



## Health-related suffering: from *Lancet* Commission to DeclarAction

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As the world unites to achieve universal health coverage (UHC) and we strive to measure, adopt, adapt, and account for progress, awareness of the most basic of health-care needs and intrinsic goals of health systems has been obliterated: the prevention and alleviation of suffering. Suffering is a state of distress that manifests in physical, psychological, social, and spiritual forms.<sup>1</sup> The alleviation of suffering—reducing the pain of debriding a wound or easing the symptoms of a cancer patient—is a core component of medicine and public health.<sup>2</sup> Yet, remarkably, the need to alleviate health-related suffering has been largely ignored by health professionals. This omission is unacceptable in any conception of a decent society.

Most of the more than 61 million people worldwide who experience serious health-related suffering (SHS) have almost no access to the palliative care and pain relief that could alleviate their symptoms.<sup>1</sup> Poor countries and poor people lack even the most basic of medicines—oral immediate release and injectable morphine—to relieve their pain in moments of need. Indeed, the poorest 50% of the world live in countries that have only 1% of this essential medicine.<sup>1</sup> The *Lancet* Commission on Global Access to Palliative Care and Pain Relief, in 2017, drew attention to this access abyss, created a novel framework to measure the

burden of SHS, and proposed an inexpensive essential package of palliative care and pain relief to include as part of UHC.

The shroud of ignorance has been lifted. This *Lancet* Commission propels health systems into a new realm of accountability. Countries, as well as the global health system, must include the alleviation of suffering as they assess performance on the basis of both the volume of services delivered to patients and the value generated for the patient by these services. The alleviation of suffering must be a fundamental goal of health systems, in addition and complementary to the extension and preservation of life.

*The Lancet* encouraged this Commission to include a programme to translate its evidence into further outcomes. The Commission's report<sup>1</sup> includes a strategy for accountability, and the publication was accompanied by the creation of an implementation group comprised of global and regional civil society organisations and academic researchers, coordinated by the International Association for Hospice and Palliative Care.

On April 5–6, 2018, the implementation group and *The Lancet* spearheaded a launch of the report at the University of Miami, the host institution of this Commission. Global and regional palliative care civil society organisations attended the event, making it possible to commit to global action. These organisations, together with advocates, researchers, and health-care providers, wrote and adopted the Miami DeclarAction (appendix).

The Miami DeclarAction translates the recommendations of the *Lancet* Commission into tangible commitments. It is a bold initiative led by the palliative care community, promising to promote dignity in life and death. The Miami DeclarAction aims to revitalise health care to encompass suffering. With this broader vision to avert and alleviate human suffering, the palliative care community is presented with an opportunity to reinvigorate itself by integrating with other domains of health care, including prevention, and avoid continuing as a clinical silo.

Implementation of the Miami DeclarAction requires an accountability mechanism, which in turn must be

For the International Association of Hospice and Palliative Care see <https://hospicecare.com>

See Online for appendix



Palliative care nurse visits a patient in rural Malawi

Kieran Doolan/Panos Pictures

based on adequate metrics. As the report of the *Lancet* Commission shows, the burden of SHS has never been measured and the true burden of health-related suffering is unknown. The Miami DeclarAction includes commitments by the researchers who participated in the Commission to develop robust SHS metrics, such as suffering-intensity-adjusted life-years (SALYs), and to gather more and better data. These data will be adopted and used in policy making. In response to the Commission report, countries are already requesting detailed information on SHS, the WHO/Worldwide Hospice Palliative Care Alliance Global Atlas of Palliative Care<sup>3</sup> will begin to use SHS measures, and the International Narcotics Control Board has indicated its intention to use SHS, together with other tools, when assisting countries in estimating their requirements for medicines needed for pain treatment and palliative care.

*The Lancet* commits to partner with the Commission's implementation group to publish an annual report on SHS as a statement of accountability for civil society to take to policy makers. This annual report will promote evidence-driven advocacy and, in turn, fuel, we hope, the production of advocacy-inspired evidence. UHC is the best opportunity the health community has had since the 1978 Declaration of Alma-Ata to achieve the

goal of health for all. But there can be no health for all without a direct attack on human suffering. We pledge to make the alleviation of that suffering a central part of our collective vision for health.

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- 1 Knaul FM, Farmer PE, Krakauer EI, et al on behalf of the *Lancet* Commission on Palliative Care and Pain Relief Study Group. Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the *Lancet* Commission report. *Lancet* 2018; **391**: 1391–454.
- 2 Callahan D. Equity and the goals of medicine. World Health Forum, World Health Organization, 1997. <http://www.who.int/iris/handle/10665/55029> (accessed May 16, 2018).
- 3 Connor SR, Bermedo MCS. WHO global atlas of palliative care at the end of life. Geneva: World Health Organization, Worldwide Hospice Palliative Care Alliance, 2014.

## Pervasive genetic testing

On March 6, 2018, the US Food and Drug Administration (FDA) authorised the DNA testing company 23andMe's Personal Genome Service that offers mail-order testing for selected variants of the *BRCA1* and *BRCA2* breast cancer genes.<sup>1</sup> This service analyses DNA from a self-collected sample of saliva, and results are available through an online portal. The subsequent report may determine whether an individual is at an increased risk of developing several cancers linked to these gene mutations, including breast, ovarian, fallopian tube, peritoneal, prostate, and pancreatic cancer.

*BRCA1* and *BRCA2* mutations confer about 40–70% lifetime risk of breast cancer and 20–55% risk of ovarian cancer, along with other cancers, but these risks are not immutable;<sup>2</sup> these risks compare with 12% and 1–2% general population lifetime risks of these diseases, respectively.<sup>3</sup> Although 23andMe's Personal Genome Service detects *BRCA1* and *BRCA2*

mutations with precision, it tests for three mutations out of more than 1000 known variations. Importantly, these three founder mutations (*BRCA1* c.68\_69delAG, *BRCA1* c.5266dupC, and *BRCA2* c.5946delT) are most commonly found in the Ashkenazi Jewish population (2–3%) but are rarer in other populations.<sup>4</sup>

Genetic testing can be undertaken in patients with a medical condition (medical genetic testing) or in an otherwise healthy person (predictive or susceptibility testing). Patients should be fully informed when they agree to medical genetic tests, and predictive testing will potentially place healthy individuals in unfamiliar territory. A positive genetic test has implications for a patient's personal, family, and social life. Some individuals describe anxiety, depression, anger, distress, cancer-related worry, vulnerability, stigma, and changes in self-perception and quality of life in the first months after a positive genetic test.<sup>5</sup>

