

# Medical ethical principles may drive improvement of Quality of Dying in Hong Kong – stakeholders' perspectives

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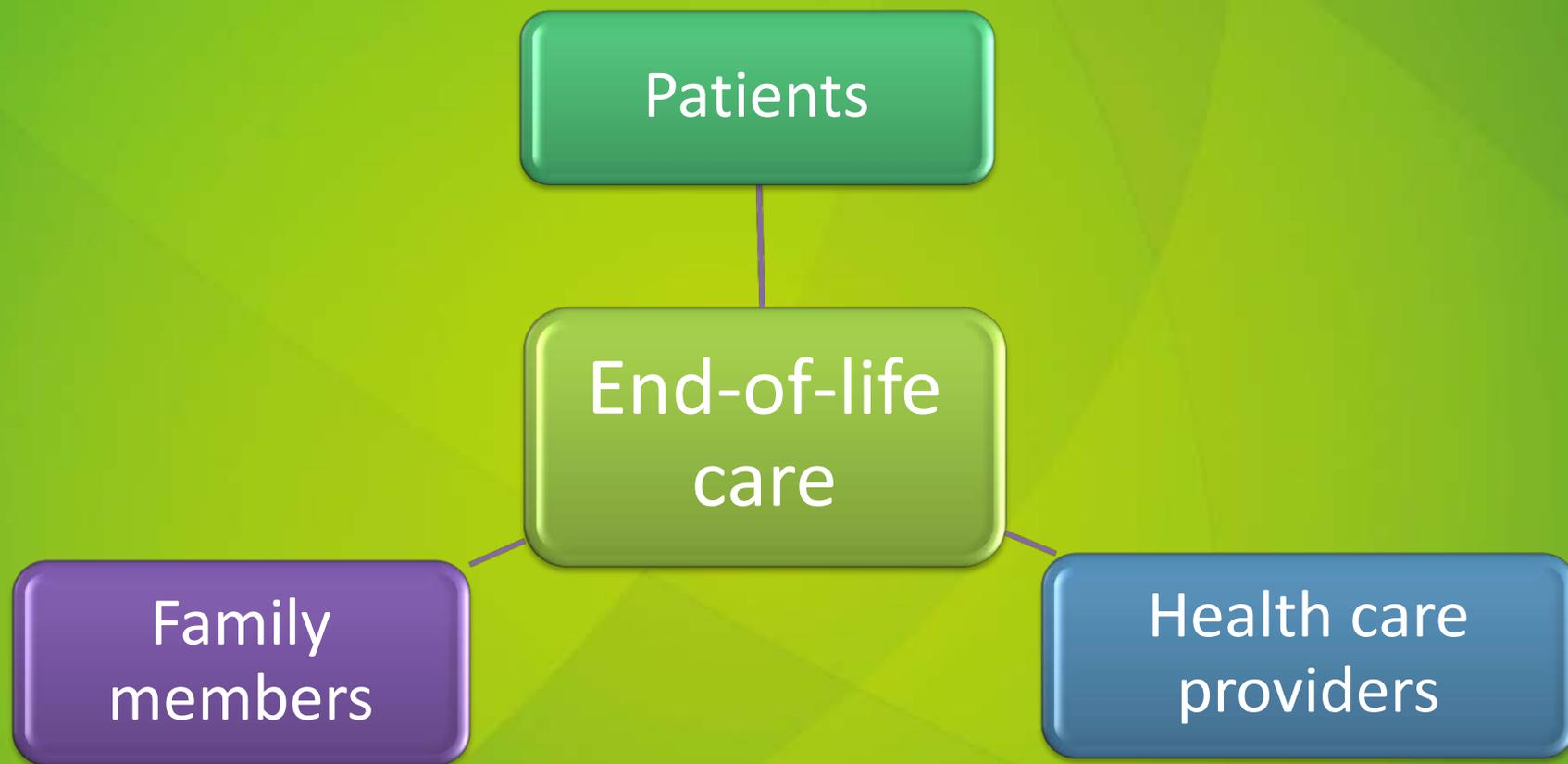
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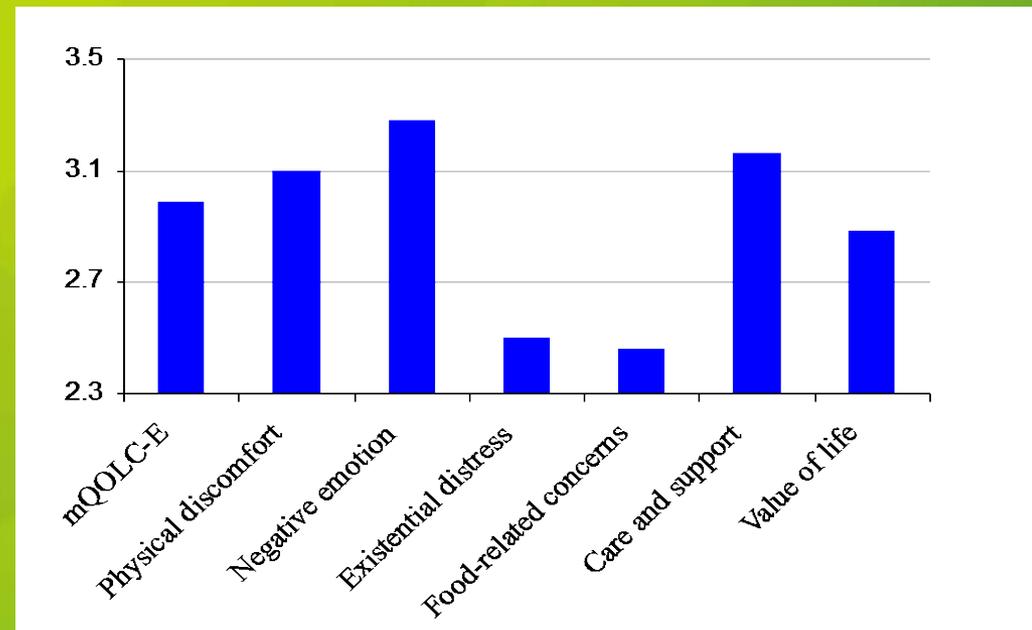
# Can we talk about death and dying issues?

- Local studies showed that Chinese patients & older people
  - Want to know more about their health conditions
  - Afraid of lingering death & suffering
  - Have some forethoughts about their future
  - Want to express their views towards future care

(Chu, Luk, Hui, Chiu, Chan, Kwan, Kwok, Lee & Woo, 2011; Mok, Ting & Lau, 2010)

# Which are the major concerns at the end of life?

- Older people with multiple morbidities living in old age homes
  - Frailty: Slow progressive functional deterioration
  - Quality of life concerns:  
Existential distress



Chan HYL, Pang, SMC. Quality of life concerns and end-of-life care preferences. *Journal of Clinical Nursing*. 2007.

# Engaging frail older people in old age home in advance care planning

- Quasi-experimental study
- N = 121
- Mean age: 83.5 years (SD 8.0)
- Female: 69.4%
- No formal education: 83.5%
- Partially ADL dependent

# “Let Me Talk” advance care planning programme



Chan HYL, Pang SMC. Let Me Talk – an advance care planning programme for frail nursing home residents. J Clini Nurs. 2010;19:3073-3084.

# “Let Me Talk” advance care planning programme

*Understanding*

*Consensus*



*Sharing*

*Reflection*

Chan HYL, Pang SMC. Let Me Talk – an advance care planning programme for frail nursing home residents. J Clini Nurs. 2010;19:3073-3084.

# End-of-life care goal

Quasi-experimental study – To test the feasibility of engaging frail residents in advance care planning

	Intervention group (n=42)	Control group (n=36)	<i>p</i> value
	<i>n</i> (%)	<i>n</i> (%)	
<b>6 months after the programme</b>			0.016
Remain uncertain	3 (7.1)	8 (22.2)	
Indicated end-of-life care wishes	39 (92.8)	28 (77.8)	

Chan HYL, Pang SMC. Let Me Talk – an advance care planning programme for frail nursing home residents. J Clin Nurs. 2010;19:3073-3084.

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<b>6 months after the programme</b>			0.016
Remain uncertain	3 (7.1)	8 (22.2)	
Indicated and communicated	15 (35.7)	4 (11.1)	
Indicated but not communicated	24 (57.1)	24 (66.7)	

Chan HYL, Pang SMC. Let Me Talk – an advance care planning programme for frail nursing home residents. *J Clin Nurs*. 2010;19:3073-3084.

# Readiness of frail older people for discussing end-of-life care issues



Chan HYL, Pang SMC. Readiness of Chinese frail old age home residents to end-of-life care decision making. J Clin Nurs. 2011;20:1454-1461

# Readiness of frail older people for discussing end-of-life care issues

- Many of them were willing to openly discuss end-of-life issues
    - ? Less likely to share their views with their family members and health care providers
  - Autonomy (right to self-determination) is not their major concerns
    - Trust in family members health care providers
  - Not aware of treatment futility
- Pang, M. C. & Chan, H. Y. L. (2008). Ethical challenges of engaging Chinese in end-of-life talk. In R. Luppicini & R. Adell (eds.). Handbook of Research on Technoethics (pp.316-327). Hershey, PA: Information Science Reference.

# A community-based advance care planning programme to improve end-of-life care in patients with advanced disease

Funded by the Health and Medical Research Fund (2014 – 2016)

- Design: Randomised controlled trial
- Inclusion criteria
  - Gold Standard Framework (GSF)
  - Communicable
  - Living at home
- Intervention:
  - Let Me Talk ACP programme
  - Home visits with family members present

# Engaging community-dwelling patients with advanced disease in advance care planning

## Preliminary results – Experimental group (n=118)

- Mean age: 77.7 years
- Major diagnoses: COPD, CHF (6-month mortality rate: 20.3%)
- Nearly all have never heard of advance directives / ACP
  - 82.2% prefer comfort care as goal of end-of-life care
  - 11.0% cannot decide for specific life-sustaining treatment (esp. tube feeding)
    - 30.9% wished to sign advance directives
    - 21.6% signed advance directives
    - Others did not sign mainly because they could not get family consensus

# Family view

- Upset with the study
  - Found the topic sensitive or emotional
  - Deprive the hope of “recovery” – too early to broach the issues
- Refused to participate in / Withdraw from the study
- Perceived roles & responsibilities
  - Filial piety
  - Treatment decision – Collective family decision (overriding patients’ care wishes)
  - Shared decision making process

# Family view

## Qualitative interviews with bereaved family of oncology patients

- ***Being informed***
  - *Information about the patient's condition*
  - *Information about the treatment plan*
  - *Information about funeral arrangements*

Chan HYL, Lee LH, Chan CWH. The perceptions and experiences of nurses and bereaved families towards bereavement care in an oncology unit. *Supportive Care Cancer*, 2013;21:1551-1556.

# 明愛棄救病翁 家屬否認同意

(Mingpao,  
11/7/2012)

【明報專訊】92歲老翁去年在家中昏迷，送往明愛醫院一日後不治。家屬趕到醫院時赫然發現老翁的牌板被寫上「放棄搶救」字眼，老翁的死因研訊昨展開。事件出現羅生門，院方指當日做得家屬同意方放棄搶救，但家屬堅決否認，更質疑院方醫生超越職權，「係咪我爸爸90幾歲就無生存嘅權利？」



死者黃耀新的主診醫生李楚山（右）聲稱與死者兒子黃卓萬討論後，理解對方明白及接受放棄搶救。（郭慶輝攝）



事主女兒黃玉華（圖）昨仍十分激動，更一度指批父親主診醫生當日的決定未有考慮他們一家感受。（林綺琪攝）

## 死者女兒稱多次要求搶救

有8名子女的事主黃耀新（92歲），去年4月14日在家中洗手間昏倒送明愛醫院，翌日去世。事主女兒黃玉華憶述，4月15日當日傍晚6時許前往醫院探望父親，她當日是首名到院的家屬。當時院方指父親已無呼吸脈搏，惟他發現父親的牌板上竟寫上「家人同意放棄搶救」字眼，令她愕然。她多次要求院方搶救父親，可惜至當晚7時許，老父終返魂乏術。

黃玉華稱對院方放棄搶救的決定，

「我哋人兄弟姊妹無一人知」。惟代表醫管局一方的律師昨稱，事主的兒子黃卓萬於15日曾追問主診醫生李楚山「老實會唔會無得救」；當時李解釋，事主年紀大、血受感染，情況轉差，不適宜做大創傷性手術如插喉、心外壓等，黃卓萬當時亦有點頭表示明白，但黃卓萬昨否認曾與李有此對話。

## 醫生指家屬點頭表示明白

李楚山醫生昨解釋，92歲的事主病歷多，由於獲救的機會甚低，故並不

主張創傷性急救；平衡過後，認為搶救的壞處多於好處。他與黃卓萬討論後，理解對方明白及接受放棄搶救，亦感覺對方會向其他家人解釋，詎料其後家屬「反口」指雙方未有討論。

明愛醫院病理科高級醫生盧恩輝指出，事主在其左脅腹腔內長有「左脅內動脈瘤」，動脈瘤破裂令腹腔出血700毫升，是事主的主要死因。他解釋，此類個案非常罕見，但該動脈瘤一旦破裂即十分危險。研訊今續。

【案件編號：CCDI306/11】

## 主診醫生：院方決定 毋須家屬簽紙

黃耀新的主診醫生李楚山昨稱，情理上醫生應向家屬解釋病人情況，令對方接受放棄搶救，但院方決定不搶救病人其實毋須家屬簽名同意。社區組織協會幹事彭鴻昌批評，此種做法在醫學上沒有錯，「但於病人而言，醫生應多關顧病人家屬」。

明愛醫院護士長林友蓮昨指搶救垂死病人未必是上策，「心外壓會將肋骨

壓斷，斷骨或會插到肺部」。內科醫生吳志豪亦表示，幾乎所有放棄搶救的個案，醫生都會先徵得家屬同意，但大多只會與一名家屬討論，因為家屬之間或會出現矛盾。但他強調，即使院方得悉有一名家人反對放棄搶救，院方都必定會尊重家人意願。

社協幹事彭鴻昌則認為，現時不少醫生僅口頭徵詢家屬同意，未有好好

處理對方情緒；醫生或認為「都無乜好做」，故希望盡快討論處理病人的方式，此舉在醫學上雖正確，但未有好好關顧病人家屬。

## 社協：醫學上正確 未顧家人情緒

他建議前線醫生可俯聽處理放棄搶救的個案，如準備文件簽署；又或可記錄雙方對話，以免發生爭拗。

# Health care providers' views

- Ethical environment for end-of-life care decision-making<sup>1</sup>
  - Prognostication based on biomedical markers
  - Cure-oriented culture
- Discrepancies in views when they were in different capacity (health care providers and patients)
  - Conflicting values: Clearly understand the limitations of life-sustaining treatment

1. Pang MCS, Volicer L, Chung PMB, Chung YMI, Leung WKA, White P. Comparing the ethical challenges of forgoing tube feeding in American and HK patients with advanced dementia. *J Nutr, Heal, Aging*. 2007;11:495-501
2. Pang MC, Wong KS, Dai LK, Chan KL, Chan MF. A comparative analysis of Hong Kong general public and professional nurses' attitude towards advance directives and the use of life-sustaining treatment in end-of-life care.
3. Wong KKY, Chan HYL. Attitudes of Hong Kong physicians and nurses towards artificial nutrition and hydration for patients with terminal cancer. *Newsletter of Intern Soc Nurs in Cancer Care*,. 2012;24:7.

# Major challenges / obstacles perceived by health professionals

- Focus group interviews with nurses, doctors, allied health professionals
- Long-term care setting
- Concerns
  - Timing to initiate the discussion / planning
  - Preparedness of health professionals
  - Mental capacity of patients
  - Readiness of family

# Experience of oncology nurses

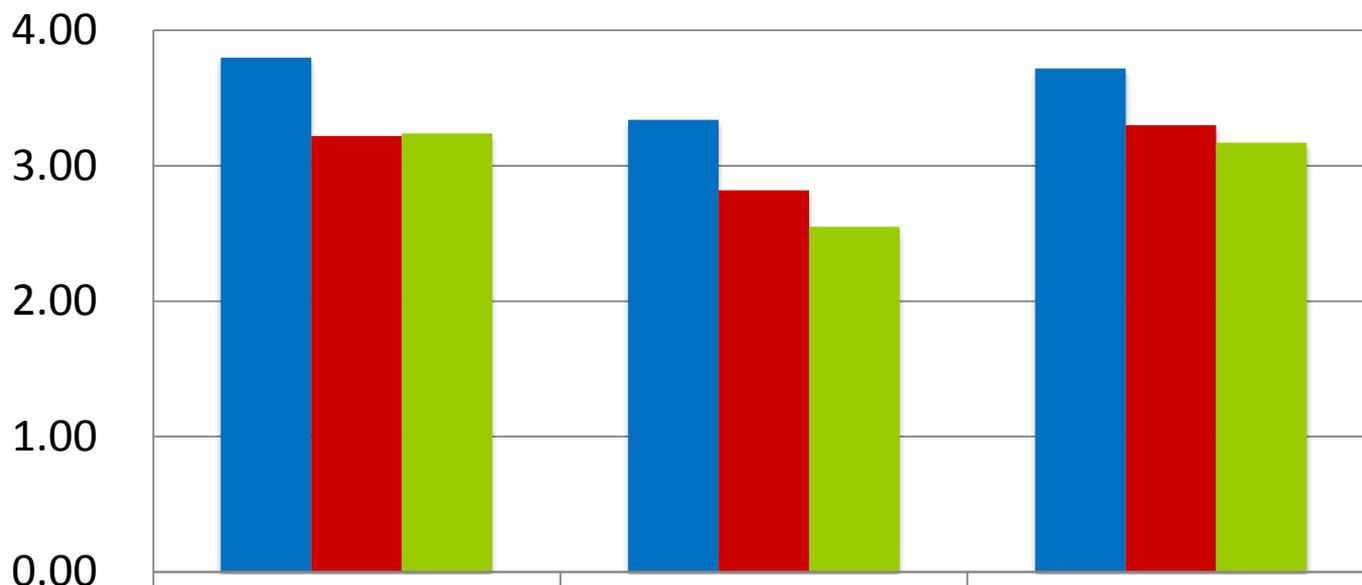
- Training needs
  - Feeling inadequately prepared
- Emotional needs in providing end-of-life care
  - Feeling wronged and helpless
  - Coping with grief
  - Feeling frustrated
  - A lack of support

Chan HYL, Lee LH, Chan CWH. The perceptions and experiences of nurses and bereaved families towards bereavement care in an oncology unit. *Supportive Care Cancer*, 2013;21:1551-1556.

# Preparedness of old age home staff

- A pilot study on palliative and end-of-life care in old age homes (Funded by la Caixa Foundation and Bank of East Asia)
- To evaluate the preparedness of care home staff
  - Willingness, Perceived competence, Self-care
  - Questionnaire
- Chan HYL, Chu GKM, Man CW, Leung EMF. Development and validation of an instrument for assessing staff preparedness for end-of-life care in residential care homes for the elderly. J Am Geri Soci (under review)

# Comparison between staff groups (baseline)



	Willingness	Perceived competence	Self-care
Professional	3.80	3.34	3.72
Frontline	3.22	2.82	3.30
Others	3.24	2.55	3.17



# Barriers of good end-of-life care

## 1. Patients and their families

- Low public awareness towards patients' right to choices
- Culture of protectiveness

## 2. Health care providers

- Regard life saving as an absolute duty
- Lack of sufficient training, time and experience

## 3. Inter-sectoral collaboration

- Ambulance
- Coroners' Ordinance

- Woo J, Chan HYL, Chong AML, Zou M, Chung RY et al. Medical ethical principles may drive improvement of quality of dying in HK. *J Palliat Care Med*. 2015;5:227. doi:10.4172/2165-7386.1000227
- Chan, H.Y.L., Pang, S.M.C. & Leung, E.M.F. (2014). Challenges of promoting end-of-life care in residential care homes in Hong Kong. In *End-of-life care: Ethical issues, practices and challenges*. New York: Nova Science Publishers.



**Thank you**



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