Cure or care – diagnosing death in the modern era

Joseph M Sawyer is a junior doctor with a passion for integrating compassionate care into modern medical practice. Influenced by Indo-Tibetan philosophy and medicine, he shares his thoughts on how medical professionals should deal with death, using the concepts of interdependence, community and compassion

What are the objectives of a healthcare service? The UK mandate for 2015–16 presents a range of principles, one of which being to 'prevent people dying early'.[1] At face value this principle seems unquestionable; however, if we unpack its true meaning in the context of modern society, we find ourselves with many unanswered questions.

The majority of patients I treat are elderly people, often with more than one chronic condition. As their health inevitably deteriorates with age, they come to rely on a cocktail of prescribed drugs and expensive social support. In this cohort of people, the concept of 'preventing an early death' seems rather ambiguous. Failing to address this ambiguity often leads to the default position of prolonging life. While this may seem virtuous, it does beg the question, by what means and to what end?

In a system primarily geared towards prolonging life, death has come to represent failure. Failure is a demoralising feeling, and attempts to distance ourselves from this lead to defensiveness and create a fertile ground for suspicion and fear. Through these emotions we create suffering for ourselves, the person concerned and the community we are part of.

Key points

- In a healthcare system where primary objectives are geared towards prolonging life, death has come to represent failure.
- As physicians, our fear to engage in discussions about death leads us to focus solely on managing abnormal disease physiology.
- We must move to harness the influence of compassionate human relationships, placing them at the core of a system that recognises suffering beyond physical parameters.

Returning to the core

As a medical practitioner, my actions are fuelled by a desire to reduce suffering. I believe this can be achieved through the skilled expression of fellow feeling and compassion. When I achieve this I am rewarded with feelings of self-worth and gratification. There is a clear difference between this and simple altruism or sentimental 'niceness'. This difference relates to the concept of interdependence – that our existence is inherently related to everything and everyone around us, as opposed to us being individuals living in isolation.

Death is something I recognise as a process that has tremendous impact not just on the dying person, but also me as a practitioner, the family and the society in which we live. Through personal experience, I have come to appreciate that reducing suffering around death is entirely distinct from preventing death. Indeed, a system that only seeks to prolong life may seem at odds with a system that values life and limits suffering.

How do we deal with death?

In a desperate attempt to bring order to, and control, the process of life, Western culture is forever preparing for the future. Medical institutions are no different, planning for disease outbreaks while training future generations of professionals to manage all manner of terrible eventualities. Given that we spend so much time preparing for events that may or may not occur, how ironic is it that we meet the only certainty in life completely unprepared?

The extent of our ignorance of death is noticeable in all reaches of society. We are taught to deny death, shielding ourselves from its potential meaning and replacing it with emotions of annihilation and loss.

The resulting absence of dialogue is reflected in death's conspicuous absence from all forms of media and popular culture.

Dealing with death in a health system designed to keep people alive is a complicated and emotive topic, but one we can no longer ignore. Literature and social media are littered with anecdotes of the health system 'failing to let go'.[2] In addition there is documented evidence of a 'lack of ability to identify patients approaching the end of life', leading to overly aggressive treatment and poor communication with families.[3] Research has suggested that a lack of preparation for death may be an indicator for the risk of developing psychiatric morbidity.[4,5] Although this body of research is in its preliminary stages, it is easy to see how anxiety around death forms a vicious cycle that perpetuates in those approaching their own personal transition towards death.

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Understanding the problem

For all our technological advancements we have little understanding of what death is or what happens during and after death. This, in combination with the healthcare structures we have created to shield us from death, has understandably made us uncomfortable and fearful of its reality.

The gradual transition to a more materialistic society has resulted in a lack of exposure to death in day-to-day life. By surrounding ourselves with things of permanence, we shield ourselves from the truth that life is nothing but a dance of birth and death, a continuum of energy to which we all contribute. This concept is mirrored throughout the natural world, from the autumnal shedding of leaves to the rushing by of a mountain stream. Acknowledging this concept is key to obtaining the freedom that comes with being content and happy. As William Blake wrote:

'He who binds to himself a joy
Does the winged life destroy
But he who kisses the joy as it flies
Lives in eternity's sunrise'[6]

Yet how far from this are we in modern society? We pursue happiness through material possessions and social status. Death is the ultimate threat to our way of life, removing one's life achievements in a second.

As we continue down this path, our own health system has become our saving grace from confronting the unwelcome mirror of death. Born out of compassion, it now serves as yet another material structure shielding us from the certainty of death.

Those in the medical profession, particularly physicians, are acutely aware of the fear surrounding death and anxious about engaging in conversations on the topic. We prefer to focus on the 'positives' and exhibit a form of 'niceness' that neglects the true meaning of human compassion. Our fear to engage on this level leads us to take the task-centred approach of managing abnormal disease physiology. We busy ourselves, and the patient, in often painful and invariably tiresome procedures. Burying fear behind these structures and reassuring ourselves and everyone else that 'everything is being done' is both clinically and morally lazy. People spend their lives moving towards death and are denied the chance to prepare for it by our preference to operate within the known academic limits of success, rather than bet on the possibilities of emotional, interpersonal contact. These issues are compounded by the hyperspecialisation and careerism of the medical profession. Narrower realms of expertise mean we are accustomed to focusing on certain parts of patients' bodies and objectifying them, as opposed to considering

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the whole individual, while competition among staff can weaken team ethic and prevent staff members from engaging on a different level.

This 'task-centred' approach is often reinforced by patient's relatives. Imminent death may draw on feelings of guilt, as people feel they have not valued the time afforded with the patient before illness set in. Being detached from the dying process until it is impossible to ignore it means there is no compassionate connection or sense of how the body and mind have suffered to the point of exhaustion. Distraught by these feelings, families also tumble down the path of 'doing everything possible'.

Experiencing complex and conflicting emotions, we look to our leaders to re-affirm our direction and offer us the tools to overcome suffering. But we meet a discourse which, by and large, views compassion and kindness as superficial concepts that are somehow inferior to those of economics. Death rates have been used as the focal point for an argument on how to best improve service provision, rather than how to best gather around collective issues and define what it is to be human.

Nowhere has this been more apparent than in the latest restructuring of the NHS, which prioritises the extension of competition, an accepted tactic among economists to drive improvements in an industrial setting.[7] Although there are similarities between healthcare and industry, there is a fundamental difference in the complexity of the services offered and the type of people using them.

The way forward

As society, healthcare workers, the media and political leaders join in denying the importance of death, how are we to emancipate ourselves from the suffering associated with it? First there needs to be a fundamental shift away from the industrialisation of healthcare. Primary objectives must not only speak a language of economics, but also recognise the concepts that drive us to do good – interdependence, community and compassion.

The concept of interdependence assumes that acting in pure self-interest and ignoring the bond between individuals only works to our detriment at a personal, community and global level. It follows that citizens must take responsibility for each other. With respect to healthcare, patients must appreciate the risk of illness or accident while accepting collective responsibility for resource limitations. Healthcare professionals must accept that they are not just service providers and that their actions at the interface of human existence help define our society.

With this as a platform, we must move to harness the influence of compassionate human relationships, placing them at the core of a system that recognises suffering beyond physical parameters. This concept needs to be given space to develop at the level where we interact with our patients and train future generations of professionals, as within it is the essence of what drives us to do good to others.

Accepting interdependence and using compassion as a force for change could afford us the space to recognise the different stages of life and help us as we move through them. Recognising these transitional stages – in other words, 'diagnosing death' – could give us powerful opportunities for liberating ourselves from suffering and dispersing the cloud of misery that shrouds death. The effects can be far-reaching, spanning through generations. The fundamental message is that, for those who are prepared, 'death comes not as a defeat but as a triumph, the crowning and most glorious moment of life'[8] ■

Declaration of interest
The author has no competing interests.

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References
1. Department of Health. A mandate from the Government to NHS England: April 2015 to March 2016. 2014. www.gov.uk/government/publications/nhs-mandate-2015-to-2016 (last accessed 26/05/2016)
2. Paton A. Letting go. *Clin Med (Northfield Il)* 2010; **10:** 295–295.
3. Cooper H, Findlay G, Goodwin APL *et al. Caring to the End? A review of the care of patients who died in hospital within four days of admission.* National Confidential Enquiry into Patient Outcome and Death, 2009. www.ncepod.org.uk/2009report2/Downloads/DAH_report.pdf (last accessed 26/05/2016)
4. Barry LC, Kasl SV, Prigerson HG. Psychiatric disorders among bereaved persons: the role of perceived circumstances of death and preparedness for death. *Am J Geriatr Psychiatry* 2002; **10:** 447–457.
5. Hebert RS, Schulz R, Copeland VC, Arnold RM. Preparing family caregivers for death and bereavement. Insights from caregivers of terminally ill patients. *J Pain Symptom Manage* 2009; **37:** 3–12.
6. Blake W. Eternity. *Blake Complete Writings.* Oxford and New York: Oxford University Press, 1972.
7. Armstrong M, Sappington D. Regulation, competition, and liberalization. *J Econ Lit* 2006; **44:** 325–66.
8. Rinpoche S. *The Tibetan Book of Living and Dying.* London: Rider, 2008.

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