Advance Directive

If good, why not?

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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

The SUPPORT Principal Investigators. *JAMA* 1995;274(20):1591-98.

AD & PSDA: A US$28M lesson

Negative results, positive insights

	AD form completed by patient	% of completed AD form recorded by physician
Before SUPPORT intervention	21%	6% - 35%
After SUPPORT intervention	21%	78%

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

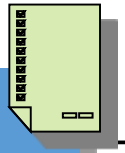
Advance Care Planning before AD

PROCESS

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

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

Can ACP and AD improve EOL Care?

Bischoff KE. et al. J Am Geri Soc. 61(2):209-14, 2013

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 (aRR1.68, 95% CI 1.43-1.97)
- AD and ACP discussion were each independent predictor of PC use ($P < .01$)

Detering KM. er al BMJ. 340:c1345, 2010

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?

Nicholas LH et al. JAMA. 306(13):1447-53. 2011 Oct

AD associated with

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

Teno JM et al. . J Am Geri Soc 55(2):189-94, 2007.

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

Tse DMW, Chan KS, Lam WM, Lau KS, Lam PT. The impact of palliative care on cancer deaths in Hong Kong: a retrospective study of 494 cancer deaths. Pall Med 2007;21:425-433.

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

Year	Body	Publication
1998	Hospital Authority	Guidelines on In-Hospital Resuscitation Decision
1999	Medical Council	Section on “Care for the Dying” under Code of Conduct – Euthanasia is not acceptable
2002	Hospital Authority	Guidelines on Withholding and Withdrawing Life-sustaining Treatment for the Terminally Ill
2006	Law Reform Commission	Report on Substitute Decision-Making and Advance Directives in Relation to Medical Treatment
2009	Food & Health Bureau	Consultative Paper on Introduction of the Concept of Advance Directives in Hong Kong
2009	Law Reform Commission	Consultative Paper on Enduring Powers of Attorney for Personal Care (excluding LST)
2010	Hospital Authority	Guidance for HA clinicians on AD in adults
2013	Hospital Authority	Consultative Paper on Guidelines for DNACPR in HA

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

Study	Population	Awareness
Pang et al (2006)	Nurses vs Healthy Chinese adults in community	> 70% of public preferred LST even when terminally ill and in coma
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
Wong et al (2012)	Chinese advanced cancer patients	NA

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?

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…..

_____

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

The Model AD Form
What will be available?

☐ **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…..

_____

What is basic care?

- 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

DMW Tse Hong Kong J Nephrol 2009;11(2):p50-58.

Renal Advance Care Planning (ACP) - 1

The Setting

- Conducted by team of specilaist, 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


Hospital Authority
Caritas Medical Centre
Department of Medicine & Geriatrics
Renal Advance Care Planning (ACP)

Please affix gum label with address/MED/HN number

Patient status: ☐ CMC in-patient ☐ CMC out-patient ☐ PMH in-patient ☐ PMH out-patient
Refers for: ☐ RPC clinic ☐ RPC bed ☐ Renal ACP
Family carer to be contacted by MSW:

Notes by Renal/Palliative Care Physician

1. Cause of CRF/ESRD
☐ DM ☐ HT ☐ GN: ☐ PCKD
☐ Unknown ☐ Others:
2. Latest serum creatinine=
3. Patient's dependence level
☐ Walks unaided ☐ Walks with assistance
☐ Chair-bound ☐ Bed-bound
4. Patient's mental capacity
☐ Fully competent ☐ Limited ☐ MIP
5. Discussant
☐ Patient ☐ spouse
☐ Family member: ☐ children
☐ Friends ☐ parents
☐ Guardian ☐ others:
6. Patient's social network
☐ Lives alone ☐ Lives with family/relatives
☐ Lives with unrelated ☐ Lives in institution/OAH
☐ Others:
7. Prognosis & treatment options discussed
8. Remark:

Comorbidities (check, >6 months)
☐ HT ☐ Hyperlipidaemia ☐ Psychiatric illness
☐ Long-term device / HT / Foley / Ch
☐ Others:

Modified Charlson Comorbidity Index (MCCI)

Score	Medical condition	Tick if present	Score
Age Score	For every decade >40 years of age, give 1 point to the score		
1	IHD		
	CHF		
	PVD		
	CVA		
	COPD		
	Peptic ulcer		
	Connective tissue disease		
	Hepatitis		
	DM		
	Dementia		
2	Hemiplegia		
	Moderate to severe renal disease		
	DM with end-organ damage		
	Any tumor, leukaemia, lymphoma		
3	Cirrhosis of liver		
6	Metastatic solid tumor		
	AIDS		
	Total MCCI Score:		

Date: ☐☐-☐☐-☐☐ Date: ☐☐-☐☐-☐☐ Chop/sign:

Other Remarks/Nurse Assessment (optional)
☐ Pre-dialysis education
☐ Demonstration of PD exchange technique

Treatment Decision
Opts for ☐ RPC ☐ PD
☐ HD ☐ Transplant
By ☐ Patient ☐ Patient & family
☐ Family ☐ Doctor ☐ Guardian
Why not dialysis
☐ Physical ☐ Psychological ☐ Social

Confirmed by Dr.
on ☐☐-☐☐-☐☐

Case Conference
Date: ☐☐-☐☐-☐☐

Date:
Staff chop/sign

Last revision date 5/9/2011

- Standardised ACP form to record contents and decision

Joint team case conference

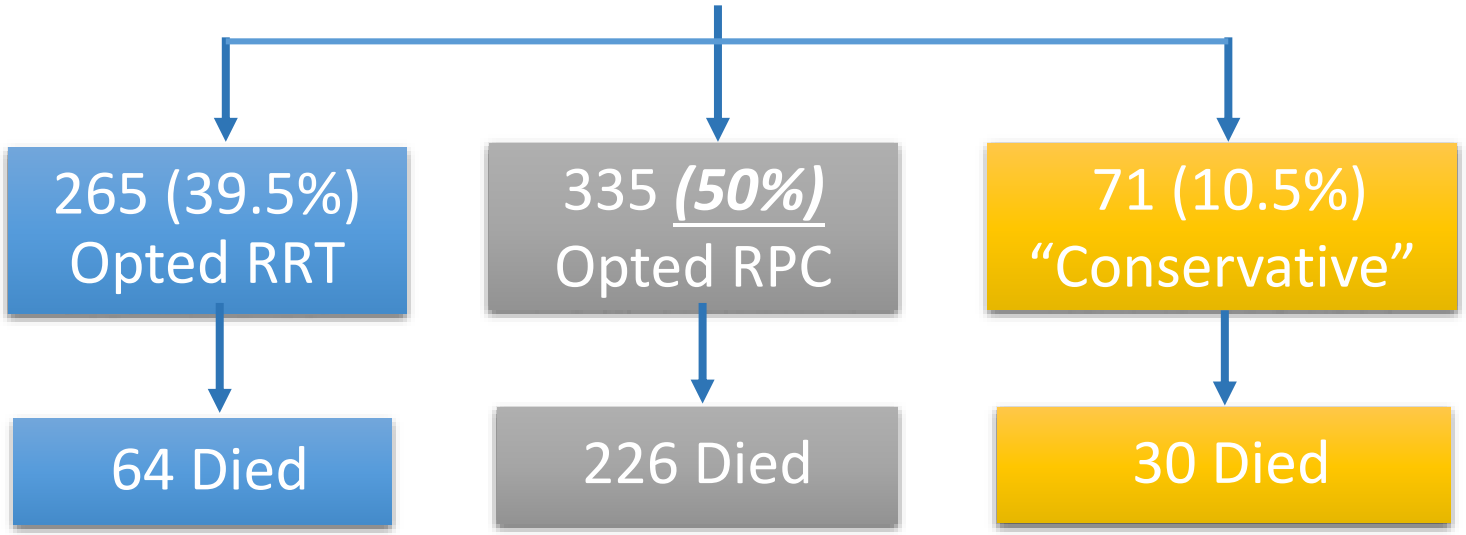
- Peer review process
- Choice entered into patient's computer record for access

Enrolled into RPC

Renal Advance Care Planning (ACP)

671 ESRD underwent ACP

From 2007 to end of 2011 in CMC



Reason for declining dialysis:

Physical burden 87.2%

Psychological burden 8.4%

Social burden 21.8%

Characteristics of 335 RPC patients

	Mean (±SD) age (years)	76.8 ± 9.1
	Median follow up (days)	146 (45.7 – 304.8)
	Diabetes mellitus	63.3%
	Charlson comorbidity Index	8.9 ± 2.3
Functional status	Walk unaided / with aid	83.6%
	Chair bound	14.2%
	Bed bound	2.2%
Mental capacity	Full	78.5%
	Limited	13.7%
	MIP	7.8%
Discussants engaged	Patient	87.2%
	Family	83.6%
Who decide?	Patient	38.2%
	Patient & Family	48.1%
	Family	13.1%
	Doctor	0.6%

Satisfaction of the bereaved

Satisfaction on EOL care & dying scene	n = 112
Fully	92.9%
Partial	5.4%
Not at all	1.8%
ACP decision impact	
Satisfied	98.1%
Regretful	/
Others[1]	1.9%
Perceived as most helpful service	
Physical symptom	90.7%
Psychosocial support	79.4%
Practical care assistance	76.6%

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

Chan HM, Tse DMW, Wong KH, J Chan. Ruiping Fan (ed.), *Family-oriented Informed Consent*, Dordrecht: Springler, 2013

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

	For patient	For myself		
	Agree DNR	Want DNR	Want CPR	Non-decisive
Doctors	70.0%	78.3%	13.0%	8.7%
Nurses	44.7%	58.5%	36.6%	4.9%
Patients	20.8%	16.7%	66.7%	16.7%
Family	32.8%	22.5%	67.5%	8.7%

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

	For patient	For myself		
	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%

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

Chan HM, Tse DMW, Wong KH, J Chan. Ruiping Fan (ed.), *Family-oriented Informed Consent*, Dordrecht: Springler, 2013

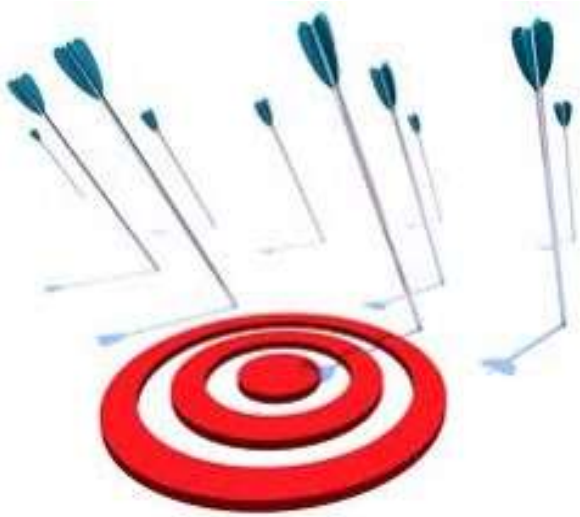
To conclude

From AD to Promote EOL Care through exercising autonomy

Oversimplified
Never straight forward

- 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

Palliative Care in Place

"Respect what I don't want"

"Address what I need"