Ethical Challenges in End-of-Life Care: Local Perspectives in Hong Kong

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Ethical Challenges in end-of-life care

1) Breaking bad news
2) Euthanasia requests
3) Symptomatic treatment that may shorten life
4) Withholding and withdrawing life-sustaining treatment

Withholding and withdrawing life-sustaining treatment (LST) in end-of-life care

Before talking about the situation in Hong Kong

- let us first look at the situation in Taiwan

The “Patient Autonomy Act” (病人自主權利法) in Taiwan

- Law passed in 2016, to become effective in 2019.
- Advance directives will then have legal status.
- Before that, only has “Hospice Palliative Care Act” (安寧緩和醫療條例), which is only for **terminally ill** patients:
  - allows a competent patient to refuse futile LST, and family members to refuse futile LST for incompetent patients.

Scope of “Patient Autonomy Act”

- Extends beyond the terminally ill:
  - 處於不可逆轉之昏迷狀況；irreversible coma
  - 永久植物人狀態；persistent vegetative state
  - 極重度失智；severe cognitive impairment
  - 其他經中央主管機關公告之病人疾病狀況或痛苦難以忍受、疾病無法治癒且依當時醫療水準無其他合適解決方法之情形。Other officially announced irreversible conditions

Why are Hospice Palliative Care Act and Patient Autonomy Act necessary in Taiwan?

- According to Taiwan legislator 楊玉欣 Yang Yuxing, who spearheaded the Patient Autonomy Act:

- Because of particular articles in Medical Care Act, Physicians Act, and Criminal Code of Taiwan, unless the patient has legal documents signed under the **Hospice Palliative Care Act** or **Patient Autonomy Act**, the doctor has to perform resuscitation for all patients.

Situation in Hong Kong

Providing life-sustaining treatment to a patient in Hong Kong

- Competent patients: must have consent

- Incompetent patients:
  - a doctor may provide life-sustaining treatment to an incompetent patient without consent if this is **in the best interests** of the patient (Mental Health Ordinance Cap 136 Section 59ZF)

That means: Cannot provide life-sustaining treatment to a patient

- If a competent patient refuses the treatment.
- If the treatment is considered NOT in the best interests of an incompetent patient.

Whether a treatment is in the best interests of the patient or not

- balancing the burdens and benefits of the treatment towards the patient;
- often involves quality-of-life considerations and can be **value-laden**.

For an incompetent patient

- The prior wishes and values of the patient is important in deciding what is in the patient's best interests;

- Important to build consensus with the family members.

Difficulties in building consensus with the family members

- Family members may not know the prior wishes of the patient.
- Family members may have denial of the terminal condition, and have unrealistic expectations on the outcome of treatment.
- Family members may misunderstand that, to show filial piety, one should never forgo treatment for their loved ones.

Good if the patient's views are made known to others before losing capacity

Advance directives in Hong Kong

- No legislation on advance directives.
- Under common law: A **valid** and **applicable** advance decision refusing life-sustaining treatment has legal status, and must be respected.
- In Hong Kong, the term **Advance Directive (AD)** usually refers to this.
- A proxy directive on healthcare issues currently does not have legal status in Hong Kong.

Enduring power of attorney (EPA)

- Under the current legislation in Hong Kong (Cap 501), a person can appoint an attorney to make decisions on **property** and **financial matters** on behalf of the donor when the donor becomes incompetent.

- The Government of Hong Kong is considering extending the power of the EPA to personal care decisions, including healthcare decisions. Still not sure whether the law will include life-sustaining treatment or not.

The Law Reform Commission (LRC) Report on AD 2006

- Recommended AD to be promoted under the existing common law framework instead of legislation.
- Proposed a model AD form, the scope of which is limited to
  - the terminally ill,
  - irreversible coma, and persistent vegetative state.
- But it is not the only format of AD that can be used under common law.

Government of Hong Kong 2009

- Suggested to make the concept of AD accessible to the public;
- No intention to advocate the general public to make AD.

The Hospital Authority (HA) of Hong Kong issued Guidelines on AD in 2010, revised in 2014 and 2016

HA AD Form

- Modified from LRC model form;

- In 2010 version, scope limited to:
  - the terminally ill,
  - irreversible coma, and persistent vegetative state.

- Addition of another category "**other end-stage irreversible life-limiting condition**" in 2014.

Who would make an AD and how?

- In HA, usually made by patients with advanced irreversible illnesses via advance care planning.
- Added a new section on advance care planning in the HA Guidelines on Life-Sustaining Treatment in 2015.

Advance care planning

- Emphasizes the communication process among the patient, the family and the healthcare providers.

- Encompass not just decisions on specific LST, but also preferences, values and goals of care in a broad sense.

ACP process

- Sensitive discussion with good communications skills:
  - Avoid a rigid, routinized or checklist approach
  - Staff with necessary knowledge and skills
  - Ongoing process; review may be required.
- Good documentation
- A standardized template for ACP documentation for the whole of HA is being developed.

Outcome of ACP

- Competent patient:
  - preferences for future medical or personal care;
  - make an AD;
  - assign a family member for future consultation.
- Incompetent adult or minor:
  - consensus between family and healthcare team about plans on future medical or personal care.

Challenges and concerns

(1) Lack of specific legislation on AD in HK

- Law Reform Commission Report of 2006:
  - Under the existing common law, a valid and applicable AD refusing medical treatment has the **same effect as a contemporaneous oral instruction**.

- The Mental Health Ordinance Cap 136 Section 59ZF (a doctor may provide LST to an incompetent patient without consent if this is in the best interests of the patient) does not specify its relationship with an AD.

(1) Lack of specific legislation on AD in HK

- Usually, an Ordinance over-rides common law if there are conflicts.
- Though should not affect the legal status of AD in the great majority of cases, there could be grey areas.

- **Good to have legislation to clarify the relationship of the Mental Health Ordinance and an AD.**

(2) Respecting an AD in an emergency situation

- Not easy:
  - An AD has to be judged to be valid and applicable before it is followed
- USA: Physician Order for LST (POLST)
- HK: The HA DNACPR form for non-hospitalized patients

Guidelines on Do-Not-Attempt Cardiopulmonary Resuscitation (DNACPR) 2014

- Extension to seriously ill **non-hospitalized** patients.
- Emergency Department staff can follow the DNACPR recommendation.
- Unfortunately, this is not yet accepted by the ambulance crew:
  - concern over the “duty to resuscitate” in the Fire Services Ordinance

(3) Problems among professional staff

- Confused by the complexities of the issues:
  - Different countries have different approaches because of differences in cultural and legal contexts
- Lack of knowledge and skills in end-of-life decision-making and communication.
- Inadequate time in the clinics to have proper communication with patients and families.

(4) Difficulties in discussing death issues with patients and family

- Lack of understanding of LST, AD, DNACPR.
- Taboo in talking about death issues in Chinese culture.

(5) Problems in community discussion

- Mixing up physician assisted death and foregoing life sustaining treatment.

- Mixing up promotion of making AD among patients with advanced irreversible illness and among healthy members of the public.

Ways forward

What can be done to reduce difficulties in end-of-life decisions in HK?

- The need of a government policy on end-of-life care, revising/enacting relevant legislations as necessary.
- More education among healthcare professionals.
- Healthcare professionals allowed to spend more time in end-of-life care.
- HA is considering establishment of a corporate-led steering group on education and implementation of AD/DNACPR related issues.

What can be done to reduce difficulties in end-of-life decisions in HK?

- Promote AD in patients with advanced incurable illnesses, as part of ACP, involving the family early.
- Death education among the public.
- For elderly but relatively healthy members of the public:
  - To understand the meaning of LST and AD;
  - To encourage discussion with family members about preparation of death;
  - To express personal values and preferences about end of life care;
  - May assign a family member for future consultation.

What can be done to reduce difficulties in end-of-life decisions in HK?

- Overall improvement in service provision in end-of-life care,
  - both in quality and access,
  - both at the individual service provider level and at the system level.

Thank you!