The precariousness of balancing life and death

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We are pleased to submit an invited Comment on the Value of Death Commission
The Comment, invited by Dr Jocalyn Clark is entitled The precariousness of balancing life and death
It presents an overview of the Commission from the perspective of balancing life and death in low-income countries, and for those in regions of conflict Fasiuddin Khan Research Foundation Bangladesh
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Death is at the heart of life; it belongs in the rough and raw of nature and the experience of death is recorded im in sacred scriptures, icons, poetry, myths, and stories. Across cultures, death carries varied meanings including but not limited to a passing place, an escape, a health failure, a punishment, an ending. Nevertheless, despite the centrality of death to our lives, people from many societies avoid meaningful conversations about death, and its value as a fundamental human experience has been largely lost. Death and dying have become unbalanced. Diminishing the inevitability and humanity of this milestone in all human life has obscured our understanding of health and life.

The story of dying in the 21st century is, the Lancet Commission on the Value of Death argues, a story of paradox. (1) Spurred by the advances of technologies, science, medicine, artificial intelligence, and pharmaceuticals, it has become harder to die, harder for clinicians working in high-resourced health systems to let go. Many people today die after substantial efforts at what is often called futile care. Such overtreatment in hospitals mostly serving those with higher incomes contrasts sharply with a great global abyss of undertreatment. From the perspectives of those living in countries without adequate health care resources, the story of dying is a story of gross inequity. More than 61 million people experience serious and avoidable health-related pain and suffering, and many people continue to die from preventable illness. (2) The poorest 50% of the world live in countries that have only 1% of the distributed morphine equivalent medication essential to alleviating pain. (3)

Is the Commission relevant in countries where the challenge is to constantly balance dying and death in poverty and inequity? In highly indebted poor countries three delays determine death and dying. The delay in knowing what is happening because services are absent, or patients fear to attend because of cost, or health staff fear to break bad news because of cultural, social, and time pressure reasons; the delay in receiving the right level of care with either aggressive costly interventions, or 'back-of-the-ward' neglect because of lack of resources, training, or drugs; and the delay in getting to the right or the safe place to die because of silo health services, the lack of homestead basics such as sheets, mattresses and running water. The delays are all addressable. Indeed, unlike so many other priorities in global health, affordability is not the greatest barrier to accessing services of care to die well. Valuing those who are dying is.

Dying has become one of the costliest of all 'healthcare' events. Spending in the last year of life accounts for a disproportionate share of total health expenditure notes the Commission. And the irony is that the global gap in services and therapies does not mean death or dying is cheap for those living in low-income countries. The lack of investment in effective palliative care interventions contributes to intergenerational poverty, children have been taken out of school when savings for schools fees are averted as families continue to search for cures but never find them. (4)

Our death connects us to a cycle enacted in nature, in the seasons, in our planet's health. The Commission draws parallels between the need to rebalance our relationship with death, with that of balancing our relationship to the planet. The climate crisis, ecosystem collapse and biodiversity loss are not only causing untimely deaths, but they point towards planetary death. Ill health and death have been brought closer by the direct and indirect impacts of climate on health, but as more demands are put on the health sector the more the sector becomes a driver of the climate crisis. Is this profound separation that we now have from nature connected to our equally profound detachment from death, as perhaps we delude ourselves into believing we can manipulate, tame, and manage both nature and death?

The Commission uses the construct of 'death systems' to explore the complex components that determine how care of the dying and the dead is given, who is included and excluded from such care, where care happens, and the dynamic shift in who 'owns' death. Thirty recommendations are laid out to bring about radical change in the death systems, acknowledging that death systems are unique to societies, shaped by culture, religious beliefs, and resources. But what happens when death of those speaking out against the state, or of certain minority communities becomes the intent of a political regime, or when dying is on such a scale that the death system folds into the collapsing life system such as in Yemen, and Syria, and increasingly in Afghanistan. As the 21st century positions itself to be the century of mass migration, we need to be learning lessons from refugees, internally displaced peoples and persecuted communities who are balancing life and death in fragility. Their voices are not heard in the Commission. Does death hold a different value when it becomes a tool? The anniversary of the military coup in Myanmar on the 1st February is a stark reminder that the health workers, whose raison d'etre is to preserve life, have been the target of Junta murders. The Rohingya Community in Cox's Bazar, Bangladesh, and refugees making crossings of the Mediterranean have had to develop ways of facing death and caring for the dead and dying which sit outside the surrounding societal structures and norms. In these cases death and life are not unbalanced, but in a precarious balance, we can learn much about how to balance the presence of death with the fragility of life, and still retain hope.
Death, the Commission notes, occurs through conflict, accident, natural disaster, pandemic, violence, suicide, neglect, or disease. The World Economic Forum Global Risks Report 2022 identifies the 10 most severe risks over the next 10 years (livelihood and debt crisis, severe weather, infectious disease, environmental damage, geo-economics confrontation) and points to a world where there will rarely be a singular cause of death. (5) Perhaps the greatest challenge we face in re-positioning death systems will be to move from silo sectors into interconnected ones.

In so many societies we have lost trust in, and relegated, our ability to deal with death. The over-medicalisation of death, and the capability or otherwise of a health system to manage death has come to determine the way that death is treated. The Commission argues that only by reestablishing the value of death will we be able to transform our health systems. A vision of a new system for death and dying is offered, underpinned by five principles - tackling the social determinants of death, dying, and grieving; seeing death as a relational and spiritual process; enabling networks of informal and formal care; normalising conversations and stories of death, dying, and grief; and recognising death has a value. These point the ways to improve the experience of death and dying globally. Achievement of the Commission's vision will require a renewed belief in a shared humanity, the recognition that we are born equal, but into very unequal circumstances, and while we cannot change the inevitability of death, we can change the circumstances, averting preventable deaths and providing the time, space, comfort and compassion to die.

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