Call for Action for Better End-of-life Care

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Presentation Content:

- The Death & Dying Issue for an Ageing Population
- Quality of Death in Hong Kong
- The Service Landscape and Needs
Ageing Tsunami

Elderly population will increase to 34.5% of total by 2050

Elderly dependency ratio will increase to 64.6 per 100 population aged 15-64

Source: U.S. Census Bureau, International Database, 2015

Prof C Chan Palliative Social Work Symposium 2015
Deaths in Hong Kong (2014)

- a total of 46,000 deaths, 90% happened in Hospital Authority
- In the recorded deaths about 80% are elderly >65 years old and half are >80 yrs old
- By 2035, number of death to increase to 69,000
- By 2046, number of death to increase to 92,000

Leading causes of death in Hong Kong (Age >65)
Cancer 9267
Pneumonia 7072
Heart Diseases 5347
Cerebrovascular 2793
Chronic Lower RD 1622
Renal 1516
Dementia 1095
Septicemia 793
The 2015 Quality of Death Index
Ranking palliative care across the world
A report by The Economist Intelligence Unit

Overall Quality
Palliative and Healthcare Environment
Human Resources
Affordability of Care
Quality of Care
Community Engagement

Hong Kong
Taiwan
Singapore
Japan
South Korea
RANK: 22  Hong Kong

<table>
<thead>
<tr>
<th>Rank/80</th>
<th>Score/100</th>
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<tbody>
<tr>
<td>Quality of Death overall score (supply)</td>
<td>22</td>
</tr>
<tr>
<td>Palliative and healthcare environment</td>
<td>28</td>
</tr>
<tr>
<td>Human resources</td>
<td>20</td>
</tr>
<tr>
<td>Affordability of care</td>
<td>-18</td>
</tr>
<tr>
<td>Quality of care</td>
<td>-20</td>
</tr>
<tr>
<td>Community engagement</td>
<td>-38</td>
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“Revolving Door” syndrome of frequent admission to and out of hospitals
Elders have to go through a series of resuscitation in the ambulance and A&E to be admitted into hospital care
Public hospitals are crowded and have fixed visiting hours and is not a good place to die

Source: Mingpao 02102016 report on Survey findings of School of Public & Primary Health, Chinese University
<table>
<thead>
<tr>
<th>Finding</th>
<th>%</th>
<th>Source</th>
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<tbody>
<tr>
<td>To be with my loved ones</td>
<td>33.9%</td>
<td>Chinese University School of Public Health (2016)</td>
</tr>
<tr>
<td>Reduce pain &amp; discomfort</td>
<td>33.9%</td>
<td>Hong Kong University FOSS, JCECC Project (2016)</td>
</tr>
<tr>
<td>I find life meaning</td>
<td>8.5%</td>
<td>Society for Hospice Care (2004)</td>
</tr>
<tr>
<td>Minimize pain and discomfort</td>
<td>40.6%</td>
<td>Chinese University School of Public Health (2016)</td>
</tr>
<tr>
<td>Not a burden to others</td>
<td>11.7%</td>
<td>Society for Hospice Care (2004)</td>
</tr>
<tr>
<td>No need to worry about family’s livelihood</td>
<td>9.1%</td>
<td>Society for Hospice Care (2004)</td>
</tr>
</tbody>
</table>
Population Survey Findings on where people want to die

- **Hospital**: 51.8% (54.8%)
- **Home**: 30.8%
- **Institution**: 16.2% (1.8%)

Chinese University School of Public Health (2016)
FOSS, JCECC Project (2016)
Preparations for Death – Gaps between Knowing and Doing “have you thought about? Talked with your family? Written down?”:

雖然近六成受訪者「有諗過」

預先作出醫療選擇及作心理準備，

但對此有所行動的卻是佔少數

HKU Sau Po Center on Ageing
「終老的選擇」網上問卷調查
共458回應 (30% 56歲以上)
Death is the Most Neglected Chapter .... for the Individual and for the Society facing an ageing population
What are the Challenges?

- **Social Taboo**
- **Medicalized death process**
- **Not enough services**
Service Landscape in Hong Kong

**Social Care System**
- New funding requirement for contract homes to provide EoL care
- RCHEs pilot EoL programs
- Life and Death education for elders in DECC / NEC
- Enhanced Home Care & Integrated Home Care

**Health Care System**
- 300+ palliative beds + home outreach service
- Patient Resource Centers
- Community nurse (CNS)
- Enhanced CGAT EoL care
- Fast-track clinical admission for Eol patients

**Private Funding Support**
- Hospice beds for the poor
- Patient resources centers
- EoL care in RCHEs projects
- Community eol care projects
6 Areas of Service Needs:

- Integrated medical-social care service models
- Service to empower elders and families
- Increase home care support services
- Public education and community engagement
- Advocate for policy change
- Creative entrepreneurial solutions
1. Integrated medical-social care service models
   - Each person is seen as an individual – personalized care planning
   - Need to address the holistic medical, psycho-social & spiritual needs, maximizing comfort and well-being of the dying
   - Ensure the continuity and co-ordination of care in honoring the care preferences of the dying
   - Providing a peaceful & supported dying environment for the dying and the family

2. Empower the dying elders and families
   - Support communication and mutual understanding of emotions & concerns facing death
   - Facilitate joint preparation and planning for the dying process & post death arrangements, including care preference decisions, assigning of care proxy, financial and burial decisions
   - Support dialogue with the formal care systems to ensure care wishes could be honored
3. Increase home care support services
   - 81.4% elders prefer living at home -> inadequate outreach medical home care
   - Examples of logistics support, include: medical equipment loan, “smart home” facilities & emergency call service
   - Outreaching of nursing care, therapist and personal care support to the home
   - Training & support to home carers

4. Creative entrepreneurial solutions
   - Support social businesses, stimulate market solutions to meet the needs of different segments of the ageing population
   - Support consumer education and protection
5. Public Education & Community Engagement
- To build awareness & understanding of dying and death to reduce social taboos - promote life and death education in schools; target adult children with elderly parents
- Train and mobilize volunteers or other community informal care groups, like patients mutual help & faith-based groups
- Training & support to home carers

6. Advocate for Policy & System Change
- To remove legal and administrative barriers
- To have an overarching End-of-life care strategy to align public services, including medical, social, burial, funeral services, to deliver integrated and holistic care pre and post death for an ageing population
The 5 major domains of End-of-Life Care Strategy

Referencing the national strategies on end-of-life care in countries where quality of death is ranked high in the EIU report, we have learnt the importance of

(1) awareness and understanding,
(2) appropriateness and effectiveness of services,
(3) leadership and governance,
(4) public accountability and
(5) capacity and capability

They set a comprehensive framework for Hong Kong to strategically develop policies, systems, services and manpower for providing quality end-of-life care, by shedding light on both strengths and weaknesses in our local context.
Strategies for building Compassionate Communities
(Summarized from 28 cases in the UK)

- Reconfiguring End-of-Life Care
  - Advocate for overarching Eol policy; removing legal & administrative barriers

- Supporting Existing Networks - Community Development
  - Work with faith-based gps, mutual support gps etc.

- Establishing Formal Projects, e.g. Volunteer Schemes
  - NGOs Eol projects and hospice volunteers, medical equipment loan, etc.

- Individual Acts of Compassion with Friends and Families
  - E.g. Personal experience leading to change (local champions) etc.

- Public Health Promotion and Death Awareness
  - E.g. School projects, Death Cafes, funeral planning, art projects, will writing etc.

- Compassionate Communities

- Companionship Networks
  - Community Development

- Public Health Promotion and Death Awareness
References


