Advance Care Planning and Advance Directives: Application and Challenges

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Contemporary developments in medicine

- Near the end of life, many high tech treatments are possible to prolong life
- However, some may
  - Only prolong the dying process
  - Do more harm than good
- How to decide?

HA Guidelines on Life-sustaining Treatment (LST) in the Terminally ill in 2002

When is it appropriate to withhold or withdraw LST?

- When it is the wish of a mentally competent patient
- When the treatment is futile

Determination of futility

- balancing the burdens and benefits of the treatment towards the patient, and asking whether the treatment is in the **best interests** of the patient.

- involves quality of life considerations and can be **value-laden**.

- **consensus building process** between the healthcare team and the patient and family.

Problems when the discussion on the issue is made only when the patient is dying

- Unable to obtain the view of the patient
- Inadequate time for the patient and family to accept the bad news and to make an appropriate decision

Advance care planning (ACP)

- "a process of communication among patients, their health care providers, their families, and important others regarding the kind of care that will be considered appropriate when the patient cannot make decisions."

Teno JM, Nelson HL, Lynn J. Advance Care Planning: Priorities for Ethical and Empirical Research. Hastings Center Report 1994;24(suppl):S32.

Advance care planning (ACP)

- Should instigate ACP only if the process is considered beneficial to the patient
- The process must be voluntary
- Must approach the discussion sensitively
- Dialogue over a period of time
- The contents of the discussion should be determined by the patient
- Staff need appropriate knowledge and communication skill
- Confidentiality must be respected

Outcome of discussion

- Competent patients:
  - Statement of wishes and preferences
  - **Advance directive** (adults)

Outcome of discussion

- Incompetent patients:
  - An agreement with the family on what is in the best interests of the patient

Other outcomes of discussion

- The family members that the patient would like to be involved in decisions about future care;
- The patient's preferred place of care;
- The patient's needs for religious, spiritual or other personal support.

Advance directive (AD) 預設醫療指示

- While mentally competent, an **adult** may make an **advance refusal of life sustaining treatment (LST)**, specifying what LST one does not want under what situations (e.g. terminally ill; irreversible coma)

- In Hong Kong, the term “AD” usually refers to this.

- Has legal status; helps to reduce the difficulties faced by the healthcare team and the family members.
- A **valid** and **applicable** advance refusal of LST must be respected.
- A proxy directive on healthcare issues does not have legal status in Hong Kong.

The Law Reform Commission (LRC) Report on AD in 2006

- Recommended promoting AD under the existing common law framework instead of legislation.

The Law Reform Commission (LRC) Report on AD in 2006

- 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.

Guidance for HA Clinicians on AD issued in 2010

Guidance for HA Clinicians on AD

- The Guidance is not for "promoting the use of AD in HA", though it could facilitate the use of AD in selected patients, e.g. in the terminally ill.

- AD form modified from the LRC model form

Validity of the AD

- An AD is valid if the patient is mentally competent and properly informed when making the directive.

Applicability of an AD

- A valid AD becomes applicable when the patient suffers from the **pre-specified condition**, and is **no longer competent**.

Applicability in unforeseen circumstances

- If the presenting medical condition is due to an unforeseen situation, for example, injury caused by a traffic accident, the AD is not applicable.

If in significant doubt:

- Continue to provide clinically indicated emergency life-sustaining treatments, while waiting for clarifications.

Revocation of AD:

- Can be revoked orally.
- LRC and HA recommend written revocation.

Challenges to an AD:

- If challenged, while waiting clarifications, clinically indicated life sustaining treatments should be provided;
- If the AD is clearly valid and applicable, but the family members simply objects to it, the AD should be respected;
- In difficult cases, may consult the cluster/hospital clinical ethics committee.

Controversial issue

- Withdrawal of artificial nutrition and hydration in non-terminally ill patients, e.g. persistent vegetative state and irreversible coma.

Legal uncertainties

- According to 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.
- Does an AD override the best interests principle ?

Problem of CPR for terminally ill patients dying at home or long term care homes

Problem when the dying patient reaches the A&E Department

- The receiving team is not the original care team of the patient;
- Difficult for the receiving team to make a decision not to perform CPR, even if the patient has an AD,
  - There may be doubt about the validity and applicability of the AD.

Extend the coverage of HA Guidelines on DNACPR to include **non-hospitalized** patients

- To **communicate** the DNACPR decision to the receiving team in an appropriate manner.

Safeguards for the DNACPR communication

- A specific standardized communication format to the receiving team:
  - Standardized DNACPR form for non-hospitalized patients.
- To ensure appropriateness of the decision:
  - Two doctors are required, one being a specialist;
  - Periodic review and endorsement required.

Safeguards for the DNACPR communication

- The DNACPR decision should be unambiguous and non-controversial.
  - Only when there is a valid and applicable AD refusing CPR,
  - or when the DNACPR decision is made through an explicit advance care planning process (minors or incompetent adults);
  - In defined categories of seriously ill patients with end-stage irreversible diseases.

Assessment by receiving team before withholding CPR

- The receiving healthcare team should ascertain that the decision to withhold CPR remains valid and unchanged, and that the patient's condition when presented to the team falls within the DNACPR form.

- If in doubt, CPR should be given.

Legal concerns

- Being a new paradigm in Hong Kong, there are legal concerns to overcome.

- The guidelines on DNACPR for non-hospitalized patients is not yet accepted by the ambulance crew, who belong to a different Bureau under the Government structure.

Should ACP/AD be widely promoted among healthy members of the public?

Practice overseas: USA

- The Patient Self-Determination Act
  - requires facilities such as hospitals that accept Medicare and Medicaid money
  - to provide written information to all patients concerning their rights under State law to refuse or accept treatment and to complete advance directives.

- Agency for Healthcare Research and Quality 2003

Practice overseas: UK

- Potential benefits and risks of advance care planning
- The importance of sufficient information for the patient to make a decision, which may be overwhelming and cause distress
- Professionals should instigate ACP only if it is judged to be of benefit to the patient

- Fionna Randall and Robin Downie 2010
- National End of Life Programme 2012

Problems in signing an AD while healthy

- May not have proper medical information
- May not have discussed with family
- May not have understood the multitude of scenarios that may happen, e.g. when “terminally ill”
- The preference may change when the person actually becomes ill

The ways forward

- Promotion in patients with advanced incurable illnesses, as part of the advance care planning process, involving the family early.
- Legislation to confirm the relationship between AD and the best interests principle. Review the Fire Services Ordinance (Cap 95) related to the duty of the ambulance crew.
- The need of a government policy on end-of-life care in Hong Kong.
- Training among healthcare professionals.

Ways forward

- Death education among the public:
  - To contemplate the meaning of life and death, so as to be more positive about life.

- For the more elderly 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, but NOT necessarily signing an AD before having any serious illnesses.

Thank you!