Aligning Efforts and Bridging Gaps:

Building Capacity for End-of-Life Care in Hong Kong

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

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Foreword

Ms. Imelda Chan, Head of Charities (Health & Older Adults Cluster), The Hong Kong Jockey Club

Patients with advanced and incurable illnesses have been turning increasingly to palliative and end-of-life care. However, the present provision of relevant support is insufficient to meet this rising demand for services.

The Hong Kong Jockey Club Charities Trust has long supported palliative and end-of-life care, funding programmes for hardware facilities and other services. In 2016, the Trust initiated and funded the Jockey Club End-of-Life Community Care Project (JCECC) – Hong Kong's first large-scale community end-of-life support scheme – with an approved donation of about HK$623 million. It aims to improve the quality of end-of-life care, enhance the capacity of service providers and raise awareness of the importance of this issue. To date, JCECC has served more than 23,700 terminally ill elderly patients and their families and provided systematic training to more than 61,000 health and social care workers. It has improved quality of life for patients and their families significantly and also helped to increase capacity in the field, creating a more robust and sustainable ecosystem.

Last year, the Government passed legislative proposals on Advance Medical Directives and Dying in Place, establishing a framework to honour patients' decisions and enhance quality of life during their final days. With such policy measures in place, demand for palliative and end-of-life care is expected to increase comprehensively along with public awareness of this issue. The Trust will continue to work closely with the Government and relevant stakeholders to develop such services in Hong Kong.

The Trust would like to take this opportunity to congratulate the CUHK Jockey Club Institute of Ageing for its efforts in strengthening field capacity for end-of-life care and building a more compassionate community.

Preface

Prof. Jean Woo, Director, CUHK Jockey Club Institute of Ageing

Hong Kong's population is ageing rapidly. While life expectancy has increased substantially due to medical advances, patients reaching the end-of-life may face prolonged and unnecessary suffering, if not provided with the appropriate care that aligns with their preferences. The importance of end-of-life care had been underappreciated in our society until recent years, with impact on the quality and provision of end-of-life care services.

To address these issues, 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 implemented three phases of Capacity Building and Education Programmes on End-of-Life Care, in collaboration with the Hospital Authority and various non-governmental organizations to deliver training and educational activities, with the aim of disseminating knowledge and raising awareness on end-of-life care among healthcare professionals, patients with limited life expectancies, and the general public.

After nearly ten years, there is a marked change in terms of the public sentiment and perception about end-of-life care, with much discussion about advance care planning and documentation of wishes regarding end-of-life care management, from the patients' perspective. This report documents what has been done and what remains to be done. It is particularly relevant in the light of the recent legislation on Advance Medical Directive, which has since then aroused attention and some uncertainty in implementation. For example, there have been comments that there is still avoidance of discussions relating to dying and the dying process, such that our community may not yet be prepared for the enactment of this legislation. As a result, there are some observations from policymakers that more effort should be placed on education and promoting public acceptance. This report shows that currently, there is general acceptance of advance care planning in preparation for the last stage in life among the general public, as a result of public education initiatives supported by the JCECC project. However, barriers exist with respect to communication with relevant healthcare professionals as well as timely documentation, suggesting that more needs to be done in terms of communication between patients and health and social care professionals, as well as documentation of the patients' wishes. It is still uncertain in the current healthcare system when and what is the optimal setting and with whom patients and their families will be holding such discussions. Hopefully this summary report may serve as a valuable reference to guide future policy directions.

Last but not least, I would like to take this opportunity to, on behalf of the CUHK Jockey Club Institute of Ageing, express our sincere gratitude to The Hong Kong Jockey Club Charities Trust. Without its unwavering support throughout the ten-year period, it would not have been possible for us to achieve such fruitful results. Building on these experiences and lessons learnt, we will continue to strive for the betterment of end-of-life care in Hong Kong.

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

Hong Kong is facing a rapidly ageing population, with the number of elderly suffering from terminal illnesses increasing correspondingly. In view of the growing demand for end-of-life care services in the community, The Hong Kong Jockey Club Charities Trust has approved approximately HK$623 million to initiate and fund the "Jockey Club End-of-Life Community Care Project" (JCECC). Launched in 2016, the project aims to improve the quality of end-of-life care, enhance the capacity of service providers, as well as raise public awareness.

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

The Trust's partners in JCECC are The University of Hong Kong Faculty of Social Sciences, The Chinese University of Hong Kong Jockey Club Institute of Ageing, Hong Kong Association of Gerontology, Haven of Hope Christian Service, The Hong Kong Society for Rehabilitation, St James' Settlement, S.K.H. Holy Carpenter Church District Elderly Community Centre, Tung Wah Group of Hospitals, Hong Kong Sheng Kung Hui Welfare Council Limited and The Salvation Army. For details, please visit http://www.JCECC.hk/

List of Abbreviations

- ACP: Advance Care Planning
- AMD: Advance Medical Directive
- A&E: Accident and Emergency
- BiPAP: bi-level positive airway pressure
- CBioE: Centre for Bioethics
- CCTP: Central Commissioned Training Programme
- CGAT: Community Geriatric Assessment Team
- CHP: Centre for Health Protection
- CME: Continuing Medical Education
- CMS: Clinical Management System
- CNE: Continuing Nursing Education
- COPD: chronic obstructive pulmonary disease
- CPR: cardiopulmonary resuscitation
- CQI: Continuous Quality Improvement
- CSSA: Comprehensive Social Security Assistance
- C&SD: Census and Statistics Department
- DNACPR: do-not-attempt cardiopulmonary resuscitation
- EOL: end-of-life
- EPA: enduring power of attorney
- FHB: Food and Health Bureau
- GovHK: The Government of the Hong Kong Special Administrative Region
- HA: Hospital Authority
- HARRPE: Hospital Admission Risk Reduction Program for Elderly
- HKDU: Hong Kong Doctors Union
- HKEC: Hong Kong East Cluster
- HKeL: Hong Kong e-Legislation
- HKWC: Hong Kong West Cluster
- HRC: Health Resources Centre
- IOA: Institute of Ageing

- JCECC: Jockey Club End-of-Life Community Care Project
- JCHH: Jockey Club Home for Hospice
- KAB: knowledge-attitude-behavioral
- LST: life-sustaining treatment
- MSW: medical social worker
- NAWA: Network of Ageing Well for All
- NGO: non-governmental organization
- NTEC: New Territories East Cluster
- NURSE: naming, understanding, respecting, supporting, exploring
- PDSA: plan-do-study-act
- SBAR: situation, background, assessment, recommendation
- SC-DWS: Self-Competence in Death Work Scale
- SICG: Serious Illness Conversation Guide
- SPHC: Society for the Promotion of Hospice Care
- SPIKES: setting, perception, invitation, knowledge, empathy, summary
- SWD: Social Welfare Department
- WHO: World Health Organization

Introduction

1.1 Background

Populations around the globe are ageing, and Hong Kong is experiencing this phenomenon at a particularly fast and noticeable rate. The proportion of people in Hong Kong aged 65 or above was about 21% in 2022 (Census and Statistics Department [C&SD], 2023a) and is projected to exceed 36% by 2046 (C&SD, 2023b). Crucially, this ageing trend is accompanied by a rapidly increasing life expectancy, which was only 67.8 years for males and 75.3 years for females back in 1971, but which has skyrocketed to 82.5 and 87.9 years, respectively, in 2023 (Centre for Health Protection [CHP], 2024). While longevity is commonly considered a type of blessing, especially since it is one of the much desired “five good fortunes” (五福) in the traditional Chinese culture, we have come to the realization that if not handled properly, a merely prolonged lifespan may only lead to suffering and dampened quality of life. In fact, albeit unbeknownst to many of us, the last component of the “five good fortunes” is “good death” (善終), which hints that we should pay equal emphasis on our quality of life, both during the ordinary lifetime and while nearing the end. To ensure that everyone can have a good death, it is essential for the Hong Kong society, including government agencies, stakeholders, and relevant parties from the community, to undertake collective efforts to address the complex issues related to dying and death. In particular, the subject that the present initiative will focus and work on is end-of-life (EOL) care.

1.2 Overview of end-of-life care

1.2.1 Definitions

Researchers from different academic disciplines and healthcare practitioners from different sectors have used a range of terminologies to refer to the type of care services provided to patients with serious illness, especially those with terminal conditions. In Hong Kong, for instance, the term palliative care was used when hospitals began to provide this sort of services in the 1980s, and had continued to be the predominant term for many years. Later, organizations and institutions that aimed at providing hospice care started to come into sight, and even more recently, the term

EOL care has gained more usage and popularity, especially among government bodies, academia, and the social welfare sector. Although loosely speaking, these terms can be considered synonyms sharing the same spirit of prioritizing the comfort and well-being of patients over the mere extension of life, they still convey slightly different meanings and viewpoints, especially when used in different contexts. To put it roughly, when viewed as a medical specialty, palliative care primarily focuses on pain relief and symptom management, which is intended for patients at any stage of a serious, life-limiting illness. When viewed as an umbrella term, palliative care may also consist of a wide range of healthcare and social support services that comprehensively address both the medical and non-medical needs of patients, as well as that of their family members. Typically, since the patients under consideration are not yet facing imminent death, active curative treatments will still be provided along with comfort care. In comparison, hospice care is more oriented towards those who are really nearing the end of their lives, as quantified by a very limited life expectancy that is less than six months, usually on the scale of weeks or days. In this case, active curative treatments are withdrawn since the illness has already become irreversible. Finally, EOL care is, similar to the above two notions, a holistic care approach targeted towards end-stage patients, but this time around the timeframe of care provision and nature of treatment are more flexible and may depend on the actual situations.

To better align with the objectives and underlying philosophy of the present initiative, we will mainly adopt and focus on the term EOL care throughout this report, unless when citing or retaining the specific wordings used by other sources. As a remark, it should be noted that regardless of whether we are talking about palliative, hospice, or EOL care, which differ in terms of their provision timeframe, all of them necessitate earlier and preparatory efforts from all relevant parties to ensure that the quality of care provided is optimal with respect to the needs and preferences of the care recipients. This is the concept of EOL planning, which, despite not usually being incorporated into the definition of EOL care, is one of the most pivotal notions that deserves our special attention.

1.2.2 Key components

From the above, it should be clear that EOL care is not a one-off medical treatment, therapy, or intervention. Instead, EOL care is a multi-component concept that represents a continuum of services whose nature may vary and depend on the patient’s conditions, for instance the type and trajectory of disease. First and foremost, EOL care should begin with the identification of patients who are suitable for this type of care service. The value and importance of this procedure cannot be overstated, since if the timing is too early, then the patient may not need to receive EOL care in the first place. On the other hand, if it is too late, then the patient may have already missed the golden opportunity to receive comfort care, rendering subsequent efforts less effective. Typically, EOL care provision may begin when the remaining life expectancy is around six to 12 months, and the traditional screening tool is the so-called “surprise questions” (see Downar, Goldman, Pinto, Englesakis, & Adhikari, 2017, for a review). Besides these surprise questions, there is another prognostic criterion in Hong Kong, namely the “HARRPE”[1] score (Tsui, Au, Wong, Cheung, & Lam, 2015), which has demonstrated its clinical value and started to come into play in recent years (e.g., Mo, Wong, Po, Chan, & Kng, 2023). After identifying the care recipients, an often overlooked yet essential component is EOL conversation, which allows the preferences and needs of patients to be recognized and understood by the care providers. Based on the understanding obtained from this communication process, a multi-disciplinary team of health and social care professionals, which may include specialists in geriatric and palliative medicine, nurses, social workers, clinical psychologists, counsellors, physiotherapists, occupational therapists, speech therapists, health workers, and personal care workers, will then provide the desired medical treatments, nursing care, as well as psychosocial and spiritual support. Sometimes, the scope of EOL care may be extended to help family members handle the post-death situation. For this reason, bereavement services including grief support groups and counselling therapy may also be considered a component of EOL care. To emphasize again, EOL care is multi-faceted in nature and is more than just a single instance of medical treatment.

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[1] This acronym stands for the “Hospital Admission Risk Reduction Program for Elderly.”

Because of that, the responsibility of providing high-quality EOL care cannot and should not be delegated to a single individual or profession. Instead, the involvement of and contribution from every member of the healthcare team is indispensable.

Figure 1. Generic workflow of EOL care.

1.2.3 Advance Care Planning and Advance Medical Directive

The above definition and description of EOL care are stated from the perspectives of care providers. However, to ensure that the services provided to the care recipients do align with their preferences and needs, the involvement of patients and family members is of equal importance. In particular, patients are not simply the passive beneficiaries of EOL care services. Instead, they play a major role in deciding the type and quality of EOL care that they end up receiving. If patients do not think about and express their preferences in advance, then it will be quite difficult for healthcare professionals to deliver EOL care in a way that matches their best interests. This brings up two important notions in EOL care, namely Advance Care Planning (ACP) and Advance Medical Directive (AMD).

In Hong Kong, AMD[2] refers to a class of legal documents that specifies the medical actions to be taken when the signatory becomes incapable of making sound decisions (Hospital Authority [HA], 2020). More specifically, it allows individuals to indicate that they will refuse to receive certain life-sustaining treatments (LSTs), for instance cardiopulmonary resuscitation (CPR), in some specific circumstances. The underlying motive of AMD is to prevent the pain and suffering caused by futile LSTs, for instance sternal fractures resulting from CPR. As its name implies, AMD is entirely about making and documenting concrete medical decisions.

Notwithstanding its relevance and importance in EOL care, AMD unfortunately does not consider the non-medical aspects, for instance the life goals and personal values, of the patients. In contrast, ACP can be thought of as a more upstream and integral version of AMD, which corresponds more closely to the original intention of EOL care. Broadly speaking, ACP refers to the iterative process in which patients communicate, articulate, and document their EOL and post-death preferences. Topics to be discussed in this process may include, but are not limited to,

- personal perspectives on death and the dying process,
- unfinished business and life goals,
- prognosis and possible treatment options,
- preferences on LSTs and care approaches,
- preference on the place of death,
- funeral and burial arrangements, and
- succession matters.

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[2] In Hong Kong, AMD was originally and more commonly known as Advance Directive, or simply AD.

As compared with the limited scope of AMD, ACP is much more comprehensive in nature and requires the tripartite participation from patients, family members, and healthcare professionals (HA, 2019). Here, the involvement of family members is necessary, since this allows them to understand the preferences of the patients, thereby being able to act as surrogate decision-makers when necessary. Furthermore, it should be emphasized that ACP is, unlike AMD, not just a piece of official document that requires a registered medical practitioner to serve as the witness. Instead, it represents a continual communication process in which patients can regularly review their previous decisions and update the record if needed. Because of that, ACP itself may carry therapeutic benefits, and is not something that can be completed hastily when the patients are already about to die. Instead, depending on the disease progression and actual circumstances, ACP can be initiated prior to the timeframe of EOL care provision, and may even be considered relevant across our entire lifespan (Sudore et al., 2017).

1.3 End-of-life care in Hong Kong

To foster the betterment of EOL care provision in Hong Kong, it is essential to first examine what has been done, and what remains to be done, in this regard. While the development of EOL care services seems to be moving forward at a tremendous pace in recent years, it is still of importance to keep track of its historical root and evolution process, such that future advancement will remain true to its original aspirations and not go astray from the right path or simply “reinvent the wheel.” To this end, we first briefly review the development of EOL care services in Hong Kong from a historical lens. After that, we highlight some of the unresolved issues and barriers, suggest the corresponding enabling factors, and thereby provide the background contexts for motivating the present initiative.

1.3.1 History and milestones

1.3.1.1 Hospital Authority

Public hospitals under the HA constitute the major EOL care service provider in Hong Kong. The provision of palliative care originated in Our Lady of Maryknoll Hospital in 1982 (Yee, Ng, Lau, & Fong, 2019), which was later expanded to four other hospitals in that decade, and now to all the seven HA clusters. During its early development, palliative care was predominantly provided to cancer patients (Lam, 2019). However, it was later observed that many older people in Hong Kong passed away due to advanced chronic diseases, which may entail more prolonged suffering than cancer. In view of this, based on the successful pilot results of several pioneering initiatives (e.g., CADENZA, 2010) and an additional government funding of about $34 million per year (The Government of the Hong Kong Special Administrative Region [GovHK], 2016), provision of EOL care has been gradually extended to non-cancer patients, for instance those with organ failure, since 2010. In 2012, the HA started to allocate more resources to clinical psychologists and medical social workers (MSWs), enabling them to provide better and more timely psychosocial interventions to EOL patients and family members (GovHK, 2016). More recently, the HA established the Strategic Service Framework for Palliative Care (HA, 2017), which laid down the overarching structure of EOL care provision in the subsequent decade. Accordingly, several HA working groups were formed with the aim of actively promulgating the concept of EOL care and the implementation of ACP and AMD. In some HA clusters, there are senior medical officers designated to oversee and advocate the implementation of EOL care in their respective hospitals or departments, as well as to monitor its performance and effectiveness in the name of attaining Continuous Quality Improvement (CQI). These top-down, administrative actions indicate that the HA has been attaching more priority to EOL care provision. In terms of actual execution, there are various measures related to internal promotion and education being undertaken. For instance, the HA has issued various guidelines on ACP, AMD, LSTs, and do-not-attempt cardiopulmonary resuscitation (DNACPR), which serve as instruction manuals and reference materials for clinical practice. For another instance, frontline staff begin to receive more training on EOL care, for instance, through the means of Continuing Medical Education (CME) and Continuing Nursing Education (CNE). Encouragingly, there is a trend in which such training is no longer delivered in an isolated manner. Instead, it starts to be incorporated into the centralized and regular training programmes (e.g., Central Commissioned Training Programme [CCTP]), and is not confined to certain specific specialties such as palliative medicine and oncology. On the other hand, there are also measures that promote the uptake of ACP among the care recipients. For instance, the Community Geriatric Assessment Teams (CGATs) commenced a funded initiative in 2015 (GovHK, 2016), in which the HA's multi-disciplinary teams help identify EOL patients and, if deemed appropriate, initiate and conduct the ACP process, during their routine visits to various Residential Care Homes for the Elderly (RCHEs). This initiative is a particularly noteworthy one, as it heralded a new phase of strengthened collaboration between public hospitals and the social welfare sector in the provision of EOL care.

1.3.1.2 Non-governmental and community efforts

Apart from the HA, various non-governmental organizations (NGOs) also play a vital role. The earliest development can perhaps be dated back to 1986, when the Society for the Promotion of Hospice Care (SPHC) was established to, as its name suggests, advocate hospice care. Later, the SPHC and several other organizations, including the Haven of Hope Christian Service and Hong Kong Anti-Cancer Society, began to offer hospice beds and customized hospice facilities. Besides these NGOs that specialize in hospice care, more and more RCHEs started to get involved in the provision of EOL care, typically by practicing some sorts of short-term programmes on their own initiatives. Drawing on these experiences, additional funding and manpower resources were allocated by the Social Welfare Department (SWD) in 2015 to some of the new contract RCHEs, such that they can incorporate EOL care services into their routine practices (Food and Health Bureau [FHB], 2014). While the above community efforts are directly oriented towards the provision of care, some others are targeted towards education, promotion, knowledge acquisition, and capacity building. The most prominent example in this regard is perhaps the Jockey Club End-of-Life Community Care Project (JCECC) launched in 2016, which was where the present initiative originated from (see Section 2.1). Recently, in addition to the more traditional and widely known community partners, which usually only specialize in a few aspects of EOL care, several emerging social enterprises were also established, on a self-financing basis, to provide one-stop EOL care services covering ACP, the signing of legal documents, life parties, psychosocial support, and burial arrangements. These services, however, generally come at a somewhat higher price.

1.3.1.3 Legal framework

In the past few years, much of the development of EOL care in Hong Kong seemed to have revolved around the legislative process of AMD and DNACPR. Prior to this, Hong Kong had no legislation that provides for the legal status of AMD and DNACPR orders, and only the former was considered legally binding under the common law (e.g., Kan, 2010). Consequently, for many years it had been controversial and conflicting as to whether in emergency situations, healthcare professionals should follow the signed AMD and DNACPR order, adhere to the patient's decisions, and withhold the unwanted LSTs. This issue is particularly evident from the perspectives of ambulance crew and other paramedics, since the Fire Services Ordinance (Hong Kong e-Legislation [HKeL], 2021) states that their duties shall be to "resuscitate or sustain the life of any person who needs immediate medical attention." Adding to the list of concerns, the Mental Health Ordinance (HKeL, 2022b) states that treatment can be carried out on a mentally incapacitated person without consent provided that, as a matter of urgency, the treatment is considered necessary and in the best interests of that person, which means that prior medical decisions can potentially be overridden. To resolve these issues through the establishment of a statutory framework for LSTs, a public consultation was conducted by the then FHB (2009) to examine whether the legislative process of AMD and DNACPR should and could be embarked upon, but unfortunately, the result was not that positive. Nearly ten years had passed, and The Chief Executive's 2018 Policy Address (GovHK, 2018) raised this issue again and set out the administrative plan to allow EOL patients more options for their own treatment. Accordingly, another public consultation was conducted (FHB, 2019), and this time around the conclusion was more supportive. Finally, at the end of 2023, the "Advance Decision on Life-sustaining Treatment Bill" was published in the gazette and introduced to the Legislative Council for enacting the relevant legislative proposals (GovHK, 2023). One important guiding principle mentioned in the bill was "cautious making, easy revoking," implying that the conditions of making an AMD should be stringent, whereas revocation will be made simple and straightforward (HKeL, 2023). Although the bill was undeniably an important milestone in the history of EOL care development, the operation details and actual execution of the ordinance, such as the introduction of an electronic and centralized AMD registration system, as well as its unification with the existing Clinical Management System (CMS), are still uncertain and remain to be observed.[3]

Besides the concerns about AMD and DNACPR, another legal issue related to EOL care, which will be briefly touched upon here, is "dying in place." In most cases, it means spending the final days at home or in an RCHE, but not in a hospital. For many years, the standard practice of RCHEs was to send EOL residents to hospitals, often resulting in repeated readmissions and discharges (Chung & Au, 2023). This phenomenon could likely be attributed to the constraints imposed by the Coroners Ordinance (HKeL, 2022a). Drawing on the opinions and insights gathered from the public consultation in 2019, the Coroners Ordinance was amended in 2024 such that under normal circumstances, if a EOL resident passes away in an RCHE due to natural causes, then there is no longer a need to report to the coroner via police (GovHK, 2024a). Again, it will take more time for the effects of this amendment to be manifested.

[3] After the bill was passed in late 2024, the government official stated that it may take about 18 months of transitional period for the medical system and relevant parties to prepare for its full-fledged implementation (GovHK, 2024b).

1.3.2 Barriers and enablers

The above summary reviewed the major achievements in EOL care development throughout the past decades. There is a strong indication that the overall atmosphere in Hong Kong is becoming more conducive to the provision of EOL care. In fact, the ranking of Hong Kong in the Quality of Death Index drastically improved from the 22nd among 80 places around the globe (The Economist Intelligence Unit, 2015), which was trailing behind even some of the lower-income and developing countries, to the more satisfactory 9th among 81 (Finkelstein et al., 2022).[4] However, if the question is whether the mission has been completed, then the answer is a definite no. In recent years, there has been a growing body of academic studies, review articles, and think tank reports summarizing the major service gaps and barriers regarding EOL care in Hong Kong (e.g., Chung et al., 2020). Some of these barriers have been tackled to a certain extent, whereas some others remain largely unresolved today. Among these unsettled issues, many are visible even to a layperson's eyes, and have already received much attention and discussion in our society, which include, for instance, the lack of palliative medicine specialists and hospice beds. Although these issues are easily identifiable, they are perhaps too difficult or even unrealistic to deal with, merely through non-governmental efforts. In contrast, there are some other issues belonging to the software facet that probably do not get mentioned as much, but which also play an equally important role. These software issues are perhaps more manageable in the sense that immediate measures can be undertaken, typically in the form of education and training, by community partners. In view of the above, and to motivate the present initiative, we list some of these software issues and describe what can be done to fill such gaps.

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[4] Technically speaking, this comparison should be interpreted with caution, since the Quality of Death Index was defined differently in the two occasions.

1.3.2.1 Negligence of the importance of end-of-life conversations

In Hong Kong, the cure-oriented nature of medicine has been deeply ingrained in the mindsets of many healthcare professionals, which makes them difficult to fully appreciate the importance of, and thereby focus more on, the non-medical aspects in their clinical practice. Because of that, many of them lack the proper attitude, confidence, motivation, empathy, and techniques to engage in EOL conversations with patients and family members. To cope with their busy schedules and heavy workload, many simply resort to the default medical procedures and try to keep the patients alive for as long as possible, without establishing proper communication and mutual understanding in advance. Consequently, there may be mismatches between the patients' expectations and the treatments that they end up receiving.

This situation has unfortunately been further exacerbated in recent years by how ACP and AMD are framed when being promulgated to our society. As mentioned previously, ACP is supposed to be a holistic version of AMD that puts equal emphasis on the non-medical aspects of EOL care. Under this interpretation, ACP is the more fundamental notion, whereas AMD is just an official document intended to make sure that the preferences elicited by patients through ACP discussions can be actualized in practice. However, due in part to the legislative process of AMD, it seems that most of the attention has been directed from the communication aspect of ACP to the legal status and execution plans of AMD. In this sense, EOL care in Hong Kong is, at its core, regressing to a more mechanical and primitive state.

For healthcare professionals, although they begin to receive more regular training related to EOL care, the actual content covered in such training is typically about either end-stage medical treatments or the legal issues of AMD. Notwithstanding the importance of these topics, training on EOL communication skills or the concrete techniques for initiating and conducting ACP conversations remains scarce. Similarly, although the HA has launched various initiatives in different hospitals and departments to promote the implementation of ACP, there is a tendency of mistaking ACP for AMD or relegating it to a tick-box exercise. In other words, many healthcare professionals may treat ACP as a standardized form or checklist that they need to complete as part of their daily workflows, and thus fail to recognize the importance of the underlying communication process. When they were informed that that EOL care should be planned in advance, some of them may erroneously equate this with the necessity of pushing the patients to sign an AMD or DNACPR form as early as possible. Furthermore, due to the widespread misconception that EOL conversations are only about decision-making on LSTs, it is common for nurses and other allied health and social care professionals to believe that such responsibility rests entirely with doctors who have relevant medical qualifications (cf. Section 1.2.2), resulting in further fragmentation in the care delivery process. On the other hand, the public may also be shaped into thinking that ACP is just about signing a document, as in the case of a will or Enduring Power of Attorney (EPA). Consequently, many people do not realize that they can and should engage in thorough conversations with their care providers, ultimately undermining their role in determining the quality of life during their final moments.

To remedy this, it is of utmost importance for both healthcare professionals and the public to, amid the “surging trend” of AMD, establish a clear mindset and distinguish ACP from the legal document. Healthcare professionals need to learn that an effective communication process is the core that underlies everything else in the provision of EOL care. They need to be aware that ACP is different from a patient’s chart board and should not be considered a task to be completed in a hasty and mechanical manner. In addition, since communication precedes medical decision-making, they need to understand that all members in the healthcare team should play a role in the conversations, as long as they are involved in the care of end-stage patients and family members. On the other hand, the public should be taught about the value and importance of EOL conversations, and should also be encouraged to engage in in-depth discussions before rushing to get an AMD signed.

1.3.2.2 Misconception about public acceptance and death taboo

Apart from the above, there is one other major reason why healthcare professionals may choose to abstain from discussing EOL issues with their care recipients. As about 92% of the Hong Kong's population is Chinese (C&SD, 2022), our society is often considered as not being conducive to the discussion of life-and-death matters due to the presence of cultural taboo. Indeed, at least in the past, Chinese traditions and old superstitions made people tend to conceal any information related to their serious illnesses (Fielding & Hung, 1996), as well as not to receive any information related to EOL issues (Mjelde-Mossey & Chan, 2007). However, most of these phenomena have already become history, as more recent studies and observations have consistently shown that most people in Hong Kong, including the older generations, are in fact open and willing, if not eager, to discuss and plan for EOL matters. For instance, according to two telephone surveys conducted even prior to the recent popularization of AMD, many were inclined to sign an AMD (Chan et al., 2019), and even among those who had never heard of AMD before, most held a positive attitude towards it upon being introduced to its concept and rationale (Chung et al., 2017). More generally speaking, most people do have the incentive to know more about disease trajectories and treatment options in EOL care. When given sufficient information, fewer and fewer people prefer to solely rely on their family members or care providers to make decisions for them. Unfortunately, it is common for healthcare professionals to hold on to the stereotype that older people are afraid of death and thus unwilling to discuss EOL issues. Consequently, many may choose not to disclose or explain the "sensitive" information, such as the remaining life expectancy and prognosis, as well as the benefits and risks of different LSTs, to the patients, which significantly undermines their ability to make the right decisions for themselves. In fact, something similar can be said of the younger family members of the patients, such as their children and grandchildren. It is not uncommon for them to insist on their role as the surrogate decision-maker and refuse to communicate with the patients. This is perhaps due to their wishful thinking that this approach can minimize the psychological distress and burden brought to the patients. Of course, it is undeniable that a portion of people, especially the older ones, may still genuinely be afraid of talking about death. However, this conclusion should not be hastily generalized to the entire population, which may deprive the autonomy of those who have the desire to exert control over their final journey.

To remedy this, both healthcare professionals and the public need to be educated and updated on the fact that our society has already become much more open to the discussion of EOL issues. Early planning and conversations in this regard are no longer universally viewed as bad omens, but instead have started to become a kind of blessing. Even if some patients are seemingly unwilling to engage in the discussion, healthcare professionals and family members should give them the benefit of the doubt and try to encourage the discussion using appropriate communication techniques. In addition, it may be helpful to identify the hidden motives or agenda underlying the patients' reluctance to discuss, as it is possible and often the case that they abstain from EOL conversations not because of death taboo, but the worries that they may become a source of troubles to others. On the other hand, patients themselves should also be taught and encouraged to actively voice out their inclinations to talk about EOL issues, in case their family members and care providers are unwilling or not taking the initiative to start the conversation.

1.3.2.3 Insufficient knowledge about treatment efficacy

As mentioned above, the level of public acceptance and openness towards EOL discussions has been rising in recent years. However, this does not automatically imply that the public is well-equipped and fully ready to plan for their EOL matters. One of the major obstacles in this regard is the lack of public understanding about the symptoms and progression of different end-stage diseases, as well as the corresponding treatment options. It is common for laypeople to have unreasonably high expectations on treatment efficacy, as they may believe that medicine and surgery are supposedly able to bring a patient back to a healthy and normally functioning state. Consequently, many people do not understand that overtreatment and repeated hospitalizations may simply lead to hampered quality of life, and thus may choose to insist on receiving treatments and medicalization, which are often intrusive and futile in reality. Of course, there is nothing wrong if one decides, after thorough and deliberate considerations, to adopt a more aggressive treatment approach oriented towards life preservation. However, it becomes very problematic if that decision is made based on incomplete information or misunderstanding about treatment efficacy.

Notably, it should be pointed out that the tendency to refuse forgoing LSTs seems to be upwardly biased when people are making decisions for their family members, as compared with when doing so for themselves. Such a phenomenon is to some extent driven by filial piety (Chan et al., 2012), which, in this context, can be interpreted as trying out every curative treatment in the hope of miracles, despite the limiting and irreversible nature of diseases (Chung & Au, 2020). One particular example worth highlighting is related to the much-debated issue of tube feeding. As a patient is approaching the end of life, starvation and dehydration are usually becoming less of a concern, due to reduced metabolism and lessened sensation of hunger. In fact, previous studies have shown that parenteral nutrition may not have clinical benefits in terms of improving the survival or quality of life (e.g., Ijaopo & Ijaopo, 2019). However, since food is highly prioritized in our culture for its symbolic representation of family love and caring (Ngan et al., 2019), it is common for family members to, out of filial piety, ethical duty, or perhaps a sense of guilt, forcibly insist on the invasive tube feeding procedure such that, at least in their mind, the patient can still pass away with a "full stomach" and not as a "hungry ghost."

To remedy this, the public needs to be educated on the fact that medical interventions are not omnipotent and cannot fully cure every disease, and that forgoing treatments is not equivalent to abandonment or violation of filial piety. In particular, the public needs to understand that certain treatment procedures, such as tube feeding in the above example, are aimed towards prolonging life instead of tackling the disease from its root. Sufficient and accurate information on different treatment options should be provided to help the public establish more reasonable and realistic expectations on treatment efficacy. Of course, for this purpose healthcare professionals themselves also need to be educated and updated on the relevant medical information. Finally, family members should be reminded to put themselves in the patient's shoes when acting as surrogates, especially if their personal preferences are also to prioritize comfort over life prolongation and opt against unnecessary LSTs.

1.4 Capacity building and education as a partial solution

To summarize, from a software point of view, most of the barriers to the provision of high-quality EOL care and wide implementation of ACP in Hong Kong stem from the miscommunication and misunderstanding among patients, family members, and healthcare professionals, which in turn are due to insufficient knowledge, improper attitude, and erroneous mindset among these parties. In response to these issues, capacity building and educational endeavours that aim at imparting knowledge, raising awareness, and driving mindset shifts constitute the critical first step. In fact, this precisely formed the basis for the development of the present initiative. Of course, it is by no means a complete solution as many other issues that were not raised above, especially the ones in the hardware and infrastructure level, remain to be tackled. The key point is that one should not consider the software facet irrelevant, or at best of secondary importance. In contrast, software solutions are often the ones that have more sustainable and far-reaching benefits. For instance, allocating more resources to build specialized facilities and provide hospice beds, which is a hardware solution that one can easily think of, is only treating the symptoms, but not the root cause, as the demand of EOL care services will eventually outpace the supply. On the other hand, planting the right seeds (i.e., mindsets) in our society can hopefully set off a perpetual chain of reactions, ultimately leading to more lasting impact.

2 Overview of the Programme

2.1 Background

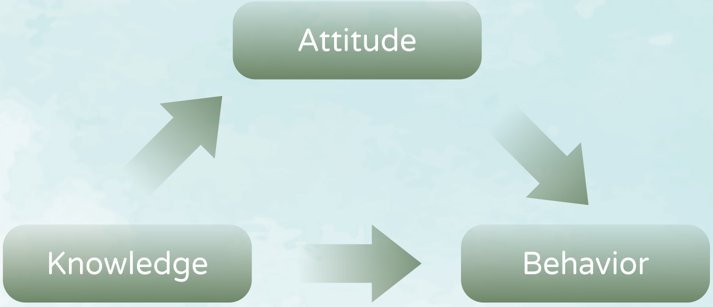
The present initiative, namely the Capacity Building and Education Programmes on End-of-Life Care (henceforth referred to as the Programme), was conducted by The Chinese University of Hong Kong (CUHK) Jockey Club Institute of Ageing (IOA) as part of the JCECC. In response to the growing demand of EOL care services in the community, the ten-year JCECC was launched in 2016 under the support of The Hong Kong Jockey Club Charities Trust (the Trust), with the aims of improving the service quality, enhancing the capacity of service providers, and raising public awareness. The JCECC was a multi-disciplinary, multi-institutional, and cross-sectoral collaboration with special emphasis on the interface between social and medical systems. Besides the IOA, various other partners ranging from academic institutions, medical associations, and NGOs were also involved in the JCECC, each of which played a slightly different but equally important role. For instance, some of the partners primarily focused on establishing and piloting an innovative EOL care service model, whereas some others served directly as the providers of care and support services to patients and older people in the community.

2.2 Objectives and target population

In contrast to some other JCECC partners that served as frontline service providers, the overarching aim of the Programme was related to capacity building, education and promotion, and knowledge acquisition. The underlying rationale is twofold. First, the Programme aimed to promote the popularization and long-term development of EOL care in Hong Kong, such that our society can be empowered on a permanent basis and more sustainable impact can be generated. Second, the Programme sought to fully utilize the comparative advantages and existing resources of the IOA, particularly in terms of its research achievements, proven track record in conducting professional training, as well as collaborative network and exposure in the academia and medical field, to achieve division of labor within the JCECC, thereby maximizing its outcomes and benefits.

As regards the more concrete objectives, the Programme followed the Trust’s suggested practice (The Hong Kong Jockey Club, 2017) and formulated them using the knowledge-attitude-behavioral (KAB) conceptual framework (Bettinghaus, 1986), which asserts that human behavior can be modified by working on these three constituent components in a stepwise and progressive manner.

Figure 2. Graphical representation of the KAB framework.



Under this framework, the Programme set up the following objectives in the hope of addressing the specific issues raised in Section 1.3.2.

- Instill basic concepts in EOL care, particularly those that are related to ACP and EOL conversations, in both healthcare professionals and the public (knowledge)
- Clarify misconceptions related to disease trajectories and treatment efficacy, and elucidate the differences between ACP and AMD (knowledge)
- Train healthcare professionals on the practical skills required to provide EOL care, for instance communication and symptom management techniques (knowledge)
- Raise awareness towards, and increase the extent of importance attached to, the issues in EOL care (attitude)
- Enhance the confidence and motivation of healthcare professionals in implementing ACP and initiating EOL conversations (attitude)
- Nurture a perspective-taking and patient-centered mindset among healthcare professionals (attitude)
- Redirect the cure-oriented mentality among healthcare professionals to a more holistic and care-oriented one (attitude)

- Cultivate a collaborative atmosphere in the EOL care setting where every member of the healthcare team can contribute to the care delivery process (attitude)
- Routinize the provision of EOL care, particularly in terms of the implementation of ACP, among healthcare professionals (behavior)
- Encourage and empower the public to commence early EOL planning, document their preferences, and engage in EOL conversations (behavior)

As can be seen from these objectives, the two major target groups of the Programme were healthcare professionals and the public. More specifically, among the first target group, the intended beneficiaries included

- doctors who are from public hospitals or in private practice,
- nurses who work in hospital wards or in the community setting,
- allied health and social care professionals in public hospitals, such as medical social workers, physiotherapists, occupational therapists, and speech therapists,
- frontline practitioners and staff working in different types of RCHEs, such as social workers and personal care workers, and
- prospective professionals who may develop their careers in related fields, such as medical, gerontology, and social work students.

Here, it should be emphasized that the Programme deliberately targeted a wide range of beneficiaries, even including some who may not be considered healthcare professionals in the traditional sense. This approach was in accordance with the underlying principle of the Programme, which stresses that not only those specializing in certain medical fields should be engaged in the provision of EOL care. One example worth mentioning is the family physicians in private practice. At first glance, family medicine seems to have nothing to do with EOL care, since end-stage patients will probably be hospitalized and no longer need to consult their family doctors. Nonetheless, family physicians can still play a role in and contribute to the development of EOL care in Hong Kong, especially since more and more individuals, including the healthier ones, are trying to seek advice on the matter of ACP and AMD. In this regard, if family physicians are sufficiently knowledgeable about the basic concepts in EOL care, then they may be able to address the enquiries of their clients, as well as to help them plan and prepare for their EOL matters.

On the other hand, the second target group of the Programme can be further categorized into

- the general public,
- caregivers and community health volunteers, and family members of RCHE residents or end-stage, hospitalized patients, and
- older people, especially the community-dwelling ones.

By "general public," it is meant to convey the message that the Programme accommodated the healthier and younger individuals in our society. That is because, while EOL care is intended for end-stage patients and both ACP and AMD are applicable predominantly only in the later portion of life, EOL planning is something that can and should be carried out much earlier, and building a proper understanding of EOL care is always relevant and important to all people at different life stages.

As regards the geographical scope, the Programme mainly focused on those regions that fall within the New Territories East Cluster (NTEC), including, for instance, Shatin, Tai Po, and the North District. This was due in part to proximity considerations and the fact that the IOA had built connections in these regions during other previous initiatives. Nonetheless, as the IOA started to gain reputation and recognition for its work in this field, the coverage of the Programme has been gradually extended to other areas, including the Hong Kong East Cluster (HKEC) and Hong Kong West Cluster (HKWC).

In addition to the two major target groups as mentioned above, the Programme was also dedicated to, from a more macroscopic perspective, approaching the executive and management level of the HA to promulgate and advocate the best practice of EOL care in the name of attaining CQI. In other words, besides its bottom-up efforts in capacity building and education, the Programme also sought to make a modest contribution to achieving a complete overhaul of EOL care services in Hong Kong, through top-down and administrative endeavors.

2.3 Implementation strategies

The Programme was led and overseen by a multi-disciplinary team in the IOA with a diversified range of expertise and experiences including, for instance, geriatrics and gerontology, nursing and thanatology, social work and community elderly services, and academic research. Chronologically speaking, the Programme was divided into three major phases (1st phase: 2016 to 2018, 2nd phase: 2019 to 2021, 3rd phase: 2022 to 2025), with each of them building on past experiences and scaling up its efforts in a continual manner. More precisely, the Programme followed the plan-do-study-act (PDSA) quality improvement cycle (see Woo, 2019), in which its strategic plans and implementation details were regularly reviewed and revised based on the previously gathered observations and evaluation results. Such a flexible and dynamically evolving approach was adopted, given that the Programme was among the first of its kind in Hong Kong and piloting efforts were required to probe into the actual needs and acceptance level of the target populations. As regards its content, the Programme was decomposed into four major components, namely capacity building, public education, development and dissemination of educational resources, and academic research. In what follows, we briefly describe the overall execution plans of each of these components, as well as the evaluation strategies. A more comprehensive summary of the underlying rationales for these components, as well as what have been done and achieved, will be deferred to Chapter 3, 4, and 5.

2.3.1 Capacity building

The capacity building component was geared towards healthcare professionals and mainly consisted of training activities aiming to raise their capacity in providing EOL care and conducting EOL conversations. The main topics covered in these activities included, but were not limited to,

- the guiding principles and philosophy of EOL care,
- basic concepts of ACP and AMD, as well as their differences,
- methods for identifying patients in need of EOL care or ACP discussions,
- communication skills for breaking bad news, initiating EOL conversations, and facilitating the uptake of ACP,
- practical skills for providing physical, psychosocial, and spiritual care,
- clinical ethics and legal considerations,
- communication and collaboration within the healthcare team, and
- self-care and emotional regulation techniques.

The project team was mainly responsible for designing the content and format of these training activities, inviting the relevant experts and practitioners to serve as instructors, and providing administrative and logistical support. Whenever feasible, the pedagogical approach of each activity would be tailored to the prior knowledge and experiences, roles and duties, and specific needs of the target beneficiaries, as well as the work culture and environment of their affiliated units. Noteworthily, since EOL conversations and ACP discussions were very heavily emphasized in the Programme and communication skills are not something that can be taught in a traditional lecture-based setting, these activities incorporated a variety of innovative modalities, such as role-play simulations and experiential learning, to ensure the training effectiveness. To provide further motivation and incentives to the target beneficiaries, most of these activities were accredited for CME or CNE points.[5] In addition, some activities were conducted via Zoom or delivered through an open online course platform, such that a wider range of healthcare professionals could benefit from the training, even amid their busy work schedules.

[5] A small portion of activities were also accredited under the Continuing Professional Development Scheme.

2.3.2 Public education

The public education component mainly consisted of promotional and educational activities aiming to raise public knowledge and awareness of EOL issues. The main topics covered in these activities included, but were not limited to,

- the usefulness and significance of early EOL planning and documentation,
- general life-and-death issues,
- basic concepts of ACP, AMD, DNACPR, and euthanasia, as well as their differences,
- treatment approaches, LSTs, and care options,
- financial matters, EPA, and will-making,
- funeral and burial arrangements,
- practical skills and tips for initiating ACP and EOL conversations, and
- access to existing community resources in EOL care, especially those related to dementia.

The project team was responsible for conducting most of these activities, and occasionally for inviting relevant experts and professionals to serve as the speakers. Whenever possible, the breadth and depth of content were adjusted for each activity with respect to the prior knowledge, cognitive capacity, psychological readiness, and specific needs of the target beneficiaries. In general, most activities were non-technical in nature and were delivered through a wide spectrum of informal modalities, such as interactive workshops, tours and visits, and exhibitions. While the majority of activities were conducted at various elderly centres and RCHEs within the aforementioned geographical scope, some large-scale public events were also conducted, on a territory-wide basis, to reach the entire Hong Kong population.

2.3.3 Educational resources

A wide array of educational resources including, for instance, micro-movies, educational videos, celebrity interviews, toolkits, booklets, and leaflets, were produced either for self-learning and reference purposes, or to serve as supplementary materials for other training or educational activities. The content covered by these resources was intended to accommodate both healthcare professionals and the public, which included

- the basic concepts in EOL care,
- ACP and AMD,
- EOL conversations and communication skills,
- disease trajectories and symptom management, and
- clinical ethics and practical issues in EOL care.

Most of these resources were either disseminated during the Programme activities or directly sent to various public hospitals (particularly the Health Resources Centres [HRCs]), RCHEs, and JCECC partners for circulation and public access. In addition, the project team welcomed and encouraged other initiatives or parties that also aim at providing training and education on EOL care to utilize these resources, whenever deemed appropriate.

2.3.4 Academic research

In addition to the above components that were intended for capacity building, promotion, and educational purposes, various research activities were also conducted under the Programme to enquire into the development and current situations of EOL care in Hong Kong, with the aims of stimulating reflections and facilitating knowledge acquisition. The importance of these research activities cannot be overstated, since EOL care was still a relatively new topic in the local academia and studies in this regard had been scarce for many decades. During the 1st phase, the development of EOL care in Hong Kong was still at its early stage, thus the primary focus of research activities was put on identifying service gaps and barriers, from the perspectives of different stakeholders. On the other hand, as the Programme progressed to its end, the development of EOL care in Hong Kong had matured a bit and, as mentioned in Section 1.3.1.1, the HA started to implement ACP regularly through the CGATs. In response to this, the primary focus of research activities in the 3rd phase was then put on examining the effectiveness of these ACP implementation strategies.

2.3.5 Programme evaluation

As mentioned above, the Programme followed the PDSA cycle to ensure that its implementation could be adjusted and improved in the long run. During this continual refinement process, a critical component is the “S” (i.e., study) step, which refers to the evaluation efforts in testing the validity of the original plan as well as identifying problems and areas for improvement. In this regard, the project team carried out a series of evaluation strategies, which, at the implementation level, could be categorized into the quantitative and qualitative ones.

As regards the quantitative aspect, self-administered questionnaire was the main tool used to gather feedback and comments from the target beneficiaries. Instruments with sound psychometric properties were constructed and distributed during most of the Programme activities. The Likert-type items contained in the instruments were designed to be performance indicators for examining whether the activities had achieved the Programme objectives as listed in Section 2.2. Participants responded to these items (usually on the scale of 1 = strongly disagree and 5 = strongly agree) by rating the extent to which they had benefited from the activity in each of the KAB domains. Typical examples of items in each domain included

- “the activity increased my knowledge about EOL care and ACP” (knowledge),
- “the activity increased my knowledge about the treatment options in end-stage diseases” (knowledge),

- “the activity raised my awareness towards EOL care” (attitude),
- “the activity improved my confidence in initiating EOL conversations” (attitude),
- “the activity improved my motivation in initiating EOL conversations” (attitude), and
- “the activity prompted me to initiate more EOL conversations in the future” (behavior).

In addition to the KAB domains, several satisfaction metrics were also included to examine the acceptance of the participants and their level of endorsement towards the activities. As a remark, since the Programme put its emphasis on the general concepts and communication aspects of EOL care, the questionnaire items were designed correspondingly to revolve around these themes. Thus, there were occasions where the item wording did not match the topics and content covered in the activity, in which case the questionnaire would not be administered to ensure that all the responses collected could authentically capture what we intended to measure.

The above remark alludes to the importance of the qualitative aspect of evaluation strategies. While many other similar initiatives predominantly focus on the quantitative aspect of the evaluation procedures and tend to measure their effectiveness only based on numerical outcomes, the Programme placed equal emphasis on the qualitative counterpart. Unlike academic research, the project team deliberately adopted a more flexible and informal approach when conducting qualitative evaluation. That is, the format of qualitative evaluation was not confined to rigorous interviews or focus groups that strictly adhere to some sorts of pre-established study protocols. Instead, what happened in practice was that the project team members took turns participating in most of the Programme activities, during which they were responsible for conducting on-site observations and documenting any responses and comments from the participants. In this way, the project team could capture not only the participants’ most authentic perceptions of the activities, but also their personal experiences and reflections on EOL issues, particularly in terms of the barriers to and facilitators of conducting EOL conversations and ACP. Although these observations per se might not seem to be directly indicative of the quality and effectiveness of the Programme, they were of immense importance to the PDSA cycle as they could provide valuable insights to guide the direction and focus of subsequent activities.

3 Programme Activities

3.1 Overview

In this Chapter, we recapitulate the first two components of the Programme, namely capacity building and public education, by presenting their implementation details and deliverables (counting from January 2016 to February 2025), and discussing the insights gathered from the evaluation results and observations. It should be noted that given the great amount and diversity of Programme activities, we do not intend to provide an exhaustive summary for all of them. Instead, we aim to highlight some of the key activities and point out their underlying rationales, as well as to document the overall development and progressive advancements of the Programme.

3.2 Capacity building

The capacity building component was geared towards a wide range of healthcare professionals as listed in Section 2.2. During the ten-year period, more than 500 training sessions were delivered to over 20,000 participants. To ease the presentation, in what follows we organize the Programme activities in accordance with the types of target beneficiaries. Section 3.2.1 and 3.2.2 focus on the training specifically designed for doctors and nurses, respectively, whereas Section 3.2.3 summarizes the training provided to all other kinds of professionals, practitioners, and frontline staff. Section 3.2.4 then mentions the activities designed for students majoring in relevant fields. Last, Section 3.2.5 includes some large-scale, multi-disciplinary events that were intended to benefit all target groups.

3.2.1 Doctors

A total of 124 training sessions were delivered to 5,135 doctors. Most of the on-site sessions were provided to those from Shatin Hospital, a major non-acute hospital in the NTEC, whereas online training and self-learning courses were usually made openly available to all, including those in private practice or from the Department of Health. It should be mentioned

that for each activity, the project team applied for accreditation from as many CME providers (i.e., colleges representing different medical specialties) as possible, such that doctors with diverse backgrounds were given the same incentive and opportunity to benefit from the training. To reiterate again, this approach was in line with the overarching principle of the Programme that EOL care is relevant to not only specialists in certain fields like palliative medicine and oncology, but the entirety of the medical profession.

3.2.1.1 Role-play training

Role-play workshop was the most important and frequently offered type of doctor training. Most of these workshops were conducted face-to-face and in a small-group format, and were targeted towards the junior doctors (i.e., resident doctors) from the NTEC.[6] To further encourage participation and engagement, the workshops were designed to, in addition to attaining the original learning objectives, help these junior doctors prepare for their qualification examinations. In each workshop session, the instructor, who was usually a senior doctor specializing in geriatrics or palliative medicine, first gave a brief review of the important concepts of EOL care and ACP, and introduced and demonstrated some communication techniques for breaking bad news and conducting EOL conversations. In particular, the Serious Illness Conversation Guide (SICG; Ariadne Labs, 2016) was heavily used in these workshops, which is a set of patient-tested, Cantonese-adapted guidelines on language expressions and conversation flows that provide doctors with a validated tool for asking EOL patients about their goals, values, and treatment preferences. After that, participants took turns to practice the acquired techniques through a role-play simulation exercise. This exercise was intended to mimic the scenario of a EOL conversation or ACP discussion in real life, in which experienced actors were recruited to play as the patient and family member, and the participants were given the task to initiate and conduct the conversations. During the exercise, participants would receive constructive feedback and comments from the instructor, their colleagues, and other senior doctors in attendance, such that they could pinpoint the inadequacies of their communication skills and make improvements

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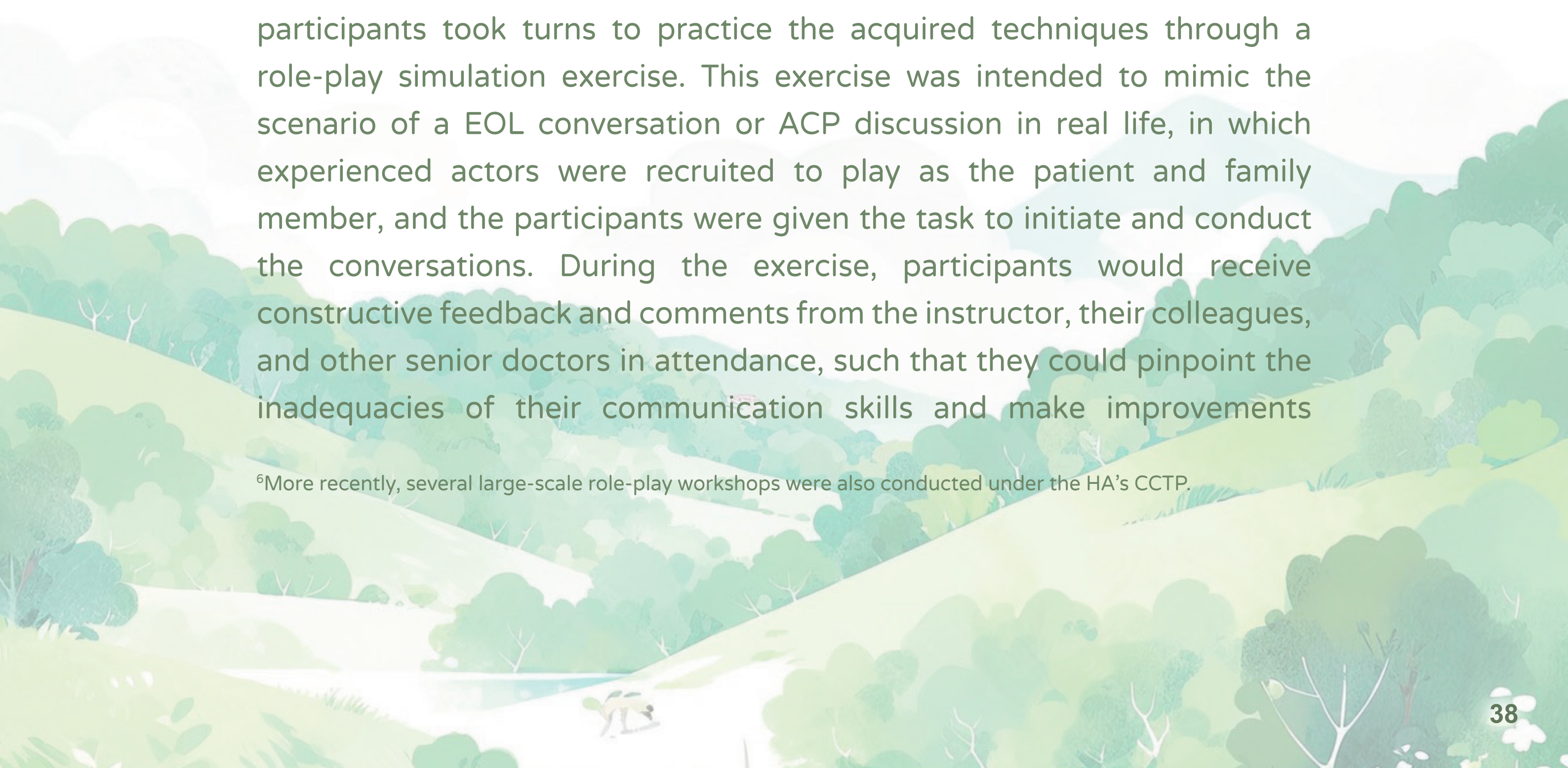
[6] More recently, several large-scale role-play workshops were also conducted under the HA's CCTP.



accordingly. In addition, the actors would sometimes deliberately escalate their emotions and refuse to follow the typical conversation flow as implied by the SICG, such that the scenario would better reflect the reality, and that the exercise would become more challenging and thought-provoking. Ultimately, the participants were expected to understand that they should not blindly and mechanically follow the conversation protocol. Instead, they needed to digest the principles of the SICG and be able to apply them in practice, in a flexible and empathic manner.

Figure 3. Role-play simulation exercises in doctor training.

3.2.1.2 Seminars and lectures

Besides the innovative role-play format as described above, more traditional, knowledge-oriented seminars and lectures were also provided to instill basic concepts of EOL care in the participants and help them build a correct mindset in this regard. For instance, some sessions delved into the issue of careful hand feeding and provided the participants with the updated evidence that nasogastric tube feeding is, in contrast to common belief, not necessarily beneficial in terms of reducing the risk of aspiratory pneumonia and increasing the survival rate of demented patients (Yuen et al., 2022). As compared with the soft skills in the communication aspect, this kind of technical knowledge was no less important as it enabled the participants to provide more accurate information on treatment options when conducting EOL conversations, as well as to refine their clinical practice to better align with the preferences of the patients and family members.

Figure 4. Seminars and lectures for doctors.

3.2.1.3 Online courses

During the 1st phase, nearly all doctor training was conducted live and in a face-to-face manner. However, due to the COVID-19 pandemic and the subsequent social distancing policy that took place in the middle of the 2nd phase, some of the training sessions were switched to the online format. While such a measure was originally thought to be temporary and undertaken only because there were no alternatives, the project team later transformed this crisis into an opportunity by recognizing that the online format could become a more sustainable and equally effective modality of delivering the training. While the online format was also applicable to most of the other Programme activities, we mention and highlight it here within the context of doctor training, since among all target groups, doctor participants, especially those on on-call duties, tended to have the busiest schedules and were the least likely to find the spare time to attend a training session with a fixed and pre-specified timeslot. In view of the above considerations, the project team pre-recorded a collection of lecture videos and, after appropriate post-production, released them onto an online platform as open courses, which were then promoted and distributed to the HA and various medical associations, such as the Medical Council of Hong Kong. The interested viewers could watch the video anytime and anywhere, and at their own pace. In addition, a stimulating quiz was included to ensure comprehension of the lecture materials. Topics covered in these online courses included, for instance, EOL communication skills, ACP for demented patients, clinical ethics, and assessment of mental capacity for the purpose of signing an AMD.

Figure 5. Online training for doctors.

3.2.1.4 Collaboration with the Hong Kong Doctors Union

In addition to organizing various activities and online courses for doctors in the name of the IOA, the project team also partnered with the Hong Kong Doctors Union (HKDU) to deliver training on its behalf. More specifically, the HKDU would regularly host symposia, conferences, webinars, and lectures for its members, some of which were related to the topics of EOL care. In some of these occasions, the project team would send out representatives or help invite relevant professionals to serve as the speakers, as well as provide administrative and logistical support. Topics covered in these HKDU sessions included, for instance, the status quo of ACP in Hong Kong, issue of dying at home, fatigue management in EOL care, and legal considerations related to AMD. In general, these HKDU sessions were large-scale in nature and often attracted hundreds of participants with diverse backgrounds. Through this valuable platform, the coverage of the Programme was substantially extended to different kinds of doctors in private practice.

Figure 6. Doctor training conducted with the HKDU.

3.2.1.5 Death audits

As a final remark, it is worth mentioning that there was an additional effort undertaken by the project team, which could build capacity among doctors, but which was not delivered as an ordinary, tangible training activity. For public hospitals under the HA, different departments and units need to hold death audits during their regular meetings, which are intended to review whether the medical treatments provided to recently deceased patients were appropriate and in alignment with their best interests. In this regard, the project team advocated and pushed forward the incorporation of elements related to EOL care into the death audit procedures, for instance the documentation of EOL conversations and the patients' preferences. These death audit meetings could then serve as an excellent opportunity for the doctor attendees to further appreciate the importance of effective communication and transparent documentation in the process of delivering EOL care. Furthermore, this could also help promote the normalization of EOL care among doctors, by conveying the message that it is an integral part of medical care and thus should be taken equally seriously in clinical practice.

3.2.2 Nurses

A total of 274 training sessions were delivered to 10,470 nurses. During the 1st and 2nd phases, most of the training sessions and courses were targeted towards nurses from the HA hospitals in the NTEC, particularly Alice Ho Miu Ling Nethersole Hospital and Tai Po Hospital. In comparison, during the 3rd phase, training provision in the NTEC became more routinized, and the Programme started to switch focus towards hospitals in the HKEC and HKWC, such as Pamela Youde Nethersole Eastern Hospital and Queen Mary Hospital, with the aim of further extending its coverage and impact.

3.2.2.1 Role-play training

As in the case of doctor training, role-play simulation was a critical component in nurse training. In fact, this training format was frequently incorporated into a wide range of activities, which will be mentioned again in Section 3.2.2.2 and 3.2.2.3. Here, we first highlight a featured collaboration with the HKEC, in which an interactive workshop was designed and conducted with full emphasis on its role-play simulation component. This workshop was by invitation only and was aimed at equipping the participants, who were already somewhat familiar with the concept and practice of ACP, with more advanced therapeutic communication techniques for initiating and conducting EOL conversations. Around 40 invited participants were assigned into four groups, each of which took part in a separate role-play session under the guidance of an experienced facilitator. These facilitators, who were senior doctors or nurses well-versed in conducting EOL conversations, were

responsible for holding the debriefing session after the role-play exercise. Within each group, one participant was nominated to take part in the role-play exercise together with two externally recruited actors, who played as the patient and family member, respectively, whereas the remaining participants served as spectators and were asked to provide feedback. After the role-play session, four groups gathered to exchange their experiences, learnings, and reflections, which marked the end of this two-hour workshop. The overall format of the role-play session was akin to that described in Section 3.2.1.1, but this time around the project team utilized the resources and facilities available in the HKEC, in particular the simulation laboratory in the Training Centre for Healthcare Management and Clinical Technology, to further enhance the realism of the role-play exercise and hence the training effectiveness.

Figure 7. Featured role-play workshop for nurses from the HKEC.

3.2.2.2 Train-the-trainer series

The train-the-trainer paradigm is a well-known pedagogical framework aimed at establishing a competent and motivated workforce by first empowering the current or soon-to-be leaders, who are in turn expected to mentor and support their subordinates and junior colleagues. Following this approach, the train-the-trainer series was a sequence of activities specifically designed for advanced practice nurses and ward managers, with the aim of enabling them to promote the concept and practice of ACP, thereby cultivating a collaborative work atmosphere that gives prominence to the best interests of patients and the communication aspect of EOL care. Here, it should be emphasized that the nature of the train-the-trainer series was somewhat different from that of the other nurse training activities, since this series was not directly intended to train communication skills in a bottom-up manner, but to generate "ripple effects" and make the work environment of nurses more conducive to EOL conversations and ACP implementation.

As regards its implementation details, the train-the-trainer series began with a seminar on the recent development of EOL care and ACP, serving as a brief refresher for the nominated participants who were already knowledgeable and experienced in this aspect. After this introductory session, participants attended an interactive role-play workshop, during which they reflected on the barriers to conducting ACP and EOL conversations that they had encountered in clinical practice, and were guided to develop strategies for tackling the identified challenges. After that, participants were required to, as part of the training paradigm, apply and advocate these strategies in their affiliated units during the post-workshop period. Finally, a two-month follow-up session was conducted to provide the participants with the opportunity to share their experiences and take stock of the progress made.

Figure 8. Train-the-trainer workshops series for senior nurses.

3.2.2.3 Communication skills series

In EOL conversations, the skill of communicating with patients is not the only aspect at which nurses need to be proficient. Indeed, since ACP requires the integral participation of patients, family members, and different types of healthcare professionals, and since nurses can usually play a bridging role in this process by establishing connections between the involved parties, it is important for them to be able to communicate effectively with not only the patients, but also their family members and other colleagues within the healthcare team.

In view of the above, the communication skills series was precisely designed to train communication skills with respect to these three areas. More specifically, the series consisted of three interactive workshops, in which the first two sessions introduced and focused on a collection of communication protocols that were designed to help nurses articulate their empathy and support to, as well as elicit thoughts and preferences from, EOL patients and their family members. Notably, given the different roles played by doctors and nurses in the communication process, the protocols introduced in these sessions were not the same as the one mentioned in Section 3.2.1.1. Instead, the most heavily used ones among nurses were the NURSE[7] (Baile et al., 2000) and SPIKES[8] (Pollak et al., 2007) statements, both of which are acronyms demonstrating the typical flow and procedure of an effective EOL conversation. Sample dialogue quotes in Cantonese were given to illustrate the application of these communication protocols, and role-play exercises were also included to provide the participants with the opportunity to practice what they learnt. Finally, the third session of the series was about communication within the healthcare team, in which participants learnt how to use the SBAR[9] protocol (Leonard, Graham, & Bonacum, 2004) to make concise and informative nurse calls, how to resolve interpersonal conflicts caused by disagreement over treatment plans, and how to establish a cohesive and respectful communication culture in their workplace.

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[7] NURSE stands for naming, understanding, respecting, supporting, and exploring.

[8] SPIKES stands for setting, perception, invitation, knowledge, empathy, and summary.

[9] SBAR stands for situation, background, assessment, and recommendation.

Figure 9. Communication skills workshop series for nurses.

3.2.2.4 Seminars, lectures, and interactive workshops

Besides the featured activities as mentioned above, a wide array of seminars, lectures, and interactive workshops were also provided to nurses on a regular basis. During the 1st and 2nd phases, most of these training sessions focused on conventional topics such as basic concepts in EOL care, ACP and AMD, EOL communication skills, treatment options and efficacy, pain control and symptom management, and clinical ethics. Later on, as the Programme evolved and the content of nurse training had become somewhat saturated, especially in the NTEC, the project team started to offer sessions on more "unorthodox" topics such as spiritual care, bereavement support, mindfulness and meditation, emotional regulation and coping strategies, art and music therapy,[10] and community resources related to EOL care. The choices of these training themes again reflected the bridging role and holistic nature of nurses in the EOL care setting. While some of the knowledge delivered in these sessions might not seem directly relevant to nursing practice, it could enable the participants to coordinate the care provided by different members within the healthcare team, as well as to alleviate the sufferings of patients and family members through their compassionate presence.

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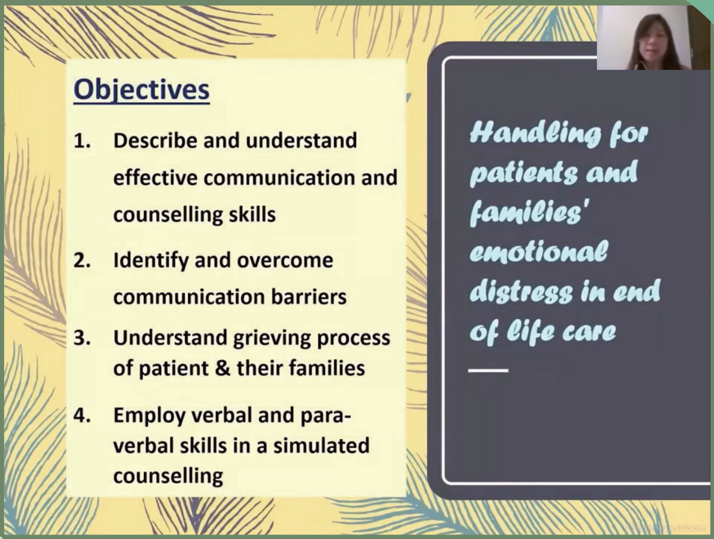
[10] For the benefits of art therapy for EOL care providers, see Potash, Ho, Chan, Wang, & Cheng (2014).

Figure 10. Mindfulness and meditation training for nurses.

3.2.2.5 Online courses

Similar to the case of doctor training (see Section 3.2.1.3), online courses were also offered to nurses for motivating and facilitating their self-learning. Given the manifold roles played by nurses in their work environment, themes covered in these online courses were more diversified, which, in addition to more ordinary topics such as ACP and EOL care for demented patients, also included psychological pain management, anticipatory grief and emotional distress, compassion fatigue, and art and music therapy.

Figure 11. Online training for nurses.



Objectives

1. Describe and understand effective communication and counselling skills
2. Identify and overcome communication barriers
3. Understand grieving process of patient & their families
4. Employ verbal and para-verbal skills in a simulated counselling

Handling for patients and families' emotional distress in end of life care

3.2.3 Other professionals, practitioners, and frontline staff

A total of 148 training sessions were delivered to 5,625 individuals in this target group. While some training was specifically designed for social workers (see Section 3.2.3.1), others were more generic activities that could benefit all relevant staff working in NGOs, including, for instance, community nurses, physiotherapists, personal care workers, and programme workers. It should be noted that in general, the training for this target group was less technical and more oriented towards the non-medical aspects of EOL care. For instance, while social workers were, just like doctors and nurses, trained on the concept of ACP and EOL communication skills, the focus was usually shifted from disease trajectories, diagnosis and prognosis, and treatment options to the personal values and life goals of the patients, as well as post-death matters.

3.2.3.1 Collaboration with the Social Welfare Department

The project team established a collaborative relationship with the SWD in 2021. Since then, a large-scale, half-day or two half-days training course has been conducted annually for social workers recruited through the SWD,[11] including those from the Elderly Branch or the Licensing and Regulation Branch at the headquarters, as well as those from various NGOs across different districts. The training course usually consisted of three main components. The first component was about the basic concepts in EOL care, ACP, and AMD, as well as how to provide comprehensive support to patients and family members from a social work perspective. The second component was an introduction to EOL communication skills, which was accompanied and facilitated by role-play demonstrations. The third component was a sharing of lessons learned from the Programme, in particular the implementation details and benefits of the ACP family sessions[12] (see Section 3.3.2.1). This last component was intended to offer an empirically validated service model for the participants to refer to and adopt, thereby empowering them to promote EOL planning and ACP in their practice.

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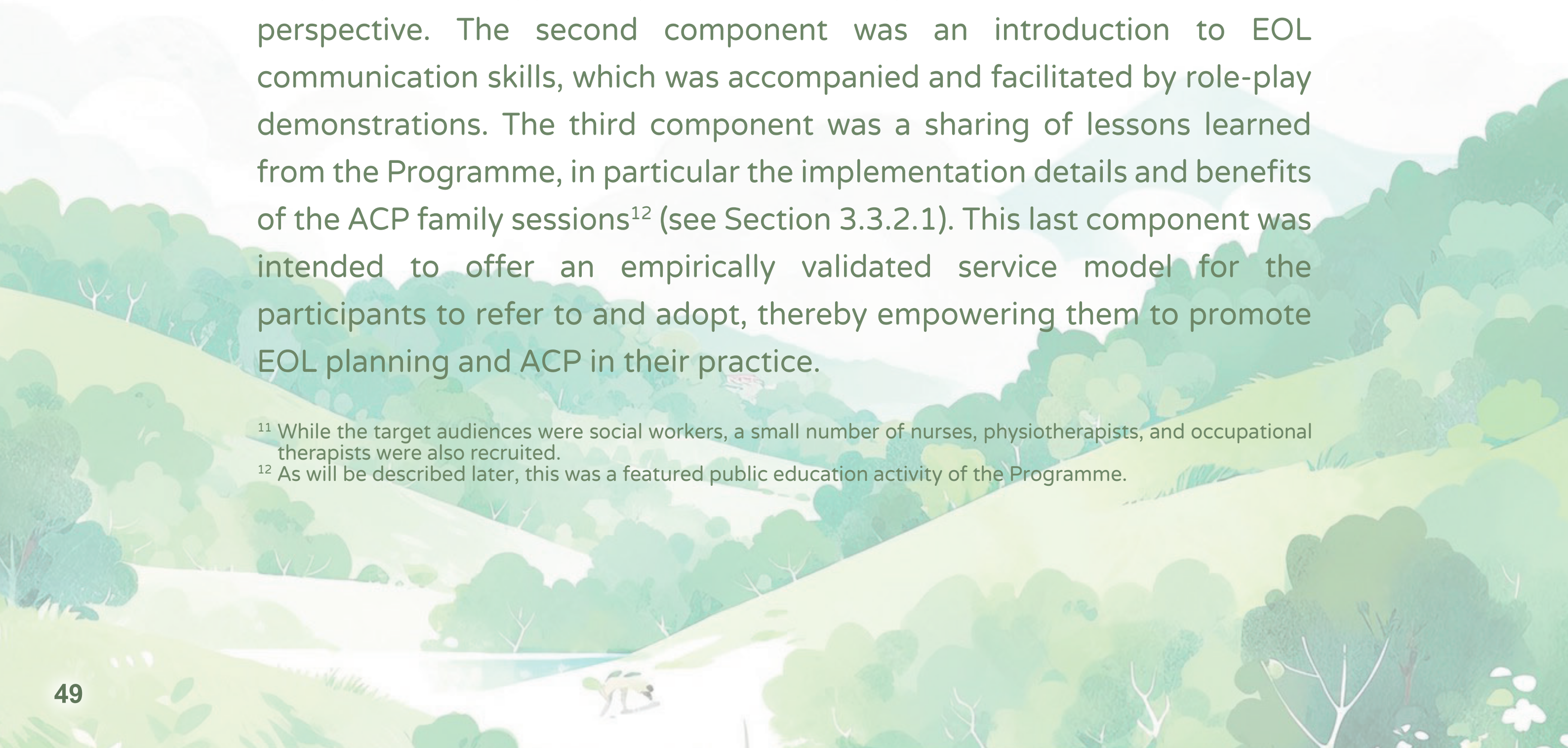
[11] While the target audiences were social workers, a small number of nurses, physiotherapists, and occupational therapists were also recruited.

[12] As will be described later, this was a featured public education activity of the Programme.



In addition, the project team also delivered several training sessions to MSWs from the SWD stationed at various public hospitals. Since MSWs frequently need to interact with patients and family members in their daily routines, the focus of these training sessions was placed on EOL communication skills. More specifically, the SICG was introduced to the participants, and they were given the opportunity to practice the communication protocol through role-play exercises. Notably, since the SICG was originally intended for the use of doctors and MSWs are not supposed to be as proficient in the medical aspect, the instructor paid special attention in this regard and let the participants understand how they may respond to the technical and medical questions that may arise in EOL conversations. This pedagogical approach again stressed that different members of the healthcare team, regardless of their medical knowledge and qualifications, can play an equally important role in the EOL communication process.

Figure 12. Large-scale training course conducted with the SWD.

3.2.3.2 Guided tours

In the context of EOL care, one critical role that frontline staff in RCHEs can play is referring their clients to, or providing them with information about, the suitable community resources, service agencies, and support systems, thereby facilitating their death preparation process. To fulfill this role, frontline staff need to be knowledgeable about the existing service network in the EOL care sector. In view of this, the project team organized two guided tours to a group of frontline staff recruited via the Tung Wah Group of Hospitals, serving as an experiential learning activity for the participants to acquire first-hand knowledge in this regard. The destination of the first tour was the Jockey Club Home for Hospice (JCHH), a hospice centre affiliated with the SPHC. During this field trip, participants were given the opportunity to inspect various facilities in the JCHH, including self-contained ensuites, farewell room, memorial garden, and mortuary. In addition, they were informed of the specifications and mechanisms of these facilities, as well as the modes of service delivery of the JCHH, such that they could have a better grasp of whether this kind of hospice care services would be relevant and applicable to their clients. As regards the second tour, the destination was the dissecting laboratory in the CUHK. This field trip was intended to further sensitize the participants to life-and-death issues and enable them to understand more about post-death arrangements, such as funeral and burial procedures and issues related to body donation. The lessons learned in this tour were also beneficial with respect to EOL conversations, as they would constitute a good triggering point for frontline staff to open up the dialogue with their clients.

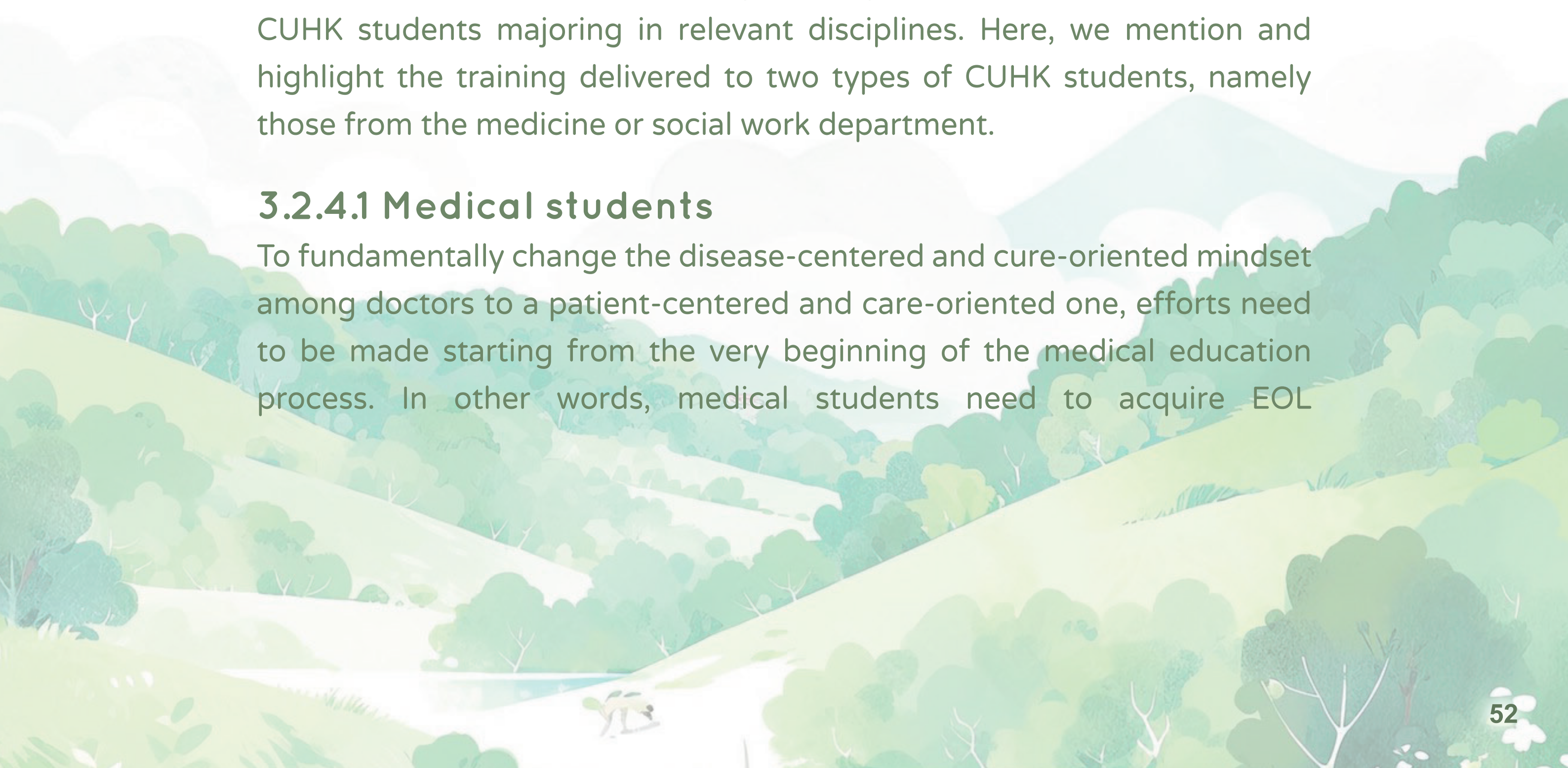
Figure 13. Guided tour to the CUHK dissecting laboratory.

3.2.3.3 Talks, information sessions, and interactive workshops

In addition to the abovementioned featured activities that were offered in a one-off manner, the project team also conducted regular activities for frontline staff from a large number of RCHEs across different districts. These activities were designed and revised in accordance with the previously accumulated experiences and feedback, so as to cater to the specific types of work environment and job duties of the participants. For instance, in some RCHEs, the organizational culture and status of the residents (e.g., already demented) were such that the frontline staff might not have many opportunities to engage in EOL conversations, in which case the focus of the training would be put on the general concepts in EOL care, AMD and legal issues, financial arrangements, and pain management. In contrast, for some other RCHEs with more favorable atmosphere and conditions, emphasis of the training would be placed on ACP and EOL communication skills. Occasionally, techniques in art, music, and horticultural therapy were also covered, enabling the frontline staff to break communication barriers and build rapport with the residents through these alternative, casual means.

3.2.4 Prospective professionals

As mentioned in Section 2.2, the project team sought to capitalize on the advantages of the IOA as an academic institution to maximize the benefits of the Programme. One prominent aspect was that the IOA could help nurture prospective healthcare professionals and inject fresh impetus into the EOL care sector by providing training and educational activities to CUHK students majoring in relevant disciplines. Here, we mention and highlight the training delivered to two types of CUHK students, namely those from the medicine or social work department.



3.2.4.1 Medical students

To fundamentally change the disease-centered and cure-oriented mindset among doctors to a patient-centered and care-oriented one, efforts need to be made starting from the very beginning of the medical education process. In other words, medical students need to acquire EOL communication skills and be able to appreciate the importance of the non-medical aspects in EOL care before they even enter the residency stage. Noteworthily, education in this regard should not be provided simply in the form of extracurricular activities, since otherwise students may consider it secondary to the medical knowledge that they gain from regular courses. In view of the above, the project team advocated for, and acted as the driving force behind, the incorporation of various training elements related to EOL communication into the formal medical curriculum in CUHK. As a result, learning modules, interactive training sessions, and tutorials were regularly offered to students during medical grand round, medical clerkship, and other undergraduate courses. Through these channels, a total of 253 training sessions were conducted and 3,799 medical students learnt about the principles and philosophy of EOL care, and the techniques of using both verbal and non-verbal expressions to articulate empathy and handle difficult emotions during EOL conversations.

3.2.4.2 Social work students

The project team established a collaborative relationship with the Department of Social Work, CUHK, in 2019. Since then, a training session has been organized annually for both undergraduate and postgraduate students from the department, benefiting a total of 209 participants. In the first few years, the training sessions were delivered in a more traditional classroom setting, in which the participants learnt about the basic concepts in EOL care and ACP, EOL communication skills, spiritual and holistic care, and the making of a will. The choice of topics covered in these sessions prioritized breadth over depth, which was intended to sensitize the participants to as many aspects of EOL care as possible, such that they built the basic awareness and became capable of looking up relevant information, when necessary, in their future practice. More recently, the delivery of training had evolved into an experiential learning format, in which the participants gained first-hand knowledge about post-death arrangements through site visits to various funeral service providers in Hong Kong.

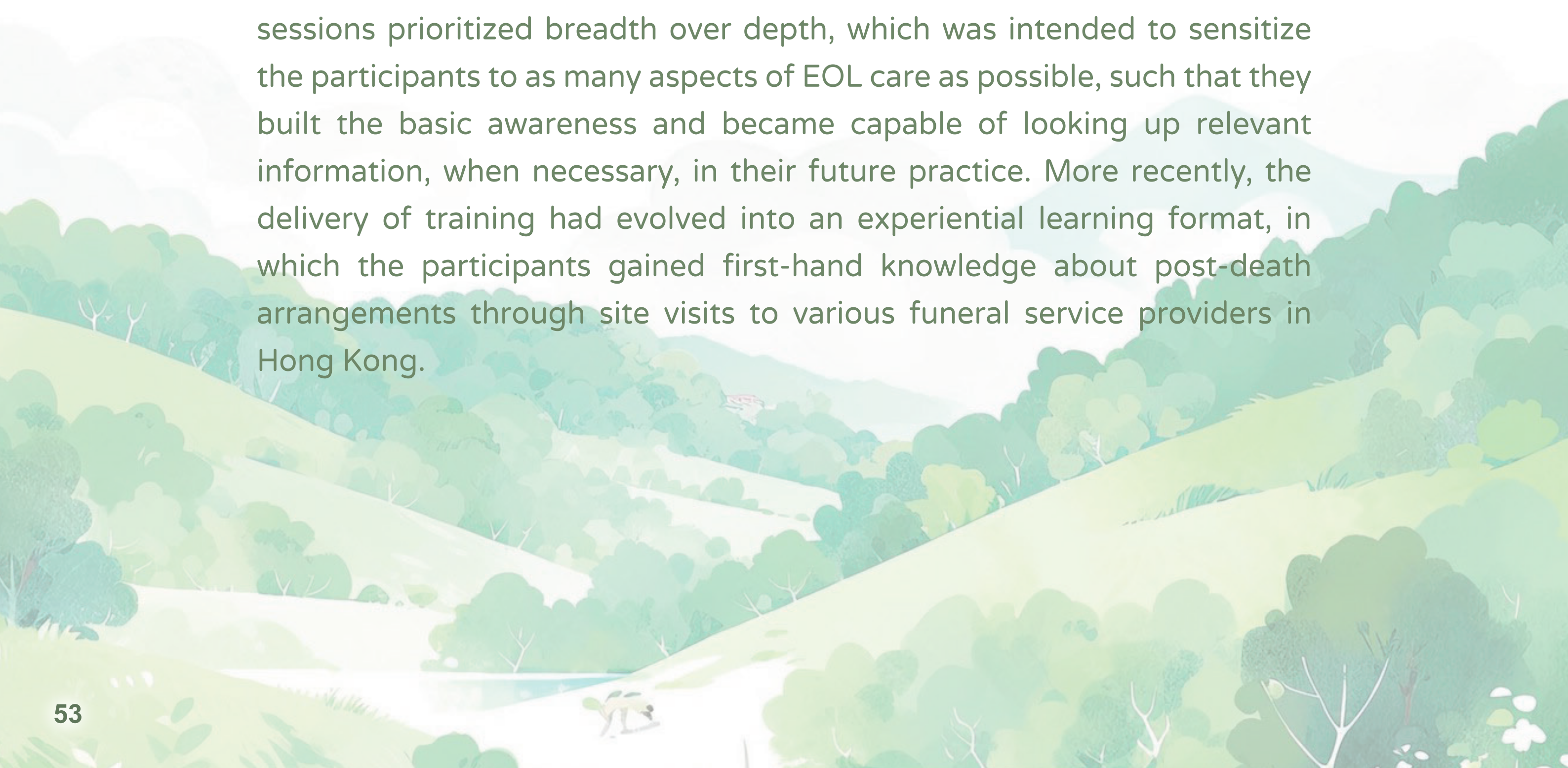


Figure 14. Site visits to funeral parlor for CUHK social work students.

3.2.5 Multi-disciplinary events

Besides the aforementioned activities that were designed for specific target groups, the project team also conducted two large-scale, multi-disciplinary activities with the aim of fostering the exchange of knowledge and perspectives among different types of healthcare professionals, as well as spreading the key message that EOL care is relevant to all members in the healthcare team.

The first such event was a webinar titled "End-of-Life Care for Older People in the Context of COVID-19." During the pandemic, the provision of EOL care services was significantly hampered by the inevitable reality that most healthcare professionals were deployed to deliver emergency care and implement infection control measures (World Health Organization [WHO], 2020), which were given the highest priority superseding the original routines and practices in EOL care (e.g., Luk, 2021). Due to the acute nature of COVID-19, many patients deteriorated quickly and needed to be mechanically ventilated, implying that they had insufficient time and minimal opportunities to plan for EOL care and prepare for their deaths. Worse still, there was a particularly difficult period when compassionate visiting arrangements were suspended in all public hospitals and RCHEs.

Consequently, some patients were not even given the chance to say goodbye to their family members, let alone a "good death" experience. Drawing lessons from this unprecedented crisis, the webinar was conducted to prepare the participants for handling similar extreme situations in the future. More specifically, the webinar offered insights into the provision of EOL care during COVID-19 in palliative care wards and in the residential care setting, respectively, and discussed how to ensure compassion and respect in the delivery of care while not sacrificing public health protection. The webinar was a major success, attracting a total of 350 participants from across the globe with diverse backgrounds.

Figure 15. The webinar on "End-of-Life Care for Older People in the Context of COVID-19."

The second multi-disciplinary activity was another webinar titled "Mind the Gap: Making Advance Care Planning and Actual Experiences of End-of-Life Care." Given the recent legislative proposal on AMD,[13] it was foreseen that the public would have increasing demands and expectations on the implementation of EOL care and ACP, which might not be met or satisfied in reality. In this regard, the webinar aspired to bridge the gaps between the needs of patients and family members, and the actual practice of healthcare service providers. More specifically, the webinar was

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[13] To make it clear, the bill on AMD had not been passed when the webinar was conducted.

delivered using a panel discussion format, which revolved around two real-life cases related to patients with neurodegenerative diseases. These two cases were drawn from the experiences shared by participants of previous Programme activities, and were deliberately chosen to highlight the importance and unmet needs of EOL conversations. Based on these cases, the moderator and panelists shed light on how healthcare professionals can provide optimal care to patients by considering their medical conditions and other relevant background information. Notably, the discussion was intended to be non-academic, non-technical, and non-philosophical in nature. Instead, it was conducted from a purely practical point of view, with special emphasis being placed on frontline experiences. In addition, as compared to the first webinar, the project team spent even greater efforts in encouraging the participation of all kinds of healthcare professionals in different roles and disciplines, which again echoed with the established philosophy of the Programme that everyone working in the field of EOL care can and should make contributions. The webinar attracted a total of 984 participants worldwide, which consisted of, in addition to doctors and nurses, senior hospital executives, physiotherapists, occupational therapists, social workers, psychologists, chaplains, and even several dentists, pharmacists, and dietitians.

Figure 16. The webinar on "Mind the Gap: Making Advance Care Planning and Actual Experiences of End-of-Life Care."

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Jockey Club End-of-Life Community Care Project

Mind the Gap:

Making Advance Care Planning and

Actual Experiences of End-of -Life Care

Points for discussion

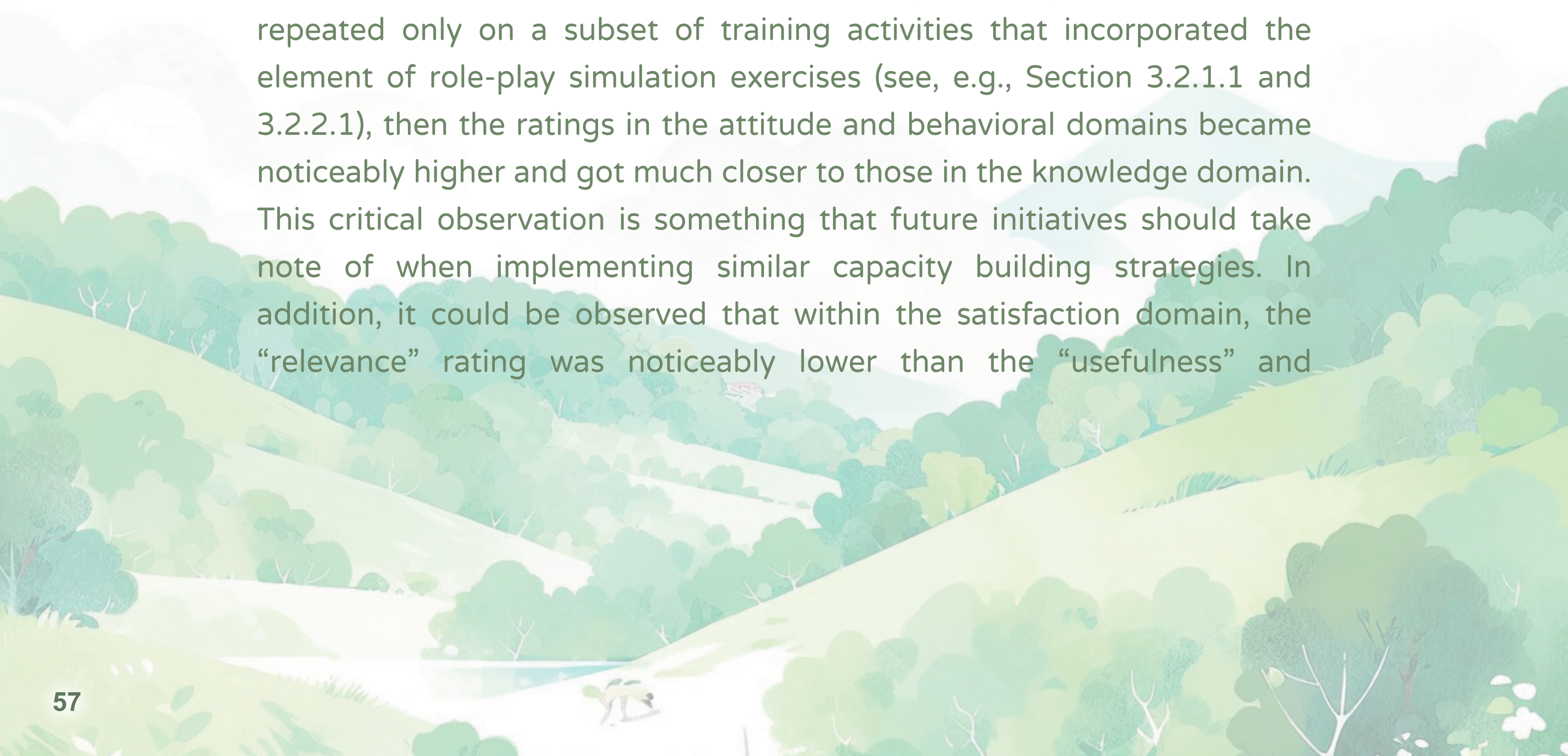
- In discussion of ACP, what goals are we trying to achieve?
- Is ACP only a procedure to get a consensus and signing of ACP/AMD form?
- What are the patient's and family's needs in ACP discussion?
- What kind of support we should/could provide?
- What kind of care we should/could provide from now (ACP discussion) to the very end?

3.2.6 Evaluation results

In what follows, we present the evaluation results of the capacity building component. Section 3.2.6.1 first summarizes the questionnaire findings that directly captured the effectiveness of the training activities. Section 3.2.6.2 then highlights some of the observations documented during the training activities and discusses their implications.

3.2.6.1 Questionnaire findings

Table 1 summarizes the quantitative evaluation results of training activities for healthcare professionals. To ease the presentation, a few representative items are selected for each of the KAB and satisfaction domains (see Section 2.3.5). Considering that the items were rated on a 5-point Likert scale, results show that the training activities were effective and well-received, in the sense that the average scores of all items were above 4. However, it could be observed that in general, the “behavior” rating was less than those in the attitude domain, which in turn were less than those in the knowledge domain. In addition, the “behavior” rating induced the highest level of variability, showing that the participants were least certain about the effectiveness of training in this aspect. Altogether, the above indicates that while it may be relatively simple to impart knowledge to healthcare professionals, converting such benefits into attitudinal and behavioral changes still requires extra effort. This is the reason why the project team put much emphasis on the practical aspects, hands-on experiences, and interactive modality when designing the Programme activities, as opposed to merely delivering the training in a traditional lecture format. In fact, if the descriptive analyses in Table 1 are repeated only on a subset of training activities that incorporated the element of role-play simulation exercises (see, e.g., Section 3.2.1.1 and 3.2.2.1), then the ratings in the attitude and behavioral domains became noticeably higher and got much closer to those in the knowledge domain. This critical observation is something that future initiatives should take note of when implementing similar capacity building strategies. In addition, it could be observed that within the satisfaction domain, the “relevance” rating was noticeably lower than the “usefulness” and

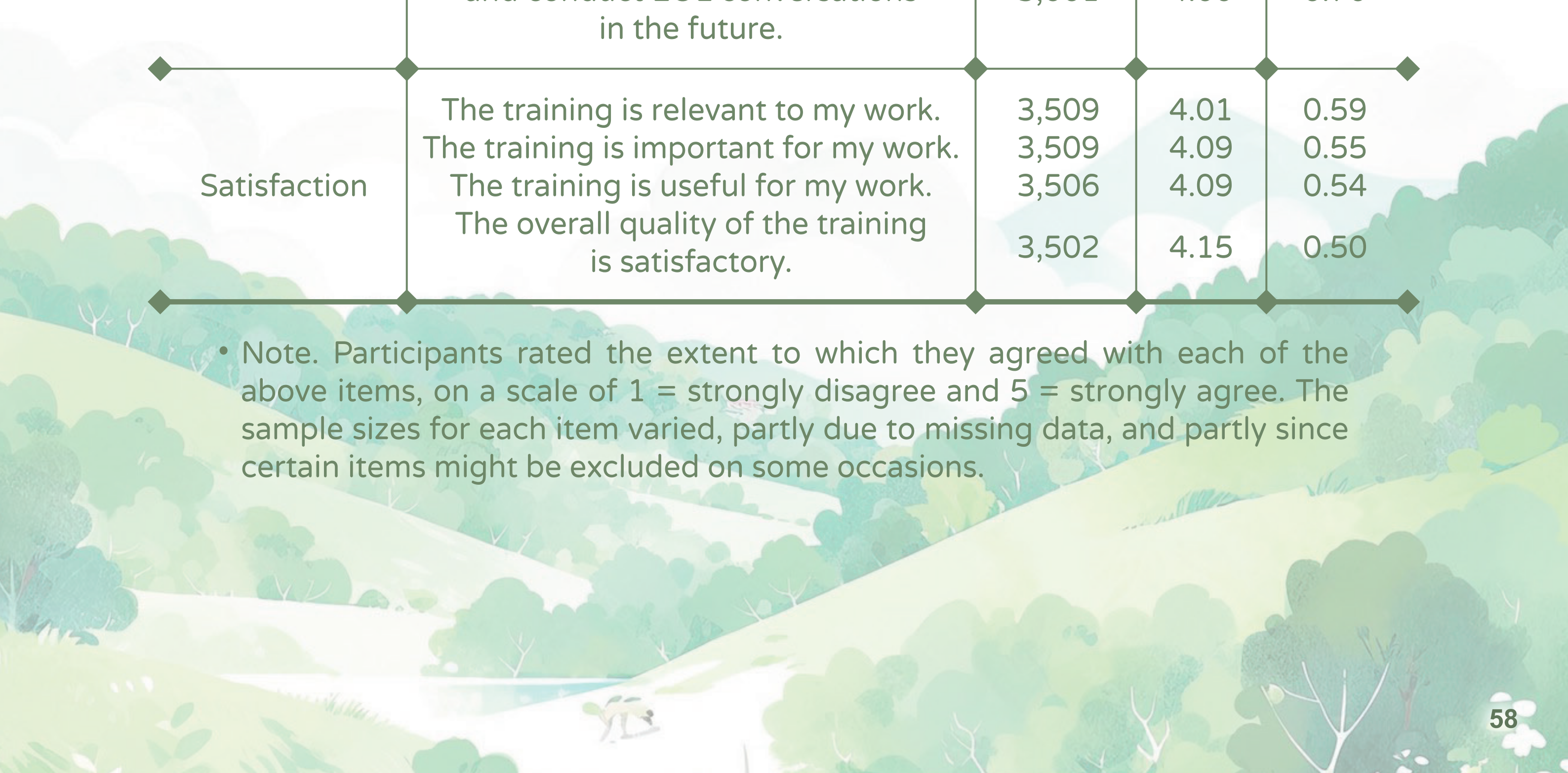


"importance" ones. In fact, this phenomenon was especially evident among doctor participants, indicating that at least some of them still perceived EOL care to be extraneous to their clinical practice. The implication of this will be discussed in more detail in Section 3.2.6.2, together with other observations revolving around doctor participants.

Table 1.
Evaluation results of training activities for healthcare professionals.

Domain	Item	N	M	SD
Knowledge	The training increased my knowledge of EOL care.	3,721	4.12	0.56
	The training raised my awareness of EOL care.	3,466	4.20	0.57
	The training improved my EOL communication skills.	2,796	4.10	0.56
Attitude	The training improved my confidence in initiating and conducting EOL conversations.	3,049	4.06	0.67
	The training increased my motivation in initiating and conducting EOL conversations.	2,797	4.04	0.67
Behavior	The training prompted me to initiate and conduct EOL conversations in the future.	3,001	4.00	0.70
Satisfaction	The training is relevant to my work.	3,509	4.01	0.59
	The training is important for my work.	3,509	4.09	0.55
	The training is useful for my work.	3,506	4.09	0.54
	The overall quality of the training is satisfactory.	3,502	4.15	0.50

- Note. Participants rated the extent to which they agreed with each of the above items, on a scale of 1 = strongly disagree and 5 = strongly agree. The sample sizes for each item varied, partly due to missing data, and partly since certain items might be excluded on some occasions.



On the other hand, the evaluation of training activities designed for CUHK medical students (see Section 3.2.4.1) was performed in a slightly different manner. Since these activities were embedded into the academic curriculum, they were delivered throughout the entire semester, which enabled longitudinal assessment of the participants. Taking advantage of this, pre-post training comparisons[14] were conducted using paired t-tests to more explicitly capture the effectiveness of the activities. As shown in Table 2, medical students became significantly more prepared to conduct EOL conversations with patients and their family members. In particular, they became more capable of responding to the emotions of their care recipients, as well as using non-verbal techniques to facilitate the communication process.

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[14] The post survey was usually administered about three weeks after the training.

Table 2.
Pre-post training comparisons of medical students' perceived preparedness in conducting EOL conversations (N = 401).

Item	M (SD)		t	p
	Pre	Post		
Discuss bad news with patients and their family members about serious illness	2.38 (0.68)	3.10 (0.65)	13.27	< .001
Respond to emotions from patients and their family members	2.40 (0.69)	3.00 (0.58)	11.58	< .001
Use non-verbal communication to facilitate serious illness conversations	2.58 (0.68)	3.25 (0.68)	12.14	< .001
Use verbal expressions to show empathy in serious illness conversations	2.48 (0.65)	3.14 (0.63)	11.49	< .001
Elicit concerns or needs from patients and their family members	2.55 (0.65)	3.15 (0.62)	10.98	< .001

- Note. Participants rated the extent to which they were prepared to carry out the action as described in each of the above items, on a scale of 1 = not at all prepared and 5 = extremely prepared. The analysis only considered those who completed both the pre- and post-surveys.

3.2.6.2 Key observations and discussions

The first key point is about the role-play simulation exercise, which was universally perceived by all participants to be an innovative and effective modality for delivering the training. In particular, many doctor participants thought that it was a precious learning experience, since they rarely had the chance to acquire and practice communication skills using this kind of approach before. But perhaps because of this, it could be observed that, as compared with nurses and social workers, doctor participants tended to underperform in these role-play simulation exercises. For instance, it was common for the externally recruited actors, who played as the patients or family members, to make the comment that doctor participants were perceived to be simply reading the communication protocol out loud, instead of responding in an authentic, empathic, and compassionate manner. When the actors sometimes escalated their emotions deliberately, doctor participants might resort to repeating the same responses[15] and fail to continue the conversation or identify the agenda hidden underneath those emotional expressions. More generally speaking, many of them were nervous and became stuttered, especially when the scope of conversation fell beyond their medical expertise. They were often reluctant to directly talk about the prognosis and remaining life expectancy so as to avoid negative reactions. When explaining the treatment options, they were also inclined to use English and technical jargons, which were likely something that they were more comfortable with, but which rendered the conversations less comprehensible from a layperson's perspective. In contrast, nurses and social workers, albeit less confident and proficient in handling the medical aspects of the conversation, tended to be able to address the needs and concerns of the actors, as well as to alleviate their emotions. To conclude, many doctors were, perhaps in accordance with our stereotypical impressions, not as competent in conducting EOL conversations. While the Programme activities, especially the role-play simulation exercises, were effective in improving the communication skills of the participants, or at least in terms of making them aware of their own inadequacies, it must be acknowledged that the coverage of these activities for doctors was still less than ideal. For instance, the total number

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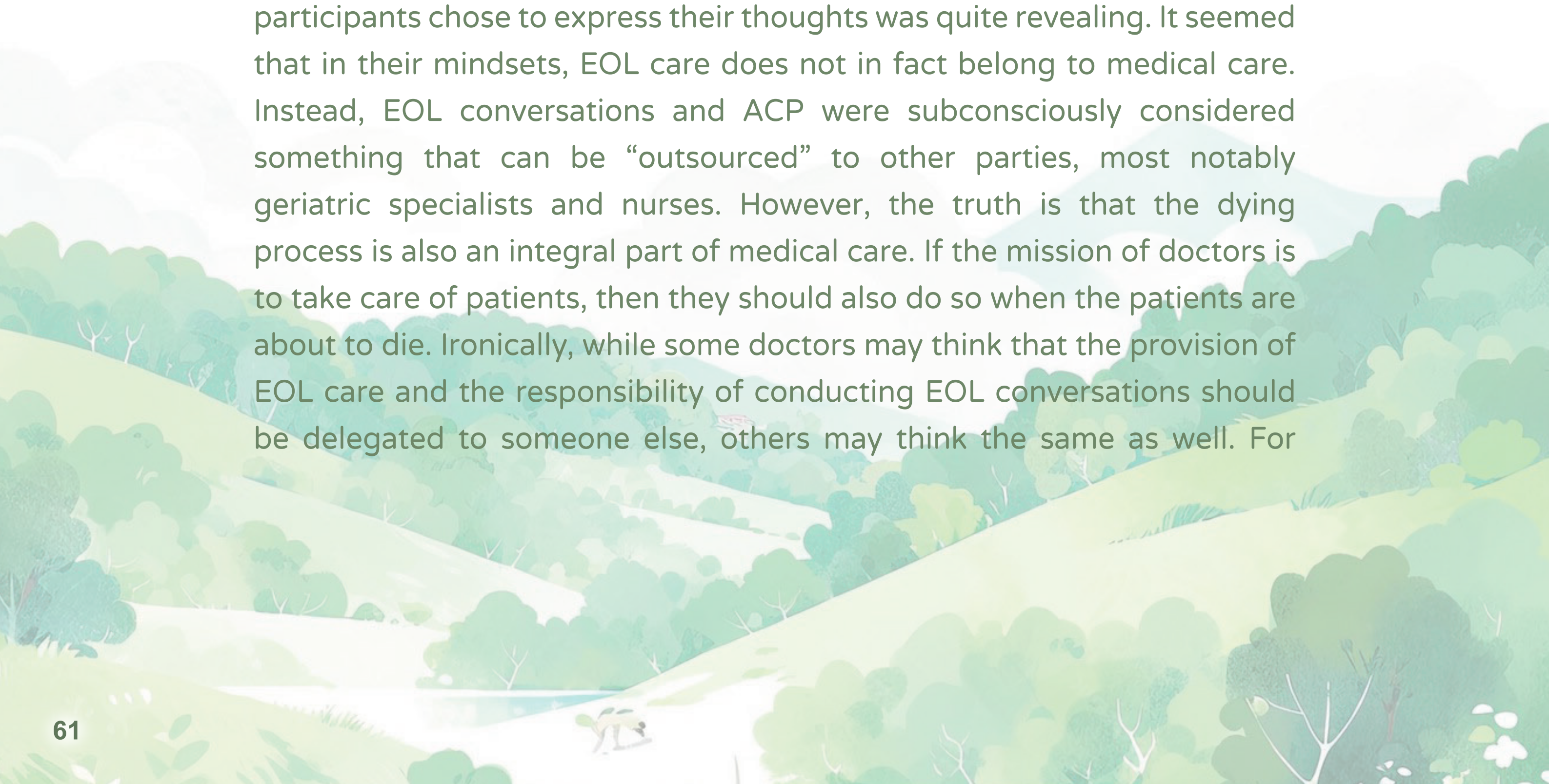
[15] For instance, participants might repeat the phrase "I understand your feelings" over and over again.

of training sessions, as well as the average training duration and participation rate, were regrettably the lowest among doctors, despite a comparable level of resources being allocated. It could be noticed that while the training for nurses had gradually become saturated over the ten-year period, such a phenomenon did not occur among doctors. The underlying factor was that doctors tended to have less time and motivation to learn about EOL communication skills, especially if they considered such skills irrelevant prior to attending the training. The implication drawn from this observation is that training for doctors should indeed be made compulsory and initiated as early as possible, that is, during the stage of undergraduate education (see Section 3.2.4.1). In addition, it is recommended that the HA should continue to place higher priority and put more advocacy efforts on the training for doctors. Ideally, training on EOL communication skills that incorporates the element of role-play simulation exercises should be delivered to doctors in a more routinized manner, whose frequency and duration are on par with that of the training for nurses.

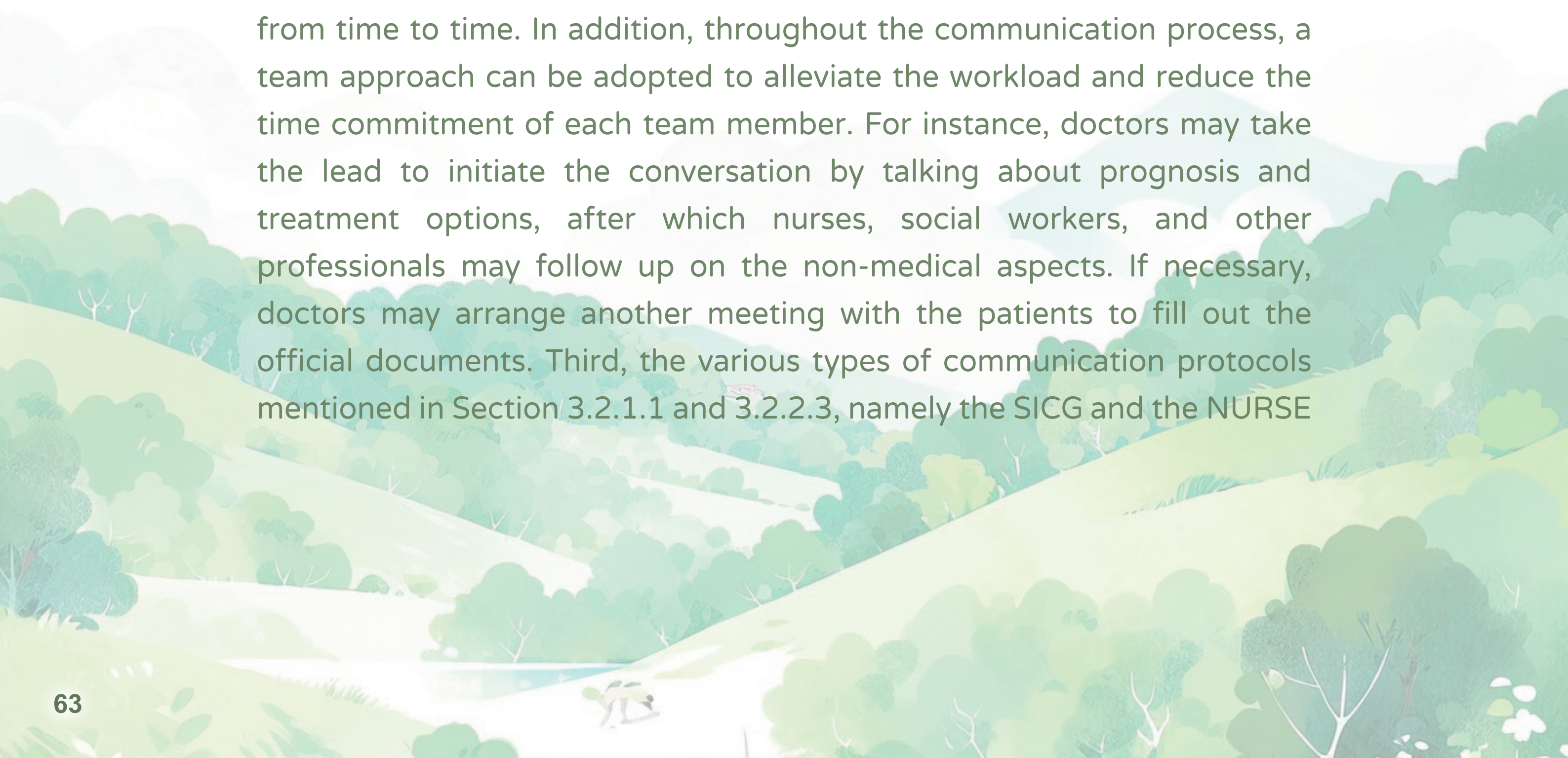
The second key point, which has already been touched upon several times throughout the present report, is that many participants still perceived the responsibility of delivering EOL care as something that should be dedicated to a specific profession or specialty. For instance, during several training activities for doctors, some participants explicitly stated that their job nature was to “provide medical care” and, because of that, they were not supposed to “deal with” EOL conversations. The wording that these participants chose to express their thoughts was quite revealing. It seemed that in their mindsets, EOL care does not in fact belong to medical care. Instead, EOL conversations and ACP were subconsciously considered something that can be “outsourced” to other parties, most notably geriatric specialists and nurses. However, the truth is that the dying process is also an integral part of medical care. If the mission of doctors is to take care of patients, then they should also do so when the patients are about to die. Ironically, while some doctors may think that the provision of EOL care and the responsibility of conducting EOL conversations should be delegated to someone else, others may think the same as well. For



instance, during the second multi-disciplinary webinar as mentioned in Section 3.2.5, several participants with a non-medical background claimed that the discussion process of ACP is too medical and technical, and thus they were puzzled about their roles and potential contributions in this regard. In particular, one question was raised as to whether a dedicated case manager or medical officer should be assigned to conduct ACP for each patient, and whether this would constitute a better approach. While this question certainly had good intentions, it perhaps overlooked the fact that the number of people who can benefit from this will never catch up with the number of people needing it. As the annual number of deaths in Hong Kong has exceeded 50,000 in recent years (C&SD, 2024), it would be infeasible to assign dedicated personnel to conduct EOL conversations with each of the dying patients. More crucially, overemphasizing the existence and uniqueness of such dedicated personnel may only prompt the remaining members in the healthcare team to shirk responsibility and form a deadlock in which nobody is willing to take the initiative, as is evident from the above observations. This is precisely the reason why the project team strongly advocates the approach in which the responsibility of conducting EOL conversations is distributed across different disciplines and specialties, and that EOL communication should be considered a core skill to all. While the Programme activities were certainly effective in correcting the above misunderstandings, it is clear that more ongoing efforts are still required. In particular, multi-disciplinary training is essential for bringing different professions together and enabling them to appreciate the importance of the team approach to delivering EOL care. Throughout the ten-year period, it could be noticed that, despite the best endeavours of the project team,[16] most participants and training coordinators preferred the activities to be delivered separately for different target groups. To illustrate, some doctors thought that it would be “strange” for them to attend a training together with nurses and social workers. In view of this, it is recommended that the HA and other future initiatives should put more advocacy efforts on the normalization and routinization of this kind of multi-disciplinary training.

[16] Although this Chapter presents the deliverables separately for each target group, most of the Programme activities in fact welcomed participants from other professions or disciplines, whenever the content was deemed appropriate.

The last key point that deserves mention is also the most commonly received feedback among frontline participants, that is, the lack of time to conduct EOL conversations in their work environment. Regarding this issue, instructors and speakers of the training activities have provided a wealth of insightful comments. Given that time constraint is such a prominent and universal concern, it is valuable to document these comments here for future references. First, EOL conversations should not be thought of as something that can be sacrificed by default when time and manpower are limited. In some sense, EOL conversations are not that distinct from other medical procedures, as both are simply different ways to achieve the same objective of maintaining the well-being of patients. If it is considered reasonable and necessary to spend 30 minutes performing, say, a tube feeding procedure, then the same should apply for EOL conversations as well. In fact, from the perspective of maximizing the benefits of patients, it is arguably more “worthwhile” to spend at least some time on EOL conversations, since it is the only way to guarantee that care can be provided on a best-interest basis. Again, it should be emphasized that EOL communication is an integral part of medical care. While it is understandable that healthcare professionals may face time constraints and stress, it is not a proper justification to lower the priority or even dismiss the necessity of EOL conversations. Second, the EOL communication process cannot and should not be completed in one go. Because of that, if time does not permit, then there is no need to arrange for a formal, hour-long session to discuss everything. Instead, healthcare professionals may gradually build rapport with patients and family members through daily interactions, and attempt to elicit their preferences from time to time. In addition, throughout the communication process, a team approach can be adopted to alleviate the workload and reduce the time commitment of each team member. For instance, doctors may take the lead to initiate the conversation by talking about prognosis and treatment options, after which nurses, social workers, and other professionals may follow up on the non-medical aspects. If necessary, doctors may arrange another meeting with the patients to fill out the official documents. Third, the various types of communication protocols mentioned in Section 3.2.1.1 and 3.2.2.3, namely the SICG and the NURSE



and SPIKES statements, are particularly useful when healthcare professionals need to conduct EOL conversations under time constraints. These protocols can be timesaving, not because they convert the communication process into a quick and streamlined check-box exercise, but because they enable healthcare professionals to more easily and effectively probe into the thoughts of patients, which ultimately determine their decision-making. Notably, it seemed that the NURSE and SPIKES statements were relatively well-known among nurse participants. In contrast, the majority of doctor participants had not heard of the SICG before, which perhaps contributed, at least partially, to the phenomenon that they were the most likely to claim that there was insufficient time to conduct EOL conversations. In view of this observation, the project team has made the best efforts to further promote the use of the SICG, for instance, by producing several informational videos on this communication protocol (see Section 4.3.1).

3.3 Public education

During the ten-year period, more than 240 promotional and educational sessions were conducted to raise public awareness towards EOL care, which, in conjunction with other intangible activities, benefited more than 30,000 individuals from our society. To ease the presentation, in what follows we organize the Programme activities in accordance with the types of target beneficiaries. Section 3.3.1 summarizes the most generic types of activities that were open and applicable to all interested individuals from the general public, including the younger generations. Section 3.3.2 focuses on the activities that were specifically designed for caregivers and family members of current or soon-to-be EOL patients. Last, Section 3.3.3 mentions the activities intended for older people, including the community-dwelling ones and those who were residing in RCHEs.

3.3.1 The general public

As emphasized throughout Section 1.2.1, although EOL care is intended for end-stage patients, EOL planning is something that can and should be initiated at the earlier life stages. In view of this, the project team also put emphasis on educating the general public, even though most of these target beneficiaries were not facing imminent death. Under this category, a great variety of regular activities as well as several large-scale events and exhibitions were organized, reaching and benefiting individuals from all backgrounds and age groups.

3.3.1.1 Dying Matters Awareness Event

The Dying Matters Awareness Event (henceforth referred to as the Event) was a series of signature activities and multi-media campaign organized throughout the year of 2020. Drawing inspiration from the Dying Matters coalition in the United Kingdom, the Event was aimed at generating a moment and opportunity for the public to engage in reflections and open discussions about EOL issues. The main theme of the Event was “Live Free, Die Well” (“安心來・安心去”), which advocated that everyone should start to think about EOL planning as early as possible and thereby be able to live without any worries about death.

The key activity that ran through the Event was a territory-wide drawing competition, the objective of which was to enable participants to depict their perspectives on EOL care and life-and-death issues through the means of arts. To convey the message that the competition welcomed and encouraged the participation of all individuals with different ages and backgrounds, five categories of entries were included in the competition, namely the secondary students' group, tertiary students' group, healthcare professionals' group, older people's group, and open group. Altogether, the competition attracted 260 submissions. Subsequently, the award-winning entries were showcased at the Art Community Gallery in various MTR stations, as well as the Sha Tin Town Hall Exhibition Gallery. In addition, these entries were converted into souvenir calendars, which were widely distributed in the community to maximize the promotional benefits of the competition. As a finale to the Event, a closing cum award presentation ceremony was organized at the end of that year. During the ceremony, some of the awardees were invited to share the thought process underlying their artwork, as well as their personal reflections as stimulated by the competition. Besides, the ceremony also featured a mini concert, in which a renowned musical band from Forget Thee Not[17] performed several popular funeral songs to remind the audiences that life-and-death issue are in fact pervasive in their daily lives.

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[17] Forget Thee Not is a social enterprise aiming to promote EOL planning, ACP and AMD, and funeral and burial services.

Figure 17. MTR Art Community Gallery displaying the winning entries of the "Live Free, Die Well" drawing competition.

Overall, the Event was a major success and gained wide popularity through its presence in various social media platforms. For instance, the YouTube channel specifically created for the Event had accumulated a total of 332,963 views[18] and attracted 1,640 subscribers during the concerned period, while the Facebook page had accumulated 19,535 views, 1,518 likes and 649 followers.

3.3.1.2 Talks and information sessions

Besides the Event, most of the other Programme activities designed for the general public loosely fell under the category of talks and information sessions. In the earlier days of the Programme, the majority of these sessions focused on the conventional topics in EOL care and were delivered in a more traditional format. Examples in this regard included a public library talk series conducted throughout 2016 and 2017, which introduced the concepts of ACP and AMD, and a large-scale talk conducted in 2019 with the Hong Kong Life and Death Studies Association, which aimed to promote EOL planning, organ donation, and the "Silent Teacher"[19] body donation scheme.

As the Programme evolved, the project team gradually diversified the content and formats of these sessions, with the aim of sensitizing the participants in a more comprehensive and engaging manner. For instance, in 2020, an innovative session was organized in collaboration with Forget Thee Not to impart knowledge about ACP and AMD. This session featured an immersive theatre experience, in which the participants were guided to contemplate life-and-death issues through the means of interactive dialogues. For another instance, in an online talk series conducted throughout 2021, the project team invited two local academics, one with a background in history and one with a background in cultural and religious studies, to share their knowledge and understandings about EOL care from a Chinese tradition's and a Buddhist's perspective, respectively. More recently, the project team also explored the possibility of delivering some of the sessions on ACP using a "human library" format. More specifically, in these sessions, several doctors and caregivers were invited to serve as "human books" to share their life stories and personal experiences related

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[18] As part of the multi-media campaign, the project team produced two videos, including a micro-movie and a celebrity interview, for the Event. The details of these videos will be described in Section 4.3.3 and 4.3.4.

[19] This scheme enables deceased individuals to bequeath their bodies to the dissecting laboratory of the CUHK for teaching and academic purposes.

to ACP and EOL conversations. Through this way, the participants could develop more authentic understandings about how EOL care is delivered in actual practice.

Figure 18. Immersive theatre conducted with Forget Thee Not.

3.3.1.3 Network of Ageing Well for All

Established and maintained by the main body of the IOA, the Network of Ageing Well for All (NAWA) is a platform for older people and other interested individuals to gain knowledge, improve awareness, and share their diverse voices on ageing issues. Through this platform, the project team conducted an annual series of public education events called "吾好吾理," which consisted of talks, guided tours, interactive workshops, and other experiential learning activities. We specifically bring up this platform here and differentiate its activities from those mentioned in Section 3.3.1.2, because of the following reasons. The NAWA does not treat its members as passive beneficiaries. Instead, it emphasizes the active role of its members and encourages them to take the initiative and promote healthy ageing within their own communities. Following this philosophy, a so-called "NAWA EOL alumni association" was established under the guidance and assistance of the project team, which consisted of passionate NAWA members who had participated in one or several of the previous “吾好吾理” activities. The members of this association were devoted to acting as community ambassadors and promoting EOL care among the general public through volunteering efforts. Some members even formed a working committee, which, together with the project team, was responsible for overseeing the planning and execution of some of the subsequent “吾好吾理” activities. The importance of this initiative cannot be overstated, since it indicates that the benefits of the Programme with respect to raising public awareness can be sustained, even after the ten-year period.

Figure 19. Interactive activities organized by the NAWA EOL alumni association.

3.3.1.4 Roving exhibitions

Throughout the ten-year period, roving exhibitions were held periodically at various public hospitals and libraries, for publicizing the general concepts and knowledge of EOL care, as well as for promoting the resources and materials produced under the Programme. Some of these exhibitions did not only provide information about EOL care, but also featured an interactive zone in which viewers could share their thoughts and experiences with others by leaving a message on the board. Considering the high flowrate in these public areas, it was estimated that over tens of thousands of passers-by were attracted to view the exhibitions.

Figure 20. Roving exhibitions at various public hospitals.

3.3.2 Caregivers, health volunteers, and family members

Unlike many people from the general public who may not have a personal stake in life-and-death issues, knowledge related to EOL care is of direct and immediate concern to caregivers, health volunteers, and family members of patients who are undergoing the dying process. For this reason, educational activities designed for this target group were not only intended to publicize the general concepts in EOL care, but were also aimed to impart more concrete knowledge about treatment and care options, EOL conversations, and the executional details of ACP and AMD.

3.3.2.1 Family sessions on Advance Care Planning

The highlighted activity in this category was the so-called ACP family session, which has been held approximately once per month since 2021. The family session originated from a collaboration with Tai Po Hospital back in 2020 (see To et al., 2020) and was later adapted to Shatin Hospital as a regularized activity. The participants were mostly caregivers or family members of patients who were hospitalized in the infirmary ward or the medicine and geriatric ward.[20] As compared with other public education activities, these family sessions were small-group in nature (i.e., less than ten participants) and longer in duration (i.e., around 2 to 2.5 hours). The

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[20] Starting from 2024, some participants were general visitors externally recruited via the HRC.

reason for this was to create an informal and more comfortable environment for the participants to conduct sharing, as well as to provide them with sufficient time to build a solid understanding of EOL care, even including some of the more medical and technical aspects that were typically not covered as much in other public activities.

Each family session was led by a social worker and a geriatrician. It began with a scenario-based discussion, in which the participants were guided to think about and express their own preferences on EOL care in some hypothetical circumstances. Echoing with the point made in Section 1.3.2.3, the purpose of this warm-up activity was to enable and encourage the participants to put themselves in the patients' shoes when conducting EOL conversations. Next, participants were introduced to the concepts in EOL care with the aid of various educational materials, in which the emphasis was put on the importance of early EOL planning, differences between treatment approaches, implementation details of ACP and AMD, and practical tips related to post-discharge arrangements. Throughout this process, participants were encouraged to share their personal thoughts and feelings at any time, which were usually related to the difficulties that they had encountered when taking care of the patients. The social worker in charge then played the role of acknowledging the participants' experiences and providing them with some comforting feedback and recommendations for handling the identified challenges. Finally, the geriatrician was responsible for elaborating on the benefits and risks of various LSTs, such that the participants could have a firmer grasp on what to expect from each treatment option.

Besides the main content covered in the family session, there were two features of this activity that deserve special mention. First, on some occasions, doctors and nurses from the corresponding wards, social workers from the HRC, as well as the patients themselves, were also invited to participate in the family sessions. For the attending healthcare professionals, this served as a platform for them to better understand the needs, worries, and struggles of their care recipients. On the other hand, the patients could use this as an opportunity to articulate and document their preferences on EOL care, thereby ensuring that their thoughts could be well understood by their care providers and family members. Second, follow-up meetings were arranged after the family sessions, on an as-needed basis, for the participants such that they could obtain more detailed information about EOL care and personalized advice based on their individual situations. If deemed appropriate, the social worker and geriatrician would assist the participants in initiating the ACP discussion process with the patients, as well as preparing the signing of AMD and DNACPR order.

Figure 21. ACP family sessions at Shatin Hospital.

3.3.2.2 Talks and information sessions

Talks and information sessions were held intermittently for caregivers in various community centres across districts. The target audience included not only family members of EOL patients, but also community health volunteers who might sometimes provide assistance in the delivery process of EOL care. Topics covered in these sessions included, for instance, how to initiate EOL conversations with patients, how to utilize existing resources and support systems, and how to regulate emotional distress and deal with caregiver strain. Noteworthily, the last theme above is related to self-care for caregivers, which is often overlooked in the context of EOL care, since the quality of life of patients is always being put under the spotlight. In view of this, as the Programme evolved, the project team gradually introduced more elements related to this topic into the educational activities. Ultimately, these efforts could empower the caregivers, such that they had enhanced capacity, both physically and psychologically, to provide better care for the patients.

Figure 22. Talks for community health volunteers.

3.3.3 Older people

For this category of educational activities, the major objective was to help the participants kickstart their EOL planning and documentation process. This was because among all target groups, they probably had the most urgent need to do so. For this purpose, the sessions were designed not only to impart knowledge and elicit awareness, but also to directly prompt the participants to articulate and record their EOL preferences.

3.3.3.1 Group session series on the Advance Care Planning Handbook

The first featured activity under this category was a group session series on the so-called "Advance Care Planning Handbook," a handbook published by the project team that will be introduced in detail in Section 4.2.2. The series usually comprised three to four sessions, which were conducted weekly in an elderly centre, using a small-group and face-to-face format. The first session began with some ice-breaking activities, which were designed to make the participants comfortable talking about life-and-death matters, as well as to get them familiar with each other such that they could interact more freely and proactively in the discussion. Subsequently, the participants were guided to think about their EOL preferences and record them using the handbook. During this process, additional staff members from the project team and volunteers (i.e., the ones mentioned in Section 3.3.1.3) would offer a helping hand to the participants, if necessary, to ensure that they could complete the documentation smoothly, irrespective of their levels of literacy and mental capacity. After each session, participants would be encouraged to share what they documented on that day with their family members, which served as an excellent opportunity for them to initiate the communication process and articulate their preferences.

Figure 23. Group sessions on the Advance Care Planning Handbook.

3.3.3.2 Horticultural workshops

The second type of featured activity under this category was horticultural workshop. These sessions were mainly intended for RCHE residents or palliative day care service users who had relatively poor health and mental conditions. In accordance with the characteristics of these participants, the primary objective was no longer to spread information or raise awareness on EOL care. Instead, the workshops were designed to provide a relaxing environment, through the means of experiential horticultural activities, for the participants to engage in self-introspection and express their final thoughts, under the accompany of their family members.

3.3.3.3 Talks and information sessions

Last, ordinary talks and information sessions were also regularly provided to older people in various RCHEs. The topics covered in these sessions were, as compared with those mentioned in Section 3.3.1.2 and 3.3.2.2, not as diversified or rich in knowledge. Instead, most speakers simply adopted a casual, chit-chat style to discuss life-and-death matters with the participants.

Figure 24. Talks for older people in RCHEs.

3.3.4 Evaluation results

In what follows, we present the evaluation results of the public education component. Section 3.3.4.1 first summarizes the questionnaire findings that directly captured the effectiveness of the educational activities. Section 3.3.4.2 then highlights some of the observations documented during the educational activities and discusses their implications.

3.3.4.1 Questionnaire findings

Table 3 summarizes the quantitative evaluation results of educational activities for the public. To ease the presentation, a few representative items are selected for each of the KAB and satisfaction domains (see Section 2.3.5). Considering that the items were rated on a 5-point Likert scale, results show that the educational activities were effective and well-received, in the sense that the average scores of all items were above 4. Similar to the results in Table 1 (Section 3.2.6.1), the ratings in the knowledge domain were higher than those in the attitude and behavior domains, but to a lesser extent. This provides indirect evidence that, in comparison with healthcare professionals, it was easier to motivate and prompt the public to take concrete actions and initiate EOL conversations. Furthermore, all of the public ratings, including the “relevance” one, were noticeably higher than the healthcare professionals’ counterparts. Taken together, these results corroborate the claim that the societal taboo around death had mostly faded away and was no longer making the public afraid of receiving information related to EOL care. The implication of this will be mentioned again in Section 3.3.4.2.

Table 3.
Evaluation results of educational activities for the public.

Domain	Item	N	M	SD
Knowledge	The activity increased my knowledge of EOL care.	1,399	4.30	0.51
	The activity raised my awareness of EOL care.	1,397	4.27	0.52
Attitude	The activity improved my confidence in discussing and making plans for issues in EOL care.	1,262	4.25	0.54
	The activity increased my motivation in discussing and making plans for issues in EOL care.	1,261	4.25	0.55
Behavior	The activity prompted me to discuss and make plans for issues in EOL care in the future.	1,297	4.22	0.56
Satisfaction	The activity is relevant to my personal life.	1,479	4.35	0.53
	The activity is important to my personal life.	1,478	4.32	0.53
	The activity is useful for my personal life.	1,476	4.35	0.52
	The overall quality of the activity is satisfactory.	1,480	4.40	0.49

- Note. Participants rated the extent to which they agreed with each of the above items, on a scale of 1 = strongly disagree and 5 = strongly agree. The sample sizes for each item varied, partly due to missing data, and partly since certain items might be excluded on some occasions.

3.3.4.2 Key observations and discussions

The first aspect of observations is a further elaboration of the points highlighted in Section 1.3.2.2. It could be noticed that in most, if not all, of the educational activities, no participants were reluctant to receive information or talk about the issues in EOL care. Quite the contrary, many of them were extremely eager to learn more about this topic. Some older participants stated that as time has changed, there is no longer any reason to be afraid of EOL conversations. When asked about their planning in this regard, many claimed that they had already thought thoroughly and decided to opt against the use of LSTs, while some others said that they wanted to get the financial arrangements done so as to feel less worried. To conclude, it seemed that the taboo of thinking and talking about life-and-death matters, while certainly existing in the past, has become history in the modern era. However, since some healthcare professionals still stuck with the perception that older people are unwilling to talk about deaths, or perhaps since they used this as an excuse, they did not offer enough assistance to guide patients and family members to document their preferences. In fact, prior to attending the educational activities, many participants did not realize that they needed to express and record their thoughts, because no one had brought up such issues to them. On the other hand, among those with higher levels of awareness and readiness, many had the bad experiences of being “rejected” by the healthcare team in this regard. For instance, a 90-year-old participant claimed that he wanted to sign the AMD, but unfortunately to no avail because none of the doctors was willing to perform a mental capacity assessment for him. In view of the above, many participants thought that the educational activities were delivered in a particularly timely manner, in the sense that they now became aware of the importance of communicating and documenting their preferences, and that they were given practical guidance on how to initiate the conversation with their care providers, as well as on how to seek assistance from other parties when necessary.

The second aspect of observations is about the ACP family sessions[21] as described in Section 3.3.2.1. Through collaboration with the geriatric ward and HRC at Shatin Hospital, the project team has established a referral mechanism to get in touch with the family members of seriously ill patients. This was a valuable interface, especially since these caregivers were supposedly the ones who urgently needed to learn more about EOL care and ACP, such that they could make better plans for their care recipients. Interestingly, however, a significant number of participants were not aware of the topics and content to be covered in the sessions. More precisely, many participants thought that the session was only about some practical techniques and tips for delivering care, such as feeding skills that are applicable to demented patients. Some of them indicated that they were simply too busy taking care of the patients and handling the repeated admissions and discharges, and thus became overly fixated on those issues and had no room to think about other aspects. Because of that, they found the session extremely useful, as it covered some important topics that they might have overlooked, in particular the pros and cons of LSTs, as well as the compromises between different treatment approaches. In addition, due to the small-group nature of the sessions, many participants were willing to disclose and share their personal stories. As a concrete example, one pair of participants expressed that they were experiencing some struggles while trying to work out the optimal EOL care plan for the patient, because of the incompatible recommendations given by different doctors and departments. Through this process, participants could not only seek second opinion and professional advice from the speakers, but also channel their emotions and thereby alleviate the caregiver strain. This demonstrates that the ACP family session also carried some therapeutic benefits in its own right.

The last aspect of observations is related to different types of questions raised by participants during the educational activities. In general, participants from the public were much more enthusiastic in asking

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[21] This paragraph only documents the observations recorded during the ACP family sessions. Other thoughts and remarks on the sessions as revealed by more in-depth interviews with the participants will be covered in Section 5.6.

questions and giving comments, as compared with the healthcare professionals' counterpart, again corroborating the claim that the public was open and willing to learn more about the issues in EOL care. Among these questions, there were two major categories that deserve special mention here. The first category was about financial matters and legal issues in post-death arrangements. Many participants were very interested in the specific details of the will and EPA, to the extent that they would raise these questions even when the activities were not supposed to cover such topics. In the earlier days of the Programme, speakers often could not provide a definite response, as they did not receive any formal training in the legal field. In view of this, the project team arranged more specific sessions starting from the 2nd phase, in which solicitors were invited to provide in-depth explanations on the legal issues in EOL care, as well as to address the questions and concerns more directly. Encouragingly, it turned out that these sessions were highly regarded among not only the participants, but also the NGOs and RCHEs that made the request to organize such kind of activities. The second category of questions, which was usually raised by caregivers, was related to the available resources and existing EOL care services in the community setting. For instance, some participants wanted to know more about post-discharge arrangements and how to apply for subsidized long-term care services. Among them, many found it difficult to select the most appropriate care home, because the staff from public hospitals tended not to provide this kind of information explicitly so as to avoid conflict of interest. In view of the above, the project team has paid more attention to this topic starting from the 2nd phase. For instance, content related to accessible community resources and referral network in EOL care was more frequently mentioned in the information sessions for caregivers (see Section 3.3.2.2). In addition, an experienced social worker from the project team would occasionally provide personalized recommendations to the participants, based on their situations and actual needs, as to which kinds of community resources suit them best.

4 Educational Resources

4.1 Overview

In this Chapter, we provide an exhaustive summary of the educational resources produced under the Programme, describing their content as well as how they were used and distributed. Broadly, these resources can be categorized into publications[22] and videos, which will be the focus of Section 4.2 and 4.3, respectively. To facilitate easy reference and achieve sustainable utilization of these resources, most of them were uploaded to the IOA website and YouTube channel. In addition, an online knowledge transfer platform is currently being constructed to compile these resources. In a similar vein, multiple versions of souvenir USBs, which were designed to provide convenient, one-stop access to these resources, were produced and distributed to the participants of the Programme activities.

4.2 Publications

Table 4 is a complete list[23] of publications produced during the ten-year period. All publications are available in both print and electronic formats. In general, most of the printed copies were distributed during the Programme activities. Notably, other parties such as JCECC partners, NGOs, and frontline practitioners were welcomed and encouraged to request copies of these publications, such that they could distribute them to their clients and make the best use of them in practice. The project team advocated and employed this resources-sharing approach, with the aims of maximizing the utilization and benefits of the publications, avoiding unnecessary production of duplicated resources, and promoting the collaboration and interoperability between different parties.

[22] Here, we only refer to publications intended for educational purposes. Other publications for academic and research purposes will be covered in Chapter 5.

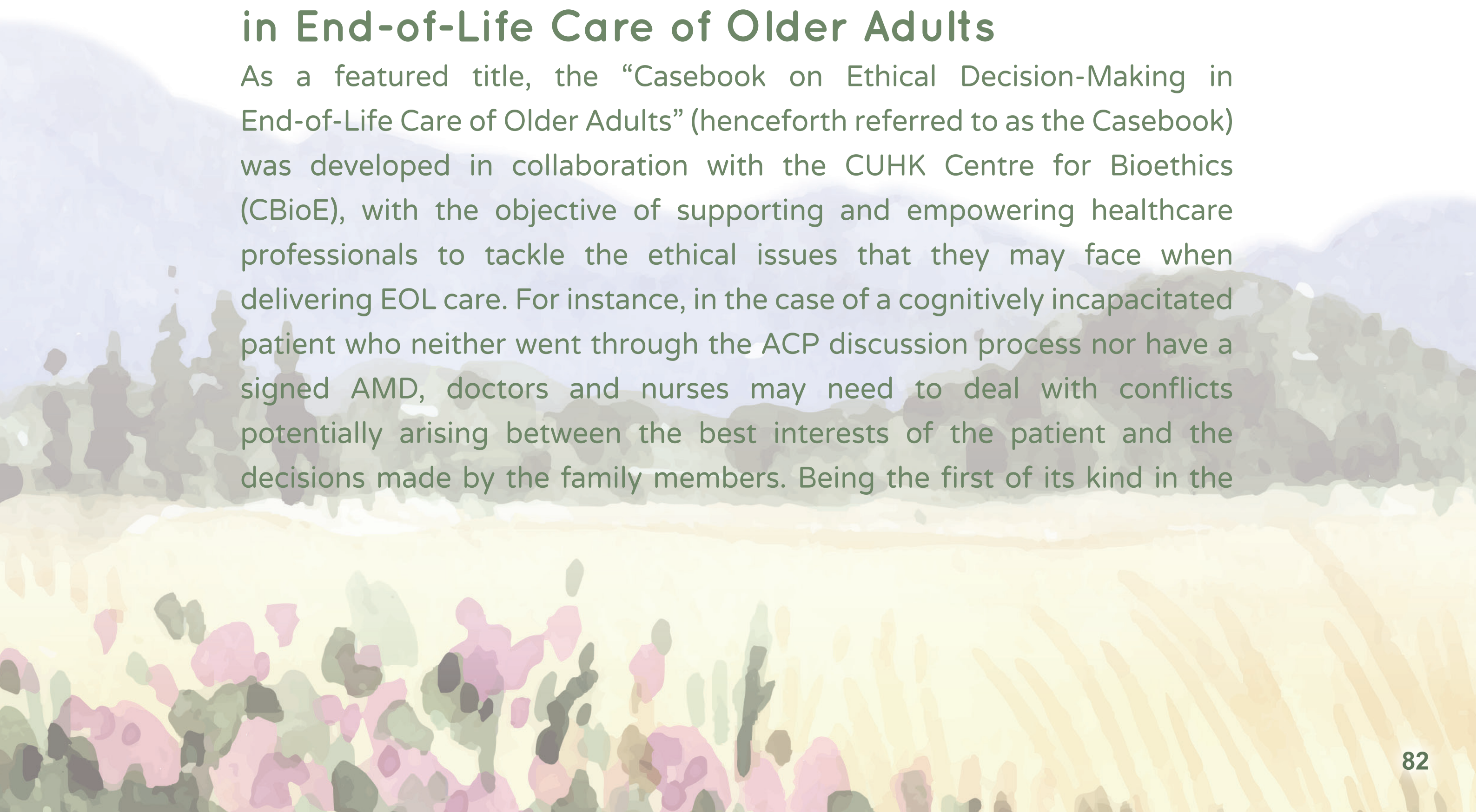
[23] For brevity, we omit some of the miscellaneous items such as leaflets and pamphlets.

Table 4.
List of publications.

Title	Language	Number of printed copies
Casebook on Ethical Decision-Making in End-of-Life Care of Older Adults	Chinese English	2,000 5,300
Advance Care Planning Handbook	Chinese	17,200
Good Death Booklet	Chinese	25,300
Training Kit for Healthcare Professionals	Chinese English	2,400 1,300
安心包	Chinese	5,850
嫲嫲的圓滿旅程	Chinese	1,000
Learning for Life, Planning for Death: Building Capacity for End-of-Life Care in Hong Kong	English	300
Live Free, Die Well: Building Capacity for End-of-Life Care in Hong Kong	English	300

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

As a featured title, the “Casebook on Ethical Decision-Making in End-of-Life Care of Older Adults” (henceforth referred to as the Casebook) was developed in collaboration with the CUHK Centre for Bioethics (CBioE), with the objective of supporting and empowering healthcare professionals to tackle the ethical issues that they may face when delivering EOL care. For instance, in the case of a cognitively incapacitated patient who neither went through the ACP discussion process nor have a signed AMD, doctors and nurses may need to deal with conflicts potentially arising between the best interests of the patient and the decisions made by the family members. Being the first of its kind in the



local context, the Casebook documents scenarios for depicting common ethical dilemmas in EOL care, which were adapted from real-life cases, and provides expert commentaries to guide the readers to recognize and resolve the moral challenges using a pragmatic approach. Regarding these commentaries, the project team invited field experts from different backgrounds to share their insights, including members of the HA's clinical ethics committee, senior doctors, clinical lecturers, nursing educators, and ethicists, with the aim of providing more diversified perspectives and a comprehensive picture on this subject. In addition to the case scenarios and commentaries, the Casebook contains several "backgrounder" articles that probe into the general issues of clinical ethics, from a slightly more scholarly and philosophical perspective, such that the academic-oriented and sophisticated readers can also be catered for. Given the popularity of the Casebook among healthcare professionals, it had been updated on a regular basis since the 2nd phase, in which one new case article was added to the collection and issued on the IOA website annually. Through active promotional efforts via Facebook posts and advertisement in the Hong Kong Medical Diary, the online version has accumulated a total of 31,798 views over the ten-year period. As regards the printed version, three editions of the Casebook were published, with a total of 7,300 copies being produced and disseminated. In particular, it was distributed during several HA Conventions, symposia and seminars held by the CBioE, and was also used by various academic institutions as supplementary material for their courses, for instance the CUHK's undergraduate medicine programme and The University of Hong Kong's Master of Public Health programme.

Figure 25. The 3rd edition of the Casebook on Ethical Decision-Making in End-of-Life Care of Older Adults.

CASE 15

Mr. Woo

Toileting Issues In End Of Life Care

Mr Woo (85 years old) is a patient with late-stage liver cancer, who has only about half a year of remaining life expectancy. Before being diagnosed, Mr Woo had decent physical and psychological conditions. He could take care of himself and had never needed to be hospitalized for treatment. For this reason, Mr Woo was very proud of himself. However, his conditions have recently been deteriorating at a rapid pace, forcing him to be hospitalized immediately. Since Mr Woo does not genuinely believe that he is about to die, he wants to create a sense of "feeling alive" for himself, and he does not want the healthcare staff to treat him like a dying patient. However, it is an undeniable fact that Mr Woo's conditions are getting worse, as he begins to experience symptoms such as dizziness and drowsiness, thereby needing to stay in bed for most of the time. Given Mr Woo's frail conditions, the healthcare staff believes that if he is allowed to go to the toilet by himself, then the risks of falling and fainting may arise. In view of this, the nurse told Mr Woo, "Since you are currently on an IV drip, it may not be that convenient for you to go to the toilet on your own. We will help you put the diapers on." Mr Woo nervously asked, "Diapers? Do you mean that I need to stay in bed while toileting? Don't tell me you can't send a staff to assist me with the toileting routines!" The nurse answered, "I am very sorry about that. Our manpower is limited. In addition, we are worried about your safety." Mr Woo became angry and did not accept the nurse's explanation, as he perceived the use of diapers to be a severe violation of his dignity. After a while, Mr Woo even ranted, "As the doctor said that I cannot live for much longer, why can't you satisfy my humble wish of being able to go to the toilet on my own, even when I am approaching the end of my life? Why are you forcing me to use the diapers, even when I can walk independently and still have a call of nature, and I am not like those incontinent patients who can't control themselves? As I am already about to die, why do you think it matters to me if I am safe or not when going to the toilet?"

In the above case, given the shortage in resources and manpower, the actions taken by the healthcare staff seemed to be reasonable, yet they indeed contradicted with Mr Woo's preferences. So, given that Mr Woo is dying soon, how should the healthcare staff balance his interests in different aspects and thereby provide the optimal end-of-life care? What would be the considerations with respect to clinical ethics?

Questions to think about:
- How should the healthcare staff apply the ethical principle of "respect for autonomy" in this case?
- What is the role played by the patient's dignity in end-of-life care?
- Can the efficiency and safety of care provision override the patient's subjective preferences? Why?
- How should the person-in-charge of a ward or department strike a balance between resources allocation and satisfaction of the needs of individual patients?

CASEBOOK
ON ETHICAL DECISION-MAKING
IN END-OF-LIFE CARE OF
OLDER ADULTS

Commentary

– Prof Roger Y. Chung
Co-Director, Centre for Bioethics
Associate Director, Institute for Health Equity
Associate Professor, School of Public Health and Primary Care
The Chinese University of Hong Kong

Here are some of the morally relevant features of the case:
- Conditions:
  - Terminal cancer patient
  - Irreversible condition
  - Continually deteriorating with debilitating symptoms
  - Risk of fall if not escorted
  - With certain degree of mobility (i.e., can walk)
  - Not incontinent
- Patient's perspective:
  - Patient does not accept his disease's terminal status and/or being regarded as a terminal patient
  - Using adult diapers is a matter of dignity to the patient
  - Clearly rejects the use of adult diapers
  - Seems to understand the risk of fall, and does not think that it outweighs the concern for dignity and autonomy
- Environmental/external factors:
  - Limited human resources for caring of essential activities of daily living

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4.2.2 Advance Care Planning Handbook

The "Advance Care Planning Handbook" ("晚晴照顧手冊," henceforth referred to as the Handbook) is a colourfully illustrated, easy-to-follow manual that is intended to aid the public, especially older people with relatively limited cognitive capacities, to document their thoughts and preferences on EOL care in a step-by-step manner. The design of the Handbook was motivated by the observation that despite the importance of ACP, there only existed a limited number of tools for recording the communication process, most of which were tedious documents that were not the most user-friendly from a layperson's point of view. Although theoretically speaking, there are no restrictions on how ACP communication should be recorded, it is always beneficial to create a specific tool that can facilitate the documentation process and aid the subsequent record-keeping, hence the creation of the Handbook. Once the Handbook has been completed, it can be used as the basis for initiating and conducting EOL conversations, and can also serve as a record for others to take reference of, especially during emergency situations. The Handbook was used extensively throughout various public education activities, particularly the group sessions as mentioned in Section 3.3.3.1. Given its conciseness, simplicity and practical usefulness, the Handbook was among the most popular and highly regarded titles. In fact, many NGOs actively approached the project team and requested extra copies of the Handbook, such that their staff could make use of it to open up conversations with their clients. Since its original release in 2016, the Handbook has undergone several revisions and reprints, with a total of 17,200 copies being produced and distributed.

Figure 26. The 5th edition of the Advance Care Planning Handbook.

晚晴
照顧手冊

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人生列車的完美一程

晚晴照顧手冊

我們每個人都坐着自己的人生列車，從出生的起點站開始，一路經歷不同的人生旅程，由學業、工作、結婚、生兒育女、安居置業、以至退休…

列車上，會有家人、朋友或遇上不同的人與我們同行，有人上車、有人落車，有聚有散…

當列車駛近終點站的時候，您希望怎樣渡過？您又可以如何與身邊的家人和摯愛分享您的想法？

2

4.2.3 Good Death Booklet

The “Good Death Booklet” (“吾該好死,” henceforth referred to as the Booklet) can be considered a more elaborate and extended version of the Handbook, which is more oriented towards the general public rather than specifically towards older people. Similar to the Handbook, the Booklet navigates the readers through the EOL planning and documentation process, but this time around with more detailed information and guidance provided along the way. For instance, the Booklet compiles a comprehensive list of recommended wordings and dialogues that the readers can refer to when initiating and conducting EOL conversations. For another instance, the Booklet includes the sample forms of ACP, AMD, and EPA in its appendix, such that the readers can build a more solid understanding of how these documentations are performed in actual practice. Since the Booklet contains a wealth of information that is subject to change from time to time, the project team published a total of seven editions during the ten-year period to ensure that all content was accurate and up to date. Altogether, 25,300 copies of the Booklet were produced and distributed. Finally, it should be mentioned that to attract more viewership and facilitate comprehension, the Booklet was also converted into an audiobook, which can be accessed via the IOA website.

Figure 27. The 7th edition of the Good Death Booklet.

引言

根據香港衞生防護中心的統計資料[1]，2023年有超過56,000人離世，而過往數字亦顯示年長及長期病患者佔大多數，其中65歲及以上人士佔多於80%。死亡的主要原因包括疾病已到達晚期或出現併發症等，少數是出於突發疾病或意外。對長者或長期病患人士來說，了解晚期照顧能為自己人生晚晴作好準備。

俗語有云「好頭不如好尾」，何不了解並計劃自己的晚期照顧，使人生達至圓滿。誠邀閣下與我們一起了解這個重要的議題，以積極的態度面對人生至最後一刻。

[1] 香港特別行政區政府衞生署衞生防護中心(2024)。二零二三年按主要死因、性別及年齡組別劃分的死亡數目。
取自https://www.chp.gov.hk/tc/statistics/data/10/27/340.html

吾該好死
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4

4.2.4 Training Kit for Healthcare Professionals

During the 1st phase, many participants of the capacity building activities suggested that the project team should find a way to store the expertise and insights shared by the experienced speakers. Evidently, this kind of knowledge and information was relevant and beneficial to other non-participants as well. In view of this, the “Training Kit for Healthcare Professionals” (henceforth referred to as the Training Kit) was developed to compile the wisdom and lessons learned from these previous activities for future reference and self-learning purposes. Topics covered in the Training Kit include ACP and AMD, symptom management, EOL communication skills, clinical ethics, and self-care techniques for tackling compassion fatigue. The printed version of the Training Kit was delivered, together with a souvenir USB as mentioned in Section 4.1, inside an exquisite package box. This turned out to be a valuable design, as the eye-catching appearance helped this treatise draw attention from, and gain wide popularity among, the target readers. During the 2nd and 3rd phases, a total of 3,700 copies of the Training Kit were produced and distributed.

Figure 28. Training Kit for Healthcare Professionals.

BUILDING CAPACITY FOR
END-OF-LIFE CARE
IN HONG KONG
TRAINING KIT FOR HEALTHCARE PROFESSIONALS

Chapter 1

Introduction and Symptom Management
of End-of-Life Care

BUILDING CAPACITY FOR
END-OF-LIFE CARE
IN HONG KONG
TRAINING KIT FOR HEALTHCARE PROFESSIONALS

Chapter 1
Introduction and Symptom Management
of End-of-Life Care

1.1 Overview of End-of-Life Care in Hong Kong

In Hong Kong, acute medical and surgical wards in public hospitals are intended for acute curative management of ill patients and they are not generally well-designed for dying with dignity and privacy.[2] The Quality of Death Index by the Economist Intelligence Unit in 2015 showed that Hong Kong ranked 22nd in palliative care across the world in relation to quality, availability and affordability.[3] Hong Kong was way behind Western countries such as the United Kingdom (UK; 1st) and the United States (US; 9th), as well as other Asian neighbours, including Taiwan (6th) and Singapore (12th). This reveals that there is room for improvement and development of palliative care in Hong Kong and that most people have limited understanding about this topic.

	Rank / 80	Score / 100
Quality of Death overall score (supply)	**22**	**66.6**
Palliative and healthcare environment	28	50.4
Human resources	20	62.1
Affordability of care	=18	82.5
Quality of care	=20	81.3
Community engagement	=38	32.5

Figure 1. 2015 Quality of Death Index of Hong Kong

P.9

4.2.5 安心包

“安心包”[24] (henceforth referred to as the Resources Kit) is a collection of six short and self-contained volumes, each focusing on a specific topic in EOL care that is of relevance and importance to the public, namely EOL planning, ACP and AMD, treatment options and approaches, caregiving of EOL patients, financial arrangements, and other post-death matters. Altogether, the content covered in the Resources Kit per se is akin to that of the Booklet. The main difference is that the Resources Kit splits its content into individual chapters, such that the readers can more easily and conveniently look up the desired information. The printed version of the Resources Kit was delivered inside a paper bag bundle, which also contains several small “gadgets” designed to prompt the readers to think about EOL issues through some entertaining mini-games. During the 2nd and 3rd phases, a total of 5,850 copies of the Resources Kit were produced and distributed.

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[24] The hidden meaning behind this title is “包安心,” which conveys the blessing that the readers can live without any worries about death. In addition, it is intended to echo with the main theme of the Event as mentioned in Section 3.3.1.1.

Figure 29. The paper bag bundle “安心包.”

4.2.6 嫲嫲的圓滿旅程

“嫲嫲的圓滿旅程” (henceforth referred to as the Picture Book) was developed near the end of the 2nd phase and was, apart from the present report, the last title published by the project team. At that time, due in part to the efforts undertaken by the Programme and in part to the advancements of ACP and AMD in our society, there had already been abundant information about EOL care made available to the public. With this in mind, the project team designed the Picture Book, which, as hinted by its name, is not meant to spread and impart knowledge. Instead, it is a storybook filled with colorful illustrations, which is intended to sensitize the readers in a more casual manner, such that the issues of EOL care can be naturally woven into the fabric of their everyday lives. During the 2nd phase, a total of 1,000 copies of the Picture Book were produced and distributed. Notably, several copies were sent to the public library for archiving purposes and were made available for borrowing, such that a wider range of readers can be reached.

Figure 30. The colorful illustrations in “嫲嫲的圓滿旅程.”

看完嫲嫲的生命故事冊後，我立刻告訴爸爸。

爸爸笑着說：

「我原本打算明天才把這本故事冊拿給你看，
沒想到你已經找到了。

其實，嫲嫲生前已經將她的臨終意願和心底感受
告訴了我們。

幸好她願意**及早準備晚晴計劃**，
我們才可以更容易**適從和執行**。」

4.2.7 Summary reports

As the predecessors of the present report, “Learning for Life, Planning for Death: Building Capacity for End-of-Life Care in Hong Kong” (IOA, 2018) and “Live Free, Die Well: Building Capacity for End-of-Life Care in Hong Kong” (IOA, 2021) were compiled as the summary of the 1st and 2nd phase, respectively. While these reports are seemingly not intended for educational purposes, their informational value should not be underestimated, as they document not only the fruitful outcomes of the Programme, but also its underlying rationale and evolution process, which can serve as reference for future initiatives, policymakers, and other relevant stakeholders (see Section 1.3). A total of 600 copies of the two summary reports were produced and directly distributed to various NGOs, academic institutions, and other JCECC partners.

Figure 31. Summary reports for the 1st and 2nd phases.

Learning for life, planning for death:

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

策劃及捐助 Initiated and funded by:

香港賽馬會慈善信託基金
The Hong Kong Jockey Club Charities Trust

合作院校 Partner Institution:

香港中文大學
The Chinese University of Hong Kong

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

4.3 Videos

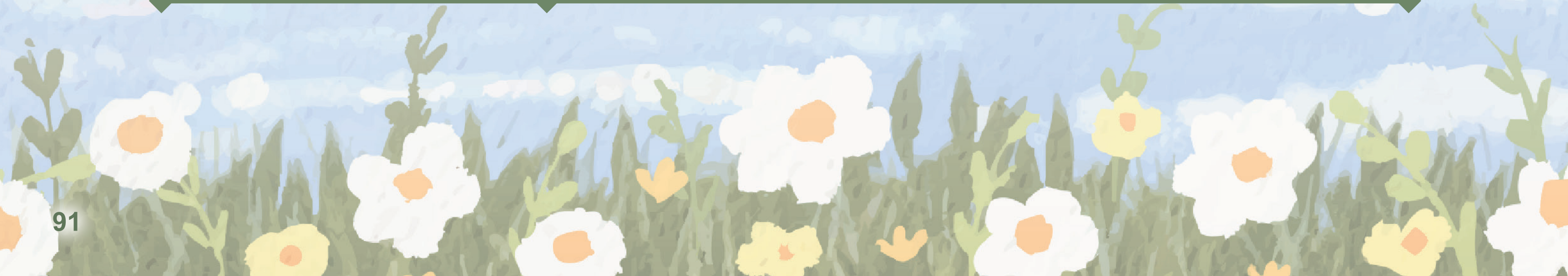
Table 5 is a complete list[25] of videos produced during the ten-year period, all of which can be accessed via the YouTube channel and will also be available on the upcoming online knowledge transfer platform. Broadly, they can be categorized into informational videos, companion videos, micro-movies, and celebrity interviews. Videos in the first two categories were frequently played during the Programme activities, with the aim of facilitating the comprehension and learning of the participants, whereas those belonging to the last two categories are primarily intended to increase our exposure to the public through the means of social media. As in the case of publications, the project team welcomed other parties to utilize these videos at their discretion. Encouragingly, it turned out that some videos were indeed used by frontline practitioners to aid the process of explaining the concepts of EOL care and ACP to their clients, while some others were used by educators for teaching and training purposes. Notably, some of them were even uploaded by the HA to the Smart Patient Palliative Care Platform and HKEC's website for public access.

---

[25] Around 40 lecture videos designed for the capacity building component (i.e., online courses for doctors and nurses) are not included in this list, as they can only be accessed from the courseware platform during a specific period. In addition, some miscellaneous and non-educational items, such as event highlight videos, are omitted here for simplicity.

Table 5.
List of videos.

Category	Title
Informational video	Introduction to Advance Care Planning and Advance Medical Directive
	How to Start End-of-Life Conversations with Healthcare Professionals
	How to Start End-of-Life Conversations with Patients and Relatives
	Goals of Care Options for Patients with Advanced Chronic Obstructive Pulmonary Disease
	Understanding Care Decisions in Advanced Heart Failure
	Serious Illness Communication
	Serious Illness Communication with Caregivers
	Breaking Bad News to Patients' Family Members
	End-of-Life Care for Demented Patients
	End-of-Life Care: Advance Care Planning
	Making Difficult Decisions: Sharing from Family Members of People with Dementia
	Advance Care Planning: Empowering Families to Prepare for Medical Decision-Making for the Loved Ones
Companion video	Feeding Tube Decision for a Dying Demented Patient
	Disagreements over Timing for Advance Care Planning
	Miscommunication with Family in Advance Care Planning
	How to Use the Advance Care Planning Handbook
Micro-movie	Plan Well, Leave Well
	Patients' Perspectives on End-of-Life Care
Celebrity interview	Plan Well, Leave Well: Interview with Chow Chung
	Death Journey: Experiential Interview with C AllStar



4.3.1 Informational videos

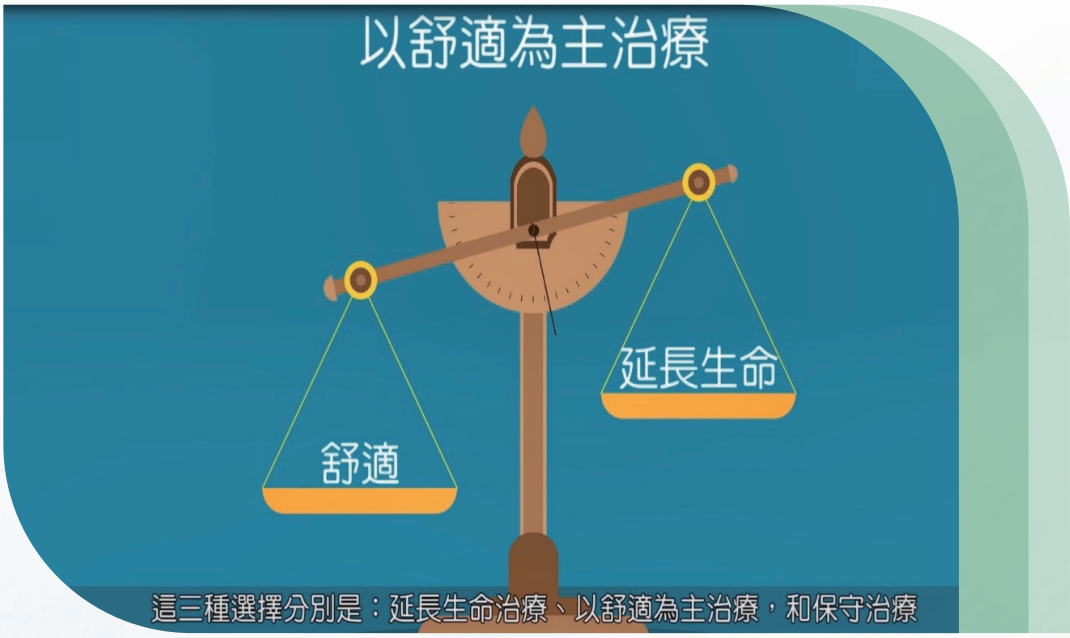
The majority of videos, especially the ones produced during the 1st phase, are information-oriented and presented using a more traditional and didactic approach. In what follows, we describe in detail several featured videos in this category.

First, “Goals of Care Options for Patients with Advanced Chronic Obstructive Pulmonary Disease” and “Understanding Care Decisions in Advanced Heart Failure” are “disease-based” videos explaining the trajectories of two terminal conditions that are commonly encountered in EOL care, namely chronic obstructive pulmonary disease (COPD) and heart failure, as well as the benefits and risks of different treatment approaches, including life-prolonging care, comfort-focused care, and conservative care. Several specific treatment options are also discussed, for instance bilevel positive airway pressure (BiPAP) ventilator for COPD, and implantable cardioverter defibrillator for heart failure. Shortened versions of these two videos were frequently played in various kinds of public education activities (e.g., Section 3.3.2.1) to help the participants build a more nuanced understanding of the differences and tradeoffs between different treatment approaches.

Second, “Serious Illness Communication,” “Serious Illness Communication with Caregivers,” and “Breaking Bad News to Patients’ Family Members” are videos specifically designed to illustrate, using a step-by-step approach, how healthcare professionals can utilize the SICG, as well as the NURSE and SPIKES statements, to initiate and conduct EOL conversations. These videos were usually played during the training activities for doctors and nurses when there was insufficient time for the participants to gain hands-on experience through role-play simulation exercises. The realistic demonstrations offered by these videos can guide the viewers to pay extra attention to the non-verbal aspects in EOL conversations, such as facial expressions, eye contact, and body gestures, which are soft skills that cannot be acquired simply by reading through the communication protocol or a list of recommended dialogues.

Last but not least, “End-of-Life Care for Demented Patients” is a video that emphasizes the importance of setting up the so-called “three instruments of peace” (“平安三寶”), which include an EPA, an AMD, and a will, for demented patients or individuals who show early signs of cognitive decline. Notably, this was among the first attempts made by the project team to incorporate storyline elements and professional casting into the video, which was aimed at improving its entertainment value and thereby attracting more casual viewers from the public.

Figure 32. “Disease-based” videos illustrating the differences between three major treatment approaches.



這三種選擇分別是：延長生命治療、以舒適為主治療，和保守治療

4.3.2 Companion videos

As the implementation of the Programme gradually progressed and more publications had been added to the repository (see Section 4.2), the project team began to produce companion videos to serve as supplementary materials for some of these publications, such that these two types of educational resources can be used side by side and in a mutually complementing manner.

More specifically, three videos titled “Feeding Tube Decision for a Dying Demented Patient,” “Disagreements over Timing for Advance Care Planning,” and “Miscommunication with Family in Advance Care Planning” were produced in accordance with the 2nd, 5th, and 10th article in the

Casebook (see Section 4.2.1), respectively. They are meant to illustrate the ethical dilemmas as described in the case scenarios, and to elucidate the resolution techniques as indicated in the expert commentaries. These videos were sometimes played during the training activities for doctors and nurses when the focus was on clinical ethics.

On the other hand, an animated video titled “How to Use the Advance Care Planning Handbook” was produced to, as its name implies, guide the viewers navigate through the Handbook (see Section 4.2.2) in a self-contained manner. The creation of this video was largely motivated by the observation that while most people appreciated the simplicity and usefulness of the Handbook, some of those with limited literacy skills or cognitive capacities might still require a helping hand in the documentation process. In addition, the video can serve as a medium for caregivers to explain to their care recipients about how to fill out the Handbook, thereby providing further opportunities for them to initiate and conduct EOL conversations.

Figure 33. Companion video for the 10th Casebook article.

4.3.3 Micro-movies

In the later portion of the ten-year period, the project team attempted to expand the types of videos being produced, such that a wider range of viewers, especially those from the younger generations, could be attracted via social media platforms. To this end, the project team filmed two videos using a micro-movie format, with the intent to maximize their storytelling effects, rather than to spread information merely in a "spoon-feeding" manner.

The first micro-movie, titled "Patients' Perspectives on End-of-Life Care," depicts the real case of an end-stage COPD patient who, despite his willingness and readiness, was not given the chance to express to his family members and attending doctor that he preferred to withdraw BiPAP ventilation and CPR. Echoing with the points highlighted in Section 1.3.2.2, the main theme of this micro-movie is to alert and remind the viewers that patients and older people nowadays are becoming more open to talk about EOL issues, and that it is incorrect, and often a regrettable decision, to shut down the communication channel simply out of wishful thinking.

The second micro-movie, "Plan Well, Leave Well," was produced in accordance with the main theme of the Event as mentioned in Section 3.3.1.1. This micro-movie stars several famous television actors including, in particular, Mr. Chow Chung. The storyline of this micro-movie was written to bring out the importance and necessity of early EOL planning and documentation, from an older person's perspective. Through active promotion on various social media platforms, the micro-movie has accumulated over 132,000 views since it was released in 2020.

Figure 34. The "Plan Well, Leave Well" micro-movie.

4.3.4 Celebrity interviews

To gain further popularity and exposure, the project team conducted and filmed two celebrity interviews, in which several influential public figures were invited to share their personal thoughts and experiences on the topic of EOL care.

The first interview, titled "Plan Well, Leave Well: Interview with Chow Chung," is a sequel to the "Plan Well, Leave Well" micro-movie mentioned in Section 4.3.3. In this documentary-styled interview, Mr. Chow Chung, the leading actor of the micro-movie, shared that he wanted to experience a good death without suffering, and for this purpose, he believed that he should plan ahead and express his preferences to his family members, which is precisely the message that the interview is intended to convey. Through active promotion on various social media platforms, the interview has accumulated over 296,000 views since it was released in 2021. In addition, the interview received editorial coverage in several media outlets, including Sing Tao Daily, Headline Daily, and Sky Post, indicating its success in terms of generating topicality and stirring attention in our society.

The second interview, titled “Death Journey: Experiential Interview with C AllStar,” was another featured video produced for the Event as mentioned in Section 3.3.1.1, which documents the process of a simulated death journey. In this death journey, one member from the C AllStar[26] group was asked to, with the accompany of his teammate, took a funerary portrait photo, wrote his last words, wore the shroud, and lay inside a coffin to mimic the experiences that he would have gone through in an actual burial ceremony. After the death journey, the two C AllStar members shared their personal reflections on this simulated experience, as well as their opinions on EOL planning and LSTs. Through active promotion on various social media platforms, the interview has accumulated over 178,000 views since it was released in 2021.

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[26] C AllStar is a popular local male singing group formed by four members, two of whom were involved in the filming of this experiential interview.

Figure 35. Experiential interview with C AllStar.

5 Academic Research

5.1 Overview

In this Chapter, we summarize the insights gained from several academic studies conducted by the project team.[27] These studies are listed and presented in chronological order of publication date. First, Section 5.2, 5.3, and 5.4 as a whole contains three studies (Cheung et al., 2018; Chan, Lee, & Woo, 2020; Cheung et al., 2020) that were conducted back in the 1st phase for examining the capacity, unaddressed needs, and obstacles regarding the implementation of EOL care and ACP.[28] Second, Section 5.5 is a quantitative study (Chung et al., 2024) that was conducted in the 2nd phase for probing into the issues of social determinants and health inequity, which is an important, yet not so thoroughly investigated topic in EOL care. Third, Section 5.6 contains two recently conducted studies (Chan, Lee, et al., 2025; Chan, Lam, et al., 2025), which, as a wrap up of the Programme, were aimed at evaluating the benefits of ACP in the local context and whether its implementation was facilitated by the efforts undertaken by the project team. Last, Section 5.7 briefly mentions a systematic review[29] (Chan & Woo, 2025) of factors affecting the uptake and initiation of ACP among family members of demented patients.

Before presenting the results, two important remarks are in order. First, these studies were not conducted only for the sake of generating academic outputs. Instead, the project team adopted an "action research" mindset, emphasizing how these studies might contribute to eliciting critical reflections and bringing transformational changes to the Programme and future practices (see also Section 2.3.5). In other words, solving real-life problems was prioritized over the philosophical or methodological aspects. In particular, for most studies that were conducted in collaboration with the HA, the project team stressed that they should be done "as a matter of course" (i.e., as part of CQI strategies for evaluating the service quality), and that their academic nature was of lesser importance. Second, as a follow-up to the first remark, the present Chapter is not merely meant to be a condensed version of these studies. Instead, we attempt to interpret and present them in an informal way to illustrate how they were intertwined with the implementation of the Programme, for instance, how they affected the design of subsequent Programme activities.

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[27] For brevity, a large portion of background information and methodologies will be omitted. Results may also be selectively presented.

[28] For these studies, some of the findings have already been discussed throughout Section 1.3.2. Nonetheless, they are mentioned here again to stress their importance.

[29] Since this study was only a review of research conducted outside Hong Kong, it will be covered less extensively in this Chapter.

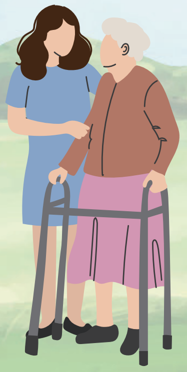
5.2 Self-competence in death work among healthcare professionals

5.2.1 Background

For healthcare professionals, the provision of EOL care can be burdensome because of its closeness to death. To deliver high-quality care, it is essential for them to be mentally competent in handling death work (i.e., working with death-related situations). For instance, they need to understand the nature of death work, accept that death is inevitable, and be able to cope with the stress and emotions induced by their work. While the technical skills of healthcare professionals in delivering EOL care had often been discussed or even disparaged in our society, this kind of psychological capacity tended to be overlooked. In view of this, the study was conducted to provide a descriptive assessment of the perceived competence in death work among healthcare professionals in Hong Kong, as well as to examine its correlates.

5.2.2 Methods

The study administered a validated inventory, namely the Self-Competence in Death Work Scale (SC-DWS), to a cross-sectional, convenience sample of 885 participants consisting of doctors, nurses, social workers, other healthcare professionals, and personal care assistants working in the field of EOL care. The SC-DWS is composed of 16 Likert-type items, most of which can be categorized into two subscales, namely the existential subscale and emotional subscale. Participants were asked to respond to each item by rating the perceived compatibility between their own attitudes and the real-life situations (1 = completely incompatible and 5 = completely compatible). Sample items include “I can fully accept that suffering is inevitable, for example, the suffering of patient/service user during the dying process” and “I can fully accept the nature of death work, including pity or depressed feelings.”



5.2.3 Results

The mean score of the SC-DWS was 60.16 out of 80 (i.e., 3.76 out of 5). The mean score of the existential subscale was 37.90 out of 50 (i.e., 3.79 out of 5), whereas that of the emotional subscale was 14.46 out of 20 (i.e., 3.62 out of 5). Considering that a score of 4 in a 5-point Likert scale indicates satisfactory compatibility, results showed that the overall perceived competence in death work was less than satisfactory. Further analyses showed that young nurses working in acute hospitals tended to have the lowest level of competence.

5.2.4 Discussions

The findings of this study revealed yet another facet of soft skills in EOL care that many healthcare professionals were lacking. Noteworthily, nurses working in acute hospitals, who are arguably the type of profession that may encounter deaths the most frequently, ironically turned out to be the least competent in performing death work, which was a particularly worrying phenomenon. Overall, the study had significant implications on the design and development of the Programme. If healthcare professionals cannot establish a proper coping mechanism to deal with the emotional challenges induced by death experiences, then they themselves will be overwhelmed and deprived of the capacity to show empathy to patients, which ultimately means that it becomes much less effective, if not impossible, to train them on compassionate communication skills. Because of that, as mentioned throughout Section 3.2, the Programme had incorporated various “unorthodox” topics, such as mindfulness practice and emotional regulation techniques, into the regular training activities to address issues in this regard, especially among nurses (see Section 3.2.2.4 and 3.2.2.5).

5.3 Service gaps in end-of-life care

5.3.1 Background

As mentioned in Section 1.3.2, the Quality of Death Index reported in 2015 showed that the quality of EOL care services in Hong Kong was falling behind. At that time, since the widespread implementation and normalization of EOL care were still at an embryonic stage, it was important to first identify what remained to be done. For this purpose, this study was conducted to contribute to the growing body of literature on the service gaps in Hong Kong, as viewed from the perspectives of different stakeholders.

5.3.2 Methods

This study adopted a qualitative and exploratory approach, in which face-to-face, semi-structured interviews were conducted. Following a purposive snowball sampling scheme, a total of 131 participants, including patients, family members, and various types of healthcare professionals, were recruited. Each interview was conducted either on an individual basis for about 60 minutes, or in a focus group format for about 120 minutes. All interviews were audio-recorded and transcribed verbatim. Thematic analysis was performed to identify and extract the key messages, which were then categorized in accordance with the PESTEL[30] framework.

5.3.3 Results

Regarding the political aspect, a clear framework for directing EOL care services was lacking. Low priority was given to EOL care in the administrative agenda due to the presence of other more pressing societal and economic issues, for instance housing and education.

Regarding the economic aspect, the amount of government funding for EOL care was not comparable to that invested in inpatient or acute care services. As a result, most initiatives were supported by philanthropic bodies in a one-off manner, leading to high manpower turnover rates and sustainability issues.

Regarding the socio-cultural aspect, the “lingering” perception of death taboo created an unfavorable environment for EOL conversations. This led to a vicious cycle in which patients tended to rely on doctors to make the medical decisions for them, and healthcare professionals in turn assumed that patients were unwilling to discuss.

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[30] PESTEL stands for political, economic, socio-cultural, technological, environmental, and legal.

Regarding the technological aspect, EOL care attracted much less attention from the local academia and industries than, say, clinical trials in biomedical sciences that directly aim at curing diseases and lowering mortality rates. Empirical research on EOL care was lacking due to insufficient funding and other difficulties caused by ethical concerns.

Regarding the environmental aspect, most wards in the HA's public hospitals were cramped, implying that it was difficult to deliver EOL care in a humane and considerate manner. Worse still, patients might not have better alternatives. Even if they requested to be discharged from public hospitals, the process might be obstructed by administrative and liability issues.

Finally, regarding the legal aspect, it was generally conceived that the legislative route of AMD, despite having its merits, might not necessarily be conducive to promoting public awareness. Confusion and misunderstanding about legal provisions remained common among healthcare professionals.[31]

5.3.4 Discussions

The findings of this study revealed a number of factors that might have hindered the development of EOL care in Hong Kong. The PESTEL framework called special attention to the fact that these factors were multi-dimensional in nature and interconnected with different types of societal issues. This indicated the necessity of a cross-sectoral and public health approach, as opposed to a purely clinical or diseased-based one, in addressing these service gaps.

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[31] It should be emphasized that this phenomenon can still be observed as of today, suggesting that despite the legislative proposal on AMD, legal concerns about EOL care have not been eliminated.

5.4 Barriers to Advance Care Planning

5.4.1 Background

Despite being the central notion in EOL care, ACP was largely unheard of in our society a few years ago, especially since the Programme was still taking time to fully generate its impact. Under this context, the aim of this study was to examine in greater detail the obstacles hindering the discussions and implementation of ACP, from the perspective of EOL care service users.

5.4.2 Methods

This study adopted a qualitative and exploratory approach, in which face-to-face, semi-structured interviews were conducted. Following a purposive snowball sampling scheme, a total of 17 patients and 13 family members were recruited from a palliative day care centre through referrals, all of whom had never initiated or participated in the ACP process. Each interview was conducted either on an individual basis for about 25 minutes, or in a focus group format for about 60 minutes. All interviews were audio-recorded and transcribed verbatim. Thematic analysis was performed to identify and extract the key messages, which were then grouped into several major themes in a stepwise manner.

5.4.3 Results

Major barriers to ACP could be categorized into the following four aspects. First, patients tended to have limited participation in the EOL decision-making process. Instead of indicating their preferences, many patients relied on their surrogates to make the decisions for them. One of the underlying reasons was that doctors and family members tended to be reluctant to disclose the relevant medical information. As a result, patients might consider themselves incompetent in making the decisions or simply choose to withdraw from the communication process to avoid any interpersonal conflicts.

Second, there was a general inclination for patients to believe in the predetermination of life and thereby accept the inevitability of death. However, many of them erroneously concluded that the discussion of EOL issues entails a pessimistic attitude or even a disruption to the “peace of mind,” and failed to recognize that while death as an outcome may not be controllable, its process is. These misunderstandings led to emotional barriers that prevented patients from expressing their wishes.

Third, patients and family members might need extra time to accept the bad news and digest the overwhelming amount of information given to them from different sources. Consequently, most of them would not be immediately ready to engage in further conversations. While they were fixating towards the bad news and prognosis, they might not have the spare mental capacity to understand the advantages and importance of ACP.

Last, it was common for healthcare professionals to lack the time, empathic attitude, and communication skills for addressing the holistic needs of patients and family members. Some were unable to provide clear and concise information from a medical standpoint, let alone to help the care recipients alleviate their psychological distress. As a result, it was difficult for the three parties to develop a long-term, mutually trusting relationship and engage in a continual communication process.

5.4.4 Discussions

The findings of this study provided insights into the prohibitive factors regarding the uptake and implementation of ACP. It could be observed that none of these factors were related to hardware infrastructure of the healthcare system. Instead, they were mostly shaped by how patients, family members, and healthcare professionals interacted with each other, as well as their perception and attitude of EOL care. This is again why the Programme put so much emphasis on cultivating the correct mindset among the target beneficiaries.

5.5 Impact of socioeconomic status on end-of-life care

5.5.1 Background

As EOL care has gradually become a hot topic in the past decade, more and more self-financed social enterprises and profit-making companies started to provide services of a higher caliber, but which might also come with a less affordable price. This raised a concern about health inequity, as more well-off individuals could opt for better services offered by the private sector, whereas less well-off individuals could not. While this phenomenon was largely market-driven and not entirely avoidable, it would be desirable if, at the very least, the public healthcare system could grant equitable access to basic EOL care services. Motivated by the above, this study was conducted to examine whether socioeconomic gradients existed in the utilization of EOL care services in public hospitals.

5.5.2 Methods

This study adopted a retrospective cohort design. Records of hospital admissions and Accident and Emergency (A&E) visits from 2004 to 2014 for patients who were Hong Kong residents aged 45 or above at the time of medical consultation were retrieved from the HA database. The Comprehensive Social Security Assistance (CSSA) and RCHE residency statuses of the patients were treated as indicator variables for proxying their socioeconomic positions. The study focused on a particular subset of the original data that satisfied the following criteria:

- The discharge status of the last record of the patient was "deceased."
- The last record was logged during the last year of the patient’s life.

In other words, only data of deceased patients who had utilized any forms of public hospital services in the last year of their lives was considered. Upon preprocessing, the final sample consisted of 1,878,982 records of 375,506 patients and 1,237,044 records of 357,853 patients, respectively, for the hospital admission and A&E visit data.

For both data, the frequency of hospital utilization (i.e., the total number of records) was plotted against proximity-to-death (in months) to graphically examine the pattern for each socioeconomic category. Generalized linear models were then used to examine, after controlling for other demographic covariates, the associations between the two socioeconomic variables and the frequency of hospital utilization, as well as the length of hospital stays.

5.5.3 Results[32]

Regarding the graphical analysis, results showed that the patterns of hospital utilization during the last year of life were comparable across all socioeconomic categories. In any case, the frequency of hospital utilization first exhibited a steady growth over the last 12 to two months, which was then followed by an abrupt increase during the last month before death.

Regarding the generalized linear models, results showed that patients with lower socioeconomic position (i.e., being a CSSA recipient and/or an RCHE resident) in fact tended to have higher hospital utilization rates, both in terms of frequency and length of stays.

5.5.4 Discussions

The findings of this study showed that poor socioeconomic status did not create a significant barrier to accessing public EOL care services. In fact, these services were, at least in terms of quantity,[33] pro-poor in nature. It was a reassuring sign that the public healthcare system could serve as a “safeguard mechanism” for the lower social class, ensuring that they could receive the basic form of care during the last year of their lives. Of course, a higher hospital utilization rate is not always, ceteris paribus, a desirable thing. Quite the contrary, successful provision of EOL care should imply a reduction in unnecessary and avoidable hospitalizations (see Section 1.3.2.3). In view of this, future studies should explore how one’s socioeconomic determinants may affect the quality, not only the quantity, of EOL care services received. Incidentally, it should be mentioned that this study in its own right also prompted the project team to pay more

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[32] Owing to space constraints, only the interpretation of main results will be presented here. Interested readers may refer to the original article for plots and statistical tables.

[33] The indicators used in this study could not reflect the quality of EOL care delivered to patients.

attention to promoting health equity in the public education activities, for instance, by covering content related to existing community resources and referral network in EOL care. Through this way, less well-off individuals can gain equitable access to not only the services provided by public hospitals, but also those provided by the social welfare sector.

5.6 Effectiveness of Advance Care Planning and its advocacy efforts

5.6.1 Background

As mentioned in Section 1.3.1.1, the CGATs commenced a funded initiative back in 2015, in which muti-disciplinary teams from the HA started to promote and facilitate the uptake of ACP during their regular visits to RCHEs. As such practices became more routinized and mature, the project team carried out a study to review the effectiveness of this service model, by examining whether patients and their family members who went through the communication and documentation process genuinely perceived ACP to be beneficial. This study was further motivated by the fact that multiple systematic reviews of academic articles published in the Western countries consistently stated that ACP was in fact not useful in terms of enhancing the likelihood of goal-concordant care and improving the quality of life (see, e.g., Morrison, Meier, & Arnold, 2021). Evidently, while ACP is a concept with good intentions, its outcomes may largely depend on its actual execution, hence the need to scrutinize the effectiveness of the CGAT's service model in reality.

On the other hand, as mentioned in Section 3.3.2.1, the project team has regularly conducted family sessions to promote ACP at Shatin Hospital. Similar to the case of the CGAT service model, the project team carried out a study (on top of other ordinary evaluation strategies as mentioned in Section 2.3.5) to examine whether these ACP family sessions had attained the intended outcomes, that is, whether patients and family members were willing to initiate the ACP process, and whether ACP brought any concrete benefits to them.

5.6.2 Methods

Both studies adopted a qualitative and exploratory approach, in which individual, semi-structured interviews were conducted via telephone. For the study on the CGAT's service model, interviewees were family members of patients who were beneficiaries of the HA's ACP initiative. In other words, all of these patients had already gone through the ACP communication and documentation process under the assistance of the CGAT. For the study on the ACP family sessions, interviewees were previous participants of these sessions. Some of them had completed the ACP process with their care recipients, but some had not. The final samples of the two studies both consisted of 23 individuals. All interviews, which lasted for about 15 to 60 minutes in duration, were audio-recorded and transcribed verbatim. Thematic analysis was performed to identify and extract the key messages.

5.6.3 Results

Regarding the CGAT's service model, participants first expressed that this initiative allowed patients to bypass the assessments and diagnostic tests usually performed in the emergency units and thus be admitted to the sub-acute medical wards directly. This pragmatic arrangement was highly regarded, as it could reduce waiting time and unnecessary suffering. Second, participants were grateful that the CGAT actively approached them, provided detailed explanations on the patients' conditions and treatment options, and guided them through the ACP process. It was perceived that the healthcare team knew the patients better and thus had a better understanding of when to initiate the conversations. Third, participants acknowledged the value and importance of the ACP process. Some stated that it provided a turning point for them to gradually accept the idea of forgoing LSTs, while some others stated that it helped minimize the conflicts among different family members. Notably, many participants thought that the involvement of the CGAT created a particularly positive experience, as they could genuinely feel the care and support from the healthcare team. Psychological benefits such as reducing anxiety, worries, and caregiver strain, as well as achieving "peace of mind," were also

commonly reported. Fourth, however, some participants expressed that the ACP process was not as helpful with respect to the actual care that the patients ended up receiving. While making decisions throughout the ACP process was certainly meaningful, participants also wanted to do something more tangible to make the patients feel comfortable.

Regarding the ACP family sessions, participants first expressed that they were receptive to the information about EOL care, ACP, and treatment options as disseminated in the sessions. They generally endorsed the philosophy behind ACP, as they believed that it could help the healthcare team meet the patients' needs in a holistic manner. Second, for those who had completed the ACP process, all believed that the discussion and documentation could enable them to make better psychological preparations for the patients' deaths. For instance, some stated that the conversations helped bring and unite different family members together, such that they could support each other and thereby reduce their sense of guilt and regret. Third, however, some perceived the ACP discussion per se to be not very useful in terms of improving the status quo of patients. Similar to the case of the other study, many participants expected more concrete follow-up actions to be taken to provide immediate comfort to the patients. Fourth, the success rate of converting the fruitful outcomes of the sessions (as elaborated in Section 3.3.4.2) into actual ACP implementations was relatively low. More precisely, only five out of 23 participants had completed the ACP process under the assistance of the project team. The main barrier was that many patients were already demented by the time the sessions were delivered. Consequently, most of them had lost mental capacity and could no longer get involved in the ACP communication process.

5.6.4 Discussions

For both studies, it turned out that it was rather difficult to explicitly examine the effectiveness of ACP in terms of its potential improvements in the patients' quality of life. Since ACP was an unfamiliar concept to most participants, they might have little idea of what to expect from the communication process. Consequently, some of them might be disappointed that not much could be done immediately to make the patients feel more comfortable. In some other cases, since a consensus on treatment options had already been reached beforehand, the ACP process might not have made much of a noticeable difference to the final outcome. Nonetheless, it was a positive signal that most participants were receptive to the concept and philosophy of ACP, and that many experienced therapeutic benefits in the communication process. Furthermore, the "low success rate" of the ACP family sessions was primarily driven by the unfortunate timing, rather than by the participants' negative perceptions or anything inherently flawed with the sessions. The implications of the two studies for the Programme are as follows. First, when educating the public and promoting the uptake of ACP, it is important to clarify what ACP is, and what it is not, thereby setting more realistic expectations. Second, it is also beneficial to provide more practical guidance to family members along the way, regarding what they can do to make the patients feel better. When their pressing needs are properly addressed, family members may be able to liberate their mind and thus have the spare capacity to better understand and appreciate the importance of ACP. Third, when running the service model of the ACP family sessions in the future, further efforts can be made to identify patients who are still mentally capable of being involved in the ACP process. At the same time, other kinds of support and assistance (i.e., not only in terms of encouraging the implementation of ACP) can be provided to demented patients and their family members.

5.7 Factors affecting Advance Care Planning for demented patients

5.7.1 Background

Results of the aforementioned study on the ACP family sessions (Section 5.6.3) revealed the special needs of patients with advanced dementia and

their family members in EOL care, which should not be overlooked given the significance and prevalence of this condition. In particular, it seems that special considerations need to be taken into account when determining the appropriate timing for initiating ACP discussions. In addition, it is conceivable that the barriers to and facilitators of ACP for this group of people may differ from those observed in the general population (e.g., Section 5.4). To inform future policies and practices, the project team conducted this final study to examine the factors affecting the uptake and initiation of ACP among demented patients and their family members.

5.7.2 Methods

This study was a systematic review. A literature search was conducted on the academic databases Ovid MEDLINE, PsycINFO, and CINAHL Ultimate to identify peer-reviewed research articles published up to 13 June 2023. The main search query was "Advance Care Planning" AND "timing" AND ("dementia" OR "Alzheimer's disease") AND ("family surrogate" OR "family member") AND ("healthcare worker" OR "healthcare professional") AND ("barrier" OR "facilitator"). Search results were assessed using a pre-defined checklist of evaluation criteria. Studies meeting the criteria were then processed using the NVivo software to identify relevant patterns and themes.

5.7.3 Results[34]

Six out of 42 articles obtained from the database search satisfied the selection criteria. Two additional papers identified through other sources were also included.

Regarding the timing for initiating ACP discussions, it can be challenging to identify the most appropriate moment to engage patients, unless their conditions have already progressed to a point where they become a burden to others. In general, the optimal time would be between the diagnosis of dementia and admission to nursing homes. Initiating ACP discussions at the exact moment of admission is often considered less ideal, as family members may need more time to adjust and settle into the transition process.

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[34] For brevity, only findings directly and specifically related to dementia will be presented here.

Regarding the barriers to ACP, a clearly evident challenge is that many patients with dementia can no longer actively participate in discussions. The primary reason for this delay and missed opportunity is that family members tend not to perceive dementia as a terminal condition. Consequently, they often direct their limited energy towards managing the patients' immediate deterioration and other pressing issues, rather than future planning and preparation for death.

Regarding the facilitators of ACP, a critical factor is the patients' and family members' understanding and acceptance of the disease trajectory of dementia, which in turn necessitates more active engagement and clearer communication from the healthcare team. This again underscores the importance of capacity building in this context, especially training in communication skills. In addition, family members may benefit from observing other residents' conditions and disease progression, which could help them recognize the importance of ACP.

6 Conclusions

In this final Chapter, we first reiterate several key messages representing the core philosophy of the Programme, which we want to convey to the readers through the present report. We then summarize the Programme by stating its significance and achievements, in both local and global terms. Last, we conclude the report by making several recommendations on how future initiatives can further advance the development and normalization of EOL care in Hong Kong.

6.1 Key learnings

EOL care is an integral part of medical care. It is essential to communicate with patients and family members to understand and document their preferences in advance. The responsibility of delivering the care and conducting conversations should not be assigned to a single specialty. Instead, a team approach should be adopted, in which professionals from across different fields and backgrounds should all contribute to the care delivery process. As the public has become more open and willing to discuss matters related to EOL care, healthcare professionals should also take a step forward to equip themselves with the prerequisite knowledge and communication skills.

6.2 Significance and achievements of the Programme

6.2.1 Local impact

Through its effective implementation strategies, the Programme has successfully attained the objectives of building capacity and raising awareness on EOL care among the Hong Kong population. To briefly reiterate, the Programme has offered over 700 training and educational sessions to more than 50,000 individuals from different age groups and backgrounds, issued and distributed over 60,000 copies of printed materials, produced a collection of self-learning and promotional videos that accumulated over 600,000 views on various social media platforms, and conducted various research activities leading to a better understanding of the current situations and unmet needs of EOL care in Hong Kong. These efforts and their successful results have been

documented extensively in the present report. On the other hand, the achievements and significance of the Programme were also covered in a variety of media outlets including, for instance, the opinion column of the South China Morning Post, the Cubic Zine magazine, and the book "Take Charge of Your Own Aging: Growing Old in Hong Kong" published by the CUHK press.

6.2.2 Global recognition

In addition to its substantial local impact, the Programme has also extended its presence and influence beyond the regional borders. For instance, the service model for running the ACP family sessions as mentioned in Section 3.3.2.1 was featured by the WHO on its "Decade Knowledge Platform" (WHO, 2021) for acknowledging its contribution to the "United Nations Decade of Healthy Ageing" initiative. Relevant parties and stakeholders from around the globe can visit this platform and take reference of this successful model when developing their own strategies for promoting EOL care. For another instance, in recognition of its pioneering efforts and achievements in raising capacity of healthcare professionals, the Programme was selected as a finalist of the "Innovation of the Year: Caregiver Model" by the "Asia Pacific Eldercare Innovation Awards 2020," which was presented during the renowned "Ageing Asia 2020: World Ageing Festival." Last but not least, the project team conducted or was invited to attend poster presentations in several international conferences including, for instance, the "2019 Taipei International Symposium on Palliative Care," "8th Advance Care Planning International Conference," "Asia Pacific Hospice Palliative Care Conference," and "International Conference on Primary Care Ecosystem: Integrated Care for Successful Ageing."

6.3 Future directions

There were two major achievements in the Programme that particularly deserve to be carried forward, namely the role-play simulation exercises designed for healthcare professionals, and the service model for running the ACP family sessions at Shatin Hospital. Regarding the first one, as mentioned in Section 3.2.6.2, role-play simulation exercises should be routinized and incorporated into the curriculum design of regular training, especially those intended for doctors. Regarding the second one, geriatric wards and HRCs at other public hospitals can draw lessons from this pilot implementation and take the lead to identify patients and family members who may benefit from ACP discussions by, for instance, referring to the HARRPE score. NGOs and community partners in future initiatives can then go to hospitals regularly and arrange educational sessions for this group of target beneficiaries, which serve as a kickstart to provide them with basic knowledge about EOL care. After that, participants who are interested and ready to initiate the EOL communication process can be referred back to the healthcare team for follow-up actions. This is a good example of medical-social collaboration illustrating how existing community resources in the academia and social welfare sector can be utilized to share the workload of healthcare professionals in the public medical system, as well as to promote the uptake of ACP in a more sustainable manner.

As a remark, the HARRPE score as mentioned above is an index composed of various risk factors, such as prior hospital utilization and co-morbidity, and is automatically calculated by the HA’s CMS, on a daily basis, for newly admitted patients aged 60 years or above. According to internal clinical data, a score of ≥0.4 roughly corresponds to an average life expectancy of six months, thus it can serve as an effective tool enabling the healthcare team to identify the right timing for initiating the EOL communication process (see Section 1.2.2). Given its usefulness and accessibility, the HARRPE score should indeed be advocated and more widely used among healthcare professionals.

Last but not least, future training and educational endeavors may revolve around certain topics that have yet to be covered in the current Programme activities, but which have drawn interest from many of the previous participants. These include, for instance, how to conduct EOL conversations in more specific settings such as paediatrics, intensive care unit, and emergency department, as well as how to facilitate dying in place from the perspective of RCHE staff.

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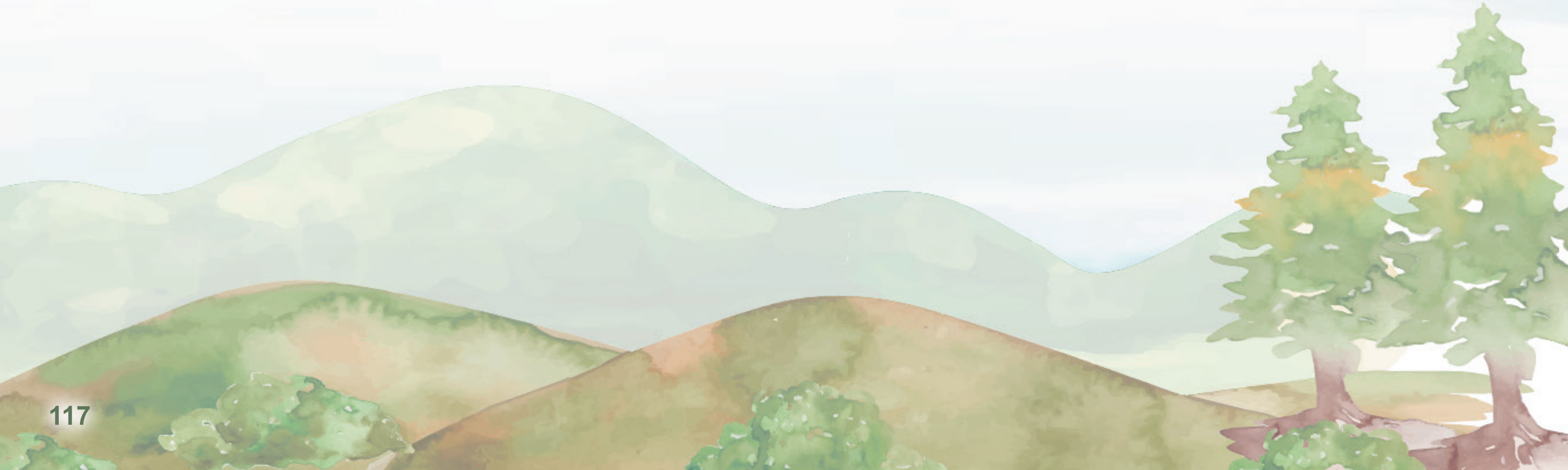

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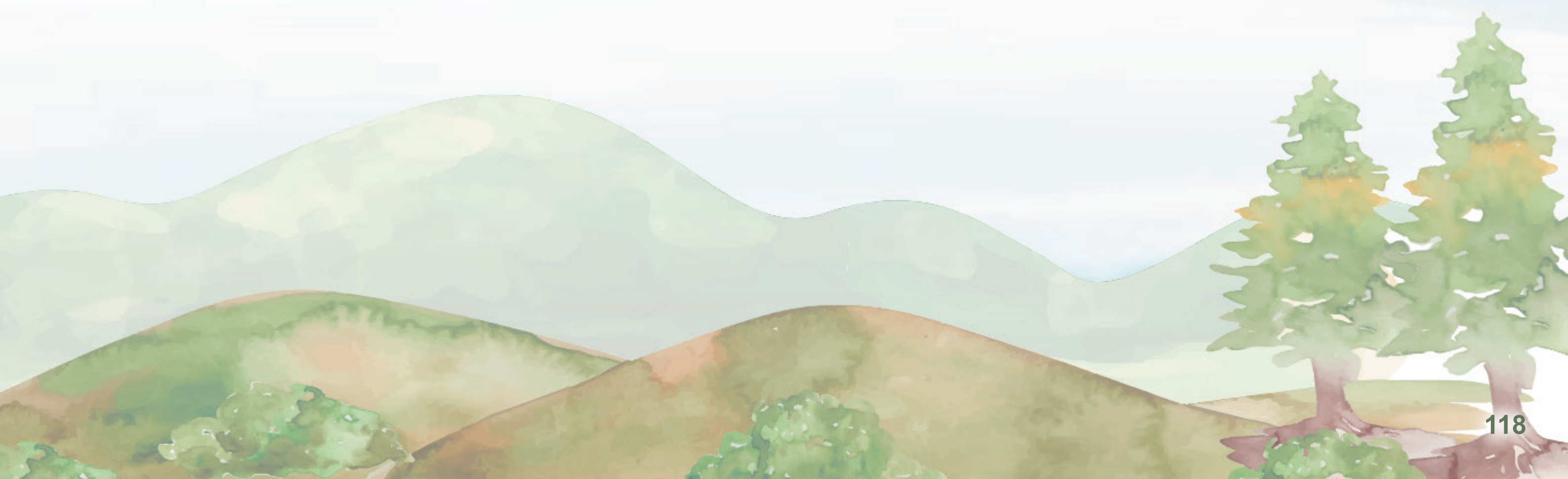

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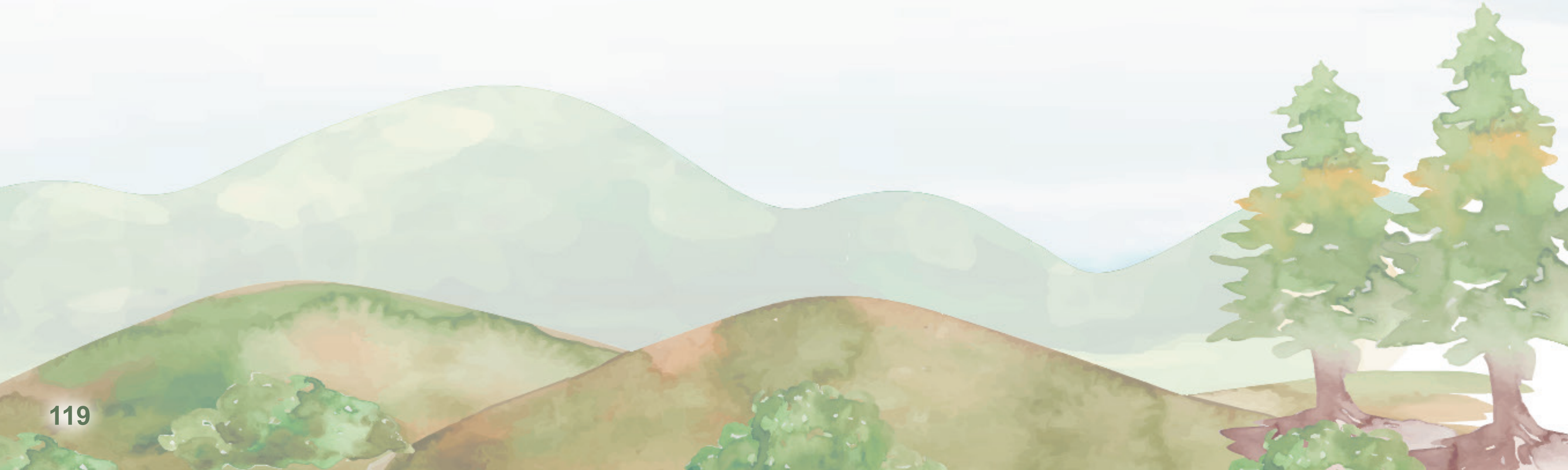

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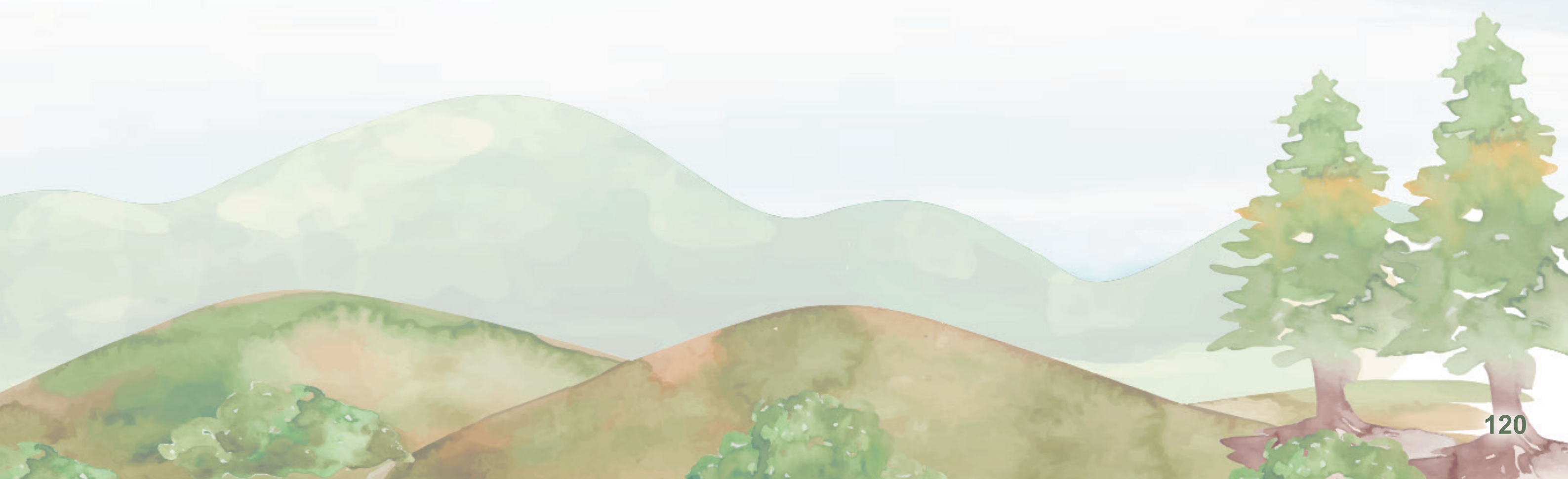

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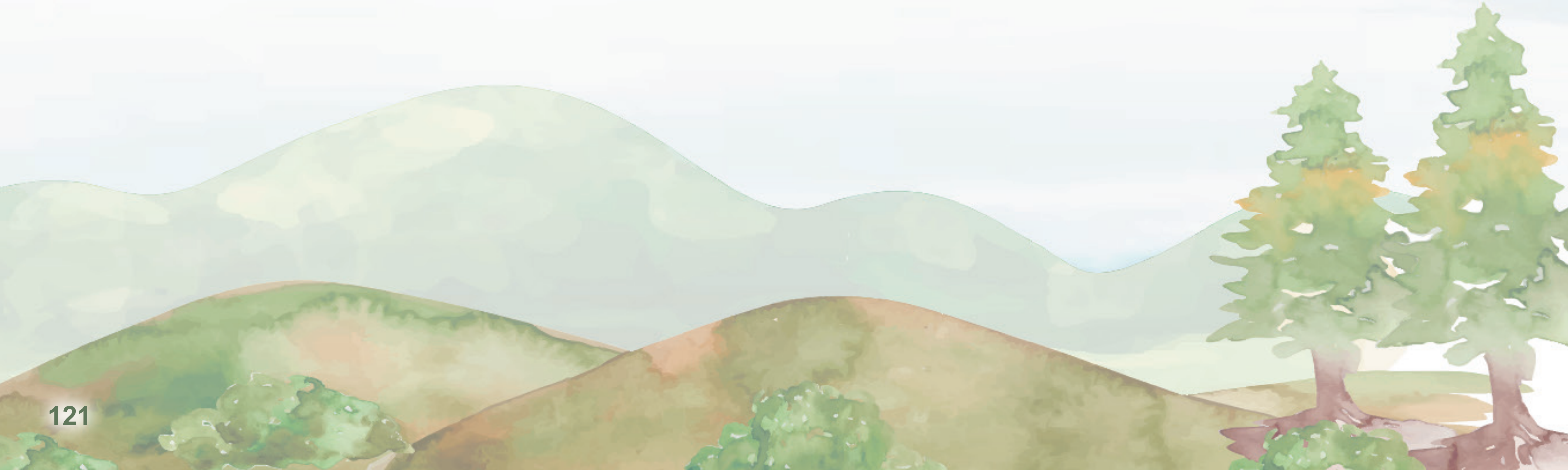

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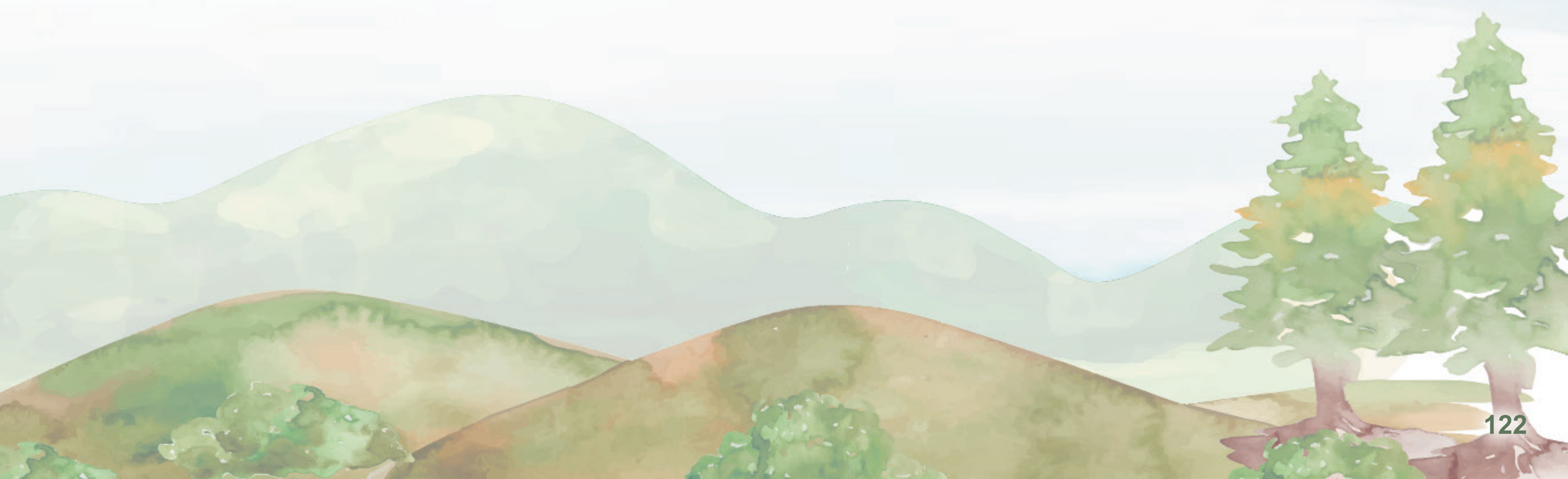

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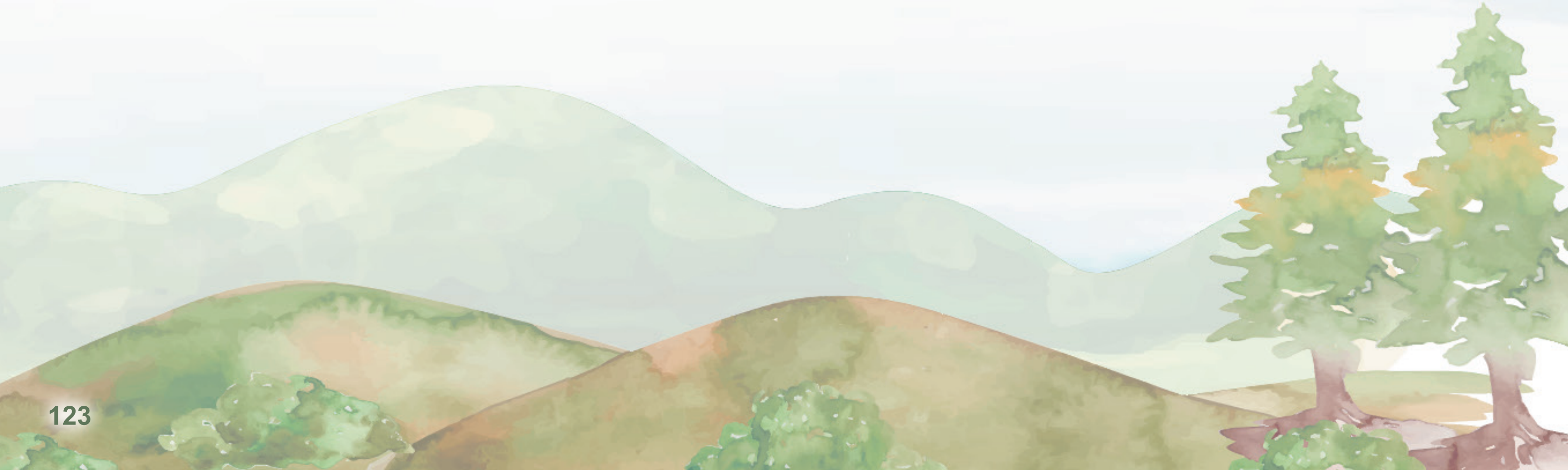

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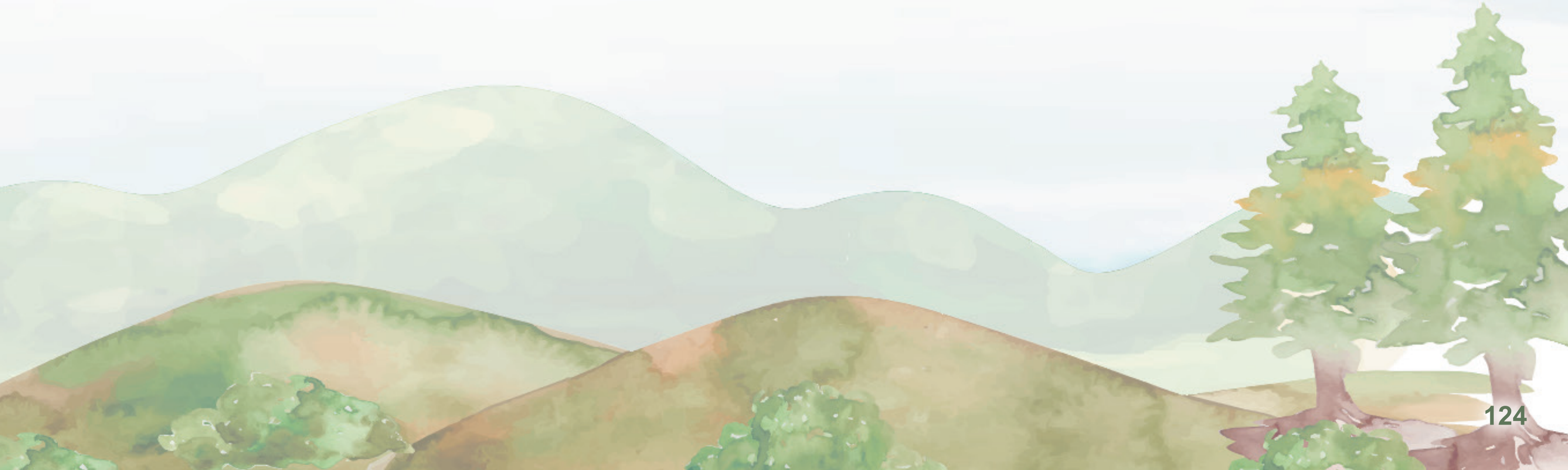

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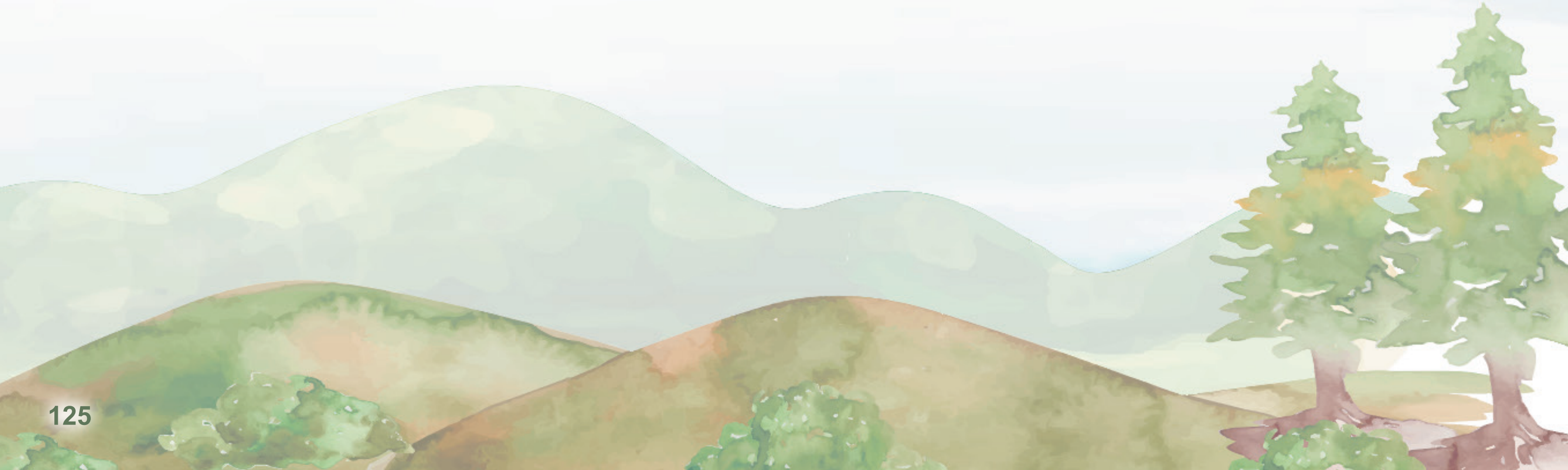

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