Care of Hong Kong Elders near End of Life:

Why paradigm won't shift

Derrick K. S. AU

Director, CUHK Centre for Bioethics

Workshop on Ageing: Intergenerational Justice and Elderly Care (CUHK 28-29th April, 2017)

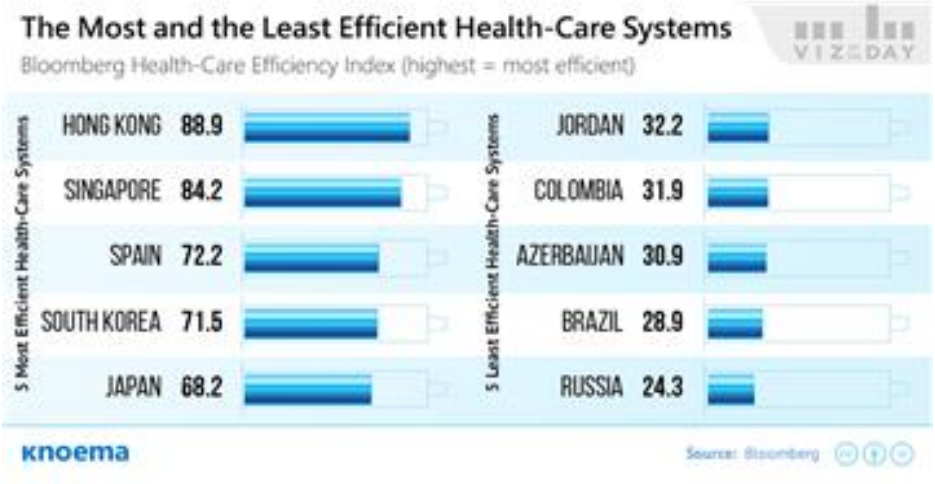
A quick overview of the Hong Kong scene in care of the elders near end of life
And a question triggered by a piece of reading

A matter of concern carried from the last job…

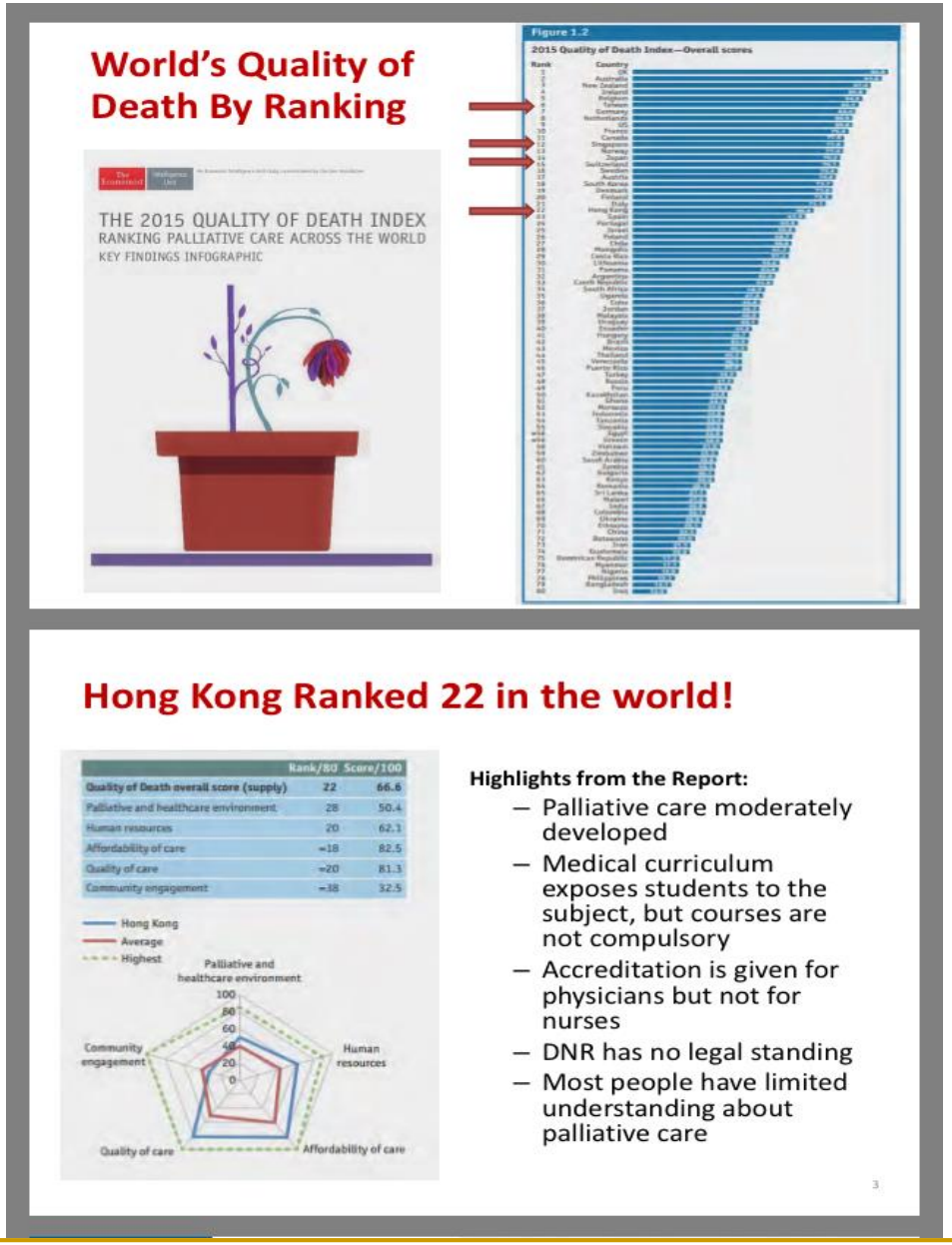
- Hospital Authority
  - Quality & Safety Division
    - Patient Safety & Risk Management
      - HA Clinical Ethics Committee
        - *Working Groups on Advance Directives (and Advance Care Planning)*

How Hong Kong is

- Health care highly efficient , accessible and equitable health care system (Bloomberg)
- Overloaded public hospitals and long waiting time, ultra-short patient contact time
- Lacks a coherent primary care system



How Hong Kong is (EOL care)



Source: Roger Chung et al. Presentation at JCECC 2017

Prof. John Leong, Chairman of Hospital Authority of Hong Kong since 1 Dec 2013

Yuen: "New thinking needed."

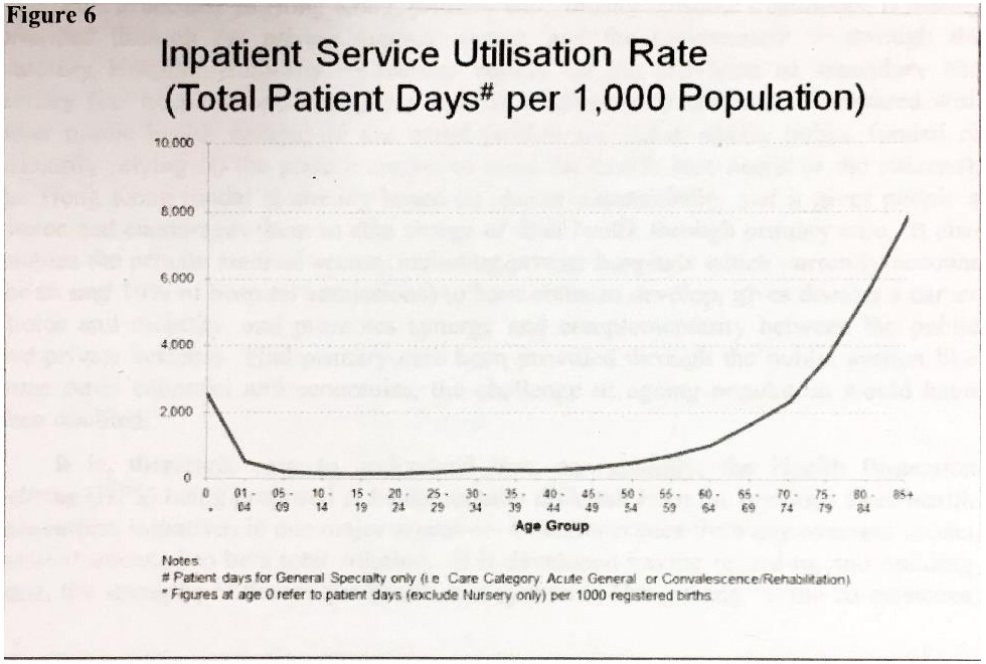
Richard Yuen
Ex-Permanent Secretary for Food and Health

PAAP 17.1:01-14 *Public Administration and Policy*

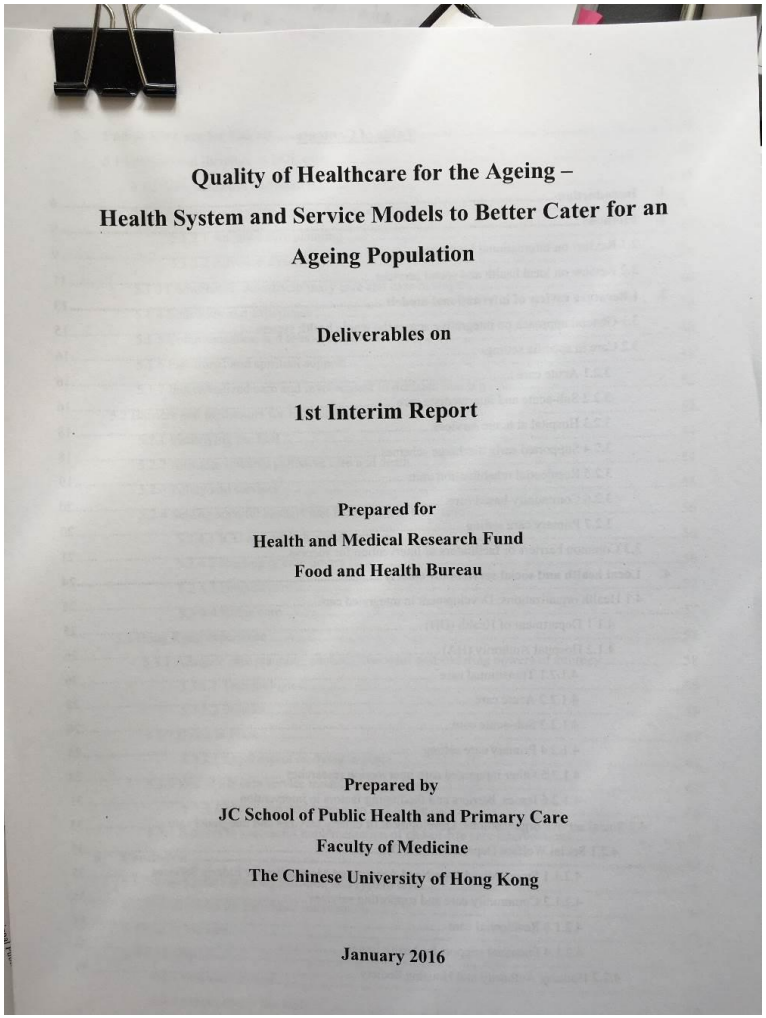
The Challenges of an Ageing Society from a Health Care Perspective

Richard M.F. Yuen
Permanent Secretary for Health, The Hong Kong SAR Government

Figure 6



Model of Care: CUHK JC School of Public Health and Primary Care: Looking into the system of care and the barriers



Quality of Healthcare for the Ageing –
Health System and Service Models to Better Cater for an Ageing Population

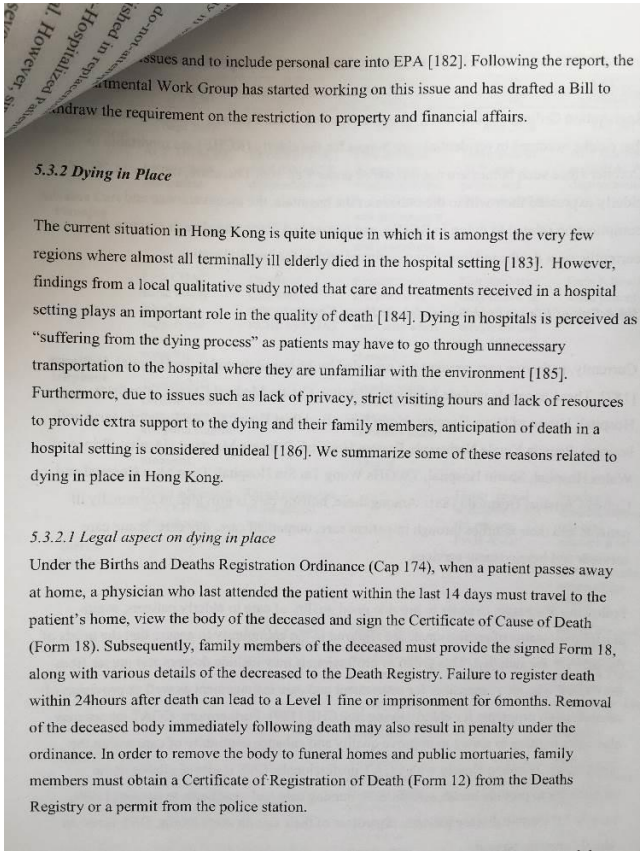
Deliverables on

1st Interim Report

Prepared for
Health and Medical Research Fund
Food and Health Bureau

Prepared by
JC School of Public Health and Primary Care
Faculty of Medicine
The Chinese University of Hong Kong

January 2016



...ssues and to include personal care into EPA [182]. Following the report, the ...timental Work Group has started working on this issue and has drafted a Bill to ...ndraw the requirement on the restriction to property and financial affairs.

5.3.2 Dying in Place

The current situation in Hong Kong is quite unique in which it is amongst the very few regions where almost all terminally ill elderly died in the hospital setting [183]. However, findings from a local qualitative study noted that care and treatments received in a hospital setting plays an important role in the quality of death [184]. Dying in hospitals is perceived as "suffering from the dying process" as patients may have to go through unnecessary transportation to the hospital where they are unfamiliar with the environment [185]. Furthermore, due to issues such as lack of privacy, strict visiting hours and lack of resources to provide extra support to the dying and their family members, anticipation of death in a hospital setting is considered unideal [186]. We summarize some of these reasons related to dying in place in Hong Kong.

5.3.2.1 Legal aspect on dying in place

Under the Births and Deaths Registration Ordinance (Cap 174), when a patient passes away at home, a physician who last attended the patient within the last 14 days must travel to the patient's home, view the body of the deceased and sign the Certificate of Cause of Death (Form 18). Subsequently, family members of the deceased must provide the signed Form 18, along with various details of the decreased to the Death Registry. Failure to register death within 24hours after death can lead to a Level 1 fine or imprisonment for 6months. Removal of the deceased body immediately following death may also result in penalty under the ordinance. In order to remove the body to funeral homes and public mortuaries, family members must obtain a Certificate of Registration of Death (Form 12) from the Deaths Registry or a permit from the police station.

From 2011 to 2016, geriatric teams trying out new models for EOL care in residential care

Asian J Gerontol Geriatr 2011; 6: 103–6

End-of-life care in Hong Kong

REVIEW ARTICLE

JKH Luk[1] MBBS(HK), FRCP(Edin, Glasg, Irel), **A Liu**[2], PhD, **WC Ng**[3], BSc(NursStud) (Hons), MN, **P Beh**[4], MBBS(HK), FHKAM(Pathology), **FHW Chan**[1], MBBCh (Wales), FRCP(Irel, Glasg)

1 Department of Medicine and Geriatrics, Fung Yiu King Hospital
2 Department of Law, The University of Hong Kong
3 Community Care Services, Hong Kong West Cluster
4 Department of Pathology, Li Ka Shing Faculty of Medicine, The University of Hong Kong

Correspondence to: Dr James KH Luk, Department of Medicine and Geriatrics, Fung Yiu King Hospital, 9 Sandy Bay Road, Pokfulam, Hong Kong. E-mail: lukkh@ha.org.hk

INTRODUCTION

The number of people in Hong Kong over the age of 65 years amounts to 850 000, or 12.4% of the total population in the 2006 census.[1] Residents of residential care homes for the elderly (RCHE) tend to have multiple comorbidities that are irreversible and chronic. Many have poor mobility, high dependency, and poor cognitive function.[2] Good end-of-life (EOL) care is important in the management of such patients, regardless of the diagnosis (advanced dementia, chronic lung or heart diseases, end-stage renal failure, Parkinson's disease).[3] Such patients may experience distressing symptoms similar to patients dying of more commonly recognised terminal conditions.[4-7]

'GOOD DEATH'

Two important elements of a 'good death' are to have choice and control over (1) where death occurs (at home or elsewhere) and (2) who is present and shares the end.[8] Inappropriate admissions to hospital are common in Hong Kong. Almost all older patients with terminal diseases or irreversible chronic illnesses die in hospitals, as they are rarely should be given.[12] It usually means passing the last phase of life journey at home or in a RCHE.

In Hong Kong, the barriers of dying in place include social taboo, lack of death education, and lack of a systematic study of the preferences and attitudes of the elderly population.[13] People may fear depreciation of property value if the elderly die at home as well as the lack of necessary medical support (to care for the dying person at home). RCHE staff are not trained to handle dying patients, and they prefer residents not dying under their care. Many RCHEs, particularly private ones, are overcrowded, and there is no spare room in which a resident may pass away peacefully.

The Hong Kong government does not have a clear policy on developing high-quality EOL care services as a critical part of health care, nor on promoting dying in place, either at home or in a RCHE. The absence of a system of family practice, where doctors have fostered a long period of professional care and knowledge of their patients and home visit patients, is another barrier.

DYING AT HOME

JAMDA

journal homepage: www.jamda.com

Clinical Experience

A New Model for End-of-Life Care in Nursing Homes

Elsie Hui MBBS, FRCP [a,b], Hon Ming Ma MBChB, MRCP [a,b,*], Wing Han Tang MBChB, MRCP [a,b], Wai Sze Lai RN [a], Ka Ming Au LMCHK [b], Mei Tak Leung LMCHK [b], Joey S.W. Ng MBChB, MRCP [b], Winnie W.L. Ng MBChB, MRCP [a], Jenny S.W. Lee MBChB, MRCP [a], Philip K.T. Li MD, FRCP [b], Jean Woo MD, FRCP, FFPH [a]

[a] Department of Medicine and Geriatrics, Shatin Hospital, Hong Kong SAR, China
[b] Department of Community Geriatrics Assessment Team, Prince of Wales Hospital, Hong Kong SAR, China

Keywords:
End-of-life
care model
nursing homes

ABSTRACT

Objectives: This study aimed to promote quality end-of-life (EOL) care for nursing home residents, through the establishment of advance care plan (ACP) and introduction of a new care pathway. This pathway bypassed the emergency room (ER) and acute medical wards by facilitating direct clinical admission to an extended-care facility.
Design: An audit on a new clinical initiative that entailed the Community Geriatrics Outreach Service, ER, acute medical wards, and an extended-care facility during winter months in Hong Kong.
Methods: The participants were older nursing home residents enrolled in an EOL program. We monitored the ratio of clinical to emergency admissions, ACP compliance rate, average length of stay (ALOS) in both acute hospital and an extended-care facility, and mortality rates.
Results: A total of 76 patients were hospitalized from January to March 2013. Of them, 30 (39%) were directly admitted to the extended-care facility, either through the liaison of Community Geriatrics Outreach Service (group A, 19/76, 25%) or transferred from the ER (group B, 11/76, 14%). The remaining 46 patients (group C, 61%) were admitted via the ER to acute medical wards following the usual pathway, followed by transfer to an extended-care facility if indicated. The ACP compliance rate was nearly 100%. In the extended-care unit, groups A and C had similar ALOS of 11.8 and 11.1 days, respectively, whereas group B had a shorter stay of 7.6 days. The ALOS of group C in acute medical wards was 3.5 days. The in-hospital mortality rates were comparable in groups A and C of 26% and 28%, respectively, whereas group B had a lower mortality rate of 18%.
Conclusions: Nearly 40% of EOL patients could be managed entirely in an extended-care setting without compromising the quality of care and survival. A greater number of patients may benefit from the EOL program by improving the collaboration between community outreach services and ER; and extending hours for direct clinical admission to an extended-care facility.

In Hong Kong, chronic diseases, such as chronic obstructive pulmonary disease, congestive heart failure, cerebrovascular accident, and dementia-related complications, account for a high level of healthcare utilization, especially during the winter months when patients are more likely to experience acute exacerbations.[1] This phenomenon, known as winter-surge, is associated with an increase in attendances and lengthy waiting times in the emergency room (ER), and severe congestion in acute medical wards. Although only 7% of older people in Hong Kong are institutionalized, the Revolving Door Syndrome, characterized by repeated hospitalizations, is very common among nursing home residents.[2] In Hong Kong, the early (≤28 days) unplanned readmission rate to acute medical units of public hospitals is 2-fold higher among institutionalized older people than those living in the community (ie, 36% vs 18%).[3] Most of these patients had multiple comorbidities and may have reached their end-of-life (EOL) with a life expectancy of less than 12 months.[4,5]

The Prince of Wales Hospital (PWH) is a 1600-bed acute general hospital, which serves a catchment population of 0.7 million in Shatin, Hong Kong, of which 12% are older people aged over 65. There are 4800 nursing home places in the district, and these institutions

The authors declare no conflicts of interest.

* Address correspondence to Hon Ming Ma, MBChB, MRCP, Department of Medicine and Geriatrics, Shatin Hospital, No 33 A Kung Kok Street, Shatin, Hong Kong SAR, China.
E-mail address: hmma@cuhk.edu.hk (H.M. Ma).

1525-8610/$ - see front matter © 2014 - American Medical Directors Association, Inc. All rights reserved.
http://dx.doi.org/10.1016/j.jamda.2013.11.019

Palliative care teams contributing to non-cancer patients with EOL care needs

- Programmes for patients with end-stage organ failures (e.g. renal, pulmonary)
- Experienced palliative care nurses working with geriatric outreach teams in training and coordinating selective referrals

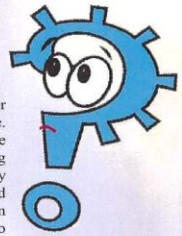
Pilot projects of EOL care in community funded through charities

- Major NGOs (e.g. The Salvation Army, Po Leung Kuk, Haven of Hope) developed programmes to allow terminally ill patients living in RCHEs to die with dignity, through staff training, appropriate care environment and processes
- The HK Jockey Club End-of-Life Community Care Project (JCECC) brings together universities, NGOs and healthcare sectors in a multi-disciplinary, cross-sector collaboration to promote EOL care in community

Hospital Authority taking steps in public education, besides developing internal guidelines

Advance Care Planning (ACP)? Advance Directives (AD)?
Do-Not-Attempt Cardiopulmonary Resuscitation (DNACPR)?
Patients and families should know more!

Foreword



As medical technology advances, many diseases become curable or can be controlled. However, there is an end to everyone's life. Some diseases will progress to a point when all treatments become futile. Yet, with modern medical technology, life-sustaining treatment (LST) (e.g. artificial ventilation, cardiopulmonary resuscitation, etc.) can still be applied to a dying patient with end stage disease. As the disease is irreversible, such treatment can only prolong the dying process which may be of little meaning to the patient, or even aggravate his/her suffering. In such a case, the patient, family and healthcare workers can discuss whether futile LST should be provided or not, so that the patient can secure a peaceful death.

The Hospital Authority agrees that it is acceptable to withhold or withdraw LST when:

- A mentally competent and properly informed patient refuses the LST; and
- The treatment is futile.

If the patient is unconscious, a decision on futility of treatment is made by discussion between clinicians and the family according to the best interests of the patient. If the patient has not previously expressed his/her values and treatment preferences, which are important in the consideration of his/her best interests, then the medical team may have difficulty reaching a consensus with the family. Therefore, it is useful if the patient has expressed prior wishes on the preferred care, or even signed an AD when he/she is mentally competent.

Indeed, it is not easy for healthcare workers to discuss death with the patient and family. When the timing is appropriate, healthcare workers can discuss with the patient and family via an ACP process, to enable them to understand the issues and options, before a decision is made. The aim of this website is to provide relevant information for better understanding of the subject by the patient, family and the public.

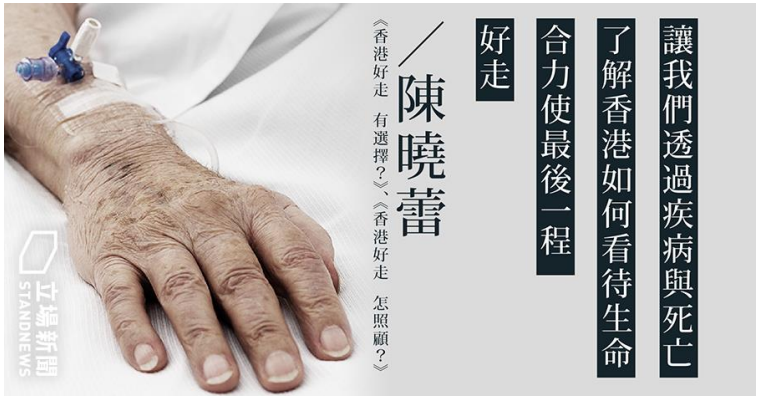
醫院管理局
HOSPITAL AUTHORITY

HA Clinical Ethics Committee 2016

Content

1. What is life-sustaining treatment (LST)?
   - What is cardiopulmonary resuscitation (CPR)?
   - Why would LST become futile?
2. What is "in the patient's best interests" ?
3. Is withholding or withdrawing futile life-sustaining treatment (LST) the same as euthanasia?
4. What is advance care planning (ACP)?
   - Parties involved in the ACP process and their roles
   - Scope of ACP discussion
   - What is the appropriate timing for ACP discussion?
   - What follow-up is needed after the ACP?
5. What is an advance directive (AD)?
   - Use of AD in Hospital Authority patients
   - Points to note for making an AD
6. Overcome barriers to advance care planning (ACP)
   - What are the advantages of ACP?
7. Besides patients with advanced illnesses, should healthy people initiate advance care planning (ACP) or make an advance directive (AD)?
8. Special circumstances
   - If the patient is under the age of 18, what can the parents do ?
   - Dementia
9. Patient stories
   - A cancer patient
   - A dementia patient

Chan: One journalist's campaign to prompt Hong Kong to face end of life care issues



Why paradigm won't (easily) shift

Discharge planning and advance care planning

Public hospitals in Hong Kong:

- Discharge planning is an established part of care for hospitalized elderly in Hong Kong.
- Programmes on integrating discharge support and care after discharge have been implemented with positive results.
- Advance care planning is standard practice in palliative care units, but not yet a regular part of care planning in general wards including geriatric settings

In various forums there is a sense that improvements are incremental (and slow)… and felt like an up-hill battle

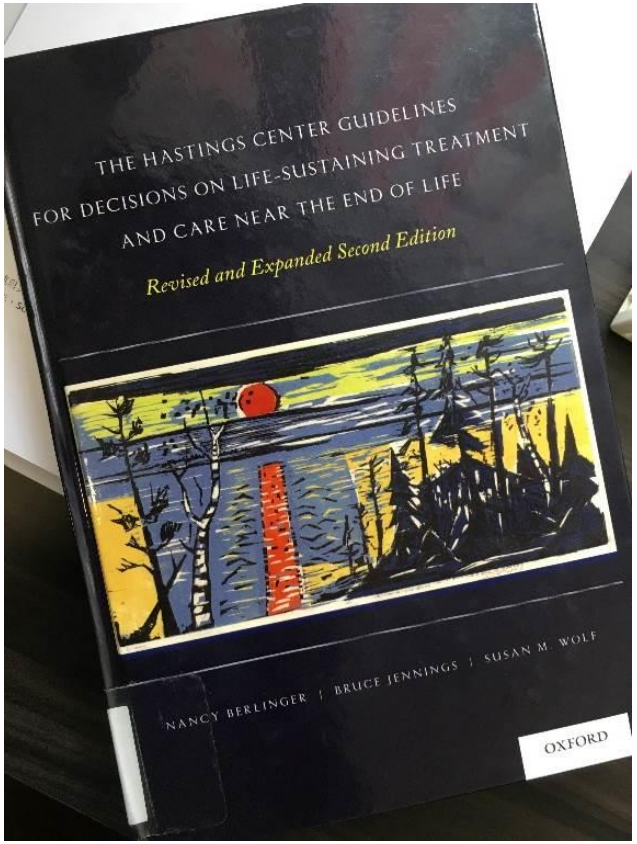
Ambivalence?

- "Inject resources to build capacity."
- "Empower the elders, let them demand ACP and AD."
- "Legislate for AD."
- "Building capacity in community takes time."
- "The hospital outpatient clinics cannot cope."
- "Think twice it is controversial."

Ambivalence?

- "The Government must lead."
- "Must change the Law."
- "Legislate for AD."
- "The Government is overloaded with agenda."
- "Start with what is in sight."
- "Think twice it is controversial."

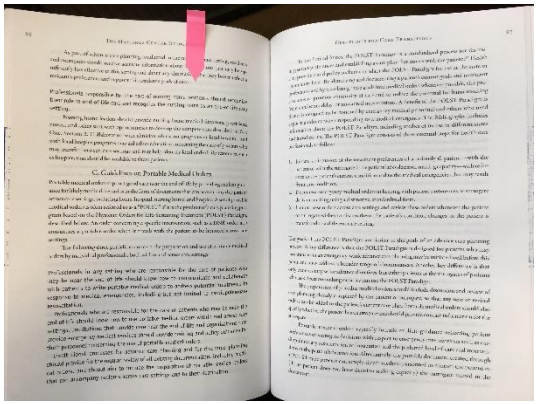
Reading the Hastings Guidelines for Decisions on Life-sustaining Treatment and Care near the End of Life



Hastings Guidelines, p. 97, on portable medical order

- POLST: Physician Orders for Life-Sustaining Treatment
- "In the United States, the POLST Paradigm is a standardized process for discussing patient preferences and establishing a care plan that travels with the patient."
- POLST is one form of Portable Medical Order. POLST-type process can take various forms.

"The context (and laws) in HK is different, but…."



Advance care planning and portable medical orders for hospitalized elders: Framed as an ethical imperative?

(Quoting Hastings Guidelines)

- "Professionals involved in discharge planning should recognize an **ethical obligation** to create sound plans - including preparation of discharge orders (on end of life care)." (p.99)
- "This is an **ethical imperative** for health care institutions and an ethics education priority." (p. 116)

It is part of a broader recommendation to integrate of palliative care into treatment and care plans in all care settings for all patients, including patients near the end of life [making it a standard of care]

Pros and cons of the ethical paradigm

- Momentum for change
- A common language
- Worry of inadequate capacity and unthinking poor routines
- Moralistic tone may backfire?

Care need, informed choice, or the elder's right?

- Care needs: may be prioritized
- Ethical imperative: possibly a duty of care, or standard of care
- The elder patient's right
  - Right to be informed (of the choice)
  - Right to indicate personal value and preference at a sufficiently early stage

Thank you for your attention