



香港中文大學醫學院
Faculty of Medicine
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Overview of End-of-Life Care in Hong Kong Now and to the Future

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JCECC Conference: Collaboration in Creating Compassionate
Holistic End-of-Life Care for the Future

World's Quality of Death By Ranking



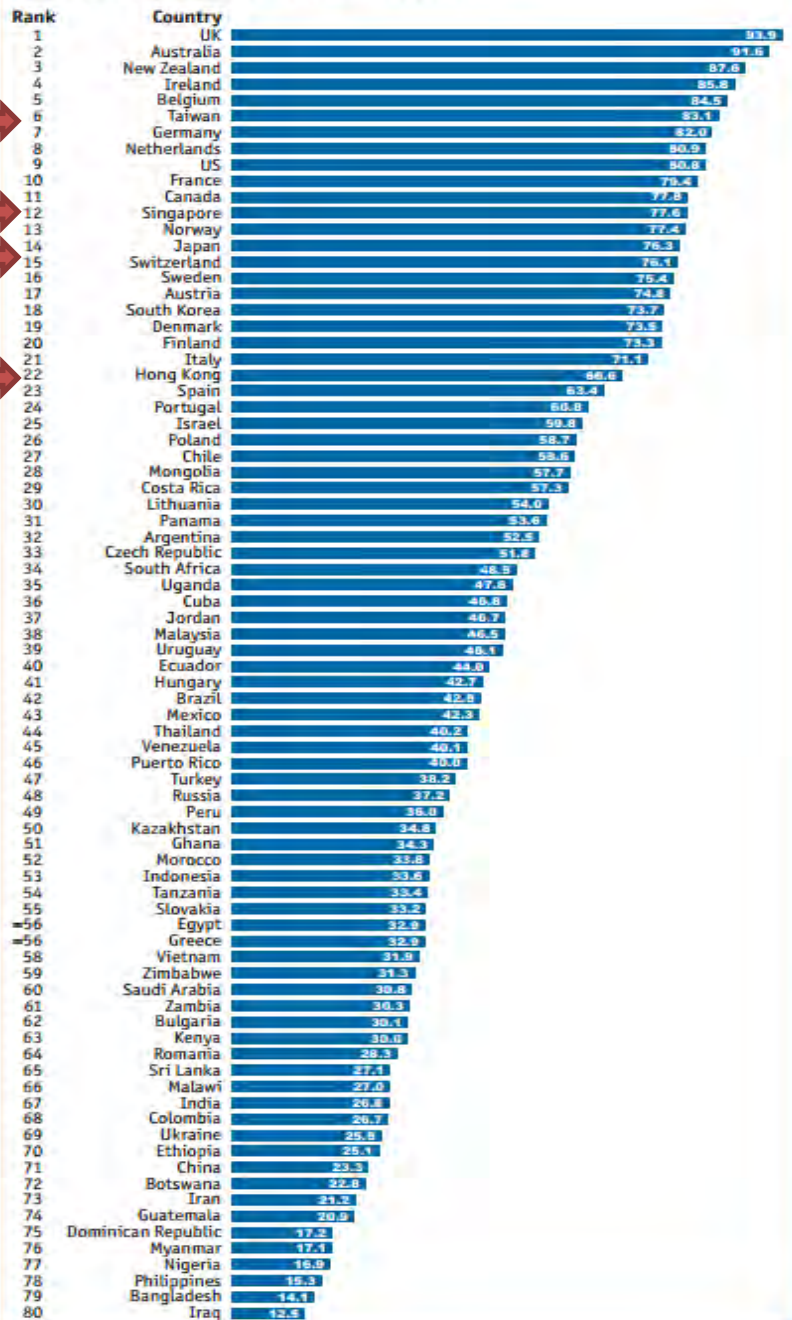
An Economist Intelligence Unit study, commissioned by the Lien Foundation

THE 2015 QUALITY OF DEATH INDEX RANKING PALLIATIVE CARE ACROSS THE WORLD KEY FINDINGS INFOGRAPHIC



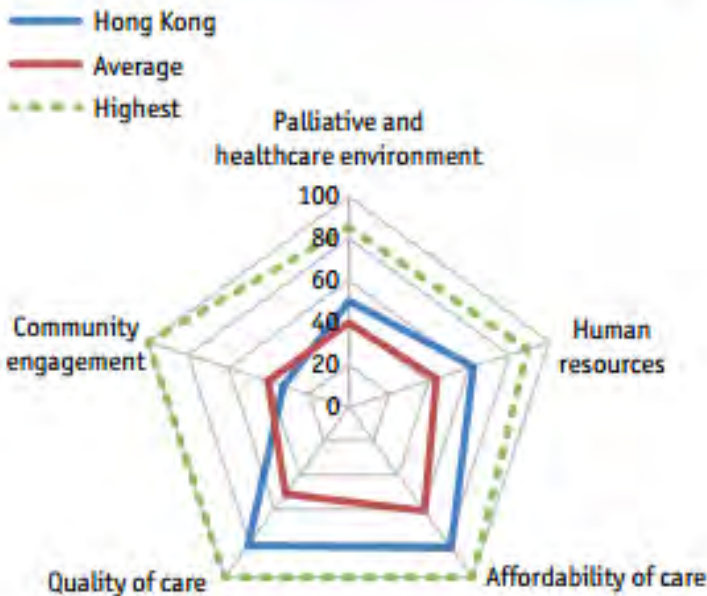
Figure 1.2

2015 Quality of Death Index—Overall scores



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

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 come ‘Free Hong Kong doctors to help dying patients end their days at home’

PUBLISHED : Sunday, 1
UPDATED : Monday, 11



Former health minister calls for legal and operational barriers to be lifted so that fewer people have to spend their last days in hospital

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

COMMENTS:



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

With only 19 palliative care specialists in the city, priorities and training must change, they say

PUBLISHED : Wednesday, 22 June, 2016, 8:02am
UPDATED : Friday, 24 June, 2016, 4:15pm

COMMENTS: 4



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

Academic says government needs to enact legislation to back up such documents

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

COMMENT: 1





最新調查

中大公共衛生及基層醫療學院剛完成電話調查，訪問1,067名30歲以上香港市民，以下為部分結果：



中大醫務公共衛生及基層醫療學院院長、前衛生福利及食物局局長陳志偉。

生死那條界

一個資深醫生，也是家人的取捨
 「我感受很深，還有好多事……」陳志偉在談到醫務界改革時，忍不住哽咽。他談到，在過去二十九年，本人去過許多地方，走過許多地方，見證了許多事情。他談到，在過去二十九年，本人去過許多地方，走過許多地方，見證了許多事情。

醫生要懂得講「死」

考試可操縱試題，表演可操控，唯獨死亡無法排練，而人亦終須一死。我們自小就讀過逝學其書畫，却從沒學過如何面對死亡，不

導導

無論是自己的，還是身邊人的，那麼，如何死得好？

早前我們報導中大公共衛生及基層醫療學院受政府委託，對香港港的臨終照顧，院方剛完成電話調查，訪問了一千零六十七名三十歲以上香港市民，橫跨不同年齡、學歷、了解大眾對「如何死得好」的期望。調查結果顯示，市民對臨終照顧的期望，可說是「生老病死」的昇昇然而道，那這「願其自然」的昇昇然而道，那這「願其自然」的昇昇然而道，那這「願其自然」的昇昇然而道。

如何死得好好

87.3% 希望能夠得到治療，但可選擇性三
 12.4% 盡可能以醫療手段延長生命，但會感到痛苦、不適

「最後半年」
 港人進出三次醫院
 中大醫務公共衛生及基層醫療學院，最近完成了一項關於香港市民對臨終照顧的期望的調查。調查結果顯示，市民對臨終照顧的期望，可說是「生老病死」的昇昇然而道，那這「願其自然」的昇昇然而道，那這「願其自然」的昇昇然而道。

一個人死
 好好死，壞好壞
 香港大學社會工作主任陳志偉表示，臨終照顧的期望，可說是「生老病死」的昇昇然而道，那這「願其自然」的昇昇然而道，那這「願其自然」的昇昇然而道。

死得好好



「最後半年」
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2 你希望在哪裏去世？

3 若你不希望在家去世，你的選擇是……

4 若你希望在家去世，若你無法法律立ADP嗎？

Advance Directive
 預設醫療指示
 調查顯示，在有人見證下訂立的醫療指示，如預設指示(ADP)，在緊急情況下進行心肺復甦治療，不能開立ADP嗎？

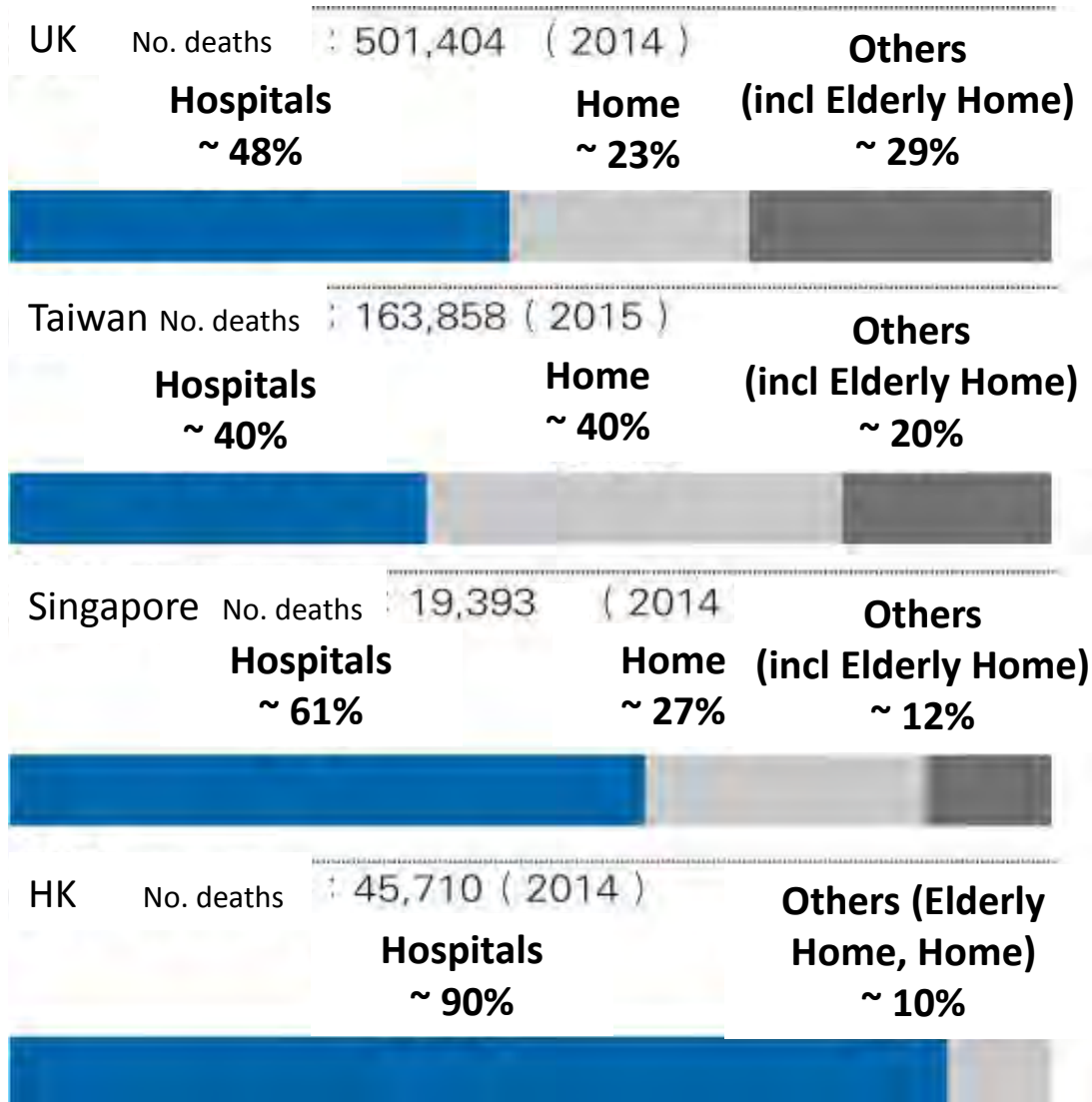
Advance Care Planning
 預立護理計劃
 試行計劃 直入護理醫院
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死在香港
 打999
 救護車
 救回
 急症室
 留醫
 醫院病房
 公家病房(割斷)
 醫院病房
 公家病房(割斷)

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編輯 | 區國影 圖 | 李柏青、安新源攝供 2016/10/02

Comparisons across countries – Place of Death



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**

Methods

Key informant interviews

- 10 management-level informant from the health and social care sectors
- 4 legal experts
- 3 pathologists and mortuary staff
- 2 private sector medical doctors
- 2 private funeral agents

Focus groups

- 11 groups of staff from the healthcare sector
- 11 groups of staff from the social care sector

Current Barriers and Gaps

Issues, Gaps and Barriers

	Anticipation & Preparation	EOL Care Delivery	Death and Post-death
Legal	<ul style="list-style-type: none"> • Advance Directives (AD) and Advance Care Planning (ACP) • Mental Health Ordinance (Cap 136) • Powers of Attorney (Cap 31) & Enduring Powers of Attorney 	<ul style="list-style-type: none"> • Fire Services Ordinance (Cap 95) 	<ul style="list-style-type: none"> • Coroners Ordinance (Cap 504)
Operational & Organizational	<ul style="list-style-type: none"> • Low uptake and lack of formal status for AD • Lack of standardized policy, protocol, and formal status of for ACP • Uncertainties of EOL prognostication • Lack of continuous EOL care conversation 	<ul style="list-style-type: none"> • Inadequate capacity, support and resources for supporting EOL care in the community • Inadequacy for supporting EOL care in the hospital settings • Inadequate medical-social interface and coordination 	<ul style="list-style-type: none"> • Dying at hospitals • Death on/before arrival to A&E • Dying at RCHE • Dying at nursing home • Dying at home
Socio-cultural & Practical	<ul style="list-style-type: none"> • Death as a cultural taboo • Inadequate discussion and education • Challenge for healthcare providers to initiate conversations 	<ul style="list-style-type: none"> • Lack of appropriate culture, mindset and skills of staffs to deliver EOL care • Inadequate training and education on EOL issues for medical, nursing and residential care home staffs • Misconception of EOL care in the general public 	<ul style="list-style-type: none"> • Dying at home • Dying at RCHE • Dying at nursing home • Concerns of the general public over reportable deaths • General concerns over funeral and cremation services • Lack of emphasis on post-death and bereavement services

Issues, Gaps and Barriers

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LEGAL

Anticipation and Preparation

Advance Directives (AD)

- Disputes over types of decision to be included in AD, e.g.
 - Duration of validity
 - Option to revoke a previous decision
 - Refusal of life-sustaining treatments only or also basic care, which is broadly defined in the UK Mental Capacity Act 2007 as *“actions that are needed to keep a person comfortable, e.g. warmth, shelter, actions to keep a person clean and the offer of food and water by mouth.”*)
- Operates under common law framework, but not legislated yet
- Still a debate: Should AD be legislated?

Advance Care Planning (ACP)

- No formal legal standing → ACP wishes not binding

LEGAL

Anticipation and Preparation

Mental Health Ordinance (Cap 136)

- Uncertainties with definition of “mental incapacity”
 - refer to Law Reform Commission’s report *Substitute Decision-making and Advance Directives in Relation to Medical Treatment (2006)*

Powers of Attorney Ordinance (Cap 31)

- Currently only allows the attorney to handle financial matters before and after he/she becomes mentally incapacitated

LEGAL

EOL Care Delivery

- **Fire Services Ordinance (Cap 95)**
 - Duty clause: to *“assist any person who appears to need prompt or immediate medical attention by (i) securing his safety; (ii) **resuscitating or sustaining his life**; (iii) **reducing his suffering or distress**”*.
 - Therefore, FSD is still obligated to perform resuscitation, if required, despite having completed DNACPR, ACP or AD documentations → FSD’s non-participation in the HA’s DNACPR guidelines
 - Points (ii) and (iii) may contradict in some cases

LEGAL

Death & Post-death

Coroners Ordinance (Cap 504):

- Dying at Residential Care Homes for the Elderly (RCHE):
 - **Type 16:** *“Any death of a person where the death occurred in any premises in which the care of persons is carried on for reward or other financial consideration (other than in any premises which comprise a hospital, nursing home or maternity home registered under the Hospitals, Nursing Homes and Maternity Homes Registration Ordinance (Cap 165)).”* → **death at RCHE automatically reportable**
- Dying at home:
 - **Type 2:** *“Any death of a person (excluding a person who, before his death, was diagnosed as having a terminal illness) where no registered medical practitioner has attended the person during his last illness within 14 days prior to his death.”* → **reportable but can be exempted**

Issues, Gaps and Barriers

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OPERATIONAL & ORGANIZATIONAL Anticipation and Preparation

Low uptake and lack of formal status for AD

- Only 1,919 people signed AD in public hospitals between August 2012 and March 2016
 - due to various reasons: reluctance to start EOL conversations, concerns over lack of protection for the healthcare providers, inadequate awareness and knowledge of AD and uncertainties of AD
- Lack of mechanism to alert the healthcare providers within HA of the possession of a valid and applicable AD for the patients

OPERATIONAL & ORGANIZATIONAL Anticipation and Preparation

Lack of standardized policy, protocol, and formal status of for ACP

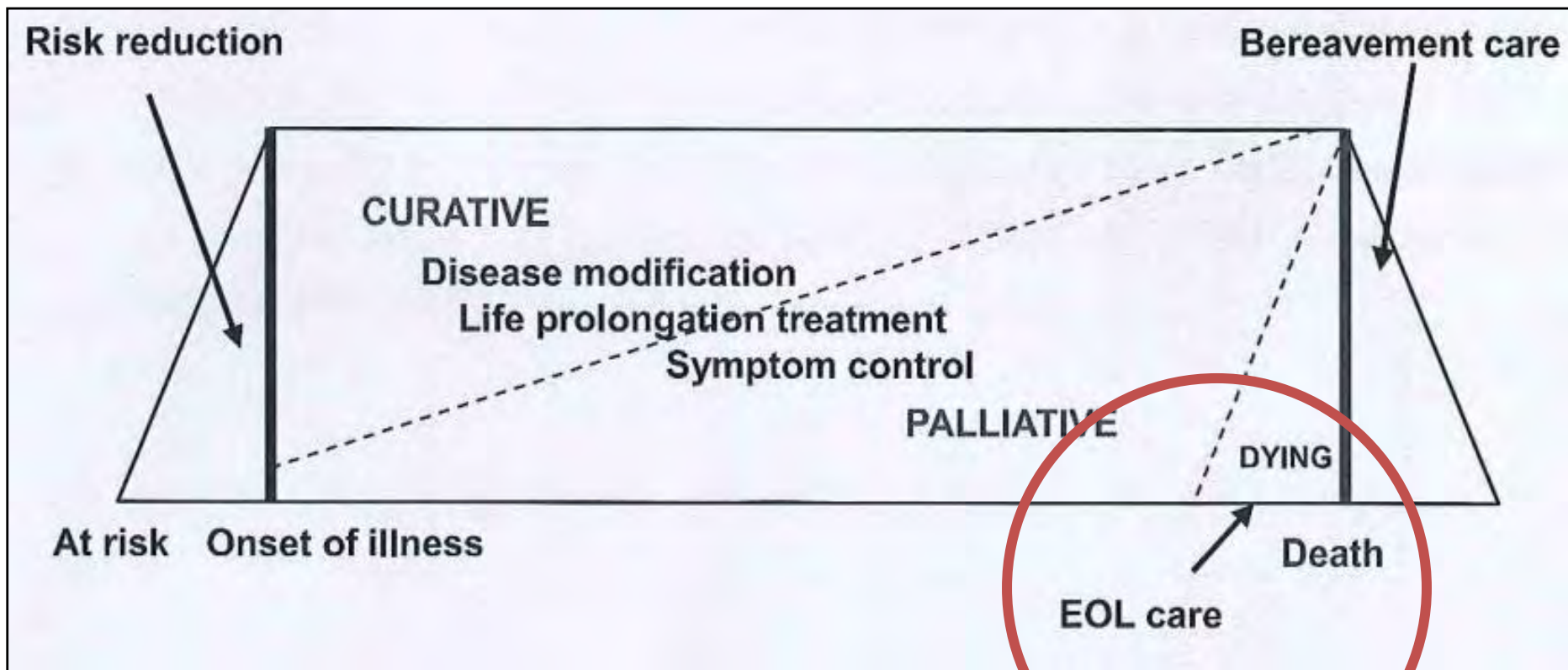
- No formal recognition by related sectors, including HA, other healthcare institutes, RCHEs, nursing homes, Fire Services Department, police
- FSD's non-participation in the HA's DNACPR guidelines

Uncertainties of EOL identification and prognostication

- Lack of standard protocol: when should the EOL conversation start?

Lack of continuity in EOL care conversation

Changing course of health care needs along the illness trajectory (Adapted from WHO)



OPERATIONAL & ORGANIZATIONAL EOL Care Delivery

Inadequate capacity, support and resources for supporting EOL care in the community

- **Manpower:** VMOs at RCHEs, no requirement for on-site medical doctors at nursing homes, untrained informal carers at homes and low awareness of EOL care services in the community
- **Equipment, facility and space:** e.g. wheelchairs, oxygen supply, oral suction, IV drip/syringe pump, etc.
- **Transportation:** Inadequate non-emergency transportation to the hospitals for EOL patients who require sub-acute attention

OPERATIONAL & ORGANIZATIONAL EOL Care Delivery

Inadequacy for supporting EOL care in the hospital settings

- Medical doctors traditionally trained in delivering curative care but not EOL care with palliative care at its core
- 19 palliative care specialists in HK
- Insufficient coordination and communication between the different departments (e.g. A&E with the parent team)

OPERATIONAL & ORGANIZATIONAL EOL Care Delivery

- **Inadequate medical-social interface and coordination**
 - Referral, transfer, information sharing and access, etc. to ensure timely, appropriate and continuous care
 - Mechanism and system that enables multi-disciplinary coordination (E.g. HA's pilot program of Enhanced CGAT for EOL Care in RCHEs)
 - No clarity as to whether RCHE/ nursing home staffs need to follow/execute AD/ACP made in hospitals
 - No common understanding between the 2 sectors → distrust
 - Overlaps of services provided to the patients in the community (e.g. CGAT, CNS, Integrated Care and Discharge Support, home palliative care services, other organ-specific programs as well as other community and home care visits by allied health professionals) → lack of system to coordinate and manage these services

OPERATIONAL & ORGANIZATIONAL

Death and Post-death

- **Dying at hospitals**
 - Limited space and flexibility of visiting hours at public hospitals
 - General practice to transfer/rush back patients from community to hospitals to die → ambulance → A&E
 - Inadequate understanding and coordination between A&E and other extended care facilities regarding terminally ill patients at EOL

OPERATIONAL & ORGANIZATIONAL

Death and Post-death

- **Death on/before arrival**

- Common misconception: Deaths occurred within 24 hours of A&E arrival must be reported to the coroner
 - No such legal requirement → if doctor is familiar with the case, they can sign the Medical Certificate of the Cause of Death (Form 18)
 - Patients being sent to hospital as soon as they show any early/suspected sign of dying → crowding out A&E resources, false alarm, revolving door syndrome

OPERATIONAL& ORGANIZATIONAL

Death and Post-death

- **Dying at RCHE**
 - RCHE not designed to facilitate dying in place!
 - Limited in space, may lack extra air-conditioned room
 - No required storage of non-designated drugs in RCHEs
 - RCHE staff not trained and equipped to handle death and post-death
 - Counseling of bereaved family members and to assist them with handling police investigation, death reporting and registration, etc.

OPERATIONAL & ORGANIZATIONAL

Death and Post-death

- **Dying at nursing home**

- Legal (non-reportable), but...
- Not all nursing home have regular medical practitioner available 24 hours a day → Difficulty to find doctor to view the body and issue Form 18
- Limited in space, may lack extra air-conditioned room
- Non-coroner's case
 - A resting place is required for storage before burial/ cremation
 - Alternative: funeral parlor services which incur more costs than deaths at hospitals and reportable deaths
- Counseling of bereaved family members and to assist them with handling police investigation, death reporting and registration, etc.

OPERATIONAL & ORGANIZATIONAL

Death and Post-death

- **Dying at home**

- Legal (non-reportable), but...
- Difficulty to find doctor to view the body and issue Form 18
- Home deaths may generate fear and discomfort to neighbors living nearby
- Removal of body:
 - May cause inconvenience to neighbors
 - Handled by funeral parlor services for non-reportable deaths → incur more costs
- Home deaths may trigger police investigations → distress to family members

Issues, Gaps and Barriers

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SOCIO-CULTURAL AND PRATICAL

EOL Care Delivery

- **Lack of appropriate culture, mindset and skills of staffs to deliver EOL care**
 - Good EOL care will not fall into places with only operational protocols and policies
 - Inadequate medical ethics training
 - Fear and feeling of uncertainty of legal liabilities for administering EOL care (e.g. AD/ACP, DNACPR, withdrawal of life-sustaining treatments)
- **Inadequate training and education on EOL issues for medical, nursing and residential care home staffs**
 - Inadequate emphasis on psychological and spiritual needs of patients and family members
- **Misconception of EOL care in the general public**
 - Feeling of guilt if they do not care enough for the patients (Andershed & Harstade 2007)
 - Filial piety to do the utmost ← inadequate EOL education and discussion
 - Inadequate discussion and understanding between patients and their family

SOCIO-CULTURAL AND PRATICAL

Anticipation and Preparation

- **A vicious cycle:**

- Death as a cultural taboo <-> Inadequate discussion and education in general public
- Reluctance to engage in discussions on life-and-death and EOL among younger generations, more so than the elderly

Challenge for healthcare providers to initiate conversations

- 90% medical students felt that they did not have sufficient knowledge on EOL and were unprepared to handle such issues (Siu MW et al. 2010)
- Administering palliative care = giving up hope

SOCIO-CULTURAL AND PRATICAL

Death and Post-death

- **Dying at home**

- Fear and discomfort of neighbors ← socio-cultural/religious beliefs, taboo and concept that body would quickly decompose and smell
- Inadequate knowledge of administrative procedure for dealing with death at home
- Patient might not have expressed their wishes to die at home to family members, who may not prefer the patient to die at home (e.g. going back home = giving up hope, hospital is the best place for dying, **perceived fear of depreciation of property value!**)

SOCIO-CULTURAL AND PRATICAL

Death and Post-death

- **Dying at RCHE**
 - Fear and discomfort of staff and housemates
 - General concern over decomposition and smell of the body
 - General concern over possible requirements for autopsy if coroner's process is triggered
- **Dying at nursing home**
 - Similar to RCHE
 - No expectation for family members of the patient to die at nursing home

SOCIO-CULTURAL AND PRATICAL

Death and Post-death

- **Concerns of the general public over reportable deaths**
 - Perceived notion: time-consuming and onerous for family members
 - Socio-cultural/religious belief: “completeness” of the body
- **General concerns over funeral and cremation services**
 - 15 days of waiting list for cremation service on average
 - Some family members choosing convenient time and “auspicious” date
 - Hospital mortuaries are free-of-charge for storage
- **Lack of emphasis on post-death and bereavement services**
 - Lack of awareness of such services even when available



JAMDA

journal homepage: www.jamda.com



Original Study

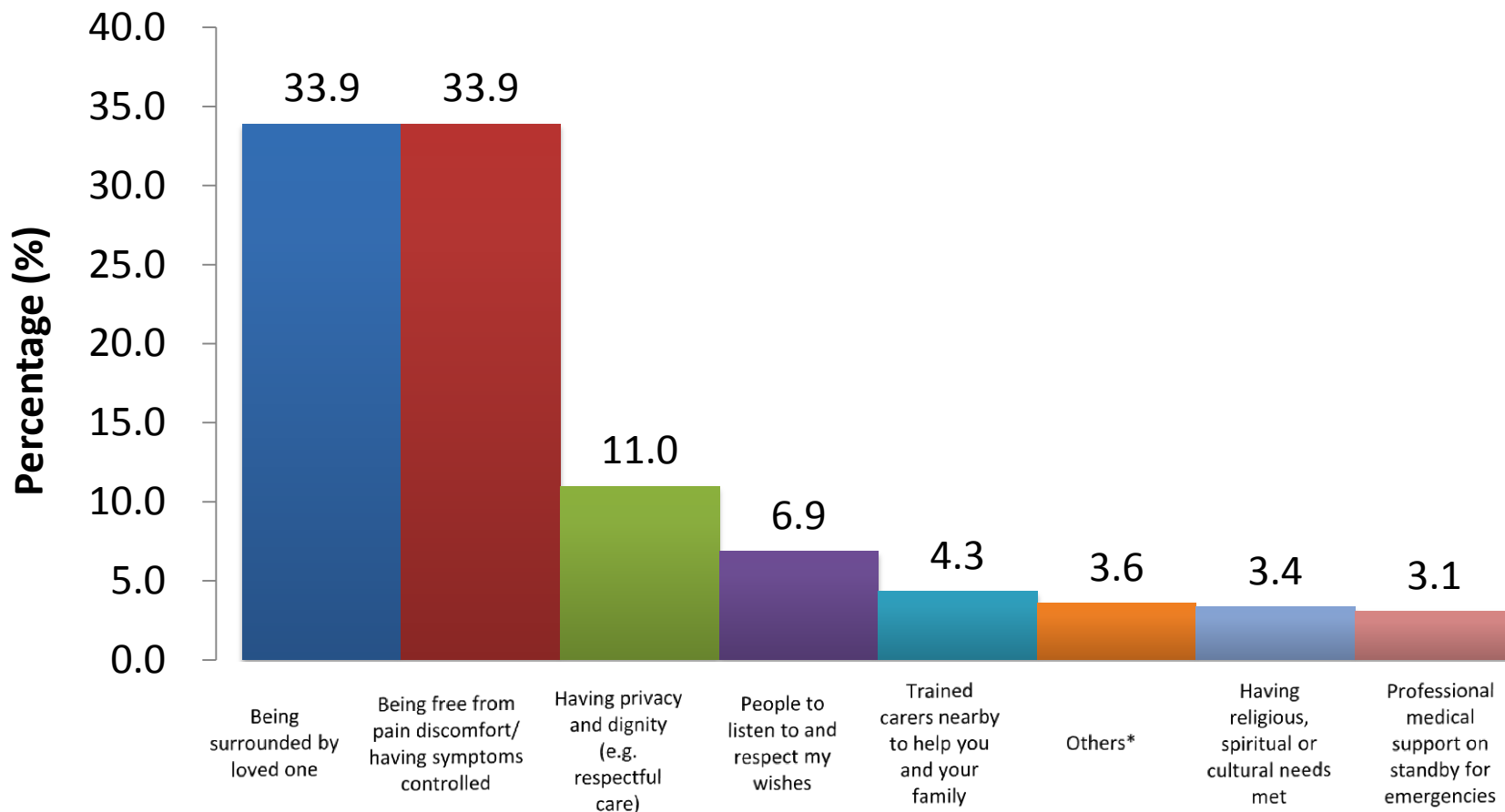
Knowledge, Attitudes, and Preferences of Advance Decisions,
End-of-Life Care, and Place of Care and Death in Hong Kong.
A Population-Based Telephone Survey of 1067 Adults

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 – EOL Care

Most important element of EOL care if you were being diagnosed to be terminally ill:



* To be sure that I am not a burden to other people ; Being in a familiar surrounding; Access to professionals for last minute concerns regarding family or legal affairs ; Nothing important; Didn't answer

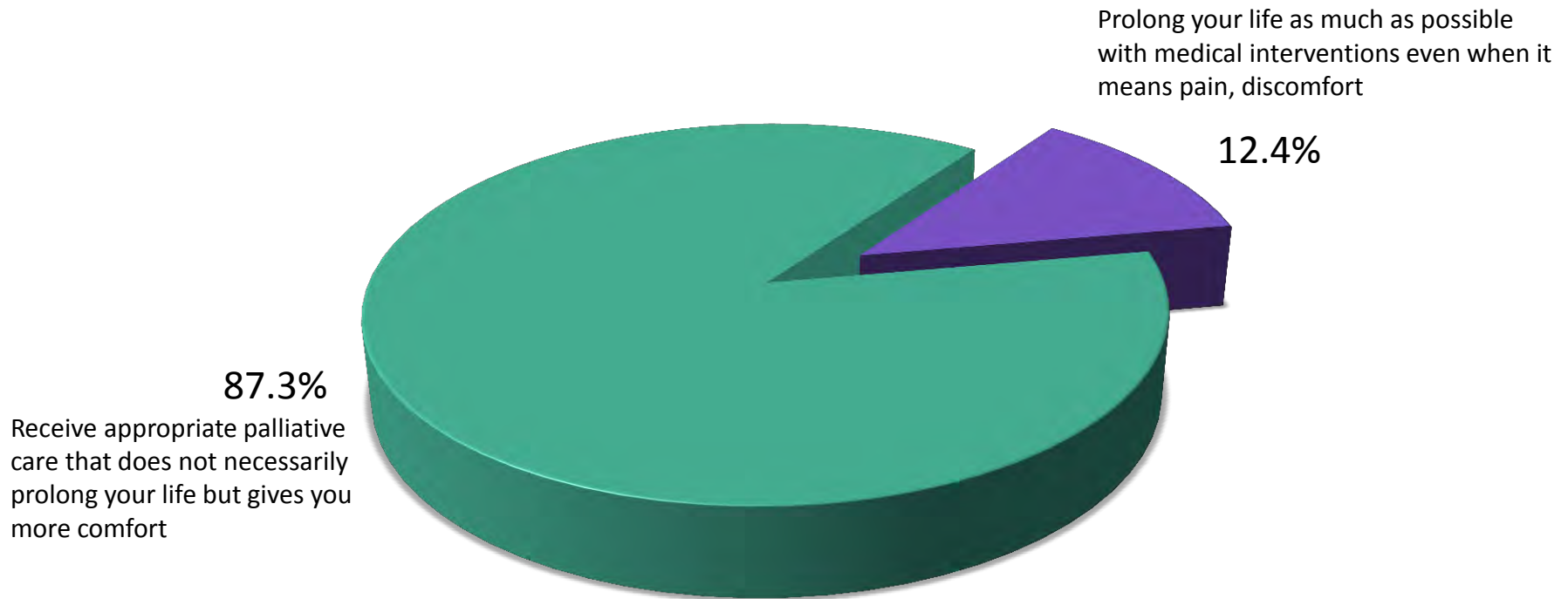
Main Findings – EOL Care

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

- Prolong your life as much as possible with medical interventions even when it means pain, discomfort and suffering
- Receive appropriate palliative care that does not necessarily prolong your life but gives you more comfort

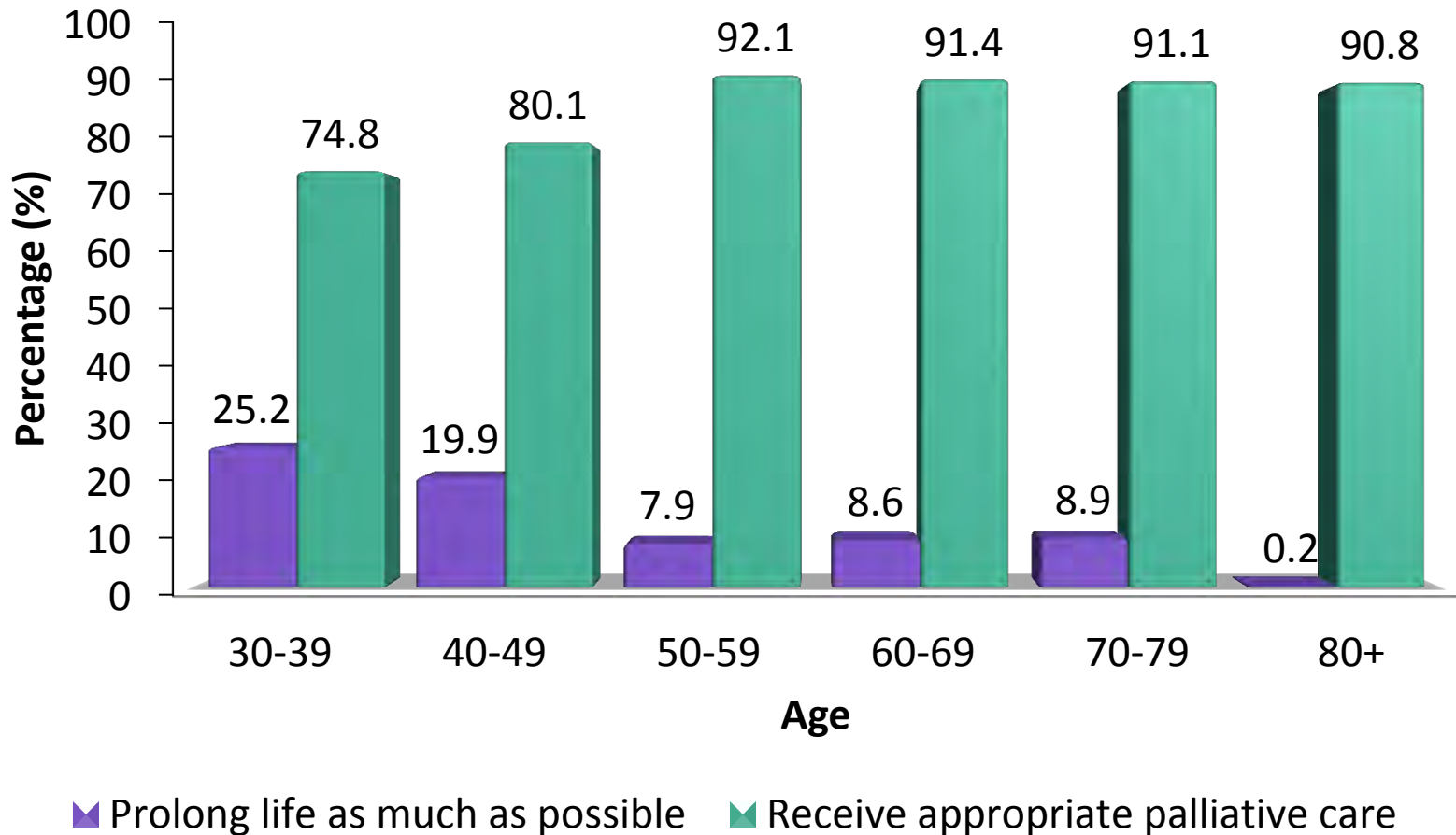
Main Findings – EOL Care

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



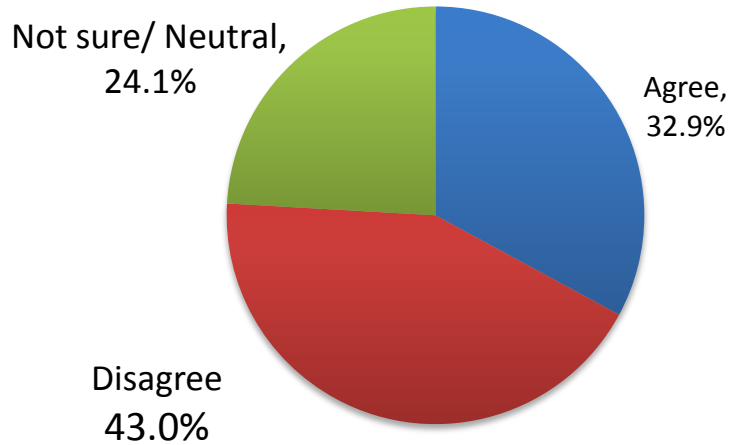
Main Findings – EOL Care

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

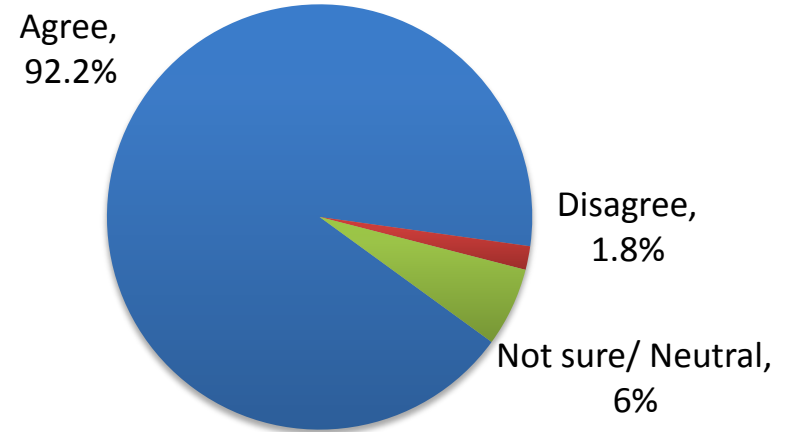


Main Findings – EOL Care

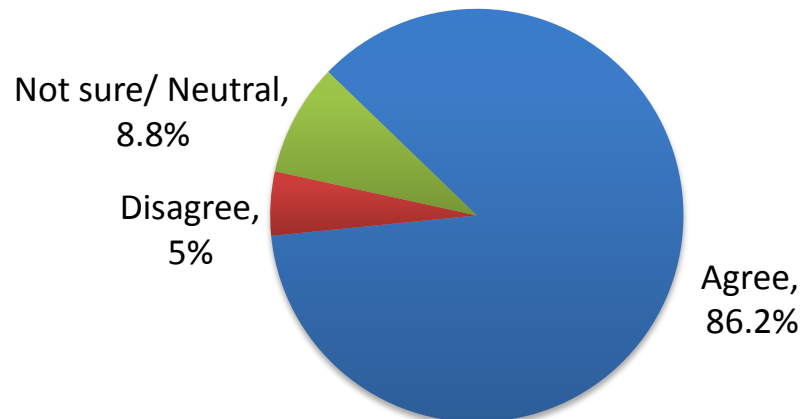
Doctors should generally try to keep their patients alive by any means (e.g. machines, intubation) for as long as possible, even if it means pain, discomfort, and suffering



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



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



Main Findings

Advance Directive

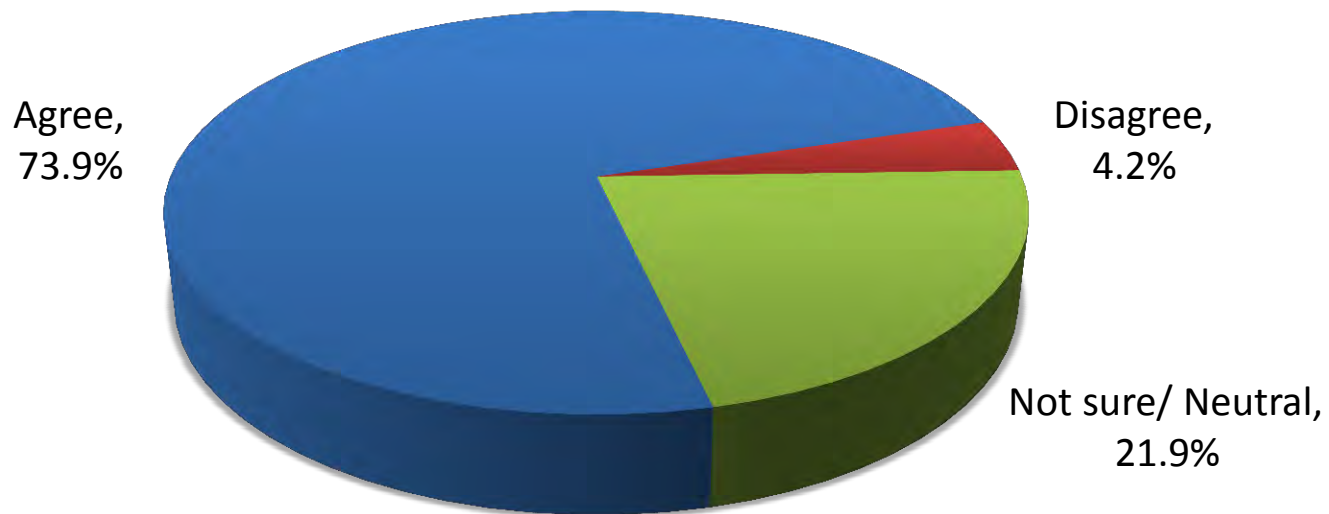
Main Findings – Advance Directive



85.7% have not heard of Advance Directive (AD)

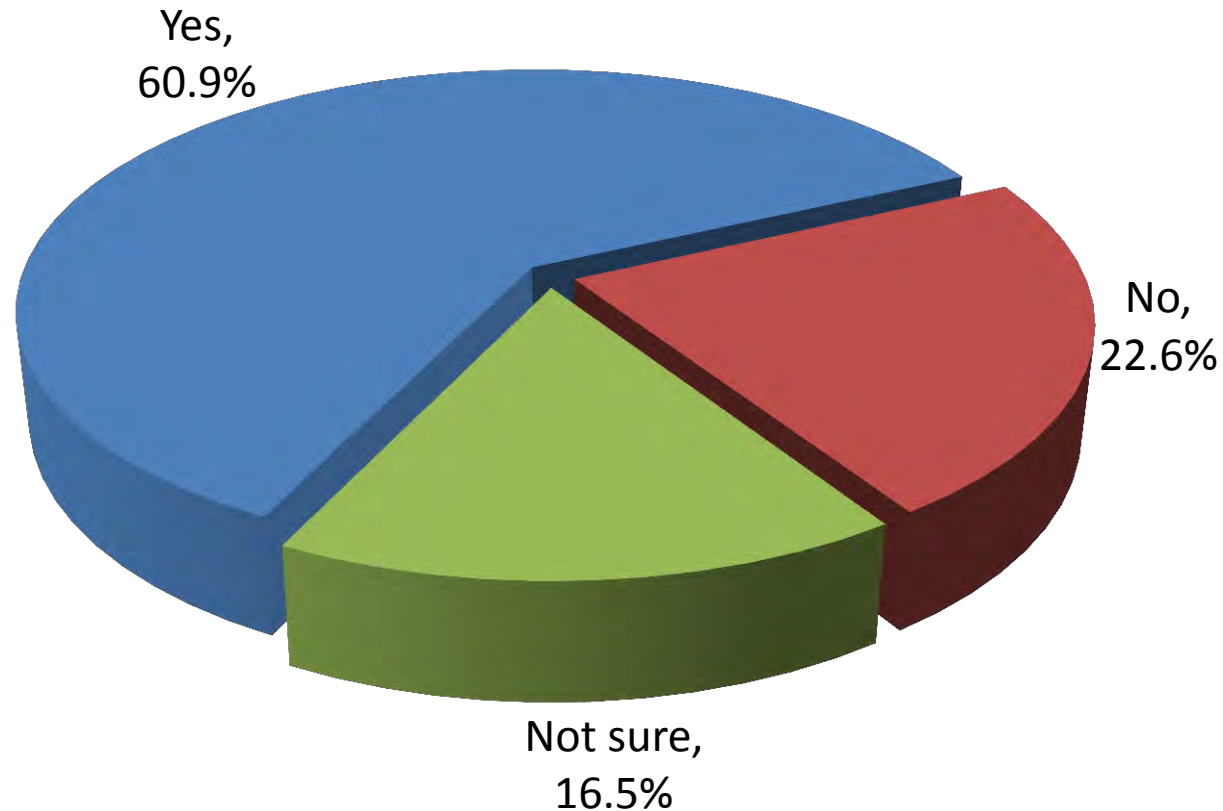
After explanations of what AD means...

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



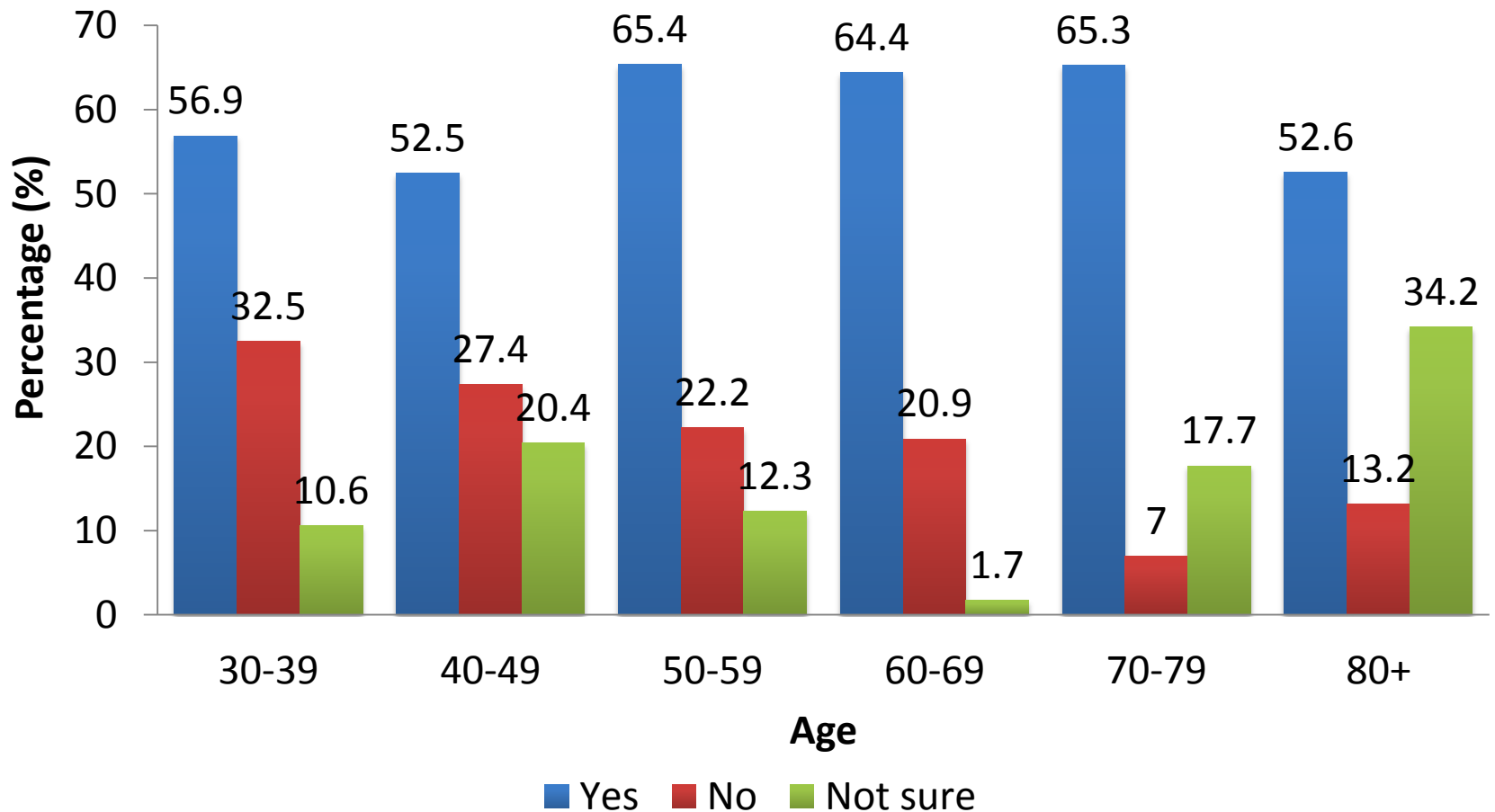
Main Findings – Advance Directive

Would make AD if formally legislated in HK



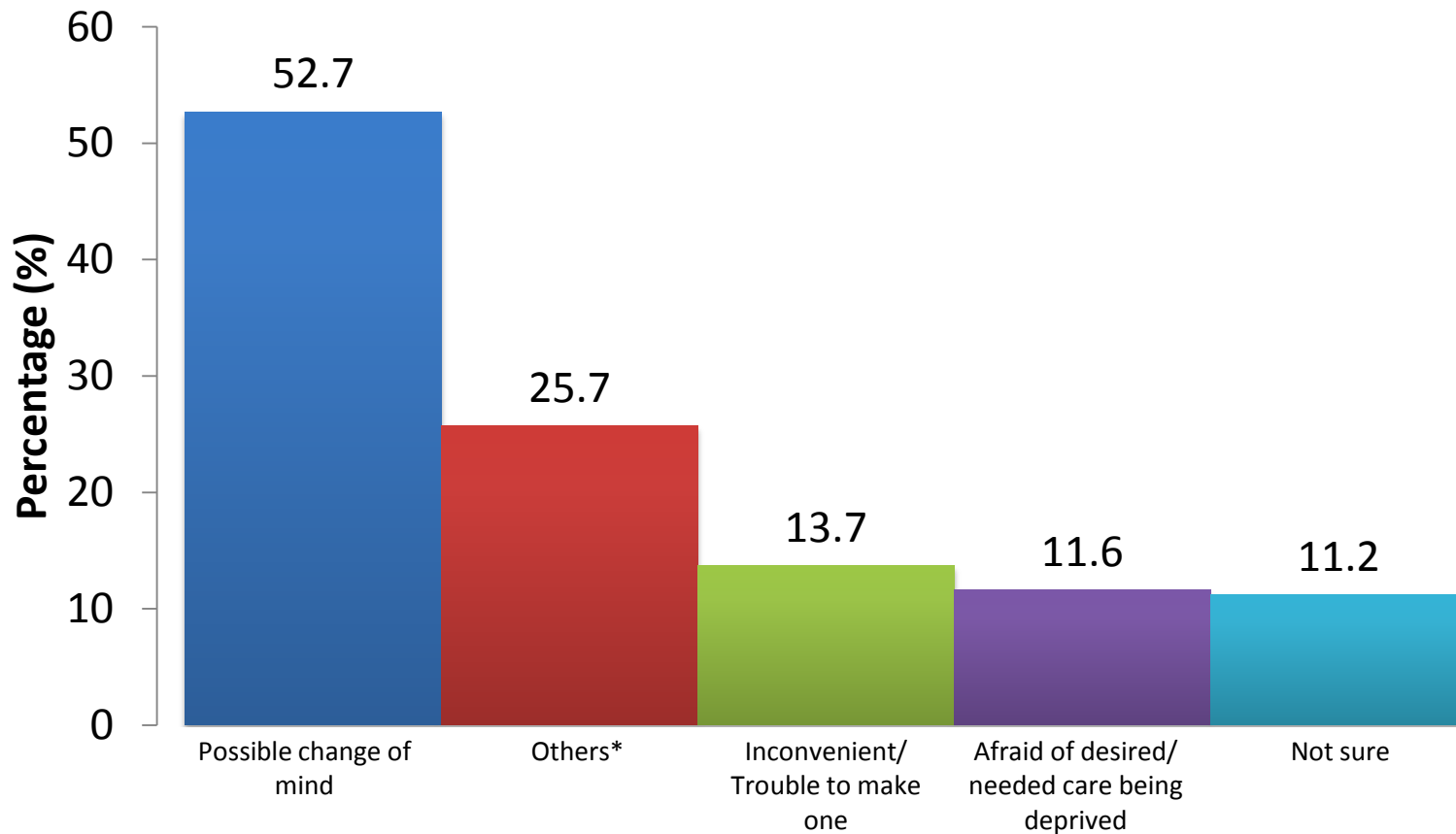
Main Findings – Advance Directive

Would make AD if formally legislated in HK



Main Findings – Advance Directive

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







* Too young, haven't thought about it, not necessary, more understanding needed

Main Findings

Preferred Place of Care/Death

Main Findings – Preferred Place of Care

	Home 	Hospital 	RCHE/ Nursing Home/ Hospice 	Others 
Last Year	618 (57.9%)	180 (16.9%)	251 (23.5%)	9 (0.8%)
Last Weeks	430 (40.3%)	430 (40.3%)	186 (17.4%)	12 (1.1%)
Last Days	358 (33.6%)	524 (49.5%)	164 (15.4%)	12 (1.1%)

↓ Decreasing Increasing ↓

Main Findings – Preferred Place of Death



Home
30.8%



Hospital
51.8%



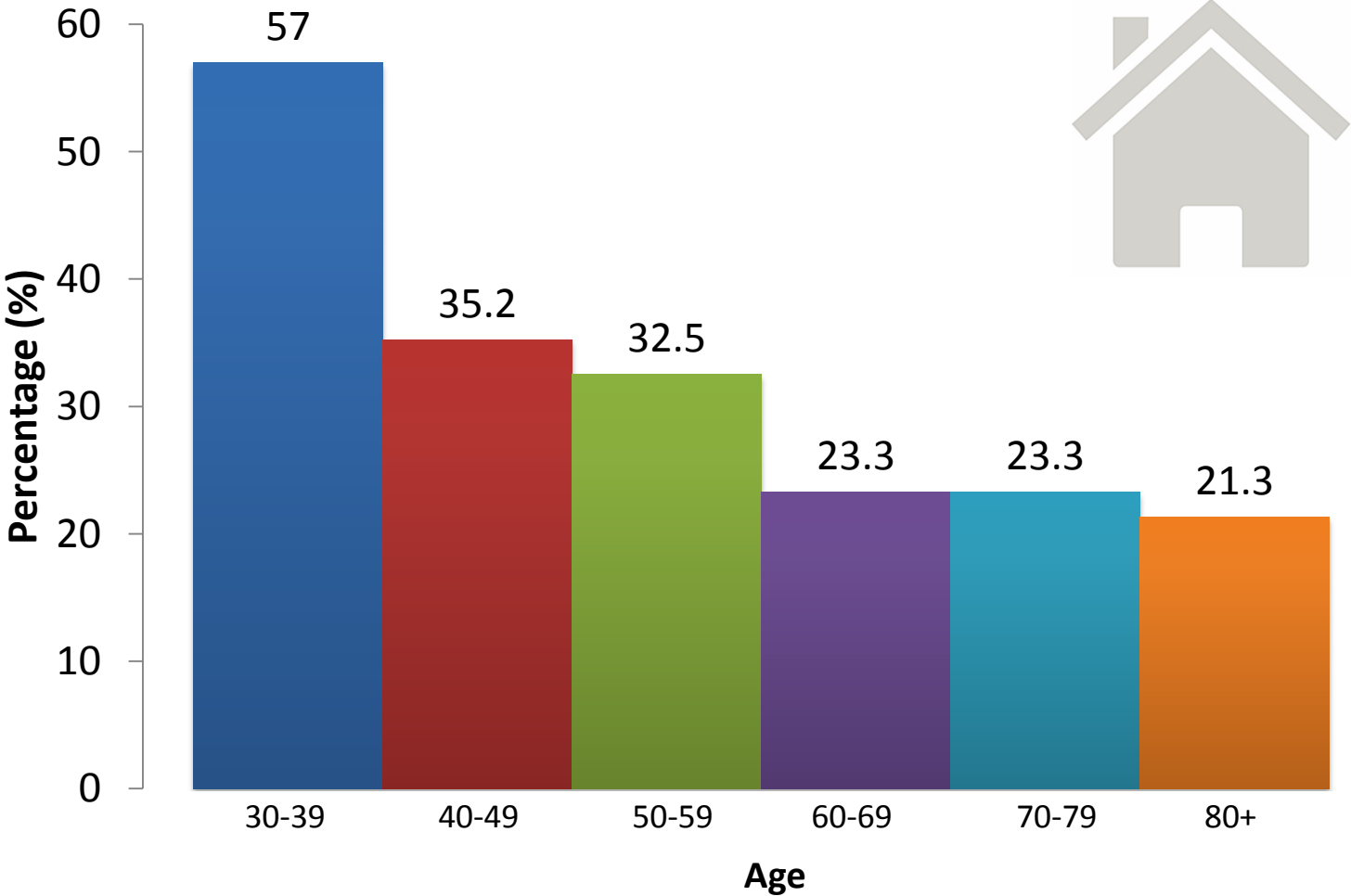
Aged/ Nursing
home/ Hospice
16.2%



Others
0.2%

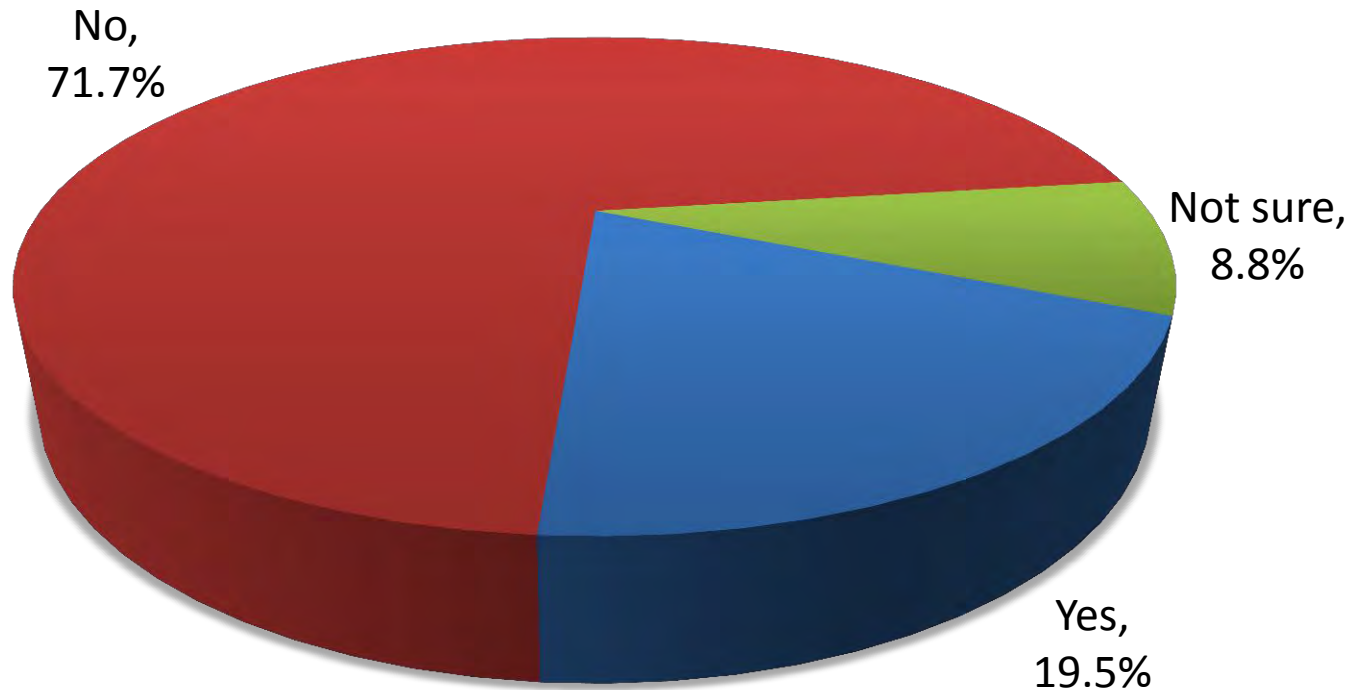
Main Findings – Preferred Place of Death

A clear trend of increasing age for lower preference to die at home



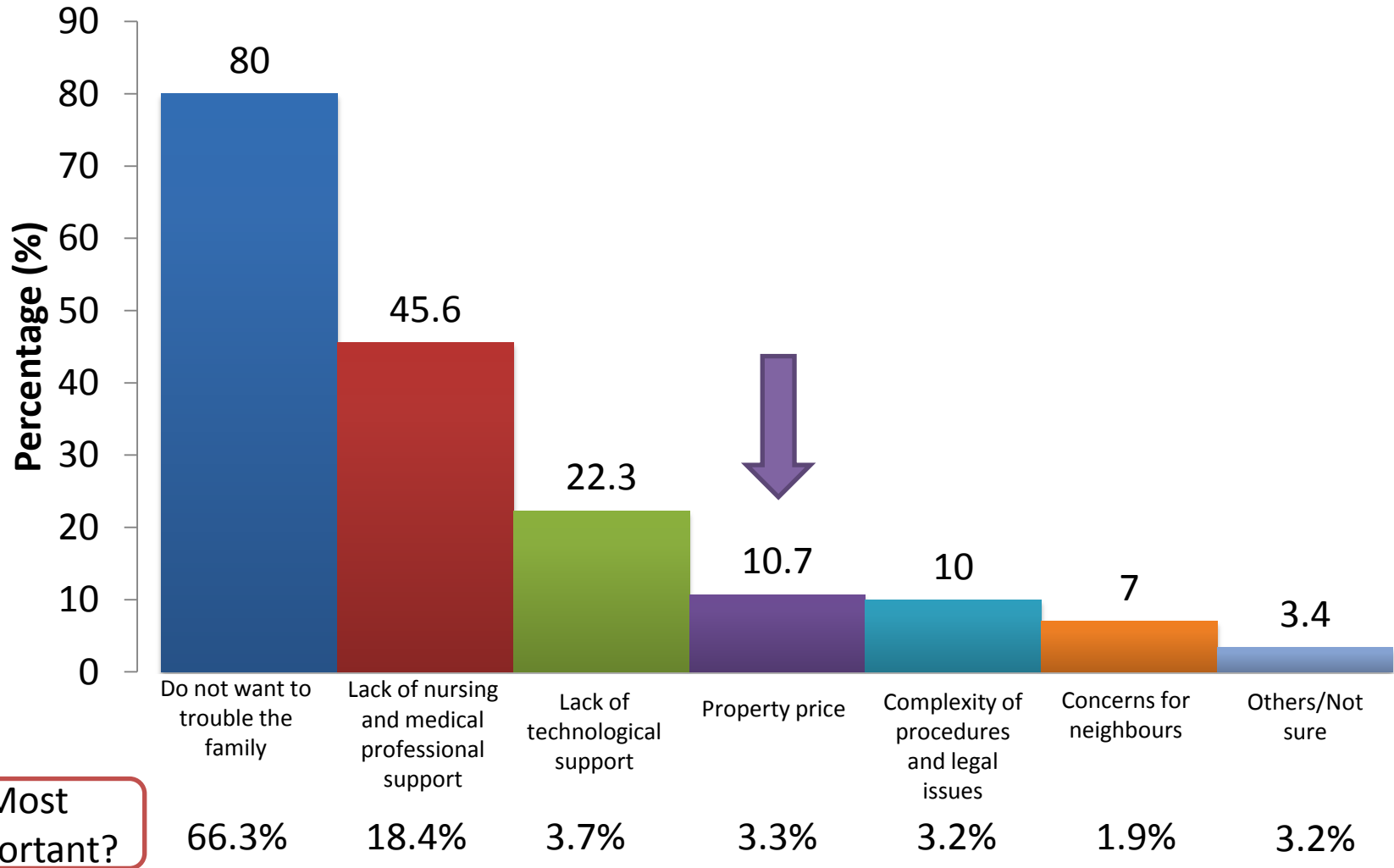
Main Findings – Preferred Place of Death

Would you still prefer to die at home even if you did not have sufficient support and care from family and friends or the social and medical professionals?



Main Findings – Preferred Place of Death

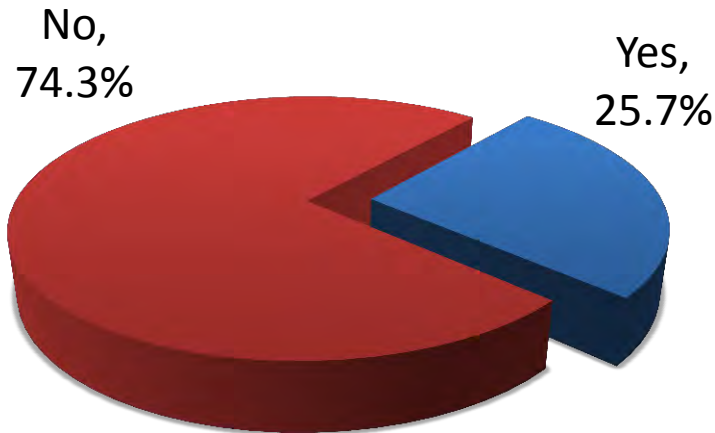
Reasons for not choosing home as place of death
(can choose more than one)



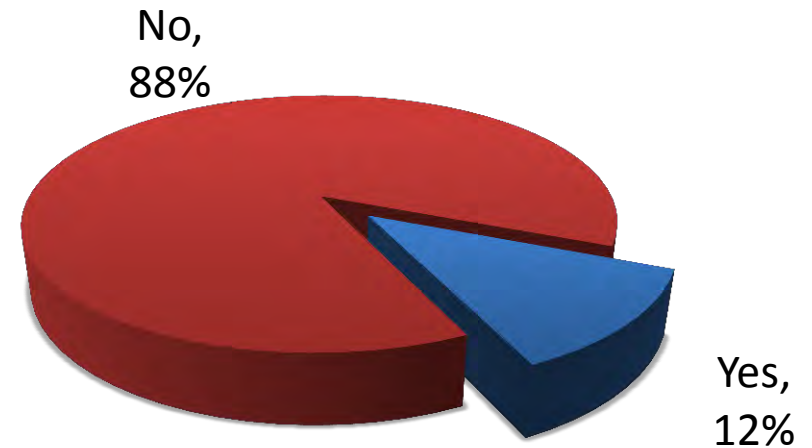
Main Findings – Preferred Place of Death

If a person passes away at home naturally, in other words, not by accidents, injuries, external causes...

Feeling uncomfortable about the house



Feeling the house is “haunted” (凶宅)



Take-Home Messages

1. First comprehensive population-based survey on the matters in HK
2. Most important aspects of EOL care are the close relationships and being free from pain and discomfort
3. EOL care with palliative care as its core needs to be more emphasized
4. Patient's autonomy should be considered as an important aspect of their best interest
5. Most people want to make advance wishes for themselves → AD legislation can be considered
6. The gap between people's wishes and reality in terms of preferred place of death is very wide → Hospitals may be crowded out in the future due to population aging → need to be more options!
7. Most important reason not to die at home is about their family members, NOT property price!
8. Still misunderstanding of what "haunted house" (凶宅) entails → public education across life course needed

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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

References

1. 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. 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. *JAMDA* xxx (2017) 1.e1e1.e9
2. The Law Reform Commission of Hong Kong., *Substitute Decision-making and Advance Directives in Relation to Medical Treatment*. 2006.
3. Food and Health Bureau., *Introduction of the Concept of Advance Directives in Hong Kong: Consultation Paper*. 2009.
4. Hospital Authority Clinical Ethics Committee., *Guidance for HA Clinicians on Advance Directives in Adults*. 2014.
5. Kaan, T., *Law and the end of life in Singapore*. 2011.
6. Legislative Yuan of Taiwan., *The Patient Autonomy Act*. 2015.
7. The Law Reform Commission of Hong Kong., *Enduring Powers of Attorney: Personal Care*. 2011.
8. Department of Health., *Mental Capacity Act*. Vol. 6. 2005, London: HMSO. 2005--2006.
9. Hospital Authority., *HA Guidelines on Life-sustaining Treatment in the Terminally Ill*. 2015.
10. Hong Kong Legislative Council., *Powers of Attorney Ordinance (Cap 31)*. 1999.

Thank You!

