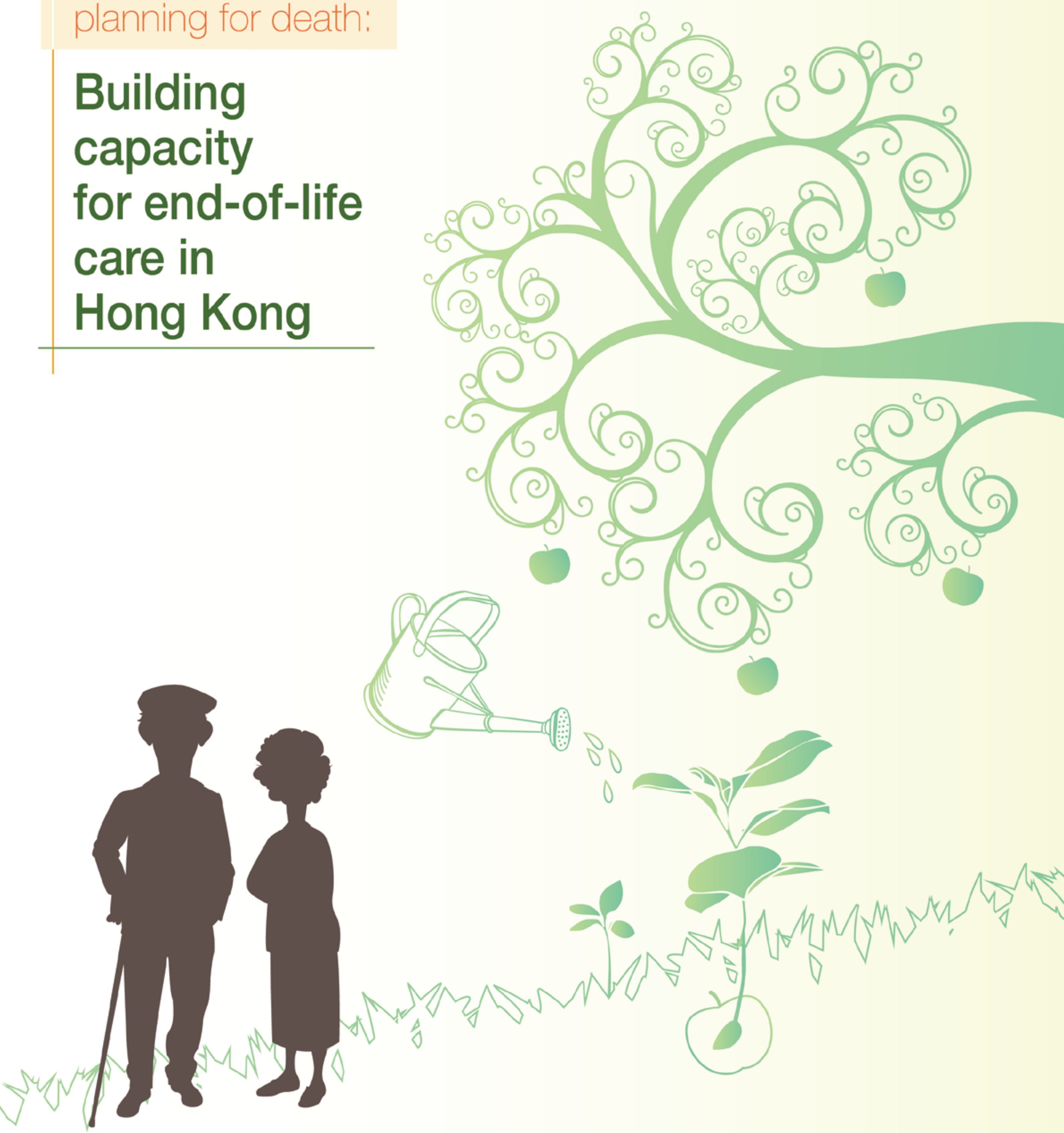
賽馬會安寧頌
JCECC
Jockey Club End-of-Life Community Care Project

Learning for life,
planning for death:

Building capacity for end-of-life care in Hong Kong



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香港中文大學
The Chinese University of Hong Kong

香港中文大學賽馬會老年學研究所
CUHK Jockey Club Institute of Ageing

Learning for life, planning for death: Building capacity for end-of-life care in Hong Kong

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Preface: The Hong Kong Jockey Club

Hong Kong is facing a rapidly ageing population. Not only is the number of elderly people suffering from terminal illnesses set to increase, but also the demand for end-of-life care will see significant growth.

To address these evolving challenges, The Hong Kong Jockey Club Charities Trust earmarked HK$131 million in 2015 to fund the Jockey Club End-of-Life Community Care (JCECC) project, a three-year initiative aimed at promoting dignified, holistic and person-centred end-of-life care for patients in their final journey of life.

The importance of building professional capacity for delivering such services has been widely recognised, as the palliative needs of patients are usually complex. With the concerted efforts of our project partners, more than 7,400 health and social care professionals from hospital and community settings have already been trained in specific end-of-life care knowledge and skills during the past two-and-a-half years. Among the various capacity building programmes, the CUHK Jockey Club Institute of Ageing has put emphasis on nurturing health care practitioners to provide end-of-life care in hospitals. They have laid the foundation for future service development by building a high quality and sustainable workforce.

As one of the world's top ten charity donors, the Club’s Charities Trust proactively identifies and initiates projects that anticipate future community and social needs. We have designated four areas of strategic focus, namely Youth, the Elderly, Sports, and Arts, Culture and Heritage. Under the elderly strategy, we attach great importance to advocating positive ageing and enhancing the quality of life of Hong Kong's senior citizens. One of our Trust-initiated projects, JCECC, is a notable example of this.

On behalf of The Hong Kong Jockey Club Charities Trust, I would like to express my deepest gratitude to the JCECC Project Team, and particularly thank the CUHK Jockey Club Institute of Ageing for their efforts in strengthening capacity in this field, as well as helping to build end-of-life care knowledge within the local community.

Mr Leong Cheung
Executive Director, Charities and Community
The Hong Kong Jockey Club

Preface: CUHK Jockey Club Institute of Ageing

In the light of an ageing population in Hong Kong, an increasing number of people are suffering from various life-limiting conditions, thus driving the demand for end-of-life care. Nevertheless, an overemphasis on curative treatment in hospitals and the community results in unnecessary suffering for many patients. We need change, and the change agent is available.

In this context, it is timely for The Hong Kong Jockey Club Charities Trust to launch the three-year Jockey Club End-of-Life Community Care Project in 2015. As one of the project partners, CUHK Jockey Club Institute of Ageing implemented a capacity building and education programme in the New Territories East Cluster of the Hospital Authority. We partnered with the Hospital Authority and community organizations to train health and social care workers, and educated patients, carers, and the public on end-of-life care. This publication documents the fruit of our group effort on the programme, which has witnessed better communication skills in end-of-life care and knowledge gain of advance directives, advance care planning, wills, and enduring powers of attorney, among other things.

On behalf of the Institute, I would like to express my gratitude to the support by The Hong Kong Jockey Club Charities Trust. The outcome and impact of the programme in the New Territories East Cluster could serve as valuable references for programme planners to improve end-of-life care in other parts of Hong Kong. The Institute will continue to collaborate with different partners to contribute to end-of-life care in Hong Kong, thereby improving the quality of life and quality of death of elderly patients.

Prof Jean Woo, MD, FRCP, FRACP
Director, CUHK Jockey Club Institute of Ageing
The Chinese University of Hong Kong

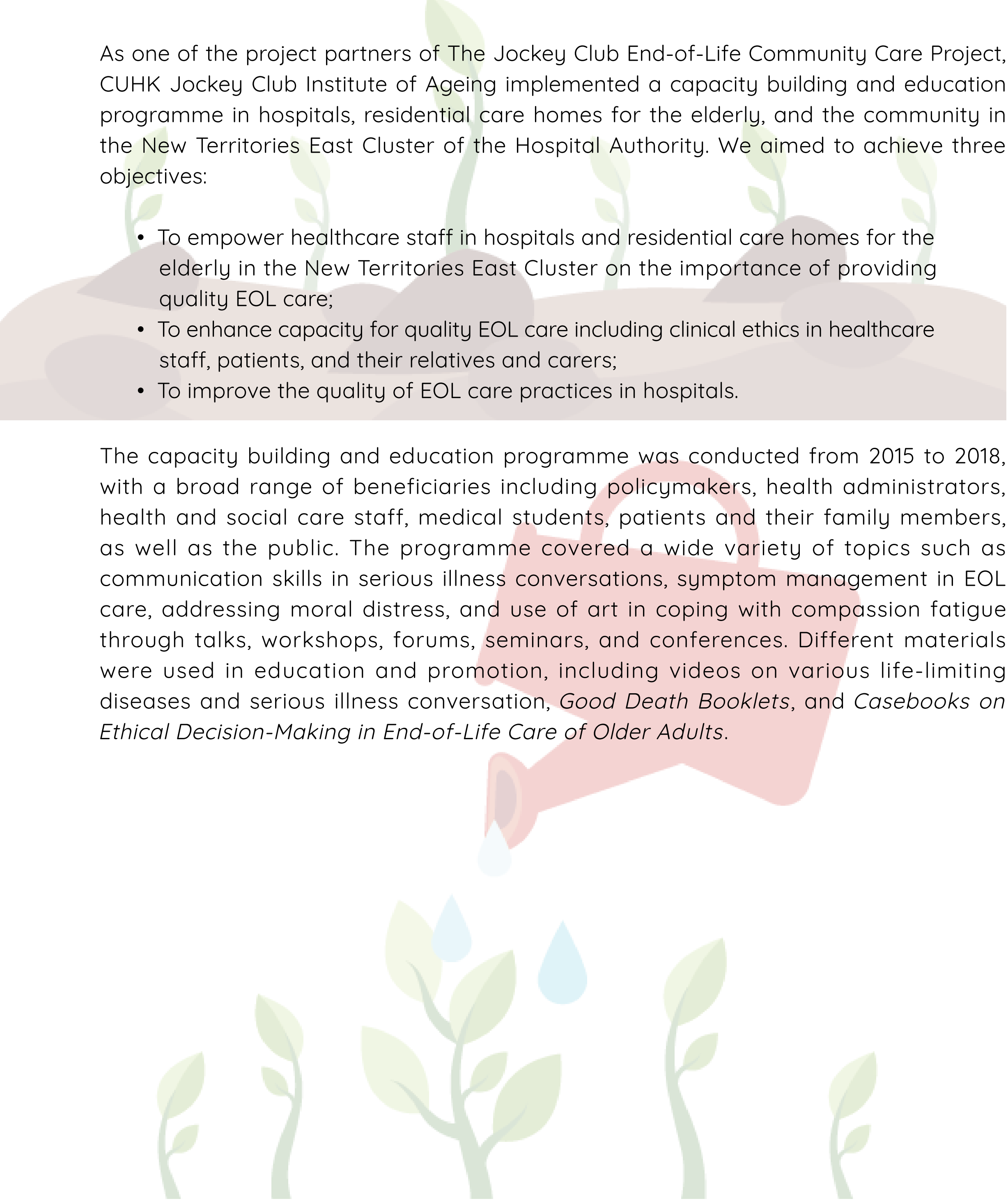
Executive Summary

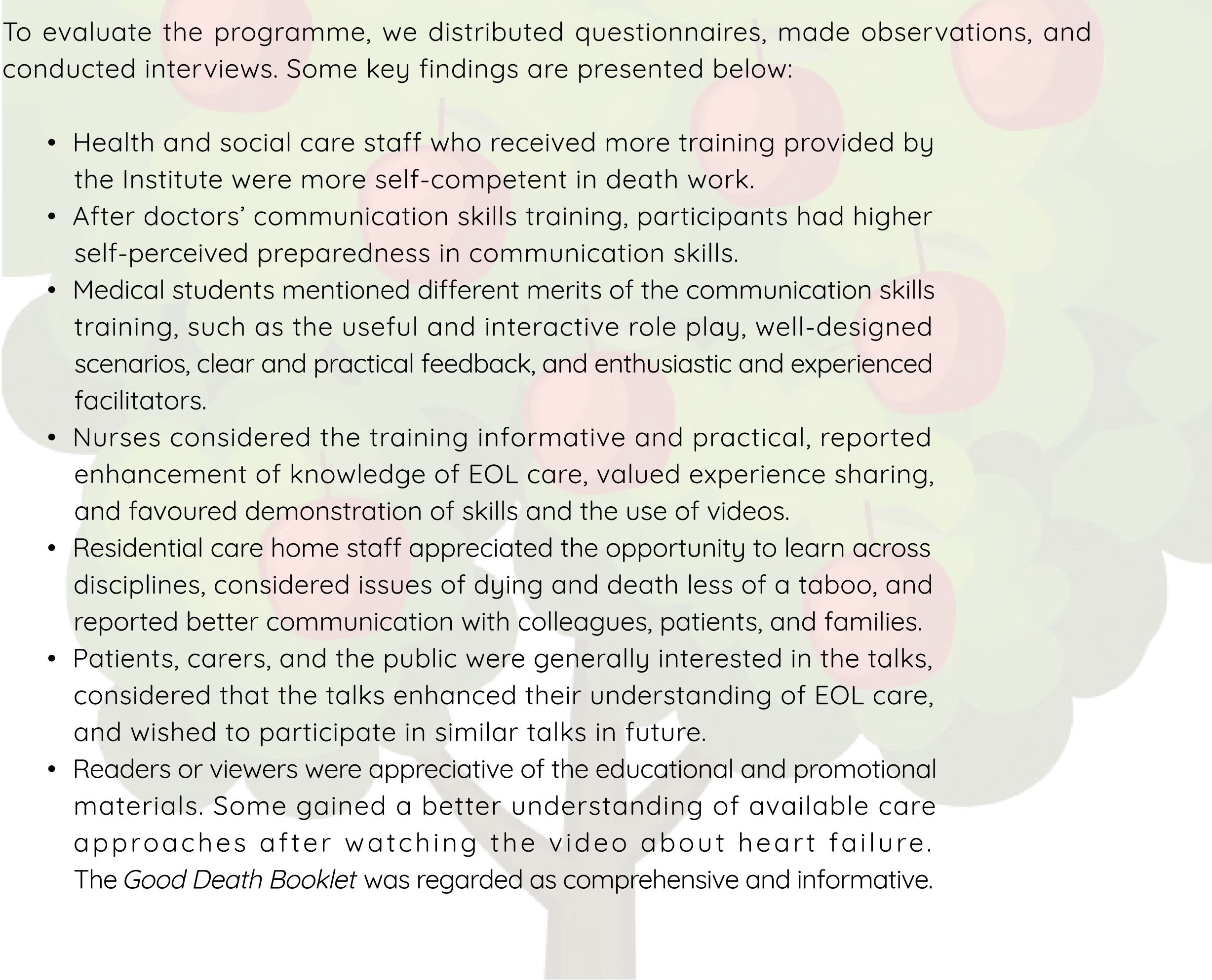
Inadequate end-of-life (EOL) care is affecting an ageing Hong Kong. We are facing a myriad of problems in this domain, such as an overemphasis on curative treatment; a lack of attention on EOL care for non-cancer patients; poor public awareness of advance directives; insufficient support for family carers; and ineffective communication among patients, families, and healthcare professionals. It is time to reflect on how we can ameliorate the situation.

As one of the project partners of The Jockey Club End-of-Life Community Care Project, CUHK Jockey Club Institute of Ageing implemented a capacity building and education programme in hospitals, residential care homes for the elderly, and the community in the New Territories East Cluster of the Hospital Authority. We aimed to achieve three objectives:

- To empower healthcare staff in hospitals and residential care homes for the elderly in the New Territories East Cluster on the importance of providing quality EOL care;
- To enhance capacity for quality EOL care including clinical ethics in healthcare staff, patients, and their relatives and carers;
- To improve the quality of EOL care practices in hospitals.

The capacity building and education programme was conducted from 2015 to 2018, with a broad range of beneficiaries including policymakers, health administrators, health and social care staff, medical students, patients and their family members, as well as the public. The programme covered a wide variety of topics such as communication skills in serious illness conversations, symptom management in EOL care, addressing moral distress, and use of art in coping with compassion fatigue through talks, workshops, forums, seminars, and conferences. Different materials were used in education and promotion, including videos on various life-limiting diseases and serious illness conversation, *Good Death Booklets*, and *Casebooks on Ethical Decision-Making in End-of-Life Care of Older Adults*.





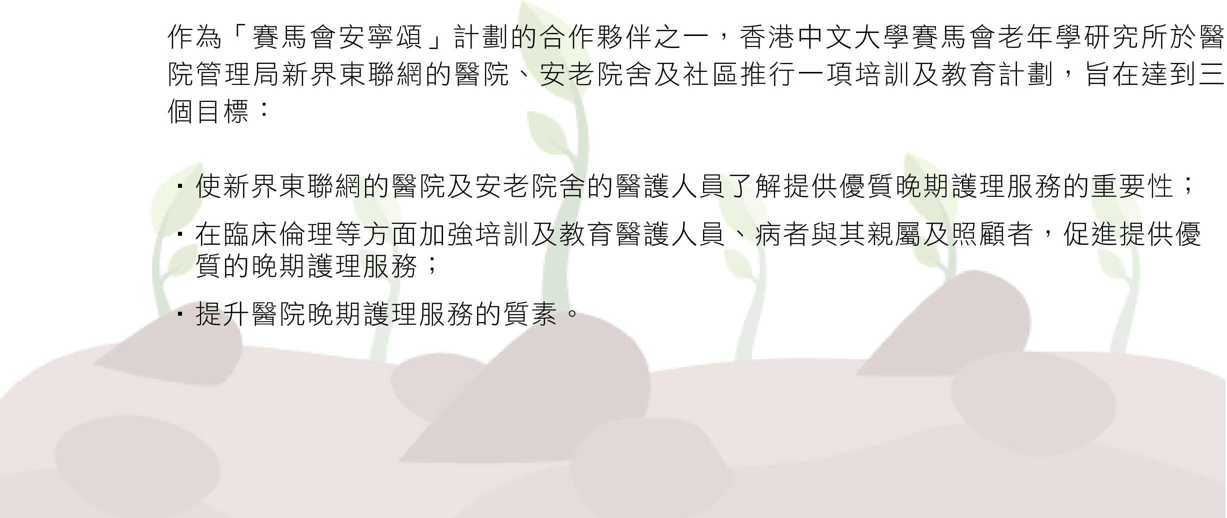
To evaluate the programme, we distributed questionnaires, made observations, and conducted interviews. Some key findings are presented below:

- Health and social care staff who received more training provided by the Institute were more self-competent in death work.
- After doctors' communication skills training, participants had higher self-perceived preparedness in communication skills.
- Medical students mentioned different merits of the communication skills training, such as the useful and interactive role play, well-designed scenarios, clear and practical feedback, and enthusiastic and experienced facilitators.
- Nurses considered the training informative and practical, reported enhancement of knowledge of EOL care, valued experience sharing, and favoured demonstration of skills and the use of videos.
- Residential care home staff appreciated the opportunity to learn across disciplines, considered issues of dying and death less of a taboo, and reported better communication with colleagues, patients, and families.
- Patients, carers, and the public were generally interested in the talks, considered that the talks enhanced their understanding of EOL care, and wished to participate in similar talks in future.
- Readers or viewers were appreciative of the educational and promotional materials. Some gained a better understanding of available care approaches after watching the video about heart failure. The *Good Death Booklet* was regarded as comprehensive and informative.

With the work accomplished and experience gathered during these three years of capacity building, we have gained valuable insights to guide future strategies. They also served as foundation for our future work to improve EOL care in Hong Kong.

行政摘要

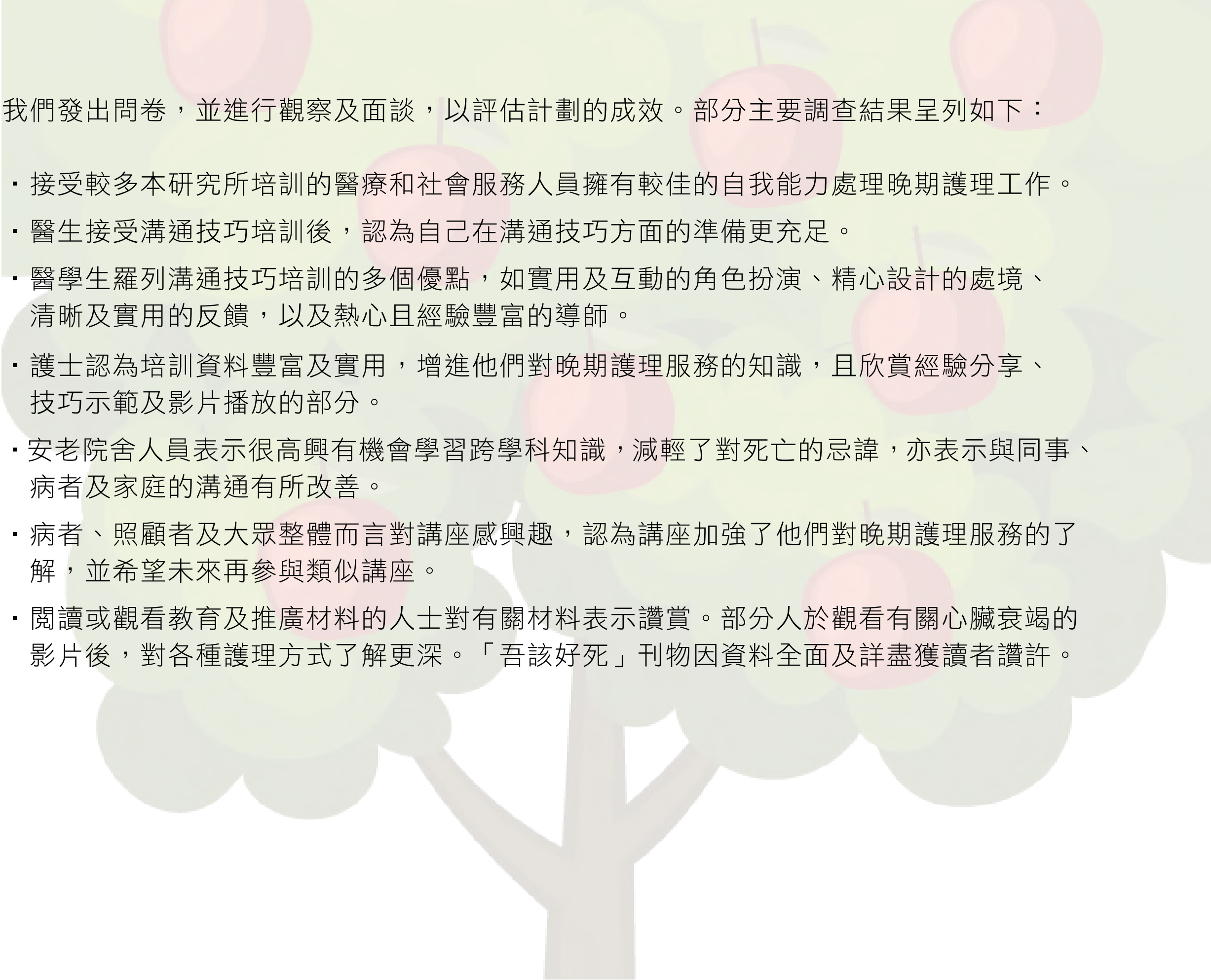
晚期護理服務不足持續影響日趨老化的香港。我們在這方面面對一系列的問題，例如過分強調治癒性治療、對非癌症病者的晚期護理服務關注不足、大眾對預設醫療指示缺乏認知、家庭照顧者欠缺支援，以及患者、家庭及醫護人員之間溝通不良。現在是時候反思我們應如何改善這個境況。



作為「賽馬會安寧頌」計劃的合作夥伴之一，香港中文大學賽馬會老年學研究所於醫院管理局新界東聯網的醫院、安老院舍及社區推行一項培訓及教育計劃，旨在達到三個目標：

- 使新界東聯網的醫院及安老院舍的醫護人員了解提供優質晚期護理服務的重要性；
- 在臨床倫理等方面加強培訓及教育醫護人員、病者與其親屬及照顧者，促進提供優質的晚期護理服務；
- 提升醫院晚期護理服務的質素。

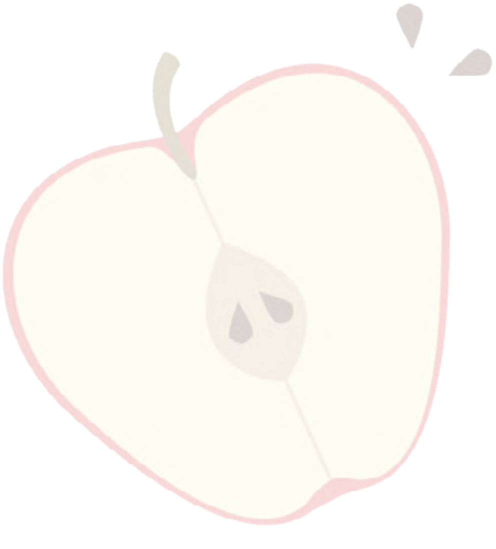
培訓及教育計劃於2015至2018年間推行，惠及各界人士，包括決策者、醫療機構的管理人員、醫療和社會服務人員、醫學生、病者及其家庭成員以至大眾。計劃以講座、工作坊、論壇、座談會及大型會議形式涵蓋廣泛題材，如嚴重疾病對話的溝通技巧、晚期病者的症狀管理、處理道德困擾，以及運用藝術緩解悲慟疲憊等。教育及推廣工作方面運用到各類材料，包括關於不同危疾重症及嚴重疾病對話的影片、「吾該好死」刊物以及「年長病人晚期護理服務醫學倫理個案集」。



我們發出問卷，並進行觀察及面談，以評估計劃的成效。部分主要調查結果呈列如下：

- 接受較多本研究所培訓的醫療和社會服務人員擁有較佳的自我能力處理晚期護理工作。
- 醫生接受溝通技巧培訓後，認為自己在溝通技巧方面的準備更充足。
- 醫學生羅列溝通技巧培訓的多個優點，如實用及互動的角色扮演、精心設計的處境、清晰及實用的反饋，以及熱心且經驗豐富的導師。
- 護士認為培訓資料豐富及實用，增進他們對晚期護理服務的知識，且欣賞經驗分享、技巧示範及影片播放的部分。
- 安老院舍人員表示很高興有機會學習跨學科知識，減輕了對死亡的忌諱，亦表示與同事、病者及家庭的溝通有所改善。
- 病者、照顧者及大眾整體而言對講座感興趣，認為講座加強了他們對晚期護理服務的了解，並希望未來再參與類似講座。
- 閱讀或觀看教育及推廣材料的人士對有關材料表示讚賞。部分人於觀看有關心臟衰竭的影片後，對各種護理方式了解更深。「吾該好死」刊物因資料全面及詳盡獲讀者讚許。

從這三年培訓的工作成果及經驗，我們累積了寶貴的知識。這些知識指引未來的工作策略，並為改進香港未來的晚期護理服務奠下基礎。

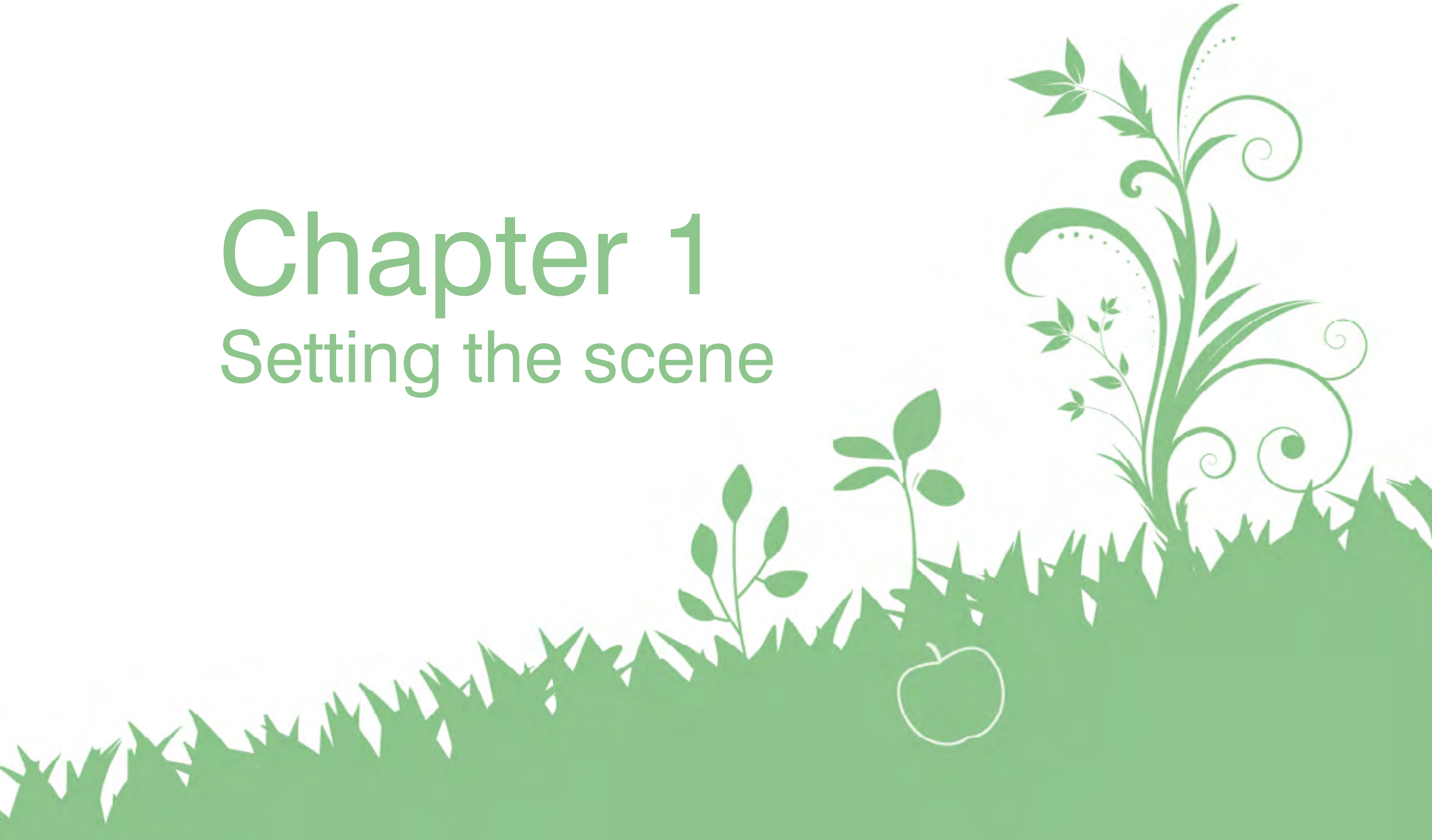


Abbreviations

ACP	Advance care plan/planning
AD	Advance directive
A&E	Accident and Emergency Department
AHNH	Alice Ho Miu Ling Nethersole Hospital
BBH	Bradbury Hospice
BiPAP	Bi-level positive airway pressure
CGAT	Community Geriatric Assessment Team
COPD	Chronic obstructive pulmonary disease
CPR	Cardiopulmonary resuscitation
CUHK	The Chinese University of Hong Kong
DNACPR	Do-Not-Attempt Cardiopulmonary Resuscitation
EOL	End of life
HA	Hospital Authority
ICU	Intensive Care Unit
JCECC	Jockey Club End-of-Life Community Care Project
NDH	North District Hospital
NGO	Non-governmental organization
NIV	Non-invasive ventilation
NTEC	New Territories East Cluster
NURSE	Naming, Understanding, Respecting, Supporting, Exploring
PWH	Prince of Wales Hospital
RCHE	Residential care home for the elderly
SC-DWS	Self-Competence in Death Work Scale
SCH	Cheshire Home, Shatin
SD	Standard deviation
SH	Shatin Hospital
SICG	Serious Illness Conversation Guide
TPH	Tai Po Hospital
TWGHs	Tung Wah Group of Hospitals
UK	United Kingdom
US	United States

Chapter 1

Setting the scene



1.1. International situation

In tandem with population ageing, chronic disease burden is ever-increasing, giving rise to a huge demand for palliative care throughout the world (Hall, Petkova, Tsouros, Costantini, & Higginson, 2011). It has been estimated that over 20 million people require palliative care in the last stage of their life in a single year (Connor & Bermedo, 2014). In 2015, palliative care across the globe was evaluated in terms of quality, availability, and affordability, resulting in compilation of the Quality of Death Index (The Economist Intelligence Unit, 2015b). Overall, Hong Kong ranked 22nd, way behind some Western countries such as the United Kingdom (UK; 1st) and the United States (US; 9th), as well as some Asian countries including Taiwan (6th) and Singapore (12th). A brief description of perspectives from the UK and the US is presented below.

1.1.1. Perspectives from the UK

A large-scale project was undertaken in 2015 by the British Medical Association to understand doctors' and the public's views on end-of-life (EOL) care (British Medical Association, 2017). It has been recommended that EOL care should be high on the agenda and be supported by a clear plan and ample funds, publicity campaigns providing accurate information on EOL care and motivating people to consider their EOL care preferences should be launched, mechanisms for collating and publishing data on EOL care should be implemented, and provision of EOL care with better communication skills should be emphasized as an indispensable component of doctors' and medical students' training (British Medical Association, 2016).

In the publication ***Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*** (National Partnership for Palliative and End of Life Care, England, 2015), six ambitions are proposed for delivery of quality care. These include recognizing the uniqueness of each person, ensuring fair access to care for all people, maximizing comfort and well-being, improving coordination of care, preparing all healthcare staff for care, and creating a supportive environment in society. Honest and timely conversations, with consideration of patients' preferences and provision of information for patients and their families to make informed choices, are emphasized in the first ambition. As regards the ambition of preparing all healthcare staff for care, training should be provided to staff at all levels for developing an ethos of professional service and sustaining their compassion and empathy. "Palliative and end of life care" may be promoted as a collective concept, as evidenced by the frequent use of the phrase in the publication.

It is noteworthy that Dying Matters is a coalition formed in England and Wales which heightens public awareness of and encourages open discussion on dying, death, and bereavement (Hospice UK, 2018a). An Awareness Week comprising hundreds of volunteer-led activities is held annually by the coalition (Hospice UK, 2018b). A cross-sectional survey was conducted on 177 people, including patients, their relatives, and staff in a British hospital in the Awareness Week in 2016 (Smith, Wright, Dargan, & Henderson, 2017). It was revealed that the most important constituents of EOL care were involvement in decision making, company of people whom they considered important, and compassionate care.

1.1.2. Perspectives from the US

Communication among patients, their family members, and healthcare professionals is of paramount importance as the lack of which may contribute to provision of care against patients' wishes, culminating in a poor quality of death (Pizzo, 2016). In the book ***Being Mortal***, a ***New York Times*** bestseller (Gawande, 2014), an American surgeon revealed his moral distress which stemmed from avoidance of discussion of patients' preferences and goals of care. His suggestions for tackling the distress included early initiation of serious illness conversations and organization of communication skills workshops targeting doctors as well as other healthcare professionals. The Serious Illness Care Program was devised to train clinicians to initiate discussions on goals of care with patients, and its evaluation in a cluster-randomized trial showed that the intervention group had more, earlier, and more patient-centred conversations on patients' goals and values than the control group (Bernacki et al., 2015).

In the report ***Dying in America*** (US Institute of Medicine, 2015), it was mentioned that patients, families, and healthcare professionals tended to wait for each other to start the advance care planning (ACP) process; there were insufficient specialists in palliative care; and most adults did not recognize the need to express their EOL wishes. In view of these issues, some recommendations were put forward in the report, including orientation of care towards patients and their families, improvement in doctor-patient communication, involvement of primary care and other specialties, training of healthcare professionals, and education and engagement of the public.

1.2. Situation in Hong Kong

1.2.1. Government

The leading causes of death in Hong Kong, viz. cancer, pneumonia, and heart diseases, contribute to rising numbers of deaths (Centre for Health Protection, Department of Health, Hong Kong, 2018), implying an increasing number of terminally ill patients in dire need of palliative and EOL care. In the light of this trend, the Chief Executive has announced some measures in the 2017 Policy Address to ameliorate the local palliative and EOL care services, such as raising the number of home visits by nurses, training staff in residential care homes for the elderly (RCHEs), and possibly amending the law to enable dying in place (Government of the Hong Kong Special Administrative Region, 2017). Palliative care for cancer patients is also a component of the Integrated Chinese-Western Medicine Pilot Project in seven public hospitals, as mentioned in the 2016 Policy Address (Government of the Hong Kong Special Administrative Region, 2016). These show that the government has been taking steps towards better palliative and EOL care at the policy level.

1.2.2. Hospitals

In Hong Kong, most patients with life-limiting diseases utilize the service in public hospitals and the vast majority of deaths (around 90% in 2014) take place in public hospitals (Hospital Authority, 2017). Therefore, the Hospital Authority (HA), which manages public hospitals, plays a pivotal role in providing better palliative and EOL care. There is nevertheless an overemphasis on palliative care in cancer, despite the applicability of principles and models of palliative care in cancer to that in other chronic diseases (Woo, 2017b). It has been reported that patients with advanced non-cancer chronic diseases commonly have symptoms such as fatigue, oedema, and pain, similar to their counterparts with cancer (Lau, Tse, Lam, & Lam, 2008; Woo, Lo, Cheng, Wong, & Mak, 2011). Non-cancer patients suffer from arguably greater disease burden, compared to cancer patients, in terms of disability-adjusted and quality-adjusted life years alike (Woo et al., 2015). As a result, it is necessary to orient palliative and EOL care towards both cancer and non-cancer patients.

The HA has published guidelines on Do-Not-Attempt Cardiopulmonary Resuscitation (DNACPR) (Hospital Authority, 2016c) and life-sustaining treatment in terminally ill patients (Hospital Authority, 2015), in addition to a document with guidance on advance directives (ADs) (Hospital Authority, 2016b). As public awareness of EOL issues is conducive to successful implementation of the guidelines/guidance, the HA has also prepared an educational material for the public to improve their understanding of ACP, ADs, and DNACPR (Hospital Authority, 2016a).

Despite recognition of the legal status of ADs under common law, ADs have not been formally legislated as part of the statute or case law in Hong Kong (Woo et al., 2015). Some may attach more importance to the public's acceptance of ADs than legalization of ADs (Jockey Club School of Public Health and Primary Care, The Chinese University of Hong Kong, 2017). Most members of the general public, however, are not aware of ADs and do not incline to document an AD owing to concern over a potential change of mind in future (Chung et al., 2017). The fact is that they can change their preferred treatments at any time, but most of them seem ignorant of this fact because of the lack of education and promotion of ADs. Therefore, it is unsurprising that only 3,275 patients with cancer or other advanced irreversible diseases (around 22 patients per hospital per year) had made advance directives in 30 hospitals over a period of about 5 years from August 2012 to June 2017 (Tse, 2018). Moreover, patients in private hospitals are likely not provided with forms of ADs, which were designed by the HA and subsequently made available in public hospitals (Woo et al., 2015). Promotion of ADs across all hospitals, public and private, is absolutely warranted.

Recently, the HA has established the Strategic Service Framework for Palliative Care as a guide for enhancing palliative care services in the years to come (Hospital Authority, 2017). The strategic directions include fostering cooperation between palliative care specialists and non-palliative care professionals, and improving palliative care in ambulatory settings and the community for better patient support and minimization of inessential hospitalizations. Providing adequate support to RCHEs through Community Geriatric Assessment Teams (CGATs) and mobilizing community resources by joining hands with non-governmental organizations (NGOs) serve as examples of the strategies.

1.2.3. Need for professional training

ACP consists of many components, such as clarifying patients' wishes; understanding their views towards death; and discussing their preferred approach of care, place of EOL care, distribution of estates, and funeral rites, to name but a few. Take the place of EOL care as an example. A local cross-sectional study on more than 1,000 adults aged 30 or over found that 58.4% of them wished to receive EOL care at home, their most familiar setting, in the final year of life (Chung et al., 2017). Prof Charles Kao, who has advanced Alzheimer's disease, also expressed a preference for a peaceful death at home in the company of family members instead of in hospital (Tsang & Cheung, 2016). There is nevertheless inadequate assistance for family carers, given the lack of resources such as local palliative care specialists (E. Cheung, 2016). Under the HA, there were over 40 doctors, 300 nurses, as well as 60 allied health professionals offering full-time palliative care in 2017 (Yeung & Chan, 2017). It is noteworthy that palliative medicine is an unpopular specialty among trainee doctors, with not more than 10 specializing in it per year (E. Cheung, 2016). Depending on these specialists to provide quality care is conspicuously unrealistic. A viable alternative is to train more healthcare professionals in EOL care such that they have a sound knowledge in this regard and are capable of offering support to patients as well as their carers in different settings.

At present, many problems can be identified in communication on EOL care between patients and healthcare professionals. For instance, the doctor may wait for the patient to share his/her preferences, while the patient may wait for the doctor to discuss EOL care options. The healthcare team sometimes do not reach a consensus on the goal of care, accounting for their hesitation to initiate an EOL conversation with patients (H. Y. L. Chan, Lee, Woo, & Yi, 2017). Additionally, certain patients and families may be unready to talk about their views on EOL issues (Jockey Club School of Public Health and Primary Care, The Chinese University of Hong Kong, 2017). They may consider these as a taboo or they may be mentally unprepared to talk about these upsetting things (H. Y. L. Chan et al., 2017). Moreover, doctors' authority in making treatment decisions may negatively impact communication, inasmuch as many patients and families believe that doctors are knowledgeable in medical care and assume that doctors are able to make the best decision for patients without involving patients and their family members (H. Y. L. Chan et al., 2017). Some doctors' lack of empathy and poor communication skills also hamper EOL communication. Even if there is EOL conversation, the focus may be on the disease but not the patients' preferences and needs (J. T. K. Cheung, Au, Yuen et al., 2018).

Some doctors may be reluctant to disclose the prognosis to patients, but a study found that cancer patients who lacked awareness of their prognosis had an increased likelihood of experiencing anxiety and encountering difficulty in communicating with their family members (W. C. H. Chan, 2011). If healthcare professionals start discussing EOL care with patients at an early stage, when patients have the capacity to make their own decisions, care provided in future will be aligned with the patients' choices and decisional stress on their families will be relieved (Jockey Club School of Public Health and Primary Care, The Chinese University of Hong Kong, 2017). In general, healthcare professionals under-recognized that comfort may be more important than prolongation of life when an advanced, irreversible disease renders treatment options futile (R. S. K. Wong & Wong, 2017). Excessive attention has been given to curative care involving advanced medical technologies and potent medications (H. Y. L. Chan et al., 2017), rather than palliative care which enables patients to pass away comfortably and peacefully.

1.2.4. Medical and nursing education

According to the report on the Quality of Death Index (The Economist Intelligence Unit, 2015a), courses on palliative care were not mandatory for undergraduates in medical schools. Additionally, a study on 220 medical students in Hong Kong identified that 90% of them had insufficient self-perceived knowledge of ADs and felt unprepared to handle EOL issues (Siu et al., 2010). It should nonetheless be noted that medical schools have been paying more attention to palliative and EOL care in recent years. In the Faculty of Medicine of the University of Hong Kong, groups of interdisciplinary undergraduates (one medical student, one nursing student, and one pharmacy or Chinese medicine student in each group) were required to complete a Patient Care Project (Li Ka Shing Faculty of Medicine, The University of Hong Kong, 2016). Each group had to engage with a patient who was receiving palliative care and learn from his/her last stage of life, the pain of bereavement, and the funeral.

Nursing students also seemed to be acquiring knowledge of palliative and EOL care. In the Nethersole School of Nursing of the Chinese University of Hong Kong (CUHK), students learnt EOL communication skills, such as how to broach the subject of ACP and perform a life review for EOL patients to boost their self-worth (The Chinese University of Hong Kong, 2014). Another example was the School of Nursing of the Hong Kong Polytechnic University, in which undergraduates gained an understanding of EOL issues including the interdisciplinary nature of palliative care, spiritual and psychosocial support for the dying, communication skills in EOL care, bereavement, and carer stress in about 120 hours (including class contact, a literature review, and presentations) (The Hong Kong Polytechnic University, 2017).

1.2.5. Shatin Hospital as a role model

As part of a Jockey Club project, a continuous quality improvement initiative was implemented in Shatin Hospital (SH), a non-acute hospital, in 2009 to enhance the quality of EOL care in patients with non-cancer diseases (Woo et al., 2009). The initiative involved seminars, ward meetings, and role-plays for doctors and nurses, with continual record of observations and collection of feedback from various stakeholders to change the culture of EOL care and refine the relevant guidelines and care protocols. After one year, the evaluation showed that the patients enjoyed the benefits of shorter hospital stay, fewer unnecessary investigations, less severe symptoms, reduced transfers to an acute hospital, and more follow-ups by CGATs; their family carers' satisfaction increased as well (Woo et al., 2011). As a local pioneer in enhancing medico-social collaboration with RCHEs in EOL care, SH served as the basis for formulation of an HA corporate strategy to improve EOL care in RCHEs, with the effort of CGATs across public hospitals. The New Territories East Cluster (NTEC) received the HA best team award in 2018, which was attributable to the EOL initiative in SH.

1.3. Desirable palliative and end-of-life care

First and foremost, it is necessary for the government to understand the merits of quality palliative care, hence formulation of pertinent policies and integration of the care into the healthcare system (Choy, 2017). In Hong Kong, palliative care has become an indispensable part of patient care provided by hospitals managed by the HA. According to the HA, palliative care should be holistic and cover four major domains, namely physical care, psychological care, social support, and spiritual support for both patients and their relatives (Hospital Authority, 2018b). Palliative care should ideally be available in the early stages of life-limiting conditions based on patients' needs (Hospital Authority, 2017). Early initiation of ACP among patients, families, and healthcare professionals is highly recommended by local researchers to allow sufficient time for patients to understand the different care options available and clarify their values and preferences (H. Y. L. Chan et al., 2017). It prepares the stakeholders for the moment of decision-making and brings them peace of mind (Woo et al., 2015).

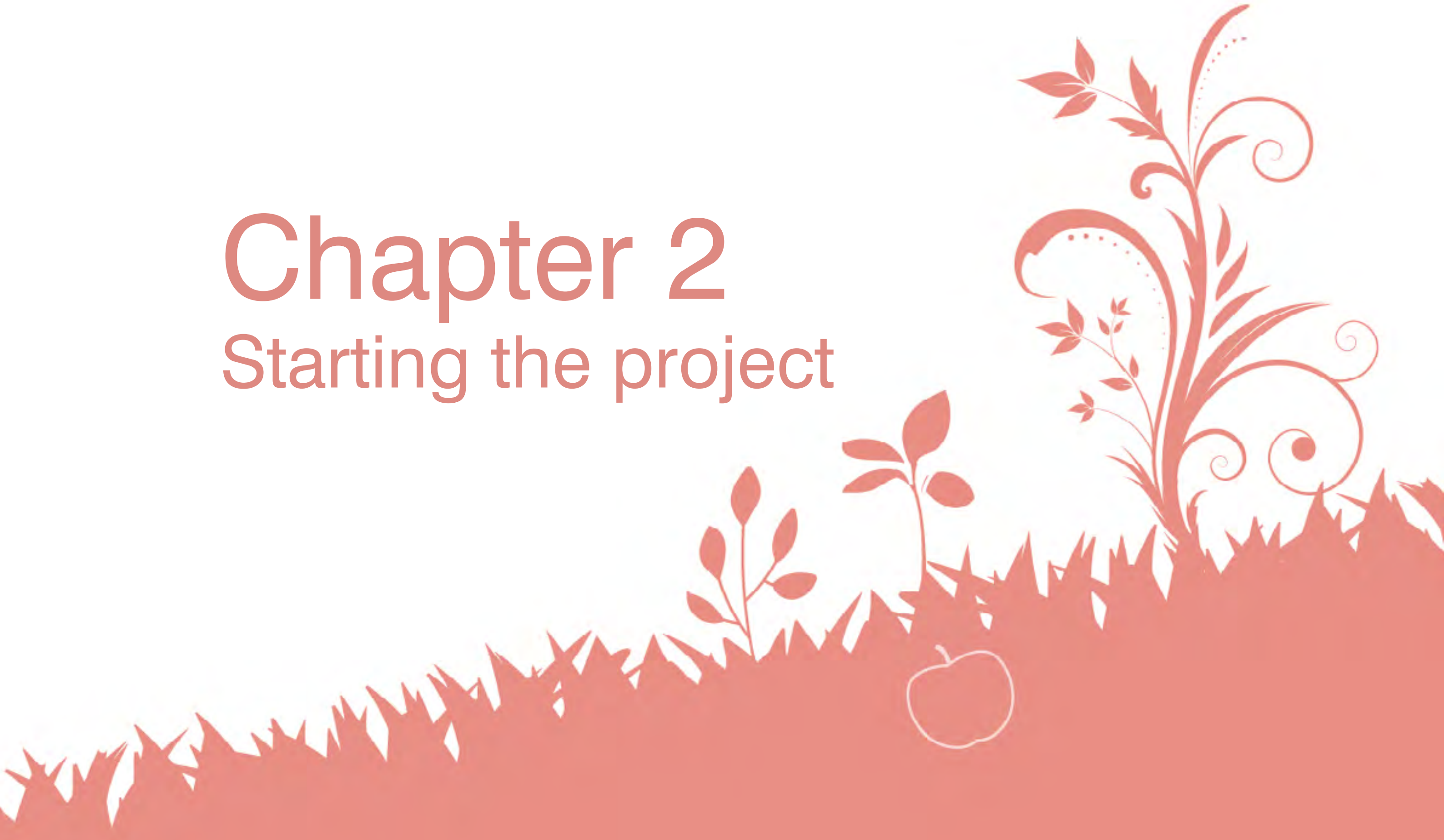
Every patient should receive personalized EOL care according to his/her wishes and views (Cosford, 2018), instead of authoritative decisions made by medical professionals (H. Y. L. Chan et al., 2017). This is corroborated by a local, population-based study on over 1,000 adults, in which more than 86% agreed or strongly agreed that the treatment for a patient should be determined based on the patient's wishes (Chung et al., 2017). The majority (84%) of participants in another community-wide survey in Hong Kong also preferred making EOL care decisions themselves (Faculty of Social Sciences, The University of Hong Kong, 2017b). These illustrate the importance of respecting patients' autonomy, one of the fundamental principles of biomedical ethics.

In order to provide personalized palliative and EOL care, healthcare professionals in Hong Kong need to be better trained in delivering the care, as their training used to emphasize curative treatment (Chung et al., 2017). Every doctor ought to be capable of providing palliative care, in consultation with specialists in palliative medicine in circumstances beyond his/her competence (Wee, 2016). Local academics in public health suggested that patients' needs should be assessed in a timely and regular manner to identify patients who are nearing the end of life (Jockey Club School of Public Health and Primary Care, The Chinese University of Hong Kong, 2017). Not only do healthcare professionals need to improve patients' cognitive understanding of the disease trajectory, but it is also important for them to help patients and their loved ones to cope with grief and fear, and to confront challenges ahead such as their anticipation of loss. Empathy and good communication skills are of paramount importance in interaction with patients, their families, and other members of the healthcare team, as emphasized by RCHE staff in a local qualitative study (R. S. Lo et al., 2010).

In conjunction with education of healthcare professionals, raising public awareness of EOL care and destigmatizing death are crucial for improving EOL care in the whole community (Goh, 2018), as public opinions aggregate to form a critical mass for driving policy and system change. A case in point is that the public needs to understand the importance of early documentation of ADs such that they are interested in discussing the issue of ADs in public consultations. The public's understanding of the underlying concept of palliative and EOL care is also essential in that they will not misinterpret the provision of such care as a money-saving approach or failure of healthcare professionals to save patients' lives. Talks, online information, leaflets, and booklets are some possible means of educating the public on EOL issues, as suggested by some local researchers (W. C. H. Chan, Tin, Chan, Chan, & Tang, 2010).

Chapter 2

Starting the project



2.1. Project introduction

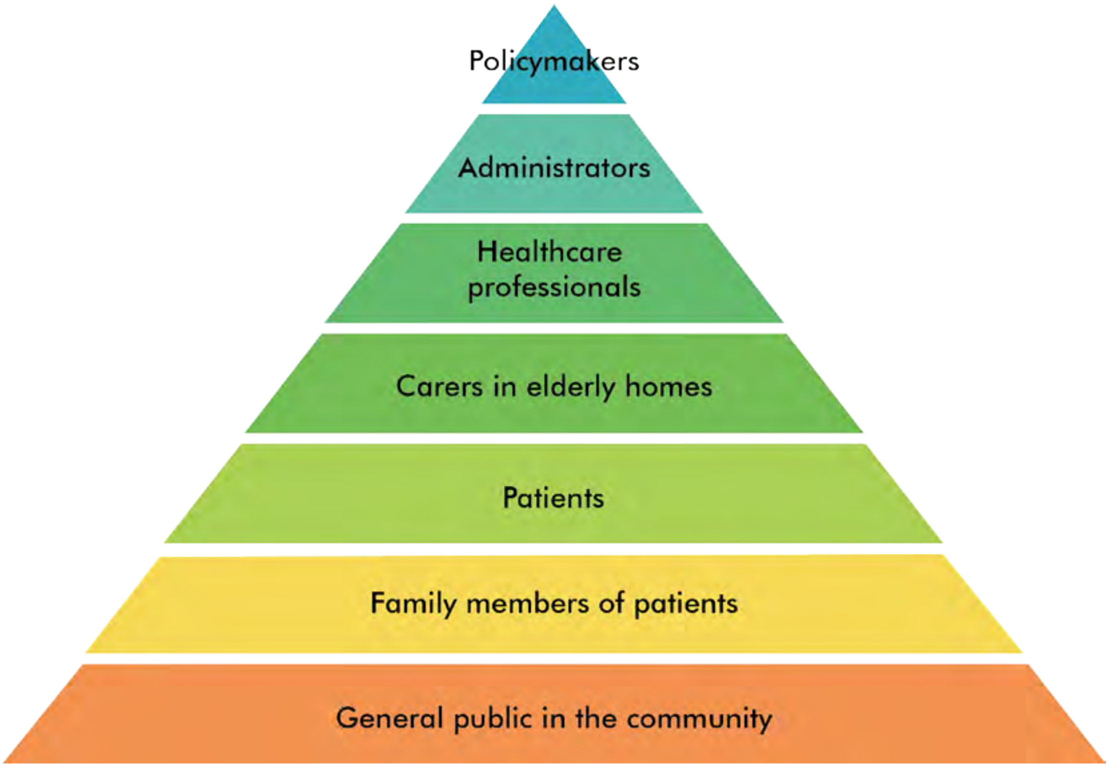
To contribute to achieving the desirable palliative and EOL care discussed in Chapter 1.3, The Hong Kong Jockey Club Charities Trust approved funding of HK$131 million to launch the Jockey Club End-of-Life Community Care Project (JCECC) in 2015 (Faculty of Social Sciences, The University of Hong Kong, n.d.). The three-year project involved collaboration across different disciplines, institutions, and sectors. There were seven partners, namely the Faculty of Social Sciences of The University of Hong Kong, CUHK 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.

For CUHK Jockey Club Institute of Ageing, we implemented a capacity building and education programme in hospitals, RCHEs, and the community in the NTEC of the HA. A comprehensive top-to-bottom approach (Figure 1) was adopted to target the policymakers, health administrators, healthcare professionals, patients and their family members, as well as the general public through meetings, information sessions, workshops, seminars, and forums. We implemented the programme as a continuous quality improvement initiative, following the 'Plan-Do-Study-Act' cycle (Moen & Norman, 2010), as proven successful in the project in Shatin Hospital (see Chapter 1.2.5). The programme was planned and carried out, followed by analysis of the data collected and consideration of changes to be made to the programme. It was piloted in the NTEC, with evaluations of its benefits and potential transferability and applicability to other hospital clusters in Hong Kong. The aim was to achieve step-by-step improvement in local EOL care in the iterative process.

Our multi-disciplinary team consisted of professors with expertise in gerontology and geriatrics, experienced doctors and nurses, social workers, as well as administrative and research staff. We collaborated with a wide range of parties, including:

- CUHK Centre for Bioethics;
- District Elderly Community Centres and Neighbourhood Elderly Centres;
- Faculty of Medicine, CUHK;
- Hong Kong Alliance of Patients' Organizations;
- Hong Kong Doctors Union;
- Hospital Authority;
- Hospitals and RCHEs in the NTEC;
- The Jockey Club School of Public Health and Primary Care, CUHK;
- The Nethersole School of Nursing, CUHK.

Figure 1 | Conceptual framework for the capacity building and education programme



2.2. Programme objectives

The objectives of the programme are listed below:

- To empower healthcare staff in hospitals and RCHEs in the NTEC on the importance of providing quality EOL care;
- To enhance capacity for quality EOL care including clinical ethics in healthcare staff, patients, and their relatives and carers;
- To improve the quality of EOL care practices in hospitals.

2.3. Target population

The programme was piloted in the NTEC of the HA, which includes Shatin, Tai Po, and North District. The total population in these three districts was 1,268,000, or 17.5% of the population in Hong Kong in 2016 (Census and Statistics Department, Hong Kong, 2017). Over 29% of the population in the three districts were aged 55 or above, with 30.6%, 30.5%, and 29.4% in Shatin, Tai Po, and North District respectively. The age structures and population sizes of the three districts are presented in Table 1.

Table 1 Demographics of the three districts in the New Territories East Cluster of the Hospital Authority in 2016

	Number (%)		
	Shatin	Tai Po	North District
Age groups			
0-44	338,600 (51.5)	158,900 (52.9)	168,000 (54.1)
45-54	117,300 (17.8)	49,800 (16.6)	51,300 (16.5)
55-64	98,000 (14.9)	48,800 (16.3)	46,300 (14.9)
≥65	103,300 (15.7)	42,600 (14.2)	45,000 (14.5)
Total population	657,200 (100.0)	300,100 (100.0)	310,700 (100.0)

Data extracted from population and household statistics (Census and Statistics Department, Hong Kong, 2017). Percentages may not sum to 100 due to rounding.

In these three districts, the programme was mainly administered in seven acute and non-acute hospitals in the NTEC as shown in Table 2, as well as many RCHEs in the cluster.

Table 2 Seven hospitals in the New Territories East Cluster in which the programme was administered

Hospital	**Type**
Shatin	
Prince of Wales Hospital (PWH)	Major acute regional hospital and teaching hospital of Faculty of Medicine, CUHK
Shatin Hospital (SH)	Extended-care hospital
Cheshire Home, Shatin (SCH)	Extended-care hospital
Bradbury Hospice (BBH)	Specialized palliative care centre
Tai Po	
Alice Ho Miu Ling Nethersole Hospital (AHNH)	Acute general hospital
Tai Po Hospital (TPH)	Extended-care hospital
North District	
North District Hospital (NDH)	Acute general hospital

Information extracted from the website of Hospital Authority (2018a).

2.4. Overview of strategies

We have included the following components in our programme:

- A capacity building programme for health and social care professionals such as doctors, nurses, and allied health professionals in the hospitals, CGATs, and RCHEs in the NTEC, as well as medical students in CUHK;
- Workshops and seminars on specific target groups including policymakers, health administrators, and the general public;
- Forums involving all stakeholders, including policymakers, health administrators, health and social care professionals, and the general public;
- Information sessions for patients and their family members in the hospitals and RCHEs in the NTEC.

Conducting talks alone may not be effective in eliciting behaviour change despite its usefulness in providing information. We therefore implemented a multi-pronged capacity building programme, with workshops, forums, seminars, and conferences. The format and content of training in each institution, whether it is a hospital, RCHE, or community centre, varied to suit its culture and situation.

In general, we educated the health and social care professionals, administrators, and policymakers on the following issues:

- Learning how to identify EOL patients;
- Understanding their physical, psychosocial, and spiritual needs and planning their management according to quality of life rather than the standard curative approach;
- Grasping the use of ADs;
- Acquiring communication skills of initiating ACP and serious illness conversation with patients and family members;
- Identifying and designing initiatives to overcome barriers to improving the quality of dying.

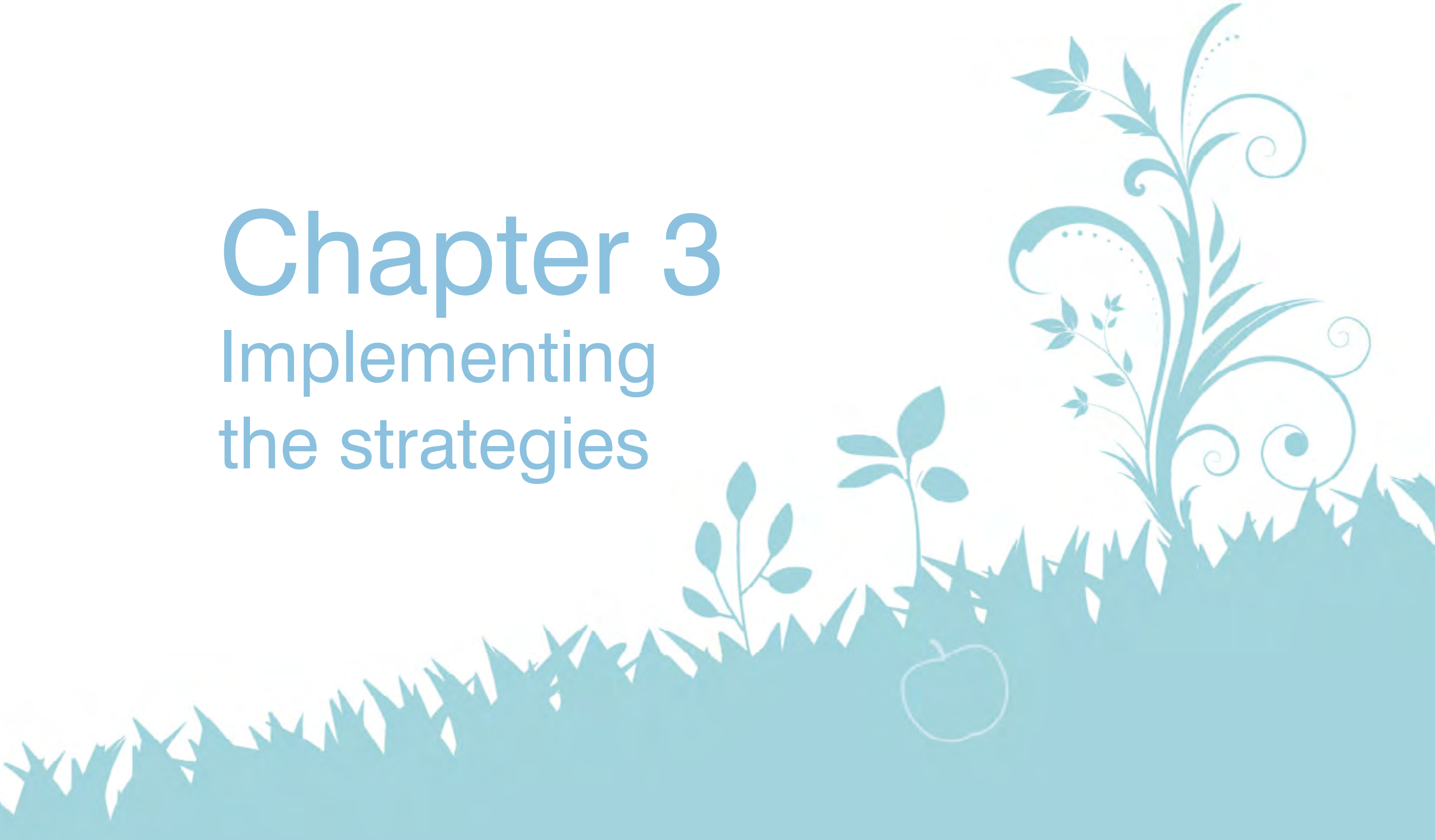
Emphases of educating patients and their relatives, carers, and the public are as follows:

- Introduction to ACP and ADs;
- Current EOL service provisions in public and private sectors in Hong Kong;
- Practical guide of handling the body from hospital to cremation/burial;
- Information on enduring powers of attorney, including how to enact them;
- Arrangement of financial affairs and will making;
- Communication skills of initiating ACP with family members and healthcare professionals.

Sessions for different stakeholders were planned to be delivered in terms of talks with case presentations; group discussion on individual experiences; art and video clips; and role play especially for doctors' training in communication skills. Details of the sessions will be set out in Chapter 3.

Chapter 3

Implementing the strategies



3.1. Meetings with policymakers and health administrators

Since November 2015, meetings had been arranged with health administrators, including Dr Hung Chi Tim, the then Cluster Chief Executive of the NTEC in HA, as well as Hospital Chief Executives and other key executives covering geriatric outreach and in-patient services in NTEC hospitals.

In December 2015, a meeting was held among The Hong Kong Jockey Club, JCECC project team, School of Public Health of CUHK, and Food and Health Bureau. The meeting discussed various topics, including collaboration with hospitals and JCECC's role in improving EOL care services, collaboration between the HA and project partners, capacity building on EOL care for medical professionals, and the role of legislation and policies involved.

In April 2017, another meeting was held among The Hong Kong Jockey Club, JCECC project team, and Food and Health Bureau. We provided an overview of and observations in the capacity building and education programme on healthcare professionals and our collaboration with hospitals in the NTEC. There was also a discussion on various topics, such as legislation and policy initiatives to improve delivery of EOL care services, collaboration between the HA and project partners in maintaining the continuity of care from hospitals to the community, and capacity building in medical and social care professionals to facilitate holistic care of EOL patients and their families.

3.2. Chart audit in an acute hospital

To investigate the situation of EOL care such as AD, ACP, EOL conversations, and treatments provided in the acute hospital setting, a chart audit was performed in AHNH from January 2016 to September 2016 (Au et al., 2017). Sixty-one patients who were deceased between November 2014 and April 2015 were identified, and their charts in the 180 days before death were reviewed. Over half (54.1%) of the patients were admitted from an old age home. The mean age at death was 84.7 years. Characteristics of the patients are shown in Table 3.

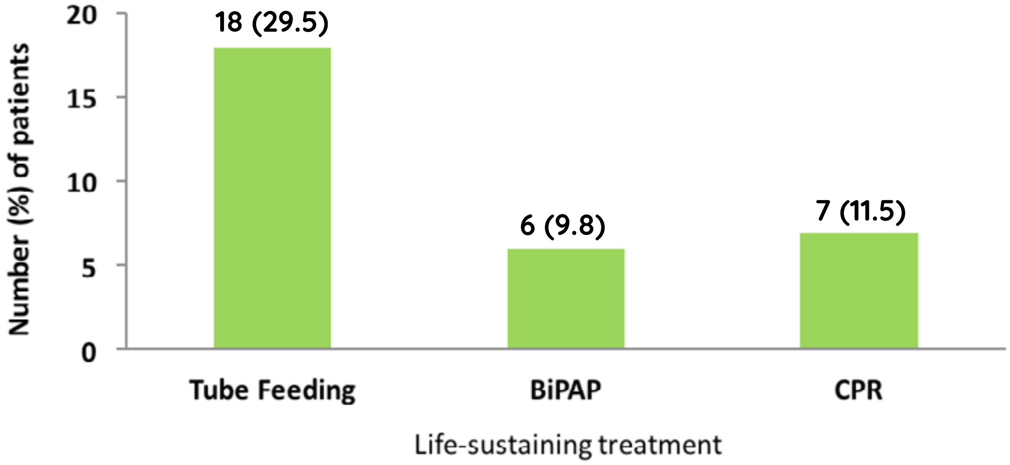
Table 3 Characteristics of 61 deceased patients in a chart audit in an acute hospital. Values are numbers (percentages) unless stated otherwise

Characteristics	Number (%)
Female	36 (59.0)
Admitted from an old age home	33 (54.1)
Referred to specialist palliative care	2 (3.3)
Bed-bound	16 (26.2)
Chair-bound	22 (36.0)
Bed-bound and chair-bound	4 (6.6)
Mean (standard deviation) age at death (years)	
All patients	84.7 (12.1)
Females	88.0 (10.2)
Males	79.9 (13.0)
Median (interquartile range) length of hospital stay (days) in the last 180 days of life	11.0 (4.0–22.5)

Table adapted from a poster presented at the Conference on Collaboration in Creating Compassionate Holistic End-of-Life Care for the Future, as part of the Jockey Club End-of-Life Community Care Project (Au et al., 2017).

According to the documented information on the charts, none of the patients were engaged in ACP or made an AD, although 21.3% had EOL conversation with healthcare professionals and 78.7% had a DNACPR order documented. Of the patients who had EOL conversation, 75% discussed EOL issues one day before death, and the content was primarily concerned with their condition with little opportunity for discussing their preferred treatment options. Less than one-third (29.5%) received tube feeding, the most common type of life-sustaining treatment (Figure 2), while at least one special procedure was conducted on 67.2% of the patients, with invasive procedures undergone in 1.6–4.9% of them (Figure 3).

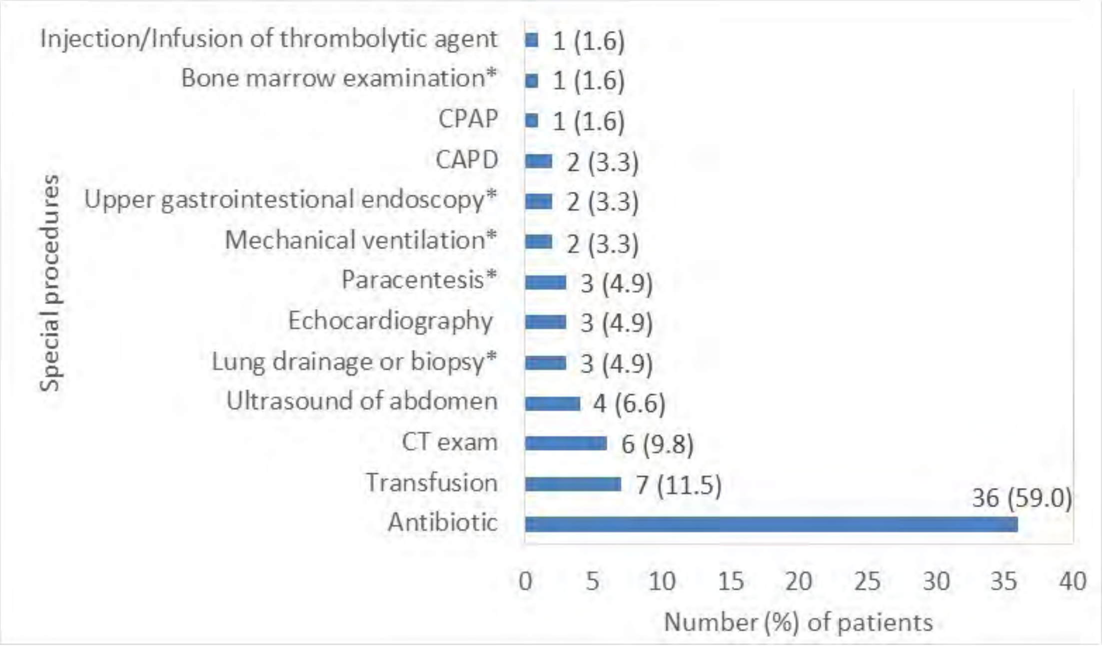
Figure 2 | Use of life-sustaining treatments in the last 180 days of life of 61 patients in an acute hospital



BiPAP = Bi-level positive airway pressure; CPR = Cardiopulmonary resuscitation.

Figure adapted from a poster presented at the Conference on Collaboration in Creating Compassionate Holistic End-of-Life Care for the Future, as part of the Jockey Club End-of-Life Community Care Project (Au et al., 2017).

Figure 3 | Use of special procedures in the last 180 days of life of 61 patients in an acute hospital



*Invasive procedures

CPAP = continuous positive airway pressure; CAPD = continuous ambulatory peritoneal dialysis; CT = computed tomography.

Figure adapted from a poster presented at the Conference on Collaboration in Creating Compassionate Holistic End-of-Life Care for the Future, as part of the Jockey Club End-of-Life Community Care Project (Au et al., 2017).

There was an obvious lack of documentation of ACP and ADs. This might imply inadequate documentation or poor knowledge of ACP and ADs among healthcare professionals and patients. Many patients did not discuss EOL issues with healthcare professionals, and three quarters of those who did so were engaged in EOL conversation on the day preceding death. The patients should have been given the chance to express their preferences regarding treatment approaches at an early stage. In the light of these problems, we emphasized the importance of ACP, ADs, and EOL conversation and set out to empower healthcare professionals and patients in our programme.

3.3. Survey on self-competence in death work in 2016

'Self-competence' refers to the ability to use personal attributes or experiences and apply coping approaches in 'death work', which includes therapeutic, supportive, and remedial work pertinent to death, such as counselling patients at the EOL, providing palliative care, and initiating ACP (W. C. H. Chan & Tin, 2012).

To assess health and social care workers' self-competence in death work, we used the 16-item Self-Competence in Death Work Scale (SC-DWS), which has been shown to be valid and reliable in these workers in Hong Kong (W. C. H. Chan, Tin, & Wong, 2015). It consists of two subscales, the 10-item Existential subscale and the 4-item Emotional subscale. The Existential subscale measures the competence in coping with existential issues such as meaning of life and attitudes towards suffering and death, while the Emotional subscale examines the competence in handling emotions arising from death work, for example, grief and anxiety. For each item, participants indicated the level of compatibility with their present situation, on a Likert scale from 1 (very incompatible) to 5 (very compatible). The scores on the items were totalled to give a score on SC-DWS (possible range: 16 – 80) and scores on the two subscales (possible range on Existential subscale: 10 – 50; Emotional subscale: 4 – 20). A higher score meant that the participant was more self-competent in death work. Following the SC-DWS, there was an open-ended question seeking participants' views on death work. Information on participants' demographic and death work-related characteristics was also collected.

The questionnaires were distributed to 885 health and social care workers in RCHEs and seven hospitals in the NTEC from January 2016 to October 2016 (J. T. K. Cheung, Au, Chan et al., 2018). Participants were conveniently sampled in talks, seminars, and workshops in our project. Most of the participants were female (81.6%), worked as nurses (65.3%), and had at most 10 years of experience in death work (62.7%). Characteristics of the participants are presented in Table 4.

Table 4 Characteristics of 885 health and social care workers in a survey on self-competence in death work in 2016

Characteristic	Number (%)
Gender	
Male	162 (18.4)
Female	720 (81.6)
Age	
18-29	227 (26.1)
30-39	160 (18.4)
40-49	256 (29.4)
≥ 50	228 (26.2)
Marital status	
Single	341 (39.4)
Married	494 (57.1)
Divorced	30 (3.5)
Occupation	
Doctor	55 (6.3)
Nurse	572 (65.3)
Allied health professional	41 (4.7)
Personal care assistant	149 (17.0)
Social worker or other care worker	59 (6.7)
Work experience	
≤ 10 years	380 (46.9)
> 10 years	431 (53.1)
Death work experience	
≤ 10 years	405 (62.7)
> 10 years	241 (37.3)

Institution	
Acute Hospital A	56 (6.3)
Acute Hospital B	115 (13.0)
Acute Hospital C	126 (14.2)
Rehabilitation Hospital A	66 (7.5)
Rehabilitation Hospital B	191 (21.6)
Hospice A	31 (3.5)
Nursing Home A	106 (12.0)
Residential care home for the elderly	194 (21.9)
Personal bereavement experience	
Yes	756 (86.7)
No	116 (13.3)

Numbers may not sum to 885 due to missing data. Percentages may not sum to 100 due to rounding.
Table adapted from J. T. K. Cheung, Au, Chan et al. (2018).

The mean score on the SC-DWS was 60.2 (standard deviation [SD] 8.4), while those on the Existential and Emotional subscales were 37.9 (SD 5.3) and 14.5 (SD 2.6) respectively. Participants aged 50 or above (compared with 18-29), divorced (compared with single), working in Hospice A (compared with Acute Hospital A), working as personal care assistants (compared with nurses), or with bereavement experience were more self-competent in death work, existential coping, and emotional coping. Compared with their counterparts in Acute Hospital A, health and social care workers in Rehabilitation Hospital B (with a quality improvement initiative in EOL care implemented) and Acute Hospital B (with a caring, Christian culture) were more self-competent in death work and existential coping.

Participants' views on death work were categorized as personal resources; existential challenges and coping; emotional challenges and coping; and suggestions for enhancing quality of death work. For personal resources, some felt helpless and found their death work challenging. On the other hand, some felt compassion towards dying patients and their families. Regarding existential challenges and coping, many showed acceptance of life's limit and had a strong sense of meaningfulness of life. Concerning emotional challenges and coping, some were unable to dissociate themselves from patients' and families' emotions when they were off, and several were distressed by their own bereavement experience. Suggestions for enhancing quality of death work included additional training in communication skills and emotion-focused coping, administrative support, and change in workplace culture.

The results reveal that self-competence in death work in health and social care workers can be further improved, especially younger ones, nurses, and those working in acute hospitals. The lack of self-competence in nurses suggests that training related to death work needs to be strengthened in nursing schools. As participants without bereavement experience had lower self-competence, training for health and social care workers may include role-play sessions which allow them to experience real-life situations including bereavement. Some acute hospitals paid little attention to palliative and EOL care, possibly explaining why their staff had lower self-competence in death work. Identification of barriers and training in palliative and EOL care, including communication skills and emotional management, are indicated. The initiatives implemented in the institutions should vary according to their unique culture and service demands.

3.4. Capacity building in healthcare staff and medical students

3.4.1. Doctors and medical students

From November 2015 to May 2018, we delivered 36 sessions to 656 doctors (mean = 18) and 36 sessions to 724 medical students (mean = 20). These sessions are described as follows.

3.4.1.1. Talks and conferences involving doctors

In July 2016, **Ms Chan Hiu Lui**, founder of Big Silver Community and author of books on dying, shared her insights into dying in Hong Kong at PWH. Ms Chan highlighted current problems faced by patients in addressing EOL care issues from the perspective of the public. As an example, she talked about a cancer patient aged over 50 who was receiving radiotherapy. The patient had difficulty finding an affordable care home upon hospital discharge. Although the patient would like to receive care at home, necessary equipment was not available for home use. Ms Chan hopes that EOL care will be improved to allow patients to choose the care approach and the place of death.

In April 2017, **Prof Poon Chung Kwong**, President Emeritus of The Hong Kong Polytechnic University, delivered a talk on how to face life, ageing, disease, and death from a Buddhist perspective at PWH. Prof Poon encouraged the audience to actively cope with these stages rather than adopt an avoidance approach. He opined that there should be additional training in kindness and life philosophy in order to improve junior doctors' ability to care for patients.

Talks were also delivered to doctors through the Hong Kong Doctors Union. **Dr Raymond Lo**, Cluster Coordinator (Hospice and Palliative Care) of the NTEC, spoke on the topic "Palliative Care and Communication in Serious Illness" to 50 members of Hong Kong Doctors Union in December 2016. **Dr Vincent Tse**, Founding Chairman of the Society for Life and Death Education, gave a talk on communication in EOL care to 200 members of Hong Kong Doctors Union in March 2018.

In the *Advances in Medicine* conference organized by CUHK in May 2017, CUHK Jockey Club Institute of Ageing organized a forum on EOL care. **Prof Lui Siu Fai**, Adjunct Professor of the Institute, gave a talk on EOL conversations highlighting the situation that many doctors endeavour to prolong patients' lives without explaining their prognosis clearly or enquiring their preferences. He stressed the importance of honest and open conversations in ensuring a good death, the final blessing in one's life. There should be five types of EOL conversations: (1) among healthcare professionals; (2) between healthcare professionals and social care professionals; (3) between healthcare professionals and the patient/ family; (4) in the patient's family; and (5) in society at large.

Ms Faye Chan, Nursing Officer of the Institute, shared with the audience on the topic of "Practical Approach to Advance Care Planning (ACP) / Advance Directive (AD)". Ms Chan elaborated the concepts of AD and ACP, reviewed the benefits of and barriers to ACP, explored practical means of facilitating ACP in various settings, and discussed strategies for facilitating ACP between a patient with a life-limiting disease and his/her family. The sharing concluded with a take-home message that engaging patients with a life-limiting disease in ACP at an early stage increases satisfaction of patients and their families.

3.4.1.2. Serious Illness Conversation Guide

The Serious Illness Conversation Guide (SICG) is a patient-tested, structured guide for engaging a patient in a serious illness conversation (Ariadne Labs, n.d.). The Institute has funded doctors and nurses to attend a three-day course in using the SICG organized by Harvard Medical School Center for Palliative Care, Ariadne Labs, and Dana-Farber Cancer Institute. Additionally, the course involved a train-the-trainer approach for participants to learn the key principles of training others to use the SICG and participate through hands-on practice. After the course, our team modified and translated the SICG into Cantonese, and subsequently used it in a training session for doctors with live demonstration by the instructors.

3.4.1.3. Workshops for doctors

Five training workshops in serious illness conversation had been provided to 23 doctors in SH, NDH, TPH, and AHNH by **Prof Lui Siu Fai, Prof Wong Wai Tat** (Assistant Professor, Department of Anaesthesia and Intensive Care, Faculty of Medicine, CUHK), **Dr Jacqueline Yuen** (Clinical Lecturer, Department of Medicine & Therapeutics, Faculty of Medicine, CUHK), and **Ms Faye Chan** by the end of May 2018. In each hospital, a seminar on communication tools for delivering serious news preceded each workshop. The seminar covered the perspectives of seriously ill patients and their families, a conversation road map for discussing serious illness with patients and families, and skills of responding effectively to emotion with empathy. Mnemonics were used to help doctors memorize the road map and skills. The conversation road map, presented as SPIKES (Setting, Perception, Invitation, Knowledge, Empathy, and Summary) (VITALtalk, n.d.), was demonstrated with a case of pneumonia (https://youtu.be/EjIOfJZJazk). NURSE (Naming, Understanding, Respecting, Supporting, and Exploring) statements were introduced to facilitate verbalization of empathy in serious illness conversations (Table 5) (VITALtalk, 2017b).

Table 5 **NURSE statements for verbalizing empathy with bilingual examples**

Skill	Example	Note
Naming	You seem worried. 你似乎好擔心。	This statement is helpful even if you name the wrong emotion. The patient/family can correct you and explain what they're really feeling.
Understanding	I can see how difficult this must be for you. 我睇得到呢個情況對你嚟講真係好艱難。	Think of this as putting yourself in the patient/family's shoes but do not pretend you understand everything.
Respecting	I can see how much you care about your mother. 我睇到你好關心你媽媽。	Praise is also appropriate here, e.g. "I think you did a great job."
Supporting	Don't worry I will be back soon to check on you. 唔駛擔心，我等陣會再嚟睇你。	Making a promise avoids feelings of abandonment.
Exploring (the emotion)	Tell me what you're worried about now. 你話比我知你依家擔心啲咩呢？	Asking a focused question about the statement just said helps explore the emotion behind it.

Information adapted from VITALtalk (2017b).

In the initiative in SH (see Chapter 1.2.5), EOL case scenarios were presented as role-play sessions, in which research assistants acted as patients or relatives, while doctors practised communication skills by having conversations with them (Woo et al., 2009). The format of the workshops was similar in the current project, although actors instead of research assistants played the role of patients' relatives. Auditions were held beforehand to select actors who could memorize the script, give responses flexibly, and express emotions clearly. A rehearsal was organized for the actors before each role-play exercise.

In the workshops, learning goals were first defined by participants (numbers varied from three to six), who mentioned the difficulties encountered in their EOL care work. Participants then took turns to practise communication skills with the actors, with intermittent feedback from the facilitators and the other participants. Two cases were used for practice in each workshop, followed by a video using REMAP (Reframe, Expect, Map, Align, Plan) skills for discussing goals of care (VITALtalk, 2017a) (https://youtu.be/HxrggHP9qgo) regarding the conversation between a doctor and the daughter of a patient with chronic obstructive pulmonary disease (COPD). The workshop ended with a debriefing and take-home messages.

3.4.1.4. Training of medical students

CUHK Jockey Club Institute of Ageing also provided training to medical students in penultimate and final years in serious illness conversations. A total of 185 students completed 32 training sessions from June 2017 to February 2018. The training took different forms, including online training, reflective writing, and 2-hour small-group tutorials involving role play. Medical students also learnt from experts in palliative and EOL care in Medical Grand Rounds. For instance, **Dr Raymond Lo** spoke on the topic "Communication in Serious Illnesses Situation: Can We Do Better?" to 96 students in a Medical Grand Round in November 2016. **Dr Jacqueline Yuen** also shared her knowledge on care for dying patients with 147 students in another Medical Grand Round in September 2017.

3.4.2. Nurses and other health and social care staff

From November 2015 to May 2018, the Institute organized 122 training sessions for 4,479 nurses and other health and social care staff in RCHEs and the seven hospitals in the NTEC.

3.4.2.1. Hospital nurses

The Institute jointly organized training sessions for nurses in the seven hospitals in the NTEC with the Central Nursing Division of the NTEC. Some sessions were held across the seven hospitals so that nurses in all these hospitals could benefit from our training. The sessions encompassed a broad range of topics, including symptom management in EOL care; identifying EOL patients; exploring carers' own death anxiety in EOL care; nurses' perspective on clinical ethics in EOL care; communication in EOL care with a team approach; communication skills of facilitating ACP and addressing patients' spiritual suffering; anticipatory grief intervention for patients and families; supporting family members in grief and bereavement stages; addressing moral distress; and use of art in coping with compassion fatigue. Speakers or facilitators are experienced doctors and nurses, including **Dr Vincent Tse, Dr Jacqueline Yuen, Ms Faye Chan, Ms Faith Liu** (Nurse Consultant, Hong Kong Association of Gerontology), and **Ms Clare Lai** (Nursing Officer, In-patient unit, Bradbury Hospice). To facilitate interaction among the participants and between the participants and speakers/facilitators, the class size was limited to a maximum of 25.

Take the workshop on the use of art in coping with compassion fatigue as an example. Participants first warmed up by drawing an image of themselves. They then painted a picture related to EOL, followed by discussion with the facilitator and the other participants. Afterwards, they coped with compassion fatigue by creatively changing anything in their picture as they wished, followed by another discussion. Next, the facilitator gave a lecture on compassion fatigue, vicarious traumatization, and burnout, and the workshop ended with a question-and-answer session. The whole workshop revolved around the use of art in facing the challenges of work in death, dying, and bereavement.

Another example was the workshop on addressing moral distress in EOL care. The workshop covered the definition, prevalence, causes, impact, and examples of moral distress, as well as what nurses can do to address moral distress. There was a group discussion in which each participant identified a recent scenario of moral distress at work. After the participants described different scenarios, ideas on how to address the moral distress were exchanged. Mindfulness was practised to allow the participants to relax and relieve their moral distress.

3.4.2.2. Residential care home staff

In addition to doctors, medical students, and nurses in hospitals, we also trained staff in RCHEs, including those under Tung Wah Group of Hospitals (TWGHs); Sik Sik Yuen; The Lok Sin Tong Benevolent Society, Kowloon; and The Chinese Rhenish Church Hong Kong Synod. The training catered to different needs of our beneficiaries such as health and social care professionals (e.g., nurses and social workers) and supporting staff (e.g., health workers, care workers, and programme workers).

3.4.2.2.1. Health and social care professionals

Our talks to health and social care professionals covered the following issues: skills of supporting and communicating with EOL patients using a team approach; EOL care for patients with advanced dementia, heart failure, renal failure, and COPD; holistic needs of EOL patients; the use of art in coping with compassion fatigue; anticipatory grief intervention for patients and families; clinical ethics in EOL care; talking about death in a relaxed manner; and understanding frailty in EOL care.

In the session on using a team approach in communicating with EOL patients, participants learnt about good death; the importance of better EOL conversations; ACP as a process of ongoing communication; and the interdisciplinary team approach to serious illness conversations based on the SICG (see section 3.4.1.2) and NURSE statements (see Table 5 in section 3.4.1.3). A role-play demonstration using a case of COPD illustrated the approach to serious illness conversations, followed by a role-play exercise among the participants using a case of Parkinson's disease. After the exercise, the participants discussed what they learnt from the exercise, difficulties encountered, and how to tackle the difficulties.

The session on how to support and communicate with patients was another example. The content covered principles of communication; patients' needs; how to show empathy and be a good listener and observer; appropriate types of questions to patients; and communication skills, including tone, content, facial expressions, and body language. The speaker encouraged the audience to ask patients to hope for something realistic and achievable other than treatments, to assist patients to search for meaning of life, and to motivate patients to focus on the present.

3.4.2.2.2. Supporting staff

Topics of training for supporting staff included ADs; holistic needs of EOL patients; symptoms of impending death; symptom control; skills of supporting and communicating with EOL patients; talking about death in a relaxed manner; and how to (a) identify EOL patients, (b) improve quality of life of EOL patients, (c) manage emotions of EOL patients and families, (d) initiate EOL conversations with patients and families, and (e) deal with unfulfilled wishes of EOL patients.

The session on improving the quality of life of EOL patients serves as an example of our training. The speaker introduced the concept of providing holistic care to patients and families in the whole disease trajectory by an interdisciplinary team. The importance of providing psychological and spiritual support to patients was emphasized with approaches suggested, such as performing a life review with appreciation of the patient's accomplishments, bequeathing letters and videos to loved ones, and fully experiencing and treasuring the present moment.

In another session on EOL care and holistic needs of EOL patients, the speaker attached great importance to patients' values, dignity, and quality of life. Components of a good death were discussed based on research findings. The physical, psychological, social, and spiritual needs of EOL patients were described, followed by discussion of holistic needs of a patient with aspiration pneumonia among the participants.

3.5. Education of patients, carers and the public

3.5.1. Patients and carers

From November 2015 to May 2018, we organized 49 talks for 1,135 patients and carers at RCHEs, hospitals, patient organizations, District Elderly Community Centres and Neighbourhood Elderly Centres, churches, and the Jockey Club CADENZA Hub. The talks covered a wide range of topics, including ACP; ADs; enduring powers of attorney; burial and funeral arrangements; stress management; holistic needs of EOL patients; treatment options at the EOL; talking about death in a relaxed manner; EOL care in hospitals and the community; and how to (a) support and communicate with patients, (b) initiate EOL conversations, and (c) make a will.

In one of the sessions at SCH, patients and their family members learnt about their right to make EOL care decisions; examples of futile treatments; concepts and benefits of ACP and ADs; enduring powers of attorney; importance of and barriers and attitudes to communication on death and dying; and how to conduct an EOL conversation. Participants discussed how to answer potential questions raised by patients, and the speaker provided some appropriate replies as examples.

We also held workshops on ACP for carers which covered the concept and benefits of ACP, as well as the importance of respecting patients' values. Participants would imagine what care they would like to receive and the needs they would have if they were dementia patients. A mini-movie named *The Tail Before* (蚪尾), produced by the Jockey Club Centre for Positive Ageing, was shown (https://www.youtube.com/watch?v=Ftjn2I69eKk). It showed the story of a daughter caring for her mother with dementia and facing the challenges of dying and death. Participants gained a deeper understanding of ACP through the mini-movie and shared their feelings and ideas of EOL care and bereavement.

3.5.2. Public

3.5.2.1. Talks in public libraries

We delivered talks on ADs, ACP, enduring powers of attorney, attitudes to death, and how to handle stress when caring for EOL patients. Our project team gave four talks to 57 participants in public libraries in Fanling, Sheung Shui, Tai Po, and Shatin from October 2016 to November 2017.

In the sessions on attitudes to death, the speaker **Ms Connie Tong** (Project Officer, CUHK Jockey Club Institute of Ageing) mentioned that some people thought of death as a taboo, thus avoiding death-related issues. Participants shared their views of death and discussed whether they would receive life-sustaining treatment or palliative care if they were EOL patients. Benefits of ACP were listed and participants were encouraged to live to the fullest.

3.5.2.2. Roving exhibitions

Roving exhibitions were held in four public libraries in Sheung Shui, Fanling, Shatin, and Tai Po; seven hospitals in the NTEC; and CUHK from August 2016 to December 2017. The exhibited content included information on JCECC, CUHK Jockey Club Institute of Ageing, our capacity building and education programmes, Quality of Death Index, good death, ACP, ADs, making a will, and initiating EOL care conversations. Leaflets introducing our public talks, exhibitions, ACP, issues for patients to consider before starting an EOL conversation with their family members were distributed to the public. A "Dying Wall" was set up in each exhibition for people to freely express their wishes when reaching their "final destination". The total number of passers-by was estimated as 30,000.


3.5.2.3. Talks organized in collaboration with NGOs and hospitals

We also organized 35 talks for the public in collaboration with NGOs and hospitals from January 2016 to May 2018. Participants learnt about the basics of EOL care; stress management; talking about death in a relaxed manner; ACP; ADs; enduring powers of attorney; treatment approaches; holistic needs of EOL patients; and how to (a) initiate conversations on EOL care or death, (b) make a will, (c) make financial arrangements, (d) support and communicate with patients, (e) manage emotions of EOL patients and families, (f) improve the quality of life of EOL patients, and (g) deal with unfulfilled wishes of EOL patients.

In the session on the basics of EOL care, the speaker **Ms Kenway Ng**, former Project Officer of the Institute, presented the concept of palliative and EOL care; principles of EOL care; needs of EOL patients; types of EOL care services; holistic care for EOL patients; and community support for older adults and carers. Finally, participants discussed their preferred treatment approach if they were (a) a patient with end-stage colon cancer and (b) the patient's daughter.

Besides, we organized sessions to improve public knowledge of helping EOL patients cope with stress. Participants gained an understanding of the definition of stress; the magnitude of EOL patients' stress; sources of their stress; and deleterious effects of chronic stress. The speaker **Ms Connie Tong** then moved on to explore different means of tackling stress, categorized into physical, psychological, social, and spiritual means. At the end, participants performed self-relaxation exercise under the guidance of the speaker.

3.5.2.4. Large-scale public events

From June 2017 to August 2018, we organized four large-scale public events to educate the public on EOL care planning (Table 6). They were held on Saturdays to encourage participation of working adults. In each event, talks and workshops were organized, and exhibitions and booths were set up in the venue.

Table 6 Large-scale public events organized from June 2017 to August 2018

Date	Venue	Topic of talk	Speaker	Workshop
19 June 2017	The Chinese University of Hong Kong	How to Start a Conversation with the Doctor on End-of-life Care Planning	Dr Vincent Tse (Founding Chairman, Society for Life and Death Education)	1. Mini-movie viewing and sharing on advance care planning 2. Advance Care Planning Handbook making 3. Understanding life and death through horticulture
12 August 2017	Hong Kong Teachers' Association Lee Heng Kwei Secondary School	Advance Care Planning and Advance Directives	Dr Lai King Son (Geriatrician, Tai Po Hospital)	
		How to Start Advance Care Planning in Residential Setting	Mr Rex Wong (Project Coordinator, Tung Wah Group of Hospitals)	
		How to Start Serious Illness Conversations with Doctors	Dr Jacqueline Yuen (Clinical Lecturer, Department of Medicine & Therapeutics, Faculty of Medicine, The Chinese University of Hong Kong)	
24 March 2018	The Chinese University of Hong Kong	How to Make a Will	Ms Angelina Luk (Solicitor and Notary Public of Hong Kong)	The three workshops above
		Introduction of Advance Care Planning and Advance Directives	Dr Jenny Lee (Chief of Service, Department of Medicine & Geriatrics, Tai Po Hospital)	+ Appreciating life and death through Zentangle
18 August 2018	The Chinese University of Hong Kong	Advance Care Planning for Older People with Dementia	Prof Timothy Kwok (Director, Jockey Club Centre for Positive Ageing)	1. The application of "Serious Illness Conversation Guide" 2. Understanding life and death through horticulture 3. Clinical ethics in end-of-life care 4. Advance Care Planning Handbook making
		Serious Illness Conversation Guide: Initiating the Conversation	Dr Raymond Lo (Cluster Coordinator [Hospice and Palliative Care], New Territories East Cluster)	
		End-of-Life Care Planning: Spiritual Care in End-of-Life Care	Dr Antony Leung (Medical Superintendent, Haven of Hope Sister Annie Skau Holistic Care Centre) and Dr Paul Wong (Deputy Medical Superintendent, Haven of Hope Sister Annie Skau Holistic Care Centre)	

We publicized the events through a vast array of channels listed below, attracting 179, 218, 327, and 471 participants to the four events respectively:

- Facebook page of CUHK Jockey Club Institute of Ageing (www.facebook.com/ioacuhk/);
- Website of CUHK Jockey Club Institute of Ageing (www.ioa.cuhk.edu.hk/en-gb/);
- Website of JCECC (foss.hku.hk/jcecc/en/);
- Website of the Network of Ageing Well for All (www.ioa.cuhk.edu.hk/en-gb/nawa/nawa-events/);
- Emails to members of the Network of Ageing Well for All;
- Weekly Digest of Mass Mails to students and staff of CUHK;
- A district post in the New Territories East;
- Residents in NTEC through Hongkong Post (10,923 residents in Shatin, 11,120 in Tai Po, and 16,595 in Sheung Shui and Fanling);
- Posters to various patient groups, District Elderly Community Centres, and Neighbourhood Elderly Centres.

In the event in June 2017, **Dr Vincent Tse** introduced common medical terms in EOL care and shared his insights into how patients and their family members could converse with a doctor on EOL care. When attending a consultation, he suggested writing down all the questions, be honest, and ask any question on things that seem difficult or confusing.

Three other talks were organized in the event in August 2017. **Dr Lai King Son** (Geriatrician, TPH) talked about the definition of EOL and life-sustaining treatment, introduced ACP and ADs, as well as described the principles and different aspects of EOL care. **Mr Rex Wong** (Project Coordinator, TWGHs) pointed out the lack of preparation for death among the public, and mentioned that few made an AD although many thought about making care decisions in advance. He also gave an overview of components of ACP. For the talk entitled "How to Start Serious Illness Conversations with Doctors", **Dr Jacqueline Yuen** encouraged patients to request the doctor to be honest, enquire the information they want and the options they have, share their values, and seek the doctor's advice. She emphasized that there should be ongoing serious illness conversations but not a one-off.

In the event in March 2018, **Ms Angelina Luk** (Solicitor and Notary Public of Hong Kong) described, from a legal perspective, the “Three Instruments of Peace” (平安三寶), namely a will, an enduring power of attorney, and an AD. Interesting videos were used to illustrate the importance of making a will. There was another talk named “Introduction of Advance Care Planning and Advance Directives” by **Dr Jenny Lee** (Chief of Service, Department of Medicine & Geriatrics, TPH). She talked about symptoms and prognosis of EOL patients, followed by an overview of ACP and ADs.

Four speakers delivered talks in the event in August 2018. **Prof Timothy Kwok** (Director, Jockey Club Centre for Positive Ageing) spoke on the topic “Advance Care Planning for Older People with Dementia”. He described the characteristics of patients with advanced dementia, dispelled myths surrounding tube feeding in dementia, and introduced ADs and ACP as means to safeguard patients’ quality of life. **Dr Raymond Lo** advocated earlier planning of EOL care and showed a video on serious illness communication to illustrate how to apply the SICG to an actual conversation with a patient and its benefits to patients. The talk “End-of-Life Care Planning: Spiritual Care in End-of-Life Care” was given by **Dr Antony Leung** (Medical Superintendent, Haven of Hope Sister Annie Skau Holistic Care Centre) and **Dr Paul Wong** (Deputy Medical Superintendent, Haven of Hope Sister Annie Skau Holistic Care Centre). They discussed the psycho-spiritual needs of EOL patients and the spiritual care which can be provided to them. A video showing provision of holistic care to an EOL patient was played to demonstrate the benefits of spiritual care.

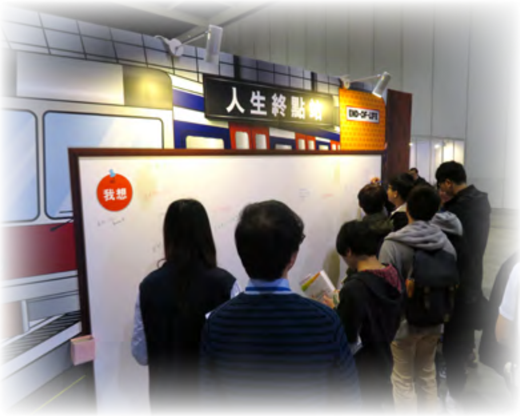
In the events in June and August 2017, participants attended one of the three concurrent workshops, which were interactive and led by experts in the respective spheres, including **Ms Faye Chan**, **Ms Connie Tong**, **Mrs Katy Kwong** (former Service Director, The Hong Kong Society for the Aged), and horticultural therapists. The first workshop was viewing of the mini-movie *The Tail Before* (蚪尾) (see section 3.5.1), followed by a talk and discussion on ACP. The second one was a class on making an *Advance Care Planning Handbook*. Participants were given the chance to think about the directions of their EOL care and get ready for such conversations with their family members and healthcare professionals when they are mentally competent. They could take away the handbook and review their decisions later. The third one was a class on understanding life and death through horticulture. A horticultural therapist talked about life and death of plants and discussed how to initiate a conversation with a patient through horticulture.

Apart from the aforementioned workshops, a certified Zentangle teacher led an additional workshop on appreciating life and death through Zentangle in the event in March 2018. After introducing the background and principles of Zentangle, participants had the opportunity to practise Zentangle skills. In August 2018, **Dr Maria Chui** (Consultant, CUHK Jockey Club Institute of Ageing) led a workshop on the application of the SICG. The appropriate time of and approach to conducting a serious illness conversation was discussed, and a case of Parkinson's disease was used in the ensuing practice. There was also a workshop on clinical ethics in EOL care. **Dr Derrick Au** (Director, CUHK Centre for Bioethics), **Dr Jacqueline Yuen**, and **Ms Faye Chan** identified ethical issues healthcare professionals face in EOL care and introduced some principles and guidelines for addressing ethical dilemmas. Case scenarios were used in discussion for participants to apply the acquired knowledge.

3.5.2.5. Conferences

3.5.2.5.1. Golden Age Expo & Summit

CUHK Jockey Club Institute of Ageing contributed a session on EOL care to the Golden Age Expo & Summit 2017 held in Hong Kong Convention and Exhibition Centre in January 2017 to promote collaboration across sectors and generations in building a “Smart Ageing City”. **Prof Helen Chan** (Associate Professor, The Nethersole School of Nursing, CUHK) gave a talk on ACP. She dispelled myths around EOL care, such as sustaining life by all means as a filial obligation, understanding of patients’ preferences and best interests by healthcare professionals and families without discussion, and the equivalence between making an AD and euthanasia. In addition, **Prof Roger Chung** (Assistant Professor, The Jockey Club School of Public Health and Primary Care, CUHK) spoke on the topic “The Road Map of End-of-Life Care in Hong Kong: Now and to the Future”. He compared the quality of death in Hong Kong with that in other countries, and reported the findings of a research project on the current road map of places of care and death, people’s preferred places of care and death, barriers to and service gaps in local EOL care, as well as recommendations to address the problems. **Ms Angelina Luk** then presented the “Three Instruments of Peace” (平安三寶), i.e. a will, an enduring power of attorney, and an AD. The importance and procedures of making these three instruments were discussed. The moderator of the subsequent panel discussion was **Prof Diana Lee**, Deputy Director of CUHK Jockey Club Institute of Ageing.



The Institute also set up a booth at the venue. It comprised exhibition boards introducing JCECC and the capacity building and education programmes by the Institute, Quality of Death Index, good death, ACP, ADs, making a will, and initiating EOL care conversations. A “Dying Wall” was set up for people to express their wishes at their “final destination” of life.

3.5.2.5.2. Conferences at universities

The JCECC Conference on Collaboration in Creating Compassionate Holistic End-of-Life Care for the Future was held at the University of Hong Kong in March 2017 (Faculty of Social Sciences, The University of Hong Kong, 2017a). **Prof Jean Woo**, Director of CUHK Jockey Club Institute of Ageing, chaired a session entitled “Forum on the Beginning of the End: When to Start Advance Care Planning and End-of-Life Conversation?” with three speakers. **Prof Lui Siu Fai** discussed five types of EOL conversations: (1) among healthcare professionals; (2) between healthcare professionals and social care professionals; (3) between healthcare professionals and the patient/family; (4) in the patient’s family; and (5) in society at large. **Prof Helen Chan** spoke on the topic “When and How to Start End-of-Life Conversation: Perspectives from Doctors, Patients, and Relatives”. She presented the barriers to EOL conversation encountered by these three parties and quoted research findings showing that some patients felt relieved by making an ACP with their significant others. **Prof Roger Chung** gave an overview of EOL care in Hong Kong at present and its future prospects. He stressed the importance of support from family and friends, minimization of pain and discomfort, and patients’ autonomy in EOL care. In addition, **Prof Doreen Au** (Research Assistant Professor, CUHK Jockey Club Institute of Ageing) presented a poster titled “An exploratory investigation into advance care planning, end-of-life communication and decision-making in an acute hospital setting” (findings summarized in section 3.2).

A conference on “Promoting Intrinsic Capacity in Ageing” organized by CUHK Jockey Club Institute of Ageing for around 270 participants in CUHK in December 2017 also discussed EOL care. **Prof Yeoh Eng Kiong** (Director, The Jockey Club School of Public Health and Primary Care, CUHK) shared his insights in the topic “Quality of End-of-Life Care in Hong Kong: Current Status and Future Direction”. He compared the quality of death in Hong Kong with that in other countries, summarized the findings of a research project on EOL care, and made recommendations on improving local EOL care. **Prof Susan Block** (Senior Advisor, Serious Illness Care Program, Ariadne Labs) talked about serious illness care in the US and presented evidence-based benefits of clinician-patient communication on plans of serious illness care. The take-home message was that more, earlier, and better serious illness conversations are desirable. **Dr Nancy Berlinger** (Research Scholar, The Hastings Center) shared her views on ethics for ageing societies. She mentioned that primary palliative care provided by doctors in internal medicine might help meet the increasing demand for palliative care. The audience was led to consider ethical issues in ageing, chronic conditions, and the end of life.

The talks were followed by a panel discussion on ethics for ageing societies among **Prof Cecilia Chan** (Project Director of JCECC and Chair Professor, Department of Social Work and Social Administration, The University of Hong Kong), **Dr Raymond Lo**, and **Dr Derrick Au**.

3.5.2.5.3. Hospital Authority Convention

The Hospital Authority Convention 2018 was held in May 2018 at the Hong Kong Convention and Exhibition Centre. **Prof Lui Siu Fai** and **Dr Jacqueline Yuen**, together with many other experts, conducted a masterclass on the topic "Difficult Conversation – Interactive Case Discussion and Use of Applied Mediation Skills to Resolve Conflicts in End-of-life Care" to around 620 participants, including 80 from Hong Kong Alliance of Patients' Organizations. Issues of good death and feeding options were raised. There was promotion of casebooks on ethical issues in EOL care of older adults (see section 3.6.4), with about 500 copies disseminated to the audience. A case of pneumonia whose family members had different views on tube feeding was described, followed by introduction of mediation skills by **Mr Norris Yang** (Solicitor and Accredited Mediator). Role play, interspersed with humour, was used to demonstrate the application of mediation skills in resolving conflicts in EOL care. The participants learnt more about the skills used from Mr Yang's elaboration. Afterwards, there was a panel discussion on EOL care and conversation among **Prof Paul Lai** (Chairman, Department of Surgery, Faculty of Medicine, CUHK), **Prof Lui Siu Fai**, **Dr Tang Kam Shing** (Hospital Chief Executive of Duchess of Kent Children's Hospital, TWGHs Fung Yiu King Hospital, and MacLehose Medical Rehabilitation Centre), **Mr Charlie Yip** (Vice-Chairperson, Hong Kong Patients' Voices), and **Mr Yuen Siu Lam** (Chairperson, Hong Kong Alliance of Patients' Organizations). The masterclass ended with a question-and-answer session.

3.6. Educational and promotional materials

A wide range of educational and promotional materials was used in our project. They are summarized in Table 7 and detailed in this section.

Table 7 **Educational and promotional materials in our project**

Category	Title	Language	Link
Educational videos	Introduction of JCECC: Capacity Building and Education Programmes on End-of-Life Care	Cantonese, with Chinese subtitles	www.ioa.cuhk.edu.hk/en-gb/resources
	Introduction of Advance Care Planning & Advance Directive		
	How Could a Patient Start the End-of-Life Care Conversation with Healthcare Staff?		
	How to Start Conversation? (For Healthcare Staff)		
Videos on various diseases and serious illness conversation	Goals of Care Options for Patients with Advanced Chronic Obstructive Pulmonary Disease	Cantonese, with Chinese subtitles	
	Understanding Care Decisions in Advanced Heart Failure	Cantonese, with Chinese and English subtitles	
	End-of-Life Care for Dementia Patients		
	Video on Serious Illness Communication		
Video of a public event	End-of-Life Care Planning: Event Highlights on 24 March 2018	Cantonese, with Chinese subtitles	youtu.be/-wZUcObalj0 www.cpr.cuhk.edu.hk/cutv/detail/982

Leaflets	Capacity Building and Education Programmes on End-of-Life Care	English	www.ioa.cuhk.edu.hk/images/content/others/Eol/Leaflet/JCECC%20Leaflet_Eng_Final.pdf
		Chinese	www.ioa.cuhk.edu.hk/images/content/training/EOL/resource/Leaflet_CBEP_chin.pdf
	How to Initiate End-of-Life Care Conversation	Chinese	www.ioa.cuhk.edu.hk/en-gb/component/jce/?view=popup&tmpl=component&img=images/content/others/Eol/leaflet-120617-01.jpg&title=
Booklets	Good Death Booklet	Chinese	www.ioa.cuhk.edu.hk/images/content/training/EOL/resource/Good_Death_Booklet.pdf
	Advance Care Planning Handbook	Chinese	www.ioa.cuhk.edu.hk/images/content/training/EOL/resource/Advance_Care_Planning_Handbook.pdf
	Casebook on Ethical Decision-Making in End-of-Life Care of Older Adults	English	www.ioa.cuhk.edu.hk/en-gb/casebook
		Chinese	www.ioa.cuhk.edu.hk/zh-tw/casebook
Media	Healthpedia: Professional training in end-of-life care	Cantonese	foss.hku.hk/jcecc/zh/「精靈一點」安寧醫療服務的專業培訓 - 香港電台
	Jockey Club End-of-Life Community Care Project: Providing Holistic Support for End-of-Life Patients		foss.hku.hk/jcecc/zh/同途有心人 - 商業電台 /
	Excellent Collaboration between Hospitals and Society		www.rthk.hk/radio/radio1/programme/healthpedia/episode/469736
	Conversation is the Best End-of-Life Treatment	Chinese	news.mingpao.com/pns/dailynews/web_tc/article/20170109/s00005/1483898081236
	Write down Your Concerns and Ask the Doctor		news.mingpao.com/pns/dailynews/web_tc/article/20170109/s00005/1483898081626
	The End is Coming. Why Don't You Tell Me?		news.mingpao.com/pns/dailynews/web_tc/article/20170403/s00005/1491155787779
	Learn to Face Death and Pass Away Peacefully		news.mingpao.com/pns/dailynews/web_tc/article/20170403/s00005/1491155788543
	How to Initiate an End-of-Life Care Conversation with the Doctor?		hk.thenewslens.com/article/68634

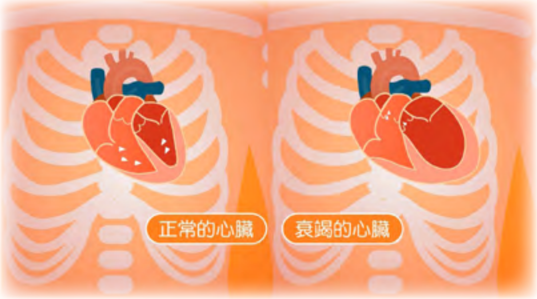
3.6.1. Educational videos

Four videos were uploaded onto our website. The video ***Introduction of JCECC: Capacity Building and Education Programmes on End-of-Life Care*** introduces our capacity building and education programmes. It aims at heightening awareness of EOL issues including good death, preparation for dying, and importance of communication in EOL care in patients, families, and healthcare professionals. In the second video, ***Introduction of Advance Care Planning & Advance Directive***, Dr Jenny Lee educated the public on definitions of AD and ACP, timing of ACP discussion, the difference between ACP and ADs, and advantages of ACP and documentation of an AD. In the third video, ***How Could a Patient Start the End-of-Life Care Conversation with Healthcare Staff***, Dr Vincent Tse gave advice to patients, carers, and the public on when and how to start the ACP conversation, self-preparation for the conversation, importance of frank conversation with the doctor, and tips for effective communication with the doctor. The fourth video, ***How to Start Conversation? (For Healthcare Staff)***, Prof Helen Chan provided skills in talking about ACP, outlined challenges in talking with patients and relatives and how to handle them, and shared some cases related to ACP. At the end of May 2018, 3,084 views were recorded for the four videos in total.

3.6.2. Videos on various diseases and serious illness conversation

The Institute collaborated with various departments and units of hospitals and CUHK to produce videos about some life-limiting diseases and serious illness conversation. The video ***Goals of Care Options for Patients with Advanced Chronic Obstructive Pulmonary Disease*** targets the patients, their families, and healthcare staff. In collaboration with Department of Respiratory Medicine, PWH and Department of Medicine & Therapeutics, CUHK, this video was made to introduce three treatment options (invasive life-prolonging treatment, non-invasive life-prolonging treatment, and comfort care) for COPD patients to understand the anticipated treatment procedures and the impact. It aids patients and family members to make medical decisions based on their goals and values. The video will also be used in training healthcare staff to discuss and make ACPs with patients.

The video ***Understanding Care Decisions in Advanced Heart Failure*** targets patients, their families, and healthcare staff. We collaborated with Supportive Heart Failure Clinic and The Nethersole School of Nursing, Faculty of Medicine, CUHK to produce the video, which helps patients and their family members to understand more about advanced heart failure and different options of medical care for early preparation and consideration. It serves as an aid for helping the patient and family members to identify a treatment option for the patient's best interests. The video will also be used for training healthcare staff.



Furthermore, we collaborated with Jockey Club Centre for Positive Ageing to produce the video ***End-of-Life Care for Dementia Patients***. The video targets patients, patients' families, and healthcare staff. It consists of a dementia patient's story and information on wills, enduring powers of attorney, and ADs, encouraging dementia patients, carers, and the public to reflect on early preparation for EOL care such as making a will or an enduring power of attorney for financial arrangements and drawing up an AD for treatment decisions. It conveys the message that if EOL care is planned too late, the patient's mental state may not allow him/her to participate in the discussion.

We also collaborated with Dr Raymond Lo to make the ***Video on Serious Illness Communication***. It serves as a tool for training healthcare professionals, especially doctors, to initiate serious illness conversation with patients and their families.

The video includes demonstration of EOL conversations with a patient using the SICG and shows the impact on the patient. Healthcare professionals can refer to wordings and phrases used in the video and learn to use the guide step by step to explore the patient's goals and values.


Serious Illness Conversation Guide

現在希望和你談一談病情及未來進展，可以嗎？

1. 請問你此刻了解你病情狀況有幾多呢？
2. 關於你將來的病情，你希望我告訴你幾多呢？
3. 病情：「我擔心時日無多」「有幾多得幾多」
4. 若你健康轉差，哪幾項人生目標對你是最重要？
5. 關於你將來的健康，你最擔心及恐懼的是甚麼？
6. 當你考慮到將來的病況，有甚麼最能給到你力量？
7. 有哪方面的能力你覺得是最重要，如失去了便難以繼續活下去？
8. 若你病得更重，你願意接受幾多來換取更長壽命？
9. 你家人知道你所着重的及所願望的有幾多？
10. 似乎這… 對你來說十分重要？
11. 顧及到你的目標及首要考慮，及了解到你此刻的病況，
   我建議…
12. 我們會一齊去面對.

3.6.3. Video of a public event

Highlights of the public event in March 2018 were presented in a video which was uploaded onto YouTube and CUTV, an online platform with videos showcasing events at CUHK. The video shows participants taking photos in the event, expressing their views towards life and death, participating in our workshops, and sharing their ideas and thoughts. We hope the participants' enthusiastic response shown in the video will attract more participants to the forthcoming public events, thereby improving knowledge of EOL care of a larger number of people.

3.6.4. Leaflets and booklets

We prepared leaflets on our capacity building and education programmes and how to initiate EOL care conversations, as well as a ***Good Death Booklet*** (「吾該好死」) and an ***Advance Care Planning Handbook***. The goal of the *Good Death Booklet* is to empower and support readers to prepare for EOL care matters. Topics of the booklet include 1) initiating EOL care conversations among patients, families, and doctors; 2) introduction of ACP, ADs, enduring powers of attorney, and the will; 3) symptom control and management; and 4) funeral arrangements. *Advance Care Planning Handbooks* allow users to record their wishes, their desired amount of information on the disease, preferences on treatment options and the place of care, as well as contact information of their surrogate. Healthcare professionals and family members will be able to learn about the patient's preferences if the handbook is shared with them so that they can honour the preferences of the patient.

The leaflets and booklets are available on the website and the Facebook page of the Institute, as well as the website of JCECC. A total of 25,200 leaflets, 2,580 *Advance Care Planning Handbooks*, and 2,411 *Good Death Booklets* had been disseminated through a variety of means by the end of May 2018:

- Talks and public events;
- HA resource centres;
- RCHEs;
- District Elderly Community Centres and Neighbourhood Elderly Centres;
- JCECC partners;
- Hong Kong Alliance of Patients' Organizations;
- Faculty of Medicine, CUHK;
- University Library, CUHK;
- Public libraries;
- Jockey Club CADENZA Hub;
- Jockey Club Centre for Positive Ageing.

In particular, *Good Death Booklets* had been distributed to over 100 organizations/ units in hospitals, community partners, patient associations, and different NGOs including NDH; Hong Kong Sheng Kung Hui Welfare Council Limited covering most of their service units in Hong Kong, Macau, and the Mainland; Haven of Hope Christian Service; The Hong Kong Society for Rehabilitation (targeted on professionals in the aforementioned organizations); the Hong Kong Young Women's Christian Association; and Caritas-Hong Kong (targeted on front-line staff in elderly and rehabilitation services in these two organizations). A total of 70 copies were donated to public libraries such that the general public can access the hard copies.

Similar to the Singapore Bioethics Casebook (Centre for Biomedical Ethics, National University of Singapore, 2017), we have compiled a ***Casebook on Ethical Decision-Making in End-of-Life Care of Older Adults*** in collaboration with CUHK Centre for Bioethics. This is a series of commonly encountered EOL cases involving ethical dilemmas in Hong Kong. Through this casebook, we aim to improve healthcare staff's recognition of ethical problems in clinical practice, particularly around EOL care decisions, and to equip them with an ethical framework to approach dilemmas in their clinical practice.

By the end of May 2018, six cases had been written by Dr Jacqueline Yuen. A commentary is provided for each case by an expert who provides his/her perspective on the ethical challenges and practical clinical approaches. The expert commentators include Dr Tse Chun Yan (Honorary Advisor, Hong Kong Society of Palliative Medicine; Member of Clinical Ethics Committee, HA), Dr Derrick Au, and Dr Doris Tse (Cluster Chief Executive of Kowloon West Cluster). There are three backgrounders on salient topics in EOL care, namely decisions about feeding tubes in advanced dementia, EOL care communication, moral distress among health professionals, and concepts and developments of ACP and ADs in Hong Kong. Both Chinese and English versions are available on the website of CUHK Jockey Club Institute of Ageing so health and social care professionals and the public alike can read it at their convenience. By the end of May 2018, there had been 1,558 views online and 541 casebooks had been distributed to healthcare professionals attending the HA Convention 2018 and health and social workers in RCHEs.

Jockey Club End-of-Life Community Care Project

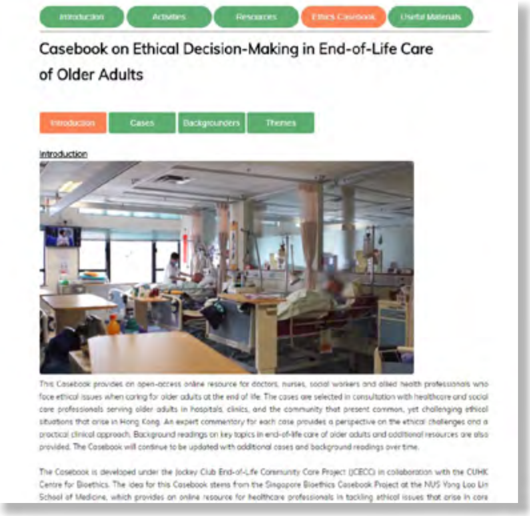
Case: Mr Lau

Conflict between team members

Mr. Lau is an 89-year-old long-term resident at a home for the aged. He started living at the home about 8 years ago after he was hospitalized for a stroke resulting in right-sided weakness and became wheelchair bound. He was never married and has two sisters who visit him every now and then.

Two weeks ago, Mr. Lau was admitted to the hospital after falling from his wheelchair and broke his hip. He was admitted to the orthopaedics ward. Dr. Shan, the orthopaedic consultant felt he was not a surgical candidate for hip replacement due to his poor underlying health status and he was already wheelchair-bound. Over the next few days, Mr. Lau developed a fever and cough, and was diagnosed with pneumonia. Despite being treated with antibiotics, his respiratory status worsened. He struggled to maintain oxygenation despite being on the maximum amount of oxygen that can be delivered to his face mask.

Given his deteriorating condition, the orthopaedics medical officer, Dr. Lo, phoned Mr. Lau's sisters and explained: "Your brother has a serious pneumonia. If we don't connect him to a breathing machine soon, he will soon die." His sisters agreed with inserting a breathing tube, and Mr. Lau was connected to a ventilator. A feeding tube was inserted and tube feeds were initiated.



Casebook on Ethical Decision-Making in End-of-Life Care of Older Adults

This Casebook provides an open-access online resource for doctors, nurses, social workers and allied health professionals who face ethical issues when caring for older adults at the end of life. The cases are selected in consultation with healthcare and social care professionals serving older adults in hospitals, clinics, and the community that present common, yet challenging ethical situations that arise in Hong Kong. An expert commentary for each case provides a perspective on the ethical challenges and a practical clinical approach. Background readings on key topics in end-of-life care of older adults and additional resources are also provided. The Casebook will continue to be updated with additional cases and background readings over time.

The Casebook is developed under the Jockey Club End-of-Life Community Care Project (JCECC) in collaboration with the CUHK Centre for Bioethics. The idea for this Casebook stems from the Singapore Bioethics Casebook Project at the NUS Yong Loo Lin School of Medicine, which provides an online resource for healthcare professionals in tackling ethical issues that arise in care

3.6.5. Media coverage

In April 2016, Prof Jean Woo, Dr Susanna Lo (Consultant of CUHK Jockey Club Institute of Ageing), and Ms Faye Chan talked about EOL care and the capacity building and education programme organized by the Institute on radio (Faculty of Social Sciences, The University of Hong Kong, 2016). It was mentioned that EOL care aims at improving patients' quality of care, reducing their suffering, meeting their needs, maintaining their dignity, and supporting their family members. The objectives, target population, as well as the components of our programme were introduced. It was stressed that EOL care needed further promotion in Hong Kong, and the barriers involved were discussed. Listeners were encouraged to contact the Institute for further information on our programme.

In May 2016, Dr Susanna Lo participated in a radio programme (Hong Kong Commercial Broadcasting Company Limited, 2016). She introduced the aims and target groups of our capacity building and education programme. Other issues discussed included the quality of death in Hong Kong as compared with that in other countries; barriers to providing quality EOL care in Hong Kong; how our programme helped address the barriers; responses of participants in our programme; and concepts of EOL care and ADs. Activities organized by the Institute were promoted at the end.

In January 2017, Dr Susanna Lo published a newspaper article entitled "Conversation is the Best End-of-Life Treatment" (S. S. C. Lo, 2017a). She mentioned that the major aims of EOL care are to reduce physical pain and sadness, as well as to ensure a peaceful death. Doctors ought to facilitate communication between patients and their family members, and manage their emotions in the process. A case of end-stage renal failure was used to illustrate doctors' role in EOL care communication. The doctor encouraged the patient to share his views with his family and a consensus was reached after several conversations. The patient felt relieved and faced the disease together with his family. After stating the role of healthcare professionals in initiating EOL care conversations, the capacity building and education programme of the Institute was briefly introduced. Dr Lo hopes that the quality of life of patients and their families will be improved through our efforts.

Prof Jean Woo shared her views on EOL communication on the same page as Dr Lo's article (Woo, 2017c). She encouraged patients with life-limiting diseases to talk about their thoughts candidly with their family members. Before attending a follow-up consultation, they may make notes of what they will tell and ask the doctor. Despite the availability of online information, some may not be accurate or appropriate, so it is better to ask healthcare professionals. Communication among the patient, his/her family members, and healthcare professionals is likely to contribute to a desirable EOL care plan for the patient. Readers were encouraged to visit the JCECC website to know more about EOL care and related activities.

In April 2017, Dr Susanna Lo published another newspaper article with the title "The End is Coming. Why Don't You Tell Me?" (S. S. C. Lo, 2017b). She used a case of advanced colon cancer to show that patients may not be able to accept the disclosure of prognosis by healthcare professionals at a very late stage. They may have unfulfilled wishes, which could have been satisfied if they had been informed of the prognosis at an early stage. In another case of advanced heart failure, although the patient's family members requested the doctor not to disclose the prognosis to the patient, the doctor suggested seeking the patient's view on whether he would like to know the truth. The patient preferred to know and made the decision not to receive life-prolonging treatment owing to the associated pain. He enjoyed his family's company at the end of life and peacefully passed away. The article concluded that having honest communication with parents and fulfilling parents' wishes at the end of life are consistent with the notion of filial piety.

On the same page as Dr Lo's article, Prof Jean Woo expressed her views on EOL care in another article titled "Learn to Face Death and Pass Away Peacefully" (Woo, 2017a). She advocated that every member of hospital staff who cares for patients should grasp the concept of EOL care. Doctors are responsible for informing patients of their prognosis and patients have the autonomy to decide how they spend the last phase of their lives. The Institute trained healthcare professionals in the capacity building and education programme to increase their competence in providing quality EOL care. The public should also learn about dying and express their preferences regarding EOL care to their family members at an early stage but not the last stage of life. Only through honest communication can every person have their needs met and have a serene death.

In May 2017, Mr Cheung Nga Lok (former Project Coordinator, CUHK Jockey Club Institute of Ageing) and Ms Kenway Ng discussed how patients can initiate an EOL care discussion with the doctor in an online article (N. L. Cheung & Ng, 2017). Patients can express their concerns to the doctor and make decisions after considering different treatment options together. They may learn about their diagnosis, prognosis, and effects of treatments on their quality of life from the doctor. At the same time, they may share their views and feelings of dying such as their preferred place of death and the important things they wish to complete before passing away. Family members are encouraged to attend medical consultations such that they know about the patient's values and goals. The public event on EOL care planning organized in June 2017 was promoted at the end of the article.

In November 2017, Dr Susanna Lo and Ms Faye Chan talked about medico-social collaboration in palliative and EOL care on radio (Radio Television Hong Kong, 2017). It was mentioned that some patients would like to receive care at home or in other community settings. Enhancing medico-social collaboration can reduce their hospitalizations at the end of life such that they can stay at their preferred community setting. In order to achieve this, both healthcare professionals' and the public's awareness of EOL care need to be raised. For doctor-patient communication, some doctors tend to avoid talking about death to avoid being misunderstood that they have given up saving the patient. At the same time, patients may wait for the doctor to initiate a conversation on their illness and prognosis. In view of this problem, the Institute trained doctors' communication skills through talks and workshops which involved role-play exercise. Some doctors' positive feedback were shared, demonstrating the effectiveness of our training.

3.7. Research collaboration and strategies for engaging healthcare professionals

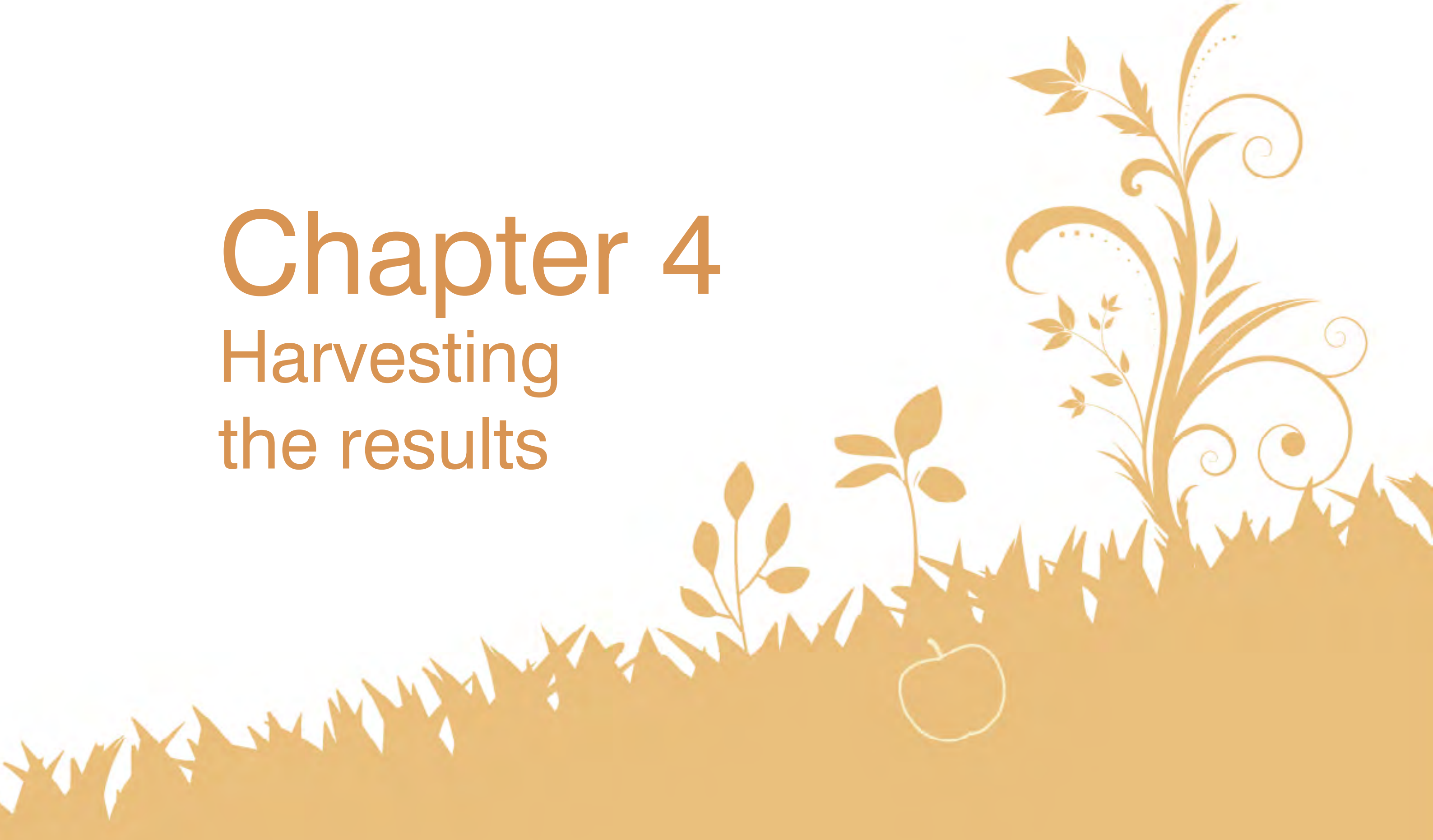
We collaborated with various researchers to engage more healthcare professionals in capacity building and education on EOL care. Prof Helen Chan spearheaded a study to examine the acceptability and feasibility of ACP in 12 patients and 9 relatives in an extended care hospital (H. Y. L. Chan, Lo, Lam et al., 2018). She trained 8 nurses in the hospital based on the SICG, followed by delivery of an ACP programme by nurses and doctors, with her continual coaching. Patients and their relatives were encouraged to share their concerns, personal values and beliefs, and experience of illness or care. For patients who would like to complete an AD, the doctor was ready to act as the witness after reviewing their understanding of different treatment options.

Prof Helen Chan was the principal investigator of another study on experiences of non-invasive ventilation (NIV) and preferred EOL care options in 22 patients with end-stage COPD and 6 relatives in an acute and a subacute hospital (H. Y. L. Chan, Lo, Ng et al., 2018). Ward nurses helped to identify potential subjects for the study. A research nurse and two research assistants were trained to review medical records of the patients over the preceding 24 months. The nurse also received two-hour training on interview skills. Individual, semi-structured interviews were then conducted to understand the patients' experiences of receiving NIV and the patients' and relatives' decision-making process for receiving the treatment.

Dr Susanna Ng (Honorary Clinical Assistant Professor, Division of Respiratory Medicine, CUHK) headed a research team to conduct a cross-sectional study to examine the characteristics of 16 patients with advanced COPD. Doctors and nurses were trained to identify potential subjects and collect data such as demographic characteristics, use of NIV, frailty, and preferences regarding goals of care, cardiopulmonary resuscitation, and intubation. The number of patients who favoured comfort care was measured.

Chapter 4

Harvesting the results



4.1. Survey on self-competence in death work in 2018

4.1.1. Methods and results

To revisit health and social care workers' self-competence in death work, we distributed questionnaires to 614 health and social care workers in RCHEs and seven hospitals in the NTEC from February 2018 to June 2018. Participants were conveniently sampled in talks, seminars, and workshops in our project. Questionnaires were also sent to the institutions by post, and an online questionnaire was provided as an alternative. The questions were largely similar to those in 2016 (see section 3.3), except that there were two additional questions on the attendance of training sessions organized by CUHK Jockey Club Institute of Ageing in the past two years and the types of training sessions attended.

Most of the participants were female (81.1%), worked as nurses (79.7%), and had at most 10 years of experience in death work (60.3%). Participant characteristics are presented in Table 8.

The mean score on the SC-DWS was 59.98 (SD 8.35) (possible range: 16–80), while those on the Existential and Emotional subscales were 37.74 (SD 5.27) (possible range: 10–50) and 14.41 (SD 2.63) (possible range: 4–20) respectively. Participants who received more training provided by the Institute were more self-competent in death work, as evidenced by higher scores on the SC-DWS and the two subscales (Table 9). The difference in self-competence of attendees and non-attendees varied according to the type of training received (Table 10), with the largest benefit observed in training in symptom control (difference in means 3.19), followed by the sessions on introduction to EOL care (difference in means 2.34).

Concerning the open-ended question seeking participants' views on death work, their responses were mostly related to existential and emotional coping. For existential coping, many considered dying an inevitable stage of life and recognized the importance of living to the fullest:

> 助人了解死亡， 能有助人更活在當下， 尋找生命的意義。（急症醫院 B，護士，基督教）
> *(Translated) Help others to understand death, therefore helping them to live more at the present moment and search for the meaning of life. (Acute Hospital B, nurse, Protestant)*
>
> 死亡只是一個過程，是必然的。最重要是在世上時，沒有留下遺憾和憂慮。（護養院 A，個人服務助理，基督教）
> *(Translated) Dying is only a process, an inevitable one. The most important thing is not to regret or feel anxious when alive. (Nursing Home A, personal care assistant, Protestant)*
>
> 生死有命，以尊重溫和的態度面對。（復康醫院 B，護士，沒有宗教信仰）
> *(Translated) Destined for life and death. Face [them] with respect and gentleness. (Rehabilitation Hospital B, nurse, no religion)*

Regarding emotional coping, some showed acceptance, dealt with death anxiety with religious coping, and valued mutual support among their colleagues:

> 突如其來的苦難會使人傷痛也需要接受。（復康醫院 A，護士，基督教）
> *(Translated) Suffering which suddenly arises will make one feel painful but acceptance is needed. (Rehabilitation Hospital A, nurse, Protestant)*
>
> 若有宗教信仰者，對死亡就能減少恐懼。（急症醫院 C，護士，基督教）
> *(Translated) If one believes in a religion, the fear of death will be reduced. (Acute Hospital C, nurse, Protestant)*
>
> 因為同事們的互相支持 [我] 才有信心面對未知的挑戰。（急症醫院 C，醫生，基督教）
> *(Translated) Only with mutual support among colleagues [am I] confident in facing unknown challenges. (Acute Hospital C, doctor, Protestant)*

Table 8 Characteristics of 614 health and social care workers in a survey on self-competence in death work in 2018

Characteristic	Number (%)
Gender	
Male	114 (18.9)
Female	489 (81.1)
Age	
18-29	168 (28.4)
30-39	118 (20.0)
40-49	189 (32.0)
≥ 50	116 (19.6)
Marital status	
Single	264 (44.1)
Married	320 (53.5)
Divorced	14 (2.3)
Occupation	
Doctor	23 (3.9)
Nurse	475 (79.7)
Allied health professional	3 (0.5)
Personal care assistant	71 (11.9)
Social worker or other care worker	24 (4.0)
Work experience	
≤ 10 years	262 (55.2)
> 10 years	213 (44.8)

Death work experience	
≤ 10 years	353 (60.3)
> 10 years	232 (39.7)
Institution	
Acute Hospital A	125 (20.4)
Acute Hospital B	125 (20.4)
Acute Hospital C	35 (5.7)
Rehabilitation Hospital A	124 (20.2)
Rehabilitation Hospital B	78 (12.7)
Hospice A	6 (1.0)
Nursing Home A	53 (8.6)
Residential care home for the elderly	67 (10.9)
Personal bereavement experience	
Yes	513 (85.9)
No	84 (14.1)

Numbers may not sum to 614 due to missing data. Percentages may not sum to 100 due to rounding.

Table 9 **Association between attendance of training sessions organized by CUHK Jockey Club Institute of Ageing in the past two years and mean scores on Self-Competence in Death Work Scale and its subscales**

	Mean score (standard deviation)		
Number of training sessions attended	**Full scale**	**Emotional subscale**	**Existential subscale**
0	59.68 (8.02)	14.35 (2.57)	37.58 (5.04)
1-2	60.38 (8.48)	14.51 (2.70)	37.91 (5.38)
≥3	63.72 (9.85)	15.34 (2.79)	40.03 (6.41)

Table 10 Association between category of training sessions attended and mean score on Self-Competence in Death Work Scale

	Mean score		
Category	**Attended**	**Not attended**	**Difference in means**
Introduction to end-of-life care	61.67	59.33	2.34
Communication skills	60.90	60.00	0.90
Advance directive / Advance care planning	61.56	59.59	1.97
Symptom control	63.02	59.83	3.19
Needs of end-of-life patients	60.86	60.06	0.80
Use of art as a coping approach	60.43	60.28	0.15
Self-management of emotions	61.25	60.11	1.14
Existential issues	61.06	60.19	0.87

4.1.2. Discussion

The association between more training by the Institute and higher self-competence in death work points to the effectiveness of our capacity building and education programme. The training in symptom control seemed the most effective in improving participants' self-competence, possibly because it helped them recognize their contribution to relieving patients' suffering and thus find meaning in their work. Their existential and emotional coping approaches were illustrated by their responses to the open-ended question.

If health and social care workers can effectively use their personal resources and cope with emotional and existential challenges in their death work, they may feel more confident in providing EOL care and derive satisfaction from their work. At the same time, it is possible for their patients to enjoy a better quality of care. Therefore, the importance of increasing self-competence in death work among health and social care staff must never be overlooked.

4.2. Doctors and medical students

4.2.1. Evaluation of doctors’ training in communication skills

4.2.1.1. Methods and results

For doctors’ communication skills training, questionnaires were distributed immediately after training to evaluate the change in the participants’ preparedness in communication skills; their perceived importance and relevance of the training to their clinical practice; and their views on the training. Twenty questionnaires were collected from doctors in SH, AHNH, TPH, and NDH. They rated their preparedness in communication skills in six items on a 5-point Likert scale from 1 = not at all prepared to 5 = very well prepared (Table 11). Percentage increases in their self-perceived preparedness ranged from 24.6% to 40.3% (mean 33.1%). The largest improvement was found in the preparedness to explore goals of care with seriously ill patients or their families, while the preparedness to respond to family members who want treatments that the doctor believes are not indicated improved to the smallest extent. Participants rated the importance of the training to the development of their clinical skills at a mean of 4.35 (SD 0.59), on a scale from 1 = not at all important to 5 = very important. There was generally positive feedback on the relevance, components, and educational quality of the training (Table 12). The pre-workshop lecture and small group role play practice were perceived to be more useful than the video demonstrations of communication skills. The majority (94.7%) would recommend the training to other physicians in their specialty and 89.5% agreed that all higher physician trainees in their specialty should be required to attend the training.

Table 11 Preparedness in communication skills of 20 doctors who attended communication skills training

Overall, how well prepared do you feel you were/are to:	Mean score (standard deviation) Before training	After training	% change
Give bad news to a patient/family about their loved one's illness	3.00 (0.32)	4.15 (0.49)	38.3
Conduct a family meeting	3.05 (0.39)	3.90 (0.64)	27.9
Express empathy	3.05 (0.51)	4.05 (0.69)	32.8
Explore goals of care with seriously ill patients/families of serious ill patients	3.10 (0.45)	4.35 (0.75)	40.3
Respond to families who deny the seriousness of their loved one's illness	2.90 (0.31)	3.90 (0.64)	34.5
Respond to family members who want treatments that you believe are not indicated	3.05 (0.22)	3.80 (0.52)	24.6

The items were rated on a 5-point Likert scale from 1 = not at all prepared to 5 = very well prepared.

Table 12 Views of doctors on communication skills training

Item	Mean score (standard deviation)
Relevance of training	
Relevance of topic content to your area of clinical practice	4.45 (0.60)
Components of training	
Usefulness of pre-workshop lecture	4.30 (0.66)
Usefulness of small group role play practice	4.32 (0.58)
Effectiveness of the small group leaders	4.30 (0.73)
Usefulness of actors in small group sessions	4.50 (0.51)
Usefulness of video demonstrations of communication skills	3.65 (0.81)
Overall evaluation	
Educational quality of the training	4.30 (0.57)

The items were rated on a 5-point Likert scale from 1 = poor to 5 = excellent.

In the open-ended question on experiences in the training programme, a respondent appreciated the training as it could "facilitate communication and reduce conflicts between relatives and healthcare providers". Another respondent replied that he/she "had benefited immensely especially in the role play and discussion". It was also commented that the workshop was "excellent" and it was "very good to 're-play' and correct". If a follow-up communication course is offered, respondents would like the course to cover good case scenarios; setup of goals and values; how to handle complex family dynamics; discussion on ADs; and how to deal with family members' misunderstanding and misconception.

In addition to the questionnaires, our team also made observations in the training sessions. We found that some participants were able to identify the skills used by their peers which they had just learnt in the talk and the workshop. When asked to comment on their peers' performance, they praised their peers as well as gave suggestions. When the patient's relative insisted that pneumonia was a minor illness, a doctor could address the knowledge gap patiently. Nonetheless, not every doctor performed well. When the patient's relative asked a barrage of questions, a doctor was confused and impatient and therefore spoke hastily. Another example was that when the patient's relative had poor knowledge and showed anger and mistrust, the topics discussed were becoming increasingly irrelevant to what the doctor intended to talk about. A doctor also found it challenging to break the news that the patient was at the EOL when another doctor previously said the patient's condition was okay. Concerning the participants' feedback, some opined that the skills covered are "powerful", especially the skill of "understanding" and the statement "hope for the best and prepare for the worst". Some suggested audio-recording their own case scenario practice so that they could reflect on it after the workshop.

4.2.1.2. Discussion

The results showed the effectiveness of our training in boosting doctors' confidence in serious illness conversation. However, they were not confident in responding to family members when their preferred treatment options differed from those of family members. Future training should target this skill as this situation seems to arise frequently in the clinical context. Participants' feedback on the training was, on the whole, positive and encouraging. Not surprisingly, they found engaging in the role play practice more useful than watching video demonstrations of communication skills. About 90% agreed that the training should be mandatory for all higher physician trainees in their specialty, showing the importance of serious illness conversation across different specialties. Room for improvement in some participants' communication skills was noticed, such as in responding to questions, addressing knowledge gap and emotions, and breaking the news of sudden deterioration in the patient's condition.

4.2.2. Evaluation of medical students' training in communication skills

4.2.2.1. Methods and results

Medical students were also trained in skills of serious illness communication. From June 2017 to February 2018, 185 questionnaires were collected from the trainees in 32 sessions. The feedback was predominantly positive, as indicated by the high levels of agreements with the questionnaire items such as usefulness of content, helpfulness of the role play format, and improvement in confidence in serious illness conversations (Table 13). Respondents mentioned different good points about the course (Table 14), including the useful and interactive role play; practical application of skills in a small group tutorial; well-designed scenarios; learning of communication skills; clear and practical feedback; and enthusiastic and experienced facilitators.

Table 13 Views of 185 medical students on communication skills training

Item	% agreed or strongly agreed
The course has achieved its objectives.	98.9
The content of the online e-lectures was useful.	98.9
The length of the online e-lecture was appropriate.	94.6
The small group tutorial enhanced the knowledge you gained from the e-lectures.	99.5
The role play format of the small group tutorial was helpful for improving your communication skills.	100.0
The duration of the small group tutorial was appropriate.	96.8
The course facilitator(s) has/have enhanced your learning in this course.	99.5
The course has improved your confidence in talking with family about serious illness.	95.7
I am satisfied with this course as a whole.	97.8

Respondents indicated their level of agreement with each item on a 5-point Likert scale from “strongly disagree” to “strongly agree”.

Table 14 Good points about the communication skills training mentioned by medical students

Category	Quote
Useful and interactive role play	The role play demonstrated that in real life it may not be so ideal that we can run the conversation smoothly as we expected and it was a good exercise for us.
	Interactive sessions are very helpful in practicing communication skills and apply [applying] what we learnt online.
Practical application of skills in a small group tutorial	It's in format of small group tutorial, participation helps understanding the scenarios.
	Chance to practice with some scenarios, small group as everyone can practice.
Well-designed scenarios	Have a better understanding of communication with other relatives. The case scenarios are well designed.
	The scenarios are very realistic and are commonly encountered in wards.
Learning of communication skills	Taught us how to break bad news in a better way, which we need to do when we become doctors.
	Skills in carrying out a difficult consultation and application in a simulated scenario.
Clear and practical feedback	Very clear and practical feedback from both teacher and groupmates.
	Targeted to practical communication skills. Tailor-made improvement and comments given.
Enthusiastic and experienced facilitators	Having a clinician as a tutor to guide our workshop was extremely beneficial.
	The teachers are very enthusiastic in teaching and their advice is very practice [practical] as well. We get to do some realistic training. Good course.

When asked to list the two most important things they learnt, the most cited were soft skills; the approach to discussing serious illness or breaking bad news to patients and family members; expressing empathy; and establishing relationship with family members and supporting them. Some mentioned addressing emotion of patients and family members; checking the patient's understanding of his/her condition; listening to the patient's and family members' concern; and exploring goals of care. Knowledge gained by the participants is illustrated by the examples below:

> Need to determine and be honest to family when patient is dying, don't give false hope.
>
> Give headlines to facilitate understanding, lengthening details might overwhelming [overwhelm] patients.
>
> Having empathy is not enough, show it!

As regards areas for improvement, participants would like earlier conduction of the training; more time for e-learning; additional and longer communication skills workshops; more role play scenarios; videos with demonstrations by doctors; exam-oriented practice; and practice conducted in English:

> Introduce the content earlier, e.g. in pre-clinical years.
>
> Communication skills is an important topic, it would be helpful if multiple communication skills workshops were held throughout the year, even in surgical rotation.
>
> The 2 cases both have similar purpose- to explain poor prognosis/ inability to survive in a patient with multiple comorbidities. May introduce other elements e.g. new serious illness in a previously healthy patient, explain diagnosis etc.

Other than the questionnaires, we also made observations in the training sessions. In a role play, the daughter of a dying COPD patient who was on bi-level positive airway pressure (BiPAP) was requesting that the BiPAP be removed because of the discomfort. The medical student told the daughter that the BiPAP could not be removed because it was "medically necessary". When the facilitator asked students what could be provided to promote the goal of comfort, students could only suggest DNACPR. They did not understand the principles of comfort care or see role models of quality EOL care on the wards. The discussion that followed was the first time they learnt about promotion of comfort in a dying patient.

When final-year medical students encountered an EOL case in the exam, they too often referred the patient to a surgeon, oncologist, or social worker. Many did not make a prognosis, initiate ACP, or attend to the patient's and relatives' needs. A lack of empathy and avoidance of EOL issues were common.

4.2.2.2. Discussion

Although the medical students reported higher confidence in serious illness conversations and practical feedback from facilitators and peers, the medical students had poor communication skills and did not behave according to ethical principles in the exam. Despite expressing empathy being mentioned as one of the most important things learnt in the training, many students showed a lack of empathy in the exam. As in the feedback from the students, additional and longer communication skills workshops as well as videos with demonstrations by doctors may help improve their communication skills. They also require more exposure to EOL care to become well-equipped doctors capable of providing quality EOL care.

4.3. Hospital nurses

4.3.1. Questionnaires

4.3.1.1. Methods and results

The Institute distributed questionnaires in training sessions for hospital nurses to collect their feedback. Participants were asked to evaluate the session on eight items on a 4-point scale from "strongly disagree" to "strongly agree". Of the 400 respondents from November 2015 to May 2018, 168 were from acute hospitals (PWH, AHNH, and NDH) while 232 were from subacute ones (SH, SCH, BBH, and TPH). Over 95% agreed or strongly agreed with each item in Table 15.

Table 15 Evaluation of training sessions by 400 hospital nurses

Item	Number (%) agreed or strongly agreed
1. The time is appropriate.	382 (96.0)
2. The venue is appropriate.	382 (95.5)
3. You are interested in the topic.	394 (98.5)
4. The session increases your understanding of end-of-life care.	369 (98.9)
5. The session is helpful to your work.	392 (98.2)
6. You hope there will be more similar activities in future.	393 (98.3)
7. If similar activities are organized in future, you will continue to join them.	390 (97.5)
8. You will recommend similar activities to your colleagues/ friends.	392 (98.2)

The total number of responses to each question may be fewer than 400 due to missing data.

Starting from January 2018, there were two additional questions assessing nurses' readiness to initiate EOL conversations with patients and families. Participants indicated their readiness on a 5-point Likert scale from 1 = not prepared at all to 5 = fully prepared. There had been 90 responses to each question by the end of May 2018. For EOL conversations with patients, the mean readiness score was 3.41 (SD 0.86) while that for EOL conversations with families was 3.43 (SD 0.86).

Qualitative feedback was also obtained on questionnaires distributed by the Institute and hospitals. Respondents mentioned merits of the training, identified room for improvement, and gave suggestions. In the bracket after each quote below, the fictitious name of the hospital was followed by the name of the training session.

(1) Merits of training

Usefulness

Many respondents found the training useful, particularly in view of the rising demand for EOL care:

> Thank you very much. It's very helpful since other geriatric population is increasing. (Rehabilitation Hospital A, Identification of Patients at End Stage of Life and Symptom Control)

Some considered the training informative and practical, and some appreciated the broad scope of topics:

> 內容豐富，資料實用，對臨床工作很有效用。（急症醫院 B，晚期照顧的症狀控制）
> *(Translated) The content is rich. The information is useful and very relevant to clinical work. (Acute Hospital B, Symptom Management in End-of-Life Care)*

> Comprehensive & evidence base [evidence-based]. (Acute Hospital C, Identifying Patients at the End of Life)

Some regarded the training as an opportunity for self-reflection or relaxation:

> 對個人自身解構，好似心靈綠洲。（復康醫院 B，探討照顧者自身的死亡焦慮）
> *(Translated) It improves my self-understanding. Just like an oasis of calm. (Rehabilitation Hospital B, Exploring Caregivers' Own Death Anxiety in End-of-Life Care)*

> 可舒緩工作壓力。（急症醫院 B，照顧者的自我照顧）
> *(Translated) Can reduce work-related stress. (Acute Hospital B, Use of Art in Coping with Compassion Fatigue for Self-Care)*

Respondents would like the training to be provided to more healthcare staff:

> Please invite WM [Ward Manager], APN [Advanced Practice Nurse], more staff to attend this meaningful course. (Acute Hospital A, Use of Art in Coping with Compassion Fatigue)
>
> To be promoted to all health care givers. (Acute Hospital B, Identifying Patients at the End of Life)

Knowledge improvement

Respondents gained knowledge of dying-related issues and it was noteworthy that one considered the content of training new to her:

> 題目內容很新鮮，深入淺出，帶出本港安寧狀況，令我更了解一個人面對死之所遇到的情況。（急症醫院 C，晚期照顧系列：洞悉香港的死亡狀況）
> *(Translated) The topic and content are novel. The content is profound but easy to understand. The situation of end-of-life care in Hong Kong was introduced, improving my understanding of what happens when one faces death. (Acute Hospital C, A Better End-of-Life Care Series: An Insight into Dying in Hong Kong)*

Respondents reported enhancement of knowledge of EOL care, such as dignity, grief, ADs, ACP, DNACPR, communication, symptom control, and criteria for end of life:

> Learn more in EoL [end of life] on the group intervention of dignity. (Rehabilitation Hospital B, Anticipatory Grief Intervention for Patient and Family; Supporting Family Members in Grief and Bereavement)
>
> Appreciate the framework and "NURSE" statement [Naming, Understanding, Respecting, Supporting, and Exploring]. (Acute Hospital B, Team Approach Communication in End-of-Life Care)

Formats

Respondents valued experience sharing, which boosted their confidence in providing EOL care:

> Vivid interesting story telling and sharing. (Acute Hospital C, Addressing Moral Distress)
>
> 組員及講員都有分享真實的經歷及個案，令我更有信心面對正面臨死亡的病人及其家屬。（急症醫院 B，支援病人與家屬面對分離之哀傷）
> *(Translated) Groupmates and the facilitator shared real-life experiences and cases, increasing my confidence in facing dying patients and their relatives. (Acute Hospital B, Anticipatory Grief Intervention for Patient and Family; Supporting Family Members in Grief and Bereavement)*

Respondents considered the examples used in the training clear and useful:

> I like those examples stated during comfort [for comforting] patient / relatives when breaking bad news / starting end of life [care]. Love, useful! (Acute Hospital C, Team Approach Communication in End-of-Life Care)

The format of discussion was regarded as interactive, and the questions raised allowed participants to think and reflect:

> [提出了] 很多問題，[討論] 能給予清晰的指示，給我有更多的思考。（急症醫院 B，臨床倫理及預設照顧計劃）
> *(Translated) Many questions [were raised]. [The discussion] could give [me] clear directions and let me think more. (Acute Hospital B, Clinical Ethics and Advance Care Planning)*

Other than discussion, respondents favoured demonstration of skills and the use of videos:

> Skills demonstration and analysis of REMAP techniques [Reframe, Expect, Map, Align, Plan]. (Acute Hospital B, Team Approach Communication in End-of-Life Care)
>
> Video 好有啟發性。（急症醫院 B，探討照顧者自身的死亡焦慮）
> *(Translated) The video is very inspiring. (Acute Hospital B, Exploring Caregivers' Own Death Anxiety in End-of-Life Care)*

The use of art to learn about EOL care and express feelings was appreciated:

> Very good to use "drawing" to illustrate critical element of "loss", "bereavement". (Acute Hospital A, Anticipatory Grief Intervention for Patient and Family; Supporting Family Members in Grief and Bereavement)
>
> 集中於以藝術發掘內心而非講座模式。（急症醫院 B，照顧者的自我照顧）
> *(Translated) Focused on using art instead of a talk to explore deep feelings. (Acute Hospital B, Use of Art in Coping with Compassion Fatigue for Self-Care)*

Speakers

Respondents thought very highly of the speakers:

> The sharing by Dr. Tse is very interesting and impressive. (Acute Hospital C, Addressing Moral Distress)
>
> Speaker fully shows her empathy. (Acute Hospital C, Use of Art in Coping with Compassion Fatigue)

(2) Suggestions and room for improvement

Time arrangements

Some respondents would like a longer duration for some sessions, such as Communication with Patients and Families on Advance Care Planning, Team Approach Communication in End-of-Life Care, and Symptom Management in End-of-Life Care. On the other hand, a respondent mentioned that the duration of a session (Nurses' Perspective on Clinical Ethics in End-of-Life Care) could be shorter.

Time clash with the handover period was mentioned as well:

> Could start @ 1400 as AM duty not yet hand-over to PM shift [at] 1330 to almost late in class. (Rehabilitation Hospital B, Anticipatory Grief Intervention for Patients and Families; Supporting Family Members in Grief and Bereavement)

Format

Respondents would like theories to be well-supported with examples, which can take the form of videos:

> Based on the current AD & ACP application, the frontline staffs are not well familiar with its application & the limitations, suppose this lesson would reinforce the staffs some certain level of knowledge, but it would be improved if some example with the use of video story can be more easy for the staff to improve their understanding. (Acute Hospital B, Clinical Ethics and Advance Care Planning)

There seemed to be a lack of discussion in some sessions:

> 更多的實際例子分享，有討論分享時間更好。（急症醫院 B，臨床倫理及預設照顧計劃）
> *(Translated) Sharing of more real examples. Even better to leave some time for discussion and sharing. (Acute Hospital B, Clinical Ethics and Advance Care Planning)*

Respondents expressed the need to apply the knowledge learnt, possibly in role play:

> 想知死亡是否需要演習，Drill 一次，包括自己、家人。（護養院 A，面對晚期病人精神痛苦的溝通技巧 - 晚期生命的意義）
> *(Translated) Want to know if a death drill is needed. Have a drill. Involve myself and family members. (Nursing Home A, Communication Skills Addressing Patient's Spiritual Suffering - Meaning of Life in Facing End of Life)*

Content of training

Some respondents preferred in-depth discussion on specific topics while some others would like to learn about non-conventional treatments:

> Need to have to separate session only discuss DNA CPR & AD issue. (Acute Hospital B, Clinical Ethics and Advance Care Planning)

> More explore on alternative treatment on symptom control. (Acute Hospital B, Symptom Management in End-of-Life Care)

Other suggestions

Respondents would like the training materials to be provided to them. The need to heighten public awareness of EOL issues was also mentioned:

> 加強公眾教育，不局限於安老院及醫院。（復康醫院 A，晚期照顧在醫院的挑戰）
> *(Translated) Strengthen public education. Not limited to residential care homes for the elderly and hospitals. (Rehabilitation Hospital A, Dying Well - Challenges of End-of-Life Care in Hospital Settings)*

4.3.1.2. Discussion

In the quantitative evaluation, nurses' feedback was predominantly positive. Their readiness to initiate EOL conversations with patients and families warrants improvement, as the mean readiness score was 3.41 (out of 5) for patients and 3.43 for families. Additional training on communication skills in EOL care should therefore be provided for nurses.

The qualitative feedback was varied. Many appreciated the usefulness and broad scope of the training. It was encouraging to know that respondents would like the training to benefit more healthcare staff. In view of respondents' positive comments, our future training will continue to include experience sharing; illustration with examples; interactive discussion; skills demonstration; video viewing; and art workshops. When scheduling the sessions, the handover period of nurses should be taken into account to facilitate their participation. Role play may be considered for participants to practise the knowledge and skills learnt from the training. Notes or PowerPoint slides used by speakers could be provided to participants for their reference.

4.3.2. Observations

4.3.2.1. Methods and results

Observations were made in nurses' training by staff from the Institute and typed afterwards. These observations are categorized and summarized in Table 16. It was found that nurses experienced moral distress when their views differed from those of doctors or patients' families. Experiences in their work or personal life shaped their mindset, hence improvement in the quality of EOL care they provided. They felt stressed owing to time constraints in communicating with families and difficulty in dealing with families' emotions. The workshop about using art as a coping approach was highly regarded. Room for improvement in their EOL care work was mentioned, and they expressed interest in enhancing their knowledge in this regard.

Table 16 Observations in nurses' training

Category	Observation
Moral distress	They disagreed with the doctor over the treatment prescribed in many cases, but they would rather be silent. They were unable to put what they learnt to practice.
	The patient requested the truth about the prognosis while the family members demanded not to disclose any information, giving the patient false hope.
Experiences which shaped their mindset	A nurse talked about her dad's last days of life. The doctor broke the news that her dad only had three months of life left and nothing could be done. She cried behind her dad, and she remembers this forever. After this event, she became more careful when communicating with patients and their families to avoid causing harm to them.
	As some patients wanted to leave a good impression to their family, a nurse helped arrange a haircut, letting the patients die with dignity and a tidy appearance.
	A patient wanted to be neat and clean and to wear her preferred clothes when the moment came. She wanted to be missed and memorized by her family members. The nurse learnt to respect and honour patients' preferences.
Stress related to family members	Nurses thought that family members did not understand the experience and suffering of patients with the tubes and machine so they always asked for resuscitation. Nurses can apply resuscitation easily and quickly while it takes time to explain its drawbacks to family members. However, time constraints are always an issue.
	Some nurses said they lacked knowledge of how to deal with family members' emotions.

Views on the workshop about using art as a coping approach	Most participants did not like drawing or seldom drew but they did enjoy using art to relieve their moral distress. For many, it was their first time to experience art therapy which was unexpected and relaxing.
	The workshop was highly regarded. Participants mentioned that the workshop reduced their negative emotions, relieved their stress, gave them a chance to share their regret and remorse, and allowed them to know more about their colleagues' thoughts and reflect on the meaning of life.
	A nurse felt disinclined to attend the workshop at first due to her tight schedule, but later she felt it was worth the time. The workshop reminded her of her passion and she learnt to slow down and communicate with patients to understand their needs.
	One suggested showing the drawings or paintings of patients to healthcare staff in training sessions to improve their understanding of patients' mind.
Room for improvement in end-of-life care	Nurses are so busy that they have inadequate time to establish rapport with patients and families.
	Some noted that there is a lack of private space for end-of-life patients and their families.
	Excessive engagement with patients' and families' feelings made nurses suffer. Nurses were not well trained to manage their own emotions. Some found it difficult to handle family members' emotions when they themselves were emotionally distressed.
	Some nurses were lacking in communication skills and had difficulty broaching the topic of dying.
Interest in improving their knowledge	Nurses were very keen to know more about the arrangement of dying at home.
	They were eager to know how to raise awareness and understanding of end-of-life issues in patients, family members, and healthcare professionals.
	Some wanted to know whether there is any additional clinical support that they can offer to patients.
	Some would like to learn about patient counselling and receive guidelines or training on how to use forms about advance care planning, advance directives, and do-not-attempt-cardiopulmonary resuscitation.

4.3.2.2. Discussion

The professional hierarchy in the healthcare system seemed to contribute to moral distress when nurses disagreed with doctors over the treatment approach. Another source of moral distress was the patient's family, who might request nurses not to disclose the prognosis to the patient. As a coping approach, the art workshop organized by the Institute looks promising. Participants enjoyed the art therapy, which reduced their negative emotions. They regarded the workshop as a chance to learn about their colleagues' experiences and reflect on the meaning of life.

As nurses had difficulty broaching the topic of dying and handling families' and their own emotions, further related training, possibly combining the forms of talk, role play, and discussion, could be provided to nurses. It is indeed encouraging to find that nurses had the motivation to improve their knowledge of EOL care. When nurses receive more training in EOL care, coupled with what they learn in their personal life and work, we can foresee that they will be more capable of providing EOL care.

4.4. Residential care home staff

4.4.1. Questionnaire survey

4.4.1.1. Methods and results

From February to March 2018, a questionnaire survey was conducted in 5 RCHEs to investigate the knowledge, attitudes, and practice of RCHE staff, and to evaluate the effectiveness of our programme. RCHE staff who attended our training sessions were invited to fill in a questionnaire distributed by our collaborators in RCHEs. Most participants in the survey were female (88.9%) and aged 30 or above (71.4%). Participants' characteristics are presented in Table 17.

Table 17 **Characteristics of 66 participants in a survey conducted in 5 residential care homes for the elderly in the New Territories East Cluster**

Characteristic	Number (%)
Gender	
Male	7 (11.1)
Female	56 (88.9)
Age	
18-29	18 (28.6)
30-39	20 (31.7)
40 or above	25 (39.7)
Education level	
Upper secondary or below	24 (38.1)
Associate degree, higher diploma, or equivalent	23 (36.5)
Bachelor's degree or above	16 (25.4)
Occupation	
Nurse	23 (35.9)
Social worker	17 (26.6)
Health worker, programme worker, or care worker	21 (32.8)
Other	3 (4.7)

Numbers may not sum to 66 due to missing data. Percentages may not sum to 100 due to rounding.

To measure participants' knowledge of EOL care, we designed a true-false test with 10 items (Table 18). One point was awarded for each correct answer, while no point was given to each incorrect or missing answer. The mean total knowledge score was 8.24 (SD 1.66, range 1–10). Only slightly more than half (54.5%) knew that palliative care and EOL care are different (Item 1). It is also worth noting that one-quarter (25.8%) had the misconception that EOL patients usually do not want to know their prognosis (Item 5). Respondents participating in more training sessions organized by the Institute had better knowledge of EOL care (mean 7.86 for one session v 8.65 for two sessions v 8.77 for three or more sessions).

Table 18 Numbers (percentages) of participants who answered knowledge items correctly in the survey

Knowledge item	Number (%)
1. Palliative care is the same as end-of-life care.	36 (54.5)
2. Palliative care should be provided to patients as well as their families.	62 (93.9)
3. Repeated hospitalizations in the past year is one indicator of a patient whom I should prioritize for an advance care planning discussion.	54 (81.8)
4. We should provide comfort care to all end-of-life patients to reduce their pain.	54 (81.8)
5. End-of-life patients usually do not want to know the prognosis of their illness.	49 (74.2)
6. One of the "five blessings" is "good death".	56 (84.8)
7. Advance care planning is a discussion among healthcare professionals and family members and does not involve patients.	57 (86.4)
8. Psychological pain may cause physical discomfort.	62 (93.9)
9. Spiritual support is not part of palliative care.	56 (84.8)
10. After one end-of-life care conversation among healthcare professionals, the patient, and the family, the process of advance care planning ends.	58 (87.9)

The answers are 'true' for items 2, 3, 4, 6, and 8; 'false' for items 1, 5, 7, 9, and 10.
The total number of respondents to each question was 66 unless there was missing data.

Participants' attitudes to EOL care were assessed using a 5-point Likert scale, on which they indicated their level of agreement with nine items (Table 19). About half (51.5%) agreed or strongly agreed that they were confident in applying the knowledge and skills learnt from the training to their EOL care work (Item 4). Similarly, slightly less than half (48.5%) agreed or strongly agreed that they were capable of using the knowledge and skills to improve EOL care (Item 5). Around one-third (34.8%) agreed or strongly agreed that they knew how to conduct ACP conversations with patients (Item 8). The proportion is slightly higher (37.8%) for conducting ACP conversations with patients' relatives (Item 9). It was found that the perceived importance of initiating ACP discussion with EOL patients (Item 3) and the confidence in conducting ACP conversations with patients (Item 8) increased with the number of training sessions attended (Table 20).

Table 19 Attitudes to end-of-life care of participants in the survey

	%				
Attitude	**Strongly disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly agree**
1. Providing quality end-of-life care to my patients is one of my responsibilities.	0	1.5	10.6	59.1	28.8
2. Providing end-of-life care to patients gives me satisfaction in my work.	0	1.5	10.6	74.2	13.6
3. I think it is very important to initiate advance care planning discussion with end-of-life patients.	1.5	0	9.1	63.6	25.8
4. I am confident in applying the knowledge and skills learnt from the training to my work.	0	3.0	45.5	50.0	1.5
5. I am capable of using the knowledge and skills learnt from the training to improve care of end-of-life patients	0	1.5	50.0	45.5	3.0
6. I feel confident in coping with the stress arising from providing care to patients at the end of life.	0	0	42.4	54.5	3.0
7. I feel capable of tackling different challenges of end-of-life work.	0	0	47.7	50.8	1.5
8. I know how to conduct advance care planning conversations with patients.	0	15.2	50.0	31.8	3.0
9. I know how to conduct advance care planning conversations with patients' relatives.	0	13.6	48.5	33.3	4.5

The total number of respondents to each question was 66 unless there was missing data.

Table 20 Associations between the number of training sessions attended and percentage of participants agreed or strongly agreed with the following attitude statements. Values are percentages unless stated otherwise

	Number of training sessions		
Attitude	**1**	**2**	**≥3**
I think it is very important to initiate advance care planning discussion with end-of-life patients.	86.1	88.2	100.0
I know how to conduct advance care planning conversations with patients.	27.8	29.4	61.5

Participants indicated their agreement on a 5-point Likert scale from 1 = strongly disagree to 5 = strongly agree.

For the respondents' EOL care practice, six (15.0%) had more ACP/EOL conversations with patients and/or families in the previous 3 months, compared to the 3 months before training. Since participation in our activities, 22 (34.4%) referred more patients to the Die-In-Home Team of the RCHEs. When asked about the difficulties in providing EOL care in an open-ended question, lack of manpower and time was the most commonly mentioned. Other difficulties included poor acceptance of death-related issues in residents, need for soliciting families' understanding, legal issues, difficulty in identifying EOL patients, and difficulty in communicating and collaborating with colleagues (Table 21).

Table 21 **Difficulties in providing end-of-life care mentioned by participants in the survey. Each English quote is translated from the Cantonese quote above**

Category	**Quote**
Lack of manpower and time	人手及時間不足， 需顧及院務， 未能有足夠人手及時間提供安寧服務。（社工） *Manpower and time are inadequate. Need to handle other tasks. Unable to allocate sufficient manpower and time to provide end-of-life care. (Social worker)*
	當人手不足， 工作時間緊張， 未能聆聽到院友的心聲。（護士） *When there's inadequate manpower and the schedule is tight, [I] can't listen to the voice of residents. (Nurse)*
Poor acceptance of death-related issues in residents	長者拒絕面對生死問題， 對生活大感消極。（活動工作員） *Older adults refuse to face issues of death, feeling very pessimistic about life. (Programme worker)*
	部分長者拒絕談論生死議題。（社工） *Some older adults refuse to discuss issues of death. (Social worker)*
Need for soliciting families' understanding	家人的理解和意願。（社工） *Family members' understanding and preferences. (Social worker)*
	［安寧］服務未普及， 家人未必明白。（護士） *[End-of-life] care is not commonplace. Family members may not understand. (Nurse)*

Legal issues	一些患有認知障礙症患者雖能表達其對預設醫療指示的意願而家人亦同意， 但仍不能為他簽署有關指示， 到最後亦進行了一些患者不想進行的醫療計劃（包括插胃喉），完全不能按院友的意願為他提供適切的服務。（社工） *Although some patients [a patient] with dementia could express his preference for an advance directive and the family members agreed, [the family members] still could not sign the directive on his behalf. In the end, some treatments (including tube feeding) were administered against the patient's wishes. Can't follow the resident's preference at all and provide appropriate service to him.* *(Social worker)*
	院友在院舍可否安詳離世此等法律問題仍未得到解決。（護士） *Legal issues such as whether residents can pass away peacefully in residential care homes are still unsolved. (Nurse)*
Difficulty in identifying EOL patients	如何介［界］定長者是否合適參加安寧服務。（社工） *How to determine whether an older adult is suitable for receiving end-of-life care. (Social worker)*
Difficulty in communicating and collaborating with colleagues	團隊之間的溝通；如何具體落實協助院友"安辭"及院舍同工的配合。（社工） *Communication among team members; how to put the idea of "peaceful death" of residents into practice and collaborate with colleagues in residential care homes. (Social worker)*

Since attending the training organized by the Institute, 42 (64.6%) found that more patients could benefit from EOL care. When asked to list two main learning points, many mentioned general knowledge of EOL care and importance or skills of communication with patients and relatives. The learning points and quotes illustrating the points were shown in Table 22.

Table 22 **Main learning points listed by participants in the survey. Each English quote is translated from the Cantonese quote above**

Category	Sub-category	Quote
General knowledge of EOL care	-	認知安辭服務的性質及內容。（護士） *Know the nature and content of end-of-life care. (Nurse)*
		如何幫助病人善終。（保健員） *How to contribute to patients' good death. (Health worker)*
Communication with patients and relatives	Importance	與院友及其家屬溝通的重要性。（社工） *Importance of communicating with residents and their relatives. (Social worker)*
		除了跟服務使用者的溝通外，跟服務使用者家屬的合作同樣重要。（未知職業） *Apart from communication with service users, collaboration with relatives of service users is equally important. (Unknown occupation)*
	Skills	如何利用藝術與晚期病患者溝通及進行介入。（社工） *How to use art to communicate with and conduct intervention on patients with end-stage disease. (Social worker)*
		大概掌握與家人溝通時的注意事項（關於晚期照顧）。（活動工作員） *Have a general understanding of things to note when communicating with family members (on end-of-life care). (Programme worker)*

Needs of patients and relatives	Holistic needs	從服務使用者的身心社靈需要入手介入。（未知職業） *Conduct intervention on physical, psychosocial, and spiritual needs of service users. (Unknown occupation)*
		當病人步入晚期時候，為照顧者及家[人]提供不同資訊，如：照顧病人的技巧方法，病人的身體狀況，過程，相關服務資訊等，以解照顧者及家人的無力感。（社工） *When patients enter an advanced stage, provide different information to carers and family members, such as skills of and approaches to patient care, patients' physical condition, the trajectory, and information on relevant service to deal with carers' and family members' sense of powerlessness. (Social worker)*
	Psychological needs	明白更多晚期病人及家屬的心理需要。（活動工作員） *Understand more about psychological needs of end-of-life patients and relatives. (Programme worker)*
		完成院友最後心願是很重要。（護士） *Fulfilling residents' final wishes is very important. (Nurse)*
	Physical needs	症狀紓緩對晚期病人是十分重要。（護士） *Symptom relief is very important to end-of-life patients. (Nurse)*
		老[腦]退化症院友不能透過語言表達自己痛症，但可透過面部表情，其身體行為了解院友所需。（護士） *Residents with dementia cannot verbally express their pain, but [we] can understand residents' needs through their facial expressions and physical behaviour. (Nurse)*
Advance care planning	-	以病人的意願作大前提。（護士） *The basic premise is [to follow] patients' preferences. (Nurse)*
		晚期病人可以為自己預設照顧計劃。（護理員） *End-of-life patients can make an advance care plan for themselves. (Care worker)*

Advance directives	-	［訂立］預設醫療指示是對臨終病人其中一份尊重，作為照顧專業團隊，［我們］應向其家屬解釋及幫助家人親屬了解預設醫療指示背後的意念。（社工） *[Making] an advance directive is a kind of respect for end-of-life patients. As a professional care team, [we] should explain and help relatives to understand the underlying concept of advance directives. (Social worker)*
General knowledge of palliative care	-	意識及掌握紓緩治療是什麼。（活動工作員） *Become aware of and grasp what palliative care is. (Programme worker)*
Benefits of EOL care to patients	-	提早對晚期病患者展開安寧服務的好處。（護士） *The benefit of providing end-of-life care earlier to patients with end-stage disease. (Nurse)*
		有尊嚴地離開的信息。（護士） *The message of passing away with dignity. (Nurse)*
Other self-gains	-	同理心增加。（未知職業） *More empathic. (Unknown occupation)*
		除工作外，［我］對其他有需要的人士之敏感度加強。（護士） *Apart from work, [I] have increased sensitivity to other people in need. (Nurse)*
		學懂及體驗透過藝術抒發情緒。（社工） *Learn and experience emotional management with the use of art. (Social worker)*

Participants were also asked to suggest topics useful to their EOL care work, in addition to the topics of training provided by the Institute. The most popular category of topic was “skills”, including skills of bereavement counselling, communication, spiritual support, dignity preservation, and care in general. Other suggestions included education on life and death; legal issues; hands-on workshops; life-limiting diseases; and innovative treatments:

> 如何讓病者活得有尊嚴？（護士）
> *(Translated) How to let patients live with dignity? (Nurse)*
>
> 提供安寧服務時， 可能與家人及病人如涉及法律問題，不知如何處理。（護士）
> *(Translated) When providing end-of-life care, legal issues related to patients and family members may be involved. Don’t know how to handle. (Nurse)*
>
> 香薰治療，狗醫生到訪。（護士）
> *(Translated) Aromatherapy, visit by Doctor Dog. (Nurse)*

4.4.1.2. Discussion

Many respondents did not recognize the difference between palliative care and EOL care. Health and social care staff should know that palliative care is needs-based, whereas EOL care is time-based (Wee, 2016). It is important to understand that palliative care can be applied in the early stages of life-limiting illness (World Health Organization, 2018b), with the benefits of reducing unnecessary hospitalizations and utilization of health services (World Health Organization, 2018a). Moreover, one-quarter had the misconception that most EOL patients are unwilling to know their prognosis. In fact, evidence showed that the vast majority of patients would prefer the doctor to provide realistic and detailed information on their prognosis (Hagerty et al., 2005). Despite these knowledge deficits, the mean total knowledge score was 8.24 out of 10, showing that the participants had good knowledge of EOL care on the whole. The programme effectiveness was implied by the better knowledge of respondents who attended more training sessions organized by the Institute.

Confidence in applying the knowledge and skills learnt to EOL care work may not translate into actual behavioural change. While about half were confident in applying the knowledge and skills learnt from the training to their EOL care work and around one-third considered themselves to know how to conduct ACP conversations with patients or relatives, only 15% had more ACP/EOL conversations with patients and/or relatives. Additional training should be provided to enhance communication skills of staff in RCHEs, thereby increasing their capability to conduct ACP conversations with patients and relatives. Lack of manpower and time, the most frequently encountered barrier to providing EOL care, needs to be addressed by the management of RCHEs, although the feasibility depends on the amount and allocation of resources.

As participants in more training sessions perceived greater importance of initiating ACP discussion with EOL patients and had higher confidence in conducting ACP conversations with patients, our programme may be regarded as effective in these areas. However, we cannot rule out the effects of other forms of training they received, such as the professional training in the Die-In-Home Service Project implemented in the RCHEs (C. R. Wong, 2017).

In future, our training programme may help health and social care staff break barriers to EOL care such as poor acceptance of death-related issues in residents, difficulty in identifying EOL patients, and difficulty in communicating and collaborating with colleagues. Based on the useful topics suggested by the participants, we may also organize more sessions on bereavement counselling, communication, spiritual support, dignity preservation, and legal issues.

4.4.2. Focus group interview

4.4.2.1. Methods and results

A semi-structured, face-to-face focus group interview was conducted to evaluate our programme in RCHEs. Four of our collaborators in organizing the training sessions were asked to comment on our programme and express their views on how to improve it. The interview lasted about 45 minutes and was audio-recorded, with written consent obtained from the participants beforehand.

The participants were team members of a service project aiming at improving EOL care of residents in RCHEs. Two were social workers while the other two were registered nurses. There were one male and three females. They were diverse in terms of age (18-29 for one of them; 30-39 for two; and 60 or above for one) and education level (upper secondary level for one; bachelor's degree for two; and postgraduate level for one). Their experience in EOL care ranged from 0.5 to 3.5 years, and the number of training sessions attended varied from 3 to 23.

In the interview, participants talked about benefits of our programme, shared their views on programme components, and gave suggestions for future training.

(1) Programme benefits

Knowledge enhancement

Participants were unfamiliar with EOL issues before our training. They also found that these issues were new to their colleagues, so our training could enrich their knowledge in this area:

> 我就睇返啲 evaluation [results]，可能有啲同事都覺得 [培訓] 係有啲幫助嘅，始終 EOL 係啲新嘅野啦對大家，所以knowledge 層面上面係認識多咗嘅。（社工，共參與 11 次培訓）
> *(Translated) I took a look at the evaluation [results]. Maybe some colleagues thought [the training] was somewhat helpful. After all, EOL was something new to us, so in terms of knowledge, [we] know more. (Social worker, attended 11 training sessions)*

The opportunity to learn across disciplines was greatly appreciated:

> 我諗最主要對於社工方面，啲個醫護上面嘅知識，尤其是慢性疾病嘅病歷嘅發展啊，有啲咩可以做啊，有咩情況會出現呢，我諗對於社工或者唔係護理同事呢有個知識上面嘅補足。（社工，共參與 23 次培訓）
> *(Translated) I think mainly for social workers, the clinical knowledge, particularly the course of chronic diseases, what can be done, what situations may appear, I think to social workers or colleagues who aren't nurses, [the training] supplemented their knowledge. (Social worker, attended 23 training sessions)*

Participants were pleased to learn about the broad range of topics covered in the programme, including different life-limiting diseases, treatments, bereavement counselling, communication skills, and legal and ethical issues:

> 始終每次［培訓］topic 都唔同，暫時都未係 repeat 嘅。接觸嘅野係闊嘅，唔同 area 涉獵嘅野，可能病症每一種都都會 specific 咁講，有時又有輕鬆嘅手法去同大家 relax，其實都見到啲 topic 冇重覆嘅同時其實係可以豐富到同事嘅知識。（社工，共參與 11 次培訓）
> *(Translated) The topic of each [training] was different. Not repeated up to now. The scope was broad. Covered things in different areas. Each disease was discussed specifically. Sometimes a relaxing approach was used for us to relax. The topics were not repeated, and at the same time, colleagues' knowledge was enriched. (Social worker, attended 11 training sessions)*

> 咁喺 nurse 個情況呢，對於即係掌握咗 end-of-life case 嘅心社靈方面反而就比較 enrich 咗，佢哋 grief 個個 process，主要掌握個 bereavement 好似實淨咗啲，同埋對病人嘅溝通，同家人嘅溝通呀都係比較掌握得好啲。（註冊護士，共參與 11 次培訓）
> *(Translated) For nurses, [knowledge of] psychosocial and spiritual [care] for end-of-life cases was enriched. The process of their grief. Seems [I have] better knowledge of bereavement. And better understanding of communication with patients and family members. (Registered nurse, attended 11 training sessions)*

Attitude improvement

In terms of attitude, participants observed that their colleagues considered issues of dying and death less of a taboo after training:

> 其實我就覺得好好嘅就係 Connie 有幾個 workshop 係比前線嘅同事，輕輕鬆鬆談生死，可以學習點樣同病人溝通同埋臨終嘅關懷 ...... 同埋全個院舍嘅人都知道呢個知識其實都係有個難度係度，但我覺得係好咗嘅，有啲 practical 嘅野比前線同事佢哋個 mindset 其實真係好咗，或者佢哋係 open 啲嘅。（社工，共參與 11 次培訓）
> *(Translated) I think it's really good that Connie ran several workshops for front-line colleagues, called "Talking about Life and Death in a Relaxed Way". [They] could learn how to communicate with patients and [show their] love and care to end-of-life [patients]...And all people in this care home know it's difficult to [grasp] this knowledge. But I suppose it's better. Some practical stuff was given to front-line colleagues, and their mindset became better, or they were more open. (Social worker, attended 11 training sessions)*

Behavioural change

Participants reported better communication and collaboration with their colleagues, who gained a better understanding of EOL care after training. For example, their colleagues referred EOL patients and provided useful information to them:

> 佢哋［院舍同事］個［晚期照顧嘅］意識其實係真係有提升到，佢哋無論 refer［病人］俾我哋啊，同我哋講番一啲老人家嘅情況，佢哋 observe 到，請我哋去跟進，咁其實呢啲都幫到我哋好多，起碼我哋可以有及時嘅介入係好重要。（社工，共參與 23 次培訓）
> *(Translated) Their [Residential care home staff's] awareness [of end-of-life care] has really improved. They refer [patients] to us. Tell us the condition of some older adults. They observe and invite us to follow up. These are very helpful to us. At least we can intervene in a timely manner, which is very important. (Social worker, attended 23 training sessions)*

The programme also improved participants' communication with patients and families as they could develop a better understanding of patients' condition and thus provide accurate information to their families:

> 同家人嘅 role 係，即係點樣演繹佢 end of life 嘅 client 嘅病況，可以掌握多啲，同埋講得準確啲，個準確度大啲，家人明白多咗嘅。至於喺個 symptom control 方面我都覺得比初初入黎係掌握咗多咗嘅。（註冊護士，共參與 11 次培訓）
> *(Translated) [I] gain a better understanding of how to tell family members the end-of-life client's condition, and express more accurately. The accuracy is higher. Family members understand better. And for symptom control, I think [I] have a better understanding, compared to when I was on board. (Registered nurse, attended 11 training sessions)*

A participant observed that her colleagues had more EOL conversations with patients' family members and referred more patients to the EOL care team:

> 其實我又睇到有啲 RN 同事，佢都表達過佢哋會同啲家人有多咗關於 end-of-life issues 嘅傾談。反而我覺得係咪因為我哋有呢個服務所以佢哋會 refer 咗比我哋……不過我同意佢講就佢哋個意識上，佢哋識 refer 已經係一個進步嚟。（註冊護士，共參與 11 次培訓）
> *(Translated) I found that some RN [registered nurse] colleagues expressed that they had more conversations about end-of-life issues with family members. I think, is it because we offer this service [end-of-life care service] they refer [patients] to us…But I agree that in terms of their awareness [of end-of-life issues], it's already an improvement when they learnt to refer. (Registered nurse, attended 11 training sessions)*

(2) Views on programme components

The format of case study was highly regarded by all participants. They could flexibly apply the skills learnt to different cases through interactive discussion and expose themselves to different people's views:

> 因為即係好似 Dr Yuen 咁，上堂嘅時候佢有啲 case study，即係例如 case study 入面去學 symptoms control，即係可能係點靈活運用，咁我覺得係可以加深啲我哋對嗰個 topic 嘅掌握。(註冊護士，共參與 3 次培訓)
> *(Translated) Say, In Dr Yuen's sessions, there were some case studies. For example, learning of symptom control through case studies. That means, like, how to flexibly apply [the knowledge]. I think [this] can deepen our understanding of that topic. (Registered nurse, attended 3 training sessions)*
>
> Group discussion, case study interactive 啲，傾下個 case，原來唔同人諗嘅野都唔同，都幾得意嘅。(社工，共參與 11 次培訓)
> *(Translated) Group discussion and case studies were interactive. When discussing a case, different people thought of different things. It's quite interesting. (Social worker, attended 11 training sessions)*

The workshop about the use of art in coping with compassion fatigue was popular. Participants commented that it offered a novel way for them to relax and think about dying. Art was considered a good approach to self-help and emotional management:

> 我諗呢個都係一個好嘅元素，助人者都需要自助嘅，如果只係不斷地去補充緊你自己嘅知識啦，一啲 skills 啦，意識呀 value 咁，但人係會有 frustrate 架嘛，咁都需要好好去學習愛惜自己，呢個 topic 都係一個同自己溝通同埋學去表達一啲情感，都係一個嘅 recovering，去行更遠嘅路嘅一個必要嘅元素。(社工，共參與 23 次培訓)
> *(Translated) I reckon this [art] is a good element. Helpers need to self-help. If it's only about continually supplementing your [their] knowledge, some skills, awareness, value, people will get frustrated. [They] need to learn to love themselves. This topic is an essential element to self-communicate and to learn to express some emotions, to recover, to walk a longer distance. (Social worker, attended 23 training sessions)*

Nevertheless, participants were not skilful in drawing and preferred to use other relaxation methods:

> 我 art 都麻麻地，因為本身已經擁有啲 relaxation 嘅方式，所以我就用我最 comfortable 嘅方式去放鬆自己，咁就未必會用到課堂教畫畫嘅方式。(社工，共參與 23 次培訓)
> *(Translated) I am not quite good at art. As [I] already have some relaxation approach, I use my most comfortable way to relax myself. So [I] may not use the approach of drawing covered in the session. (Social worker, attended 23 training sessions)*

(3) Suggestions for future training

To raise their interest in attending EOL care training, they suggested inviting professionals in different disciplines to share their knowledge. The use of technology in patient care was also an appealing subject:

> 如果講提升我嘅參加意欲，我就覺得如果係由其他 specialties 去講啲 professional knowledge 對我黎講係幾吸引嘅野，因為唔係喺我嘅範圍識嘅野，而呢啲知識係可以補足到我工作上嘅野……例如啲 ST 呀，OT, PT 呀，即係啲唔同嘅人黎講唔同嘅 topic，就住 end of life 呢個 topic，例如 PT 又有啲做法啲貢獻可以話比我知，大家都可以去做嘅，例如啲新嘅 technology 嘅東西。(社工，共參與 23 次培訓)
> *(Translated) To motivate me to attend [training sessions], I think if [professionals in] other specialties talk about [their] professional knowledge, it's quite appealing to me. Because it's not within my circle of knowledge, and this knowledge can supplement my work…Say, ST [speech therapist], OT [occupational therapist], PT [physiotherapist], different people speak on different topics, about the topic of end of life, like PT can tell me some approaches, some contribution that we can make, like some new technology stuff. (Social worker, attended 23 training sessions)*

> 係嘅，啲 technology 都幾吸引，起碼 for 我哋 team 可以與時並進。有時可能啲 knowledge 嘅野我哋都想 keep 住知道。但一啲 technology 嘅野我哋都想識多啲宜家，可能係醫 cancer 已經可以再有啲進深啲嘅醫學，咁知多樣野對於我哋……同家人去傾嘅時候又再容易啲啲咁啦。(社工，共參與 11 次培訓)
> *(Translated) Right, technology is quite appealing. At least our team can keep abreast of the latest developments. Sometimes perhaps we want to know the latest knowledge. But now we want to know more technology stuff. Say, in cancer treatment, there may already be some more advanced medical [technology]. Knowing some more means…it's slightly easier for us when talking to family members. (Social worker, attended 11 training sessions)*

Visiting RCHEs and EOL service units in other countries was suggested as an interesting means to learn about EOL care and provide inspiration for improving local EOL care. Visiting local sites was another suggestion:

> 殯葬設施呀，都係一啲好嘅。例如無言老師呀，或者［賽馬會］善寧之家，或者譬如講一啲生死議題，點樣引起對呢個 topic 嘅興趣呢，或者去打破個忌諱。除咗講之外，其實都可以去啲實地參觀，都係一啲好嘅做法。（社工，共參與 23 次培訓）
> *(Translated) Funeral facilities are good [sites to visit]. Like "Silent Teachers" or [Jockey Club] Home for Hospice or say, talking about some issues of dying, how to raise interest in this topic or break the taboo? Other than talking, some site visits can be considered. These are some good approaches. (Social worker, attended 23 training sessions)*

Participants expressed the need to devote more time to learning practical techniques or knowledge. They valued the formats of case study, role play, and case sharing:

> 我覺得可以試下 role play，如果係溝通技巧上，特別前線可能你畀一個實際嘅 case study，咁各自分組大家做一個 role play，究竟點同屋企人 interactive 咁。大家可能會，即係大家各自發揮，可能屋企人大家爆出啲唔同嘅 situation，咁各自又點樣回應呢？（註冊護士，共參與 3 次培訓）
> *(Translated) I think role play can be tried. Say, for communication skills, you give a practical case study to, especially, front-line (colleagues). Form groups and they role-play interacting with family members. They may, that means they act as they wish, maybe they think of different situations. Then how does each of them respond? (Registered nurse, attended 3 training sessions)*
>
> Case sharing，可以係講座之中嘅有一個環節，過來人或者我哋遇到嘅一啲 case 呀，可能出黎 brainstorm 下。佢哋要抽時間出黎圍住一個 topic，但講座都係好難免。（註冊護士，共參與 11 次培訓）
> *(Translated) Case sharing may be part of a talk. People who have been there or we encountered some cases. Maybe share and brainstorm. They have to spend time discussing a topic, but talks are unavoidable. (Registered nurse, attended 11 training sessions)*

As not all staff had the chance to participate in all training sessions, the need to repeat the sessions was also identified:

> 人手唔夠所以佢哋上嘅堂都唔全面，我哋編得幾全面佢哋都上得唔全面，就算 repeat 我都覺得唔緊要，應該為佢哋而設。（註冊護士，共參與 11 次培訓）
> *(Translated) There's inadequate manpower, so they [residential care home staff] didn't attend all sessions. No matter how well we planned the schedule, they couldn't attend all sessions. I don't think there's any problem with repeating [the sessions]. Should do this for them. (Registered nurse, attended 11 training sessions)*

A suggestion was given on improving knowledge of life-limiting diseases and EOL care in family members and the public:

> 可能就住唔同院友佢哋一啲特別嘅病徵，其實都係似 Dr Yuen 嘅 topic，只不過係 for 家人版。讓佢哋更清楚知道病症嘅去向，我覺得係佢哋有權知道嘅野。有時可能喺醫院佢哋未必知咁清楚，但反而一個講座可能一個鐘，咁可以比家人知道佢哋未來嘅走動，或者可能做啲咩，變咗佢哋自己可以預測到，等到佢地，或者首先家人或者大眾知道 EOL [care] 同 palliative [care] 嘅關係係點。咁呢啲都係需要循序漸進咁去做，但如果家人有呢個 mindset 嘅時候，可能對於我哋 EOL team 做嘅野佢哋都唔會太抗拒嘅。
> （社工，共參與 11 次培訓）
> *(Translated) Maybe [some sessions on] specific symptoms of different residents. In fact, the topics may be similar to those [discussed by] Dr Yuen, but [tailored] for family members. Let them know the course of the disease more clearly. I think it's something they have the right to know. Sometimes they may not get such clear information from hospitals, but say, in a one-hour talk, [we] may let family members know their [patients'] prognosis or what may be done. Then they themselves [patients] can predict [what may happen]. Let them, or family members or the public know what the relation between EOL [care] and palliative [care] is like. This needs to be done step by step. But if family members have this mindset, perhaps they won't be too resistant to the work of our EOL team. (Social worker, attended 11 training sessions)*

4.4.2.2. Discussion

Participants found our programme useful in improving their knowledge of EOL care. They favoured the wide range of topics covered and the chance to learn from professionals in other disciplines, showing their appreciation of the multi-faceted and interdisciplinary nature of EOL care. Their feedback also showed better attitude and behaviour of both themselves and their colleagues. Our programme played a role in breaking the taboo on dying and improving the participants' collaboration with their colleagues. There was also better communication with patients and families, a vital component of quality EOL care, after attending the training sessions. The format of case study and the use of art as a coping approach will continue to be included in future training, on the basis of the positive comments.

Valuable suggestions were made by the participants. Although the speakers we invited were from different disciplines (e.g. doctors, nurses, social workers, and lawyers), the possibility of allied health professionals (such as physiotherapists, occupational therapists, and speech therapists) conducting training in EOL care seemed to have been overlooked. Participants expressed their interest in learning about the use of technology in EOL care, which may be introduced by biomedical engineers. Visiting sites related to EOL care and dying seems more interesting and may help shatter the taboo on death. Based on participants' suggestions, more time may be allocated to role play and case sharing in future training sessions.

4.5. Patients, carers and the public

4.5.1. Evaluation of talks

4.5.1.1. Methods and results

The Institute distributed questionnaires in talks for patients, carers, and the public to collect their feedback. Participants were asked to evaluate each session on eight items on a 4-point scale from “strongly disagree” to “strongly agree”. Of the 434 respondents from November 2015 to May 2018, 97.0% or above agreed or strongly agreed with each item in Table 23.

Table 23 Evaluation of talks by 434 patients, carers, and members of the public

Item	Number (%) agreed or strongly agreed
1. The time is appropriate.	432 (99.5)
2. The venue is appropriate.	431 (99.3)
3. You are interested in the topic.	426 (99.1)
4. The session increases your understanding of end-of-life care.	429 (99.3)
5. The session is helpful to your life/work.	426 (98.6)
6. You hope there will be more similar activities in future.	431 (99.5)
7. If similar activities are organized in future, you will continue to join them.	426 (98.8)
8. You will recommend similar activities to your friends/family members/colleagues.	420 (97.0)

The total number of responses to each question may be fewer than 434 due to missing data.

In the open-ended question seeking their comments on the talk, some respondents gave positive comments while some made suggestions and pointed out the room for improvement. In the bracket after each quote below, the category of respondents is followed by the topic of the talk.

(1) Positive comments

Sessions

Respondents were very satisfied with the sessions and regarded them as very useful. Patients appreciated the opportunity to attend the sessions, which might offer them peace of mind:

> 我已得知我已有肺癌，但我因為身體都可以支持我去活動，所以便來聽這個講座。多謝！（病人，晚期照顧計劃 - 人生列車）
> *(Translated) I already know I have lung cancer, but my physical conditions still allow me to come and attend the talk. Thank you! (Patient, End-of-Life Care Planning – The Life Train Journey)*
>
> 覺得安心啲。（病人，輕鬆談死）
> *(Translated) Feel more at ease. (Patient, Talking about Death in a Relaxed Manner)*

Speakers

The delivery was considered very good and clear. The friendliness of speakers was mentioned by some respondents:

> 陸律師非常親善又清澈［楚］表達，容易明白。（病人家屬，什麼是「持久授權書」及「遺囑」?）
> *(Translated) Lawyer Luk is very nice and delivered [the talk] clearly. Easy to understand. (Patient's family member, What are 'Enduring Power of Attorney' and 'Will'?)*

(2) Suggestions and room for improvement

Content

Respondents would like to learn about a broader range of dying-related issues, including ADs, wills, financial arrangements, decision-making, and euthanasia:

> 希望了解遺囑、預設財產安排、子女意見不合的最終決定。（安老院舍工作員，預設照顧計劃及預設醫療指示）
> *(Translated) Want to know about wills, advance financial arrangements, the final decision when children disagree with each other. (Worker in a residential care home, Advance Care Planning and Advance Directives)*

Some would like the content to be more concrete and practical:

> 內容只是認識壓力，建議提供具體方法。（圖書館職員，照顧者減壓無難度）
> *(Translated) The content is only for knowing about stress. Suggest providing concrete approaches [to stress management]. (Library staff, No Difficulty in Reducing Stress in Carers)*

Formats

Different formats of sessions were suggested, such as video viewing, role play, case study, case sharing, and small group discussion:

> 多些片段或角色扮演加深參加者［對題目］的認識。（醫院義工，如何打開「晚期照顧 / 死亡」的話匣子及預設照顧計劃 / 預設醫療指示）
> *(Translated) More videos or role play to enhance participants' understanding [of the topic]. (Volunteer in a hospital, How to Initiate a Conversation on 'End-of-Life Care/ Dying' and Advance Care Planning/ Advance Directive)*
>
> 分［到每組］的人太多，最好 6 - 8 人，可討論好些，和分享多些題目。（醫院義工，如何處理晚期病人的未完心願；如何面對及處理晚期病人 / 家屬的情緒）
> *(Translated) Too many people allocated [to each group]. 6–8 people would be the best. Can discuss better, and share more topics. (Volunteer in a hospital, How to Handle End-of-Life Patients' Unfulfilled Wishes; How to Face and Handle End-of-Life Patients/ Relatives' Emotions)*

Handouts

It was suggested that notes and booklets could be distributed to the participants:

> 資料很多，講得太快，可講慢一些及給全部資料筆記。（醫院義工，如何處理晚期病人的未完心願；如何面對及處理晚期病人 / 家屬的情緒）
> *(Translated) Loads of information. Spoke too fast. Could speak more slowly and provide notes on all information. (Volunteer in a hospital, How to Handle End-of-Life Patients' Unfulfilled Wishes; How to Face and Handle End-of-Life Patients/ Relatives' Emotions)*
>
> 有關內容最好能有小冊子，便可讓多些人知道此問題。（未知身分，如何打開「晚期照顧 / 死亡」的話匣子）
> *(Translated) Relevant content would best be [presented in a] booklet. Then more people can know this issue. (Unknown category, How to Initiate a Conversation on 'End-of-Life Care/ Dying')*

Promotion

Respondents were in favour of large-scale promotion of EOL issues to benefit more people:

> 多培訓生死教育課題的義工，大範圍推動、推廣不同年齡層人士對此的認知、瞭解，能面對死亡，準備後事，便能好好活著，珍惜在世的每一天。（長者地區中心義工，什麼是「持久授權書」及「遺囑」?）
> *(Translated) Train more volunteers in topics of life and death education. Promote understanding of these in people of different ages on a large scale. [If people] can face death and prepare for it, [they] can live well and make every day count. (Volunteer in an elderly/community centre, What are 'Enduring Power of Attorney' and 'Will'?)*
>
> 多舉辦同類活動，廣泛宣傳此活動，通過 internet 宣傳，電視和收音機宣傳，報紙雜誌。（病人家屬，預設醫療指示）
> *(Translated) Organize more similar activities. Widely publicize this activity. Promote through the Internet, promote through TV and radio, newspapers and magazines. (Patient's family member, Advance Directive)*

Duration

Some recommended a longer duration to allow sufficient time for a question-and-answer session:

> 講座時間需要長些，因為講解及提問只得 1 小時是不足夠。（長者，如何訂立平安紙）
> *(Translated) The time for the talk needs to be lengthened, since only one hour is not enough for lecturing and asking questions. (Older adult, How to Make a Will)*

4.5.1.2. Discussion

Patients, carers, and the public gave very positive quantitative feedback on the sessions organized by the Institute. In the qualitative comments, they showed their appreciation of the useful sessions and felt relieved after learning more about dying. Based on their suggestions, more sessions may be organized to enhance their understanding of decision-making in EOL care and euthanasia (especially the difference between euthanasia and advance care planning). Practical approaches such as those to stress management were favoured, so both theory and practice should be covered in future sessions. It should be noted that participants preferred interesting formats including video viewing and role play to the traditional format of a talk. They would like to receive notes and booklets on the topics covered in the talks and found the duration of the talks too short, indicating their interest in these topics. It is also encouraging to know that the participants were in favour of large-scale promotion of EOL issues, which may be taken into consideration in related projects.

4.5.2. Evaluation of public events

4.5.2.1. Methods and results

4.5.2.1.1. Talks

In the public events, questionnaires were distributed to the participants to evaluate the talks. Of the 508 respondents, 60.3% were aged over 60. Their characteristics are presented in Table 24.

Table 24 **Characteristics of 508 respondents to evaluation of talks in public events**

Characteristic	**Number (%)**
Category	
Older adult	250 (57.5)
Patient's/Older adult's family member	88 (20.2)
Healthcare professional	26 (6.0)
Patient	7 (1.6)
Other	64 (14.7)
Age	
40 or below	48 (10.1)
41-50	28 (5.9)
51-60	112 (23.6)
61-70	166 (35.0)
Over 70	120 (25.3)

Numbers may not sum to 508 due to missing data. Percentages may not sum to 100 due to rounding.

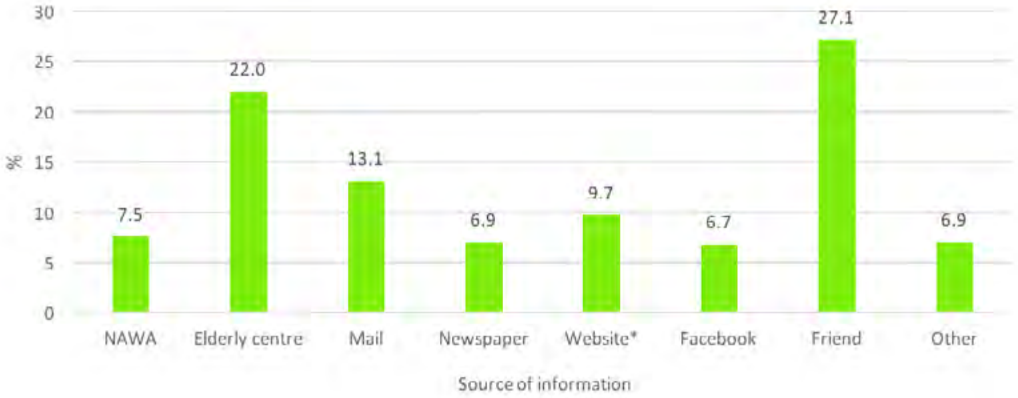
Respondents evaluated the talks by indicating their agreement with each of the seven items in Table 25 on a 4-point scale from 'strongly disagree' to 'strongly agree'. More than 96% agreed or strongly agreed with each item.

Table 25 Evaluation of talks in public events by 508 respondents

Item	Number (%) agreed or strongly agreed
1. You are satisfied with the speaker's performance.	486 (97.8)
2. You are interested in the topic.	479 (98.0)
3. The talk increases your understanding of end-of-life care planning.	481 (98.0)
4. The talk is useful to initiation of end-of-life care conversations in future.	480 (98.2)
5. If similar activities are organized in future, you will continue to join them.	471 (97.3)
6. You will recommend similar activities to your family members/friends.	471 (96.9)
7. You are satisfied with this talk.	448 (97.4)
The total number of responses to each question may be fewer than 508 due to missing data.	

The Institute promoted the public events through a variety of means (Figure 4). About half (49.1%) of respondents knew about the events from elderly centres and their friends.

Figure 4 | Percentage of respondents knowing about the public events through each means of promotion



NAWA = Network of Ageing Well for All, a platform established by the Institute to involve older adults in contributing to an age-friendly city
*Website of the Institute or the Jockey Club End-of-Life Community Care Project

It was the first time for the majority (78.7%) of respondents to attend an event related to EOL care. Over half (56.3%) had not heard of ACP before joining the event, while the percentage was lower (44.7%) for ADs. Most (62.7%) did not have family members facing issues of EOL care.

Apart from the questionnaires, questions raised by participants in the talks were documented. Some participants would like some notes summarizing the content for them to read later; some others would like more information on EOL care services and funeral expenses.

4.5.2.1.2. Workshops

To evaluate the workshops in the public events, we collected qualitative, written comments from participants and made observations in the workshops.

Mini-movie viewing and discussion on advance care planning

A participant appreciated the mini-movie as it was touching and he/she had similar experiences. The involvement of famous actors was mentioned:

> 非常感謝「[賽馬會] 耆智園」製作這個微電影，十分感人。個人有很強代入感，當中有若干情節也曾同樣經歷過。感謝劉玉翠小姐、泰臣先生及小演員們的傾力演出。(病人 / 長者家屬，年約 51-60 歲)
> *(Translated) Many thanks to [Jockey Club] Centre for Positive Ageing for making this mini-movie. Very touching. I have a very strong sense of being one of the actors. I have experienced some scenes in it. Thanks Ms Lau Yuk Tsui, Mr Tyson [Chak], and other actors for [your] painstaking performance. (Patient's/Older adult's family member, aged 51-60)*

More promotion of EOL care was recommended to improve public awareness and knowledge, with making movies on the topic as one of the means:

> 可以在電視或互聯網等媒體作推廣 " 晚晴照顧 " 訊息，使社會大眾正視及接納這資訊。(照顧者，年約 41-50 歲)
> *(Translated) Can promote "end-of-life care" on media such as TV or the Internet, enabling the general public to face and accept this information. (Carer, aged 41-50)*
>
> 製作多些有關係的實用電影，以加深學習者的認識。(長者，年約 51-60 歲)
> *(Translated) Make more relevant, practical movies to enhance learners' knowledge. (Older adult, aged 51-60)*

Based on the usefulness of the workshop to older people, a participant suggested specifying this target group on the poster:

> 發現今天的講座及工作坊也適合年老的媽媽出席，讓她［在晚期照顧方面］有初步的概念。但因講座宣傳沒有這方面的資訊，所以沒有邀請她來，覺得可惜。日後若有類似講座，不妨在海報上註明：歡迎長者出席。（病人 / 長者家屬，年約 41-50 歲）
> *(Translated) Found that today's talk and workshop are also suitable for [my] old mum to attend to let her get a basic idea [of end-of-life care]. But because no such information was included in the promotion of the talk, [I] didn't invite her to come. It's a pity. In future, if there are similar talks, [the organizer] may specify on the poster: Older people are welcome. (Patient's/Older adult's family member, aged 41-50)*

Richer content and more time for asking questions seemed necessary:

> 不夠深入，時間不夠，應可多些時間發問。（未知身分及年齡）
> *(Translated) [The content is] not rich enough. Insufficient time. Should have allowed more time for asking questions. (Category and age unspecified)*

Making an *Advance Care Planning Handbook*

Participants found the workshop meaningful, and were interested in learning about community resources and healthcare facilities related to EOL care:

> 此活動很有意義，希望能安排參觀［賽馬會］善寧之家。（長者，年約 70 歲或以上）
> *(Translated) This activity is very meaningful. Hope a visit to [Jockey Club] Home for Hospice can be organized. (Older adult, aged over 70)*

More activities on and large-scale promotion of EOL care were recommended:

> 希望多些類似活動，宣傳需要加強，普及推廣。（長者，年約 61-70 歲）
> *(Translated) Hope [there will be] more similar activities. Need to step up the promotion. Promote on a large scale. (Older adult, aged 61-70)*

In the workshop, participants who were living alone and had little interaction with their family members said they never thought about EOL care issues as no one discussed these issues with them. Imagining their last stage of life, some preferred to receive care in hospital due to availability of doctors. Home care was not a favourable choice to them as they had the belief that their home would become haunted and they would not want to be a burden to their family members. Some would want the truth of their condition from the doctor, ask the doctor how much time was left, and plan for death.

Understanding life and death through horticulture

Some considered it novel to learn about life and death through horticulture:

> 以前很少人用園藝講生死，其實很好，學咗野。（未知身分及年齡）
> *(Translated) Few people used to talk about life and death using horticulture. In fact, it's very good. Learnt something. (Category and age unspecified)*

Many enjoyed horticulture and gained much knowledge. One became more open-minded and one associated it with good fortune:

> 好開心，種了花很茂盛，盆滿砵滿。（未知身分及年齡）
> *(Translated) Very happy. I grow very lush flowers. The pot is full [meaning 'rake in big bucks' in Cantonese]. (Category and age unspecified)*

Participants were eager to join similar classes in future:

> 日後多些開這個班，使老人家更開心。（長者，未知年齡）
> *(Translated) Organize more such classes in future, making older people happier. (Older adult, age unspecified)*

From our observation, there was an enjoyable atmosphere and participants liked the self-made colourful plants. Participants mentioned that they would like more information on the relation between the life cycle of plants and death or meaning of life. They found the 1.5 hours insufficient, and suggested shortening the presentation, thereby leaving more time for them to make the plants and share their views with each other.

Appreciating life and death through Zentangle

For this workshop, some wondered how EOL patients can use Zentangle as an emotion-focused coping approach:

> 如何可以引導晚晴人士，以這方式令他們感覺平靜？如該人士已在病床。（病人 / 長者家屬，年約 40 歲或以下）
> *(Translated) How to guide end-of-life people and make them feel calm using this approach? Say, the person is already on the hospital bed. (Patient's/Older adult's family member, aged 40 or below)*

There were suggestions of having a longer workshop and more volunteers to help the participants. A participant would like to receive the slides used by the instructor:

> 若果可以的話，可否 email 今天的 PowerPoint 給我，我想和自閉症的兒子或學生分享，謝謝。（病人 / 長者家屬，年約 51-60 歲）
> *(Translated) If possible, could [you] email today's PowerPoint to me? I want to share with [my] autistic son or students. Thanks. (Patient's/Older adult's family member, aged 51-60)*

4.5.2.2. Discussion

Quantitative feedback on the talks in public events was very positive. The Institute promoted the events through various channels to benefit a wide range of people. However, if resources are limited, promotion in elderly centres followed by word of mouth will likely be the most effective, according to the evaluation results. It was the first time for most respondents to attend an event about EOL care, indicating that EOL issues may be new to many members of the public. Although many did not have family members facing issues of EOL care, they attended an event on these issues, implying their interest in gaining related knowledge. Moreover, some would like to receive notes summarizing the content covered in the talks, which may be considered in future events. Some others would like to obtain additional information on EOL care services. Taking this into account, we distributed *Good Death Booklets*, which consist of this information in the appendices, in the third event in March 2018. We may continue to distribute the booklets, subject to the budget of our future project.

For the workshops, the involvement of famous actors seems a good idea to attract the attention of the public. Based on respondents' recommendation, we will continue to promote EOL care to the public to improve their awareness and knowledge. More interaction is desirable, so there could be better time management to leave more time for participants to raise questions and share their ideas. Visiting healthcare facilities related to EOL care was suggested, but privacy and dignity of patients should be taken into account when planning such visits. Participants who were socially isolated had never thought about EOL care issues as no one discussed these issues with them. They were probably reached by post, which appears a good way to recruit people who lack social participation. Some did not consider home care a favourable choice as they did not want their home to become haunted. In fact, it should be regarded as a blessing to pass away peacefully at home, in contrast with the bad fortune associated with accidental death, murder, or suicide (Hui & Lee, 2017). The workshop on Zentangle was a pilot to use Zentangle as a means to reflect on life and death issues. Responses revealed that it is necessary for the instructor to suggest possible ways to apply the approach of Zentangle to EOL patients.

4.5.3. A glimpse of Dying Walls

"Dying Walls", boards for people to express their wishes when reaching their "final destination", were set up in roving exhibitions in public libraries, hospitals, and CUHK; the Golden Age Expo & Summit 2017; and public events organized by the Institute. Their wishes are presented in Table 26.

Table 26 **Wishes of the public when reaching their “final destination”. Each English quote is translated from the Cantonese quote above unless stated otherwise**

Theme	**Sub-theme**	**Category and quote**
Death	Attitudes to dying	Go with the flow ……3. 人生自古誰無死。 4. 天下無不散之延 [筵] 席。 *…3. No one is immortal. 4. All good things must come to an end.*
		No regret 無憾離去，走得瀟灑。 *Leave with no regret. Go in a cool way.*
	Hopes about death	Die comfortably 睡夢中無痛安詳死去。 *Die in a dream, in peace and without pain.*
		Die with dignity 我希望能有尊嚴及舒適地離世。 *I hope [I] can pass away with dignity and in comfort.*
		Die happily 開心走到終點。 *Reach the destination happily.*
		Do not give up 請你千其唔好放棄，加油 !!! *Please, by all means, do not give up. Hang in there!*
		Make their own choices 想在最後的階段，我可以為自己照顧做決定。 *I want to make choices for my care in the last stage.*
		Euthanasia 快快實行安樂死，醫生及家人 / 病人同意便應實行，死得舒服是老人希望。 *Be quick to practise euthanasia. Should do it when the doctor and a family member/the patient agree. Dying comfortably is older people’s wish.*
		Company of family 自己的屋企人都係身邊陪伴。 *In the company of all my family members.*
		Funeral arrangements 若我真的要走了，請別喧鬧，一切從簡便是，把我 [的骨灰] 撇 [撒] 在 [紀念] 花園，回歸自然。 *If I really have to go, please don’t make so much noise. Just keep everything simple. Scatter me [my ashes] in a Garden [of Remembrance]. Return to nature.*
		Start over 希望有機會再來。 *Hope there’s a chance to start over.*

	Religious coping	Buddhism 萬般帶不走，唯有孽隨身，行善積德。 *Can't take away anything but sin. Do good deeds and lead a life of virtue.*
		Christianity 笑著回天家見天父，祂說我是 " 又忠心、又良善的僕人 " 。 *Smile and meet God in heaven. He says I am "a loyal and kind servant".*
		No specific religion 不枉此生，無愧於神。 *This life is not wasted. Not ashamed in front of God.*
	To-do before death	Review their life 好好回味一下我一生中的苦與樂，快樂地和大家一起吃個飯。 *Take a good look at the pain and joy throughout my life. Have a meal with everyone happily.*
		Fulfil their responsibilities 完成所有責任，然後靜靜地離開。慢 > 空 > 悟 *Fulfil all responsibilities, then leave quietly. Slow >Empty > Enlighten*
		Meet loved ones See my good teacher and BFFs [best friends forever] again! (written in English)
		Spend time with loved ones 臨終前能與家庭溫暖愉快地渡過。 *Can spend warm and happy moments with family before death.*
		Express gratitude to loved ones 感謝爸爸媽媽的養育之恩。 *Thanks Dad and Mum for raising me up.*
		Positively influence others 將愛送給所有人，生命影響生命。 *Love everyone. Life affects life.*
		Travel 完成心願，環遊世界。 *Fulfil wishes. Travel around the world.*
		Become rich 買張六合彩中頭獎。 *Buy the lottery and win the first prize.*

Life	Attitudes to life	Make every moment count 活在當下。 *Live in the present.*
		Meaningfulness is important 生命不在乎長短，只在乎意義。 *The meaning of life matters but not the length of it.*
	Hopes about life	Excel academically 考試希望能拿到 100 分。 *Hope [I] can score 100 in the exam.*
		Develop their career 成為一名藝術家。 *Become an artist.*
		Have a large family 兒孫滿堂。 *Lots of children and grandchildren.*
		Fulfil their dreams All my dreams come true and have more dreams! (written in English)
		Be happy and healthy 活著每天都健康，無憂無慮天天快樂。 *Be healthy every day. Be happy and free from worries every day.*
Love	Family	Wishes to their family 家人好好生活 !! 比佢地有好日子過！長命百歲！ *May family members have a good life!! Let them have a good life! Longevity!*
		Love of family members 希望得到媽媽的愛。 *Want mum's love.*
		Not be a burden to family 葬禮係記念 [紀念] 花園就 OK，唔好比太大負擔親人去做葬禮同比錢骨灰位。 *It's ok to [hold] the funeral in a Garden of Remembrance. Do not cause too much burden to relatives for holding the funeral and paying for the niche.*
	World	Wishes to the world 世界和平，人人健康。 *May the world be peaceful and everyone be healthy.*
		Help the poor 我要助養非洲小朋友。 *I want to sponsor children in Africa.*

4.6. Educational and promotional materials

4.6.1. Video about heart failure

To understand the acceptability and feasibility of using the video about heart failure to facilitate ACP discussion, the video was shown to three healthy older adults aged 60 or above. A questionnaire was used to elicit their verbal comments and observations were made.

The older adults were all female. Two were single while one was widowed; two received secondary education whereas one received tertiary education. They considered the content objective, unbiased, and easy to understand. They regarded the length of the video as appropriate. After watching the video, they gained a better understanding of available care approaches and were motivated to discuss with the doctor the care approach for themselves or their family members in future. The video was seen as a medium for starting a conversation about treatment decisions with their family members. They would recommend it to patients with heart failure to help them understand their autonomy and treatment options. None felt strong emotions while or after watching the video.

A viewer said that she would not choose any of the three options if she had heart failure. She disliked using tubes or any other instruments, which were part of all options presented in the video. She also worried that some patients' emotions might be affected and acceptability of the video to young people might be low.

Based on the feedback, it is possible that some viewers may not understand that the video showed examples only but not all possible options. There should be further elaboration of the care options when showing the video to patients or families to ensure that they grasp the concept of the care options. Emotional support should be provided if necessary. Despite the generally positive comments, it should be noted that only three people gave their feedback and they were all healthy older adults with secondary or tertiary education. There should be further evaluation which involves a diverse group of patients and families to examine the acceptability and feasibility of using the video to facilitate ACP discussion.

4.6.2. Video of a public event

The link of the video with highlights of the public event in March 2018 was sent to the management and some doctors of the seven hospitals in the NTEC. Their replies showed their appreciation of the information delivered and the Institute's efforts:

> Many thanks for the valuable information! It would be very useful for us in promoting End-of-life care and advance care plan in patient service.
>
> Thank you very much for the sharing from Prof Jean Woo. Congratulations on such a successful and meaningful event!
>
> Thanks for sharing. My team and I will surely take a look.
>
> Thanks for your update and congratulations to the team for the success of the move. Certainly thank you very much.

4.6.3. Booklets

4.6.3.1. Good Death Booklet

Readers of the *Good Death Booklet* provided positive, qualitative feedback through email and instant messaging application. Their feedback is shown below:

Professors and doctors

> Thanks for the comprehensive booklet. Very informative.
>
> It is well designed (colourful with cartoons). Very useful for both healthcare workers, patients and their families.
>
> Thanks for the material which nicely describes this difficult topic. It is very helpful too.
>
> It will surely help with our daily practice and patient care.
>
> Will share the link with nursing students and colleagues.
>
> It looks very nice.
>
> Great work!

Staff from non-governmental organizations

> Very informative, well-written, well-organised, simple, straightforward and easy to understand. We want to get 8 copies more.
>
> I hv [have] read your book la. It's informative and easy to read. Can let more ppl [people] understand ACP, AD.

The public

> Hi, thx [thanks] for the book 唔［吾］該好死 [*Good Death Booklet*]. Where can I get further copies for my folks n [and] friends?
>
> Your book is very comprehensive! Tks [Thanks].
>
> They [The authors and editors] did a good job and should be proud.
>
> p30 怎樣回應病人，平安紙及遺產分配很實用。
> *(Translated) p30 [page 30] how to respond to patients, [and the parts on] wills and distribution of estates are very useful.*

It is very encouraging indeed to receive the favourable comments from readers of the *Good Death Booklet*. They were appreciative of the comprehensiveness, usefulness, design, and organization of the booklet. There were comments that the booklet was "easy to read" and "easy to understand", probably attributed to the colourful layout and the use of bullet points, tables, pictures, and short paragraphs. When designing booklets for the public in future, the use of similar design will definitely be considered. Some readers would like to obtain additional copies or share the link of the booklet with students and colleagues to benefit them. We would like to express our gratitude to them for increasing the reach of the booklet.

4.6.3.2. Casebook

A Nurse Consultant (Intensive Care) found the *Casebook on Ethical Decision-Making in End-of-Life Care of Older Adults* "very suitable for conduction of the training" for nurses working in intensive care units (ICUs) in the HA. A total of 53 registered nurses attended the 90-minute class "Ethical Issues in ICU – From theory to practice" as part of their ICU specialty training in March 2018. Their work experience in ICUs was around two to three years. Cases in the casebook were provided as hardcopies, followed by discussions. Afterwards, they were invited to share their thoughts, with facilitation by nurse lecturers (including the Nurse Consultant).

The feedback from the students and the nurse lecturers alike was positive and encouraging. They welcomed class conduction in the format of discussion. The cases were considered "real" and "down to earth". From the Nurse Consultant's observation, the students were more engaged and had more discussion, compared with previous classes. He encouraged the students to visit the Institute's website for further information on ethical issues in EOL care.

Common, real-life scenarios in the casebooks were favoured by participants, who probably encountered these scenarios in their day-to-day work. In future, organizing training sessions with the use of casebooks could be considered. Discussion may account for a large proportion of the session, as it has been shown to be effective in motivating participants to learn about EOL care.

4.7. Research projects

4.7.1. Study on advance care planning

In July 2017, Prof Helen Chan trained 8 nurses in an extended care hospital in a 2-hour session for them to implement an ACP intervention from October 2017 to May 2018 (H. Y. L. Chan, Lo, Lam et al., 2018). In the intervention study, the ages of the 12 patients ranged from 33 to 83 (mean 57.9). There were 8 males and 4 females. After the intervention, their readiness for ACP was assessed with 5 items on a 5-point Likert scale from 1 = not ready to 5 = ready. The mean scores for the items ranged from 2.09 to 3.00. Evaluation of support for ACP on a 5-point Likert scale from 1 = inadequate to 5 = adequate showed a mean score of 3.00 for informational support, 3.27 for family respect, and 3.40 for healthcare team respect. No ACP discussion was documented in patient records, and none signed an AD in the study.

As some patients were young, they might find it too early to make an ACP, thus feeling unready for ACP. Another reason could be the lack of information they received. In EOL care, adequate information ought to be given to patients on various treatment approaches to facilitate their decision-making. Documentation of ACP discussion is necessary to ensure continuity of care, and completion of an AD means that the patient's preferences are more likely to be honoured. Therefore, both should be encouraged in care of EOL patients.

Data of patient transfers from the extended care hospital to the Accident and Emergency Department (A&E) from the first quarter of 2015 to that of 2018 was obtained to measure the effectiveness of the intervention in reducing patient transfers to A&E. From the fourth quarter of 2016 to that of 2017, the number of patient transfers to A&E dropped by 62.5% (from 24 to 9) for the Infirmary Unit; 37.5% (from 8 to 5) for the Disabled Unit; and 56.3% (from 32 to 14) for the total number (Figure 5). When comparing the numbers of patient transfers to A&E in the first quarters from 2015 to 2018, the numbers in 2018 were the lowest (Figure 6). The number fell by 76.9% (from 26 in the first quarter of 2017 to 6 in that of 2018) for the Infirmary Unit; 55.6% (from 9 to 4) for the Disabled Unit; and 71.4% (from 35 to 10) for the total number. The trend of patient transfers to A&E from the first quarter of 2015 to that of 2018 was also examined (Figure 7), with the numbers of transfers from the Infirmary Unit and the Disabled Unit reaching record lows in the first quarter of 2018.

Nurses which implemented the intervention was trained in the third quarter of 2017, and the intervention spanned from the fourth quarter of 2017 to the second quarter of 2018. The results of fewer patient transfers in the fourth quarter of 2017 (compared with that of 2016) and in the first quarter of 2018 (relative to all other quarters since the first quarter of 2015) seemed to support the effectiveness of the nurses' training and the ACP intervention in reducing patient transfers to A&E. It was likely that healthcare professionals learnt about the option of comfort care and introduced it to more patients. If more patients preferred comfort care, symptom management on the ward, rather than invasive care at A&E, would become the main treatment approach.

Figure 5 | Numbers of patient transfers to the Accident and Emergency Department in the fourth quarters from 2015 to 2017

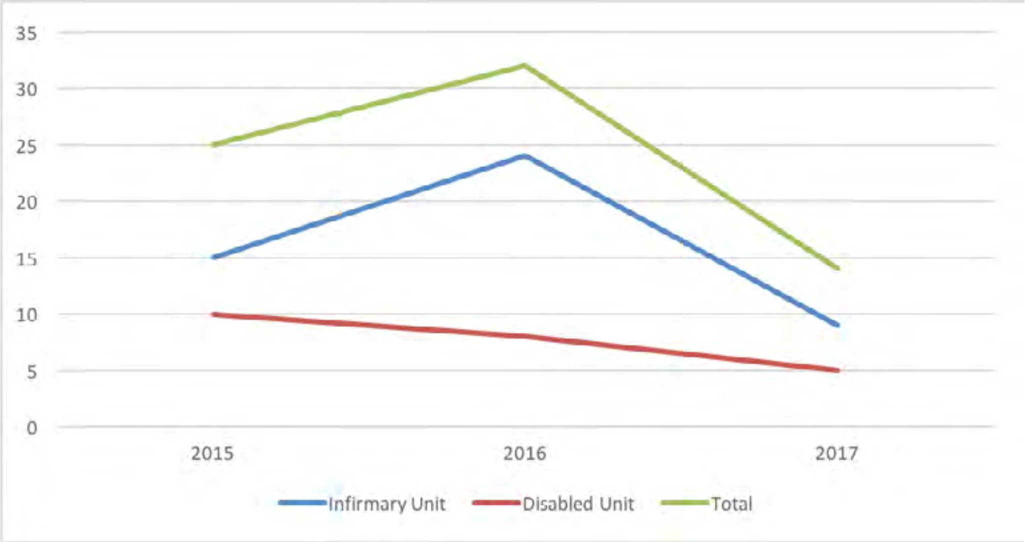


Figure 6 | Numbers of patient transfers to the Accident and Emergency Department in the first quarters from 2015 to 2018

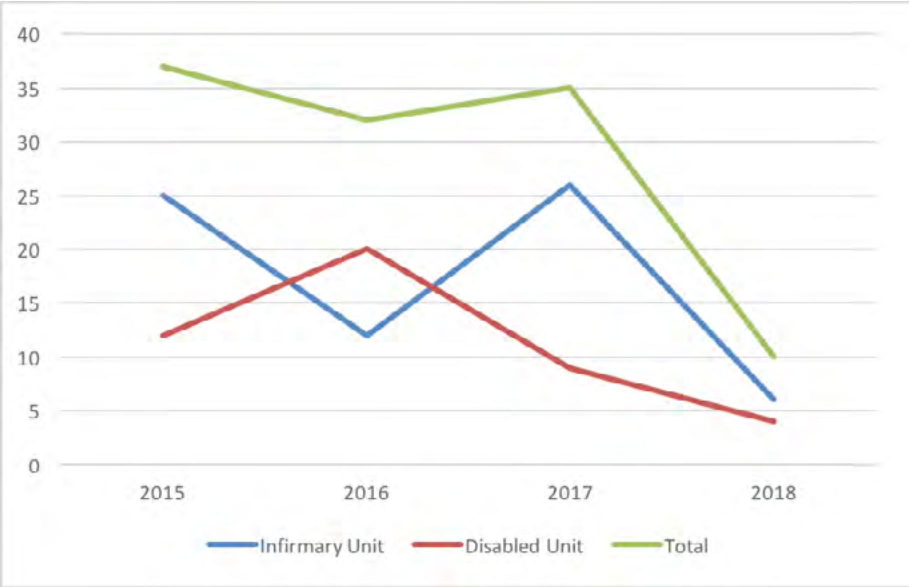
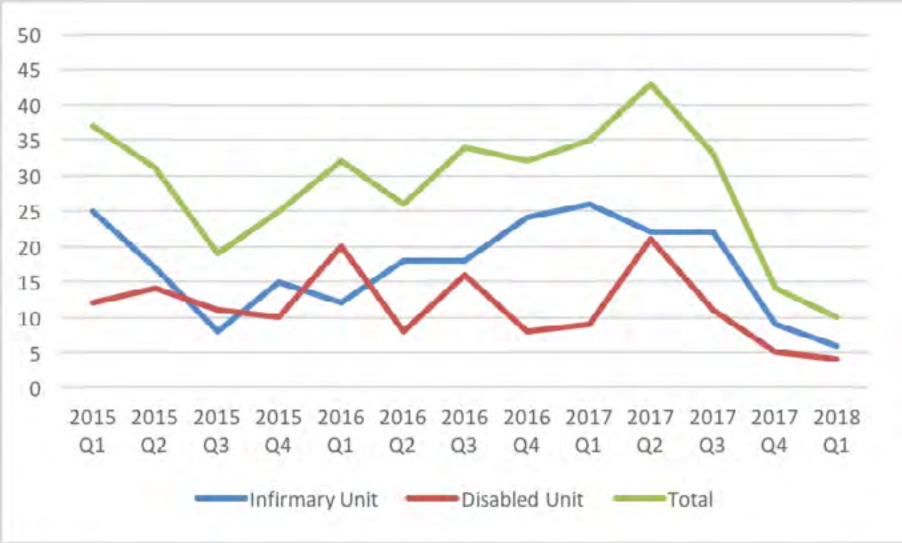


Figure 7 | Numbers of patient transfers to the Accident and Emergency Department from the first quarter of 2015 to that of 2018



Q1 = first quarter; Q2 = second quarter; Q3 = third quarter; Q4 = fourth quarter.

4.7.2. Study on experiences of non-invasive ventilation

In the study on 22 patients with end-stage COPD and 6 relatives in an acute and a subacute hospital (H. Y. L. Chan, Lo, Ng et al., 2018), individual, semi-structured interviews were conducted to understand the patients' experiences of receiving NIV and the patients' and relatives' decision-making process for receiving the treatment. The mean age of the patients was 77.6 (SD 8.2; range 59–92), and there were 17 men and 5 women; the mean age of the relatives was 62.7 (SD 7.0; range 52–70), and there were 1 man and 5 women. Three of the relatives were spouses while three were children of the patients.

None of the patients had discussed EOL issues with the doctor. The patients acknowledged that the NIV helped maintain their life but lowered its quality. Although they preferred comfort care as the goal of care, they did not see the necessity to discuss with the doctor as they would like the doctor to make the decision. They also found it difficult to broach the topic of EOL care with their family. For the relatives, they showed uncertainty about the use of NIV and they would rather let the doctor make the decision.

The life-sustaining nature of NIV was not in line with the patients' preference for comfort care. They nevertheless did not discuss EOL issues with the doctor. Both patients and relatives relied on the doctor for decision-making. In order to provide care consistent with patients' wishes, patients need to be encouraged to convey their values and goals to healthcare professionals and their relatives. The decision-making process should involve patients, their relatives, and healthcare professionals but not the doctor alone.

4.7.3. Study on goals of care of patients with advanced chronic obstructive pulmonary disease

Dr Susanna Ng headed a research team to conduct a cross-sectional study to examine the characteristics and goals of care of 16 male patients with advanced COPD. Of the 14 participants who reported their education levels, 2 did not receive formal education, whereas 7 received primary education and 5 secondary education. Preferences regarding goals of care, cardiopulmonary resuscitation (CPR), and intubation were expressed by 7 participants. Two of them preferred comfort care, while 3 preferred limited medical care and 2 life-prolonging care. Five expressed their wish not to receive CPR, while 1 wished to receive it and 1 was unsure. Four expressed their wish not to receive intubation, while 1 wished to receive it and 2 were unsure.

It seemed that few advanced COPD patients in the study preferred comfort care, although large proportions chose not to receive CPR and intubation. The discrepancy might be explained by their preference for these two specific approaches of comfort care. In future, patients' choice as to each specific approach should be elicited to know about patients' preferences accurately.

4.7.4. Study on barriers to advance care planning

As an exploration of barriers to ACP in patients with serious illness and their families in Hong Kong, the Institute conducted focus group interviews and individual interviews on 17 patients receiving palliative day care in a rehabilitative hospital and 13 family carers (J. T. K. Cheung, Au, Yuen et al., 2018). It was revealed that some patients were unable to make ACP decisions since some family members concealed the diagnosis and prognosis from them. Some patients placed great trust in doctors and were disinclined to engage in decision-making. Poor knowledge and attitude about ACP discussion was evident. Patients tried to avoid death anxiety and considered ACP discussion useless. Family members thought that patients did not express their feelings and were unready for early discussion. Worse still, healthcare professionals seemed unready for ACP discussion, and the healthcare system was not conducive to discussion. Some doctors were reluctant to forgo life-sustaining treatments and did not offer adequate information to patients and family members. Time constraints and consultations with different doctors were systemic issues discussed by patients and family members.

In the light of these barriers to ACP, more education of patients, families, and healthcare professionals on this aspect is warranted. They need to understand the importance and benefits of informing patients of the diagnosis and prognosis. When patients know more about their right of autonomy, they may be interested in making decisions after discussing with their families and healthcare professionals. The significance of ACP at an early stage should be highlighted as well. Some doctors have a deeply entrenched mindset of saving people's lives by all means. While the Institute has been endeavouring to change their mindset by organizing different training sessions, we acknowledge that breaking with precedent is always a challenging task, and changing doctors' mindset is no exception. In future, we will enlist the support of more health administrators and continue our efforts to address their mindset.

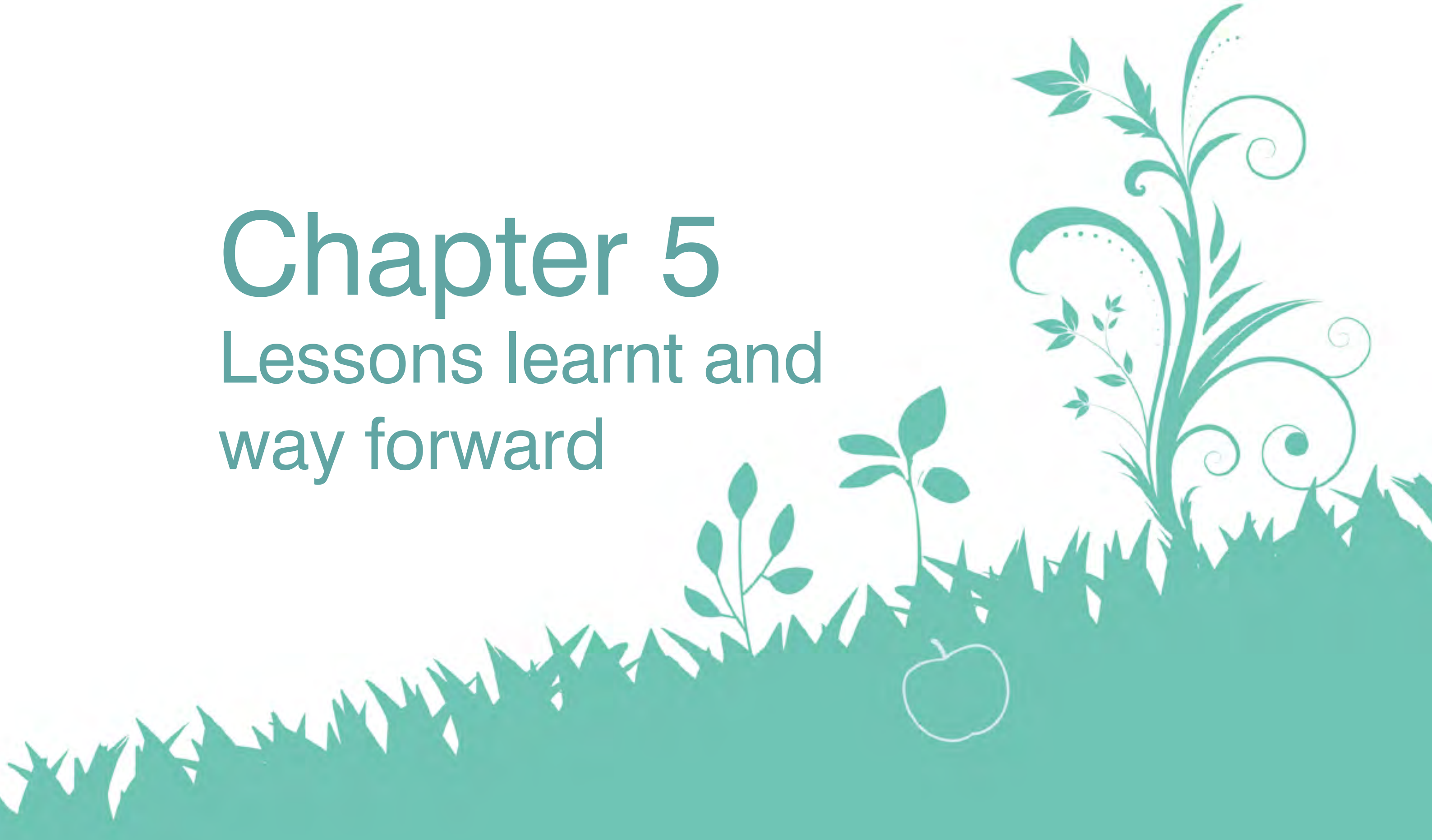
4.7.5. Study on the public's views on good death

A questionnaire survey was conducted to investigate the public's preference as to life-sustaining treatment and their concept of good death (W. T. Wong, Lai, Au, & Joynt, 2018). The mean age of the 798 respondents was 59.0 (SD 12.6) years and 41.9% were male. Their concept of good death consisted of four components, namely physical symptoms, psychological issues, social issues, and self-control. The data of 20.0% of the respondents were found to be inconsistent in that they preferred withholding or withdrawing life-sustaining treatment but would like to be resuscitated. After removing these inconsistent responses, 17.7% opted for aggressive treatment after considering the minimal chance for meaningful recovery. Respondents who were more concerned about physical symptoms were less likely to prefer aggressive treatment.

This study found that psychosocial issues and autonomy, apart from physical symptoms, were constituents of good death from the perspective of the public. In our programme, we trained health and social care staff on these constituents to facilitate their contribution to people's good death. In view of some respondents' inconsistent responses, the public may need to be better informed of the concept and different kinds of life-sustaining treatments. The proportion (17.7%) of people choosing aggressive treatment is worthy of note. As always, care for each patient should be individualized based on their values and preferences. If patients prefer aggressive treatment after weighing the pros and cons of each treatment approach (particularly the possible severity of physical symptoms), healthcare professionals must respect their choice.

Chapter 5

Lessons learnt and way forward



Future efforts

With the experience gathered during these three years of capacity building, valuable insights have been accumulated to guide future strategies. It is clear that hospital management should place this topic as an integral part of quality care in hospitals, utilizing existing processes in place, that is: hospital accreditation, advance directives, and advance care planning. For example, hospitals could institute regular audit meetings that include quality of end-of-life care as part of mortality and morbidity meetings; auditing the presence of documentation of conversations and patients'/families' wishes. Regular serious illness communication workshops should continue, with participation of all levels of professional staff involving different specialties, introducing the use of videos as decision aids in such sessions. Patient, family, and public education regarding choices, and how to carry out serious illness conversations with healthcare professionals could be run in parallel. Continuing partnership with bioethics input to highlight bioethical principles of end-of-life care to change culture and as a basis to resolve staff-patient conflict would be helpful. Finally end-of-life care could be included as a core part of the final year undergraduate medical student curriculum.

The effectiveness of end-of-life care education may be assessed using the conventional four levels of learning evaluation (Kirkpatrick, 1967):

- Reaction to the learning experience (Pre-Post questionnaires)

- Changes in confidence, knowledge and/or attitudes (ditto)

- Changes in behaviours (documentation/AD/ACP), performance in real or simulated scenarios

- Changes in patients'/family members' experience or outcomes

Use of the end-of-life care casebook series with ethical comments in the teaching of healthcare professionals could be monitored. It is possible that adding bioethical perspectives may draw more attention to end-of-life care, resulting in change of mindset and culture. The adoption rate by various organizations for teaching could be documented.

Conclusion

Creation of a compassionate community for end-of-life care has at its origin compassionate care at the point of transition between curative and life prolongation, a point that depends on healthcare professionals in hospitals to be fully engaged in. This should be woven into the fabric of existing quality care frameworks with regular audits, accompanied by improved training in serious illness conversations for doctors and medical students. Patients and families should be engaged in this process and their perspectives be the central driver to improving the quality of end-of-life care.

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