

Good Practice Series COVID-19 Number 8

Palliative care and COVID-19: Challenges for the humanitarian sector

Summary

The coronavirus (COVID-19) pandemic is affecting people in many different contexts. While the right to life with dignity is universal, each response to the pandemic must be contextualised to apply the humanitarian standards appropriately for that environment. This case study offers examples of good practice.

Many people have suffered serious illness or died of COVID-19, isolated from loved ones, a situation that runs counter to the ethical belief that people have the right to a dignified death. Palliative care – the prevention and relief of suffering and distress associated with life-limiting illness – is slowly gaining recognition as an important part of the healthcare continuum, alongside life-saving treatment in humanitarian response. **A new Sphere standard** now includes palliative care. The current pandemic is providing an opportunity to put palliative care on the humanitarian agenda. It's time for all humanitarian actors to document, share and learn from their stories of caring for people affected by COVID-19.¹

Key question

How can humanitarian standards on palliative care guide responses to the COVID-19 pandemic?

Humanitarian standards

The new Sphere **health standard 2.7** requires that "people have access to palliative and end-of-life care that relieves pain and suffering, maximizes their comfort, dignity and quality of life, and provides support for family members", including bereavement care after someone has died. This standard is supported by the **Humanitarian Charter**, **Core Humanitarian Standard** Commitments and **Protection Principles**, which demand that people are treated as human beings, not just cases. Human dignity is fundamental.

Island Hospice & Healthcare, Harare, Zimbabwe

By August 2020, Zimbabwe had reported 4,650 cases of COVID-19, but this was thought to be a large underestimate. Case numbers rose as community transmission spread rapidly. Services that were overstretched before the COVID-19 pandemic worsened dramatically. "Years of neglect and doctors' strikes had pushed the Zimbabwean health system to the brink." As cases of the virus led to increased deaths, many people died alone, isolated from their loved ones due to the risk of transmission. The pandemic highlighted the importance of palliative care.

Island Hospice & Healthcare was established in 1979 as the first hospice in Africa to provide people with quality palliative and bereavement care. At its foundation is the belief that everyone has a right to human dignity as long as they live, even to the very end of their life. When someone has died, the hospice cares for those who are impacted by that loss. Palliative care is about 'total pain', which includes physical, emotional, spiritual, psychological and social pain. Accordingly, Island Hospice has



¹ Makoni, Munyaradzi. "Covid-19 Worsens Zimbabwe's Health Crisis." *The Lancet*, 396.10249 (2020): 457-457, https://doi.org/10.1016/S0140-6736(20)31751-7

multidisciplinary teams that work with families and communities to reduce suffering and manage pain. This is particularly challenging in resource-poor settings with insufficient equipment and medication.

Similarly, a recent survey of humanitarian agencies by the Global Health Cluster COVID-19 Task Team found that in many front-line settings, the main technical challenge was a lack of basic tools, equipment and medication. "A really simplified tool for frontline workers is the first step. It's this idea of starting with what we can. Simple steps can be taken – psychological first aid, having conversations or preparing care plans," says Eba Pasha, coordinator of the Global Health Cluster COVID-19 Task Team.

Island Hospice drew on its experience of dealing with a spike in mortality during Cyclone Idai in March 2019. "Cyclone Idai was so traumatising as it was so unexpected. We were ill-prepared for it as a nation. People had to be buried two, three, four in one grave. In some cases, bodies were never found, thereby presenting challenges of closure for the surviving family members. That caused emotional and psychological pain to their loved ones. It was very clear that palliative care had to be an integral part of the response for a population recovering from the trauma that hit them," asserts Monalisa Matonda of Island Hospice.

Island Hospice uses a community-based approach. This involves training health professionals, community volunteers, traditional healers and faith healers so that they are able to manage pain, refer patients, provide end-of-life care and break bad news. Community leaders are also trained so that they understand and support the approach. These are **key actions of Sphere Standard 2.7**.

Learning from further afield, the Ebola crisis in West Africa also highlighted the need to tap into the wisdom of local communities in caring for people who were suffering and dying, and what cultural values and understandings of dignity illness and dying can teach us. "We need to recognise that there is a plurality: there's not going to be a one-size-fits-all. We can't assume that palliative care models with origins in the Western world will work in every context. One stark example was the black body bags in Liberia that did little to help families grieve when white is the cultural colour of mourning," reports Rachel Coghlan of Deakin University.

Despite some progress, palliative care still does not receive enough attention in humanitarian response. We need to remind ourselves of its importance, particularly in the fight against COVID-19. The pandemic should serve as a catalyst. There are plenty of grassroots initiatives, but it's time to prepare the policy framework for government and humanitarian agencies (key action 1 of Sphere standard 2.7).

Lessons

Palliative care is not a new intervention or a specialist discipline: it goes back to the root of the humanitarian ethos and ethics.² The right to live – and by extension, to die – with dignity is central to the Humanitarian Charter. Having the right to dignity is about the value and respect of the individual, no matter who they are, their age, their gender, their language, what group they are from, or what their life prognosis is.

"We see the person, not the disease, in the sense that when we treat them, we use a holistic approach, not just concentrating on doing the operation, but also looking at how the disease has affected the person, their emotions and feelings, and their family members. It's about seeing people as human beings," concludes Aninia Nadig of Sphere.

Humanitarian actors should be aware of and respect local ways of making decisions about caring for people who are ill and dying.



Resources

- To learn more about applying humanitarian standards in palliative care, watch the webinar recording
- Read Sphere's health standard 2.7 on palliative care
- Read the <u>Sphere guidance on COVID-19 response</u>
- Global Health Cluster guidance on Quality of Care in Humanitarian Settings

For more information, contact:

- Eba Pasha, Global Health Cluster: healthcluster@who.int
- Monalisa Matonda, Island Hospice & Healthcare, Zimbabwe: monalisa@islandhospice.co.zw
- Rachel Coghlan, Centre for Humanitarian Leadership, Deakin University: rjcoghlan@deakin.edu.au
- Aninia Nadig, Sphere Standards: aninia.nadig@spherestandards.org
- Sphere: handbook@spherestandards.org

² Rachel Coghlan, <u>Palliative care in humanitarian crises: innovation or radical reclaiming of roots?</u>, Center for Humanitarian Leadership – September 2019