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

LIVE FREE
DIE WELL

Building Capacity for End-of-Life Care

in Hong Kong

Initiated and Funded by:
The Hong Kong Jockey Club Charities Trust

Partner Institution:
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

Live Free, Die Well

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Author CUHK Jockey Club Institute of Ageing
Publisher The Hong Kong Jockey Club
Tel. (852) 3943 3143
Email ioa@cuhk.edu.hk
Website http://www.ioa.cuhk.edu.hk

Project team:
Prof. Jean Woo, Director
Dr. Christopher Lum, Consultant
Dr. Susanna Lo, Consultant
Ms. Faye Chan, Nursing Officer
Ms. Connie Tong, Project Manager
Ms. Jenny Chan, Project Officer
Ms. Mandy Tsui, Project Officer
Mr. Derek Lai, Research Assistant
Ms. Candy Wong, Event Executive

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Foreword

End-of-life care is an important issue that affects us all and our loved ones. With a rapidly ageing population there is growing concern about, and demand for, expanded provision and choice of end-of-life care in the community.

To enhance the capacity of service providers in this respect and improve the quality of care, The Hong Kong Jockey Club Charities Trust initiated and has funded the Jockey Club End-of-Life Community Care Project (JCECC) since 2016, with approved donations totaling HK$255 million.

The project has to date helped more than 9,500 terminally ill patients and families and trained over 20,000 health and social care professionals through structured programmes. The ultimate aim is for more people in their final days to be well cared for, with dignity and respect.

Positive Ageing and Elderly Care form one of the Trust's strategic focus areas. For many years, we have worked actively with our partners on a wide range of programmes to enhance the quality of life for people as they age. JCECC is an example of this and an extension of the Club's continued commitment to the development of Hong Kong's healthcare services and the welfare of its citizens.

Our support for the JCECC and all our other initiatives have been made possible by the Club's integrated business model, through which we make tax contributions and charitable donations for the betterment of society. As one of the top ten charity donors in the world, we embrace innovation, collaboration and capacity-building for stronger progress.

The JCECC's significant accomplishments would not have been possible without the CUHK Jockey Club Institute of Ageing's focused efforts to strengthen field capacity and disseminate related knowledge, as well as the invaluable work of other project partners and the project team.

We hope you find this publication informative and that it serves to advance end-of-life care in our city.

Mr. Leong Cheung

Executive Director, Charities and Community

The Hong Kong Jockey Club

Preface

Hong Kong's population is rapidly ageing. While longevity is commonly considered desirable, it may also entail prolonged and unnecessary suffering from various life-limiting conditions. Unfortunately, owing to the lack of public awareness and inadequate training for healthcare professionals, the importance of end-of-life care is often underappreciated in our society, and the quality of healthcare services in this regard has remained suboptimal.

In order to remedy this situation, The Hong Kong Jockey Club Charities Trust launched the Jockey Club End-of-Life Community Care Project in 2016. As one of the collaborating partners, the CUHK Jockey Club Institute of Ageing has implemented two phases of the Capacity Building and Education Programme, during which it has worked with the Hospital Authority and various community organizations to deliver educational and training activities for healthcare professionals, as well as the general public, with the aim of disseminating knowledge and raising awareness about the proper concepts of end-of-life care. The present report serves as a summary of the programme, documenting and sharing its successful and fruitful outcomes.

On behalf of the institute, I would like to express our sincere gratitude to The Hong Kong Jockey Club Charities Trust for its unwavering support throughout the implementation of the programme. Building on the experience and lessons learned over the last six years, the institute will continue to collaborate with all relevant parties to contribute to the betterment of end-of-life care in Hong Kong.

Prof. Jean Woo

Director, CUHK Jockey Club Institute of Ageing

The Chinese University of Hong Kong

About the Jockey Club End-of-Life Community Care Project

Hong Kong has a rapidly ageing population, and the number of elderly residents suffering from terminal illness has also grown correspondingly. In view of the growing demand for end-of-life (EoL) care services in the community, The Hong Kong Jockey Club Charities Trust approved a total donation of HK$255 million to initiate the Jockey Club End-of-Life Community Care Project (JCECC). Launched in 2016, the six-year project aims at improving the quality of EoL care, enhancing the capacity of service providers, as well as raising public awareness.

JCECC is a multi-disciplinary, multi-institutional and cross-sectoral collaboration aimed at enhancing EoL care in Hong Kong with special emphasis on the interface between social and medical systems. Service models are being developed and shaped to provide holistic support to terminally ill elderly residents, both in the community and care homes. The goal is to enable the city's older people to have informed choices about care and experience an improved quality of life. The Trust's partners in JCECC are the Faculty of Social Sciences of The University of Hong Kong, The Chinese University of Hong Kong Jockey Club Institute of Ageing, Hong Kong Association of Gerontology, Haven of Hope Christian Service, The Hong Kong Society for Rehabilitation, St James' Settlement, and S.K.H. Holy Carpenter Church District Elderly Community Centre.

Faculty of Social Sciences
The University of Hong Kong
香港大學社會科學學院

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

Hong Kong Association of Gerontology
香港老年學會

聖雅各福群會
St. James' Settlement

基督教靈實協會
HAVEN OF HOPE CHRISTIAN SERVICE
尊重生命 • 改變生命

香港復康會
The Hong Kong Society for Rehabilitation

聖公會聖匠堂長者地區中心
S.K.H. HOLY CARPENTER CHURCH DISTRICT ELDERLY COMMUNITY CENTRE

Executive Summary

The present report documents and summarizes the outcomes of the Capacity Building and Education Programmes on End-of-Life Care (the programme) under the Jockey Club End-of-Life Community Care Project. The layout of the report is as follows:

- Chapter 1 provides a theoretical overview of the two major concepts that are of particular importance to the programme (viz. end-of-life care and Advance Care Planning), and examines their current situation and challenges in Hong Kong.
- Chapter 2 introduces the programme and outlines how strategies were devised to address any unmet needs and problems.
- Chapter 3 reviews and summarizes the two major streams of programme activities and evaluates their effectiveness using both quantitative and qualitative methods.
- Chapter 4 presents the various training materials and educational resources produced under the programme.
- Chapter 5 briefly describes the methods and results of several exploratory studies on EoL care in Hong Kong.
- Chapter 6 concludes the report by recapitulating the significance of the programme and suggesting directions for future initiatives.

Keywords: end-of-life care, Advance Care Planning, Advance Directive, palliative care, capacity building, communication skills, healthcare professionals

List of Abbreviations

- **A&E**: Accident & Emergency
- **ACP**: Advance Care Planning
- **AD**: Advance Directive
- **AHNH**: Alice Ho Miu Ling Nethersole Hospital
- **BBH**: Bradbury Hospice
- **BiPAP**: Bi-level positive airway pressure
- **C&SD**: Census and Statistics Department
- **CGAT**: Community Geriatric Assessment Team
- **CHP**: Centre for Health Protection
- **CME**: Continuing Medical Education
- **CND**: Central Nursing Department
- **CNE**: Continuing Nursing Education
- **COPD**: Chronic obstructive pulmonary disease
- **CoS**: Chief of Service
- **CPR**: Cardiopulmonary resuscitation
- **CQI**: Continuous quality improvement
- **CSSA**: Comprehensive Social Security Assistance
- **CUHK**: The Chinese University of Hong Kong
- **DECC**: District Elderly Community Centre
- **DNACPR**: Do-Not-Attempt Cardiopulmonary Resuscitation
- **DoJ**: Department of Justice
- **EoL**: End-of-life
- **EPA**: Enduring power of attorney
- **FHB**: Food and Health Bureau
- **HA**: Hospital Authority
- **HCE**: Hospital Chief Executive
- **HKDU**: Hong Kong Doctors Union
- **HKEC**: Hong Kong East Cluster
- **HKGS**: The Hong Kong Geriatrics Society
- **HKJC**: The Hong Kong Jockey Club
- **HKSAR**: Hong Kong Special Administrative Region

- **HKWC**: Hong Kong West Cluster
- **ICNARC**: Intensive Care National Audit & Research Centre
- **IoA**: Institute of Ageing
- **IoM**: Institute of Medicine
- **JCECC**: Jockey Club End-of-Life Community Care Project
- **JCHH**: Jockey Club Home for Hospice
- **JCSPHPC**: Jockey Club School of Public Health and Primary Care
- **KAB**: Knowledge-attitude-behavior
- **LST**: Life-sustaining treatment
- **M&G**: Medicine and geriatrics
- **MSW**: Medical social worker
- **NAWA**: Network of Ageing Well for All
- **NDH**: North District Hospital
- **NGO**: Non-governmental organization
- **NTEC**: New Territories East Cluster
- **PRC**: Patient Resource Centre
- **PWH**: Prince of Wales Hospital
- **QMH**: Queen Mary Hospital
- **QoL**: Quality of life
- **RCHE**: Residential care home for the elderly
- **SCH**: Cheshire Home, Shatin
- **SH**: Shatin Hospital
- **SICG**: Serious Illness Conversation Guide
- **SPHC**: Society for the Promotion of Hospice Care
- **SWD**: Social Welfare Department
- **TPH**: Tai Po Hospital
- **TWGHs**: Tung Wah Group of Hospitals

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Chapter 1 Introduction

1.1 Background

Populations around the globe are rapidly ageing, and Hong Kong is no exception to this worrying phenomenon. The proportion of people in Hong Kong aged 65 or above was approximately 17.7% in 2019 (Census and Statistics Department [C&SD], 2019), and is estimated to nearly double by 2066 (C&SD, 2017b). Moreover, the life expectancy of Hong Kong residents has steadily increased over the past decades, from 67.8 years for males and 75.3 years for females in 1971, to 82.2 years and 87.6 years, respectively, in 2018 (Centre for Health Protection [CHP], 2019a). Unfortunately, despite often being considered a blessing in traditional Chinese culture, longevity may also entail prolonged frailty and suffering. If not handled properly, extending the lifespan of terminally ill patients may only result in further deterioration of their quality of life (QoL). In order to ensure a "good death" experience for everyone, it is imperative for the Hong Kong society to recognize and understand the complexities of life-and-death issues, and to address the specific needs of those facing imminent death.

1.2 End-of-Life Care

Researchers, practitioners and professionals across different fields and sectors have adopted a wide array of terminology, most notably palliative care, hospice care, and end-of-life (EoL) care,[1] to describe an entire category of healthcare services that are specifically provided to patients in later life. Although these synonyms share a common philosophy that prioritizes the QoL of patients over the mere prolongation of life, they may carry different meanings on different occasions and at different times. If used interchangeably and inconsistently in the absence of an agreed definition, this terminology may be a source of confusion for both the public and healthcare service providers. In order to standardize the nomenclature and be consistent, we have predominantly adopted the term EoL care throughout the present initiative, as well as in this report. Nevertheless, the definitive meaning of EoL care remains to be clarified. To this end, we first provide a brief account of the conceptual linkages and theoretical differences between EoL care and other terminology. After that, we offer an operational definition of EoL care, with reference to the scope and target of the present initiative.

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[1] Commonly used Chinese terminology includes 善終照顧, 紓緩治療, 寧養照顧, 安寧照顧, 晚晴照顧.

1.2.1 Theoretical definition

As an attempt to establish a standard and unifying nomenclature for the field, the Institute of Medicine[2] (IoM, 2015) performed a content analysis on several existing definitions proposed by other renowned scholars and institutions, and concluded that

> Palliative care provides relief from pain and other symptoms, supports quality of life, and is focused on patients with serious advanced illness and their families. Palliative care may begin early in the course of treatment for a serious illness ... Palliative care encompasses hospice and specialty palliative care, as well as basic palliative care.

According to this definition, palliative care is an umbrella term that covers a spectrum of approaches aimed at delivering high-quality care to patients at any stage of a serious illness, as well as involving their family members. On the other hand, hospice was defined by the IoM as "a service delivery system that provides palliative care", suggesting that it can be viewed as a particular approach for implementing palliative care. Finally, the IoM stated that

> End-of-life care refers generally to the processes of addressing the medical, social, emotional, and spiritual needs of people who are nearing the end of life. It may include a range of medical and social services, including disease specific interventions a [*sic*] well as palliative and hospice care for those with advanced serious conditions who are near the end of life.

According to this definition, EoL care is, as its name suggests, mainly targeted at patients in the terminal phase. Therefore, neither patients in the earlier stages of the serious illness nor their family members are incorporated under this definition. On the other hand, as compared with palliative care which mainly focuses on pain relief and symptom control, EoL care constitutes a more holistic approach that goes beyond the medical aspects and places equal emphasis on the social, emotional, and spiritual well-being of the patient.

1.2.2 Operational definition

Although the above results helped to distinguish the subtle differences among various types of terminology, they yielded a relatively narrow definition for EoL care whose limited scope may render it of little pragmatic use. More explicitly, since EoL care is considered a holistic approach, excluding the family members of the patients from the core unit of care may, to a certain extent, violate its original intent. On the other hand, the definition also raises a

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[2] Currently known as the National Academy of Medicine, the IoM was founded to provide international advice on issues relating to health and medicine.

practical issue on how to operationalize and identify a "suitable" timeframe for implementing EoL care. While there exist a number of valuable prognostic criteria and clinical screening tools to guide the identification of patients who are nearing the end of life, for instance, the well-known "surprise questions" (see Downar, Goldman, Pinto, Englesakis, & Adhikari, 2017, for a review), most of these cannot scientifically and rigorously indicate whether a patient is in an imminently terminal condition (cf. Section 6.2.2), especially since the symptoms and progression trajectories may vary significantly across different diseases. More crucially, overly relying on a definite timeframe or prognostic limit in this identification process may represent a missed opportunity for timely intervention in the earlier phases, which may ultimately cause irreparable harm to the QoL of patients and thereby defeat the whole object of EoL care.

In view of these considerations, and in order to maximize the impact and coverage of the present initiative, we here extend the definition of EoL care and use it to refer to a holistic approach that delivers care to patients during the entire course of a serious illness, as well as including their family members. In essence, we use a broader notion that captures and merges the definitions of palliative care and EoL care as given by the IoM. In the subsequent chapters of this report, we will use the term EoL care in place of other similar terminology as adopted by other institutions in Hong Kong and across the globe, for instance, the Hospital Authority (HA) and World Health Organization (WHO), whenever appropriate.[3]

1.2.3 Key components and involved parties

Under the current definition, EoL care represents a continuum of healthcare services intended for patients and their family members as a serious illness gradually progresses from its onset to an irreversible and life-threatening stage. Depending on the phase of the disease, EoL care may be manifested in various forms, including

- identification of patients who are eligible for EoL care
- initiation and facilitation of EoL conversations
- guidance for patients and their family members to plan and prepare for EoL issues
- medical treatment, symptom control and personal nursing care
- psychosocial and spiritual support
- post-death care and bereavement counseling

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[3] The terms palliative care and hospice care are sometimes used in a more specific way to refer to certain medical specialties or academic subfields, in which case they will not be generically replaced by the term EoL care.

Typically, EoL care services are provided by a multidisciplinary team, which normally includes geriatric and palliative care specialists, nurses, medical social workers, clinical psychologists, counsellors, physiotherapists, occupational therapists, speech therapists, health workers, and personal care workers.

1.3 Advance Care Planning

Although patients are usually considered passive beneficiaries of healthcare services, they do play a major role in determining the quality and nature of the EoL care that they receive. More specifically, patients need to consider and express their preferences in this regard, otherwise it would be very difficult, if not impossible, for healthcare professionals to be able to provide them with target-oriented and value-aligned care. The necessity of the active participations from patients in EoL care suggests the notion of Advance Care Planning (ACP).

1.3.1 Definition

Broadly speaking, ACP refers to the process by which patients communicate their preferences regarding the type of care that they would like to receive when they are no longer able to make a sound decision. Regrettably, a unifying definition of ACP is lacking, as experts in this field have failed to agree on its purposes, goals, and key components (Sudore et al., 2017). At one end of the spectrum of definitions, ACP is considered to be a continuing process of conversations between the involved parties and is primarily intended to encourage patients to share their life goals and personal values. At the other end, ACP is considered to be a method for documenting the treatment preferences of the patients. On this second view, it is considered essential for patients to arrive at concrete medical decisions, for instance, by signing an Advance Directive[4] (AD).

In the hope of maximizing the impact and coverage of the present initiative, we seek to adopt an operational definition that places equal emphasis on conversation and documentation and strikes a balance between process and outcome-oriented measures. To this end, we use the interpretation by Rietjens et al. (2017) as the backbone of our definition:

> Advance care planning enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers ... It encourages

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[4] AD refers to a class of legal documents that specifies the medical actions to be taken when the signatory becomes incapable of making sound decisions (see HA, 2014).

individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they, at some point, be unable to make their own decisions.

In addition, since ACP is a revisable process that focuses on future decisions rather than the current ones and is relevant across the entire lifespan (Sudore et al., 2017), we adopt the stance that even healthy individuals from all age groups can, and should be encouraged to, engage in ACP whenever deemed appropriate, although it may be particularly of immediate relevance and benefits to patients with a serious illness.

1.3.2 Key components and involved parties

The key components of ACP can roughly be grouped into three major categories: (1) self-reflection, (2) healthcare and medical decisions, and (3) post-death matters. More specifically, topics for discussion in an ACP process may include

- personal values and views on life-and-death issues
- life goals and unfinished business
- prognosis, medical conditions and treatment options
- preferences on treatment and healthcare approaches
- acceptance or refusal of life-sustaining treatments (LSTs)
- signing of AD[5]
- preferences on place to receive care and place of death
- funeral and burial arrangements
- succession matters

ACP is multifaceted in nature and it demands the active, tripartite, and integral participations from patients, their family members, and healthcare service providers (HA, 2019a). Most notably, the involvement of family members is essential, since this process helps them recognize the wishes and preferences of the patients, thereby enabling them to act as surrogates for making EoL decisions when emergency situations arise.

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[5] It should be reiterated that such a formal and legal document for making medical decisions is not a necessary component in ACP.

1.4 Current Situations and Challenges

The two core concepts highlighted above (i.e., EoL care and ACP) both play vital roles in determining the QoL of patients in later life (e.g., see Houben, Spruit, Groenen, Wouters, & Janssen, 2014, for a review), and are therefore of particular importance to the present initiative. In order to foster betterment in these aspects, it is critical to first scrutinize their current situation in the local context. To this end, we first examine whether the public has sufficient knowledge and awareness of, and a positive attitude to and acceptance of, EoL issues. Following this, we will probe our healthcare system and examine whether it constitutes an enabling environment for promoting EoL care, ACP, and other associated matters.

1.4.1 Public awareness and perception

Ethnicity and cultural background are important factors that may influence an individual's views on life-and-death issues, readiness to talk about EoL matters, and the acceptance of ACP and AD.[6] Over 92% of Hong Kong's population is Chinese (C&SD, 2017a), and are often regarded as being culturally conditioned to regard death as an anxiety-provoking taboo (Chan, Chan, Tin, Chow, & Chan, 2006). Under the influences of death taboo and other traditions, most notably filial piety (Chan et al., 2012), discussion and planning on EoL issues have been rare in Hong Kong (Chan, Tin, Chan, Chan, & Tang, 2010), which has greatly obstructed EoL decision-making and the preparation for death. For instance, many Chinese families in Hong Kong have preferred, perhaps due to wishful thinking, to conceal any information associated with serious illness (Fielding & Hung, 1996), which made it difficult for patients to exercise their autonomy when making EoL decisions.

Nurtured in such a death-denying atmosphere, Hong Kong people have inevitably been insufficiently exposed to the concept of EoL care. Indeed, according to a local survey, the majority of respondents were not at all interested in receiving any EoL information (Mjelde-Mossey & Chan, 2007). As a result, Hong Kong people generally have not had sufficient knowledge and understanding in this regard (The Economist, 2015a; Mok, Ting, & Lau, 2010), which may lead to the following negative consequences. On the one hand, people may be uncertain about their EoL preferences and thus tend to overly rely on the authorities for making the final EoL decisions (Chan & Pang, 2007). On the other hand, people may base their EoL decisions on myths and misconceptions, thereby resulting in mismatches between

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[6] Although AD completion is not a necessary precursor to ACP and high-quality EoL care, it will be discussed rather extensively in the current sections, since its prevalence may serve as a proxy indicator for reflecting the maturity of the development of EoL care and ACP in Hong Kong.

expectations and actual outcomes. For instance, perhaps out of the fear of misfortune or that their property might lose value, it is common for Hong Kong people to avoid dying at home (Luk, Liu, Ng, Beh, & Chan, 2011). In fact, as an intimate environment coupled with the presence of family members, their homes may be a good place for them to die.

Nevertheless, notwithstanding such communication barriers and lack of awareness, the public may not be genuinely indifferent towards EoL decisions. On the contrary, a number of studies (e.g., Mok et al., 2010) have shown that Hong Kong people had concerns over various EoL issues, in particular the use of LSTs. According to Chan et al. (2019), although the AD completion rate was extremely low in Hong Kong, most of those who had heard about AD before were quite inclined to sign an AD. In fact, as shown by a recent telephone survey, even among respondents who had no prior exposure to AD, most had a positive attitude towards AD upon being briefly introduced to its concept and rationale (Chung et al., 2017). These studies demonstrated that the public does have the incentive and willingness to make EoL decisions once sufficient information and explanations are given.

1.4.2 Healthcare environment

In Hong Kong, the government and various institutions have put a considerable amount of effort into building the infrastructure and capacity for providing high-quality and sustainable EoL care. Most notably, the HA recently established the Strategic Service Framework for Palliative Care (2017), which formulated four major directions for improving EoL care services:

- enhance governance by developing Cluster-based services with the collaboration of medical and oncology palliative care specialists
- promote collaboration between palliative care and non-palliative care specialists through shared care model according to the patient's needs
- enhance palliative care in the ambulatory and community settings to support patients and reduce unnecessary hospitalization
- strengthen performance monitoring for continuous quality improvement

Notwithstanding these visions and valuable efforts, EoL care is still a relatively neglected area in the current healthcare environment, and its quality is poorer than expected (Chan, Wong, et al., 2019), especially given our economic prosperity. This inadequacy was amply captured and revealed by the Quality of Death Index (The Economist, 2015a), according to which the overall score of Hong Kong was 66.6 (out of 100) and was only ranked 22nd (out of 80).

More specifically, Hong Kong scored an unsatisfactory 50.4 in the domain of "Palliative and Healthcare Environment", trailing behind several lower-income countries. In order to ascertain what has gone wrong in our healthcare system, we will assess some of the key indicators on which the Quality of Death Index was based (The Economist, 2015b)[7] and examine these aspects in further detail.

1.4.2.1 Provision of End-of-Life care services

Currently, most of the medical and surgical wards in public hospitals are primarily intended to provide acute curative treatment but are not suited to providing a "good death" experience to patients and their family members (Luk, 2018). Although specialty services designed to cater for EoL needs have been being provided at 16 public hospitals in all seven HA clusters (HA, 2018), patients may not always be referred to these services (Luk et al., 2011) owing to a limited supply. While the number of public hospital beds in the hospice specialty field has gradually increased over the past decade (HA, 2010, 2018), it is still barely capable of meeting the actual demand.

Apart from public hospitals, non-governmental organizations (NGOs) constitute another major source of EoL care services in Hong Kong. Residential care homes for the elderly (RCHEs), premises where individuals aged 60 years or above are habitually received for the purposes of care (Social Welfare Department [SWD], 2013), constitute a prominent example of such agencies.[8] Regrettably, as in the case of public hospitals, most RCHEs are underequipped and ill-prepared to deliver high-quality EoL care (Chung & Yeoh, 2019). In particular, some RCHEs are overcrowded, and staff may prefer not to handle dying patients (Luk et al., 2011). Moreover, the routinized and communal style of operation in RCHEs is simply inadequate for providing flexible and personalized EoL care to meet individual needs (Fang, Lou, & Kong, 2016).

Finally, although there exist certain EoL service providers in the private sector that are dedicated to providing specialized and high-quality EoL care, they mostly operate on a fee-for-service basis, which renders their services much less affordable and accessible by the general public, particularly the poorer members of society.

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[7] "Palliative and Healthcare Environment" was originally defined as a domain primarily concerned with healthcare spending and government-led policy. However, for our purpose we will also focus on some indicators in other domains that are associated with healthcare environment in a more general sense.

[8] Although RCHEs are not specifically intended to provide EoL care services, they do play a key role in this aspect, especially since a considerable number of elderly residents prefer to die at RCHEs (Chu et al., 2011).

1.4.2.2 Human resources and education

A sufficient and competent workforce is essential to improving the accessibility and quality of EoL care services, as well as facilitating patients and their family members to engage in ACP and EoL conversations. However, while there are over 40 doctors, 300 nurses, and 60 allied health professionals in the HA who specialize in providing EoL care (The Government of the Hong Kong Special Administrative Region [HKSAR], 2017), this number is insufficient to cope with escalating demand in Hong Kong.[9] In particular, there is a severe lack of doctors specializing in palliative medicine. Fewer than ten trainees specialize in this area each year (Cheung, 2016).

Besides the issue of insufficient manpower, the ability and capacity for healthcare professionals to deliver EoL care are also less than desirable. For instance, these professionals may be relatively unaware of the symptoms of non-cancer EoL patients, thereby resulting in suboptimal pain assessment and management (Woo, Lo, Cheng, Wong, & Mak, 2011). Beyond the scope of medical care and treatment, healthcare professionals may also lack the proper attitude, confidence, motivation, empathy, and communication techniques to engage in ACP interventions or EoL conversations with patients and their family members (e.g., Siu et al., 2010). More fundamentally, the cure-oriented nature of medicine has been deeply ingrained in the mindsets of many healthcare professionals, which makes them unable to appreciate the importance of, and focus more on, the non-medical or palliative aspects in their clinical practice (Chung et al., 2017). Consequently, to cope with the excessive number of patients, busy healthcare professionals may resort to the default procedural protocol and simply try to keep the patients alive while neglecting their psychological well-being and QoL. It is also quite common for healthcare professionals to suffer from moral distress in an EoL care setting (Chan, 2017), which may further hamper their ability to provide care in an empathetic manner. Finally, these shortcomings and problems may also apply to prospective healthcare professionals. For instance, it has been found that most nursing students lacked knowledge and clinical experience in, and a favorable attitude to and perceived competency in EoL care (Chow, Wong, Chan, & Chung, 2014).

From a more positive angle, it should be mentioned that increasing emphasis has indeed been given to raising the knowledge, awareness and preparedness for healthcare professionals in this regard. For instance, the HA has issued guidelines on ACP, AD, LSTs, and Do-Not-Attempt Cardiopulmonary Resuscitation (DNACPR) over the last few years (HA,

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[9] Judging from the fact that there were more than 30,000 people who died from chronic illnesses in 2018 (CHP, 2019b), there may be thousands of patients in need of EoL care at this very moment.

2015, 2016a, 2016b, 2019b), which serve as the basic instruction manuals and reference tools for all healthcare staff. In addition, several HA working groups have been established to promulgate the uses of ACP and AD, as well as to facilitate staff training in EoL care (e.g., Ho & Chan, 2020). As regards prospective healthcare professionals, some medical and nursing schools have shown encouraging signs as they started to incorporate more EoL-related elements into their curricula, for instance courses on communication skills and bioethics.

1.4.2.3 Legal and policy issues of Advance Directive

AD completion is indisputably beneficial in terms of helping healthcare professionals recognize and respect the medical preferences of the patients, particularly those on invasive LSTs. However, irrespective of its level of public acceptance, the widespread implementation of AD is still problematic owing to the absence of statute and case law on its legal status. More specifically, although AD is recognized as legally binding under the common law, it currently does not have any statutory framework (Kan, 2010). Consequently, healthcare professionals may find it difficult to examine the validity and applicability of an AD in emergency situations,[10] or to adhere to an AD and withhold LSTs even when it is seemingly contradictory to the best interests of the patients (Tse, 2010). This problem is further exacerbated when the Mental Health Ordinance (Department of Justice [DoJ], 2019b) is taken into account, which states that a treatment can be carried out without consent,

> if that registered medical practitioner or registered dentist intending to carry out or supervise the treatment considers that as a matter of urgency that treatment is necessary and is in the best interests of the mentally incapacitated person.

It is foreseeable that such legal uncertainties and controversies, as well as dilemmas in clinical ethics, which impose additional burden to healthcare professionals, will persist if no specific legislation is enacted. In view of these issues, the government has conducted public consultations back in 2009 to examine whether AD should be introduced via a legislative process. However, according to the Food and Health Bureau (FHB, 2009),

> it would be premature to attempt to formulate a statutory framework and to embark on any legislative process for advance directives, without greater public awareness of the issues involved.

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[10] Despite not being considered healthcare professionals in an ordinary sense, the emergency rescue workforce (e.g., ambulance crew) may also find these situations challenging to handle.

It can be seen that the issues associated with public awareness and perception are also the key obstacles to the legislation of AD. Ten years on, the public acceptance of AD has improved considerably, which, together with a significant growth in the AD completion rate, has prompted the government to review and reconsider the appropriateness of the legislative process recently (FHB, 2019).[11] Nonetheless, even if legislative changes of AD take place, the effectiveness of its enforcement and implementation will remain to be decided.

1.4.3 Capacity building and education as a partial solution

As illustrated above, the overall environment and conditions in Hong Kong are not ready for the full development and implementation of ACP, AD, and EoL care. To identify a feasible solution, we may adopt a "divide and conquer" strategy and first divide the identified gaps and obstacles into two major categories: (1) the "hardware" components, which include healthcare infrastructure and facilities, financial resources, laws and policies, and manpower supply, and (2) the "software" components, which include public awareness and perception, and the capacity and mindsets of healthcare professionals. Admittedly, an advancement in the "hardware" aspect necessitates a long-term strategic development and deliberate planning for resource allocation, as well as active participation from governmental bodies, law authorities and other stakeholders from the community, and thus is a difficult and demanding challenge that cannot, and indeed should not, be tackled with a hasty and ad hoc approach.

In contrast, improvements in the "software" facet are much more manageable, in the sense that relatively straightforward measures can be readily undertaken to address the underlying issues. More specifically, educational, promotional, and training activities can be conducted to confront the death taboo in our society, give publicity to EoL issues, raise awareness and cultivate mindset change, and enhance the capacity and preparedness of healthcare professionals to provide high-quality EoL care and facilitate ACP implementations. Being a partial solution to the ultimate problem, these capacity building and educational endeavors precisely form the basis for the development of the present initiative.

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[11] According to the most up-to-date report on this consultation (FHB, 2020), the government has now considered it appropriate to embark on the legislative route of AD.

Chapter 2 Overview of the Programme

2.1 Background

Under the Jockey Club End-of-Life Community Care Project (JCECC), The Chinese University of Hong Kong (CUHK) Jockey Club Institute of Ageing (IoA) launched the Capacity Building and Education Programmes on End-of-Life Care[12] (the programme) in 2016. Aiming to address the issues mentioned in Section 1.4, the programme was conducted by a multi-disciplinary team comprising professors of gerontology and geriatrics, clinical lecturers, senior doctors and nurses, social workers, as well as research and administrative staff, in collaboration with a wide spectrum of parties including, for instance,

- HA hospitals
- Faculty of Medicine, CUHK
- CUHK Centre for Bioethics
- Hong Kong Doctors Union (HKDU)
- The Jockey Club School of Public Health and Primary Care (JCSPHPC), CUHK
- The Nethersole School of Nursing, CUHK
- NGOs and patient associations in the community

The first phase of the programme (from 2016 to 2018) was a major success, with more than 250 training and educational activities being delivered to over 8,000 individuals (IoA, 2018), and a collection of highly regarded resources being produced and widely disseminated. Building on this accomplishment, the Trustees of the Hong Kong Jockey Club Charities Trust devoted an additional grant of $12 million to commencing the second phase of the programme (from 2019 to 2021), with the aim of further extending and deepening its impact.

2.2 Target Population

The two major target groups of the programme were healthcare professionals and the public. Among healthcare professionals, target beneficiaries included

- doctors either from public hospitals or in private practice
- nurses from public hospitals
- allied healthcare professionals from public hospitals, such as medical social workers

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[12] The Chinese title of the programme is "賽馬會安寧頌 – 安寧服務培訓及教育計劃".

and occupational therapists

- health and social care professionals from RCHEs and District Elderly Community Centres (DECCs), for instance, community nurses and personal care workers
- prospective healthcare professionals, such as medical and nursing students

It should be emphasized that doctors from across all backgrounds, not only those specializing in geriatrics, oncology, or palliative care, were included in the target population. The philosophy was that the scope of EoL care is not limited to certain medical subfields; instead, the best practice of EoL care is relevant and should be promoted to all doctors.

On the other hand, target beneficiaries among the public encompassed

- the general public
- patients
- family members and caregivers
- elderly people

Following the practice of the previous phase (IoA, 2018), the geographical scope of the present programme was mainly confined to the regions that belong to the New Territories East Cluster (NTEC), including Shatin, Tai Po, and North District. The underlying rationale was twofold, namely, (1) to further pilot the programme, estimate its acceptability and applicability, and establish a validated service model, and (2) to concentrate resources on nurturing more profound mindset changes and building a long-term collaborative network. Both these factors can ultimately help generate a sustainable impact and improve the situation of EoL care in Hong Kong on a continuing basis.

2.3 Objectives

The core aim of the programme was to spread knowledge, raise awareness, and build capacity regarding the issues of EoL care among the target population. At this point, it should be made clear that the programme was, unlike other similar initiatives, not meant to serve as a direct provider of EoL care services. Instead, in order to ensure the popularization and development of EoL care in the long run, the programme was intended to generate mindset and behavioral changes so that the target beneficiaries would be empowered to benefit from EoL care on a permanent basis. To this end, the programme followed the well-known knowledge-attitude-behavioral conceptual framework (KAB; Bettinghaus, 1986), in which its major objectives can be formulated as follows:

- to instill basic EoL knowledge in healthcare professionals and the public, as well as to challenge myths and clarify misconceptions (knowledge)
- to train healthcare professionals in the practical skills in EoL care, as well as to introduce them the relevant concepts in clinical ethics (knowledge)
- to cultivate a more positive perception of EoL care and ACP (attitude)
- to raise awareness towards, and increase the degree of importance attached to, the issues in EoL care (attitude)
- to enhance the motivation and confidence of healthcare professionals in implementing high-quality EoL care and ACP interventions (attitude)
- to nurture a perspective-taking and patient-centered mindset among healthcare professionals (attitude)
- to increase the willingness and openness of the public to discuss death-related topics (attitude)
- to routinize the provision of EoL care among healthcare professionals and improve its quality (behavior)
- to encourage the public to commence early EoL planning and ACP discussions (behavior)
- to prompt both the patients and healthcare professionals to take an active initiative in engaging in EoL conversations (behavior)

The last objective listed above was of paramount significance. Judging from previous experience, there is apparently a vicious circle prohibiting the two parties from engaging in EoL conversations with each other. On the one hand, healthcare professionals commonly make hasty generalizations and have the impression that patients are universally reluctant to talk about death, and thus refrain themselves from touching upon any EoL issues. On the other hand, many patients perceive that all healthcare professionals are busy and preoccupied and thus do not try to initiate any conversations or discuss the details of EoL care. In order to overcome this stalemate position, it was particularly important and worthwhile for the programme to aim at motivating and enabling each of these parties to take the first step in the communication process.

Furthermore, from a more macroscopic perspective, the programme was also dedicated to approaching the health administrators and senior executives of the HA to promulgate and advocate the best practice of EoL care using a top-to-bottom approach, and as a means of attaining continuous quality improvement (CQI) in its healthcare services. After all, a successful reformation of EoL care services will require the HA to serve as an authoritative agency to guide and oversee the process as well as to provide the necessary infrastructural support. In this regard, the programme was intended to take up the supportive, yet essential role of facilitating the HA to implement its service model and strategic framework, thereby generating long-term, sustainable impact to the whole of Hong Kong society.

2.4 Implementation Plans

The programme comprised three major components, namely (1) the capacity building programme, (2) the public education programme,[13] and (3) the development and dissemination of educational resources. The following sections provide a brief overview of the implementation strategies for each of these components.[14]

2.4.1 Capacity building programme

The capacity building programme was geared towards healthcare professionals and mainly consisted of training activities aiming to raise their capacity for providing EoL care and facilitating ACP discussions. Major topics covered in the programme included

- the overarching values and philosophy of EoL care
- identification of patients in need of EoL care
- physical, psychosocial, and spiritual care
- the concepts and practical issues of ACP and AD
- communication skills for initiating ACP and EoL conversations with patients and their family members
- communication and collaboration among the team of healthcare professionals
- clinical ethics and legal considerations
- self-care and emotional regulation

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[13] Henceforth, the term "the programme" may also be used, when its meaning is clear from the context, to refer only to the capacity building programme or the public education programme.

[14] A detailed summary of the implementation details and project deliverables will be deferred to Chapter 3 and Chapter 4.

The scope and depth of the content were tailor-made for each activity to conform to the prior knowledge and experience, roles and duties, and the specific needs of the target audience, as well as the culture and environment of their affiliated institutions. In addition, for the purpose of offering a more comprehensive and interactive learning experience instead of a traditional mode of knowledge instillation, a wide range of delivery modalities, for instance, role-play and demonstration, interactive workshops, forums, seminars, lectures, and conferences, were incorporated into the programme.

Most of the training activities were conducted at the public hospitals under the NTEC, namely Alice Ho Miu Ling Nethersole Hospital (AHNH), Bradbury Hospice (BBH), North District Hospital (NDH), Prince of Wales Hospital (PWH), Cheshire Home, Shatin (SCH), Shatin Hospital (SH), and Tai Po Hospital (TPH). These activities were introduced to the hospitals as a CQI initiative, the implementation of which was coordinated by the Hospital Chief Executives (HCEs), service directors, Chiefs of Services (CoSs), Central Nurse Department (CND), and other senior staff under the NTEC. The project team was mainly responsible for inviting and liaising with the instructors and speakers, as well as providing the administrative and logistic support. Notably, the programme was accredited as a provider of Continuing Nursing Education (CNE) and Continuing Medical Education (CME), which gave healthcare professionals additional incentives to partake in these activities.

In addition, some training activities were conducted at the various RCHEs located inside the target regions, or were delivered online instead of in a face-to-face format due to the COVID-19 pandemic.

2.4.2 Public education programme

The public education programme, as its name implies, was geared towards the general population and mainly consisted of promotional and educational activities aiming to raise public knowledge and awareness of various EoL issues. Major topics covered in the programme included

- the concepts of, and differences among, EoL planning, ACP, AD, DNACPR, and euthanasia
- guidance on how to utilize the existing EoL services and community resources
- treatment and healthcare options

- financial matters and will-making
- enduring power of attorney (EPA)
- communication skills for initiating ACP and EoL conversations
- self-reflection on life-and-death issues

The scope and depth of the content for each activity were adapted for the demographic backgrounds, prior knowledge and experience, and psychological readiness of the target audiences. Adopting a multi-pronged approach, the major delivery modalities included information sessions, group sharing sessions, interactive workshops, tours and visits, exhibitions, and open competition.

While most of the educational activities were conducted at various RCHEs, DECCs and public areas inside the target regions, some public events were also organized on a territory-wide scale to accommodate the entire Hong Kong population. In addition, some activities were delivered online instead of in a face-to-face format due to the COVID-19 pandemic.

2.4.3 Educational resources

A wide array of educational resources, including micro-movies, educational videos, celebrity interviews, toolkits, booklets, and leaflets, were produced to serve either as self-learning and reference materials, or as supplementary tools to be used in conjunction with the programme activities. The content coverage of these resources was intended to cater for both healthcare professionals and the public, which included

- basic concepts in EoL care
- financial and post-death arrangements
- symptom management techniques
- disease-specific EoL communication skills
- clinical ethics

Most of these educational resources were either disseminated during the various programme activities or were directly dispatched to public hospitals (in particular, the Patient Resource Centres [PRCs]), RCHEs, and other partner institutions for circulation and public access.

2.5 Programme Evaluation

Outcome evaluation is an indispensable precondition for the continual refinement and future extension of any initiatives. In order to convert the programme into a mature and well-established service model, we have regularly assessed its quality and effectiveness through a series of evaluation strategies which, as with the programme objectives, were formulated with reference to the KAB framework. In addition to the ordinary KAB domains, a "satisfaction" metric (The Hong Kong Jockey Club [HKJC], 2017) was also included to gauge the acceptance of the target beneficiaries and their level of endorsement of the programme. At the implementation level, the evaluation process adopted a mixed-method design comprising both quantitative and qualitative approaches. These evaluation methods were mainly intended for the capacity building programme and the public education programme, the results of which will be presented in Chapter 3. On the other hand, educational resources were, comparatively speaking, not the subject of the systematic evaluation procedure, owing to several feasibility considerations. For instance, it would be impractical to trace all the viewers of a particular educational video and request their feedback and comments. Nonetheless, attempts have been made to collect opinions on these educational resources through various informal channels which, however, for maintaining the rigor and credibility of the evaluation process, will not be elaborated on further in the present report.

2.5.1 Quantitative methods

The main tool for capturing quantitative feedback was a questionnaire. Self-constructed instruments[15] (either paper-and-pencil or computerized) with sound psychometric properties were administered during most of the programme activities, in which participants responded to Likert-type items and indicated the perceived extent to which they had benefited from the activities in each of the KAB domains,[16] as well as rated their perception of, and level of satisfaction with the activities. Statistical analysis was then performed, whenever deemed appropriate, to examine whether the target beneficiaries had experienced significant improvements after attending the activities.

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[15] A more detailed description of the instruments (e.g., items, anchor points, labels) will be deferred to Chapter 3 since they were specific to each type of programme activity.

[16] For certain types of programme activities, not each and every of the KAB domains was the primary focus, thus participants might not be asked to rate their perceived improvements for all three domains.

2.5.2 Qualitative methods

During most of the programme activities, a trained research staff member was assigned to conduct on-site observations and document any responses and comments from the participants revolving around two major themes, namely (1) their perceptions towards the activities, and (2) their personal experience and reflections on EoL issues, particularly with respect to the barriers to implementing ACP interventions, and the concerns about EoL decisions and conversations. Based on the aforementioned evaluation framework, the participants' perceptions towards the activities were considered a direct indicator of the quality and effectiveness of the programme. On the other hand, participants' personal experience and reflections, albeit not explicitly related to the quality of the activities, were also of immense value to the evaluation process since they allowed us to examine whether the activities had adequately focused on and addressed the issues with which the target beneficiaries were mostly concerned.

Chapter 3 Programme Activities

3.1 Capacity Building Programme

The capacity building programme was designed for healthcare professionals and was aimed at enhancing their capacity for providing high-quality EoL care. During the following sections, we recapitulate the programme by presenting the implementation details, project deliverables (counting from January 2019 to July 2021), and evaluation results of the activities, respectively, for each major group of target beneficiaries, namely, doctors (Section 3.1.1), nurses (Section 3.1.2), allied healthcare professionals (Section 3.1.3), and prospective healthcare professionals (Section 3.1.4), with the exception of the webinar on "End-of-Life Care for Older People in the Context of COVID-19" (Section 3.1.5), which was an interdisciplinary activity intended for all of the aforementioned target groups.

3.1.1 Doctors

A total of 31 training sessions were conducted, in various delivery modalities, for 954 doctors either from NTEC hospitals or in private practice. Aligning with the programme objectives, training was provided to not only doctors specializing in geriatrics, oncology, or palliative care, but also those from other medical fields. Topics covered in the training were mostly concentrated on EoL conversations and communication skills, which are perhaps the most prominent deficits exhibited by doctors in the EoL care setting.

3.1.1.1 Interactive workshops

An interactive workshop was the major component of the doctor training. During each of the regularly scheduled one-hour sessions, the instructor first gave a brief lecture to review some basic EoL concepts and introduced and demonstrated the Serious Illness Conversation Guide (SICG; Ariadnes Labs, 2016).[17] After that, participants took turns to take part in a role-play exercise to apply and practise the acquired techniques. Critically, they also received constructive feedback and comments from both their colleagues and other senior consultants regarding their conversation flow, wording, and non-verbal expressions, which contributed immensely to helping them improve their EoL communication skills.

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[17] The SICG is a set of patient-tested guides on conversation flow and language expressions, which offers a validated tool for doctors to ask patients about their goals, values, and treatment preferences.

Figure 3.1 The lecture session and role-play exercise in an interactive workshop for doctors.

3.1.1.2 Seminars and lectures

Besides the aforementioned interactive workshops that placed special emphasis on the role-play exercises, traditional seminars and lectures were also conducted for doctors aiming to further deepen their awareness and knowledge of EoL conversation skills. Topics covered in these seminars not only included the SICG, but also other special issues encountered in difficult conversations regarding, for instance, DNACPR and tube feeding.

Figure 3.2 A doctor seminar on the SICG and difficult conservations.

3.1.1.3 Symposium

During the project period, a large-scale symposium was hosted each year in collaboration with the HKDU, in the course of which a special lecture on a specific topic related to EoL care was delivered. For instance, in March 2019, a lecture titled "The 'whys' and 'whats' in EoL care" was given, attracting a total of 175 attendees. This lecture highlighted some diet-related issues in EoL care, stressing that priority should be given to the appetite and well-being of patients before considering a restriction on food intake.

Figure 3.3 A lecture on EoL care was given during the HKDU symposium.

3.1.1.4 Online training

Due to the COVID-19 pandemic and the subsequent social distancing measures, some of the doctor training sessions were switched to an online format. More specifically, several one-hour lectures were delivered live online, using a teleconferencing software platform. These lectures were then recorded, post-produced and distributed to NTEC hospitals, The Medical Council of Hong Kong, and The Hong Kong Geriatrics Society (HKGS). Topics covered in these online lectures included EoL communication skills, ACP for patients with dementia, clinical ethics, and the special considerations in the provision of EoL care during the COVID-19 pandemic.

Figure 3.4 Online lectures for doctors.

Ethics of Clinical Decision-making for End-of-life Patients

Dr. Derrick Au

Director, CUHK Centre for Bioethics

CUHK JC Institute of Ageing training (2021)

Communications for Breaking Bad News

Dr. Christopher Lum

3.1.1.5 Death audits

All units in the HA hospitals hold regular death audits in their monthly departmental meetings, during which reviews are conducted on some of the deceased patients to examine whether the given medical treatments were appropriate and in alignment with their best interests.

Commenced as a CQI initiative, the programme has facilitated the administrators and management levels in some of the NTEC hospitals to incorporate the documentation of EoL preferences of the deceased patients as well as the communication process into the death audit procedure (e.g., Fung, 2021), on a regular and continual basis. These death audits serve as an excellent learning opportunity for the doctor attendees to further appreciate the importance of transparent documentation and effective communication with patients, their family members, and other colleagues in the healthcare team.

3.1.1.6 Evaluation

3.1.1.6.1 Quantitative results

The quantitative evaluation results of the doctor training are presented in Table 3.1. As can be seen from the table, the scores of all the items were above 3,[18] indicating that the doctor participants have improved in all the KAB domains and had a positive attitude towards the training activities. Most notably, the training has succeeded in helping the participants clarify their misconceptions about EoL care. Indeed, many doctors were deeply yet erroneously convinced that medicine was only intended to cure disease and thus were under the misapprehension that EoL care meant the abandonment of patients. In this regard, the doctor training was extremely efficacious in terms of rectifying this misunderstanding.

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[18] According to one-sample *t*-tests (not shown in the table), all scores were in fact significantly greater than 3, which is the theoretical neutral point.

Table 3.1 Quantitative evaluation results of the doctor training.

Domain	Item	*N*	*M*	*SD*
Knowledge	Increase knowledge of EoL care	191	3.84	0.73
	Clarify misconceptions about EoL care	108	4.12	0.64
	Raise awareness of EoL care	107	4.25	0.53
	Improve skills in communicating with EoL patients and their family members	108	4.16	0.57
Attitude	Improve confidence in communicating with EoL patients and their family members	190	3.76	0.75
	Increase motivation to initiate EoL conversations	107	4.04	0.66
Behavior	Initiate more EoL conversations	188	3.65	0.80
Satisfaction	The training is relevant	191	3.85	0.79
	The training is important	191	3.91	0.79
	The training is useful	191	3.92	0.78
	The quality of the training is good	187	4.12	0.65

Note. Respondents rated the extent to which they agreed with each statement in the questionnaire (1 = *Strongly Disagree*, 5 = *Strongly Agree*). The items as shown above captured the psychological constructs that these statements measured, but were not necessarily the actual wording displayed to the respondents. All results were aggregated, whenever applicable, across all training sessions.

3.1.1.6.2 Qualitative observations

Although most of the doctor participants had profound experience and expertise in practising medicine in their specialized fields, many of them did lack the basic understanding and general knowledge of EoL care, foremost among which was communication skills. Indeed, it could be observed from the role-play exercises in the interactive workshops that many participants were not comfortable in expressing empathy to patients and their family members. Instead, they tended to overly focus on the curative nature of medicine and include excessive medical information and terminology into the conversations. Through the comments given by the instructors, participants were reminded that empathetic and emotional support, as compared with factual and medical details, are more important to most patients and their family members. As an outcome of the training, participants became more aware of what they should address and discuss, and what their manner of speaking should be, in an EoL conversation.

Besides communication skills, it was also quite common for doctor participants to encounter difficulties in making treatment decisions for EoL patients. For instance, some participants were uncertain as to whether tube feeding or careful hand feeding would be more suitable for patients with end-stage chronic obstructive pulmonary disease (COPD).[19] In this regard, through the sharing of experience and case-by-case analyses conducted by the senior instructors, the training has helped the participants understand how to identify and select the optimal treatment approach that is in the best interests of the patients.

3.1.2 Nurses

A total of 92 training sessions were conducted, in various delivery modalities, for 3,545 nurses from the NTEC hospitals. While a wide array of topics was covered in order to address the various needs, ACP implementation and EoL communication skills were the quintessential themes of the nurse training.

3.1.2.1 Train-the-Trainer series

The Train-the-Trainer paradigm is a well-known framework for establishing a competent and motivated workforce by empowering the current or soon-to-be leaders to mentor, guide, and support their subordinates or other junior colleagues. This top-down approach has the merit of being cost effective and sustainable, and has been frequently employed in training and intervention programmes across various disciplines (e.g., Chan et al., 2020; Lai et al., 2017).

Following this pedagogical model, the Train-the-Trainer series was a sequence of training activities specifically designed for the more senior nurses (e.g., advanced practice nurses, ward managers), in the hope of enabling them to enforce and promote the provision of high-quality EoL care in their workplace. Ultimately, the Train-the-Trainer series was aimed at cultivating a collaborative atmosphere that gives prominence to the QoL and best interest of patients, thereby generating capacity for the junior nurses to be able to provide high-quality EoL care even in such an intensive and demanding work environment.

As regards the implementation details, the Train-the-Trainer series began with a seminar on the recent development of EoL care, which primarily served as a refresher course for the shortlisted participants who were already knowledgeable and experienced in this domain. After the introductory session, the same group of participants attended an interactive

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[19] The training sessions have also served as a platform for doctor participants to voice their concerns. In response to the expressed concerns, the COSs of several NTEC hospitals are currently planning to organize training for doctors on EoL care that specifically address the issue of careful hand feeding.

workshop, during which they were guided to reflect on the practical barriers to implementing ACP and high-quality EoL care, as well as building specific strategies for tackling these identified challenges. During the subsequent post-training period, participants were asked to vigorously promote ACP interventions and EoL care in their affiliated units, as well as to apply and pilot the devised strategies whenever deemed appropriate. Finally, participants exchanged views and shared experiences in a two-month follow-up session, which served as an opportunity for them to take stock of and track the progress of their work and efforts.

Figure 3.5 Train-the-Trainer series for the senior nurses.

3.1.2.2 Communication skills series

In EoL conversations, the skills of communicating with patients are by no means the only aspect in which nurses should be proficient. Indeed, ACP requires the integral participations from patients, their family members, and healthcare professionals, among which nurses may play a particularly important role in setting up the bridge of communication for the involved parties. In view of this, the communication skills series was designed to equip nurses with a wide range of tools and techniques, such that they can confidently and effectively communicate with not only their patients, but also their family members and other colleagues in the healthcare team.

The communication skills series consisted of three workshops that were regularly offered on a rotational basis. The first two workshops focused on a collection of communication protocols designed for guiding nurses to articulate their empathy, respect and support to, and elicit thoughts and preferences from, EoL patients and their family members. These protocols included the well-known NURSE[20] (Baile et al., 2000) and SPIKES[21] (Pollak et al., 2007) statements, both of which are mnemonics that have been validated and widely applied in the

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[20] N: Naming; U: Understanding; R: Respecting; S: Supporting; E: Exploring.

[21] S: Setting; P: Perception; I: Invitation; K: Knowledge; E: Empathy; S: Summary.

context of oncologist communication. Sample quotes in both English and Chinese were given to illustrate the usage of these statements, and role-play exercises were included to provide participants with the opportunities to apply and practise the protocols.

In a similar vein, participants learned another set of protocols in the third workshop, namely the SBAR[22] (Leonard, Graham, & Bonacum, 2004) acronym, such that they can become more capable of making concise and comprehensive nurse calls, which ultimately enables doctors to provide patients with optimal EoL care in a timely manner. In addition, expert advice was given to help participants resolve interpersonal conflicts that were pervasive in their workplace, thereby encouraging and facilitating them to provide high-quality EoL care to patients as a decentralized, non-hierarchical and cohesive entity.

Figure 3.6 Communication skills series for nurses.

3.1.2.3 Workshops and talks

Besides these training series, interactive workshops and talks on other miscellaneous topics including clinical ethics, spiritual care, and bereavement support were also delivered to nurses.

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[22] S: Situation; B: Background; A: Assessment; R: Recommendation.

Figure 3.7 Workshops on self-care, emotional regulation, and mindfulness for nurses.

3.1.2.4 Online training

Due to the COVID-19 pandemic and the subsequent social distancing measures, some nurse training sessions were switched to online format. More specifically, several one-hour lectures were delivered live online, using a teleconferencing software platform. These lectures were then recorded, post-produced and distributed to NTEC hospitals, in particular their CNDs, and The Nursing Council of Hong Kong. Topics covered in these online lectures included EoL communication skills, the recent developments in ACP, clinical ethics, and mindfulness training.

3.1.2.5 Evaluation

3.1.2.5.1 Quantitative results

The quantitative evaluation results of the nurse training are presented in Table 3.2. As can be seen from the table, the scores of all the items were above 3,[23] indicating that the nurse participants have improved in all the KAB domains and had a positive attitude towards the training activities. Crucially, most participants have enhanced their confidence and motivation in initiating EoL conversations with patients and their family members. Before the training, in comparison, many participants were doubtful as to whether they were capable of, and whether they should be responsible for, conducting EoL conversations. In this regard, a particularly rewarding outcome of the training was that participants were reminded and reassured of their important and equal role, as a member of the healthcare team, in the provision of high-quality EoL care. Consequently, nurse participants were encouraged and empowered to take the active initiative to engage in EoL conversations in their daily work.

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[23] According to one-sample *t*-tests (not shown in the table), all scores were in fact significantly greater than 3, which is the theoretical neutral point.

Table 3.2 Quantitative evaluation results of the nurse training.

Domain	Item	*N*	*M*	*SD*
Knowledge	Increase knowledge of EoL care	2,073	4.09	0.57
	Raise awareness of EoL care	2,054	4.12	0.57
	Improve skills in communicating with EoL patients and their family members	2,005	4.08	0.57
Attitude	Improve confidence in communicating with EoL patients and their family members	2,025	4.06	0.56
	Increase motivation to initiate EoL conversations	2,007	4.00	0.60
Behavior	Initiate more EoL conversations	2,007	4.00	0.59
Satisfaction	The training is relevant	2,088	4.09	0.61
	The training is important	2,089	4.09	0.59
	The training is useful	2,088	4.07	0.61
	The quality of the training is good	2,082	4.12	0.55

Note. Respondents rated the extent to which they agreed with each statement in the questionnaire (1 = *Strongly Disagree*, 5 = *Strongly Agree*). The items as shown above captured the psychological constructs as measured by these statements, but were not necessarily the actual wording displayed to the respondents. All results were aggregated, whenever applicable, across all training sessions.

3.1.2.5.2 Qualitative observations

During the training sessions, many nurse participants expressed concern over their lack of medical knowledge and the self-perceived inadequacy in conducting EoL conversations. Specifically, many participants claimed that they were reluctant to engage in EoL conversations since they were not sure about how to properly address the technical questions raised by patients and their family members that fell inside the medical scope, for instance, diagnosis and prognosis, and the differences between various treatment options. In particular, participants tended to find it challenging to handle the situations where a definite and accurate estimate on the remaining life expectancy of the patient was requested. Consequently, participants often avoided touching upon these issues and chose to entirely direct the responsibility of initiating EoL conversations to doctors and other senior nurses.

As regards this seemingly unmanageable condition, the experienced instructors offered a simple yet inspiring solution to the participants—it is not at all necessary to respond to the unanswerable questions directly; instead, it is far more important to explore and identify the genuine concerns underlying these difficult questions (i.e., the hidden agenda), for instance, the negative emotions experienced by the patients (e.g., fear of death), and the interpersonal conflicts and special dynamics that existed among the family members. Although these issues by themselves may also be difficult to handle, in most situations it suffices for nurses to demonstrate their empathetic understanding, or to simply allow for a few moments of silence if no other appropriate response can be given. From the above, participants recognized and understood that medical knowledge and qualifications are not indispensable preconditions for EoL conversations to succeed; on the contrary, compassion and wholeheartedness are the most important factors contributing to an effective and fruitful communication process.

3.1.3 Allied healthcare professionals

A total of 46 training sessions were conducted, in various delivery modalities, for 1,588 allied healthcare professionals, the majority of whom were community nurses, social workers, personal care workers and programme workers from various RCHEs. Since these target beneficiaries seldom bear the responsibility of breaking bad news and discussing the prognosis and treatment options with patients and their family members, emphasis of the training sessions was primarily given to the non-medical aspects of EoL conversations, ACP and AD, as well as the most fundamental concepts in EoL care. More generally speaking, the training sessions were not as skill-based or knowledge-oriented; instead, they were more focused on making the participants aware of the existence and importance of EoL care.

3.1.3.1 Serious Illness Conversation Guide training series

As a preliminary attempt to further extend the geographical scope of the present programme,[24] an SICG training series was organized, in collaboration with the Medical Social Services Department of Queen Mary Hospital (QMH), for the medical social workers (MSWs) from the Hong Kong East Cluster (HKEC) and Hong Kong West Cluster (HKWC). The training series consisted of two online sessions. The first session reiterated the importance of ACP and EoL conversations and introduced and demonstrated the SICG. The second session further illustrated the applications of the SICG through role-play and reviewed the progress and efforts of ACP implementation in various hospitals and institutions.

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[24] As the service model is becoming mature, it is proposed that the upcoming third phase of the programme can be extended to cover at least four of the seven HA clusters.

3.1.3.2 Art workshops

Despite not being well recognized and popularized, the use of art can in fact effectuate a complementary, yet significant function in EoL care. Art may serve as a platform for healthcare professionals to provide support and spiritual care to patients and their family members (e.g., Safrai, 2013). At the same time, art may be an unorthodox yet effective solution to a variety of problems that healthcare professionals may frequently encounter, including death anxiety, compassion fatigue, and burnout (e.g., Potash, Ho, Chan, Wang, & Cheng, 2014), all of which are hindering factors that may obstruct the provision of high-quality EoL care.

In view of this, several art workshops were organized, in an exploratory manner, for allied healthcare professionals with the aim of encouraging them to incorporate artistic elements into their daily work and self-care activities, thereby enhancing the quality of EoL care in an indirect manner.

Figure 3.8 Art workshops for allied healthcare professionals.

3.1.3.3 Guided tours

3.1.3.3.1 Jockey Club Home for Hospice

Typically, neither public hospitals nor government-subvented RCHEs are sufficiently equipped and prepared to provide EoL care conforming to the optimal standard. Consequently, healthcare professionals, especially those from the public and non-medical sector, may not be able to fully appreciate the specifications and modes of operation of those agencies that are exclusively intended to provide EoL care services.

In light of this, a tour of the Jockey Club Home for Hospice (JCHH), which is a hospice center affiliated under the Society for the Promotion of Hospice Care (SPHC), was organized for a group of allied healthcare professionals from the Tung Wah Group of Hospitals (TWGHs), during which they were guided to visit and inspect the various facilities in the JCHH, for instance the farewell room and mortuary. In brief, the overarching objective of the tour was to acquaint participants with the setup and service process of the specialized agencies in the EoL care sector, which may ultimately be relevant and conducive to their daily practice (e.g., casework with elderly patients).

Figure 3.9 Guided tour of the JCHH.

3.1.3.3.2 Dissecting laboratory

Post-death arrangements, in particular funeral and burial matters, are usually an issue of critical importance to both patients and their family members. Regarding this aspect, it is conceivable that allied healthcare professionals may play a much more active and vital role in facilitating discussions among the involved parties, as compared with doctors and nurses who may focus more on the medical aspects in EoL conversations.

In view of this, a guided tour of the dissecting laboratory in CUHK was organized for a group of allied healthcare professionals from the TWGHs. The goal of the tour was to further sensitize the participants on various post-death issues, especially with respect to funeral services and body donation, such that they could become more competent and confident in catalyzing the communication process.

Figure 3.10 Guided tour of the dissecting laboratory in CUHK.

3.1.3.4 Talks and information sessions

Besides the aforementioned major components, talks and information sessions covering the most fundamental concepts in EoL care, ACP and AD, and other miscellaneous topics were also delivered to allied healthcare professionals from various RCHEs. In particular, several sessions on symptom management were specifically offered to this group of target beneficiaries in the hope of making up for their relative deficiency of medical knowledge.

Figure 3.11 Talks and information sessions for allied healthcare professionals from RCHEs.

3.1.3.5 Online training

Due to the COVID-19 pandemic and the subsequent social distancing measures, some sessions for allied healthcare professionals were switched to an online format. More specifically, several one-hour sessions were delivered live online, using a teleconferencing software platform. These sessions were then recorded, post-produced and distributed to various RCHEs and partnering NGOs. Topics of these sessions largely duplicated those covered in the face-to-face sessions.

3.1.3.6 Evaluation

3.1.3.6.1 Quantitative results

The quantitative evaluation results of the training for allied healthcare professionals are presented in Table 3.3. As can be seen from the table, the scores of all the items were above 3,[25] indicating that the participants had improved in all the KAB domains and had a positive attitude towards the training activities. Expectedly, given the mostly non-technical nature of the training, improvements of the participants in the "knowledge" and "behavior" aspects were comparatively mild. Nonetheless, it was critical that participants had significantly increased their awareness and perceived importance towards EoL care, which was arguably the more important outcome of these training activities.

Table 3.3 Quantitative evaluation results of the training for allied healthcare professionals.

Domain	Item	*N*	*M*	*SD*
Knowledge	Increase knowledge of EoL care	249	3.55	0.68
	Raise awareness of EoL care	97	4.10	0.53
	Improve skills in communicating with EoL patients and their family members	39	3.95	0.56
Attitude	Improve confidence in communicating with EoL patients and their family members	190	3.32	0.62
	Increase motivation to initiate EoL conversations	39	3.87	0.61
Behavior	Initiate more EoL conversations	162	3.09	0.77
Satisfaction	The training is relevant	266	3.59	0.76
	The training is important	266	3.56	0.73
	The training is useful	263	3.53	0.75
	The quality of the training is good	263	4.06	0.78

Note. Respondents rated the extent to which they agreed with each statement in the questionnaire (1 = *Strongly Disagree*, 5 = *Strongly Agree*). The items as shown above captured the psychological constructs as measured by these statements, but were not necessarily the actual wording displayed to the respondents. All results were aggregated, whenever applicable, across all training sessions.

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[25] According to one-sample *t*-tests (not shown in the table), all scores except for the item under the "behavior" domain were in fact significantly greater than 3, which is the theoretical neutral point.

3.1.3.6.2 Qualitative observations

It was noticed that one of the most common concerns raised by allied healthcare professionals was about the difficulty in identifying the appropriate occasion for initiating the provision of EoL care. For instance, during the guided tour of the JCHH, many participants from the social work sector said that they were unsure as to whether and when to make case referrals to the JCHH for follow-up services. Upon further observations, there was apparently a misconception about EoL care underlying these struggles—participants wrongfully assumed that EoL care is only relevant and applicable to patients in their final hours, and consequently, they arrived at the paradoxical conclusion that there seemed to be no optimal timing for interventions as any efforts would have already been too late for the dying patients.

Reassuringly, much of this uncertainty has been successfully reduced as speakers and instructors presented and repeatedly emphasized the correct concepts of EoL care during the various activities. As a result, participants realized that EoL care is important and beneficial to not only the imminently dying but also to those who are in the earlier stages of a serious illness, as well as their family members.

3.1.4 Prospective healthcare professionals

In the hope of nurturing prospective healthcare professionals and injecting fresh impetus to the EoL care service sector, various training and educational activities were provided to CUHK students majoring in medicine, social work, and gerontology.

3.1.4.1 Medical curriculum

As regards the medical students, instead of offering them elective courses or optional activities, a concerted effort has been made to include the training and education on EoL care, in particular with respect to communication skills, as part of the formal and compulsory medical curriculum, thereby allowing the students to better appreciate the inextricable linkage between EoL care and the other clinical aspects on which they are usually more intensively trained. Examples of such efforts included

- communication skills session in the Medical Grand Round
- micro-modules in "Integrated Clinical Communication Skills I/II/III" (undergraduates)
- regular lectures in "Principles and Perspectives of End-of-Life Care" (postgraduates)
- serious illness communication tutorials in "Senior Medical Clerkship" (undergraduates)

Through these channels, a total of 1,475 medical students received training and education on the principles and philosophy of EoL care, and the techniques of using various verbal and nonverbal expressions to conduct EoL conversations, articulate empathy, and handle difficult emotions.

3.1.4.2 Interactive workshops

Besides the training for medical students, two three-hour interactive workshops were conducted for a total of 87 social work students who were particularly interested in the topic of EoL care. These workshops took a step-by-step approach and progressively covered a range of topics from ACP and AD, EoL conversation skills, to psychological and spiritual care.

Figure 3.12 Interactive workshops for social work students in CUHK.

Finally, an interactive workshop on music therapy was conducted for 18 gerontology students, during which participants learnt about and gained firsthand experience of how to use music as a means of engaging and empowering EoL patients and their family members (see also Section 3.1.3.2).

Figure 3.13 Music therapy workshop for gerontology students in CUHK.

3.1.4.3 Evaluation

3.1.4.3.1 Quantitative results

As compared with most of the other programme activities that were one-off in nature, some training for medical students, namely the micro-modules in "Integrated Clinical Communication Skills I/II/III", took an entire semester to complete, which enabled the longitudinal tracking and assessments of participants. Taking the advantage of this, a pre-post comparison using paired *t*-tests was performed to evaluate the effectiveness of the training,[26] the results of which are presented in Table 3.4. As can be seen from the table, the medical students became significantly more capable of conducting EoL conversations with patients and their family members after the training. In particular, these medical students showed the most notable improvement in responding to the various negative emotions (e.g., shock, anger, grief) that may be evoked in an EoL conversation.

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[26] Unlike other questionnaires which asked the respondents to explicitly evaluate the perceived effectiveness of the activity in each of the KAB domains, this set of pre-post questionnaires was intended to implicitly evaluate the training by measuring the level of competence of the respondents in two different timeframes, namely before and three months after the training.

Table 3.4 Pre-post training comparison of medical students' perceived preparedness in conducting EoL conversations.

	M (SD)			
Item	**pre**	**post**	***t (df)***	***p***
Discuss bad news with patients and their family members about serious illness	2.47 (0.69)	3.06 (0.63)	11.37 (259)	< .001
Respond to emotions from patients and their family members	2.34 (0.64)	2.99 (0.59)	13.57 (257)	< .001
Use nonverbal communication to facilitate serious illness conversations	2.68 (0.70)	3.30 (0.68)	12.00 (259)	< .001
Use verbal expressions to show empathy in serious illness conversations	2.53 (0.67)	3.15 (0.66)	11.38 (258)	< .001
Elicit concerns or needs from patients and their family members	2.60 (0.69)	3.16 (0.63)	10.70 (260)	< .001

Note. Respondents rated the extent to which they agreed with each statement in the questionnaire (1 = *Not At All Prepared*, 5 = *Extremely Prepared*). The items as shown above captured the psychological constructs as measured by these statements, but were not necessarily the actual wording displayed to the respondents. All results were aggregated, whenever applicable, across all semesters and academic years.

On the other hand, the quantitative evaluation results of the interactive workshops for social work students are presented in Table 3.5. As can be seen from the table, the scores of all the items were above 3,[27] indicating that the participants have improved in all the KAB domains and had a positive attitude towards the workshops. Notably, most participants became even more interested in the topic of EoL care and would take the initiative to actively seek more information in this domain. This was a particularly fruitful outcome of the workshops since it could encourage and motivate these prospective social workers to specialize in the EoL care service sector in their future career.

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[27] According to one-sample *t*-tests (not shown in the table), all scores were in fact significantly greater than 3, which is the theoretical neutral point.

Table 3.5 Quantitative evaluation results of the workshops for social work students (*N* = 43).

Domain	Item	*M*	*SD*
Knowledge	Increase knowledge of ACP and AD	4.37	0.49
	Increase knowledge of EoL conversations	4.42	0.54
	Clarify misconceptions about EoL care	3.84	0.53
	Understand the spiritual needs of EoL patients and their family members	4.26	0.54
	Raise awareness of EoL care	4.19	0.50
	Improve skills in initiating EoL conversations	4.37	0.49
Attitude	Become more empathetic towards EoL patients and their family members	4.47	0.50
	Become more interested in the topics of EoL care	4.47	0.50
	Appreciate the importance of EoL care	4.12	0.63
	Improve confidence in initiating EoL conversations	4.00	0.58
Behavior	Seek more information on EoL care	4.07	0.40
Satisfaction	The quality of the training is good	4.23	0.68

Note. Respondents rated the extent to which they agreed with each statement in the questionnaire (1 = *Strongly Disagree*, 5 = *Strongly Agree*). The items as shown above captured the psychological constructs as measured by these statements, but were not necessarily the actual wording displayed to the respondents. All results were aggregated across the two sessions.

3.1.4.3.2 Qualitative observations

In general, medical students were very supportive of incorporating the education and training on EoL communication skills into their medical curriculum. Many of them believed that empathy, appropriate wording, and compassionate expressions are vital to an effective and comfortable EoL conversation, and they agreed that the training sessions have helped them improve significantly in all these aspects. In addition, they approved of the small-group workshop format of the training, which they perceived as enhancing their communication skills in a more definite, non-theoretical, and effective manner.

However, notwithstanding the usefulness and benefits of the training, many students claimed that it was provided too late and that its duration and coverage were insufficient for them to become fully proficient in EoL communication skills. More specifically, many students suggested that such training should have been provided from the beginning of their study schedule, as well as more regularly and frequently throughout the six academic years, instead of in an overly hurried, last-minute manner. This observation further corroborated the effectiveness and acceptability of the training and showed that future phases of the programme should increase the effort in this regard to provide education on EoL care to not only senior medical students, but also those in their pre-clinical years.

3.1.5 Webinar on "End-of-Life Care for Older People in the Context of COVID-19"

During the COVID-19 pandemic, the provision of high-quality EoL care services has been severely hampered by the unfortunate reality that many healthcare professionals have been deployed to deliver emergency care and implement infection control procedures (WHO, 2020), which are given the highest priority superseding the original practices and routines in EoL care (e.g., Luk, 2021). More concerning is that owing to the acute nature of COVID-19, many patients deteriorate rapidly and need to be mechanically ventilated soon after their conditions have become critical (Intensive Care National Audit & Research Centre [INCARC], 2020), implying that there was simply insufficient time and few opportunities for the relevant parties to discuss EoL issues and plan for the imminent death. Consequently, COVID-19 has posed an unprecedented challenge to the EoL care sector worldwide.

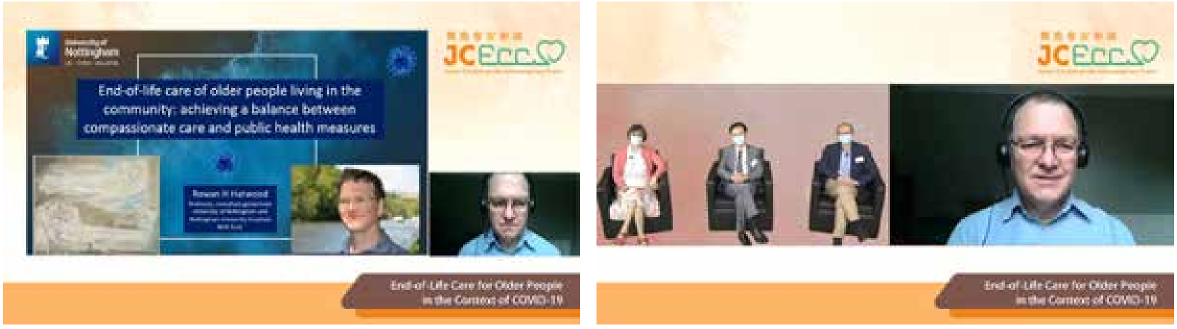
In the local context, despite the relatively low number of excess deaths that was directly attributable to COVID-19 (CHP, 2020), the impact of the pandemic on EoL care is still clearly visible. Most notably, for a considerable period of time, compassionate visiting arrangements were suspended in all public hospitals and RCHEs. As a result, some patients who passed away during this difficult time were not given the chance to say goodbye to their family members, let alone have a "good death" experience.

Evidently, the COVID-19 pandemic is a substantial problem that healthcare professionals cannot fully resolve on their own. Nonetheless, by drawing lessons from the crisis, healthcare professionals can hopefully become better prepared for similar situations that may occur in the future. In view of the above, a webinar titled "End-of-Life Care for Older People in the Context of COVID-19" was conducted in July 2021. The renowned speakers, which comprised both local and international experts in the field, shared their perspectives and insights on the following topics: (1) EoL care during COVID-19 in the context of palliative care wards, (2) EoL care during COVID-19 in the residential care setting, and (3) the balance between compassionate EoL care and public health measures during COVID-19. Concluding with a panel discussion and Q&A session, the webinar was a major success and attracted a total of 350 attendees from across the globe (see Table 3.6) with diverse backgrounds, including health administrators, academic researchers, doctors, nurses, pharmacists, social workers, counsellors and therapists, as well as students from various disciplines.

Table 3.6 Geographical distribution of the participants of the webinar on "End-of-Life Care for Older People in the Context of COVID-19".

Region (in alphabetical order)	***N* (%)**
China	5 (1.4)
Hong Kong	280 (80.0)
India	1 (0.3)
Malaysia	7 (2.0)
New Zealand	2 (0.6)
Philippines	31 (8.9)
Singapore	2 (0.6)
Switzerland	1 (0.3)
Taiwan	5 (1.4)
United Kingdom	6 (1.7)
United States of America	5 (1.4)
Vietnam	5 (1.4)

Figure 3.14 The webinar on "End-of-Life Care for Older People in the Context of COVID-19".



3.2 Public Education Programme

The public education programme was intended to raise public knowledge and awareness of EoL issues. In the following sections, we recapitulate the programme by presenting the implementation details, project deliverables, and evaluation results, respectively, for each major group of target beneficiaries, namely, the general public (Section 3.2.1), patients and their family members (Section 3.2.2), and elderly people (Section 3.2.3).[28]

3.2.1 General public

3.2.1.1 Dying Matters Awareness Event

Drawing inspiration from the Dying Matters Coalition (Hospice UK, 2020), the Dying Matters Awareness Event was a series of educational activities and promotional campaigns organized throughout the year of 2020 with the aim of engaging the general public in active and open discussions about EoL issues. The main theme of the event was "Live Free, Die Well",[29] the implied meaning of which was the hope that everyone could initiate EoL planning as early as possible and thereby be able to live without fear or worry.

3.2.1.1.1 Drawing competition

The major highlight of the Dying Matters Awareness Event was a territory-wide drawing competition, the objective of which was to encourage the participants to reflect on what constituted a "good death" experience, as well as to view and understand EoL care from a more positive perspective. There were five categories in the competition, namely, secondary students, tertiary students, healthcare professionals, elderly people, and the general public, altogether attracting 260 submissions. The award-winning entries were made into a souvenir calendar, which was then widely distributed to various sectors in the community for maximizing the promotional impact. In addition, these entries were showcased at the MTR Art Community Gallery in Hin Keng and Prince Edward stations, as well as at the Sha Tin Town Hall Exhibition Gallery, with the aim of attracting attention from passers-by and sensitizing them on EoL issues.

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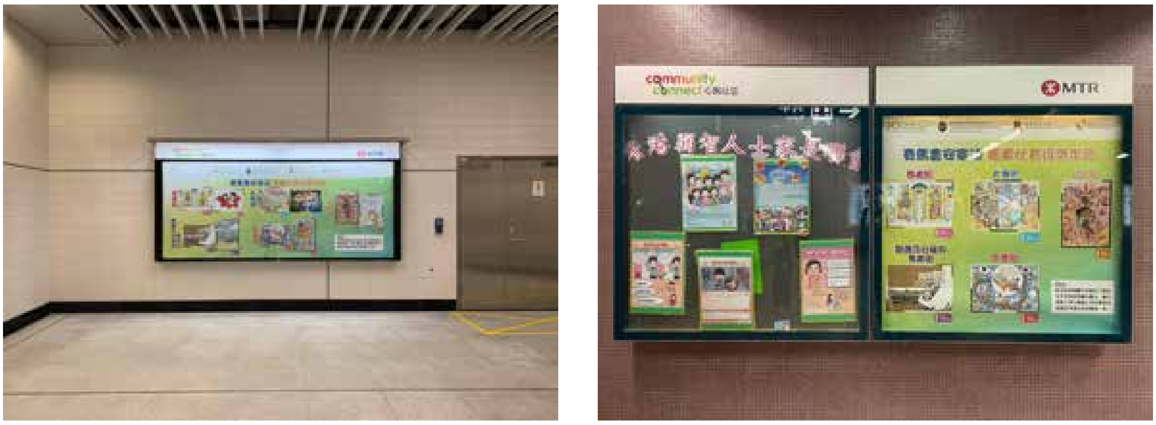
[28] This categorization was used to emphasize the differences in the scopes and objectives of the various programme activities. For instance, activities organized for the "general public" were all-encompassing in nature, whereas those organized for the "patients and their family members" were more specifically oriented towards the needs and interests of this target group.

[29] The theme name was "安心來 · 安心去" in Chinese.

Figure 3.15 Souvenir calendar for the "Live Free, Die Well" drawing competition.

Figure 3.16 MTR Art Community Gallery of the "Live Free, Die Well" drawing competition.



3.2.1.1.2 *Multimedia campaign*

In order to reach out to the general public to an even greater extent, a Facebook page and a YouTube channel were established respectively, on which information and videos about EoL issues, as well as various advertising materials, were posted on a regular basis. Through active promotional efforts, both social media platforms have attracted wide publicity among the general public. More specifically, the Facebook page has accumulated a total of 19,535 views, 1,518 likes and 649 followers, and the YouTube channel has accumulated a total of 332,963 views and 1,640 subscribers during the period concerned.

As regards the advertising materials, two videos including a micro-movie and a celebrity interview[30] were specifically produced to echo the main theme of the Dying Matters Awareness Event and generate further interest among the general public.

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[30] The details of these videos are described in Section 4.2.1.1 and Section 4.2.4.1, respectively.

3.2.1.1.3 Closing ceremony

To mark the successful end of the Dying Matters Awareness Event, a large-scale online closing ceremony was organized in December 2020, attracting a total audience of 211. The ceremony started with an award presentation of the drawing competition, during which some of the awardees were invited to share their thoughts and reflections on various life-and-death issues that were provoked by the competition. After that, the ceremony proceeded with a micro-movie screening session, as well as a brief review of the previous work and achievements accomplished by the programme. The grand finale of the ceremony was a mini concert presented by a renowned band from Forget Thee Not,[31] during which several popular funeral songs were performed with the aim of presenting the importance of cherishing life and planning for EoL matters.

Figure 3.17 The mini concert performed during the closing ceremony.

3.2.1.2 Experiential workshop series

Besides the Dying Matters Awareness Event, another key component of the programme was "吾好吾理", an experiential workshop series organized in collaboration with the "Network of

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[31] Forget Thee Not is a social enterprise aiming to promote EoL planning, ACP and AD, and environmentally friendly funeral and burial services.

Ageing Well for All" (NAWA).[32] The ultimate objective of the series was to nurture volunteers and future leaders in the community and transform them into a pivotal point for disseminating knowledge and fostering public participation in issues related to EoL care.

To this end, the series began with several introductory sessions on general EoL issues, which were intended to engage a wide spectrum of audiences and, in the meantime, identify and gather a group of motivated individuals who were interested in undertaking a leading and advocacy role in promulgating the concepts and importance of EoL care to the community.

Figure 3.18 Introductory sessions of the "吾好吾理 " workshop series.

Then, the series proceeded with various in-depth and small-group sessions, including in particular a guided tour of the Jockey Club Life Journey Centre, which aimed to impart more advanced knowledge and leadership competencies to the shortlisted participants. After that, these participants became volunteers and formed a working committee that was responsible for coordinating talks and workshop activities, on a regular and ongoing basis, for raising public awareness of EoL care. For instance, the committee helped arrange and organize an online session in July 2020, which consisted of a series of experiential activities (e.g., floral arts and acupressure massage) aiming to convey the importance of EoL care to the general public. In addition, the committee is currently also planning to establish an "alumni association", which is intended to recruit more like-minded volunteers and expand the educational efforts in a sustainable manner.

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[32] NAWA is a platform established by the IoA aiming to facilitate and empower elderly people with diversifying profiles to collectively contribute to building a more age-friendly Hong Kong.

Figure 3.19 Advanced sessions of the "吾好吾理" workshop series.

3.2.1.3 Talks and information sessions

In May 2019, the IoA co-hosted a large-scale talk titled " 吾該好死 " with the Hong Kong Life and Death Studies Association to promote and emphasize the importance of early EoL planning, attracting a total of 212 participants. Topics covered in the talk included ACP, EoL decision-making, organ donation, and the "Silent Teacher" body donation scheme.[33]

Figure 3.20 A large-scale talk on ACP and post-death matters.

In addition, several talk sessions on other miscellaneous topics were organized, in both face-to-face and online format, for a total of 180 participants from the general public, a notable example of which was the subject talk titled "End-of-Life Care Planning: The Life Train Journey" held in the Yuen Chau Kok Public Library.

3.2.1.4 Interactive theatre

In January 2020, the IoA organized an interactive theatre in collaboration with Forget Thee

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[33] The "Silent Teacher" body donation scheme enables individuals to, at the time of death, bequeath their bodies to the Faculty of Medicine, CUHK, for anatomical examination in relation to teaching and research purposes.

Not, with the aim of promoting ACP and AD to the general public in a more innovative, lively, and engaging manner. During the theatre play, actors illustrated and emphasized the adverse consequences of not having sufficient preparation for EoL matters and guided the audiences to contemplate EoL issues through interactive dialogs. The performance attracted a total of 62 participants from all age groups.

Figure 3.21 Interactive theatre on ACP and AD.

3.2.1.5 Roving exhibitions

Throughout the programme, roving exhibitions were staged intermittently in various communal areas, including NTEC hospitals and public libraries, for publicizing general EoL knowledge to the passers-by. Notably, the exhibition panels did not only display factual information about EoL care, but also featured a message zone for the viewers to write down and share their personal thoughts in this regard.

Figure 3.22 The "Life Train Journey" roving exhibition.

3.2.1.6 Evaluation

3.2.1.6.1 Quantitative results

The quantitative evaluation results of the educational activities for the general public are presented in Table 3.7. As can be seen from the table, the scores of all the items were above 3,[34] indicating that the participants have improved in all the KAB domains and had a positive attitude towards the educational activities. Notably, many participants hoped that further similar activities could be held in the future, in which they would be highly motivated and enthusiastic to participate. Coinciding with Section 1.4.2, this result shows that the general public is indeed inclined to know more about EoL issues, suggesting that the future phases of the programme should continue to expand the current efforts in this regard to address the unmet educational needs.

Table 3.7 Quantitative evaluation results of the educational activities for the general public.

Domain	Item	*N*	*M*	*SD*
Knowledge	Increase knowledge of EoL planning	83	4.33	0.52
	Increase knowledge of ACP and AD	118	4.33	0.56
Attitude	Become more willing to discuss and plan for EoL issues	84	4.21	0.54
Behavior	Seek more information on EoL issues	119	4.31	0.55
Satisfaction	The time and duration are appropriate	120	4.16	0.62
	The venue is appropriate	85	4.27	0.56
	The activity corresponds with my interests and expectations	119	4.26	0.62
	Hope that a similar activity can be organized in the future	119	4.24	0.58
	Willing to participate in a similar activity	120	4.29	0.59
	The quality of the activity is good	119	4.34	0.57

Note. Respondents rated the extent to which they agreed with each statement in the questionnaire (1 = *Strongly Disagree*, 5 = *Strongly Agree*). The items as shown above captured the psychological constructs as measured by these statements, but were not necessarily the actual wording displayed to the respondents. All results were aggregated, whenever applicable, across all educational sessions.

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[34] According to one-sample *t*-tests (not shown in the table), all scores were in fact significantly greater than 3, which is the theoretical neutral point.

3.2.1.6.2 Qualitative observations

It was often noticed that many participants from the general public, despite being willing to think about life-and-death issues when prompted to do so, often had troubles differentiating among the various major concepts in EoL care. For instance, some participants mistook ACP and AD for euthanasia and thus were worried about their legitimacy and legal consequences. For another instance, some participants confused ACP with AD and overly focused on the official documentation procedure, rather than the supposedly more important communication process. At the extreme end, some young and healthy participants even had the urge to finalize their EoL decisions and sign the AD form immediately after the activities.

From the above observations, it was evident that many participants had been treating and planning for EoL issues in the wrong way. Reassuringly, through disseminating knowledge and providing guidance, the programme activities have successfully rectified this situation. Consider again the young and healthy participants as an example. After attending the activities, these participants became aware that the premature completion of AD is not conducive, if not harmful, to their EoL well-being; instead, they realized that early and open conversations about their EoL preferences, coupled with appropriate, albeit perhaps informal documentations, are much more critical and beneficial in this regard.

3.2.2 Patients and their family members

3.2.2.1 Family sessions

Given the importance of communication between patients and their family members in an ACP process, educational activities should ideally aim at encouraging joint participation from these two parties. In practice, however, it is rare for the patients and their family members to attend these activities together, thereby rendering it less effective to promote and facilitate EoL discussions between them. Furthermore, although many patients and their family members are willing and inclined to know more about EoL issues and initiate the ACP process, they are seldom given the chance to do so, owing to the heavy workload and busy schedules of the frontline healthcare staff.

As an attempt to address the above concerns, a pilot scheme of small-group family sessions was launched at TPH and SH, in which patients from either the infirmary wards or the medicine and geriatrics (M&G) wards and their family members were simultaneously recruited to take part. During each family session, basic concepts of EoL care, ACP and AD, and treatment options were first introduced through interactive case sharing and scenario-based discussions, after which patients and their family members were prompted and encouraged to directly share their thoughts and preferences with each other. Critically, several doctors and nurses from the corresponding wards were also invited to join in each family session, which constituted a valuable opportunity for them to further acquire EoL conversation skills through observational learning and build confidence in communicating with patients and their family members. If deemed appropriate, follow-up meetings were also arranged on a case-by-case basis such that interested participants could receive further information in this regard, or even launch the ACP discussion and AD signing process, if any decisions had been made, under the guidance of senior healthcare staff (To et al., 2020).

Figure 3.23 Family sessions for patients and their family members.

3.2.2.2 Talks and information sessions

Besides the family sessions, several talks including both face-to-face and online sessions were conducted for a total of 200 family members. Considering that most of these participants were the main caregivers of the patients, special emphasis was placed on EoL communication skills, treatment options, and personal care techniques, with the aims of enhancing their caretaking competence and ability to initiate EoL conversations, ultimately empowering them to provide quality care that aligns with the best interests and preferences of the patients.

Figure 3.24 Talks and information sessions for family members.

3.2.2.3 Art workshops

Art is not only useful to healthcare professionals practising EoL care but may also be directly beneficial to patients and their family members. Consider horticultural art as an example; it may serve as an informal and relaxing occasion for patients to engage in introspection and articulate their thoughts, thereby allowing their significant others to understand their EoL preferences.

As an exploratory attempt to utilize these advantages, several horticultural art workshops were conducted for a group of patients from SCH and SH who, accompanied by their family members, were guided to contemplate EoL issues through a series of gardening and plant-based activities.

Figure 3.25 Horticultural workshops for patients and their family members.

3.2.2.4 Evaluation

3.2.2.4.1 Quantitative results

The quantitative evaluation results of the educational activities for patients and their family members are presented in Table 3.8. As can be seen from the table, the scores of all the items were above 3,[35] indicating that the participants have improved in all the KAB domains and had a positive attitude towards the educational activities. Notably, many patients and their family members became more willing to discuss and plan for EoL issues, which was a particularly rewarding outcome considering that EoL preparation and conversations are conceivably the most pressing for this group of participants.

Moreover, in order to more specifically gauge the effectiveness of the family sessions, an

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[35] According to one-sample *t*-tests (not shown in the table), all scores were in fact significantly greater than 3, which is the theoretical neutral point.

additional set of pre-post comparisons using two-sample *t*-tests[36] was performed, the results of which are shown in Table 3.9. As can be seen from the table, participants had significantly improved their knowledge on treatment options, LSTs, and concepts of ACP and AD after attending the family sessions. Incidentally, it can also be noticed that most participants already had a high level of perceived importance and incentives of initiating early EoL planning even before attending the sessions. This finding again demonstrates that many patients and their family members are willing and motivated to discuss and know more about EoL issues, suggesting that more similar activities should indeed be organized in the future to accommodate these needs.

Table 3.8 Quantitative evaluation results of the educational activities for patients and their family members.

Domain	**Item**	***N***	***M***	***SD***
Knowledge	Increase knowledge of EoL planning	18	4.44	0.51
	Increase knowledge of ACP and AD	18	4.39	0.61
Attitude	Become more willing to discuss and plan for EoL issues	18	4.56	0.51
Behavior	Seek more information on EoL issues	18	4.44	0.62
Satisfaction	The time and duration are appropriate	108	4.25	0.60
	The venue is appropriate	80	4.33	0.59
	The activity corresponds with my interests and expectations	109	4.39	0.54
	Hope that a similar activity can be organized in the future	109	4.37	0.60
	Willing to participate in a similar activity	109	4.29	0.66
	The quality of the activity is good	109	4.43	0.55

Note. Respondents rated the extent to which they agreed with each statement in the questionnaire (1 = *Strongly Disagree*, 5 = *Strongly Agree*). The items as shown above captured the psychological constructs as measured by these statements, but were not necessarily the actual wording displayed to the respondents. All results were aggregated, whenever applicable, across all educational sessions.

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[36] Due to anonymity issues, the identities of the participants in the family sessions were not tracked, thus Welch's *t*-tests were used in place of paired *t*-tests.

Table 3.9 Quantitative evaluation results of the family sessions using pre-post comparisons.

	M (SD)			
Item	**pre**	**post**	***t (df)***	***p***
Understand the importance of early EoL planning	4.45 (0.63)	4.45 (0.69)	0 (55.63)	1
Wish to initiate early EoL planning	4.52 (0.57)	4.45 (0.57)	-0.46 (56.00)	.649
Understand the differences between various treatment options	4.10 (0.82)	4.38 (0.49)	1.56 (46.05)	.127
Understand the different types of LSTs	3.07 (0.84)	4.21 (0.73)	5.51 (54.81)	< .001
Understand the concept and objectives of ACP	3.76 (0.87)	4.34 (0.55)	3.06 (47.36)	.004
Understand the concept and objectives of AD	3.34 (0.77)	4.38 (0.62)	5.63 (53.66)	< .001

Note. Respondents rated the extent to which they agreed with each statement in the questionnaire (1 = *Strongly Disagree*, 5 = *Strong Agree*). The items as shown above captured the psychological constructs as measured by these statements, but were not necessarily the actual wording displayed to the respondents. All results were aggregated, whenever applicable, across all family sessions.

3.2.2.4.2 Qualitative observations

During the family sessions, it was observed that most participants, including both patients and their family members, were willing and eager to express their preferences and opinions on EoL care. Notably, however, there seemed to be certain disagreements between these two parties over some of the major EoL decisions, which might have arisen under the influence of the traditional philosophy of filial piety. More specifically, when asked hypothetically whether they would prefer to receive any LSTs (tube feeding in particular) in an emergency condition, most if not all of the participants replied, with great certainty, in the negative. In contrast, when asked whether they would agree to provide any LSTs to the EoL patients, a considerable number of family members gave, after some initial hesitation, a completely opposite response asserting that the lives of the patients must be given the highest priority and saved at all costs. Apparently, the factors being considered when determining whether LSTs should be provided may be very different when viewed from the above two perspectives.

As regards this paradoxical situation, the family sessions precisely served as the ideal platform enabling the patients and their family members to communicate with each other and thereby align their thoughts and decisions on EoL care. Equally importantly, the sessions also allowed the two parties to recognize and appreciate the predicament that each of them was facing respectively, thereby promoting compassionate and empathetic understanding, as well as the healthy channeling of emotions and concerns.

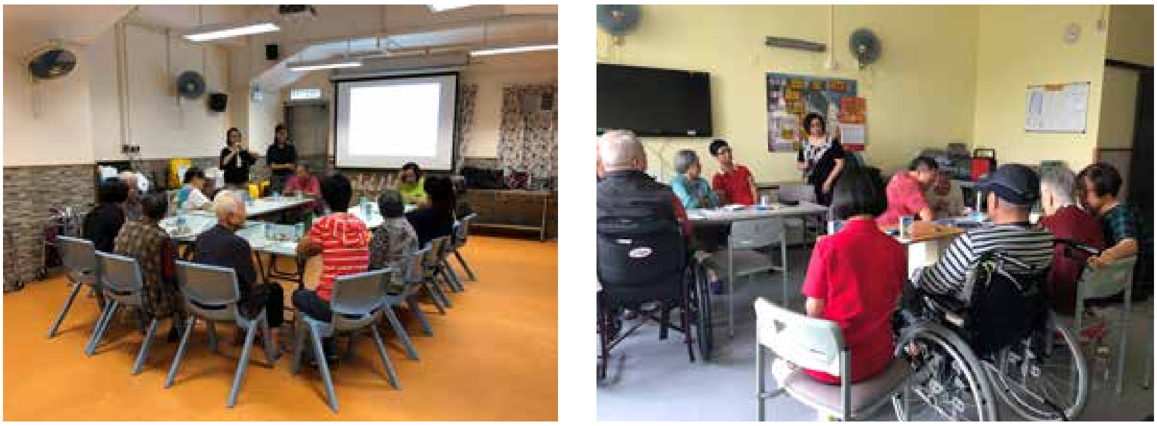
Finally, it was encouraging that a significant portion of participants also attended follow-up meetings and engaged in the ACP discussion and AD signing processes, on a voluntary and active basis, after the family sessions (see also To et al., 2020). All in all, these sessions successfully helped healthcare professionals identify patients and family members who were suitable for ACP interventions, as well as lightening their workload by facilitating and catalyzing the entire communication process.

3.2.3 Elderly people

3.2.3.1 Advance Care Planning Handbook sessions

A series of five ACP Handbook sessions were conducted for a total of 35 elderly people residing in various care and attention homes under the TWGHs. As the name implies, these small-group sessions made extensive use of the ACP Handbook (see Section 4.1.4) to instruct and assist the elderly participants to contemplate and document their thoughts and preferences regarding EoL issues. To provide the necessary guidance and one-to-one support to the participants who were beginning to suffer from cognitive decline, several volunteer helpers recruited from the "吾好吾理" workshops series (see Section 3.2.1.2) were also invited to attend these sessions.

Figure 3.26 ACP Handbook sessions for elderly people.



3.2.3.2 Talks and information sessions

In addition, a total of nine talks, including both face-to-face and online sessions, were delivered to 978 elderly people to introduce them to the general concepts of ACP and AD. These sessions made substantial use of the various educational videos and micro-movies produced under the programme (see Section 4.2) to take into account the limited cognitive capacity of the elderly participants and thereby ensure their comprehension and information retention.

Figure 3.27 Talks and information sessions for elderly people.

3.2.3.3 Evaluation

3.2.3.3.1 Quantitative results

The quantitative evaluation results of the educational activities for elderly people are presented in Table 3.10. As can be seen from the table, the scores of all the items were above 3,[37] indicating that the participants have improved in all the KAB domains and had a positive attitude towards the educational activities.

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[37] According to one-sample *t*-tests (not shown in the table), all scores were in fact significantly greater than 3, which is the theoretical neutral point.

Table 3.10 Quantitative evaluation results of the educational activities for elderly people.

Domain	Item	*N*	*M*	*SD*
Knowledge	Increase knowledge of EoL planning	27	4.59	0.57
	Increase knowledge of ACP and AD	46	4.22	0.79
Attitude	Become more willing to discuss and plan for EoL issues	27	4.59	0.57
Behavior	Seek more information on EoL issues	46	4.24	0.60
Satisfaction	The time and duration are appropriate	46	4.43	0.58
	The venue is appropriate	46	4.33	0.67
	The activity corresponds with my interests and expectations	19	4.42	0.51
	Hope that a similar activity can be organized in the future	46	4.17	0.85
	Willing to participate in a similar activity	46	4.22	0.81
	The quality of the activity is good	46	4.57	0.50

Note. Respondents rated the extent to which they agreed with each statement in the questionnaire (1 = *Strongly Disagree*, 5 = *Strongly Agree*). The items as shown above captured the psychological constructs as measured by these statements, but were not necessarily the actual wording displayed to the respondents. All results were aggregated, whenever applicable, across all educational sessions.

3.2.3.3.2 Qualitative observations

During the ACP Handbook sessions, it was observed that most of the elderly participants were initially quite unwilling to talk about EoL issues. However, as time progressed, and under the appropriate guidance of the volunteers, many participants gradually started to make their feelings known and reveal the reasons behind their reluctance to engage in EoL conversations. For instance, some participants stated that, despite already having made up their minds about various EoL decisions, they simply could not find anyone to talk to due to the presence of unresolved family matters. In another instance, some participants did not realize that their EoL preferences, unless explicitly communicated and documented, might not actually be carried out. In this regard, the ACP Handbook sessions were of profound significance as they served as a communication platform providing the precious opportunity and suitable occasion for the elderly participants to voice and record their EoL preferences.

Chapter 4 Educational Resources

During the project period, a vast variety of educational resources were produced and widely distributed to healthcare professionals and the public, serving either as self-learning toolkits or as supplementary materials for the programme activities. In the following sections, we broadly categorize these resources according to their media formats (i.e., publication vs. video), and respectively give a brief summary on their contents and dissemination progresses.

4.1 Publications

Building upon the success of their previous versions, most of the publications issued during the first phase of the programme have been updated and reprinted. These included the Casebook on Ethical Decision-Making in End-of-Life Care of Older Adults (the Casebook), the Advance Care Planning Handbook (the ACP Handbook), and the Good Death Booklet. On the other hand, the Training Kit for Healthcare Professionals (the Training Kit) and the Resources Kit were two new titles published during the current phase of the programme. All the above publications are available in both print and electronic versions, a complete list of which is provided in Table 4.1.

Table 4.1 A complete list of newly produced or reprinted publications

Title	Language version	QR code
Training Kit for Healthcare Professionals	English	
	Chinese	
Resources Kit	Chinese	
Casebook on Ethical Decision-Making in End-of-Life Care of Older Adults[38]	English	
	Chinese	
Advance Care Planning Handbook	Chinese	
Good Death Booklet	Chinese	

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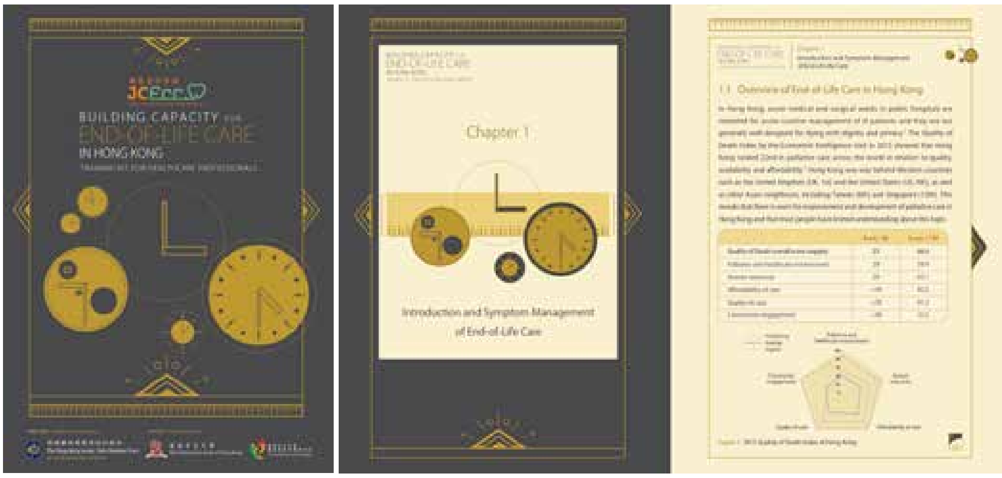
[38] The Casebook has been being updated on a continual basis (see Section 4.1.3). Interested readers may directly access the most up-to-date version via https://www.ioa.cuhk.edu.hk/en-gb/casebook (instead of in PDF format).

4.1.1 Training Kit for Healthcare Professionals

During the various training activities in the capacity building programme, distinguished specialists and experienced practitioners imparted their valuable expertise and knowledge of EoL care, which, in addition to being useful to the attendees, were also of relevance and benefit to other non-participants and the broader community. In view of this, the Training Kit was a booklet precisely designed to compile these words of wisdom for future reference and educational purposes. The main content of the Training Kit included ACP and AD, symptom management, EoL communication skills, clinical ethics, and self-care techniques. Being distinct from other publications, the Training Kit was intended to provide a relatively technical treatment of EoL care from a more medical perspective and, as its name suggests, was primarily geared towards healthcare professionals, in particular direct care practitioners.

During the period concerned, a total of 2,800 printed copies[39] of the Training Kit were issued, among which 2,466 of them have been disseminated among doctors and nurses from NTEC hospitals, Community Geriatric Assessment Teams (CGATs), social workers and personal care workers from RCHEs and NGOs, as well as various higher education institutions.

Figure 4.1 Training Kit for Healthcare Professionals.



4.1.2 Resources Kit[40]

The Resources Kit was a series of booklets serving as a reference guide for the reader to explore and identify their EoL preferences and understand how to provide the optimal care to and effectively communicate with EoL patients. The booklet series consisted of six chapters,

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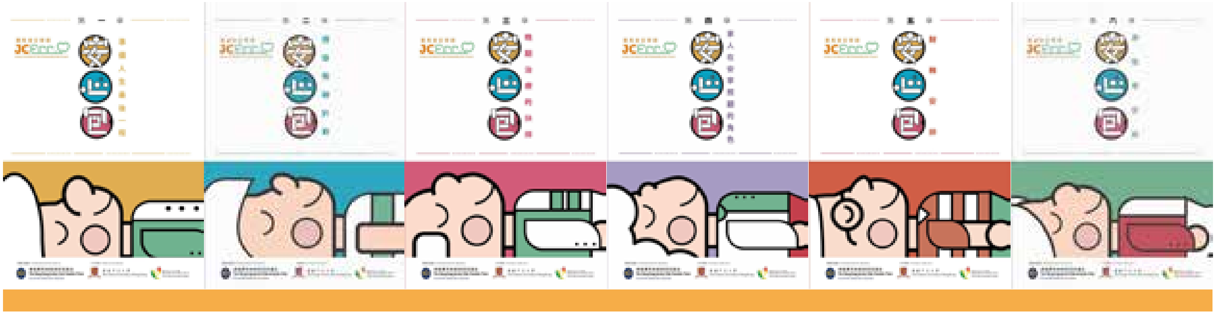
[39] Each printed copy of the Training Kit had a USB attached, containing the full collection of educational resources.

[40] The Chinese title of the Resources Kit is "安心包".

which covered topics ranging from the general concepts of EoL care, ACP, and treatment options, to post-death matters.

During the period concerned, a total of 3,650 printed copies[41] of the Resources Kit were issued, among which 3,281 of them have been distributed to participants of the public education programme, various RCHEs, NGOs, and PRCs, as well as some counseling practitioners from the funeral industry.

Figure 4.2 The six chapters of the Resources Kit.



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

Developed in collaboration with the CUHK Centre for Bioethics, the Casebook was intended to support and empower healthcare professionals to tackle the ethical issues that may frequently arise in the context of EoL care. Being the first of its kind, the Casebook documented several case studies on ethical dilemmas in EoL care, and provided expert commentaries to guide the readers to analyze and resolve the moral conflicts using a step-by-step approach. In order to more vividly demonstrate the case scenarios and the resolution techniques, several companion educational videos were also produced (see Section 4.2.3). Finally, the Casebook contained some background articles that probed into the issues of clinical ethics from a more academic perspective, which may be of particular interest to more sophisticated readers.

The Casebook has been being updated on a continual and regular basis. More specifically, one to two new cases together with the expert commentaries have been annually uploaded to the IoA website. During the period concerned, two editions of the Casebook comprising 4,000 printed copies were issued, among which 3,512 of them have been distributed to doctors and nurses from NTEC hospitals, the CUHK Centre for Bioethics, the JCSPHPC, and several other CUHK departments, as well as various RCHEs, NGOs, and HA committees. In addition, the online version of the Casebook has accumulated a total of 1,346 page views.

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[41] Each printed copy of the Resources Kit was accompanied by some interesting gadgets aiming to raise public awareness towards EoL care in a more casual and lively manner.

Figure 4.3 Casebook on Ethical Decision-Making in End-of-Life Care of Older Adults.

4.1.4 Advance Care Planning Handbook

The ACP Handbook was designed as a well-illustrated, easy-to-follow manual that can reassuringly guide the public, especially elderly people, to record their thoughts, values, and EoL preferences. Once an individual has completed this documentation process, the ACP Handbook can also serve as a valuable reference that ultimately enables the family members and healthcare professionals to deliver value-aligned and goal-concordant care.

During the period concerned, three different editions of the ACP Handbook comprising 3,300 printed copies were issued, among which 2,986 of them have been disseminated among participants of the public education programme, as well as various RCHEs, NGOs, PRCs, and higher education institutions.

Figure 4.4 Advance Care Planning Handbook.

4.1.5 Good Death Booklet[42]

The Good Death Booklet resembled a more detailed and extended version of the ACP Handbook—it was also intended to navigate the readers through the entire EoL planning and documentation process, yet in a more elaborate and informational manner. For instance, the Good Death Booklet contained a comprehensive list of suggested wordings and dialogs that the readers can use to initiate EoL conversations with their family members and healthcare professionals. In another instance, the Good Death Booklet included the sample ACP, AD, and EPA forms in its appendix, which may help the readers build a more concrete understanding of what these official documentations look like in actual practice.

During the period concerned, a total of 1,000 printed copies of the Good Death Booklet were issued, among which 726 of them were distributed to various RCHEs, NGOs, and PRCs, as well as a number of interested individuals from the general public.

4.2 Videos

Under the current programme, a total of seven videos with differing content, objectives, and target audiences have been produced and released. Broadly, these videos can be grouped into the following categories: (1) micro-movie that aimed to deliver the intended messages in a less formal and more entertaining manner, (2) educational video that aimed to provide information, impart knowledge, and expound on the technical details, (3) Casebook companion video that aimed to illustrate the ethical dilemma scenarios and resolution techniques described in the Casebook, and (4) celebrity interview that primarily aimed to arouse interest from the public. A complete list of these videos together with their corresponding YouTube links is given in Table 4.2.

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[42] The Chinese title of the Good Death Booklet is "吾 · 該好死".

Table 4.2 A complete list of newly produced videos.

Category	Title	QR Code
Micro-movie	Plan Well, Leave Well	
	Patients' Perspectives on End-of-Life Care	
Educational video	Breaking Bad News to Patients' Family Members	
	End-of-Life Care: Advance Care Planning	
Casebook companion video	Feeding Tube Decision in a Dying Demented Patient	
	Disagreements over Timing for Advance Care Planning	
Celebrity interview	Plan Well, Leave Well: Interview with Chow Chung	

4.2.1 Micro-movies

4.2.1.1 Plan Well, Leave Well

This 9-minute micro-movie was a major component in the multimedia campaign of the Dying Matters Awareness Event (see Section 3.2.1.1.2). Featuring several well-known television actors including Mr. Chung Chow, Ms. Samantha Chuk, and Ms. Sze Yan Cheung, the video stressed the importance and necessity of early EoL planning and communication. Through the active promotion on various social media platforms, the video has accumulated a total of 27,080 YouTube views during the period concerned.

Figure 4.5 Plan Well, Leave Well.

4.2.1.2 Patients' Perspectives on End-of-Life Care

This 17-minute micro-movie depicted the real case of an EoL patient who, suffering from COPD, had unfortunately not been given the chance to reveal his inclination to refuse receiving bi-level positive airway pressure (BiPAP) treatment and cardiopulmonary resuscitation (CPR). Aiming to highlight the importance of being clear, patient, and empathetic in an EoL conversation, the video was intended for healthcare professionals and was primarily broadcast during the training sessions in the capacity building programme.

Figure 4.6 Patients' Perspectives on End-of-Life Care.

4.2.2 Educational videos

4.2.2.1 Breaking Bad News to Patients' Family Members

Using the case of the COPD patient from the second micro-movie (i.e., Section 4.2.1.2) as an illustrative example, this 12-minute educational video demonstrated how to use the SPIKES statements to break bad news to the family members. The video was intended for healthcare professionals and served primarily as a supplementary material for the training sessions on EoL communication skills.

Figure 4.7 Breaking Bad News to Patients' Family Members.

4.2.2.2 End-of-Life Care: Advance Care Planning

This 16-minute educational video introduced the concepts, major components, and importance of ACP to both the public and healthcare professionals. The benefits and necessity of ACP were emphasized from the perspectives of each party, respectively, and the typical procedures of conducting an ACP were demonstrated with the aid of animations. The video was broadcast during multiple programme activities and has also accumulated a total of 554 views on YouTube.

Figure 4.8 End-of-Life Care: Advance Care Planning.

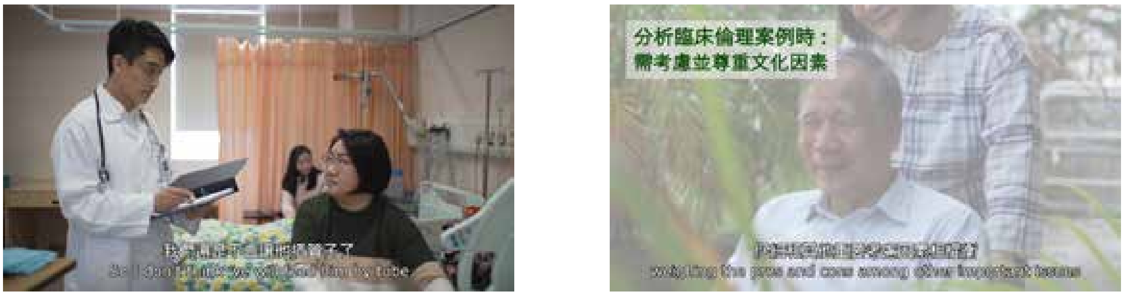
4.2.3 Casebook companion videos

Two Casebook companion videos were produced to vividly illustrate two of the scenarios documented in the Casebook, as well as to elucidate the corresponding expert commentaries (see Section 4.1.3), the aim of which was to enable the audiences to generate a clearer picture of the ethical dilemmas that may arise in the context of EoL care, and to have a better grasp of the resolution techniques. Due to the specific nature of their content, these videos were mostly shown during the training on clinical ethics, as well as the third session of the communication skills series for nurses (see Section 3.1.2.2).

4.2.3.1 Feeding Tube Decision in a Dying Demented Patient

Based on the second case of the Casebook, this 12-minute video was aimed at probing into the various ethical factors that healthcare professionals should take into considerations when determining whether it is appropriate to perform CPR and feeding tube treatment on EoL patients.

Figure 4.9 Feeding Tube Decision in a Dying Demented Patient.



分析臨床倫理案例時：
需考慮並尊重文化因素

4.2.3.2 Disagreements over Timing for Advance Care Planning

Based on the fifth case of the Casebook, this 11-minute video was aimed at discussing the issue of moral distress that may arise when healthcare professionals have disagreements over the treatment timing and approaches that are optimal for the EoL patients.

Figure 4.10 Disagreements over Timing for Advance Care Planning.

個案中護士因照顧晚期病人而產生的「道德困擾」，
我們可以思考：
1. 怎麼知道護士的建議對病人是否最適切？

4.2.4 Celebrity interviews

4.2.4.1 Plan Well, Leave Well: Interview with Chow Chung

This 6-minute interview with Mr. Chung Chow was intended to serve as a follow-up video to the "Plan Well, Leave Well" micro-movie (see Section 4.2.1.1). During the interview, Mr. Chow shared his thoughts on various life-and-death issues, and showed the importance of early EoL planning and conversations. Gaining over 245,000 YouTube views in just a short period of time, the interview gained widespread popularity and attracted the attention and coverage from a number of mainstream media in Hong Kong including, for instance, Sing Tao Daily, Headline Daily, and Sky Post.

Figure 4.11 Plan Well, Leave Well: Interview with Chow Chung.

4.2.4.2 Death Journey: Experiential interview with C AllStar[43]

Besides the seven videos listed above that had already been finalized and published, an experiential interview with C AllStar has also finished filming and is currently in the post-production stage. In this 15-minute interview, one of the C AllStar members experienced a simulated death journey as he, accompanied and assisted by another group member during the process, took a funerary portrait photo, wrote his last words, wore the shroud, and finally lay inside a coffin to mimic the conditions of a burial ceremony. After the simulated death journey, the two C AllStar members shared their reflections on this experience, as well as their opinions on EoL planning and the use of LSTs.

Figure 4.12 Death Journey: Experiential interview with C AllStar.

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[43] C AllStar is a well-known local male singing group formed by four members, two of whom were involved in the filming of the experiential interview.

Chapter 5 Research Activities[44]

5.1 Overview

In addition to the primary components of the programme that were aimed at raising the capacity of healthcare professionals and educating the public, various research projects have also been conducted to enquire into several key topics in EoL care, with the purpose of stimulating reflections and fostering knowledge in this regard.

More specifically, as an extension to Section 1.4, two qualitative exploratory studies were conducted to examine the service gaps in EoL care (Study 1 [Section 5.2]; Chan, Lee, & Woo, 2020) and barriers to implementing ACP (Study 2 [Section 5.3]; Cheung et al., 2020), respectively, from the perspectives of different stakeholders.

Furthermore, it is conceivable that the problem of health inequalities may also arise in the context of EoL care, thereby further worsening the QoL of underprivileged patients. In view of this, a retrospective database study was conducted to explore whether socioeconomic gradients have imposed an additional burden on the already vulnerable EoL care service sector (Study 3 [Section 5.4]; Chung et al., 2021).

5.2 Service Gaps in End-of-Life Care

5.2.1 Background

As depicted in Section 1.4, the quality of EoL care services in Hong Kong remains suboptimal despite considerable efforts and endeavors. In view of this, the aim of this study was to identify barriers and challenges that hindered the development of EoL care in Hong Kong, and ultimately to lead the way towards a complete overhaul of existing policies and practices.

5.2.2 Methods

5.2.2.1 Design

The study adopted a qualitative exploratory approach in which face-to-face semi-structured interviews were conducted.

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[44] This chapter is intended to provide a brief and integrated summary of a number of academic studies conducted under the programme, but is not meant to cover all aspects of these studies in full detail.

5.2.2.2 Sample

Following a purposeful snowball sampling scheme that aimed to ensure a sufficient sample heterogeneity, a total of 131 participants were recruited and interviewed in the study. The demographic characteristics of the participants are shown in Table 5.1.

5.2.2.3 Procedures

Each interview was conducted by the principal investigator or a trained research assistant, either on an individual basis for approximately 60 minutes, or on a group basis for approximately 120 minutes. All participants completed a written consent form beforehand.

5.2.2.4 Data analyses

All interviews were audio-recorded and transcribed verbatim, from which thematic analysis was performed to identify and extract key messages (i.e., factors obstructing the development of EoL care in Hong Kong). Subsequently, these messages were categorized and presented in accordance with the PESTEL framework[45] (Cox & Rawlinson, 2008).

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[45] P: Political; E: Economic; S: Socio-Cultural; T: Technological; E: Environmental; L: Legal.

Table 5.1 Demographic characteristics of the participants in Study 1 (N = 131).

Variable	Category	*N* (%)
Identity	Patient	25 (19.1)
	Family member	15 (11.5)
	Doctor	15 (11.5)
	Nurse	16 (12.2)
	Social worker	7 (5.3)
	Physiotherapist	7 (5.3)
	Speech therapist	3 (2.3)
	Clinical psychologist	2 (1.5)
	Frontline care staff	15 (11.5)
	Chaplain	3 (2.3)
	Administrator	15 (11.5)
	Others (e.g., researchers and lawyers)	8 (6.1)
Sex	Male	54 (41.2)
	Female	77 (58.8)
Age	< 30	11 (8.4)
	31–40	29 (22.1)
	41–50	26 (19.8)
	51–60	40 (30.5)
	> 60	25 (19.1)
Education	Primary or below	11 (8.4)
	Secondary	23 (17.6)
	Tertiary	97 (74.0)

Note. Adapted from "Diagnosing gaps in the development of palliative and End-of-Life care: A qualitative exploratory study", by Chan, H. Y. L., Lee, D. T. F., & Woo, J., 2020, *International Journal of Environmental Research and Public Health*, *17*(151).

5.2.3 Results

5.2.3.1 Political

Participants generally considered that a policy framework for directing EoL service development was lacking. Low priority was given to EoL care in the policy agenda owing to the presence of other more pressing social and economic issues, for instance housing and education.

5.2.3.2 Economic

Participants noted that the amount of government funding for EoL care was negligible compared to that invested in inpatient and acute care. Consequently, initiatives in this regard were mainly supported by philanthropic bodies in a one-off manner, which unavoidably resulted in staff instability and service unsustainability.[46]

5.2.3.3 Socio-Cultural

Participants pointed out that the concept of death remained a cultural taboo in the community, thereby creating an unfavorable environment for healthcare professionals to promote EoL care and discuss the related issues with patients and their family members. For instance, many patients simply relied on doctors for making treatment decisions and did not bother to make their EoL preferences known to their family members and other healthcare professionals.

5.2.3.4 Technological

Participants perceived that EoL care attracted much less attention from healthcare professionals, academics, and medical industries, than, say, the biomedical sciences, which aim at curing diseases and lowering mortality rate. Consequently, empirical research on EoL care was lacking due to insufficient funding and hindrances caused by ethical concerns. Healthcare professionals, especially those who need to handle patients in life-limiting conditions, did not receive sufficient training in EoL care and, worryingly, might only have a minimal level of knowledge and awareness in this regard.

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[46] This is precisely the reason behind why the present initiative has attached great importance to its capacity-building nature and long-term sustainability.

5.2.3.5 Environmental

Participants mentioned that the environment in public hospitals was generally cramped, implying that it was difficult to carry out EoL care in a humane and calm manner. Unfortunately, patients might not have other better alternatives, especially since administrative problems and liability issues might arise when they requested to be discharged from public hospitals.

5.2.3.6 Legal

Participants argued that the legislative route of AD might not necessarily be conducive to promoting public awareness and increasing its completion rate, although most of them were supportive of such legislation. In addition, some participants raised various legal concerns regarding the Powers of Attorney Ordinance (DoJ, 2018) and the Coroners Ordinance (DoJ, 2019a), which they considered to be a source of confusion and a major hindrance to their daily practice of EoL care.

5.2.4 Conclusions

Consistent with Section 1.4, the findings of this study revealed a number of factors that have prohibited the development of EoL care in Hong Kong. These factors are intertwined with a range of economic, technological, environmental, and legal issues, which makes the problem inherently complicated to tackle. In view of this, mere governmental policies and separate efforts from the professional bodies are insufficient for completely reforming the entire EoL care sector. Instead, cross-sector collaboration advocating the development of EoL care under a public health approach is necessary for ensuring a consistent and equitable access to high-quality EoL care services in the long run.

5.3 Barriers to Advance Care Planning

5.3.1 Background

ACP is an important process for facilitating the identification and documentation of treatment preferences for the patients. However, it remains poorly recognized by the public, foremost among which are EoL patients and their family members who are in most need of such a communication process. In view of this, the aim of this study was to further explore, from the perspectives of these parties, the barriers to initiating ACP.

5.3.2 Methods

5.3.2.1 Design

The study adopted a qualitative exploratory approach, in which semi-structured focus groups and individual interviews were conducted to explore the personal experiences and attitudes of the participants with respect to ACP interventions.

5.3.2.2 Sample

Following a purposive sampling scheme that aimed to ensure content saturation, a total of 17 patients and 13 family members who had never initiated or participated in an ACP process were recruited from a palliative day care center through referrals. The demographic characteristics of the participants are shown in Table 5.2.

Table 5.2 Demographic characteristics of the participants in Study 2 (*N* = 30).

Variable	Category	*N* (%)
Identity	Patient	17 (56.7)
	Family member	13 (43.3)
Sex	Male	14 (46.7)
	Female	15 (50.0)
Age	< 60	4 (13.3)
	60–69	11 (36.7)
	70–79	11 (36.7)
	>= 80	3 (10.0)
Marital status	Single	4 (1.3 3)
	Married	19 (63.3)
	Divorced	1 (3.3)
	Widowed	3 (10.0)
Religion	Protestantism	6 (20.0)
	Taoism	4 (13.3)
	Buddhism	4 (13.3)
	Catholicism	1 (3.3)
	No religious belief	12 (40.0)

Note. Figures may not add up to the total due to missing data. Adapted from "Barriers to advance care planning: A qualitative study of seriously ill Chinese patients and their families", by Cheung, J. T. K., Au, D., Ip, A. H. F., Chan, J., Ng, K., Cheung, L., ... & Woo, J., 2020, *BMC Palliative Care*, *19*(80).

5.3.2.3 Procedures

Focus group discussions and individual interviews, which lasted for approximately 60 and 25 minutes respectively, were conducted by two moderators using a semi-structured interview guide. All participants completed a written consent form before the interview.

5.3.2.4 Data analyses

All interviews were audio-taped and transcribed verbatim by a nursing student. Qualitative content analysis was performed to extract all manifest and latent information from the transcription and convert them into meaningful units, which were then gradually categorized into several major themes through a stepwise replication process.

5.3.3 Results

Four major barriers to initiating ACP were identified and are summarized below.

5.3.3.1 Limited participation of patients

Patients tended to participate only to a limited extent in their EoL decision-making process. Instead of identifying and indicating their own preferences, patients usually relied on their surrogates (i.e., their family members and doctors) to make the decisions for them. Although some patients ascribed this behavior to trust and faith, many others did so simply because they wanted to avoid any interpersonal conflicts, or because they considered themselves incompetent in understanding the medical details of different treatment options. In addition, family members also tended to be reluctant in disclosing medical information to the patients, thereby further undermining their participations in this regard.

5.3.3.2 Cognitive and emotional barriers encountered by patients

Many patients believed in the predetermination of life and accepted the inevitability of death. As a result, some of them prioritized happiness and positivity during the EoL stages and refused to discuss EoL issues in order to maintain "peace of mind", whereas others had a more pessimistic attitude and believed that ACP was in any cases meaningless and unnecessary. On the other hand, as elderly patients typically had a minimal education background and poor communication skills, they often had difficulties expressing their inner feelings and thus were reticent about EoL issues.

5.3.3.3 Lack of readiness and awareness among patients and their family members

Patients and their family members may need a considerable amount of time to understand, digest, and accept the unfortunate reality after receiving this particularly type of bad news. Therefore, they might not be ready and able to engage in ACP discussions immediately afterwards. Furthermore, some had not even been aware of the advantages and necessity of early EoL planning and communication. Altogether, these factors contributed to creating substantial delays and missed opportunities in initiating the ACP process.

5.3.3.4 Unpreparedness and incompetence of healthcare professionals

Patients and their family members generally agreed that, from the service users' point of view, healthcare professionals were reluctant and unable to address their medical and emotional needs. More elaborately, perhaps owing to the lack of time, empathy, and communication skills, some healthcare professionals were unable to provide clear and concise information about the diagnosis, prognosis, and treatment options available to the patients and their family members, let alone help them alleviate the psychological distress. Consequently, it was difficult for these three parties to develop a long-term, mutually trusting relationship and engage in a continual communication process.

5.3.4 Conclusions

This study provided further insights into the barriers to initiating and engaging in ACP, specifically from the perspective of the EoL care service users. Notably, these prohibitive factors indicate agreement with those indicated in Section 1.4, showing that these obstacles are not unique to ACP implementation, but part of a much bigger problem prevailing in our cultural environment and healthcare system that affects the entire EoL care service sector.

5.4 Impact of Socioeconomic Status on End-of-Life Care

5.4.1 Background

Inequality of access to EoL care services is a crucial yet often underappreciated aspect in health equity research. In some sense, the presence of health inequity in EoL care is inevitable since more well-off individuals can always opt for the higher-quality services provided by the private sector. Nonetheless, the more important question to ask is whether the public healthcare system, which is already overburdened, can still provide basic EoL care services to the remaining population (i.e., the less well-off individuals) in an equitable manner. In view of the above, the aim of this study was to investigate the existence of socioeconomic gradients in the access to public EoL care services in Hong Kong.

5.4.2 Methods

5.4.2.1 Design

A retrospective cohort design was adopted in the study. Data of hospital admissions and Accident & Emergency (A&E) visits from 2004 to 2014 for patients who were Hong Kong residents aged 45 or above at the time of consultation were retrieved and analyzed. The Comprehensive Social Security Assistance (CSSA) status and RCHE residency[47] were treated as indicator variables for proxying the socioeconomic positions of the patients.

5.4.2.2 Sample

The raw datasets of hospital admissions and A&E visits contained 10,014,999 and 10,990,081 records of 1,754,647 and 2,338,555 patients, respectively. Of these records, the study only focused on a particular subset that satisfied the following criteria:

- the discharge status of the last record of the patient was "deceased"[48]
- the record was logged during the last year of life of the patient

After preprocessing the data and screening out some erroneous entries, a total of 1,878,982 records of 375,506 patients, and 1,237,044 records of 357,853 patients, were extracted from the hospital admission and A&E visit data. The sample characteristics of these cleaned datasets are shown, respectively, in Table 5.3 and Table 5.4.

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[47] RCHE residency was available only for the hospital admission data, but not the A&E visit data.

[48] In other words, only patients who died during the period concerned (i.e., from 2004 to 2014) were included.

Table 5.3 Sample characteristics of the hospital admission data in Study 3 (N = 375,506).

Variable	Category	*N* (%)
Age of death	40–49	8,191 (2.2)
	50–59	30,681 (8.2)
	60–69	45,942 (12.2)
	70–79	98,661 (26.3)
	>= 80	192,031 (51.1)
Sex	Male	206,914 (55.1)
	Female	168,590 (44.9)
CSSA recipient	No	246,192 (65.6)
	Yes	129,314 (34.4)
RCHE resident	No	269,288 (71.7)
	Yes	106,218 (28.3)

Note. Adapted from "Health inequalities in access to end-of-life care: An examination of 395,019 patients using public hospital records over a ten-year period", by Chung, R. Y. N., Lai, D. C. K., Hui, A. Y. K., Chau, P., Wong, E., Yeoh, E. K., … & Woo, J. W., 2021. *BMJ Supportive & Palliative Care*.

Table 5.4 Sample characteristics of the A&E visit data in Study 3 (N = 357,853).

Variable	Category	*N* (%)
Age of death	40–49	7,957 (2.2)
	50–59	29,598 (8.3)
	60–69	43,067 (12.0)
	70–79	92,228 (25.8)
	>= 80	185,003 (51.7)
Sex	Male	197,569 (55.2)
	Female	160,284 (44.8)
CSSA recipient	No	238,158 (66.6)
	Yes	119,695 (33.4)

Note. Adapted from "Health inequalities in access to end-of-life care: An examination of 395,019 patients using public hospital records over a ten-year period", by Chung, R. Y. N., Lai, D. C. K., Hui, A. Y. K., Chau, P., Wong, E., Yeoh, E. K., … & Woo, J. W., 2021. *BMJ Supportive & Palliative Care*.

5.4.2.3 Procedures

Requests were made to the HA for obtaining authorized access to the datasets. The database was queried and analysis was performed using the R software (R Core Team, 2019), via an encrypted computer located in the JCSPHPC.

5.4.2.4 Data analyses

For both datasets, the frequency of EoL hospital utilization[49] was plotted against the time-until-death variable for each socioeconomic category to investigate the potential existence of differential patterns. Generalized linear models[50] were also used to examine, after controlling for other demographic covariates, the associations between socioeconomic variables, and frequency and duration of EoL hospital utilization.[51]

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[49] Frequency of EoL hospital utilization was operationalized as the total number of records identified in the datasets.

[50] More specifically, negative binomial regression with the log link function was used to model the overdispersed count data.

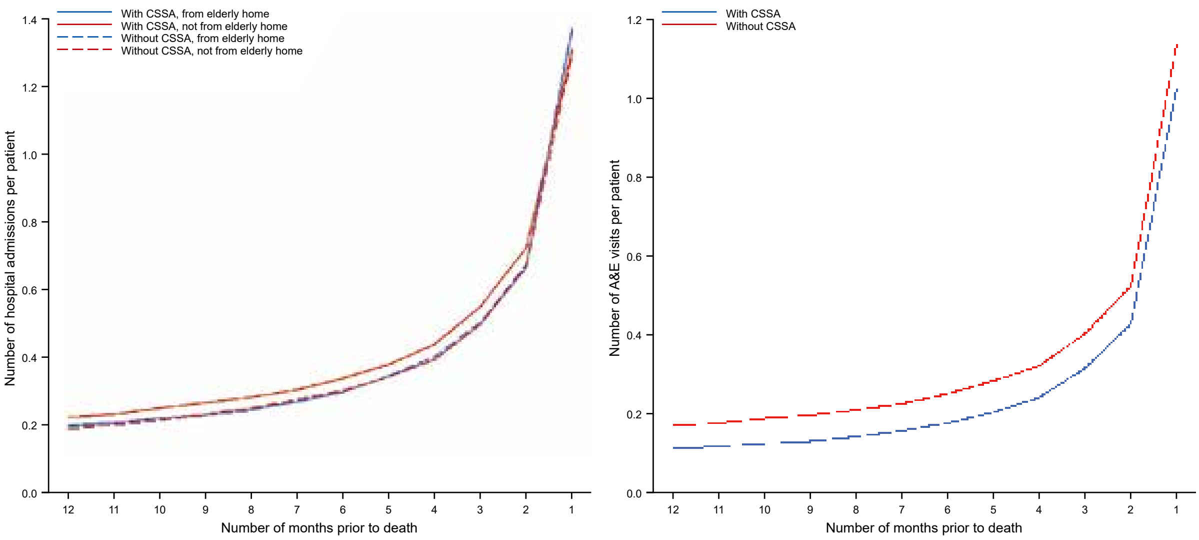
[51] Duration of EoL hospital utilization was operationalized as the total length of stay (in days), which was only applicable for the hospital admission data.

5.4.3 Results

5.4.3.1 Trajectory of End-of-Life hospital utilization

The plots of frequency of EoL hospital utilization against time-until-death are respectively shown in Figure 5.1, from which can be seen that the patterns of hospital utilization during the last year of life are comparable across all socioeconomic categories. In any case, the frequency of hospital utilization first exhibited a steady growth over the last 12 to 2 months, which was then followed by an abrupt increase during the last month before death.

Figure 5.1 Frequency of EoL hospital utilization against time-until-death.



Note. Adapted from "Health inequalities in access to end-of-life care: An examination of 395,019 patients using public hospital records over a ten-year period", by Chung, R. Y. N., Lai, D. C. K., Hui, A. Y. K., Chau, P., Wong, E., Yeoh, E. K., … & Woo, J. W., 2021. *BMJ Supportive & Palliative Care*.

5.4.3.2 Generalized linear models on End-of-Life hospital utilization

5.4.3.2.1 Hospital admission data

Table 5.5 and Table 5.6, respectively, summarize the results of the generalized linear models on frequency and duration of EoL hospital utilization for the hospital admission data. After controlling for other demographic covariates, all analyses yielded similar results regarding the interaction effect of CSSA status and RCHE residency. In brief, while each of these socioeconomic variables was a positive predictor of EoL hospital utilization per se, being both a CSSA recipient and an RCHE resident did not amount to an even higher utilization rate.

Table 5.5 Negative-binomial regression analysis on the total number of hospital admissions during the last year of life (*N* = 375,506).

Independent variables	**aIRR**	**95% CI**	***p***
Age of death, years	0.985	0.985, 0.985	< .001
Sex			
Male (reference group)	1		
Female	0.986	0.980, 0.991	< .001
CSSA recipient			
No (reference group)	1		
Yes	1.100	1.091, 1.109	< .001
Elderly home resident			
No (reference group)	1		
Yes	1.197	1.185, 1.209	< .001
CSSA x Elderly home	0.928	0.915, 0.940	< .001

Note. aIRR: adjusted incidence rate ratio; CI: confidence interval. For brevity, not all statistics related to the demographic covariates are reported. Adapted from "Health inequalities in access to end-of-life care: An examination of 395,019 patients using public hospital records over a ten-year period", by Chung, R. Y. N., Lai, D. C. K., Hui, A. Y. K., Chau, P., Wong, E., Yeoh, E. K., … & Woo, J. W., 2021. *BMJ Supportive & Palliative Care*.

Table 5.6 Negative-binomial regression analysis on the total length of stay (in days) during the last year of life (*N* = 375,506).

Independent variables	aIRR	95% CI	*p*
Age of death, years	0.994	0.994, 0.994	< .001
Sex			
Male (reference group)	1		
Female	0.991	0.985, 0.998	.009
CSSA recipient			
No (reference group)	1		
Yes	1.167	1.156, 1.178	< .001
Elderly home resident			
No (reference group)	1		
Yes	1.230	1.216, 1.245	< .001
CSSA x Elderly home	0.806	0.793, 0.819	< .001

Note. aIRR: adjusted incidence rate ratio; CI: confidence interval. For brevity, not all statistics related to the demographic covariates are reported. Adapted from "Health inequalities in access to end-of-life care: An examination of 395,019 patients using public hospital records over a ten-year period", by Chung, R. Y. N., Lai, D. C. K., Hui, A. Y. K., Chau, P., Wong, E., Yeoh, E. K., … & Woo, J. W., 2021. *BMJ Supportive & Palliative Care*.

5.4.3.2.2 Accident & Emergency visit data

Table 5.7 summarizes the results of the generalized linear model on frequency of EoL hospital utilization for the A&E visit data. After controlling for other demographic covariates, the analysis showed that CSSA recipients utilized the A&E services more frequently than non-recipients.

Table 5.7 Negative-binomial regression analysis on the total number of A&E visits during the last year of life (N = 357,853).

Independent variables	**aIRR**	**95% CI**	***p***
Age of death, years	1.002	1.002, 1.002	< .001
Sex			
Male (reference group)	1		
Female	0.959	0.954, 0.964	< .001
CSSA recipient			
No (reference group)	1		
Yes	1.280	1.274, 1.287	< .001

Note. aIRR: adjusted incidence rate ratio; CI: confidence interval. Adapted from "Health inequalities in access to end-of-life care: An examination of 395,019 patients using public hospital records over a ten-year period", by Chung, R. Y. N., Lai, D. C. K., Hui, A. Y. K., Chau, P., Wong, E., Yeoh, E. K., … & Woo, J. W., 2021. *BMJ Supportive & Palliative Care*.

5.4.4 Conclusions

Findings of this study did not provide any convincing and supportive evidence corroborating the claim that a poor socioeconomic position (mainly indicated by the CSSA status) directly constituted a barrier to accessing the public EoL care services. On the contrary, CSSA recipients in general had a higher hospital utilization rate during the last year of life, indicating that the public EoL care services were, at least in terms of quantity, pro-poor in nature.[52]

However, it remains premature to rule out the prospect of health inequalities in EoL care, even if the obvious discrepancy between public hospitals and the self-financed service providers is temporarily put aside. After all, it is reasonable to assert that a successful provision of EoL care should imply a reduction in unnecessary and avoidable hospitalization (see HA, 2017). In view of this, it is imperative for future studies to directly examine the impact of socioeconomic factors on the quality, rather than the quantity, of EoL care with which an individual is provided.

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[52] Admittedly, since the study did not adopt a rigorous experimental design, other interpretations of the results are also possible. For instance, it might be the case that patients with a lower socioeconomic status tended to have poorer health conditions, thereby necessitating additional hospital utilization.

Chapter 6 Conclusions

6.1 Significance of the Programme

6.1.1 Summary of local impact

Through its effective implementation, the programme has successfully attained all its intended objectives. To summarize its impact in the local context, the programme has offered over 300 activity sessions to more than 30,000 participants from both the public and the healthcare sector, issued and distributed roughly 15,000 copies of printed materials, published a collection of educational videos and micro-movies accumulating over 250,000 views on the mainstream social media platforms, and conducted a number of research projects leading to publication in several high-impact academic journals. All in all, by following the KAB framework, the programme has effectively imparted knowledge about EoL care and communication skills, induced attitudinal changes towards the importance of EoL planning and documentation, prompted reflections and conversations on EoL issues, and facilitated the implementation process of ACP interventions.

Besides these KAB domains, an equally important aspect that should be considered is the acceptability of the programme. Reassuringly, in addition to being highly regarded by the target beneficiaries, the programme has also received enthusiastic support from the HA management levels, health administrators, the SWD, as well as various partnering NGOs and academic institutions. Altogether, the programme has successfully established its popularity and reputation in the community, and has also built and consolidated a territory-wide collaborative network with different sectors of the society.

6.1.2 Global recognition

In addition to its substantial local impact, the programme has also expanded its external presence and influence into the wider Asia region. For instance, in recognition of its pioneering efforts and achievements in raising the capacity of healthcare professionals to deliver high-quality EoL care, the programme was selected as a finalist of the "Innovation of the Year: Caregiver Model" by the "Asia Pacific Eldercare Innovation Awards 2020", which, being a major event in the "Ageing Asia 2020: World Ageing Festival", has contacted over 5,000 international delegates from 35 countries. In another instance, several project team members were invited, as representatives of the programme, to take part in the "2019 Taipei

International Symposium on Palliative Care", during the course of which medical specialists and academic experts from around the globe gathered to conduct knowledge exchanges and experience sharing on the topic of compassionate EoL care. From the above, it is evident that the programme has gained a global reputation and was widely acknowledged by the other internationally renowned entities in the EoL care sector.

Figure 6.1 Finalist award of the "Innovation of the Year: Caregiver Model".

6.2 Future Directions

Based on the major success of the first two phases of the programme, as well as the invaluable experiences and wisdom accumulated over the period, it is foreseeable that a further extension of the programme would bring immense benefits to the popularization and development of EoL care in Hong Kong. In this regard, we will conclude the present report by remarking on several aspects towards which the future phases of the programme should direct its attention and efforts.

6.2.1 Extension of the geographical coverage

As mentioned in Section 2.2, the first two phases of the programme have predominantly focused on the NTEC for the purposes of piloting their effectiveness and acceptability. Despite its positive and successful outcome, the programme has yet to fully realize and harvest its benefits owing to its restricted geographical scope. Given that its service model, implementation strategies, and support network have become well-established, the programme is ready to be, and indeed should be extended to other regions in Hong Kong. In this regard, considering the already existing collaborative relationship between the project team and QMH (see Section 3.1.3.1), the HKEC and HKWC may serve as the key entry points for the future phases of the programme.

6.2.2 Automated approach for identifying patients in urgent need of End-of-Life care

Although it was argued in Section 1.2.2 that EoL care is relevant to patients at any stage of a serious illness, healthcare professionals do need to identify and pay special attention to those who are nearing the end of life, such that these patients can be provided with suitable EoL care and ACP interventions in a timely manner. While in theory healthcare professionals can use their extensive knowledge and experience to make clinical judgments, in reality the time-consuming and technically demanding nature of this approach may render it inappropriate to be incorporated into routine practice. Notably, a potential solution to this problem, namely the HARRPE[53] score system (Tsui, Au, Wong, Cheung, & Lam, 2015), has in fact existed for several years already. In rough terms, the HARRPE score was developed as an automatically generated statistical index, aiming to predict the risk of hospital readmissions among elderly patients. Remarkably, the index was also found to be able to aid clinical judgments in prognosticating the remaining life expectancy of the patients (Chan, Po, et al., 2019). In other words, the index can serve as a scientific, reliable, automated, and timesaving assessment tool for healthcare professionals, who seek to identify patients in urgent need of EoL care and ACP interventions. In view of the anticipated usefulness of the HARRPE score system, future phases of the programme can aim to expand the use of this index beyond its original intent and promulgate its applications in the EoL care setting.

6.2.3 Expansion of online training and education

A significant portion of the programme activities were switched to an online format due to the influence of the COVID-19 pandemic. Encouragingly, despite the lack of physical interaction, the online activities were still appreciated and valued by most participants. In fact, many doctor and nurse participants considered the online modality to be more convenient and flexible, as they were able to plan their study schedules to fit into their busy work environment, as well as learn and review the materials at their own pace, thereby ensuring comprehension and knowledge consolidation. As an additional benefit, it is relatively straightforward to apply for CME and CNE accreditation for these online training materials, which may offer the potential viewers an extra incentive to attend the training. Finally, it is evident that compared with the face-to-face format, online training can be provided more regularly and frequently, without being restricted by any geographical boundaries, thus

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[53] The acronym was derived from the Hospital Admission Risk Reduction Program for Elderly.

having the ability to reach a wider range of target beneficiaries, over a shorter period of time. In view of the above, future phases of the programme can aim to, where appropriate,[54] further promote and normalize the provision of online training and education,[55] even when the impact of the COVID-19 pandemic fades.

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[54] Undoubtedly, the training on certain topics, particularly those related to EoL communication skills, do necessitate a face-to-face format in order to fully maximize its benefits.

[55] For instance, stimulating questions and structured quizzes can be incorporated into the online videos to reinforce understanding and prompt reflections from the participants.

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- Prof. SO Man Kit Albert, practising solicitor
- Ms. TAM Sau Han Maia, registered horticultural therapist, Hong Kong Association of Therapeutic Horticulture
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賽馬會安寧頌

JCECC

Jockey Club **End-of-Life Community Care** Project

The Chinese University of Hong Kong
Jockey Club Institute of Ageing

🏠 Suite 908, 9/F, Yasumoto International Academic Park,
The Chinese University of Hong Kong,
Shatin, New Territories, Hong Kong
☎ (852) 3943 3143
✉ ioa@cuhk.edu.hk
🌐 http://www.ioa.cuhk.edu.hk

9 789887 458920