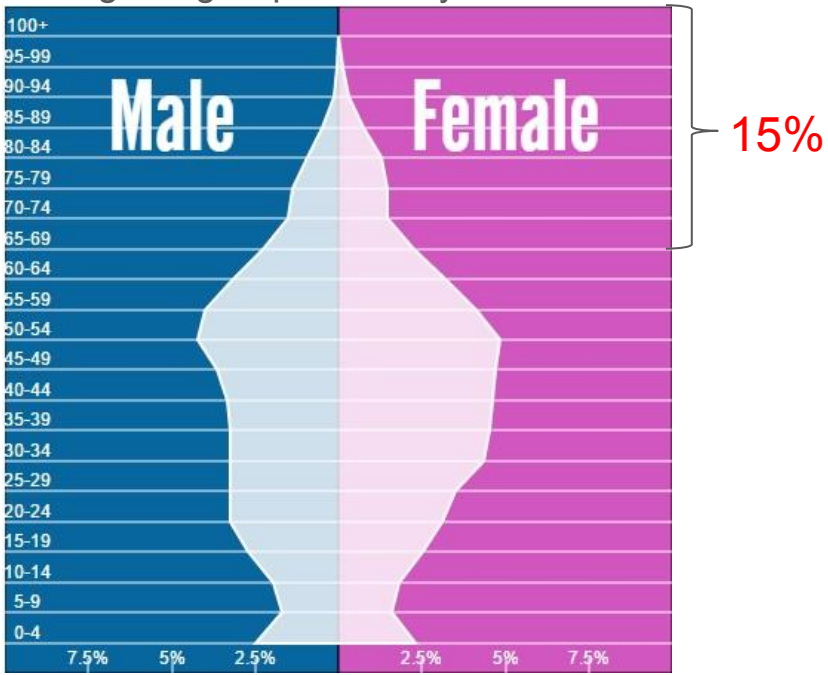
Attitudes towards End-of-Life Medical Decisions among Healthcare Practitioners in Hong Kong

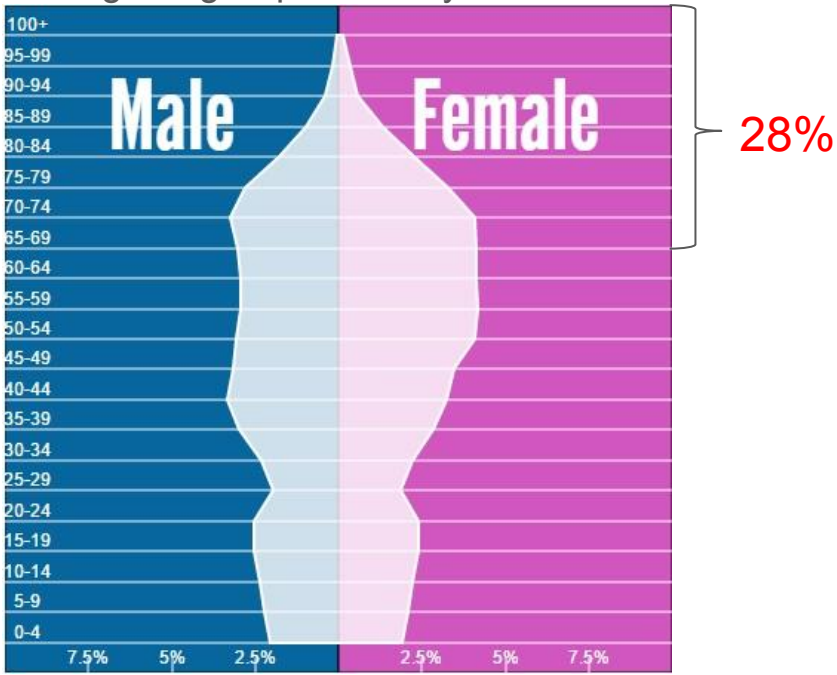
Cheuk Lap Ting
School of Public Health
Chinese University of Hong Kong
Project Coordinator (Health in Action)

Background

Hong Kong Population Pyramid 2014



Hong Kong Population Pyramid 2034



- Population growth → aging problem
  - A increase of 13% of aged 65 or above population in 20 years(2)
  - Life expectancy of the population is increasing
    - Female: 87.66; Male: 81.7 [2017]

https://populationpyramid.net/hong-kong-sar-china/2014/ ; https://populationpyramid.net/hong-kong-sar-china/2034/

Table 1.1 Number of Inpatient Discharges and Deaths by Type of Institution 2013/14 and 2014/15
表 1.1 二零一三/一四年度及二零一四/一五年度按機構類別劃分的住院病人出院人次及死亡人數

Type of institution 機構類別	2013/14						2014/15					
	Inpatient discharges 住院病人出院人次		Inpatient deaths 住院病人死亡人數		Total 合計		Inpatient discharges 住院病人出院人次		Inpatient deaths 住院病人死亡人數		Total 合計	
	Episode 人次	% 百分比	Number 人數	% 百分比	Episode 人次	% 百分比	Episode 人次	% 百分比	Number 人數	% 百分比	Episode 人次	% 百分比
Hospital Authority institutions 醫院管理局轄下機構	1,532,926	79.8	36,405	95.9	**1,569,331**	**80.1**	1,592,148	80.0	36,538	95.9	**1,628,686**	**80.3**
Correctional institutions* 懲教署機構*	18,671	1.0	0	0.0	**18,671**	**1.0**	16,683	0.8	0	0.0	**16,683**	**0.8**
Private institutions*† 私人機構*†	369,031	19.2	1,574	4.1	**370,605**	**18.9**	380,169	19.1	1,562	4.1	**381,731**	**18.8**
All institutions* 所有機構*	**1,920,628**	**100.0**	**37,979**	**100.0**	**1,958,607**	**100.0**	**1,989,000**	**100.0**	**38,100**	**100.0**	**2,027,100**	**100.0**

Notes: Figures include day inpatients and are on an episode basis.
Figures may not add up to total due to rounding.
* Provisional figures for year 2014/15.
† Refers to the institutions licensed under the Hospitals, Nursing Homes and Maternity Homes Registration Ordinance (Cap. 165).

Sources: Department of Health.
Hospital Authority.

註釋: 數字包括日間住院病人及以人次計算。
由於進位關係，個別項目的數字相加可能不等於其總數。
* 二零一四/一五年度的是臨時數字。
† 指根據《醫院、護養院及留產院註冊條例》(第165章)註冊的機構。

資料來源: 衞生署。
醫院管理局。

Public Hospital:
- Handling inpatient deaths 95.9%

Private Setting:
- Only accounts for 4.1%

Gaining pressure from the society
- Quality of Death
- Quality of Life during the end-stage
- Rights of the stakeholders

http://www.ha.org.hk/haho/ho/stat/HASR1415_2.pdf

Why Healthcare Practitioners?

- The character of healthcare practitioner is crucial in determining the end-of-life medical decision making among patients and caregivers. (1)
- Information Asymmetry
  - Practitioners have more information than patients or caregivers
  - Responsibility?

CROSS SECTIONAL SURVEY ON ADVANCE CARE PLANNING ACCEPTANCE AND END OF LIFE CARE PREFERENCES AMONG COMMUNITY DWELLING ELDERLY WITH COMPLEX MEDICAL PROBLEMS AND THEIR CARERS

Summary of patient and carers reply (in percentage)

	Strongly Disagree	Disagree	Agree	Strongly Agree	Uncertain
Decision making process					
I want my doctor(s) to make all decisions					
Patient's response	2.3	13.3	53.9	29.7	0.8
Carer view	8.0	17.0	60.0	15.0	
I want my family to make all decisions for me					
Patient's response	10.9	35.9	46.1	6.3	0.8
Carer view	6.0	53.0	38.0	3.0	
I want to make decision by myself					
Patient's response	4.7	22.7	53.9	18.0	0.8
Carer view	2.0	29.0	58.0	11.0	
I want to make conjoint decision with my family					
Patient's response	4.7	26.6	53.1	15.6	
Carer view	3.0	16.0	57.0	24.0	

Overall, do you wish your medical doctor to discuss with you on these treatment options when you are approaching an advanced stage of disease but not acutely ill?

	patient	carer
Discuss with me (patient)only	21.1	9.1
Discuss with me and my relative together	57.0	70.7
Not to discuss at all, doctor make decision	12.5	8.1
Discuss with relative only	9.4	12.1

Why Healthcare Practitioners?

Impact of Death Work on Self: Existential and Emotional Challenges and Coping of Palliative Care Professionals

Wallace Chi Ho Chan, Agnes Fong, Karen Lok Yi Wong, Doris Man Wah Tse, Kam Shing Lau, and Lai Ngor Chan

External professional resources (for example, professional training, peer support, and supervision) are needed to support palliative care professionals (for example, social workers), especially those who are relatively inexperienced in the field of palliative and end-of-life care. We also propose that professional training focusing on the development of self-competence is an important means to effectively prepare helping professionals to cope with the existential and emotional challenges in death work.

End-of-life care research in Hong Kong: A systematic review of peer-reviewed publications

Table 2. *Participants in the included studies*

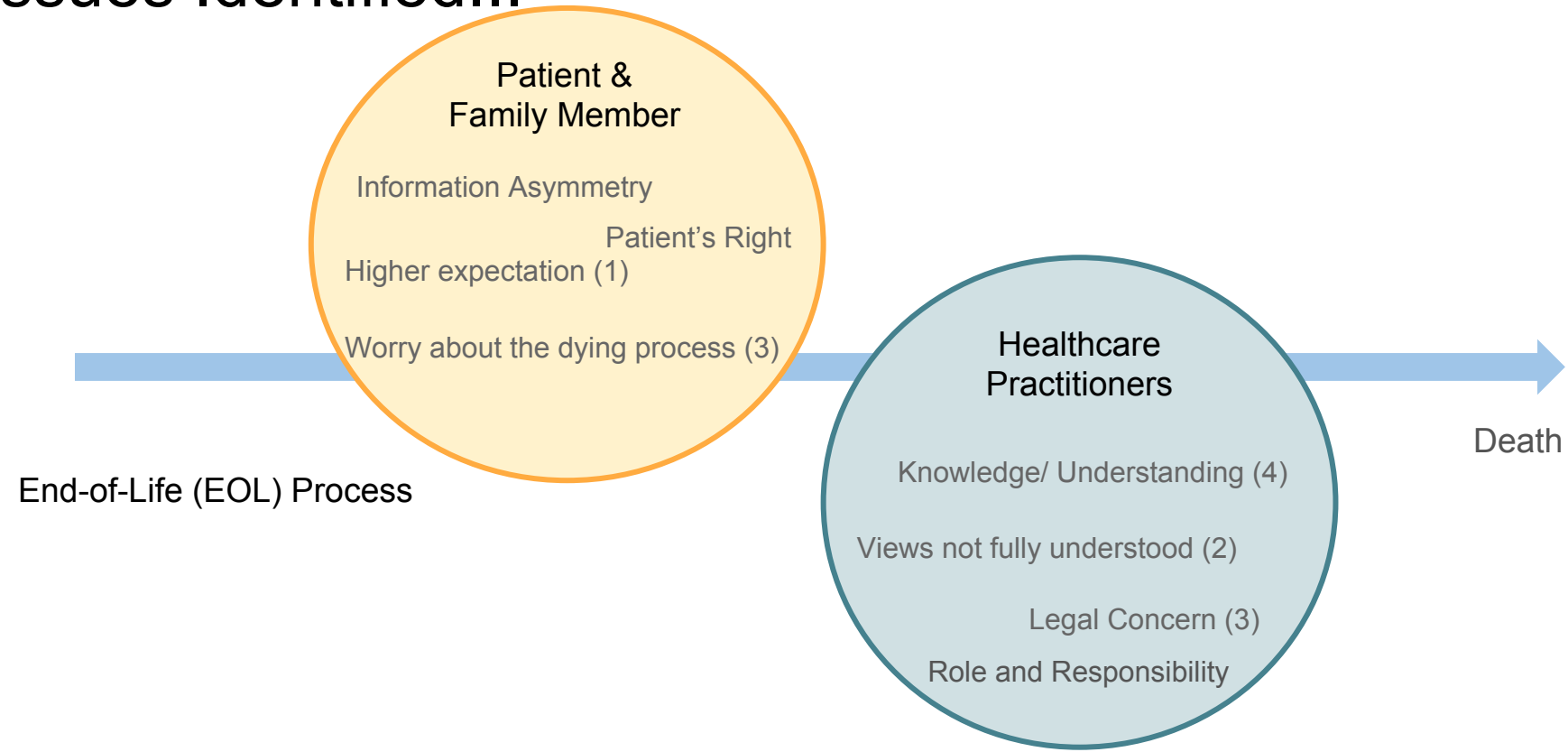
Participants	Number of Studies
Cancer patients	42*
Noncancer patients with chronic illnesses	5*
Patients with end-stage renal disease	7
Patients with dementia	2
Patients with chronic obstructive pulmonary disease	1
Patients with acute myeloid leukemia	1
Nursing home or long-term care residents	14
Deceased individuals	7
Community older adults	5
Care professionals	17
Family caregivers	9

- In a systematic review (2) that carried out in Hong Kong, only 17 out 107 papers are related to care professionals, in which not only specified on healthcare practitioners, but also other stakeholders such as social workers.
- However, from the practitioners' perspectives
  - Studies that published are not comprehensive enough to cover different types of practitioners
    - Mainly targeted on nurses

Why Healthcare Practitioners?

- There is no current law, regulation or even general guidelines for practitioners. (3)
- Besides, a study also showed that Medical Students are (4)
  - Worried that they were unprepared
  - Lack of understanding and knowledge towards End-of-Life

Issues Identified...



Research Objective & Significance

Aim: To understand the Healthcare Practitioners' attitudes towards the End-of-Life medical decision in Hong Kong

Objective

1. To investigate the healthcare practitioners' perspectives on the end-of-life medical decision
2. To explore their current approaches when handling cases that with progressive or terminal diseases, and to learn about the influential factors that determine their approaches
3. To explore the possibilities for legalizing (AD/ACP) or setting up clearer guidelines on end-of-life medical decision making

Significance

With increasing importance of Quality of Dying among the world and Hong Kong,

➔ Implication:

1. To better acknowledge their characters when facing cases that are in progressive conditions
2. To create a supportive environment
3. To improve patient's quality of dying with better consensus making as well as sufficient information provisioning.

Methodology

Method - Qualitative Study

- In-depth Individual interview - Semi-structured
  - Language: Cantonese
  - Duration of Interview: 40 - 60 mins (Phone Interview)
  - Recorded with verbal consent obtained
- Recruitment (Purposive sampling): Through gatekeepers, e.g. medical students' mentors or attachment teachers, or through snowball approach to increase sample size
- Data Collection: May 2017 - Oct 2017
- Ethics Approval: Survey and Behavioural Research Ethics

Study Subjects and Recruitment

Interviewee	Current Healthcare Practitioners	Hong Kong Permanent residents	Experience/ Related Department	Recruitment Channels
D1	✓	✓	A&E (4.5 Years)	Through Friends
D2	✓	✓	Oncology (2 Years)	Through Friends
D3	✓	✓	Geratology (25 Years)	Supervisors
D4	✓	✓	Gastroenterology (16 Years)	Academic Organisation
D5	✓	✓	Nephrology (**Private**) (40 Years)	Medical Student's Mentor
D6	✓	✓	Geratology (29 Years)	Supervisors
N7	✓	✓	Geratology (16 Years)	Snowball
N8	✓	✓	Brain/ ICU (2 years/ 1 month)	Through Friends

D: Doctor
N: Nurse

Original Quota: 10
*Stopped as the data saturated

Analysis

Analysis

Recordings and Data: 1) Transcribed and coded with revision by independent researcher as well as supervisors, 2) Member checking is needed (within interviewers) and if conflicts occurs, will handle through discussions

Data Analysis:

Opening Coding → Axial Coding → Selective Coding

Grounded theory analysis with reference to the four domains.

- Patient Journey, Support and Training, Public Education, Legal Issue
- Recommendation

Abbreviation

Advance Directive: AD

Advance Care Plan: ACP

End-of-life Medical Decision: EOL MD

Hospital Authority: HA

Result

Coding (1)

EOL Discussion & Execution	1. Identification EOL patient for EOL MD Discussion 2. Experience in EOL MD Discussion 3. Department Coordination 4. Good Planning of EOL MD 5. Change in Practice
Support and Training	1. Insufficient Training 2. Lack of Supportive Environment
Public Education	1. Life and Death Education 2. Informed Consent
Legal Issue	1. Legalisation of the Advance Directive and Advance Care Plan 2. Ordinance Amendment
Recommendation	1. Suggestions to Hospitals or HA 2. Recommendation on Increasing the usage of EOL MD among Healthcare Practitioners

EOL Discussion & Execution

1. Identification EOL patient for EOL MD Discussion
   - 1.1. **Competent to identify EOL patient** with the hospital-based guidelines and matched with the Hospital Authority general standard
   - 1.2. Input experience

   "...the patient's body has appeared some signs of deteriorating, or your patient is already at stage 4, or there is not much medication could be used, is already the timing for discussing it." (D2)

2. Experience of EOL MD Discussion
   - 2.1. **Standard Steps**, i.e. Situation telling, establishing goals, etc.
   - 2.2. Most Discussion **led by Doctors**, but only some would followed up by the nurses
     → However **lack in division of labour** and **cooperation were showed**
   - 2.3. **Private Sector and Community setting had little participation** in the EOL MD
   - 2.4. Willing for Conservation, but with **changing view** regarding die with dignity
   - 2.5. Deterring factors among the physicians, i.e. **"saving life" thinking**

   "...for the doctor's training, is to save life and to solve some problems. We think that [illness/disease] is problem." (D3)

Medical judgment on futile treatment

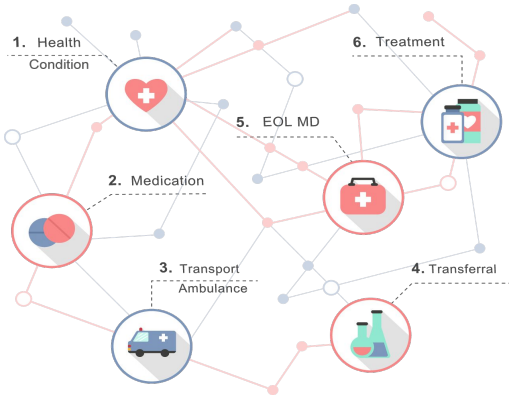
Rapport and relationship building

EOL Discussion & Execution

3. Department Coordination
   - 3.1. Patient journeys **varied in different departments**, e.g. referral system, facility, patient support
   - 3.2. **Poor coordination between different hospitals**

> *"...sometimes the family members would even do not want to inject the antibiotics, because it would need to set the hepblock, and it would be painful. **But sometimes when [patient] is in the acute medicine**, then the doctor would not care and still do the injection. Then **maybe it would stop [treatment] when transfers to us**." (N7)*

→ Lack of **consistency** among the practices leads to confusion in practice



Support and Training

1. Trainings
    - 1.1. **Varied Understandings** towards EOL MD, e.g. A&E doctor did not know about ACP
    - 1.2. **Insufficient Training** on EOL MD and communication skill
    - 1.3. **Private sectors had a poor access** to the related information

      → Further decrease in incentive to practice EOL MD

*"Therefore, in every level you would need to have a good example. When we are recruiting the medical students, **what criteria we use to recruit them**? Those who got the **highest mark in the DSE.** Those who got the **highest mark in IB**. Those who get **most A in the A-level.** ...we do not test if they are capable in this area [communication]. Then it is hoped that when they are studying, somehow you talk about, such as we could do some communication tutorial to continuous to practice. Or it would be okay. **When after you graduate, if it is like to put out the fire** [busy schedule], **then you would not have the time to communication with the people** [patient and family members]." (D6)*

Support and Training

2. Lack of Supportive Environment
   - 2.1. **Public Sector**
     - 2.1.1. **Heavily burdened** health care systems: lack of time, large number of patients
     - 2.1.2. Lack of manpower

   → Public Hospitals' Capacity on handling EOL Medical Decision

   "Very often, even the time for communicate or discuss with patients would not have [do not have time], then it would become…. numb and it is like machinery working. For care that aspect, it is really not sufficient." (N8)

   - 2.2. **Private and Community Sector**
     - 2.2.1. Coverage of community support was limited, e.g. Home Care
     - 2.2.2. **Poor bridging systems** between private sectors, community setting as well as the public systems

   "....they [ambulance men] would say no and 'only could go to the nearest public hospital." (D5)

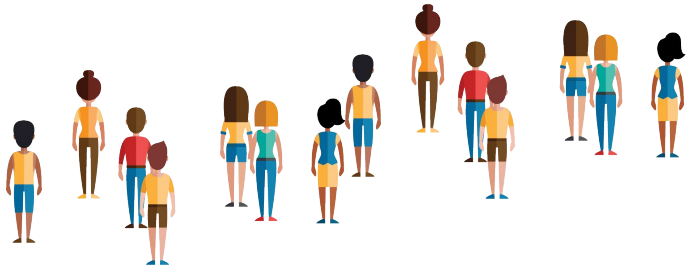
Public Education

1. Lack of Life and Death Education
   - 1.1. The society was more open to the topic, but still did **not have the mindset of EOL MD**
     - 1.1.1. **Lack in awareness and knowledge**
     - 1.1.2. **Lack in official and active promotion**
       → Myths and Misconceptions
   - 1.2. People's perceptions of healthcare technology might lead to conflicts in the EOL Care

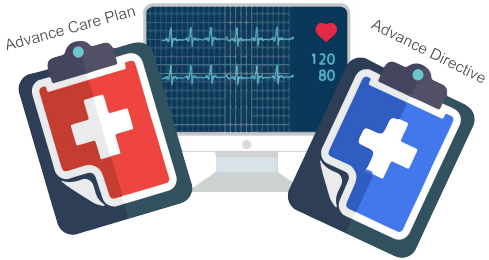
*"...the family would **think whatever diseases is curable**, as the current technology is so advanced. So everything is curable, **if he [patient] is not cured, it's your doctor not good enough**." (D6)*

2. Insufficient Informed Consent
   - 2.1. **Doubtful** on whether **enough informed consent** is given
     → Due to the time restraint, doctor's perceptions…

*"We sometimes would **take that [certain agreement on treatment] for granted**, these usually would be performed, unless you specifically mention that you would not do that." (D4)*



Legal Issue



1. Legalisation of the Advance Directive and Advance Care Plan
   - 1.1. **Inevitable process** as a protection for all parties

     "That legalisation would be ...the best case." (D1)
   - 1.2. Concerns about the **compatibility** in current Private and Public system, and the **overruling** would still exist
     → Multidisciplinary approach would be needed, i.e. Education

2. Ordinance Amendment
   - 2.1. **Fire Ordinance is not compatible with the usage of some EOL MD**, e.g. AD, ACP, Home Care
   - 2.2. Death Certificate, e.g. Home Certifying Death as a supporting measures for the private sector

→ Need to **clarify the liability and responsibility**

"...if the patient starts getting worse, actually they could call us… could directly admit to the hospital. But if they need to hospitalise, and they are laying on bed, then they would call ambulance as well. ***Those ambulance men could completely ignore that paper [form]... our Advance Directive and they do not care.*** *As long as they think the patient is not breathing or [could not feel] the pulse, then they would not get the patient back to our ... Hospital. Even though we offer a bed, but they would end up in the A&E." (N7)*

Recommendation

1. Suggestions to Hospitals/ HA
    1.1. Trainings of EOL MD for healthcare practitioners as a **general education**, e.g. interactive approach, and to learn from experiences
    1.2. **Promotion** should be **continuous and regular**
    1.3. Trained specialists in each related department as **facilitator**
    1.4. **Palliative Care as an individual team** to handle the increasing chronic morbidity rate and aging population

    "...they could still publish some guidelines, but I think [there should be] a very practical synopsis, or what we called a FAQ [Frequently Asked Questions], or a 'lazy guy package' [Abstract information], at the end it needs to be handed to the healthcare professionals to [easily] receive [absorb]." (D4)

Recommendation

2. Recommendation on Increasing the usage of EOL MD among healthcare practitioners
   - 2.1. **Clarification of the responsibility**
   - 2.2. **Practical supporting measurements** should be provided, e.g. coaching system for skills training, provide supportive environment

     *" ... teach them with case by case and to offer a lot support, or accompany them to see the family members, or they can observe when we [senior doctor] are seeing patients. So **actually we drafted these schemes, the person to execute in the day to day daily care is the junior doctor**." (D3)*

   - 2.3. **Motivation** for Healthcare Practitioners, e.g. non-monetary incentives, acknowledgment on importance of EOL MD from top management

     *"You need to appeal to their ethics ground. **Why we become physicians, but not bankers or lawyers? [It] is because we believe in such a ethics ground, and to make a difference.**" (D3)*

Recommendation

3. Recommendation on increasing the usage of EOL MD among Patients, Family members and General Public
    a. Promotion on EOL MD
    b. **Education and knowledge transfer** during regular hospital appointments
    c. Clear Informed Decisions and Choices
    d. Community involvement

Discussion

Discussion

1. Local & Oversea experience
   - 1.1. Common issues in HK and other countries – public education, quality of communication, role & responsibility of healthcare practitioners
   - 1.2. **Health system** support “die with dignity” – inter-department coordination, facility & resources and hospitals partnership
   - 1.3. **Legal issue** to facilitate “die with dignity” – fire department , legal status of AD/ ACP

Discussion

2. Good references for the development of EOL in HK
   - 2.1. Taiwan (5)
   - 2.2. USA, e.g. *Guideline on Palliative and End-of-Life Care for Patients With Cardiopulmonary Diseases* (6)
   - 2.3. UK, e.g. The state of hospice services in England 2014 to 2017 (7)

Discussion

3. Recommendations

3.1. Societal Level

3.1.1. Policy & Strategy

3.1.2. Public Education

3.1.3. Legal Aspect

3.2. Corporate Level

3.2.1. Practical Trainings : Coaching system

3.2.2. Expand the capacity through partnership with the private sector and community groups

3.2.3. Recognition of the importance of EOL medical decision

Limitation

1. Time limitation
2. Refusal by some healthcare practitioners
    2.1. Family medicine doctors, dietitians

Future Direction

1. Explore the **views of other healthcare practitioners**, dietitian, speech therapies, OT, PT,
2. Explore the availability, willingness and capacity of EOL care in **community setting**, e.g. subsidized / private elderly home, NGO
3. Explore the views from **general practitioners** (death certification) and **private hospital** (expertise and facility) on EOL care

Acknowledgment

Special Thanks to my co-investigators
Prof. Eliza Wong & Maggie Li

Reference

1. Tsang M, Yeung K, Wong K, Lam P. Cross Sectional Survey on Advance Care Planning Acceptance and End of Life Care Preferences Among Community Dwelling Elderly with Complex Medical Problems and Their Carers. BMJ Supportive & Palliative Care. 2013;3(2):258-259.
2. Wang Chan C. End-of-life care research in Hong Kong: A systematic review of peer-reviewed publications. Palliative and Supportive Care. 2015;13(6):1711-1720.
3. Chan W, Tin A, Wong K, Tse D, Lau K, Chan L. Impact of Death Work on Self: Existential and Emotional Challenges and Coping of Palliative Care Professionals. Health & Social Work. 2015;41(1):33-41.
4. Siu, M., Cheung, T., Chiu, M., Kwok, T., Choi, W., Lo, T., Ting, W., Yu, P., Cheung, C., Wong, J. and Chua, S. (2010). The preparedness of Hong Kong medical students towards advance directives and end-of-life issues. *East Asian Arch Psychiatry*, 20(4), pp.155-162.
5. Chou, W. C., Lai, Y. T., & Hung, Y. S. (2013). Comparing end-of-life care in hospitalized patients with chronic obstructive pulmonary disease with and without palliative care in Taiwan. *Journal of research in medical sciences: the official journal of Isfahan University of Medical Sciences*, *18*(7), 594.
6. Selecky P, Eliasson C, Hall R, Schneider R, Varkey B, McCaffree D. Palliative and End-of-Life Care for Patients With Cardiopulmonary Diseases. Chest. 2005;128(5):3599-3610.
7. *The state of hospice services in England 2014 to 2017*. (2017). Retrieved 27 October 2017, from https://www.cqc.org.uk/sites/default/files/20171013_state_of_hospice_services.pdf

Thank you