



Difficulties and opportunities of hospice care—the role of doctors

Yali Cong

Department of Medical Ethics and Law, the School of Health Humanities, Peking University, Beijing, China

Correspondence to: Yali Cong. Dean, Professor, Member of the Lancet Commission on the Value of Death. Department of Medical Ethics and Law, the School of Health Humanities, Peking University, Beijing, China. Email: ethics@bjmu.edu.cn.

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Unhealthy relationship with death

Our relationship with death is unhealthy, as the Lancet Commission on the Value of Death website pointed out clearly on their home page: “Modern health care has an unhealthy relationship with death. We are exploring how to make it healthier.” (Figure 1).

As early as the end of the 16th century, Francis Bacon divided medicine into three offices: preservation of health, the cure of disease, and prolongation of life. With the development of modern medicine, the responsibility of doctors has gradually been set on the third. For this, Ivan Illich sharply criticized that, the relationship between death and life was natural before, but today, such a relationship has been largely distorted. Death becomes a commodity and the socialized medicine becomes a tool of the so-called “the managed life”, medicine is the rule maker, doctors are the umpire of death. The rules forbid leaving the game and dying in any fashion that has not been specified by the umpire. Death no longer occurs except as the self-fulfilling prophecy of the medicine man (1).

It is hard for modern health care to find excuses from such unhealthy situation. It is we ourselves who portray ourselves as fighters who are against death and refuse to accept the arrival of death.

Hospice care: death inequality from a global perspective

The unhealthy relationship with death is primarily manifested in the end-of-life stage.

According to the data in Table 1 (2), from 2011 to 2013, the number of terminally ill patients in China who suffered from pain is 17 times that of the UK, but the consumption of pain relief medicine in China is less than half that of the

UK, and the US is 50 times that of China. Hospice care globally shows a stark contrast between developed and developing countries, as well as the inaccessibility of the poor to palliative care (3). Pain control of patients at the end of life in various countries is an important parameter to measure the quality of death and the equality of death. From a global perspective, some people have access to hospice care, while others don't; some people hope to get hospice care but cannot afford it; some people can afford it but refuse to accept it. Such discrepancies are due to individual values differences, but more relates to the inequality of death caused by society and system.

The fundamental path of hospice care development—the transformation of concepts

Living and dying are two sides of our human life

Some cultures feel comfortable talking about death, while others prefer to purposefully neglect this subject. Chinese culture still treats death with taboo, fear, and anxiety. The Analects of Confucius saying “once enlightened, one can die early but happily” conveys that living is to explore the value of life, while death itself is meaningless even be taken as a mean sometimes. A living person must struggle/work hard, but dying means that one can rest, forever.

German philosopher Heidegger explicitly advocated the value of death itself. His “Being-towards-death” brought/showed big wisdom. Living and dying are two separate time dimensions of life and the two sides of the essence of life. When we live, we are practicing life; but we should also know that people are walking towards death once they are born. But in terminal stage, being and death expose to us simultaneously, and this touches us powerfully because “one body and two sides” is illustrated in front of us at this

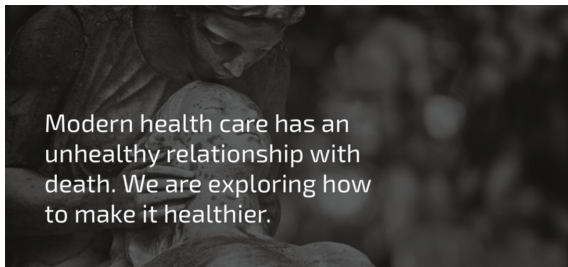


Figure 1 Unhealthy relationship with death. Available at <https://commissiononthevalueofdeath.wordpress.com>

moment. Every day, many people are passing away, and they deliver a message to us, we may authentically become who we are due to our death, but we usually ignore it intentionally or unintentionally.

Death is a gift from terminally ill patients to our human beings

Death is a gift from terminally ill patients to their caregivers. Each of us has received or will receive this gift. Connecting dying and gifts can help us understand and accept death and prepare for its coming. Mauss’s book “The Gift” claimed “the soul of gift”, which proposes that people expect the gift but also fear it because they dare not to possess the gift alone. Giving, receiving, and reciprocating are three obligations connected to the gift. It is a mandatory obligation to return with dignity. Refusing a gift implies a fear of reciprocation (4). There is no way by which the dying person can avoid his death, so Levinas believes that in being-for the other in their dying in the same way that I am with a friend. There is a being-with, a communing, an attending-to, which is an end and value in itself (5).

Our living ones are benefited from the death of others, as well as we receive gifts. However, we cannot return gifts to terminally ill patients because they will soon pass away. We wish to repay, but unfortunately, the other party can no

longer receive it, so we express our “regret” in various ways. However, these regrets may haunt us for the rest of our lives. In essence, the idea of the return of a gift to a specific person, is limited, and too narrow. This tradition of return between two individuals is not applicable to the return of the decedents. If we interpret the death of a specific person in an abstract way, we can truly understand that death is the gift of the decedents to our human beings/kind, which suggests a transformation of our concepts about death. If we can change from fear of dying to gratitude for death, then our society can relocate resources of the healthcare and bring more resources for end-of-life care. In this way, everyone can receive proper care in the final stage of life, relieve both physical and mental pain, improve the quality of death, and ultimately promote equality of death. Then each of us will also be a beneficiary.

Reimagining death and dying—the commission’s realistic utopia

The report believes that only by recognizing the value of death can we revolutionize the health and death system. In the twelfth part of the report, the Commission on the Value of Death paints a new blueprint for the hospice care and outline its five principles (5):

- (I) The social determinants of death, dying and grieving are tackled.
- (II) Dying is understood to be a relational and spiritual process rather than simply a physiological event.
- (III) Networks of care lead support for people dying, caring, and grieving.
- (IV) Conversations and stories about everyday death, dying, and grief become common.
- (V) Death is recognised as having value.

Kerala is a small state in southwest India with a population of 35 million. Of the 2,000 palliative care services in India, 80% are in Kerala. Although limited, at least every district in Kerala can provide services that are estimated

Table 1 A comparison of whether decedents were accompanied by pain and pain relief in China, UK, and USA

Country	Population (thousand)	Total number of decedents in need of palliative care (thousand)	Consumption of medications for pain relief NME_2011–2013 (Kg)	Percent SHS need met by DOME (%)
China	1,383,925	5,501	3,291.6	15.93
UK	64,716	317	7,606.30	523.32
USA	321,774	1,310	167,493.50	3,146.86

SHS, serious health-related suffering; DOME, distributed opioid morphine-equivalent.

to cover more than 70% of those in need (5). The Kerala model illustrates that achieving such a utopia is realistic. Its success can be summed up in the following: the palliative care services in Kerala were initiated by visionary doctors, supported by civil society organisation, actively involved by groups of volunteers, the long history of social action, the culture of creating a community network of death and chronic diseases, and last but not least, local health policy reformation makes opioids practically accessible.

Doctors should be the protagonists in bringing death back to life

The example of Kerala has told the world that to change social values on death, a community needs to lead its people to take the first step. Importantly, this change in society has no necessary relationship to the economic development of a society. The report also mentioned the Liverpool Care Pathway (which was an attempt to extend palliative care beyond hospices and specialists into routine care in acute hospitals) in the UK. But it failed to improve the experience of dying. It's not that big hospitals can't provide hospice care services, but the lack of training matters, and should not be financially incentivised. Plus, they must be used as guidance not a checklist, with brains and hearts engaged (5).

In fact, many doctors hold the concept of hospice care, but the medical system and most doctors are often coerced by society and patients' families, and were required to work tirelessly to treat. The subtitle of the report of the Lancet Commission on the Value of Death is "bringing death back into life", and doctors are the helmsman to reverse our relationship with death. For doctors, this is a challenge, but also an opportunity.

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