

Challenges of End of Life Care and Dying at Home for Older People with Terminal Conditions in Hong Kong

老齡化社會臨終照顧及在家安寧照顧的挑戰

Dr. Edward M F Leung

President, Hong Kong Association of Gerontology

Director, Geriatric Medicine Centre (Healthy Ageing), Hong Kong Sanatorium and Hospital

HKEC Symposium on Community Engagement

25-6-2016



Presentation Outline

- Ageing Population and Mortality Trends
- End of Life Needs in An Ageing Population
- Dying in Place and Choice of Place of Death
- Future Development and Challenges

Population Ageing in Hong Kong

<u>Year</u>	<u>65-69</u>	<u>70-74</u>	<u>75-79</u>	<u>80-84</u>	<u>85+</u>	<u>65+</u>
13-14	326,600	212,100	209,900	164,400	150,600	1,063,600
14-15	364,600	214,900	209,900	166,000	160,000	1,115,400
15-16	397,500	222,900	206,900	167,300	170,200	1,164,800
16-17	414,800	251,800	198,900	170,600	178,500	1,214,600
17-18	429,900	282,200	193,000	172,700	187,700	1,265,500
18-19	447,500	313,000	192,900	173,200	196,800	1,323,400
19-20	461,900	349,800	196,200	173,700	203,000	1,384,600
20-21	483,300	381,400	204,500	171,900	209,700	1,450,800
21-22	507,600	398,800	232,000	165,600	216,400	1,520,400
22-23	535,500	413,800	260,800	161,400	223,000	1,594,500
23-24	556,500	430,900	290,200	162,200	228,300	1,668,100
24-25	576,100	445,100	324,500	166,000	231,400	1,743,100

Leading causes of death in US for those above age of 65

- 1. Heart Diseases
- 2. Cancer
- 3. Stroke
- 4. COPD
- 5. Pneumonia

Alzheimer disease ranked number 10

Leading causes of death in Hong Kong (Age >65) 2014

• Cancer	9267
• Pneumonia	7072
• Heart Diseases	5347
• Cerebrovascular	2793
• Chronic Lower RD	1622
• Renal	1516
• Dementia	1095
• Septicemia	793

Table 5.2: Ten most common underlying causes of death in people aged 75 and over, persons, England, 2006–08

Description	Underlying cause category	n (average per year)	% deaths
I25: Chronic ischaemic heart disease	Cardiovascular	31,296	10.0%
J18: Pneumonia, organism unspecified	Respiratory	23,085	7.4%
I21: Acute myocardial infarction	Cardiovascular	19,344	6.2%
I64: Stroke, not specified as haemorrhage or infarction	Cardiovascular	18,878	6.0%
J44: Other chronic obstructive pulmonary disease	Respiratory	14,711	4.7%
C34: Malignant neoplasm of bronchus and lung	Cancer	13,278	4.2%
F03: Unspecified dementia	Other	12,955	4.1%
I67: Other cerebrovascular diseases	Cardiovascular	9,154	2.9%
R54: Senility	Other	8,855	2.8%
I50: Heart failure	Cardiovascular	7,049	2.2%
Total (ten most common causes)		158,605	50.5%
All causes		313,942	

Source: South West Public Health Observatory from Office for National Statistics data

Age Specific Mortality Rate in 2013

Per 1000 population

Age groups	Male	Female
40-44	1.2	0.7
45-49	2.0	1.1
50-54	3.1	1.7
55-59	5.2	2.8
60-64	8.4	3.9
65-69	12.6	5.8
70-74	22.5	10.5
75-79	36.0	18.4
80-84	61.4	36.6
85+	128.9	90.0
All Ages	7.2	5.0

Deaths in Hong Kong

- In 2014,
- a total of 46,000 deaths, 90% happened in Hospital Authority
- By 2035, number of death to increase to 69,000
- By 2046, number of death to increase to 92,000

Principles of Good Death

(The Future of health care of Older People, Age Concern, UK 1999)

- To know when death is coming, and to understand what can be expected
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and other symptom control
- To have choice and control over where death occurs
- To have access to information and expertise of whatever kind is necessary
- To have access to any spiritual or emotional support required
- To have access to hospice care in any location, not only in hospital
- To have control over who is present and who shares the end
- To be able to issue advance directives which ensures wishes are respected
- To have time to say goodbye, and control over other aspects of timing
- To be able to leave when it is time to go, and not to have life prolonged pointlessly

Definition of End of Life Care

(General Medical Council, UK 2010)

- For those people who are likely to die within the next 12 months
- Include those people whose death is imminent (expected within a few hours or days) and
- Those with
 - Advanced, progressive incurable conditions
 - General frailty and co-existing conditions that mean they are expected to die within 12 months
 - Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
 - Life-threatening acute conditions caused by sudden catastrophic events

End of Life Care

(National Institute for Clinical Excellence NICE, UK)

- Treat the patients as individual
- Show patients respect and preserve their dignity
- Help with control of symptoms particularly pain
- Offer psychological, social and spiritual support
- Reassure patients that their families and carers will receive support during their illnesses

UK NHS End of Life Care Program commenced 2004

- Greater choice for patients of place of care and place of death
- Fewer emergency admissions of patients who wish to die at home
- Fewer patients transferred from a care home to hospital in the last week of life
- Improved skills among generalist staff in the provision of end of life care

End of Life Issues in Chinese Communities

- Death and Dying – a subject often avoided in many Chinese societies
- Institutionalization of death – most people will be sent to hospital when they are dying at home or in residential homes
- Admission to acute hospitals causes unnecessary interventions to terminally ill patients



End of Life Issues in Chinese Communities

- Breaking bad news in chinese patients and their family members
- Older patients' wishes in end of life decision making
- Advance Care Planning / Advance Directives
- Need for more public education on life and death issues and professional training

The 2015 Quality of Death Index

Ranking palliative care across the world

A report by The Economist Intelligence Unit

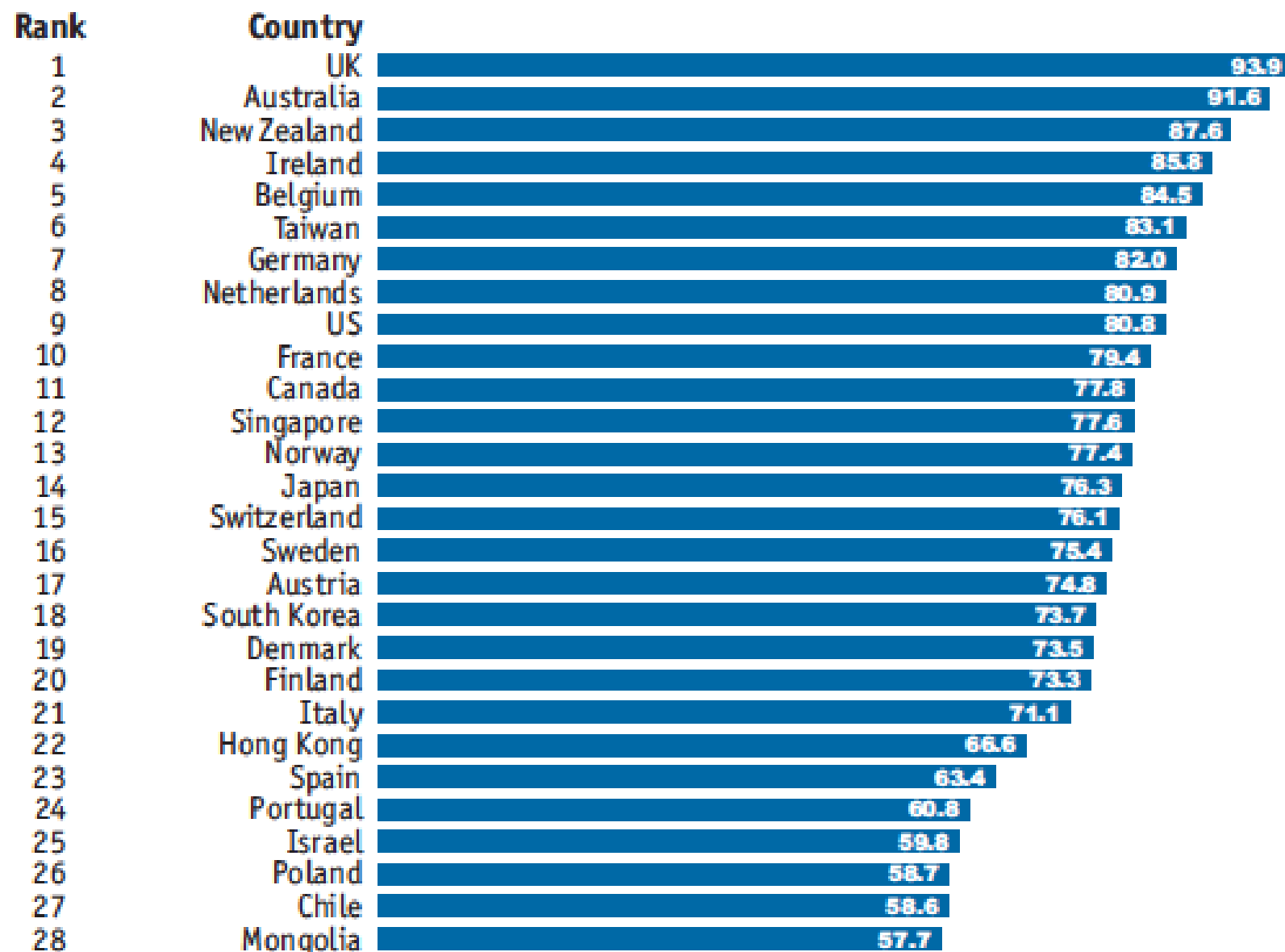



Commissioned by



Figure 1.2

2015 Quality of Death Index—Overall scores





Across the world, large numbers of people die in hospital each year, yet many would rather spend their final days at home or in a hospice. In the UK, this is something the palliative care community is working to change—not only to increase the quality of care people receive but also to help the country's National Health Service cut costs.

Recent research by Age UK, a charity, found that the average number of patients kept in hospital unnecessarily while waiting for community or social care rose by 19% between 2013/14 and 2014/15. An NHS bed costs on average £1,925 (US\$2,980) per week, Age UK estimates, compared to about £558 for a week in residential care or £357 for home care.⁴²

End of Life in Chinese Older People interviewed

- Older people and their family members support the idea of End of Life care
- Most older people are not afraid or anxious about death, it is not a taboo to them

Preparation for Promoting End of Life Care in Older People with Terminal Illness

- Patient and Family Communication
- The use of Advanced Directives and Advance Care Planning
- The application of DNACPR order
- Agreement of Care Plan between the Medical Practitioner with Patient and Family members
- Issues of Futility Treatment Vs Quality of Life



Goal of Care in the Terminally Ill Patient

Appropriate palliative care

Improve quality of life

Support to family

Right to a good death

Die with dignity

Protecting physical and psycho-spiritual integrity

Avoid distress, pain and suffering

Respecting the choice of the person


Treasuring the terminal phase of life





Dying at Home as a Choice


Case Study


- Madam Wan
- 88 years old lady
- Enjoy good physical health all along
- Enjoyed a full month Canadian Family Reunion in August 2015
- Noted Bowel Discomfort while at the end of August before return back Hong Kong


- 
- Developed progressive abdominal distension in September 2015 after returned to Hong Kong
 - Consulted GI Surgeon on 19/9/15
 - CBP/RFT normal
 - LFT – ALP 167, GGT 142, Alb 34


- 
- CT Abdomen (22/9/15)
 - Ill defined heterogeneously enhancing tumor is evident in the pancreatic tail, measuring 5.5x5.7x6.2 cm. The tumor is encasing Splenic Vein
 - Liver – multiple metastasis with size up to 3.2x2.9 cm
 - Multiple enhancing peritoneal metastases with malignant ascites detected, consistent with peritoneal carcinomatosis
 - Diagnosis – Ca Tail of Pancreas with Liver and Peritoneal Metastasis

- 
- Admitted to St Paul's Hospital from 25-28 September 2015 for abdominal distension
 - Ultrasound guided drainage done with a total of 2 litres drained in 3 days
 - Discharged with Aldactone 25 mg daily
 - Inoperable condition and family wish for Palliative Care

- 
- First consultation on 5/10/2015
 - Come with 2 daughters and granddaughter
 - Sound Mental state, Mobility and ADL independent
 - Examination showed Ankle edema and Ascites
 - Wished to have out patient management
 - Daughters expressed that patient did not aware of abdominal tumor yet

- 
- Noted progressive abdominal distension and shortness of breath in the following days by relatives
 - Agreed to be admitted for further drainage of ascites
 - Admitted on 10/10/15 with ultrasound guided insertion of pigtail catheter
 - Also noted pneumonia in CXR
 - Patient strong wish to be discharged back home instead to stay in hospital
 - Discharged with pigtail catheter for continuing drainage of ascites at home same day evening
 - FU next Wednesday in clinic

- 
- Further followed up on 14/10/15 morning
 - A total of 1.5 litres of blood stained ascites fluid drained
 - Examination showed large mass over left side of abdomen
 - Diagnosis of abdominal tumor disclosed to patient in presence of relatives
 - Patient requested to be cared at home as far as possible

- 
- Further discussion with daughters and son
 - Expressed the wish to have their mother to be cared at home and die at home if possible
 - Explained to family that not much monitoring and intervention could be performed at home and patient may die much earlier
 - Family understand and accept the management at home
 - Since patient is already very weak so will be arranged for Home Medical Follow up

Management Plan

- Continue with Pigtail Drainage at home to relieve abdominal discomfort
- Continue Oral Antibiotics for Chest Infection
- Adequate Pain Relief
- For Arrangement of Dying At Home
- Advise given to contact Funeral Agency for prior arrangement of dead body handling upon death



15/10/15

Pain relieved with oral morphine

Further Home Visit in the evening of 15/10/15 to review progress and support the family

All family members understand that she will be dying soon

Agreed to continue to be cared at home until death

Advised to call when patient further deteriorated in BP and pulse

Plan for review next day

16/10/15

- Informed by Daughter at 1:30 pm that it seems that her mom has passed away because her BP is not recordable and not arousable
- Arrived her home at 3:00 pm, still pupil response to light, no respiration, very weak femoral pulse palpated
- Pupil fix and dilated at 3:54 pm and certified death at home with Form 18 and Form 2



16/10/15

- Patient son able to arrive Death Registry before closing hour and obtained the Official Certificate of Death
- Funeral Parlour pick up body at 7:50 pm

Summary

- Patient with a Terminal Illness with limited life expectancy
- Family and Patient strong wish to be managed at home
- With provision of Home Medical Care patient's family is able to fulfill the wish of their mother
- Family members were gathering together with the patient in the last 2 days of life and Grace her in her religion
- All family members have a fulfilling experience during the death of their parent





Sharing from patient's daughter

- 感恩！可以完成媽媽的意願，因她很害怕住醫院
- 平安！早上有神父為她傅油，下午整家人陪伴在旁，她離開時很平靜很安祥，雖是不捨，但是有機會和時間和空間讓親友可前來告別，子女孫兒在床邊跟她談心和表達感激之情，細訴其養育之恩，讓她可以安心上路，曾孫女送她一個蘋果并放在手中，寓意他平安回到天家，眾家人及親友均可目送他上靈車，好像出發到新的家鄉，現在偶爾我的孫兒都會叫太婆食飯，仍然覺得她與我們在一起
- 還有是感激：有醫生不怕煩，隨時用whatsapp及上門診症
- 再要感激是殯儀的負責人及其同事，因為他們的專業服務，令人十分舒服

林余儷玲



Reason for success

- Experience on End of Life Decision making important
- Adequate communication with patient and family
- Appropriate use of Advance Decision Making with family – Advance Care Planning
- Educated and Supportive Family
- Appropriate arrangement for funeral handling before death

Enabling Dying at Home in Hong Kong

- Advance Directive or Advance Care Planning
- Adequate Communication with family and advise on aspects of terminal care at home
- At least able to see the patient within 14 days
- Adequate symptom relief
- Certifying death with Form 18 and Form 2 available and ready
- Funeral Parlour Arrangement

ing Post

day, June 21, 2016 / See live updates at www.scmp.com

SUBSCRIPTION COPY
ONLY - NOT FOR SALE

HEALTH

Allowing patients to die at home 'will ease hospital strain'

**Former health minister heads study into ways
for Hongkongers to spend final days at home**

The Way Forward

- Promotion of Advance Care Planning and Advance Directives
- Training and Education for Health Care Professionals
- Home Medical Care – Extension of Public Private Interface in End of Life Care
- Home Palliative Nursing Support
- Body Movement, Mortuary and Funeral Arrangement
- Public Education



Thank you

Dr. M F Leung

Emfleung@yahoo.com.hk