Medical Social (M+S) Collaboration for EOL Care

Dr. James LUK

MBBS(HK), MSc(Experimental Medicine) (UBC), MRCP(UK), FRCP(Edin), FRCP(Glasg), FRCP(Irel), FHKCP, FHKAM(Medicine)

Consultant and Chief of Service, TWGHs Fung Yiu King Hospital (FYKH)

Hon. Clinical Associate Professor, HKU

President, The Hong Kong Geriatrics Society

Medical Social (M+S) Collaboration

- Collaboration is working together to solve a problem or to achieve a goal
- Collaboration takes place between individuals/organizations to tackle shared goals and objectives
- Collaboration > cooperation

Advantages of M+S collaboration

- **Synergy** 1+1 >2
- Community Awareness
 - Increased participation leads to increased community awareness.
- Share resources
- Overcome Obstacles
- Avoid Duplication
- Access to Constituents
 - Sometimes one partner may have strong organizational capacity for planning and implementing programs, but does not have a trusting relationship with the community it wishes to serve. They may benefit from partnering with others who serve as a bridge into the community.
- Access to funding sources

Successful M+S collaboration in EOL care - the 12 S model

- 1. Share goals and values
- 2. Share knowledge and information
- 3. Share program development (structure and process)
- 4. Share governance
- 5. Share manpower and resource
- 6. Share care (avoid duplication)
- 7. Share risk and responsibility
- 8. Share training
- Share promotion
- 10. Share monitoring and auditing
- 11. Share researches
- 12. Share outcomes and rewards



1st 5

Share goals and values



- 1. To provide comfort care for older residents in RCHEs
- 2. To promulgate and establish Advance Care Planning (預設照顧計劃)
- 3. To equip RCHE staff skill for EOL care
- 4. To promote dignified death
- To reduce unnecessary A&E attendances and hospital admissions
- 6. To bring a change of culture in HK for managing older patients approaching EOL

2nd 5

Share knowledge and information

- EOL needs of the older people
- Good death
- Legal and ethical issues
 - How to foster EOL care within the Coroner Ordinance
- Advance Care Planning and Advance directive
- Selection criteria and prognostication
- Existing EOL services in RCHE e.g. PC service
- Use of Careful Hand Feeding in RCHE
- Ambulance and police
- Dying in AED logistics
- Legal advice from experts......

Death is certain, but dying well is not.....

Principles of a good death

- 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 (at home or elsewhere)
- 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 ensure 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

Section 4, Coroner Ordinance

- According to the **Section 4, Coroner Ordinance,** (CAP 504) —"it is a reportable death of a person where the death occurred in any premises in which the care of persons is carried on for reward or other financial consideration (other than in any premises which comprise a hospital, nursing home(Cap 165))".
- Failure to report can be subject to a fine and/or imprisonment (2 weeks!)

There is a wish and a need in RCHE for EOL care

- Study showed 1-year mortality 34% among those with advanced dementia (AMT=0)
 - (Luk JKH, WK Chan, WC Ng et al HK Med J Vol 19 No 6 Dec 2013)
- Advance directive and end-of-life care preferences among Chinese nursing home residents in Hong Kong -35% would prefer to die in RCHEs
 - (Chu LW, Luk JKH, Hui E et al. Am Med Dir Assoc. 2011 Feb;12(2):143-52)

Selection Criteria

- Cancer
- Organ failure (e.g. severe CHF, COPD, CRF etc)
- Advanced dementia
- Degenerative neurological diseases

+ Surprise question -

Would you be surprised if this person was to die within the next 6 months (instead of 1 year)?

3rd 5

Share program development (structure and process)



- Establish working group meeting with NGOs
- Develop the protocol, workflow, and logistics together
 - Share existing protocols (HA and NGO)
 - Division of labour to write up workflow
 - Division of labour to formulate assessment tools and monitoring instruments, avoid duplication
 - Training
 - Promotion and road show

EOL pilot program for RCHE elderly

Collaboration with TWGH Jockey Club Care and Attention Home since 29th September 2009.

EOL Program in RCHE in HKWC

FYKH Pathway

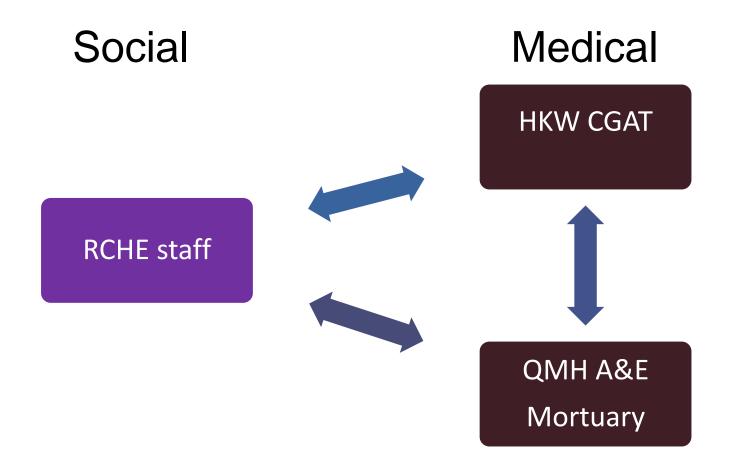
 Arrange elderly admit to FYKH for EOL care via expedite pathway



AED Pathway

- Elderly stay in RCHE until the last moment (BP unmeasurable, unconscious)
- Transported to AED and stay there at last journey of life instead of admitting to acute wards

A Tripartite Collaboration



Tripartite collaboration to integrate EcEoL care into healthcare spectrum

4th 5

Share governance

- Share responsibility in governing the program
 - HKW CGAT governed by SD (P&CHC) and Clinical leader – Consultant in geriatrics
 - NGO governed by RCHE superintendent and her supervisor
- EOL WG meeting chaired by SD (P&CHC)

5th S

Share manpower and resources

- More on manpower as pilot program
- HKW CGAT assigned designated geriatricians and APNs to run the program
- RCHE assigned RNs to lead to program in RCHE
- VMO in RCHE also assisted in the program
- RCHE prepared equipment e.g. oxygen and single room for managing EOL patients
- HKW CGAT investigation costs, drug costs etc

6th S Share care

Empowerment of RCHE staff to take care of EOL patients



In RCHEs

- 1. Advance Care Planning (ACP) and DNACPR, family conferences, bereavement assessment
- 2. RCHE staff provides first line care for EOL patients
- Link CGAT nurse timely telephone support and onsite consultation
- 4. Visiting MO perform on-site management for symptom control and ad hoc problems
- Geriatrician timely professional support (on site or fast track clinic in FYKH)

Share care model

- RCHE staff join with CGAT staff to see patients, and perform Advance Care Planning (ACP) and DNACPR (non-hospitalized).
- Holding regular case conferences for special cases
- Early discussion of ad hoc problems via direct telephone contact between RCHE and CGAT

When patient deteriorate (FYKH pathway)

- During office hours, Link CGAT nurse, after consultation with Geriatrician, will arrange direct admission to FYKH for EOL care
- RCHE staff may choose to send patients directly to AED if they are critically ill with unstable vital signs, or outside the CGAT service hours

When patient deteriorate (AED Pathway)

- More frequent follow-up
- Symptoms handled by RCHE staff
- Intensive off-site or onsite support by CGAT nurse and geriatrician
- Visiting MO ad hoc support
- AED informed for expected death of EOL case
- Last moment (decided by RCHE staff) to AED by ambulance with ACP and DNACPR (non-hospital) form
- CPR would not be performed in AED

7th S Share risk and responsibility

- Complaints
- Legal and ethical questioning
- Police and ambulance men questioning
- AED staff questioning
- Staff sentiments



8th S Share training

- ✓ End of life concept
- ✓ Symptomatic management e.g pain, respiratory distress
- ✓ Use of Medication
- ✓ Nutrition and feeding
- ✓ Briefing of ECEOL in RCHEs

9th S Share promotion

Medical Social Collaboration -Towards a dignified dying process conference (12 March 2011) at HKECC, Wanchai

2011 Asian J Gerontol Geriatr 2011; 6: 103-6

End-of-life care in Hong Kong

REVIEW ARTICLE

JKH Luk1 MBBS(HK), FRCP(Edin, Glasg, Irel), A Liu2, PhD, WC Ng3, BSc(NursStud) (Hons), MN, P Beh4, MBBS(HK), FHKAM(Pathology), FHW Chan¹, 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
- 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,

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

End-of-life care: towards a more dignified dying process in residential care homes for the elderly

2010

irrespective of their premorbid status, diagnoses, and irreversible, chronic diseases. prognosis. A proportion of them die in hospitals on (or soon after) admission.3 Others will, as a rule, be placed in acute wards where they are provided with intensive treatments, instead of comfort care. This may not accord with what the patients perceive to be a 'good' or 'dignified' death. An acute ward setting is not an ideal place for an anticipated death; there are strict visiting hours, privacy is a luxury, and spiritual care is lacking. Nurses are torn between their regular duties and the special needs of the bereaved family members. When an anticipated death is not properly dealt with, deaths in a hospital may come as a shock to family members. This may result in unnecessary disputes between family members themselves, and, worse still, blame or even complaints being levelled and develop a clear policy fostering dying in RCHE. against hospital staff.

Hong Kong's older population is growing fast, their own RCHE. A pioneer programme in the Haven amounting to 850 000 (12,4%) in the 2006 Census,1 of Hope Nursing Home showed that nearly 30% of Of these, around 70 000 were living in residential all residents chose to die there.9 Admittedly, some care homes for the elderly (RCHE). Older RCHE patients or family members may prefer intensive residents tend to have multiple co-morbidities and care in hospitals. We believe that it is imperative irreversible chronic medical illnesses.2 Many have to educate both patients and the public about EOL high dependency and poor cognitive function, care choices. The public need to understand that the Residential care homes for the elderly usually send curative approach emphasised by modern medicine older residents to acute hospitals when they are sick, may be unsuitable for older people with end-stage,

> Patients and their families can only choose dying in place when it is a real option. This depends on the availability of a network of supportive services. Currently, most RCHE workers have yet to acquire sufficient knowledge and skills to handle patients in need of EOL care. Some may even suffer fear of, and lack of confidence about, providing EOL care in the RCHE. Many RCHE, private ones in particular, are overcrowded. There is no spare room in which an individual may pass away peacefully. The geriatric support services available to RCHE are limited, and the Government has yet to designate high-quality EOL care services as a crucial part of health care services

> > Another common obstacle to dying in RCHE

REVIEW ARTICLE

End-of-life services for older people in residential care homes in Hong Kong

James KH Luk *

This article was

published on 4 Aug 2017 at www.hkmj.org.

This version may differ

from the print version.

Good end-of-life care is needed for older people living in residential care homes with advanced irreversible chronic medical illnesses and cancers. At present, the usual practice of residential care homes is to send older residents to acute hospitals when they are unwell, and some residents will die in hospital. Dying in hospital without choice for older people may not be in alignment with the principle of 'good death'. There are many barriers for older people to die in the place of their choice, particularly in a residential care home. In the community, to enhance end-of-life care for elderly people living in residential care homes, pilot end-of-life programmes have been carried out by community geriatric assessment teams. In 2015, the Hospital Authority started the 'Enhance JKH Luk*, FHKCP, FHKAM (Medicine) community geriatric assessment team support to end-of-life patients in residential care homes for the elderly' programme in four clusters. In the hospital setting, an end-of-life clinical plan and end-of-life

ward in geriatric step-down hospitals may improve the quality of death of elderly people. In September 2015, the Hospital Authority guideline on lifesustaining treatment for terminally ill people was updated. Among other key end-of-life issues, careful (comfort) hand feeding was first mentioned in the guideline. The possible establishment of enduring powers of attorney for health care decision-making and enhancement of careful (comfort) hand feeding are new developments in the coming years.

Hong Kong Med J 2017;23:Epub DOI: 10.12809/hkmj166807

Department of Medicine and Geriatrics, Fung Yiu King Hospital, Pokfulam,

* Corresponding author: lukkh@ha.org.hk

Mortality and health services utilisation among ${{0}\atop{A}\atop{R}}$, ${{1}\atop{T}\atop{T}}$, ${{1}\atop{C}\atop{L}}$, ${{1}\atop{E}\atop{L}}$ older people with advanced cognitive impairment living in residential care homes

James KH Luk 陸嘉熙 WK Chan 陳偉光 WC Ng 吳穎珍

Patrick KC Chiu 趙嘉俊 Celina Ho 何潔儀

TC Chan 陳端正

Felix HW Chan 陳漢威

Objectives To study the demography, clinical characteristics, service utilisation, mortality, and predictors of mortality in older residential care home residents with advanced cognitive impairment.

Design Cohort longitudinal study.

Residential care homes for the elderly in Hong Kong West.

Participants Residents of such homes aged 65 years or more with advanced cognitive impairment.

Results In all, 312 such residential care home residents (71 men and 241 women) were studied. Their mean age was 88 (standard deviation, 8) years and their mean Barthel Index 20 score was 1.5 (standard deviation, 2.0). In all, 164 (53%) were receiving enteral feeding. Nearly all of them had urinary and bowel incontinence. Apart from Community Geriatric Assessment Team clinics, 119 (38%) of the residents attended other clinics outside their residential care homes. In all, 107 (34%) died within 1 year; those who died within 1 year used significantly more emergency and hospital services (P<0.001), and utilised more services from community (B 0.004) + 17 P + 1

2013

10th S Share monitoring and auditing



Demographic data

- Number of patients studied N=64
- Male = 23, Female = 41
- Average age = 87 ± 7 (range = 62 to 108)

11th S Share researches

Nursing Manuscript

Dignified Palliative Long-Term Care: An Interpretive Systemic Framework of End-of-Life Integrated Care Pathway for Terminally III Chinese Older Adults American Journal of Hospice & Palliative Medicine® 1-9 © The Author(s) 2015 Reprints and permission: sagepub.com/journalsPermissions.nav DOI: 10.1177/1049909114565789 ajhpm.sagepub.com

\$SAGE

Andy Hau Yan Ho, PhD, MFT, FT^{1,2,3}, James K. H. Luk, FHKCP, FHKAM⁴, Felix H. W. Chan, FHKCP, FHKAM⁴, Wing Chun Ng, MN⁵, Catherine K. K. Kwok, BSW⁶, Joseph H. L. Yuen, MSS⁶, Michelle Y. J. Tam, MSc³, Wing W. S. Kan, MSW², and Cecilia L. W. Chan, PhD³

12th S Share outcomes and rewards

Prof Pang, Geriatrician from Singapore, visited CGAT team and RCHE to know about HKW CGAT EOL program



