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

THE 2015 QUALITY OF DEATH INDEX
RANKING PALLIATIVE CARE ACROSS THE WORLD
KEY FINDINGS INFOGRAPHIC
Hong Kong Ranked 22 in the world!

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

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

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
## Comparisons across countries – Place of Death

<table>
<thead>
<tr>
<th>Country</th>
<th>No. deaths</th>
<th>Hospitals</th>
<th>Home</th>
<th>Others (incl Elderly Home)</th>
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<td>UK</td>
<td>501,404 (2014)</td>
<td>~48%</td>
<td>~23%</td>
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<td>Taiwan</td>
<td>163,858 (2015)</td>
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<td>Singapore</td>
<td>19,393 (2014)</td>
<td>~61%</td>
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<td>HK</td>
<td>45,710 (2014)</td>
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Ref: Mingpao News July 10, 2016
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

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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?
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
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
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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 $\rightarrow$ ambulance $\rightarrow$ 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 \(\rightarrow\) incur more costs
  – Home deaths may trigger police investigations \(\rightarrow\) distress to family members
## Issues, Gaps and Barriers

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SOCIO-CULTURAL AND PRACTICAL 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
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
Most important element of EOL care if you were being diagnosed to be terminally ill:

- Being surrounded by loved one: 33.9%
- Being free from pain discomfort/having symptoms controlled: 33.9%
- Having privacy and dignity (e.g. respectful care): 11.0%
- People to listen to and respect my wishes: 6.9%
- Trained carers nearby to help you and your family: 4.3%
- Others*: 3.6%
- Having religious, spiritual or cultural needs met: 3.4%
- Professional medical support on standby for emergencies: 3.1%

* 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:

- **87.3%** Receive appropriate palliative care that does not necessarily prolong your life but gives you more comfort

- **12.4%** Prolong your life as much as possible with medical interventions even when it means pain, discomfort
Main Findings – EOL Care

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

- **Prolong life as much as possible**
- **Receive appropriate palliative care**

![Bar chart showing preferences by age group. The chart indicates that a higher percentage prefers to receive appropriate palliative care compared to prolonging life.](chart_image)

- **30-39**: 25.2% Prolong, 74.8% Palliative
- **40-49**: 19.9% Prolong, 80.1% Palliative
- **50-59**: 7.9% Prolong, 92.1% Palliative
- **60-69**: 8.6% Prolong, 91.4% Palliative
- **70-79**: 8.9% Prolong, 91.1% Palliative
- **80+**: 0.2% Prolong, 90.8% Palliative
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

- Not sure/Neutral, 24.1%
- Agree, 32.9%
- Disagree, 43.0%

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

- Not sure/Neutral, 8.8%
- Disagree, 5%
- Agree, 86.2%

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

- Agree, 92.2%
- Disagree, 1.8%
- Not sure/Neutral, 6%
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

- Yes, 60.9%
- No, 22.6%
- Not sure, 16.5%
Main Findings – Advance Directive

Would make AD if formally legislated in HK

<table>
<thead>
<tr>
<th>Age</th>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>30-39</td>
<td>56.9</td>
<td>10.6</td>
<td>32.5</td>
</tr>
<tr>
<td>40-49</td>
<td>52.5</td>
<td>27.4</td>
<td>20.4</td>
</tr>
<tr>
<td>50-59</td>
<td>65.4</td>
<td>22.2</td>
<td>12.3</td>
</tr>
<tr>
<td>60-69</td>
<td>64.4</td>
<td>20.9</td>
<td>1.7</td>
</tr>
<tr>
<td>70-79</td>
<td>65.3</td>
<td>17.7</td>
<td>7</td>
</tr>
<tr>
<td>80+</td>
<td>52.6</td>
<td>13.2</td>
<td>34.2</td>
</tr>
</tbody>
</table>
Main Findings – Advance Directive

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

- Possible change of mind: 52.7%
- Others*: 25.7%
- Inconvenient/ Trouble to make one: 13.7%
- Afraid of desired/ needed care being deprived: 11.6%
- Not sure: 11.2%

* 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

<table>
<thead>
<tr>
<th></th>
<th>Home</th>
<th>Hospital</th>
<th>RCHE/ Nursing Home/ Hospice</th>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Last Year</td>
<td>618 (57.9%)</td>
<td>180 (16.9%)</td>
<td>251 (23.5%)</td>
<td>9 (0.8%)</td>
</tr>
<tr>
<td>Last Weeks</td>
<td>430 (40.3%)</td>
<td>430 (40.3%)</td>
<td>186 (17.4%)</td>
<td>12 (1.1%)</td>
</tr>
<tr>
<td>Last Days</td>
<td>358 (33.6%)</td>
<td>524 (49.5%)</td>
<td>164 (15.4%)</td>
<td>12 (1.1%)</td>
</tr>
</tbody>
</table>
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?

- Yes, 19.5%
- No, 71.7%
- Not sure, 8.8%
Main Findings – Preferred Place of Death

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

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do not want to trouble the family</td>
<td>80</td>
</tr>
<tr>
<td>Lack of nursing and medical professional support</td>
<td>45.6</td>
</tr>
<tr>
<td>Lack of technological support</td>
<td>22.3</td>
</tr>
<tr>
<td>Property price</td>
<td>10.7</td>
</tr>
<tr>
<td>Complexity of procedures and legal issues</td>
<td>10</td>
</tr>
<tr>
<td>Concerns for neighbours</td>
<td>7</td>
</tr>
<tr>
<td>Others/Not sure</td>
<td>3.4</td>
</tr>
</tbody>
</table>

Most Important?

- Do not want to trouble the family: 66.3%
- Lack of nursing and medical professional support: 18.4%
- Lack of technological support: 3.7%
- Property price: 3.3%
- Complexity of procedures and legal issues: 3.2%
- Concerns for neighbours: 1.9%
- Others/Not sure: 3.2%
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

- Yes, 25.7%
- No, 74.3%

Feeling the house is “haunted” (凶宅)

- Yes, 12%
- No, 88%
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
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
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4. Hospital Authority Clinical Ethics Committee., Guidance for HA Clinicians on Advance Directives in Adults. 2014.


Thank You!