The Development of AD, ACP and DNACPR in Hong Kong in Relationship to Dying at Home

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Medicalization of death

- Over 90% of deaths in Hong Kong take place in hospitals.
- For the terminally ill, being surrounded by machines instead of their loved ones in the hospital is not conducive to a good death.

Recent studies showed that many people prefer to die at home if suffering from advanced irreversible illnesses

Knowledge, Attitudes and Preferences of Advance Decisions, End-of-life Care and Place of Care and Death in Hong Kong. A Population-based Telephone Survey of 1,067 Adults.

Journal of the American Medical Directors Association. 2017

Table A1
Number of Study Participants (%) for the Preferred Place of EOL Care and Death (n = 1067)

	Home n (%)	Hospital n (%)	Elderly Home* /Hospice n (%)	Others n (%)
Last year	618 (58.4)	180 (17.0)	251 (23.7)	9 (0.9)
Last weeks	430 (40.6)	430 (40.6)	186 (17.6)	12 (1.1)
Last days	358 (33.8)	524 (49.5)	164 (15.5)	12 (1.1)
Death	329 (31.2)	553 (52.4)	171 (16.2)	2 (0.2)

Figures may not add up to total because of missing data.

*Elderly home in the Hong Kong context includes both residential care homes for the elderly (RCHEs) and nursing homes.

Dying at home: What to do at time of death?

- Call ambulance, dead body sent to A&E, then:
  - Dead body sent to public mortuary as coroner case.
  - Dead body sent to hospital mortuary, with death certificate signed by parent team (under special arrangement).
- Dead body directly sent to funeral parlor, after death certificate (form 18) signed by the doctor who saw the patient at home.

Multiple barriers to overcome

- Legal
- Social
- Logistics
- Clinical:
  - Hospitalization for symptom control
  - Hospitalization for nursing and supportive care
  - Hospitalization for life-sustaining treatment

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Hospitalization for life-sustaining treatment

- For a terminally ill patient, life-sustaining treatment (LST) sometimes may only prolong the dying process,
  - Not in the patient's best interests;
  - Against the patient's wish.

To avoid being sent back to the hospital unnecessarily for futile LST

- To allow a patient to state his/her decision or preference against futile LST:
  - Advance directives (AD)
  - Advance care planning (ACP)
  - Decision on "Do-not-attempt cardiopulmonary resuscitation" (DNACPR) for non-hospitalized patients

Development of AD, ACP and
DNACPR in Hong Kong

Advance directive (AD) 預設醫療指示 in Hong Kong

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

Advance refusal of life-sustaining treatment

- Has legal status: A **valid** and **applicable** advance refusal of LST must be respected.
- In other countries, called a **living will** or an **advance decision refusing treatment** (ADRT).

Advance Directives in other countries

- May also include appointment of a proxy decision maker on healthcare issues.

- However, a proxy directive on healthcare issues currently does not have legal status in Hong Kong.

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 public to make AD.

Hospital Authority (HA) of Hong Kong

- Guidance for HA Clinicians on AD issued in 2010, revised in 2014 and 2016

HA AD Form

- Modified from LRC model form;
- Scope limited to (2010 version):
  - the terminally ill,
  - irreversible coma, and persistent vegetative state.

Revision of Guidance for HA Clinicians on AD in Adults and the AD forms in 2014

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

- Addition of another category “**other end-stage irreversible life-limiting condition**” to the full HA AD form
  - Irreversible loss of major cerebral function not falling into “irreversible coma and PVS”;
  - Other end-stage organ failure not falling into “terminal illness”.

Who would make an AD and how?

- Different countries have different approaches;
- In HA, usually made by patients with advanced irreversible illnesses via **advance care planning** 預設照顧計劃.

Limitation of AD

- Need for contemporaneous decisions:
  - Blanket refusal of all LST may not be appropriate in all situations;
  - View about LST may change when medical condition changes.

- Difficulty in respecting an AD in an emergency situation:
  - Difficult to assess validity and applicability by clinicians who do not know the patient.

Advance care planning

- "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."

More than just signing an AD

- To express values, wishes and preferences for medical and personal care:
  - Useful for formulating care plans and making contemporaneous treatment decisions in future.
- To prepare patient and family emotionally for future deterioration of patient's condition.
  - "Transformational" and not just "transactional".

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**."

Guidelines on ACP in HA

- New section on ACP in revised Guidelines on Life-Sustaining Treatment in the Terminally Ill of 2015.
  - Scope includes discussion with family members of incompetent and minor patients.

- A standardized template for ACP documentation for the whole of HA is being developed, and
- the ACP guidelines will further be developed into an independent set of guidelines.

Initiation of ACP

- Following the diagnosis of a life limiting condition with rapid downhill course.
- Early cognitive decline in dementia.
- Discontinuation of disease targeted treatments.
- Recovery from an acute severe episode of a chronic disease.
- Patient becomes institutionalized.

- **Approach individualized.**

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.

Outcome of ACP

- Competent patient:
  - make an AD;
  - preferences for future medical or personal care;
  - assign a family member for future consultation (though no legal status yet).
- Incompetent adult or minor:
  - consensus between family and healthcare team about plans on future medical or personal care.

- Patient and family more prepared emotionally for future deterioration of patient's condition.

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Respecting AD in an emergency situation

- 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.
- Specific DNACPR form: **signed by doctors**, for defined categories of seriously ill patients with end-stage irreversible diseases, certifying that
  - the patient has a valid AD, and the patient already falls into the condition specified in the AD, or
  - CPR is not in the patient's best interests.
- Will be respected by receiving team in A&E Department, unless suspicion of accident or foul play.

Obstacles to implementation of AD, ACP and DNACPR

- Lack of acceptance by family members.
- Worry about legal status of AD among healthcare workers.
- Inadequate knowledge and skills in ACP among staff looking after dying patients.
- Inadequate awareness and compliance among staff on AD and DNACPR in general.
- Inadequate public/private interface strategies, e.g. how to handle ADs signed in private sector.
- Ambulance crew would not follow DNACPR recommendation:
  - "Duty to resuscitate" in Fire Services Ordinance.

We need

- More public education.
- Systematic staff training programs.
- Improved strategies for public/private interface.

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Why do we need to send the dying patient back to the hospital?

- Patient's choice.
- Doctor not available to certify death at patient's home.
- For symptom control:
  - Inadequate home care support
- Difficult to have the dead body sent directly from **home** to the funeral parlor:
  - Logistics issue
  - Social issue
- Unable to have the dead body sent directly from a **residential care home** to the funeral parlor:
  - Legal issue: requirement in Coroner Ordinance

Multiple barriers to overcome

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- Social
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- Clinical:
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  - Hospitalization for nursing and supportive care
  - Hospitalization for life-sustaining treatment

- Just having an established system for AD, ACP and DNACPR is not adequate.

Thank you!