Reflections on the Development of Advance Directives in Hong Kong

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Framework of my talk

- Brief description on the development of AD in Hong Kong.
- Three issues for discussion:
  - Whether HK should enact specific legislation on AD
  - Advance refusal of oral feeding
  - Whether AD should be widely promoted among healthy members of the public in HK
- Discussion in my personal capacity.

Discussion on AD in Hong Kong

- AD seldom discussed among healthcare professionals or among the public until 2004, when
  - the Law Reform Commission of the Government of Hong Kong issued a consultation paper on AD.

2002 HA Guidelines on life sustaining treatment (LST)

- A small paragraph on AD, quoting relevant sections from the British Medical Association Guidelines in the appendix.

The Law Reform Commission (LRC) Report on AD

- LRC released Report on AD in 2006.
- LRC recommended AD to be promoted under the existing common law framework instead of legislation.
- AD in the local context means an advance refusal of life-sustaining treatment, which has legal status under common law. A proxy directive has no legal status in Hong Kong.

The Law Reform Commission (LRC) Report on AD

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

Food and Health Bureau of the Government of Hong Kong SAR Consultation Paper 2009

- Suggested to make the concept of AD accessible to the public;
- No intention to advocate the public to make AD;
- Suggested to have guidelines for professionals;
- Considering whether to promote the concept of advance care planning (ACP) in Hong Kong.

Guidance for HA Clinicians on AD issued by HA in 2010

- A valid and applicable advance refusal of life-sustaining treatment must be respected.
- Validity:
  - An AD is valid if the patient is mentally competent and properly informed when making the directive.
- Applicability:
  - A valid AD becomes applicable when the patient suffers from the **pre-specified condition**, and is **no longer competent**.

HA AD Form in 2010

- Modified from LRC model form;

- Scope limited to
  - terminally ill,
  - irreversible coma, and
  - persistent vegetative state.

Revision of AD Guidance and forms in 2014, together with revision of DNACPR Guidelines

- Creation of a short HA AD form for terminally ill patients refusing CPR only;

- Revision of the full HA AD form, to include the category "**other end-stage irreversible life-limiting condition**" to the form, in order to tally with the DNACPR form for non-hospitalized patients.

Current usage of AD in HA

- Currently, AD usually made by patients with advanced irreversible illnesses via advance care planning.

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

- First HA-wide Guidelines promulgated in 1998:
  - Guidelines on In-Hospital Resuscitation Decision
- Guidelines updated in Oct 2014:
  - Renamed as Guidelines on DNACPR

Extension of DNACPR Guidelines to seriously ill **non-hospitalized** patients

- DNACPR form signed only when
  - there is a valid and applicable AD refusing CPR, or
  - the DNACPR decision is made through an explicit advance care planning process (minors or incompetent adults without AD); and
  - in defined categories of seriously ill patients with end-stage irreversible diseases.
- Not yet accepted by the ambulance crew:
  - concern over the "duty to resuscitate" in the Fire Services Ordinance.

New section on “advance care planning” added in 2015 to Guidelines on LST

- For patients with progressive diseases
- Sensitive discussion with good communications skills, avoiding a rigid or routinized approach
- A competent patient may:
  - Express preferences for future medical or personal care;
  - Make decisions regarding individual LST or disease targeted treatments;
  - Make an AD;
  - Assign a family member for future consultation.

Issues for discussion

Issue 1

- Whether HK should enact specific legislation on advance directives?

No 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**.
  - AD to be promoted under the existing common law framework instead of legislation.

Legal concern

- The Mental Health Ordinance Cap 136 Section 59ZF:
  - a doctor may provide life-sustaining treatment to an incompetent patient without consent if this is in the best interests of the patient.
- Relationship with an advance refusal of treatment is not mentioned.
- If there is conflict, specific legislation overrides common law, i.e. **best interests override AD**.

Assessing best interests

- “Even when the best interests of the MIP is considered under the Mental Health Ordinance, the doctor and the guardian must take into account not only clinical benefit but also the MIP's value and belief and what the MIP might have wanted if competent.
- A valid and applicable AD must be treated as an explicit expression of a patient's wish to refuse medical treatments in specified conditions.”

Guidance for HA clinicians on AD

- In the great majority of cases, **best interests will be in line with the patient’s advance refusal**.

Possible exceptions

- A 40 years old Jehovah Witness patient with an AD refusing blood transfusion is admitted unconscious after a road traffic accident. Blood transfusion is needed to save his life, and it is expected that he can make a full recovery with optimal treatment.

Possible exceptions

- A 50 years old sociology professor signed an AD saying that she would refuse all medical treatment if she has a stroke leading to inability to read sociology texts. She now has a stroke with global aphasia. She can walk slowly with a quadripod with assistance, and can take food orally when fed. She seems to enjoy the food, enjoy music and enjoy the accompaniment of her family members.
- She then develops a pneumonia. The doctor considers that if not given antibiotics, she may die.

Difficulties in making a decision

- How to balance autonomy and beneficence
- How to balance critical interest and experiential interest
- Difficulty to reach consensus between healthcare team and family members

What can be done to reduce the difficulties?

Limiting the specified conditions to non-controversial situations in the AD forms

- The specified conditions in the Law Reform Commission AD form and Hospital Authority AD forms are non-controversial situations.

- However, does not preclude a person making an AD using other formats.

Clarifying the legal relationship between AD, and best interests

- In UK, a valid and applicable advance refusal of treatment overrules:
  - A decision of lasting power of attorney made **before** the AD
  - A decision to treat based on the best interests of the patient

Mental Capacity Act (MCA) Code of Practice: section 9.33

If the UK approach is followed, does this mean that treatment should be withheld for the 2 cases?

An AD has legal status only if it is valid and applicable

Whether AD is valid and applicable

- If the person:
  - has done anything that clearly goes against their advance decision
  - would have changed their decision if they had known more about the current circumstances.

MCA Code of Practice: quick summary of chapter 9, p. 159.

Jehovah Witness patient

- The patient is refusing transfusion due to religious reason, and the decision is independent of the actual clinical situation;
- He understood that he may die without transfusion and still signed the advance refusal.

The sociology professor

- Did she know that she could still have a “happy” life despite inability to read sociology texts?
  - If no, then the AD may not be valid or applicable.
  - If yes, but she still decides to refuse medical treatment, we have to follow the AD.
  - If in doubt, treatment may be provided until clarification.

My view

- It is useful to clarify the relationship between the Mental Health Ordinance Cap 136 Section 59ZF and an AD, following the approach in UK.

Issue 2

- Should an advance refusal of oral feeding be followed?

Is this situation ethical?

- Following the patient's advance decision to refuse oral feeding, a demented patient is not given food despite the patient pleads for food.

Paper by Prof Paul Menzel

- Then-self and now-self
- Critical interests and experiential interests
- Sliding scale: "*the authority of an advance directive to withhold life-sustaining food and water or refuse life-saving treatment increases as the person's capacities to generate new critical interests and enjoy life decrease.*"

Menzel and Chandler-Cramer, Advance directives, dementia, and withholding food and water by mouth, *Hastings Center Report*, 2014.

Approach in UK and in HA

- Guidance for HA clinicians on AD:
  - A patient cannot use an AD to refuse basic care;
  - Non-artificial nutrition and hydration form part of basic care (wordings from Law Reform Commission).
- UK: "An advance decision cannot refuse actions that are needed to keep a person comfortable (sometimes called basic or essential care). Examples include warmth, shelter, actions to keep a person clean and the **offer of** food and water by mouth."

MCA Code of Practice: Section 9.28

My views

- The offer of oral food is not the same as forced feeding.
  - Consider: voluntary refusal of oral food.
- Oral feeding is not medical treatment, even if feeding requires assistance by another person.
  - Consider: infants.
- Not offering basic care is against human dignity.
  - Consider: keeping warm and clean.

My views

- Offer oral food, but no forced feeding.
- No artificial nutrition and hydration.
- Serves as an indication of the patient's perception that life is not worth living.
  - This should be taken into account when considering life-sustaining treatments not included in the advance refusal of the patient.

Issue 3

- Should AD be widely promoted among healthy members of the public in HK?

Different countries have different approaches

- Wide promotion among the public in USA
- More judicious approach in UK

Potential problems of healthy members of the public signing an AD

Utilizing LRC and HA forms

- Scope in LRC model form:
  - Terminal illness
  - Irreversible coma and persistent vegetative state
- Additional scope in HA form:
  - Other end-stage irreversible life-limiting condition
    - Irreversible loss of major cerebral function not falling into "irreversible coma and PVS"
    - Other end-stage organ failure not falling into "terminal illness"

(a) Irreversible coma or PVS;
(b) Irreversible loss of major cerebral function not falling into (a)

- May result from unexpected catastrophic events, e.g. massive stroke or trauma.
- Life-sustaining treatments are not withheld until “irreversibility” is clear.
- Poor quality of life regardless of the underlying cause of the conditions.
- Not much controversy to have an advance decision on these conditions.

Terminally ill and other end-stage irreversible life-limiting condition

- A wide range of possible scenarios, with different disease burdens and trajectories.
- Outcome of different LST may be very different in the different scenarios.
- To be properly informed to make an advance decision when healthy, information needed may be overwhelming and distressing (Randall and Downie 2010)
- In the great majority of cases, patients are **competent** when the advanced illness is diagnosed.

Terminally ill and other end-stage irreversible life-limiting condition

- Are there advantages in making an advance decision well before the patient is ill?
  - Reduces the stress to make end of life decisions when the patient is ill?
  - To cover the rare situation, when the patient is already incompetent on presentation of the illness?

- If the person simply does not want LST, regardless of the nature of the terminal illness, are the detailed clinical information necessary?

Reduces the stress to make end of life decisions when the patient is ill?

- If the patient reassesses the actual situation, then there will still be stress.

- If the patient does not reassess the actual situation, he/she may have missed the chance to change his/her mind:
  - A person's preference for treatment may change when the person actually becomes ill.

A person's preference for treatment may change when the person actually becomes ill

- The acceptability of treatment resulting in certain diminished states of health may increase with time, and increased acceptability is more likely among patients experiencing a decline in that same domain (Fried et al 2006).

- A healthy person's perception on hypothetical illness states may be worse than the perception of a chronically ill patient (Patrick et al 1997).

To cover the rare situation, when the patient is already incompetent on presentation of the illness?

- Mental incompetence on presentation of a previously undiagnosed end-stage illness may often be **reversible** with treatment.

- A person's preference for treatment may change when the person actually becomes ill.

Are the detailed clinical information necessary if the person simply does not want LST, regardless of the nature of the terminal illness?

- If the advance decision is refusal of CPR,
  - not much controversy regardless of the nature of the terminal illness.
- For other LST, the balance of burdens and benefits may be very different in different scenarios.
  - For some patients, the last few months of life can be very meaningful to him/her and the family members.
  - A broad brush refusal of all LST in terminal illness may lead to loss of meaningful survival.
  - Is it appropriate to make a refusal **not** knowing the burdens and benefits of what are refused?

Routinized "checklist" approach:

- Examples in "Are some conditions worse than death?" in *Consumer's Toolkit for Health Care Advance Planning* of American Bar Association Commission on Law and Aging 2005.
  - "no longer can walk but get around in a wheelchair"
  - "no longer can control your bladder"

- Oversimplifies the scenarios, and
- Issues are taken out of context.

Specified condition in the AD is NOT advanced and NOT irreversible

- Very controversial
- Potential "gain"
  - Avoid suffering from treatment if treatment is invasive
  - Avoid suffering while waiting to see if condition is reversible or not
- Definite loss
  - Lost chance of meaningful recovery
- Does the person know any details of the burdens and benefits of the treatments refused?

Respecting Choices of Gundersen Medical Foundation, USA

- "It is clearly impossible and would be dangerous to plan for everything that might afflict a human being."
- "1st step" (for healthy people over age 55)
  - Appoint surrogate decision maker
  - Advance refusal would be limited to the goals of care in the event of **permanent severe neurological injury**.

Papers on ACP from USA

- Henry S. Perkins, **Controlling Death: The False Promise of Advance Directives**, *Ann Intern Med* 2007;147:51-57.

- "Many experts blame problems with completion and implementation, but the advance directive concept itself may be fundamentally flawed… Because advance directives offer only limited benefit, **advance care planning should emphasize not the completion of directives but the emotional preparation of patients and families for future crises**."

Papers on ACP from USA

- Rebecca L. Sudore, and Terri R. Fried, **Redefining the "Planning" in Advance Care Planning: Preparing for End-of-Life Decision Making**, *Ann Intern Med* 2010 August 17; 153(4): 256–261.

- "… shifts the focus [of advance care planning] from having patients make premature decisions based on incomplete information, **to preparing patients and their surrogates for** the types of decisions and conflicts they may encounter when they do have to engage in **in-the-moment decision making**."

My views

- For patients with advanced irreversible illnesses:
  - To encourage advance care planning and AD, involving family members early.

- 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.

My views

- For elderly but relatively healthy members of the public:
  - AD limited to the goals of care in the event of **permanent severe neurological injury**,
    - irreversible loss of major cerebral function,
    - irreversible coma, PVS.
- When having more serious illnesses:
  - To review AD and consider extending the AD to other scenarios.

My views

- For younger members of the public:
  - To encourage death education.
- For healthcare professionals:
  - To encourage more education regarding end of life care.

Open discussion