The Choice of Dying at Home

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Over 90% of deaths occurring at public hospitals of Hospital Authority

30% population over aged 65 (2041)
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.

‘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.
死在家可以嗎？
CURRENT JOURNEY OF PLACE OF CARE AND DEATH AT AND OUTSIDE HOSPITAL

- Acute Hospital
- Subacute Hospital
- Palliative Care Unit
- RCHE
- Nursing Home
- Home
- Acute Hospital A&E
- Hospital Mortuary
- Funeral Parlour
- Burial/Cremation

ACP cases – Clinical Admission to "Virtual Ward" (Bypassing Coroner)

- Call 999 ambulance
- Dr to certify death, issue F18 + F2
- Family to get F12, F10 + F3 during office hr (within 24 hrs after death)

- Public mortuary (Coroner case)
- Coroner issue F11 + inquest
- Coffin Van
- If death has clearly occurred, coffin van

- With F12 & F10, funeral parlour to move body (must do so within 48 hrs after death)

Need to refer to coroner
i) Clause 2: if not seen by a doctor past 14 days (except was diagnosed with terminal illness)
ii) in any premises with reward or other financial consideration (other than nursing homes)

Birth and Death Registration Ordinance (Cap 174)
F10: Certificate or Registration of death (burial permit)
F11: Burial/Cremation Permit (Coroners)
F12: Certification of Registration of death (going-out pass)
F18: Medical certificate of the cause of death

Public Health and Municipal Services Ordinance Cap 132)
F2: Medical certificate (Cremation)
F3: Cremation permit
CURRENT BARRIERS AND GAPS
• **Coroners Ordinance (Cap 504):**
  
  – **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

  – **Type 2** reportable deaths require the medical practitioner’s medical certificate of death and may give rise to logistic issues to facilitate the choice of deaths at home

  – Failure to report reportable deaths that occurred at home to the coroner is a criminal offense

  – Non-Type 2 deaths at homes will be reported to the coroner via the Police → an investigation by the Police and forensic pathologist to be followed, if necessary, by a post-mortem examination → reluctance for patients to consider dying at home
ORGANIZATIONAL & OPERATIONAL

• Inadequate resources for EOL care at home
  – Manpower:
    • Medical, nursing, social care and allied health support as well as coordinated services
    • Rapid response service that directly treats patients at home
    • Specialist community palliative care teams
  – Equipment, facility and resources:
    • Machines, equipment and medications for basic and palliative care; e.g. catheters, needles and dressings wheelchairs and oxygen supply for basic care and symptom control (e.g. oral suction, IV drip/syringe pump, etc.)
  – Space:
    • HK tends to have lack of space at homes
    • For patients who need assistance or aids for mobility and activities of daily living

• Thus, patients to be transferred back to hospitals
  – Usually via emergency ambulance (which may perform unnecessary resuscitation for dying or terminally ill patients due to Fire Services Ordinance (Cap. 95)), for care and support within the hospital by medical and nursing staff, possibly crowding the resources and manpower that may otherwise be used to care for more acute, non-terminal hospital cases
However... Lack of transport for non-emergency consultations

- Home dwellers who do not have access to the medical follow-up and assessment services by the CGAT, geriatric follow-up consultations are carried out in hospital General Out-Patient Clinics or Specialist Out-Patient Clinics → must travel to hospitals → difficult or even impossible for them to travel without assistance for consultations for some patients with functional disability or mobility impairment

- Current service inadequate:
  - HA’s Non-Emergency Ambulatory Transfer Service (NEATS):
    - for transportation for Mobility-disabled patients who are unable to take public transportation or the transportation services provided by the Hong Kong Society of Rehabilitation, e.g. geriatric day patients, patients discharged from hospitals or Accident and Emergency (A&E) Departments, specialist out-patient clinic patients
    - with only 198 vehicles and 647 staff, eligibility for the service is limited to patients in very extreme situations who are bedbound, require constant oxygen supply, live alone, wheelchair-bound without direct elevator access, or mental/sensory impairment who are not escorted by friends or relatives
  - Additional transportation services by the Hong Kong Society for Rehabilitation (including Rehabus Service, The Elderly Transport Service of Easy-Access Transport Services Ltd., Accessible Hire Car and Easy-Access Travel Ltd.) are also insufficient to fill the service gaps: very long queue – booking around 60 days in advance

• Thus, patients to be transferred back to hospitals via ambulance again!
ORGANIZATIONAL & OPERATIONAL

• **Lack of transport for EOL patients to sub-acute facilities**
  
  – no provision for ambulance transportation in Hong Kong catering for transfers and admissions to sub-acute services for EOL patients who do not require acute medical attention
  
  – A&E admissions may generate excessive and unnecessary investigations and futile interventions (including sometimes invasive and inappropriate interventions) for EOL patients in these acute hospital settings.
  
  – Pilots: EOL cases that can be re-admitted directly to non-acute hospital /palliative care setting for patients enlisted in EOL care programs for RCHEs (e.g. the pilot program of “Enhanced CGAT Service for EOL Care in RCHEs” and other ad-hoc EOL care programs in some hospitals)

• **Thus, patients to be transferred back to acute facilities via ambulance again!**
ORGANIZATIONAL & OPERATIONAL

• Community service capacity and support for palliative and EOL care: generally low awareness of where and how to access palliative and EOL care services in the community.
  – Family members of the patients usually have to work during day time, and they can only assume the role of informal carers after work.
  – Some families rely on foreign domestic helpers for EOL care; however, there is no requirement for foreign domestic helpers to be trained in caring for the patients and the elderly.
  – The concepts of “aging in place” and “dying in place” are also not widely recognized, unlike many other developed countries.
• **Death certification procedure and doctor availability**
  
  – Difficulty in finding doctors who have attended to patients within 14 days of death and willing to visit the home to certify death and issue Form 18 (Coroners Ordinance to be exempted from Type 2 reportable deaths)
  
  – The Birth and Death Registration Ordinance (Cap 174) requires that a medical practitioner is present at the place of death to ascertain how death has occurred before issuing the Medical Certificate of the Cause of Death (Form 18).
  
  – The procedure of obtaining Form 18 and then form 12 (Certificate of Registration of Death) within 24 hours of death and before removal of the body is unfamiliar for families, creates hassle and is a barrier to dying in the home.
ORGANIZATIONAL & OPERATIONAL

• Mortuary capacity and financial costs for natural deaths at home
  – No requirement to notify coroners for natural deaths at home (those exempt from Type 2) → Hospital or public mortuary facilities are therefore not available to accommodate the deceased.
  – Additional costs from funeral parlour transport and accommodation of the deceased
  – Application for burial grants for CSSA recipients
SOCIO-CULTURAL & PRACTICAL

• **Fear and discomfort**: neighbors and fellow housemates may experience fear, discomfort or inconvenience from dying in the home.

• **Small houses and densely populated buildings**: high density and close proximity of small apartments with limited living spaces.

• **Depreciation in property value**: some people may fear property value depreciation after a death has occurred at home → Misconceptions about haunted house still exist in HK

• **Fear of legal procedures**: legal and administrative requirements for deaths occurring at home are not well understood among the public and people fear criminal liability for procedural breaches.
The FHB Commissioned Research Project
“Quality of healthcare for the ageing – Health system and service models to better cater for an ageing population”

A Telephone Survey of 1,067 adults of the General Hong Kong Population above 30 years old (Chung RY, et al.)
# Main Findings – Preferred Place of Care

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

<table>
<thead>
<tr>
<th>Age</th>
<th>Percentage (%)</th>
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<tr>
<td>30-39</td>
<td>57</td>
</tr>
<tr>
<td>40-49</td>
<td>35.2</td>
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<tr>
<td>50-59</td>
<td>32.5</td>
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<td>60-69</td>
<td>23.3</td>
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<tr>
<td>70-79</td>
<td>23.3</td>
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<tr>
<td>80+</td>
<td>21.3</td>
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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

- 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)

- 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%
ENABLING CHOICE
Enabling choice

• **Palliative care**
  – Increasing importance as terminal illness progresses

• **Clarify concepts of palliative care, EOL care, advance care planning, advance directives, enduring powers of attorney, mentally incapacitated persons, etc.**

• **Advance care planning**
  – “a process of communication among patients, their healthcare providers, their families, and important others regarding the kind of care that will be considered appropriate when the patient cannot make decision.”
  – Can/should be done immediately
  – Agreement, recognition and documentation of the ACP protocol across all sectors, esp. medical-social interface
Enabling choice

- **Legal**:
  - **Reinterpretation of the Fire Services Ordinance (Cap. 95)** to exclude resuscitation for those terminally ill patients who do not wish to receive futile resuscitation.
  - **Deliberation on legislation of advance directive**
    - Standardized terminology: advance directive?, advance medical directive?, etc. to avoid confusion
    - ACP policy should be implemented regardless whether AD is legislated or not
  - **Amendment of Mental Health Ordinance (Cap. 136)**
    - Clearer definition of “mentally incapacitated persons”
    - Separation of mental health and mental capacity
  - **Amendment of Powers of Attorney Ordinance (Cap. 31)**
    - Powers of attorney to make decisions for patients on life-sustaining treatments and EOL care should be considered
  - **Power of the Guardianship Board (Mental Health Ordinance (Cap 136) Section 59R)**
    - Alternative option to facilitate making decisions on life-sustaining treatments for mentally incapacitated persons
Enabling choice

• Organizational and Operational:
  – Develop a standardized protocol and guidelines for care at the EOL for health and social care professionals, carers in the community and at people’s own homes, and informal carers, family members as well as the patients
  – Non-A&E transportation from the community to the hospitals: expansion of current NEATS and NGO services.
  – Transportation to public mortuary for non-coroner’s cases outside of hospitals.
Enabling choice

• Organizational and Operational (cont’d):
  – Development of a Continued Community Care Outreach Program (CCCOP): multi-disciplinary outreach primary care services
    • Integrate medical and social sectors for managing and coordinating home and community care services as well as RCHE/nursing home care services.
    • Integrated operational guideline for dying management, which includes medical certification by medical doctors in the community
    • An extension of the ICDS with Integrated Care Model case manager coordinating home visits and telemedicine support for remote advice.
      – can integrate other home care support programs, e.g. palliative home care, other organ-specific home care programs, CNS, as well as other community and home care visits by allied health professional such as physiotherapists and occupational therapists currently in place.
Enabling choice

- **Socio-cultural and Practical:**
  - **Public education** on concepts of ageing and dying in place
  - **Debunk** misconceptions, myths and cultural taboos surrounding death and dying
  - **Build a compassionate community** for patients at risk of dying and at the EOL:
    - Individual acts of compassion with friends and family;
    - **Public health promotion and death awareness** including creative health promotion approach, e.g. school projects, death cafes, art, media, festivals and events;
    - **Community development approaches** with schools, community and religious groups and existing networks and programs;
    - **Establishing formal projects** such as volunteering schemes giving practical support and help to those at their EOL; and
    - **Engagement of communities in dialogue** and reconfiguring EOL care by demanding policy change and lobbying
Thank you!
Changing course of health care needs along the illness trajectory (Adapted from WHO)