The New Medico Legal Society of Hong Kong

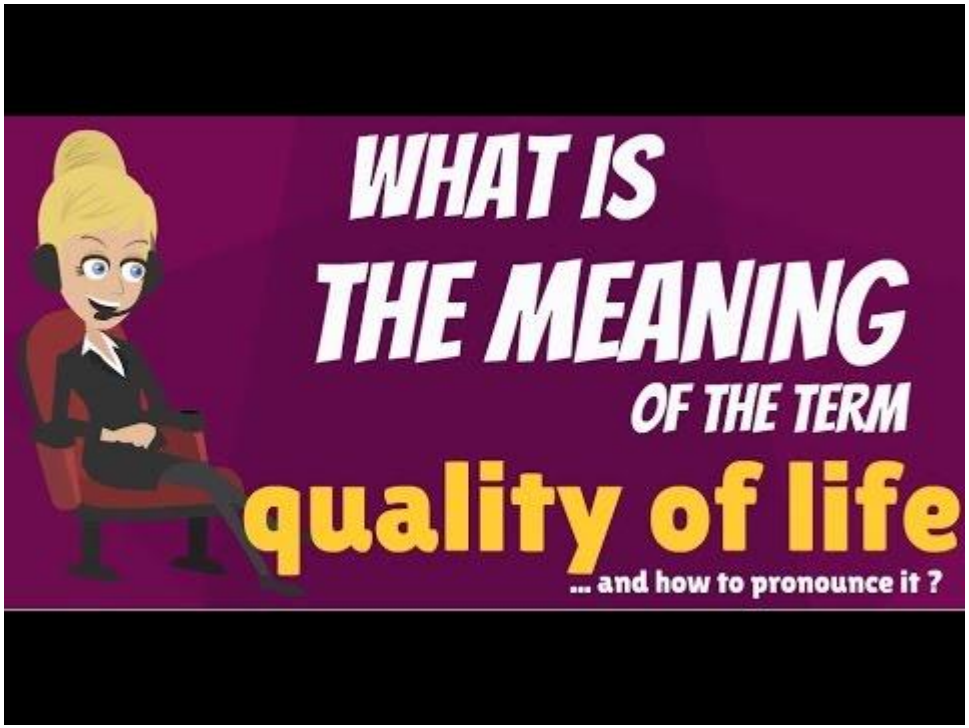
Quality of Death – Law and Ethics

Kar-wai Tong (29.8.2017)

Table of Content

Introduction

- Do you love quality of life?

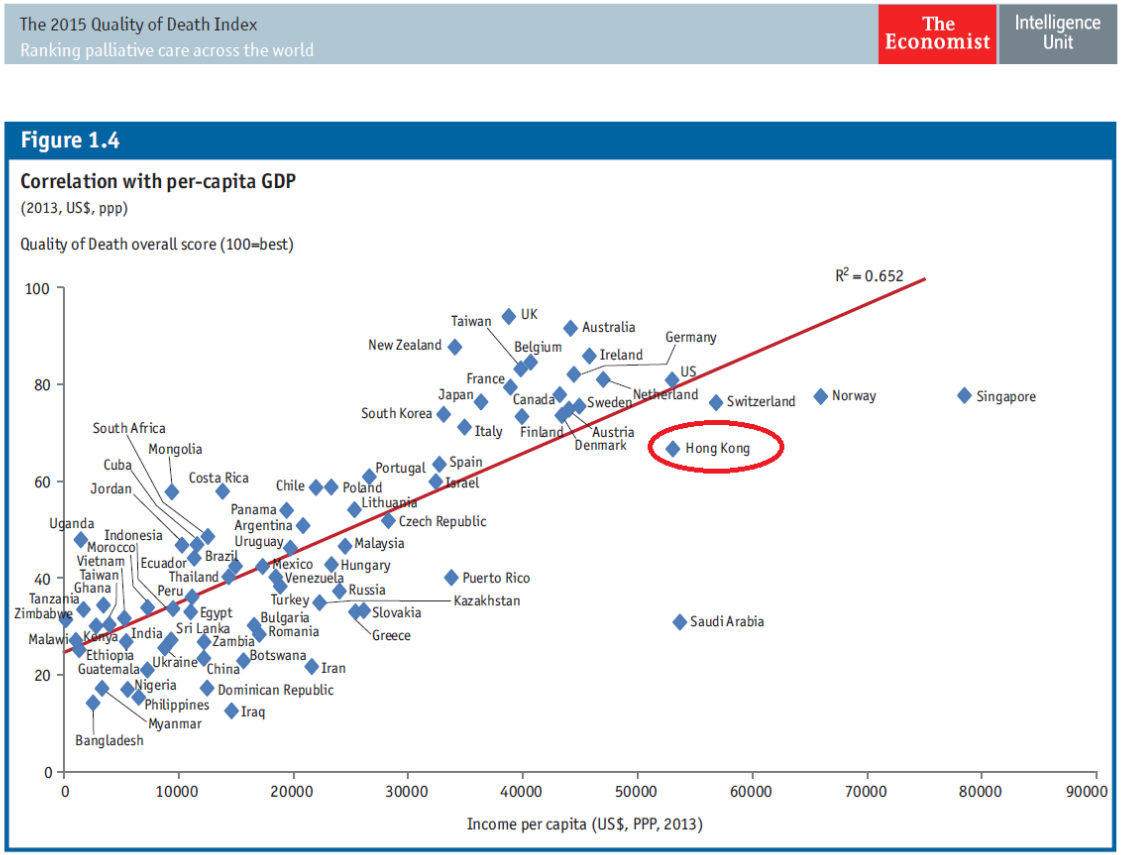


Introduction

- Do you want quality of death?

Quality of Death

- *The 2015 Quality of Death Index* (The Economist Intelligence Unit 2015, p. 17, Figure 1.4)
  - High-income countries may not perform well in the Index.



Quality of Death

- What is quality of death?

Good Death

- The Institute of Medicine of the USA defined a good death in 1997 as:
  - "A decent or good death is one that is: free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' families' wishes; and reasonably consistent with clinical, cultural, and ethical standards." (cited in Forero et al, 2012, p. 2)

Good Death

- The Debate of the Age Health and Care Study Group (1999) identified 12 principles of good death (as cited by Smith, 2000, pp. 129 -130):

1) To have an idea of when death is coming and what can be expected
2) To be able to retain reasonable control of what happens
3) To be afforded dignity and privacy
4) To have control of pain and other symptoms

Good Death

5) To have reasonable choice and control over where death occurs
6) To have access to necessary information and expertise
7) To have access to any spiritual or emotional support required
8) To have access to 'hospice' style quality care in any location

Good Death

9) To have control over who is present and who shares the end

10) To be able to issue advance directives to ensure one's wishes are respected

11) To have time to say goodbye and to arrange important things

12) To be able to leave when it is time, and not to have life prolonged pointlessly

- People's ability to control over their living is of significant importance.

Good Death

- The end-of-life decision making is prevalently increasing as the ageing population and medical treatments see people surviving horrendous insults to their bodies.
- Media's roles along with the perceived risks of litigation have increased to the burden of such decision making.

Good Death

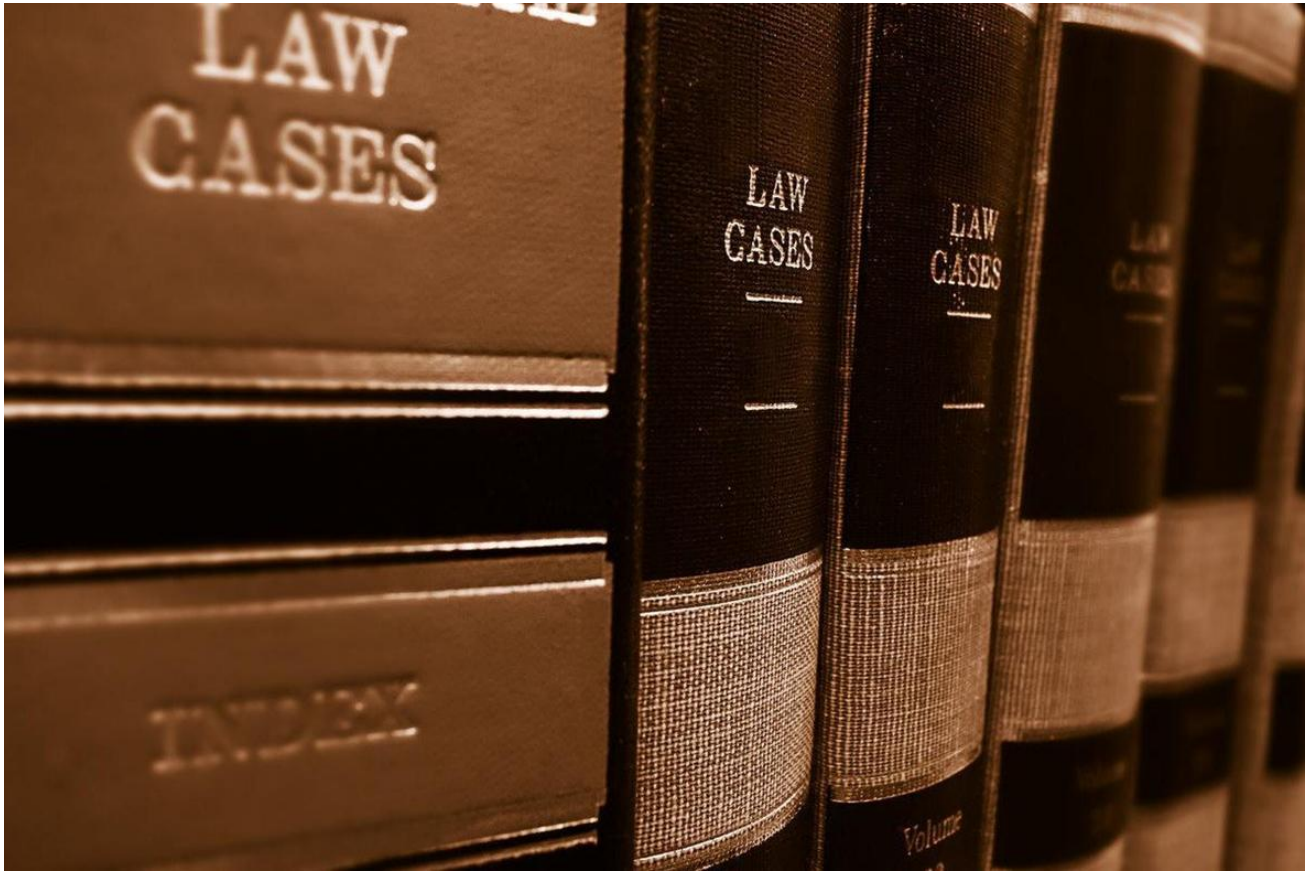
- Not uncommonly, it appears that the outcome is the provision of treatment that a patient, if competent, would not have agreed to.
- When to stop life-sustaining treatment is a question left unanswered despite discussion and debate for years.
- Some dying patients do not comply with the basic understanding of a good death (Forero et al., 2012, p. 2)

Good Death

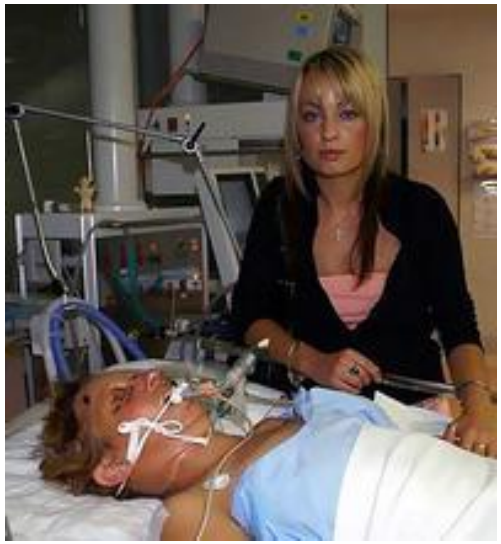
- Problems affecting patients' choices (Tong, 2014)
  - Does the current law facilitate patients' control?
- Problems arising from other parties (Gardner, 2008, pp. 166-167)
  - The level of understanding of the law on the part of medical practitioners
  - The extent to which clinical decisions override other factors
  - Uncertainty in the process of determining the best interests of the patient
  - The role of family members
  - The managing of disputes

A Few Stories

- Remark: The speaker is **not** advocating euthanasia or physician-assisted death!



Victoria – Maria Korp



- In Victoria, Maria Korp, a 50-year old woman, was found laying in the boot of her car for four days in February 2005.
- She was admitted to hospital and diagnosed as one of post-coma unresponsiveness ("vegetative state").
- She was administered enteral feeding by using a percutaneous endoscopic gastrostomy (PEG).
- This case became a movie afterwards.

Victoria – Maria Korp

- Despite maximal artificial nutrition and hydration, Maria continued to lose weight. Her muscles were wasting, leading to severe limb contractions and deterioration of certain internal functions.
- Treatment other than palliative care was futile.
- Decisions were made about removing Maria's tracheostomy, whether to aggressively treat infections, not to return her to the intensive care unit (ICU), and not to use cardiopulmonary resuscitation.
- The critical remaining decision was whether or not to stop artificial nutrition and hydration.

Victoria – Maria Korp

- The treating clinical team could stop futile treatment (non-palliative care) which was not in Maria's best interests.
- However, the media interest arising from the circumstances leading to her injuries and the contemporaneous death of Terri Schiavo in the United States (*Schiavo ex rel. Schindler v. Schiavo* 403 F.3d 1289 (11th Cir. 2005)) deterred the clinical team to do so.

Victoria – Maria Korp

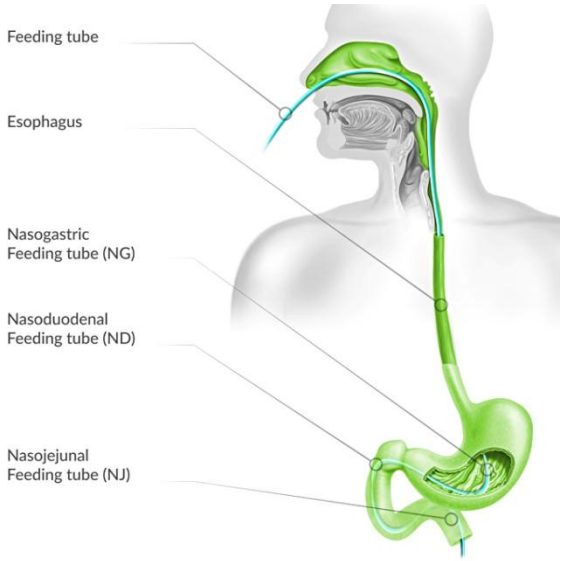
- The decision making was complicated by the public statement of Maria's husband
  - He had been charged with her attempted murder.
  - He would oppose in court any attempt to stop treatment.
  - He argued that his wife was a devout and practising Catholic and would like to continue treatment indefinitely.

Victoria – Maria Korp

- Subsequently the hospital applied to the Victorian Civil and Administrative Tribunal.
- The Public Advocate became Maria's guardian by law, based on the following considerations:
  - Maria's husband had a conflict of interest
  - Her daughter declined the onerous responsibility
  - Other family members were rejected
- Powers of the guardian include the decision-making power as to the continuity of medical treatment.

Victoria – Maria Korp

- In Victorian law, legal issues involved:
  - Whether enteral feeding constituted medical treatment (which could be refused) or palliative care (which could not be refused).
  - The Victorian Supreme Court in the case of *Mrs BWV (Re BWV; Ex parte Gardner* (2003) 7 VR 487) in 2003 ruled that PEG feeding was medical treatment.
- Maria's guardian could therefore lawfully refuse the enteral feeding, provided doing so was in her best interests.



Victoria – Maria Korp

- The guardian
  - conducted an investigation, including the review of the tests and clinical observations, her prognosis, treatment options, and the risks arising from all options;
  - held meetings with specialists such as neurologists, physicians, palliative care specialists, and nurses;
  - questioned and tested medical opinions at those meeting;
  - centred on ascertaining Maria's wishes and values; and
  - concluded that no evidence was available showing her views or wishes about medical treatment.

Victoria – Maria Korp

- It was also concluded that she was a devout and practising Catholic.
- Because of the controversy, the guardian explored this element by applying the medical facts to a statement entitled 'To the participants in the International Congress on "Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas"' given by the former Pope John Paul II on the issue of withdrawing nutrition.

Victoria – Maria Korp

- Pope John Paul II (2004, para 4) said,
  - "I should like particularly to underline how the administration of water and food, even when provided by artificial means, always represents a *natural means* [with emphasis] of preserving life, not a *medical act* [with emphasis]. Its use, furthermore, should be considered, in principle, *ordinary and proportionate* [with emphasis], and as such morally obligatory, insofar as and until it is seen to have attained its proper finality, which in [the case of vegetative state] consists in providing nourishment to the patient and alleviation of his suffering."

Victoria – Maria Korp

- The guardian consulted a Catholic priest who was expert in ethics.
- The priest agreed that withdrawal was consistent with the statement of Pope John Paul II.
- Treatment other than palliation was then withdrawn.
- Maria died within 9 days.

UK – Diane Pretty

- The right to die?
  - Although the rights to life and health are recognised internationally (e.g. articles 3 and 25(1) of the Universal Declaration of Human Rights, there is no agreement on the right to death.
  - The right to die is extremely controversial, which is obvious in the heated debate on euthanasia and physician-assisted suicide.

UK – Diane Pretty

- In *Pretty v. United Kingdom* (Application 2346/02), (2002) 35 EHRR 1, [2002] 2 FCR 97 (European Court of Human Rights), Diane Pretty suffering from an advanced stage of motor neurone disease wanted to control when and how she died.
- Her husband agreed to assist her suicide if the Director of Public Prosecutions (DPP) in the UK would undertake not to prosecute him for the offence of assisting suicide contrary to section 2(1) of the Suicide Act 1961.
- Suicide is not a crime in the UK, but helping others commit suicide is a criminal offence.

UK – Diane Pretty

- Diane appealed to the European Court of Human Rights at last and claimed that her rights under certain articles, including Article 2 (everyone's right to life shall be protected by law) of the European Convention on Human Rights 1950 (ECHR 1950) had been infringed upon.
- The European Court of Human Rights held that the right to life guaranteed by Article 2 of ECHR 1950 did not offer a right to die and was "unconcerned with issues to do with the quality of living or what a person chose to do with his or her life."

UK – Purdy

The Telegraph

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Chief judge Lord Phillips admits to 'sympathy' for assisted suicides

Lord Phillips, Britain's most senior judge, has said he feels "enormous sympathy" for terminally ill patients who want to end their own lives in assisted suicides.

Campaigners are claiming that Lord Phillips' private views clouded his role in the Debbie Purdy case Photo: DAVID ROSE

Law and Order
News » UK News »

In Law And Order

Operation Strong Tower

Hatton Garden heist

By Mary Riddell and James Kirkup
10:19PM BST 10 Sep 2009

Lord Phillips of Worth Matravers said he sympathised with people facing a "quite hideous termination of their life" as a result of "horrible diseases" who wanted to avoid a prolonged death and spare their relatives pain or distress.

In an interview with *The Daily Telegraph*, the president of the new Supreme Court said the issue of assisted suicide was a "very difficult area" for the law to deal with.

However, in a candid admission for a senior judge, he disclosed a view

- In the UK, the Assisted Dying for the Terminally Ill Bill failed to pass the Parliament (Coggon, 2006, p. 219, Footnote 2 & p. 23).
- Case law is not favourable to assisted death, despite the fact that Chief Judge Lord Phillips showed "enormous sympathy" for terminally ill patients wanting to terminate their lives through assisted suicide (Riddell & Kirkup, 2009) after the ruling of the House of Lords (now "the Supreme Court" since 1 October 2009) in *R (on the application of Purdy) v DPP* [2009] UKHL 45.

UK – Charlie Gard

- Timeline of Charlie's case: http://www.bbc.com/news/uk-england-40745988 (accessed 26 August 2017)

UK – Charlie Gard

- *Great Osmond Street Hospital v Constance Yates, Chris Gard, and Charlie Gard* (by guardian) FD17 P00103 and FD17 P00358
  - Frances J sitting at the Royal Courts of Justice ruled, inter alia, at page 3:
    - "It is not in Charlie's best interests for artificial ventilation to continue to be provided to him and it is therefore lawful and in his best interests for it be drawn."

UK – Charlie Gard

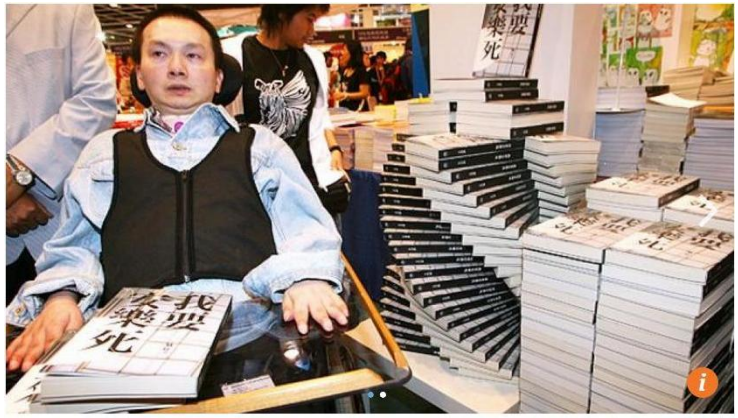
- Healthcare institutes and practitioners faced pressure (see the last page of the judgment)

6. For the avoidance of doubt no one shall in connection with these proceedings publish or reveal:-
   a. The identity of any agency care provider, health professional or expert who has been or may be engaged by Charlie's parents in relation to proposed arrangements for Charlie's care, other than those set out at paragraph 4(i)-(iii) above;
   b. For the avoidance of doubt, the doctors who attended court on 25th and 26th July 2017 on behalf of GOSH are part of Charlie's treating team and therefore are covered by the terms of the reporting restrictions order made by the Supreme Court dated 8th June 2017 and amended on 17th July 2017.
   c. The identity of the Hospice and/or its actual or approximate location (including the County in which it is situated)
   d. The identity of any treating staff from the Hospice
   e. The details of the Confidential Annexe
   f. Any picture of any of the above

HIGH COURT OF JUSTICE
27 JUL 2017
FAMILY DIVISION

Hong Kong – Siu-pun Tang (Ah Bun)

- Ah Bun's story:
  - Mr. SP Tang, with a nicked name "Ah Bun", a quadriplegic, would like to end his life and urged the government in 2003 to legalize euthanasia.
  - He wrote a book in Chinese entitled "I Want Euthanasia".
  - Upon its publication in 2007, he changed his mind about ending his life and rediscovered hope.
  - He died at the age of 43 in 2012 because of septicaemia, or blood poisoning.



Hong Kong – Siu-pun Tang (Ah Bun)

- The standpoint of the Hong Kong Government by the reply of the then Secretary for Health and Welfare (Legislative Council of Hong Kong 2000, pp. 3598–3599):
  - Although the term euthanasia is not used in our local statutes, the acts involved in euthanasia are illegal in Hong Kong by virtue of the provisions in the Offences Against the Person Ordinance (Cap 212) which provides [*sic*] that a person [*sic*] "aids, abets, counsels or procures the suicide of another to commit suicide shall be guilty of an offence". A person also commits the crime of murder if he unlawfully kills another person with the intent to kill or cause grievous bodily harm.

The Netherlands (as An Example)

- In the Netherlands
  - Euthanasia has been decriminalized since 1973 (Fenigsen, 1990).
  - Physician-assisted suicide was legalized in 2001 when the Dutch Parliament passed "the Evaluation of Ending Life on Request and Assistance in Suicide and A Change of the Penal Code and the Burial Act (Law Evaluating Ending Life and Assistance with Suicide)" (Kimsma & Leeuwen, 2001, p. 445).

Good Death?

- Good death is about control and access, but a number of factors influence people's choices:
  - Law
    - The right to control death is not absolute under law
    - Law depends on the ethical standard of a jurisdiction
    - Different countries take very different approaches.

Good Death?

- Good death is about control and access, but a number of factors influence people's choices:
  - Other non-legal concerns
    - Cultural belief, e.g. taboos
    - Economic considerations
    - Pressure imposed by the public/mass media vs. clinical judgement
    - How to ensure the choice to die (if applicable) is final?

Advance Directives

- Problems arise with end-of-life situations when a person, because of a disability, lacks the capacity to exercise their autonomy by consenting to or refusing medical treatment.
- An issue relating to the capacity discussion is the advance directives.

Advance Directives

- The concept of advance directives has been introduced in countries such as Australia, Canada, United Kingdom, Singapore, the United States, etc. to minimize the uncertainty faced by a doctor or family members about the medical treatment that a patient wishes to receive when he is no longer mentally competent to make such decisions (Food and Health Bureau of Hong Kong, 2009, p. 1)

Advance Directives

- The Law Reform Commission of Hong Kong (2006, p. 12) gives a definition as follows :
  - An advance directive for health care is described as a statement, usually writing, in which a person indicates when mentally competent the form of health care he would like to have at a future time when he is no longer competent.
- The Law Reform Commission of Hong Kong (2006, p. 161) recommended in 2006 to retain the existing law and promote the concept of advance directives by non-legislative means.

Advance Directives

- A sample of advance directives in Hong Kong:
  - http://www.ha.org.hk/haho/ho/psrm/CEC-GE-1_appendix1_en.pdf (accessed 29 August 2017)
- The current use of advance directives in Hong Kong?

Conclusion

- "People are always talking about 'vision' and they will make many strategies to achieve the vision. If a vision is so important in one's life, maybe we can take death as the ultimate vision for us. If so, not many people have strategies or planning or whatever management to achieve such a last vision of life" (Tong, cited in Keys, 2010, p. 201)

Conclusion

- Good death – health concerns
  - Advance care planning is important.
  - For patients who do not have the capacity to decide on life-sustaining treatment for themselves, it is important to build consensus with patients' families to determine the best treatment for that individual, at that time, and in that place. (NSW Health of Australia, 2005 (2012 reviewed), p. 2)
  - Development of palliative care

Conclusion

- Good death – legal aspects, for example,
  - Review of advance directives
  - To facilitate home death, including but not limited to:
    - Births and Deaths Registration Ordinance (Cap 174)
    - Coroners Ordinance (Cap 504)
    - Public Health and Municipal Services Ordinance (Cap 132)
- Good death – public education
  - Euthanasia vs. withholding/withdrawal of futile treatment

Conclusion

- To end with a short video:
  - A father's love for his son
  - https://www.youtube.com/watch?v=ts8F6dV_0uM (accessed 26 August 2017)

Conclusion


CARING
HANDS


BE
PREPARED


SUSTAINABLE FUTURE
Equitable Societies
Living within means
sustainable development
Healthy
Food & Ecosystems
EDUCATION
INSPIRATION
innovation
KNOWLEDGE
SKILLS
VALUES
ATTITUDES


A Big
THANK
YOU!

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