Family Members of End-of-Life Care Patients as Secondary Patients

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What is End-of-Life Care?

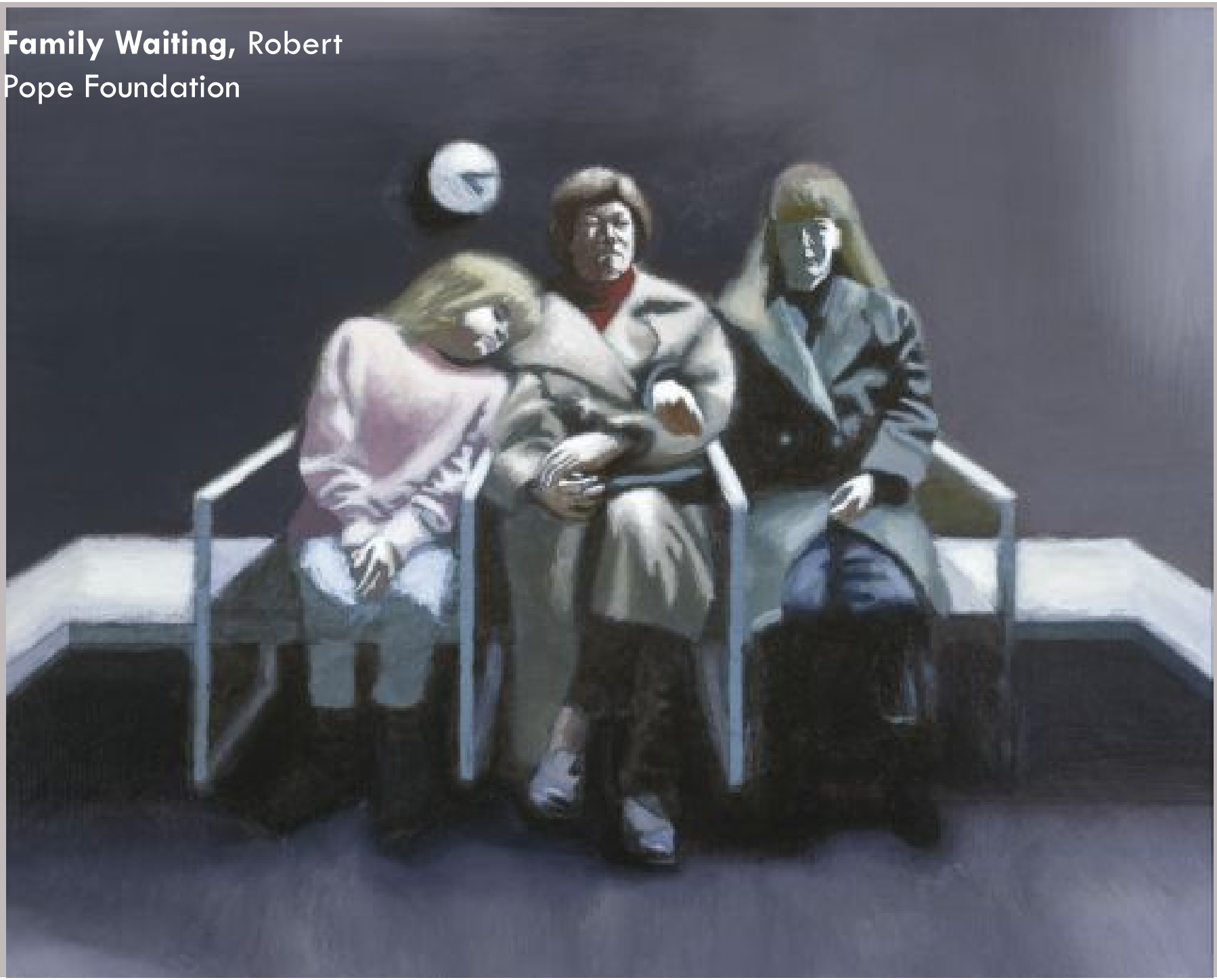
The term "End-of-Life" originates from North America and encompasses more than the phase immediately before death (NCAOP, 2008)

What is End-of-Life Care?

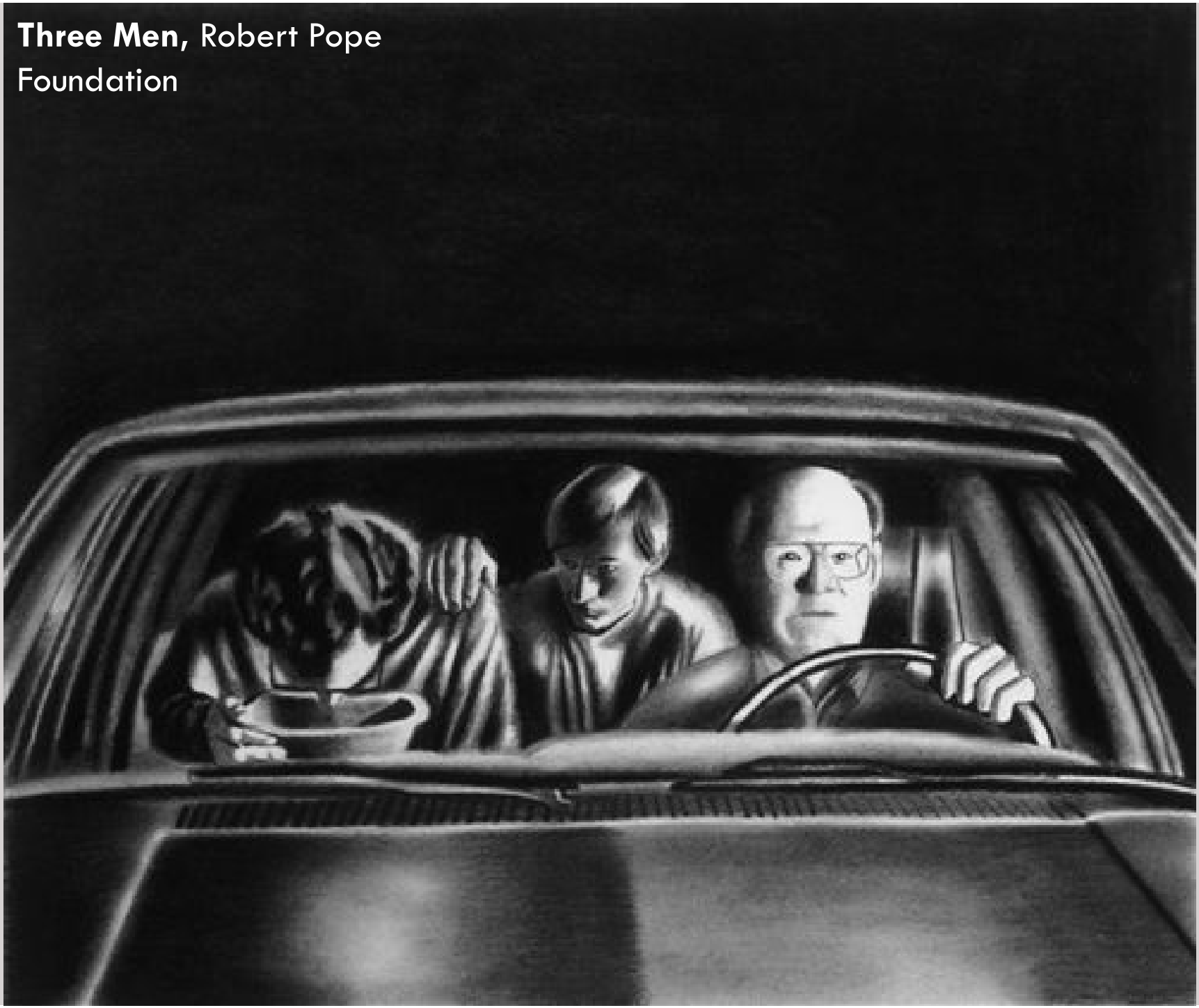
End-of-Life Care is for those who are living with, or dying from, progressive or chronic life-threatening conditions…it is sensitive to personal, cultural, and spiritual values, beliefs and practices and encompasses support for families and friends up to and including the period of bereavement (NCAOP, 2008)

End-of-Life Care

- Taiwanese Concept of End-of-Life Care
- 5 Wholes 一五全一
  - Whole person 全人
  - Whole journey 全程
  - Whole family 全家
  - Whole team 全隊
  - Whole community 全社區
- Family as the unit of care

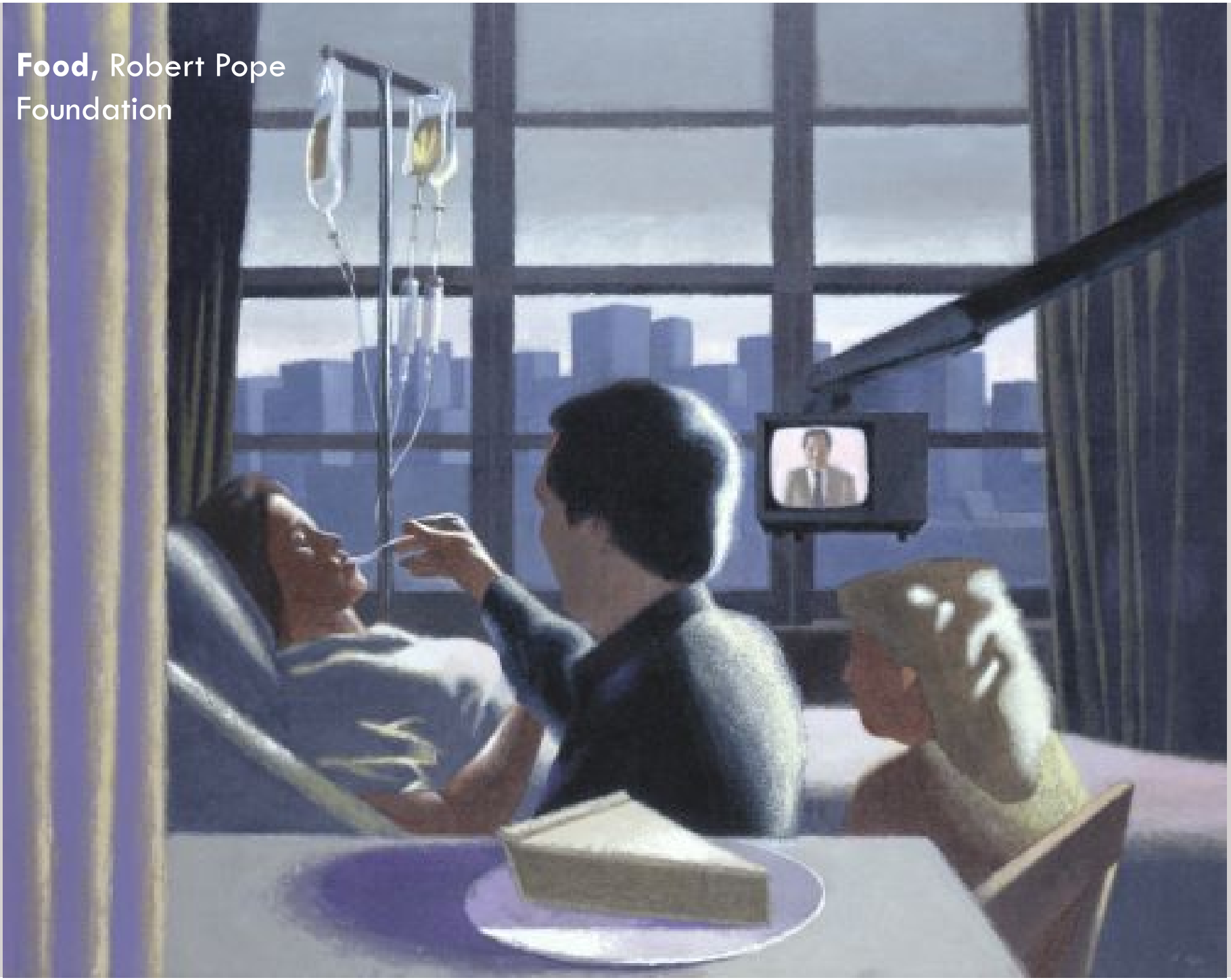


Family Waiting, Robert
Pope Foundation



Three Men, Robert Pope
Foundation

A friend's Story, Robert
Pope Foundation

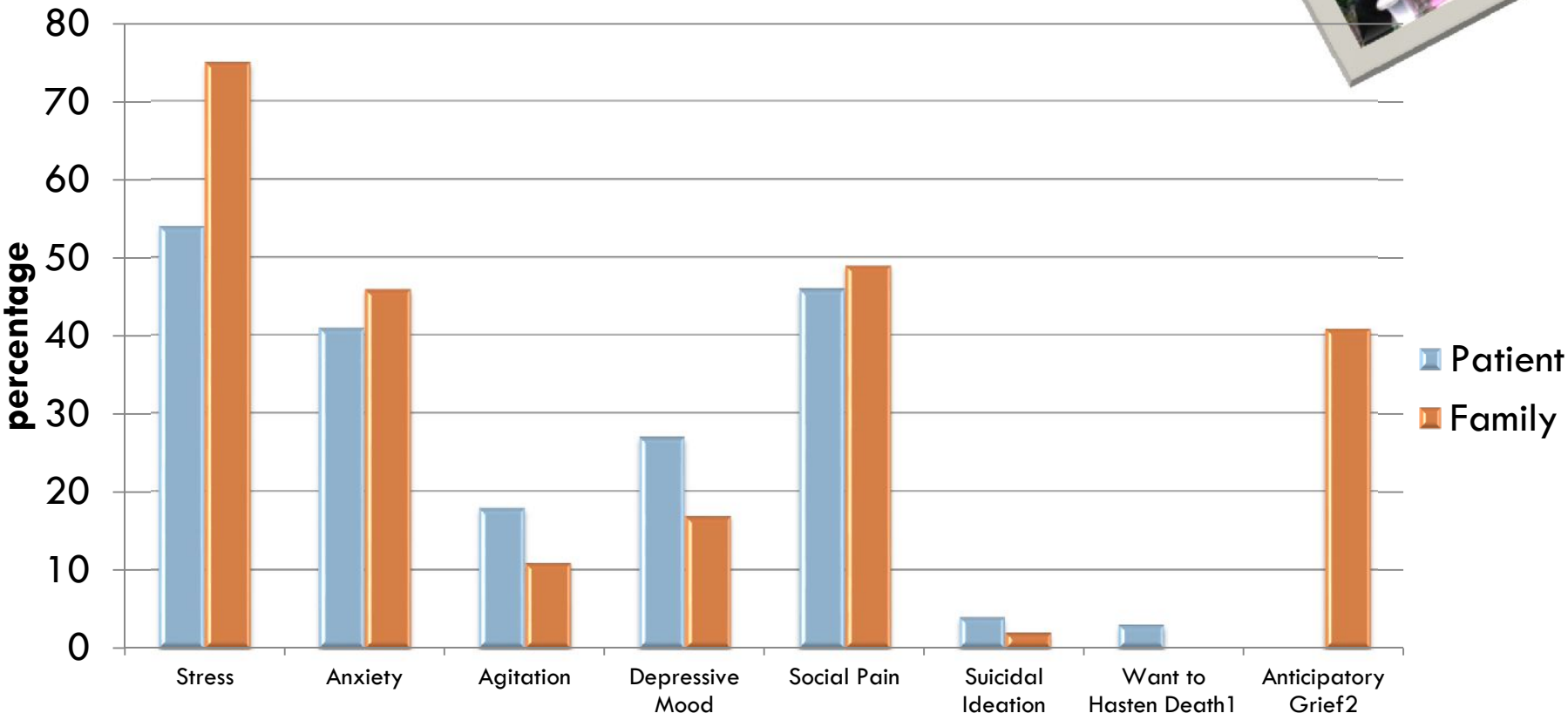


Food, Robert Pope
Foundation

Family Members

- As a secondary patient
  - The livelihood of patient and family members are tied very closely together
  - Common for individual family members to see the same clinician with the patients
  - Secondary patient as another individual to whom the clinician offered a discernible service (Hickman et al., 2014)

Psychosocial Distress of Patients and Families (N=324) (Chow & Chan, 2012)

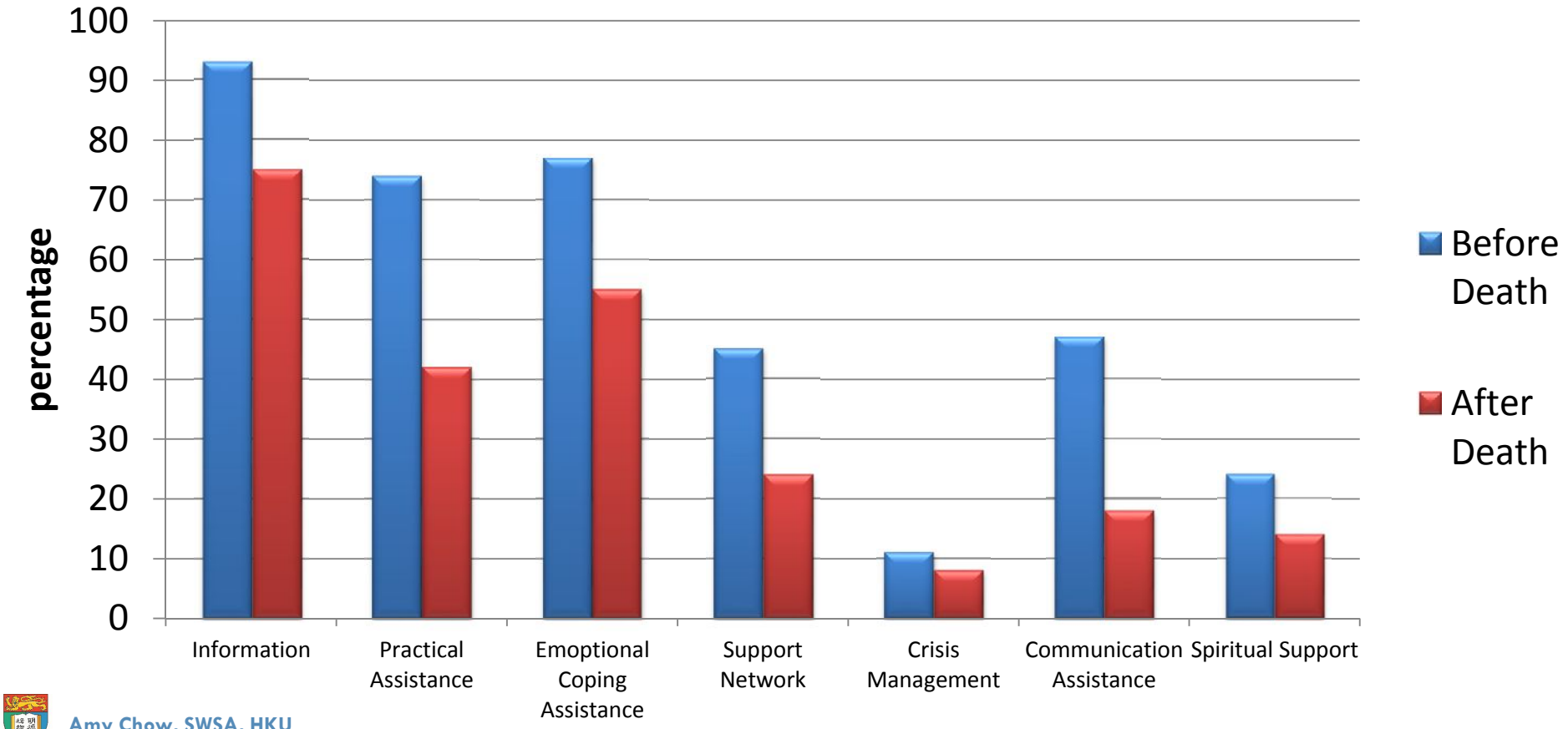


[1] Want to Hasten Death applied to patient only

[2] Anticipatory grief applied to family only

Psychosocial Distress of Patients and Families (N=324)

(Chow & Chan, 2012)



Place of Care

Table 2 Utilization of health care service and oncology treatment in last 6 months of life

	Overall (n = 494)	PCS-PCD (n = 247)	PCS-NPCD (n = 86)	NPCS-NPCD (n = 161)	P-value
(A) Utilization of non-palliative care services (excluding oncology service)					
Mean no. of admissions into non-palliative care wards (SD)	2.5 (2.3)	2.2 (1.9)	3.0 (2.2)	2.7 (2.8)	0.013
Mean duration of stay in non-palliative care wards in days (SD)	25.1 (27.3)	19.7 (22.3)	32.0 (28.4)	30.0 (31.8)	<0.001
Mean no. of attendance to non-palliative care clinics (SD)	3.4 (3.4)	3.2 (2.9)	3.2 (3.8)	3.7 (3.8)	0.249
Mean number of ICU/HDU admissions (SD)	0.078 (0.343)	0.004 (0.636)	0.070 (0.369)	0.199 (0.510)	0.000

(Tse et al. (2007) p.428)

Place of Care

Table 2 Utilization of health care service and oncology treatment in last 6 months of life

	Overall (n = 494)	PCS-PCD (n = 247)	PCS-NPCD (n = 86)	NPCS-NPCD (n = 161)	P-value
(C) Utilization of palliative care service					
Mean total duration of stay in palliative care ward in days (SD)	—	24.1 (21.9)	6.5 (15.1)		<0.001
Mean no. of admissions into palliative care ward (SD)	—	1.5 (0.9)	0.4 (0.8)		<0.001
Mean no. of palliative care clinic visits (SD)	—	1.3 (2.5)	1.1 (2.3)		<0.001
Mean no. of palliative care home visits (SD)	—	3.7 (8.3)	1.6 (4.2)		<0.001
Inpatient PC (% yes within group)	—	247(100.0%)	24 (27.9%)		<0.001
Outpatient PC (% yes within group)	—	113 (45.8%)	31 (36.1%)		<0.001
Home care (% yes within group)	—	124 (50.2%)	23 (26.7%)		<0.001
Consultative (% yes within group)	—	37 (15.0%)	37 (43.0%)		<0.001
Referral to PC within last 2 weeks of life (% within group)		67 (27.1%)	37 (43.0%)		0.267
Median time of referral to palliative care service to death in days (inter-quartile range)		35 (13,93) IQR = 80	31 (10,112) IQR = 102		0.17
Mean duration of stay in both non-palliative care wards and palliative care wards in days (SD)	38.4 (31.1)	43.9 (29.5)	38.5 (31.1)	29.8 (31.8)	0.000

What are the sources of stresses for family members?

Physical

- Caring stress
  - Clinic visit
  - Participation in different activities (OT, PT, alternative medicine, medical investigation, emergency admission)
- Quality of Life
  - Sleep
  - Meals

What are the sources of stresses for family members?

Psychological

- "Time is not on our side"
- "Am I am making the right choice?"
- Worrying about future regrets
- Loss of control
- Helplessness
- Guilt of being relieved

Disclosure Rate (Fielding et al, 1994)

153 radio-oncologist or surgeons, in recalling their most recently deceased cancer patient

Diagnostic disclosure 68%,

Prognostic disclosure (incurable nature of the illness)

- Partially 38%
- A specific statement on the expected outcome of the illness 10% (But 70% of the patients' families were given this statement)

Disclosure Rate (Fielding et al, 1994)

22% of family requested doctor not to tell the patient and eventually 14% of the patient not given the Dx & Prognosis

Expectation of Disclosure

(Fielding and Hung, 1996)

2% preferred not to be given a diagnosis

2% preferred not be given a prognosis

5% did not want to be involved in the treatment decision

Why not Breaking it?

American researchers wanted to know why Japanese physician not disclosing the diagnosis, but Japanese researchers wanted to know why American physicians were disclosing the diagnosis.

(Elwyn et al., 2002)

What are the sources of stresses for family members?

Social

- Communication blocks
- Suspicious attitude
- Family Dynamics
  - What is filial piety?
  - The eldest or the most educated?
  - The daughter or the son? Or the spouse?
- Torn between other roles

What are the sources of stresses for family members?

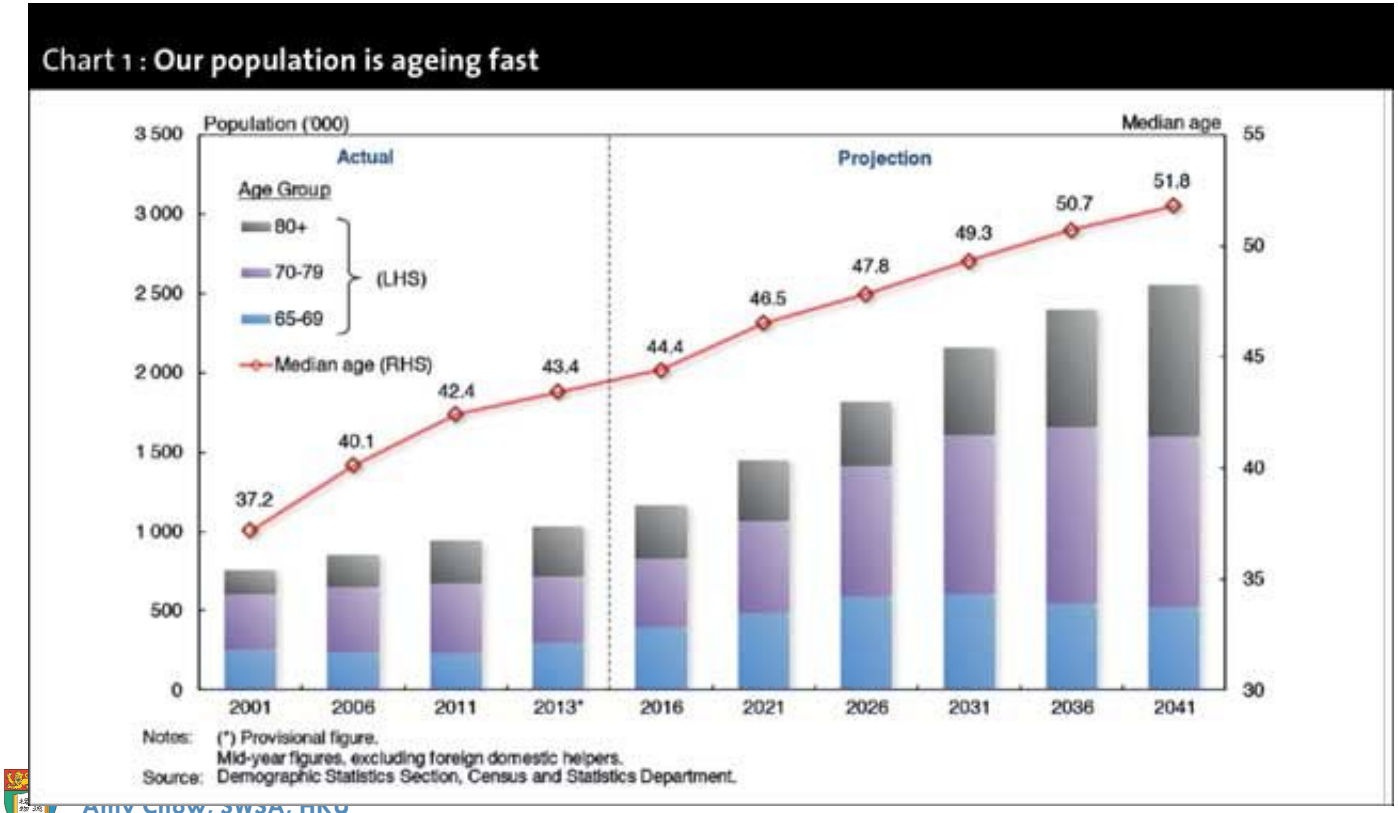
Spiritual

- Spiritual doubts
  - "why bad things happen to good people?"
  - "why him/her?" " why not me?" "why me?"
- Testing of faith
- Being powerless

Other Challenges

Aging Population

- In 2013, 14.3% are aged 65 above but is expected to raise to 33.3% in 2041



Govt HKSAR, 2013, p. 73)

Other Challenges

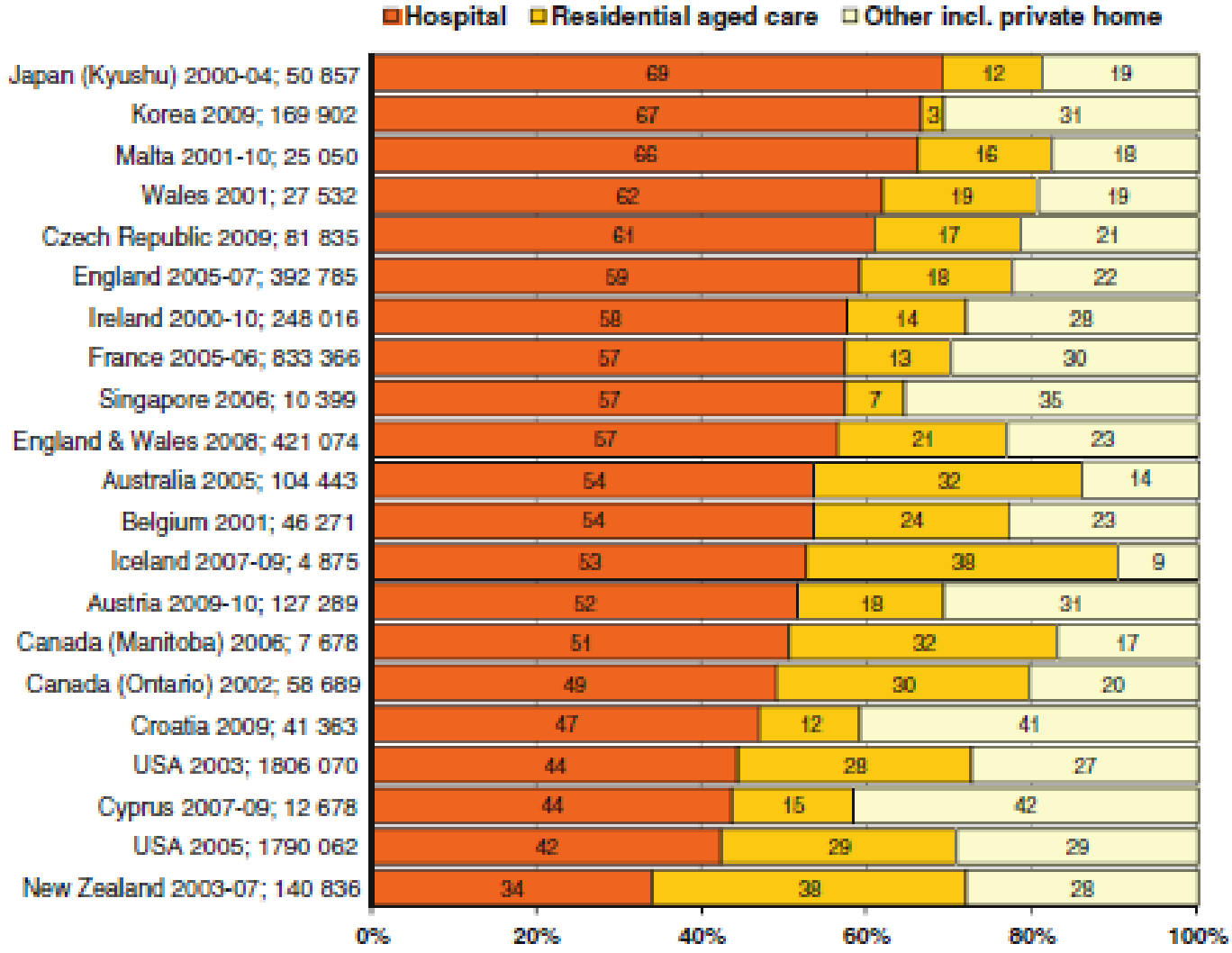
More forms of illnesses are included…

Disease Group	Male	Female	Total No.
Malignant Neoplasms (Oncology)	7934	5655	13589
Diseases of heart	3210	2624	5834
Pneumonia	3690	3140	6830
Cerebrovascular Diseases	1657	1595	3252
External causes of morbidty/mortality	1202	658	1860
Chronic lower respiratory disease	1325	418	1743
Nephritis, nephrotic syndrome and nephrosi	763	826	1589
Septicaemia	406	446	852
Dementia	388	611	999
Diabetes mellitus	181	179	360
All other causes	3396	3095	6491
All causes of Deaths	24152	19247	43399

(Data from Centre of Health Protection, 2015)

Other Challenges

Fig. 2 Location of death among people aged 65+ years in 21 populations reporting deaths in residential aged care [percentage of all deaths occurring in hospital, residential aged care (RAC) and Other incl. private home], showing the years covered and total number of deaths in the period, ordered by percent of deaths in hospital



Place of Death (Deaths of Age 65+): an international view

Broad et al, 2013, p. 261

Other Challenges

the changing death patterns lead to different death trajectories (Murray et al., 2008)

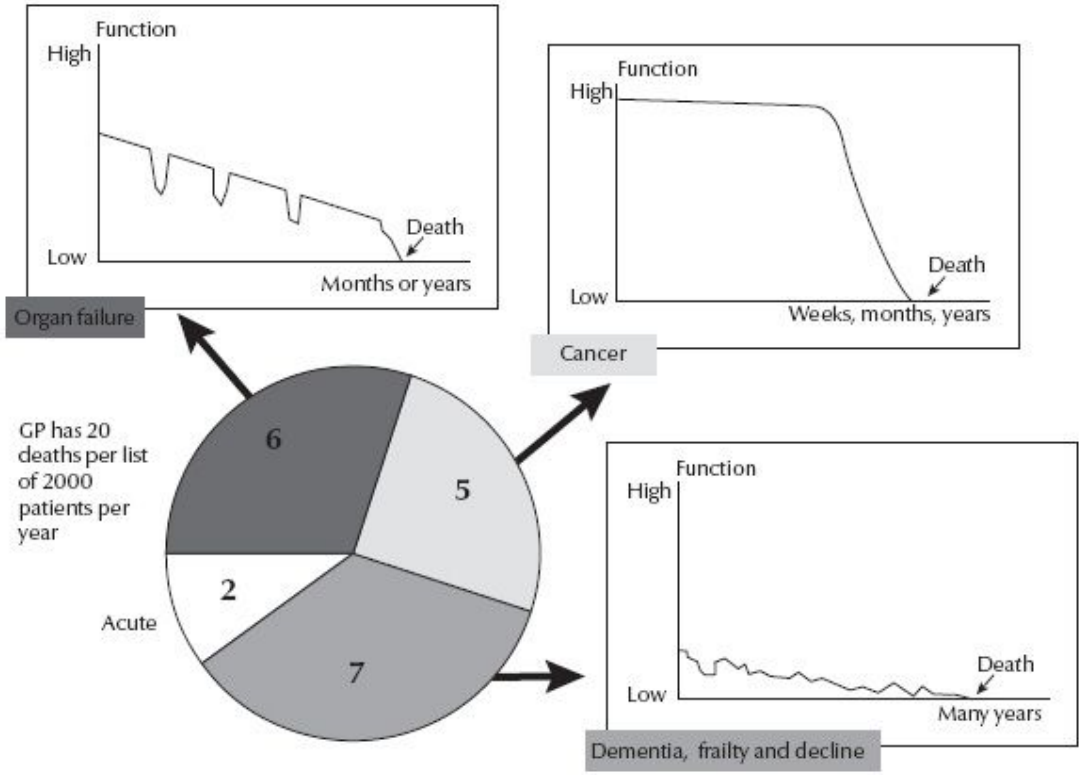
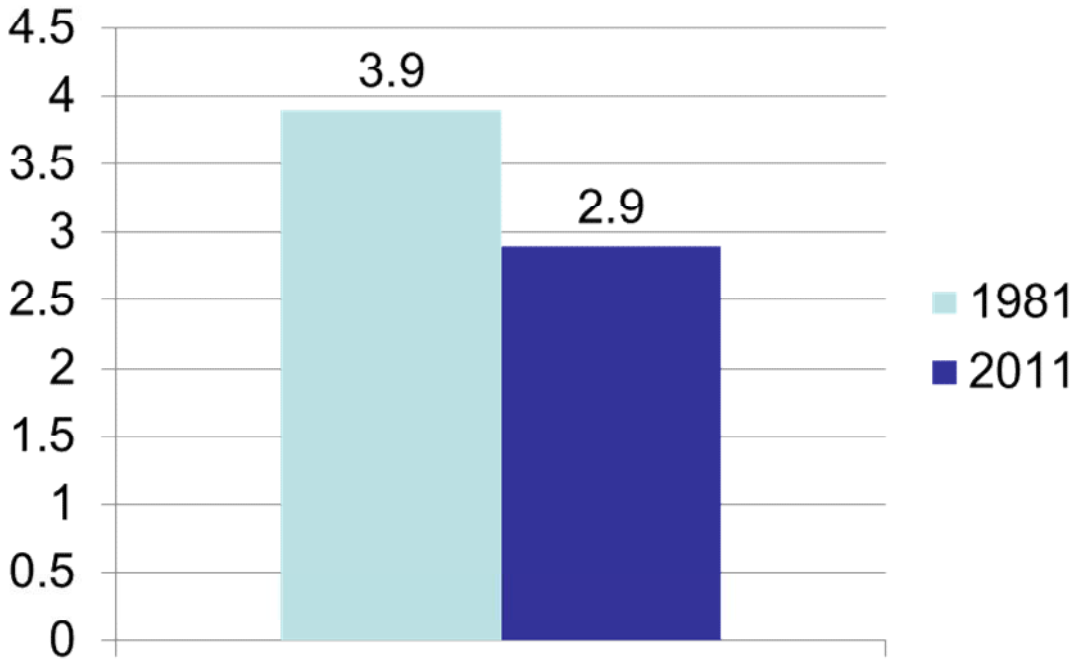


Figure 1 Causes of death in the United Kingdom and trajectories of function of chronic illnesses. Source: [8]

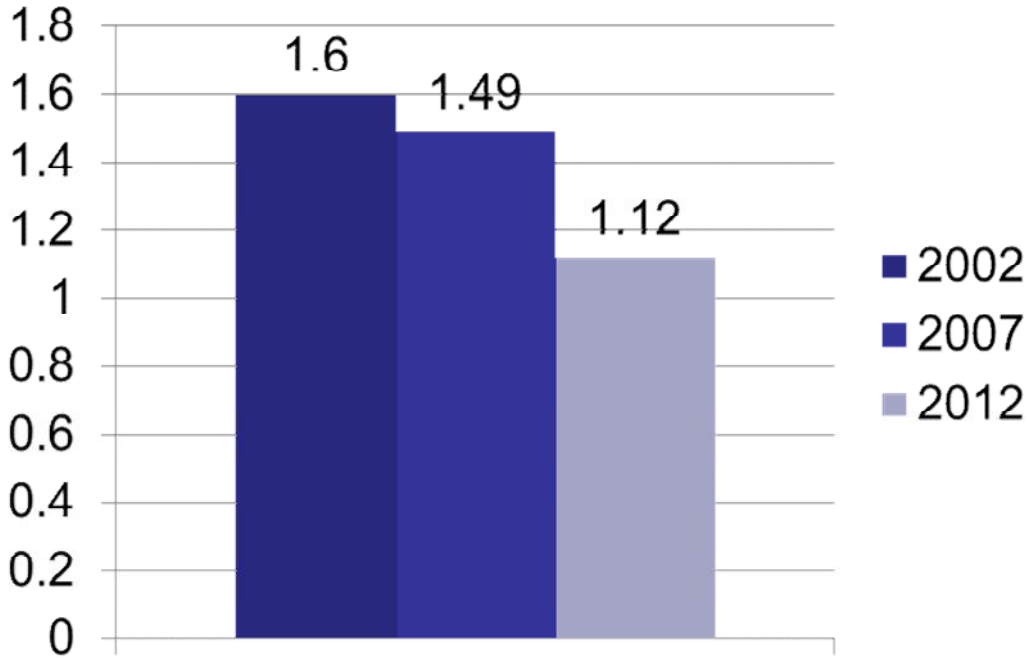
Other Challenges

Reducing mean house-hold size in Hong Kong



Other Challenges

Reducing number of children



International Solution

European Association for Palliative Care
www.eapcnet.eu

Community Palliative Care is an agenda for different countries around the world.

Promoting palliative care in the community: producing a toolkit to improve and develop primary palliative care in different countries internationally

Report of the European Association of Palliative Care (EAPC) Taskforce in Primary Palliative Care

EAPC

This document is endorsed by Wonca

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International Solution

wpca worldwide palliative care alliance

World Health Organization

Global Atlas of Palliative Care at the End of Life

January 2014

SIXTY-SEVENTH WORLD HEALTH ASSEMBLY — WHA67.19

Agenda item 15.5 — 24 May 2014

Strengthening of palliative care as a component of comprehensive care throughout the life course

The Sixty-seventh World Health Assembly,

Having considered the report on strengthening of palliative care as a component of integrated treatment throughout the life course;[1]

Recalling resolution WHA58.22 on cancer prevention and control, especially as it relates to palliative care;

Taking into account the United Nations Economic and Social Council's Commission on Narcotic Drugs' resolutions 53/4 and 54/6 respectively on promoting adequate availability of internationally controlled licit drugs for medical and scientific purposes while preventing their diversion and abuse, and promoting adequate availability of internationally controlled narcotic drugs and psychotropic substances for medical and scientific purposes while preventing their diversion and abuse;

Acknowledging the special report of the International Narcotics Control Board on the availability of internationally controlled drugs: ensuring adequate access for medical and scientific purposes,[2] and the WHO guidance on ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines;[3]

Also taking into account resolution 2005/25 of the United Nations Economic and Social Council on treatment of pain using opioid analgesics;

Bearing in mind that palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual;

Recognizing that palliative care, when indicated, is fundamental to improving the quality of life, well-being, comfort and human dignity for individuals, being an effective person-centred health service that values patients' need to receive adequate, personally and culturally sensitive information on their health status, and their central role in making decisions about the treatment received;

[1] Document 67/31.

[2] Document E/INCB/2010/1/Supp.1.

[3] Ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines. Geneva: World Health Organization; 2011.

Possible local strategies

- **Community End-of-Life Care**
  - **Empowering family members and community in caregiving**
  - **Consolidating community services with better social and health care interfaces**
    - **Staff development**
    - **Cultural changes**
    - **Flexible models**

Possible local strategies

- More choices of place of care and place of death
  - Home
  - Long term care facilities
  - Hong Kong Jockey Club Hospice Home (Society for the Promotion of Hospice Care)

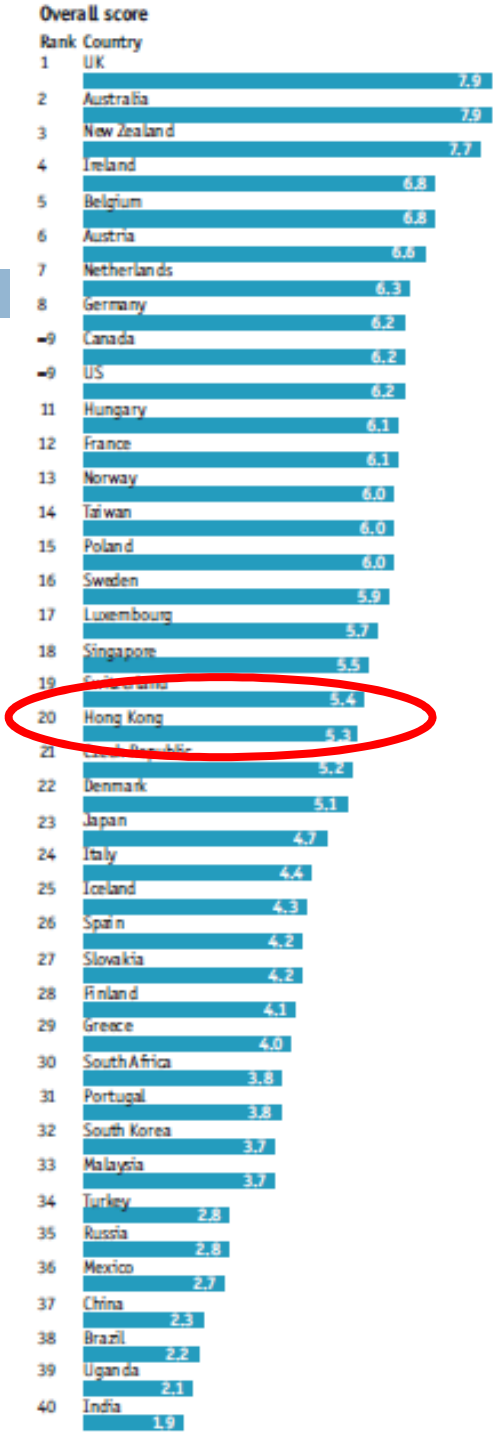
Possible local strategies

- More Support for Family Caregiving
  - Caregiving leave
  - Donation of unclaimed leave to colleagues

- More Life and death education
  - Discussion of advanced care planning
  - Reduction of fear of death

Quality of Death

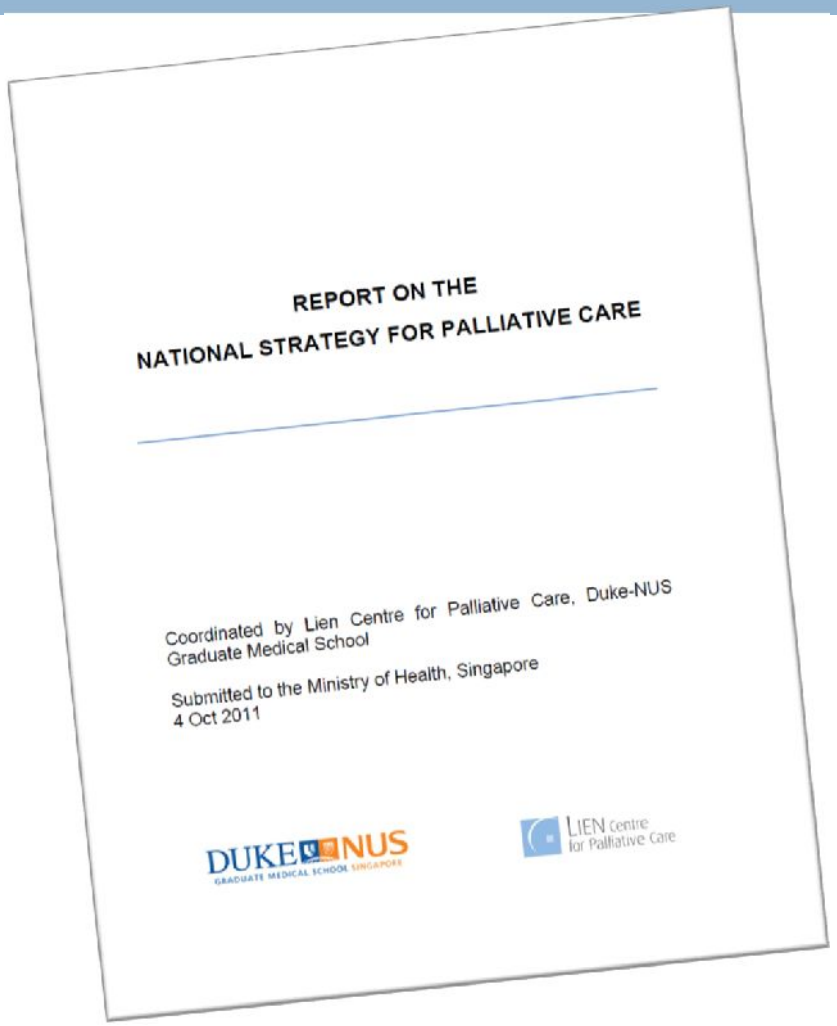
Hong Kong ranked 20th out of 40.



Only a minority of countries across the world recognise end-of-life care in their healthcare and medical education policies. In the Index, one indicator in the "Availability" category is "Existence of a government-led national palliative care strategy", registering whether the country has a formal strategy specific to such care. Of the 40 countries in the Index, 29 have no such strategy, with only seven—Australia, Mexico, New Zealand, Poland, Switzerland, Turkey and the United Kingdom—having a national policy in place, and four—Austria, Canada, Ireland and Italy—in the process of developing this kind of policy.

Economist Intelligence Unit (2010). The Quality of death: Ranking end-of-life care across the world. London, The Author. (p.27)

Singapore is moving ahead…



REPORT ON THE
NATIONAL STRATEGY FOR PALLIATIVE CARE

Coordinated by Lien Centre for Palliative Care, Duke-NUS Graduate Medical School

Submitted to the Ministry of Health, Singapore
4 Oct 2011

DUKE NUS GRADUATE MEDICAL SCHOOL SINGAPORE

LIEN centre for Palliative Care

Thank You

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