JCECC | Jockey Club End-of-Life Community Care Project

A CASE STUDY

Executive Summary

Hong Kong is facing a rapidly ageing population, and the number of elderly people suffering from terminal illnesses has escalated correspondingly. When asked what they need at the end of their lives, Hong Kong's elderly have two top priorities: to be surrounded by their loved ones and to be free from pain and suffering.

These goals are greatly facilitated by the availability of End-of-Life (EoL) Care, which provides the combined medical and psychosocial services needed to help the elderly "die in place" and enjoy a better quality of life in their final days.

Unfortunately in Hong Kong, EoL care is sorely insufficient. Hong Kong was ranked first in the world in healthcare system efficiency by Bloomberg[1] in 2018, but ranked 22nd in the world on the Quality of Death Index[2] in 2015, lagging behind our neighbouring economies Taiwan (6th), Singapore (12th) and Japan (14th).

The discrepancy between the ranking is an analogy for a problem we face in Hong Kong: we have a system that is overly medical, and imbalanced toward curative care in hospitals, rather than palliative care in communities. More than 90% of Hong Kong deaths occur in hospital, despite the reality that 47% of the public would prefer to die in community-based settings[3].

In response to this challenge, The Hong Kong Jockey Club Charities Trust (the Trust) allocated a total of HK$255 million to launch the Jockey Club End-of-Life Community Care Project (JCECC) since 2016. The Trust's partners in JCECC are The University of Hong Kong Faculty of Social Sciences, The Chinese University of Hong Kong Jockey Club Institute of Ageing, Hong Kong Association of Gerontology, Haven of Hope Christian Service, The Hong Kong Society for Rehabilitation, St James' Settlement, and S.K.H. Holy Carpenter Church District Elderly Community Centre.

JCECC provides a powerful case study because it presents a model for addressing choice and quality of death in the Chinese cultural context, and lays the groundwork for changing the system and practice of EoL care in Hong Kong.

The Project is designed to promote dignified, holistic and person-centred EoL care for older people in their final journey of life in the community.

The service models piloted in the first phase of JCECC between 2016 and 2018 have shown strong results in improving the quality of life of patients and family members, as well as enhanced the competence of service providers on providing EoL care and strengthened community engagement through volunteer training and community education programmes. Our ambition in the second phase is to refine these service models and lay the foundation for further service development.

End-of-Life Care

What is End-of-Life Care?

End-of-Life (EoL) care provides holistic support to people with terminal illness and their family members, covering equally the physical, psychosocial and spiritual aspects. In its early iterations, EoL care was mainly offered to cancer patients. More recently, it has been expanded to five domains relevant to a broader service target group (the Who); the place of care and place of death (the Where); the timing of care (the When); service providers (the Whom); and care content (the What).

WHO

- People with life-threatening illness and their family
- Covering both physical and psychosocial needs

WHAT

- Health care, Psychosocial-spiritual care
- Practical care
- Information

WHERE

- Hospice, Hospital, Patients Home, Residential Care Home, In the Community
- Patients' preferred place of care

WHOM

- By interdisciplinary team of health care and social care professionals
- Patients, family members, volunteers and all in the community

WHEN

- Prognosis of 6 to 12 months
- Palliative care can start at the diagnosis of a life- threatening illness

End-of-Life Care is a Global Challenge

The world is rapidly ageing. By 2050, one in five people will be 60 years or older, totalling two billion people worldwide[4]. Non-communicable illnesses such as heart disease and cancer are on the rise[2], therefore the need for palliative care will continue to grow fast.

Until recently, there has been little dedicated effort and investment toward EoL care. However, public engagement and policy interventions to improve the quality of death through the provision of high-quality palliative care is now gaining momentum worldwide, and some countries have made great strides in improving affordable access to palliative care.

Two examples from the 2015 Quality of Death Index:

Case Example: United Kingdom

As at 2010, the UK ranked first in the Quality of Death Index. Its leading position reflects a high quality of care as well as comprehensive national policies, the extensive integration of palliative care into its National Health Service, and a strong hospice movement[2].

Case Example: Taiwan

Positioned 6th, Taiwan is the highest ranked place in Asia-Pacific. Government engagement has been critical for its success: Taiwan's National Health Insurance scheme determines insurance coverage and the level of reimbursement for specific services, making care services more affordable. Taiwan has also made the most progress in life and death education for the general public in the Chinese cultural context.

Despite the positive momentum, there is still a long way to go. The Quality of Death Index reports that even top-ranked nations struggle to provide adequate palliative care services for every citizen.

The UK, for example, an acknowledged leader in palliative care, still sees regular complaints about poor symptom control, poor communication and planning, not responding to the needs of the dying, inadequate out-of-hours services and delays in diagnosis and referrals for treatment[2].

Experts say the biggest persistent problem is that the healthcare systems are designed to provide acute care, whereas what is needed for the patients tilts more toward chronic care. Cultural shifts are also needed; to move from a mindset that prioritises curative treatments to one that values the quality of life for dying patients and their families.

The End-of-Life Care Situation in Hong Kong?

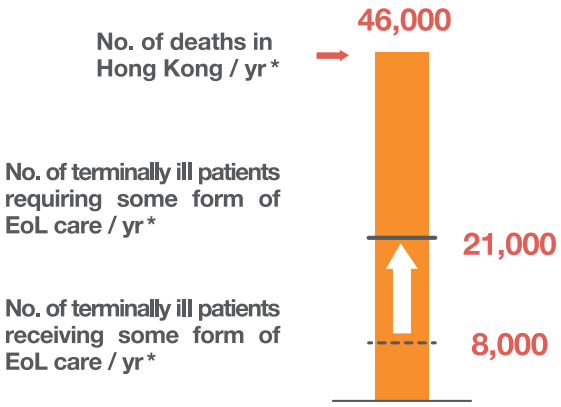
‘5-C’ Challenges:

i Low Coverage ii Limited Choice iii Weak Continuity iv High Medical Cost
v Low Competency and Empowerment

Low Coverage of EoL Care

Our current coverage for EoL care is estimated to be far lower than needed, particularly for patients with cardiac, pulmonary and neurodegenerative diseases, as well as dementia[5].

Based on available data, it is estimated that Hong Kong only covers **38%** of the total need for EoL care. The vast majority of this gap will be for elderly patients.



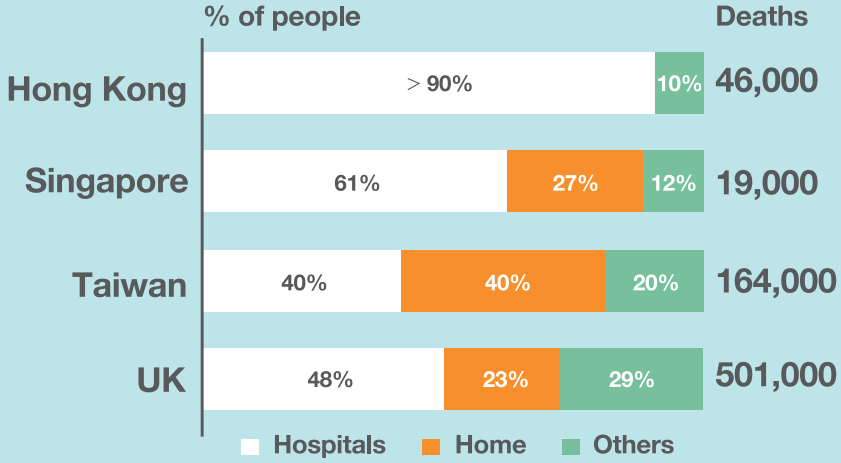
Estimated coverage of EoL care in Hong Kong 2016

Assumptions

* The 21,000 figure is calculated after taking into account that ~ 30,000 deaths in 2016 were caused by malignant or non-malignant diseases (excluding deaths from external or other unspecified causes), and also using a WHO estimate[6] that 70% of total deaths required some form of EoL care.
* The 8,000 figure is calculated using 2018 death statistics for cancer and non-cancer deaths multiplied by the % of those receiving EoL care from 2006 survey data from Lau et al (2010) - sample size of 839[7].
* While the above assumptions have their obvious limitations, they provide an estimate for coverage using available data in Hong Kong.

Limited Choice of Place for EoL Care

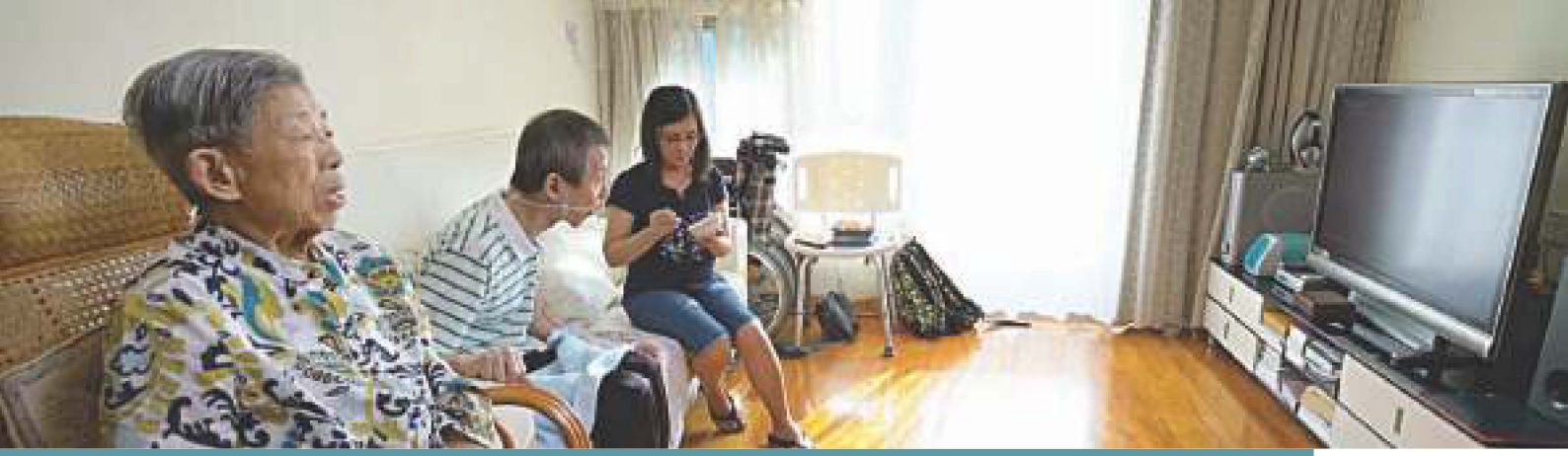
People prefer to die outside hospital, but that is where more than 90% do die[8,9].



Estimated place of death comparison: Hong Kong vs UK, Taiwan, Singapore[10]

In Hong Kong, 47% prefer to die outside hospital, 30.8% prefer to die at home and 16.2% prefer nursing homes and hospices.

However, more than 90% of deaths happen in hospital, the highest rate in the world[8,9]. This is far above peer benchmarks with Singapore at 61% and Taiwan at 40%.



Weak Continuity of EoL Care

Continuity of care means seamless and holistic care both within the hospital as well as between hospitals and the community. Currently, the medical system in Hong Kong is fragmented and over-specialised, and disconnected from social services. While aspects of EoL care are offered within the medical services of the Hospital Authority (HA) and community services subvented by Social Welfare Department, no formal and structured partnerships have ever been established to provide co-ordinated and holistic EoL care to patients.

High Medical Cost in the Last Stage of Life

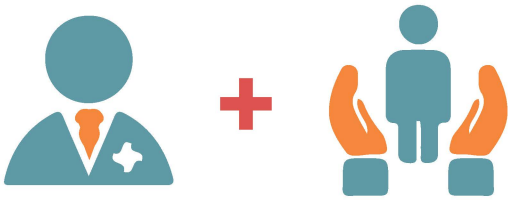
Analysis of HA data in 2014 shows substantial Accident & Emergency (A&E) attendances, hospital admissions and hospitalisation days by patients in their last year of life[5].

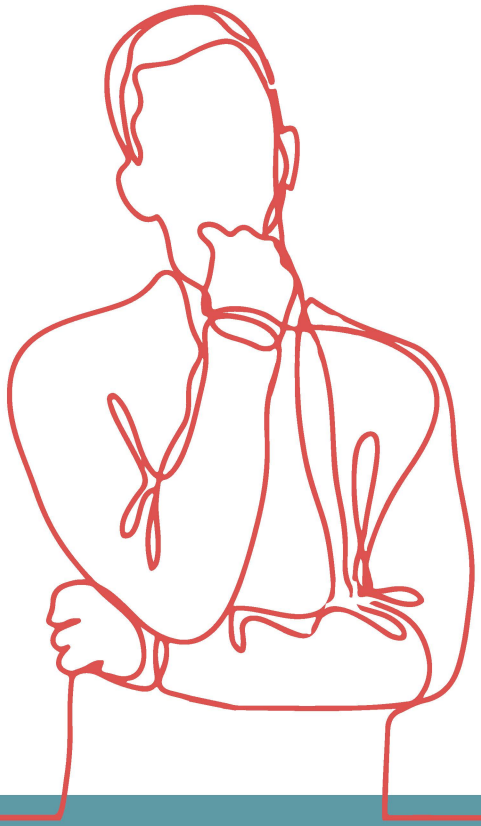
The rise in utilisation starts in the last six months of their lives and surges in the final two months. This applies both to patients suffering from cancer and those with organ failure. In particular, the average number of A&E attendances and hospitalisation days of elderly patients in their last year of life were five and ten times that of other elderly patients respectively[5].

Low Competency and Empowerment

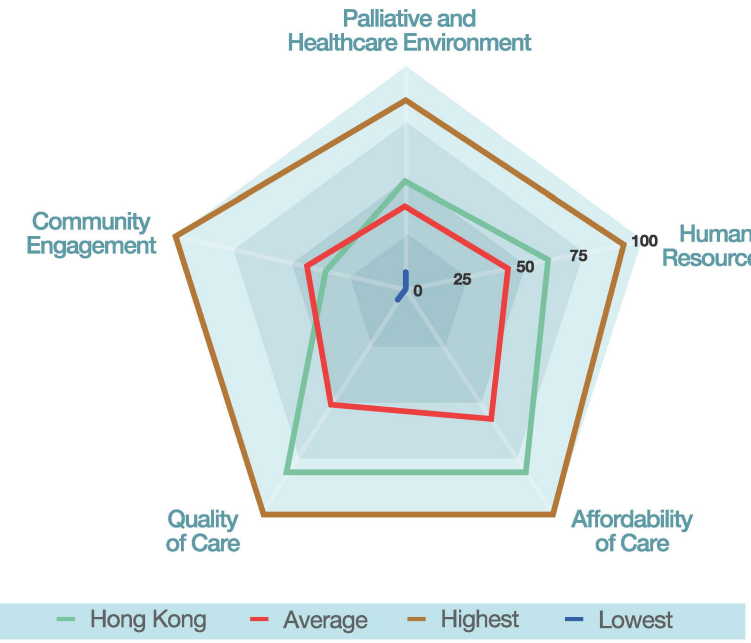
Of the 8,127 fellows registered under the Hong Kong Academy of Medicine, only 23 work in palliative medicine[11]. From top to bottom, EoL care knowledge and competencies among health and social care professionals are inadequate[12,13].

There is a pressing need to establish formal and standardised education curricula for EoL care[14]. In addition to formal education, there is an even greater requirement to build the capacity of family carers and volunteers in the community.





... which results in Hong Kong lagging in end-of-life care and ranking 22nd in Quality of Death Index

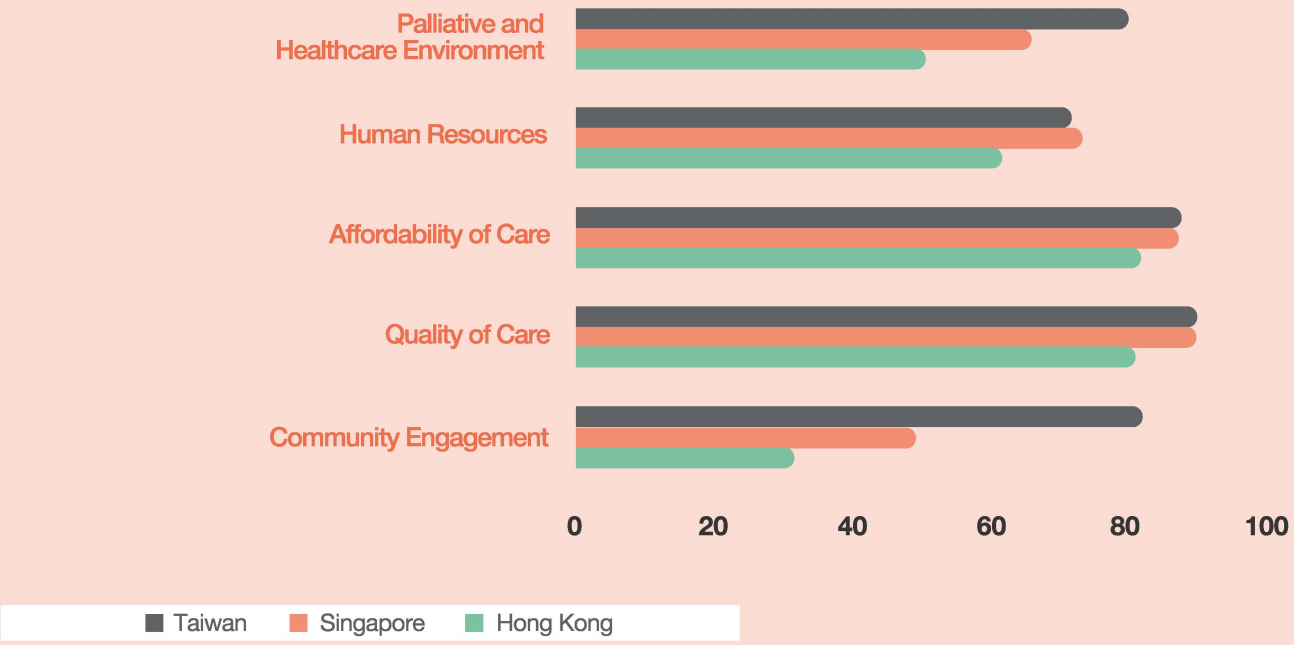


RANKED 22nd/80

All these factors contribute to Hong Kong being ranked 22nd in the Quality of Death Index[2], below Taiwan (6th), Singapore (12th) and Japan (14th).

Hong Kong's palliative care network is moderately developed, but has performed below average in terms of community engagement. Indicators in the "community engagement" category include public awareness and the number of volunteer workers. The report points out that most Hong Kong people have limited understanding about palliative care.

Hong Kong falls behind Singapore and Taiwan in every category, with big gaps in community engagement and the palliative and healthcare environment :



Score of Hong Kong, Singapore and Taiwan on the five categories in the 2015 Quality of Death Index

End-of-Life care is COMPLICATED in Hong Kong.

Elderly people have no choice but to die in hospital (more than 90% of deaths happen in hospital in Hong Kong[4]), often separated from the beloved ones.

> *I want to go home (her residential home).*

> *I would rather die than to leave my family.*

Caregivers / families often feel exhausted by the care burden, helpless and lonely due to lack of access to information and services.

> *I was burnt out.*

> *Even the domestic helper can rest on Sunday, but I cannot.*

Society is not willing to talk about death, because of superstitions, fear and inability to cope with the topic.

> *I want to discuss (EoL care and post-death arrangements) with them, but they (her children) always avoid mentioning it.*

> *The cleaner refused to enter the room for EoL patients because of fear.*

> *The staff don't have confidence to deal with EoL care and the easiest way for them is to send her/him to the hospital.*

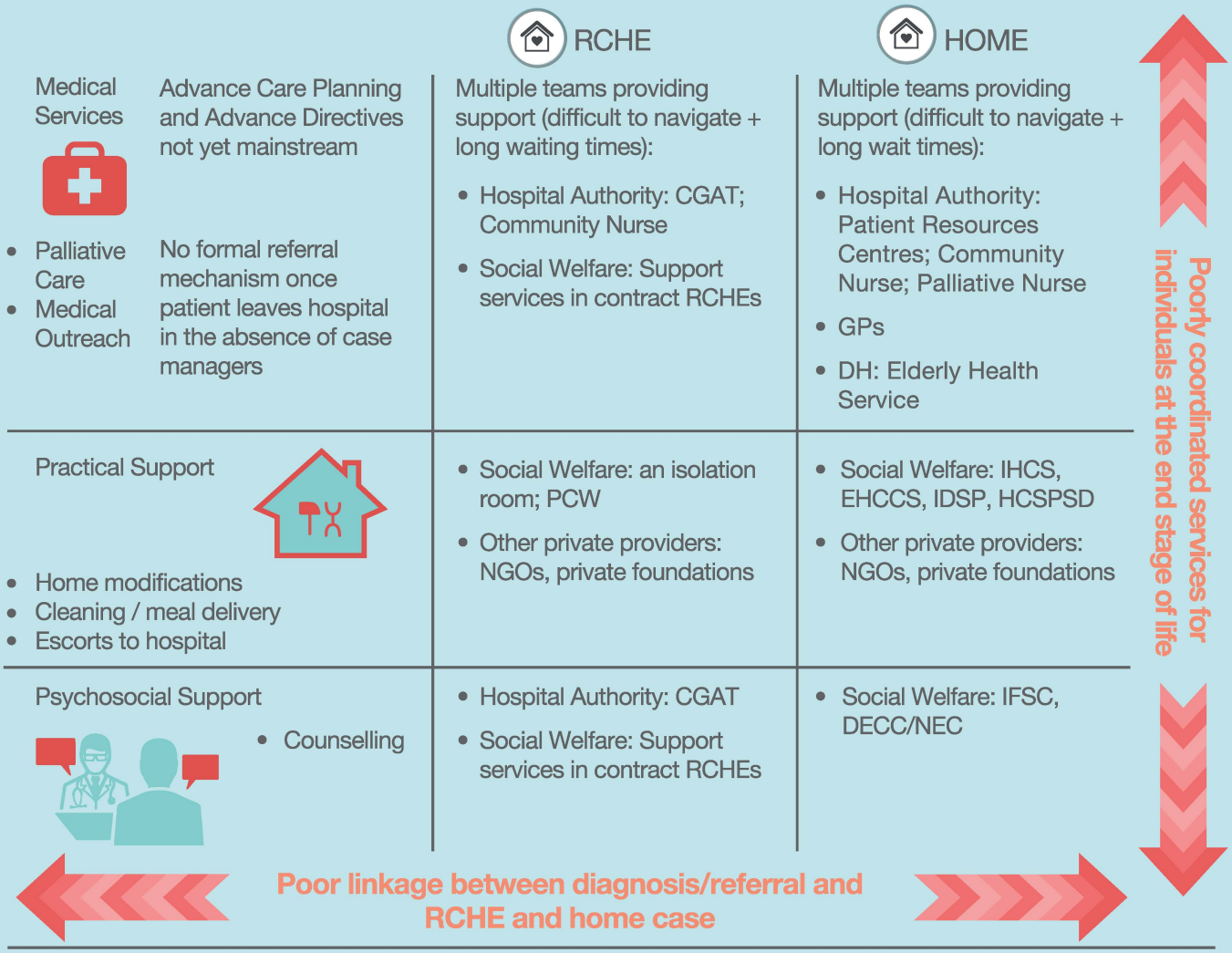
The problem is exacerbated in Hong Kong for four main reasons...

1 Fragmented medical and social services

EoL care services comprise medical services, practical support and psychosocial support. These services exist and are provided by various parties across the continuum from diagnosis to EoL care delivery. However, there are two major problems:

Firstly, there is no formal process linking the patient from the diagnosis of a terminal illness to the services needed at either the Residential Care Home for the Elderly (RCHE) or in the community, once the patient is discharged from hospital. Without a formal referral mechanism and case management, navigating these services can be complex for a patient, not to mention the significant waiting times for practical support.

Secondly, there is no formal link between the different types of support and each party operates in its own silo. This makes it difficult to co-ordinate care services according to the needs of a patient.



Abbreviations

CGAT : Community Geriatric Assessment Team
DECC : District Elderly Community Centre
DH : Department of Health
EHCCS: Enhanced Home and Community Care Services
GPs : General Practitioners
HCSPSD: Home Care Service for Persons with Severe Disabilities
IDSP : Integrated Discharge Support Programme for Elderly Patients
IFSC : Integrated Family Service Centre
IHCS : Integrated Home Care Services
NEC : Neighbourhood Elderly Centre
NGO : Non-Governmental Organisation
PCW : Personal Care Worker

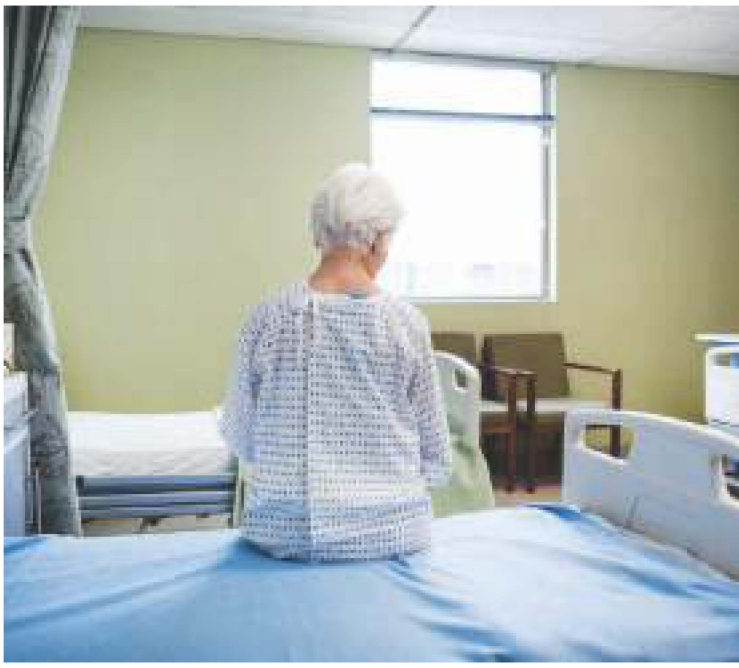
2 Overly medical approach and over-burdened healthcare system

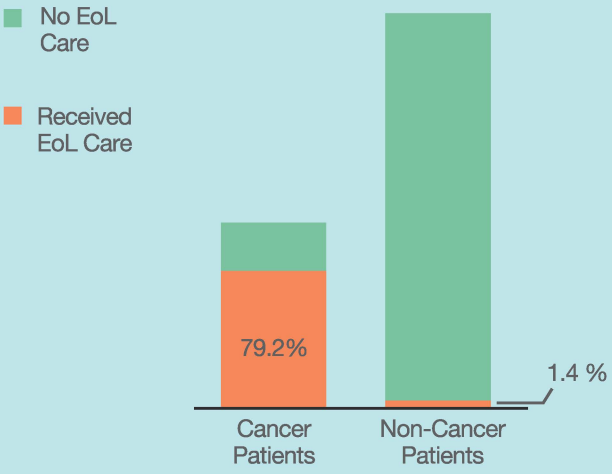
Older people at the end of life need both medical and psychosocial support. When asked "what would be the most important element of EoL care if you were diagnosed to be terminally ill?", psychosocial needs and medical needs were equally prioritised (n=1,067)[3].

Yet, EoL care is regarded as a predominantly medical issue. Currently, 79.2% of cancer patients receive some form of EoL care, in contrast with only 1.4% of non-cancer patients[7].

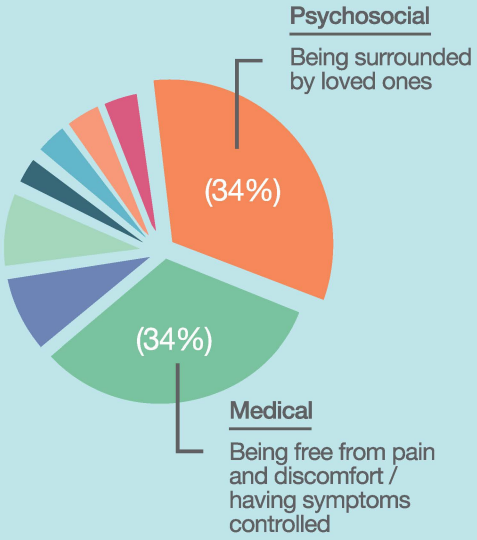
On the one hand, Social Welfare Department requires NGOs to provide relevant services but has no specific budget for EoL care provision. On the other hand, HA is too overwhelmed to provide individualised psychosocial support - while they have a multidisciplinary care team, they still focus on medical needs and provide limited psychosocial support.

This is because HA is significantly short of the manpower to cover the needs of EoL care. Hong Kong has 23 palliative medicine specialists[11] and about 360 palliative care beds to cope with 46,000 deaths/year[15]. Hong Kong has 23.4 nurses per 1,000 palliative care related deaths (non-accidental), half that of Taiwan and one third that of Singapore[2]. In February 2019, the average medical inpatient bed occupancy rate in Hong Kong public hospitals was 103.8%[16].





Ratio of Patients Receiving EoL Care



Priority at the End of Life

(n=1,067)[3]

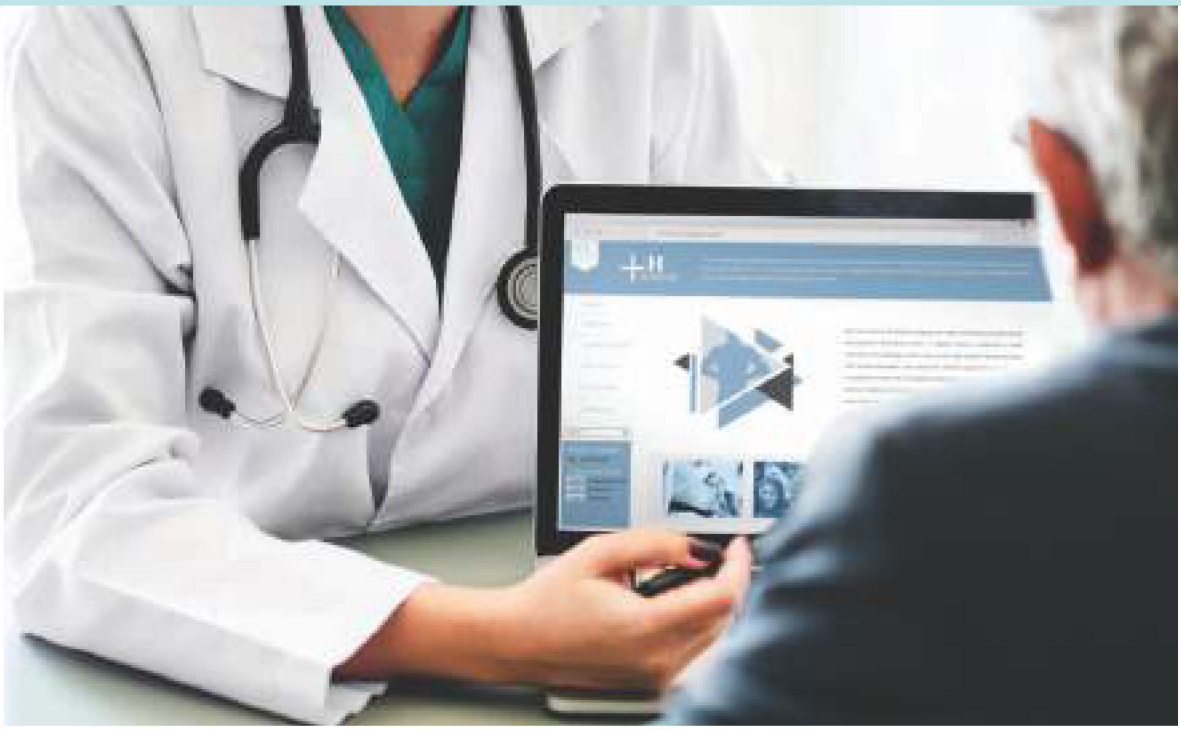
> ***If it were not for the Project Team who organised the briefing session at the elderly home discussion on EoL, I wouldn't know the options that we could choose from for grandma.***
>
> *daughter-in-law of an elderly EoL patient*

3 Low palliative care literacy and priority

Most Hong Kong people are not aware of the need and options for EoL care. They are used to a highly effective and affordable medical system and hold on to the hope that curative treatment can make them live longer.

In the 2015 Quality of Death Index[2], Hong Kong scored 25/100 in the category "Public awareness of palliative care", while Taiwan and Japan scored 75, and Singapore scored 50. It shows the public has limited understanding and awareness of palliative care services. In fact, many medical professionals also have limited knowledge of palliative care. There is little-to-no information available on government portals and community mechanisms.

Moreover, 85.7% of the public have never heard of Advance Directives (ADs)[3]; they do not realise they have a choice in how to be cared for in their final days[17].



> ***At the core, medical doctors are trained in delivering curative care but not in palliative care.***
>
> *Dr Roger Chung*

4 Legal complexity makes end-of-life care and dying in place difficult

Hong Kong has neither statutes in place nor direct case law available on the legal status of ADs. Patients can ask doctors to sign ADs to indicate their preferences on what life-sustaining treatments should not be used during the last days of life, e.g. the desire not to be resuscitated.

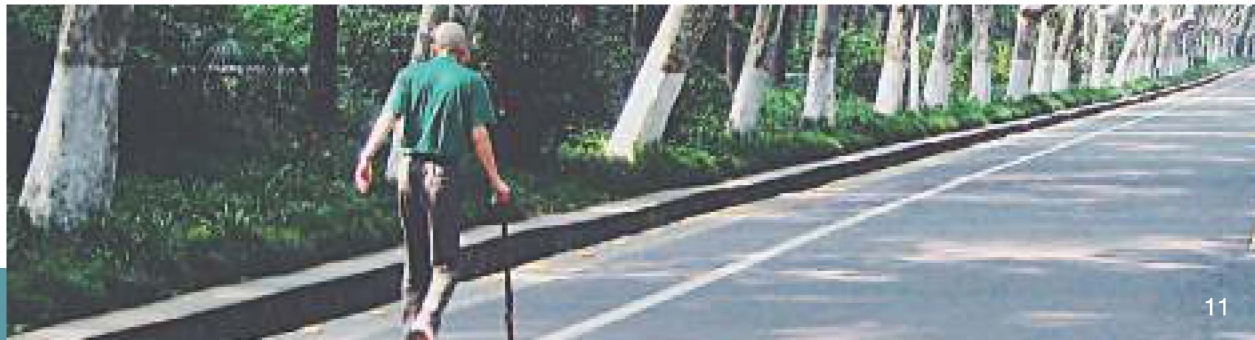
However, there is potential conflict between the patient's wishes of "Do Not Resuscitate" and the obligation of emergency rescue personnel under the Fire Services Ordinance to perform resuscitation on anyone who appears to need prompt or immediate medical attention[18].

Only 5,561 ADs in total were signed during the period 2012 to 2018[19].

Though no law prohibits dying in place in Hong Kong, there is a requirement to report it to a Coroner unless the death occurred at home due to natural causes and the patient was diagnosed as having terminal illness or was attended by a registered medical practitioner during his/her last illness within 14 days prior to death. When a death case occurs at a RCHE, police will be involved and the RCHE needs to go through a series of administrative procedures, including reporting the case to Social Welfare Department.

> ***I was so sad to see my mom suffering from two broken ribs during the resuscitation when the ambulance came...***
>
> *daughter of an RCHE resident*

> ***We are too busy to fill in all the forms needed when we report a death case...***
>
> *Management of RCHE*



To narrow or even close the gap, three paradigm shifts are needed for creating new models and building EoL care capacity:

FROM	TO
Medical	Medical + Psychosocial (person-centred)
Hospital-based	Community-focused
Death as Taboo	Preparation and acceptance of death

Jockey Club End-of-Life Community Care Project (JCECC)

Project Overview

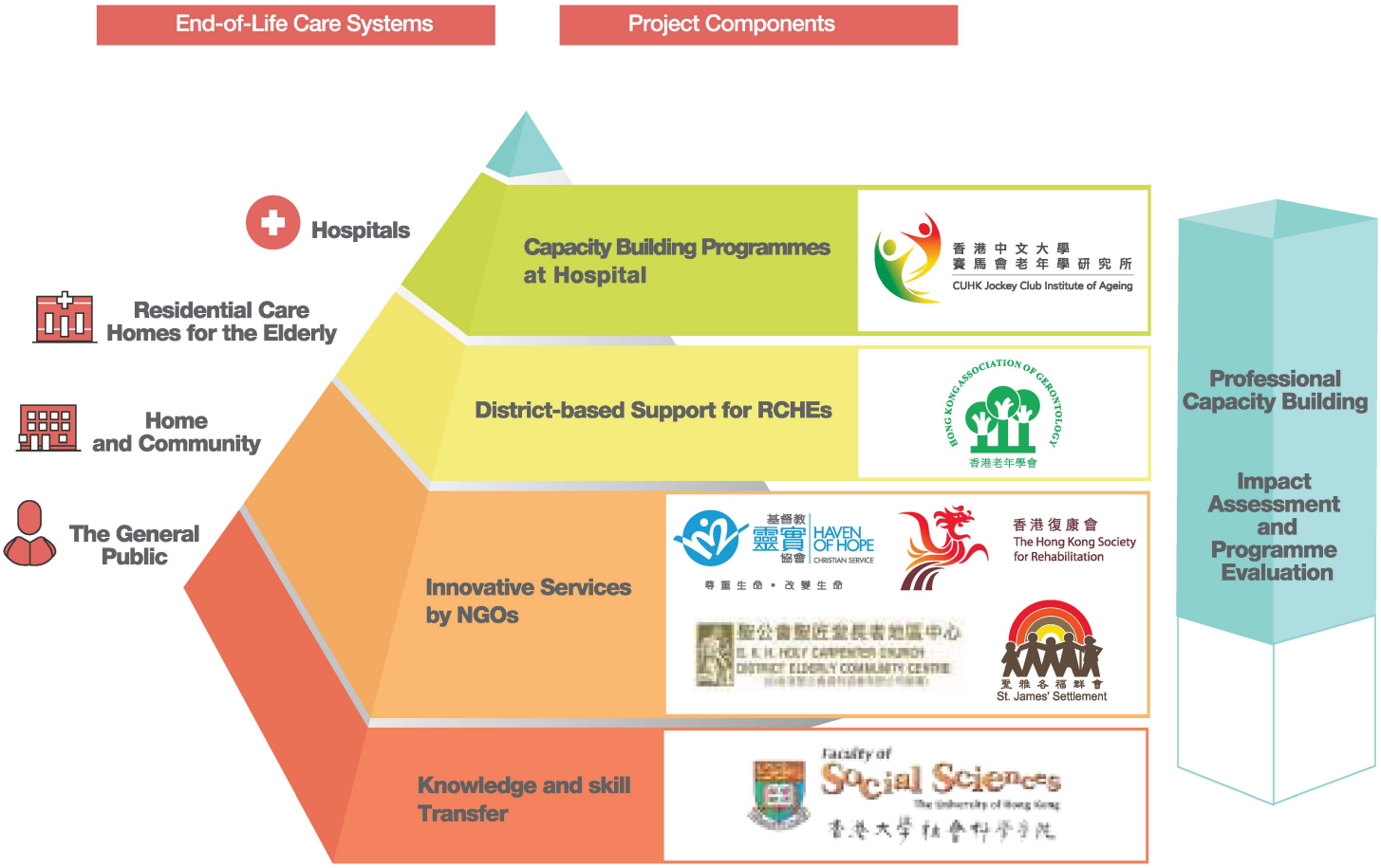
With a view to fostering this paradigm shift, the Trust has earmarked HK$ 255 million to initiate the "Jockey Club End-of-Life Community Care Project" (JCECC). Launched in 2016, the six-year project aims at improving the quality of end-of-life care, enhancing the capacity of service providers, as well as raising public awareness.

JCECC is a multi-disciplinary, multi-institutional and cross-sectoral collaboration to help enhance end-of-life care in Hong Kong with special emphasis on the interface between social and medical systems. Service models are being developed and shaped to provide holistic support to terminally-ill elders in the community and elderly homes. The goal is to enable the city's older people to have informed choices of care and have an improved quality of life.

The Trust's partners in JCECC are The University of Hong Kong Faculty of Social Sciences, The Chinese University of Hong Kong Jockey Club Institute of Ageing, Hong Kong Association of Gerontology, Haven of Hope Christian Service, The Hong Kong Society for Rehabilitation, St James' Settlement, and S.K.H. Holy Carpenter Church District Elderly Community Centre.

Four Distinctive Principles of JCECC

Project Framework



Key Accomplishments

JCECC achieves a wide breadth of coverage in Phase 1 between 2016 and 2018:

Developing evidence-based EoL service models	Capacity Building	Raising Public Awareness
5,002 patients and their family members served	**2,256 professional and frontline staff** of elderly homes trained	**350,000 views** recorded from multi-media channels
36 RCHEs served, covering almost a quarter of all subvented elderly homes in HK	**8,192 healthcare and social care professionals** in hospitals and community trained	**586 volunteers** engaged and trained

JCECC Four Main Project Components

JCECC phase 1 piloted EoL service models in RCHEs and the community, provided capacity building and drove public education.

1. End-of-Life Care Service Model in Elderly Homes

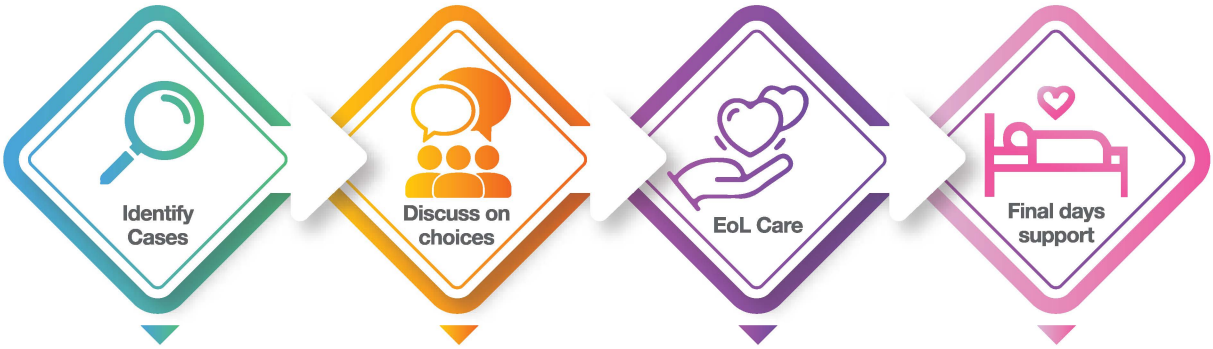
Under JCECC, Hong Kong Association of Gerontology (HKAG) is responsible for piloting a district-based model to support RCHEs in implementing EoL care services.

MODEL HIGHLIGHT:

- HKAG sets up **a care team** to promote EoL concepts and liaise among resident, family members and staff, as well as between RCHE and HA
- HKAG provides **intensive coaching** and **on-site support** to RCHE staff, equipping them with EoL care knowledge and confidence to better identify and cope with residents' needs
- A home-like **EoL room has been set up at each RCHE** for residents to pass their last days surrounded by families in a familiar place, with **24 hours of care**

The model was implemented in 36 RCHEs, representing about one quarter of the total subvented RCHEs in Hong Kong. It adopted a **district-based approach, operating through an EoL multi-disciplinary team**: in each team a nurse (1 to 4 RCHEs) and social worker (1 to 12 RCHEs) worked closely with RCHE staff, HA's CGAT and a Visiting Medical Officer (VMO) to provide person-centred care to residents entering their EoL and their families. Under this model, HKAG helped change the mindset of RCHE staff through structured training programmes on basic palliative and EoL care and on-site coaching.

Service Flow:



Output:

2,256 professional and frontline workers of elderly homes were trained

2,610 residents and family members were served at RCHEs

6 Community Geriatric Assessment Teams of Hospital Authority had collaboration established with Project Team

> ***HKAG's support team give our colleagues full support and they are now more willing and have the confidence in taking care of and handling EoL patients.***
>
> *Management of RCHE*

2. Community-based End-of-Life Care Service Models

Under JCECC, four NGOs piloted innovative community-based service models to enable EoL services to be carried out at the patients' home.

The four models are all underpinned by strategic partnerships with public hospitals, with each model having unique features based on the hospitals' capabilities: e.g. stellar interdisciplinary team, strong family-oriented psychosocial care, active volunteer engagement, and better symptom management. However, the four models share the same six intervention focus area.

Key success factors of these models are the close collaboration with public hospitals on case referral and management; timely and intensive support to patients and their family members using a case management approach; and the training and engagement of volunteers.

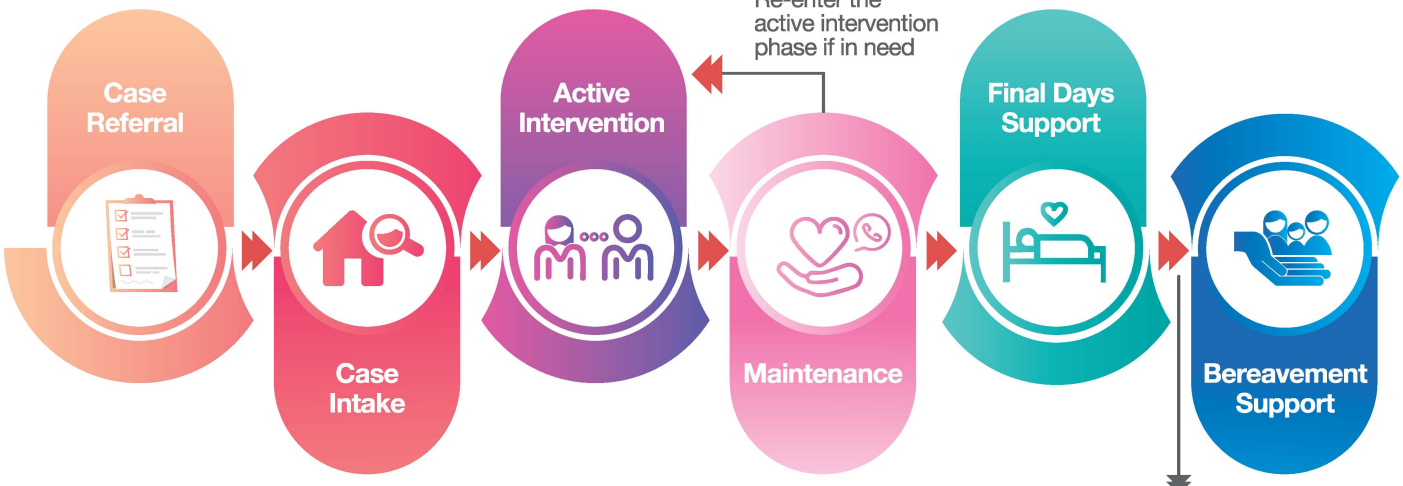
Six Intervention Focus Areas

Typical Service Pathway:

- Symptom management and optimising health functions
- Psychosocial-spiritual support
- Positive death preparation
- Connecting to community resources

by hospital and social service organisations

Re-enter the active intervention phase if in need



case manager visits the patient to understand patient's physical and psychosocial needs

Regular calls/visits by volunteers providing psychosocial support, and regular assessment by social worker

Patient passed away

Collaboration between NGO & Hospital *

* Collaboration between NGO and hospital includes case discussion, seeking advice and referral back, to better utilise existing service provided by hospital

Each NGO tailored its model and offered unique strengths based on its capabilities:

Assisted home-based model	• Established an interdisciplinary team working close on each case • Provided seamless continuity of care through case management • Emphasised psychosocial-spiritual support and focused on facilitating Advance Care Planning
Integrated community-care model	• Adopted a family-oriented care approach to help fulfil the patient's last wishes and encourage quality family time with EoL patients • Helped reduce the family's level of grief after their family member passed away
Volunteer-based community support model	• Actively engaged volunteers to provide psychosocial support to reduce the elderly patient's loneliness and increase their quality of life • Built a strong medical-social partnership with Tuen Mun Hospital through monthly case conferences with the hospital's healthcare team
Non-cancer care model	• Adopted "Integrative Body-Mind-Spirit" techniques • Tailored personal action plans for non-cancer EoL patients to improve their physical well-being with better symptom management

Output:

2,395 patients and family members were served in the community

7 public hospitals of the Hospital Authority had collaboration established with Project Team

586 volunteers were engaged in supporting services in the community

3. Capacity Building Programmes for Professionals and Volunteers

Under JCECC, The University of Hong Kong Faculty of Social Sciences and The Chinese University of Hong Kong Jockey Club Institute of Ageing have trained professionals and built EoL care capacity in community and hospital settings respectively.

HOSPITAL SETTING

Objective

To instil mindset change among healthcare professionals in handling patients with terminal illnesses

How was it conducted?

In total 5,590 medical and allied healthcare professionals were trained by The Chinese University of Hong Kong Jockey Club Institute of Ageing through a multi-pronged programme including talks, workshops, conferences and role-play practice sessions

Five training focus areas

1. Learning how to identify EoL patients
2. Understanding EoL patients' needs and planning their management according to quality of life rather than the standard curative approach
3. Grasping the use of ADs
4. Acquiring communication skills in initiating Advance Care Planning and serious illness conversations with patients and family members
5. Identifying and designing initiatives to overcome barriers to improving the quality of dying

COMMUNITY SETTING

Objective

To enhance the competence of social and health care professionals in EoL care across different levels from top management to frontline practitioners in the community

How was it conducted?

The University of Hong Kong Faculty of Social Sciences organised various events for 2,602 health and social care professionals through talks and seminars, international conferences, leadership training, round-table and executive forums, etc.

Seven training focus areas

1. Overarching values and knowledge
2. Symptom management, comfort of family
3. EoL decision-making
4. Self-care and self-reflection
5. Communication skills
6. Psychosocial and spiritual care
7. Bereavement care

Output:

5,590 healthcare professionals in New Territories East Cluster attended 175 training sessions

539 penultimate and final year medical students attended 21 training sessions

130 leaders, policymakers and key stakeholders were engaged in 6 roundtable and executive forums

47 service leaders, were engaged in two one-year leadership training programmes

56 professional training workshops were delivered by renowned local and international experts

Capacity Building Programmes for Volunteers

Why Volunteers are needed in End-of-Life care

Studies from overseas[20,21] show that volunteers play pivotal roles in EoL care. Volunteers make major contributions in EoL care because they are able to:

- Provide more individualised services to patients and families
- Facilitate person-centred psychosocial and spiritual care
- Engage community stakeholders in providing EoL care services
- Help create a caring atmosphere in the community for supporting EoL patients and their families

The Role of Volunteers in End-of-Life care

The EoL care volunteers under JCECC focused on providing psychosocial support. Depending on the programme design, some volunteers also provided other types of support to patients and families. The roles and functions of EoL care volunteers covered:

- Companionship and social support: visiting patients at home or hospitals, facilitating communication between patients and family members, group activities, accompanying them on outings
- Psychosocial-spiritual care: life review, actualisation of wishes, leisure activities
- Family support: bereavement care to families
- Practical support: escorting to clinics, housekeeping
- Funeral support: accompanying families in arranging and attending funerals
- Physical activities: motivating and teaching patients to do exercises to stay active

Course content:

JCECC developed a standardised training course for volunteers covering:

- EoL care concept
- Late stage symptom care
- Physical-psycho-social and spiritual support
- Art of communication in EoL care
- Self-care
- EoL care decision making
- Life and death education, bereavement

Output:

91 Volunteers enrolled in the four-session centralised volunteer core course

16 Hours of core training delivered

4. Public Education

Key campaigns and productions included…

JCECC organised public education activities to reduce the stigma of "death" in the Chinese culture, reaching an expected 29,025 beneficiaries in the first three years.

JCECC has created an impact in increasing public awareness of death-related topics. A three-year public survey of more than 1,500 respondents each year between 2016 and 2018 showed a significant and steady increase in the percentage of people having heard of EoL care, rising from 30% to 39%[17].

"My Little Story with Mom" mini-movie

JCECC Publications

JCECC Case Videos

Output:

1 MINI-MOVIE "My Little Story with Mom"

42 PUBLIC SEMINARS and FORUMS on various topics conducted by renowned local and international speakers

20+ EPISODES of radio programmes

19 ISSUES of newspaper columns in Ming Pao on EoL care

Strong Evidence-based Outcomes and Impact of Phase 1

JCECC has made progress on the three paradigm shifts by bringing better quality of EoL care to elderly people and their families at the individual level. At the system level, JCECC has enhanced EoL care capability and capacity, and established a stronger social-medical interface to reduce the burden of hospitalisation.

Paradigm Shifts

Medical + Psychosocial (person-centred)

Community-focused

Preparation and acceptance of death

Outcomes

Enhance quality of death for EoL elderly	Support and prepare the family through the journey	Enhance EoL care capability and capacity	Reduce burden of hospitalisation through medical and social collaboration
Provide the elderly with EoL care **choices** in the community and at RCHEs, offering **personalised** care plans in a **familiar** place	Provide practical information and support to reduce **caregivers' burden and anxiety** and improve **communication among family members**	Provide **training** to medical and social care professionals, as well as frontline workers in different settings, to raise **EoL awareness and service capacity**	Strengthen **social-psychological support** and provide **effective interface** between hospitals and NGOs/RCHEs to reduce unnecessary hospitalisation

1 Enhance quality of death for elderly people with terminal illnesses

> ***We wish that during her last days, she can be at peace and comfort. We don't want her to feel the pain…***
>
> *Caregiver*

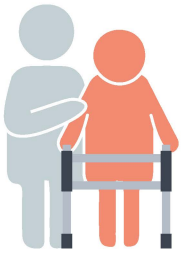
Improving the quality of life at EoL:

An elderly person had always hoped to watch a traditional play at the theatre. After the social workers helped fulfil this wish, he felt encouraged to do more activities at the last stage of his life; for instance, he took a half-day trip to his hometown in Mainland China and made a family portrait. The EoL programme made him and his family realise that dying does not have to be a lifeless experience.

Our evaluation showed that JCECC improved the quality of life of terminally-ill elderly people

55% reduction in **practical problems**

31% reduction in **anxiety** symptoms



47% reduction in **depression** symptoms

15% reduction in **barriers of sharing feelings**

2 Supporting and preparing the family through the end-of-life journey

Tangible support for families:

After patients were discharged from hospital, the EoL team installed adaptive equipment at their homes to make their daily life more convenient. Nurses would provide tailored and professional advice on how to take care of the elderly at home. At RCHEs, EoL care rooms were set up for caring residents at the final stage of life, providing them with 24-hour nursing care and allowed their families to stay overnight. Families were extremely thankful for the timely and high quality EoL care services provided.

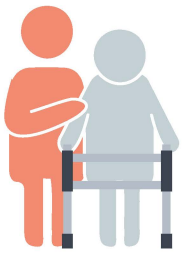
Capacity building for caregivers:

A caregiver learned and applied simple non-verbal communication skills to care for his brother. "My brother couldn't talk anymore. Thus, I followed the instructions of the social worker and used physical touching to communicate with him. He teared up the moment I touched his hands, so did I."

Our evaluation highlighted the clear effectiveness of supporting family members and caregivers:

19% reduction in **caregiver strain**

27% reduction in **family anxiety**



> ***They helped us plan in advance…unite the whole family to paint together with grandma. Now the painting is a precious souvenir for us.***
>
> *Family*

3 Enhancing end-of-life care capability and capacity

> ***Staff used to be afraid of even going into an EoL room. Now they are not afraid anymore...***
>
> *Nurse*

Empowering frontline workers:

Some doctors, nurses and personal care workers explained how the EoL training empowered them to provide more psychosocial support to terminally-ill seniors - "We learned how to design individualised care plans for each EoL patient."

Our evaluation highlighted the effectiveness of JCECC's capacity building programmes

89.8% of **case referrers** would recommend the services to others

47.5% improvement in **leadership skills** among trained NGO leaders

23.4% improvement in **overall EoL care competencies** among participants in professional training programmes

36.9% increase in the number of RCHEs had **established written guidelines, policies, procedures and mechanisms** for EoL care

4 Reducing burden of hospitalisation by linking up medical and social sectors

An estimated cost savings of HK$26,000 for each patient:

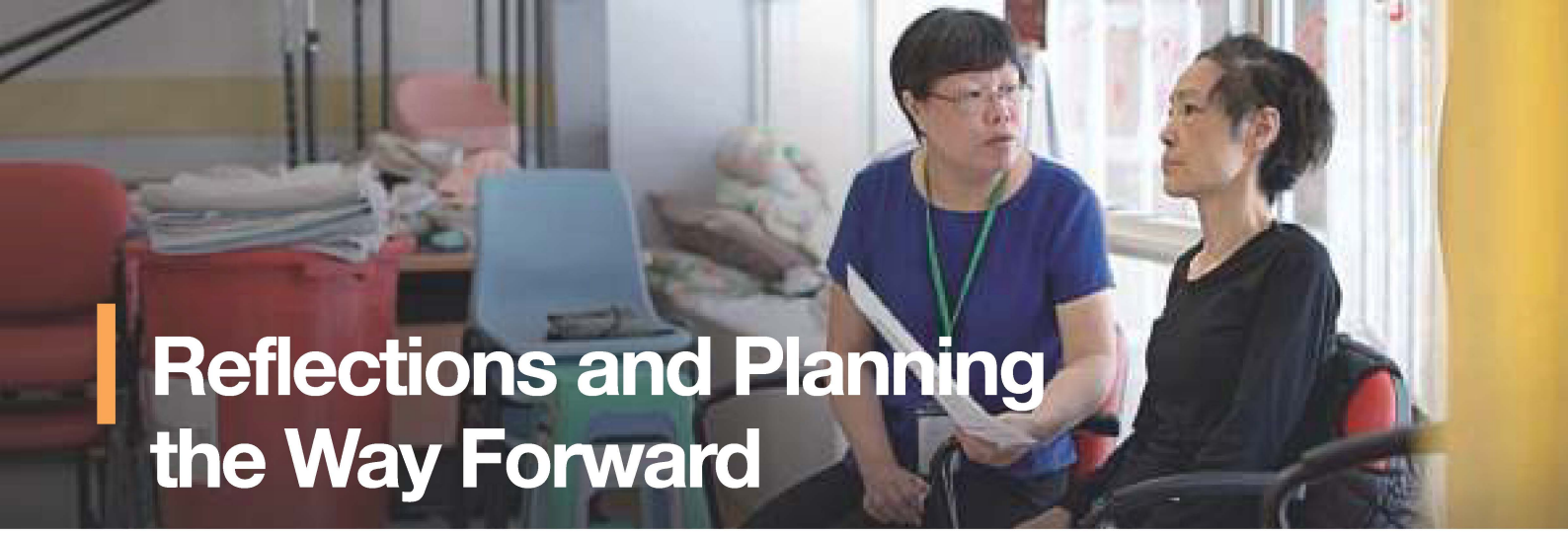
Our evaluation showed the potential of the JCECC programme to reduce the burden of hospitalisation by providing community-based EoL care services for terminally-ill elders in the last six months of their lives:

22.2% **ICU** bed days saved

12.5% reduction in **length of stay** in hospital

11.6% reduction in **A&E** attendance

> ***Through the programme we now have a monthly case conference with the NGO to look at the case from a medical-social perspective...***
>
> *Dr Cheng from Tuen Mun Hospital*



Reflections and Planning the Way Forward

Reflections and Challenges in Phase 1

End-of-Life care is a complex issue, and we share our reflections on the challenges at three levels: the individual, the system and the community.

At the individual level

The prognosis of non-cancer end-stage disease remains tricky for physicians, and it can be difficult to meet each patient's needs for care perfectly, since care needs vary among individuals and along different disease trajectories. Changing the mindset of frontline practitioners and professionals was challenging, but not impossible.

For families and caregivers, communicating and confronting the topic of death remains challenging. The stress of caregivers is often higher than the patient's stress and often insufficiently addressed and supported. Therefore, in thinking of EoL care, the whole family should be regarded as a unit of care and supported through Advance Care Planning and psychosocial intervention.

Advance Care Planning is needed to facilitate communications between patients, family members and care providers. Psychosocial interventions have been proven to improve physical and emotional symptoms and reduce unnecessary hospitalisation.

At the system level

The medical and social care sectors require more trust-building to fully realise interdisciplinary collaboration and continuity of care.

The legal barriers are also important. There is a need to clarify the legal basis for mental incapacity and address the legal barriers for ADs. This includes resolving issues with the Fire Services Ordinance, where the current requirement to resuscitate might conflict with Do-Not-Attempt Cardiopulmonary Resuscitation or AD decisions.

The burden is also great for elderly care workers in residential care homes; long working hours and continued high stress culminate in high staff turnover rates, making it difficult to attract and retain the labour required. Even though competency training has been shown to be effective, staff are often too busy to attend it, despite recognising its value.

At community level

There is a growing number of EoL patients due to the overall ageing population. More elderly people are also living alone or apart from their families, while EoL care coverage is being expanded to non-cancer diseases. It is clear that the current formal services alone cannot meet this growing demand, and that informal, community-based services – for example through volunteerism – will be needed to meet future needs for EoL care in the community.

Making community-based care a reality will require far greater public awareness and mindset changes. Hong Kong will need to put much more effort into raising public awareness and knowledge of EoL care.

Way Forward

Phase 2 focuses on preparing JCECC's model to be widely adopted in Hong Kong and will focus on four key areas:

In response to the reflections and challenges from Phase 1, Phase 2 will prioritise four opportunity areas that will help strengthen the potential for JCECC components to be mainstreamed and regularised into existing services.

1. Standardise the service model

While different service models were tested in Phase 1, Phase 2 will see the models standardised and needs-based assessments adopted. The cost-effectiveness of this standardised service will be assessed, and specific manpower resource requirements determined, so that it is clear what incremental cost and labour requirements would be needed for incorporation into Government services.

In addition, service improvements will be made to further strengthen psychosocial interventions and develop comprehensive community-based EoL care, including a review of how to recruit, train and incentivise informal caregivers in the community, and scale their quality and quantity.

2. Accelerate capacity building

Phase 2 will see capacity building accelerated by the design of a training curriculum and the establishment of an online platform to make training more flexible and accessible. This will enable training to fit better into routine work by making the courses shorter and more frequent – especially important given the current high staff turnover rates.

Opportunities to integrate training earlier into student curricula will also be explored, as well as new specialisations for professionals, and new service protocols for sharing the operating models and best practices with other service providers in the field.

3. Expand stakeholder and Government engagement

Achieving community-based care requires primary care, most of which is in the private sector in Hong Kong. Phase 2 will explore how to engage private sector professionals in providing community-based EoL care. In addition, JCECC will continue to work closely with the Government to propose a plan for their reference as they look towards service sustainability.

4. Create a movement to change mindsets

Phase 2 needs to go beyond individual awareness campaigns to create a consolidated, powerful movement that can change mindsets and shift social norms on EoL care. This will involve expanding the coverage of community education to all districts both online and offline, encouraging volunteerism, and promoting practical solutions such as Advance Care Planning to spark conversation and open dialogue between families and the community.

The aforementioned four key areas map closely to the low scores for Hong Kong on the Quality of Death Index. Together, we can move the needle on Hong Kong's position and improve the quality of life for elderly people at their EoL.

Indicators where Hong Kong scored a "moderate" or "lower" score on Quality of Death Index 2015[2].

	Indicators	JCECC' s focus areas
Lower Score	• Healthcare spending	
	• Capacity to deliver palliative care	✓
	• Number of nurses per 1,000 palliative care-related deaths	✓
	• Presence of Do Not Resuscitate (DNR) policy	
	• Public awareness of palliative care	✓
Moderate Score	• Availability of research-based policy evaluation	
	• General medical knowledge of palliative care	✓
	• Number of doctors per 1,000 palliative care-related deaths	
	• National pension scheme coverage of palliative care services	
	• Use of patient satisfaction surveys	✓
	• Availability of volunteer workers for palliative care	✓

JCECC can move the needle on Quality of Death Index given its focus on increasing service capacity, public education and awareness and capacity building for professionals.

Conclusion

In Hong Kong, EoL care is a complex issue and systematic efforts are needed to address demand, supply and linkage within the ecosystem.

On the demand side, a movement is needed to shift social norms so the general public understands the concept of choice at the end of life and actively asks for and demands EoL care services.

On the supply side, both formal care services and community-based, informal support services need to be strengthened with urgency. Greater attention to psychosocial support is needed, as well as a primary focus on growing community-based, informal care, as formal services will never be enough to meet growing demand. This will require new collaborations and partnerships, including stronger primary care integration with GPs and allied health professionals, together with well-co-ordinated and scalable volunteer networks.

Finally, the overall ecosystem needs to be better linked through stronger case management and active medical social workers. Systems need to talk to one another and provide seamless transition so that care can be much more person-centred than disease-centred.

JCECC provides a big step forward along this journey and represents the systems approach that is needed. It presents a collaborative and evidence-based model for addressing choice and quality of death in the Chinese cultural context and lays the groundwork for changing the whole ecosystem and practice of EoL care in Hong Kong.

We hope this case study inspires society to ponder on the related issues of EoL care and that we can all work together to improve the quality of death and care in Hong Kong and across the region.

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Glossary

AD	Advance Directives
A&E	Accident & Emergency
CGAT	Community Geriatric Assessment Team
DECC	District Elderly Community Centre
DH	Department of Health
EHCCS	Enhanced Home and Community Care Services
EoL	End-of-Life
GP	General Practitioner
HA	Hospital Authority
HCSPSD	Home Care Service for Persons with Severe Disabilities
IDSP	Integrated Discharge Support Programme for Elderly Patients
IFSC	Integrated Family Service Centre
IHCS	Integrated Home Care Services
JCECC	Jockey Club End-of-life Community Care Project
NEC	Neighbourhood Elderly Centre
NGO	Non-Government Organisation
PCW	Personal Care Worker
RCHE	Residential Care Home for the Elderly
VMO	Visiting Medical Officer

The Hong Kong Jockey Club Charities Trust's Role in JCECC

- Initiate and fund the project
- Identify the right partners
- Foster cross-sector collaboration
- Engage Government and relevant stakeholders

The Advisory Committee represents a wide range of stakeholder groups

The Trust invited key Government stakeholders, namely Food and Health Bureau, Labour and Welfare Bureau, the Hospital Authority and Social Welfare Department to provide guidance and advice on the JCECC project. The exchange and close engagement has been maintained yearly throughout the project life.

Convenor

- Executive Director, Charities and Community, The Hong Kong Jockey Club

Advisory Committee Members

- Under Secretary for Food and Health, Food and Health Bureau
- Permanent Secretary for Labour and Welfare, Labour and Welfare Bureau
- Chairman, Elderly Commission
- Chief Executive, Hospital Authority
- Deputy Director of Social Welfare (Services), Social Welfare Department
- Director, The Jockey Club School of Public Health and Primary Care, The Chinese University of Hong Kong
- Chief Executive, The Hong Kong Council of Social Service
- Representative from The Hong Kong College of Family Physicians

Ex-officio Members

- 6 ex-officio members from the Project Team

賽馬會安寧頌

JCECC

Jockey Club End-of-Life Community Care Project

www.jcecc.hk

Initiated and 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

Project Partners

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CUHK Jockey Club Institute of Ageing

Faculty of Social Sciences

香港老年學會

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