Advance Directive
If good, why not?

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Chief of Service,
Dept of Medicine & Geriatrics /ICU
Caritas Medical Centre.
Advance Directive – If good, why not?

Not about arguments for and against
But reflections from the perspective of a palliative care physician
Landmark Cases

Nancy Cruzan
1957 – 1990

Karen Ann Quinlan
1954 – 1985

Living will

Patient Self Determination Act (PSDA)

- Allow patients to make their own medical decisions, should they be unable to do so.
- Requires hospitals & health organizations to tell patients their rights to make EOL medical decisions.
- Requires that AD be maintained in patients' charts.
Advance Directive

Patient anticipating serious illness

Patient’s autonomy

Complete AD FORM
AD & PSDA : A US$28M lesson

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)
A multi-centered trial of intervention to improve EOL care

Phase I: 2-yr observational study
Involved 4,301 hospitalized seriously ill patients

Results:
- Only 47% of physicians knew their patients prefer no CPR
- 46% of DNR orders were written only 2 days before death
- 38% of deaths spent at least 10 days in ICU
- >50% of families reported moderate to severe pain in patients

AD & PSDA: A US$28M lesson

Negative results, positive insights

<table>
<thead>
<tr>
<th></th>
<th>AD form completed by patient</th>
<th>% of completed AD form recorded by physician</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before SUPPORT intervention</td>
<td>21%</td>
<td>6% - 35%</td>
</tr>
<tr>
<td>After SUPPORT intervention</td>
<td>21%</td>
<td>78%</td>
</tr>
</tbody>
</table>

However:
No improvement in communication about AD decisions
No change in documentation of discussions regarding DNR
No change in the frequency of attempted CPR

i.e.
No improvement in communication & No change in practice
Using AD to improve EOL Care

1. Completion of AD is not the end, but only a tool
2. Advance care planning (ACP) - the ongoing process of communication is important
Advance Care Planning (ACP)

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

**PROCESS**

**MEANS**
- Complete AD Form
- Document the discussion
- Assign someone as proxy

**OBJECTIVES**
- Enhance autonomy of patient
- Relieve decision burden of caregivers
- Strengthen relationships with loved ones

**ULTIMATE GOAL**
- IMPROVE EOL CARE

Advance Care Planning before AD

Enhance autonomy of patient

Relieve decision burden of caregivers

Strengthen relationships with loved ones

Advance Care Planning before AD

Complete AD Form

Document the discussion

Assign someone as proxy

Ultimate goal

Improve EOL care
Elders with ACP were

- Less likely to die in a hospital (aRR 0.87, 95% CI 0.80-0.94)
- More likely to receive PC (aRR 1.68, 95% CI 1.43-1.97)
- AD and ACP discussion were each independent predictor of PC use (P < .01)

ACP as compared with control group is associated with

- EOL wishes more likely to be known and followed (86% vs 30%; P<0.001).
- Family members had significantly less stress (P<0.001), anxiety (P=0.02), and depression (P=0.002)
Can ACP and AD improve EOL Care?

AD associated with

• lower hospital expenditure
• lower adjusted probabilities of in-hospital death
• higher adjusted probabilities of PC use

Patients with AD (> 70% of > 1,500 US deaths)

• More likely to die at home with PC or in a nursing home
• Less likely to have a feeding tube in last month (17% vs 27%)
• Less likely to use a respirator in the last month (11.8% vs 22.0%)
Impact of Palliative Care on Cancer Deaths in Hong Kong

- less admissions and stay in non PC wards / ICU
- less invasive interventions initiated in last 2 weeks
- more symptoms documented by doctors and nurses
- less likely to receive no analgesics
- more likely to receive strong opioids
- not unduly sedated to unconsciousness before death
- more DNR order in place & less CPR performed

**Note:** none of the patients had AD

Using AD to improve EOL Care

1. Completion of AD is not the end, but only a tool
2. Advance care planning (ACP) - the ongoing process of communication is important
3. ACP is more than advance refusal, often about expressing wish for place of death and access to palliative care
Hong Kong Scenario: Development of AD
<table>
<thead>
<tr>
<th>Year</th>
<th>Body</th>
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<tbody>
<tr>
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<td>Medical Council</td>
<td>Section on “Care for the Dying” under Code of Conduct – Euthanasia is not acceptable</td>
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<tr>
<td>2002</td>
<td>Hospital Authority</td>
<td>Guidelines on Withholding and Withdrawing Life-sustaining Treatment for the Terminally Ill</td>
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<td>Food &amp; Health Bureau</td>
<td>Consultative Paper on Introduction of the Concept of Advance Directives in Hong Kong</td>
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<tr>
<td>2009</td>
<td>Law Reform Commission</td>
<td>Consultative Paper on Enduring Powers of Attorney for Personal Care (excluding LST)</td>
</tr>
<tr>
<td>2010</td>
<td>Hospital Authority</td>
<td>Guidance for HA clinicians on AD in adults</td>
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<tr>
<td>2013</td>
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Recommendations from LRC Report on Substitute Decision-making & AD

• Premature to legislate on AD when the concept is still new and most people have little knowledge.

• Suggested a model AD form for use

• The AD would be triggered only where the individual is
  (1) terminally ill,
  (2) in a persistent vegetative state or
  (3) in an irreversible coma.

• Those who wish to make an advance directive to seek legal advice and to discuss the matter first with family. Family members should also be encouraged to accompany the individual when he makes the AD.
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How about Enduring Power of Attorney (EPA)?

Recommendation of LRC on EPA for Personal Care 2006

- Scope of EPA in “personal care” should include everyday decisions as to the donor’s health care, but **NOT** decisions involving the giving or refusing of life-sustaining treatment.
Hong Kong Scenario: Readiness for AD & ACP
All ready to start?

Wait for the physician to initiate
Fear of abandonment
Fear of losing control instead

Filial piety
Protect by withholding information

Fail to recognize transition to palliation/EOL
Lack of time and skill
Fear of triggering/handling emotions

- Uncomfortable to talk about death and dying
  - Death as conflict and failure
- Poor understanding/misunderstanding of terms
## Local awareness and acceptance

<table>
<thead>
<tr>
<th>Study</th>
<th>Population</th>
<th>Awareness</th>
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<tbody>
<tr>
<td>Pang et al (2006)</td>
<td>Nurses vs Healthy Chinese adults in community</td>
<td>&gt; 70% of public preferred LST even when terminally ill and in coma</td>
</tr>
</tbody>
</table>
| Yeung (2006)        | Nurses                                   | 1/3 agreed nurses had a role  
1/4 felt competent and comfortable  
> 1/2 reported training needs                                    |
| Siu et al (2010)    | Medical students yr 3-5                  | 70% heard of it, 30% certain about it  
26% aware of LRC report  
Knowledge of AD score  5.5 / 10                                    |
| Chu et al (2011)    | Chinese nursing home residents           | 96% never heard of it                                                                                                                  |
| Ting & Mok (2011)   | Chinese elders with chronic disease      | 81% never heard of it  
73% never discuss                                                      |
Concept of AD and ACP

*Important to understand “What it is”*
*Equally important to understand “What it is not”*

- Advance directive ≠ Request specific treatment
- Withholding or withdrawing futile LST ≠ Euthanasia
- Let go ≠ Abandonment
Hong Kong Scenario:
The Model AD Form
The Model AD Form
Condition for application

Case 1 – Terminally ill
"terminally ill" means suffering from advanced, progressive, and irreversible disease, and failing to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few months; and the application of life-sustaining treatment would only serve to postpone the moment of death

Case 2 – Persistent vegetative state or a state of irreversible coma

Preset condition that may not happen to the patient
Conditions such as dementia not included
The Model AD Form
What to refuse?

Model AD Form
(Note: In this instruction-
"life-sustaining treatment" … includes,
e.g. CPR, vasopressors, … chemotherapy
Or dialysis, antibiotics., and artificial
nutrition and hydration.

☐ Save for basic and palliative care, I
do not consent to receive any life-
sustaining treatment. Non-
artificial and hydration shall, for the purpose of this form, form part of basic care.

☐ I do not want…..

---------------------

All inclusive?

The relative risks and benefits of each treatment varies with:

• State of patient
• Goals of treatment
• State of science

A tick for all may preclude patients from an effective palliative treatment
The Model AD Form
What to refuse?

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(Note: In this instruction-
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☐ Save for basic and palliative care, I 
do not consent to receive any life-
sustaining treatment. Non-
artificial and hydration shall, for 
the purpose of this form, form 
part of basic care.

☐ I do not want.....

☐ I do not want....

☐ A
☐ B
☐ C

Specific choice?
Exhaustive list?

A check list approach may 
not meet patients’ needs

Focus on 1 or 2 items may 
end up in a narrow cone of 
autonomy

Singer PA et al 1998
Emanuel LL et al 1991
Emanuel LL et al 1989
Save for basic and palliative care, I do not consent to receive any life-sustaining treatment. Non-artificial and hydration shall, for the purpose of this form, form part of basic care.

I do not want....

- Basic is not about settling at the minimal
- Basic is not necessarily automatic
- Meeting basic needs e.g. Relief from pain
  Palliation of other symptoms
  Accompanied by loved ones
- Depends on equitable access to quality EOL care

A choice on paper?
Or a real option?
Hong Kong Scenario:
The ACP process
Potential benefits of ACP

- Improve trust
- Strengthen relationship
- Reducing burden of caregiver
- Useful icebreaker

Rhee JJ et al. 2013
Potential harm of ACP

- Emotional trauma - distressing to think about death in details
- Difficult to contemplate based on hypothetical scenarios – a prospective autonomy
- Being “forced” or pressurised to undergo ACP
- Conflicts between patient and relatives’ wishes
- Family members may find their role marginalised
- Inflict sense of abandonment when focus on forgoing LST without active palliation
- False sense of control over uncertainties in medicine
Potential harm of ACP
An operator dependent process

- Dependent on operator’s time, knowledge, skill and relationship with patient and family
- Prognostic telling is difficult especially for non-cancer
- Fear of litigation
- Lack of formal training
- Unlike AD form, no “model” or “standard” way to conduct and record
- Variable quality
Integrating ACP into Palliative Care for Non-cancer Experience of Renal ACP in CMC

Renal Palliative Care Program (RPC)
• Collaboration of palliative care & renal team
• ACP as integral part in care for ESRD
• Renal PC as a choice at ACP
Model of Renal Palliative Care & ACP

**Patients refer for ACP**
Cr > 350 (DM)
Cr > 450 (non-DM)

**Decided not for dialysis:**
1. Personal choice
2. Too frail
3. Too many comorbidities

Renal Palliative Care (RPC) Program

**Specialised PC Team**

**Service delivery**
- RPC Clinic
- Home care
- Admissions
- Consultative service

**Care components**
- Disease management
- Symptom control
- Psychosocial/spiritual care
- Support family
- End-of-life care
- Bereavement care

Renal Advance Care Planning (ACP) - 1

The Setting

- Conducted by team of specialists, designated social worker, specialty nurses
- Took place in a designated ACP clinic
- Patient and family members invited

Ground rules

- Emphasis on informed choice, not withholding of dialysis
- Open door policy adopted
- Patients can change their mind or request more ACP
Renal Advance Care Planning (ACP) - 2

The Contents

- Treatment options of RRT & RPC
- Disease parameters affecting prognosis
  - Underlying cause of ESRD
  - Cr level
  - Charlson Co-morbidity index
  - Functional status
- Discussants involved
- Mental capacity of patient
- Social network
- Main decision maker
- Reason for declining RRT

An informed choice
Renal Advance Care Planning (ACP) - 3

Documentation & communication

- Standardised ACP form to record contents and decision
- Peer review process
- Choice entered into patient’s computer record for access

Joint team case conference

Enrolled into RPC
671 ESRD underwent ACP
From 2007 to end of 2011 in CMC

- **265 (39.5%)** Opted RRT
  - 64 Died

- **335 (50%)** Opted RPC
  - 226 Died

- **71 (10.5%)** “Conservative”
  - 30 Died

Reason for declining dialysis:
- Physical burden 87.2%
- Psychological burden 8.4%
- Social burden 21.8%
### Characteristics of 335 RPC patients

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (±SD) age (years)</td>
<td>76.8 ± 9.1</td>
</tr>
<tr>
<td>Median follow up (days)</td>
<td>146 (45.7 – 304.8)</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>63.3%</td>
</tr>
<tr>
<td>Charlson comorbidity Index</td>
<td>8.9 ± 2.3</td>
</tr>
<tr>
<td>Walk unaided / with aid</td>
<td>83.6%</td>
</tr>
<tr>
<td>Chair bound</td>
<td>14.2%</td>
</tr>
<tr>
<td>Bed bound</td>
<td>2.2%</td>
</tr>
<tr>
<td>Full</td>
<td>78.5%</td>
</tr>
<tr>
<td>Limited</td>
<td>13.7%</td>
</tr>
<tr>
<td>MIP</td>
<td>7.8%</td>
</tr>
<tr>
<td>Patient</td>
<td>87.2%</td>
</tr>
<tr>
<td>Family</td>
<td>83.6%</td>
</tr>
<tr>
<td>Patient &amp; Family</td>
<td>38.2%</td>
</tr>
<tr>
<td>Family</td>
<td>48.1%</td>
</tr>
<tr>
<td>Doctor</td>
<td>13.1%</td>
</tr>
<tr>
<td>Who decide?</td>
<td>0.6%</td>
</tr>
</tbody>
</table>
# Satisfaction of the bereaved

<table>
<thead>
<tr>
<th>Satisfaction on EOL care &amp; dying scene</th>
<th>n = 112</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fully</td>
<td>92.9%</td>
</tr>
<tr>
<td>Partial</td>
<td>5.4%</td>
</tr>
<tr>
<td>Not at all</td>
<td>1.8%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ACP decision impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfied</td>
</tr>
<tr>
<td>Regretful</td>
</tr>
<tr>
<td>Others¹</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Perceived as most helpful service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical symptom</td>
</tr>
<tr>
<td>Psychosocial support</td>
</tr>
<tr>
<td>Practical care assistance</td>
</tr>
</tbody>
</table>
Hong Kong Scenario: Autonomy? How about my family?
Patient’s autonomy and role of family

Individualistic liberal model vs familial model

A family member as the surrogate

- Serves as extension of patient in medical decision making
- Based on hierarchy of:
  - Expressed views → Substituted judgment → Best interest
- Family merely serves as a means for the patient to exercise his autonomy or protect his best interests.

However,

- Research findings have shown that Chinese were more likely to prefer family-based decision making

(Chan, 2004; Tse, Chong & Fok, 2003)
Alternative model for HK?

• A local study on attitude of patients, their families members, doctors and nurses towards AD

• By questionnaires and face-to-face interviews

• Two vignettes were also presented
  • asked to approve or disapprove of the decisions made by the doctors in the vignette.
  • asked to state their own preferences if they were in a similar situation.
  • state reasons for the decisions

**Vignette 1:**

- 58-yr-old lady with surgery for CA colon, developed metastases, underwent chemotherapy and was stabilised
- Sustained a heart attack resulting in cardiac arrest
- Husband said she did not want CPR
- CPR was not performed

<table>
<thead>
<tr>
<th></th>
<th>For patient</th>
<th>For myself</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Agree DNR</td>
<td>Want DNR</td>
</tr>
<tr>
<td>Doctors</td>
<td>70.0%</td>
<td>78.3%</td>
</tr>
<tr>
<td>Nurses</td>
<td>44.7%</td>
<td>58.5%</td>
</tr>
<tr>
<td>Patients</td>
<td>20.8%</td>
<td>16.7%</td>
</tr>
<tr>
<td>Family</td>
<td>32.8%</td>
<td>22.5%</td>
</tr>
</tbody>
</table>
For patient

Agree to give antibiotics | Want antibiotics | No antibiotics | Non-decisive
---|---|---|---
Doctors | 95.2% | 82.6% | 13.0% | 4.3%
Nurses | 80.5% | 70.7% | 22.0% | 7.3%
Patients | 92.0% | 72.4% | 6.7% | 20.7%
Family | 90.6% | 71.1% | 13.2% | 15.8%

Vignette 2:

- 68-yr-old man with terminal liver cancer but lived as normal
- Made an AD to refuse LST under life-threatening condition
- Had an episode of life-threatening pneumonia
- Doctor decided to prescribe antibiotics
Alternative model for HK?

• Their responses to vignettes could not be explained by adoption of one dominant value such as autonomy
• They used the same value to justify different preferences and different values to justify the same choice
• EOL decision making shaped by multiple values including:
  • Patient’s autonomy,
  • Professional’s medical knowledge and experience,
  • Family,
  • Patient’s QOL

• The most preferred decision model was the shared-decision-making participated by the healthcare providers and the family

To conclude
From AD to Promote EOL Care through exercising autonomy

Oversimplified
Never straightforward

- AD is only a means, not the end
- Dying is a family event, not a personal event
- Goals of ACP are beyond autonomy
- Meeting needs at EOL is more than refusal of LST
- EOL can be a complex process with diverse needs
A paradigm shift to improve EOL Care

Refusal in Advance

“Respect what I don’t want”

Palliative Care in Place

“Address what I need”