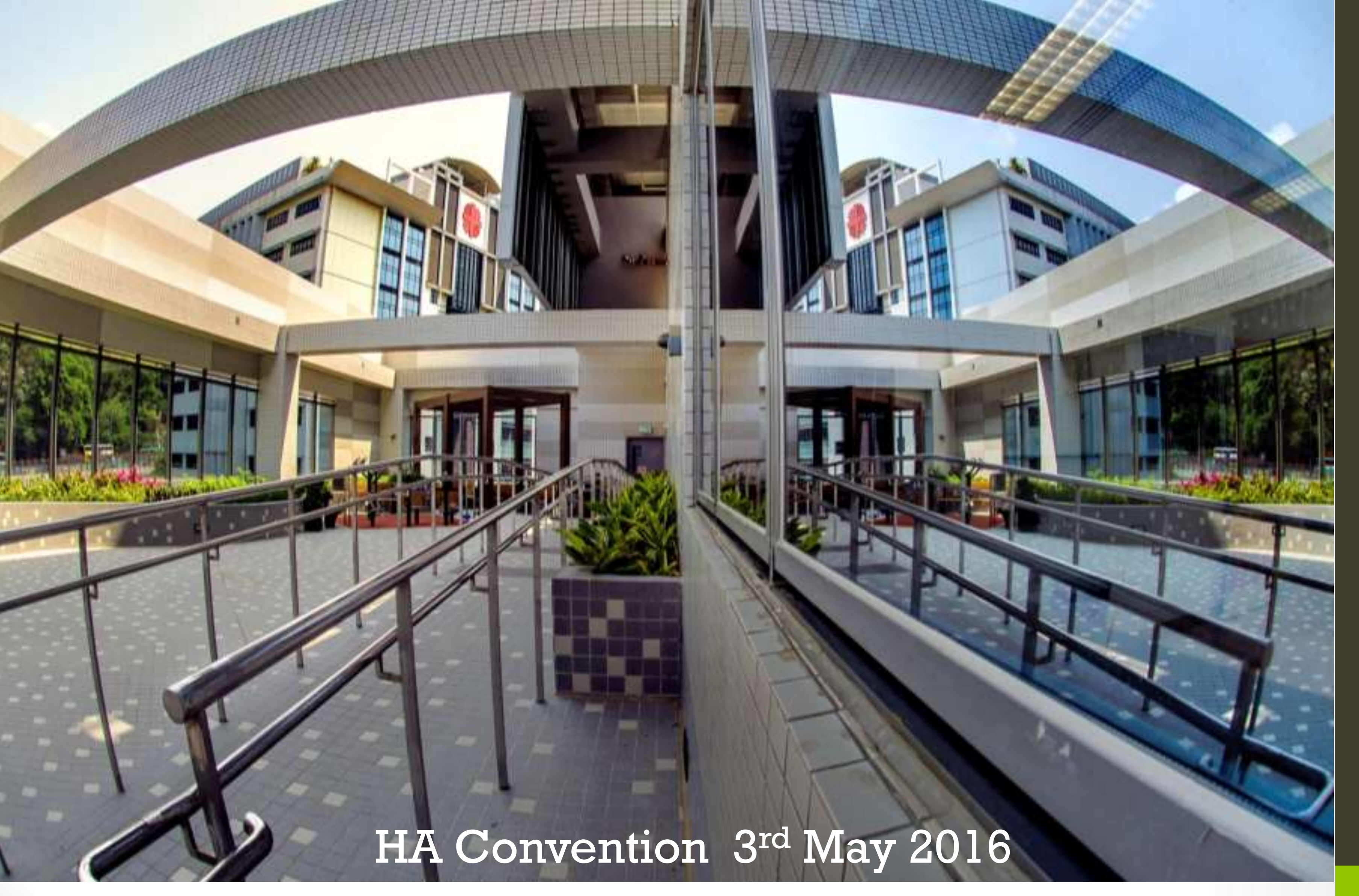


HA Convention 3rd May 2016

Dr. TSE Man Wah, Doris,

Clinical Stream Coordinator (Medical), Kowloon West Cluster

Hospital Chief Executive, Caritas Medical Centre

INTRODUCTION

MEETING THE NEEDS OF PATIENTS WITH LIFE LIMITING ILLNESS: ADVANCE CARE PLANNING IN LOCAL SETTING

What is advance care planning?

Patient's self determination
in anticipation of life limiting illness

- ADVANCE = in anticipation (given time)
- CARE = medical and personal care
- PLANNING = informed decision making

- A mentally competent adult may choose to complete an Advance Directive (AD) for refusal of treatment after ACP

Why ACP should be an integral part of chronic disease management?

Because of needs arising from:

- Aging population
- More life limiting illnesses
  - cancer
  - organ failure
  - dementia
  - neurodegenerative disease
- Patients' autonomy and engagement

Life limiting illness in the Paediatric age group also on rising trend

Fraser LK et al. Paediatrics 2012;129;e923

- Congenital
- Metabolic
- Perinatal
- Neurological
- Cancer
- Respiratory
- Haematological

Some of them will survive to adulthood

Involve children with life limiting conditions in decisions to stop treatment, says new guidance

BMJ 2015;350:h1621 doi: 10.1136/bmj.h1621 (Published 24 March 2015)

My Choice

ACP AND LOCAL CONTEXT

- Aging Population
- Social Culture
- Policies and Legislations

AGING POPULATION

Longer life expectancy and more vulnerable to age-related diseases

AND

Declining fertility rates and shrinking proportion of economically active population

Aging Rate in Hong Kong

2019

5 working persons supporting 1 elderly

1 in 6

2029

3 working persons supporting 1 elderly

1 in 4

2039

2 working persons supporting 1 elderly!

1 in 3!

Causes of Death in Elderly

Comparing Noncancer and Cancer Deaths in Hong Kong: A Retrospective Review

Kam Shing Lau, MD, Doris Man Wah Tse, MD, Tracy Wai Tsan Chen, MD, Po Tin Lam, MD, Wai Man Lam, MD, and Kin Sang Chan, MD

704 *Journal of Pain and Symptom Management* Vol. 40 No. 5 November 2010

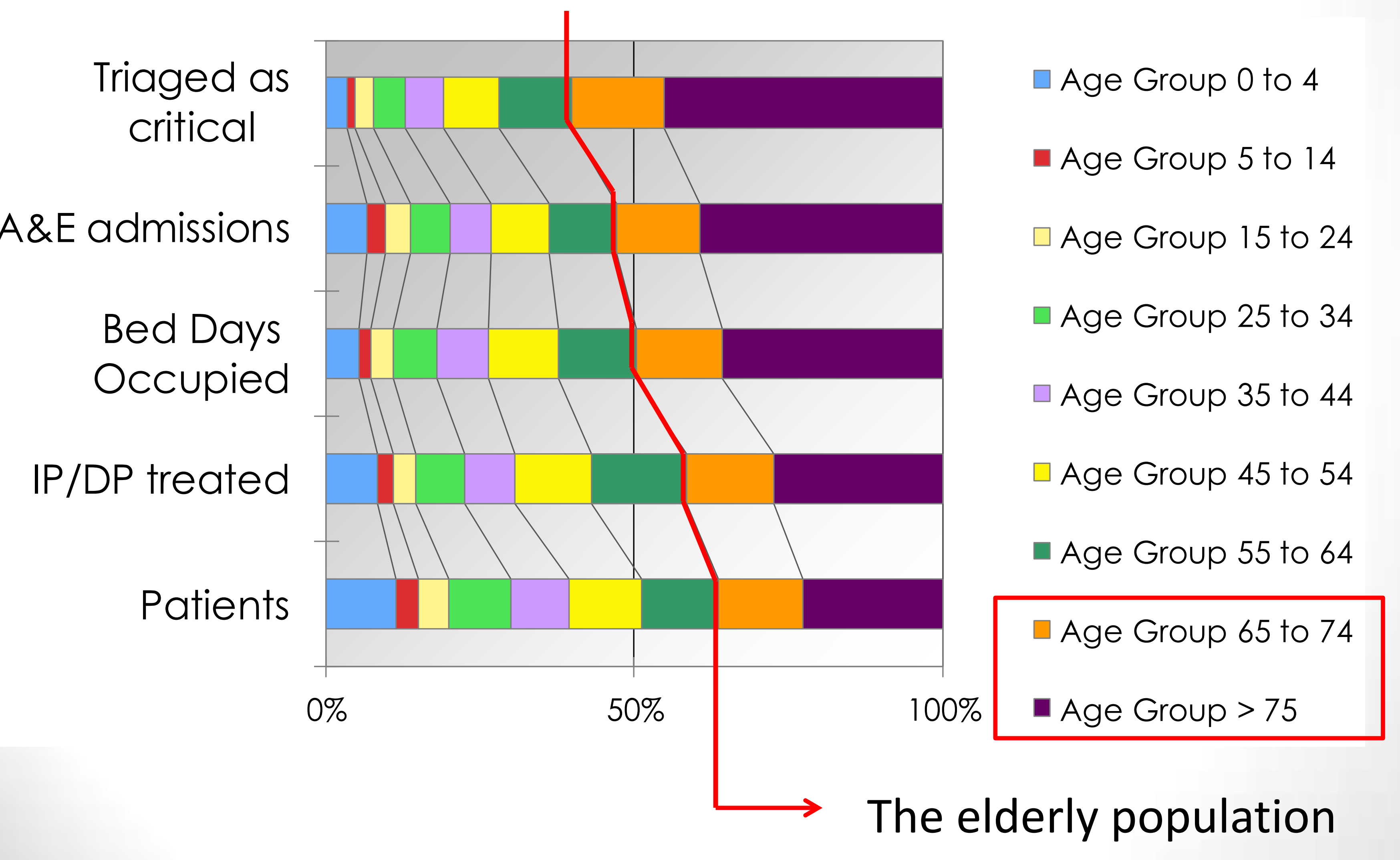
	Cancer (n=183)	CRF (n=239)	COPD (n=242)	CHF (n=175)
Mean age	71.1±12.4	76.5±10.4	78.8±7.9	83.1±9.0
DM	24%	51.5%	8.7%	34.9%
Stroke	12%	27.6%	10.3%	29.1%
IHD	11%	28.0%	15.3%	51.4%
CHF	8%	26.8%	9.9%	-
CRF	6%	-	5.8%	34.3%
Dementia	5%	13.4%	10.7%	20.6%

All $p < 0.05$

- Patients who died of organ failure were older
- Multiple life limiting illnesses

Age gradient in HA hospital use

- At any one time, half of HA beds is occupied by patients > 65



SOCIAL CULTURE:

TRADITIONAL VS CONTEMPORARY

Filial piety "Xiao"

"The son carrying the old"

- Family "Jia"

SHUFA.ARTX.CN

"Pigs under the same roof"

Filial Piety in modern Hong Kong

- Dual piety model : Authoritative and Reciprocal
- Transformation of filial piety behaviour

Traditional	Contemporary
AUTHORITATIVE relationship	RECIPROCAL relationship
Obligatory duty	Compassionate role
Task fulfillment	Emotional connection
Obedience or submission	Mutual respect
Guilt and shame	Appreciation & forgiveness

N Chow. Asian J Gerontol Geriatr 2006; 1: 31–5.
Wong et al. Asian Journal of Social Science Vol. 34, No. 4 (2006), pp. 600-617
Chen et al. Asian Journal of Social Psychology. Vol. 10(4), Dec 2007, pp. 213-223.

Obligation and Mutual Relationship

Chan, C; Ho A; Leung P, Chochinov H; Neimeyer R; Pang S, Tse DMW. Journal of Ethnic & Cultural Diversity in Social Work Vol.21(4), 2012, 277-296

Study on Hong Kong Chinese adult children caregivers.

- Traditional filial beliefs provide motivation for family caregiving
- But also inflicts regrets of unfulfilled filial responsibilities, create emotional distance between parents and children

Ho A, Chan C, Leung P, Chochinov H, Neimeyer R, Pang S, Tse MWD. Age and Aging 2013;42:455-461

Study on local advanced cancer patients receiving PC

"Chinese older patients were not anxious about death, but instead desire ACP to relieve family burden"

Change in local households

%

100
90
80
70
60
50
40
30
20
10
0

65-69 70-74 75-79 80-84 85+ Age

- Non domestic household
- With others
- With children only
- With spouse only
- With spouse and children
- Alone

Domestic household

- Smaller households
- More elders living alone
- More elders in institutions
- More women (caregivers) working

Source: 2011 Population Census

Decision making in local families

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

- Local study on palliative care patients
- The most preferred decision model was the shared-decision-making participated by the healthcare providers and the family

Lee et al. A Systematic Review of Advance Directives and Advance Care Planning in Chinese People From Eastern and Western Cultures. Journal of Hospice & Palliative Nursing 2014: 16;75-85.

- Little difference in results from Eastern versus Western countries
- A family decision-making model may be more appropriate for discussions with Chinese people about ACP and AD

POLICIES & LEGISLATIONS

Singapore 	**Advance Medical Directive Act (1996)** **Mental Capacity Act (2008)** **National implementation of ACP (2011)**
Australia 	**Advance Care Directives Act (2013)**

Hong Kong Scenario

Law Reform Commission papers

2006	Report on Substitute Decision-Making and Advance Directives in Relation to Medical Treatment
2009	Consultative Paper on Enduring Powers of Attorney for Personal Care

- AD NOT promoted under legislative framework
- Society not ready
- Model form suggested and only for 3 conditions:
  (1) terminally ill,
  (2) in a persistent vegetative state or
  (3) in an irreversible coma.

- Medical decisions for LST NOT included

Revision of HA Guidelines

Ethical and Legal Framework

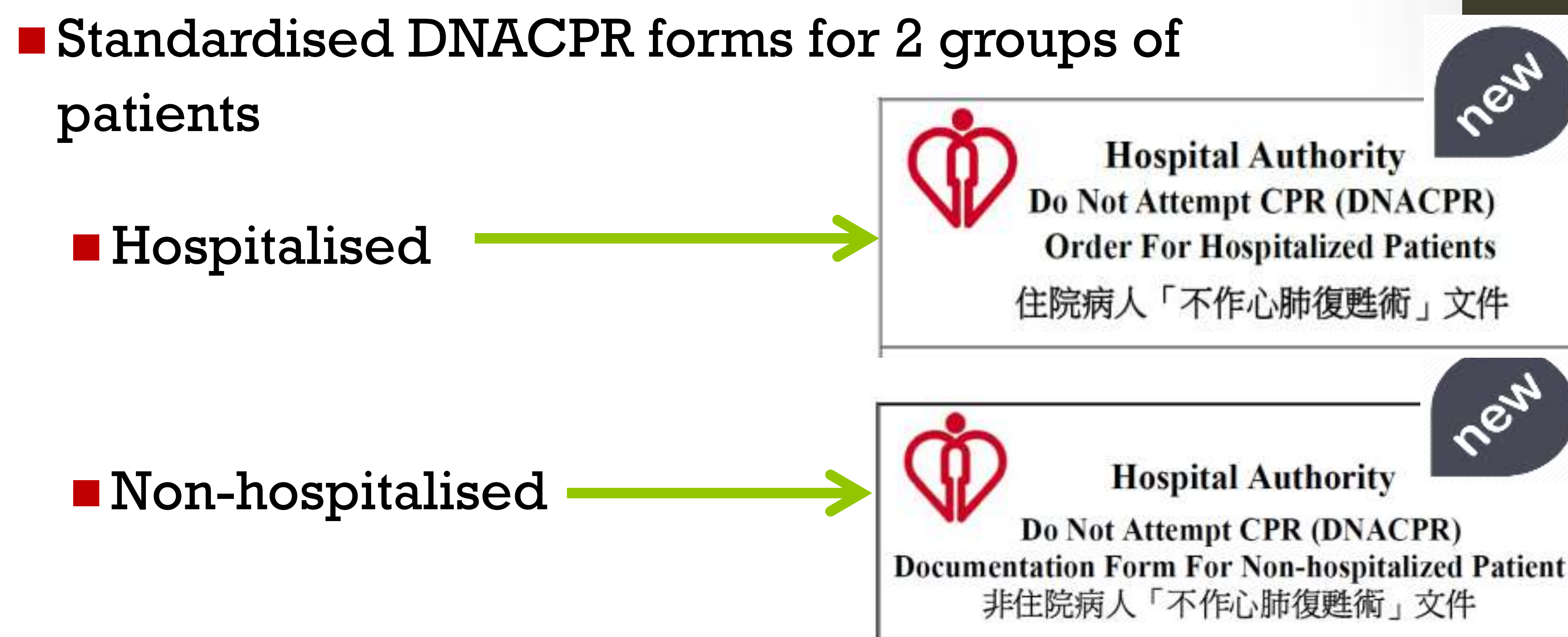
- Respect patient's autonomy
- Consideration of patient's best interests
- Consensus building with patient & family at ACP
- AD is legally binding under Common Law

Recent revisions

2014	HA Guidelines on DNACPR to include DNACPR for non-hospitalised patients
2014	Guidance for HA clinicians on AD in adults to include seriously ill non-cancer disease in AD forms
2015	Guidelines on Withholding & Withdrawing LST for the Terminally Ill to include section on ACP

Standardised DNACPR Forms in HA

- Standardised DNACPR forms for 2 groups of patients
  - Hospitalised
  - Non-hospitalised



- For recognition across HA, in particular AED

Standardised AD Forms in HA

Standard AD form to include the condition of other end-stage irreversible life limiting condition e.g. organ failure, severe brain damage from other causes

Revised

ADVANCE DIRECTIVE[1]

A short AD form for refusal of CPR only to reduce patient burden in completion

new

ADVANCE DIRECTIVE
(TO REFUSE CARDIOPULMONARY RESUSCITATION WHEN SUFFERING FROM TERMINAL ILLNESS)

Hospital Authority

Do Not Attempt CPR (DNACPR) Documentation Form For Non-hospitalized Patient

非住院病人「不作心肺復甦術」文件

Patient's s

(Patient's Gum I

the patient's nam

and

I. DIAGNOSIS:

II. CURRENT CONDITION:

- ☐ Terminally ill
- ☐ Irreversible coma o
- ☐ Irreversible loss of
- ☐ Disabled child with
  that the child and/or family feel that further treatment is more than can be born
- ☐ Others : ____________

- Preceded by Advance Care Planning
- Accompanied by a completed short AD form for refusal of CPR

For this named patient, the following is in place:

- ☐ An advance care plan
- ☐ A valid and applicable advance directive with a refusal of CPR

ACP in HA - Recognition

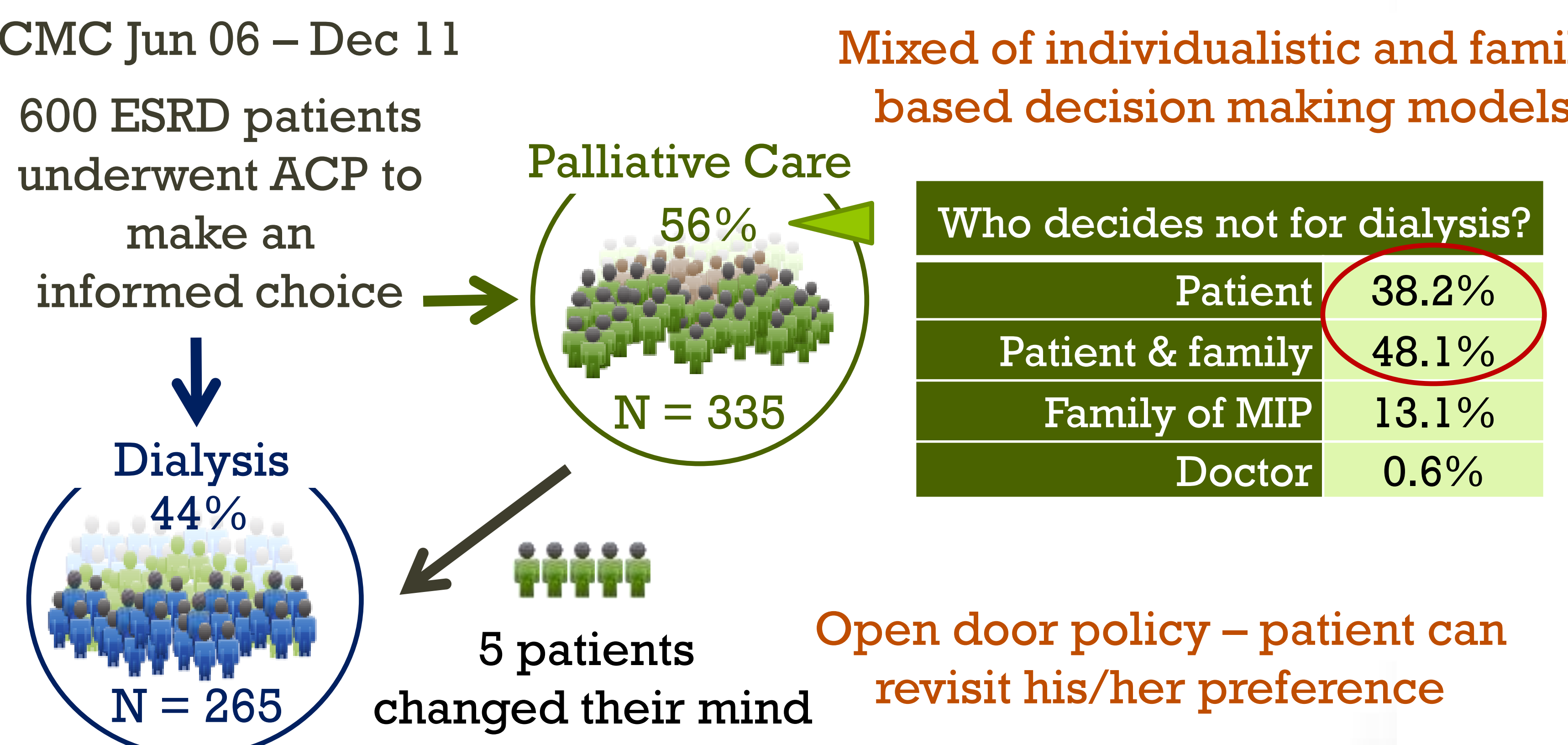
- ACP is an overarching and preceding process for expressing preferences for medical and personal care…
- ACP should be considered in suitable patients in anticipation of progressive deterioration, before death is imminent.
- ACP is an integral part of palliative care and should be promoted to a wider scope of patients with advanced progressive diseases.

(HA Guidelines on DNACPR 2014)

(HA Guidelines on withholding and withdrawing LST 2015)

ACP in renal palliative care program:

Decision making model and preference stability



Who decides not for dialysis?	
Patient	38.2%
Patient & family	48.1%
Family of MIP	13.1%
Doctor	0.6%

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

SK Yuen, M Suen, A Kwok, D Yong, D Tse. HKJN accepted for publication 15 April 2016

IS ACP AN EVIDENCE BASED PRACTICE?

The effects of advance care planning on end-of-life care: A systematic review

Arianne Brinkman-Stoppelenburg, Judith AC Rietjens and Agnes van der Heide

Palliative Medicine
2014, Vol. 28(8) 1000–1025

- More DNACPR orders
- More AD completion
- Less life sustaining treatment
- More palliative care service
- Less hospital admission
- Compliance with patient's EOL wishes
- Less caregiver distress

Especially for complex ACP interventions

Patient's self determination

SOME ISSUES OF ACP

- Operator dependent process
- Seamless communication
- Uncertainties in medicine
- Wishes and promises

- *ACP is an operator dependent process and not without potential harm*
- *In some places overseas, non-medical personal are trained as ACP facilitators*
- *Locally, doctors, nurses, social workers are involved in ACP*

An Operator Dependent Process

- Depends on facilitator's
  - time
  - knowledge
  - communication skill and
  - relationship with patient and family
- Unlike AD form, no "model" or "standard" way to conduct and document
- Scope of discussion may be variable
- Quality may be variable

Potential harm of ACP

- Emotional trauma - distressing to talk about death
- Being "forced" or pressurised to undergo ACP as presumably good
- Family members may find their role marginalised
- Inflict sense of abandonment when focus on forgoing LST without active palliation
- Becomes a routine and tick box exercise
- Backfire if poorly conducted

Seamless communication is

- *what it takes for continuity of care…*
- *what it takes for patients to detour from the conveyor belt in modern health care*

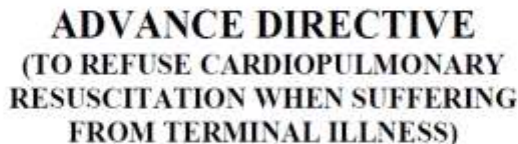
The conveyor belt in modern health care

- To detour, patient has to say "NO" in advance
- But any guarantee that "NO" will be recognized and honoured by stakeholders along the path?

Communication system in HA

Hospital Authority

Do Not Attempt CPR (DNACPR)
Documentation Form For Non-hospitalized Patient
非住院病人「不作心肺復甦術」文件



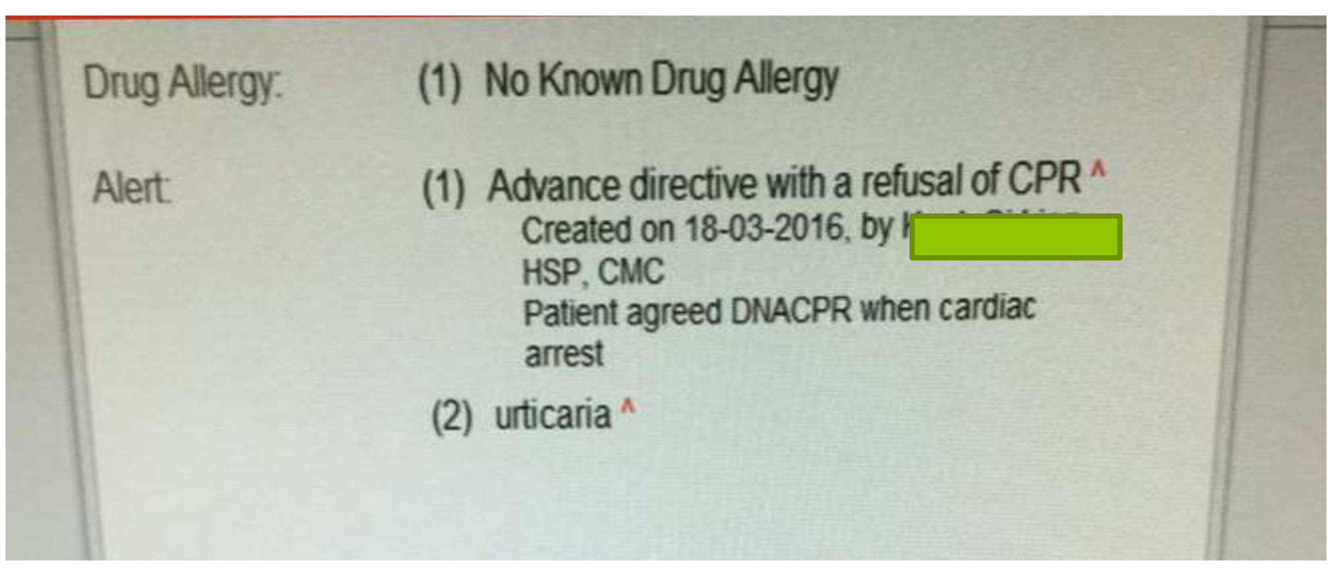
After completion →

- Doctor to enter the information into the electronic patient's record
- However the forms are <u>NOT</u> recognised by the ambulance crew

- Patients may have CPR performed till arrival in AED

HA Electronic Alert System

- Flagging of AD for refusal of CPR
- Flagging of DNACPR for non-hospitalised patients

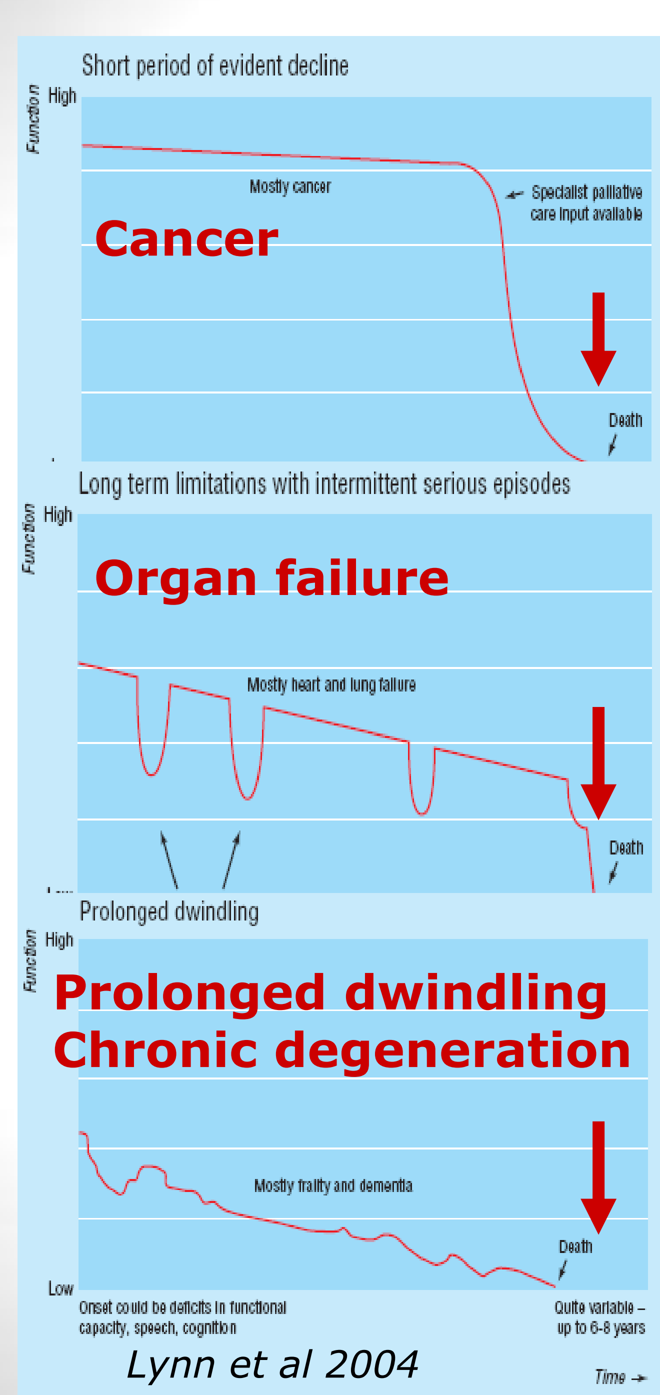


- Depends on clinician's effort to enter or revise
- Not an AD registry
- But serves as a reminder for staff
- A total of 726 entries in 2015

We cannot evade uncertainties in medicine and have to admit the difficulties in

- *prognostic telling*
- *identifying the appropriate time for ACP discussion*

Prognostic Difficulty and ACP timing



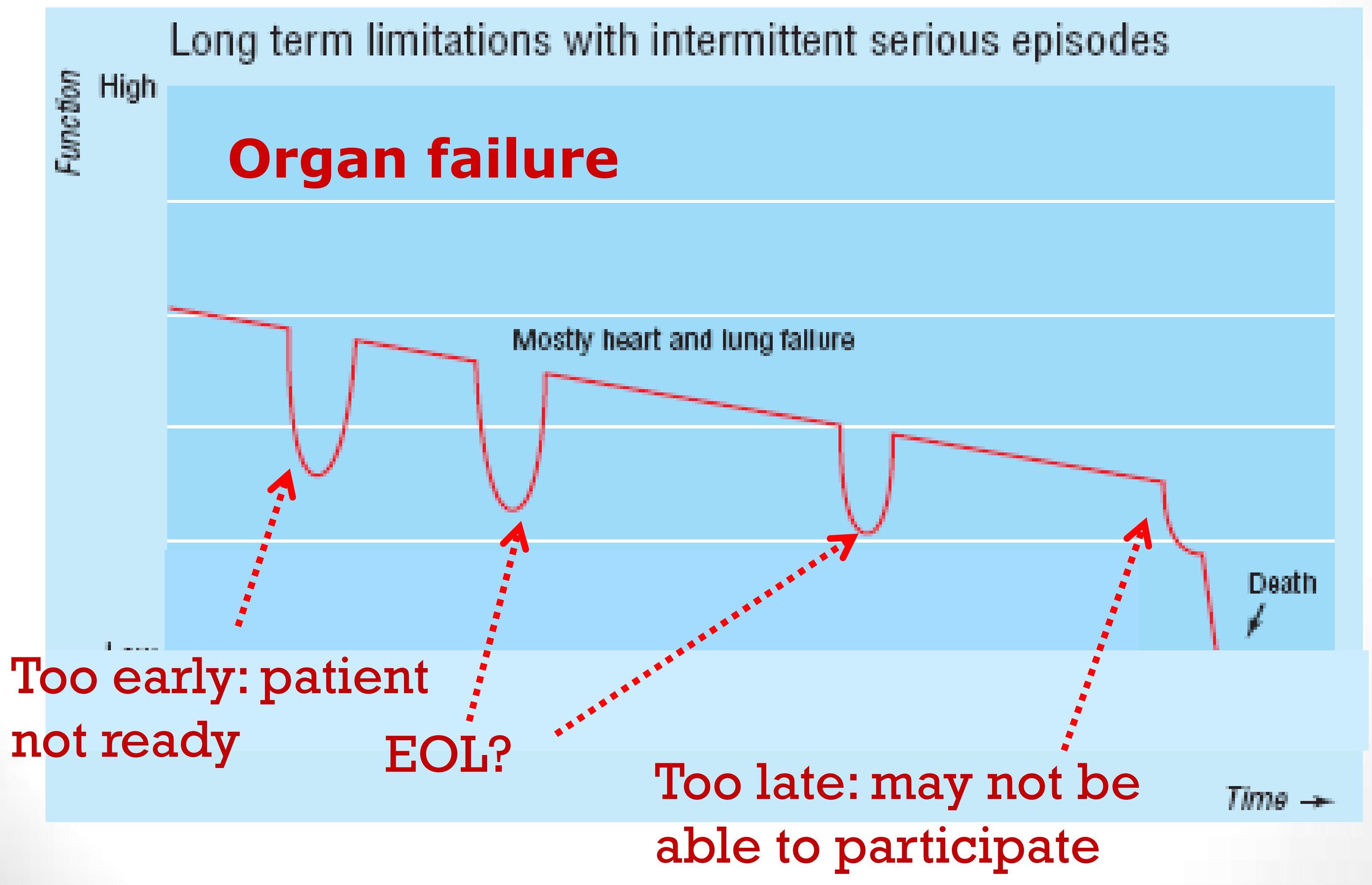
- Relatively predictable
- Unpredictable with acute episodes

  Challenge: engage patient at the right time

- Cognitive decline

  Challenge: engage patient before mentally incompetent

Prognostic Difficulty & ACP Timing



Lynn et al 2004

Prospective autonomy

- Prospective autonomy
  - Hypothetical facts
  - Variable circumstances
- Difficult to know what I will prefer when seriously ill or mentally incompetent
- So can the AD be determinative of the post competence medical decision?

Norman L. Cantor, *Prospective Autonomy: On the Limits of Shaping One's Postcompetence Medical Fate*, 8 J. Contemp. Health L. & Pol'y 13 (1992).

Do patients really understand?

Preferences for Resuscitation and Intubation Among Patients With Do-Not-Resuscitate/ Do-Not-Intubate Orders

Jesus et al. Mayo Clinic Proceedings. 88(7):658-65, 2013 Jul.

Among 100 patients with DNACPR orders in place

- 28% wanted intubation for severe pneumonia
- 20% wanted trial of CPR despite no hope of recovery

A choice contradicting DNR / DNI status!

Do patients change their mind?

Original Investigation

Stability of End-of-Life Preferences
A Systematic Review of the Evidence

Catherine L. Auriemma, MD; Christina A. Nguyen; Rachel Bronheim; Saida Kent, BS; Shrivatsa Nadiger, MD; Dustin Pardo, MD; Scott D. Halpern, MD, PhD

JAMA Intern Med. 2014;174(7):1085-1092. doi:10.1001/jamainternmed.2014.1183
Published online May 26, 2014.

- In 17 out of 24 studies, > 70%of patients' preferences for EOL care were stable over time.
- Patients with higher education and who had engaged in ACP had greater preference stability
- Stability of seriously ill patients > older adults without serious illnesses ($P < .002$)

Wishes and promises

Will my wish be respected?

Death is inevitable
Dying well is not

Are we ready to support our patients when they fall?

Advance Refusal of LST

"We only forgo futile life-sustaining treatment, we never abandon patients"

- Symptom control and psychosocial care should be actively provided
- Patient should have access to palliative care as needed
- Poor symptom control inflicts sense of guilt and regret in the bereaved

But ACP is more than advance refusal of LST…

ACP may cover...
Refusal of LST
Personal care
Personal wish
Place of care
Place of death

END WITH
CHALLENGES AHEAD IN
HONG KONG

Dying cannot wait for legislation!
Bottom up approach

Silver Tsunami
Graying baby boomers

Overloaded Health Care System where most deaths occur

- 90% or more of HK deaths occur in HA
- 40% of HA deaths from OAH
- 82% of HA deaths age > 65

Hong Kong hospital crisis: overcapacity, overworked doctors and peak flu season will make it worse

South China Morning Post 9.3.201[illegible]

After bed occupancy rate ex[illegible] Tuesday, Dr Ko Wing-man s[illegible] suspending non-emergency [illegible]

公院急症室及內科病床使用[illegible]

醫院	求診人次	經急症入內科人次	內科[illegible]病床佔[illegible]
博愛醫院	422	46	131[illegible]
威爾斯親王醫院	454	55	126%
伊利沙伯醫院	636	78	124%
聯合醫院	617	93	124%
仁濟醫院	460	74	124%
明愛醫院	509	80	123%
[illegible]	[illegible]	87	118%
[illegible]	[illegible]	51	117%
[illegible]	[illegible]	81	117%
[illegible]	[illegible]	49	[illegible]
[illegible]	[illegible]	46	[illegible]

- We need to talk
- But we don't have time to talk

Even more crowded places to live in, not to mention to die

Challenges in meeting the needs

Refusal of LST

Personal care

Personal wish

Place of care

Place of death

Thank You

I will not cause pain without allowing something new to be born

Isaiah 66:9