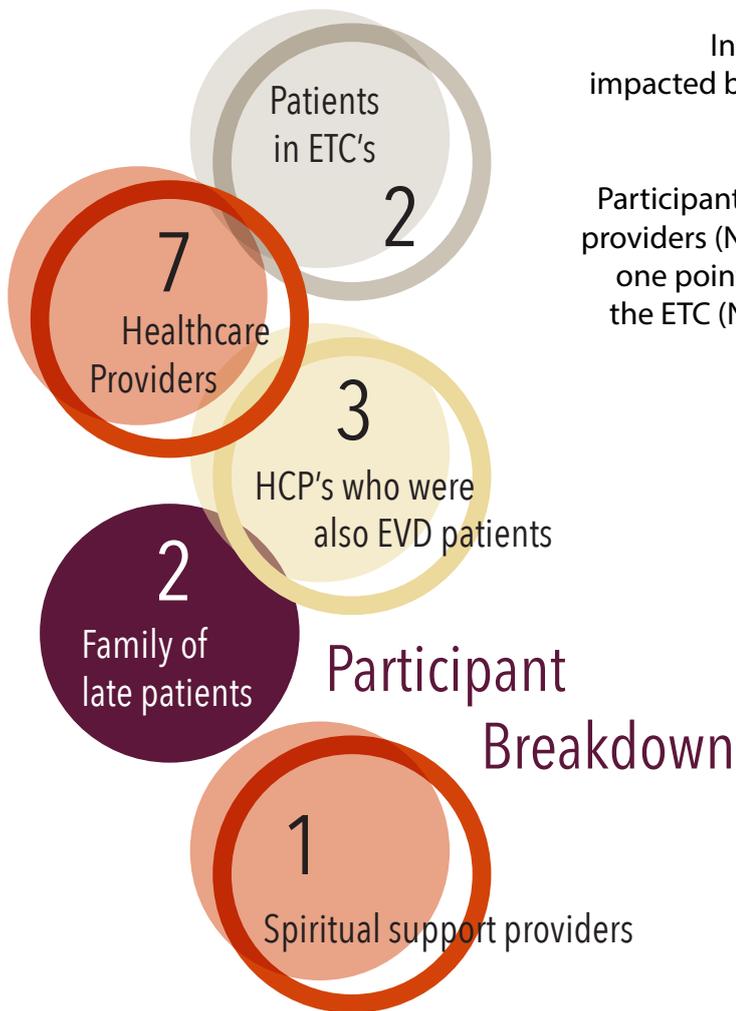
The West Africa EVD outbreak represented a turning point in the humanitarian healthcare consciousness of palliative care. The extremely high mortality rate of EVD was one most humanitarian healthcare providers had never experienced. It underlined the absolute necessity that humanitarian healthcare providers, even if maintaining a primary goal of saving lives, prepare for the provision of end-of-life palliative care. The goal of this study was to document and deepen understanding of experiences and expectations related to end-of-life palliative care for patients infected with EVD in West African Ebola Treatment Centers during the 2013-2016 outbreak.

Case Study Key Findings

Provision of palliative care during this public health emergency involved:

- Negotiating several structural and biological challenges unique to this level 4 pathogen, including needing to quickly build up facilities and staff to manage cases safely; the need to isolate patients; working in head to toe Personal Protective Equipment (PPE); and limited understanding of a high fatality, high acuity [I want to say rapid progress of] disease
- Negotiating several social challenges, including intense fears and real risks of infection and death amongst providers and patients; stigma associated with the disease; and high distrust of the national and international response
- Fellow patients played essential roles in caregiving
- Identified as most crucial to the possibility of a dignified death in Ebola Treatment Centres is accompaniment.
- Only one participant identified a preference for Guinean (national) as opposed to foreign healthcare providers. Others did not see this as a significant factor, though they acknowledged the importance of an individual who is not a national seeking to understand and accommodate cultural preferences, values, and norms
- The provision and experience of receiving care amidst such high levels of death, fear, and suffering was lived as horrific, and haunts many survivors.
- Many patients in ETCs, especially at the peak of the outbreak, died without any healthcare provider at their side.

How the Case Study was Conducted



Infographic 15 semi-structured interviews with individuals impacted by EVD in a Guinean Ebola Treatment Centre (ETC) during the West Africa outbreak.

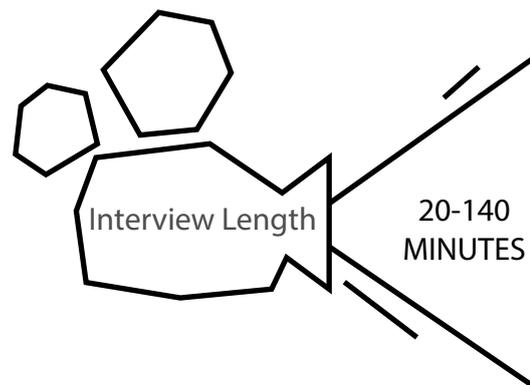
Participants : patients in Ebola Treatment Centres (N=2); healthcare providers (N=7); healthcare providers who were also EVD patients at one point (N=3); family relations who visited patients who died in the ETC (N=2); or, providers of spiritual support to patients in ETCs and their family (N=1).

The majority (14 of 15) were Guinean nationals.

Interviews lasted 21 to 140 minutes and were conducted between April and July 2018.

Analysis was team-based, supported by Nvivo 11.0 (QSR), and applied an interpretive descriptive approach to transcribed interviews.

APRIL - - - - - JULY 2018



Participants were asked...

- To reflect on conditions, perceptions, and expectations of palliative end-of-life care in Guinean Ebola Treatment Centres (ETC) during the West Africa Ebola Virus Disease (EVD) outbreak.
- What matters most to a Guinea at the end of life in their assessment
- To identify circumstances that rendered a death in the ETC more peaceful
- To reflect on the significance of providers being Guinean versus foreign/expatriate.

Challenges to Palliative Care in ETCs



Care in a context of generalized and overwhelming loss and risk. The prevalence and rapid succession of deaths witnessed by individuals we interviewed left many evidently haunted at the time of the interview. Several participants described multiple family members, mentors, and colleagues falling severely ill and dying from Ebola in quick succession. Some described being unable to shake images of incessant death and the pain of life inside the Ebola Treatment Centres:

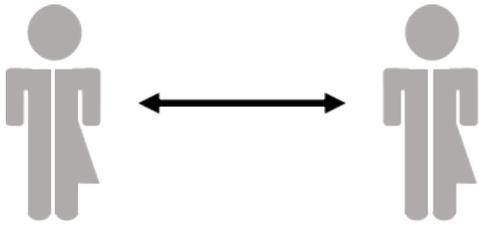
"I still see the death before me, like that. I don't even see you. I see myself in the centre, like that. I see myself with the deceased patients. I see myself with friends who passed." (Participant 6, local HCP)

Alongside this witnessing of death and dying, participants described their own and their family members' fears for their lives, given the very real risk of death they faced as patients or providers. This fear of death was often exacerbated knowledge that Ebola was highly stigmatized in Guinea at the time of the outbreak (as it still remains to some extent). Alongside fear of biological death, the infected and those at risk of contagion as care providers faced the risk of social death through association with the disease if they survived. The exceptionally high levels of mortality, fear, and personal risk that marked the EVD outbreak in Guinea constitute unique conditions faced by healthcare providers caring for the sick and dying in this public health emergency.



Patient distrust a barrier to care provision. Patients' distrust and fear posed challenges to the provision of patient care generally, including the provision of palliative care. Many participants stressed the difficulty of alleviating symptoms in patients who entered ETCs believing rumors these had been created with goals to harm rather than heal and help the sick (e.g. created as centers to kill Guineans and harvest organs or blood for sale).

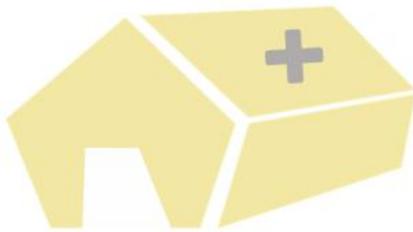
"There was the case of a woman who didn't take her drugs. When the doctors would give her the drugs, she would take them in her hands and do as though she was taking them. Then, after the doctors would leave, she would dispose of them. I told her, 'If you don't take those capsules you will die.' She did not listen, and she died a few days after." (Participant 4, patient/survivor)



Limited human contact with and for patients. All care in Ebola Treatment Centres had to be provided while HCPs were in PPE. The PPE limited the ability for providers to stay inside with patients, rendered tasks such as inserting IVs or goals of building rapport with patients more challenging, and also slowed down healthcare providers' abilities to respond rapidly to patients' needs.

"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 12, local HCP)

All clinical staff in the ETC work in pairs, in accordance with protocols for the safe use of Personal Protective Equipment for handling of Level 4 pathogens. The need to work in pairs further reduced already stretched staff presence inside the infected patient areas. Care was often not possible at night. Several participants reported patients dying under the watch of other patients only, or alone, at night.



Spatial Architecture of the ETC. At the height of the outbreak, ETCs included space for dozens of patients in a room, sometimes lying on cots on the floor close together. Such conditions were far from ideal for the provision of a peaceful and supportive care environment. The ETCs' physical structure and the density of patients within these frequently meant patients were confronted with other patients, sometimes including family members, dying alongside them. Some recalled with evident distress personnel preparing the bodies of the dead for removal from the Centre. Such witnessing compounded the burden of suffering experienced by patients, survivors, HCPs, and by extension likely also those who died.

"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)



Prognostic limitations increasing risks for untreated end-of-life pain. A unique reality of EVD was the absence of any formal treatment for the virus, outside of experimental trials at the time. A reality of prognostic uncertainty was the limited predictability of EVD infection outcomes. Patients who initially fell ill were able to recover, while other patients who were stable quickly deteriorated and died. The rapid deterioration of patients led to instances of patients dying with no one at their side, and without provision for their potential end of life anxiety and pain.

Strategies to Reduce Suffering

Non-abandonment

*"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)*

Several patients described non-abandonment as central to Guinean notion of dying 'ready' and 'in honour'. Outside the context of this public health emergency, in Guinea the norm is for family and friends to provide emotional and moral support through accompaniment, prayer, facilitation of any needs the dying may have to put their affairs in order. Family and friends also normally provide important assistive support (hygiene, assurance of comfort) to the dying. Providers can affirm respect for this cultural norm through a commitment to non-abandonment.

The thought of dying without customary post-mortem religious rituals was evidently deeply disturbing to many interviewed, and yet a reality of death in the ETC. Efforts were made by HCPs in Guinean ETCs to respect this practice by praying for patients with family present at a distance. This was reported as a positive and appreciated practice.

Connecting patients with their families outside the ETC

*"Visiting someone who is sick, that gives them hope. If you receive a family member at the ETC, for the rest of the day, your mind is at peace. It gives you the courage to heal quickly, and finding yourself with members of the family. It was also like if we spoke on the phone. It gave me the impression I was already back in the neighborhood."
-(Participant 9, family of deceased)*

Due to the vastly transmissible nature of Ebola Virus Disease (EVD), the ETC prohibits visitation unless the patient was reaching near their end-of-life. In light of this barrier, staff have implemented efforts to connect patients with their family members outside the ETC, through providing patients with phones. This connection provides psychosocial support to patients and their families. When a patient's health begins to decline and death is foreseeable, a final visitation is arranged for family members to come and be with the patient. A participant highlights that dying accompanied allowed for deaths within the ETC to be less distressing to both patient and family members.

"very very early, hurt or pain or distress was always at the center of our concern"

-(Participant 15, expatriate HCP)

Pain and symptom relief

"She would give me advice. She treated me like one of her sons."

-(Participant 3, patient/local HCP)

Patients supporting patient

In the face of personnel shortages, patients spent much of their time in ETCs without a healthcare provider at their side or in their section of the Centre. Patients reported becoming each other's closest supports. The strong familial-like bonds formed amongst many provided highly valued comfort as well as practical mutual caring, and was identified by patient survivors interviews as crucial to relieving distress and pain in the absence of genuine family accompaniment.

Some who recovered fully from EVD stayed on in the ETC to continue to help their fellow Guineans. Affectionately named "Nounous" by survivors, these individuals were sometimes volunteers, but sometimes also hired as psychosocial supports. Seemingly immune to further infection, these individuals took on many supportive tasks for those still struggling to overcome acute infection, such as bathing, dressing and feeding sick patients, as well as accepting medication. Nounous could hold and carry babies on their backs.

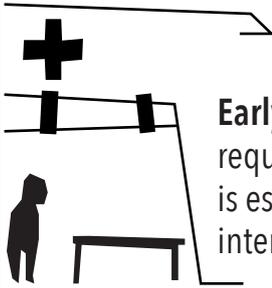
"As I was saying, one has to always avoid provoke a mood of despair in the patient. You understand? And within religions, we know that when we ask on the priest to intervene, it generally is towards the end. It is that there is no longer any choice, isn't that correct? Certainly there is that way of thinking. So that, doing this would have causes a lot of events. And it wasn't worth it actually. They [the patients] just needed hope: to believe [in possible recovery]."

-(Participant 2, patient/local HCP)

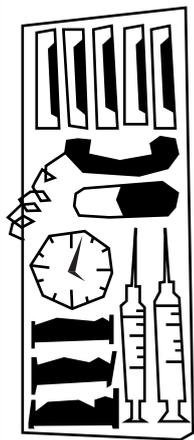
Absence of death-associated symbols

Some participants vocalized how they do not see a benefit in receiving spiritual services to supplement existing psychosocial support. To some patients, the presence of religious leaders in the ETC indicated the presence of impending death, which had a counterintuitive effect by elevating patient distress.

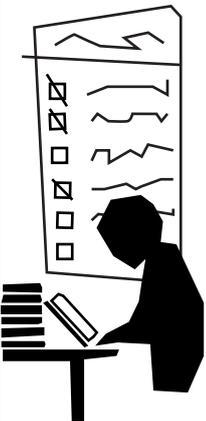
Actionable Recommendations



Early integration of treatment-focused, supportive care. The assertion of palliative care requires the full implementation of this treatment-focused supportive care. Early intervention is especially critical for EVD, as measures to address symptoms are intertwined with those intended to support survival.

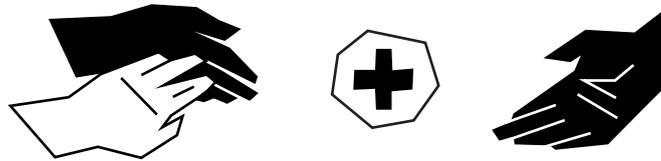


Focus on facilitating heightened humane care will support better palliative care. Measures that limit extreme suffering and death among patients while maintain a safe, functional environment for HCP are needed. Some areas of concern included: how and where bodies are cared for, and the inability to alleviate patient suffering in a timely manner. The spatial architecture of the ETC were also a source of suffering for patients. To combat these concerns, re-examining the number of staff and infrastructure needed to support ETC patients are needed. Other measures recommended to mitigate these specific elements include: optimizing PPE utilization, timing of clinical encounters, and virtual communication between patient and provider to negate transmission.

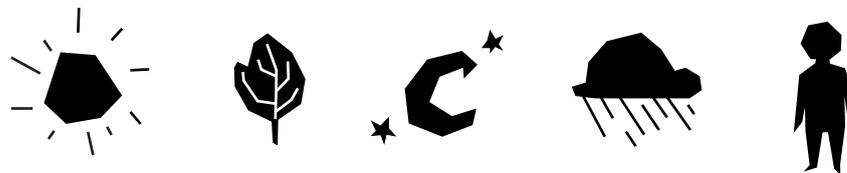


Effective public health palliative care response. HCP have raised concerns with a lack of preparedness for addressing palliative care needs and death. The participants have expressed many accounts of patient suffering without relief, to a degree that is deeply disturbing. An effective public health palliative care response requires action to areas such as lack of awareness and skills, availability of medications, staffing shortfalls and PPE limitations, cultural biases of providers and patients, and policy and procedural supports. Planning needs extend to staff training, drug and equipment availability, care policies and protocols, and ongoing clinical program support. Such planning and further implementation of action will enhance care delivery and mitigate HCP moral distress and vicarious trauma.

Collaboration between domestic and international HCP to enhance trust. There is deep mistrust between citizens and HCPs which is historically instilled in individuals due to how HCPs handled past public health emergencies. The climate of mistrust, conspiracy, and fear was a significant contributor to breakdowns in patients seeking care, spread of the epidemic, and the ability to deliver care in ETC's. However, participants spoke of the value of having Guinean providers alongside international providers have enhanced their trust.



Palliative care involves appreciation for one's cultural and spiritual context. A failure to appreciate and address the deeply held cultural and spiritual beliefs around illness, dying, and death undermined the response at every level. Palliative care calls for a need in addressing the crucial role of psychosocial and spiritual aspects of care to be included and addressed with open dialogue and efforts at mutual understanding and accommodation. These actions involve an honest examination of the cultural, ethical and practical issues around disclosure.



Attention to cultural-specific needs for end-of-life. A deeply held Guinean value is Dying in Honour. There are many limitations to this cultural practice due to the nature of EVD and the necessary measures taken within the ETCs to ensure safety for all, however accommodations should be considered to honour this practice. One essential aspect is presence with the dying, wherever possible by family caregivers. The ability for family and loved ones to provide holistic care is something a HCP cannot provide, and must be valued and supported. Accommodations and adaptations that prioritize maintaining connections should be implemented and enhanced wherever possible. Another vital importance is the end-of-life spiritual rituals and care of the body. This practice is commonly under looked within the medical maelstrom of public health emergencies, however attention is needed in addressing this underappreciation. Modifications and adaptations to protocols should be made when possible to allow families and spiritual care providers to meet these needs for those nearing death.

Humanitarian healthcare organizations may anticipate and think through best ways to **support patient-to-patient support.** This may include identifying criteria and opportunities for employment or volunteer positions to recovered patients; training. It is also important to recognize that not all patients facing the enormous pressures of loss and disease alongside any other pressures they may be bringing into the ETC will have the capacity to be a source of support to fellow patients. At no point can humanitarian organizations expect patients to fill in the gaps in healthcare provision.

Implications for Humanitarian Practitioners & Policymakers

- Palliative and supporting care skills are needed for healthcare providers at all points along the disease pathway.
- An integrated, transdisciplinary access-network will help link primary care clinicians to broader health and caregiver resources.
- Small actions such as enhanced privacy or family tracing can have a powerful impact.
- Public education about palliative care and the alleviation of suffering is needed to maintain hope while counteracting stigma around serious illness and pain relief medication.
- Palliative care should never become a substitute for health care system improvements and comprehensive curative treatment, the lack of which leads to prematurely necessitating palliation.
- Synchronous global and local efforts are needed to remove barriers and dispel myths around essential medications and to suffering associated with death and dying.



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Further Reading:

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