Ethical Issues of End-of-Life Care in Hong Kong

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International Workshop on Ageing:
Intergenerational Justice and Elderly Care
CUHK Centre for Bioethics
April 28, 2017

World's Quality of Death By Ranking

The Economist Intelligence Unit

An Economist Intelligence Unit study, commissioned by the Lien Foundation

THE 2015 QUALITY OF DEATH INDEX

RANKING PALLIATIVE CARE ACROSS THE WORLD

KEY FINDINGS INFOGRAPHIC

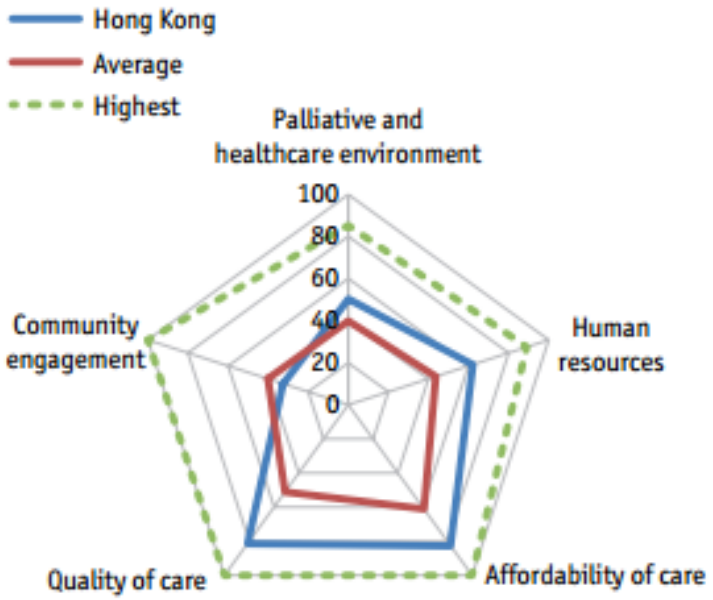
Figure 1.2

2015 Quality of Death Index—Overall scores

Rank	Country	
1	UK	93.9
2	Australia	91.6
3	New Zealand	87.6
4	Ireland	85.8
5	Belgium	84.5
6	Taiwan	83.1
7	Germany	82.0
8	Netherlands	80.9
9	US	80.8
10	France	79.4
11	Canada	77.8
12	Singapore	77.6
13	Norway	77.4
14	Japan	76.3
15	Switzerland	76.1
16	Sweden	75.4
17	Austria	74.8
18	South Korea	73.7
19	Denmark	73.5
20	Finland	73.3
21	Italy	71.1
22	Hong Kong	66.6
23	Spain	63.4
24	Portugal	60.8
25	Israel	59.8
26	Poland	58.7
27	Chile	58.6
28	Mongolia	57.7
29	Costa Rica	57.3
30	Lithuania	54.0
31	Panama	53.6
32	Argentina	52.5
33	Czech Republic	51.8
34	South Africa	48.5
35	Uganda	47.8
36	Cuba	46.8
37	Jordan	46.7
38	Malaysia	46.5
39	Uruguay	46.1
40	Ecuador	44.0
41	Hungary	42.7
42	Brazil	42.5
43	Mexico	42.3
44	Thailand	40.2
45	Venezuela	40.1
46	Puerto Rico	40.0
47	Turkey	38.2
48	Russia	37.2
49	Peru	36.0
50	Kazakhstan	34.8
51	Ghana	34.3
52	Morocco	33.8
53	Indonesia	33.6
54	Tanzania	33.4
55	Slovakia	33.2
=56	Egypt	32.9
=56	Greece	32.9
58	Vietnam	31.9
59	Zimbabwe	31.3
60	Saudi Arabia	30.8
61	Zambia	30.3
62	Bulgaria	30.1
63	Kenya	30.0
64	Romania	28.3
65	Sri Lanka	27.1
66	Malawi	27.0
67	India	26.8
68	Colombia	26.7
69	Ukraine	25.5
70	Ethiopia	25.1
71	China	23.3
72	Botswana	22.8
73	Iran	21.2
74	Guatemala	20.9
75	Dominican Republic	17.2
76	Myanmar	17.1
77	Nigeria	16.9
78	Philippines	15.3
79	Bangladesh	14.1
80	Iraq	12.5

Hong Kong Ranked 22 in the world!

	Rank/80	Score/100
Quality of Death overall score (supply)	**22**	**66.6**
Palliative and healthcare environment	28	50.4
Human resources	20	62.1
Affordability of care	=18	82.5
Quality of care	=20	81.3
Community engagement	=38	32.5



- Highlights from the Report:
  - Palliative care moderately developed
  - Medical curriculum exposes students to the subject, but courses are not compulsory
  - Accreditation is given for physicians but not for nurses
  - DNR has no legal standing
  - Most people have limited understanding about palliative care

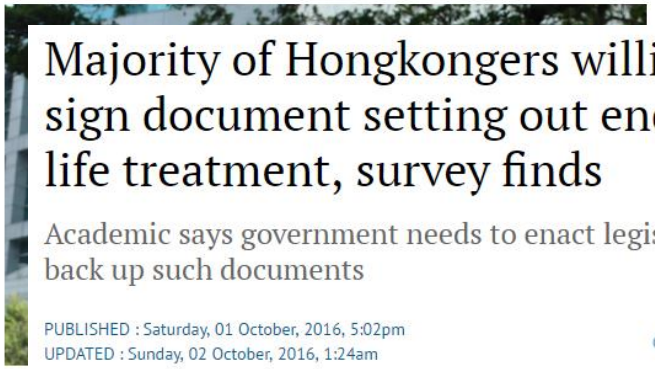
South China Morning Post

Nobel winner wants to die in peace at home, wife says, as she urges Hong Kong to change culture on end-of-life care

Physicist Charles Kao Kuen, who has end-stage dementia, does not want to be kept alive in hospital when his time comes

PUBLISHED : Sunday, 10 July, 2016, 7:17pm
UPDATED : Monday, 11 July, 2016, 6:00pm

COMMENTS: 6



Majority of Hongkongers willing sign document setting out end-o life treatment, survey finds

Academic says government needs to enact legislatic back up such documents

PUBLISHED : Saturday, 01 October, 2016, 5:02pm
UPDATED : Sunday, 02 October, 2016, 1:24am

COMMEN

明報

港聞

2017年3月15日 星期三

病危醫不醫 六成人想預設指示 調查：八成人未聽過 學者倡探討立 ▾

上一篇 下一篇

病危醫不醫 六成人想預設指示 調查：八成人未聽過 學者倡探討立法

讚好 688

圖2之1 - 本港目前未就「預設醫療指示」立法，但在普通法下，按個人意願所 .....

PUBLISHED : Monday, 11 July, 2016, 8:02am
UPDATED : Monday, 11 July, 2016, 8:02am

End-of-life care in Hong Kong severely lacking, doctors warn

With only 19 palliative care specialists in the city, ining must change, they say

港聞二

une, 2016, 8:02am
16, 4:15pm

COMMENTS: 4

The FHB Commissioned Research Project

"Quality of healthcare for the ageing – Health system and service models to better cater for an ageing population"

Objectives:

- To identify barriers and recommend service models for end-of-life (EOL) care in Hong Kong
- To recommend service models and changes (including legislation) if required

Outline

- Ethical Principles related to EOL care
- The Big Conversation
- Palliative Care
- Advance Decisions: DNACPR/AD/EPA

Principles of Biomedical Ethics

(Beauchamp & Childress, 2012)

1. Autonomy
2. Non-maleficence
3. Beneficence
4. Justice

Not a Formula or Guideline!

They are the different aspects that need to be balanced!

Autonomy

- *Free to act according to their personal values and beliefs, provided that it does not cause harm to others*
- To ensure that the capacity of others to make choices is both defended and enhanced
- Examples:
  - Treatment vs. non-treatment
  - Confidentiality
  - Public health policies

Non-maleficence and Beneficence

- Non-maleficence: *Premum non nocere (First, do no harm)*
- Beneficence: Positive requirement to do good to others: e.g. prevention of harm, removal of harm, counterbalance harm with benefits, promote health and well-being
  - However, practice of medicine can entail harm: e.g. side effects, invasive and aggressive treatments → Medical Paternalism
  - Medical Paternalism:
    - Doctors always know best
    - Treatments according to perceived "best interest" for the patients that act against the patients' wish (beneficence vs. autonomy)

Invasive and futile treatments

- Medical futility:
  - Interventions that are unlikely to produce any significant benefit for the patient
  - May be against the objective of maintaining and restoring health
  - Burden on patient

The Big Conversation

The Big Conversation

- Some issues:
  - Common practice esp. in Asian context: Concealment of the seriousness of the condition from the healthcare professionals and the family
  - No evidence linking truth-telling to worse outcomes
  - Violation of Principle 1. Autonomy → how can a patient concealed of the truth make informed choices?
  - Healthcare professionals not trained in communicating bad news

JAMDA xxx (2017) 1.e1–1.e9

JAMDA

journal homepage: www.jamda.com

Original Study

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 1067 Adults

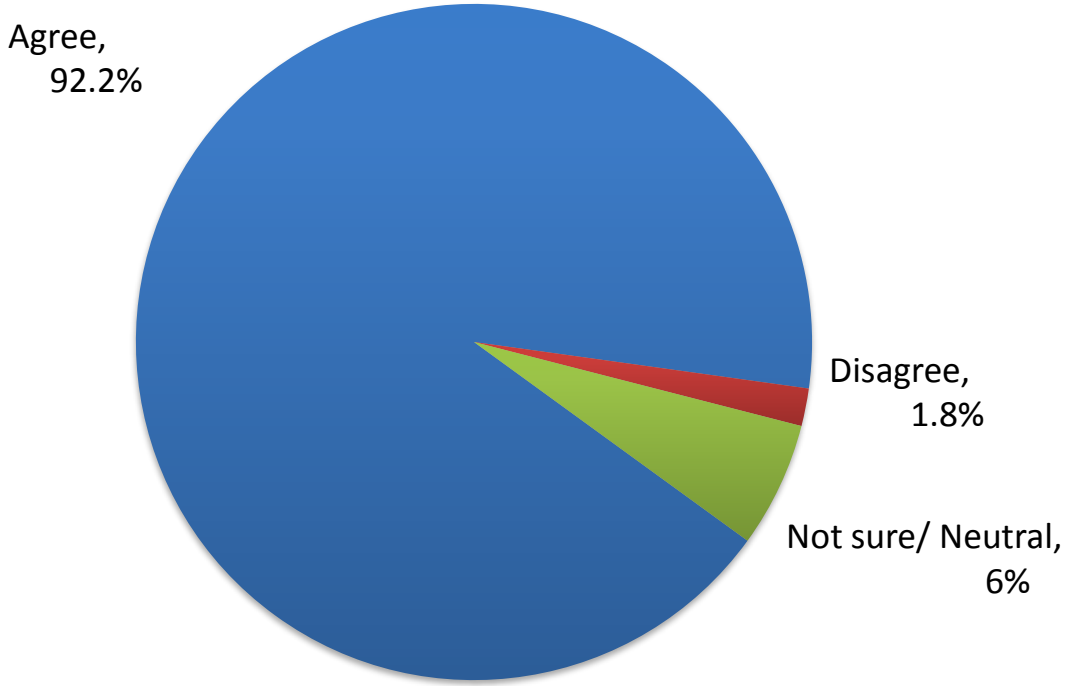
A Telephone Survey of 1,067 adults of the General Hong Kong Population above 30 years old

Roger Yat-Nork Chung, Eliza Lai-Yi Wong, Nicole Kiang, Patsy Yuen-Kwan Chau, Janice Lau, Samuel Yeung-Shan Wong, Eng-Kiong Yeoh, Jean Woo

Main Findings
The Big Conversation

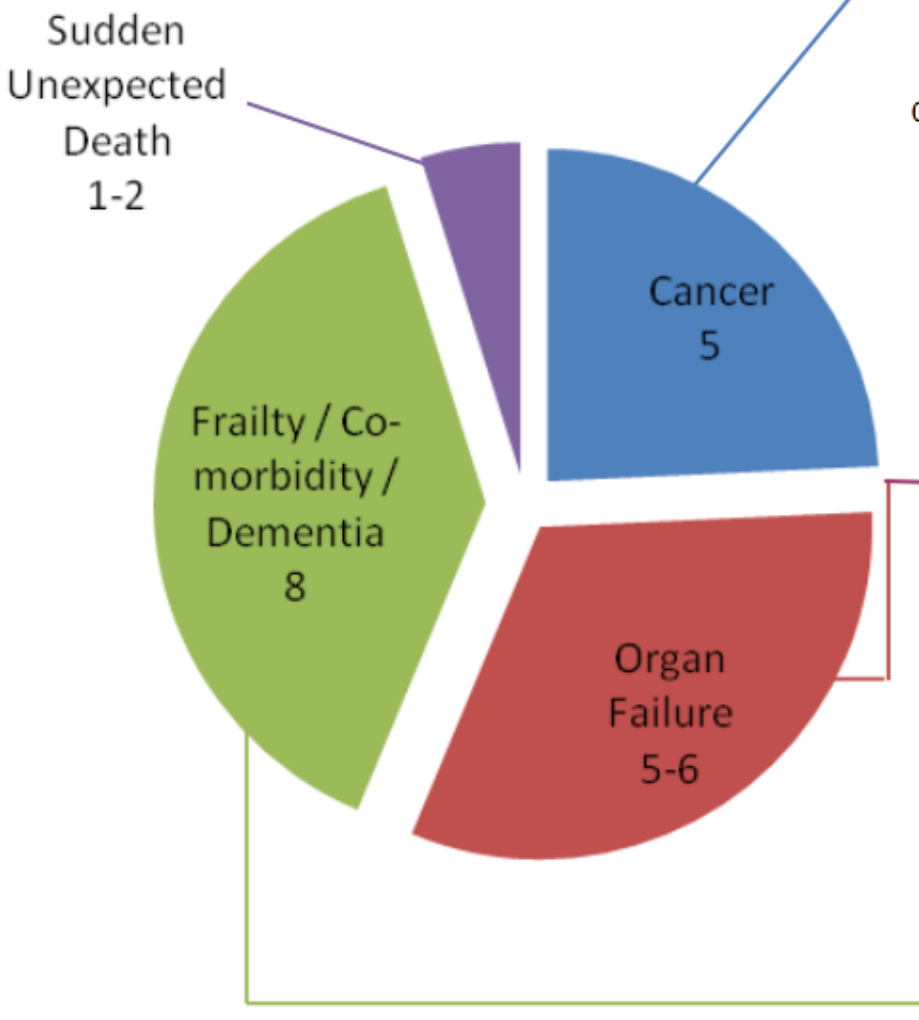
Main Findings – The Big Conversation

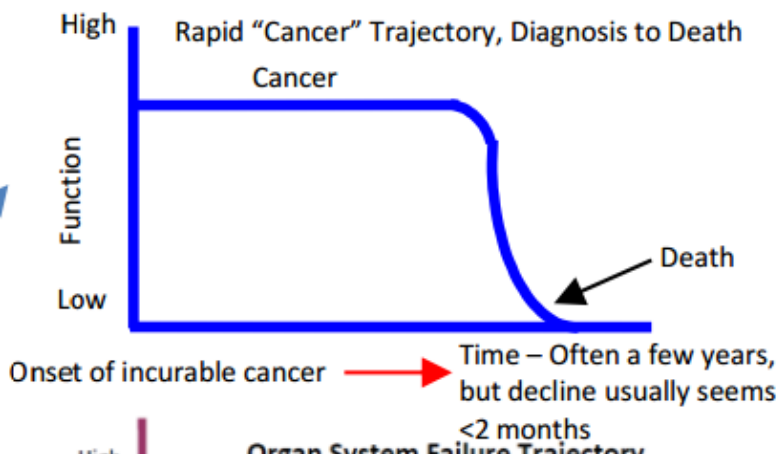
It is a good practice for medical staff directly inform patient about their situation and end of life care plans

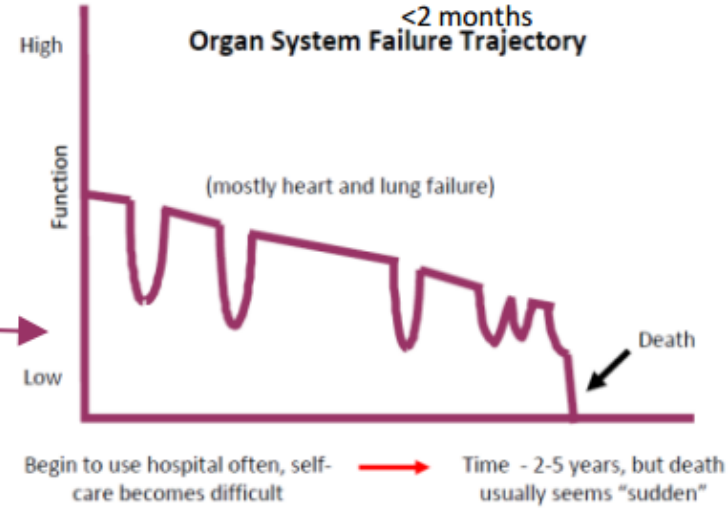


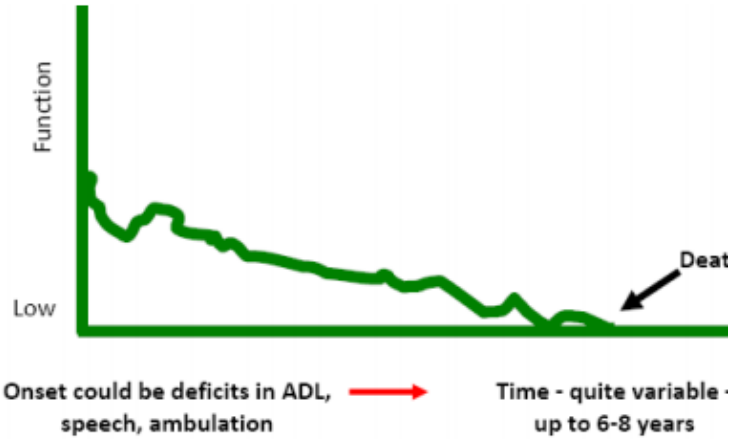
Ref: Chung RY, et al. Knowledge, Attitudes, and Preferences of Advance Decisions, End-of-Life Care, and Place of Care and Death in Hong Kong. A Population-Based Telephone Survey of 1067 Adults. J Am Med Dir Assoc. 2017 Apr 1;18(4):367.e19-367.e27.

Average GP's workload – average 20 deaths/GP/year approx. proportions









Ref: The Gold Standards Framework Centre In End of Life Care CIC, Thomas K et al 2011

End of Life

- End of Life (EOL):
  - Unpredictable prognosis or trajectory → difficult to identify the dying phase and EOL
  - Prognostication may be easier for those with more experience in EOL care and for those with training, but is likely to remain an ongoing challenge due to unpredictable trajectories

Terminally Ill

- “The terminally ill are patients who suffer from advanced, progressive, and irreversible disease, and who fail to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few months.” (HA, 2002)

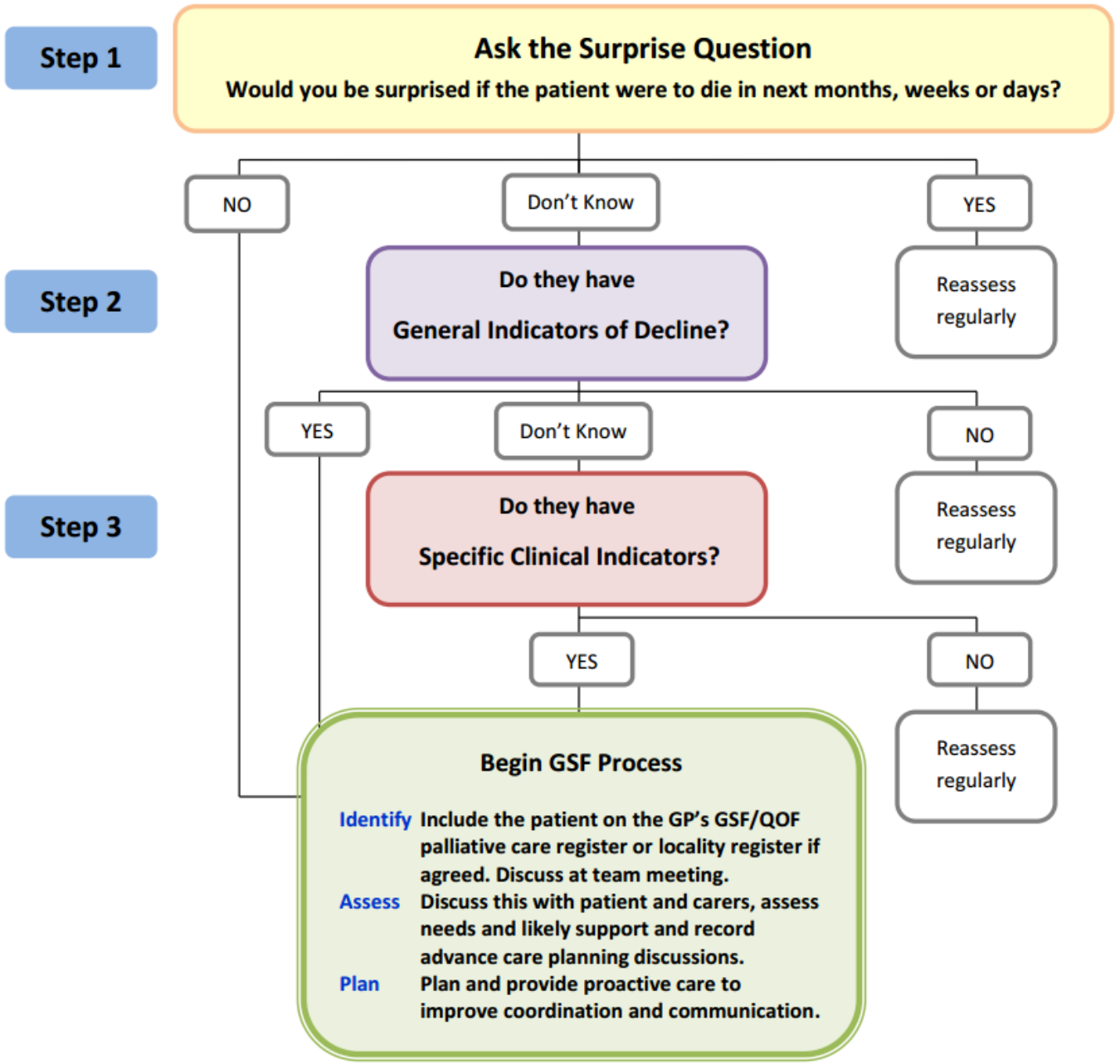
Ref: Working Group on Clinical Ethics of the Hospital Authority Clinical Ethics Committee, *HA guidelines on life-sustaining treatment in the terminally ill, Hospital Authority (HA)*, 2002, Hong Kong Hospital Authority: Hong Kong.

The UK Gold Standards Framework

- Three triggers that patients are nearing EOL
  1. The Surprise Question: “Would you be surprised if the patient were to die in next months, weeks or days?”
  2. General indicators of decline – deterioration, increasing need or choice for no further active care
  3. Life-threatening acute conditions caused by sudden catastrophic events

the gold standards framework

Summary of suggested three steps for earlier identification



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Palliative Care vs. Curative Cure

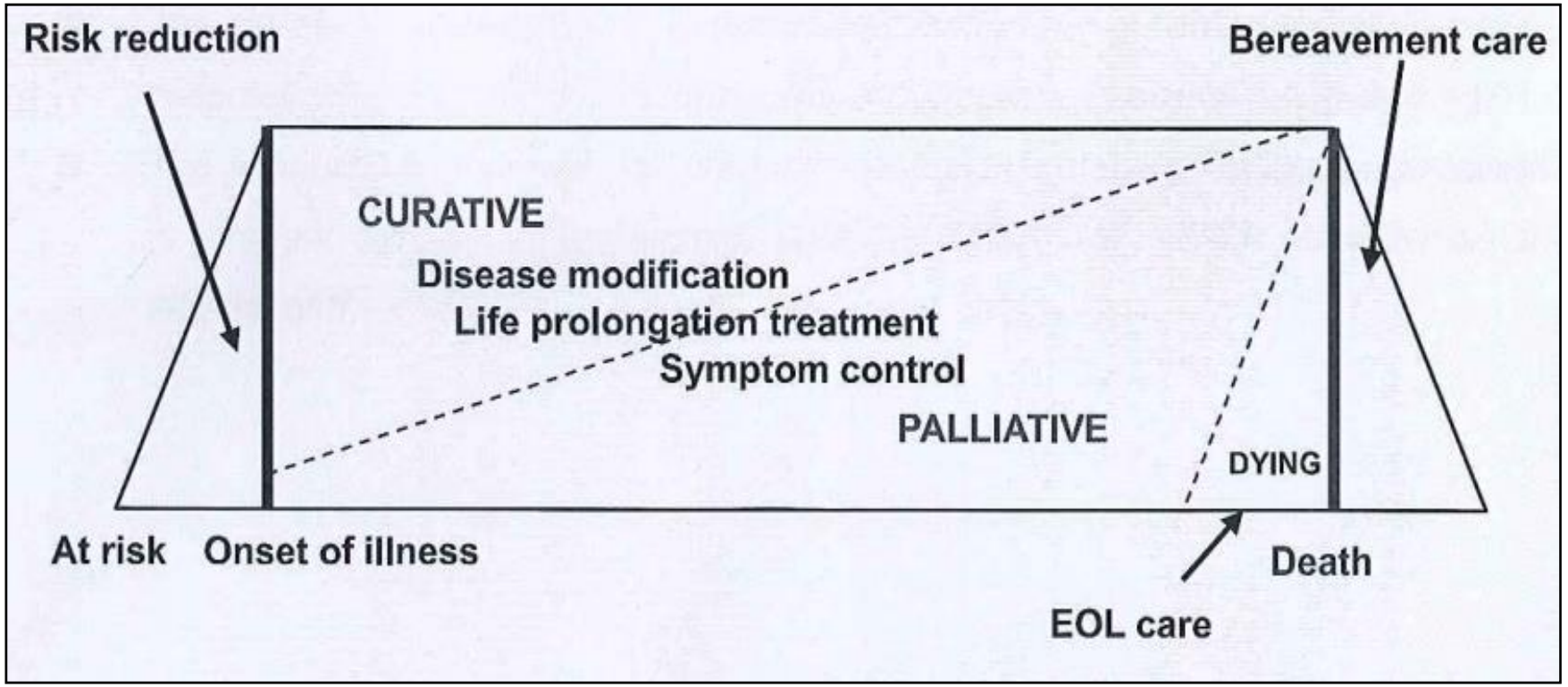
Palliative Care

- “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO 2015)
- Comfort-care given by inter-disciplinary team consisting of care professionals (e.g. medical doctors, nurses and other allied health professionals), most commonly in the clinical settings of hospitals, extended care facilities, and nursing homes , and can be extended to the home settings through palliative outreach professionals.
- Traditionally, palliative care has focused more on cancer patients, and has increasingly extended to include non-cancer patients with other terminal illnesses, such as organ failure, and more recently dementia.
- Begins earlier at the start of the prognostication of the disease, and an integral part of EOL care

Palliative Care

- Virtue ethics and care ethics
- Utilitarianism
  - Vs. Curative Care (maximizing the utility, in this case **life span**)
  - maximizing the **quality of life/death**

Changing course of health care needs along the illness trajectory



Continuum of Care!!

Ref: WHO, *Cancer control: Palliative care- WHO guide for effective programmes*, 2007.

Points for Discussions

- Would you consider administering palliative and EOL care giving up hope on the terminally ill patient?
- Who would still try everything (including invasive yet futile treatments) to save that terminally ill patient?
- Do you consider yourself achieving your goal/objective if the person you saved do not have much quality of life afterwards?

Points for Discussions

- If you were a patient being diagnosed to have a terminal condition with no hope of recovery, would you prefer to
  - Prolong your life as much as possible with medical interventions even when it means pain, discomfort and suffering; or
  - Receive appropriate palliative care that does not necessarily prolong your life but gives you more comfort

JAMDA xxx (2017) 1.e1–1.e9

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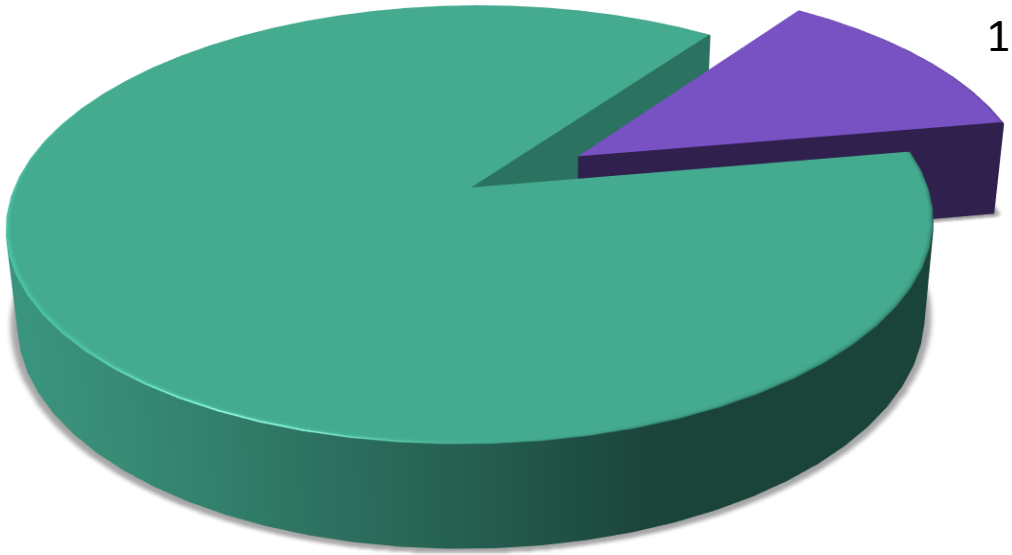
Main Findings
Palliative Care

Main Findings – Palliative Care

If you were being diagnosed to be terminally ill, you would prefer to:



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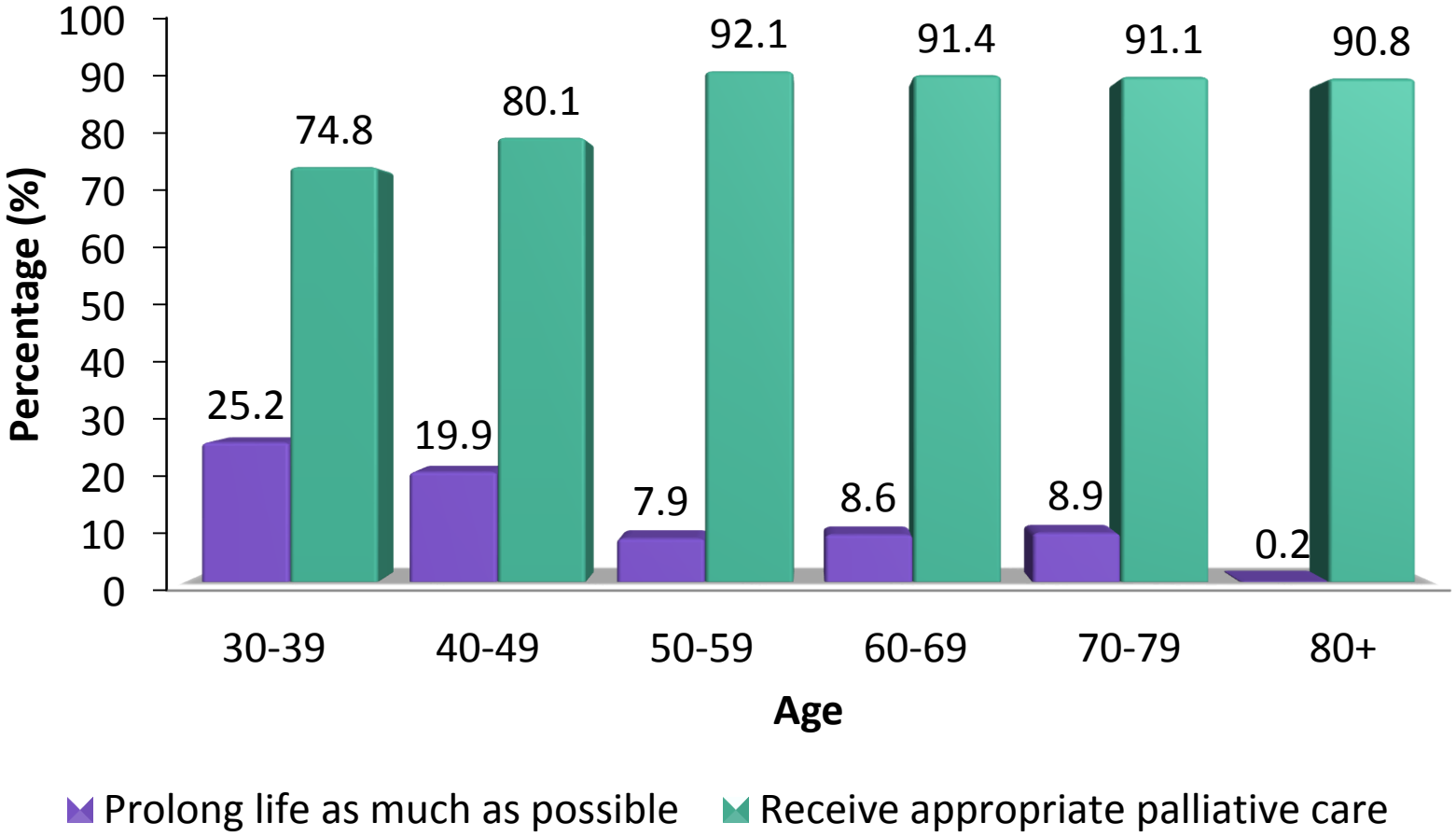

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Main Findings – The Big Conversation

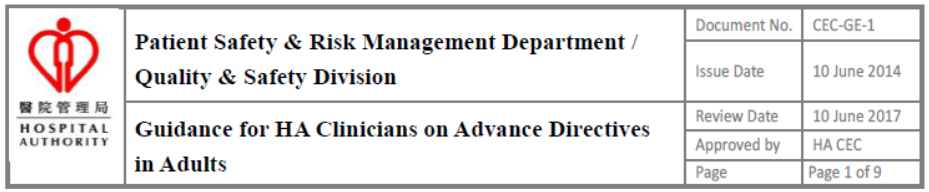
- Adjusted logistic regression showed that palliative care was more preferred by age groups 50 years or above (OR = 2.229 – 3.047) but was less preferred by those who did not care for their family members with chronic diseases (OR = 0.505)
  - Implication: experience does matter!

Do-Not-Attempt-Cardiopulmonary Resuscitation/ Advance Directive/ Enduring Powers of Attorney

Advance Directive

- **Existing recommendations and reports for ADs in Hong Kong:**
  - The Law Reform Commission (LRC) 2006 report '*Substitute Decision-making and Advance Directives in Relation to Medical Treatment'* made recommendations and provided a model AD form.
    - Recommendations: first promoting and disseminating the model ADs by non-legislative means and later for the government to review how widely the use of ADs had been taken up; how many disputes had arisen; and the extent to which people had accepted the model form of ADs.
  - 2009: Food and Health Bureau '*Consultation Paper on the Introduction of the Concept of Advance Directives in Hong Kong'*
    - Recommendations: providing more information regarding AD and developing guidelines on AD, and made minor modifications to the LRC model form.
  - 2014: the updated Hospital Authority '*Guidance for HA Clinicians on Advance Directives in Adults'* provided standardized full and short versions of ADs to all HA public hospitals in Hong Kong.
    - ADs are applicable where a person is (i) terminally ill, (ii) in a persistent vegetative state or a state of irreversible coma, or (iii) in other specified end-stage irreversible life limiting condition.

Advance Directives in HK



醫院管理局 HOSPITAL AUTHORITY	Patient Safety & Risk Management Department / Quality & Safety Division	Document No.	CEC-GE-1
		Issue Date	10 June 2014
	Guidance for HA Clinicians on Advance Directives in Adults	Review Date	10 June 2017
		Approved by	HA CEC
		Page	Page 1 of 9

Guidance for HA Clinicians on Advance Directives in Adults

Version	Effective Date
1	8 July 2010
2	6 October 2014

Document Number	CEC-GE-1
Author	Working Group on Advance Directives (July 2010) HA Clinical Ethics Committee (June 2014)
Custodian	Patient Safety & Risk Management Department
Approved By	HA Clinical Ethics Committee
Approval Date	9 June 2014

- AD only recognized under the common law framework
- Not legislated
- Fire Services Department does not participate in guidelines

醫院管理局
HOSPITAL AUTHORITY

ADVANCE DIRECTIVE[1]

Please Use Block Letter or Affix Label

SOPD / Hospital No. : ……

Name : ……

I.D. No : ……..Sex …… Age……

Dept : ……Team :……Ward/Bed :…/……

Section I : Personal details of the maker of this advance directive

Name : …… *(please use capital letters)*

Identity Document No.: ……

Sex : **Male / Female**

Date of Birth : _____ / _____ / _____
(Day) (Month) (Year)

Home Address : ……

……

Home Tel. No. : ……

Office Tel. No. : ……

Mobile Tel. No. : ……

Section II : Background

1. I understand that the object of this directive is to minimise distress or indignity which I may suffer or create when I am terminally ill or in a persistent vegetative state or a state of irreversible coma, or in other specified end-stage irreversible life limiting condition, and to spare my medical advisers or relatives, or both, the burden of making difficult decisions on my behalf.

2. I understand that euthanasia will not be performed, nor will any unlawful instructions as to my medical treatment be followed in any circumstances, even if expressly requested.

3. I, _____ (please print name) being over the age of 18 years, revoke all previous advance directives made by me relating to my medical care and treatment (if any), and make the following advance directive of my own free will.

4. If I become terminally ill or if I am in a state of irreversible coma or in a persistent vegetative state or in other specified end-stage irreversible life limiting condition as diagnosed by my attending doctor and at least one other doctor, so that I am unable to take part in decisions about my medical care and treatment, my directives in relation to my medical care and treatment are as follows:

(Note: Complete the following by ticking the appropriate box(es) and writing your initials against that/those box(es), and drawing a line across any part you do not want to apply to you.)

[1] The Form was proposed by the Law Reform Commission on 16 August 2006; amended as in Food and Health Bureau Consultation Paper on 23 December 2009; modifications made and footnotes added by the Hospital Authority in May 2010 and in Jun 2014.

(A) Case 1 – Terminally ill

(Note: In this instruction –

"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, and

"Life-sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration. (Artificial nutrition and hydration means the feeding of food and water to a person through a tube.))

☐ **I shall not be given the following life-sustaining treatment(s):**

- ☐ **Cardiopulmonary resuscitation (CPR)**
- ☐ **Others:** _____

_____

☐ **Save for basic and palliative care, I shall not be given any life-sustaining treatment[2]. Non-artificial nutrition and hydration shall, for the purposes of this form, form part of basic care.**

- ☐ **However, I want to continue to receive artificial nutrition and hydration, if clinically indicated, until death is imminent and inevitable.**

(B) Case 2 – Persistent vegetative state or a state of irreversible coma

(Note: In this instruction -

"Life-sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration[3]. (Artificial nutrition and hydration means the feeding of food and water to a person through a tube.))

☐ **I shall not be given the following life-sustaining treatment(s):**

- ☐ **Cardiopulmonary resuscitation (CPR)**
- ☐ **Others:** _____

_____

☐ **Save for basic and palliative care, I shall not be given any life-sustaining treatment[4]. Non-artificial nutrition and hydration shall, for the purposes of this form, form part of basic care.**

- ☐ **However, I want to continue to receive artificial nutrition and hydration, if clinically indicated, until death is imminent and inevitable.**

[2] Care should be taken to ensure that the patient has really decided not to consent to receive "all" life-sustaining treatment.

[3] Note that to withdraw artificial nutrition and hydration (ANH) in a non-terminally ill patient who is in a persistent vegetative state or a state of irreversible coma (PVS/IC) can be contentious even in the presence of an AD. For patients presenting with such a directive and in PVS/IC, advice should be sought from the HCE/CCE and HAHO to consider whether an application to the Court is required. A patient wishing to make a directive to withdraw ANH, or to withdraw all life-sustaining treatments under this Section, should be alerted about this special caution.

[4] Care should be taken to ensure that the patient has really decided not to consent to receive "all" life-sustaining treatment.

(C) Case 3 – Other end-stage irreversible life limiting condition, namely:

_____

(Note: In this instruction -

"Other end-stage irreversible life limiting condition" means suffering from an advanced, progressive, and irreversible condition not belonging to Case 1 or Case 2, but has reached the end-stage of the condition, limiting survival of the patient. Examples include:

(1) patients with end-stage renal failure, end-stage motor neuron disease, or end-stage chronic obstructive pulmonary disease who may not fall into the definition of terminal illness in Case 1, because their survival may be prolonged by dialysis or assisted ventilation, and

(2) patients with irreversible loss of major cerebral function and extremely poor functional status who do not fall into Case 2.

"Life-sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration. (Artificial nutrition and hydration means the feeding of food and water to a person through a tube.))

☐ **I shall not be given the following life-sustaining treatment(s):**

☐ **Cardiopulmonary resuscitation (CPR)**

☐ **Others:** _____

_____

☐ **Save for basic and palliative care, I shall not be given any life-sustaining treatment[5]. Non-artificial nutrition and hydration shall, for the purposes of this form, form part of basic care.**

☐ **However, I want to continue to receive artificial nutrition and hydration, if clinically indicated, until death is imminent and inevitable.**

5. I make this directive in the presence of the two witnesses named in Section III of this advance directive, who are not beneficiaries under:

(i) my will; or
(ii) any policy of insurance held by me; or
(iii) any other instrument made by me or on my behalf.

6. I understand I can revoke this advance directive at anytime[6].

_____ _____
Signature of the maker of this advance directive Date

Section III : Witnesses

Notes for witness :

A witness must be a person who is not a beneficiary under –
(i) the will of the maker of this advance directive; or
(ii) any policy of insurance held by the maker of this advance directive; or
(iii) any other instrument made by or on behalf of the maker of this advance directive.

5. Care should be taken to ensure that the patient has really decided not to consent to receive "all" life-sustaining treatment.
6. A written revocation can be directly signed on the advance directive form, or written and signed on a separate piece of paper and attached to the advance directive form.

Statement of Witnesses

First Witness

(Note: This witness must be a registered medical practitioner, who, at the option of the maker of this directive, could be a doctor other than one who is treating or has treated the maker of this directive.)

(1) I, _____ (please print name) sign below as witness.

(a) as far as I know, the maker of this directive has made the directive voluntarily; and

(b) I have explained to the maker of this directive the nature and implications of making this directive.

(2) I declare that this directive is made and signed in my presence together with the second witness named below.

_____ _____
Signature of 1st witness Date

Name: ……

Identity Document No. / Medical Council Registration No. [7]: ……

Office Address: ……

……

Office Tel. No. : ……

Second Witness

(Note: This witness must be at least 18 years of age)

(1) I, _____ (please print name) sign below as witness.

(2) I declare that this directive is made and signed in my presence together with the first witness named above, and that the first witness has, in my presence, explained to the maker of this directive the nature and implications of making this directive.

_____ _____
Signature of 2nd witness Date

Name: ……

Identity Document No.[8]: ……

Home Address / Contact Address : ……

……

Home Tel. No. / Contact No. : ……

7. It is not necessary for HA staff to provide the Identity document No. / Medical Council Registration No. since staff code or address of hospital ward/unit would be sufficient for the identification of the 1st witness.
8. It is not necessary for HA staff to provide the Identity document No. since staff code or address of hospital ward/unit would be sufficient for the identification of the 2nd witness.

Advance Directive

- **Potential conflicts in real life situations (Case 1):**
  - Mr X signed an AD at the age of 75 agreeing to DNACPR, believing that he doesn't want to suffer so much during his EOL dying process. However, he is not diagnosed to have terminal illness, and he would just like to have autonomous control over his life.
  - However, he did not specify in his AD this particular situation when he thinks that CPR is not necessary.
  - At the age of 78, he fell down the stairs one day, and needed CPR to save his life.
  - Should the paramedics "follow" his AD wish or save him using CPR?

Advance Directive

- **Potential conflicts in real life situations (Case 2):**
  - Mrs M, aged 85, diagnosed to be terminally ill, signed an AD indicating that she agrees to DNACPR towards her EOL
  - However, her doctor in charge told her that an operation may be able to sustain her life and improve her quality of life afterwards, but she may run the risk of putting herself in a situation that possibly needs CPR during the operation. She was advised that if she agreed to the operation, the doctor needs to perform CPR on her if necessary.
  - Is this a violation to her DNACPR wish? Should the doctor perform DNACPR on her or not?

Advance Directive

- **ADs in HK not covered by legislation and therefore may be overridden:**
  - Common-law framework: anyone can formally document their EOL wishes in advance by way of an AD and this is legally recognised.
  - An AD for health care is defined as a *"statement, usually in writing, in which a person indicates when mentally competent the form of health care he would like to have at a future time when he is no longer competent".*
  - Validly-made ADs refusing life-sustaining treatment have been held to be legally binding at common law in the UK and other jurisdictions (e.g. Australia, Canada and Singapore). Notwithstanding the absence of legislation in Hong Kong, a valid AD will still be recognized unless challenged on the grounds such as incapacity or undue influence. However, uncertainties do remain regarding ADs under common law.

Advance Directive

- **Potential conflicts with other statutory provisions:**
  - **AD vs. 'best interest principle'**:
    - Potential conflict between an AD made in advance for someone who later becomes mentally incapacitated and the obligation for practitioners to carry out treatment in the 'best interest' of the patients
    - **Principle 1 (Autonomy) vs. Principle 3 (Beneficence)**
    - The Mental Health Ordinance (Cap 136) Section 59ZF states: '*Where a registered medical practitioner … considers that treatment is necessary and is in the best interests of the mentally incapacitated person, then he may carry out that treatment without the consent of the mentally incapacitated person or that person's guardian (if any) accordingly'*)
    - In 2014, the HA Clinical Ethics Committee stated that when the best interests of a mentally incapacitated person must be considered under the Mental Health Ordinance, the doctor and the guardian must consider clinical benefits and the person's values or belief and what the person might have wanted if being competent. In other words, a valid and applicable AD must be respected as an explicit expression of a patient's wish to refuse medical treatments in specified conditions.

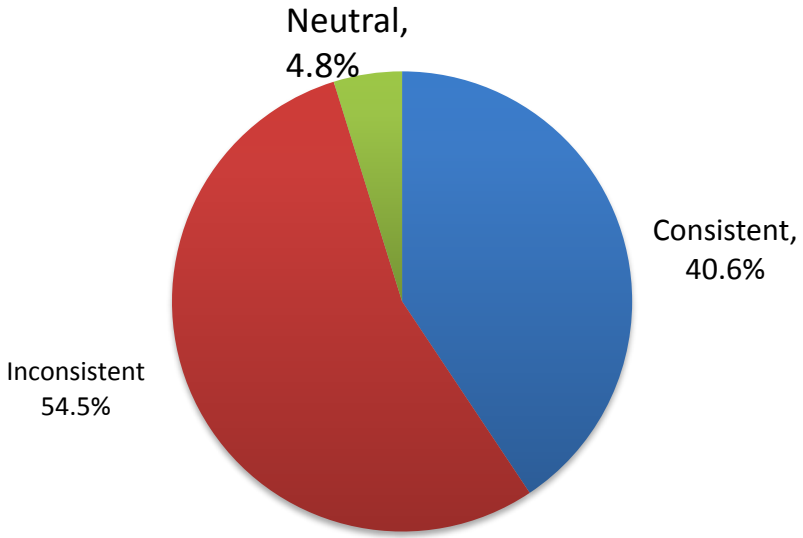
Advance Directive

- **Potential conflicts with other statutory provisions:**
  - **AD vs. Fire Service Ordinance**:
    - Potential conflict between wishes expressed in ADs and the Fire Services Ordinance (Cap 95) obligation to resuscitate or sustain his life.
      - **Principle 1 (Autonomy) vs. Principle 3 (Beneficence) → Violation of Principle 2 (Non-maleficence)?**
    - Acute emergency care (not sub-acute care) may be given at A&E Department, which is the only place the FSD ambulance would transfer the patients to
      - **Violation of Principle 2 (Non-maleficence) & Principle 3 (Beneficence)?**

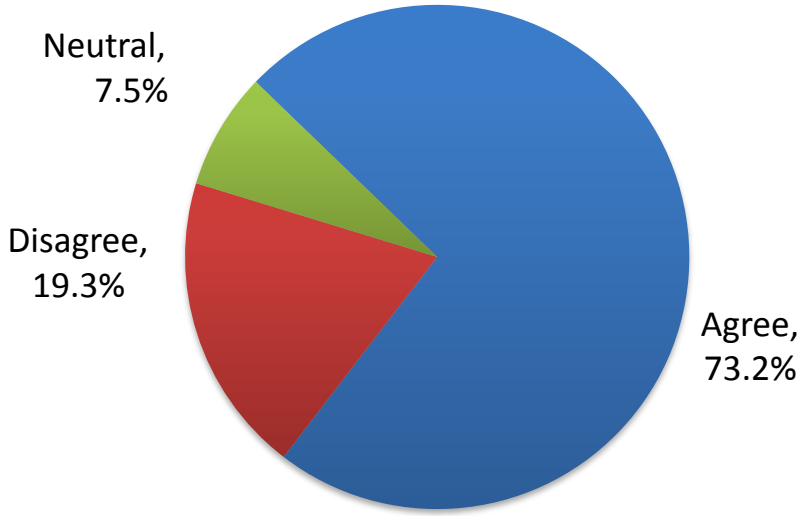
Main Findings
Fire Service Department

Main Findings – EOL Care

For the case of advanced or terminal patients, do you think "resuscitating or sustaining his life" is consistent with "reducing his suffering or distress"? (n=1600)



Do you agree that the Fire Services Ordinance needs to be revised? (n=1600)



Ref: Chung RY et al. (unpublished data)

Advance Directive

- **AD vs. Enduring powers of attorney:** Potential conflict between treatment wishes expressed in an AD and the right for appointed attorneys to make decisions for patients who are not mentally competent → not at the present moment! But something to deal with if EPA extended towards personal care
    - **Principle 1 (Autonomy) vs. Principle 1 (Perceived Autonomy)**
    - Which should take precedence?

Enduring Powers of Attorney

Enduring Powers of Attorney

- **Existing laws and recommendations in Hong Kong for appointed attorneys:**
  - The Powers of Attorney Ordinance (Cap 31): "*a person shall be regarded as being mentally incapable or suffering from mentally incapacity*" if "*he is suffering from mental disorder or mental handicap (using meanings as assigned to them by the Mental Health Ordinance (Cap 136)) and is (i) unable to understand the effect of the power of attorney; or (ii) is unable by reason of his mental disorder or mental handicap to make a decision to grant a power of attorney*" or "*he is unable to communicate to any other person who has made a reasonable effort to understand him, and intention or wish to grant a power of attorney*".
  - Currently only allows the appointed attorney to handle financial matters of the donor before and after he/she becomes mentally incapacitated.
  - In July 2012, the LRC report *Enduring Powers of Attorney: Personal Care* recommended to extend the scope of an EPA, to include decisions on the donor's **personal care but excluding life-sustaining treatments**, and leave the role of making decisions on life-sustaining treatments to the AD.

Enduring Powers of Attorney

- **Legislation does not cover the role of appointed attorneys in decisions on personal care and life-sustaining treatment:**
  - Patients may not wish to formally document care preferences using ADs because of the uncertainty in prognosis or the difficulty in planning for one's own death.
  - In such cases, being able to appoint trusted attorneys to act on one's behalf may bring comfort to patients and their family members.
  - While safeguards and caution are important, excluding life-sustaining treatment from EPA decisions does not reflect and address the reality of many situations where patients lack mental capacity, have not made ADs and where important treatment decisions on life-sustaining treatment must be made.

Enduring Powers of Attorney

- **Uncertainty whether ADs or EPA take precedence**:
  - Care preferences in an AD may conflict with the legal right of appointed attorneys to make decisions on the patient's behalf.
  - The current situation is ambiguous – there is no *legislation* stating whether ADs or EPAs take precedence in cases of conflict.

Enduring Powers of Attorney

- **International experience:**
  - The UK Mental Capacity Act (2005) provides for lasting powers of attorney to include decisions to the continuation of life-sustaining treatments.
  - The UK's Mental Capacity Act 2005 (Section 11) has introduced **safeguards and restrictions** for making decisions on behalf the patients on life-sustaining treatments.

Enduring Powers of Attorney

- **The UK's Mental Capacity Act 2005 (Section 11) Lasting powers of attorney: restrictions**
  - *(7) Where a lasting power of attorney authorises the donee (or, if more than one, any of them) to make decisions about P's personal welfare, the authority—*
    - *(a) does not extend to making such decisions in circumstances other than those where P lacks, or the donee reasonably believes that P lacks, capacity,*
    - *(b) is subject to sections 24 to 26 (advance decisions to refuse treatment), and*
    - *(c) extends to giving or refusing consent to the carrying out or continuation of a treatment by a person providing health care for P.*

Enduring Powers of Attorney

- **The UK's Mental Capacity Act 2005 (Section 25) Validity and applicability of advance decisions**
  - *(2) An advance decision is not valid if P—*
    - *(a) has withdrawn the decision at a time when he had capacity to do so,*
    - *(b) has, under a lasting power of attorney created after the advance decision was made, conferred authority on the donee (or, if more than one, any of them) to give or refuse consent to the treatment to which the advance decision relates, or*
    - *(c) has done anything else clearly inconsistent with the advance decision remaining his fixed decision.*
  - *(7) The existence of any lasting power of attorney other than one of a description mentioned in subsection (2)(b) does not prevent the advance decision from being regarded as valid and applicable.*

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JAMDA

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Original Study

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 1067 Adults

A Telephone Survey of 1,067 adults of the General Hong Kong Population above 30 years old

Roger Yat-Nork Chung, Eliza Lai-Yi Wong, Nicole Kiang, Patsy Yuen-Kwan Chau, Janice Lau, Samuel Yeung-Shan Wong, Eng-Kiong Yeoh, Jean Woo

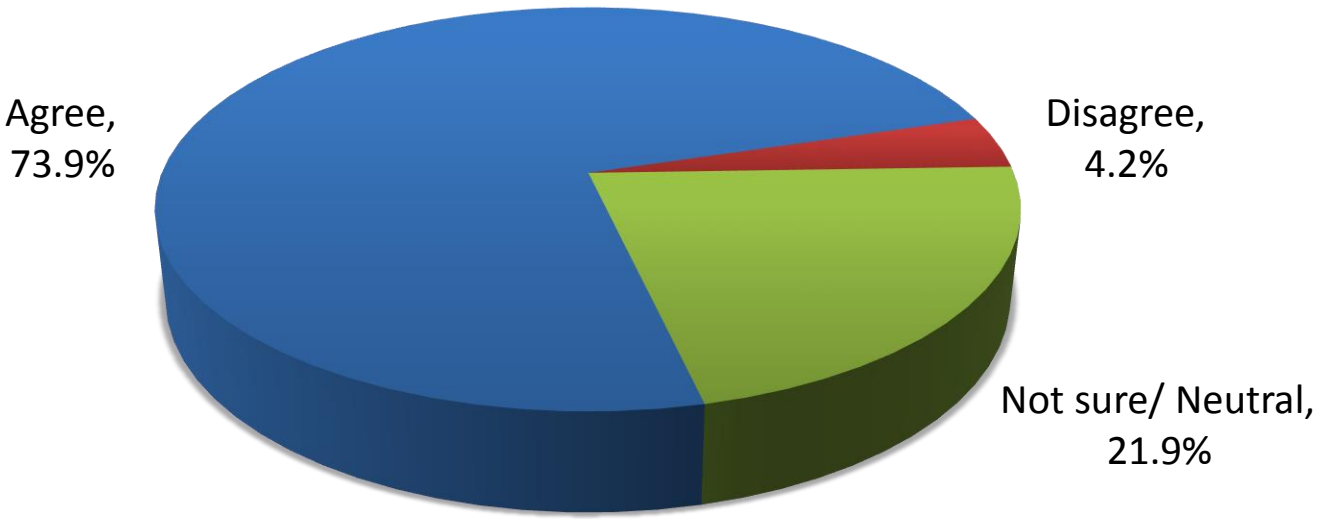
Main Findings
Advance Directive

Main Findings – Advance Directive

85.7% have not heard of Advance Directive (AD)

After explanations of what AD means…

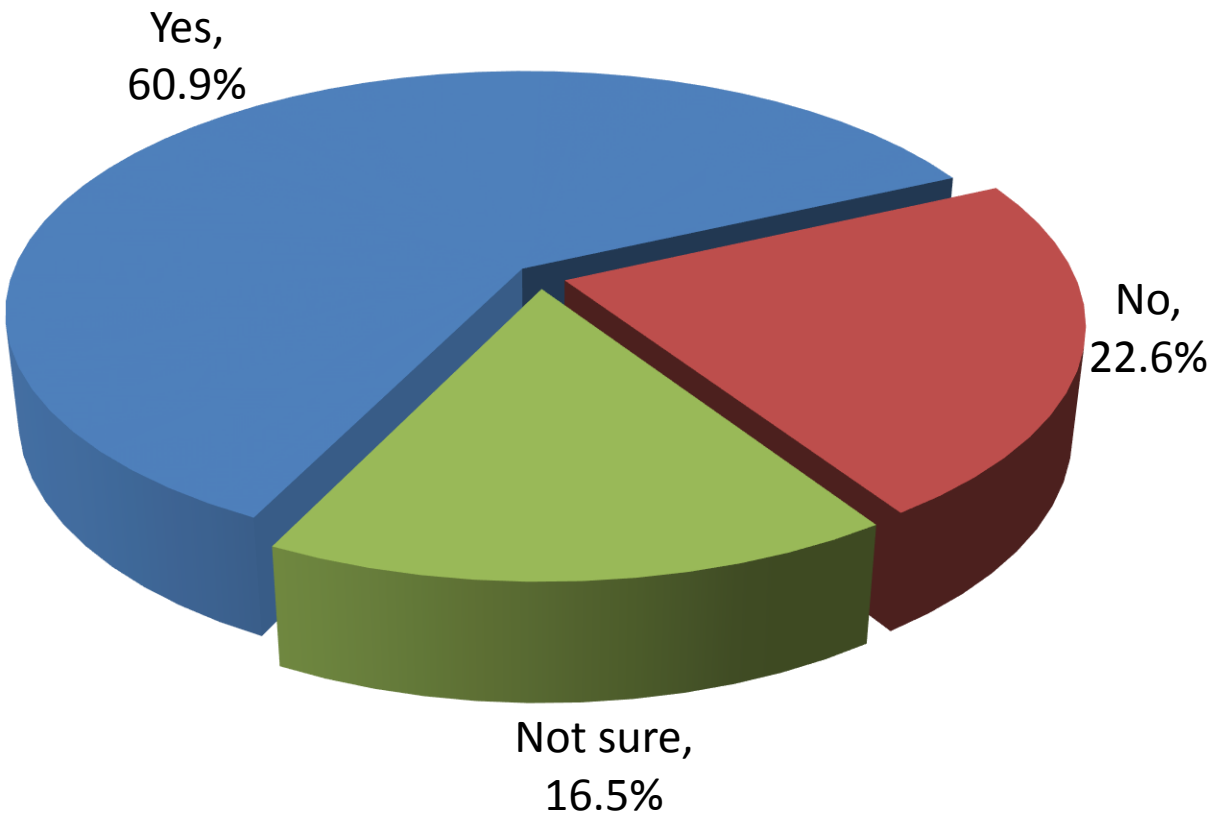
It is a good approach to make an advance directive when a patient is diagnosed to be have an incurable disease.



Ref: Chung RY, et al. 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 1067 Adults. J Am Med Dir Assoc. 2017 Apr 1;18(4):367.e19-367.e27.

Main Findings – Advance Directive

Would make AD if formally legislated in HK



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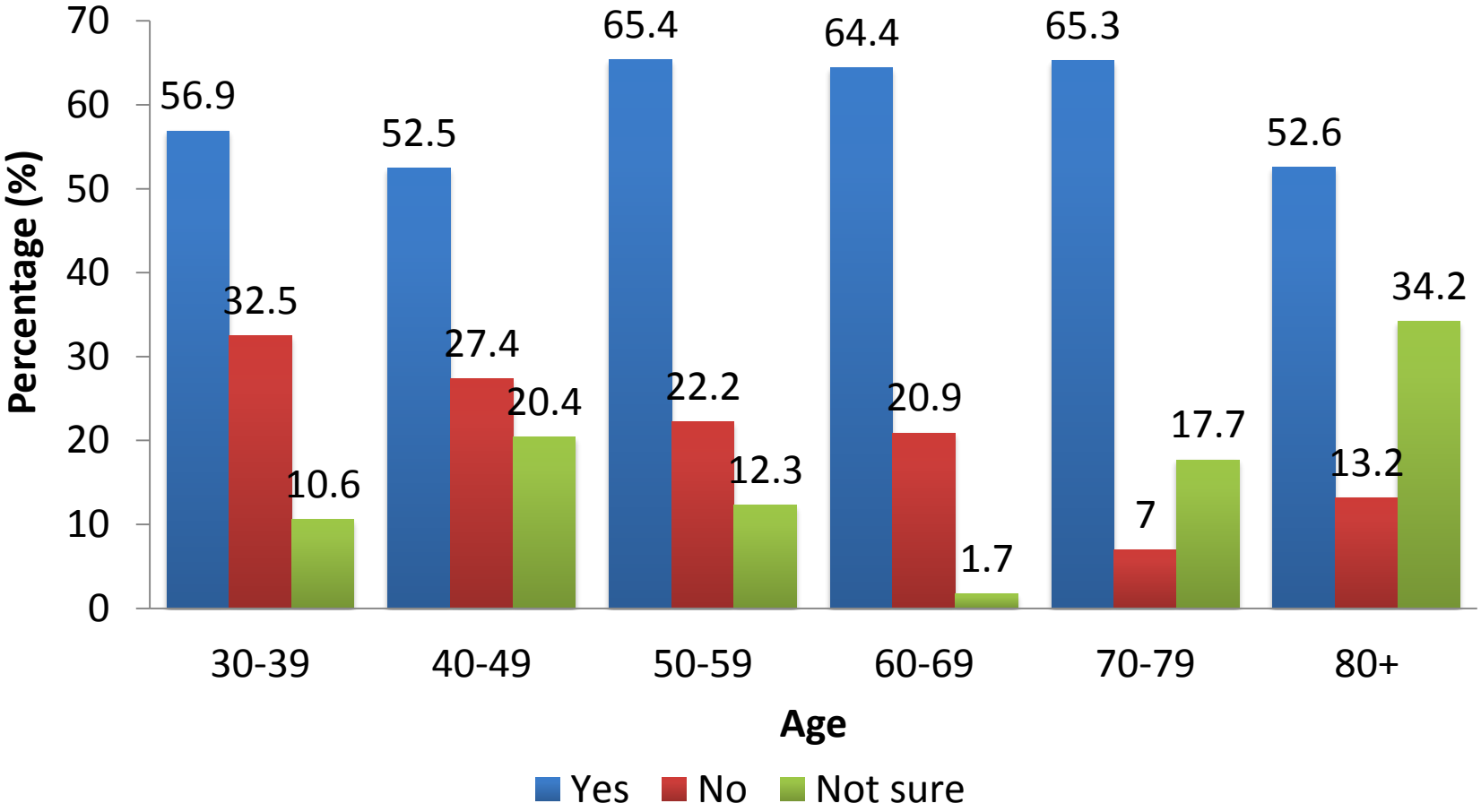

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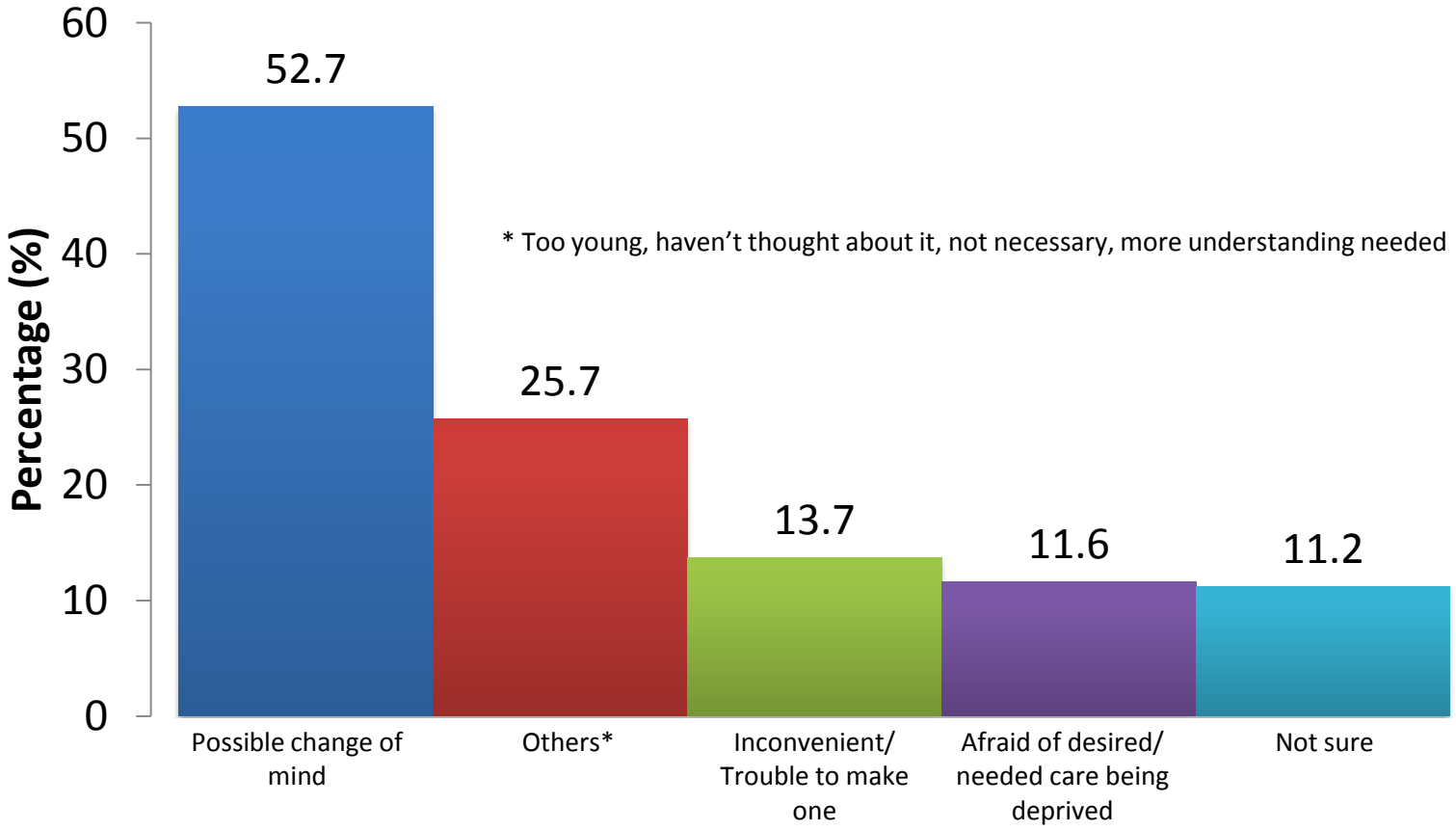
Main Findings – Advance Directive

Reasons for not making an AD (Can choose more than one)



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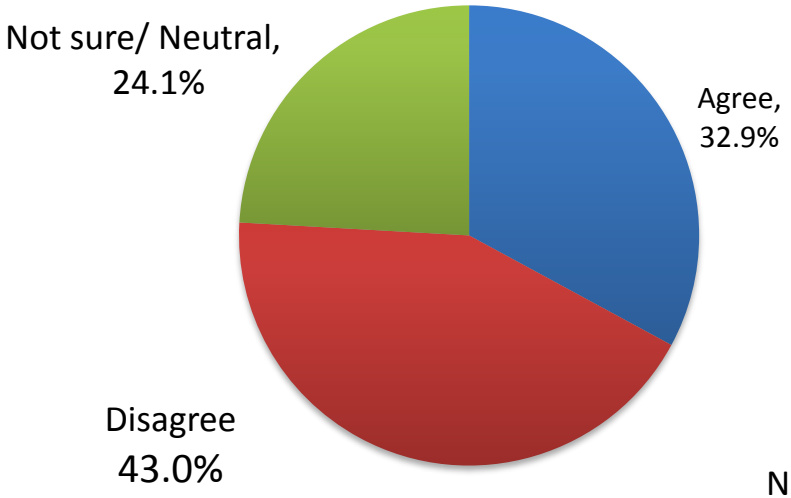
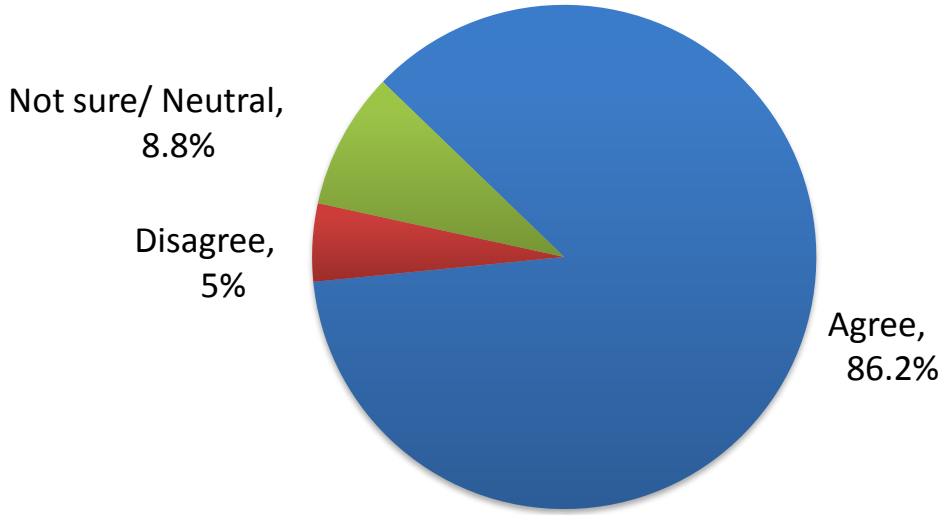
Main Findings – Advance Decisions

Doctors should generally try to keep their patients alive by any means (e.g. machines, intubation) for as long as possible, even if it means pain, discomfort, and suffering



The patient's own wishes should determine what treatment he/she should receive



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Concluding Remarks

- Important to think about the ethical principles behind the policies, system and clinical practice to move forward in EOL care in HK
- Cultural, environmental and system context are also important

Acknowledgement

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- The Research Team
- All participants
- Ethical approval of the research protocol was granted by the Survey and Behavioural Research Ethics Committee of the Chinese University of Hong Kong

Wishing You All The Five Good Lucks

Health (壽), Wealth (富), Longevity (康寧), Love of Virtue (攸好德) and Good Death (考終命)