What Do We Know About the End of Life?

Perspectives from: *What doctors say about care of the dying in Singapore (2011)*

Associate Professor Jacqueline Chin
Centre for Biomedical Ethics, Yong Loo Lin School of Medicine
National University Health System

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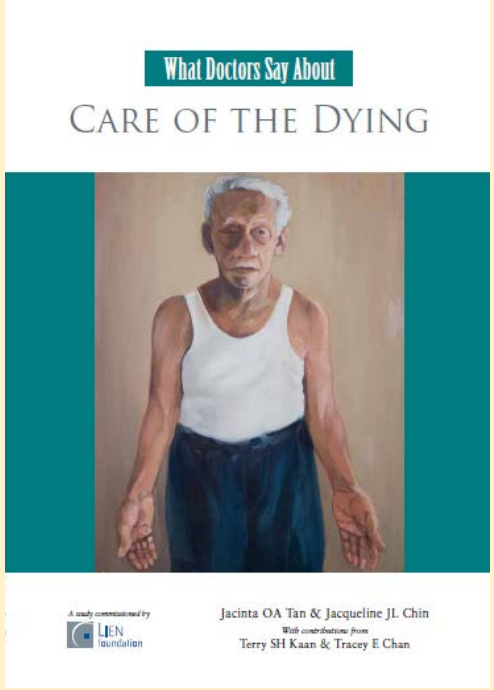
In 2010-2011, CBmE conducted 45 interviews with 78 doctors for their perspectives on care of dying patients in Singapore



Qualitative Research

The Lay Report

Executive Summary

Introduction

Topic 1: The concept of the end-of-life and its significance

1.1: The definition of ‘end-of-life’

1.2: The significance of ‘end-of-life’

1.3: The role of the doctor at the end-of-life

1.4: Religious influences at the end-of-life

1.5 Societal attitudes to the end-of-life

Available@ the CBmE www.centres.sg website (resources pages)

and The Lien Foundation www.lienfoundation.org website (publications pages)

Lecture Focus

- Conceptual analysis of primary data. In this presentation, I am:
  - Looking at a key term ‘end-of-life’, as used in ‘end-of-life care’, ‘end-of-life issues’, etc. We collected a wide range of meanings and uses of this term. What’s the significance of this?
  - Framing or constructing the data to answer questions about the ways that doctors understand the term ‘end-of-life’, its social significance, and their professional obligations

Framing the term ‘end-of-life’ as a set of concerns (Summary)

A. ‘End-of-life’: Not the same as ‘dying’; more than a medical concern and invokes many other types of concerns; can be triggered at any time of life, often by the experience of illness

B. ‘End-of-life’: Marks a concern about the inevitability of dying; societal outlook, education, religion, beliefs about legitimate death are factors which shape its meaning for individuals

C. ‘End-of-life’: Defined for provisioning and resource allocation (legal, financial, infrastructural, skills development), but otherwise dispensable

D. ‘End-of-life’: Definitions are not very useful as guides to end-of-life care decision-making; individual patient characteristics, goals and needs are more important; matching them to available services

The ‘many other concerns’ are commonly triggered by illness, so doctors have been confronted by them, such as patients not wanting to suffer, their concerns about family members, about finances, care support, about choices, about last wishes and a respectable ending, their need for ‘explanations’ of their suffering.

A. NOT JUST ABOUT DYING, BUT MANY OTHER CONCERNS

Not the same as ‘death itself’

JC: When we approached this topic we didn't want to make any assumptions that we understand what end-of-life means to different doctors. Could you explain to us what that term strikes you as and what it means to you, end-of-life?

F: [having paused for 4 seconds] End-of-life – many definitions. Death by itself is not the end of life. It's just the end of a living body. We all know that's death. But I think in real terms end-of-life is not just the mind going but a lot of the functions are also practically gone. To me that's what it means, really, end of life.

Not the same as ‘dying’

JT: Okay. So it's the end of earthly life? That's your definition of dying. What about the term *end-of-life?* Is that the same as dying or something else? Is it a different thing for you?

F: Uh, I guess dying would be more a finite sort of thing. End-of-life brings a more fuzzy and a wider sort of perspective of everything. For example, is a person who is brain dead alive? At what point is end-of-life? End of living?

JT: And what is living? [JT laughs.]

F: I must confess I don’t have that much in depth thought. If you take it as end-of-life, it's end of physical earthly life then that’s fine. But if it's beyond that, then there are many ramifications.

A longer process

JT: Now, what's the meaning of the term end-of-life? It's a term that may mean all sorts of things. What do you think?

F2: It means preparations for death.

JT: Okay. What do you mean by preparations?

F2: I think when a patient is about to die, there are lots of things to settle. So the process of dying is not just die. It's a lot of things to settle--emotional, financial ... there are a lot of things to settle before you die. The whole process, I think, is longer than just dropping dead.

Death and dying: bio-psychosocial aspects

‘DEATH’ (S Luper, The Philosophy of Death, 2009)

- Ambiguous; various meanings

‘END OF BEING ALIVE’

- State of life’s being over, e.g. end of consciousness, end of personhood, end of the human being

‘END Of EXISTENCE’

- Could occur deathlessly, as vital processes continue to create new life forms

‘DYING’

- *Process* whereby a life ends
- *Events* in the dying process, e.g. threshold or ‘irreversible’ death, ‘integration death’ or loss of functionally integrated life, ‘denouement death’ which is when dying is complete

Conceptual differences

Ageing v. Dying

Dying v. Not being alive

Not being alive v. Being dead

Ethics

"Ethics explores the values that are most important in guiding individual and social choices." (Thomas Attig)

Some current debates are distinguishing values towards

- Ageing
- Dying
- Being dead
- Being alive

Debating Dying

People have the right to die

Many people think that each person has the right to control his or her body and life and so should be able to determine at what time, in what way and by whose hand he or she will die.

Behind this lies the idea that human beings should be as free as possible - and that unnecessary restraints on human rights are a bad thing.

And behind that lies the idea that human beings are independent biological entities, with the right to take and carry out decisions about themselves, providing the greater good of society doesn't prohibit this. **Allied to this is a firm belief that death is the end.**

- BBC Ethics Guide

Secular opponents argue that whatever rights we have are limited by our obligations. The decision to die by euthanasia will affect other people - our family and friends, and healthcare professionals - and we must balance the consequences for them (guilt, grief, anger) against our rights.

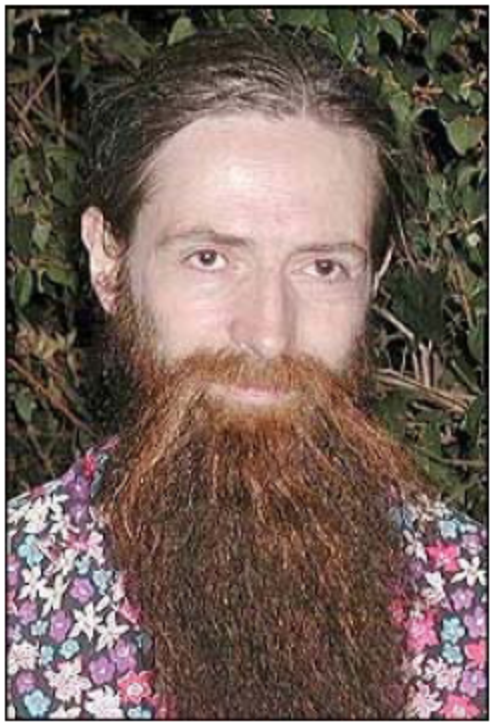
Religious opponents disagree because they believe that the right to decide when a person dies belongs to God.

Debating Ageing

'We will be able to live to 1,000'

By Dr Aubrey de Grey
University of Cambridge

Life expectancy is increasing in the developed world. But Cambridge University geneticist Aubrey de Grey believes it will soon extend dramatically to 1,000. Here, he explains why.



Aubrey de Grey: "The first person to live to 1,000 might be 60 already"

Ageing is a physical phenomenon happening to our bodies, so at some point in the future, as medicine becomes more and more powerful, we will inevitably be able to address ageing just as effectively as we address many diseases today.

I claim that we are close to that point because of the SENS (Strategies for Engineered Negligible Senescence) project to prevent and cure ageing.

public opinion is entrenched in a "pro-aging trance" - a state of resolute irrationality

Debating Being Dead

- Clinical death v Brain death: the cessation of breathing and heartbeat v. irreversible end of all brain activity in the whole brain or brain stem

- The current understanding of death is that it is a series of physical events, and not any one event. The determination of permanent death now depends on factors beyond the cessation of heartbeat and breathing.

- Ethical arguments surrounding defining death as
  - Whole brain death (Harvard criteria)
  - Higher brain death (e.g. PVS)
  - Brain stem death (Royal College of Physicians UK)
  - Anencephaly, or being born without the forebrain

  Weighing n the balance are:
  - Losses (human being, personhood, mind/consciousness)
  - Gains (organ transplantation to save other patients)

Debating Being Alive

- Vegetative state and minimally conscious states v. coma
- Two dimensions of recovery:
  - recovery of consciousness (awareness of self and the environment, consistent voluntary behavioral responses to visual and auditory stimuli, and interaction with others)
  - recovery of function (communication, ability to learn and to perform adaptive tasks, mobility, self-care, and participation in recreational or vocational activities)
- Locked-in syndromes

Practical distinctions

B. THE MEANING OF END-OF-LIFE IN A GIVEN SOCIETY

Marks a concern about the inevitability of dying; societal outlook, education, religion, beliefs about legitimate death are factors which shape its meaning for individuals

A concern about the inevitability of dying

F: Okay so end of life, to me is, preparing for the inevitability of dying.

JT: Okay. That's very loose in a sense that it's inevitable I would die.

F: Yea so end of life, for me, is defined as preparing for the inevitability of dying. So the key words are number one: preparing. You actually need to take active steps to prepare well for end of life. So preparing is the action word, versus passively waiting for the days to tick by…It also implies that we have to start from birth, to prepare for death.

…your image is also dependent on your background, the country you live in, how open they are to discussing these things in public, in the public arena. And even your education and your experience.

Process shaped by …societal outlook & education and road maps: religion, culture & legitimation

M: I think each of us must have a road map of what is 'end-of-life', what we'll do with it (not only for doctors but for the lay person too). Of course your prescription and my prescription of the road map would be quite different . …But I think it would be still correct to say that each of us, each of us would want to have less suffering. I won't say no suffering. Less suffering if possible. But what if you're Christian there's this…the trials and tribulations that Jesus go [sic] through. …Their thought is that you should remember that life is important and therefore the person should not die prematurely. That means, like, end-of-life must be legitimate. If the person dies because of lack of care, then that's a shame *lah*.

Ethical and policy questions

Are there important ethical questions for state and policy planners? Various efforts, e.g. QOD Index, National Palliative Care Strategy

- What is it like to die in Singapore? What is the quality of end-of-life care in Singapore?
- What images come to mind for us in Singapore, across the different socioeconomic strata, age groups, and residential status, when we think of end-of-life? Is there 'legitimacy'?
- Do we see patients in Singapore having more or less control over their 'roadmap' in the future? How do we see 'more control' and who will have it?
- Is death over-medicalised in Singapore? Is this good or bad? Who else besides health professionals should have end-of-life care skills?
- Are culture and religion relevant in clinical settings? How should this be approached, even harnessed?

We found that the term ‘end-of-life’ has some usefulness, in particular, as a term which marks a set of concerns to do with how one’s life could end

C. A TERM USED MORE BY PLANNERS

And...

The scope of key provisions, including:

a) Legal and quasi-legal provisions: advance directives, appointment deputies, advance care planning

b) Financing: types of life-limiting conditions, expected costs over critical periods

c) Service provision: home care, nursing homes, counseling, bereavement services, etc.

d) Skills training: palliative care training for more categories of health professionals

Definitions for coverage purposes

F: Have I told you that there's a national strategy work group which is ongoing. They're also coming up with their own definition, from MOH on a national platform, of what end-of-life is. We're supposed to submit our own versions of end-of-life definitions to them.

JT: Okay. What's the significance or meaning of having a standardised notion of end of life?

F: I think it's for policy-making and for funding.

JT: It could be a two-edged sword.

F: You know, it could be, but if you look at it from the MOH perspective, they're involved in policy and funding. They need to have a definition of end-of-life so they can direct funding into the right areas. But that has nothing to do with individuals' definitions of end-of-life.

Operational (legal) definitions for the imminently *dying*

JT: So. Right, so to get right back in, in your view, what's the meaning of the term end-of-life?

F: I'll probably take two different definitions for it. In the day-to-day discussions with patient, I will take probably the AMD definition, you know, terminal illness that is irreversible and it is associated with the sure consequence of death in the near future. And it is not reversible with the traditional means. And may stretch to extraordinary means as well…

JT: Ah, okay. Yea.

I also take into consideration another definition which I tend to use for (almost) dead people. And when I use that definition, I may not necessarily bring in the concept of what is ordinary versus extraordinary means. I will put in other contextual definitions that include futility. In a sense that if I think that a particular treatment is futile, then I would still believe that end-of-life is on the horizon. So it's a very complicated definition. It's not a simple definition and I didn't prepare for this.

It also appears that the term ‘end-of-life’ has less importance in healthcare decision-making at the clinical level than might have been thought. Goals of care and needs in different phases of illness are more important concepts for patients with end-of-life issues.

D. NOT A USEFUL TERM FOR MAKING CLINICAL DECISIONS

Preferred approach: define goals and needs in illness phases, rather than ‘end-of-life’

F: So maybe we shouldn’t worry too much about the word. So I don't think the term end-of-life should be given priority. We shouldn't be too obsessed with the term end-of-life. Maybe we should be more obsessed with needs or a better term for it, or goals of care. Yes, we should be more obsessed with goals of care and needs than on end-of-life. Because that boxes people in.

Beginning with the individual patient

F: But you know, how do I view ‘end-of-life’ individualistically? I don’t know I can’t tell when, whether it’s really ‘end-of-life’. I can tell you that life-limiting illness will eventually lead to needing end-of-life care. The difficulty for us is ‘end-of-life’ can go on for years. Some illnesses can go on for years and some can last only for a short time. There's a wide spectrum. Anyone with life-limiting illness will have end-of-life care needs. But when that care need starts, I don't know.

Matching service capabilities to individual goals and needs

M4: When you talk about operationalisation, it is a matter of how you look at this factor, because you are so limited in resources, not just manpower but physical-based. So if you intend to treat it you just need to work within that framework. …Maybe there are issues to address, psychosocial issues or medical symptoms or physical symptoms we can help to manage. …And hence the operational part of it tends to come in, much more often than not, than the philosophy of it.

I have come to realize that each institution has its strengths, its resources and its limitations, and this has basically moulded how each service runs. For some services it's a doctor-led service, for some services it's a nurse-led service.

For some others…they are very good at management of symptoms because they have so much more experience in their case load. For some services they have strength in apprehending the needs in psycho-social aspects because they have end-of-life experience and manpower to know how to deal with it. There's a lot of diversity, and sometimes when you want to see in terms of how to do it, I see it as trying to match the patient's needs … first trying to identify his needs and then try to match the services with that patient's needs.