

Jockey Club End-of-Life Community Care Project

The Development of End of Life Care in RCHEs in Hong Kong - Issues of Capacity Building

Dr Edward MF Leung President, Hong Kong Association of Gerontology 17/6/2021 JCECC Conference

捐助機構 Funded by:



香港賽馬會慈善信託基金 The Hong Kong Jockey Club Charities Trust ^{回心同步同進} RIDING HIGH TOGETHER</sup> 合作夥伴 Project Partner:



香港老年學會 Hong Kong Association of Gerontology

Rising aging population in Hong Kong





Source: Hong Kong Population Projections (2017 – 2066), Census & Statistics Department, HKSAR

3

Health status of older people in the community & in residential homes in HK, 2005

- Community
 - 71.6% chronic disease
 - 28.3% 1 disease
 - 21.0% 2 diseases
 - 11.6% 3 diseases
 - 10.8% 4+ diseases

- Residential Homes
 - 95.7% chronic disease
 - 16.7% 1 disease
 - 24.4% 2 diseases
 - 23.1% 3 diseases
 - 31.4% 4+ diseases

Source: Thematic Household Survey No 21, October 2005, Census and Statistic Department, HK



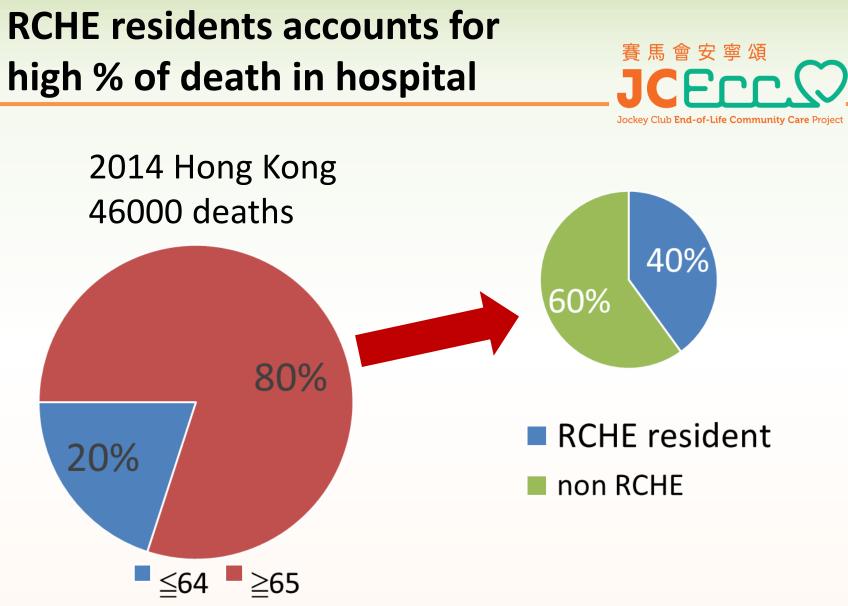
High institutionalization rate of elderly population in HK



	rate
Hong Kong (2009)#	6.8%
China (2008)*	1.0%
Taiwan (2009)#	2.0%
Japan (2006)#	3.0%
Singapore (2006)#	2.3%

aged 65 or above *aged 60 and above

> Source: Chui. et al (2009). Elderly Commission's Study on Residential Care Services for the Elderly - Final Report



Source: Strategic Service Framework for Palliative Care Hospital Authority, 2017



	Age at death	average	89.2
		median	90
		range	61 - 109
37.2%			
stay in	Stay in RCHE	average	5.8 years
RCHE	before death	median	4.4 years
for <u>< 3</u>	4	range	8 days – 32.3 years
<u>years</u>			
before	·		
death	Principal	Heart Failure	21.4 %
	Diagnosis of	Dementia	15.4 %
	residents died (Top 4)	Cancer	12.4 %
		Stroke	11.9 %

Survey on Dying Residents in 34 RCHEs in HK 2018 Total number of death 457 (HKAG 2018)



Health Services Utilization of residents 90 days before death Death rate of residents per Hospital **RCHE** per year Length of stay Admission A&E visit episode Maximum 3.27 35.92 25.0% 3.09 3.80% 0.67 0.53 2.0 Minimum Median 10.87% 1.91 1.71 19.14 11.06% 1.93 1.80 20.10 Average

Principles of a Good Death



1. To know when death is coming and to understand what can be expected 2. To be able to retain control of what happens 3.To be afforded dignity & privacy 4. To have control over pain relief & other symptom control 5. To have choice & control over where death occurs (at home or elsewhere) 6. To have access to information and expertise of whatever kind is necessary 7. To have access to any spiritual or emotional *support* desired 8. To have access to hospice care in any location, not only in hospital 9. To have control over who else is present & shares the end 10. To be able to issue advance directives which ensure wishes are respected 11. To have time to say goodbye, and control over the aspects of timing 12. to be able to leave when it is time to go, and not to have life prolonged pointlessly

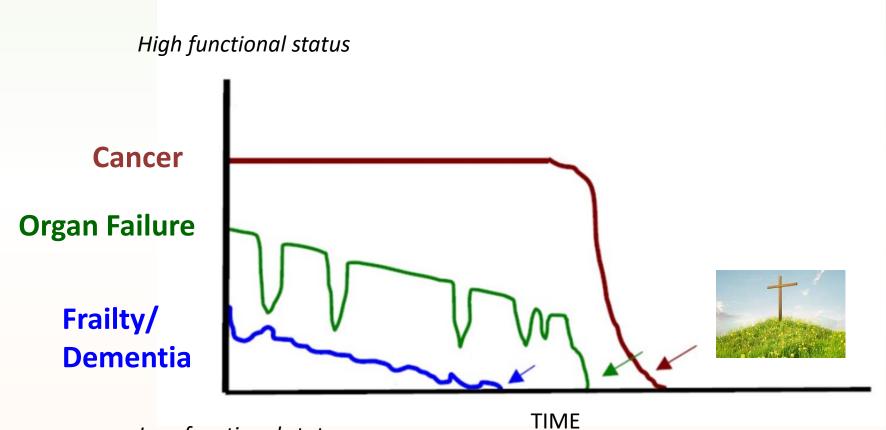
The Future of Health and Care of Older People: The Best is Yet to Come Age Concern, England 1999

Definition of End of Life Care General Medical Council, UK 2010^{年長會安寧頌}

- For those people who are likely to die within the next 12 months
- Include those people whose death is imminent (expected within a few hours or days) and
- Those with
 - Advanced, progressive incurable conditions
 - General frailty and co-existing conditions that mean they are expected to die within 12 months
 - Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
 - Life-threatening acute conditions caused by sudden catastrophic events

Illness trajectory





Low functional status

Murray et al: BMJ 2005; 330:1007-1011

Is it possible to develop End-of-Life Care in RCHEs?



2007-2009

Hong Kong Association of Gerontology (HKAG) partnered with

- International Collaboration for the Care of Elderly (ICCE) &
- •National Institute in the Care of Elderly (NICE) of Canada

End-of-Life Care Project for Hong Kong and Chinese Communities

End-of-Life Care Project for Hong Kong and Chinese Communities

JCECCO Jockey Club End-of-Life Community Care Project

Survey findings

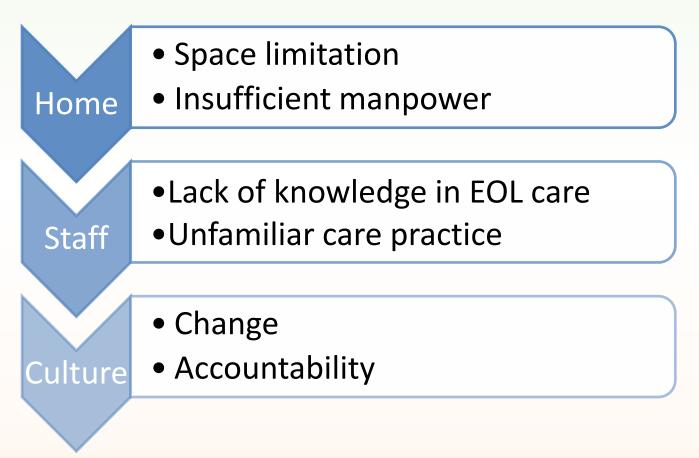


Most older people feel comfortable to talk about death and support the idea of EOL care Policy makers, Senior management, RCHE managers are positive in the development of EOL care in Homes

End-of-Life Care Project for HK and Chinese Communities



However.....



Let's try to develop End-of-Life Care in RCHEs!



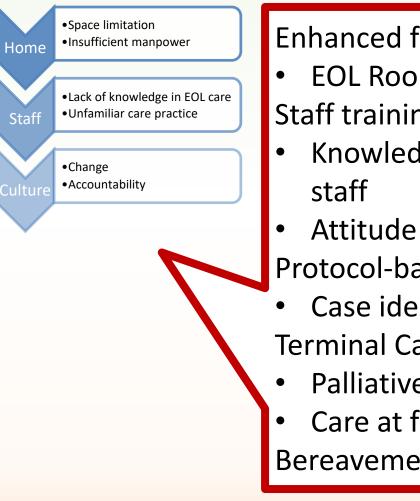
2010-2016

HKAG collaborated with Salvation Army Hong Kong & funded by La Caixa Foundation and Bank of East Asia Foundation

To pilot palliative care service in 6 Residential Care Homes in HK

Palliative care service in **Residential Care Homes**





Enhanced facilities for end-of-life care

- EOL Room
- Staff training
 - Knowledge & skill training to all level of
- Attitude change in staff
- Protocol-based model
- Case identification and referral **Terminal Care Pathway**
- Palliative Care Service
- Care at final days

Bereavement support to family

Palliative care service in Residential Care Homes



Evaluation on Success Criteria





Jockey Club End-of-Life Community Care Project



JCECC: End of Life Care in Residential Care Homes for the Elderly 2016 - 2021

捐助機構 Funded by:



香港賽馬會慈善信託基金 The Hong Kong Jockey Club Charities Trust ^{同心同步同進 RIDING HIGH TOGETHER} 合作夥伴 Project Partner:















JCECC: End-of-Life Care in Residential Care Homes for the Elderly (2016 – 2021)

Project Aims

- ➤To develop a End-of-Life (EOL) care model for in care for the terminal ill elders in RCHEs
- To serve 48 subvented RCHEs on delivering the EOL care services
- To test out the District-based model

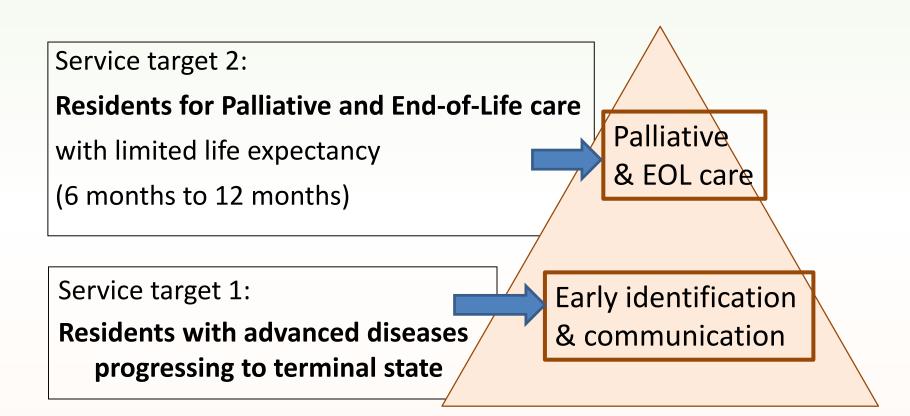


Project Components

- 1. Capacity Building of RCHES in End of Life Support
- 2.District-based EOL team (nurses & social workers)
- 3.Standardized protocol:
- •Case selection & referral
- •Promoting choice of care die in place; promote wish and preferences at final days (AD, ACP)
- •Symptom management
- •Support to carers + Individualized support during resident's final days in EOL Room,
- •Medical Social interface between RCHE & CGAT
- Bereavement support

EOL care service model





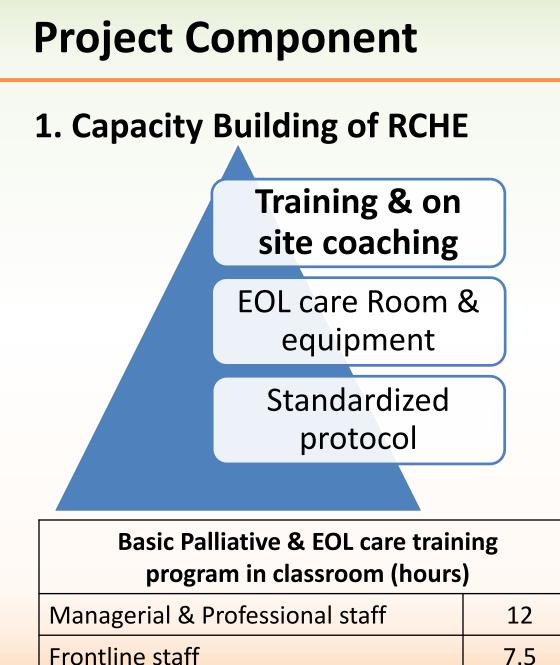


<u>Option 1</u>: Resident cared in RCHE until expected dying within one to two days; send out to AED

Option 2: Resident cared in RCHE until the last moment and send out to AED

<u>Option 3</u>: Resident cared in RCHE until the last moment and certified death by Project Doctor in RCHE Only applicable to Nursing Homes & with prior arrangement made with Funeral parlor

<u>Option 4</u>: Resident cared in RCHE and send to Hospital according to wish of resident/family



賽馬會安寧頌 JCECCO JCECCO

Knowledge & skill transfer Attitude building

- Personal experience in death & loss
- Attitude towards death & dying
- Identification of residents nearing end-oflife
- Symptom management
- Psycho-social spiritual care
- Communication skills
- Bereavement counselling skills
- Ethical & Legal issues in end-of-life care

EOL Training sessions in RCHE





EOL Training session via Zoom





Project Component



2. EOL room for residents during final days

✓ For family to accompany residents

✓ Comfortable home-like environment







EOL room equipped with necessary medical equipment

- Oxygen concentrator
- •Suction machine
- •BP monitor
- •Oximeter
- •Ripple bed
- •Stethoscope





3. Standardized EOL care service protocol

- Awareness Building in residents & family through promotion talks
- Early identification of residents requiring EOL care
- •Referral to discuss the need & plan for end-of-life care service Resident and Family EOL care services
- ✓ Advance Care Planning
- ✓ Nursing Care support
- ✓ Psycho-social-spiritual support
- ✓ Family support
- ✓ Collaborate with CGAT / Parent teams

✓ Promoting End-of-Life choice & care of residents in final days Bereavement counselling to family after residents' death

Collaboration between JCECC EOL team & HA CGAT



Bi-monthly Case Conference together with RCHE staff on need basis

Communication by email (Name, RCHE, EOL team nurse;	EOL Care Plan		
		Condition changes	
	Share the care plan		Final Days acc. to
readiness for ACP/ NH-DNACPR)	Case Record kept in RCHE	RCHE inform CGAT	choice of resident
	EOL team – Prepare ACP discussion, discuss final wishes, EOL choices, family	Management by CGAT/parent team	EOL team/RCHE inform CGAT when send to AED/start EOL Room service
	support	-	Medical & Nursing support in EOL Room based on

Phone contact between EOL team and CGAT nurse as required

Promotion talks in RCHE







Standardized EOL care service protocol and forms





Designated-EOL Nurse & EOL Social Worker

- •Regular on site visits to RCHEs
- •Coaching & guidance to the RCHE staff
- •Close working together relationship & demonstration to RCHE staff
- •Ongoing assessment for resident and family and provide resident-centred and family-oriented holistic care
- •Enhance collaboration with CGATs and parent medical teams in the care and medical management of residents
- Arrange Medical Practitioners and Private Bank Nurses to provide medical and nursing care support during the imminent death of the terminal ill residents

District based EOL team





EOL team & RCHE staff



Jockey Club End-of-Life Community Care Project



Project Component - summary



Capacity building of RCHE -

in care of residents in advanced illnesses, end-of-life stage and at final days

People development Hardware & manpower support

- Staff knowledge & skill training
- Supervised Practicum putting theory into practice
- Environment improvement EOL Room for final days
- Medical Equipment for care of resident in EOL Room
- Full day Nursing care support in care of residents in EOL room

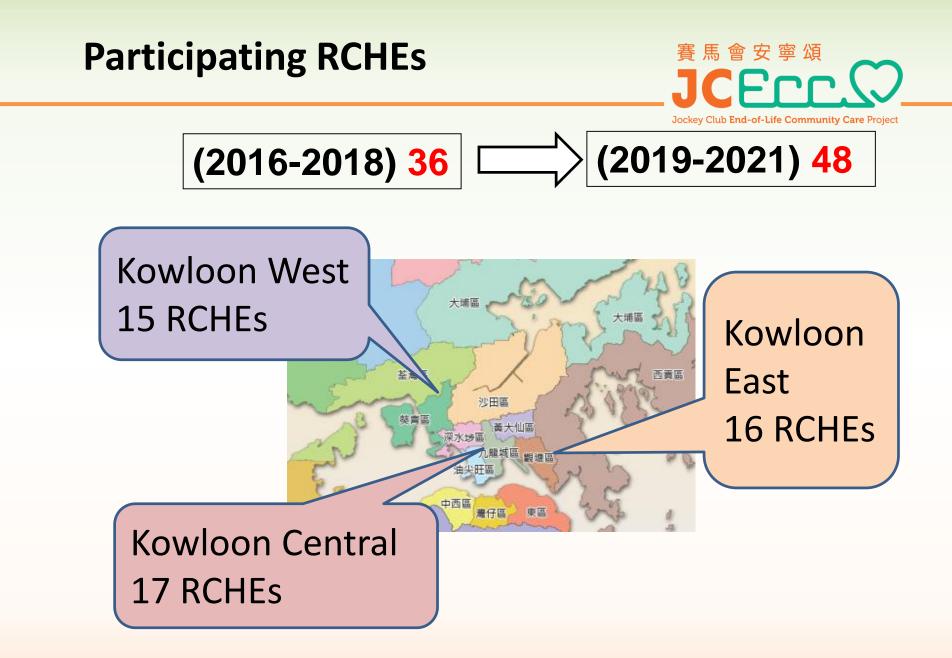
Standardized EOL care service workflow

- Promotion and death education
- Identify residents at advanced illnesses
- Discussion on Advance Care Planning and End-of-Life decision
- Provide choices in End-of-Life care
- Collaborate with CGAT/ parent medical teams
- Care of residents at end-of-life
- Care of residents at final days
- Family support services

District based EOL team (nurse & social worker)



Project output	2016-2018	2019 to 2020
No. of participated Homes	36	48
No. of elderly participants	384	447
No. of family members	2226	1017
No. of RCHE staff trained	2256	1273
No. of visits for ACP	1128	1750
No. of visits for symptom management	5369	9913
No. of counselling & support sessions	4852	9849



Participated NGOs/ Agencies = 24

- Caritas Hong Kong
- Chi Lin Nunnery
- Chinese Rhenish Church Hong Kong Synod (The)
- Christian Family Services Centre
- E.T. Investment Limited
- Evangelical Lutheran Church Social Service - Hong Kong
- ✓ Grace Healthcare Limited
- ✓ Helping Hand
- ✓ Hong Kong Buddhist Association (The)
- ✓ Hong Kong Christian Service
- ✓ Hong Kong Chinese Women's Club (The)
- Hong Kong Lutheran Social Service, the Lutheran Church – Hong Kong Synod Limited

Hong Kong Sheung Kung Hui Welfare
 Council Limited

Jockey Club End-of-Life Community Care Project

- ✓ Hong Kong Society for the Aged (The)
- Hong Kong Young Women's Christian Association
- Kiangsu Chekiang and Shanghai Residents (Hong Kong) Association
- Lok Sin Tong Benevolent Society, Kowloon (The)
- ✓ Po Leung Kuk
- Pok Oi Hospital
- Sik Sik Yuen
- Tung Wah Group of Hospitals
- ✓ Wai Ying Investment Limited
- Yan Chai Hospital
- Yuen Yuen Institute (The)

Collaborating Hospital Authority CGAT (2016-2021) 【CECCS

Jockey Club End-of-Life Community Care Project

- Community Geriatric Assessment Team (CGAT) from
- •Yan Chai Hospital
- •Princess Margaret Hospital
- Caritas Medical Centre
- •Kwong Wah Hospital
- United Christian Hospital
- •Haven of Hope Hospital
- Queen Elizabeth Hospital

Results of Capacity Building for Phase 1 - 36 RCHEs



1. EOL training – RCHE Staff knowledge test

Assessment made

- before training session (pre)
- after training session (post)
- one year after training session completed

Staff knowledge test after a year (RCHE=36)



Jockey Club End-of-Life Community Care Project

Topics	N	Pre (SD) (T0)	Post (SD) (T1)	After 1 year (SD) (T2)	Pre vs Post	Post vs after 1 year	Pre vs after 1 year
Professionals							
臨終照顧倫理與法律議題	274	2.78 (0.80)	3.53 (0.69)	3.03 (0.80)	0.75***	-0.51***	0.25***
末期病患者不適徵狀處理 (I)	235	2.69 (1.00)	3.74 (0.55)	2.47 (1.02)	1.05***	-1.26***	-0.21*
末期病患者不適徵狀處理 (II)	226	2.54 (0.86)	3.62 (0.56)	2.55 (0.74)	1.08***	-1.07***	0.09
瀕死期徵狀評估及護理	224	2.92 (0.86)	3.83 (0.45)	2.84 (0.91)	0.92***	-0.99***	-0.08
心理社交及靈性需要照顧	224	3.21 (0.90)	3.75 (0.57)	3.45 (0.74)	0.54***	-0.30***	0.25***
預設圓願照顧計劃及照顧 家屬心社靈需要	207	2.77 (0.77)	3.61 (0.65)	2.87 (0.70)	0.85***	-0.74***	0.11
哀傷輔導及處理	241	3.43 (0.65)	3.78 (0.46)	3.38 (0.74)	0.35***	-0.41***	-0.05 40

p<0.01 *p<0.001

Staff knowledge test after a year (RCHE=36)



Topics	N	Pre (SD) (T0)	Post (SD) (T1)	Follow-up (SD) (T2)	Pre vs Post	Post vs after 1 year	Pre vs after 1 year
Frontlines							
臨終照顧倫理與法律議題	384	2.58 (0.76)	3.47 (0.66)	2.72 (0.80)	0.88***	-0.75***	0.14*
末期病患者不適及臨終徵 狀處理	391	2.74 (0.77)	3.68 (0.67)	2.76 (0.80)	0.94***	-0.91***	0.03
預設圓願照顧計劃及照顧 家屬心社靈需要	361	2.73 (0.70)	3.58 (0.62)	2.83 (0.64)	0.85***	-0.75***	0.10*
與末期病患者及其家屬之 溝通技巧	386	1.60 (0.80)	3.23 (1.07)	1.55 (0.76)	1.63***	-1.68***	-0.05

p<0.01 *p<0.001

Results of Capacity Building for Phase 1 - 36 RCHEs

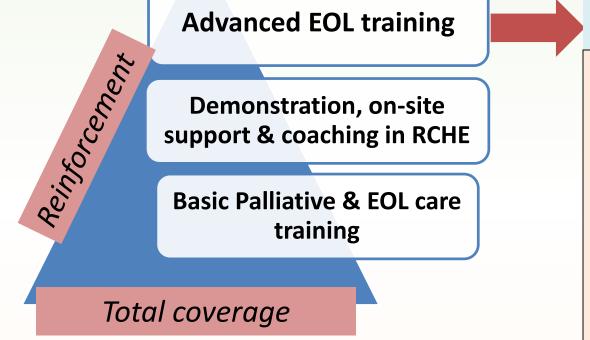


1. EOL training – RCHE Staff knowledge test

Significant improvement in staff knowledge after training session ***Retention of knowledge dropped after one year

Add - Advanced EOL training

賽馬會安寧頌 **JCECCO** Knowledge, skill transfer



Advanced EOL training program in classroom (hours)						
Managerial & Professional staff	12					
Frontline staff	6					

Using case scenarios

- Implementation of EOL care service in RCHE
- End of Life care plan & management of residents
- Identification & management of residents in their final days
- Discussion of Advance Care Plan & EOL care planning with resident & family members

Advanced EOL training



• Organized via on line mode in 2020

Result	Professional staff	Frontline staff
No. of attendance	34 (Nurses - 65% SW, OT, PT – 24%)	40 (Personal care workers – 58% Program assistant & care workers – 25%)
Satisfaction to the program*	4.3 - 4.4	4.4 - 4.7
Completed the assessment (optional)	8 100% passed	24 100% passed

*5-point scale: 1 = very dissatisfied, 5 = very satisfied



2. Staff preparedness for palliative and EOL care

Assessed by a 16-statement questionnaire

- Statements were categorized into 3 components:
- 1.Willingness (W)
- 2.Capability (C)
- 3.Resilience (R)

-5-point Likert scale from '1 completely disagree', '2 disagree', '3 neutral', '4 agree' to '5 completely agree'

Assessment made

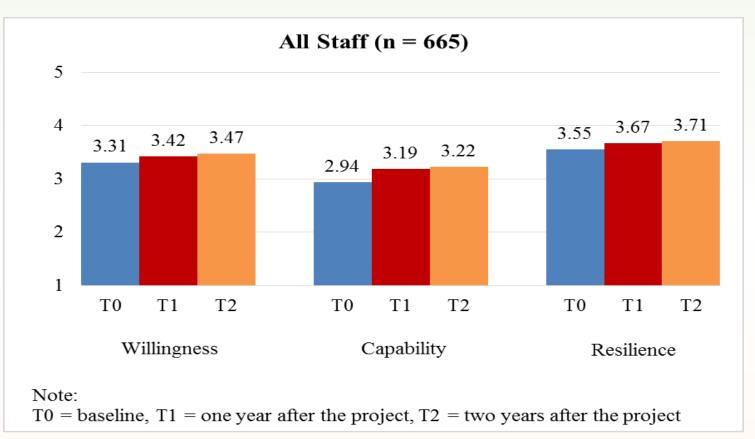
- before EOL service start (TO)

-one year after service implementation (T1)

-two years after service implementation (T2)

Staff preparedness for palliative and EOL g in RCHEs (Phase 1)

Jockey Club End-of-Life Community Care Project



Significant improvement in staff preparedness

Staff preparedness for palliative and EOL care in RCHEs (RCHE=36)

All staff	T ₀ -T ₁	T ₀ -T ₂
Willingness (W)	Significant	Significant
	increase***	increase***
Capability (C)	Significant	Significant
	increase***	increase***
Resilience (R)	Significant	Significant
	increase***	increase***

*p< 0.05, **p< 0.01, ***p< 0.001

Significant improvement in staff preparedness & sustained after 2 years

Jockey Club End-of-Life Community Care Project

Results of Capacity Building for Phase 1 - 36 RCHEs



3. Benchmarking - RCHE EOL service implementation standard

The level of palliative and EOL care provision in RCHEs was measured using the Benchmarking instrument.

The instrument consists of 30 items on EOL care provided by RCHE (palliative care -16 items; EOL care - 7 items; & postmortem care - 7 items)

Assessment made

- before EOL service start (TO)
- one year after service implementation (T1)
- two years after service implementation (T2)



	Palliative care					EOL care						
	Т ₀ %	T ₁ %	T ₂ %	T _{0 -} T ₁ % Diff	T ₁ -T ₂ % Diff	T ₀ -T ₂ % Diff	Т ₀ %	T ₁ %	T ₂ %	T _{0 -} T ₁ % Diff	T ₁ -T ₂ % Diff	T₀-T₂% Diff
0	32.9	3.0	2.9	-29.9	-0.2	-30.1	41.3	3.7	1.6	-37.6	-2.0	-39.6
1a	5.1	3.4	1.6	-1.6	-1.8	-3.4	0.0	8.2	6.9	+8.2	-1.2	6.9
1b	9.8	12.0	10.2	+2.3	-1.8	+0.4	5.2	6.9	4.9	+1.8	-2.0	-0.3
2	51.2	80.1	84.5	+28.9	+4.4	+33.2	18.7	62.0	70.6	+43.4	+8.6	+52.0
N/A	1.0	1.4	0.9	+0.4	-0.5	-0.2	34.9	19.2	15.9	-15.7	-3.3	-19.0

0 = Neither had written guidelines/policies/procedures/mechanisms nor execution and documentation
 1a = Had written guidelines/policies/procedures/mechanisms but no execution or documentation
 1b = No written guidelines/policies/procedures/mechanisms but had execution and documentation
 2 = Had both written guidelines/policies/procedures/mechanisms and execution and documentation

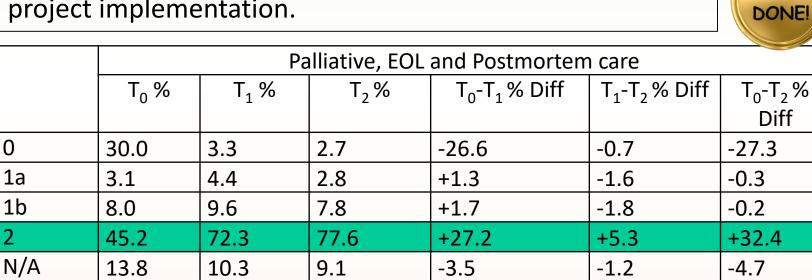


	Postmortem care						
	T ₀ %	T ₁ %	T ₂ %	T _{0 -} T ₁ % Diff	T ₁ -T ₂ % Diff	T ₀ -T ₂ % Diff	
0	11.9	3.7	3.3	-8.2	-0.4	-8.6	
1a	1.6	2.9	1.2	-1.3	-1.6	-0.4	
1b	6.7	6.9	5.3	-0.2	-1.6	-1.4	
2	57.9	64.9	69.0	+7.0	+4.1	+11.0	
N/A	21.8	21.6	21.2	-0.2	-0.4	-0.6	

0 = Neither had written guidelines/policies/procedures/mechanisms nor execution and documentation
1a = Had written guidelines/policies/procedures/mechanisms but no execution or documentation
1b = No written guidelines/policies/procedures/mechanisms but had execution and documentation
2 = Had both written guidelines/policies/procedures/mechanisms and execution and documentation

Result of Benchmarking

77.2% of participating RCHE had written guidelines/policies/procedures/mechanisms on palliative and EOL care provision in RCHEs and had shown execution and documentation of their services two years (T2) after project implementation.



0 = Neither had written guidelines/policies/procedures/mechanisms nor execution and documentation

1a = Had written guidelines/policies/procedures/mechanisms but no execution or documentation

1b = No written guidelines/policies/procedures/mechanisms but had execution and documentation

2 = Had both written guidelines/policies/procedures/mechanisms and execution and documentation

WELL

賽馬會安寧頌

Health Services Utilization of RCHE residents before death (Year 2020)

Jockey Club End-of-Life Community Care Project

	Health services utilization of RCHE residents one year before death n=10208 ^{Note 1} (Total/average per resident)						
	270-365181-27091-18090 days365 daydays beforedays beforedays beforebeforebeforedeathdeathdeathdeathdeath						
AED visit	6195 (0.61)	6680 (0.65)	8837 (0.87)	21135 (2.07)	42847 (4.20)		
Hospital admission episode	5135 (0.50)	5786 (0.57)	8076 (0.79)	26098 (2.56)	45095 (4.42)		
Length of hospital stay (days)	47608 (4.66)	55069 (5.39)	77678 (7.61)	279972 (27.43)	460327 (45.09)		

Note 1 Hospital Authority statistics for patient with last episode admitted from Elderly Home and aged 60+ and death in HA hospitals (specialty M&G)^ during 2020 (N= 10,208)

Result of Health Services Utilization (March 2016 – March 2021)



Jockey Club End-of-Life Community Care Project

	90 days before RCHE residents' death n=10208 ^{Note 1} (Total/average per resident)	90 days before participating residents' death n=387 (Total / average per resident)	Change (%)
AED visit	21135 (2.07)	623 (1.61)	-22.2%
Hospital admission episode	26098 (2.56)	589 (1.52)	-40.6%
Length of hospital stay (days)	279972 (27.43)	5108 (13.20)	-51.9%

Decrease in visits to A&E, Hospital admissions and length of stay

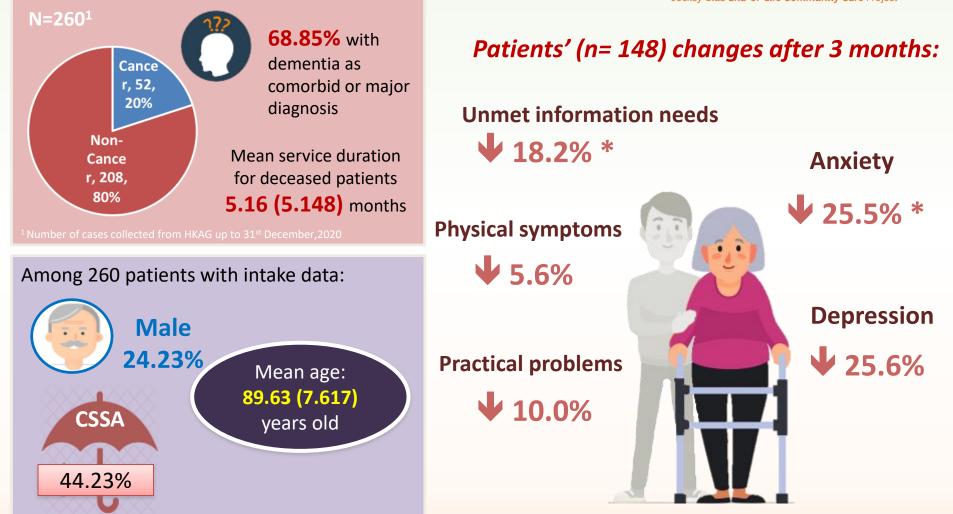
Note 1 Hospital Authority statistics for patient with last episode admitted from Elderly Home and aged 60+ and death in HA hospitals (specialty M&G)^ during 2020 (N= 10,208)

Benefits to residents and family



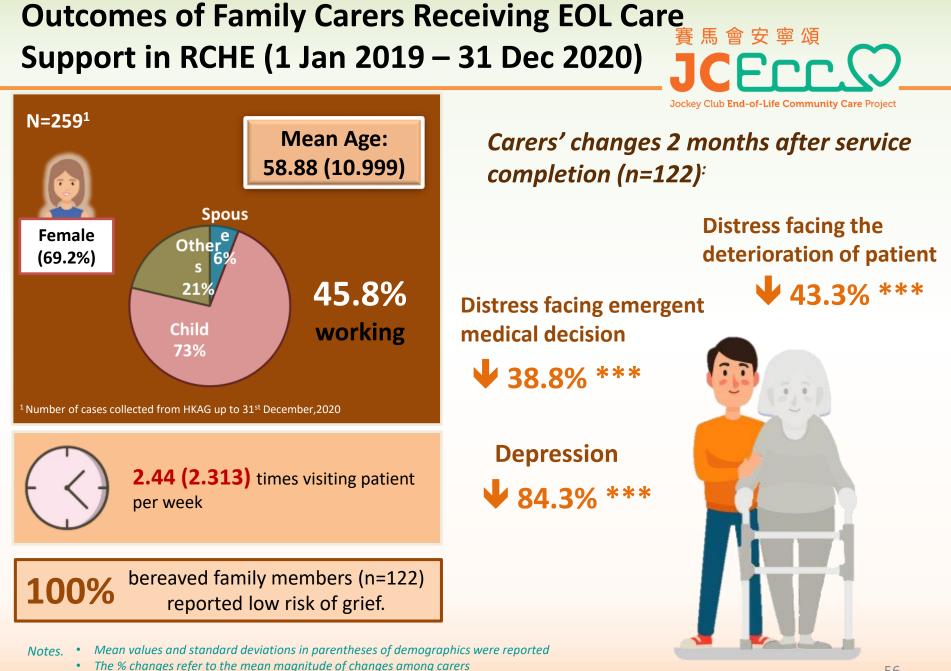
Outcomes of Residents Receiving EOL Care Support in RCHE (1 Jan 2019 – 31 Dec 2020)





Notes. • Mean values and standard deviations in parentheses of demographics were reported

- The % changes refer to the mean magnitude of changes among patients.
- Level of significance was represented as * p<.05



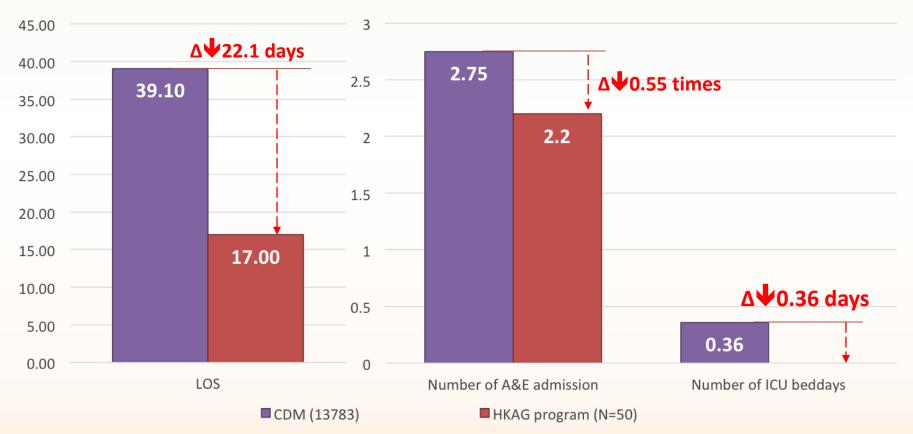
• Level of significance was represented as *** p<.001

Service Impact on Medical Service Usage in the Last 6 Months of Life (1 Jan 2019 – 31 Dec 2020)



57

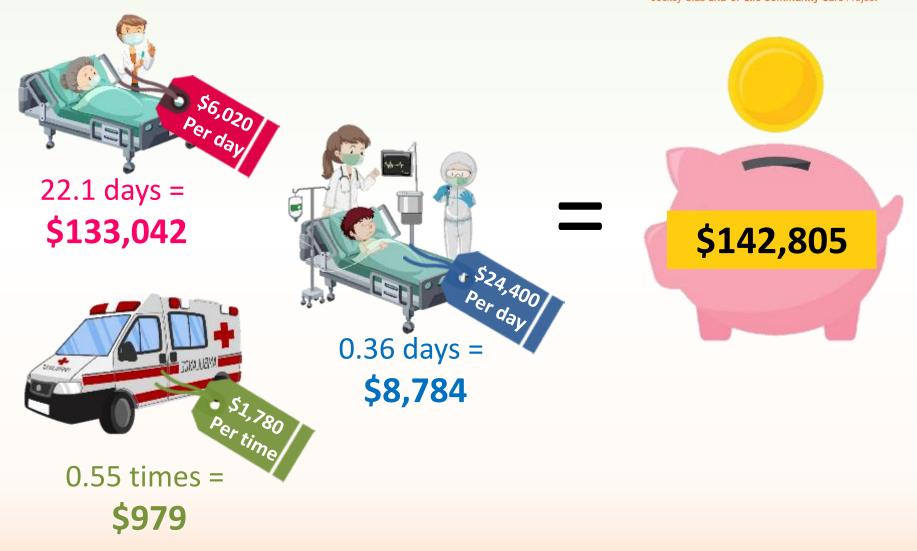
<u>Comparison Between Residents under JCECC and Patients in General in</u> <u>the Utilisation of Medical Services¹ in the Last 6 Month of Life (N=50)</u>



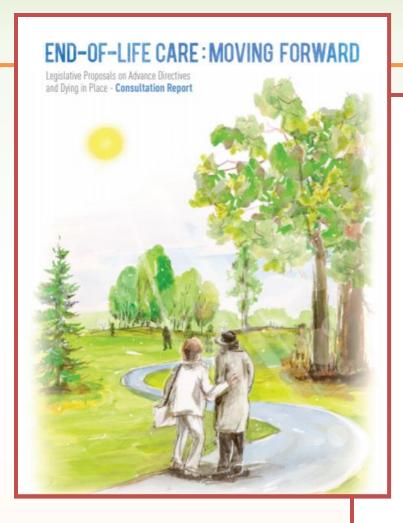
1 The University of Hong Kong obtained data of the medical services in the last 6 months of life among patients who died of cancer, chronic obstructive pulmonary disease, heart failure, end-stage renal disease, motor neuron disease, and Parkinson's disease from the central database of Hospital Authority. After clinical data mining, the impact of the project on patients' use of medical services was evaluated through comparing with the data of six-month before the death of patients.

Estimated Economic Impact per Resident Receiving EOL Care in RCHEs¹





¹ According to Hospital Authority Annual Report 2019- 2020, the cost per A&E attendance and per LOS has updated.





Jockey Club End-of-Life Community Care Project

Moving Forward

End-of-life Care:

Legislative Proposals on Advance Directives

and Dying in Place

Food and Health Bureau

July 2020

Ready to provide choice of End of Life Care in RCHES in Hong Kong

- 賽馬會安寧頌 **JCECCO** Jockey Club End-of-Life Community Care Project
- Legislation in place to allow Dying in Aged Homes
- Build Up Capacity in Aged Homes to care for Advance Illness and Dying at Aged Home
- Necessary Medical and Nursing Support for Advanced Illness and End of Life in Aged Homes
- Enhance Medical Social Interface and Public Private Interface



Jockey Club End-of-Life Community Care Project



捐助機構 Funded by:



香港賽馬會慈善信託基金 The Hong Kong Jockey Club Charities Trust ^{同心同步同進} RIDING HIGH TOGETHER</sup> 合作夥伴 Project Partner:

