

A REFLECTION ON PALLIATIVE CARE

"There is plenty that can be done once there is nothing more to be done": so said the pioneers of palliative care. It's a notion that comes in handy for further reflection on this delicate mode of care, especially when working in African settings, whose cultures of death differ greatly from the West's.

TEXT BY / SANDRO SPINSANTI / JANUS INSTITUTE FOR MEDICAL HUMANITIES

Palliative care has acquired the "right to citizenship" in our health care system. However, it is sometimes practiced in ambiguous ways that risk discrediting it and pushing it to the fringe of health care. The biggest obstacle to this form of care is an underlying notion that has long animated the practice of medicine: traditionally, medical treatment was provided for as long as possible, at which point doctors would discreetly withdraw to make room for the clergy members in charge of caring for their patients' souls.

Today, this binary model risks being perpetuated in a converse fashion: once further treatment becomes impracticable, having already been pushed beyond the limits of both possibility and reasonableness, curative care "passes the buck", calling not for the pastor, but for the palliative doctor. The message sent to patients – "There's nothing more we can do for you" – is a harsh one that is likely to leave them with a sense of abandonment.

The assumption "poisoning" palliative care – i.e., the belief that at a certain point "there is nothing more to be done" – is not just conceptually but also practically absurd, something that those who care for the sick at this end-of-life stage are well aware of. Indeed, the slogan adopted by the pioneers of palliative care in Italy runs thus: "There is plenty that can be done once there is nothing more to be done". Palliative caregivers know what a massive task they face to help diminish their patients' pain, alleviate common symptoms such as shortness of breath, nausea, vomiting, constipation, itching, asthenia and so forth, and accompany them through their grieving process. There is also a need for the caregivers themselves to receive care, to help them deal with the emotional burden they must shoulder. All of this

requires not just great professional expertise but also great compassion.

Hindering an active transition to palliative care is the persistent cultural attitude that the path to the end of life for such patients should not be openly acknowledged, but (at most) simply alluded to. Frequently the very mention of the words "palliative care" is avoided, or masked through euphemisms, to avoid communicating a death sentence to patients or engendering a sense of abandonment by caregivers.

In reflecting on palliative care, one can see how the mode of care provided to patients with illnesses tilted inevitably toward the end of life is closely intertwined with broader cultures of life and death. It is therefore essential that those who intend to deliver medical services far from their own places of origin, such as CUAMM – Doctors with Africa – bear this in mind. Africa's cultures of death differ greatly from those in the West.

It is worth recalling Louis-Vincent Thomas's classic treatise, *La Mort Africaine*. Though it dates back to 1982, it still retains relevance today, showing how African cultures feature symbols and rituals to help people transcend the sense of anguish brought by the precariousness of life and contextualize death within the larger cycle of life. This should make us vigilant in the future about repeating mistakes made by the West today vis-à-vis care in Africa, isolating palliative care as a phase that starts up only after active care has "surrendered". We also have a great deal to learn from African civilizations in this sphere, for example, the ideal of "the good death" as related to the cult of life, the symbolic support of shared rituals, and the collective handling of individual deaths.