



INNOVATION • IMPACT

THE FOUNDATION OF

COMMUNITY-BASED END-OF-LIFE CARE

IN HONG KONG

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EDITED BY

Iris K. N. Chan, Candy H. C. Fong, Eva Y. Wong, Vivian W. Q. Lou & Cecilia L. W. Chan

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END-OF-LIFE CARE IN HONG KONG

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FOREWORD

Hong Kong is facing a rapidly ageing population. Not only is the number of elderly people suffering from terminal illnesses set to increase, but also the demand for end-of-life care (EoLC) will see significant growth. People have come to recognise that a good death is an important part of a quality life, while ageing in place is a preference expressed by the majority of the elderly. Yet there is insufficient service provision and a lack of care and treatment choices in Hong Kong to allow elderly people to die with dignity and comfort at the end of their life.

To address these evolving challenges, The Hong Kong Jockey Club Charities Trust initiated the Jockey Club End-of-Life Community Care (JCECC) project in 2015 with a vision to promote the quality of dying for terminally-ill seniors.

The Trust has brought together key stakeholders of the social and health care sectors to pilot five community-based EoLC service models in this multi-disciplinary, multi-institution and cross-sectoral collaboration. We hope to enhance community EoLC at three levels: at the individual level, to allow patients an informed choice of care and improve both their own quality of life and that of their caregivers during their last days; at community level, to increase public knowledge and understanding of end-of-life concepts, such as advance directives and advance care planning; and at system level, to drive systemic change in the delivery of such services by building the competence of EoLC practitioners. This will strengthen the capacity of the field as a whole, as well as establish evidence-based practices that can be used as reference for future service development.

With the concerted efforts of our partners, we are encouraged that about a quarter of all subvented elderly homes in the city have already participated in this project in the past three years. The five community service pilots have also helped make home-based care a reality for over 3,700 terminally-ill patients and their family members. We are equally encouraged that over 9,400 professionals and front-line workers have been trained under the project, with more than 560 volunteers joining hands to support EoLC.

To further strengthen the sustainable development of EoLC in Hong Kong, the Trust has extended the project for another three years, with an enhanced integrated service model and extended coverage of EoLC programmes in elderly homes.

On behalf of The Hong Kong Jockey Club Charities Trust, I would like to express my heartfelt thanks to all those involved, and particularly The University of Hong Kong for their tremendous effort in compiling this booklet. We believe that with the experience of the project implementation and evidence-based service models it documents, the booklet will further facilitate intellectual exchanges on EoLC in Hong Kong.

Ageing is a normal and natural process that everyone must undergo, and the Club would like to help make the journey more fulfilling and colourful. I believe that through our collaborative efforts, we can make our city a more caring community.

Mr. Leong Cheung

Executive Director, Charities and Community
The Hong Kong Jockey Club

FOREWORD

Hong Kong is facing a rapidly ageing population, and so end-of-life care is an important issue for our community, yet it is easily neglected owing to the traditional Chinese cultural taboo of talking about death. Because of these sensitivities, raising public awareness and scholarly understanding about end-of-life care is important if we are to provide greater care for patients and families going through this inevitable stage of life.

The Faculty of Social Sciences of the University of Hong Kong is dedicated to addressing social well-being issues in order to make a difference to society and humanity. The University is grateful to the generous support from The Hong Kong Jockey Club Charities Trust, which enabled us to work together with the Chinese University of Hong Kong and five NGO partners to launch the Jockey Club End-of-Life Community Care Project (JCECC) in 2015.

JCECC has gone through three fruitful years. This multi-disciplinary, multi-institutional and cross-sectoral collaboration has created a tremendous positive impact on the general community, and end-of-life care professionals in particular, through structured training and international wisdom sharing. The Project has also enhanced awareness of these issues and created a partnership between experts and the general public to develop a compassionate community through public education and volunteering activities.

The JCECC achievements fit perfectly with the University of Hong Kong's strategic vision: Internationalisation, Innovation and Interdisciplinarity, all converging on Impact.

This book, *"Innovation • Impact: The Foundation of Community Based End-of-Life Care in Hong Kong,"* is a testament to the impact generated by the Project on healthcare services to Hong Kong, and the first of its kind – offering valuable information to Chinese communities in Mainland China, Asia Pacific and around the world.

My sincere congratulations to the JCECC Project team and all its stakeholders who have helped make this book a reality. I hope it will stimulate academics and researchers to think more deeply about the innovative and effective advancement of healthcare services, which will generate a better quality of life for those suffering from terminal illness, and help build a more compassionate society.

Professor Xiang Zhang

President and Vice-Chancellor
The University of Hong Kong

FOREWORD

In the face of an ageing population and the prevalence of chronic diseases, the Government attaches great importance to improving end-of-life care. To provide holistic care to terminally-ill patients and their families in the public system, the Hospital Authority (“HA”) has been offering comprehensive palliative care services at all seven clusters through a multidisciplinary team of professionals. The services cover in-patient service, out-patient service, day care service, home care service, bereavement counselling, etc. In 2017, HA promulgated the “Strategic Service Framework for Palliative Care”, to guide its development of service model and system infrastructure of adult and paediatric palliative care service in the coming five to ten years.

To strengthen the provision of end-of-life care services, we need concerted efforts from both the public and the private sectors. The “Jockey Club End-of-Life Community Care Project” (“JCECC”) is a good example of enhancing the capacity of service providers in the delivery of end-of-life care, as well as raising public awareness and comprised Innovative Service, Specialised Training, Knowledge and Skill Transfer as well as evaluation of the Project.

I am very happy to learn that Phase 1 of the JCECC was a great success and Phase 2 will be launched in January 2019. I hope that the experience and insights documented in this book will encourage healthcare and social care professionals to continue their contributions to the community end-of-life care in Hong Kong.

Professor Sophia Chan

Secretary for Food and Health
The Government of HKSAR

FOREWORD

Hong Kong has the world's longest life expectancy. The latest global data collated by Japan's health, labour and welfare ministry in 2018 showed Hong Kong women live to an average of 87.66 years and men 81.70 years. However, living longer may not be a blessing to some, especially if longer life implies prolonged frailty, illnesses and most of all, physical and psychological sufferings for the patients in their final days, owing to the lack of quality end-of-life care (EoLC) in the territory.

The development of EoLC in Hong Kong is dated back to the 1960s when the Nam Long Hospital was built for cancer patients with 120 beds in 1967. More residential and home care services, as well as psychological support and bereavement services are later provided by the Hospital Authority and non-government organisations (NGOs). The Jockey Club End-of-life Community Care (JCECC) project implemented in 2015 is a proactive and timely response to the needs of our ageing population by piloting various community-based comprehensive EoLC services, either in elderly homes or at patients' own homes, along with staff training and public education programmes. By joining with two universities, five NGOs and the public and private healthcare sectors, the project has successfully taken its first step to devise feasible, cost-effective and sustainable solutions to meet the ever-increasing demand for EoLC in Hong Kong; and build professional and community capacity, which spark off more multi-disciplinary, cross-sector discussion and collaboration in society.

This book is a useful and comprehensive documentation of the work-in-progress for the JCECC. It gives an introduction of the development of EoLC in Hong Kong and showcases the innovative EoLC community services provided by the NGO partners through this project. It serves as a guideline to all industry players and also a valuable source of reference to the academia researching on the topic of EoLC.

As stated in 2018 Policy Address, the SAR Government will consult the public next year on arrangements of advance directives and the relevant end-of-life care to allow terminally-ill patients more options of their own treatment and care arrangements. It showed the SAR Government's strong determination to optimise the provision of EoLC in community. I am sure the continuation of the project for another three years goes in line with the Government's strategic intent and sheds light on how to better the EoLC in Hong Kong.

Dr. Lam Ching-choi

Member, Executive Council

PREFACE

“A bad death” is one of the worst curses ever in the Chinese culture. With the goal of promoting a good death for the terminally ill patients, The Hong Kong Jockey Club Charities Trust initiated the Jockey Club End-of-life Community Care Project (JCECC) to pilot a community intervention model that is evidence-based and relevant to the local context. Patients with a prognosis of less than 6 months from major hospitals will be referred to community partners to enable patients to gain the best quality of life with dignity and autonomy by staying in their own home or long-term care residential facilities.

There is ample evidence that community support can empower patients and their family members to communicate with the health care professionals and among themselves so that their preference on end-of-life care and advance care plans can be established and shared. International experts are invited to Hong Kong to train health and social care professionals to enhance their clinical and communication competence. Through systematic professional training and leadership programs, the general awareness and level of competence among professionals were greatly enhanced.

Death and End-of-Life Community Care are very important, yet taboo topics in the predominantly Chinese community of Hong Kong. The JCECC organised large scale community education campaign, use of social media, produce mini-movies and documentaries, newspaper and publications. The changes of public knowledge and attitude on end-of-life were tracked by large scale population studies through the process of the project. With the massive public education activities in detoxifying death and culture change on the importance of death preparation, new initiatives by non-government organizations on good death and end-of-life care mushroomed in Hong Kong.

We are greatly indebted to The Hong Kong Jockey Club Charity Trust for initiating this JCECC Project. The pursue of excellence and the dedication to building viable local service models relevant to the cultural context of Hong Kong by HKJC members and staff had truly moved mountains. The Advisory Committee consisting of leaders in the Food and Health Bureau, Labour and Welfare Bureau, Hospital Authority, experts from professional organizations and organizations. They have provided the JCECC team with invaluable advice and guidance throughout the past three years.

We are very grateful to all the contributors of this book for sharing their passion, expert knowledge and vision, thus making this book possible. The colleagues from agency partners of the Project were innovative and creative in dissolving fear of death by their warmth and passion to celebrating every life until the last moment of death. We would like to express our sincere gratitude to all the volunteers and advisors for their time and effort, as they have created laughter and fun for the families who were devastated by the disease burden and stress of caregiving.

Professor Cecilia Chan, Dr. Amy Chow

Project Co-Director

The Jockey Club End-of-Life Community Care Project

ABOUT "JOCKEY CLUB END-OF-LIFE COMMUNITY CARE PROJECT"

Hong Kong is facing a rapidly ageing population, and the number of elderly suffering from terminal illnesses has also escalated correspondingly. In view of the growing demand for end-of-life care services in the community, The Hong Kong Jockey Club Charities Trust approved HK\$131 million to launch the "Jockey Club End-of-Life Community Care Project" (JCECC) in 2015. The project is a three-year initiative aimed at improving the quality of end-of-life care, enhancing the capacity of service providers, as well as raising public awareness.

JCECC is a multi-disciplinary, multi-institutional and cross-sectoral collaboration to help enhance end-of-life care in Hong Kong with special emphasis on the interface between social and medical systems. Five service models are being developed and piloted in the community to provide holistic support to elderly people suffered from terminal illness. The goal is to enable the city's older people to have informed choices of care and enjoy 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 Services, The Hong Kong Society for Rehabilitation, St James' Settlement, and S.K.H. Holy Carpenter Church District Elderly Community Centre.

Please visit <http://www.JCECC.hk/>



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S. K. H. HOLY CARPENTER CHURCH
DISTRICT ELDERLY COMMUNITY CENTRE
(由香港聖公會福利協會有限公司營運)





PART I:

INTRODUCTION

CHAPTER 1

INTRODUCTION

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The Hong Kong Jockey Club

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BACKGROUND

Hong Kong people enjoy the longest life expectancy in the world. Longevity is one of five blessings in Chinese traditional culture. Chinese families cherish the wisdom of seniors in the family, as well as the family lineage. Reciprocity and filial piety are virtues that hold Chinese families together. The caring and extended family networks provide the solid foundation on which Hong Kong social infrastructure is based. This makes Hong Kong society very special. According to the mid-2016 population distribution, the two largest Hong Kong population age groups are 50–54 years, and 55–59 years (HKSAR Census and Statistics Department, 2017a). Many individuals in these age groups have experience of taking care of elderly parents. To assist families facing the imminent death of a loved one, there has been increasing and wide-spread impetus to embrace the notion of EoLC in Hong Kong.

People in Hong Kong who are at EoL, and their families, may experience complicated and conflicting emotions. On the one hand, there are positive aspirations created by the Chinese work-ethic of “never give up”, the traditional dependency on the highly effective and affordable medical system available in Hong Kong, and the hope that with medical care, a beloved family member can live longer. On the other hand, there are negative emotions from the distress of witnessing a loved one suffering or watching them become dependent on others for daily care and/or having their enjoyment of life curtailed by severe frailty. Moreover, there is a tendency towards “death avoidance” in the Chinese culture because there is strong fear of death and a superstitious belief that the verbalisation or even thoughts of “death” will hasten it (Chan, 2009; Chan & Chow, 2006). Because of general reluctance to discuss death, people at EoL and their families can be unprepared when it happens. Without adequate preparation, a loved one’s death may leave unfinished business and regrets, which could result in mutual blaming, guilt and disputes among family members. There is no simple solution to the entanglement of mixed emotions regarding EoL.

There are also service delivery issues to consider. While the public medical community has traditionally leaned towards sophisticated high-tech acute care, the development of specialisation of palliative care and hospice support has had little momentum, and consequently it has been relatively slow to progress.

These issues are not unique to Hong Kong. With the world population growing older, common questions that societies need to face include how to preserve a good quality of life before death, where to provide the needed support, who to deliver the actual care, when to plan and start various services, and how to ensure affordability, accessibility and availability (Chan & Chow, 2006). There is a long waiting list for placement of frail older adults in elderly residential care facilities and for home care support. When a person is dying, time is limited for organising specialised care and, currently, available care options for these individuals and families are limited. Rushing frail older adults into Accident & Emergency Departments (A&E) or admitting them to acute hospital beds seem to be the only viable options. There is little doubt that such arrangements are undesirable for patients at EoL and their families, the public healthcare system and for the wider community as a whole.

THE GROWING DEMAND FOR EoLC IN HONG KONG

Hong Kong enjoys the world's longest life expectancy (81.3 years for males, 87.3 years for females). It is estimated that the proportion of people in the Hong Kong population who are 65 years and older will double in the next 40 years from 16% in 2016 to 33% in 2056 (HKSAR Census and Statistics Department, 2017a). Moreover, the expected "old-old" group (people living beyond 85 years) will increase significantly.

Currently an estimated 74.3% people aged 65 years and older live with one or more chronic conditions, such as cancer and chronic diseases of the heart, respiratory, neurological and vascular systems (HKSAR Census and Statistics Department, 2017b, Table 3.2a, p. 27). It is noteworthy that this report did not mention chronic renal systems diseases. It could be assumed that with longer life expectancy, more elderly people will also suffer from age-related frailty and chronic health conditions. Given that the "old-old" group is expected to increase approximately five-fold from 2.2% in 2014 to 10% in 2044 (Commission on Poverty, 2015), it is also anticipated that the prevalence of comorbidities and chronic illnesses in older people will increase drastically in the coming decades. To meet the needs of older adults, we will require better coordination of medical and social care services in and across different care settings in order to obtain holistic, person-centred and seamless care to meet their complex needs. Care settings include emergency departments, inpatient wards, outpatient clinics, day care centres, community support groups and residential care services.

While it is important to optimise health and functionality among older adults, it is equally important to support them as they enter to the inevitable EoL phase and subsequent death. In the past three years, there have been over 46,000 deaths per year in Hong Kong, with one-third deaths attributed to cancer and one-third to chronic non-cancer conditions (HKSAR Department of Health, 2017). Eighty per cent of deaths have occurred in people aged 65 years or older (HKSAR Centre for Health Promotion, 2016). Medical service utilisation across healthcare settings escalates as people approach the last six months of their life, and healthcare usage surges particularly in the last two months. Healthcare usage is measured as inpatient and day-patient admissions, lengths of stay and attendances at emergency departments (HA, 2017a). By using pain prevalence data on cancer, HIV/AIDS and across a range of progressive non-malignant diseases, the World Health Organization (WHO) estimated that 70% adults living with life-limiting illnesses will require some form of EoLC services, including need for pain relief (WHO, 2014). In 2016, there were around 30,000 deaths among older adults (aged 65 or above) in Hong Kong, which were caused by malignant diseases or non-malignant diseases (excluding deaths caused by external causes or other unspecified causes) (HKSAR Department of Health, 2017). If the estimate in the WHO report is applied, it is estimated that in 2016 Hong Kong had at least 21,000 older patients (aged 65 or above) who required EoLC. This number is anticipated to increase each year.

DEVELOPMENT OF EoLC SERVICES IN HONG KONG

EoLC services in Hong Kong are often considered to be hospice and palliative care (PC), which are largely regarded as belonging to medical care systems. Most hospice care services focus on serving cancer patients.

The Hong Kong Anti-Cancer Society was established in 1963 and built the 120-bed Nam Long Hospital in 1967. Not surprisingly, hospice and bereavement support in Nam Long Hospital focused on cancer patients. The first hospice care and home care teams started at Our Lady of Maryknoll Hospital, Ruttonjee Hospital, Haven of Hope Hospital and the Society for the Promotion of Hospice Care (SPHC) in 1982, 1986, 1987 and 1988, respectively, marking the development of hospital-based PC services for patients with life-limiting illnesses. The first purpose-built Bradbury Hospice started providing inpatient care in 1992. PC services are now extended to 16 public hospitals in the seven clusters under the HA, providing 379 inpatient PC beds and a wide range of services such as PC in outpatient settings, home care and day care, palliative consultations, community geriatric assessment team (CGAT) care, and bereavement care services (HA, 2017b, 2017c). In 2007, the Li Ka Shing Foundation (LKSF) extended the “Heart of Gold” Hospice Service Programme to Hong Kong to assist in funding the establishment of 10 hospice centres within oncology units in public hospitals under the HA (LKSF, 2013).

Outside the hospital system there are increasing community efforts to improve EoLC. The Hong Kong Jockey Club Charities Trust provided funding support for the University of Hong Kong (HKU) to promote life and death education in the community in 2006 through the project ENABLE (Centre on Behavioral Health, 2010). Moreover, there are non-government-funded services by non-profit organisations (NPOs) providing EoL residential and home care services. They include the Haven of Hope Sister Annie Skau Holistic Care Centre, the Hong Kong Anti-Cancer Society Jockey Club Cancer Rehabilitation Centre and the Jockey Club Home for Hospice. EoLC projects have also been piloted in RCHEs. This reflects the fact that more elderly people than ever before are living in residential care facilities and the trend towards ageing-in-place is growing in strength. **Figure 1.1** summarises the development of EoLC in Hong Kong.

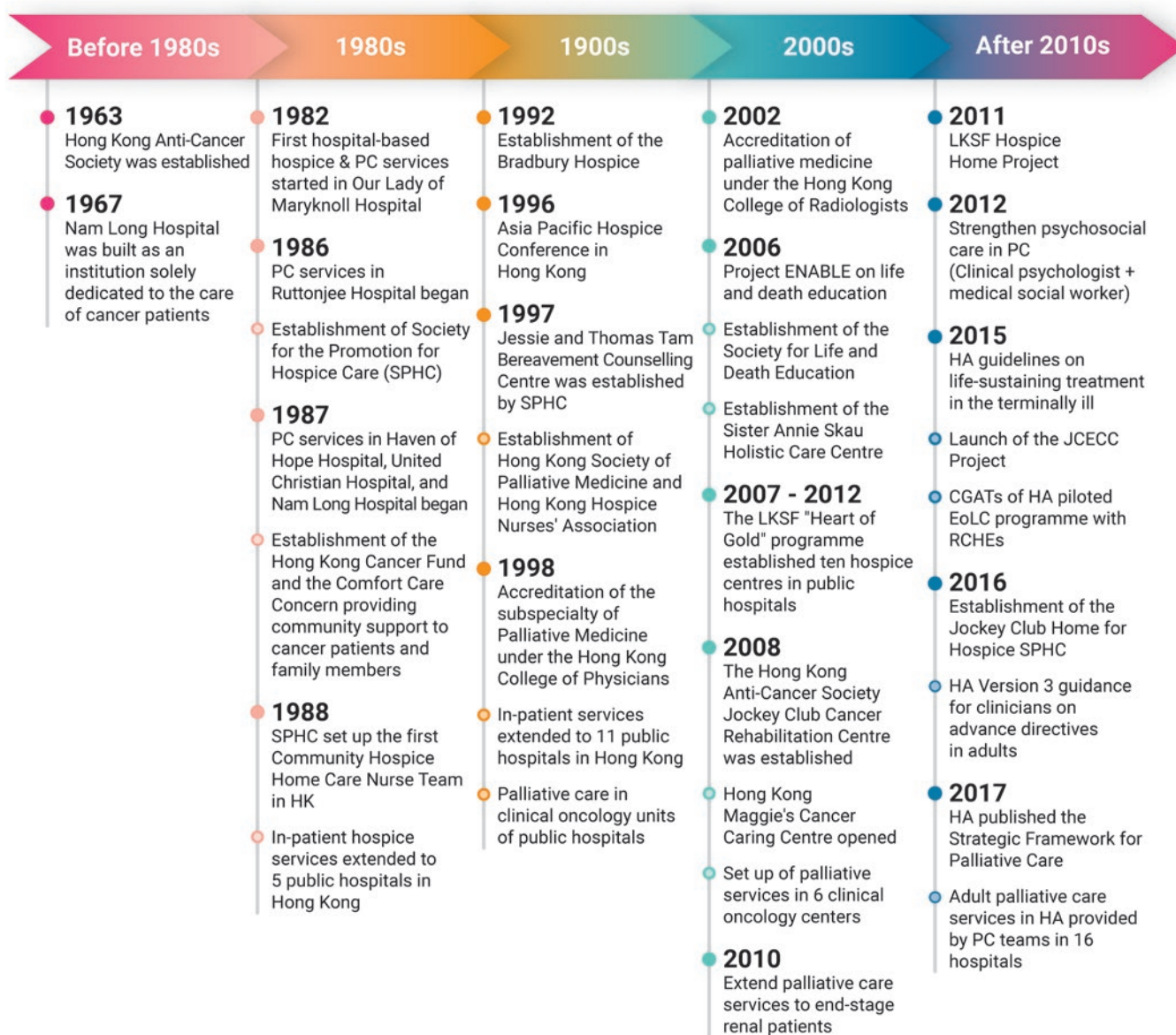


Figure 1.1 The Developmental Milestones of EoLC in Hong Kong

In terms of community support services, the Tung Wah Group of Hospitals has started providing funeral support to migrant labourers who die in Hong Kong. This hospital group runs funeral home services to support dignified burials.

In Hong Kong in the 1950s and 1960s, most people traditionally died in their homes because public hospital services were either unavailable or inaccessible. Since then, an increasing number of NPOs have provided psychosocial care in the community. Many of them have focused on bereavement support. For example, the SPHC was founded in 1986 to promote the concept of hospice services to Hong Kong; the Comfort Care Concern Group was founded in 1987 to provide education and support to children and youth in bereavement; and the SPHC Jessie and Thomas Tam Centre was started by Founding Director Dr Amy Chow in 1996. The S.K.H. Holy Carpenter Church has been providing bereavement support to families since 2004 and has conducted death education programmes, such as the DEAtHFEST in 2014, and St James' Settlement provides the "Worry-free" planning service for single older people.

These psychosocial support and bereavement services are operated by short-term private donations and are usually small in scale. They receive no regular government subsidy. Despite these organisations providing such community support services, limited numbers of patients approaching their EoL have access to them, and their needs and those of their family during the EoL period are often neglected. In the situation of shrinking family size and elderly persons taking care of other dying elderly persons, the burden of care within individual families is becoming too heavy, especially for less privileged individuals.

THE JCECC PROJECT – A CROSS-SECTORAL, INTERDISCIPLINARY AND FAMILY-ORIENTED INITIATIVE FOR CAPACITY BUILDING AND SERVICE MODEL DEVELOPMENT IN COMMUNITY-BASED EoLC IN HONG KONG

The Hong Kong Jockey Club Charities Trust initiated and funded the JCECC Project in 2015. This initiative had the aim of developing feasible, cost-effective and sustainable solutions to the surging demand for EoLC precipitated by the rapidly ageing population and increasing number of deaths in Hong Kong. In the JCECC Project, EoLC is defined as holistic care provided for patients with life-limiting advanced diseases with a prognosis of 6 months or less. The current situation is that most deaths occur in public hospitals. There is a severe shortage of EoLC support services in the community, making it almost impossible to die at home if that is the patient's wish. Chinese families are known to be very tightly knit. Unresolved grief may result in high bereavement risks that are commonly linked to chronic physical and mental problems for individuals and lower productivity for society. The JCECC Project is one of the Trust-Initiated Projects (TIPs) that sets an excellent example of how the Trust proactively addressed a social problem by bringing two universities and five non-governmental organisations (NGO) together to thoroughly investigate the problem and devise creative and practical service models that promote QoL for Hong Kong people and their family members at EoL.

The JCECC Project is a cross-sectoral, interdisciplinary and family-oriented service programme coupled with capacity building pilot initiatives aimed at strengthening community EoLC in Hong Kong. The ultimate goals are to improve quality of care, increase capacity of service providers, raise public awareness in community EoLC and facilitate informed decision-making regarding EoLC. The project assembles expertise, knowledge and practice wisdom from the partner organisations. The project has different components that address the needs of the public, communities, families, institutions, universities and hospital systems (**Figure 1.2**). Partners include two academic institutions (Faculty of Social Sciences, HKU; and CUHK Jockey Club Institute of Ageing), Chinese University of Hong Kong [CUHK]) and five community service organisations (Hong Kong Association of Gerontology, Haven of Hope Christian Service, The Hong Kong Society for Rehabilitation, St James' Settlement and S.K.H. Holy Carpenter Church District Elderly Community Centre).



Figure 1.2 JCECC Project Components

Hospital-based professional capacity building was led by the CUHK Jockey Club Institute of Ageing. The component initiates on-site professional capacity building programmes for medical professionals in one of the seven public hospital clusters in Hong Kong (the New Territories East cluster of HA). Through on-the-site workshops, seminars and support groups, these programmes seek to increase medical care team's awareness of, and enhance their competency in, the provision of EoLC in hospital settings. This component has become the exemplar which has the potential to be implemented in all seven public hospital clusters in Hong Kong (see Chapter 11 for details).

Residential facilities-based professional capacity building was led by the Hong Kong Association of Gerontology. This component focuses on providing district-based support for EoLC in 36 RCHEs in Kowloon district. Training protocols have been developed, which can be tailored to the needs of professional, semi-professional and non-professional staff in RCHEs. On-the-job training and supervision are also provided to reinforce knowledge and skills in EoLC. This component is relevant to, and could be implemented in, RCHEs in other districts in Hong Kong (see Chapter 12 for details).

Community-based professional capacity building was led by the Faculty of Social Sciences, HKU. The component focuses on changing attitudes, enriching knowledge and enhancing skills for health and social care professionals working in wider community settings. All levels of professionals, including policymakers, service managers and administrators, clinical leaders and frontline professionals, are targeted with the use of diversified and innovative strategies to facilitate mutual learning and exchange of good practices (see Chapter 13 for details).

Community EoLC service model development was led by four community service organisations. These organisations have developed and piloted community EoLC service models, drawing on their strengths and experiences in facilitating family care, providing community care, supporting families affected by non-cancer conditions, and mobilising volunteers. Coordination mechanisms have been developed with partnering public hospitals, and the breadth of experience brought by the community service organisations will underpin future pioneer community EoLC service model development (see Chapters 6–9 for details).

Community knowledge and skills transfer was jointly conducted by all partners of the project. The component increases public awareness about EoLC and promotes conversations and dialogues on EoL issues. Traditional seminars, talks, workshops and exhibitions have been organised using creative and interactive methods of information communication technology and creative media; experiential activities have been initiated; and a collaborative volunteer competence building programme has been developed with standardised training curricula and materials (see Chapters 14 and 15 for details).

Impact assessment and programme evaluation was led by the Faculty of Social Sciences, HKU. This is a unique component that provides an all-rounded assessment of the outcomes and impacts of the JCECC Project for multiple levels of partners and end-users. A contextually relevant, mixed-methods evaluation framework was developed for the project based on the framework of the Better Evaluation Initiative proposed by the Institute of Medicine (IOM) (IOM, 2014). This framework was conceptualised as 10 evaluation studies to measure the output, outcomes and impacts of the five other project components. It has generated preliminary evidence for the feasibility and sustainability of community EoLC, and sets a blueprint for integrating research, practice and service development in EoLC.

THE FIVE Cs IN EoLC

The 2015 Quality of Death report indicated that Hong Kong ranked 22nd among 80 world regions in terms of quality of death, lagging behind other Asian communities, including Singapore, Japan and Taiwan (Economist Intelligence Unit, 2015). Noteworthy was that Hong Kong ranked well on the dimensions of affordability and quality of care (ranking 18 and 20, respectively); however, it scored low in palliative and healthcare environment and human resources, especially on community engagement (38 out of 80). The JCECC Project focuses on expanding and improving bio-psychosocial and community EoLC in Hong Kong through increasing Coverage, Choices, Cost-effectiveness, Continuity of care, and Capacity and accessibility (5Cs) to preserve the dignity of persons at EoL. The elements of the 5Cs model are described next.

Coverage: holistic and need-based approach to EoLC. Coverage describes accessibility and availability of appropriate care provided at the right time to the people who need it. EoLC originated from cancer care. The model of oncology PC has matured over the last 30 years and is now relatively well-established in Hong Kong. However, there is an increasing need to expand EoLC from cancer to non-cancer chronic conditions. The WHO (2014) has recommended that EoLC should include care for non-cancer conditions such as cardiovascular diseases, cirrhosis of liver, chronic obstructive pulmonary disease (COPD), diabetes, HIV/AIDS, end-stage renal failure (ESRF) and multiple sclerosis. People suffering from non-cancer conditions encounter a wide range of symptoms, some of which are similar

to those suffered by cancer patients and some of which are specific to their condition (Moens et al., 2014). Compared to the relatively predictable illness trajectory of cancer patients, the illness trajectories of people with non-cancer conditions can be quite different. In Hong Kong, studies have suggested that 50% to 68.3% cancer patients received PC as needed (Lau et al., 2010; Lo, 2016; Tse, Chan, Lam, Lau & Lam, 2007). Statistics from the HA suggested that 44% of patients with ESRF were provided with PC in 2012–2013; however, considerable gaps remained in service coverage, particularly for patients with cardiac, pulmonary and neurodegenerative diseases, and dementia (HA, 2017a). There is no doubt of the need to expand EoLC coverage to non-cancer patients.

Mental health of patients at EoL, and that of their family members, is also gaining more attention. The four-week total prevalence of any mental disorder for patients with advanced illnesses can be as high as 31.8% (Mehnert et al., 2014). Moreover, a significant proportion of family caregivers report experiencing high levels of distress and caregiving burden, and are thus at risk of depression, anxiety and other psychiatric disorders (Grunfeld et al., 2004; Hudson, Thomas, Trauer, Remedios & Clarke, 2011; Hudson et al., 2013). It is obvious that there is a need for a holistic person-centred model of EoLC that takes into consideration psychosocial–spiritual well-being of patients at EoL, as well as that of their family members/caregivers (Chan et al., 2016; Lau et al., 2018). Holistic EoLC cannot be implemented without determining the appropriate timing of care. The standard six-month prognostic criterion has been extended to one year under the Gold Standards Framework (National Gold Standards Framework Centre, 2018). A needs-based approach in the life-course perspective of EoLC, including early identification, timely assessment and intervention, has been promoted (Gómez-Batiste & Connor, 2017). The JCECC Project strives to expand the coverage of EoLC to address the needs of cancer and non-cancer patients and to move this from a purely medical model to a holistic, family-centred approach. This should cater for the contextually relevant psychosocial–spiritual needs of patients and their entire family, and promote early identification and interventions.

Choices: enhancing autonomy. Offering choices is a way of honouring patient autonomy in EoLC. Seven areas of choices that the public and healthcare professionals regarded as important to quality EoLC were identified in a large-scale public engagement exercise in the United Kingdom (UK) (The Choice in End of Life Care Programme Board, 2015). The seven choices comprised:

I want to be cared for, and die, in a place of my choice.

I want the people who are important to me to be supported and involved in my care.

I want the right people to know my wishes at the right time.

I want support for my physical, emotional, social and spiritual needs.

I want involvement in, and control over, decisions about my care.

I want access to high-quality care given by well-trained staff.

I want access to the right services when I need them.

These can be summarised into autonomy in decision-making, choices on places of care and death, and types of care for self and family at EoL. A recent public survey in Hong Kong indicated high preference of people to be cared for in community settings, rather than hospitals, including social services agencies (72.9%), residential care facilities (72.1%) and home (54.6%) (JCECC, 2016). Moreover, 23.8% expressed the preference for being supported to die at home. In reality, however, more than 90% deaths happen in hospital settings in Hong Kong (Woo et al., 2009). Dying at home is difficult, if not impossible. Reasons for this include limited physical living spaces, legal requirements of reportable deaths and subsequent autopsies if people die at home, and also the local cultural taboos about death (Chan, 2009; Leung & Chan, 2011). Despite these challenges, it is the right of individuals to have their choices honoured on their desired places of care and death. New community-based, specialised EoLC services are therefore required to support patients who wish to stay at home for as long as they wish.

Preferred services at EoL largely depend on the patient's and family's care goals and values. Recent population surveys suggested that people at EoL tend to prioritise quality over quantity of care (Higginson et al., 2014). A survey in the UK conducted by the Sue Ryder (as cited in Weafer, 2014) found that four out of the top five priorities at EoL were related to psychosocial–spiritual needs, such as being surrounded by loved ones and staying in familiar environments. Similar findings were also reported in Chinese communities, who placed strong emphases on family and interpersonal relationships (Ho et al., 2013a; Huang, Liu, Zeng & Pu, 2015; JCECC, 2016). The availability of services that address not only physical suffering, but also psychosocial–spiritual needs, and that facilitate family connections are therefore critical to ensuring care options are available to address the complex needs of EoL patients and their family members (Chan, Reese & Chan, 2009; Ho et al., 2013b).

Continuity of care: transitions between community, residential care facilities and hospitals. Continuity of care can be defined as maintaining stable relationships, ensuring consistent communication of information and guaranteeing comprehensive, integrated care across time periods, care settings, providers and service users (D'Angelo et al., 2015). The pivotal role of care continuity in quality EoLC is well recognised in the National Institute for Health and Care Excellence (NICE) quality statement (NICE, 2011) and the clinical practice guidelines of the National Consensus Project (National Consensus Project, 2013). It is also one of the key determinants of patients' satisfaction with EoLC (Back et al., 2009).

Indeed, three of the four strategic directions suggested in the HA strategic framework for adult PC are intrinsically related to issues of continuity, coordination and transitions of care. These encompass strengthening the collaboration of medical and oncology PC specialists, promoting care coordination between PC specialists and non-PC specialists through a shared-care model to meet various levels of patients' needs, and enhancing palliative care support to RCHes and community-dwelling EoL patients through collaborations between medical and social sectors. The overarching aim of these collaborations is to reduce unnecessary hospitalisation (HA, 2017a). On the other hand, other service types, such as Integrated Home Care Services (Frail Cases) (IH) and Enhanced Home and Community Care Services (EHCCS), which provide practical and personal care to community-dwelling frail elderly people, have been provided by the Social Welfare Department of the Hong Kong Special Administrative

Region (SAR) Government. However, there are no structured partnerships between the medical and social sectors to provide coordinated and holistic care to EoL patients who are receiving care at home.

The JCECC Project has adopted two strategies to enhance continuity of care. First, it offered EoLC training to empower non-PC specialists across different levels of healthcare systems (e.g. non-PC specialties in hospitals, family doctors and general practitioners (GPs) in primary care settings) to be better able to provide primary PC in order to promote shared care with PC teams and to ensure continuity of care throughout a patient's final months of life (HA, 2017a; Hong, Lam & Chao, 2013). Second, the project has engaged the medical and social sectors to collaboratively build reference services to identify best practices that ensure seamless and consistent care during care transitions.

Cost-effectiveness: developing viable and effective EoLC services. There is consistent evidence that healthcare costs generally increase in the last few months of life, with hospital inpatient care being the main cost driver (Dumont, Jacobs, Turcotte, Anderson & Harel, 2010). Similarly, data from HA in 2014–2015 indicates significant increases in hospital service utilisation among EoL patients, with the average number of A&E admission and inpatient days in the last year of life of elderly patients being five to ten times higher than other patients (HA, 2017a). The Hong Kong population will age rapidly in coming decades, particularly the number of people living beyond the age of 85 who have the highest prevalence of comorbidities and chronic illnesses. Knowing this increasing prevalence, and the concomitant looming community needs for EoLC, it seems prudent to expand the breadth and depth of EoLC provided in Hong Kong now, rather than wait until it is more complicated to do so. In 2014–2015, the government spent HK\$23.9 billion on healthcare services for the elderly and, to keep pace with need, it is estimated that this amount will be tripled within the next 50 years (Commission on Poverty, 2015). Healthcare resources are finite, and such budgetary expansion may not be possible. It is therefore paramount that efficient and effective models of care are developed to ensure optimal and equitable EoLC that can reach all who are in need. To achieve this, there have been attempts to foster communication and collaboration between clinical and research experts to generate evidence on the cost-effectiveness of EoLC models in different settings. The impact assessments of community-based EoLC models embedded in the JCECC Project have also been designed to address this purpose.

Capacity: building a competent workforce for EoLC. Capacity refers to infrastructure and human resources available to support EoLC. Regarding infrastructure, building hospitals and clinics are long-term plans to which the Hong Kong SAR Government is committed. The particularly confronting need is to build new facilities to cater for Second World War baby-boomer healthcare needs (this group has significantly contributed to the ageing Hong Kong community). Regarding human capacity, the life-course approach to healthcare implies that EoLC should be integrated into existing health, social and community care systems. This requires three-level support services to meet the PC needs of patients facing life-limiting diseases: a community-based PC approach, general PC provided in primary care, and palliative specialist services provided in institutions (Gómez-Batiste & Connor, 2017).

Inadequate EoLC knowledge and competencies among health and social care professionals have been reported (Cheung et al., 2018; Lau, 2017), and there is a pressing need to establish formal and standardised education curricula for EoLC (Paul, 2016; WHO, 2014). EoLC competency frameworks, which provide clear guidelines for professional capacity building in EoLC, have been developed in other parts of the world. Adopting, contextualising or adapting these could provide efficiencies for building EoLC capacity in Hong Kong.. International frameworks outline necessary competences and levels and methods of training in accordance with care settings, disciplines, staff positions, nature of work and level of involvement in EoLC of health and social care professionals (National Health Service, 2016; Palliative Care Competence Framework Steering Group, 2014; see Chapter 10). Moreover, human resources in EoLC should encompass non-professionals, including family members of patients, and also community volunteers, all of whom require specific training.

SUMMARY

Addressing the EoL needs of an increasingly large ageing population in Hong Kong produces challenges for contemporary health and social care systems. The JCECC Project was a local initiative initially launched for three years to synthesise efforts from academic institutions, elderly residential care institutions and community service organisations to turn challenges into opportunities in terms of coverage, choice, capacity, continuity of care and cost-effectiveness. **Coverage** was expanded by piloting EoLC service models in RCHes and community settings, addressing the holistic needs of families and patients living with cancer or non-cancer conditions at EoL. **Choices** of place of care and death and any required psychosocial-spiritual support services were considered and made possible. **Capacity** was enhanced through professional competence building programmes in hospitals, RCHes and community settings, as well as community knowledge and skills transfer activities. **Continuity of care** was achieved with the establishment of medical-social partnerships and well-designed coordination mechanisms when developing service models, as well as capacity building activities to create a common language to facilitate effective communication across care settings and disciplines. **Cost-effectiveness** of EoLC service models was evaluated with a local framework. This consists of multiple components and mixed methodologies, generating preliminary evidence for community EoLC that informs decision-making and resource allocation. With the pilot experience gained to date from the JCECC Project, it is envisioned that community EoLC in Hong Kong will move towards an integrated shared-care model with seamless medical–social collaboration.

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CHAPTER 2

DEVELOPMENT IN END-OF-LIFE CARE: A GLOBAL PERSPECTIVE

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“Cure sometimes, treat often, comfort always” – Hippocrates

Not every illness can be cured. When patients are facing life-threatening illnesses without cure, they have as much right to support from their country’s healthcare system as people with curable illness. As early as 1842, Madame Jeanne Garnier recognised the limits of medical technology in producing cures for illness. She founded the Dames de Calaire in Lyon, the first known care setting that provided relief and comfort to patients with incurable illnesses. In 1967, Dame Cicely Saunders established the St Christopher’s Hospice in London. This is commonly referred to as the first hospice in the world because it was the first purpose-built establishment for training, research and clinical practice to care for patients with life-ending (terminal) conditions (Simms, 2007). The wisdoms generated from clinical and research practices in St Christopher’s Hospice have facilitated and shaped the development of current hospice care around the world.

Care for patients with incurable diseases has evolved significantly in the past few decades. In May 2014, during the 67th World Health Assembly (WHA) meeting, World Health Organization (WHO) Member States unanimously accepted the resolution of “Strengthening of Palliative Care as a component of comprehensive care throughout the life course” (WHA, 2014). There is growing international concern about care for patients facing advanced illness for which there is no cure. This chapter starts with a brief illustration of the concepts of care for persons with incurable illness, followed by an outline of the domains of care appropriate for people at the end of their lives. Increased understanding of end-of-life care (EoLC) has expanded the focus from people with cancer to those touched by any incurable disease. This increased focus has also led to expanding the venues where EoLC is provided, from hospitals to different settings in the community. This chapter outlines global developments in community care provided for people requiring EoLC.

BACKGROUND

TERMINOLOGY

There is a range of terminologies which are used interchangeably and inconsistently to describe care provided to people at the end-stages of their life. These include EoLC, palliative care (PC), hospice care and supportive care (Hui et al., 2013). However, these terms have different meanings.

PC is defined by the WHO as:

... an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (Worldwide Palliative Care Alliance (WPCA), 2014, p. 5)

Hospice care is a model for providing PC services (IOM, 2015, p. 349). The term EoLC was initially used to describe the care for patients in the final days, or hours, of life (Institute of Medicine (IOM), 2015). More recently, the term EoLC is used for:

... the processes of addressing the medical, social, emotional, and spiritual needs of people who are nearing the end of life. It may include a range of medical and social services, including disease-specific interventions as well as palliative and hospice care for those with advanced serious conditions who are near the end of life. (IOM, 2015, p. 27)

Similarly to palliative care, EoLC can be offered at any stage of a serious illness for active intervention in reducing suffering. In this chapter, the term EoLC is used to describe holistic care provided for patients with an advanced illness, who have a prognosis of less than 12 months of life.

The National Institute for Health and Care Excellence (NICE) in the UK published a guideline in 2004 for persons with advanced cancer titled *Improving supportive and palliative care for adults with cancer* (NICE, 2004). The most recent version, to be published in 2018, has a changed title to *Guideline on end-of-life care for adults in the last year of life*. To reduce confusion with EoLC, NICE published another guideline in 2015 entitled *Guideline for Care of dying adults in the last days of life* to specifically address the needs of patients and family in the last days of life (NICE, 2015). In Wales and India, care provided in the final days of life is referred to as Integrated Care Priorities (ICP) (Macaden, 2011).

While there is growing consensus on English terminologies regarding EoL, interpretation of the Chinese terminologies differs in different Chinese-speaking countries.

- » For many years in Hong Kong, the term 善終服務 (literally meaning good ending) was commonly used. More recently it has been interpreted as 寧養護理服務 (literally meaning peaceful and nurturing). With advancements in palliative care, the following term is now usually used 紓緩治療服務 (literally meaning symptom relief).
- » In Taiwan, the theme of peace is commonly adopted using the term 安寧照顧 (literally meaning peaceful care).
- » In Japan, a similar term is used 緩和治療 (literally meaning mediating care).
- » In mainland China, EoLC (姑息治療) has only recently been recognised. The literal meaning of the term 姑息 is palliation; however, it can also be interpreted as indulging or tolerating, which can be confusing.

The lack of a common terminology might be a source of confusion for professionals and the public. The first step of developing best practice in EoLC is to develop a standardised definition that is commonly shared between health professionals, nationally and internationally.

THE FIVE DOMAINS OF EoLC

EoLC, in its early iterations, was mainly offered to cancer patients by medical care professionals in hospital or in stand-alone institutions. More recently, EoLC has been expanded into five domains relevant to a broader service target group (the Who), the place of care and place of death (the Where), the timing of care (the When), service providers (by Whom) and care content (the What) (see **Figure 2.1**).

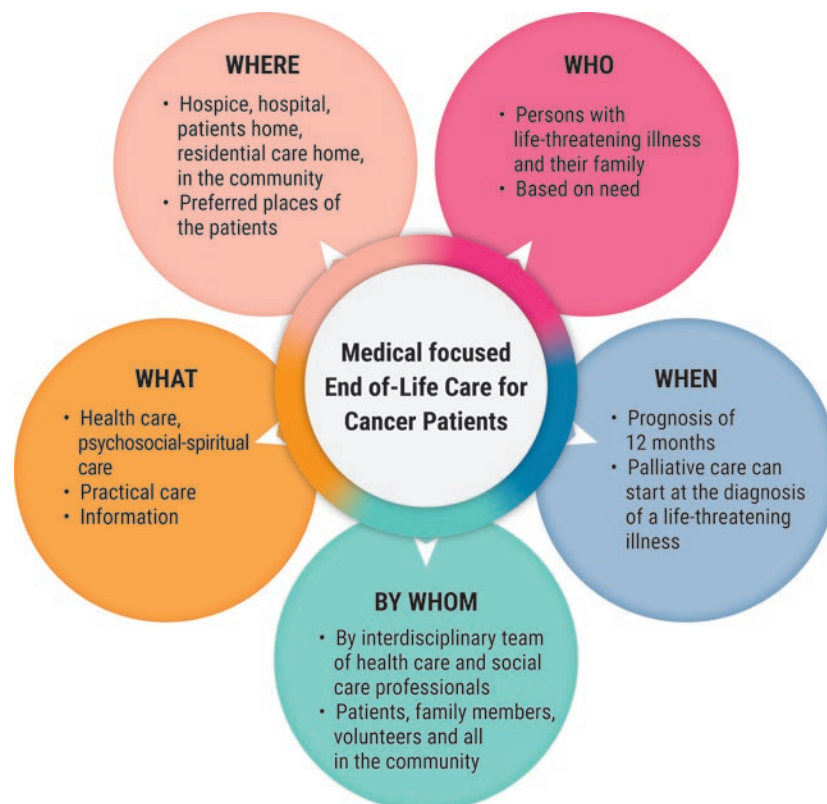


Figure 2.1 The Five Domains of EoLC

Who. With cancer being the leading cause of death worldwide for many years, delivery of EoLC was initially mainly for cancer patients. The first publication about EoLC from the World Health Organisation (WHO) was entitled *Cancer pain relief* (WHO, 1986). This document introduced a pain ladder that set the foundation of systematic symptom management for patients requiring EoLC (Gómez-Batiste et al., 2017a). Around the same time, the leading document on PC in the UK was the NICE guideline for persons with advanced cancer (NICE, 2004). However, after 2002, WHO expanded the focus of EoLC from cancer to all life-threatening illnesses (Gómez-Batiste et al., 2017a). This was reflected in a changed definition of palliative care “for patients and their families facing problem associated with life-threatening illness” (WPCA, 2014, p. 5). The IOM has also taken a similar approach by defining EoLC for “patients who have a limited life expectancy ... enter terminal stage of an illness or condition” (IOM, 2015, p. 27). EoLC should be provided according to needs, and the family is now considered to be the unit of care, rather than the patient. Based on symptom type and prevalence of illnesses which anticipate terminal outcomes, Connor and Gómez-Batiste (2017) estimated that over 20 million people per year around the world may require some form of EoLC. Among these, about one-third are cancer patients and one-tenth are persons with HIV/AIDS. The majority (95%) are adults.

Consequently, the expansion of the EoLC target group to non-cancer patients, and their families, has created new challenges in service provision. Unlike cancer, which generally has prognostic certainty, the prognosis for people suffering other terminal conditions, such as organ failure and frailty, usually has greater variability. Moreover, the trajectory of cancer progression is different from that of other terminal diseases (Murray, Kendall, Boyd & Sheikh, 2005), leading to different patient and family needs, as well as different skillsets and knowledge for those providing EoLC. For instance, there is a growing focus on providing EoLC to children and their families, despite the small proportion of deaths of young people. The death of a child can be devastating for a family, in both the short and long term, and the skillset and knowledge base for those who provide care for paediatric patients with life-threatening illness is different from those for adult cancer patients.

Where. EoLC is often perceived as being mostly provided in hospice settings. This is not now the case. With expansion of EoLC for patients with all types of illnesses, the demand for care has significantly increased and the growth of specialised hospices cannot match demand. Thus, current EoLC is not only offered in hospice settings, but also in general hospital wards (such as oncology, geriatrics and internal medicine). Moreover, with high mortality rates in intensive care wards (Aslakson, Curtis & Nelson, 2014) and hospital emergency departments (Limehouse, Feeser, Bookman & Derse, 2012a, 2012b; Wright, Lowton, Robert, Grudzen & Grocott, 2018), EoLC has been reported as also being offered in these settings.

On average, individuals spend 90% of their final year of life at home, irrespective of their place of death (Thomas, 2006). A review in 2017 of population data in Ontario, Canada, showed that in the last 180 days of life, terminally ill people spent an average of 24.5 days in an institution (e.g. acute care, complex continuing care, rehabilitation hospitals), with 86.4% of their time being spent in the community (Howard, Chalifoux & Tanuseputro, 2017). From a

clinical data mining study of cancer patients in four hospitals in Hong Kong in 2005, the mean duration of hospitalisation was 38.4 days in the last 180 days of life, indicating that 78.7% of patient time was spent in the community (Tse, Chan, Lam, Lau & Lam, 2007). A 2010 study of cancer and non-cancer patients in Hong Kong found that in the last 180 days of life, these patients spent an average of 28.5 days and 40.9 days, respectively, in hospital. This equated to 84.2% and 77.3%, respectively, of time spent in the community (Lau et al., 2010).

Realistically, patients' homes should be the core place for EoLC. To support patients at home, hospice outreach teams (or home care teams in Hong Kong) can bring specialised care to the home in collaboration with other community services. With the growing number of older people requiring EoLC, many people may be living in residential care institutions before the diagnosis of life-threatening illness. The residential care institution may be the "second home" for these patients, and this may be their preferred place of care and/or death. Moreover, a core value of EoLC is to respect the choices of patients and their families. In 2016, a Hong Kong population survey of 1,600 individuals sought people's perspectives on preferences for places in which their EoLC might be delivered. Hospital was the most popular choice (86.4%), followed by community settings (72.9%), residential care homes for the elderly (72.1%) and at home (54.6%) (Jockey Club End-of-Life Community Care Project [JCECC], 2016). It was also clear that across the trajectory of illness, patients and families might change their preference for location of service delivery due to change in symptoms, fear of being a burden or strained relationships between patients and family members.

When. A six-month EoL prognosis has generally been used as a criterion for admission to EoLC. This time frame was introduced by the Medicare Hospice Benefit group of the US in 1982, when most service users were cancer patients with a relatively predictable disease progression (IOM, 2015). However, there is a growing consensus on expanding EoLC to those with an EoL prognosis of a year. This is reflected in the title of new UK NICE guideline on *End-of-life care for adults in the last year of life* (NICE, 2018a). In a similar manner, the Proactive Identification Guidance (PIG) (Gold Standards Framework Centre in End-of-Life Care, 2016) has adopted a one-year prognosis criterion. It proposed the use of a "surprise screening question" to healthcare providers of "would you be surprised if the patient were to die in next year"? The same "surprise question" has been adopted by medical practitioners in the US (Weissman & Meier, 2011).

However, it appears that the timeframe of EoLC is now being conceptualised as even broader than 12 months. For instance, the WHO promotes early intervention for care for those challenged by life-threatening illnesses, and proposes that care should not have time or prognostic limits. It should be delivered early in the course of the illness (WPCA, 2014, p. 7). Gómez-Batiste et al. (2017b) recently proposed the adoption of "first transition" to what will be a terminal situation, as the start of EoLC. This can be weeks, months or years. In their analysis, the median survival of patients identified with the Necesidades Paliativas

(NECPAL) tool approximated two years (Gómez-Batiste et al., 2017b, p. 53). Following the rule of “first transition”, around half of the patients received two years or more EoLC services, which is more than the established 12 months criteria. Moreover, it has been proposed that the duration of EoLC extends until after the patient has died to provide bereavement care. As the family is the unit of care, EoLC should assist family members to face the loss of the loved one (NICE, 2004).

By whom. As suggested by WHO, EoLC aims to prevent and relieve suffering “by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WPCA, 2014, p. 5). With the broad scope of EoLC, it is difficult for a single health professional to effectively deliver this care. An interdisciplinary team is a common characteristic of EoLC. Generally, an interdisciplinary team describes a group of healthcare providers, with physicians and nurses as major players. The recent differentiation of three levels of PC (WPCA, 2014) expands the range of professional caregivers of PC. PC specialists, according to the WPCA, provide specialised care for patients with complex problems and needs across all care settings. Moreover, general PC practitioners, including non-palliative care physicians and other health and social care professionals, can also provide PC across all care settings. With the expansion of EoLC in the community, primary care physicians are playing an increasing role. Community care workers and volunteers, who have completed basic training related to EoLC, can assist healthcare providers by supporting patients and families, irrespective of where care is delivered. Good communication between care providers is vital to provide seamless care for patients and families within and between care settings.

The public health PC movement has been a driver in expanding the workforce engaged with delivering EoLC. Communities have an increasing role to play (Abel, Sallnow, Murray & Kerin, 2016), as indicated by the guidance document produced by the National Council for Palliative Care (NCPCC) (Abel et al., 2016). This states that the success of EoLC depends on the preparedness of communities to offer help. Community care is an efficient, effective way of supporting patients, family and friends. It can be provided by a formal professional care network of health and social care organisations, or an informal network of neighbourhoods, workplaces or educational institutions (Abel, 2018).

What. EoLC in the past has largely been medico-centric because it was generally provided by medical specialists in hospice settings. The more recent inclusion of other providers of EoLC in other care settings is shaping the future of EoLC services worldwide. In line with the recent definition of PC “...the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WPCA, 2014, p. 5), EoLC should comprehensively address multidimensions of need. As well as nursing and medical care for effective symptom control, the provision of information, practical support, as well as social and psychological care are crucial components of EoLC (Thomas, 2006). Due to the complexity of delivering person-centred EoLC, and the multiple caregivers who might be involved, it is essential that there is good coordination of information-transfer in order to optimise resources without duplication of efforts.

CUTTING-EDGE EoLC

Kellehear (2013) developed and promoted the concept of a compassionate community in community care. Aiming to incorporate death, dying and bereavement into public health ideals, Kellehear (2013) promoted the notion that PC is everyone's business. Compassionate communities adopt community development strategies of negotiations and partnerships to bring changes in the social and physical environment. The notion of compassionate communities is expected to be a cornerstone for the future development of EoLC (see **Figure 2.2**). The following sections address the elements of cutting-edge EoLC.



Figure 2.2 Components of Cutting-Edge EoLC

Community-based and Compassionate EoLC. The European Association for Palliative Care (EAPC) published a report in 2015 entitled *Promoting palliative care in the community*. This outlined the benefits of expanding the delivery of PC in, and by, the community as complementary to existing hospital-based PC services (EAPC, 2015). This requires expansion of types of settings within which care could be provided, target care recipients and workforce delivering care. Inclusion of community-based care is in line with the progressively evolving public health approach for PC delivery (Gómez-Batiste et al., 2017a). The key components of this public health approach include community development and engagement, improvement of social capital, as well as health promotion and education. This reflects the concerted and combined efforts of the government, community organisations, as well as health and social care organisations to develop sustainable social and physical environments within which to care for patients with life-threatening illness. These environments will also underpin improvements in the processes of caregiving and bereavement support for families (Public Health England, 2016).

Preventive EoLC. Early intervention and prevention are derivatives of the public health approach to EoLC. Prevention does not mean the prevention of illness, but rather the prevention of distressing symptoms, unnecessary and unwanted treatment, and mishandling of crises. While taking care of patients' current needs, EoLC also provides education about the management of symptoms and how to deal with potential crisis situations. Moreover, it promotes Advance Care Planning (ACP) for patients and families.

Inclusive EoLC. Influenced by the values of compassionate communities, no person should be excluded from access to EoLC. This reflects rising concern regarding the accessibility of EoLC for vulnerable groups, such as people with dementia, intellectual disabilities and/or mental illnesses (McCallion et al., 2017), frail older adults with multi-morbidities (IOM, 2015), as well as prisoners, street-sleepers and ethnic minorities (Joint Strategic Needs Assessment [JSNA], 2015). As an example of growing concern for EoLC for all, recently published NICE guidelines on care and support for people with learning disabilities who are growing old includes a section on EoLC (NICE, 2018b).

Cost-effective and evidence-based EoLC. The concepts of evidence-based medicine should underpin the delivery of health and social EoLC services as a way of using limited resources in the most effective manner to meet expanding demand for care. Critical examination of cost-effectiveness and efficiency of different EoLC models is crucial to establish priorities for care, as well as to ensure accountability to patients, families and communities. Most importantly, patients at EoL have limited time to try different types of care. Ideally, getting their care right the first time is the objective. Information about effectiveness of care will also ensure that patients and family members can make informed choices, which facilitate their autonomy in making rational care decisions that work for them.

Moreover, evidence collected on service delivery processes and outcomes can support ongoing education. Before evidence was routinely collected, there was a perception that EoLC was expensive due to its intensive one-on-one nature. Recent studies, however, have demonstrated that EoLC is cost-effective through reduction of unnecessary use of hospital emergency rooms, wards and/or intensive care units (Bickel & Ozanne, 2017; Gomes, Calanzani, Curiale, McCrone & Higginson, 2013). Moreover, the ground-breaking finding by Temel et al. (2010), which showed that early PC compared with curative care improved survival of lung cancer patients, is a good example of demystifying the effectiveness of EoLC.

Technologically savvy EoLC. Information technology (IT) has rapidly advanced in the past few decades, and the cost of up-to-date technology is now generally affordable by all. EoLC should capitalise on IT advances because it could lead to improved care efficiency and effectiveness. For example, remote monitoring systems can alert off-site healthcare professionals to changes in patients' medical status (IOM, 2015, p. 70) without the need for face-to-face consultations. Such monitoring systems could also empower patients and family members in self-management.

While care provided in community settings may be ideal for the healthcare providers who work there, travelling to receive, or provide, care can be a concern for both patients and healthcare professionals.

- » Transportation for patients, in particular those with mobility challenges, often has to be arranged well in advance. Escorts may also be needed. Often after patients have arrived at a clinic or hospital, they may be required to spend unpredictable amounts of time waiting for consultations. This can be expensive and exhausting not only for patients, but also for family. Because of this, some patients prefer to be sent by ambulance so that they can be hospitalised and receive immediate attention. However, this high cost, crisis-type approach may not be warranted for patients' health conditions or needs, and it may tax already overloaded healthcare services.
- » If healthcare providers visit patients at home (which may be ideal for the patient), travelling time is usually greater than the consultation time. This is inefficient for the healthcare provider, who could consult with more patients if the consultation took place at a central location (such as a clinic or hospital). Thus, home visiting might not be the optimal use of healthcare providers' time, particularly if he/she is in high demand. Telemedicine could be a viable alternative to this challenge. In the US (California Healthcare Foundation, 2014) and Taiwan, telemedicine has been successfully applied in EoLC, finding that regular contact through video-conferencing with monitoring of health status using standard health indicators, is as good if not better than face-to-face consultations. IT systems can therefore contribute to best practice assessment, information exchange, shared decision-making and provision of timely and appropriate care, particularly when there are multiple care providers in an EoLC team.

The EoL workforce has not kept up with the demands of rapidly increasing older populations, particularly in terms of ensuring equitable delivery of effective community-based care. Technology could offer a way to address service gaps. For instance, new initiatives of using robotic assistance to deliver practical care have been developed in Japan, assisting in physical care needs such as transfers, toileting and bathing. This would allow care workers to focus their time on psychological or social needs of patients (tasks that cannot be done by robots).

Legally abided and ethical EoLC. There are legal and ethical ramifications for EoLC that require ongoing and widespread debate. In some countries, a death at home (even though it is anticipated) may require a Coroner's investigation. Moreover, there are ethical and legal issues related to EoL decision documents, such as Advance Directives (AD) (for instance, living wills and the Durable Power of Attorney (DPA) for healthcare) and medical orders (such as Physician Orders for Life-Sustaining Treatment (POLST), Medical Orders for Life-Sustaining Treatment (MOLST), and Do Not Attempt Cardiopulmonary Resuscitation [DNACPR]). The legalisation of assisted dying around the world also incurs debate on legal and ethical considerations at EoL. The legal right of mentally impaired people (such as those with dementia or intellectual disabilities) in making EoL decisions is also controversial. EoLC workers must abide by the local legal and ethical regulations in provision of care, while acting as advocates for vulnerable people.

SUMMARY

Death is inevitable for all people and, without intervention, the process of dying in many instances may bring distress to patients and families. EoLC has evolved from medically focused care for terminal cancer patients in hospital-based settings, to comprehensive care for all persons with life-threatening illness and their families, delivered in their preferred place of care. Current best practice EoLC is characterised by respect for patient and family choices, with early discussions of preferred care plans. Around the world, more people are living for longer. This can bring the concomitant situation of people suffering complex EoL conditions, complicated by comorbidities of ageing. Moreover, there has been a growth in the nuclear family, underpinned by smaller numbers of children in families and an increased percentage of childless couples in the community. While assisted dying is now an option for people with terminal conditions, there is a continuing and important need to provide cost-effective, efficient, acceptable alternative EoLC to those who want to live well every day until their natural end. Community-based EoLC can be a viable solution to this challenge. With the compassionate community approach to EoLC, it is hoped that no one dies in untreated physical, psychological or social distress.

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CHAPTER 3

POLICY DIRECTIONS FOR END-OF-LIFE CARE IN HONG KONG

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The Economist Intelligence Unit, commissioned by the Lien Foundation, published *The 2015 quality of death index* to promote end-of-life care (EoLC) and encourage the facilitation of “good death” across the world (Economist Intelligence Unit, 2015). In the report, each country is given a score of 100 in the following five categories: (1) palliative and healthcare environment, (2) human resources, (3) affordability of care, (4) quality of care and (5) community engagement. A ranking among 80 countries is produced. Overall, the UK is ranked number one.

Hong Kong’s public healthcare system, which is tax-based and funded from general reserves, is ranked 22nd, lagging behind other developed Asian economies, including Taiwan, Singapore, Japan and South Korea. Hong Kong is also ranked relatively low (at 28) in terms of palliative and healthcare environment. This is lower than Panama (at 25), a middle-income country, and Mongolia (at 24), a low-income country. Hong Kong is ranked 20th in human resources,

18th in affordability of care, 20th in quality of care and 38th in community engagement. Despite the limitations of the evaluation methods used for this index, the message from the report is clear – substantial improvements in EoLC are necessary in Hong Kong to improve its world rankings.

With a growing ageing population in Hong Kong, multimorbidity from chronic disease will significantly increase over the coming decades, and there will be a dramatically increased demand for health and social services and end of life (EoL) care for older persons. A previous study predicted an increase of long-term care expenditure among older persons in Hong Kong from 1.4% in 2004 to 4.9% of gross domestic product by 2036 (Chung et al., 2009). This could crowd out other competing demands for public resources. Given Hong Kong’s high life expectancy and that over 90% of deaths occur in hospitals (Woo et al.,

2009), utilisation rates of EoLC will become increasingly important in the future. It is likely that additional resources will therefore be required to enable good EoLC to be provided for people at EoL and to ensure that the system can cope with the expected increase in EoLC demand.

In light of this, the Food and Health Bureau of the Hong Kong SAR Government (HKFHB) commissioned the Jockey Club (JC) School of Public Health and Primary Care, Chinese University of Hong Kong (CUHK), in 2015 to study the quality of healthcare for ageing people. A significant aspect of this commission was to identify current situations, gaps, barriers and issues in EoLC for terminal illness and life-limiting conditions in older persons in Hong Kong. The contents presented in this chapter are primarily based on the findings of the commissioned study.

BACKGROUND

TERMINOLOGY

EoL care and palliative care. There is no universally accepted definition for EoLC. Usage and understanding of terminology related to EoLC, and care for terminal illness and life-limiting conditions in older persons, varies by country and context. It also depends on individuals' training, background or perspectives, for example among palliative care (PC) specialists, general medical professionals, social care service providers, patients and their families, and the general public. Additional complexities in the Hong Kong setting include the choice of Chinese terms to accurately convey meaning among care workers, patients and their families, and in the wider community. It is therefore necessary to clarify the relationship between palliative care and EoLC.

Palliative care is an approach that improves the quality of life (QoL) of patients and their families when facing life-threatening illness. This care is provided through prevention, and relief, of suffering by means of early identification and comprehensive assessment and treatment of pain and other problems (whether they are psychosocial or spiritual) (World Health Organisation (WHO), 2018). This definition of PC is needs-based and can be applied early in the course of illness in conjunction with other therapies that are intended to prolonging life (WHO, 2018). It applies to acute and chronic illness and terminal EoLC (WHO, 2004). A PC approach needs to be considered early in the course of a disease and, as noted in a definition from the UK, "may be done alongside treatment intended to reverse particular conditions" (i.e. curative care) (Leadership Alliance for the Care of Dying People, 2014, p. 110). Thus, a PC approach may be provided alongside curative care, and a distinction between curative and palliative phases should not be made.

On the other hand, the definition of EoLC is time-based and therefore less standardised. For people with life-threatening illness, EoL can refer to:

1. The period that precedes death, often conceptualised as approximately 6–12 months (Thomas, 2011); or
2. The period at the very EoL (the phase of imminent dying and death).

Refer to **Figure 3.1** for the dual application of these definitions.

However, these two conceptions of EoL have understandably created confusion. For example, while the UK Gold Standards Framework uses the "surprise/trigger question": "would you be surprised if this patient were to die in the next 6–12 months?" to identify those who are approaching EoL, the Liverpool Care Pathway focuses on the last days of life when the person enters the imminent dying phase, i.e. last 2–14 days and last 48 hours (Neuberger, 2013). This has created confusion even within the same country. In addition to this confusion, there is also difficulty in identifying patients who are approaching EoL, and the variability in patient trajectories of decline (or improvement) limits accuracy of prognostication. The "surprise"

question (i.e. 6–12 months) may provide a useful indicator, but the timing of death can never be accurately predicted and, thus, this indicator cannot be solely relied upon to identify those people entering their EoL. Care providers must therefore use their experience to estimate both when patients are approaching the end of their whole life (i.e. situation A in **Figure 3.1**) and their dying phase (i.e. situation B in **Figure 3.1**). In this context, EoLC relates generally to identification of those approaching EoL, personal and legal preparation for death, facilitation of caring/dying in the patient's preferred place, medical care (in particular, palliative care) and social care. This is relevant to the first conceptualisation of EoLC during the 6–12 months before death. It also relates to preparation for the quality of the dying process, as well as the post-death care and support for families and the bereaved (which is particularly relevant to the 2nd conceptualisation of EoL care during the imminent dying phase).

This dual concept of EoL care is the understanding more commonly shared in the social care sector in Hong Kong. For the purpose of this chapter, the timeframe of EoL is conceptualised not only for the last days or hours, but also within the last 6–12 months of life when disease progression is largely irreversible and treatment benefits are waning. The EoLC periods may not be so clearly demarcated and are better understood in a continuum. However, we are also aware that the timeframe for EoLC can extend beyond the last 6–12 months due to variability in the illness trajectory even among different patients with the same illness. Therefore, EoLC in this sense does not begin at a certain time point, but rather it represents a continuum in the care of patients as the illness progresses to become life-threatening, and thus EoLC may be needed in the last years, months, weeks or days of life.

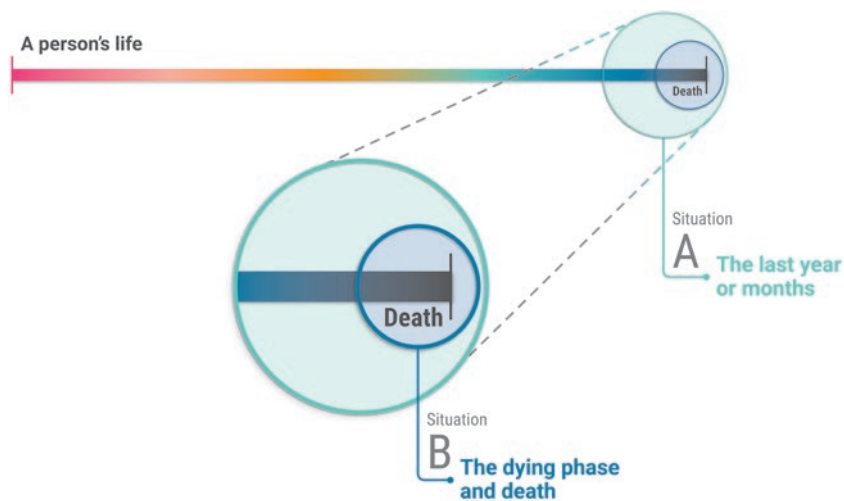


Figure 3.1 The Dual Application of the Term EoL

In summary, PC is generally viewed as a broad range of services, of which EoLC is an integral part. This is because PC is also relevant in the care of patients with acute and chronic needs, and not only those approaching their EoL. Conversely, EoLC may be viewed as a broad range of services (medical and non-medical inclusive), of which PC is an integral part. PC is a needs-based concept that defines the needs of patients and their family, while EoLC is a time-based concept that is best considered as a continuum that enables personal, legal and medical preparation for death and dying. Therefore, PC and EoLC are complementary in the system of care.

Advance Care Planning, Advance Directives and other related concepts. It is important at this point to distinguish between Advance Care Planning (ACP) and Advance Directives (AD), as many people may not be familiar with the difference and the relationship between the two. ACP is not a legal process, but may result in the formation of legal documents. More precisely, ACP is “a process of communication among patients, their healthcare providers, their families, and important others regarding the kind of care that will be considered appropriate when the patient cannot make a decision” (Teno, Nelson & Lynn, 1994, p. S33). It allows better understanding of the patient’s preferences and values to improve quality of care. ACP is related to, but distinct from, an AD in that ADs result from a formal process with specific codification of discussions. An ACP results from an overarching process of communication, from which an AD document may, or may not, be produced. After communication through ACP, a patient may make advance decisions and document their preferences through statement of wishes, formal AD documentation, and/or appointment of an attorney.

A *statement of wishes* may be made by the patient to help guide others regarding the patient’s preferences in the event they can no longer make decisions. This may be made orally or written down, and allows individuals to communicate their preferences in relation to future personal care/treatments, or to communicate how their feelings, beliefs and values govern their wishes and preferences. Personal care includes both medical and non-medical matters, which may be stated as wishes. While the statement of wishes is not legally binding, it can be used when determining the care choices that are aligned with the individuals’ best interests in the event that they lose the capacity to make decisions or communicate wishes (Oczkowski, Chung, Harvey, Mbuagbaw & You, 2016). A *formal AD document* may also result from the ACP process. ADs for persons with terminal and life-limiting conditions relate to specified and codified advance refusal of specific medical interventions under specific conditions that come into effect when individuals lose the capacity to make decisions or to communicate their needs and wishes. It is undesirable and may even be risky to produce an AD without a proper process of communication and discussion between the patient and care providers. Appointing *powers of attorney* is a legal instrument used to delegate legal authority to another person (i.e. the attorney) when a patient (i.e. the donor) subsequently becomes mentally incapacitated or unable to communicate his/her wishes. The Powers of Attorney Ordinance (Cap. 31) in Hong Kong only allows the appointed attorney to handle property and financial matters of the donor before and after he/she becomes mentally incapacitated. However, this is currently under review by the Department of Justice to introduce a new Continuing Powers of Attorney (CPA) Ordinance, which may extend to cover decisions in relation to a donor’s personal care. Nevertheless, there is no mention of whether personal care at the EoL (e.g. life-sustaining treatments) will be covered by the new CPA Ordinance.

CURRENT EoLC SERVICES

Social care of the non-government organisations and the Social Welfare Department.

Non-governmental organisations (NGOs) provide much of the community care and support for older persons in Hong Kong, either independently or via funding from the government's Social Welfare Department (SWD). However, despite the existence of these services, they are not well integrated and are inadequate for the current and anticipated increase in service demand. In this chapter, we provide a summary of the relevant services.

There are two types of elderly residential homes in Hong Kong: residential care homes for the elderly (RCHEs) and nursing homes.

- » RCHEs refer to any premises in which the care of persons is carried out for reward or other financial considerations (Hong Kong Legislative Council, 2017). Although increasingly frail older adults in Hong Kong are housed in RCHEs until death is imminent, most RCHEs are not equipped or prepared to deliver EoL care. Consequently, residents of RCHEs are usually sent to Hospital Authority (HA) hospitals before death occurs. Recently, there have been community initiatives such as the "Palliative Care in Residential Care Homes for the Elderly" pilot programme (implemented by The Salvation Army and the Hong Kong Association of Gerontology) that aims to assist residents stay in their RCHE for as long as possible before transporting them to hospital. From 2015 onwards, the Hong Kong SAR Government's SWD has required newly contracted-out RCHEs to provide EoLC with appropriate facilities and staff training.
- » Nursing homes, on the other hand, can be licenced by the Department of Health to legally allow older persons to die in the premise (i.e. non-reportable death). Nonetheless, the practice of dying in place remains rare in Hong Kong.

In 2016, the Jockey Club Home for Hospice (JCHH), established by the Society for the Promotion of Hospice Care (SPHC), was opened to allow individuals to die in place while surrounded by their loved ones (Society for the Promotion of Hospice Care, 2018). In 2015, The Hong Kong Jockey Club Charities Trust funded the launch of the three-year Jockey Club End-of-Life Community Care Project (JCECC), which aims to improve the quality of EoLC in the community, enhance service provider capacity and raise public awareness (JCECC, 2015).

In addition to residential care services, other community services may include home care support, community palliative and EoL care, education, training workshops for caregivers and bereavement care. Large and well-established NGOs also provide comprehensive community services at neighbourhood elderly centres, day care centres and support services delivered to the home (i.e. Integrated Home Care Services and Enhanced Home and Community Care Services for the Elderly). These services are population-based and generally funded by the SWD. Other community-based hospice-type care is mostly provided by privately funded organisations.

Professional bereavement counselling services are also provided by a number of NGOs, including the Comfort Care Concern Group (CCCG) and the SPHC. The Integrated Family Service Centres (IFSCs), run by NGOs and SWD throughout the Hong Kong territory, provides family bereavement services and counselling support to families in need.

Palliative care in the public healthcare sector. In Hong Kong, an adult PC service was started by Our Lady of Maryknoll Hospital in 1982. Another four hospitals (Ruttonjee Sanatorium, Haven of Hope Hospital, United Christian Hospital and Nam Long Hospital) also established their own adult PC services between 1986 and 1988. There was then a steady growth of adult PC services after the establishment of the HA in 1991. Professional bodies were established to formally recognise professional development. These include the establishment of the Hong Kong Society of Palliative Medicine and the Hong Kong Hospice Nurses Association in 1997, and the recognition of Palliative Medicine as a subspecialty under the Hong Kong College of Physicians in 1998 and the Hong Kong College of Radiologists in 2002 (Chan, 2002).

There are currently 16 Hospital Authority (HA) hospitals that provide PC services in Hong Kong. These include Bradbury Hospice, Caritas Medical Centre, Grantham Hospital, Haven of Hope Hospital, Hong Kong Buddhist Hospital, Our Lady of Maryknoll Hospital, Pamela Youde Nethersole Eastern Hospital, Princess Margaret Hospital, Prince of Wales Hospital, Queen Elizabeth Hospital, Queen Mary Hospital, Ruttonjee Hospital, Shatin Hospital, Tung Wah Group of Hospitals Wong Tai Sin Hospital, Tuen Mun Hospital and United Christian Hospital. The services provided in these sites aim to provide comprehensive care for terminally ill patients through interdisciplinary efforts. PC services are also provided at day care centres, hospitals (inpatient and outpatient settings) and in the community. Services are variable and are provided by multidisciplinary PC teams comprising PC specialists, nurses, clinical psychologists, medical social workers, physiotherapists, occupational therapists, dietitians, other allied health professionals, spiritual workers and volunteers. These services include five primary components:

1. Inpatient and consultative PC services
2. Ambulatory PC services
3. Community/home PC services
4. Bereavement services
5. Other supportive services (HA, 2016)

There were over 40 doctors, 300 nurses and 60 allied health professionals (full-time equivalent [FTE]) who provided PC services at the HA as of May 2016. The HA developed a Strategic Service Framework for Palliative Care in late 2017 to guide the development of PC services in the next five to ten years.

Community care in the public healthcare sector. There are a range of community care services provided by the public healthcare sector; however, they do not focus primarily on EoLC but rather on elderly and/or chronic care in general. These include Community Nursing Services (CNS) that offer holistic care in the community for patients with chronic disease who are discharged from hospital to stay at their own homes. They also support the 42 Patient Resource Centres, which aim to build a supportive community through health education and promotion given by community partners and volunteers for the patients, and Geriatric Day Hospitals, which provide multidisciplinary assessment, continued care and rehabilitation to geriatric patients. The Elderly Health Service of the Department of Health also provides emotional support to older persons in need.

Community Geriatric Assessment Teams (CGATs) of the HA provide multidisciplinary services (including assessment, care management and caregiving training) and community-based rehabilitation programmes to older adults through regular visits to RCHEs in the community. Since older persons staying at these RCHEs in the community tend to be frailer and approaching their EoL, CGATs services can also play a role in EoLC. In 2015–2016, the HA piloted the “Enhanced CGAT service for EoL care in RCHEs” programmes in four of the seven HA clusters. The programmes recruit patients in RCHEs with neurodegenerative diseases who are not already receiving active care by PC teams. The collaborative programme involves PC teams (principally nurses) and CGAT/RCHE staff. For each cluster, an advanced practice nurse (APN) with PC expertise provides training to both CGAT and RCHE staff. The APN also provides on-site supervision for complex cases. Joint case conferences have been adopted in some places in order to safeguard quality of care, while expanding access to PC in RCHEs through empowering non-PC specialists. Complex cases may be referred to multidisciplinary PC services. The programme was extended to Queen Elizabeth Hospital/Kowloon Hospital and Caritas Medical Centre in 2016–2017. The primary aims of the programme are to:

1. Train CGAT and/or RCHE staff to identify suitable RCHE residents and/or their family members to initiate the ACP conversation and discussion (including Do Not Attempt Cardiopulmonary Resuscitation [DNACPR]); and
2. Arrange coordinated admission from RCHE to different HA departments, such as Accidental and Emergency (A&E) and inpatient departments, to enable the most appropriate care for the patients.

Once an eligible patient has joined an EoL programme, a visiting medical officer (VMO) and nurse from the CGAT of the nearby hospital provides timely on-site consultation for symptom control, as well as psychosocial support to patients and their family members (via telephone). During RCHE visits, the CGAT may initiate discussions with the patients and their family members about their condition, or symptoms and treatment options, including (but not limited to) ACP discussion and DNACPR documents. Furthermore, most patients are “flagged” so that if they require hospital admission they can be directly admitted to the parent team or PC unit, rather than the more hectic settings for acute or emergency care. Current evaluation of these pilot programmes will inform future adopted and/or enhancement in all HA clusters.

PC and EoLC in the private healthcare sector. Outside the HA and social welfare sector, PC and EoLC services are variable and are largely underdeveloped in the private healthcare sector. They are mainly provided as fee-for-service private businesses that provide discretionary individual case support to clients. PC and EoLC are also largely underprovided in private hospitals (Cheung, 2016).

ISSUES, GAPS AND BARRIERS FOR EoLC IN HONG KONG

Although there are many practices and providers of EoLC in Hong Kong, as summarised earlier, there is currently no overarching framework for EoLC in Hong Kong that conceptualises and clarifies patients' and families' holistic needs, and how they can be provided with a comprehensive system of care. A conceptual framework for EoLC will enable development of overarching, cross-sectoral supportive policy, which should also include standardised and contextualised guidelines for care during EoL and the dying phase. The next section summarises issues, gaps and barriers for quality EoLC in Hong Kong in terms of three major levels: legal, organisational and operational, and socio-cultural.

Legal barriers to quality EoLC include the:

1. Ambiguity in the legal basis for mental incapacity and the legislative barriers for ADs;
2. Appointed attorney decisions for personal care that extend beyond financial arrangements, attorney/guardian decisions on life-sustaining treatment;
3. Issues with the Fire Services Ordinance in which its requirement to resuscitate may conflict with any DNACPR or AD decisions made in advance for EoL patients; and
4. The clarity of the legal requirements in completing death certificates by the attending doctors who might not have visited the patient personally within 14 days before death. This dilemma arises because the wording in the current Form 18 "Medical Certificate of the Cause of Death" stipulates that the physician signing Form 18 should have personally attended the patient within 14 days prior death, while Type 2 reportable death of the Coroners Ordinance (Cap. 504) (Hong Kong Legislative Council, 2017) does not specifically state that this has to be same person.

There are a number of *organisational and operational issues* that are currently not addressed by standardised guidelines for EoLC in the healthcare system (especially for the last days/weeks of life). These include (but are not limited to):

- » Difficulties in predicting illness trajectories for EoL;
- » Inconsistent approaches and recognition of ACP/AD/DNACPR across different departments of the HA, social care sector, Fire Services Department, police and private sector;
- » Inadequate medical–social record sharing system;
- » Inadequate human resources and capacity for PC;
- » Inadequate training, professional development and career prospects for people caring for older persons with terminal illness and life-limiting conditions (both in the health and social care sectors);
- » Inadequate transportation systems between service locations and non-emergency consultations that are appropriately designed for EoL patients; and
- » Inadequate resources and capacity for EoLC in the community.

To provide ongoing bereavement care after the patient's death, a key issue that needs to be addressed is the inadequate training for staff in the Food and Hygiene Department for dignified care of the deceased person, and long delays for cremation services. Despite 31.2% of the general population preferring to die at home according to a telephone survey of 1,067 adults (Chung et al., 2017), barriers to dying at home or in a community setting include:

- » Lack of space to facilitate dying in place;
- » Inadequate mortuary space for storage of bodies outside of hospitals;
- » Higher costs associated with private mortuaries for body storage; and
- » Complicated procedures for death reporting for reportable deaths.

Caregiver and bereavement support also need to be strengthened.

From a *socio-cultural* perspective, barriers to quality EoLC include:

- » General reluctance among patients and the general population to think about, or discuss, death;
- » General misconceptions and myths about death and dying;
- » Interpretation of filial piety to resemble the practice of "doing everything possible";
- » Inadequate understanding of ethical principles behind "good death";
- » Confusion about existing care options and funeral services and the legal procedures after death;
- » General misinformation or a lack of knowledge about PC practices; and
- » A uniquely local (Hong Kong) concern over the impact of home deaths on property price (which is also tied with the "haunted house" categorisation by the real estate industry).

RECOMMENDATIONS

To facilitate better understanding of how different components may fit within the general concept of EoLC for terminal illness and life-limiting conditions in older persons in Hong Kong, an illustrative conceptual framework was constructed (see **Figure 3.2**). The stages of disease progression were adopted from the highly cited model in the UK Gold Standards Framework's *More care, less pathway. A review of the Liverpool Care Pathway report* (Neuberger, 2013). The model was further adapted to the Hong Kong context to incorporate important local components of EoLC, including:

- » The interplay of curative and palliative care;
- » ACP (which includes statement of wishes, ADs and powers of attorney);
- » Care of the dying in the last weeks/days of life; and
- » Care of the deceased person and bereavement support.

This framework is currently intended only as an illustration or a flexible guide and is not intended to accurately show the order or priority of services. This will depend on individual patients' needs and actual situations.

The conceptual framework of EoLC is intended to inform and enable the development of overarching, cross-sectoral (health and social, public and private) policy for EoLC in Hong Kong, which is necessary to drive forward change and institutionalise service integration. The evidence from multiple local and international sources recommends a unified government policy and framework for long-term care, of which an integral part is EoLC. This is currently lacking. It is important to emphasise that such policy should not be just targeted to the last months and days of life, but should be an integral part of a long-term care policy. EoLC mostly concerns the last aspect of the continuum of care for patients with a life-limiting disease. It cannot be separated from earlier aspects of the care.

Common denominators of EoLC from around the world can be identified from the international literature, and these can be developed into culturally and locally appropriate policies and services. It is important that these recommendations are contextualised in a culturally sensitive manner, rather than just merely adopted from international policies from other cultures and contexts. In other words, the objective is not to prescribe any particular form of future EoLC, but rather to establish a suite of specific solutions that uphold culturally and contextually specific values and principles for EoLC delivery in Hong Kong and that address specific local issues. Recommendations for future contextually appropriate, quality EoLC in Hong Kong should tackle legal, organisational and operational, as well as socio-cultural issues, gaps and barriers. Important components of quality EoLC in Hong Kong are summarised in **Box 3.1**.

Box 3.1**Components of system-wide quality EoLC for terminal illness and life-limiting conditions for older persons in Hong Kong****Policy level**

- » Formulate an overarching EoLC framework and government policy in Hong Kong

Legal level

- » Encompassing ordinance for mental incapacity, including ADs and treatment decisions by attorneys/guardians
- » Ensure Fire Services Ordinance (Cap. 95) legislation does not conflict with valid documentation of AD and DNACPR
- » Facilitate the possibility of caring/dying in place in the community outside of hospitals (including home, RCHes and nursing homes) according to patients' preference
 - › Clarify legal status for attending doctors who might not have personally visited the patient within 14 days (but who may belong to the same care team as another doctor who may have visited the patient within 14 days before their death)
 - › Clarify the circumstances under which these doctors may complete death certificates (Form 18)

Organisational and operational level

- » Develop standardised needs-based guidelines for EoLC that can be individualised by:
 - › Timely and regular assessment to determine patients approaching EoL
 - › Consistent pan-sectoral recognition of AD/DNACPR/ACP
- » Communicate better with patients/families for shared decision-making, including during ACP
- » Implement a system for secure medical-social record sharing

Palliative care

- » Integrate better PC objectives and components in the current healthcare delivery system
- » Enable PC services and consultative support to be provided by non-PC specialists in hospitals and the community
- » Increase human resources and capacity for PC specialists (where required) and palliative training for other health professionals

Moreover, it is important to also ensure that the governmental policy for EoLC for older people with terminal illness and life-limiting conditions in Hong Kong is an evolving one. In other words, the policy should allow for necessary updates according to new practices and emerging evidence to create a living/evolving document for EoLC policy and practice over the years to come. The policy should take guidance from high-quality international literature and practices in applying the framework and making specific recommendations. Such literature includes the UK's National Institute for Health and Care Excellence (NICE) *Guidelines for the care of dying adults in the last days of life* (NICE, 2015); UK's NICE *End of life care for adults. Quality statement 13* (NICE, 2011); UK Gold Standards Framework *More care, less pathway. A review of the Liverpool Care Pathway* (Neuberger, 2013); and the US's Institute of Medicine (IOM) *Dying in America. Improving quality and honoring individual*

Primary EoLC in the community

- » Establish a consistent and comprehensive approach to community-based EoLC, with multidisciplinary primary care teams implementing the service operation and PC, and other specialists with palliative training acting as the consultant. New career paths should be created for primary care doctors and nurses with PC training

Professional development

- » Train and certify EoLC and PC professionals across sectors (including doctors, nurses, care providers, allied health professionals, social workers, etc.)
- » Strengthen undergraduate and postgraduate medical, nursing, health and social care curricula to teach best practice in EoLC

Community care

- » Enable direct transfer/transportation between service locations and non-emergency consultations, which are necessary for EoL patients
- » Provide timely community access to medical resources in elderly homes and patient's own home
- » Designate family/solace rooms during the last days of life in hospitals and elderly homes to facilitate peaceful dying

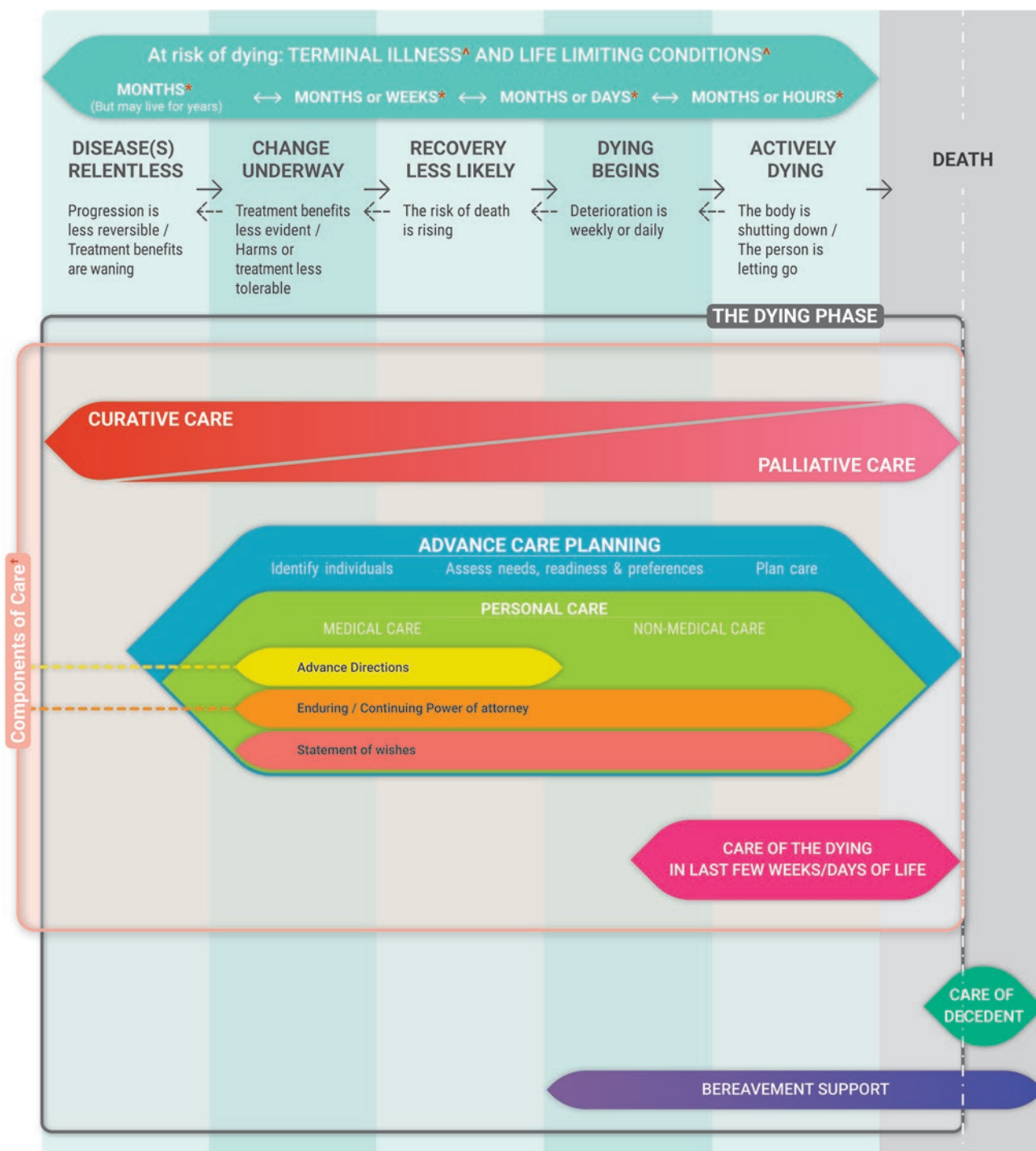
- » Provide post-death care that is:

- › Dignified for the deceased person (e.g. training of Food and Environmental Hygiene Department staff)
 - › Timely in terms of documentation to families; and timely and transparent mortuary and funeral services
 - › Evaluate current HA, nursing homes and public mortuary capacity and projected demand
 - › Commission stepped expansion to meet projected demand
- » Strengthen holistic support for caregiver/family and provide bereavement care that is continuous from the EoLC period till after death, if required

Socio-cultural level

- » Strengthen public life and death education and clarify common misconceptions about death and dying (e.g. palliative care, interpretation of filial piety to resemble the practice of "doing everything possible", the "haunted house" categorisation by the real estate industry, etc.)
- » Build an overarching public health strategy to support a compassionate community for EoL patients
- » Provide impartial and clear information on available community care services and funeral service options

preferences near the end of life (IOM, 2015). Findings from ongoing pilot programmes in Hong Kong should be incorporated into targets and objectives for local policy (e.g. the HA's "Enhanced CGAT Service for EoL Care in Residential Care Homes for the Elderly", the JCECC Project, The Salvation Army and Hong Kong Association of Gerontology's "Palliative Care in Residential Care Homes for the Elderly" programme) and other sources (such as the HA's Strategic Service Framework for Palliative Care).



Notes:

[^] "Terminal illness" refers to condition that is advanced (嚴重), progressive (持續惡化) and irreversible (不可逆轉), and failing to respond to curative therapy, having a short life expectancy in terms of days, weeks or months; and the application of life-sustaining treatment would only serve to postpone the moment of death. "Life-limiting conditions" refer to conditions that are advanced, progressive and irreversible and may not fall into the definition of terminal illness, but has reached the end-stage, limiting survival of the patients, e.g. end-stage renal failure, end-stage motor neuron disease, end-stage chronic obstructive pulmonary disease when survival may be prolonged by dialysis or assisted ventilation, and irreversible loss of major cerebral function and extremely poor functional status (i.e. frailty).

* Presented times are for approximate guidance as variability will exist between patients.

† The figure does not accurately display when, or in which order, components are needed – it is only intended as a conceptual framework.

Figure 3.2 Conceptual Framework for EoL Care for Terminal Illness and Life-Limiting Conditions of Older Persons (adapted from Department of Health UK, 2013)

SUMMARY

Over the last few years there has been considerable momentum in Hong Kong, and an increasing number of initiatives in EoLC, developed from both top-down (government effort) and bottom-up (community effort). However, there are still many issues, gaps and barriers that need to be tackled to ensure better EoLC. Now is the time to capitalise on this momentum to significantly develop sustainable and futuristic EoLC in Hong Kong.

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CHAPTER 4

STRATEGIC SERVICE FRAMEWORK FOR PALLIATIVE CARE IN HOSPITAL AUTHORITY

The Hospital Authority

Palliative care (PC) is an approach that aims to improve the quality of life (QoL) of patients facing life-threatening or life-limiting conditions. PC emphasises alleviation of distressing symptoms (e.g. pain, shortness of breath), improves quality of care and supports a more peaceful dying process. Moreover, it helps families to cope during their loved one's illness and the bereavement period through a holistic and team approach.

PC services in Hong Kong are currently provided mostly by the Hospital Authority (HA) and are led by PC specialists under the specialties of Medicine and Oncology. In the past, HA PC services focused mainly on the care of advanced cancer patients. In the last decade, PC services have been gradually extended to cover patients with other diseases, such as end-stage organ failure (e.g. renal failure) and chronic obstructive pulmonary disease (COPD).

PC services offered by HA are provided by multidisciplinary teams of professionals, including doctors, nurses, medical social workers, clinical psychologists, physiotherapists, occupational therapists, etc. HA organises and coordinates its PC service on a cluster basis. Inpatient PC services provide care for people with complex conditions or people who are dying. A range of ambulatory PC services is also available, including outpatient clinics for the management of less acute and complex symptoms; day care services for rehabilitation and psychosocial care; and home care (community) services to optimise symptom control and empower informal caregivers. Families are also supported with bereavement care before and after the patients' death.

In recent years, HA has strengthened its PC service in a range of areas. For instance, HA has developed PC services for patients with end-stage organ failure, especially patients with renal failure, by working in collaboration with other specialty areas. PC day centres have been developed through collaboration with community partners to provide one-stop multidisciplinary care for patients living in the community. Psychosocial support and bereavement care have also been enhanced by strengthening the services provided by medical social workers and clinical psychologists.

To support terminally ill patients living in residential care homes for the elderly (RCHEs), Community Geriatric Assessment Teams (CGATs) in HA work with palliative care teams, as well as RCHE staff, to strengthen the care of RCHE patients at end of life (EoL) and to provide relevant training to RCHE staff.

BACKGROUND

DEVELOPMENT OF THE HA'S STRATEGIC SERVICE FRAMEWORK FOR PALLIATIVE CARE

In the Hong Kong context of a rapidly ageing population, coupled with a growing chronic disease burden, there is an urgent need to strengthen healthcare services to provide for increasing patient needs along the care pathway. To plan and further improve the quality and sustainability of HA's PC services, as well as to cope with increasing demand, HA proposed the Strategic Service Framework for Palliative Care (the Framework) in 2017. This was established to guide the development of PC services in the next five to ten years. As a consequence, strategic directions for improving adult and paediatric PC have been formulated.

The development of the Framework commenced in early 2016. With support from the HA Board and senior management, the Framework development entailed a wide-spectrum, consultative process within HA, covering all clusters, and the Head Office. A Taskforce and Working Groups were established to advise on future service models and system infrastructures that were considered to be imperative for adult and paediatric PC. Overall, a highly participative and broad engagement approach was adopted, with contributions from different clinical specialties and disciplines, cluster management, Head Office executives and patient groups.

Through the comprehensive review and consultation process, key areas for improvement of PC in HA were identified, which included the governance and organisation of services, care coordination, place of care and performance monitoring. With reference to international practices, local experience and advice gathered through the consultation process, the comprehensive Strategic Service Framework for Palliative Care was formulated.

FRAMEWORK STRATEGIES FOR ADULT PALLIATIVE CARE

The Framework recommends four strategic directions:

1. Enhance governance by devoting for continuous quality improvement.

Under each strategic direction, strategies have been formulated with reference to identified areas of need or opportunities for improvement in order to address the service gaps and key issues. They are summarised in **Table 4.1** and discussed further in the next section.

Table 4.1 Summarising the HA Strategic Service Framework for Palliative Care

AREAS FOR IMPROVEMENT	STRATEGIC DIRECTIONS (WHERE WE ARE GOING)	STRATEGIES (HOW WE WILL GET THERE)
Governance and service organisation	Enhance governance by developing cluster-based services with the collaboration of medical and oncology PC specialists	<ul style="list-style-type: none"> » Strengthen collaboration between medical and oncology PC specialists to develop cluster-based services » Reinforce the role of Cluster Coordination Committee on Palliative Care Services to support cluster-based service organisation
Care coordination	Promote collaboration between PC and non-PC specialists through a shared-care model according to patients' needs	<ul style="list-style-type: none"> » Stratify patients' PC needs for shared care » Integrate PC into the care pathway for early identification of patients in need and initiation of Advance Care Planning (ACP) » Strengthen specialist palliative consultative service in non-PC settings
Place of care	Enhance PC in the ambulatory and community settings to support patients and reduce unnecessary hospitalisation	<ul style="list-style-type: none"> » Refine and align PC day service » Expand palliative home care service » Enhance PC support to elderly patients in care homes » Enhance medical–social collaboration to support PC in the community
Performance monitoring	Strengthen performance monitoring for continuous quality improvement	<ul style="list-style-type: none"> » Enhance data collection with standardisation of data capture and alignment of measurement tools » Identify key domains and develop indicators for evaluation and monitoring of clinical outcomes and service quality

Enhance governance by developing cluster-based services with the collaboration of medical and oncology PC specialists. Enhancing the governance of adult PC services is the cornerstone of the overall service development. This is oriented at cluster-based service organisations to improve service accessibility and coordination of care.

Adult PC services in HA have traditionally been provided by PC teams located in 16 hospitals. The teams are led by PC specialists who are either from the Department of Medicine (medical PC teams) or the Department of Clinical Oncology (oncology PC teams). Collaboration between different PC teams is limited, and the accessibility to PC services is variable, particularly for hospitals without an in-house PC team. Due to the historical emphasis in HA on cancer patients, PC coverage for non-cancer patients has been less overall than that provided for cancer patients. Medical and oncology PC teams provide services to cancer patients, while non-cancer patients are generally provided for by medical PC teams.

At HA Head Office level, PC services come under the clinical governance of the Central Committee on Palliative Care, comprising members from medical and oncology PC teams (doctors, nurses and allied health). Moreover, at cluster level, Coordination Committees on Palliative Care Services have been established to oversee these services. However, there remains room to further strengthen coordination of different PC teams and service development at cluster level.

Recommended strategies include:

1. ***Development of cluster-based services through strengthening the collaboration between medical and oncology PC specialists.*** PC services are delivered through a coordinated network of both cancer and non-cancer patients in all cluster hospitals. This enables pooling of expertise and optimal use of resources and facilities for more accessible PC.
2. ***Reinforcing the role of the Cluster Coordination Committees on Palliative Care Services*** to support cluster-based service organisations and improve implementation, coordination and monitoring of PC services at the cluster level.

Promote collaboration between PC and non-PC specialists through a shared-care model according to patients' need. Care coordination is indispensable in PC, given that patients often receive care from different medical specialties based on their needs. However, the majority of non-PC specialist teams focus on providing disease management, and there may not be as much collaboration as there could be between PC and non-PC teams. The provision of comprehensive care near the end-stage of life thus heavily relies on PC specialist teams, which may limit patients' access to holistic and patient-centred PC. Moreover, there is generally limited awareness and knowledge of PC among non-PC specialists. As a result, referrals to PC teams are often made at the very end-stage of the patients' disease trajectory, which can affect the timeliness and accessibility of PC.

In order to improve EoLC, enhancing collaboration between PC and non-PC specialists and the integration of adult PC into the care continuum are important areas for further service development. Instead of simply adding a layer of specialist PC for every patient with a life-threatening or life-limiting illness, a shared-care model should be adopted, supported by training and skills transfer between specialties. The aim is to ensure the provision of timely and appropriate care according to the needs of patients and their families/carers.

Recommended strategies include:

1. **Stratifying patients** according to their PC needs and disease complexity, as well as the professional competency of the PC teams.
 - a. The majority of patients who do not have complex PC needs should be managed by the parent team.
 - b. Patients with complex PC needs but who also require disease modifying treatments should be co-managed by both the parent teams and PC specialists through consultative support, case conferences, joint clinics, etc.
 - c. Patients with highly complex PC needs or difficult-to-manage symptoms, should be managed by PC specialists in a PC setting.
 - d. Dynamic changes frequently occur in a patient's condition, as well as their level of need. Responsive referral and coordination mechanisms therefore need to be established to acknowledge and address the changing needs of patients and the appropriate level of care required.
2. **Integrating PC into the care pathway.** It is essential for early identification of patients in need of initiation of Advance Care Planning (ACP), regardless of the specialties of the care team. With training and skill transfer, healthcare staff working in non-PC settings should be better equipped to identify the PC needs of patients and their families/carers. ACP could be conducted by the parent teams to address patients' and their families/carers' needs and preferences.
3. **Strengthening specialist palliative consultative service in non-PC settings** is a key component of the shared-care model. It is instrumental in providing proper support to the parent teams and to facilitate skill transfer in managing patients with PC needs. It is also a priority to develop PC consultative services to support hospitals with no PC teams.

Enhance PC in the ambulatory and community settings to support patients and reduce unnecessary hospitalisation. Patients approaching EoL, especially in the last year of life, tend to have high utilisation rates of hospital services, such as Accident & Emergency attendances and acute hospital admissions, even though many of these patients may prefer to spend their last stage of life in a familiar environment. Acute hospitalisation can be stressful to patients and families/carers, and it also puts significant and potentially unnecessary pressure on the healthcare system. The lack of PC services in the ambulatory and community settings in the past potentially account for this situation.

It is therefore important for HA to strengthen ambulatory and community PC services. This will support patients and their families/carers to facilitate the provision of appropriate care-in-place of choice and reduce unnecessary hospitalisation. The emphasis should be on enhancing day care and home care, support to residential care homes, and community partnerships.

Recommended strategies include:

1. **Refining and aligning the PC day service model** across clusters to provide a “one-stop-shop” for integrated and multidisciplinary care. Service components should be refocused to provide more programme-based services and therapeutic procedures for symptom management.
2. **Expanding palliative home care services** with a cluster-based arrangement and adopting a case management approach to support both cancer and non-cancer patients. Collaboration between palliative home care nurses and Community Nursing Service (CNS) nurses should be strengthened under the principle of shared-care models.
3. **Enhancing PC support** to RCHes through expanding the EoLC programme provided by CGATs, working in collaboration with the PC specialties and RCHE staff.
4. **Enhancing medical–social collaboration** with community partners, such as non governmental organisations (NGOs), patient groups and volunteers in order to better mobilise community resources and also to complement the PC services of HA for more holistic support to patients and their families/carers.

Strengthen performance monitoring for continuous quality improvement. At present, there are limited data on the performance and outcome of PC services in HA. Most information is captured manually and it is not standardised. Quality indicators are yet to be developed for systematic performance monitoring, benchmarking across units and for informing service planning. It is acknowledged that systematic monitoring of the quality and outcomes of PC services is instrumental to drive service improvement.

Recommended strategies include:

1. **Enhancing data collection** with standardisation of data capture and alignment of measurement tools. Apart from throughput data, other useful parameters should be identified, and data definition and collection mechanism should be standardised.
2. **Identifying key domains and developing indicators** for the evaluation and monitoring of clinical outcomes and service quality. Selection of key parameters for benchmarking could assist in driving service development and improving consistency in service provision among clusters.

THE FUTURE SERVICE MODEL FOR ADULT PC

Under the Framework, HA is moving towards realising the vision of providing timely, coordinated and holistic PC to patients and families/carers in need. Specialist adult PC services will be organised in a cluster-based arrangement, with strengthened governance through closer collaboration between medical and oncology PC teams. Timely and coordinated PC should be achieved through shared care between PC and non-PC specialists. PC is integrated into the care pathway of patients suffering from a life-threatening or life-limiting illness regardless of the specialties of their care team. Moreover, ambulatory and community PC services should be enhanced to support care-in-place and reduce unnecessary hospitalisation. Overall, performance monitoring should be strengthened to facilitate service improvement. The new service model of adult PC in HA is illustrated in **Figure 4.1**.

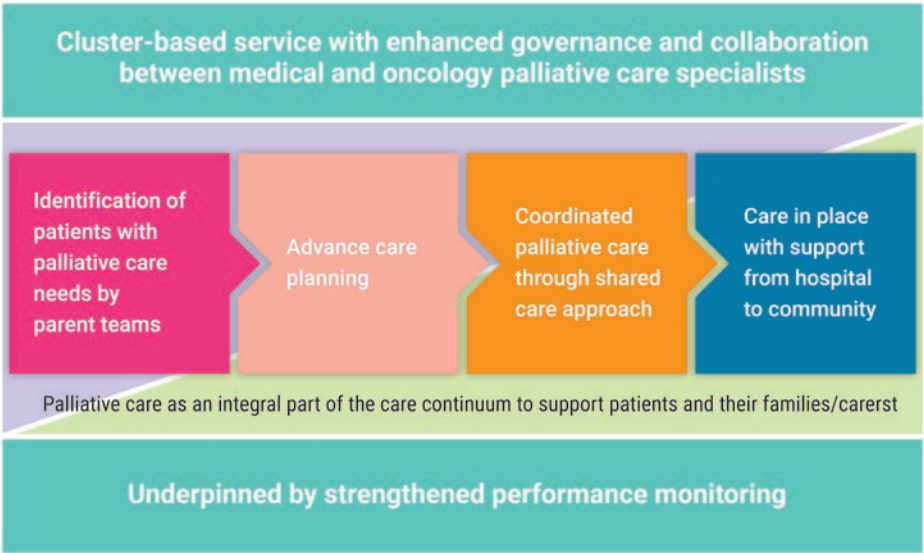


Figure 4.1 Future Service Model of Adult Palliative Care in HA

FRAMEWORK STRATEGIES FOR PAEDIATRIC PC

Specialist PC is currently not available in HA for paediatric patients. Children suffering from life-threatening or life-limiting illness are usually managed by a paediatric subspecialty team, which mainly delivers disease management. It may also manage the children's PC needs if required. Community support for these patients is generally limited, even though collaborations have been developed in recent years between paediatric departments in hospitals and NGOs to bridge service gaps. Overall, structured paediatric PC services are yet to be developed in HA.

The disease trajectories of paediatric patients facing life-limiting diseases are often very different from those of adult patients. The wide spectrum of serious paediatric illnesses, including inherited and congenital conditions, together with the fact that children are also growing physically, cognitively, socially and emotionally as they go through their illnesses, are particular features that increase the complexity of paediatric PC services. Moreover, as serious illnesses are not common among children in a developed economy such as Hong Kong, service demand and availability of specialised expertise for paediatric PC in HA is considerably lower than for adults.

Taking into consideration existing service gaps, factors limiting the development of paediatric PC and learnings from overseas experiences, a dedicated framework has been formulated to underpin the establishment of structured paediatric PC services in HA. There are three strategic directions for paediatric PC:

1. Establish territory-wide paediatric PC services in HA
2. Promote integrated and shared care with the parent teams
3. Enhance community support for children and families in need of PC

Establish territory-wide paediatric PC services in HA. A future service model for paediatric PC should include territory-wide paediatric PC services under single clinical governance. A centralised paediatric PC team should be established, led by paediatricians to coordinate the development of age-appropriate and family-centred care that caters for the special needs of paediatric patients facing life-limiting and life-threatening conditions. Services should be in the best interests of the children. The centralised team should work with the designated care team of doctors and nurses at regional level to provide comprehensive PC services oriented to the needs of children. The latter plays a significant role in coordinating care with community partners, special schools and local paediatric subspecialty teams, and also in the provision of palliative home care service in local communities. The centralised PC team should be based in the Hong Kong Children's Hospital. A continuum of paediatric PC services should underpin service delivery, covering inpatient, outpatient and home care support to schools and bereavement care.

Promote integrated and shared care with the parent teams. Paediatric PC teams should work closely as partners with paediatricians and other members in the parent teams who are managing the patient's condition. PC should be integrated into paediatric services, taking a shared-care approach to meet different levels of patient needs. Under the territory-wide service model, local care provision should be supported if patients and families wish to receive services at home or close by.

Enhance community support for children and families in need of PC. Children often prefer to be cared for at home when they are sick. Moreover, most families opt to care for their children at home if feasible. School is another familiar environment to children, providing a sense of reassuring rhythm to normal life with education and social life. As such, community-based services are an integral part of paediatric PC. Support and empowerment should be given to patients, their families and carers in schools to allow patients to live as fully as possible in their communities.

Paediatric palliative home care services should be further developed to support patients and families at home. In particular, support should be provided to special schools and residential schools. Training and skills transfer may be required for nurses who may serve as care coordinators, as well as school staff. Community partnerships for paediatric PC need to be strengthened. Relevant NGOs and patient groups should be engaged to provide complementary support to patients and their families. **Figure 4.2** summarises the future HA service model for paediatric PC.

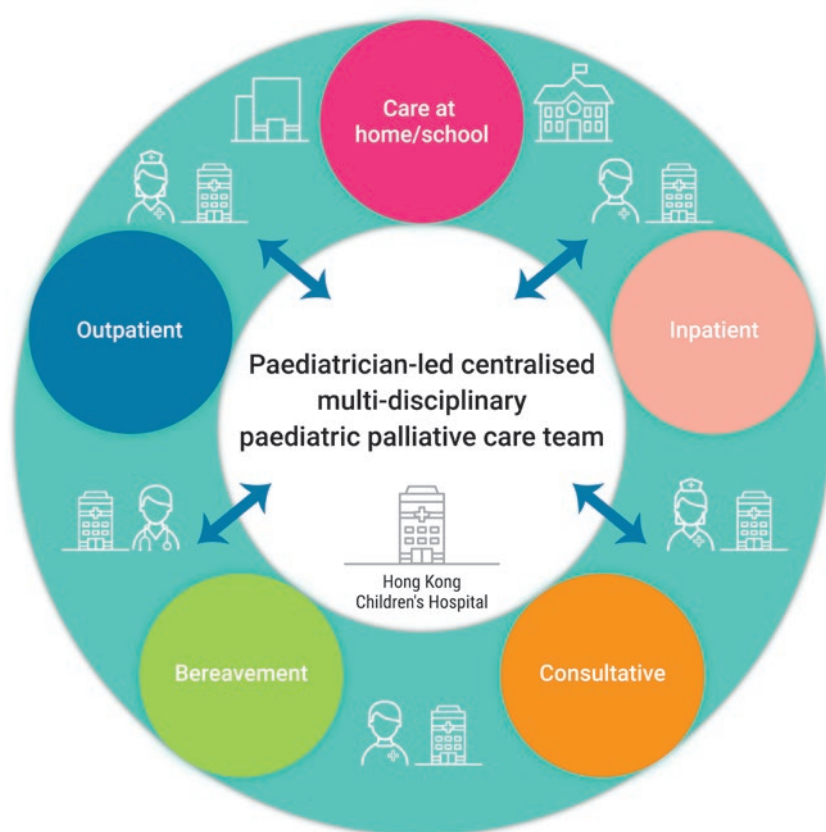


Figure 4.2 The Future Service Model for Paediatric PC

OTHER ORGANISATIONAL ISSUES REQUIRED AT BOTH ADULT AND PAEDIATRIC LEVELS

In order to facilitate the development of best practice PC service models and to support effective implementation of the Framework strategies for adults and children, a number of key enablers are essential. These include manpower and training, facilities, logistic support in hospital wards, information technology (IT) support and transport.

MANPOWER AND TRAINING

Training is fundamental to drive system and cultural change in integrating PC into the care continuum. It must be conducted by taking a systems approach and by targeting healthcare staff from both PC and non-PC settings, with collaboration between HA, academia and professional organisations.

First, basic training for all healthcare staff across disciplines and specialties is required to raise general knowledge and awareness of adult and paediatric PC. It covers the basic principles and ethical concepts of PC and ACP, as well as communication skills and practical care to enable patients to be supported along their disease trajectory.

Second, more advanced training is needed for non-PC teams working directly with adults and children who are suffering from life-threatening or life-limiting illnesses. Emphasis should be placed on skills transfer to enhance the competency of the teams to provide shared care with PC teams. Training should be focused on developing skillsets to initiate ACP discussions, symptom management and bereavement care.

Third, specialist training programmes should be consolidated to provide specialist PC services system-wide. These are provided by the Hong Kong College of Physicians and the Hong Kong College of Radiology for the training of medical and oncology PC subspecialties, respectively. For nurses, the Institute of Advanced Nursing Studies in HA organises a Post-Registration Certificate Course in Palliative Care Nursing. There are also designated training programmes for allied health professionals working in PC settings, coordinated by HA's Institute of Advanced Allied Health Studies.

In addition to this, however, detailed workforce planning is vital for doctors, nurses and allied health professionals to enable them to meet the escalating service demand. A cluster-based perspective of workforce planning and deployment is required to support the cluster-based Framework. Manpower standards must be established for inpatient, ambulatory and community PC to inform service planning and resource allocation. As well as manpower strength, reporting lines and career paths for professional development are also important areas for consideration.

FACILITIES

The physical design of environments in which to deliver adult and paediatric PC should be incorporated into hospital development and redevelopment projects in HA. Home-like, peaceful and soothing environments are essential design principles for PC facilities to relieve stress and improve patients' and families' perception of the quality of care.

It has been suggested that single rooms for patients approaching EoL provide more privacy. Moreover, interview rooms where patients and families/carers can engage in more intimate discussions should be made available if possible in both PC and non-PC settings in all hospitals. The design of mortuaries is another area to be improved on. This will affect the experiences and memories of patients' families/carers. Modernisation of the overall design of mortuaries is also required to better suit operational workflow and the needs of families/carers.

In addition to the design, capacity planning covering inpatient and ambulatory facilities for PC should be put in place to cope with projected service demand. This needs to take account of changes in the service Framework. The Central Committee on Palliative Care should work with cluster management to align future planning to the Framework.

LOGISTIC SUPPORT IN HOSPITAL WARDS

The logistics and operations of hospital wards should be designed to cater for the needs of patients and their families/carers. Consideration should be given to individual patient's conditions, including their psychosocial and emotional needs, especially during their last phase of life. For instance, flexible visiting hours should be considered so that patients can spend more time with their loved ones. Arrangements can also be made for families/carers to stay overnight with patients, if hospital operation allows.

IT SUPPORT

Better IT support is required to enable implementation of the Framework. IT systems need to be enhanced to support workflow, communication and care coordination across disciplines, specialties and care settings along the PC journey, especially between PC and non-PC specialists, as well as between home care teams and CGATs. Establishing a common platform to document ACP is also important for clinical communication and ongoing reviews. A database of PC patients is required to identify patients, document care management and monitor performance at both clinical and system levels. Furthermore, the development of tele-care, mobile apps and website support should be explored to support care-in-place and empower patients and families/carers.

TRANSPORT

In line with the development of better and more streamlined ambulatory care, transportation support for patients such as Non-Emergency Ambulance Transfer Service (NEATS) must be strengthened. This will help patients attend day care programmes more easily and use day services better. Moreover, transportation support is also important to facilitate hospital discharge and the transfer of patients between hospitals or to RCHes.

SUMMARY

PC is an integral part of the care continuum. All patients facing life-threatening or life-limiting conditions, and their families/ carers, should receive timely, coordinated and holistic PC to address their needs. They should have greater participation in planning their care, be aware of the choices they can make and have the best possible QoL until the end of the patient's life journey. The HA Framework outlines strategies to achieve this vision.

The Framework strategies will be implemented in stages and will consider the service needs and organisational readiness at both clinical and cluster levels. Short, medium and long-term implementation plans have been developed and will be executed under the leadership of the Central Committee on Palliative Care. For those strategies that require additional resources, these could be sought through HA annual planning processes to support implementation. Many changes have already begun, and these will continue with the momentum generated from the processes taken to develop this Framework and through the concerted efforts of all in HA.



PART II:

INNOVATIVE
END-OF-LIFE
CARE
COMMUNITY
SERVICES

CHAPTER 5

A PATHWAY TOWARDS EVIDENCE-BASED COMMUNITY-BASED END-OF- LIFE CARE IN HONG KONG: BUILDING A COMMON EVALUATION FRAMEWORK

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End-of-life care (EoLC) in Hong Kong is mainly provided by specialised units in hospitals. The foreseeable growing demand for EoLC presents a pressing need to develop strategies in the community to share the care. Under this context, the Jockey Club End-of-Life Community Care (JCECC) Project was launched in 2016 to bring together service providers and academics to build evidence- and community-based EoLC models. Four discrete community-based EoLC models have been developed and piloted. To generate knowledge and insights regarding the outcomes and implementation of these four models, the Faculty of Social Sciences, University of Hong Kong (HKU), developed a common evaluation framework. This framework is

the first of its kind in Hong Kong. There has been a proliferation of evaluation studies in EoLC in the international literature, although evaluation studies on EoLC in Hong Kong have been developed more slowly (Wang & Chan, 2015). This chapter presents the key issues, and a summary of major work pertaining to EoLC evaluation conducted worldwide. It introduces the common evaluation framework developed for the four JCECC Project models. Descriptive findings from the evaluation are then presented. Experiences of implementing the new evaluation framework, learning and implications for future advancements are discussed.

BACKGROUND

KEY ISSUES IN EVALUATION IN COMMUNITY-BASED EoLC

Conceptualising outcomes of community-based EoLC. Formal programme evaluation is essential to generate the evidence needed for continuous quality improvement. Different types of evaluation have been reported for EoLC, focusing on input/structure, process, output and/or outcomes. Among these, outcome evaluation is gaining prominence in EoLC to inform care outcomes that directly affect patients and their families. Outcome evaluation is key to quality improvement, as well as benchmarking and comparisons across care models (Bausewein et al., 2016). Defining outcomes of EoLC is not without its challenges due to the heterogeneous definitions of EoLC. The World Health Organisation (WHO) defined palliative care (PC) in 2002 as an approach that improves the quality of life (QoL) of patients facing life-threatening illness and their families. PC can assist in the relief of pain, as well as other physical, psychosocial and spiritual problems (Worldwide Palliative Care Alliance, 2014). Improving QoL has become the primary goal of PC, and the core indicator in outcomes evaluation of EoLC. In 2013, the National Consensus Project in the US established clinical practice guidelines, which defined eight domains of preferred care encompassing the WHO definition of PC (National Consensus Project, 2013). These domains are:

- | | |
|--|---|
| 1. Structure and processes of care | 5. Spiritual, religious and existential aspects of care |
| 2. Physical aspects of care | 6. Cultural aspects of care |
| 3. Psychological and psychiatric aspects of care | 7. Care of the patient nearing the end of life |
| 4. Social aspects of care | 8. Ethical and legal aspects of care |

In a recent systematic review on assessment tools, a ninth domain was identified as “multidimensional”, which promotes the concept of multidimensional QoL (Aslakson et al., 2017).

Studies examining the domains of preferred care have provided consistent evidence to show that EoLC is more effective than conventional care for patients at EoL (Catania, et al., 2015; Kavalieratos et al., 2016; Potts, Cartmell, Nemeth, Bhattacharjee & Qanungo, 2018). The most recent systematic reviews suggested that palliative EoLC benefitted patients with improved QoL, physical symptom relief, Advance Care Planning (ACP), patients’ (and families’) satisfaction with care and reduced healthcare service utilisation (El-Jawahri, Greer & Temel, 2011; Kavalieratos et al., 2016; Zimmermann, Riechelmann, Krzyzanowska, Rodin & Tannock, 2008). These reviews provide clearer conceptual frameworks regarding outcomes of EoLC for evaluation studies.

Selecting outcome measurements. A core challenge in selecting outcome measurements in EoLC is the large number and variability of existing instruments, which render meaningful comparison across research and meta-analysis difficult (Aslakson et al., 2017). In a systematic review conducted in 2007, 80 of the 97 studies included outcome instruments in PC that had been reported only once (Mularski et al., 2007). Moreover, many outcome instruments were criticised for questionable psychometric properties and irrelevant content, length and impracticality in clinical settings (Mularski et al., 2007; Stiel et al., 2012). Leading PC research organisations have advocated the use of standardised assessment tools, for instance:

- » The US National PC Research Centre has recommended a core list of outcome measures (National Palliative Care Research Centre, 2013); and
- » The European Association for Palliative Care (EAPC) Task Force was formed to develop nationally comparable assessment tools across Europe and to promote integration of outcome assessments in routine clinical care.

Subsequently, the EAPC Task Force published a White Paper in 2016 to provide expert recommendations regarding the selection, use and implementation of outcome measures in PC (Bausewein et al., 2016). Twelve recommendations were proposed. Four of these, summarised in **Table 5.1**, outline useful key decision-making parameters for selecting good outcome measures in terms of instrument design, psychometric properties, assessed domains and targeted subject(s). The use of patient-reported outcome measures (PROMs) was highlighted by the Task Force as a way of capturing patients' experiences as the ultimate outcome information. Hearing patient experiences can serve as a way for patients to provide feedback on unmet needs. Moreover, the EAPC Task Force recommended embedding outcome measures into routine clinical practice, particularly advocating for the use of outcome measures that have been translated into other languages using validated processes to support comparisons at national and international levels (Bausewein et al., 2016). **Table 5.2** summarises the properties of commonly used PROMs and outcome measures for caregivers that could contribute to clinical and research activities in EoLC.

Table 5.1 Key Decision Parameters on Selecting Outcome Measures Proposed in the White Paper of the EAPC Task Force (Bausewein et al., 2016)

	KEY DECISION PARAMETERS ON "GOOD" OUTCOME MEASURES
Measurement design	<ul style="list-style-type: none"> » Patient-reported outcome measures (PROMs) » Validated in PC » Brief and straightforward items » With complementary proxy versions to allow proxy reports when the patient is unable to self-report
Outcome domain	<ul style="list-style-type: none"> » Multidimensional measurement to enable capture of the holistic nature of PC
Subject to be assessed	<ul style="list-style-type: none"> » Using outcome measures to assess unpaid caregivers alongside patients' needs
Psychometric properties	<ul style="list-style-type: none"> » Outcome measures with sound psychometric properties (e.g. reliability, validity, responsiveness)

Two projects have been undertaken in an attempt to standardise outcome measure used nationally: Palliative Care Outcomes Collaboration (PCOC) in Australia (Palliative Care Outcomes Collaboration, 2018) and Outcome Assessment and Complexity Collaborative (OACC) in the UK (Witt et al., 2015). These projects share a similar goal of routinely incorporating agreed, standardised outcome measures into PC services in a range of care settings. The aim of this is to achieve a national clinical outcomes set that supports evaluation, quality improvement, comparisons across services and benchmarking. Both PCOC and OACC suites support holistic assessments for patients and caregivers, covering domains of illness, physical needs, psycho-spiritual needs and family care. The project teams are closely collaborating to align the tools in the two suites. Currow et al. (2015) demonstrated how the outcomes data collected with the PCOC suite has underpinned performance benchmarking, monitoring and improvement on a national level.

Table 5.2 Properties of Commonly Accepted Outcome Measurements with Patients and Caregivers in EoLC Studies

	EXAMPLES OF RECOMMENDED MULTIDIMENSIONAL PROMS IN LITERATURE			
	Edmonton Symptom Assessment Scale (ESAS) (Bruera, Kuehn, Miller, Selmser & Macmillan, 1991)	Palliative Care Outcome Scale (POS) (Hearn & Higginson, 1999)	Memorial Symptom Assessment Scale (MSAS) (Lobchuk, 2003; Portenoy et al., 1994; Sherman et al., 2007)	McGill Quality of Life Questionnaire (MQOL) (Cohen, Mount, Strobel & Bui, 1995)
Population of validation study	Patients receiving palliative care	Patients with advanced cancer	Patients with cancer	Patients with advanced illness
Time for completion (minutes)	5	4–7	20–60	10–30
Number of items	10	10	32	16
Assessed domains and items	Physical symptoms, psychological symptoms, general well-being and other concerns	Physical, psychological and spiritual needs, practical concern, family anxiety, sharing feelings with family, information needs and self-reported concerns	Physical symptoms, psychological symptoms and self-reported concerns	Physical and psychological symptoms, existential concerns, support needed, sexual function and perceived QoL
Internal consistency reliability measured	Y	Y	Y	Y
Convergent validity measured	Y	Y	Y	Y
Criterion/discriminant validity measured	N/A	Y	N/A	N/A
Responsiveness measured	N/A	Y	N/A	Y
Availability of proxy version	N	Y	Y	N
Validated Chinese version	Y (Dong et al., 2015)	N (validation on Chinese version IPOS is underway in Hong Kong)	Y (Lam et al., 2008)	Y (Lo et al., 2001)

EXAMPLES OF RECOMMENDED ASSESSMENT TOOLS ON CAREGIVERS IN LITERATURE

Modified Caregiver Strain Index (Thornton & Travis, 2003)	Short-form Zarit Burden Inventory (Higginson, Gao, Jackson, Murray & Harding, 2010)	Inventory of complicated grief (Prigerson et al., 1995)
Caregivers for patients with advanced cancer	Caregivers for persons with dementia and cancer patients	Bereaved adults
N/A	N/A	N/A
13	12	19
Multidimensional caregiver strain, both subjective and objective aspects	Items on role strain, self-criticism, and negative emotions	Symptoms of complicated grief
Y	Y	Y
Y	Y	N/A
N/A	N/A	N/A
N/A	N/A	N/A
/	/	/
Y (Chan, Chan & Suen, 2013)	Y (Tang et al., 2015)	Y (Li & Prigerson, 2016)

Strategies for improving evidence base in EoLC. PC and EoLC have long been criticised for having a weak evidence base. In a review of literature published in 2004 and 2009 (Hui et al., 2011), only 5.6% palliative oncology studies conducted in the first six months of these two years applied randomised controlled trial (RCT) designs. A more recent review identified that of all PC studies published between 1946 and 2015 only 11.4% were controlled clinical trials (CCT) (Bouça-Machado et al., 2017). Moreover, many clinical trials have been criticised for methodological flaws, such as high-risk of bias and low power (Visser, Hadley & Wee, 2015). In reality, however, it is challenging to conduct high-quality PC research, particularly with a follow-up element in the design. Many clinical trials in PC have failed to recruit the required number of participants (Hanson et al., 2014), and a high median attrition rate (44%) has been reported (Hui, Glitza, Chisholm, Yennu & Bruera, 2013). Patient factors such as symptom burden and clinical deterioration are reported to be the main barriers to adequate recruitment and retention, followed by caregivers' gate keeping (limiting access to patients) and ethical concerns (Dunleavy, Walshe, Oriani & Preston, 2018). Some studies have managed to achieve better recruitment results with the use of standard recruitment protocols and specialised recruitment staff (Dunleavy et al., 2018; LeBlanc, Lodato, Currow & Abernethy, 2013). Other studies have attempted to improve recruitment by modifying study designs (such as the use of a randomised fast-track trial with patients who have longer term prognoses; Higginson & Booth, 2011). Globally, there is an increasing trend of conducting large-scale, multi-site, high-quality collaborative research in PC by concerted cooperation between interdisciplinary research groups. The Palliative Care Research Cooperative Group in the US is one example (LeBlanc et al., 2010).

PC is a complex intervention, and mixed-methods research designs have been advocated to ensure comprehensive, in-depth, quality evaluations of processes and impact (Farquhar, Ewing & Booth, 2011). Mixed-methods designs provide many advantages to evaluators. They combine quantitative and qualitative research approaches, which not only facilitate holistic hypothesis generation, but also produce synergistic data that augments understanding of the mechanisms that produce study outcomes (Farquhar et al., 2011; Farquhar et al., 2013).

In summary, the development of international EoLC evaluation models has been characterised by increasing agreement regarding the need for evidence to support continuous quality improvement activities; use of standard outcome measures; routine incorporation of outcome measures into clinical practice; use of mixed-methods research to provide comprehensive evaluation data; and the importance of international research collaborations to enhance the global EoLC evidence base. It was therefore important when conceptualising the JCECC Project evaluation framework that it reflected these global advances.

THE HONG KONG SCENARIO

There are currently no systematic, agreed, routine outcome evaluation processes in place for EoLC. PC in Hong Kong is predominantly provided by hospitals under the auspices of the Hospital Authority (HA). The HA called for standardisation of data capture and alignment of outcome measurement tools in its sites to assess the performance and outcome of PC services (HA, 2017). This mirrors the mission statements of international groups such as PCOC and OACC, and it addresses a pressing need to develop an acceptable outcome assessment framework for PC and EoLC in Hong Kong. EoLC is provided in other settings (such as residential aged care settings); however, evaluation of such care in these settings is rare. Most studies into EoLC in Hong Kong are descriptive, and a systematic review of articles published in Hong Kong between 1991 and 2014 identified that clinical trials accounted for only 3.7% of all published local research (Wang & Chan, 2015). Pilot evaluation programmes have been implemented by major non-governmental organisations (NGOs) in Hong Kong; however, the evaluation frameworks and findings are not publicly available. Recently, an RCT of a nurse-led home-based PC programme for patients with end-stage heart failure reported significant improvements in favour of the intervention group (Ng & Wong, 2018; Wong et al., 2018). However, the study focused on only one disease group and the model was hospital-based. There is opportunity for improvements to be made in research on different community-based models of community-based EoLC, as well as for other disease groups.

THE JCECC PROJECT COMMUNITY-BASED EoLC MODELS

The four JCECC Project community-based EoLC models all involve complex interventions offered by multidisciplinary care teams. These models of care serve patients aged at least 60 years old who have been diagnosed with an incurable disease and who have a prognosis of six months or less. The models of care also serve family members.

1. The model of care provided by the Haven of Hope Christian Service is characterised by intensive home-based nursing care, Advance Care Planning and spiritual care.
2. St James' Settlement care model focuses on enhancing family communication and facilitating joyful and memorable moments through cheering-up activities.
3. The model of care provided by the Hong Kong Society for Rehabilitation takes a non-cancer patient capacity building approach, which promotes patients' competence in symptom management.
4. A community capacity building approach has been adopted in the care model delivered by S.K.H. Holy Carpenter Church District Elderly Community Centre. This model seeks to strengthen the support network of patients and families through building interfaces for patients and families with the medical team, community resources and volunteers.

Despite the differing care approaches, all four models are underpinned by strategic partnerships with hospitals, and they share the same six intervention foci in their holistic care:

1. Symptom management
2. Psychosocial care
3. Practical support
4. Family communication
5. EoL decision-making
6. Bereavement care

A pattern of interventions from the acute phase to the maintenance phase has been adopted in all models across disease trajectories. Approximately the first three months of care is called the acute phase. Intensive interventions are provided by the service team through visits and phone contacts. The care then moves to a maintenance phase, characterised by less staff involvement but regular assessment on changes in patient or family conditions which trigger interventions as changes occur. When the patient approaches death, staff involvement again increases to support the patient and family in the final days. Care is then provided during the bereavement period. More details on the interventions of each model are described in Chapters 6-9.

THE EVALUATION FRAMEWORK

The evaluation framework consists of four mixed-method sub-studies on patients and caregivers to assess the process, outcomes and impacts of the complex interventions (see **Figure 5.1**). Five specific objectives underpin these evaluations, which use different methodological approaches.

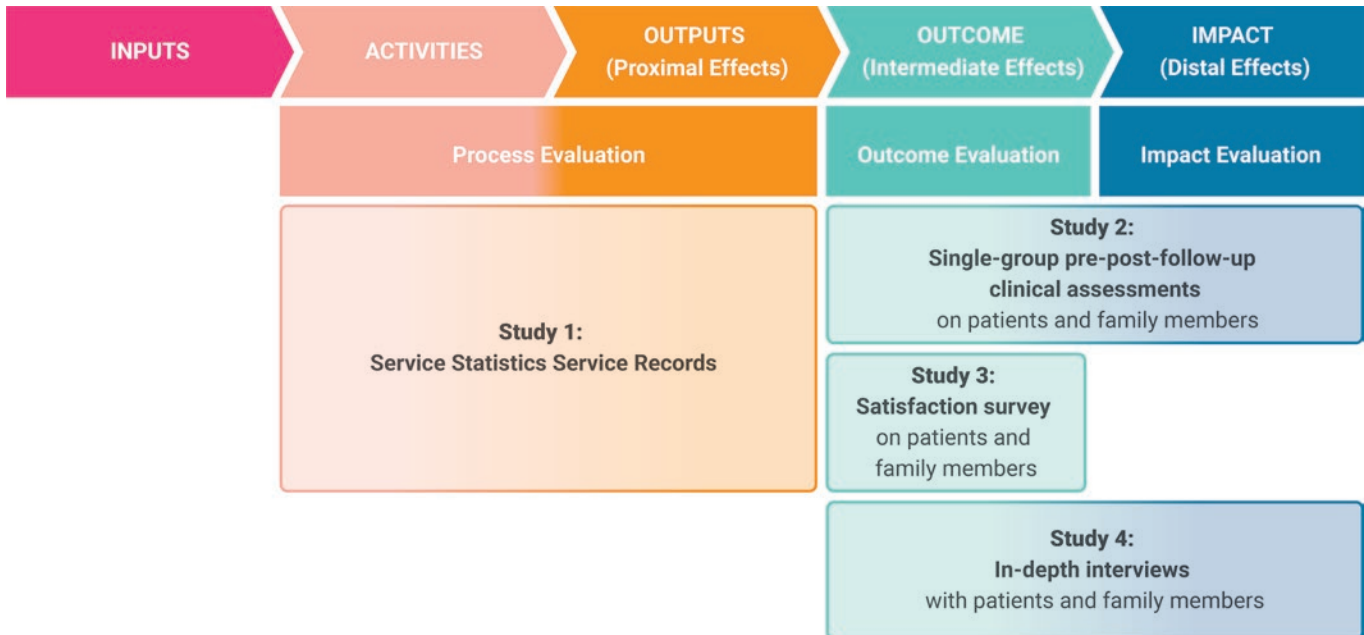


Figure 5.1 Evaluation Framework of the JCECC Community-Based End-of-Life Care Models

STUDY 1: SERVICE STATISTICS AND SERVICE RECORDS

Study 1 is a process evaluation of implementation of the models. This study enables optimisation of models when analysed with reference to programme outcomes. It collects quantitative data on service statistics, including the number of beneficiaries and service records, the number and length of service sessions, types of interventions and the healthcare professional(s) involved. A standardised service record form has been developed based on the six intervention foci common to the four care models. This study was implemented in the latter half of the second year of the project.

STUDY 2: SINGLE-GROUP PRE-POST FOLLOW-UP CLINICAL ASSESSMENTS

Study 2 evaluates objective outcomes and impacts of the care models on patients and caregivers. This study takes a quantitative, single-group pre-post follow-up design, with data collected by case workers through clinical assessments. During the development of the JCECC Project complex intervention models, the advice provided by the UK Medical Research Council guidelines (Medical Research Council, 2006) was adopted. This recommended that researchers start with small-scale, non-experimental studies to inform model refinement before embarking on a full-scale evaluation with more rigorous experimental designs. Since the four JCECC models are still evolving, a non-experimental observational design is currently considered appropriate for evaluation purposes.

The design of assessment time points should correspond to when the effect of the intervention is expected to occur (Evans et al., 2013). This was anticipated to be three months after completing the acute phase of care; however, given the high attrition rate of EoL patients, one additional time point has been introduced. Data are now collected from patients at service intake (T0), one month after service commencement (T1) and after three months (T2). Regarding caregivers, to reduce respondent burden, data are collected at two pre-death time points at service intake (T0) and three months after service commencement (T1). Since bereavement care is provided in all four models, a bereavement assessment has also been established two months after the patient's death (T2).

Outcome measures were selected according to key parameters recommended by the EAPC Task Force (Bausewein et al., 2016). For patients, the Integrated Palliative Care Outcome Scale (IPOS) was adopted to assess QoL. The IPOS is a recent development in the Palliative Care Outcome Scale (POS) suite of measures, proposed by scholars at the Cicely Saunders Institute of Palliative Care & Rehabilitation, King's College London. With approval from the POS development team, the IPOS was translated into Chinese by the HKU research team, and then validated by a standard forward-backward translation procedure supervised by the multidisciplinary professional group. The selection of IPOS is a proactive attempt to align the local evaluation with international developments in EoLC.

The IPOS (three-day recall) is a 19-item multidimensional QoL PROM with a complementary proxy version. It builds on the internationally accepted POS (Hearn & Higginson, 1999). Despite its relatively brief history, cultural validation studies of IPOS in different parts of the world are growing. Confirmatory factor analysis of the English version suggested a two-factor model was appropriate (Harding & Guo, 2017), including:

- » A 7-item psychological and communication subscale that addresses psychological symptoms (2 items), spiritual needs, sharing of feelings with family members, perceived anxiety of family members, practical concerns and information needs; and
- » A 10-item physical symptom subscale that addresses pain, shortness of breath, weakness, nausea, vomiting, poor appetite, constipation, sore or dry mouth, drowsiness and poor mobility.

All items are measured on a 5-point Likert scale ranging from 0 (best) to 4 (worst). The IPOS also includes an open-ended question on the patient's main problems in the preceding three days. Items can be analysed separately or summed as a total score ranging from 0 to 68, with higher scores representing more severe problems. In the current validation study, Cronbach's alpha statistics of the psychological and communication subscale, the physical symptom subscale and the overall scale were 0.75, 0.74 and 0.77, respectively. Empirical experience suggests that the average time for completion of IPOS is 10 minutes. The original English version of IPOS is free to use after registration on the POS website (<https://pos-pal.org/>).

For family members, outcomes of caregiver strain, perceived intimacy with patient and complicated grief are measured. The validated Chinese version of the 13-item modified caregiver strain index (C-M-CSI) (Chan et al., 2013; Thornton & Travis, 2003) was selected. The sum of the scale scores ranged from 0 to 26, with higher scores indicating higher levels of caregiver strain. The Cronbach's alpha statistic of the C-M-CSI in this study was 0.89. A single item was used to assess perceived intimacy with patients on a 0 (not intimate at all) to 4 (very intimate) scale. At T2, bereaved caregivers were assessed on their levels of grief using the 19-item Chinese version Inventory of Complicated Grief (ICG) (Tang & Chow, 2017). The items are rated on a 5-point Likert scale ranging from 0 (never) to 4 (always). A single factor was suggested, and respondents who scored over 25 on the scale were considered to have higher risk of complicated grief, which may require intervention (Prigerson et al., 1995). The ICG obtained a Cronbach's alpha coefficient of 0.91 in our study.

It is hypothesised that irrespective of which model of care is provided, it will promote psychosocial well-being of patients and caregivers, thereby reducing unnecessary medical service utilisation (of either group) of Accident & Emergency (A&E) presentations, admission to public hospital general wards or Intensive Care Units (ICU), or other medical services. For each time point, patients and family caregivers were asked about their use of medical services in the previous month. Per-month utilisation rates were compared between pre-intervention and post-intervention periods. Demographics, caregiving conditions and health status of caregivers were collected from patients and caregivers at T0. **Table 5.3** summarises the outcome indicators collected at each assessment time point.

Table 5.3 Outcome Indicators by Assessment Time Point

	MEASURE	DESCRIPTION OF ITEM(S)
Patients		
Psychological symptoms	IPOS	Two items on intensity of depression and anxiety
Physical symptoms	IPOS	Intensity of 10 common physical symptoms
Perceived family/friends' anxiety	IPOS	One item on anxiety of family members perceived by patient
Communication of feelings with family/friends	IPOS	One item on difficulties communicating feelings with family members/friends
Practical concerns	IPOS	One item on severity of practical problems
Information needs	IPOS	One item on information needs
Medical services utilization	Utility items	Utilisation of 20 types of medical services
Demographics	–	Age, gender, disease group, financial allowance, living arrangement
Family member		
Caregiver strain	C-M-CSI	13 items on caregiving stressors
Intimacy with patient	Self-invented	One item on perceived intimacy with patient
Medical services utilisation	Utility items	A&E admission, hospital bed days in the last month
Complicated grief	ICG	19 items on symptoms of complicated grief
Caregiving situations	Self-invented	Hours per week providing care, days per week needed to accompany patient to medical clinics/hospitals, satisfaction with support from family members
Health status	Self-invented	Diagnosis of chronic diseases
Demographics	–	Age, gender, relationship with patient, income, living arrangement

Notes. IPOS=Integrated Palliative Care Outcome Scale; C-M-CSI=Chinese version modified caregiver strain index; ICG=Inventory of Complicated Grief.

	MONTHS IN SERVICE			
	Service Intake	1 Month	3 Months	2 Months Post-Patient's Death
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STUDY 3: SATISFACTION SURVEY

The objective of this study was to assess service satisfaction. A survey of patients and caregivers was taken at three months after service commencement, and a second survey was taken of caregivers, two months after the patient's death. Items were developed to assess satisfaction with each core service component and overall satisfaction. All items were scored on a 10-point Likert scale from 1 (very dissatisfied) to 10 (very satisfied). To maintain the objectivity of the findings, the survey was conducted independently of service providers by HKU researchers using telephone interviews. All patients and family members were invited, and the only non-completers were those unable to respond to the telephone survey. Each survey took 10 minutes on average.

STUDY 4: IN-DEPTH INTERVIEWS WITH PATIENTS AND FAMILY MEMBERS

Study 4 provides qualitative data on self-reported outcomes and service impacts, with the objective of obtaining individuals' perspectives of participating in the programme. Patients and family members were interviewed face-to-face using a semi-structured question guide. Two cases (patient and caregiver dyads) from each service model in each year were selected using a systematic sampling approach. Using the overall data on caseloads per year by each service model, these cases were identified at the 20th% and the 40th% of admissions to each programme in each year. They were invited to participate in an in-depth interview. Patients were interviewed after three months of receiving the service, and the caregiver interviewed two months after the patient had passed away. HKU researchers conducted and audio-taped the interviews. Interviews lasted for 30 and 60 minutes for patients and caregivers, respectively. Audiotapes were transcribed, and analysis was undertaken on the verbatim transcriptions. See **Table 5.4** for a summary of the four sub-studies.

Table 5.4 Summary of the Sub-Studies with Respective Objectives and Methodological Approaches

SUB-STUDIES	EVALUATION OBJECTIVES	KEY QUESTIONS TO BE ANSWERED	METHODOLOGICAL APPROACH
Study 1: Service statistics and service records	Objective 1: To evaluate the implementation of the models and enable optimisation of models when analysed with reference to outcomes	<ul style="list-style-type: none"> » What types of interventions were provided? » Who provided the interventions? » What was the dosage of interventions? 	Continuous collection of service statistics and service records recorded by case workers
Study 2: Clinical assessments with patients and family members	Objective 2: To assess the objective outcomes for patients and family members	<ul style="list-style-type: none"> » Did patient show improvements in quality of life and emotional states, and reduced medical service utilisation immediately after receiving services? » Did family caregivers show reduced caregiver strain and improved relationship with the patient after receiving services? 	<p>Single-group pre-post follow-up clinical assessment conducted by case workers</p> <p>Assess the changes in post and follow-up relative to baseline</p>
	Objective 3: To assess the impacts on patients and family members	<ul style="list-style-type: none"> » Did the model reduce medical service utilisation of patients and family caregivers? 	
Study 3: Satisfaction survey with patients and family members	Objective 4: To assess the subjective outcomes for patients and family members	<ul style="list-style-type: none"> » Were patients satisfied with the quality of care? » Were family caregivers satisfied with the quality of care? 	<p>Telephone survey with patients and caregivers conducted by HKU researchers</p> <p>Convenience sampling with invitation extended to all patients and caregivers</p>
Study 4: In-depth interviews with patients and family members	Objective 5: To solicit in-depth and subjective perceptions of patients and caregivers on the services	<ul style="list-style-type: none"> » What were the perceived outcomes and impacts of services by patients and family caregivers? » Did patients and family caregivers think that the services had achieved its goals? 	<p>In-depth interviews with patients and caregivers conducted by HKU researchers</p> <p>Systematic sampling</p>

PRELIMINARY FINDINGS

Between 1 January 2016 and 31 March 2018, among 517 patients and 477 caregivers who received the services, 176 (34%) patients completed all assessments, 105 caregivers (22%) completed the first two assessments and 107 caregivers completed the post-death T2 assessment. The main reasons for attrition of patients were death (39.4%) and clinical deterioration (21.7%), whereas refusal (45.2%) and failure to arrange an interview time (25.3%) were the primary reasons for attrition of family caregivers. There were no significant differences in demographics of patients with or without assessments. Patients received an average of 6.6 months of service (standard deviation (SD)=6.5). They had a mean age of 76.4 years (SD=10.9) and there were no gender differences. There was a range of major diagnoses, including cancer (40%), chronic obstructive pulmonary disease (21%), end-stage renal disease (19%), Parkinson's disease (6%), motor neuron disease (5%) and heart disease (4%). Family caregivers were mainly female (77.1%), middle-aged (mean=58.8 years, SD=13.0), and reflected similar percentages of spouses (44.8%) or adult children (45.7%) of patients. They had high involvement in caregiving and provided, on average, 59.3 hours of care per week (SD=60.3) to patients. Over half of these family caregivers were also suffering from one or more chronic diseases.

To stratify patients into groups of high and low needs, a threshold level was set for each outcome indicator at mean baseline score plus one standard deviation. A score above the threshold level represented high needs. Distributions of high and low needs at baseline (T0) and at the third month were compared. At baseline, the majority (85.2%) of participants reported low needs in physical symptoms. This might be attributable to the hospital-based PC received by over half of these patients at the time of programme admission. Patients indicated that their greatest problems were with sharing feelings and practical concerns, with the highest reported proportion of high needs when compared to other psycho-spiritual distresses. As anticipated, patients encountered practical difficulties related to residing in the community.

Regarding psychological distress, studies have reported that Chinese patients tended to report less psychological distress than their Western counterparts (Sham, Chan, Tse & Lo, 2006). Some have explained this finding as the tendency of Chinese people to translate psychological distress into somatic presentations (Zhou et al., 2011), while others have suggested that cultural beliefs of accepting fate help elderly Chinese patients face death anxieties (Lo, 2006). From our observations, a large number of older Chinese patients found it difficult to articulate their inner feelings, which might have impeded their capacity to share feelings not only with family members, but also with the assessors. Lower proportions of caregivers at baseline reported high needs when compared to patients, with around 15% reporting high caregiver strain and 17% reporting low intimacy in relationships with patients.

After three months of service, reduced percentages of the high-need population were observed in all assessed areas for patients and caregivers (see **Figures 5.2** and **5.3**). The most obvious improvements were in practical issues, family anxiety and barriers in communicating feelings. Paired t-tests comparing baseline and three-month data found that all changes in

the third month were statistically significant. The prevalence of complicated grief was 9.3% among the assessed bereaved caregivers, which was lower than the reported prevalence of 13.9% elsewhere (Li & Prigerson, 2016). Patients and caregivers' monthly utilisation of medical service remained low throughout the evaluation period (see **Figures 5.4** and **5.5**).

PATIENT OUTCOMES

(% of patients with higher needs)

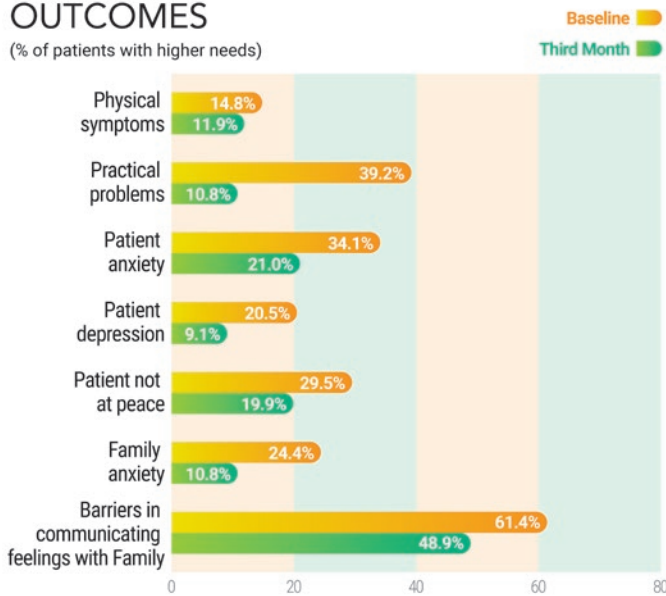


Figure 5.2 Changes in Patients' Outcomes after Three Months

FAMILY MEMBER OUTCOMES

(% of family members with high needs)

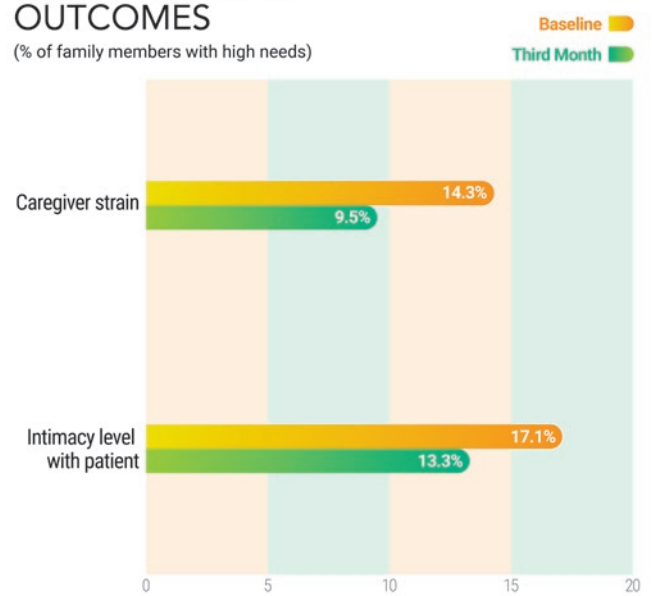


Figure 5.3 Changes in Family Members' Outcomes after Three Months

PATIENT MEDICAL SERVICE UTILIZATION

(% of patients who used the service per month)

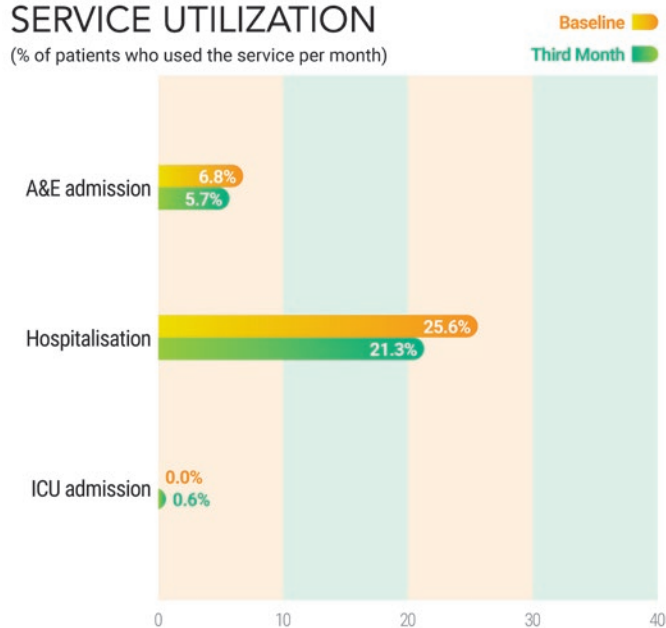


Figure 5.4 Impacts on Patients' Medical Service Utilisation after Three Months

FAMILY MEMBER MEDICAL SERVICE UTILIZATION

(% of family members who used the service per month)

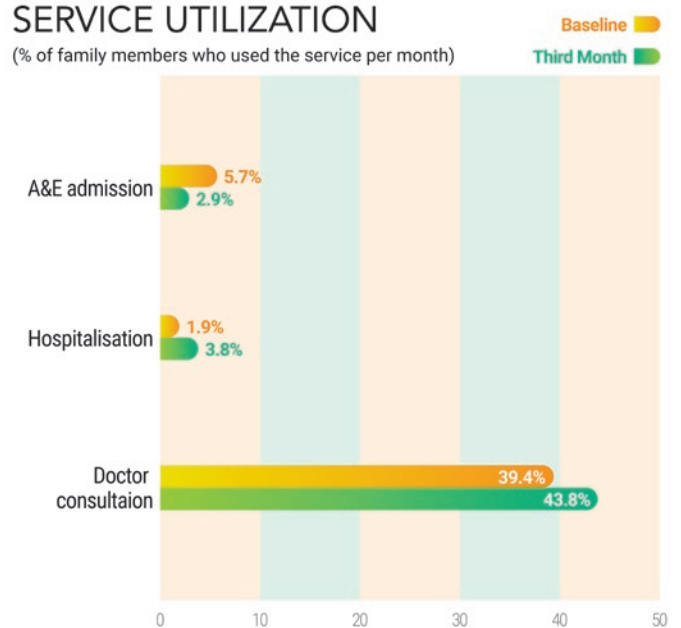


Figure 5.5 Impacts on Family Members' Medical Service Utilisation after Three Months

The satisfaction survey was completed by 73 patients and 65 family caregivers, while in-depth interviews were arranged with nine patients and nine caregivers. Overall, patients and family caregivers were very satisfied with the service, with overall mean satisfaction scores of 9.1 (SD=1.1) and 8.8 (SD=1.2), respectively (out of a possible score of 10). High ratings (means greater than 8.5) were obtained on most service components, comprising psychosocial support, communication, care planning, information and caregiving stress relief. The only element that did not rate highly was satisfaction with symptom relief. These results mirror the stronger emphasis on psychosocial care of the service models. Both patients and caregivers reported highest satisfaction with the service in engendering dignity and respect for patients and caregivers.

Support relating to the six intervention foci of holistic care were reported by interviewees. The importance of information and practical support was identified in all cases, with psychosocial care being the second most frequently mentioned support. Respondents found practical support pivotal to their QoL, e.g. equipment loan, being escorted to appointments, receiving caregiving advice and assistance with navigation to community resources. These services greatly relieved their anxiety about returning home upon hospital discharge, as well as during the times when the patient's condition changed. Regarding psychosocial care, the activities that were highly appreciated by respondents included creation of life-review books, family reconciliation, wish fulfilment, surprise activities on special dates, engagement in hobbies, family outings and facilitation of saying goodbye when the final days arrived. A patient reported that he forgot his pain when engaged in leisure activities. This showed how psychosocial interventions perhaps helped him with symptom relief. For some family members, these interventions helped restore a normal family life and ameliorate patient and caregiver anxiety and loneliness through distraction and introduction of quality family times. Most interviewed bereaved family members reported no remorse, acknowledging that they had been helped in providing the best they could for the patient, in collaboration with the service team.

Notably, the people who were interviewed presented diverse experiences and needs at the patient's EoL. These were determined by the diagnosis, illness trajectory, variations in patient and caregiver's characteristics, and family resources. Interventions were essentially needs-based, and were adjusted in a timely and flexible manner in response to the changing needs of patients and caregivers, across illness trajectories. A few family members mentioned that timely support at critical times (such as hospital discharge, sudden deterioration of the patient's condition, point of death, as well as immediately after death) were most helpful to them. Regarding improvements in the services, patients usually wished for more support to alleviate the caregiver's burden, whereas caregivers mentioned nursing care support, respite services, sitting (or visiting) services and financial support.

The data collected over the last two years has provided valuable information and clear directions towards optimising effectiveness by model integration, and further improving the evaluation design. These are discussed in the next section.

LEARNINGS, REFLECTIONS AND WAY FORWARD

GENERATING EVIDENCE ON THE EFFECTIVENESS OF THE JCECC COMMUNITY-BASED EoLC MODELS WITH A COMPREHENSIVE OUTCOME EVALUATION FRAMEWORK

Our experience has shown that the evaluation framework successfully captures the intended outcomes for patients and caregivers. The framework encompasses practical, physical, psychosocial and caregiving aspects. The selected outcome indicators are responsive to the effect of interventions after three months of delivery. The satisfaction surveys identified that patients' and family caregivers' perceived outcomes were highly positive, and these mirrored the intervention foci. Moreover, data collected through in-depth interviews provided important and additional information to the quantitative outcomes. This data provided insights into effective components in the complex care models, and it shed light on the mechanisms by which these interventions worked. For example, timely and needs-based specialised EoL psychosocial care for patients and caregivers and also practical and caregiving support for caregivers were found to relieve distress of both patients and caregivers, restore normal life activities to families and ensure maintenance of dignity, which eventually contributed to patient QoL. The evaluation framework has generated preliminary evidence that supports the effectiveness of the JCECC community-based EoLC models. By synthesising the findings of the mixed-methods studies, the effective components in the different models have been identified. This had helped to build future care models that are unified in purpose and that have integrated components.

CAPTURING WHAT MATTERS TO CHINESE PATIENTS

The core outcome measure IPOS was developed for patients in Western countries. Despite the promising results in the JCECC evaluations, cultural adaptation and validation are needed to affirm the relevance of this instrument in Chinese contexts. For instance, the responses to the open-ended question in IPOS revealed prevailing concerns related to dignity and autonomy among patients did not include a scale. Cognitive interviews with patients and caregivers on the appropriateness of Chinese-translated IPOS will help ensure the measurement captures what matters most to Chinese patients at EoL. The validation study is currently underway in a collaboration between the HKU research team and researchers at King's College London.

COMPLETING THE EVALUATION FRAMEWORK WITH EVALUATIONS BEYOND OUTCOMES

Process and economic evaluations should be included in future evaluations of the JCECC Project programmes. Process evaluation of complex interventions has been increasingly emphasised in the last decade in line with guidance by the UK Medical Research Council (Moore et al., 2015). Process evaluations ask questions such as 'Was the designed intervention delivered as planned?', 'What is the mechanism leading to changes?' and 'Will an intervention work the same in other contexts?'

Answers to such questions are crucial to optimise the intervention, and then replicate and generalise it (Medical Research Council, 2006). To answer these questions, the first step would be to assess the implementation objectively. Service records in Study 1 can be analysed in relation to outcomes and impacts. Moreover, purposive sampling according to patients' and caregivers' characteristics can be used in the in-depth interviews in Study 4 to explore how contextual factors might influence service delivery and effectiveness. Economic evaluations of the service models are essential to inform policymakers in resource allocation. A commonly used cost-utility analysis is the notion of the Quality-Adjusted Life Year (QALY), which takes both the length and quality of life into consideration, and reports the cost per unit outcome gained. On the other hand, calculating Social Return on Investment (SRoI) is a methodology for cost-benefit analysis, which has been applied to evaluate the impacts of a preventive care programme "Ageing-in-Place", a scheme implemented by the Hong Kong Housing Society (Hong Kong Housing Society, 2016). The principles, strengths and limitations of various economic evaluation methods have been discussed elsewhere (Dixon, 2018; Hodgson, 2012; Rudmik & Drummond, 2013). Appropriate economic evaluation will be incorporated into the current JCECC evaluation framework after considering the feasibility of collecting the requisite data, and the compatibility of economic evaluation methodologies with the existing evaluation study designs.

SUMMARY

Our experience has shown that a common evaluation framework underpinned by a mixed-methods research design is feasible, able to capture multidimensional outcomes of complex interventions in the four models being tested and can identify effective important intervention components for a future integrated model. The preliminary evaluation findings support the effectiveness of the four care models in improving QoL of patients and family caregivers. To further advance the current evaluation framework, process and economic evaluations should be included. Apart from evaluation, the clinical meaningfulness of outcome indicators, and their ability to inform clinical practice are as important as the evaluation design. We have set pilot threshold levels in the outcome indicators to differentiate high and low needs. These threshold levels can be applied to a risk-stratifying assessment tool to facilitate screening and to inform interventions. It is vital to articulate screening, intervention components and outcomes in any future integrated model in order to promote evidence-based practice that delivers targeted and informed interventions. It is anticipated that by sharing experiences in the development, pilot-testing and subsequent refinement of the evaluation framework, the findings will translate to learnings that will benefit similar future initiatives.

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CHAPTER 6

HAVEN OF HOPE CHRISTIAN SERVICE: “HOSPICE AT HOME” PROGRAMME

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The Jockey Club End-of-Life Community Care (JCECC) Project has been a systematic attempt to pilot and evaluate different forms of community-based palliative care (PC). It has partnered with the Haven of Hope Christian Service (HOHCS) to develop the JCECC “Hospice at Home” Programme. The goal of this programme is to develop and pilot a model to provide high-quality, holistic home care for people with life-limiting illness in Hong Kong.

It places a special emphasis on Advance Care Planning (ACP) and provision of spiritual care through an interdisciplinary care team, in addition to medical and nursing care at home. This chapter describes the features of the “Hospice at Home” services, and the use of interdisciplinary teams in addressing different needs of people at end of life (EoL). It also provides case studies on how people have benefitted from the programme

BACKGROUND

THE NEED FOR HOLISTIC HOME CARE SUPPORT TO PREVENT “REVOLVING DOOR SYNDROME”

Studies have shown that most patients at EoL (including physically frail patients) reside at home, and would prefer to stay at home for as long as possible if medical and nursing support were available (Woo, Kwok & Tse, 2018). Yet, these patients are routinely sent to public hospital Accident & Emergency (A&E) Departments when physical symptoms cannot be effectively managed. They are also highly likely to be discharged quickly due to the shortage of hospital beds. Given the limited availability of palliative home care provided by public hospitals and the shortage of private palliative home care in Hong Kong, many terminal patients in the community are deprived of essential support and thus often experience repeated A&E visits, resulting in the “revolving door syndrome”. The huge need for quality and holistic (integrated body, mind and spirit) end-of-life care (EoLC) for patients who wish to stay at home, as well as the need for support for their families, is beyond doubt (Leung & Chan, 2015; Woo et al., 2018).

THE NEED FOR ACP TO RESPECT PATIENTS’ WISHES

The objective of ACP is to prepare patients (and patient surrogates) to work with clinicians in making the best possible in-the-moment medical decisions when the patient is at the EoL (Sudore et al., 2017). There is considerable research that has shown that ACP can benefit patients and families on many different levels (see **Table 6.1**).

Table 6.1 *Benefits of ACP on Different Levels*

CATEGORY	BENEFITS
Quality of care	<ul style="list-style-type: none">» ACP is associated with improved quality of care at the EoL, including less in-hospital death and increased use of hospice (Brinkman-Stoppelenburg, Rietjens & van der Heide, 2014)» ACP improves patient and family satisfaction towards care (Detering, Hancock, Reade & Silvester, 2010)
Respect for patient’s EoL wishes and consensus on care goals	<ul style="list-style-type: none">» The patient’s EoL wishes are more likely to be known and followed (Detering et al., 2010)» ACP interventions increase the completion of Advance Directives (AD) (Houben, Spruit, Groenen, Wouters & Janssen, 2014)» ACP helps maintain concordance between patient’s preferences for care and delivered care (Houben et al., 2014)
Spiritual needs	<ul style="list-style-type: none">» Enables deeper discussions and consideration of spiritual or existential issues, allows reflection on meaning and priorities, and encourages resilience and realistic hope (Watson, 2010)
Psychosocial needs of family members	<ul style="list-style-type: none">» Family members had significantly less stress, anxiety and depression (Detering et al., 2010)

Despite the numerous benefits of ACP, the rates of completion of ACPs and ADs remain low in Hong Kong (Au et al., 2017; Chu, 2012). The relational aspect of ACP can be particularly challenging to the Hong Kong Chinese population. In Hong Kong, it has been observed that a shared decision-making model is preferred by Chinese PC patients (Chan, Tse & Wong, 2015). Lam & Lam (2013)'s research showed that a significant proportion of people with cancer wanted to involve their family in decision-making regarding their current (36%) or future (47%) healthcare. Family members thus have the potential to become either a motivator or barrier to ACP. Some patients may worry that their family members might be placed under undue stress and sadness if they are involved in the EoLC decision-making process. Indeed, disagreement is often observed among family members during the ACP process. The concept of respecting patient autonomy, which underlies both the philosophy of both ACP and AD, is not indigenous to the Hong Kong Chinese population. Traditional Chinese family values largely centre on the importance of filial piety and collective decision-making, which can hinder truth-telling, open and honest discussion of the patient's poor prognosis, and the patient's own wishes in the ACP process (Ho et al., 2015).

In addition to these relational barriers, completing an ACP is not routine practice in the Hong Kong healthcare system. As a result, many dying patients are unable to communicate their treatment preferences because they are incapacitated when the decision is required. Without a proper system for encouraging the timely completion of an ACP, patients who become incapacitated in the later course of the illness trajectory often have to undergo operations and medical procedures that they never wanted. Examples of such violations of a patient's care wishes include terminal cancer patients receiving cardiopulmonary resuscitation (CPR) against their will when they were dying, advanced dementia patients being fed through tubes and people with devastating strokes being kept alive with repeated courses of "big gun" antibiotics. Such interventions could be avoided if patients had been empowered to complete an ACP when they were still able to communicate their wishes.

THE NEED FOR SPIRITUAL CARE AT EoL

Spirituality can be defined as “the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred” (Puchalski et al., 2009, p. 887). Spiritual needs have been recognised as part of holistic PC needs (World Health Organization, 2018). In order to understand the spiritual needs of Hong Kong Chinese patients facing EoL, an assessment of the holistic well-being and spiritual needs in Chinese patients receiving the JCECC “Hospice at Home” services was conducted using a cross-sectional study design. A total of 120 patients with life-limiting illnesses were admitted to the programme between January 2016 and December 2017. They were evaluated with the Holistic Well-Being Scale (HWBS) (Chan, Chan et al., 2014). Thirty-five (29.2%) patients expressed symptoms of emotional vulnerability and 28 (23.3%) expressed loss of meaning and hope. Spiritual distress in patients with advanced illness is a distinct entity, and it was not found to be correlated with age, sex, the number of physical symptoms, functional status or social/financial status. This suggests that a considerable percentage of patients at EoL may be distressed by spiritual crisis, and routine provision of spiritual care is essential for them (Wong & Chen, 2018).

Besides helping patients to feel more at peace and lower their existential distress, good spiritual care can also positively influence PC in other domains. The UK’s National End of Life Programme proposed that conversations about spiritual needs can be a way to lead to discussions about ACP (National Health Service, 2010). This can be greatly beneficial to patients and families. By respecting the Chinese culture, integration of Eastern and Western concepts of spirituality will be advantageous to Hong Kong people at EoL, and their families (Chan, Chan, Tin, Chow & Chan, 2006; Chan, Wong & Chan, 2014). Spiritual care therefore has the potential to help with the ACP process in some Hong Kong Chinese patients, who may otherwise find it difficult to talk about their wishes in a culture that is not used to speaking about individual autonomy.

OVERVIEW OF THE JCECC “HOSPICE AT HOME” PROGRAMME

Background of Haven of Hope Christian Service. To pursue its mission of Christian ministry through holistic care, the HOHCS commissioned the services of the Sister Annie Skau Holistic Care Centre (SASHCC) in Tseung Kwan O in 2006. This Centre was purposely designed for holistic EoLC of cancer and non-cancer patients, and to date it has served over 2,000 patients. Of its 100 inpatient beds, 15–20 beds are designated as Relief and Charity Service (RCS) beds to serve the poor and sick. The Home Care Nursing Service is an extension of the inpatient and day care service, and it commenced operation on 1 April 2008. Apart from providing nursing care during home visits, the Home Care Nursing Service also provides intake assessment, telephone follow-up and counselling to patients and their family members.

Programme objectives. The HOHCS launched the JCECC “Hospice at Home” programme in January 2016 as a way of developing a comprehensive community-based palliative support team to assist people with life-limiting illnesses to remain in their community, if so desired. The programme adopted a holistic approach for total person care through an interdisciplinary team offering medical, nursing and rehabilitation, as well as personal and psychosocial–spiritual care. The programme aims to:

1. Provide intensive and holistic EoLC support to patients with terminal cancer or other chronic irreversible illnesses who, with supporting family members or caregivers, opt to spend more time at home rather than be admitted to hospital;
2. Reduce hospital stay while enhancing the quality of life (QoL) of both patients and their families through the provision of quality EoL home care;
3. Respect patients’ autonomy through facilitating ACP; and
4. Promote spiritual well-being through holistic interventions.

Target groups and sources of referrals. The target clients of the programme are people with life-limiting illnesses that are advanced, progressive and incurable, which will lead to general frailty and comorbid conditions. Their health conditions are expected to deteriorate in the short term, and death is anticipated within 6–12 months. Between January 2016 and August 2018, a total of 178 patients and 528 family members were served by the programme. The key collaborating units that referred patients to the programme were the Clinical Oncology Departments in Queen Elizabeth Hospital and Pamela Youde Nethersole Eastern Hospital. The majority of referrals (88%) were patients suffering from cancer. The remainder of the life-limiting diseases included neurodegenerative, end-stage renal failure, chronic heart failure and chronic obstructive pulmonary disease. All patients were elderly (45%, 86% and 99% were above 80, 70 and 60 years of age, respectively).

CORE SERVICE COMPONENTS

The “Hospice at Home” programme takes the needs and wishes of patients into consideration to enable them to go home, stay home and avoid the “revolving door syndrome”. To achieve this, the following service components are established as part of the programme.

A team of PC specialists. The PC physicians in the team provide strong medical support to patients, and the PC nurse specialists empower family members to assist with nursing patients at their EoL. This is the only team in the JCECC Project with PC physicians who can collaborate with the Clinical Oncology Units in public hospitals as a clinical partner.

Respite support. The SASHCC has reserved two inpatient beds for respite services provided in the programme, as well as Specialist Out-Patient Clinic (SOPC) sessions for patients in the programme. Respite support can reduce unnecessary hospital admissions because timely

symptom management can be handled in the SASHCC. Moreover, respite care for patients can help family members who need to travel or attend to their own health issues. Within nine months of offering the respite service, 17 patients received respite services, totalling 130 bed days.

Telemedicine. Relevant technological support enables doctors to provide timely medical consultations for patients at home to minimise AED attendance, clinic consultations and unnecessary hospital admissions.

Transportation. Many patients have difficulties travelling to and from hospital, especially if they are frail, use a wheelchair or require oxygen equipment. HOHCS offers transportation and escort services to these patients to enable them to travel to and from the hospital or clinic, despite suffering from deteriorating medical conditions.

Strong psychosocial–spiritual care, rehabilitation support and practical assistance. The chaplains, together with the social workers and trained volunteers, form a strong team offering psychosocial, spiritual and bereavement support to patients and their families. Physiotherapists and trained health workers offer rehabilitation training and non-pharmacological interventions to patients. In addition to rehabilitation training, health workers also provide practical assistance, such as bathing, to frail patients at home. Without this assistance, patients may have to stay in hospital or be admitted to institutions.

SERVICE DELIVERY FEATURES

The “Hospice at Home” programme has three core service delivery features embedded in it: the adoption of an interdisciplinary team approach, an emphasis on ACP, and specialised spiritual care at EoL. These three features are inter-related and are supported by the service components mentioned earlier.

Adoption of interdisciplinary team approach to care. The interdisciplinary “Hospice at Home” service team involves a PC physician and nurses, a social worker, a chaplain, a physiotherapist, health workers and volunteers. The team operated in a collaborative approach according to the Palliative Care Competence Framework developed by the Palliative Care Competence Framework Steering Group of the Health Service Executive (2014). This framework emphasises the respective roles and responsibilities of each profession in an interdisciplinary team. It also recognises the merit of interprofessional collaborations in enabling truly holistic assessment and interventions in addressing the multidimensional needs of patients facing life-limiting diseases, as well as the needs of their family members (Palliative Care Competence Framework Steering Group, 2014). The respective roles of the team members in the “Hospice at Home” service team are summarised in **Table 6.2**.

Table 6.2 Roles of Team Members in the Interdisciplinary “Hospice at Home” Care Team

TEAM MEMBERS	ROLES AND RESPONSIBILITIES
Palliative care nurse	<ul style="list-style-type: none"> » Designated nurse for each family to support the patient throughout the last journey through home visits and telephone consultations » Provide comprehensive assessment, symptom management and referral to other supportive services, and to develop care plans » Perform nursing procedures in the home, e.g. care of malignant wound, tubes and drains » Skills transfer through educating healthcare professionals and family/caregivers on PC nursing skills
Social worker	<ul style="list-style-type: none"> » Assist patients and family in making EoLC decisions based on their preferences » Support patients and families who experience fear, anger, anxiety and sadness » Provide bereavement support and family counselling to resolve conflicts and differences in values » Train volunteers to support people with life-limiting illness » Manage liaison and referral to other community resources and services
Chaplain	<ul style="list-style-type: none"> » Support for spiritual and existential concerns raised by patients and families » Explore the ultimate meaning and value of life with the patients
Physiotherapist	<ul style="list-style-type: none"> » Maintain physical function, independence and physical comfort of patients » Prescribe and provide equipment to improve mobility, e.g. wheelchairs, frames and walking sticks » Teach caregivers how to assist patients with mobility issues » Assist with the management of physical symptoms, e.g. pain relief techniques, breathlessness with breath control techniques, oedema management and fatigue management, and include bandaging, advice, exercises and massage
Health worker	<ul style="list-style-type: none"> » Offer practical assistance in the home » Assist in the patient’s transportation to and from appointments
Volunteer	<ul style="list-style-type: none"> » Offer care and support to the patients and caregivers based on their individual needs, which may include emotional support and companionship, social outings and activities, practical assistance in the home, transport to and from appointments, and respite visits to allow caregivers to take a break
Palliative care physician	<ul style="list-style-type: none"> » Provide specialist medical PC, and work in collaboration with other members of the PC team and referring partners » Mode of service: doctor home visit, consultation by telemedicine, respite care for patient in hospice setting » Participate in professional education and knowledge exchange

It is not simple for many people with life-limiting illnesses to attain a good QoL while living in the community because they may experience a variety of needs that can vary in complexity and severity during the illness trajectory. In terms of medical care needs, many people with life-limiting illnesses have to cope with multiple physical symptoms whose management routinely depends on care provided by different healthcare specialists and experts in the hospital system. To enable patients to remain at home without experiencing the “revolving door syndrome”, the PC specialists in the “Hospice at Home” service team provide intensive support for symptom management at home. During the service period of the programme (the first 32 months), the doctors in the team provided 488 visits and 233 telemedicine consultations. Nurses and other healthcare workers are also key members of the outreach team, providing 3,935 visits to patients’ homes in the service period (approximately 22 visits per patient). Social workers and volunteers made 796 visits, and the team provided 1,218 counselling sessions to patients and families (approximately seven counselling session per family). A total of 488 palliative rehabilitation visits were made by physiotherapists and trained healthcare workers. Such strong home care support to assist in managing physical symptoms contributed to many patient’s ability to stay in the community in their EoL.

Emphasis on ACP as part of psychosocial–spiritual care. ACP can be documented in the form of an ACP record or AD. Patient’s wishes regarding EoLC decisions should be respected, and family members should also be involved in the process of discussion in order to reduce the burden on family caregivers of having to make difficult decisions at a time of crisis.

ACP is an integral part in the “Hospice at Home” service and consists of five steps (see **Figure 6.1**).

Step 1 involves introducing the topic of EoLC decision-making. This usually starts with exploring the patient’s understanding about the disease and its prognosis, and their concerns regarding the future care needs and health deterioration. At this stage, the interdisciplinary team has to identify and remove barriers that may hinder the patient’s participation in ACP, such as distressing symptoms, fear, misunderstanding, lack of knowledge on EoL-related decisions and unfavourable prior related experiences.

Step 2 identifies the key family member who can participate in the ACP discussion. This family member should understand and show respect towards the patient’s wishes, be able to make decisions under stress and be accessible to the healthcare team. It is common for this family member to serve as a contact person for liaising with other family members and arriving collectively at a decision, instead of acting as the only decision-maker on behalf of the patient. Thus, it is important for this contact person to be able to communicate and engage with other key family members.

Step 3 explores the patient’s values and beliefs regarding QoL, preferences and goals of care. The care team often explores these areas by asking “what would be important to you?” This question usually leads to a discussion of accomplishments in life, last wishes, funeral arrangements and goals of care in EoL. This also has implications for psychosocial–spiritual interventions for the care team.

In Step 4, the care team clarifies care and treatment priorities with the patient. Information on various life-sustaining treatments (LSTs), the concept of PC and natural death are sensitively provided to support patients to make informed decisions. Patient's preferences are reviewed in time of changes in health status, advancing illness and changes of care setting.

Finally, in Step 5, after the patient has indicated his/her priorities of care and treatments, the discussion is documented in the patient's medical record. An ACP record form has been developed by the "Hospice at Home" programme as a means of communicating with the referring medical team. Patients are also encouraged to document their wishes and preferences using the ACP record form or AD, and patients are reminded that ACP decisions can be changed at any time. It should be noted that completion of the ACP record form is voluntary, and consensus from family members is sought before the patient signs the form. Patients who have completed the ACP record form are encouraged to communicate their preferences with their doctor in hospital with the help of the ACP record form.



Figure 6.1 Five-Step Approach to ACP in the "Hospice at Home" Programme

Strengthened spiritual care at the EoL. Although the HOHCS has a mission of providing Christian ministry, its spiritual care is tailored for people from diverse spiritual backgrounds. The “Hospice at Home” programme has served many non-religious patients (about 40% up to December 2017), as well as patients who are Chinese Folk believers, Christians, Buddhists, Catholics and Muslims, among others.

Many spiritual care methods are applicable to patients from a wide range of belief systems. Life review is one of the most popular ways to promote spiritual well-being of patients at EoL (Wang et al., 2017). Death education programmes have also been found to be useful through a pilot project of open discussions about death and reflections on the worries and issues related to death among persons with chronic illness (Leung et al., 2015). In addition, the “Hospice at Home” programme adopted an integrative body–mind–spirit intervention based on a holistic bio–psychosocial–spiritual framework in its service to patients from all religious backgrounds (Chan & Dickens, 2015).

In the interdisciplinary team in the “Hospice at Home” programme, the resident chaplain or spiritual worker is also responsible for spiritual care. Other healthcare workers on the team (including doctors, nurses and social workers) play essential roles in connecting patients with the chaplain or spiritual workers, and to help obtain a well-rounded spiritual history in their interactions with the patient. During the process of taking a spiritual history, the physician or healthcare workers may identify beliefs, values, spiritual issues and stresses of patients and family members, and may also identify and assess their potential spiritual resources and strengths. Such information is routinely shared with other members of the interdisciplinary team during case conferences to help the team formulate a holistic treatment plan for patients. During the process of spiritual care/intervention, different modalities of therapy can be used to relieve distress and ensure holistic well-being, as applicable to the individual needs of the patient and caregiver (Puchalski et al., 2009).

CASE STUDIES

The following case stories illustrate how the “Hospice at Home” programme has enabled people with life-limiting illness to spend their last days at home with quality.

CASE STUDY 1: HOLISTIC CARE PROVIDED BY THE INTERDISCIPLINARY TEAM

Amy was a retired surgical nurse with previous experience of taking care of advanced cancer patients. She was diagnosed with terminal inoperable liver cancer, with life expectancy of weeks. With her professional training and experience, she had solid knowledge and full understanding of her own prognosis. She was admitted to the “Hospice at Home” programme where she received holistic support provided by the interdisciplinary team throughout the last phase of her life’s journey:

Symptom management and respite care. Amy was suffering from the symptoms of liver failure including severe bilateral leg oedema, constipation and fatigue. The physiotherapist and the home care nurses offered oedema management to relieve her symptoms. However, as the disease progressed, she was admitted to an inpatient bed in the Centre for respite care to administer infusion of albumin to lessen the leg oedema, and to provide dietary advice and medications to ease the constipation. As the liver was failing, she had increasing difficulty in travelling to and from the clinic. Visits at her home and the use of telemedicine helped to reduce the need for her to travel for consultation.

ACP and family engagement. The team social worker discussed the goals of care with Amy and her family, and their preference was to promote comfort and to avoid CPR. Amy enjoyed good family relationships and thus her priority was to spend as much time with her family as possible and to stay at home until the very last moment. However, although she was prepared for a sudden death, she did not opt for home death as she did not want to scare her grandson, who was a toddler. The ACP record and an AD documenting her medical decision regarding EoLC were signed. Amy’s preference was honoured. She was admitted to inpatient PC when her condition could no longer be managed at home.

Psycho-spiritual support. Counselling and psycho-spiritual support were offered through engaging Amy in activities such as life review, planting and drawing.

Amy was very grateful to the “Hospice at Home” programme, as seen from her participation in the programme’s video sharing her personal story in choosing to stay at home for as long as possible (<http://foss.hku.hk/jcecc/en/madam-chans-story/>). The filming took place at her home and she passed away four days after the video interview.

Amy’s case shows that physical needs are not the only areas being focused on in the “Hospice at Home” programme. ACP and psycho-spiritual support were also offered to Amy and her family to provide holistic EoLC.

CASE STUDY 2: RESPECTING PATIENT'S EoLC CHOICES THROUGH FAMILY ENGAGEMENT IN ACP, AND BY CONFLICT RESOLUTION

Angela was a 60-year-old single lady, born and raised in Hong Kong. She was diagnosed with breast carcinoma in spring 2016 while she was working as a missionary in the rural area of a developing country. Angela was highly educated, rational and decisive. When she learnt that her cancer was metastatic, she opted for natural therapy instead of formal oncology treatments with chemotherapy and radiotherapy. Later, when told that her cancer had become incurable, she planned to optimise QoL and minimise physical suffering. Angela was well aware of her diagnosis and prognosis, and she could face death positively as her faith gave her strength. Angela's case shed light on how faith can influence ACP preferences and how the "Hospice at Home" programme team helped a family to resolve conflict over the patient's treatment decisions.

Despite Angela's preference for a palliative approach to her illness, her siblings insisted that she seek active treatment. Angela was the fourth child and she had six brothers and sisters. It was difficult to fight against the traditional Chinese culture of making decisions as a family, not as individuals. As a result, Angela returned to Hong Kong to live with her sister Betty and finally began palliative chemotherapy as per the request of her siblings. Angela privately told the "Hospice at Home" care team that she agreed to palliative chemotherapy against her wishes only because that was what her siblings wanted for her. Angela was worried that her siblings could not accept the prognosis of her terminal illness, and that Betty was suffering from caregiver stress.

Angela's symptoms improved significantly after several weeks of palliative chemotherapy and hormonal therapy. Her siblings, now convinced that they made the right decision about Angela's treatment choice, pushed Angela to seek active treatment again. A month later, many new symptoms emerged. This time, Angela insisted that she had fulfilled the wish of her siblings for a trial of palliative chemotherapy and refused to receive another line of chemotherapy. She said she would not want "to prolong her life by spending money", and would rather give the money to charity or save it for future use in quality PC.

The team understood that Angela's and her sibling's views on treatment goals were in conflict. In subsequent home visits, the interdisciplinary PC team focused on facilitating communications between Angela, Betty and the other siblings. The team helped them to vocalise their respective reasons for prioritising different treatment options. The team also worked on helping family members understand the importance of respecting an EoL patient's autonomy and spiritual needs. Eventually, the family members decided to respect Angela's decision to prioritise enjoying quality time with her loved ones instead of prolonging life. Feeling that her wishes had been honoured by her siblings, Angela achieved a sense of spiritual peace and expressed her wish to pass away comfortably and with dignity. She opted not to attempt CPR if she had a cardiac arrest and planned for admission to a PC centre in her last days of life.

In the subsequent home visits, Angela focused more on enjoying her favourite foods and meeting with loved ones. She scheduled weekly gatherings with her family and friends to relive happy memories. She also prayed every day for the poor and needy people in developing countries, which gave her meaning and peace. She passed away peacefully a few months later with no more chemotherapy or invasive interventions.

OUTCOMES

The outcomes of the “Hospice at Home” programme were evaluated by the common evaluation framework adopted across all service models under the JCECC Project and also by the organisation-specific service records. Patients’ and family caregivers’ outcomes, the utilisation of medical services predominantly in hospital admissions, and the uptake of ACP and use of LST before death are presented in this section.

PATIENTS’ PSYCHOSOCIAL–SPIRITUAL OUTCOMES AND CAREGIVERS’ OUTCOMES

Between 1 January 2016 and 31 March 2018, 32 patients were admitted to the programme and completed all three periods of assessment (at service intake, one month after service commencement and at three months after service commencement). Of these patients, 28 (87.5%) were cancer patients, while the rest suffered with dementia, heart failure, Parkinson’s disease or renal disease. The mean age of these patients was 78.9 (SD = 9.59) years. During the same time period, 19 family caregivers, mostly adult children (73.7%) and spouses (10.5%) of patients, completed the first two assessments (at service intake and at three months after service commencement). Twenty-four bereaved family caregivers completed bereavement assessment two months after the patient’s death.

Patients’ outcomes were measured with the Integrated Palliative Care Outcomes Scale (IPOS), and family caregivers’ outcomes were measured as the perceived level of intimacy with the patient. These scores were divided into low and high-need groups, using a critical threshold set at the mean baseline score plus one standard deviation, for each outcome indicator (see Chapter 5). The percentage of high-needs patients and caregivers in each outcome indicator was compared between baseline (service intake) and three months after service commencement. Paired t-tests were applied to examine if changes as a result of the intervention were significant.

The preliminary findings showed that at the third month of service, the proportions of high-need patients had reduced when compared to the time of service intake (high needs included practical problems, anxiety, not being at peace, perceived family anxiety and barriers in sharing feelings with family members). Paired t-tests showed that improvements in practical problems, perceived family anxiety, and sharing feelings with family members were significant ($p < 0.05$) (see **Figure 6.2**). At the same time, caregivers reported significantly higher sense of intimacy after three months of service ($p < 0.05$). The majority (83.3%) of bereaved caregivers reported a low risk of complicated grief. These findings showed that the “Hospice at Home” programme was particularly effective in facilitating family relationships, communicating and reducing family’s anxiety. This could be attributed to the active engagement of family members in the ACP process. The intensive home care support, transportation and respite services provided in the programme was also found to be highly effective in helping patients cope with practical problems when staying at home. Overall, patients’ psycho–spiritual well-being showed an improving trend, while physical symptoms remained low.

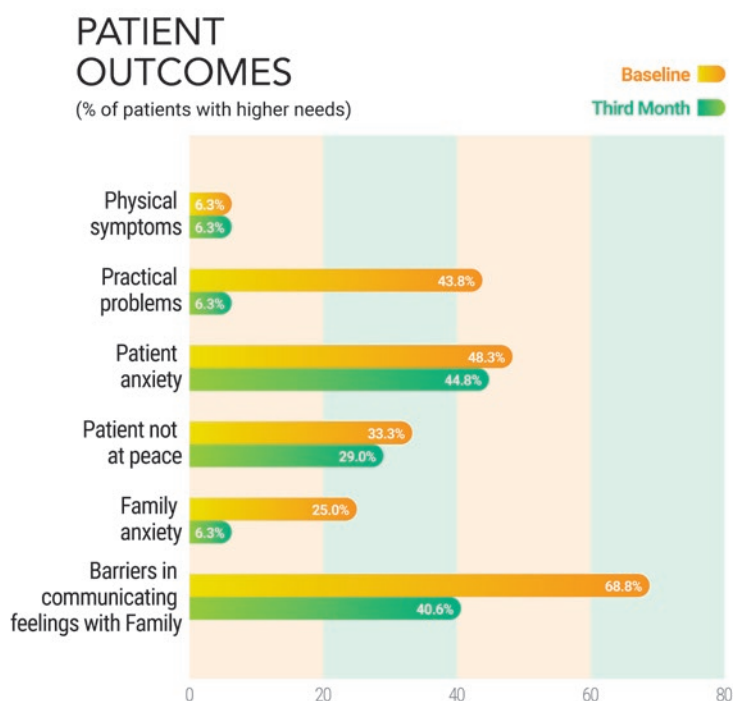


Figure 6.2 Outcomes for Patients

UPTAKE OF ACP AND LST AT EoL

Among the 130 patients who passed away between January 2016 and August 2018, 107 (82.3%) signed an ACP record or AD refusing LSTs. Among all deceased patients, the majority (N=124, 95.4%) died without receiving CPR. Significantly fewer patients received CPR in the group that had undergone an ACP compared to the non-ACP group (1% versus 17.4%).

LENGTH OF STAY IN THE LAST HOSPITAL ADMISSION

The mean length of stay (LOS) in the last hospital admission before death among “Hospice at Home” programme participants was compared to data of a local study on cancer patients receiving PC in a public hospital (Lam, 2018). For patients in the “Hospice at Home” programme, the mean LOS in the last hospital admission was seven days, which is a significant reduction when compared to the findings of 18.4 days from Lam’s study (62% deduction, $p < 0.05$). This finding suggested that the “Hospice at Home” programme could successfully enable patients with advanced cancer to stay in the community for longer (Chen, 2018).

LESSONS LEARNT AND CONCLUSIONS

The “Hospice at Home” programme service model has been found to be successful in achieving its objectives in providing holistic EoLC in the community. Its unique service features were key to the programme’s success, comprising a well-rounded interdisciplinary team providing intensive services in the community, dedication to providing high-quality spiritual care and including ACP as a routine service element for people with life-limiting illness. Evaluation of patient outcomes has shown that by facilitating ACP discussions between patients and family members, the programme’s service users have better family communications and fewer days in hospital during their final admission, which means that patients can spend more time in the community with their loved ones.

Most importantly, promoting the completion of ACP in the programme has allowed patients’ wishes and EoLC preferences to be honoured by their families and healthcare service providers. The two case stories in this chapter demonstrated the potential for such a service model to provide holistic EoLC by an interdisciplinary team working closely in the community. This was achieved by the programme’s interdisciplinary team of professionals possessing complementary skills that allowed holistic care to be provided and the patient’s needs to be met in different domains (including spiritual needs). The programme can serve as a blueprint for PC service development in Hong Kong to expand quality spiritual care at EoL, to promote the completion of ACP and to help patients spend more time in the community instead of being trapped in the “revolving door syndrome”.

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CHAPTER 7

SUPPORTING PATIENTS AT THEIR END-STAGE OF LIFE: A VOLUNTEER-PARTNERED COMMUNITY CAPACITY BUILDING APPROACH

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Service fragmentation and less-than-adequate available community supports for patients at the end-stage of their lives pose significant challenges to people who wish to receive end-of-life care (EoLC) at home. The S.K.H. Holy Carpenter Church District Elderly Community Center (HCCDECC) has a long-term mission to support community-dwelling patients at EoL. It has established a volunteer-partnered community capacity building EoLC model to provide person-centred and holistic care to home-dwelling patients who are facing life-limiting diseases, and their family members. The model features strategic partnerships between the HCCDECC service team and the Medical Palliative Medicine (MPM) Unit of

Tuen Mun Hospital (TMH). Community care services are coordinated by case managers, and community support networks are built through resourcing and mobilising volunteers and community partners. A 3Ls (Loss–Love–Legacy) volunteer-partnered psychosocial–spiritual support” framework has been consolidated during the course of the project, with the aim of promoting quality of life (QoL) with dignity for patients at EoL and their family members. This chapter introduces the rationale, objectives, strategies and components of this service model, followed by preliminary findings on its effectiveness.

BACKGROUND

S.K.H. HOLY CARPENTER CHURCH

The motto of S.K.H. Holy Carpenter Church is “To serve, not to be served”. To enact its motto, the S.K.H. Holy Carpenter Church has provided different kinds of social service in Hong Kong since 1954. The S.K.H. Holy Carpenter Church social service initiative currently has two units: the S.K.H. Holy Carpenter Church Community Centre and the S.K.H. Holy Carpenter Church District Elderly Community Centre (HCCDECC), which provide social services in the Hunghom, To Kwa Wan, Whampoa and Homantin areas. One of the core services of HCCDECC is bereavement care and death education through the Hospice and Bereavement Service Division (HBSD). This was established in 2004 and aims to serve EoL patients, their family members and bereaved persons of all ages, ethnicities, religious backgrounds and districts in Hong Kong. The HBSD is known for its work in developing death literacy among the general public through death education using various arts media (e.g. DEAtHFEST) and the PARACLETE – Care and Comfort Angels Project. This project offers funeral support and bereavement counselling by social workers and a trained volunteer team. Between 2014 and 2016, the S.K.H. Holy Carpenter Church expanded its service scope to EoL patients and family members through a pilot project on home-based hospice care, funded by the Li Ka Shing Foundation. Drawing from experiences and learnings in their pilot services, and building on their strengths in community engagement and networks with church groups, the HCCDECC HBSD expanded its efforts to promote QoL for EoL patients and their family members by introducing a new community-based EoLC support service to the New Territories West district as part of the JCECC Project.

CHALLENGES FACED BY HOME-DWELLING PATIENTS WITH LIFE-LIMITING DISEASES

Previous chapters have discussed the various challenges faced by community-dwelling people with life-limiting diseases and their family members. The lack of specialised community support services for these people, coupled with fragmented local medical and social supports, shrinking family size and increasing numbers of people living alone (or only with a spouse) make it difficult for many older people to remain living at home safely (and with high QoL) for as long as they wish whilst experiencing life-threatening diseases. Moreover, supporting elderly people to be cared for at home can place a heavy burden on family members, many of whom provide daily support. International studies report that multidisciplinary teams are best for supporting patients and families in achieving their choices regarding places to receive EoLC and to die (Leclerc et al., 2014). It has also been reported that a desirable EoL model that gives patients and their families QoL should not only rely on health professionals, but should also include the community as a whole (Kellehear, 2013; Stjernswärd, Foley & Ferris, 2007).

OBJECTIVES AND SIGNIFICANCE OF THE MODEL

In the JCECC Project, the HCCDECC HBSD developed the “Hospice in Family: Home Care Support Services” to serve community-dwelling EoL patients and their families in the Tuen Mun, Yuen Long and Tin Shui Wai districts. Of note, Tuen Mun and Yuen Long ranked 5th and 7th, respectively, as districts with the lowest median monthly domestic household income among 19 Hong Kong districts in 2016 (HKSAR Census and Statistics Department, 2017). Patients at their end-stage of life, who have a low family income, might face more difficulties in maintaining a good QoL while residing in the community. Despite such needs, at the time of this census there were no specialised EoL community support services within these districts. Establishing a new sub-base in the New Territories West, the HCCDECC HBSD strived to promote QoL of community-dwelling EoL patients in the district by developing a community-based EoLC support service, at the same time as raising public awareness and building up networks for this purpose.

The overarching objectives of the “Hospice in Family: Home Care Support Services” are to:

- » Support patients and their families to live in the community with dignity and respect;
- » Optimise QoL through care in physical, practical, psychological, medical, social and spiritual aspects;
- » Enhance community support for patients and families; and
- » Raise public awareness on death preparation and EoLC.

The concepts and theories underpinning the service model are discussed in the next section.

THE UNDERPINNING PRINCIPLES OF THE SERVICE MODEL

The volunteer-partnered community capacity building EoLC model was developed to guide the practice in the “Hospice in Family: Home Care Support Services”. This model is underpinned by three principles, comprising community capacity building, coordinated and holistic care, and dignity preservation.

Community capacity building is a process that involves different levels of action, all of which are oriented to health promotion. These actions encompass, but are not limited to, building partnerships, collaborations and networks in the community and garnering resources (human and social capital) (Simmons, Reynolds & Swinburn, 2011). Demands for EoLC always outstrip the supply of professional services, and building community capacity offers a potentially sustainable way of meeting growing demand. Indeed, community capacity building has been recognised as an important way of enhancing the ability of the community to respond to and cope with issues related to death and dying, rather than relying solely on services provided by professionals (Mills, Rosenberg & McInerney, 2015). Although community engagement in EoLC is underdeveloped in Hong Kong, there is a pressing need to empower the community through education and volunteer participation and to establish partnerships between professional and non-professional groups in the provision of care.

Coordinated and holistic EoLC is important for ensuring patients receive consistent care across settings and timelines (National Institute for Health and Care Excellence [NICE], 2011). It requires seamless care provided by different professional groups working in interdisciplinary teams across settings. It also requires information sharing between service providers to ensure consistency of care and messages to patients and families (NICE, 2011). Care coordination for people at EoL takes a holistic approach, referring to coordination of the support services required to meet the multidimensional needs of individuals (Eldercare Workforce Alliance, 2016). When putting the constructs of coordinated multidisciplinary care into practice in Hong Kong, pivotal steps have been taken to develop an interface between medical and social services through strategic partnerships. This has taken a case management service coordination approach for individual patients. In the NICE guidelines for EoLC for adults (NICE, 2011), one of the quality measures of coordinated care is evidence of regular multidisciplinary case review meetings. Studies have found that these are linked to improved QoL, optimised patient function, reduced hospitalisations, improved care coordination and planning, and information sharing (Tuckett et al., 2014). The practice of interdisciplinary case conferences in palliative care (PC) is not new, as it has been practised for some time in many specialist PC settings in Hong Kong. However, cross-sectoral interdisciplinary case conferences (involving medical and community settings) are rare, despite having a high potential to strengthen care at the medical–social interface.

Preservation of dignity is central to the practice of PC and EoLC (Guo & Jacelon, 2014). According to Rodriguez-Prat, Monforte-Royo, Porta-Sales, Escribano & Balaguer (2016, p. 2), there are two broad perspectives on dignity:

- » **Intrinsic dignity**, which can be regarded as a human innate feature that is irrevocable; and
- » **Dynamic dignity**, which is “a personal quality that is related to people’s perception of themselves and of the context in which they live in”.

Based on this definition, dynamic dignity, to a certain extent, embodies a relational view of dignity, given that people’s perception of themselves can be influenced by how others see or treat them. Guo and Jacelon (2014) reviewed the meaning of dying with dignity in the literature, and concluded that dignity is a human right that encompasses the characteristics of autonomy and independence; symptom relief; being respected; being human and being self; having meaningful relationships; receiving dignified treatment and care; spiritual satisfaction; having privacy; and being in a calm environment. Some characteristics are specific to one form of dignity (e.g. intrinsic dignity [being human] and dynamic dignity [being respected, having privacy, spiritual satisfaction]). Moreover, characteristics identified with dynamic dignity are mostly relational, such as relating with oneself (e.g. being self, autonomy and independence); relating with one’s existential self (e.g. spiritual satisfaction); relating with others (e.g. meaningful relationship, being respected); and relating with care providers (e.g. symptom relief, dignified treatment received). As such, the characteristics of dignified death described by Guo and Jacelon (2014) provide insights into what relationships should be like in order to promote the dignity of patients approaching EoL.

The social dimension of dignity is described in the social dignity inventory in Chochinov’s dignity model (2002), while Ho et al. (2013) found that familial factors play an important role in patient dignity in the Chinese context. Ho et al. (2013) suggested that dignity conservation

and spiritual care should go hand-in-hand, and interventions that promote acceptance of suffering, letting go, relationship reconciliation, meaning making, and building continuing bonds are particularly important for Chinese patients. In addition to these, studies examining a patient's sense of self at EoL also suggest that there is a temporal dimension in the sense of self or personhood. Kong, Fang & Lou (2016) examined how personhood could be conserved in older people dying in residential care homes in Hong Kong. They proposed that a person's sense of self should be explored in the "here-and-now", as well as in his/her history and in his/her preferred future, in order to know the integral self of the dying person. Carlander, Ternestedt, Sahlberg-Blom, Hellstrom & Sandberg (2011) studied self-identity (the existential question of "who am I?") of EoL patients. They found that in the face of impending death, identity reconstruction variously took place in the patient's everyday life because of ongoing changes within self, as well as in relationships between patients and significant others, and with the community. These authors further emphasised that it is "important to let the past and the former identity, as well as the new, be a vital part of the present situation" (2011, p. 12). Drawing from these studies, it seems that an element of dignity-conserving work should be aimed at helping patients maintain or retain harmonious relationships with their systems, alongside interventions on symptom relief and respect of choices and autonomy. Consideration should also be given to the temporal dimension of these relationships, and their integration to achieve a sense of completion among patients.

THE IMPLEMENTATION OF THE VOLUNTEER-PARTNERED COMMUNITY CAPACITY BUILDING EoLC MODEL

Targeted service user. The service target population is elderly patients who are receiving PC services at the MPM Unit of TMH, and are in advanced stages of disease, such as chronic renal failure, heart failure and neurodegenerative diseases (motor neurone disease, multi-system atrophy, advanced Parkinsonism, etc.) or cancer. Priority is given to those who are financially disadvantaged or who lack social support. The service serves patients and their families in Yuen Long, Tuen Mun and Tin Shui Wai.

Team composition and respective roles. The model is actioned by two service teams: the MPM Unit of the TMH (called the MPM team hereafter) and the social care team of the HCCDECC (called the social care team hereafter). The MPM team involves a PC doctor, PC nurses, nurses from the palliative home care team and a medical social worker; whereas the social care team comprises two social workers, a nurse and volunteers. The MPM team is responsible for identifying suitable cases for referral, medical and nursing care, palliative home care nursing services and the formulation of Advance Care Planning (ACP) with patients. The medical social worker of the MPM team also works closely with the social care team to coordinate care. The social care team is responsible for providing and coordinating various psychosocial and community support services for patients, supporting them and their family members to prepare for death, including fulfilling last wishes, accompanying patients and family members through the last stage of their life, as well as funeral and bereavement support.

Service delivery features. Service delivery is characterised by three features: case conferences between health and social care teams; case management or case coordination; and volunteer-partnered care and support.

Monthly interdisciplinary case conferences. These are held between the MPM and social care teams to share updated information on patient progress. This facilitates collaborative and holistic assessment and care planning. The meetings also ensure consistency of the information provided by both teams to patients and family. Issues such as the patient's and family members' preferences on care, and their wishes, are also discussed in these meetings, ensuring that all agencies coordinate care in ways that are consistent with the patient's preferences. Moreover, the MPM team often provides medical and nursing advice to the social care team. Apart from case conferences, each team has one additional designated contact person for information sharing, which ensures continuity between meetings. The two teams collaboratively formulate discharge plans in an attempt to facilitate seamless care when patients are discharged to the community from the MPM Unit. However, collaboration is not only limited to these activities. The social care team also visits patients' homes for early identification of needs for intervention from the MPM team. This results in more timely support from the hospital (e.g. early bookings for consultation or visits by palliative home care nurses), and thereby facilitates better utilisation of hospital services.

Case management. This is provided by social workers and nurses in the HCCDECC social care team and focuses on care coordination for patients and their families. Case managers conduct holistic assessments for patients and family members, and they source and coordinate support services according to needs. An array of professional services is available to patients and families to optimise function and meet practical needs at home – ultimately to enhance QoL and dignity. These include physiotherapy, occupational therapy, dietetics, home-help and escort services. The team also arranges complementary therapies, such as aromatherapy and hypnotherapy, when it was assessed to be appropriate and desired by the patient and/or family members. Moreover, the team organises patient and caregiver mutual support groups and home visits between patients of the same diagnostic group and their caregivers to expand mutual support networks. In summary, case managers play a key role in care coordination, and they act as a bridge to link and mobilise support networks for patients and their families.

Volunteer-partnered care and support. This involves training volunteers to preserve dignity by focusing on the 3Ls (Loss–Love–Legacy). The social care team has trained over 30 volunteers each year to participate in this project. Volunteers receive 30 hours of training and 20 hours of internship before they are allowed to provide formal services. They are equipped with compassionate communication skills and knowledge about EoLC to help them play a companion role for patients and families. They are matched with specific patients and families, whom they follow across the course of disease till the bereavement stage. In 2017, a 3Ls framework of psychosocial–spiritual intervention gradually emerged from the empirical experience of the social care team. The 3Ls framework was also inspired by the concepts of dynamic dignity and sense of self, as discussed in the previous section. This framework guided the practices of both case managers and volunteers.

The 3Ls framework provides guidance on assessment and psychosocial–spiritual interventions with the aim of preserving the dignity and QoL of patients at EoL (see **Figure 7.1**). Central to this framework is the notion that the dignity of a patient approaching EoL is linked to his/her relationship with the divine, with self, with family and with other significant people in his/her social network. Dignity can be enhanced by harmonising and/or mending these relationships. Moreover, there is a temporal dimension on these relationships, reflecting the past, the present and the future. Within the context of impending death, the 3Ls framework proposes that the core “harmonising task” regarding past relationships is facing **loss**; for present relationships, it is the expression of **love**; and for the future, it is leaving a **legacy** to allow the formation of continuing bonds.

The temporal dimension (past, present, future) and the relationship-type dimension (self, family, social, spirituality) forms a 4x3 matrix, with each cell representing a core task in a specific time point (past, present, future). For instance, in the cell of “relationship with family in the past”, when patients have indicated unresolved relationship issues with significant family members that has hampered patients from achieving feelings of completion and satisfaction, intervention strategies should seek to support patients to resolve conflicts with family members through creating chances for reconciliation, letting go or through family counselling. It should be noted that discussions about these relationships not only applies to patients, but also to caregivers, and both patients and family members can be engaged in this process. Our empirical experience with this framework suggests that helping patients come to terms with their values and thoughts regarding past relationships, and to have the chance to share these thoughts with family members, usually promotes harmony in relationships. Moreover, these discussions can lead to identification of important psychosocial aspects relevant to individual ACP.

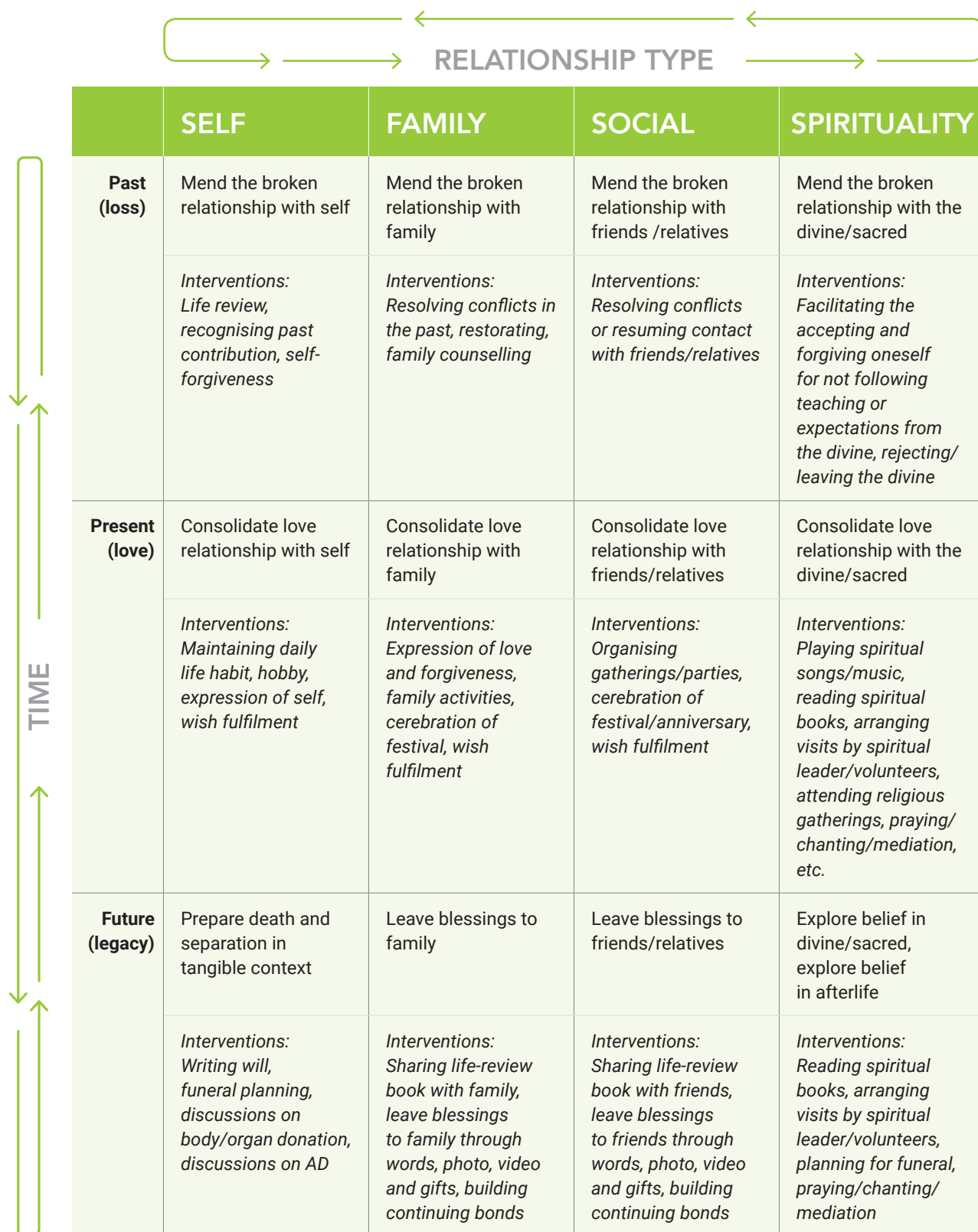


Figure 7.1 3Ls (Loss–Love–Legacy)
Volunteer–Partnered
Psychosocial–Spiritual
Intervention

Volunteers are trained to use the 3Ls framework, which equips them with values, knowledge and skills related to its application. They learn why the 3Ls are significant for service recipients, how to evaluate the needs of the service recipients using the 3Ls perspective and how to map these to their corresponding intervention choices. Case managers conduct initial patient assessments and identify aspects of the 3Ls framework that require intervention. Pre-visit briefings orient volunteers to patients' needs within the 3Ls framework so that volunteers can be coached to further explore relevant relationship aspects during their visits. The information gathered by volunteers is then shared with case managers to facilitate intervention planning. Given the level of engagement of some volunteers, this is sometimes conducted collaboratively by case managers and volunteers. For example, volunteers have actively engaged in producing life-review books, planning family gatherings and wish fulfilment activities, and sharing spiritual books and religious ornaments with patients who need the support. On the other hand, case managers might provide professional counselling when there are complicated relationship issues. To support partnerships and communication, a volunteer recording form has been developed, based on the 3Ls framework, to facilitate communication between volunteers and case managers in relation to their observations and interventions at each visit.

CARE MANAGER: VOLUNTEER-PARTNERED SERVICE DELIVERY PROCESS

The 3Ls framework features are interwoven in the assessment and service delivery process to ensure that person-centred and holistic care is offered to patients and their family members (considered as a unit) (see **Figure 7.2**). Upon receiving a referral from the MPM Unit of TMH, the social care team conducts a holistic assessment in which any practical support required by the patient and family members to maintain caregiving at home is given the highest priority. This remains a priority throughout the case manager's support service coordination.

Healthcare from the MPM team is ongoing, whereas support from the social care team is facilitated by monthly case conferences and close communication between the teams. Dignity cannot be promoted without appropriate healthcare and practical supports that work to maintain function and person–environment harmony. This is why healthcare and practical support are prerequisites in the service delivery pathway. Psychosocial and spiritual needs are the focus after any physical and practical concerns have been adequately addressed. Patients with complex needs (e.g. family conflicts, persistent intense emotional distress) and/or unstable conditions are mainly supported by case managers through counselling. However, those patients who are deemed to have lower psychosocial or emotional needs may be matched with volunteers, who will provide psychosocial care using the 3Ls framework in collaboration with case managers.

Periodic assessments of patients are conducted by case managers, who report the need for changes in care coordination when they arise. When patients are in their final weeks or days of life, they might be moved to another place of care. The MPM Unit and case manager work closely to facilitate as smooth a transition as possible to the new place of care. Spiritual support is also provided to enable patients to pass away with peace. Since the MPM Unit facilitates the completion of Advance Directives (AD) and/or Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders with patients and family members, the majority of these patients receive comfort care in hospital in their final days. At the same time, the social care team and volunteers provide companionship, and emotional and spiritual support to both patients and family members. Funeral assistance and bereavement care services are provided to bereaved family members by the social care team and volunteers upon the patient's death.

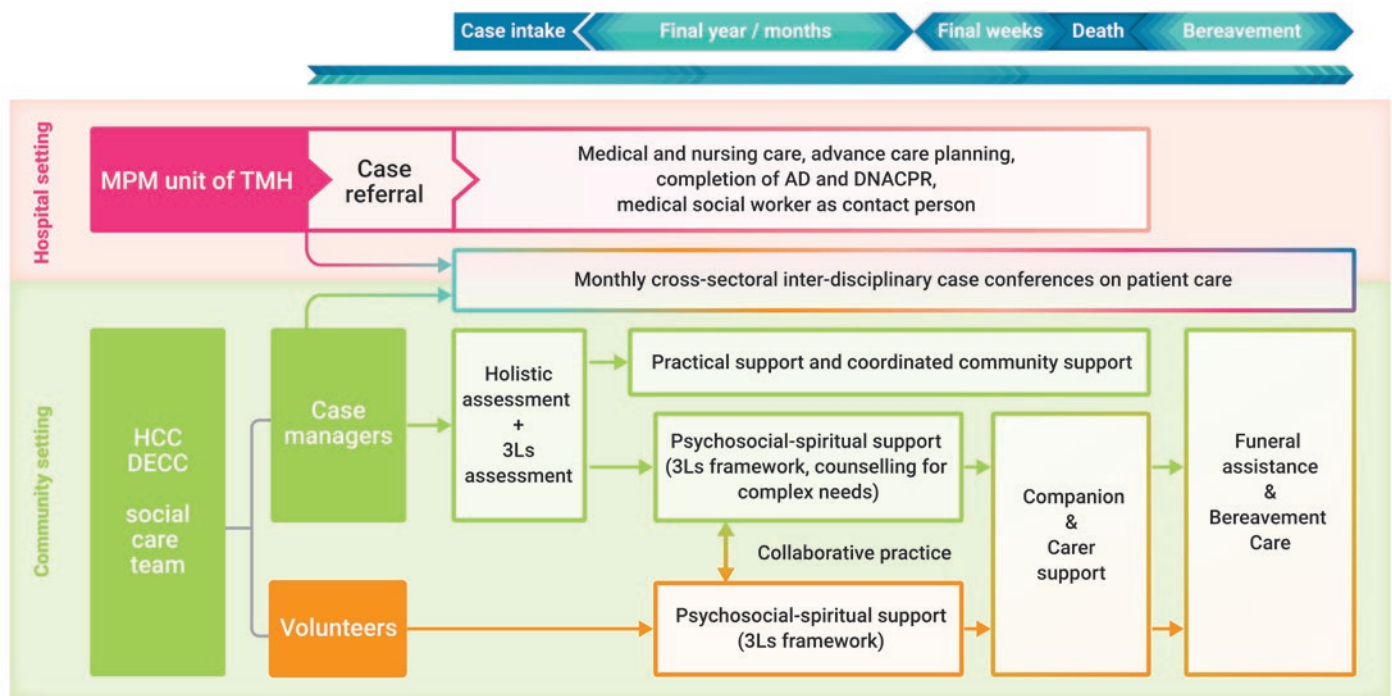


Figure 7.2 Service Delivery Pathway

BEST PRACTICES

The following two cases are used to illustrate good practices in health and social integrated care, and how the 3Ls framework has been applied to preserve dignity and enhance QoL.

CASE STUDY 1: PROMOTING SEAMLESS CARE BY SYNERGISTIC MEDICAL–SOCIAL PARTNERSHIP AND CARE COORDINATION

Mrs Lee, aged 65, was suffering from end-stage renal failure. She lived with her son, Peter. When Mrs Lee was admitted to the HCCDECC EoLC programme, she was still able to take care of herself, and could still manage to help with house chores when Peter went to work. The case manager and two volunteers visited the Lee family regularly. They usually accompanied Mrs Lee and Peter to Chinese restaurants and walked around the park with them in order to build up rapport with the family, as well as to strengthen family cohesion and understand their needs. Recently, however, volunteers found that Mrs Lee has become more reluctant to go out, unwilling to eat and feeling tired all the time. The case manager visited Mrs Lee and found that she was sleeping a lot, was worried about falling and was losing weight rapidly. In the meantime, Peter revealed that he felt physically and emotionally exhausted because Mrs Lee had lost motivation in helping with house chores and other activities which she once enjoyed.

Mrs Lee's case was discussed with the MPM team in the monthly case conference, and the MPM team arranged for the home care nurse to visit Mrs Lee. During this consultation, she also explained the deterioration expected in the end-stage renal failure to Peter, so that he could better understand his mother's seemingly "lazy behaviour". The social care team also immediately connected the family with community resources, such as the physiotherapist and the dietician, before the hospital provided its regular consultation. To help relieve Peter's caregiving stress, the social care team referred the family for home cleaning, hospital escort and personal care services. EoL-related issues were also discussed with the family, including Mrs Lee's wishes for her last days and her preferred funeral arrangements. Mrs Lee was a Christian and she wished to have her churchmates around, singing hymns and chatting with her in her final days. The social care team shared this information in the case conference. Acknowledging her wishes, the MPM team arranged a separate room in the MPM ward for Mrs Lee when she reached her final days, so that her son, her churchmates and the social care team could stay with her. To continue to promote Mrs Lee's dignity and autonomy till her very last moments, the social care team encouraged Mrs Lee to choose her favourite Christian songs to be played in her room. The team also prepared a booklet that contained the song lyrics, which could be shared with friends and churchmates during their visits. This meant that her friends were also more prepared to support Mrs Lee during her final days, in the way she wished.

CASE STUDY 2: PRESERVING DIGNITY THROUGH 3Ls INTERVENTIONS

Mr Wong, aged 60, had been suffering from motor neuron disease (MND) for a few years before he was admitted to the HCCDECC EoLC programme. Mr Wong lived with his wife and two daughters. Mrs Wong was really the only family caregiver as her two daughters seldom stayed at home during their busy working week. The case manager visited the family with two volunteers. They assessed the family's needs using the 3Ls framework.

During these visits, the social care team found many photos on the walls. Through talking about the photos, the team found that Mr Wong had been a busy businessman before he became too sick to work. While he was working, he had managed his time well, he had insisted on having dinner with the family every evening, and he had also arranged regular gatherings with his friends, or even his daughters' friends. The team and the family affirmed that Mr Wong had been a "responsible and respectable" person during his life, and Mrs Wong thanked Mr Wong for all his contribution to the family (Self – Past). The team also explored Mr Wong's current concerns, acknowledged his sadness and explored alternative ways to maintain his daily life activities (Self – Present). Mr Wong was asked about his thoughts on the preferred type of care at EoL and also his preferences for funeral arrangements (Self – Future).

Family conferences facilitated by the case managers allowed the whole family to talk about family relationships in the past. This highlighted that the Wong family had strong familial cohesion (Family – Past). The family was then encouraged to talk about their current life, which they all noted was "all about caregiving" (Family – Present). This was found to contribute to Mr Wong's sense of self-blame (seeing himself as a burden), and the family was helped to understand that Mrs Wong's commitment to care and Mr Wong's guilt feelings were actually alternative ways of expressing love and care. The social care team tried to engage the daughters in more caregiving in an effort to ensure that Mrs Wong had some personal time. With assistance from volunteers, the family collaboratively prepared a family life book to continue the love and joyful memories after Mr Wong's death, as well as to record Mr Wong's life wisdoms for posterity (Family – Future).

It was found that unplanned and unexpected visits from friends tended to interrupt the daily caregiving routine, but the family wanted to maintain connections with relative and friends. Thus, the case manager facilitated the family to set up a "visiting schedule" to ensure Mr and Mrs Wong could commit to a daily routine, as well as enjoy social activities. For instance, Wednesday and Friday mornings were scheduled for friends' visits, and some caregiving tasks were left to the afternoons (Social – Present). Volunteers also supported Mr Wong in approaching his old friends and re-engaging with them (Social – Past).

The social care team organised regular visits by the local vicar and church members (Spirituality – Present). With their support, Mr Wong learnt to forgive himself by prayers (Spirituality – Past). Although the social care team only supported Mr Wong for four months before his death, the whole team and the local church came together to support the Wong family at the funeral and in bereavement (Spirituality – Future).

OUTCOMES

Up to 31 March 2018, 58 patients who have received the “Hospice in Family: Home Care Support Services” have completed three assessments each (at service intake, one month and three months after service commencement) and 27 caregivers have completed the first two assessments (at service intake and at three months after service commencement). Twenty bereaved caregivers have also completed the bereavement assessment two months after the patient had passed away. A large number of patients could not complete all assessments because of unexpected early death or a deteriorating physical condition that rendered them unsuitable for assessment.

Of the 58 patients with full assessments, 28 (44.3%) were male. The group had a mean age of 75.8 (SD=11.2) years and they came from diverse diagnostic groups: 12 (20.7%) had cancer, 26 (44.8%) had renal diseases, 7 (12.1%) had chronic obstructive pulmonary disease, 6 (10.3%) had MND and 5 (8.6%) suffered from heart failure. Over half (56.7%) of them were living in the family home with other family members, 20.7% were living alone and 17.2% were living in residential elderly care homes with relatively poor familial support. Of the 27 caregivers who provided assessments, 8 (29.6%) were male. The caregivers had a mean age of 63.0 (SD=11.8) years, and they were mainly spouses (63%) or children (29.6%) of patients.

For evaluation purposes, the outcome indicators collected from patients and caregivers over time were divided into binary form (low- or high-needs) using a critical threshold set at the mean baseline score plus one standard deviation for each indicator (see Chapter 5). During analysis, the percentage of high-need patients and caregivers in each outcome indicator was compared between baseline (commencement) and the three-month service mark using paired t-tests.

It was found that the proportion of patients with high needs in physical symptoms at baseline increased slightly at the three-month follow-up, while the proportion at baseline with high needs in practical problems, anxiety and depression decreased at follow-up (see **Figure 7.3**). The proportion of caregivers reporting high strain at baseline reduced (but not significantly) at the three-month follow-up (see **Figure 7.4**), while caregivers who reported low levels of intimacy with patients at baseline showed a significant improvement at three months ($p<0.05$). In relation to bereaved caregivers (assessed at two months after the patient's death), 85% reported low risk of complicated grief.

PATIENT OUTCOMES

(% of patients with higher needs)

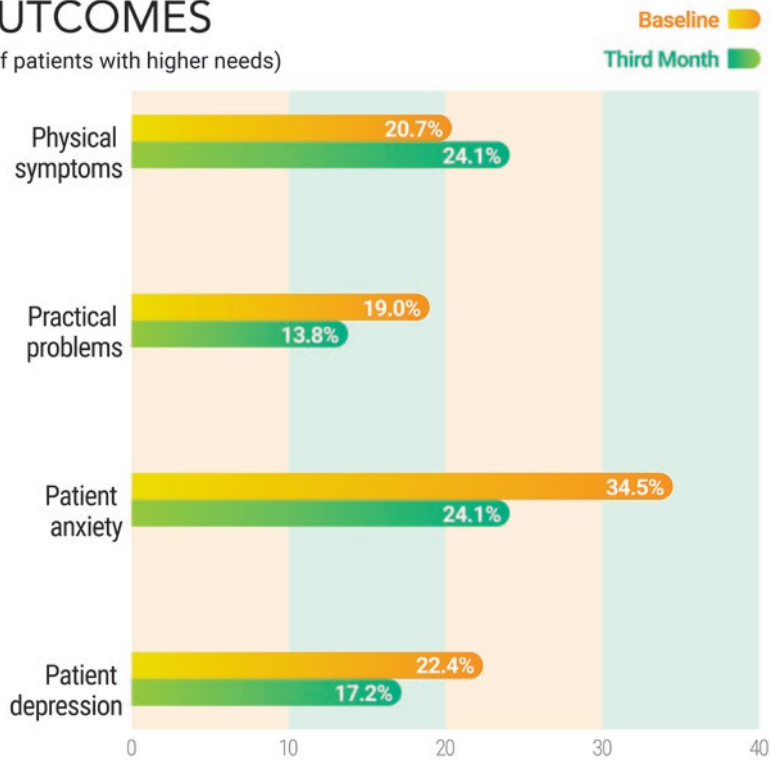


Figure 7.3 Changes in Patient Outcomes after Three Months of Service

FAMILY MEMBER OUTCOMES

(% of family members with high needs)

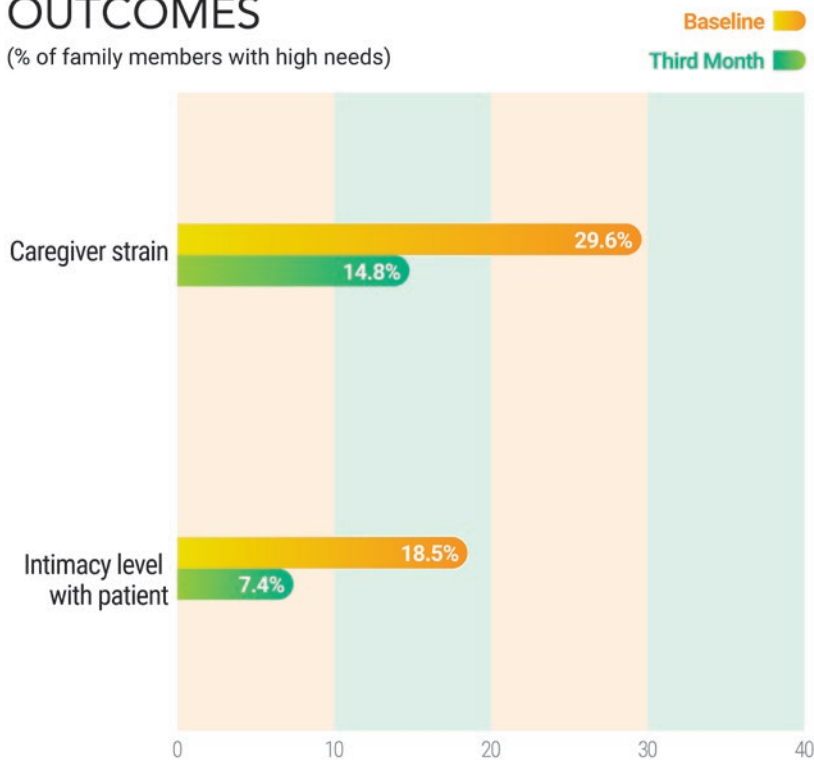


Figure 7.4 Changes in Family Members' Outcomes after Three Months of Service

By examining changes in patient and caregiver needs and concerns over their first three months receiving the “Hospice in Family: Home Care Support Services”, the service model demonstrated the potential to alleviate patients’ practical concerns and enhance their psychological well-being despite deteriorating physical conditions. Increasing physical symptoms are anticipated when patients are approaching death. However, over-time evaluations to date have shown relatively stable intensity of physical symptoms. Reduced caregiver strain over time also mirrors decreases in patients’ practical concerns. Given the considerable number of patients who were living alone or had relatively weak familial support, intensive practical support and support provided out-of-office hours may be indicated. These needs are challenging to meet with the current available levels of community support. Conserving dignity focused on relationship harmonisation, and the significant improvement in the level of intimacy between caregiver and patient provides preliminary evidence for its effectiveness.

We also examined the findings of a satisfaction survey regarding care coordination and conservation of dignity. All the surveyed patients (N=27) strongly agreed that the service “helped him/her live with dignity” and that “their wishes had been respected by the service team” (a score of 7 or above out of 10 was classed as high agreement). A newly added item on medical–social collaboration was administered to 16 patients, and all of them agreed that “the cooperation between the hospital and the service team facilitated a stable and satisfactory care for the patient”. This provides early evidence to support the effectiveness of medical–social collaboration, which is a feature of the current service model. Since the service model has been gradually evolving during the project period, the chances are that more time will be required for the impacts of the evolved model to be fully reflected by the evaluation data.

LEARNINGS, REFLECTIONS AND SUMMARY

The volunteer-partnered community capacity building EoLC model is characterised by a medical–social strategic partnership between the MPM Unit of TMH and the HCCDECC HBSD. A community capacity approach to coordinating and providing care is facilitated by a partnership between case managers and volunteers. Key highlights and lessons from the implementation of this EoLC model to date are summarised next.

INNOVATIVE MODEL THAT FILLS A GAP

The model is the first of its kind in Hong Kong, and it fills a gap in the currently fragmented and inadequate support systems available to community-dwelling patients facing life-limited diseases and their families. The model is innovative and, as such, it contributes to international EoLC knowledge.

EFFECTIVE

The model has continually evolved since its inception two years ago, in response to feedback and observed need. Preliminary evaluation findings lend support to its effectiveness in enhancing the QoL of patients residing at home, as well as that of their families. The model also supports services that appear to preserve patients' dignity, underpin seamless care experiences, and promote patients' satisfaction.

CONSTRUCTIVE FRAMEWORK AND TEAM COMPOSITION

The model was built on three clearly defined, intertwined principles relevant to community, service and family. Enacting these principles at each of these levels has significant implications for interventions and good practices. The composition of the social care team was also appropriate, as team members could successfully engage with the three service delivery features. Good practices underscored the service delivery features of the model:

- » Honouring patients' wishes and autonomy;
- » Enabling seamless and coordinated care by collaboration between the MPM Unit and social care team;
- » Mobilising the community support networks by the efforts of the social care team; and
- » Enhancing patients' dignity by case managers and volunteers using the 3Ls framework to explore and promote harmonious relationships for patients (with themselves, with family members, with others, and with their religion).

Moreover, the partnership has been shown to facilitate sharing and better use of resources in meeting patient and family needs.

A BALANCE BETWEEN STANDARDISED AND STRUCTURED ASSESSMENT AND TAILORED INTERVENTION

The three guiding principles in the model encompass the universal needs of patients at EoL, and it provides a flexible framework that supports balancing standardised and structured assessments and tailored interventions. It has been applied to, and found suitable for, patients from a broad range of diagnostic groups.

There is always room for improvement, and further refinement of the model is anticipated. In order to further enhance service effectiveness, patients should be engaged in discussing issues related to ACP (e.g. wishes, care preferences, preferences regarding funeral arrangements, etc.) using the 3Ls framework as early as possible after commencing in the programme. It was noticed that discussions on these issues became challenging if left until the patient's condition started to deteriorate and their symptoms became more distressing. It was also observed that discussing care plans, wishes and preferences with only the patients (and not the family) may not lead to real actions. However, when family members were engaged in these discussions, the plans were more likely to be enacted with the help of family members. Therefore, family members should be engaged and included, as far as possible, during care planning. Communication tools and resource packages should be developed based on the 3Ls framework to assist volunteers and case managers to easily use the framework for assessment, communication and intervention. All in all, there is sound evidence that the volunteer-partnered community capacity building model could be further developed to benefit other patients and families in the future.

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CHAPTER 8

FAMILY-ORIENTED CARE MODEL IN COMMUNITY- BASED END-OF-LIFE CARE

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The whole family is affected when a family member has an advanced illness. While family members provide invaluable support for the person with the illness, they also face stresses that deserve special care and attention. Family members of patients are thus sometimes referred to as “second patients” (Laryionava et al., 2018). One of the influences of Confucianism is filial piety, which is a central tenant of many Chinese families (Feng, 2017). The role of caring for the aged and sick has traditionally been undertaken by Chinese families (rather than by external agencies) using an informal network of shared family support. However, with recent demographic and socio-economic changes in Chinese society, as

well as increased ease of geographical mobility, Chinese family care for aged and infirm members is weakening. For instance, the average domestic household size in Hong Kong dropped from 4.2 in 1976 to 3.3 in 1996 and to 2.8 in 2016. Moreover, the per-household ratio of non-employed members to employed members is 0.9 in 2016 (HKSAR Census and Statistics Department, 2017). This means that there are fewer family members available and/or willing to undertake caring responsibilities for family members dealing with advanced illness.

St James' Settlement joined the Jockey Club End-of-Life Community Care (JCECC) Project as a service provider in 2016. This organisation has extensive experience in caring for older and/or terminally ill people, and conducting innovative life and death education in the community. Adopting the framework and philosophy of Broaden-and-Build theory (Fredrickson, 2004) and Dying Role theory (Emanuel, Bennett & Richardson, 2007), St James' Settlement developed the Cheering@Home programme to serve families caring for people who have a prognosis of living less than six months.

In this chapter, the experiences faced by families of persons with advanced illnesses are outlined. The two foundation theories that inform the Cheering@Home intervention model are explored, followed by an introduction to the model itself. To link theories and practice, two cases are presented, and preliminary outcomes of families who have received Cheering@Home interventions from St James' Settlement since 2016 are reported. Insights into, and learnings from, the St James' Settlement model are presented at the end of the chapter.

BACKGROUND

THE PHENOMENON OBSERVED IN FAMILIES FACING END-OF-LIFE ISSUES

Conspiracy of silence. Having to talk about a poor prognosis and impending death is dreadful in any situation, but particularly so for Chinese families. There tends to be a conspiracy of silence, which is usually based on good, albeit misguided, intentions to protect others from distressing news. Yoshida et al. (2013) found that Chinese family members frequently assume a dominant role in medical decision-making, as well as disclosing information about a poor prognosis to ill family members. It is also common for Chinese adult children in Hong Kong to request that the medical team do not disclose the diagnosis or prognosis to aged parents, even if the latter are mentally competent. Not knowing the diagnosis or prognosis of an advanced illness can block communication between ill people and the family members, particularly in resolving unfinished business or making end-of-life care (EoLC) plans. These opportunities are lost if patients become mentally incompetent with the progression of their illness, and this situation usually leads to life-long regrets of family members.

Sometimes, patients gain awareness of their deterioration as their condition worsens. As described by Glaser and Strauss (1965), there are four types of awareness of dying in a family. First is closed awareness, which happens when the patient is the only one who does not know that he/she is going to die. The second is suspicion awareness, which occurs when the patient suspects that he/she has a terminal condition but cannot get information from others. The third category is mutual pretence, when both patient and family are aware of the imminent death but do not communicate about it. The last category is open awareness, when patient and family acknowledge impending death and communicate about it. Having open awareness can prevent mistrust developing between patients and family. This engages family participation at an earlier stage to reduce regrets about lost opportunities, as well as improving the patient–family relationship. This also allows EoLC decisions to be made in advance.

Illness as the focus. When advanced illness is acknowledged, managing the person suffering from it becomes the focus in most families. However, family members mostly focus on the medical treatment (either curative or palliative) or health-related diet and other remedial activities. As shared by a patient, “Even though I am a patient (bing ren, 病人, literally means a person with illness), I am still a person, and illness is just a small part of me. Don’t pay all the attention to the illness, but treat me as a person!” EoLC should encompass holistic care for patients and family to address their multidimensional needs. These are not restricted to physical needs, but also include emotional, spiritual, family, social, economic and ethical needs, which emerge in a progressive process intertwined with crises (Gómez-Batiste et al., 2017, p. 227). To do this requires consistent and often substantial amounts of care, which should not only be person-centred, integrated and comprehensive, but also be delivered promptly based on appropriate holistic assessments.

Blameless guilt. Bennett (2018) coined the term “blameless guilt” perceived by caregivers of persons with advanced illness. This guilt may be groundless, and yet is commonly found among family caregivers. Filial piety is a valued attribute of Chinese family life, which also establishes an expected standard of care required from caregivers. If family members cannot care for patients at this standard, guilt may well result. Not being able to meet care expectations may occur if there are competing expectations with other duties (such as employment or other family commitments). As compensation, family members often offer financial resources for patients to seek miracle cures or they may seek expensive institutional care for their loved one. These actions sometimes produce in patients a sense of being a burden, which can affect their emotional state and quality of life (QoL). At times, caregivers may even suffer anxieties about visiting patients, which can be further complicated by a sense of indebtedness (Hennings, Froggatt & Payne, 2013). The discomfort, or even avoidance, of visiting family members with advanced illness, can waste golden opportunities to share quality time with them. Moreover, the guilt may continue even after the death of the loved one.

Unfinished family business. When patients and family members are aware that time is not on their side and there is unfinished business that requires resolution, problematic relationship issues may surface. Although it may be the wish of the dying person and family members to address relationship issues and resolve unfinished business, they may also worry about the outcomes of such discussions. These could be clouded by grief, avoidance of acknowledging and recognising the looming life-ending situation, and/or limited emotional and physical energy to pursue issues to completion. The patient’s energy can be diminished by practical issues such as their illness, the effects of treatment or fatigue, while family members’ energies can be drained by grief, guilt, the burden of unspoken issues or practical tasks of caring. Recognising this is particularly important in Chinese families who treasure wish completion, and finding ways to help them address unresolved issues must be identified (Chow, Chow, Wan, Wong & Cheung, 2011).

Exline, Prince-Paul, Root, Peereboom & Worthington (2012) focused on the study of forgiveness communication at the end of life (EoL). She found that communication of forgiveness is not as common as communication of love, gratitude or farewell. She suggested that in unresolved situations, lack of forgiveness is correlated with higher depressive symptoms in family members. Cohen, Auslander, Dror & Breuer (2016) found that involvement of patients and family members in existential tasks, such as life review, spirituality, multigenerational family relationships and preparation for death, was positively correlated with a sense of self-benefit for family members. Moreover, contrary to logical thinking, functional caregiving was not considered as a stressor. It is found to be positively, although weakly, correlated with a sense of self-benefit of family members.

When facing an EoL situation, family conflicts are often magnified, and can result in poorer bereavement adjustment (Kramer, Kavanaugh, Trentham-Dietz, Walsh & Yonler, 2010–2011). A family-centred holistic approach that addresses unfinished business and existential concerns will therefore be beneficial to the grieving family in the long term.

Figure 8.1 illustrates the phenomenon faced by patients and family when facing ramifications of advanced illness. Although the illness is primarily a medical issue, it also manifests in multidimensional needs for patients and their families. Family-based care that

is individualised and holistic is an appropriate approach to assist families in coming to terms with approaching EoL of a loved one. Families of persons with advanced illness need a platform that allows trustful and open communications when they wish to engage in them. The objectives are to communicate care preferences and planning; address unfinished business; and exchange apologies, forgiveness and gratitude. These components need to be addressed in the design of care interventions.

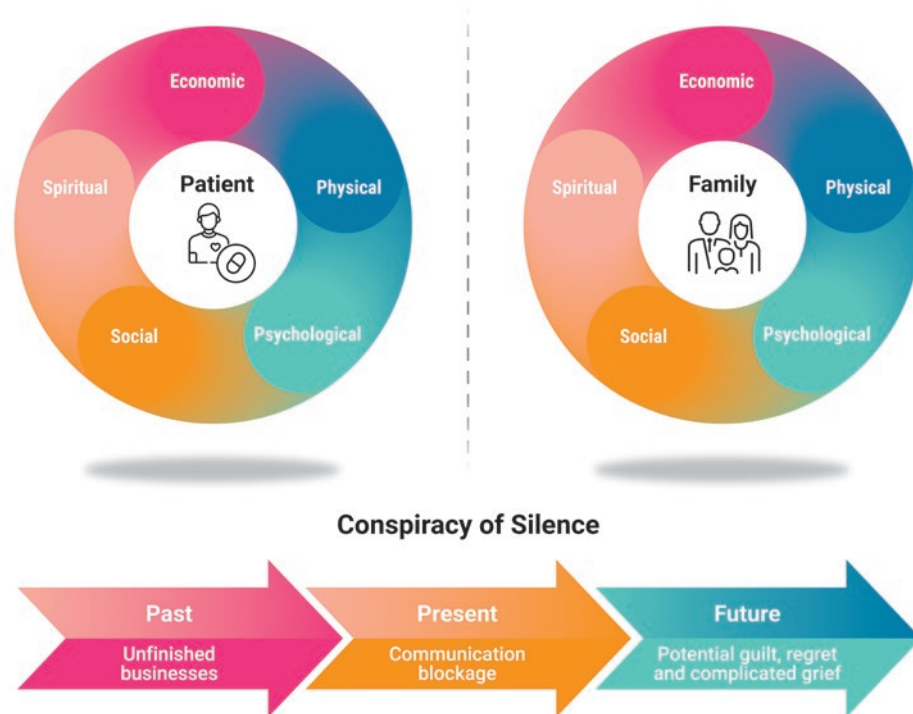


Figure 8.1 The Needs of Persons with Advanced Illness and their Families

INSIGHTS FROM THEORIES

There are two theories related to EoLC that have provided insights into the design of the St James' Settlement intervention for EoLC for patients and families. The Dying Role theory (Emanuel et al., 2007) is aligned with conclusions drawn from observations from clinical work, and the Broaden-and-Build theory of positive emotions (Fredrickson, 2004) provides an innovative approach to addressing the challenges faced by families with persons with advanced illnesses.

THE DYING ROLE THEORY

Parsons (1951) introduced the medico-sociological concept of the "Sick Role", which suggests that the person with illness has two rights (exempt from usual social roles and not being blamed for their condition) and two obligations (try to get well and seek appropriate help). Persons with advanced illness sometimes also adopt this sick role but become frustrated because no matter how much effort they make to fulfil the two obligations, it is in vain. Emanuel et al. (2007) proposed a new role theory – the 'Dying Role' – to help persons

with advanced illness negotiate final life tasks. Specifically, they proposed three types of task of the 'Dying Role': practical tasks, relationship tasks and personal tasks. Practical tasks include the handling of financial legacy, organising EoL planning, caring for dependents and arranging last goodbyes. Relationship tasks recognise the coexistence with other roles, emphasise the teaching nature of the dying role, passing the mantle to others, and placing a legacy capstone. A reciprocal relationship task is permission-giving, where the patient permits family members to live fully and happily after their death, and family members allow the patient to die. Personal tasks relate to the patient adjusting to loss, reaching closure, handling existential tasks and preparing last rites of passage. This is also considered as the patient's final growth phase.

The 'Dying Role' theory offers a clear conceptualisation of tasks to be carried out for, and by, the patient at the EoL. It also addresses the holistic nature of EoLC, in particular not skewing care towards the patient's physical needs. Relationship tasks embrace the importance of addressing and resolving unfinished business, and provide a clear and relevant contour of what to address within the family. Moreover, the personal task addresses the existential concerns that are commonly observed among persons with advanced illness. The promotion of communication, in particular the reciprocal relationship tasks of permission-giving, should reduce some of the blameless guilt experienced by family members.

THE BROADEN-AND-BUILD THEORY

While there has traditionally been a focus on distress and negative emotions in psychological studies, there is growing attention towards positive emotions. Fredrickson (2004) proposed the Broaden-and-Build Theory, which suggests that positive emotions broaden the momentary thought–action repertoire of the individual, and builds his/her resources as a consequence. Positive emotions, in Fredrickson's conceptualisation, are not restricted to joy, but also include interest, contentment and sense of love. Joy urges the individual to play, which can push their creative limits. Similarly, interest urges the individual to explore and expand particular perspectives. Contentment urges the individual to sit back and savour their current life condition. Finally, love is said to be the combination of these three positive emotions that supports the individual in experiencing a safe and pleasant relationship with those around him/her, and to positively journey towards EoL. The urges to play, explore and savour should then expand into the habitual modes of thinking and positive actions. Positive emotions are found to undo any lingering negative emotions, fuelling psychological resiliency, improving psychological and physical well-being, and building personal resources.

Advanced illness is usually linked with negative emotions. A negative emotion such as depression has a downward spiral effect, which restricts one's thinking, incurring pessimism and resulting in even worse moods. Thus, when facing EoL, investing in positive emotions for the patient and family such as joy, contentment, interest and love might prevent this downward negative mood spiral, and offer the family a better thought–action repertoire and resources in facing this life challenge.

MODEL OF INTERVENTION – CHEERING@HOME

The theories outlined earlier enrich the design of EoLC with two dimensions. The Dying Role theory proposes a task-based perspective with clear suggestions of appropriate focus of care. The Broaden-and-Build theory offers an alternative angle to viewing the phenomenon of family–patient relationships during EoL. Instead of focusing on the distress in the family, there should be an equal, if not more, focus on the positive emotions of the family. The Cheering@Home intervention model was developed from these theories.

As shown in **Figure 8.2**, the goal of the intervention is to improve the QoL of patients and family members as EoL approaches. Through bringing awareness, and experience, of positive emotions to the family and the patient, thinking–action choices are expected to be broadened, and emotional resources are built or strengthened. At the same time, multidimensional tasks, as suggested by the Dying Role theory, are addressed, which should hopefully reduce the negative impact from the illness.

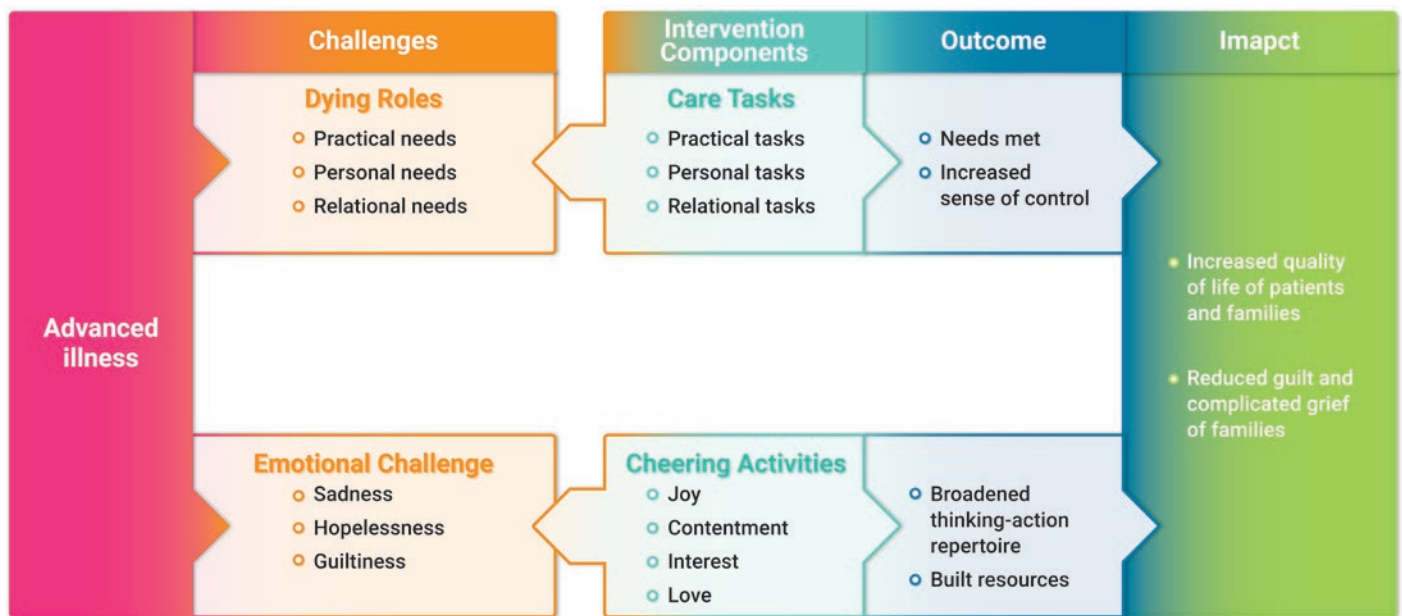


Figure 8.2 Mechanism of Change of the Cheering@Home Intervention

The Cheering@Home intervention has three features. First, related to the content of care, it adopts a holistic and family-centred approach and uses the Dying Role as a framework for organising required caring tasks. Second, which is related to the process of care, individualised and continuous assessment is carried out to ensure appropriate care is provided at the right time by the right care providers. Third, which is related to the philosophy, the intervention emphasises the importance of positive emotions. The process and components of care are outlined in **Figure 8.3**.

A referral to the Cheering@Home intervention can be received at any point of the illness trajectory. Ideally, it coincides with the start of palliative care (PC), when the prognosis of life expectancy is around six months. As part of the process of a new organisation (St James' Settlement) approaching the patient and family, the focus must be on engagement and rapport-building. Thus in the first phase, cheering-up activities, as well as practical help such as escort, daily care and equipment loan, are the focus. Cheering-up activities, including chess games, calligraphy, artwork, physical exercises, massage, group games, singing, beauty sessions, reading or cooking, are provided for the family, depending on their preference. Volunteers who are experienced in these activities are trained to lead these activities. A comprehensive assessment is done by professionals at the same time to ensure that there are strategies to meet the patient's and family's multidimensional needs.

After trust has been established and the family has been placed in a Broaden-and-Build framework, the interventions move to more intensive emotional topics such as supportive counselling to address the adjustment to loss. When the patient and family are ready, family communication and unfinished businesses are explored and addressed. The family is helped in developing legacy capstones or discussing sensitive topics such as financial legacy and EoLC planning.

When the patient is approaching the final days of life, the intervention enters the integrated care priorities (ICP) mode, where more focus is put on medical supports or funeral arrangements. The patient can choose the preferred place of death, and the team negotiates with the medical team to support these wishes. Appropriate bereavement counselling is also offered after the death of the patient to those family members who have indicated the need.

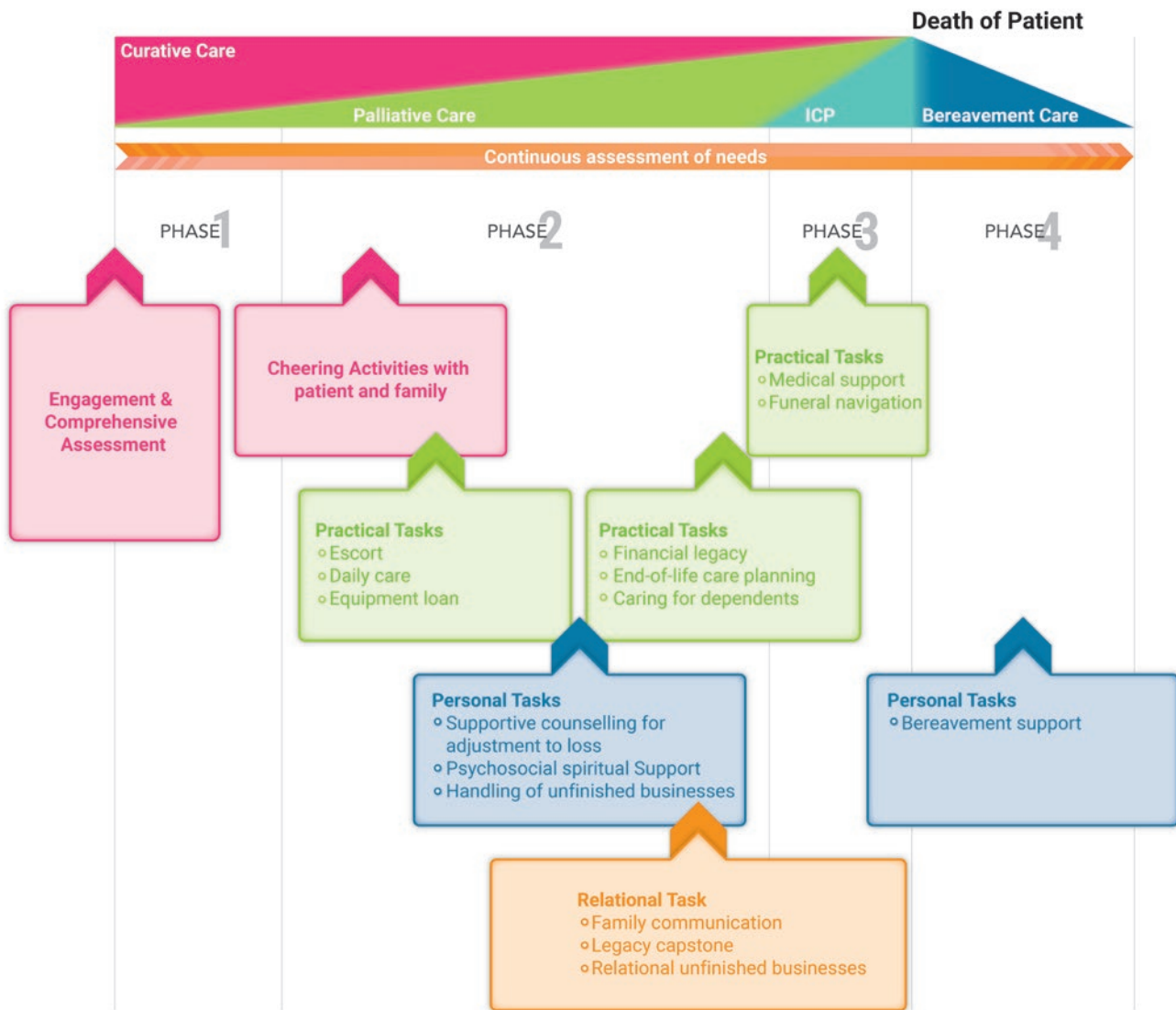


Figure 8.3
The Process and Component
of the Cheering@Home
Intervention Model

To encompass the Broaden-and-Build theory, the Cheering@Home EoLC team has developed the CHEER model to support patients and their families in eliciting positive emotions. The five core objectives of the project are embedded as an acronym of the name of the project "CHEER" (Figure 8.4).



Figure 8.4 Core Objectives
of the Cheering@Home
EoLC Programme

CASE ILLUSTRATIONS

The key component of this project is to use activities that elicit positive emotions for the family in building strength to face the challenges of illness. The following cases of Uncle Wong and Uncle Fai illustrate this.

CASE STUDY 1: UNCLE WONG

Uncle Wong was 89 years old and diagnosed with heart failure and dementia. Since his diagnosis, the family had arranged three different domestic workers to take care of him. Despite this, Uncle Wong had fallen several times at home. His daughter, Miss Wong, finally decided to take early retirement to be a full-time caregiver for him. Miss Wong was vigilant all the time because she was worried that her father might get injured by a fall. "I was woken up by a huge 'bang' one night and discovered that my father got hurt and was lying on the ground". These concerns made it difficult for Miss Wong to rest well at night. She rapidly lost weight and developed acid reflux since taking up the caregiving role. Moreover, the daily life of the Wong family was only focused on caregiving.

The Wong family was referred to "Cheering@Home End-of-Life Care Services" for psychosocial support. The case worker noticed that Miss Wong was very anxious about the future and always focused on Uncle Wong's illness. Moreover, taking a physical focus on pain and suffering made Uncle Wong question his existential issue, and he found life boring and meaningless. Therefore, after thorough assessment, the Cheering@Home case worker attempted to support the Wong family in accomplishing relationship and personal tasks as suggested in the Dying Role model. Different family activities were arranged to engage the Wong family in creating happy moments and to instil hope, which were the missing pieces in the caregiving journey. Borrowing from the Broaden-and-Build theory, "cheer-up" activities were arranged for Uncle Wong to strengthen his psychological resilience to face his sufferings.

Uncle Wong enjoyed spending time playing chess with volunteers. Those moments became something for him to look forward to. "I focus on the game and forget the discomfort", said Uncle Wong. The joy and positive emotion brought by chess games broadened Uncle Wong's capacity to manage his pain. Moreover, Miss Wong was amazed at her father's abilities and creativities. "Since my father was diagnosed with dementia, we seldom chat or enjoy any leisure activities. I only noticed his decline in health and abilities. Now it seems that his situation is not as poor as I thought." Cheering-up activities have facilitated Miss Wong and Uncle Wong to seek positive emotions together, to create special memories and to express love, appreciation and concern. "In the past, we were very quiet at home, but now we are actively thinking of new ideas, planning for outings and activities such as going out for meals, visiting Béthanie, having a party with the neighbours, etc."

The interventions also have practical implications. Miss Wong could be temporarily relieved from her routine caregiving tasks during the volunteers' visits. This enabled her to take a break to go shopping, have afternoon tea and/or just relax. Having this time to refresh and recharge helped Miss Wong to regain her energy and enthusiasm to continue her caregiving work for her father.

CASE STUDY 2: UNCLE FAI

Uncle Fai was 80 years old and diagnosed with prostate cancer. He lacked energy and had a severe hearing impairment. Being single and living alone, Uncle Fai was mainly cared by his younger sister (in her 60s) who lived some distance away. Her brother's deteriorating condition made the sister feel compelled to visit him more often, despite the long travelling distance. However, Uncle Fai refused more frequent visits by his sister because he wanted to rely on himself. They started to quarrel over minor issues. They were both worried about the future and how Uncle Fai would be cared for, although neither of them dared to talk about it.

Unfortunately, Uncle Fai slipped and fell one day, and he was sent to hospital. The family was then referred to the "Cheering@Home End-of-Life Care Services" for community support. The sister revealed her preference to move Uncle Fai to a private elderly home closer to her, so that she could visit him more often, but Uncle Fai resisted because of the financial burden on the family and the loss of his freedom. The Cheering@Home case worker realised that the family was caught in the dilemma of rationalising competing needs in practical (e.g. a feasible care plan), relationship (e.g. caregiver wish for a closer connection with patient) and personal tasks (e.g. patient hope for autonomy), and the avoidance of addressing the situation to find a solution.

In view of these concerns, the worker engaged Uncle Fai and his sister in discussing care plans in a family interview. By acknowledging the mutual care between the two parties and the common goal on finding a care arrangement that could provide better care to Uncle Fai, the worker encouraged both parties to honestly share their concerns and needs. She provided information on different care choices. As both Uncle Fai and his younger sister were prone to irritability, the worker helped both parties to objectively evaluate the pros and cons of care decisions separately at first, and then to discuss together the practicality and affordability of each choice. Gradually, Uncle Fai came to recognise the love of his sister behind her suggestion to move closer to her into a care home, while the sister improved her respect and appreciation towards Uncle Fai's self-reliance. This mutual understanding decreased the conflict, and a consensus was reached such that Uncle Fai was moved to an affordable elderly home near his sister's home. "We often had a quarrel on care planning in the past so we learnt to avoid this topic, but now we settled it peacefully", said Uncle Fai.

This arrangement fulfilled both their practical and relationship needs. Since most caregiving tasks were supported by the care home staff, the siblings could enjoy more time together for leisure. The sister's family visited Uncle Fai frequently. They went to Chinese restaurants for family time, chatted about interesting topics that may seem to be ordinary in others' eyes, but which were cheering for them all. Uncle Fai passed away one month after moving into the elderly care home, but he had spent wonderful times with family without losing dignity in the last stage of his life.

OUTCOMES

Of the patients and family caregivers who have been served by the Cheering@Home programme to date (between January 2016 and December 2017), 38 (27.1%) patients and 31 (22.3%) caregivers completed all assessments before the patient's death, and 51 (36.7%) caregivers completed bereavement assessments after death.

Patients were mostly in the old-old and oldest-old age cohorts, with a mean age of 78.9 years (SD=11.3), and 36.8% were male. There was an overall short mean length of care (5.7 months, SD=6.5) provided for the patients enrolled in the programme. Of these, 29.2% died within one month of referral. This underlines the need for timely and targeted interventions because EoL can approach very quickly. The majority of the patients enrolled in the Cheering@Home programme had been diagnosed with cancer (N=31, 81.6%), and the remaining patients suffered from heart failure (2.6%), motor neuron disease (2.6%), renal disease (2.6%), chronic kidney disease (2.6%) and a range of other individual conditions (7.9%).

There was an even gender distribution of primary caregivers (14 were male, 45.2%), and caregivers were predominantly adult children (N=17, 54.8%) or the spouse (N=12, 38.7%). The spouses were also approaching, or already in, old age (mean=60.8 years, SD=11.8).

Chapter 5 described outcome indicators and how the needs of patients and families were grouped. In summary, a threshold level was set for each outcome indicator at mean score plus one standard deviation. The proportions of high-need groups in all outcome indicators of patients and caregivers were compared between time of service intake and the third month of service, which signifies the period of active interventions.

Findings for patients supported the effectiveness of cheering activities in reducing negative emotions of patients. There was evidence of clear reduction in the proportion of patients with high needs in psychological (the proportion experiencing anxiety and depression), and spiritual areas (the proportion not-at-peace; see **Figure 8.5**). Moreover, cheering-up interventions incorporated into practical tasks appeared to be effective, as manifested by the significant reduction in reported practical problems of personal care. There was also a clear decrease in the number of patients who perceived anxiety in their family members. It may be that the alleviation of patients' practical problems might have a secondary impact on how these patients perceived family members' anxiety, through mediation activities to reduce familial distress. It is of note that despite the main focus of the Cheering@Home EoLC team on providing psychosocial-based supports, improvement in patients' physical symptoms were also observed. There are a couple of possible explanations for this finding. First, a considerable number of patients receiving the Cheering@Home intervention were also receiving specialised support from PC units. Thus, the improved physical symptoms might reflect the effectiveness of this symptom management approach. Second, patients who had developed capacity via the Broaden-and-Build model might have developed a more positive sense of self, not only in terms of emotional resilience, but also with improved subjective perceptions of their physical symptoms.

Nevertheless, over half the patients still reported difficulties in sharing feelings with family members after the months of the Cheering@Home intervention. This potentially correlates with the high proportion of caregivers who reported a reduced level of intimacy with patients (**Figure 8.6**). Conversely, the proportion of caregivers who reported high caregiver strain was halved. An explanation for this could be that while caregivers may have been relieved from stressful caring tasks because of their active involvement with the Cheering@Home intervention, their level of engagement in the care process may have been reduced to the point to be insufficient in supporting meaningful emotional exchanges with their ill loved one. Nevertheless, 94.1% of bereaved caregivers reported low risk of complicated grief, which suggested many of them were appropriately prepared to face the death of their family member.

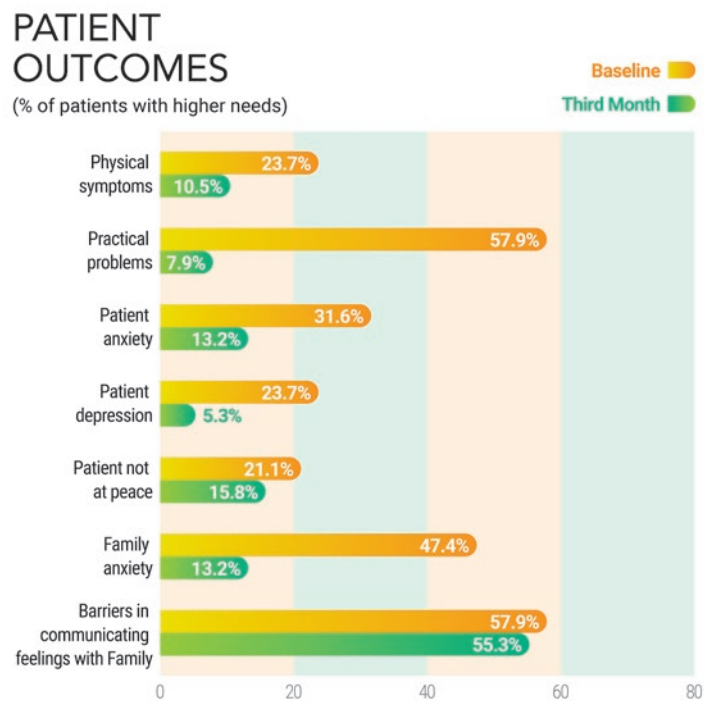


Figure 8.5 Comparison of Patient's Outcomes at Service Intake and after Three Months of Receiving the Cheering@Home Intervention

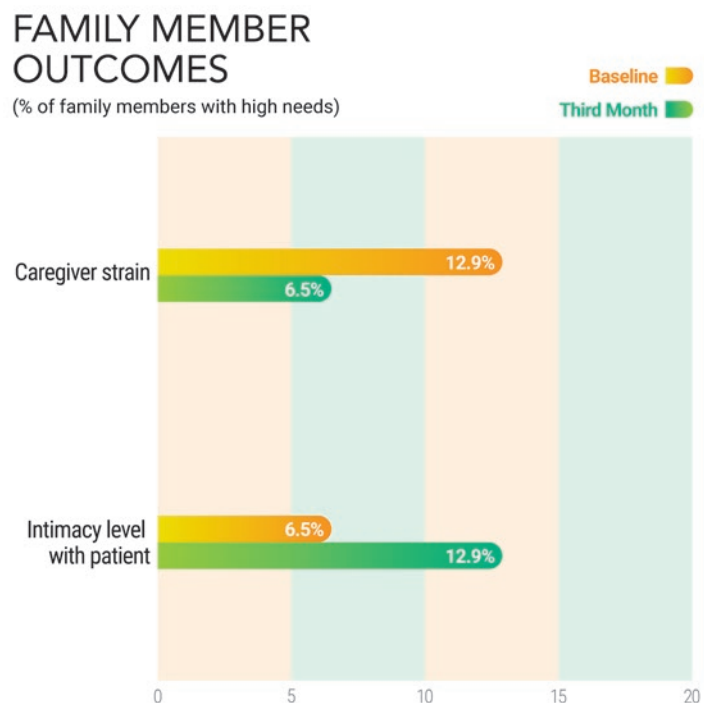


Figure 8.6 Comparison of Caregivers' Outcomes at Service Intake and after Three Months of Receiving the Cheering@Home Intervention

INSIGHTS AND FUTURE DIRECTIONS

As the Cheering@Home model of care intervention is grounded in Western theories and clinical observations, its applicability to a Chinese community requires critical examination. The two years of local Hong Kong practice offers practical insights that are not covered by the theories. These insights were gathered through clinical supervision meetings and are elaborated in the following section.

ENGAGEMENT OF FAMILY IN THE PROCESS OF CARE

The model adopts the family as the unit of care. In practice, some family members in Hong Kong are too busy with work and other commitments, and thus might not always be available to participate in the intervention. In the early stage of rolling out the Cheering@Home intervention, while some family members highly appreciated the care provided to the patient, they depended heavily on the worker to care for the patient, without joining the sessions. Consequently, the patients established strong relationships with workers and this created an unexpected tension with the family members. Although family members disengaged themselves from the patient because the Cheering@Home intervention services took care of the patients, they experienced immense guilt for not being as caring as the worker was to the patient. After identifying this outcome, the team put more effort into engaging family members in the patient's care and reducing the care that the intervention team gave the patient. Furthermore, any positive change in patients were attributed to the family members' engagement, in order to empower their participation.

The use of recreational cheering activities was a useful mechanism to engage the family, as they found it non-stressful and threatening to join in with the activities. While participating in recreational activities with the patient, some family members recalled and shared good memories they had had as families, specifically with the patient. This sharing helped to build family cohesiveness. When family members were more relaxed, the thorny topics of Advanced Care Planning (ACP) and even funeral planning could be approached and shared more naturally.

INTERESTING ACTIVITIES

When family members offered choices of a range of recreational activities to the patient, they demonstrated a sense of respect, which gave patients, even at the end-stage of life, autonomy to choose how they spent their time. While some patients preferred to participate in activities enjoyed in the past, some chose new activities. Enjoying new experiences with family members enriched patients' QoL. On top of the broaden-and-build effect of participating in interesting activities, patients were being distracted from their symptoms and the distress these caused. Patients had few complaints of symptoms when they were involved in interesting recreational activities and did not show signs of fatigue. This phenomenon is a good reflection of the impact of the Cheering@Home intervention on improving patients' and their families' QoL.

HOLISTIC CARE

The Dying Role model places practical tasks as one of its features, which refers initially to those preparing for impending death (such as determining financial legacy or EoL planning). However, although patients are facing certain death, they are still living. In this sense, there are equal, if not more, practical tasks that need to be considered related to daily life (such as being escorted to appointments, household chores, meal preparation, daily care). These tasks place great pressure on family caregivers if they are not provided with sufficient support, which in turn affects their psychosocial well-being. Patients might perceive themselves as a burden to the family and they desire a hastened death to reduce this burden. Appropriate care is therefore holistic, covering not just medical and psychosocial, but also the practical aspect of care. Providing appropriate assistance in completing practical tasks can reduce psychological and physical distress for both patient and caregiver. Moreover, reducing the demands of completing practical caring tasks on the family caregiver offers opportunity to spend more quality time with the patient.

PSYCHOLOGICAL AND PHYSICAL RESPITE CARE

Family caregivers also noted the importance of respite care. Some were torn between completing other duties (such as attending school functions of their children) and caring tasks, or between care for themselves (such as having a medical consultation of their own) and the care for the patient. Time-off from caring duties to take care of other responsibilities and to have time for themselves is essential for maintaining a balanced life. One family member shared, "This caring task is 24/7 without a break. It is the most difficult and tiring work one can have." The presence of the care worker to take care of the patient, for even a short while, therefore offers physical and psychological respite for family caregivers, which could improve their QoL.

MEDICAL AND SOCIAL COLLABORATION

Most patients' needs are multifaceted and no single person or team of people is likely to comprehensively meet all those needs. Strong, respectful collaborations between medical teams and community social care teams is required to meet the complex needs of patients and families. Consequently, the hospital medical care team who referred the patient to the community social care team should maintain regular communication through case conferences and joint interviews. The medical team should also offer an emergency consultation number to the community social care team so that they can be called upon should any changes in the patient's condition be identified. This collaboration also facilitates a seamless discharge from hospital to community.

The collaboration should be within and between disciplines. There are existing community resources for practical care to support terminally ill patients and families, such as Integrated Home Care Services, Enhanced Home and Community Care Services, and Day Respite Service for Elderly Persons. The community social care team should explore available existing support services and ensure that patients and families are aware of possible care options. The waiting lists for these services in some Hong Kong districts are relatively long and, in this instance, an interim care plan should be provided by the social care team.

TIMELY INTERVENTION

The majority of patients in the pilot programme, especially those with cancer, demonstrated progressive deterioration in health and function over time. Timely intervention is therefore essential for ensuring patients and families receive the care they need, when they need it. During the Cheering@Home pilot period, some patients died within a week of the referral being made. By focusing on timely provision of patient- and family-centred care, the Cheering@Home team was able to offer care within three days after receiving a referral.

The team made another important observation regarding changed health status over time. On referral, some patients were in a poor health state, often associated with confusion. Unexpectedly, they became clear mentally and they were able to communicate freely with their family. While thinking that this may have reflected general improvement or even a cure, the patients often died within hours. In Chinese culture, this experience is called *hui guang fan zhao* (迴光返照, literally meaning "backlighting"). In Western medical literature, there is a similar concept called terminal lucidity (Nahm, Greyson, Kelly & Haraldsson, 2012). The team now pays extraordinary attention to sudden improvement in cognition of dying patients, in order to provide timely care during what is often a limited time window.

SUMMARY

The family-oriented Cheering@Home care model for families of persons with advanced illness is founded on clinical observations and Western theories. It has been trialled in Hong Kong over the past two years. The preliminary results indicate the intervention is promising, although the model requires ongoing amendments. One change is that due to the unavailability of some family members, the intervention may be offered to the patient only. Extra effort must be made to engage and involve family members. Another change is that the multidimensional needs of patients and families requires multidisciplinary teams, and strong collaboration within and between sectors to provide the appropriate care. Communication between teams, instead of working in silos, will increase the effectiveness and efficiency of care. A third change is that the intervention must address basic practical needs to improve QoL. When patients and families are facing a multitude of often overwhelming practical demands, psychosocial counselling alone will not reduce this distress. Practical support such as home and/or respite care will provide the foundation for delivering emotional support. Moreover, continuous assessment of patient and family needs is required throughout the illness journey. It was noted that creating positive emotions, such as joy, interest, contentment and love, through activities provides a foundation for discussing serious topics. Finally, the patient's condition can change quickly and unexpectedly, and timely intervention is therefore critical to programme success.

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CHAPTER 9

IMPROVING QUALITY OF LIFE FOR PATIENTS AND FAMILIES WITH LATE-STAGE NON-MALIGNANT CHRONIC DISEASES: A HOLISTIC INTEGRATED COMMUNITY-BASED MODEL

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Although the leading cause of death in Hong Kong is cancer, non-cancer deaths comprise two-thirds of the total causes of death (HKSAR Department of Health, 2017). There is a significant disparity in access to palliative care (PC), however, as approximately only 1.5% non-cancer patients receive it, compared with 80% cancer patients (Lau, Tse, Lam & Lam, 2008; Lau et al., 2010). To fill this service

gap, the “JCECC: Life Rainbow – End-of-life Care Service” was launched by the Hong Kong Society for Rehabilitation (HKSAR) on 1 January 2016, funded by the Hong Kong Jockey Club Charities Trust in partnership with the Hong Kong East Cluster of the Hospital Authority. This chapter describes the processes entailed in establishing the service, the components and the evaluation to date.

BACKGROUND

END-OF-LIFE CHALLENGES FOR PEOPLE WITH ADVANCED CHRONIC ILLNESS

People with non-cancer terminal conditions can suffer from organ failure, decreased mobility and functioning in daily living and other debilitating physical, psychological and spiritual conditions. These all significantly undermine their quality of life (QoL). People with organ failure are more likely to experience variable health trajectories and functional incapacities than people with any other health condition. Moreover, they develop long-term progressive limitations punctuated by intermittent serious episodes (Bostwick et al., 2017; Murray, Kendall, Boyd & Sheikh, 2005). In their last six months of life, non-cancer patients are likely to report distressing symptoms such as dyspnoea, oedema, pain and fatigue. They generally have higher rates of intensive care unit admissions, outpatient clinic attendances and ward admissions, as well as longer lengths of stay in hospital than patients with cancer (Lau et al., 2008; Lau et al., 2010).

LACK OF DEATH PREPARATION AND ADVANCE CARE PLANNING

The rate of physical deterioration of people nearing end-of-life (EoL) can be variable and unpredictable. Many patients with advanced illness and their family members are influenced by death denial and death taboo. Repeated hospital admissions may give family members unrealistic expectations of recovery and longevity. When death comes, it is often regarded as being too soon and many families are unprepared for it (Murray et al., 2005). Because of limited access to end-of-life care (EoLC) support, for many non-cancer patients there is often very little Advance Care Planning (ACP) discussions or access to appropriate documentation. Discussion of the desire, or not, for resuscitation (Do Not Resuscitate [DNR]) is often only initiated when patients have a few days left to live. One study found that only 11.5% non-cancer patients were involved in ACP discussions, compared with 40.8% cancer patients. It also found and that ACP discussions were first documented within three days before death for 26.9% patients with chronic obstructive pulmonary disease (COPD) and 35.7% patients with chronic heart failure (Lau et al., 2008; Lau et al., 2010). Moreover, family members have indicated that they view discussion of ACP, or withdrawal of renal dialysis or other active interventions, as gestures of the hospital giving up on the patients. Families often react emotionally in these situations, and this emotion can block opportunities for death preparations. This also puts pressure on healthcare professionals when they attempt to initiate discussions on ACP.

JCECC: LIFE RAINBOW – END-OF-LIFE CARE SERVICE

PROJECT OBJECTIVES

The Life Rainbow project is a multidisciplinary home-based empowerment programme that adopts a holistic, integrative service model to enhance QoL for late-stage chronic disease sufferers residing in the community. A collaborative approach is adopted, aiming at fostering care partnership between hospital staff, family members, patients' self-help groups and volunteers in supporting patients and their families.

THE SERVICE MODEL

A “LET Go: Community Palliative Care Model for Chronic Patients” model (Leung & Chan, 2011) was developed for this project (see **Figure 9.1**). This is a culturally specific, family oriented holistic care model, which is strength-based and person-centred. The model comprises four themes, represented by the acronym LET Go, showing how the QoL of late-stage chronic patients and their families can be enhanced through holistic community-based service of palliative care.

Living fully despite illness – holistic care

Empowering family – capacity building

Transforming loss – person-centred

Going in peace and harmony – family-oriented

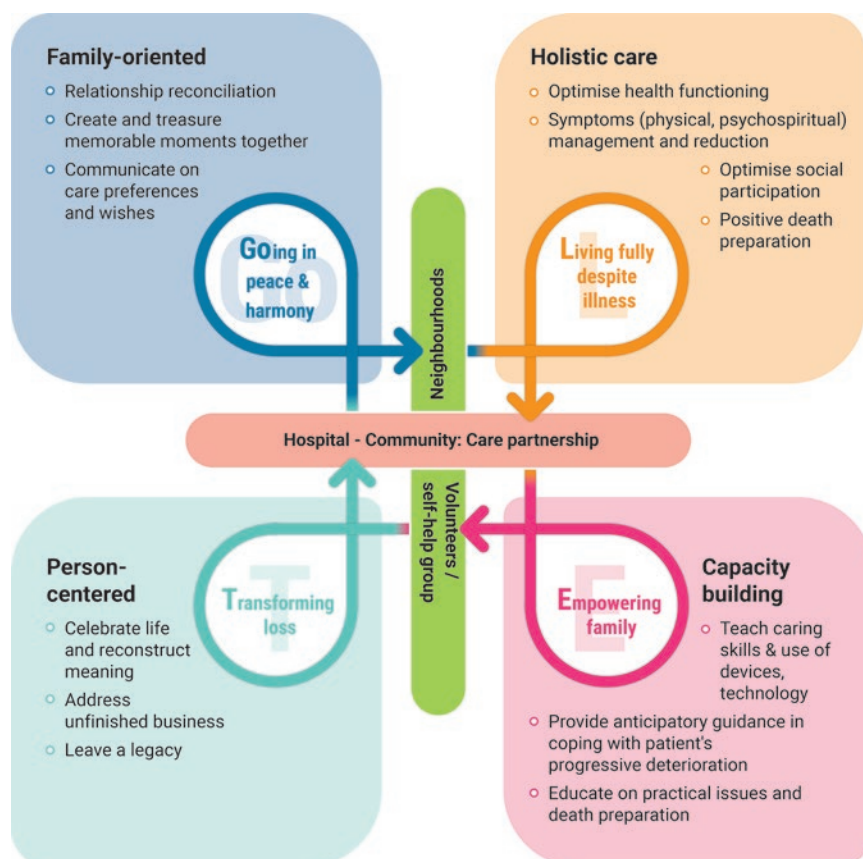


Figure 9.1 LET GO: Community PC Model for Chronic Patients and their Families

SERVICE TARGETS AND RECRUITMENT

Patients targeted for this project include those with COPD, renal failure, heart failure or neurological diseases. Patients are identified by medical teams in the Hong Kong East Cluster of the Hospital Authority (HA). These doctors and nurses select patients based on their negative responses to the question, “would I be surprised if this patient died in the next six months?” The specific selection criteria for inclusion in the project are dependent on four selected disease groups:

1. End-stage COPD
 - › Stage IV: Very severe COPD
 - › FEV1 (forced expired volume in one second)/FVC (forced vital capacity) <70%; FEV1 <30% or FEV1 <50% predicted plus chronic respiratory failure
2. End-stage kidney diseases
 - › Stage V: Kidney failure
 - › Glomerular filtration rate (GFR) <15 ml/min/1.73 m²
 - › Accepting peritoneal dialysis
3. End-stage heart disease
 - › Based on clinical condition and decision by healthcare workers
4. End-stage neurological diseases (e.g. motor neuron disease and Parkinson’s disease)
 - › Based on clinical condition and decision by healthcare workers

DEMOGRAPHY OF PATIENTS AND FAMILIES

During the first two years of the project, a total of 126 patients and 121 caregivers were treated. Patient disease typology and demographic data are reported in **Tables 9.1** and **9.2**.

Table 9.1 *Disease Classification of Patients Included in Life Rainbow (N=126)*

	FREQUENCY (%)
COPD	61 (48.4)
Renal failure	33 (26.2)
Heart failure	4 (3.2)
Neurological diseases (e.g. motor neuron disease, Parkinson’s disease)	22 (17.5)
Others (e.g. cancer, dementia, stroke)	6 (4.8)

Table 9.2 Patient's General Demographics (N=89)

	FREQUENCY (%) / MEAN (SD)
Gender (male)	61 (68.5)
Age (mean)	75.9 (10.9)
Marital status	
Married/cohabitating	63 (70.8)
Widowed	15 (16.9)
Separated/divorced	6 (6.7)
Single	3 (3.4)
Others	2 (2.2)
Relationship of primary caregiver with patient	
Spouse	46 (51.7)
Child	28 (31.5)
Domestic helper	5 (5.6)
Sibling	3 (3.4)
Relative	3 (3.4)
Others (including friends)	3 (3.4)
Parent	1 (1.1)
Friend	1 (1.1)
Living arrangement	
Living with family only	50 (56.2)
Living with a domestic helper and family	19 (21.3)
Living alone	8 (9.0)
Living with a domestic helper only	7 (7.9)
Residential care homes for the elderly (RCHEs)	5 (5.6)

THE SERVICE PATHWAY

The Life Rainbow service pathway is divided into four phases: (1) assessment, (2) active intervention, (3) maintenance and (4) dying and bereavement support (see **Figure 9.2**). The Life Rainbow model adopts a multidisciplinary team approach, including social workers, nurses, professional volunteers who have medical training background, and community volunteers. Social workers serve as case managers to conduct assessments, interventions and who monitor and coordinate services throughout the case journey. The nurses and professional volunteers are responsible for providing symptom management education to empower patients and caregivers to cope with late-stage symptoms, as well as optimise physical functioning and well-being. The community volunteers are crucial as they provide practical and emotional support to patients and family, as well as assisting in case monitoring during the maintenance phase.

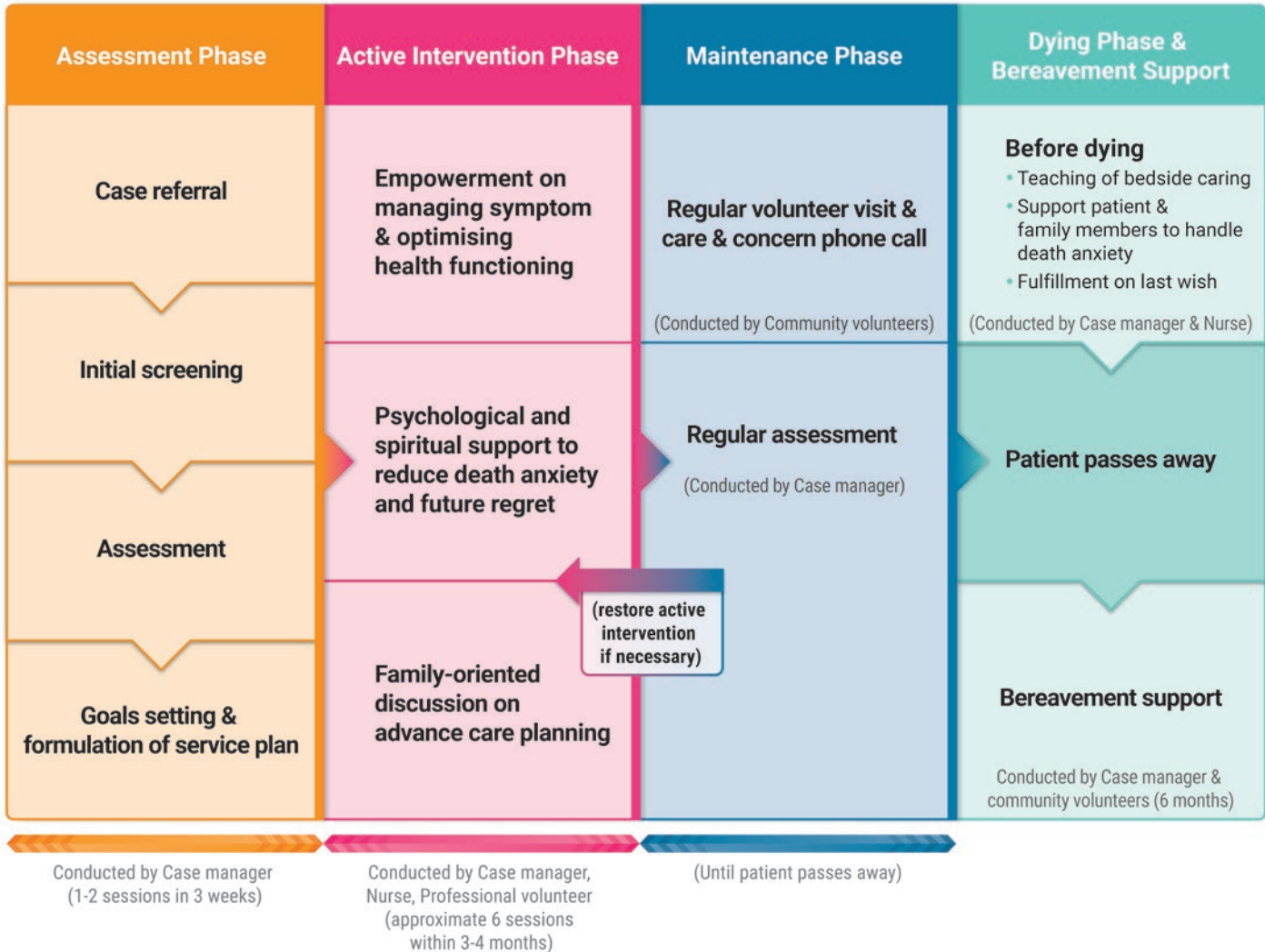


Figure 9.2 Service Pathway of the “JCECC: Life Rainbow – End-of-Life Care Service”

ASSESSMENT PHASE

Comprehensive assessment is conducted to understand the patient's physical and psychological health, social and economic circumstances, preparation for readiness for death, and other issues. After the assessment, personalised goals and service plans are established with patients and family members, aiming to improve QoL.

ACTIVE INTERVENTION PHASE

The active intervention phase comprises three components: Empowerment on managing symptom & optimising health functioning; psychological and spiritual support to reduce death anxiety and future regrets; and family-oriented discussion on ACP.

Empowerment on managing symptoms & optimising health functioning. For people with end-stage chronic illness, physical symptoms are generally their primary source of burden. The Life Rainbow model emphasises empowering patients and caregivers to improve their capacity to manage symptoms. Disease education is provided to patients and families, enabling them to understand the disease trajectory and the common symptoms of their illness. By using a “symptom management logbook”, patients and caregivers are taught to record important vital signs (e.g. blood pressure, body temperature, pulse, degree of blood oxygen saturation, etc.) and the specific symptoms with which they struggle most days. Patients regularly give scores to assess the severity of each symptom, using the Integrated Palliative Care Outcome Scale (IPOS) (see Chapter 5). These health records are useful for patients and families as well as for healthcare staff to monitor the progression of illness and be better prepared for impending physical deterioration. To relieve symptoms, self-management techniques and care skills are demonstrated by the nurses and professional volunteers. Patients and caregivers learn and practice how to regularly manage specific physical symptoms using simple and practical non-pharmaceutical methods. Educational booklets, posters and videos of symptom management skills are also provided to patients and caregivers. **Table 9.3** outlines common symptoms and management approaches.

Table 9.3 Examples of Common Symptoms for End-Stage Chronic Patients and the Management Techniques

MAJOR SYMPTOMS	SYMPTOM MANAGEMENT TECHNIQUES
Dyspnoea/ shortness of breath	Postural drainage
	Pursed-lip breathing
	Diaphragmatic breathing
	Airflow simulation
	Exercise
Weakness or lack of energy	Rearrangement of daily activities
	Distraction with personal hobbies or interesting activities
	Relaxation breathing
	Exercise
Pain	Cold/heat pack
	Relaxation exercise
	Meditation
	Massage
	Regular exercise
Oedema	Positioning
	Massage
	Restriction in water and sodium intake
	Exercise
Poor mobility	Exercise
	Proper transfer and lifting skills
	Use of proper walking aids

Moreover, the project has adopted many of the Integrative Body–Mind–Spirit (IBMS) techniques, which promote inherent strengths and the potential of patients to live well with their physical concerns. Patients are encouraged to accept their physical limitations, focus on finding meaning in their everyday lives, as well as living in the here-and-now (Lee, Ng, Leung & Chan, 2009). IBMS aims to empower patients to regain an equilibrium within their condition, instead of eliminating the problems. IBMS exercises such as Clapping Qi-Gong (拍手功), Pulling Qi-Gong (拉氣功), Shi-Qiao Shou (十巧手), Swinging hand Qi-Gong (甩手功), Backing Patting (拍背功) and Calf Stimulation (踢腿功) are taught to patients and caregivers, and they are encouraged to do daily practice.

Patients are also invited to formulate a personal action plan of health behaviour to improve their physical well-being. For example, for a patient with end-stage COPD suffering from dyspnoea, he/she might establish an action plan of “Practice three-minute pursed-lip breathing twice a day in the coming week”. For a patient with end-stage kidney disease significantly affected by fatigue, he/she might establish an action plan of “Practice one-minute Swing hand Qi-Gong three times a week in the coming month”. The case manager and caregivers help to monitor and review the implementation of the action plans. This emphasises the patient’s ability and responsibility throughout the illness, which in turn increases the patient’s self-control and self-efficacy.

CASE STUDY: MR CHENG

Mr Cheng, who was 81 years old and suffering from late-stage COPD, was frequently admitted to hospital due to dyspnoea. He had little understanding of COPD and had little confidence in controlling his dyspnoea. He lived in constant anxiety, out of fear of sudden shortness of breath attacks. He rested in bed most of the time to prevent dyspnoea, and he described himself as “a useless person who is living in a lonely jail”.

After being admitted to the project, Mr Cheng was educated in the prognosis of COPD and shortness of breath management. During home visits, professional volunteers helped Mr Cheng review and improve his breathing techniques in the use of inhalers and home oxygen. Moreover, he was educated in taking simple steps to tackle sudden attacks of shortness of breath. Mr Cheng was taught breathing exercises and IBMS techniques for relaxation, as well as lung functioning training, and these techniques were practised at each home visit. Mr Cheng also learnt to record his vital signs and measure the severity of his dyspnoea by scoring every day on a COPD self-management log book. These records provided a good reference for him to monitor changes in his illness. Once he had his self-monitoring plan in place, a case manager helped Mr Cheng set up an action plan to improve his skills in managing shortness of breath. He planned to practice pursed-lip breathing and diaphragmatic breathing every morning and evening. The case manager and community volunteers assisted in monitoring his implementation of the action plan. Finally, Mr Cheng successfully developed the habit of doing daily breathing exercises, which were effective in decreasing his dyspnoea.

The project helped Mr Cheng to gain confidence in coping with shortness of breath. He felt that he had a better sense of control of his illness, and he became more relieved and less anxious. With the help of community volunteers, he took walks in the park near his home every other week. He enjoyed going out very much and felt less lonely with companionship from volunteers.

Psychological and spiritual support to reduce death anxiety and future regrets.

Approaching EoL can induce intense frustration and disappointment for patients and carers. To facilitate patients in regaining and maintaining motivation and hope in their lives, both patients and caregivers are taught self-care and stress management skills, such as meditation, relaxation breathing, muscle relaxation exercises, mindfulness exercises, etc. Tailored therapeutic interventions (e.g. expressive art therapy and life review, etc.) are also provided by professional staff to help patients incorporate the experience of loss into self-integration, self-appreciation and positive death preparation.

Chinese people pay a lot of attention to family relationships and rituals. The project focuses on enhancing families' intimacy and connection. Case workers facilitate open discussion of fulfilment of unfinished business and life wishes among patients and family members. They are encouraged to express their appreciation, love, gratitude and forgiveness to each other through verbal, symbolic or metaphorical ways. The creation of treasurable family moments helps them capture loving memories that can reduce the feeling of after-death regrets.

CASE STUDY: DANIEL

Daniel was 58 years old with end-stage renal failure. He lived with his 90-year-old mother, and had one sister. Having dealt with drug addiction, Daniel had been in and out of prison throughout his troubled life. His sister was disappointed for his unruly behaviour and she had refused to see him for many years. Yet, she promised to take care of Daniel after his diagnosis because her mother begged her to do so.

During a home visit, the social worker facilitated Daniel to conduct a life review. Daniel's sister recalled that Daniel always protected her from being bullied by other children. She also remembered her brother always carried her on his back from school to home. During the process, they realised they used to be very close. Daniel described his life as messy and chaotic. He felt he had wasted most of his time on drugs. He was regretful and sorry for disappointing his family. Surprisingly, Daniel said his happiest stage of life was this EoL stage because of the reunion with his sister. He was very grateful that his sister was willing to accept him again. Daniel's sister was very touched by his confession.

Later, the social worker suggested Daniel express his gratitude to his sister by giving her a present. Daniel knew his sister likes Japanese food and therefore decided to make sushi for her. The social worker helped him videotape the sushi-making process. The video became a memorable legacy from Daniel to his sister. The social worker also helped arrange a family photoshoot for Daniel and his family. It was full of laughter and the family had an enjoyable time. A week after, Daniel died with a smile on his face.

Family-oriented discussion on ACP. Project case workers help patients and families work on communication and reach agreement on ACP. Project staff provide anticipatory guidance in coping with a patient's progressive deterioration, and this helps them understand the pros and cons of common life-sustaining treatments (LSTs), such as cardiopulmonary resuscitation (CPR), mechanical ventilation, etc. An ACP workbook, videos, game cards and other relevant materials are used to facilitate discussions.

CASE STUDY: PUI-YING

Pui-Ying, an 85-year-old lady who was suffering from COPD, lived alone after her husband had moved into an elderly care home two years previously. Pui-Ying was a determined person. When discussing ACP, she explained clearly her three wishes: (1) she did not want to have CPR and LSTs when she was in an irreversible life-limiting situation; (2) she wanted to have sea burial after her death; and (3) she wanted to visit her husband every day if possible.

With the help of the social worker, a family meeting was conducted to discuss the pros and cons of Pui-Ying's care plan. The family all agreed to help Pui-Ying fulfil her wishes. First, accompanied and witnessed by her son, Pui-Ying signed an Advance Directive (AD) in the hospital with her doctor, to refuse unnecessary resuscitation during EoL. She felt good and relieved after signing it because her choice was being respected. Second, a professional volunteer (retired nurse) visited her regularly to advise her on symptom management to help her maintain her physical ability for as long as possible so that she could visit her husband.

The discussion of ACP helped Pui-Ying live her life actively, according to her own preferences. She said it helped her regenerate flexibility in life, instead of focusing only on her physical disabilities.

MAINTENANCE PHASE

Life expectancy of late-stage chronic patients is unpredictable. After the active intervention phase, community volunteers provide intensive support in regularly monitoring patients' conditions. The Life Rainbow project has a team of community volunteers, composed of patient volunteers and volunteers who are ex-caregivers (e.g. family member of patients who have passed away). With personal experience in surviving illnesses themselves or walking with their sick family members through their EoL journey, these people are more empathetic and compassionate in understanding the needs of others and can easily build rapport with the project service users. Each community volunteer must attend a 12-hour PC volunteer training course. After training, they are paired up to provide home visits for patients and families who are in the maintenance phase. Playing the role of peer supporter, community volunteers accompany patients in doing exercises, support their IBMS practices, take them on outings, play games and engage with them in other joyful activities. Community volunteers also provide practical support to patients such as escorting them to hospital for medical follow-ups and doing grocery shopping. Apart from home visits, every project participant receives at least one caring telephone call from the community volunteer team.

Case workers and community volunteers keep in close communication and are kept updated on the changing conditions of their patients. Re-assessment of patient needs is conducted by the case worker every three months. Active interventions are reactivated if necessary, according to the changing condition of patients and changing needs of their caregivers.

CASE STUDY: MR SIT

Mr Sit, who was 78 years old, suffered from end-stage Parkinson's disease, was outgoing and enjoyed meeting new people. However, he was wheelchair-bound and had not been able to meet up with his old friends at a tea house since the disease had become so advanced. "I used to go to the tea house every morning, and my favourite seat and pot of tea would be waiting for me. Everyone there knew me and enjoyed listening to my stories." Mr Sit's wife had had a stroke, and their son needed to work, so neither could accompany Mr Sit on his outings.

Mr Leung was the volunteer who had been matched with Mr Sit, and tasked to visit him regularly. He had done this once every two weeks to play card games with him. After each session came the real highlight of the day – a trip to the tea house. The two would spend time trading jokes and stories. Mr Leung was not a patient with Parkinson's disease himself, but his late wife had been, and he understood the difficulties in coping with the illness. Mr Sit agreed: "He really understands what I am going through." Mr Leung said, "Being a volunteer benefits me too, not just the people I help, as here I feel I can do something worthwhile and be recognised for it."

DYING PHASE AND BEREAVEMENT SUPPORT

When patients enter the dying phase, project staff, including the nurses and case managers, actively support the patients, as well as their family members. Many of the families are stressed and helpless when they see their loved ones dying. At this time, many medical decisions must be made. Project staff provide emotional support to patients and families to help them fulfil their final wishes and to assist them in reaching mutual understanding and agreement on medical treatment. Bedside caring techniques (such as massage, comfort touching, comfort talking) are taught to family members so that they can provide psychological comfort and support to dying patients. It is very important at this stage to acknowledge family members for their contribution, love and caring for their loved ones.

CASE STUDY: JESS AND HER MOTHER

More than a decade ago, Jess left her job to become a full-time caregiver for her mother, who was diagnosed with renal disease. Losing a loved one is never easy, and it was hard for Jess to watch her mother suffer in the final stage of her disease. In the final days, Jess's mother had been in a coma. With support from the project, she was able to obtain assistance from a social worker and a nurse. After evaluating the mother's health, the nurse taught Jess some bedside skills, such as hand massage, face cleaning, etc. For Jess, it was crucial to feel connected with her mother through physical contact and bedside caring. The social worker also provided mental health support to Jess, recognising the love and effort she put in in taking care of her mother. The social worker told Jess that when a person dies, the sense of hearing is the last to go. For that reason, the social worker encouraged Jess to talk to her mother on a daily basis, for instance saying "thank you", "do not worry", "I will take good care of myself" and to tell her she loves her. Jess's mother had one last wish, which was to see her four-year-old grandchild who lived overseas. With coordination between the social worker and the hospital, a quiet corner was arranged for the family to say goodbye to the dying mother. In the end, Jess's mother passed away peacefully with her family by her side. Afterwards, Jess said that she had offered the best care for her mother and she had no regrets.

This phase of the project aims to provide bereavement support to surviving family members so that they can suffer from less complicated grief and travel a normal bereavement pathway. Bereavement support is provided to family members for about six months after patients have died. Case workers and community volunteers support families with funeral arrangements, if necessary, and case managers keep regular contact with family members to assess their bereavement progress after the funeral. In fact, many caregivers have been so devoted in caring for their loved ones (often for years) that they have neglected their own physical and psychological well-being. Case managers will match surviving family members with group work services of chronic illness management and psychosocial support provided by the Hong Kong Society for Rehabilitation – Community Rehabilitation Network (CRN) according to their needs. They are invited to join different mutual support groups, volunteer groups or caregiver group to re-establish social connections and for peer support. Meanwhile, community volunteers provide emotional support by care telephone calls, accompanying them on outings and doing things they enjoy. If there are surviving family members who have complicated grief and are at high bereavement risk, they will be referred to agencies that specialise in providing bereavement counselling.

CASE STUDY: MONICA

Monica was a full-time caregiver for her mother, who had been diagnosed with renal failure 10 years earlier. As the only daughter in the family, she was appointed as the main carer by her four older brothers. After her mother died, Monica felt empty and purposeless. She claimed that: "All my life was for her over all these years, now I seem to have nothing after she has gone." Monica was invited by the case manager to join a bereavement support group and to build up social networks with other peers. They would meet regularly for different organised social activities. She also attended some therapeutic groups, such as mindfulness experiential groups, organised by the Community Rehabilitation Network (CRN) to try to recognise her own emotions, to understand different meanings of physical symptoms and to take good care of herself. After several months, Monica felt more released from her grief and has joined the Life Rainbow project as a volunteer.

OUTCOMES

Data from 126 cases were analysed from the first two years of the pilot project (to 31 December 2017). The findings indicated that after one month of engagement with the Life Rainbow project, patients showed significant improvement in physical symptoms (shortness of breath, weakness/lack of energy, poor appetite, drowsiness and poor mobility), psychosocial well-being (depression, anxiety and not feeling at peace), family communication (family anxiety and being unable to share feelings with friends and family), as well as other practical concerns (practical difficulties and unmet information needs). After three months of engagement, the results remained positive and patients showed significant improvement in all these areas. They also reported that alleviation of physical symptoms was more significant in the first month than in the third month, while psychological symptoms as well as family communication were significantly improved from the second to third month of project engagement. In addition, medical utilisation in terms of hospital bed days were reduced significantly ($t(43) = -2.281, p=0.028$) after three months of engagement with the project.

Regarding caregivers, it was reported that family anxiety reduced significantly after receiving support from the project, while caregiving strain, as well as IBMS of the caregivers, remained stable. In the bereavement stage, the Inventory of Complicated Grief (ICG) scored 13 out of 76, with all family members in the low grief group (0–25). It was noted, however, that the number of days in the last month for caregivers being sick was significantly higher than in previous stages.

PROJECT EXPERIENCE HIGHLIGHTS AND CONCLUSION

The first insight from the JCECC: Life Rainbow project is that this multidisciplinary, holistic, community-based approach to providing EoLC is effective for relieving symptoms and improving psychosocial–spiritual well-being for late-stage chronic disease patients. It suggests that this approach is promising for meeting the estimated huge demand for local community-based PC. By adopting non-pharmaceutical approaches, such as IBMS and self-management, with collaboration of medical staff and professional and neighbourhood volunteers, the Life Rainbow project could provide support to patients and their families to more effectively improve the quality of EoLC at a lower cost.

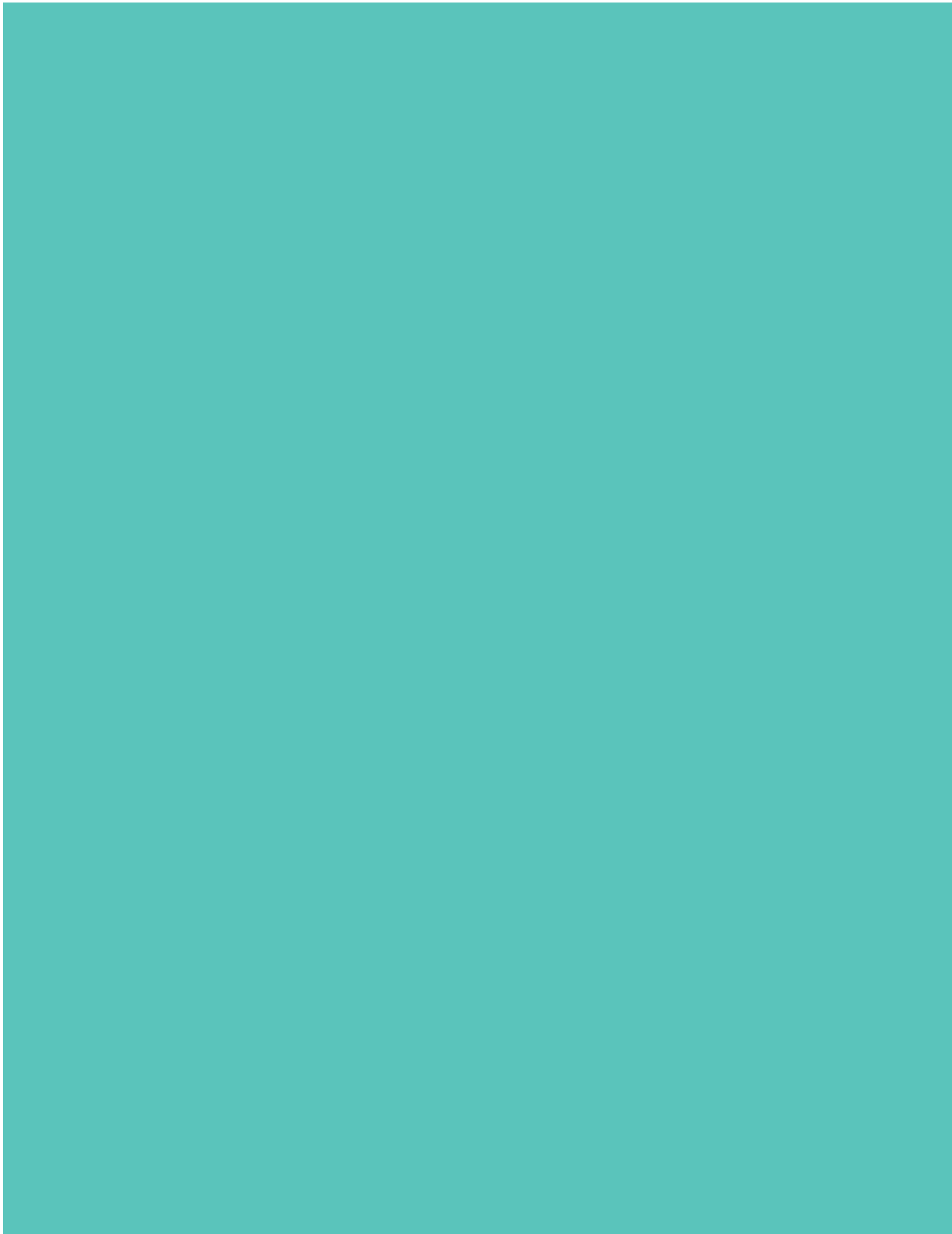
The second insight from the project is that death preparation and discussion about ACP for non-cancer patients should occur as early as possible, even at the point of early diagnosis of a disease. In the JCECC: Life Rainbow project, case managers and nurses usually initiate these discussions during the first few sessions, when providing anticipatory guidance to patients and family members about coping with the patient's progressive deterioration. Content of discussion is comprehensive, including life review, future planning, death preparation, wish fulfilment and preferred treatment options. The project found that most patients and family members are willing to discuss this openly, using a step-by-step community-based ACP approach. To date, 90% of the Life Rainbow project cases have completed ACP discussion and formulated their plans. Among those service participants who have passed away, approximately 90% of them were reported to have signed a DNR statement in hospital during their final days. Early ACP discussion is crucial to help patients and families become more competent to face increasing physical deterioration and ultimate death.

Another lesson from the project is that caregiver support should be strengthened. In the project, caregivers are very involved in the interventions (determining what they should be and delivering them if possible). They are empowered and supported to take care of their patients, and to try to meet the patient's needs and wishes. However, there is not enough emphasis on addressing caregivers' own holistic needs, including their physical health, their needs to improve emotional competence and opportunities for more social participation. It is reported that more than 50% of the caregivers in this project have different kinds of chronic health conditions, but they also claim that because of the caregiver role, they are "always busy" and do not have time to take care of their own health. They occasionally

miss their own medical appointments because of the caring demands placed on them. In view of this, the future service model should include raising awareness of caring for the caregivers and providing viable support for them, which match their busy daily schedules and are sustainable in the long term. Possible strategies include forming support groups for caregivers and organising workshops to improve their wellness and increase their readiness to face the death of their loved one. During the bereavement phase, it is important to provide ongoing support to caregivers, not only with funeral arrangements, but in other areas such as arranging companionship from peer supporters, organising short-term bereavement workshops and encouraging caregivers who have chronic health conditions to learn how to better manage their own health.

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PART III:

CAPACITY BUILDING IN COMMUNITY- BASED END-OF-LIFE CARE

CHAPTER 10

END-OF-LIFE CARE COMPETENCES FOR ALL: BUILDING A CROSS-CUTTING CORE COMPETENCY FRAMEWORK FOR HEALTH AND SOCIAL CARE PROFESSIONALS IN THE COMMUNITY

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End-of-lifecare(EoLC)shouldbethebusiness of all health and social care professionals. Education and training on EoLC should therefore target all levels of the healthcare system. Core competency frameworks in palliative care (PC), and EoLC, will inform training programmes by detailing essential training contents and expected learning outcomes. Core competency frameworks have a role to play in the standardisation of quality across curricula. In order to guide the formulation and assessment of the Jockey Club End-of-Life Community Care (JCECC) Project capacity building programme in Hong Kong communities, a cross-cutting EoLC core competency framework for all health and social care

professionals was developed, based on international competency frameworks. The JCECC Project competency framework should also guide future development of EoLC curricula. This chapter starts with clarifying the educational priorities of the JCECC Project in relation to establishing relevant core competency frameworks. An overview is presented of international PC and EoLC competency frameworks. This is followed by a discussion on the important framework properties that are relevant to the JCECC Project. The last part of the chapter describes the establishment and properties of the JCECC End-of-Life Care Core Competency Framework.

BACKGROUND

THE PRESSING NEED OF EDUCATION FOR EoLC IN HONG KONG

PC and EoLC have become a highly specialised service in Hong Kong and, consequently, so has its training. PC training is mainly provided through qualification-based continuing professional education to doctors and nurses who are preparing to work as specialists in this field. In 2016, around 40 doctors and 600 nurses were providing specialist PC in Hong Kong (Cheung, 2016; Hospital Authority [HA], 2017). In the same year, approximately 80% of the 46,000 deaths that occurred in Hong Kong were due to chronic diseases. The argument to upskill more PC specialists is compelling; however, the responsibility to care for patients facing life-limiting diseases should not be vested only in PC specialists.

The World Health Assembly (WHA) resolutions on PC, published in 2014, affirmed the importance of integrating PC into all levels of the healthcare system (WHA, 2014). Responding to this, healthcare practitioners in Hong Kong called upon the government to develop a local PC policy to promote better integration of PC into the local healthcare system (Chan, 2018). In 2017, the HA proposed a shared-care model for PC, which emphasises collaboration between PC specialists and non-specialists (HA, 2017). These initiatives all underscore the pressing need for training to be provided for health and social care professionals who are not specialised in PC.

In Hong Kong, EoLC topics are not yet integrated into the fabric of undergraduate curricula for relevant health and social care professionals. Despite continuing professional education, such as diploma or certificate courses, and workshops being offered by professional bodies and academic institutions, the content of training programmes varies. Moreover, low awareness of the need for upskilling and less-than-adequate competences have been consistently reported among health and social care professionals (Chan, 2014; Cheung et al., 2018; Hong, Lam & Chao, 2013; Lau, 2017). Although social workers have been recognised as key providers of PC services in HA, there is no specialised training currently targeted at them (Chan, 2014). In light of these training gaps, generalist training for health and social care professionals has become the priority in the JCECC Project capacity building programme. In particular, the University of Hong Kong (HKU) focuses on capacity building in the community, with a specific emphasis on psychosocial care at end of life (EoL). Before developing a training programme, it was recognised that, as a prerequisite, a competency framework needed to be established that articulated the competences required in the provision of quality EoLC (Gómez-Batiste, Lasmarías, Connor & Gwyther, 2017). As there is no published EoLC competency framework available in Hong Kong, the project team first established a contextually relevant framework before developing capacity building programmes.

OVERVIEW OF PC AND EoLC COMPETENCY FRAMEWORKS

Competency is defined as an integration of knowledge, skills, values and attitudes that underpin an individual's actual performance in particular situations (Gamondi, Larkin & Payne, 2013a). On the other hand, *competence* refers to the potential that an individual can successfully carry out a required set of actions (Orchard & Bainbridge, 2016). A PC competency framework sets out competency domains, which are required by healthcare professionals to be able to provide quality PC. In each competency domain, competences (plural form of *competence*) are defined in terms of knowledge, skills and attitude. A competency domain can contain different competence descriptors, and the required levels of proficiency (low to high proficiency). Thus, a competency framework can be used to guide curriculum development by suggesting learning topics and expected learning outcomes, and define the competences required for various proficiency levels.

Different PC competency frameworks for health and social care professionals have already been developed in different parts of the world. In 2012, a review conducted by the All Ireland Institute of Hospice and Palliative Care (AllHPC) identified 29 competency frameworks developed in the UK, US, Canada, Australia and Northern Ireland (Connolly, Charnley, Regan & AllHPC, 2012). New frameworks have been published since this review to address different care settings and target groups, and to meet the needs of different populations (e.g. Health Education England, Skills for Health & Skills for Care, 2017; McCallum et al., 2018; Sousa & Alves, 2014; Stanyon, Goldberg, Astle, Griffiths & Gordon, 2017).

Three key aspects that influence scope and application of a competency framework have been identified:

1. **Targeted professional groups.** For which discipline(s) is (are) the competency framework designed? Does the framework target single or multiple disciplines?
2. **Competence levels.** What levels of competences should be included? How are levels of competences defined?
3. **Competence domains and contents.** What are the essential competency domains and competences that should be included? How should competences be categorised into competency domains?

These three aspects interact with each other in order to determine the scope and application of a competency framework. The following section discusses these aspects of competency frameworks individually. They are then considered in terms of the selection of reference frameworks for the JCECC Project.

TARGET PROFESSIONAL GROUPS

The proliferation of interdisciplinary competency framework in PC and EoLC. Countries with advanced development in PC and EoLC have already developed competency frameworks to address the needs of a range of disciplines (medicine, nursing, occupational therapy, physiotherapy, emergency health services, dietetics, speech and hearing therapy, midwifery, pharmacy, pastoral care, social work, clinical psychology and healthcare assistants).

There are two broad types of frameworks: discipline-specific and interdisciplinary. Discipline-specific frameworks target PC competences for a specific discipline. Examples of these are the core competencies in PC social work, developed under the European Association of Palliative Care (EAPC) (Hughes, Firth & Oliviere, 2015) and the competency framework for nurses, developed by the Palliative Care Nurses New Zealand (2014). Interdisciplinary frameworks, on the other hand, are cross-cutting, such that they are relevant to, and can be applied across, multiple disciplines. Their frameworks focus on core competency domains in PC, which are common to all health and social care professions.

During the last decade, there has been a proliferation of interdisciplinary common core competency frameworks in PC and EoLC, including the Palliative Care Competence Framework developed in Ireland (Palliative Care Competence Framework Steering Group, 2014); the *Core competencies in palliative care: An EAPC White Paper on palliative care education* (Gamondi et al., 2013a); the *Common core competences and principles for health and social care workers working with adults at the end of life* in the UK (UK Department of Health, 2009); the *End of life care core skills education and training framework* in the UK (Health Education England et al., 2017); the *Developing a palliative care competency framework for health professionals and volunteers: The Nova Scotian experience* in Canada (McCallum et al., 2018); and the *Core competencies: A framework of core competencies for palliative care providers in Africa* (African Palliative Care Association, 2012).

The collaborative nature of PC and EoLC, coupled with growing recognition of the value of interdisciplinary learning in facilitating effective collaborative practice, might have underpinned this development. On the other hand, this could be a manifestation of the heightened national level impetus to enhance cross-discipline and cross-sectoral collaboration in countries with more advanced development of PC services. In the EAPC White Paper on Palliative Care Education (Gamondi, Larkin & Payne, 2013a, p. 90), it was stated that:

At the core of good collaborative practice is the ability to understand and respect boundaries of practice, to know when and how to refer for expert advice and intervention where necessary, and to ensure a meaningful communication flow of relevant information through the team, in order to provide quality care for the patient and family. One of the challenges of collaborative work is to share a common philosophy of care and common goals.

Notably, competencies in interdisciplinary frameworks are written in common language and avoid specialist terms, so that different disciplines in health and social care can relate to them (UK Department of Health, 2009; Gamondi et al., 2013a). The use of common core learning domains transcending all professional groups can also “assist in developing a consistent approach to cross-sectoral and cross-discipline learning” (Palliative Care Australia, 2010, p. 5).

Common competences as a unique feature in interdisciplinary framework. From the perspective of competence-based models in interprofessional education, Barr (1998) classified three types of competences important to interprofessional practices. An interdisciplinary competency framework should incorporate all three types of competences.

The first competence type identified by Barr (1998) is “common competences”, which are shared by all professions and can only be found in frameworks with an interdisciplinary focus.

The second competence type is “collaborative competences”, which require each profession to work with others (Barr, 1998). The Interprofessional Education Collaborative (IPEC) in the US published four core competency domains in interprofessional practice: teams and teamwork, interprofessional communication, understanding roles and responsibilities, and values and ethics for interprofessional practice (IPEC, 2011). Collaborative competences of similar contents are embedded as core competences in most frameworks, regardless of whether they are discipline-specific or interdisciplinary. Some frameworks have collaborative practices as a stand-alone competency domain, while others integrate collaborative competences into other domains.

The third type of competence in Barr’s framework (Barr, 1998) is “complementary competences”, which refer to competencies specific to one profession that are complementary to competencies specific to other professions. In other words, these are discipline-specific competences that have an interprofessional application. In reality, each discipline will contribute to the same care domain with knowledge and skills unique to their discipline. “Complementary competences” are the focus in discipline-specific frameworks, but they can also be incorporated into an interdisciplinary framework. In the competency frameworks in Nova Scotia and Ireland, complementary competences for individual disciplines are elaborated on in each competency domain (McCallum et al., 2018; Palliative Care Competence Framework Steering Group, 2014). Mapping complementary competencies for each discipline into an interdisciplinary framework has the merit of fostering an interprofessional understanding regarding roles and responsibilities of each profession, articulating with same frame of reference.

Figure 10.1 depicts how these three types of competences manifest themselves in discipline-specific and interdisciplinary frameworks. Basically, complementary and collaborative competences are central to all discipline-specific competency frameworks. On the other hand, an integral part of interdisciplinary frameworks accentuates common competences with collaborative competences (with or without additional complementary competences specified for each discipline involved). This discussion does not imply unconditional preference for interdisciplinary frameworks, as the two framework types serve different purposes. The former focuses on building a common foundation of competences across disciplines, whereas the latter focuses on specific roles and contributions most relevant to a single discipline.

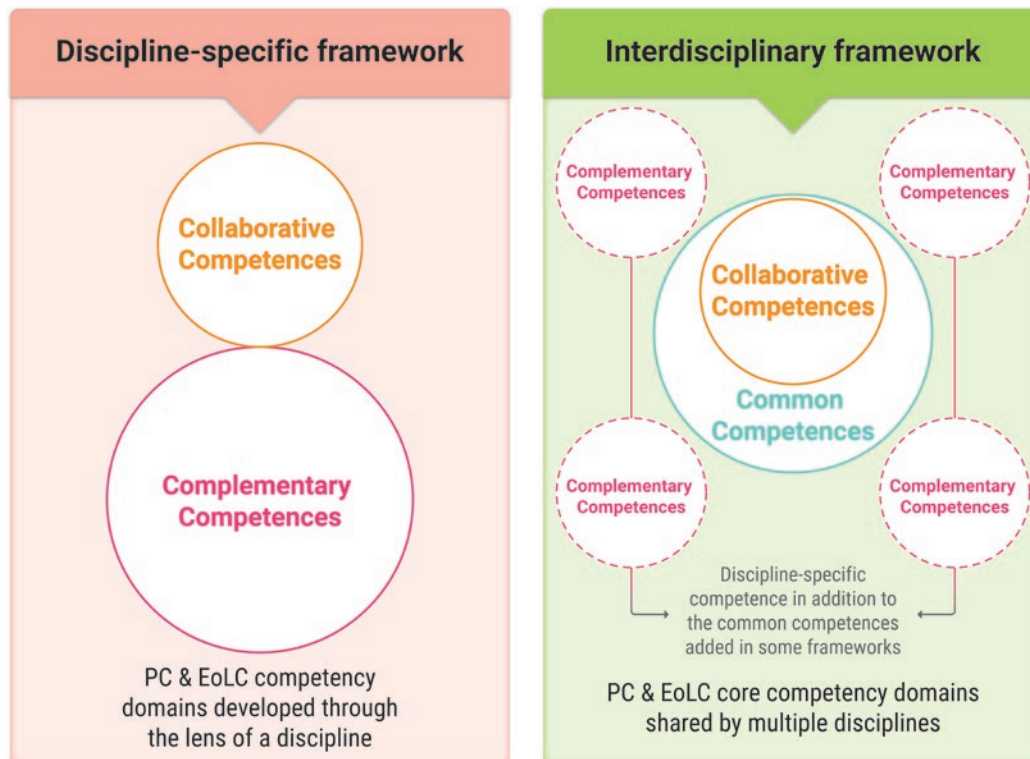


Figure 10.1 Types of Competences in Discipline-Specific and Interdisciplinary Competency Frameworks in Palliative and End-of-Life Care

COMPETENCE LEVELS: A THREE-TIERED APPROACH TO INTEGRATE PC AND EoLC INTO HEALTHCARE SYSTEMS

The resolutions on PC established by the WHA in 2014 urged countries to integrate core competencies of PC into undergraduate and postgraduate curricula, to ensure that all health and social care professionals possess the necessary knowledge and skills to provide at least a basic level of PC and EoLC to patients who need it (WHA, 2014). More importantly, it is now widely recognised that patients with life-limiting diseases have varying levels of PC needs that require services provided by people with different levels of PC expertise. Addressing these needs often requires flexible collaboration between PC specialised teams and care teams of other specialties, including primary care. For instance, some patients have persistent and complex care needs throughout their illness trajectory, which require ongoing involvement of specialist PC teams. Others may experience complex conditions only at some points in the course of their illness, and thus require only episodic interventions from specialist PC teams, while continuing to be cared by a primary care team. Yet others may follow an expected progress throughout their illness and can be well managed by non-specialists who provide generalist PC (Irish Association for Palliative Care, 2018; McCallum et al., 2018; Palliative Care Australia, 2005). Apart from a minimum level of basic knowledge in PC, intermediate level of training should therefore be tailored and provided to non-specialists according to their roles and responsibilities, care settings and involvement in patients' illness trajectories and the PC continuum.

There is an increasing use of a three-tier approach to PC, which has informed international efforts to include different levels of competences in PC competency frameworks. As early in 2001, the National Advisory Committee on Palliative Care in Ireland published a three-tier framework for PC and EoLC services, with the levels of specialisation in PC being "Palliative care approach", "General palliative care" and, lastly, the highest level, "Specialist palliative care" (Department of Health and Children, 2001). Similar three-tiered approaches have been outlined more recently in national strategies published in UK and Australia, and also in the EAPC White Paper on Palliative Care Education (Gamondi et al., 2013a; Palliative Care Australia, 2018; UK Department of Health, 2008).

Drawing on the three-tier frameworks, **Table 10.1** summarises the definition of each level of PC and EoLC, and the required training in each respective level. The first level "Palliative care approach" refers to a minimum level of core basic knowledge and attitudes in PC and EoLC that all health and social care professionals should have. The second level, "General palliative care", is a set of basic skills in PC and EoLC that should be practised by health and social care professionals who are not specialised in PC, but who frequently deal with patients with life-limiting diseases. They should be supported and advised by specialist PC team(s). Lastly, the third level, "Specialist palliative care", refers to specialised PC and EoLC services provided by health and social care professionals as their sole role. Specialist PC team(s) demonstrate high levels of expertise in managing complex symptom management and spiritual, psychosocial and bereavement care.

Table 10.1 Three-Tier Approach to Palliative Care Adapted from Definitions in the Frameworks of the UK and EAPC (UK Department of Health, 2009; Gamondi et al., 2013a)

LEVELS	DEFINITION	REQUIRED SKILLS AND KNOWLEDGE
Tier 1 Palliative care approach	Basic principles and practice in PC practised by health and social care professionals who infrequently have to deal with end-of-life care. This is integrated into the care of patients with progressive and advanced diseases in settings not specialised in PC/EoLC.	Core competences in PC in terms of knowledge and attitudes that should be demonstrated by all health and social care professionals. All professionals should also know when and how to access to specialist services or seek expert advice. Core competences should be integrated in undergraduate medical and nursing professional education, and should be taught to social care professionals through undergraduate training or continuing professional education if they did not receive this basic education in their undergraduate studies.
Tier 2 General palliative care	Intermediate level of PC that is practised by health and social care professionals who work in settings not specialised in palliative or end-of-life care but frequently or regularly have to deal with patients with end-of-life issues and provide palliative and end-of-life care as part of their role.	Additional specialist training is needed to enable health and social care professionals to apply the learnt knowledge into their care and develop good basic skills in multiple palliative and EoLC competences. Health and social care professionals in this level are in a good position to identify those patients in need of palliative and integrate Advance Care Planning (ACP) discussion early in the care pathway. These competences can be, but not necessarily, taught in undergraduate studies. They can also be taught in postgraduate learning or through continuing professional education.
Tier 3 Specialist palliative care	The highest level of PC, which is practised by health and social care professionals who work in settings specialised for palliative and end-of-life care, and provide palliative and end-of-life care as their main role. Service settings providing specialist PC may also provide consultative support services to other health and social care professionals involved in the care of people with life-limiting disease.	Qualification-based training is needed, and specialists have to be equipped with competences to work closely with multidisciplinary team to provide integrated care to patients with complex needs that are more than routine symptom management needs. These can be taught at postgraduate level or boosted through continuing professional education.

The three levels of competence are termed basic, intermediate and advanced/specialist levels in some frameworks (e.g. Martine, Nuria, Philip & Francoise, 2004), while in other frameworks they were divided into competences required by “all”, “some” and “few” practitioners (e.g. Palliative Care Competence Framework Steering Group, 2014). For simplicity, competence levels are only divided into generalist and specialist levels (e.g. Health & Social Care Northern Ireland, 2016). Not all frameworks cover all competence levels. For instance, the UK and EAPC core competency frameworks only stipulate a minimum level of competence expected of all health and social care professionals (UK Department of Health, 2009; Gamondi et al., 2013a).

COMPETENCE DOMAINS AND CONTENTS: CONVERGENCE TO A SET OF CORE SKILLS

A PC competency framework sets out competency domains to reflect the values and principles underpinning PC. However, with reference to interdisciplinary frameworks, the coverage of competency domains across frameworks varies in relation to local PC practice or performance standards, as well as the scope of target groups and proficiency levels designated in the framework. Categorisation of domains also varies across frameworks. There are a few approaches to categorising PC competency domains, such as dividing competences into generic skill areas, grouping competences into different phases in the “patient journey”, or distilling competences into different aspects of interaction involved in PC (Scottish Partnership for Palliative Care, 2007). Categorisation of generic skill aspects is most common in interdisciplinary frameworks. Despite the international variations, frameworks that target a minimum level of competence generally have common aspects, including PC principles, communication, enhancing physical comfort, addressing psychosocial–spiritual well-being, collaborative practice, care planning and decision-making at EoL (UK Department of Health, 2009; Gamondi et al., 2013a; Gamondi, Larkin & Payne, 2013b). Frameworks that extend to intermediate or specialist levels may include other domains such as leading organisations, education, advocacy, research and auditing (African Palliative Care Association, 2012; Health Education England et al., 2017; McCallum et al., 2018).

Regarding competency content, some frameworks classify competences in terms of knowledge, skills and attitude (KSA) (e.g. Health & Social Care Northern Ireland, 2016); however, the absence of a KSA classification is not uncommon in frameworks that only present generic competences. One of the drawbacks to not using this classification is the risk of overlooking one or more KSA attributes, which may lead to low proficiency. Tools to assess competencies have also been developed from some competency frameworks, e.g. the evaluation toolkit developed by Whittaker, Broadhurst & Faull (2015), which is based on the UK Common Core Competences and Principles for Health and Social Care Workers Working with Adults at the End of Life.

Table 10.2 summarises the properties of six interdisciplinary PC and EoLC competency frameworks, as well as two assessment tools developed from the UK common core competency framework, which was reviewed by the HKU project team. It should be noted that only five of the reviewed publications in the list were published by the time the JCECC Project framework was built in 2015.

Table 10.2 Summary of Key Interdisciplinary Competence Framework Documents Reviewed

DOCUMENT	COUNTRY	TARGET GROUP(S)	COMPETENCY DOMAINS AND COMPETENCES
Palliative care competence framework (Palliative Care Competence Framework Steering Group, 2014)	Ireland	12 disciplines in health and social care	Six competency domains: <ol style="list-style-type: none"> 1. Principles of PC 2. Communication 3. Optimising comfort and quality of life 4. Care planning and collaborative practice 5. Loss, grief and bereavement 6. Professional and ethical practice in the context of palliative care
Common core competences and principles for health and social care workers working with adults at the end of life (UK Department of Health, 2009)	UK	All disciplines involved in supporting people approaching EoL	Five competency domains: <ol style="list-style-type: none"> 1. Overarching values and knowledge 2. Communication skills 3. Assessment and care planning 4. Symptom management, comfort and well-being 5. Advance Care Planning
Evaluation toolkit: Assessing outcomes of end of life learning events (Whittaker et al., 2015)	UK	All disciplines involved in supporting people approaching EoL	A self-assessment toolkit based on the competency framework developed by the UK Department of Health (2009)
Palliative and end-of-life care competency assessment tool (Health & Social Care Northern Ireland, 2016)	Northern Ireland	All disciplines involved in PC and EoLC	A self-assessment tool developed using the competences from the Northern Ireland Cancer Network Framework for Generalist and Specialist Palliative and End-of-Life Care Competency (as cited in Palliative Care Competence Framework Steering Group, 2014) mapped to the five competency domains of the framework developed by the UK Department of Health (2009). Competences are categorised into knowledge, skills and attitude.
Core competencies in palliative care: An EAPC White Paper on palliative care education (Gamondi et al., 2013a, 2013b)	Europe	All health and social care professionals	Ten competency domains are as follows: <ol style="list-style-type: none"> 1. Application of PC approach 2. Enhancement of physical comfort of patients 3. Address patient's psychological needs 4. Address patient's social needs 5. Meet patient's spiritual needs 6. Respond to the needs of family caregivers 7. Clinical and ethical decision-making 8. Care coordination and interdisciplinary team 9. Interpersonal and communication skills 10. Practice self-awareness and undergo continuing professional development

TYPES AND LEVELS OF COMPETENCE INCLUDED IN COMPETENCY DOMAINS

COMMON (SHARED/OVERLAPPED)	COMPLEMENTARY (DISCIPLINE-SPECIFIC)	COLLABORATIVE
A minimum level of competences shared by the 12 disciplines	Competences in each domain are further differentiated into three levels for “all”, “some” and “few” practitioners for each discipline	Included in the domain of “care planning and collaborative practice”
A minimum level of competences expected of all health and social care professionals		
A minimum level of competences expected of all health and social care professionals		Included in the domain of “Advance Care Planning”
Two levels of common competences are stipulated, with the first level targets on generalists and the second targets on specialists in PC and EoLC	Included in the subdomain of “teamwork”	
In each competency domain, constituent competences expected of all professions are described		Included mainly in the domain of “practice comprehensive care coordination and interdisciplinary teamwork across all setting where PC is offered”

(Continued Next Page)

DOCUMENT	COUNTRY	TARGET GROUP(S)	COMPETENCY DOMAINS AND COMPETENCES
<i>End of life care core skills education and training framework</i> (Health Education England et al., 2017)	UK	Competences are defined at three tiers, with the first tier for general public, second and third tiers for health and social care professionals in general	Fourteen domains are as follows: <ol style="list-style-type: none"> 1. Person-centred EoLC 2. Communication in EoLC 3. Equality, diversity and inclusion in EoLC 4. Community skills development in EoLC 5. Practical and emotional support in EoLC 6. Assessment and care planning in EoLC 7. Symptom management in EoLC 8. Working in partnership with others 9. Support for carers 10. Maintain own health and well-being 11. Care after death 12. Law, ethics and safeguarding 13. Leading EoLC services and organisations 14. Improving EoLC quality through policy, evidence and reflection
<i>Developing a palliative care competency framework for health professionals and volunteers: The Nova Scotian experience</i> (McCallum et al., 2018)	Nova Scotia, Canada	22 disciplines in health and social care, and volunteers	The six competency domains developed in the Ireland Core Competency Framework (Palliative Care Competence Framework Steering Group, 2014) are adopted and seven extra domains are added to reflect the values of the Nova Scotia Health Authority: <ol style="list-style-type: none"> 1. Cultural safety 2. Last days and hours 3. Self-care 4. Education 5. Evaluation 6. Research 7. Advocacy
<i>Core competencies: A framework of core competencies for palliative care providers in Africa</i> (African Palliative Care Association, 2012)	Africa	Various professional care providers (doctors, nurses, clinical officers, social workers, spiritual care providers) and community care providers	Competency domains in line with the African Palliative Care Association Standards for Providing Quality Palliative Care across Africa: <ol style="list-style-type: none"> 1. Organisational management 2. Holistic care provision 3. Education and training 4. Research and management of information <p>There are subdomains under each of the four competency domains, and competences are categorised into knowledge, skills and attitude.</p>

TYPES AND LEVELS OF COMPETENCE INCLUDED IN COMPETENCY DOMAINS

COMMON (SHARED/OVERLAPPED)	COMPLEMENTARY (DISCIPLINE-SPECIFIC)	COLLABORATIVE
Two levels of common competences are defined for professional workers; one level targets professionals who infrequently work with EoL patients, the other level targets professionals who are not specialists in EoLC, but require in-depth knowledge of EoLC because they frequently work with individuals approaching EoL		Included in the domain of “working in partnership with health and care professionals and others”
A minimum level of competences shared by the 22 disciplines in health and social care, and volunteers	For each discipline, complementary competences or competency domains are additionally added	Included in the domain of “care planning and collaborative practice”
Three levels (basic, intermediate and specialist) of competences are designed in each competency domain for PC providers and community care workers separately		Included in subdomains under the domain of “holistic care provision”

BUILDING THE JCECC PROJECT EoLC COMPETENCY FRAMEWORK

Based on the information presented earlier, the UK and EAPC core competences frameworks were chosen as key references when constructing the JCECC Project framework. They were chosen because these frameworks involved only core competency domains that related to all disciplines. This focus matches the JCECC Project objective of building a solid foundation of knowledge across health and social care professionals. Moreover, the assessment toolkit developed by Whittaker et al. (2015), which is based on the UK framework, provides a sound basis for the project team to develop an assessment tool for the JCECC Project capacity building programme.

Five principles in the JCECC Project community-based EoLC programme also underpin the development of the JCECC Project End-of-Life Care Core Competency Framework:

1. Care in and by the community;
2. Respecting choice and autonomy;
3. Family as service unit;
4. Holistic care with an emphasis on psychosocial care, and
5. Evidence-based practice.

By adapting the two referenced frameworks, the JCECC Project End-of-Life Care Core Competency Framework was developed with seven competency domains. Modifications were undertaken with consideration of the aforementioned competency principles, while also reflecting the unique features of the JCECC Project capacity building programme (e.g. emphasis on psychosocial care) and adapting some competences to fit local contexts (e.g. removing items on the Gold Standards Framework and using local terms for medical orders). Before the final version was endorsed, the framework underwent several rounds of review by the JCECC Project HKU team, which ensured that it was considered by professionals with a range of backgrounds (medicine, nursing, social work and psychology).

The seven domains of the JCECC framework encompass core competencies commonly shared by all health and social care professionals in providing quality EoLC:

1. Overarching values and knowledge;
2. Communication skills;
3. Symptom management, maintaining comfort and well-being of patients and families;
4. Psychosocial and spiritual care;
5. End-of-life decision-making;
6. Bereavement care; and
7. Self-care and self-reflection.

While the framework comprises mainly common competences, collaborative competences have been incorporated into the domain of “communication skills”. Complementary competences are not the focus of the capacity building programmes of HKU. However, two of the JCECC Project partners target education programmes for doctors and nurses (see Haven of Hope Christian Service in Chapter 6 and CUHK Jockey Club Institute of Ageing in Chapter 12). The education programmes include topics on initiating ACP, Advance Directives (AD) and Do Not Attempt Cardiopulmonary Resuscitation (DNACPR). Thus, complementary competences are incorporated into the current framework. The framework takes a particular emphasis on strengthening psychosocial care and communication-related competences in EoLC by embedding two levels of competences (fundamental and intermediate levels). The fundamental level provides basic knowledge on necessary theories supporting evidence-based psychosocial and bereavement care. Application of these theories reflects the learning outcomes in the intermediate level. It should also be noted that some competences are relevant to multiple domains but are categorised under only one domain, to reflect the domain in which they have the most prominent impact. The competency statements of each domain are discussed next.

1. **Overarching values and knowledge.** Professionals have a basic understanding of societal and cultural influences on EoLC, the ethical issues in EoLC and basic knowledge on available EoLC services and support that can be provided in different settings.
2. **Communication skills.** Professionals understand the central role of effective communication in quality EoLC. They can communicate sensitively and openly with patients at EoL, and their family members, to support person-centred care. They are able to use effective communication skills with other team members in interdisciplinary EoLC teams to promote efficient information sharing and collaborative practices.
3. **Symptom management, maintaining comfort and well-being of patients & families.** Professionals have basic knowledge about common distressing physical symptoms in EoL, and awareness of the multidimensional factors contributing to this distress. They can demonstrate basic competences in assessing and helping patients and family members manage these symptoms.
4. **Psychosocial and spiritual care.** Professionals are aware of the significance of evidence-based psychosocial and spiritual care in EoLC, and can incorporate psychosocial–spiritual assessment as an integral part of a holistic assessment of patients and family members to facilitate individualised care planning. When patients and family members have indicated psychosocial–spiritual distress, professionals are able to support them with evidence-based interventions and knowledge about other support services.
5. **EoL decision-making.** Professionals are aware of the significance of respecting choices and maximising autonomy of patients in EoL. They also possess basic knowledge about legal and ethical issues surrounding EoLC in order to help patients and family members make EoL-related decisions. For intermediate learners, professionals should also be competent in assisting patients and family members resolve conflicts surrounding EoL decisions.

6. **Bereavement care.** Professionals are aware of the importance of supporting family members of EoL patients through the grieving process. While most bereaved family members can deal with loss with their own resources and support from friends and family, a minority may experience difficulties in their grieving. Professionals should possess the necessary knowledge and skills to assess bereavement care needs and provide support when needed. For intermediate learners, professionals should also be competent in intervening with bereaved individuals with evidence-based practices.
7. **Self-care and self-reflection.** Professionals should acknowledge their limitations in the face of death and be aware of the possible influence of involvement in EoLC on their own values and emotions. They should also demonstrate understanding about the significance of self-reflective practice in the delivery of good EoLC.

Table 10.3 presents the component competences under each domain and provides an indication of the type and level of each competency item. A 38-item multidimensional EoLC competence assessment tool was subsequently developed based on this competency framework. It covers six of the domains, with each competency item rated on a 10-point Likert scale between 1 (not competent at all) and 10 (very competent). The remaining domain on self-care and self-reflection is measured by the Self-Competence Scale in Death Work (SC-DW) (Chan, Tin & Wong, 2015). The assessment package has been adopted in the outcome evaluation of the JCECC Project capacity building programme delivered by HKU. The evaluation findings are presented in Chapter 13.

Table 10.3 JCECC End-of-Life Care Core Competency Framework for Health and Social Care Professionals in the Community

Domain 1: Overarching values and knowledge	<ul style="list-style-type: none"> » Understanding of societal and cultural influence on EoLC (Com-F) » Understanding on how to handle ethical issues in EoLC (Com-F) » Demonstrating knowledge on EoLC options in different settings (Com-F) » Understanding available community-based EoLC support services, and knowing how to access and collaborating with these services in their care for patients facing EoL (Com-F) » Maintaining professional boundaries when helping patients and families (Com-F)
Domain 2: Communication skills	<ul style="list-style-type: none"> » Listen to and talk with patients and family members on topics surrounding EoLC issues (Com-F) » Communicating psychosocial and spiritual concerns with patients and family members (Com-F) » Recognising and addressing patient's and family members' communication cues (Com-F) » Facilitating communication among patients, family members and care team (Collab-F) » Collaborating with other disciplines in the interdisciplinary EoLC team and appreciating respective roles of other professions in providing EoLC (Collab-F)

(Continued Next Page)

Domain 3: Symptom management, maintaining comfort and well-being of patients and families	<ul style="list-style-type: none"> » Recognising signs of approaching death (Com-F) » Helping patients with pain and distressing symptoms (Com-F) » Communicating with patients about anxieties over the dying process and what will happen (Com-F) » Working with family members in caregiving (Com-F) » Using non-pharmaceutical, complementary and alternative therapies in helping patients with distressing symptoms (Com-F)
Domain 4: Psychosocial and spiritual care	<ul style="list-style-type: none"> » Demonstrate understanding on the needs and challenges experienced by patients and family caregivers across illness trajectories (Com-F) » Using holistic assessment with patients and family members (Com-F) » Applying individualised end-of-life care plan (Com-F) » Providing information of other support services to patients and caregivers when needed (Com-F) » Understanding the benefits of evidence-based psychosocial interventions in EoLC (Com-I) » Applying evidence-based psychosocial interventions (Com-I)
Domain 5: End-of-Life decision-making	<ul style="list-style-type: none"> » Understanding legal issues relating to EoLC (Com-F) » Find out patient's wishes over care decisions should they lose capacity (Com-F) » Understanding the benefits of Advance Care Planning (ACP) (Com-F) » Preparing patients and family for the death by discussing unfinished business, wishes regarding after-death care, funeral and ritual, and body disposition (Com-F) » Build consensus and mediate conflicts between patients and families regarding EoLC decision (Com-I) » Initiating ACP discussion (Comp) » Discussing and preparing Advance Directives (AD) and Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) with patients and their families (Comp)
Domain 6: Bereavement care	<ul style="list-style-type: none"> » Understanding theories of grief, mourning and bereavement (Com-F) » Differentiating normal and complicated grief reactions (Com-F) » Offering bereavement counselling to bereaved families and individuals (Com-I)
Domain 7: Self-care and self-reflection	<ul style="list-style-type: none"> » Demonstrating emotional and existential competences towards death (Com-F) » Acknowledge the significance of self-reflective practice in the delivery of good EoLC (Com-F)

Notes: Competence type-competence levels: Competence type: Com=common, Collab=collaborative; Comp=complementary

Competence level: F=fundamental, I=Intermediate

LEARNINGS, REFLECTIONS AND THE WAY FORWARD

This competency framework is the first step to fully integrate EoLC into the Hong Kong healthcare system. It predominantly concerns basic levels of competence that correspond to the level of “palliative and end-of-life care approach” in the three-tier framework for PC education. The Hong Kong community requires more competent health and social care professionals with EoLC training that goes beyond the foundation level to provide “generalist PC and EoLC” in collaboration with specialist services. There remains a large gap in advanced training available for professionals other than doctors and nurses. To fill this, the current JCECC End-of-Life Care Core Competency Framework could readily be expanded to provide intermediate level training for non-specialists of other disciplines, as well as an advanced level of training for professionals working in specialist palliative and end-of-life care services (particularly social workers and allied health professionals). Given the complexity of competencies involved in higher levels of education, and the high likelihood that interdisciplinary practice will be required in settings which frequently deal with patients with life-limiting diseases, the competencies should be systematically defined in terms of KSA, and collaborative competences should be given greater emphasis.

CONCLUSION

The initiative to establish a core competency framework in EoLC is the first of its kind in Hong Kong. It contributes to capacity building in EoLC by suggesting a minimum level of competences in EoLC required by all health and social care professionals to provide quality EoLC in a range of settings. The cross-cutting nature of the framework also helps to cultivate a common language on EoLC among professional groups, which in turn paves the way for effective interdisciplinary collaborative practices in EoLC. The application of the framework in education planning and programme evaluation helps in promoting consistency across diverse education programmes, and aligns JCECC training content with the international standards.

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CHAPTER 11

HEALTHCARE PROFESSIONAL CAPACITY BUILDING WITHIN HOSPITALS

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This chapter presents an overview of professional capacity building of staff working with older patients in hospitals. The approach taken to raise capacity in end-of-life care (EoLC) was structured using the quality improvement Plan, Do, Study, Act (PDSA) cycle, where quality improvement is achieved incrementally through iterative PDSA cycles. This chapter details the first cycle and the beginning of the second cycle. These cycles occurred during the first two-and-a-half years of the Jockey Club End-of-Life Community Care (JCECC) Project.

BACKGROUND

OVERVIEW OF TRAINING NEEDS IN AGEING POPULATIONS

Palliative care (PC) services in Hong Kong were first developed for patients with cancer about 30 years ago, following the UK model. PC services in Hong Kong were led by the Society for the Promotion of Hospice Care and supported by the Hospital Authority (HA). The HA subsequently established a small number of hospice beds in hospitals all over Hong Kong. Formal PC training of physicians began with the establishment of the subspecialty of Palliative Medicine shortly after 1997, with the formation of the Hong Kong Academy of Medicine and constituent Colleges. A self-financed postgraduate diploma course in End of Life Care was also offered by the Chinese University of Hong Kong (CUHK) for health and social care professionals from 2007.

A few years later, in line with population ageing and the changing profile of patients in hospitals, it became apparent to geriatricians working in HA that EoLC was also a core component of quality care for non-cancer patients dying from chronic diseases. A continuous quality improvement initiative (CQI) following the PDSA cycle was initiated in Shatin Hospital (a non-acute hospital where geriatric services for the New Territories East [NTE] Region were based and developed). This promoted the perspective that all professionals should be competent in applying PC principles to those at their end of life (EoL). The first PDSA phase documented that the needs and symptoms of non-cancer patients were comparable to those with cancer (Woo, Lo, Cheng, Wong & Mak, 2011). This was followed by the development of training materials for staff; pamphlets for patients and families that were placed in each ward; weekly meetings of multidisciplinary teams to identify those at EoL; and communication skills training through role play (Woo et al., 2009). The evaluation phase showed that there was better symptom control, reduced investigations and reduced length of hospital stay for non-cancer patients at EoL (Woo, Cheng et al., 2011).

A service pathway was subsequently developed to facilitate direct admission of older people into residential care homes for the elderly (RCHes), supported as much as possible by the Hospital Authority (HA) Community Geriatric Assessment Team (CGAT) in the Shatin Hospital. Under a collaborative model between CGAT, the hospital and the Accident & Emergency (A&E) Department, it was found that 40% patients at EoL could be managed in an extended care facility without compromising their quality of care or survival (Hui et al., 2014). Advance Care Planning (ACP) was subsequently initiated in both the hospital and RCHes, with the pathway resulting in an average of only four days of acute hospital stay, 1.4 A&E attendances for the last 90 days, and improved self-efficacy and satisfaction of family members. The quality of care was rated at 70% or more for support for patients before death; support of psychosocial well-being of relatives; autonomy and empowerment; and aftercare (HA Convention May 2018 winners of Outstanding Team Award). This model is currently being promulgated to all HA clusters. Regular accreditation visits to all hospitals now have EoL care as an item for regular review. Advance Directives (AD) have been incorporated into computerised electronic health records, and ACPs are being developed in several pilot hospitals in Hong Kong. These have been adopted recently by RCHes in the New Territories West (NTW) cluster, with the aim of adopting the model throughout the other clusters.

However, the development of EoLC pathways and guidelines have not been accompanied by the skills required to deliver quality care in EoLC by professional staff. This is partly a result of high staff turnover, such that many of those who participated in the original CQI have left the hospital. Thus, the usual view that such care should be the responsibility of trained PC teams prevailed, and the key philosophy that motivated the CQI has been lost. This view has unfortunately been endorsed by the currently prevailing specialist medical organ-based approach to healthcare, which has resulted from subspecialty medical training, and media reinforcement of advances in new disease-focused technologies. Among both professionals and members of the public, there is an over-emphasis on curative treatment and life prolongation, rather than accepting life limitation and optimising quality of the remaining duration of life. This quality gap is apparent at all levels in the hierarchy of hospital services.

The JCECC Project provided an opportunity to close this quality gap. This project involves multiple partners in community, residential care and hospital settings, and it reflects the recent promulgation of compassionate communities as part of the public health approach to EoLC (Abel, 2018). Central to the ever-widening circles of care is the person with illness, whose first contact is most likely to be with hospital staff managing the illness. How this contact is managed will affect the subsequent widening of care circles, and quality improvement is therefore crucial in determining whether subsequent support networks are able to provide the required support. Currently, a large quality care gap exists in hospitals, with respect to estimating and managing the PC needs of frail older patients. For example, it has been estimated that the future principal drivers of need for PC will probably be dementia, rather than cancer, in the UK (Millington-Sanders, 2018). In Hong Kong, the average life expectancy for is between 80–90 years. Approximately 70% patients in general medical wards in Hong Kong hospitals are aged 80 years or older, with 50% classified as frail. Furthermore, between 30–50% reside in RCHes, and approximately 33% of these have dementia. It is known that the use of hospital services escalates in the last year(s) of people's lives. In this scenario, it may be expected that a substantial number of people admitted to hospital will be at the end-stage of life, and that initiation of EoLC conversations are appropriate. EoLC conversations allow discussion with family members regarding the patient's wishes, the intensity of care or life-sustaining treatments, as well as the importance of providing time for preparation and focusing on the most important things to the patient at their end of life.

A recent document, published in the UK, outlines a national framework for local action (2015–2020) (National Palliative and End of Life Care Partnership, 2015). This document promotes the uniqueness of each person, and suggests that this should be recognised by honest and timely conversations, which consider a patient's preferences and provide information for patients and their families to support them in making informed EoL choices. To facilitate this, developing good communication skills should be a key component of doctors' and medical students' training (British Medical Association, 2016). Such training programmes have also been advocated in the US Institute of Medicine report, *Dying in America* (Institute of Medicine, 2015). An example of such a programme is the Serious Illness Care Programme, which teaches early initiation of serious illness conversations in communication skills workshops (Bernacki et al., 2015).

In acute hospital settings, EoLC “should be everybody’s business” (Cox, Brighton & Russell, 2018). Education and training in EoLC should improve the quality of care and the experiences of patients and their families. Due to the increasing number of frail older people in hospitals, EoLC should not be seen as the responsibility of specialists in palliative medicine, but rather viewed as the responsibility of all health professionals. To achieve this, however, challenges to EoLC education have to be addressed. Staff competency should be improved because training should ensure an effective change in mindset and behaviour, particularly in providing holistic care that reflects a patient’s and family’s viewpoints. Organisational support, continuous training on-the-job, role modelling, roleplay, and audit and evaluation of effectiveness are all important ingredients of a knowledge-based core curriculum. For instance, a key area of competence that requires attention is how to engage in conversations about EoLC, a skill that many doctors and medical students lack (Royal College of Physicians, 2017).

STRATEGIES TO RAISE CAPACITY: THE PDSA QUALITY IMPROVEMENT CYCLE

PLAN

The standard type of educational approach using a stand-alone pre-designed curriculum may not be effective or appropriate in a busy hospital setting, although it may well be relevant in undergraduate training settings. Whichever way education is provided, it needs to be delivered on an ongoing basis, as part of quality assurance to improve quality care. For example, there are currently regular workshops in PC, as well as structured postgraduate programmes, that provide knowledge and skills to those who are already oriented to this area, but not to the majority of hospital staff. Since hospitals place a strong emphasis on quality of care, conduct regular audits in all work units and undergo regular visits from accrediting agencies, EoLC competence would be best anchored as part of a quality improvement framework and reviewed on a regular basis. Since there are hospital-by-hospital variations in staff complements, organisational culture, and patient and family characteristics, capacity building programmes need to be individually tailored to hospitals. In this way, hospital-specific requirements can be built into training and site-specific incremental improvements can be achieved, using the PDSA CQI cycle. This initiative requires support from the highest administrative levels, such that organisational mindset change may be achieved from top to bottom. At the same time, patients, family members and the general public should also be educated in EoLC to enable EoLC conversations between healthcare professionals and patients. The HA has already created AD forms and has commenced pilot projects in ACP. However, these forms are not often used and there are also many barriers to using AD forms and to ACP, for instance competition for funding by different medical specialties and territorialism, coupled with an emphasis on legal issues resulting in default defensive practice in response to complaints of medical error and/or ageism from relatives when patients die. This culture does not place the patient at the centre of care, neither does it promote the concept of individualisation at EoL.

Raising competency in EoL care among health and social care professionals: the current status in Hong Kong Hospitals. Services for end-stage non-cancer patients are poorly developed in Hong Kong compared with palliative services for cancer patients. This is despite non-cancer patients experiencing many of the same symptoms as cancer patients. Adequate staff training and experience have been identified as key features of quality EoLC, although the predominant curative focus in medical care is a barrier to providing this (Threapleton et al., 2017). A case-note audit was conducted of 61 patients (mean age 84 years) characterised by multi-morbidities and disabilities, who had died in an acute general hospital during the previous 180 days. Over half of these patients had been residents of long-term care homes. The audit found that EoLC conversations occurred for only 21% patients, with no patients having an ACP or AD, although 79% had a “do not attempt cardiopulmonary resuscitation” (DNACPR) order (Au et al., 2017).

There are few measures of competence in caring for patients who are at EoL. As a first step, we sought to obtain an indication of the degree in competence required in death work, using a locally derived and validated death competence scale (Chan, Tin & Wong, 2015). Eight hundred and fifty-five health and social care workers in the eight institutions in the NTE region, who had attended initial talks at a number of hospitals, were invited to complete this death competence survey between January and October 2016. The findings showed that competence related to organisational goals and training varied between institutions. Competence increased with age and personal bereavement experience, and thus, not surprisingly, competence was highest in Bradbury Hospice, which has 25 beds dedicated to the care of the terminally ill. In general, there was no difference in competences comparing nursing staff and personal care assistants. The number of doctors surveyed was too small for analysis. The survey identified important factors contributing to competence, namely personal resources, existential challenges and coping, emotional challenges and coping, and need for improvement in self-competence. The survey showed that there was room for improvement in self-competence in death work among health and social care workers, especially those in younger age groups, nurses and those working in acute hospitals.

The EoL Capacity Building Programme in NTE Pilot under CUHK Jockey Club Institute of Ageing. In the initial programme planning phase, a series of topics were to be covered in workshops or lectures/seminars. These would be delivered in hospitals in the NTE region as a pilot to examine feasibility, uptake and effectiveness, and would also deal with a range of current obstacles to quality EoL care, including:

- » Avoidance and lack of knowledge among hospital staff about how to talk to patients and relatives about death, resulting in default option of drugs, machines, and artificial hydration and nutrition;
- » Lack of knowledge about AD, enduring powers of attorney and other matters in situations where patients are mentally incapacitated; and
- » Lack of knowledge of patient and family regarding EoL choices; the balance between prolonging death with suffering (i.e. poor quality of dying) versus expectation of recovery and cure; and what care is available in hospital settings. This can result in conflict between hospital staff and family members.

The key points of the capacity building and education programme in the NTE region and the community at large included:

- » Identifying patients at their EoL;
- » Promoting ACP through initiating exploratory conversations with patient and family regarding their wishes and preferences;
- » Achieving mindset change among the healthcare community, patients and their relatives and/or caregivers regarding EoLC issues through discussion sessions, forums and workshops based on the principles of medical ethics (Woo et al., 2015); and
- » Partnering with HA in strengthening the quality EoLC model and practices in hospitals, and achieving sustainability through documentation of such practices in the audit and accreditation process.

The capacity building program has four components:

1. Conducting sessions for hospital staff (doctors, nurses, social workers, etc.) on the principles of EoLC in the hospital setting, and how to initiate conversations with patient and family members, with an emphasis on ethical principles such as autonomy, benefit and harm with respect to quality of life (QoL), rather than life extension as the goal of treatment. Real cases are discussed; either current ongoing problems or past cases, especially those that resulted in conflict either between family members, between patient and family, or between hospital staff and family. Simulation workshops will also be held for staff to train in communication skills.
2. Conducting sessions for family members and patients, who are in and out of the hospital system during the EoL period, to discuss curative versus palliative treatment regimens and how choices can be made by patients and families specific to their clinical conditions, e.g. AD, end-stage dementia, end-stage organ failure, disseminated cancer, etc. This can be achieved in the nature of a support group, where attendees are encouraged to express their points of view.
3. Conducting sessions in the community so that older people and their families can prepare for these scenarios both psychologically and materially (making enduring power of attorney and other financial arrangements; nominating family decision-makers; making AD and wills, etc.); and
4. Conducting sessions for RCHE staff, where the format and content is adapted to fit the RCHE setting.

The contents of the EoL capacity building programmes vary according to the target audience. The training is delivered via talks using case presentations; group discussions of individual experiences; role play, especially for training of communication skills; and using artistic media, e.g. art, drama.

FOR THE LAY PUBLIC, PATIENTS AND RELATIVES

The topics covered for patients, families and the general public include:

- » What is an AD and how to make it;
- » Understanding the three components of the current AD resulting from the Law Reform Commission recommendations and action by the HA: do not resuscitate; withholding and withdrawing artificial nutrition and hydration; use of mechanical ventilators;
- » Understanding current EoLC service provisions in Hong Kong (both public and private sectors);
- » What happens to the body: practical guide from hospital to cremation/burial;
- » What is power of attorney and how to enact it;
- » Putting financial affairs in order and making wills; and
- » How to initiate discussions regarding impending death: patient and family members; patient and healthcare professionals; family members and healthcare professionals.

FOR HEALTH AND SOCIAL CARE PROFESSIONALS, ADMINISTRATORS AND POLICYMAKERS

The topics covered for healthcare professionals include:

- » How to identify people who are at the EoL;
- » Understanding their physical, psychological and spiritual needs, and plan management according to QoL rather than standard disease management approach; common symptoms encountered; pharmacological and non-pharmacological management of symptoms; existential distress; dealing with unfinished business; anxiety/depression/denial/anger;
- » Use of AD: when and how;
- » What is power of attorney and how to enact it;
- » Understanding current EoLC service provisions in Hong Kong (both public and private sectors);
- » How to initiate discussions towards the EoL with patients and family members; and
- » Identifying and designing initiatives to overcome barriers to improving the quality of dying.

DO

From January 2016 to February 2018, a total of 201 talks, workshops and seminars were delivered to staff working in HA. The total number attending was 5,939, of which 57 were doctors and final year medical students; 32 were nurses; 52 were doctors, nurses and allied health professionals; and 5 were support staff. In addition, 13 public meetings were held (with 690 people attending) and 31 information sessions held where patients and their family members attended the participating hospitals. Commonly encountered cases were used as illustrations as much as possible.

A case book series based on real-life situations has been developed, emphasising management according to clinical ethics principles. This has involved input from the CUHK Centre for Bioethics and the Ethics Committee of the Hospital Authority, and can be found on the CUHK Jockey Club Institute of Ageing website (www.ioa.cuhk.edu.hk/en-gb/casebook/introduction). This provides open access online resources for all healthcare professionals who face ethical issues when caring for older adults at the EoL.

STUDY

A project team member made observations from audience responses and comments at these events, which serve as an indicator of current perspectives on EoLC. Members of the public welcomed the idea of expressing their wishes early in terms of AD and/or ACP while they were of sound mind, and not in physical or psychological distress, and also while they had the opportunity to discuss matters with their family members. However, many reported that doctors were reluctant to discuss these issues with them and to sign ADs. Nurses were more receptive but expressed difficulties in participating in EoLC plans when the doctors do not initiate EoL conversations. Many doctors equated EoLC with terminal care, and felt that documenting a DNACPR was sufficient. There was little knowledge about the definition of EoL, symptoms and management choices, prescription of drugs, when to initiate EoL conversations with patients and family, ADs and ACPs. At the same time, there was a reluctance to engage in this area, with commonly cited reasons including no time to talk to patients; difficult to make prognosis on life expectancy; and the usual default management position of prolonging life without engaging the patient's or family members' wishes or considerations regarding QoL. Avoidance of EoL issues was also common among final year medical students, who were concerned about the legal consequences of signing ADs. For more details of observations about this first phase, together with examples, see Woo (2017).

ACT

Based on these observations, and with the aim of changing practices and behaviours through mindset change, we formulated additional strategies to engage doctors and medical students. Since EoL care is considered as being largely provided by physicians, we sought to engage physicians by their medical specialties, through different health services projects. For example, many patients dying with chronic obstructive pulmonary disease and heart failure are admitted repeatedly to hospital in the last year of life. Another category is patients who have end-stage dementia being cared for in RCHEs or in infirmaries. The EoL team worked with individual medical specialties in joint projects. As an example, views were elicited through focus groups of patients who had received non-invasive ventilator

support. Common findings were that the treatment was an ordeal, that doctors never gave them a choice to refuse and that patients valued QoL in their remaining time. These views were likely to motivate respiratory physicians engaged in their care to initiate serious illness conversations. Consequently, communications training workshops regarding serious illness were initiated for physicians, physician trainees and final year medical students.

To facilitate serious illness communications, videos were made to describe the course of the disease and treatment options (from life prolongation to comfort care) using realistic scenarios based on current treatment options in hospitals. To date, videos have been made for chronic obstructive pulmonary disease, chronic heart failure and end-stage dementia.

RESULTS OF TRAINING

"In the third year of the project, the same questionnaire with the death competence scale (Chan, Tin & Wong, 2015) was used to understand the change of self-competence of health and social care workers in death work. In 614 questionnaires completed by health and social care workers in RCHes and seven hospitals in the NTE cluster from February 2018 to June 2018, it was found that participants who had attended more training sessions offered by the Institute perceived higher self-competence in death work as evidenced by a higher mean score on the death competence scale when compared to those who had attended fewer training sessions or none (mean = 63.72 for three and more training sessions; mean = 60.38 for one to two training sessions; mean = 59.68 for no training). The largest benefit observed in training was symptom control (difference between means = 3.19), possibly because it helped participants recognise their contribution to relieving patients' suffering and thus find meaning in their work.

For doctors' communication skills training, twenty post-training questionnaires were collected from doctors in four hospitals right after the training. Percentage increases in their self-perceived preparedness in communication skills ranged from 24.6% to 40.3% (mean = 33.1%) after training when compared to before training. The largest improvement was found in the preparedness to explore goals of care with seriously ill patients or their families. Participants rated the importance of the training to the development of their clinical skills at a mean of 4.35, on a scale from 1 (not at all important) to 5 (very important). The majority (94.7%) would recommend the training to other physicians in their specialty and 89.5% agreed that all higher physician trainees in their specialty should be required to attend the training.

From February 2018 to March 2018, 66 staff (more than half were nurses or social workers) in RCHes who had attended the training sessions had completed the post-training questionnaires. It was found that respondents participating in more training sessions organized by the Institute had better knowledge of EoL care as manifested by a higher mean score on a 10-item test (mean = 8.77 for three and more sessions; mean = 8.65 for two sessions; mean = 7.86 for one session)."

THE NEXT PDSA CYCLE

PLAN AND DO

Future plans include working closely with hospital management to position this topic as an integral part of quality care in hospitals, utilising the currently existing processes in place (hospital accreditation, ADs, ACPs), specifically:

- » Institute regular audit meetings in hospitals for EoLC as part of mortality and morbidity meetings; document conversations as well as patients' and families; wishes;
- » Conduct regular serious illness communication workshops with the participation of all levels of professional staff, and of different specialties;
- » Use videos as decision aids in such sessions;
- » Continue patient, family and public education regarding choices, and how to carry out serious illness conversations with healthcare professionals;
- » Continue partnerships with bioethics input to highlight the importance of using a bioethics framework;
- » Consider aspects of EoLC required to change culture, and as a basis to resolve conflict; and
- » Include this training as a core element of the final-year undergraduate medical student curriculum.

STUDY

Outcome evaluation plans. The effectiveness of EoLC education may be assessed using the conventional four levels of learning evaluation (Kirkpatrick, 1967):

1. Reaction to the learning experience (pre-post questionnaires);
2. Changes in confidence, knowledge and/or attitudes (pre-post questionnaires)
3. Changes in behaviours (documentation, ADs, ACPs), performance in real or simulated scenarios; and
4. Changes in patients' and family members' experience or outcomes.

The EoL case book series with ethical comments in the teaching of healthcare professionals should also be used. It is possible that adding bioethical perspectives may draw more attention to EoL care, resulting in a change of mindset and culture. The adoption rate by various organisations for teaching should also be documented.

SUMMARY

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

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CHAPTER 12

CAPACITY BUILDING FOR STAFF AT RESIDENTIAL CARE HOMES FOR THE ELDERLY

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Populations are ageing around the world. In line with escalating numbers of older people living in the community, admissions to Long-Term Care Institutions (LTCI) are increasing. Older people enter LTCI when they are no longer able to care for themselves. For most of these people, an LTCI will be their final “home”. Increasing numbers of older people are now dying in LTCIs, rather than in their own homes. As a consequence, there is a growing awareness of the importance of providing high-quality care to residents of LTCIs during their last stage of life.

This chapter reviews international developments regarding end of life care (EoLC) in LTCIs, and particularly the need for promoting and developing EoLC services in residential care homes for the elderly (RCHE) in Hong Kong. It explores capacity building for staff in RCHEs. It outlines the Jockey Club End-of-Life Community Care (JCECC) Project capacity building programme in RCHEs, and presents the outcomes to date of the programme in enhancing the knowledge and skills of staff in RCHEs.

BACKGROUND

EoLC FOR OLDER PEOPLE IN LTCIs

More people around the world are living for longer, and consequently the median age of populations is increasing. This has been mirrored by a rising need for long-term residential care for older people who can no longer live independently because of age-related systems decline. Over the last 20 years in the Western world, there has been increasing concern regarding the quality of death and dying for older people living in LTCI as their “home”. EoLC for people dying in aged care residential settings from age-related systems decline differs from conventional palliative care (PC) practices for people dying in hospitals from the ramification of disease.

There are recognised barriers to providing good EoLC in long-term residential care settings (Wowechuk, McClement & Bond, 2007). This includes knowledge, attitudes and beliefs regarding death and dying, and service gaps such as inadequate staffing levels, lack of supervision and inadequate knowledge of EoLC in supervisors and frontline workers (Wowechuk et al., 2007). Developing EoLC programmes in residential care settings requires time, a culture of learning, staff motivation, as well as management support (Watsons, Hockly & Dewar, 2006). With increasingly complex needs and frailty related dependency of older residents, staff may find it difficult to give sufficient time and energy to extend their practices. If an organisation lacks a learning culture, workers are less likely to be motivated to change, or develop (Watsons et al., 2006).

REVIEWING THE LITERATURE ON GOOD EoLC

This section reports on seminal international literature which presents definitions of EoLC, and/or aspirations for improving its quality, to raise awareness of the need for staff in RCHes to support quality end of life (EoL) experiences.

As long ago as 1999, Age Concern in the UK proposed 12 principles of good death (Age Concern England, 1999, p. 42):

- To know when death is coming, and to understand what can be expected
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and other symptom control
- To have choice and control over where death occurs
- To have access to information and expertise of whatever kind is necessary
- To have access to any spiritual or emotional support required
- To have access to hospice care in any location, not only in hospital
- To have control over who is present and who shares the end

To be able to issue Advance Directives which ensures wishes are respected

To have time to say goodbye, and control over other aspects of timing

To be able to leave when it is time to go, and not to have life prolonged pointlessly

The UK National Health Service (NHS) commenced a National End of Life Care Programme in 2004, with its objectives of providing patients with greater choices about place of death, reducing unnecessary emergency admissions of patients who wish to die at home, reducing the number of patients transferred between care homes and hospitals in the last week of life, and improving skills of general staff in the provision of high-quality EoLC (Henry & Hayes, 2009). Support for the living is equally important as support for the dying. Froggatt (2004) identified three stages in the provision of EoLC in LTCIs: (1) concerning living and losses experienced in the LTC facility; (2) supporting patients during the actual dying process and death; and (3) bereavement care after a patient's death.

In 2006, the Australian Government published its Guidelines for palliative approach in residential aged care (Australian Government, 2006). With an aim to support continuous improvement in the quality of EoLC in LTC facilities, the guidelines "incorporate the best scientific evidence available regarding all facets of a palliative approach, including early identification and treatment of physical, cultural, psychological, social and spiritual needs" (Australian Government, 2006, p. 1).

In 2010, the General Medical Council of the UK defined patients "approaching the end of life" as those who are likely to die within the next 12 months, include those people whose death is imminent (expected within a few hours or days) and those with:

- » Advanced, progressive incurable conditions;
- » General frailty and co-existing conditions that mean they are expected to die within 12 months;
- » Existing conditions if they are at risk of dying from a sudden acute crisis in their condition; and
- » Life-threatening acute conditions caused by sudden catastrophic events (General Medical Council, 2010, p. 8).

In Australia in the same year, Parker, Hughes & Tuckett (2010) published a *Comprehensive evidence-based palliative approach in residential aged care*, which demonstrated that the use of an evidence-based palliative approach and the use of an EoLC pathway in RCHes improved resident and family outcomes, as well as the quality of terminal care. Moreover, the following components were found to be crucial for the success of the approach:

- » A comprehensive palliative approach education programme, with separate education resources tailored to the training needs of all levels of staff to improve staff confidence for providing a palliative approach for residents and families;
- » Support from management;
- » A systematic approach to Advance Care Planning (ACP) to respect the wishes of residents regarding care decisions including place of care;
- » A PC case conference to facilitate the identification of the PC needs of residents and family, and provide a structure for multidisciplinary care planning, as well as to ensure that the care team, residents and family are “on the same page”; and
- » Training for staff to convene PC case conferences and use the EoLC pathways (Parker et al., 2010).

In 2011, the World Health Organization (WHO) Regional Office for Europe published its report on *Palliative care for older people: Better practices* (WHO Regional Office for Europe, 2011), which called for member countries to focus attention on improving care for older people with terminal conditions. The report urged member countries to improve EoLC for older people in a range of care settings, including nursing and residential care homes (WHO Regional Office for Europe, 2011).

In the same year (2011), the European Association for Palliative Care (EAPC) Taskforce on Palliative Care in Long-term Care Settings for Older People, was formed to identify and map the various initiatives and strategies used in developing PC in LTCIs across 13 European countries (Reitinger et al., 2013). The results of the mapping exercise suggested that a significant proportion of older people die in LTCIs (e.g. 20% in UK). Residents in LTCIs often had complex trajectories of dying, as many lived with non-cancer comorbidities and there was a high prevalence of dementia. Thus, it was clear that EoLC required a different approach to that taken in conventional PC. This approach involved changes at multiple levels: individual level (resident, family, staff), group/team level, organisational level, regional/network level, and national level (Reitinger et al., 2013).

In any ageing society, there is no doubt of the need to review EoLC needs in LTCIs and prepare LTCIs to implement good quality EoLC. In particular, staff capacity building should be an integral part of any initiative in developing EoLC services in LTCIs, given that EoLC in LTCIs is different from conventional PC practices in hospitals.

THE NEED FOR QUALITY EoLC IN RCHES IN HONG KONG

Hong Kong has a rapidly rising ageing population. It is also the country with longest life expectancy in both men and women. It is expected that by 2030 at least 25% of the Hong Kong population will be older than 65 years (see **Table 12.1**). With a predominantly Chinese population, death and dying are often subjects about which discussion is avoided. Moreover, there is a heavy reliance on hospital care in Hong Kong. Most people will be admitted to hospital during their last few months of life and it is common for residents living in RCHes in Hong Kong to die in hospital, rather than in their “home”. With the high rate of institutionalisation of older people in Hong Kong (around 7% of elderly population) and with their expected high prevalence of chronic illnesses (compared with community-dwelling elderly), ensuring quality death and dying for residents of RCHes is essential (see **Table 12.2**).

It is common practice that RCHes in Hong Kong send residents to hospital in their final days of life (to die), rather than manage their death in-house (in the RCHE). This causes disruption to the continuity of care in RCHes, as well as unnecessary distress to the older person and their family. According to statistics provided by the Hospital Authority (HA) in 2012, of all deaths in medical specialty wards in HA hospitals, the number of deaths of people aged over 60 years was 24,073. Of these, 45% were residents of RCHes (10,800). This suggests an approximate 15% yearly death rate for aged care home residents (Leung, 2013).

In a study performed in the Kwun Tong District in Hong Kong in four private RCHes over six months during 2013, 13.3% deaths occurred among residents (mortality rate approximately 26% per year) (Leung & Wong, 2013). The health conditions of those who died in this time period included advanced neurodegenerative conditions (53.8%), end-stage malignancy (21.5%) and end-stage heart and lung conditions (10.8%). It was also found that in the last three months of life, there was an average of three admissions to hospital per person, and the total admission days per person averaged 30. Lee et al. (2013) reported that many residents have frequent transitions between hospital and their RCHE because of unstable physical health and the medical ramifications of approaching death.

Improvements in EoLC practices in RCHE should improve the quality of life (QoL) and quality of death of residents. However, despite care providers trying, where possible, to meet the final wishes of the older person and their relatives, a network of supportive services that assists older people in having a quality EoL experience, may not be available in some RCHes in Hong Kong. There may be a number of residential aged care settings in Hong Kong which cannot provide EoLC, or there may be a lack of confidence, or fear, when providing it (Luk et al., 2010).

Table 12.1 Hong Kong Population Projections (2017–2066)
(HKSAR Census and Statistics Department, 2017)

YEAR	NUMBER OF PEOPLE AGE 65 AND OVER (MILLIONS)	TOTAL POPULATION (MILLIONS)	PERCENTAGE OF POPULATION AGE 65 AND OVER (%)
2017	1221.3	7389.5	16.53
2022	1524.5	7657.7	19.90
2027	1891.8	7869.6	24.07
2032	2202.2	8028.0	27.43
2037	2407.0	8163.5	29.48
2042	2541.3	8217.1	30.93
2047	2606.6	8197.1	31.80

Table 12.2 Institutionalisation Rate of Older People in Hong Kong (Leung, 2013)

YEAR	NUMBER OF PEOPLE AGE 65 AND OVER	RCHE PLACES	PERCENTAGE OF POPULATION AGE 65 AND OVER IN INSTITUTIONS (%)
01-02	747,052	56,231	7.5
02-03	777,100	60,821	7.8
03-04	795,400	62,941	7.9
04-05	819,000	64,243	7.8
05-06	834,700	66,371	7.9
06-07	852,790	69,044	8.0
07-08	972,200	71,721	8.2
08-09	882,700	72,827	8.2
09-10	893,400	73,663	8.2
10-11	912,100	75,325	8.2
11-12	941,400	75,228	8.0
12-13	977,900	75,416	7.7

To better understand the issues of EoLC practices in RCHEs in Hong Kong, the Hong Kong Association of Gerontology (HKAG) collaborated with the National Institute for the Care of the Elderly (NICE) of Canada between 2007–2009 to study EoLC needs in Hong Kong. Five focus groups were held with 30 participants from five RCHEs, and two roundtable discussions were held with elderly people, healthcare professionals and policymakers. This study found that older people and their family members were supportive of receiving EoLC in RCHEs, rather than being sent to die in hospitals. Policymakers and healthcare professionals were also positive about the development of a culture of providing EoLC in RCHEs. However, areas of concern were raised regarding the development of EoLC in RCHEs, including:

- » Care home environment and its logistic arrangement for EoL
- » Legal and policy issues
- » Staff training
- » Support

The most concern was raised regarding the lack of relevant training for RCHE staff. It transpired from this research that most of the care home staff were not familiar with EoLC. Moreover, relevant training and education, including ACP, grief and bereavement, and nursing care for dying patients, was not generally available. RCHE staff may feel uneasy about providing care for dying residents, and this stress may increase the staff turnover rate. Due to difficulty in diagnosis and determination of the nearness of EoL, it was perceived to be difficult for RCHE staff to ascertain if the resident's deteriorating conditions was reversible (or not), particularly if there is no resident doctor available to assist.

TRAINING AND SUPPORT NEEDS OF RCHEs STAFF ON EoLC

Considerable international research has shown that training is helpful for care workers, at all levels of management in RCHEs, to understand and support quality EoLC. However, training content should be designed based on the training needs of staff. A knowledge-transfer project in Hong Kong in 2013 investigated pre-post changes in staff behaviour and knowledge in RCHEs. Significant baseline knowledge gaps were identified in many areas of EoLC (Lee et al., 2013). These largely related to the impact of chronic diseases and symptom management at EoL. Moreover, staff expressed lack of confidence in managing the dying process, as well as in applying residents' ACPs in RCHEs. Communication difficulties between staff, residents and family appeared to result from lack of knowledge in assessing symptoms and providing appropriate comfort care for residents and their families at EoL (Lee et al., 2013). Following training, significant improvements were demonstrated quantitatively and qualitatively using questionnaires and interviews.

Literature also provides insights on a range of specific training needs, as well as required support for care staff to provide quality EoLC in LTCIs. For instance, training that will help staff engage sensitively, respectfully and creatively with dying residents is essential (Percival & Johnson, 2013). To deal with the emotional effects of delivering EoLC to residents who may be well-known to them, staff also need support from management and peers. For example, staffing levels must be sufficient to allow staff to spend unhurried time sitting with dying residents. Moreover, staff should be empowered to provide care in ways that resonate with the resident's personality, life history and wishes, together with the wishes of their relatives, to ensure a "civilised death" (Percival & Johnson, 2013). Having action plans and adopting a standardised approach to care for people in the last days of their life are also viewed as part of the strategies and quality markers for excellent EoLC (Gray, 2011). Having a mechanism in place to ensure that care for individuals is coordinated across organisational boundaries is thus essential for the provision of quality EoLC in RCHEs.

CAPACITY BUILDING FOR HONG KONG RCHE STAFF

This section reports on an innovative Hong Kong initiative to provide culturally appropriate training for staff in RCHEs. Between 2010 and 2016, the HKAG collaborated with The Salvation Army Hong Kong to launch a pilot project called "Palliative Care in Residential Care Homes for the Elderly in Hong Kong". This tested the feasibility of delivering PC in six RCHEs in Hong Kong, through development of care protocols, care guidelines, as well as training and education for staff. Subsequent to the successful pilot project, the HKAG received three years of funding (2016–2018) through the JCECC Project to implement EoLC in 36 RCHEs in Hong Kong. One of the core objectives of this project is to build capacity for staff in RCHEs to enable them to care for terminally ill residents in a better way than before, and to avoid unnecessary hospitalisation.

To assess the EoLC training needs of RCHE staff, HKAG conducted focus groups, interviews and a questionnaire survey in late 2017 to obtain information from staff working with elderly residents. For the questionnaire survey, 111 staff responded, with results showing that over 90% of them agreed that healthcare workers who serve older persons required EoLC training. From the interviews, respondents believed preparation on EoLC for the whole residential care industry was needed, especially for frontline staff who provide day-to-day services to residents and who require the competence to assist residents to have a quality death.

CAPACITY BUILDING CURRICULUM AND TRAINING COMPONENTS

Rationale behind designing the curriculum. The current training curricula in Hong Kong for both professional and non-professional caregivers on EoLC is limited. However, studies show that EoLC education is important to prepare healthcare workers to take care of terminally ill patients (Buss, Alexander, Switzer & Arnold, 2005; Steven, 2014). The needs of a person at EoL can be complicated and complex. Moreover, these people are often not in a situation to be able to express their needs adequately. EoLC education can enhance staff competencies in communication and empathy, and promote positive attitudes towards death and dying. Training can also increase self-efficacy, as well as improve knowledge and psychosocial skills (Adriaansen & van Achterberg, 2008; Duke, 2010; Mok, Wai & Wong, 2002; Mallory, 2003; Wong, Wai & Mok, 2001). Interactive educational programmes can heighten staff awareness, cultural sensitivities and understanding of the needs of older people who are approaching death (Fang, Sixsmith, Sinclair, & Horst, 2016).

DESIGN OF CURRICULA

Engaging all levels of staff in the RCHE. The delivery of EoLC cannot be achieved without the engagement of the whole RCHE. A structured training programme has therefore been designed to target all staff of RCHEs, with two streams of education tailored to professional (see Box 12.1) and non-professional staff (frontline staff) (see Box 12.2). This training programme was developed on the premise that healthcare workers (both professional and non-professional) can provide quality EoLC if education and on-site coaching is provided.

Core elements of the training programme for all staff include symptom control, ACP and Advance Directives (AD), legal and ethical concern in decision-making at EoL, psychosocial and spiritual care, grief and bereavement. Additional training is provided for professional staff to assess and manage symptoms. Training is delivered using multipronged approaches such as lectures, workshops, skill demonstrations and on-site coaching.

Box 12.1

Training programme elements for professional staff

The training content for professional staff of RCHEs includes:

- » Ethics and legal issues of EoLC
 - » Symptom management for terminally ill patients
 - » Dying symptoms assessment and nursing processes
 - » Psychological, social and spiritual care of terminally ill patients
 - » ACP, psychological, social and spiritual care
 - » Bereavement counselling and handling
-

Training programme elements for non-professional (frontline) staff

The training content for non-professional frontline care staff of RCHes includes some of the professional staff training, sufficient for them to be able to support the professional staff when delivering care, as well as dealing appropriately with residents and their families:

- » Ethics and legal issues of EoLC
 - » Symptom management for terminally ill patients
 - » ACP, psychological, social and spiritual care
 - » Communication skills with terminally ill patients and their family members
-

Emphasis on mindset and attitude change. Supportive attitudes and an empathic culture are essential for delivering quality EoLC, and therefore mindset-changing experiential workshops are provided to all staff in each RCHes before EoLC services are commenced. It has been regularly observed by staff in charge of the RCHes that, after this workshop, participants have shown significantly positive attitude changes, as well as enhanced empathy, when taking care of residents who are dying.

Supporting the practice through on-site coaching. Ongoing on-site coaching is provided in the participating RCHes throughout the EoLC service implementation period in order to support staff in putting what they have learnt into practice. This is actioned by a nurse and a social worker from the JCECC Project team designated to each care setting, who “walk along” with staff in their journey towards delivering quality EoLC.

OUTCOME EVALUATION

To understand the impact of the training programme on professional and frontline staff, outcome evaluations were conducted throughout the project. A quantitative approach was adopted using pre-post training measures.

Knowledge enhancement for trained staff on EoLC. To assess the effectiveness of the lectures in enhancing staff knowledge, staff were asked to complete questions on their knowledge regarding the training topics before and after the training session. Paired t-tests were used to assess knowledge gain, and findings showed that the knowledge on EoLC among professional and frontline staff had been significantly enhanced ($p<0.001$). The scores associated with each question are outlined in **Tables 12.3** and **12.4**. **Figure 12.1** provides an overview of the differences in total scores (pre-post training) for professional and frontline staff, and all staff. The score of all staff increased from 2.6 in the pre-test (SD=0.9) to 3.6 (SD=0.7) at post-test, with 4 as the maximum score.

Table 12.3 Pre-Post Training Scores for Professional Staff

PROFESSIONAL STAFF				
LECTURE TOPIC	N	PRE-TEST	POST-TEST	DIFFERENCE
Ethics and legal issues of end-of-life care	568	2.71	3.56	0.845***
Terminally-ill patients' discomfort symptoms' handling I	522	2.60	3.68	1.077***
Terminally-ill patients' discomfort symptoms' handling II	500	2.49	3.56	1.064***
Dying symptoms assessment and nursing processes	447	2.86	3.83	0.975***
Care of terminally-ill patients' psychological, social and spiritual needs	459	3.16	3.69	0.532***
Advance care planning and care of family members' psychological, social and spiritual needs	465	2.77	3.63	0.856***
Bereavement counselling and handling	459	3.35	3.79	0.483***
				*** $p < 0.001$

Table 12.4 Pre-Post Training Scores for Frontline Staff

FRONTLINE STAFF				
LECTURE TOPIC	N	PRE-TEST	POST-TEST	DIFFERENCE
Ethics and legal issues of end-of-life care	806	2.52	3.43	0.904***
Terminally-ill patients' discomfort and dying symptoms handling	732	2.69	3.64	0.948***
Advance care planning and care of family members' psychological, social and spiritual needs	725	2.75	3.55	0.799***
Communication skills with terminally-ill patients and their family members	721	1.60	3.18	1.577***
				*** $p < 0.001$

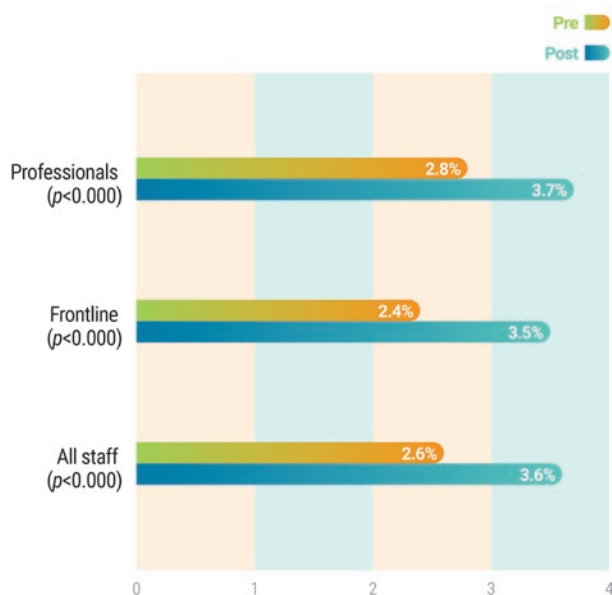


Figure 12.1 Overview of the Differences in Total Scores (Pre-Post Training) for professional and Frontline Staff, and All Staff

Promising results in trained staff's preparedness in EoLC delivery. To assess whether the project had achieved its objectives, staff readiness to deliver EoLC was measured by a 16-item validated questionnaire (Chan, Chun, Man & Leung, 2018). The questionnaire comprised three aspects of willingness, competence and resilience. Each staff member completed the questionnaire at the first activity of the project as a baseline measure, and also at one and two years after joining the project to provide longitudinal comparison. The comparison between baseline and after one year is outlined in **Figure 12.2**. The scores showed consistent improvement in readiness to deliver EoLC in terms of willingness, competence and resilience (**Figure 12.2**).

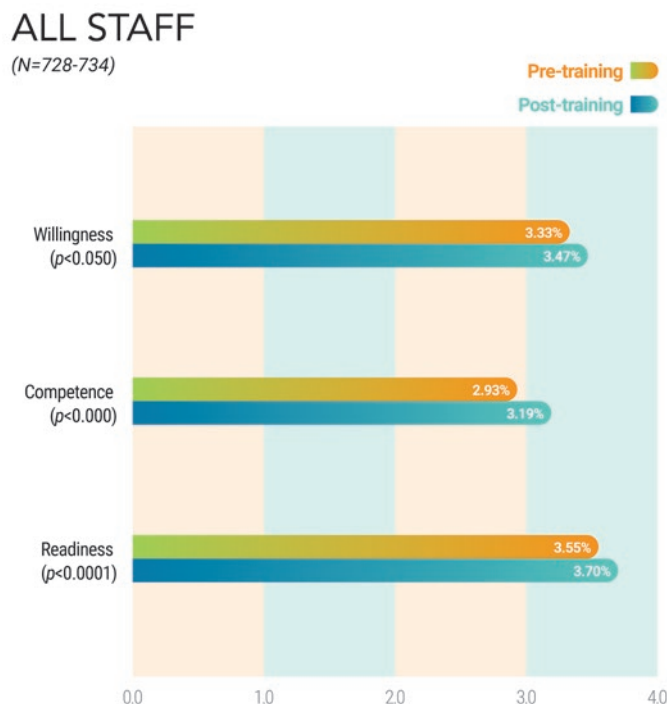
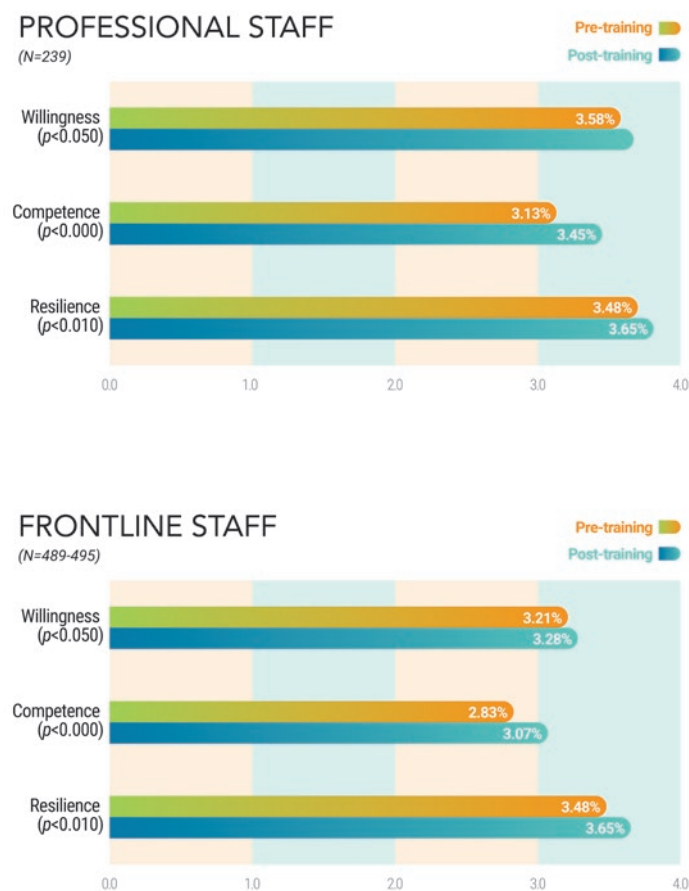


Figure 12.2 Improvements in Readiness to deliver EoLC One Year after the Initial Assessment (Baseline)

SUMMARY

There are a number of learnings and reflections from the RCHE capacity building curriculum:

- » Participants appreciated the on-site training package, which they believed was appropriate in length and depth of content.
- » Apart from the lectures and the experiential workshop, participants valued role play and discussion as learning modes.
- » On-site clinical coaching, real case planning, demonstration, practice and discussion was helpful.
- » Participants found the field visit to PC units in hospitals and nursing homes helpful because they could experience first-hand what the others were doing. Many of them noted that they found that EoLC was not as difficult as they had expected.
- » No adjustment was made to the curriculum, although it will be reviewed after the completion of the project.

The strengths and limitations of the curricula are:

- » The training is conducted by experienced nurses and social workers, which is important for credibility and case sharing with participants.
- » On-site training is appreciated because all the workers in RCHE can join the training.
- » The training curriculum is not adequate for leaders in RCHE and the professional workers who want to have more comprehensive training on EoLC. A structured and accredited course is therefore required to better address their needs.

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CHAPTER 13

EMPOWERING PROFESSIONAL COMPETENCY IN THE WIDER COMMUNITY SETTINGS

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The ongoing expansion of community-based services in end-of-life care (EoLC) brings an increasing demand for professional training and competence enhancement. The Ottawa Charter explicitly states that everyone should be able to make decisions and have control over their own life circumstances, and that society should create conditions for a health-promoting palliative care (PC) system (World Health Organization [WHO], 2000). Professionals working in elderly care and EoLC have crucial roles in creating Ottawa Charter environments for their patients.

The “PC and EoLC for all” approach outlines three layers of care (PC approach, general PC and specialist PC) for patients living with life-limiting illnesses, within a vision of providing comprehensive care to patients

and families affected by chronic and advance illnesses, through an integrative community and team-based approach.

It has been recognised that different groups of professionals require different training, levels of knowledge and skill competence in EoLC (Worldwide Palliative Care Alliance [WPCA], 2014) (see Chapter 10). Of note is that although the specialist PC is predominantly provided in hospice or specialist units in hospitals, the PC approach and general PC involve many different professionals in primary care or community settings.

Efforts have been made to estimate the human resources required to implement the three layers of EoLC. For home-based care, it has been estimated that three physicians, 12 nurses and six other clinical staff are required per 100,000 patients. For inpatient care, 1.5 medical doctors, 15.5 nurses and four other clinical staff are required for every 10 inpatient beds. An additional 25% administrative staff are required to provide leadership and to ensure compliance with regulatory and fiduciary responsibilities (Connor & Gómez-Batiste, 2017). Although no estimations have been made regarding human resources required for EoLC in other community settings, it is anticipated that the number of people engaged in community-based EoLC may be even greater, so that patients with life-limiting diseases can be provided with a real option of staying at home for as long as possible, with requisite home care supports.

In fact, the WHO has long put human resource development as one of the key items in its PC services development agenda. Education was one of the five pillars

of a public health model proposed for EoLC, which motivated for the development of comprehensive curricula, expert and general training courses and trainee programmes as early as the 1990s (WPCA, 2014). The questions that remain unanswered include “who should provide what kind of training to whom, at what time and place?” and also “how should the training be delivered?”.

To align its training with global developments and trends, the JCECC Project included professional education as one of its key components. The University of Hong Kong (HKU) project team (defined as “project team” hereafter) also piloted a target-specific and needs-based professional capacity building programme that is oriented to care professionals in the community.

BACKGROUND

MAPPING GLOBAL DEVELOPMENT AND TRENDS TO LOCAL NEEDS

In an initial effort to develop and pilot a large-scale, professional capacity building programme in EoLC for the Hong Kong community, the project team undertook four steps. These steps shared a similar rationale to the first four steps in designing a national education plan for EoLC, recommended by Gómez-Batiste, Lasmarías, Connor & Gwyther (2017). An adapted version of the first four steps recommended by Gómez-Batiste et al. (2017) were used to explain the development process of the JCECC Project professional capacity building programme (see **Figure 13.1**).



Figure 13.1 The Four Steps in Developing Education Programme for EoLC

Step 1: Conducting situational analysis and aligning with international trends. In order to inform programme design and training contents, the project team reviewed updated statistical and survey data on local ageing and death figures, and also EoLC services need (see Chapter 1). The team identified gaps in local training programmes for non-specialists and social care professionals in all levels (see Chapter 10), and conducted community-wide surveys of healthcare professionals regarding their competence in EoLC.

The key directions in the development of the JCECC Project professional capacity building programme were derived from several sources, including:

- » WHO public health model for PC (Stjernswärd, Foley & Ferris, 2007);
- » Common core competences and principles for health and social care workers working with adults at the end of life developed by the UK Department of Health (2009);
- » A review of competency frameworks conducted in Ireland (Connolly, Charnley, Regan & AIHPC, 2012);

- » The resolution WHA67.19 published by the World Health Assembly (WHA) on Strengthening of palliative care as a component of comprehensive care throughout the life course (WHA, 2014);
- » Guidelines for establishing PC training, recently published in a manual by the Technical Advisory Group of the WHO Initiative for Palliative Care (Gómez-Batiste et al., 2017); and
- » The strategic framework for PC development by the Hospital Authority (HA) (Hospital Authority [HA], 2017).

These directions comprised:

- » Identifying core competencies in PC and EoLC, and the development of a competency framework should be a prerequisite.
- » Ensuring all care professionals have basic core competences in PC and EoLC. Thus, a standardised curriculum that delivers the minimum level of competences in PC and EoLC to all care professionals is essential.
- » Tailoring training according to differentiated levels, ensuring that it is target-specific and needs-based, and is provided in accordance with the care settings, disciplines, positions, nature of work and level of involvement. Three levels of training are required (basic, intermediate and specialist), which should be compatible with the three levels of care specified in the shared-care model proposed in the Hospital Authority Strategic Service Framework for Palliative Care (2017) (see Chapter 4).
- » Training clinical and organisational leaders at the initial stage, which is essential for helping grow and develop services.
- » Using capacity building to make changes at organisation, social and policy levels.

Step 2: Select and conduct initial activities. At the beginning of the JCECC Project, the project team approached experts in various disciplines in the EoLC field, for advice on the best approach and content for EoLC training. Collaboration in training was also established. This was not only to serve the purpose of training, but also to build a platform of continuous exchange and learning of EoLC knowledge among professional groups. To meet the diversified training needs of healthcare professionals working in different settings, with various degrees of involvement in EoLC, the project team formulated the JCECC Project End-of-Life Care Core Competency Framework. This was undertaken with the aim of equipping community-based healthcare professionals from a range of disciplines with core competences in EoLC. The framework consists of seven competency domains that are considered essential for all professional groups involved in the care of patients facing end of life (EoL). A full description of each domain is provided in Chapter 10.

The project team developed and organised all the professional training courses, based on the JCECC Project End-of-Life Care Core Competency Framework, albeit with varying levels of proficiency required in specific domains. Although all competency domains are equally important, the JCECC Project training programme places a specific emphasis on communication and evidence-based psychosocial care. Moreover, there is an assumed sequential order of training in these competency domains. For instance, the domains of overarching values and knowledge, and self-reflection and self-care, should be taught first, followed by the remaining five domains. Building on a standardised competency framework, the JCECC Project EoLC training curricula enhances multidimensional competencies of healthcare professionals in community EoLC. It will also eventually improve quality of EoLC in the community.

Step 3: Identify and train by target groups. Consistent with the derived directions identified during programme development, the JCECC Project employed a target-specific approach to construct its training and competence building activities. It identified four target groups for training and appropriate capacity building strategies:

1. Policymakers, administrative leaders and relevant organisational leaders.
2. Clinical leaders across disciplines in social and healthcare systems.
3. Health and social care professionals who are non-specialists in PC and EoLC, but who work in service units for older adults, in the EoLC field, or who deal with a high caseload of patients who require chronic care specialists. They may work in long-term care facilities and/or take referrals from other care professionals.
4. All health and social care professionals.

Step 4: Build a solid nucleus of reference services. Apart from developing a capacity building programme, the JCECC Project collaborated with five non-governmental organisations (NGOs) as partners in piloting different community-based EoLC service models (see Chapters 6–9 and 12 for details). The experiences and best practices generated from these pilot service projects serve as the foundation for future development of a comprehensive training curriculum for integrated community-based EoLC services.

THE JCECC PROJECT TARGET-SPECIFIC, DOMAIN-BASED CAPACITY BUILDING PROGRAMME

The training activities in this professional capacity building programme are summarised next.

POLICY ROUNDTABLE AND EXECUTIVE FORUM

The JCECC Project Policy Roundtable sessions and Executive Forum Series provided a platform for health and social care executives, policymakers and key stakeholders to be engaged in dialogue with world-class experts on EoLC. Eight renowned international and local speakers were invited to different forums to foster partnerships and collaborations in EoLC. A total of six policy roundtable sessions and executive forums have been held to date, with 130 participants.

LEADERSHIP TRAINING PROGRAMME

The JCECC Project Leadership Training Programme 2016 and 2017 aimed to nurture a group of clinical and service development leaders in community-based EoLC. In this programme, leaders in the community were guided to review international best practices and standards of clinical excellence in community-based EoLC. The leaders were exposed to state-of-the-art, evidence-based and innovative practices in quality community-based EoLC for patients and their family caregivers. The practice-based learning approach empowered leaders to develop EoLC services in their own work settings through exemplary clinical care, international best practice and evidence-based skills training.

The programmes were conducted in two consecutive years, with modifications to the format and content throughout the process to better meet the needs of leaders in the second year. With EoLC development in its infancy in Hong Kong, the leadership programme in 2016 targeted clinical leaders who were already providing EoLC to patients. Notably, as an impetus to support the development of reference services in community-based EoLC, clinical staff and service managers in the five NGO partners in the JCECC Project were also recruited as leaders in the 2016 programme, alongside leaders from other NGOs. Twenty-four leaders participated in three full-day lectures and nine study groups, in which they worked on specific topics in EoLC. Cases were brought in for discussion and mutual learning.

The leadership programme in 2017 targeted leaders who were involved in EoLC project management and service development. The 24 leaders who participated in the 2017 programme underwent a stringent screening process. They were nominated by their respective organisations and screened through their personal statements on their expectations of the programme and vision for developing EoLC service programmes in their

work setting. The programme curricula were advanced, based on learnings from the 2016 programme. The 2017 programme consisted of 36 learning hours, distributed over four learning components that were specifically designed to achieve learning outcomes of:

- » Mastering the latest developments and best practices in local and global EoLC;
- » Familiarising leaders with evidence-based practices in quality EoLC for patients and family members;
- » Developing collective visions on scalable service models and programmes for patients at EoL, and their family members; and
- » Establishing networks with local and global leaders in community EoLC.

The learning components are detailed next.

Knowledge enrichment sessions. The eight one-hour knowledge enrichment sessions covered important topics and state-of-the-art EoLC. Prior to each session, reading materials and session handouts were presented to the leaders for preparation. The session topics included global development in PC; engaging patients, family members and community in conversations in EoLC; conducting holistic assessment and its application in EoLC for the elderly living in residential care homes for the elderly (RCHEs); integrated East–West Body–Mind–Spirit (IBMS) interventions for patients with serious illnesses; dealing with family dynamics in EoLC; dealing with conflict management; capacity building in community EoLC; developing volunteers and support networks in the community; and the role of social care professionals in Advance Care Planning (ACP).

Intensive tutorials. Following each knowledge enrichment session, there was a two-hour tutorial to facilitate more in-depth discussion on each topic. The tutorials were designed to facilitate application of learnt knowledge into practice. Leaders were divided into groups of three to five, with an assigned advisor who was experienced in EoLC. They were requested to put forward issues, cases and challenges related to the session topic in order to encourage exchanges and mutual learning, and they received advice from their advisor.

Exchange sessions with international experts. These sessions were aimed at helping leaders understand state-of-the-art global development in EoLC so they could participate in a global vision in service and strategic planning. International experts included Professor David Kissane, Professor Carl Becker and Professor Edward Canda, who are world leaders in family intervention, ACP and spiritual care in EoLC. They were invited to share recent developments in research and practice in EoLC. Leaders were given opportunities to exchange ideas with these international experts, and reflect on how international guidelines and standards could be modified to inform development in local practices in Hong Kong.

Capstone project. The idea of a capstone project in the programme was to help leaders put what they had learnt into their real-world service planning and implementation. Leaders were encouraged to develop an innovative idea to advance services in their respective work settings, integrating the knowledge and skills from all components of the project. A capstone project poster presentation session was arranged at the end of the programme in May 2018, and the posters were exhibited in the JCECC Project International Conference 2018. The topics followed global and local trends in EoLC development, with pilot projects on innovative interventions to improve patients' sense of meaning and quality of life; proposals to support family members in bereavement adjustment; pilot services of cross-cutting interprofessional teams in facilitating home death; efforts to implement ACP to different target groups such as people with intellectual disability and dementia; and the development of tools for facilitating ACP communication with the use of various media, including journaling, and information technologies.

DOMAIN-SPECIFIC PROFESSIONAL TRAINING WORKSHOPS

Professional training workshops were held by collaborating local and international experts in EoLC in the format of short courses (conducted over one to three days). These courses comprised lectures on basic concepts and theories, skill demonstrations and practice workshops. They were aimed at helping health and social care professionals to further develop knowledge and skills in specific areas, based on their professional interests and career development. These workshops were based on the JCECC Project End-of-Life Care Core Competency Framework, with the level of proficiency of competences equivalent to the intermediate level. Since the overall capacity building programme had a strong emphasis on psychosocial care and communication, most domain-specific workshops targeted psychosocial care, communication and bereavement care. In total, 49 workshops were delivered between 2016 and 2018 to more than 2,300 participants.

FOUNDATION TRAINING COURSES

The JCECC Project Foundation Training Course in Community EoLC is a one-day training course designed for health and social care professionals who wish to cover basic principles, knowledge and concepts in community EoLC. Through lectures and interactive discussion sessions with clinical experts and researchers, the course covered basic competences involved in the seven competency domains in the JCECC Project End-of-Life Care Core Competency Framework, including overarching values and knowledge; self-reflective and self-care; psychosocial and spiritual care; communication; EoL decision-making; symptom management and bereavement care. The overall course aim was to prepare health and social care professionals to serve patients and family members in community settings. The courses were delivered in February and July 2017 to 175 participants.

THE JCECC PROFESSIONAL EVALUATION FRAMEWORK

Evaluation of the outcomes and impacts of the professional capacity building programme was conducted through pre-post evaluation regarding participants' competence in EoLC, as well as satisfaction surveys.

A 38-item multidimensional EoLC competence assessment tool was developed in order to assess competence in each domain in the JCECC Project End-of-Life Care Core Competency Framework. As discussed in Chapter 10, the framework was adapted from two international documents:

- » Common core competences and principles for health and social care workers working with adults at the end life (UK Department of Health, 2009); and
- » Core competencies in palliative care: An EAPC White Paper on palliative care education (Gamondi, Larkin & Payne, 2013).

The assessment toolkit developed by Whittaker, Broadhurst & Faull (2015) from the University of Nottingham, which was based on the UK competency framework, was used as a blueprint to build the JCECC Project multidimensional EoLC competence assessment tool. This tool covers assessment of domains, including "overarching values and knowledge" (eight items), "communication skills" (eight items), "symptom management, maintaining comfort and well-being of patients & families" (six items), "psychosocial and spiritual care" (six items), "EoL decision-making" (seven items) and "bereavement care" (three items). Self-perceived competence in each domain was rated on a 10-point Likert scale, from 1=totally incompetent to 10=very competent. Domain mean scores were calculated by summing the item scores in a domain and dividing by the number of items.

Three items were specifically designed to test knowledge of community-based EoLC, which was the primary focus of the JCECC Project. These items were integrated into the domain of "overarching values and knowledge". These items were examined in analysis of findings from domain-specific and foundation courses. In addition, the Self-Competence Scale in Death Work (SC-DW) was used to assess emotional and existential competences of participants in death work (Chan, Tin & Wong, 2015).

EFFECTIVENESS OF JCECC PROFESSIONAL COMPETENCE BUILDING PROGRAMME

This section presents key evaluation findings on the leadership training programme, the domain-specific training programme and foundation training courses.

Leadership training programme. The 46 leaders who participated came from a variety of service settings, including RCHes (22.4%), long term care (LTC) community settings (44.7%), hospitals (6.4%), hospices (14.9%), and other social service settings run by NGOs which support the elderly and persons with intellectual disabilities suffering from chronic illnesses (25.5%). Leaders were predominantly social workers (74.5%), nurses (8.5%) and physicians (6.4%). The mean number of years working in the field of EoLC was 4.2 (SD = 5.3) years. The 2017 batch of leaders were, in general, more experienced than those in the 2016 batch. Pre-post follow-up assessments were conducted for course participants. Upon completion of the programme, 32 leaders who participated in post-training assessment showed significant improvements in all competence domains and leadership skills (see **Figures 13.2** and **13.3**). A post-training focus group was also conducted with participants in the 2017 programme. This indicated that their biggest gains from the leadership programme were learning to apply theories and research to support their service planning, connecting with global development of EoLC, forming networks with other practitioners in the field of EoLC and being able to bring insight and knowledge to influence other colleagues in their service agencies.

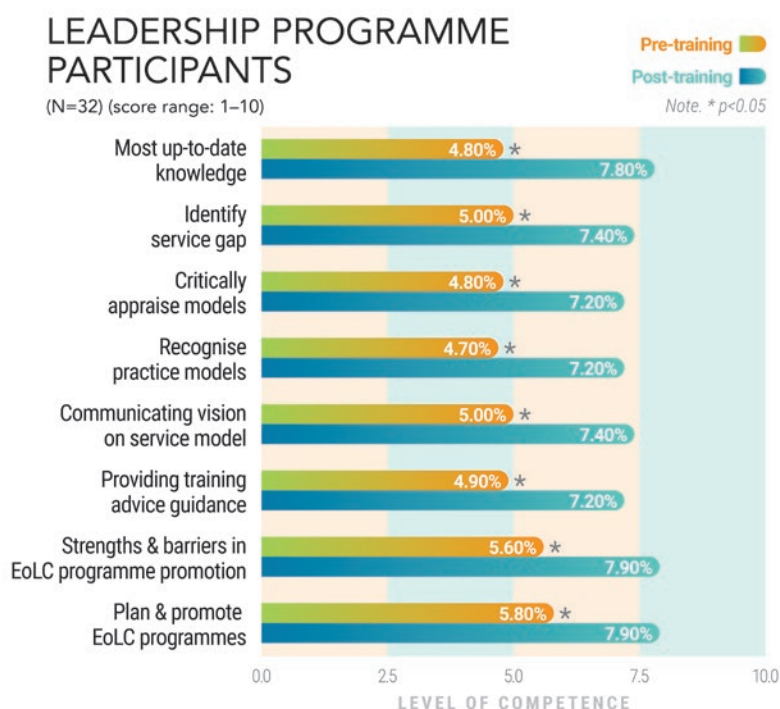


Figure 13.2 Pre-Post Changes in Competence Domains in EoLC among 2016 and 2017 Leadership Programme Participants (N=32) (score range: 1–10)

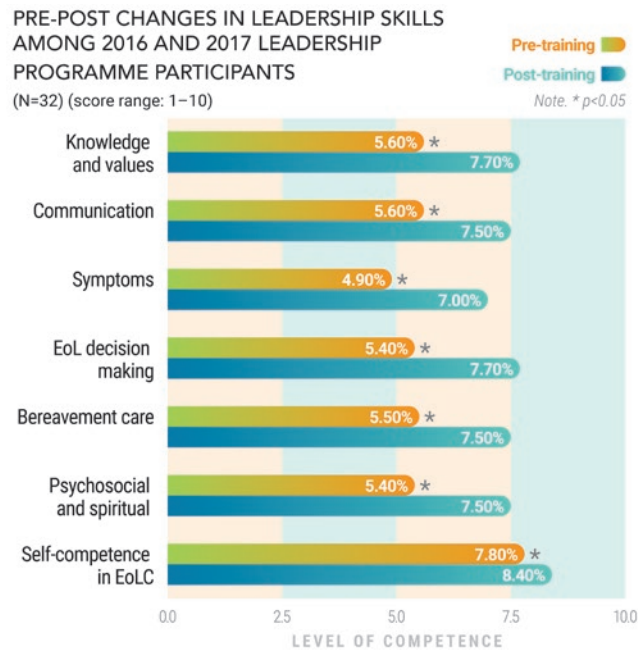


Figure 13.3 Pre-Post Changes in Leadership Skills among 2016 and 2017 Leadership Programme Participants (N=32) (score range: 1–10)

Domain-specific professional training workshops. The 2,887 professionals who registered for the workshops and provided information on their background came from variety of professions, and included social workers (33.2%), nurses (13.8%), religious practitioners (2.5%), counsellors (1.8%), doctors (1.4%) and other healthcare workers (7.6%).

A total of 874 healthcare professionals who participated in the professional workshops completed assessments of their EoLC competences before, and after, training. **Figure 13.4** outlines the changes in each EoLC competency domain. Significant improvements were reported on all measured EoLC domains. These findings supported the effectiveness of the workshops in enhancing participants' competences. There were 966 participants who responded to the post-programme satisfaction survey. On a 5-point Likert scale (from 'Strongly disagree' to 'Strongly agree'), 29% strongly agreed and 53% agreed that they were satisfied with the workshops (an overall high satisfaction rate).

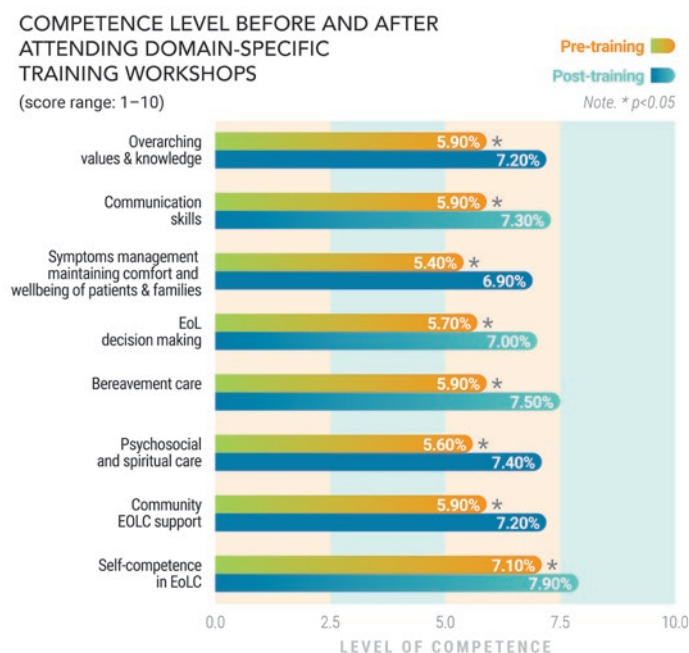


Figure 13.4 Competence Level before and after Attending Domain-Specific Training Workshops (score range: 1–10)

Foundation training course. A total of 88 healthcare professionals participated in the pre-post evaluation of the two foundation training courses. They were mostly social workers (67%) and nurses (22.7%), and they came from predominantly elderly care services (39.8%), other social service settings (29.5%) and public hospitals (12.5%). Despite only participating in one day of training, these participants showed significant improvements in all measured EoLC domains (see **Figure 13.5**)

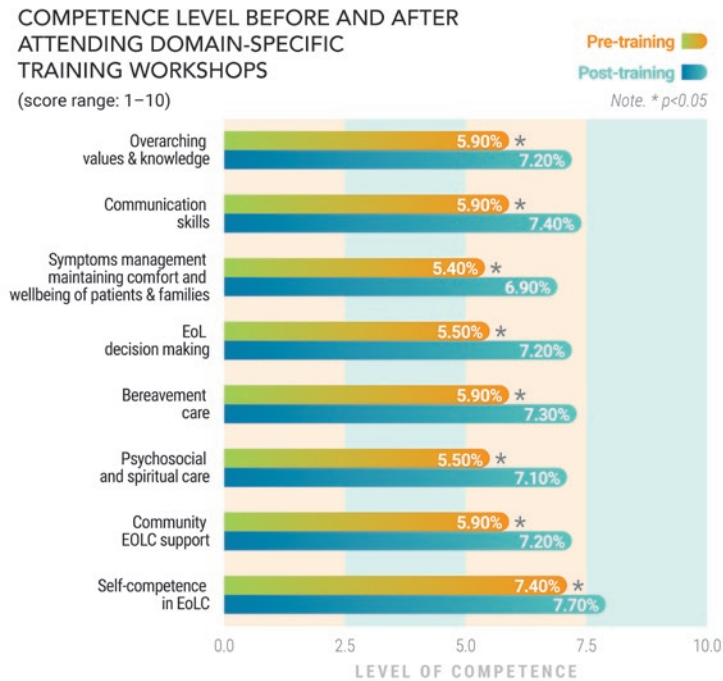


Figure 13.5 Competence Levels before and after Attending Foundation Training Course (N=88) (score range: 1–10)

LEARNINGS AND SUMMARY

The first three years of the JCECC Project has aimed at establishing professional competence programmes in EoLC relevant to the local Hong Kong context. After reviewing global trends and establishing a local strategic framework, the JCECC Project adopted a target-specific, domain-based approach, with four stakeholder targets (policymakers and organisation leaders; clinical leaders; health and social care professionals working in specialist settings; and those working in community settings). Training content has covered seven domains: overarching values and knowledge; self-reflection and self-care; psychosocial and spiritual care; communication skills; EoLC decision-making; symptom management to maintain quality of life and well-being of patients; and bereavement care.

Examination of early outcomes has provided evidence of effectiveness of the training workshops and competence building programmes. Based on these early findings, it is clear that there is room for improvement, particularly in terms of comprehensiveness of training and long-term strategic planning.

The JCECC Project only focused on Steps 1–4 of the 8-Step framework by Gómez-Batiste et al. (2017). Future directions for EoLC professional competence programmes should involve incorporating Steps 5–8 of this framework. Future programmes should also establish continuous training support and follow-up for trained professionals and leaders; design standardised short-term and long-term courses extending to intermediate and advanced levels; and plan setting-specific courses where there are high training needs. Education standards should be defined, and barriers and resultant strategies should be identified. Moreover, given the vision for PC to move towards a team-based, shared-care, integrated and coordinated approach, as outlined in the Hospital Authority Strategic Service Framework for Palliative Care (HA, 2017), interprofessional competences should also be incorporated in high-level training courses.

An issue worth further consideration is the definition of “professionals” in EoLC. The approach of “PC for all” values everyone in the circle of care, including patients, families, neighbours and community members (Abel, 2018). They are the true “experts”. Patients are experts in their own health condition and their preferences. Caregivers are experts regarding a patient’s everyday life and care; and neighbours, community members and volunteers are experts with respect to local social support and community resources. A de-professionalised approach to EoLC has been proposed that involves all members in the community. In fact, in the UK National Health Service framework of EoLC core skills education and training, the patient, caregivers and the public were included in Tier One. They were trained alongside healthcare professionals who were working in adult health and social care sectors, but who had limited contact with anyone approaching EoL (Health Education England, Skills for Health & Skill for Care, 2017). Thus, a future direction for training programmes is to develop a truly community-based approach that reconsiders who the “professionals” in EoLC are and what training they require.

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CHAPTER 14

CHANGING MINDS AND COMMUNITIES: THE USE OF INNOVATIVE STRATEGIES IN COMMUNITY ENGAGEMENT FOR END-OF- LIFE CARE IN HONG KONG

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This chapter outlines how a health promotion approach in end-of-life care (EoLC) can be applied to developing compassionate communities and better engaging communities in EoLC in Hong Kong.

BACKGROUND

THE HEALTH PROMOTION APPROACH IN EoLC

Life-threatening illnesses touch not only the patient, but also their family caregivers and the community around them. Byock et al. (2001) described the experiences of serious illness, dying, caregiving, grieving and death as “personal, but also fundamentally communal”. A large volume of evidence has demonstrated that patients and caregivers at the end-of-life face tremendous physical, psychosocial and spiritual challenges, including anxiety, depression, existential crisis and other forms of psychiatric disorders (Badr, Smith, Goldstein, Gomez & Redd, 2015; Dumont et al., 2006; Mehnert et al., 2014; Rumpold et al., 2016; Zabora, BrintzenhofeSzoc, Curbow, Hooker & Piantadosi, 2001). The health promotion approach to EoLC considers the challenges faced by patients and caregivers, such as loneliness, stigma and other social issues. These are best addressed by friends, neighbours or community members instead of healthcare professionals (Sallnow, Richardson, Murray & Kellehear, 2016).

The health promotion approach to EoLC originated from the Healthy Cities concept by the World Health Organization (WHO) (Kellehear, 2005). The Ottawa Charter for Health Promotion in 1986 stated that:

health is created by caring for oneself and others, by being able to take decisions and have control over one's life circumstances, and by ensuring that the society one lives in creates conditions that allow the attainment of health by all its members (WHO, 1986)

Five health promotion actions were identified:

1. Highlighting the important role of engaging the community in building healthy public policy;
2. Creating supportive environments;
3. Strengthening community actions;
4. Developing personal skills; and
5. Reorienting health services (WHO, 1986).

Kellehear first incorporated health promotion principles in 1999, when building the movement for compassionate communities to improve health and well-being for patients and families living with life-limiting illnesses (Kellehear, 2005). The movement encompasses large-scale, international and social efforts by communities, governments, state institutions and social or medical care organisations (Sallnow et al., 2016).

Death is now recognised as a natural process of human life that should not be hastened, nor life prolonged (Kellehear, 2005). A life-course perspective for integrative EoLC throughout disease evolution has been proposed (Gómez-Batiste et al., 2017). EoLC, in particular, is conceptualised as a series of changing needs through different stages of a patient's life. As a patient progresses from diagnosis of a life-limiting illness to death, his/her needs for disease-modifying and supportive care decrease, while palliative care (PC) needs increase.

Bereavement care for the patient's loved one after the patient's death is also included as part of EoLC, which is consistent with the WHO's definition for PC as: "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses" and should aim to offer "a support system to help the family cope during the patients' illness and in their own bereavement" (WHO, 2002).

THE ESSENCE: COMMUNITY ENGAGEMENT IN EoLC

The key to supporting a life-course approach to integrative EoLC is community-wide effort and collaboration among different professionals and community members. Abel et al. (2013) proposed a community-centred model that envisions the patient as the centre of a series of concentric circles of care. The Circles of Care model "appreciates the persons with illness in their everyday context of living within their communities" (Abel et al., 2013, p. 385). Patients living with life-limiting illnesses are supported by an inner circle consisting of a small group of family and friends. The inner circle is supported by an outer circle of a larger group of family, friends and neighbours; and this outer circle is supported by a further circle of community networks, health and social care professionals in care systems, and social security and policy frameworks. The model emphasised a de-professionalised approach in EoLC that patients, family members, health and social care team members, and all community members participate as partners in the caring process in ways that enhance meaning and value (Abel et al., 2013).

The unique contribution of community in EoLC is acknowledged; however, the question remains as to how to effectively engage the community. The WHO noted that education is one of the core pillars supporting the development of a public health PC model, articulating the need for community capacity building through media and public advocacy, and family caregiver training and support (Stjernswärd, Foley & Ferris, 2007). Sallnow & Paul (2014) considered community capacity building to be embedded within the community engagement process, which "enables communities and services to work together to understand, build capacity and address issues to improve their experience of end-of-life and bereavement and their related well-being" (Sallnow & Paul, 2014, p. 233). The authors emphasised that EoLC should move beyond "working in the community" to "working with the community" (Sallnow & Paul, 2014, p. 233). They specified a spectrum for community engagement, including information, consultation, co-production, collaboration and empowerment, with a range of factors inhibiting and/or supporting the process. The later work of these authors summarised existing community engagement projects into several strategies, including exploring and changing perceptions and reactions to death and dying; increasing awareness and competence of the public; mobilising community resources and advocating policy reform (Sallnow et al., 2016). These strategies have intertwining relationships with one another, and exploring public perceptions form the essential basis for community campaigns, education programmes and training activities for increasing awareness and competence and changing perceptions and reactions. An open and positive attitude facilitates the mobilisation of community resources to support patients and families living with life-limiting illnesses, and the empowerment of communities to advocate for policies that support EoLC. This eventually contributes to building compassionate communities.

COMMUNITY ENGAGEMENT: THE GLOBAL AND LOCAL SCENE

The spectrum of compassionate communities, and supportive strategies suggested by Sallnow et al. (2016), provide a useful framework for understanding contemporary community engagement activities. **Table 14.1** provides a brief summary of representative international projects for community engagement that have been conducted in recent years. Surveys of different scales were conducted in different countries, with the aim of developing a general understanding about public knowledge, attitude and preferences, as well as behaviours related to EoLC. Multiple innovative methods have been employed to increase awareness, enhance competence and nurture an atmosphere of openness for EoLC discussions. Although traditional one-way communication of health information remains common, there is clear evidence of the need to develop more interactive approaches, such as multi-purpose platforms, creative media and audio-visual materials, as well as community campaigns. Such approaches allow two-way communication to occur between different community members, and they provide flexibility for the content of community capacity building to be tailored to individual preferences and the range of cultural norms. Flexible responses to contextually specific cues are believed to enable greater efficacy through personalised communication, and they help health and social care professionals reach historically underserved populations more effectively (Ostherr, Killoran, Shegog & Bruera, 2016).

Increasingly popular game-based conversation tools have been introduced. These serve as important starters to facilitate daily dialogues in EoLC and help to break death taboos in fun and relaxing ways. Evaluation research often goes hand-in-hand with these innovative methods, providing preliminary evidence for their effectiveness in community capacity building and engagement (e.g. Lambert South & Elton, 2017; Lankarani-Fard et al., 2010; McLoughlin et al., 2016; Pazart et al., 2011). Projects about mobilising community resources and policy advocacy are relatively scattered and localised and are usually initiated by small groups of passionate community members within their communities. These programmes can then spread haphazardly to other communities.

Table 14.1 *The Global Scene of Contemporary Community Engagement Activities*

COMMUNITY ENGAGEMENT STRATEGIES (ROLE)	PROJECTS	EXAMPLE
<p>Explore perceptions and reactions (Consult)</p>	<p>Public surveys on end-of-life care and death issues</p>	<ul style="list-style-type: none"> » European countries: <i>Burden to others survey</i> (Bausewein et al., 2013), PRISMA survey in end-of-life cancer care (Gomes et al., 2012; Higginson et al., 2014) » UK: British Social Attitude Survey (Shucksmith, Carlebach & Whittaker, 2013), The Choice in End-of-Life Care Public Engagement Exercises (Choice in End of Life Care Programme Board, 2015), The VOICES Survey (Office for National Statistics, 2015) and <i>A time and a place: What people want at the end of life</i> (Ryder, 2013) » US: <i>Final chapter: Californian's attitudes and experiences with death and dying</i> (California HealthCare Foundation, 2012) » Canada: <i>What Canadians say: The way forward survey report</i> (Canadian Hospice Palliative Care Association, 2013) » Singapore: <i>Death attitude survey</i> (Lien Foundation, 2014a) » Taiwan: A cross-sectional survey with terminally ill cancer patients in 23 teaching hospitals in Taiwan (Liu et al., 2015) » Japan: A pilot survey of the 5th national survey in end-of-life care (Kissane et al., 2015)
<p>Increase awareness and competence, and change attitude (Inform, co-production, collaborate and empower)</p>	<p>Online/published resources and education materials Audio-visual materials, including videos for patients' and caregivers' education, documentaries and movies Platforms for information and experience exchange, and health management Innovative tools for conversation Community campaigns</p>	<ul style="list-style-type: none"> » Multi-purpose online platforms: <i>Dying matters</i> (National Council for Palliative Care, 2009), <i>The conversation project</i> (Institute for Healthcare Improvement, 2010), <i>Death over dinner</i> (2013) and <i>Good life, good death, good grief</i> (2011) » E-health management systems: Comprehensive Health Enhancement Support System (CHESS) (Gustafson et al., 2013); Making your wishes known: Planning your medical future (Green & Levi, 2011); and Together website project (Vogel et al., 2013) » Conversation tools: <i>Five wishes</i> (Aging with Dignity, 2011), <i>The one slide project</i> (Engage with Grace, 2008), PREPARE prototype website (PREPARE, 2012) » Game-based conversation tools: <i>Go wish</i> (Coda Alliance, 2006), Card sorting technique (in France for Alzheimer patients) (Pazart et al., 2011), <i>Dying to talk discussion starter: Online card game</i> (Palliative Care Australia, 2017), <i>Hello</i> (previously named 'My Gift of Grace') (Common Practice, 2018), <i>Heart2Heart</i> (Discuss Directives, 2018), <i>Have the talk of a lifetime</i> (National Funeral Directors Association, 2018), <i>Care planning cookies</i> (Life & Death Matters, 2015) and <i>Advance care planning origami fortune teller game</i> (Good life, good death, good grief, 2011) » Community campaigns: Death Cafe (Impermanence, 2011), Before I Die Walls (Ritual Fields, 2013) and Die Die Must Say (Lien Foundation, 2014b)

(Continued Next Page)

COMMUNITY ENGAGEMENT STRATEGIES (ROLE)	PROJECTS	EXAMPLE
Mobilise community resources (Co-production, collaborate and empower)	Neighbourhood/ community support networks	<ul style="list-style-type: none"> » Good Neighbour Partnership (Milford Care Centre, 2015) » Beauty Bus makeshift salon (Beauty Bus Foundation, 2018) » “The Wish Ambulance” Project (Ambulance Wish Foundation, 2007)
Advocate in policy reform (Empower)	Policy advocacy and changing social environment	<ul style="list-style-type: none"> » The advocacy of pain and PC policy of the government of Kerala (Paleri, 2008) » The WISE project on designing dementia-friendly outdoor environments (Mitchell & Burton, 2006) » The advocacy of PC policies across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes in the 67th World Health Assembly (World Health Assembly, 2014)

COMMUNITY ENGAGEMENT IN EoLC IN HONG KONG

Community engagement in EoLC is relatively underdeveloped in Hong Kong. The *Quality of Death report* released in 2015 showed that Hong Kong scored 32.5/100 in community engagement, ranking 38 out of the 80 countries surveyed. This ranking is much lower than nearby Asian countries (e.g. Taiwan, Japan and Singapore) (Economist Intelligence Unit, 2015). This low score can be partially explained by cultural taboos in discussing end of life (EoL) and other death issues among Hong Kong Chinese. Talking about death is often considered to bring bad energy and evil spirits to an individual and/or the family (Chan, 2009). People avoid mentioning “death” directly, with the use of subtle and implicit euphemistic words (Qi, 2011). A local survey found that more than 20% respondents still believed that “talking about death in the presence of a dying person would accelerate death” (Ho et al., 2007, p. 5). Reluctance to engage in EoLC discussions has also been acknowledged in the Hospital Authority (HA) Advance Care Planning (ACP) and Advance Directives (AD) public education pamphlets. People may want to defer such discussions due to a lack of necessary communication and emotional skills; fear that healthcare workers are too busy for ACP discussions; worry that patients will become down-hearted and depressed as the initiation of ACP discussion can be a reminder of death; and/or they may become anxious over healthcare workers “giving up” on a patient because they refuse life-sustaining treatments.

The taboos and reluctance to discuss death reflect misunderstandings, unexplained myths, insufficient communication skills and incompetence in handling emotional triggers in the EoLC communication process (HA Clinical Ethics Committee, 2016).

Fortunately, a number of innovative projects have been established recently to engage the broader community in EoLC and death discussions. Multi-purpose online platforms have been established since 2006.

- » The website for the ENABLE Project was the first award-winning platform to focus on promoting life and death education in local communities (Centre on Behavioral Health, 2010b). It contains online education resources, information on training courses and public events, and a platform for peer support and experience-sharing.
- » Similar platforms such as “Hospice home” (Centre on Behavioral Health, 2010a) and “I can plan ahead” (Chinese University of Hong Kong, 2016) have also been launched, which have more interactive elements such as apps and e-workbooks.
- » A number of community campaigns have also been initiated. The Death Cafe and Before I Die Wall ideas have received increasing attention. Moreover, local creative projects integrating experiential activities, creative arts, exhibitions and peer exchange elements have become popular. These have been organised by groups such as DEAtHFEST (Sheung Kung Hui Holy Carpenter Church District Elderly Center, 2015), Endless Care Services (Tung Wah Group of Hospitals, 2009) and Big Silver (Big Silver, 2015).
- » Documentaries and mini-movies such as *Snuggle* (Wong Siu-pong, 2016) and *The Tail Before* (Wong Fei-pang, 2016) have been produced, and a magazine has been published about these projects. These have been widely publicised in the local community.
- » Other community organisations such as Life and Death Education Society; Comfort Care and Concern; Haven of Hope; and St James’ Settlement are also active in organising education activities and producing education materials. Some of them have initiated volunteer projects for family photo-taking and wish fulfilment.
- » HA published public education pamphlets on ACP in 2016, helping patients and family caregivers gain an understanding on the medical decisions to be made at EoL and the relevant documentation related to this (HA Clinical Ethics Committee, 2016).

Overall, these projects have increased public awareness and helped develop an open attitude on life and death issues, which creates significant momentum for community engagement in EoLC.

THE JCECC PROJECT: A LIFE-COURSE APPROACH TO COMMUNITY ENGAGEMENT IN HONG KONG

Building upon the groundwork and experience of other projects, the (Jockey Club End-of-Life Community Care) JCECC Project has expanded the life-course perspective to community engagement in EoLC. Life is ultimately seen as a walk from the “community” ring of the circle towards the centre of the circles, in the Circles of Care Model (Abel et al., 2013). With an ageing population, every healthy community member may need to eventually assume the role of family caregiver, and inevitably the role of EoL patient themselves. The JCECC Project therefore aims to engage everyone in the community, including healthy community members, patients living with chronic or life-limiting conditions, and family members. A wide range of community engagement strategies have been adopted to tailor the variety of interests and needs for individuals from all walks of life. These approaches echoed Kellehear’s contemporary health promotion strategies of “participatory; recognises the social character of health and illness; emphasises education, information, and policy development; is designed for the well and the ill; is everyone’s responsibility, not just the individuals” (Kellehear, 1999, p. 12). **Figure 14.1** provides an overview of the JCECC Project community engagement components.

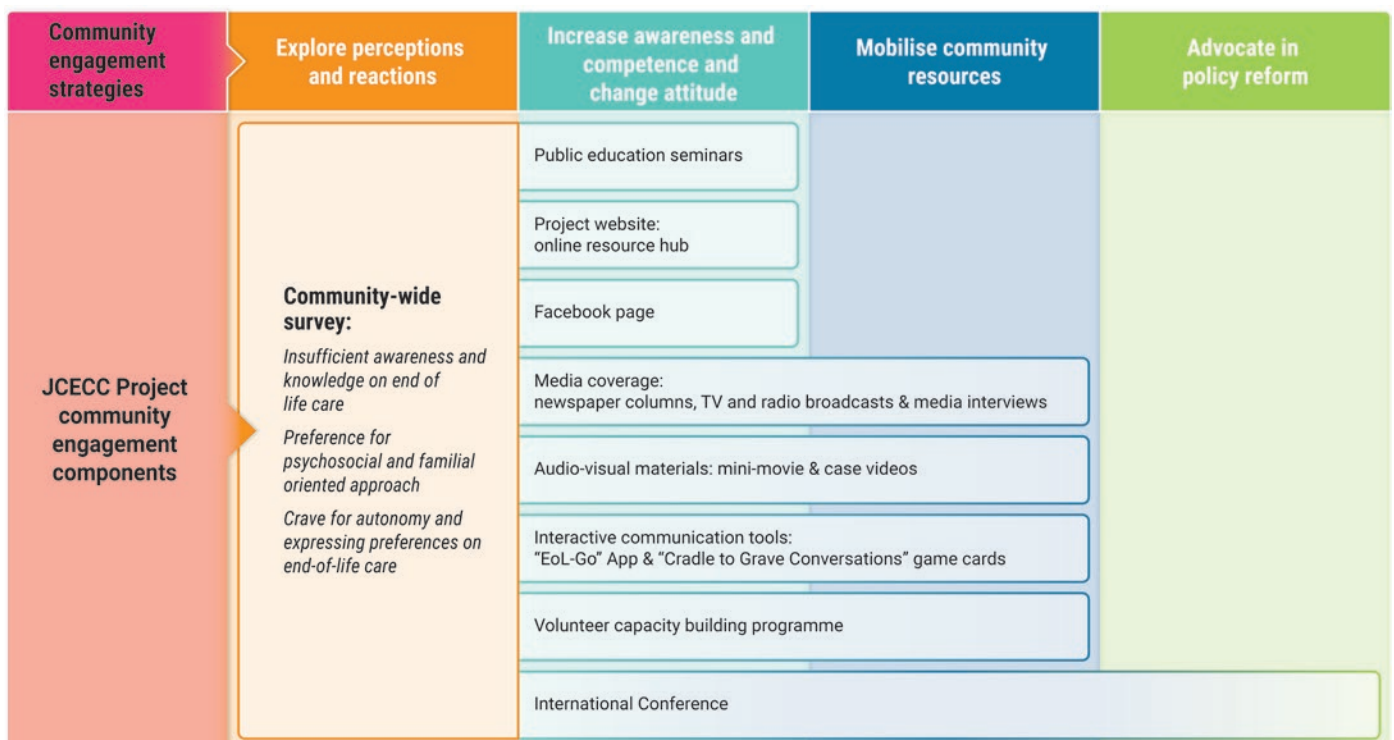


Figure 14.1 Overview of JCECC Project Community Engagement Components

THE JCECC PROJECT COMMUNITY-WIDE SURVEYS

Community-wide surveys have been conducted in the JCECC Project three times so far (2016, 2017 and 2018) in order to understand the Hong Kong public's knowledge, attitudes and preferences on EoLC. A population-based simple random sampling approach was adopted and data was collected by telephone survey. Although the results from the first wave serves as baseline data for planning community engagement activities, results from the second and third waves have been helpful in evaluating the impact of community engagement activities, and in reflecting changes on knowledge, attitudes and preferences on EoLC. Findings from the first wave survey, with 1,515 respondents, highlighted the following challenges and opportunities for community engagement in EoLC (JCECC, 2016).

Insufficient awareness and knowledge on EoLC. People in Hong Kong generally have low awareness and limited understanding of the terms and services related to EoLC. Respondents were asked whether they had heard of three terms describing support and care services for patients and families, including hospice care “善終服務”, PC “紓緩治療” and EoLC “安寧照顧”. The majority of respondents had heard about hospice care (86.6%), as the term is associated with the early development of services for dying patients in Hong Kong. Only about one-third had heard of the more recent terms PC (37.6%) and EoLC (30%). This finding is in line with the latest trends in developing care services for chronic and advanced disease conditions, and in adopting an integrated care approach that addresses physical, psychosocial and spiritual needs as illnesses progress. The percentage of respondents who were aware of PC and EoLC was relatively low compared with other countries (see **Figure 14.2**), including the UK, the US, Canada and Singapore. Many respondents were also unaware of the key basic components in EoLC. Less than half of them had heard of “grief counselling” and “Do Not Attempt Cardiopulmonary Resuscitation”, and even fewer were aware of ADs (18.5%) and “bereavement support” (12.4%).

These findings echoed findings from another local Hong Kong survey, which showed that 80% survey respondents had not heard of hospice or PC services, and over 60% did not understand how these services might help EoL patients (Federation of Medical Societies of Hong Kong, 2016). The community's limited awareness and knowledge about PC and EoLC may contribute to the taboos, misunderstandings and myths around death and dying, which in turn may restrain the community's engagement in care and support for patients and families living with life-limiting illnesses.

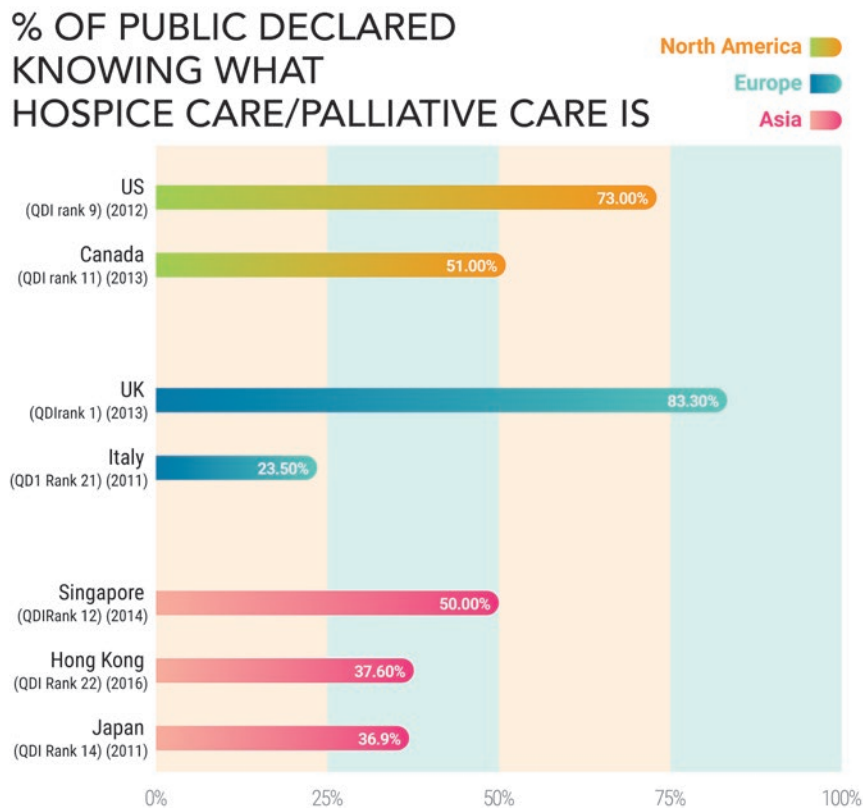


Figure 14.2 Comparison of Public Awareness on Hospice/Palliative Care with Other Countries (Benini et al., 2011; California HealthCare Foundation, 2012; Canadian Hospice Palliative Care Association, 2013; Hirai et al., 2011; JCECC, 2016; Lien Foundation, 2014a; Shucksmith et al., 2013). Adapted from JCECC, 2016, p. 20.

Preference for psychosocial and familial-oriented approach. The public indicated clear preferences towards psychosocial and familial approaches to EoLC. When being asked about the service components of care at EoL, a significant proportion of respondents mentioned counselling and psychological support (30.4%) and spiritual care (14.7%). They are, in fact, the top two service components that respondents thought were important in EoLC, and these percentages were higher than those for medical services (such as hospitalisation, home care and day care services). The responses to a hypothetical scenario when a person had only six months to live indicates what psychological and spiritual support means in the EoL stage. Having family and friends around (40.6%) and that the family lives a happy life (9.1%) were two of the top five concerns at EoL; the remaining concerns were living a meaningful life (11.7%), absence of pain or suffering (8.5%) and fulfilling wishes (4.6%). Respondents also expressed wishes to spend their remaining time creating happy memories (19.6%) and saying goodbye (11.7%) to family and friends. Consistently, respondents were happy to consider being cared for in settings outside hospital, including the family home, RCHes and social service agencies, where psychosocial care and family and social networks were more accessible. While medical care is often emphasised in EoLC, our results highlighted that psychosocial and family care can be of equal, if not greater, importance.

Craving autonomy, choices and communication on EoLC. The survey clearly indicated that the public treasured autonomy and choices in the EoLC decision-making process. The majority of respondents (84%) wanted to make their own EoLC decisions, while the remaining 16% believed that doctors, family members and others should be the decision-makers. People indicated that they wanted to have a choice about whether they would receive EoLC (79.4%); sign an AD (74.4%), and decide the place of death (73.1%). The majority (70%) wanted to discuss these decisions with their families. Not only did respondents generally accept the construction of EoLC facilities near their home (82.1%), having neighbours receive EoLC at home (76.1%) and dying at home (59.2%), but a significant percentage also showed interest in attending educational activities related to EoLC (40.4%). Over 90% felt it was acceptable to talk about death. The open attitude among respondents possibly reflected the continuous efforts of local community projects to raise awareness around the topic. The next step for community engagement in EoLC should move towards creating interactive platforms to facilitate knowledge and skills exchange, enhance communication on personal preferences and generate new ideas for service development.

CORE COMPONENTS OF COMMUNITY ENGAGEMENT IN THE JCECC PROJECT

Based on the survey findings, the JCECC Project has made use of four major components to engage local community members in EoLC:

1. Enhance EoLC literacy by provision of education activities and resources;
2. Stimulate awareness through creative media and audio-visual materials;
3. Engage all in dialogue, conversations and discussion regarding the development of innovative and interactive tools; and
4. Nurture volunteers in the community via training and service projects.

With its pilot efforts, the JCECC Project seeks to turn a new page in EoLC community engagement in Hong Kong.

Enhancing end-of-life care literacy by experts and professionals. Educational activities and resources are key to providing information and enhancing EoLC literacy in the JCECC Project. Public seminars have been frequently hosted, with the content covering a wide range of important topics in EoLC including basic terminologies; concepts and values; symptom management; psychosocial–spiritual care; family communication; decision-making and bereavement support. The seminars have been delivered by local and international experts.

Online resources, audio-visual materials, case sharing and experiential exercises have been integrated into these seminars to make the learning process interesting and interactive. All public seminars have been opened to community members on a first-come, first-served basis at no monetary cost, and English–Cantonese bilingual simultaneous interpretations were provided for seminars delivered by non-Cantonese speaking international speakers. In total, 30 public and invited events were held from December 2015 to April 2018, reaching 4,692 participants.

Participants were generally satisfied with the seminars, with a mean overall satisfaction score of 4.4 out of 5 in evaluation surveys. It was observed that a significant proportion of participants in these public events had been, or were currently, caregivers for patients living with chronic or life-limiting conditions. They were often eager to ask questions and share their caregiving experiences. As such, the public seminars provided much more than an information-provision session, as they also provided a platform to engage caregivers in experience-sharing and obtaining (and providing) peer support.

People who were not able to attend public seminars could refer to the JCECC Project online education resources, which had updates on project events, archival educational materials, research progress, as well as useful links and information on local community EoLC services, international best practices and guidelines. The JCECC Project Facebook page and social media platforms reach out to younger people and the more electronically literate public. The website hit rate (since inception date to final date of calculation) was 307,842 and the Facebook page has reached 168,436 accounts up to April 2018.

Promoting awareness and discussion through creative media and audio-visual materials.

In addition to conventional education activities and resources, the JCECC Project also engaged creative media and produced audio-visual materials to stimulate awareness and discussion in EoLC. Special collaborations have been established with a major local newspaper Ming Pao, prominent local radio and television broadcast stations including Radio Television Hong Kong (RTHK), Commercial Radio Hong Kong (CRHK) and Now-TV. Experts and frontline professionals in health and social care, such as doctors, nurses, social workers, researchers and academics, have been invited to contribute to the content of articles and interviews. They have shared their experiences on working with real cases, and have provided essential information, practical tips and advice with respect to the themes in each column or interview. Sometimes, patients and/or family members have been invited to join interviews to illustrate their experiences in working as core partners with the EoLC team. A total of 19 newspaper articles have reached an estimated 140,000 readers per issue, and 22 media interviews provided 900 minutes of radio-show airtime.

Original films have been produced, including five case stories, three documentaries on services of the JCECC non-government organisation (NGO) partners and a 16-minute mini-movie *My Little Story with Mom*. The mini-movie presented a story of a mother–daughter dyad living with advanced cancer. It was developed with reference to a real-life story and emphasised the possibility of living a quality life through maintaining autonomy and dignity at EoL. The movie was launched in November 2017, with the premiere attracting 1,092 participants and guests. YouTube, the JCECC Project website and the Facebook page view rate reached over 70,000 up to April 2018.

Engaging all in dialogue, conversations and discussion with the development of innovative and interactive tools. Innovative communication and interaction tools provide unique contributions to engage community in EoLC dialogues and conversations by the JCECC Project team. The public survey showed that people in Hong Kong treasured family times and happy memories at EoL. However, Chinese culture does not favour direct communication on tabooed topics (such as death and dying) or verbal expression of emotions (Qi, 2011). The team designed tools to integrate family activity planning, knowledge and mini-games with the purpose of facilitating family communication on EoLC. A travel-guide mobile app “EoL-Go” was developed and made available on both Google Play and Apple’s App Store. The app consists of practical tools and information on trip planning, tips on pre-trip preparation and destination recommendations for patients and caregivers planning excursions in Hong Kong and overseas. It is the first of its kind in Hong Kong and is expected to help generate meaningful family dialogues and create happy memories via the trip planning process.

The “Cradle to Grave Conversations” card game is a useful starter tool for daily dialogues and conversations about EoL. The deck comprises four sections according to the four suits of poker. “How well do you know me?” helps players to break the ice and understand each other; “Interesting facts from cradle to grave” shares interesting knowledge on medical, legal and social aspects of EoLC and death in an effort to debunk common misconceptions and myths; “From fairy tales to EoL” includes well-known stories such as the Three Little Pigs and Journey to the West to engage players in reflecting on a variety of EoLC decisions; and “Your wishes” inspires players to review their life experiences and preferences on EoL wishes. Conversation prompts, mini-games and engagement exercises are scattered over the 52 cards, not only to encourage dialogue and conversations but also to suggest actions to express love and care. A total of 1,500 packs of cards have been printed and disseminated free to the public. Although the card-game content has been designed for use by lay people, many health and social care professionals make use of them tactfully in clinical practice as ice breakers in education activities or conversation tools to prepare patients, caregivers and volunteers for more in-depth EoLC discussions.

Nurturing volunteers in the community via training and service projects. The JCECC Project has underpinned the development of volunteer programmes to mobilise community volunteers in supporting patients and families living with chronic and advanced illness. An EoLC Volunteer Collaborative Leadership model has been developed to enhance volunteer personal competences, motivations, and knowledge and skills. This has occurred through a capacity building process ranging from project promotion, recruitment and screening, training and continuous support. In collaboration with the four community NGO partners, the project team piloted a volunteer competence building curriculum in EoLC in January 2018. The trained volunteers are important partners in the EoLC team, providing tangible and timely support for patients and family caregivers, accompanying them through critical moments, empowering them in health management, enriching their life experience and relieving caregiving burdens. More details of the JCECC Project Volunteer Collaborative Leadership model can be found in Chapter 15.

CONCLUSION AND IMPLICATIONS

Building on the health promotion principle of compassionate communities, the JCECC Project has pioneered a life-course perspective to engage local community members in EoLC. The Project has proactively responded to needs and characteristics of the local community, and considered global and local development trends in community engagement. Conventional education activities remain important and well-received methods of enhancing EoLC literacy. More efforts are devoted to the use of information, communication technologies and creative media (such as websites, Facebook, newspaper, radio and television broadcasts, and audio-visual materials). These platforms have helped to extend the reach to community members, allow proactive responses to the needs of the community and deliver messages effectively in a fast-paced environment. Special highlights are the production of a mini-movie, game cards and a mobile app, which have done much to initiate community dialogues and actions in EoLC to debunk common misconceptions and myths. All community engagement components in the JCECC Project have a clear focus on psychosocial–spiritual care, communication and decision-making. Such focus does not only match the needs reflected from the baseline community-wide survey, but it also complements the recent progress of HA to educate the public on medical decisions in ACP.

The JCECC Project's community engagement components have great potential for further development. Although the Project website serves as an online resource hub, there is the possibility of further development of self-initiated learning platforms. More structured and interactive education curricula can be designed to meet the needs of different community members, who are in different aspects of the Circles of Care. Examples include health management materials for patients; daily and home care resources for caregivers; skills-drilling courses for volunteers; and community support tips for healthy community members. Learning log books, self-evaluation tools and interactive tutorials can be incorporated to allow learners to keep track of their progress, and therefore increase their motivation and effectiveness. The mini-movie and game cards can also be expanded into other community capacity building tools. Online and paper workbooks and self-help books can be published and workshops can be delivered to help community members articulate and document their EoLC preferences. The card game can potentially evolve into an interactive online tool and mobile app for self-exploration, family communication and peer exchange. Ambassador schemes to promote these tools may be feasible, in addition to volunteer programmes. The JCECC Project team should look at this to ensure that these ideas can be implemented in the Phase 2.

To establish evidence-based practice, evaluation research should be undertaken, in conjunction with community engagement activities. The JCECC Project includes a number of components to evaluate the effectiveness of its community engagement activities. The three timepoint community-wide surveys provide a robust reference frame regarding how the community engagement activities, in general, have impacted on public knowledge, attitude and preferences. The statistics on the number of participants attending education activities, visitors on website and Facebook, readers and viewers for media coverage, game cards distributed, and the amount of airtime for broadcasts provide multipronged estimates of the potential reach of the programme. Nonetheless, there is a lack of evaluation on expected outcomes and effectiveness, specific to each community engagement activity. However, this is a worldwide issue that has been identified in the use of information and communication technologies in EoLC (Ostherr et al., 2016) and interprofessional education (Institute of Medicine, 2015). Establishing comprehensive and feasible frameworks to evaluate the outputs, learning outcomes, and health and system outcomes is thus a crucial next step to advance community engagement in local contexts.

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CHAPTER 15

BUILDING VOLUNTEER COLLABORATIVE LEADERSHIP: AN ACADEMIC COMMUNITY PARTNERSHIP INITIATIVE

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End-of-life care (EoLC) should matter to everyone in today's global society. This chapter starts with the argument that volunteering can, and should, be an essential and integral part of EoLC. It then moves to a critical review of roles and models of EoLC volunteering in the US, Canada, the UK and Hong Kong. Grounded in literature and local experience, a Hong Kong-contextualised EoLC volunteer-partnered leadership model is outlined, including its objectives and basic elements of promotion, screening, capacity building and management strategies.

Findings from an evaluation of the capacity building curriculum, and feedback from volunteers, suggest that the concept of the volunteer collaborative leadership (VCL) model is feasible and effective in the Hong Kong context, and thus deserving of wider implementation. It is anticipated that greater future social capacity could be reached if the numbers of competent volunteers are increased to partner patients and families for better EoLC, with enhanced respect, dignity and choices.

BACKGROUND

EoLC IS EVERYBODY'S BUSINESS

In the Chinese context, “good death” is one of the “five blessings” (五福) that every person wishes to achieve in his/her life (Confucius (Compiler), Anonymous & Palmer (Translator), 2014). Even though Hong Kong society has been influenced by both Eastern and Western culture in its history, it is still a mega-city deeply influenced by traditional Chinese cultural and religious philosophies, including Confucianism, Taoism and Buddhism (Cultural Atlas, n.d.). Based on a critical review and an empirical exploration of Chinese culture, Chan and his colleagues (Chan, Tse & Chan, 2006) argued that “good death” is associated with Chinese philosophical and religious thought, which is embedded in the daily lived experiences of individuals and families. This notion may have profound implications for end-of-life care (EoLC) for terminally ill patients and bereaved families; hence, it is unwise to suggest that providing care and support to people at their end of life (EoL) should be the sole responsibility of healthcare professionals. Culturally contextualised EoLC should be embraced by the patient, his/her family, neighbourhood and community.

EoLC is a crucial element of palliative care (PC). The primary purpose of EoLC is to improve a patient's quality of life (QoL) across physical, psychosocial, social and spiritual realms, while respecting their healthcare treatment decisions (World Health Organization, 2004). The literature indicates that EoLC is best provided holistically using a multidisciplinary team, which involves healthcare workers from different disciplines, including palliative doctors, a palliative nurses, paraprofessionals, social workers, pastors and healthcare workers (Health Service Executive, 2017). Studies in Hong Kong have consistently demonstrated that a cross-disciplinary team is key to achieving dignity and QoL for people at EoL (Ho et al., 2015). A review of good practices of EoLC further suggests that although professional care is a core and essential component of EoLC, complementary input from the neighbourhood and local community can improve EoLC and assist terminally ill people to achieve a “good death” (Gardiner & Barnes, 2016; Pesut et al., 2018). Including volunteers opens new windows for delivery of EoLC services. Not only would engagement of volunteers increase service impact on the lives of terminally ill patients, their families and friends, but this would also encourage a culture of volunteering in EoLC programmes, which in turn would promote the development of compassionate communities (Zaman, Whitelaw, Richards, Inbadas & Clark, 2018).

EoL VOLUNTEERING: A WORLDWIDE MOVEMENT

The rapid growth of ageing populations around the world poses challenges for better integration of EoLC into global and world region health priorities and also into national health systems (Worldwide Palliative Care Alliance [WPCA], 2014). One of the greatest challenges that societies are currently facing worldwide is that the demand for EoLC exceeds the supply (Grant, Brown, Leng, Bettega & Murray, 2011; Lynch, Kenney, Haley & Resnick, 2011; Morrison & Meler, 2015). The WPCA (2014) estimated that only 14% EoL patients needing PC actually receive it. In order to help readers reach a better understanding of, and make sound judgements about, EoLC, a review was conducted of EoLC policies and the use of volunteers in EoLC services in three developed countries (the US, Canada and UK; see **Table 15.1**). This overview shows that the effective use of volunteers in palliative or EoL care seems to be a cost-effective solution in addressing under-supply of EoL services. The volunteering movement, and standards of EoLC volunteer services, have been promoted by the governments and/or leading PC and hospice associations in these three countries. The volunteering movement supports people of different ages, gender, careers, education backgrounds, socio-economic status and races to participate in serving EoL patients and their families. Volunteers are commonly considered as “unpaid help provided in an organised manner to parties to whom the worker has no obligations” (Tilly & Tilly, 1994, p. 291). They play an important role in today’s society in many sectors (transport, education, health, etc.), and more recently in EoLC programmes at residential homes and communities (Bone et al., 2017; Burbeck et al., 2014; Candy, France, Low & Sampson, 2015; Claxton-Oldfield, Gosselin, Schmidt-Chamberlain & Claxton-Oldfield, 2010; Herbst-Damm & Kulik, 2005; Institute of Development Studies, 2015).

Table 15.1 *EoLC Volunteering: A Review of the US, Canada and UK*

	US	CANADA	UK
Government involvement in PC and EoLC (Economist Intelligence Unit, 2015)	Presence of well-defined government-led strategy for development and promotion of national PC. Clear vision, specific milestones, mechanisms and guidelines on implementation are present.	Presence of government-led strategy for development and promotion of national PC. Broad vision and loosely defined milestones present, but limited mechanisms in place to achieve the milestones.	Comprehensive strategy for the development and promotion of national PC. Clear vision, specific milestones, action plan and strong mechanisms are present. Milestones are regularly reviewed and updated.
Community engagement in EoLC (Economist Intelligence Unit, 2015)	Public has a somewhat good understanding and awareness of PC services.	Public has somewhat good understanding and awareness of PC services.	Public has a strong understanding and awareness of PC services.
Volunteer involvement in EoLC	The US hospice movement was founded by volunteers. In 2011, around 450,000 volunteers provided 21 million hours of service to hospice care. Around half of these volunteers provided direct patient care (National Hospice and Palliative Care Organisation, 2017).	Around 35,000–40,000 volunteers were serving in hospice/PC programmes across Canada. In some parts of Canada, volunteers outnumber paid staff by 50:1. (Canadian Hospice Palliative Care Association, 2012)	Volunteering in the UK hospice sector started in 1960s. The estimated mean number of volunteers per hospice was 240 (Hospice UK, 2012). Most volunteers work in hospices, shops and in fundraising; some provide direct patient care, mainly in day care, bereavement and inpatient services (Burbeck et al., 2014).
Presence of organisation(s) promoting volunteer involvement in EoLC	The National Hospice and Palliative Care Organisation provide training on volunteer management. The government also requires using volunteers in hospices which participated in Medicare.	The Canadian Hospice Palliative Care Association provides guidelines on volunteer training and management, and provides support for volunteer programmes in PC.	Association of Voluntary Service Managers provides a network to managers for volunteers in PC. Hospice UK is an organisation representing hospice services involving PC volunteers
Regulations related to EoLC volunteer	As a Medicare condition of participation, hospices in the US are required to use volunteers to provide at least 5% of total patient care hours. A range of standards govern and provide direction for hospice volunteer programmes.	Volunteer engagement was emphasised in the national framework on PC, but concrete standards are not included. (Canadian Hospice Palliative Care Association, 2015).	Despite no concrete regulation over the use of volunteers in hospice/PC, volunteers often have a brief induction and occasional training (Woitha et al., 2014).

There is community-wide meaning when volunteers provide EoLC services, as patients, family caregivers, volunteers and the whole community can benefit (Claxton-Oldfield, 2015a; Walshe et al., 2016). The multidisciplinary service team of the John Hopkins Home Hospice in the US commented that “volunteers bring unique skills and approaches to working with patients and families and in their role as regular and friendly visitors can often provide needed caring beyond the scope of the other hospice team members’ contributions” (Morss, Reder, McHale, Clayton & Silva, 2003, p. 295–296). Similarly, Anne Atkinson, the Volunteer & Community Engagement Lead in St Mary’s Hospice in the UK, said: “Volunteers are our greatest resource. They bring skills, ideas and experiences. They are helpful, friendly and reliable. We couldn’t function without them – they make our team complete” (St Mary’s Hospice, n.d.).

Nowadays, there are many ways in which volunteers can lend their time and effort to EoLC. Literature on EoLC volunteers suggested three typical images or roles.

- » The first image refers to “bridges”. Trained volunteers can usually act as bridges to connect patients to hospitals, social care, financial support and the broader society, as well as facilitating better linkages between patients and their family and caregivers (Jack, Kirton, Birakurtaki & Merriman, 2011; Morris, Payne, Ockenden & Hill, 2017; Sévigny, Dumont, Cohen & Frappier, 2010).
- » The second image is as associates of the healthcare support teams. Trained volunteers can work closely with multidisciplinary teams, which may include doctors, nurses, social workers, bereavement counsellors and nutritionists, to address patients’ practical, psychological, physical, social, emotional and spiritual needs (Beasley et al., 2015; Claxton-Oldfield, 2015a; Gardiner & Barnes, 2016; Morris, Wilmot, Hill, Ockenden & Payne, 2012; Pesut et al., 2018). Volunteers can also work with family members after their relative’s death to assist them with their bereavement care needs (Scott, Butler & Wilson, 2017).
- » The third image relates to the “mobile healer” who contributes directly to patient support (Burbeck et al., 2016; National Hospice and Palliative Care Organisation, 2018). Volunteers have been reported as contributing to care delivered in a range of settings (e.g. in hospital or in a patient’s home). They can also provide care services at different levels – primary (in the community), secondary (in care homes) and tertiary levels (in hospitals). They can complete multiple tasks simultaneously, such as supporting nursing care by assisting patients with meals and drinks, helping to organise events or outdoor trips for patients, or simply spending time with patients (Burbeck et al., 2014).

These three typical images of volunteers (bridges, support teams and mobile healers) highlight the multiple roles that a community of volunteers can provide to promote death with dignity and enhance the QoL of people nearing the final stage of life, including tailor-made client-based solutions.

In summary, the literature from these three countries with mature and well-established EoLC services suggests that EoLC volunteers make unique and inspiring contributions to their community and society, and can serve as an integral part of EoLC (Burbeck et al., 2014). Volunteers also bring locally contextualised experiences to provision of EoLC, and thus it is appropriate to briefly describe volunteer movements in EoLC in Hong Kong.

HONG KONG: BOTTOM-UP APPROACH TO EoLC VOLUNTEER DEVELOPMENT

In Hong Kong, volunteer contribution to EoLC dates from the 1950s. In the beginning (1950s to mid-1980s), missionaries mainly provided spiritual care to small numbers of patients in hospitals, bringing their faith background to EoLC (e.g. Our Lady of Maryknoll Hospital [聖母醫院]). At this time, the role of volunteers was not distinguished from that of religious groups. During the 1960s and 1970s, more professionals from hospital medical teams, such as doctors and nurses, became involved in volunteering to provide EoLC in their spare time, providing mostly spiritual care and informal services to EoLC patients in hospital intensive care units. A good example of this is the Nam Long Hospital (南朗醫院). This hospital introduced EoLC services in 1987, and since 1989, 30% beds included the provision of EoLC. Nam Long Hospital was closed in 2003. At that time, only a small number of patients with particular diseases were able to enjoy organised volunteer services, provided mostly by healthcare professionals during their free time.

EoLC volunteering in Hong Kong made significant progress from the mid-1980s to the mid-2000s as the number of organisations promoting the role of volunteers in EoLC increased dramatically. For instance, non-profit organisations (NPOs), such as the Society for the Promotion of Hospice Care (SPHC) and the Comfort Care Concern Group (CCCG), were established and provided community-based training programmes on EoLC. These organisations actively recruited participants to become volunteers as part of the first formalised group that provided EoLC volunteering in Hong Kong. In addition, these NPOs regularly organised specialised seminars and conferences on EoLC topics to increase public awareness of the range of concerns that arose at the end-stage of life. Similar initiatives also occurred in medical settings around the same time. Since 2007, the Hospital Authority (HA) and the Li Ka Shing Foundation launched the “Heart of Gold” Hospice Services Programme. Up to 2016, 800 volunteers were trained as “hospice service ambassadors” to provide volunteer services in the hospice centres of public hospitals (Hong Kong Special Administrative Region Government, 2016).

The years since 2010 are now regarded as the consolidation stage of volunteer activity in EoLC in Hong Kong. This has been prompted by the establishment of the Jockey Club End-of-Life Community Care Project (JCECC) in 2016. One of the aims of the JCECC Project is to improve terminally ill patients’ quality of EoLC through collaboration between academic institutes and non-government organisations (NGOs), enhancing the capacity of service providers, recruiting volunteers and raising public awareness on EoLC. This has made a significant impact on EoLC volunteer services. Both 2016 and 2017 were milestone years in the EoLC volunteer movement in Hong Kong. Under the JCECC Project, four community partner organisations integrated volunteers into their community-based EoLC service models (St James’ Settlement, Hope of Heaven Christian Services, S.K.H. Holy Carpenter Community Centre and the Hong Kong Society for Rehabilitation). In 2017, volunteers were recognised by the HA as key members in the delivery of PC services (HA, 2017); however, there is still no official government policy to support a top-down framework for service delivery. These initiatives, and subsequent collaborations among academics, hospitals, NPO and NGOs, have injected not only new resources into EoLC, but also provided innovative directions for volunteers.

JCECC EoLC VCL MODEL

The EoLC volunteer literature calls for context-specific evidence to support strategies that aim for widespread implementation of EoLC volunteer programmes (Hall, Brooke, Pendlebury & Jackson, 2017). The JCECC EoLC VCL model filled this gap by providing constructive integration of evidence-based and community-participatory processes. To build the model framework, an extended literature review was performed to identify:

- » Roles and functions of EoLC volunteers;
- » Desirable and undesirable personal factors for EoLC volunteers;
- » Essential training topics;
- » Associated factors in effective volunteer management and retention in EoLC volunteering among existing EoLC studies; and
- » The theories that mostly applied to such studies.

In January 2016, the JCECC Project team searched scientific databases, including EBSCOhost research databases, ProQuest, PsycARTICLES, PubMed, ScienceDirect, Web of Science, Google Scholar, and the online databases of selected journals, including *Palliative Medicine*, *Journal of Palliative Care*, *Journal of Palliative Medicine*, *Palliative & Support Care*, *American Journal of Hospice & Palliative Care*, *BMC Palliative Care* and *BMJ Supportive & Palliative Care*. The search terms used comprised 'palliative care' OR 'hospice' OR 'end of life', AND 'volunteer*'. These were combined with other keywords including 'role*', 'function*', 'trait*', 'personalit*', 'recruit*', 'train*', 'education', 'manage*', 'retention', 'attrition' and 'motivation*'. The project team updated the literature review using the same searching strategy in June 2018. The only exclusion criterion were materials not written in English nor Chinese. They also reviewed government and policy reports, websites of relevant organisations in PC or EoLC volunteering, as well as training manuals for EoLC volunteers. Meanwhile, community stakeholders (service recipients, volunteers and volunteer leaders) were consulted throughout the process to inform model development.

FOUR CORE ELEMENTS

The JCECC EoLC VCL model applies four building blocks for successful EoLC volunteering. These building blocks were extracted from the literature. The four core elements included volunteer personal competences, motivation, knowledge and skills in EoLC, and a continuous capacity building process. The model also incorporated synergistic practice wisdoms relevant to Hong Kong contexts (see **Figure 15.1**).

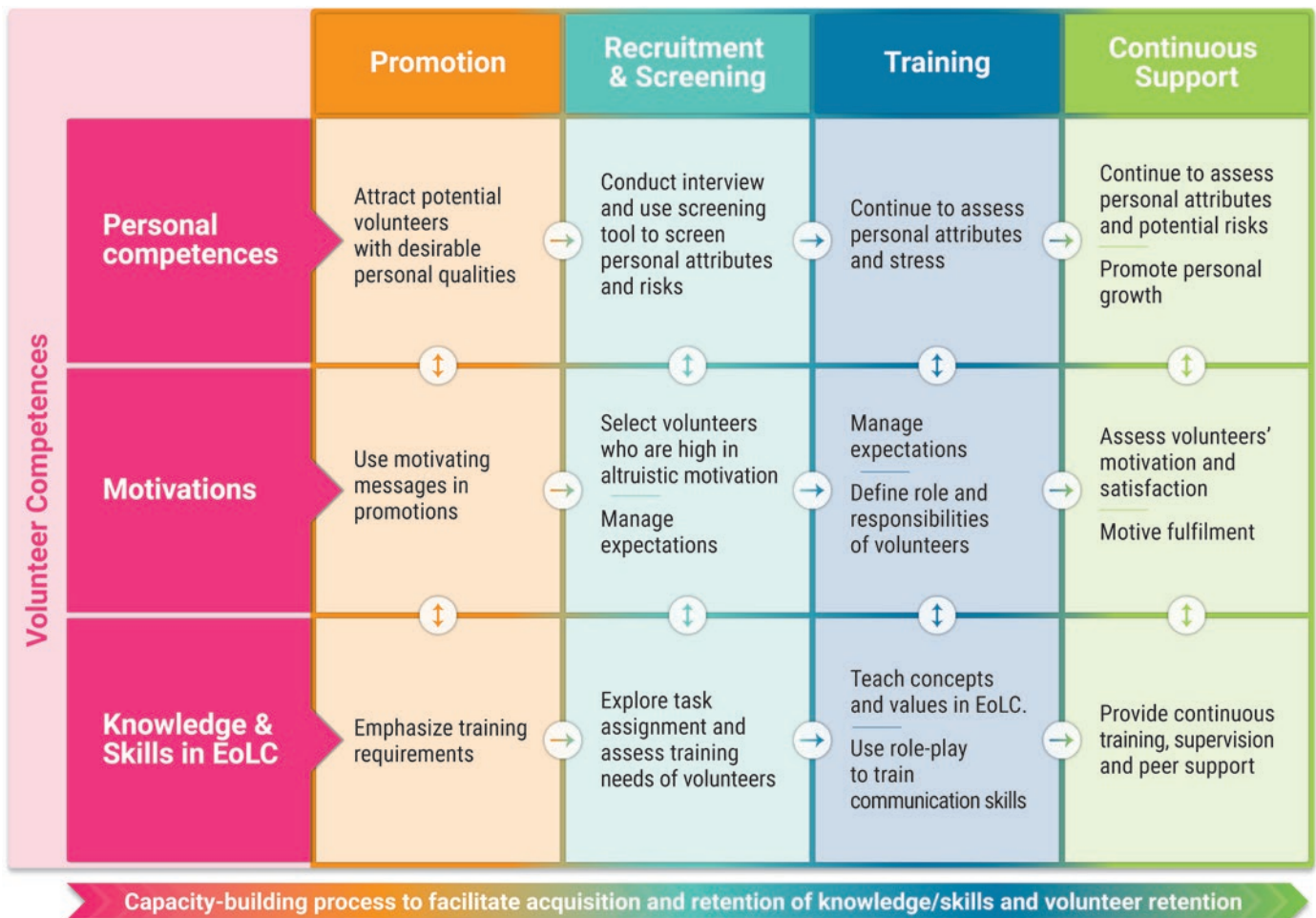


Figure 15.1
A Seamless Journey of Volunteer Collaborative Leadership under the EoLC

Competence refers to the ability of an individual to do a task or job properly. This usually requires individuals to apply knowledge and skills, and to display specific attributes. Studies have repeatedly suggested that emotional maturity and, in particular, personal qualities and motives are possessed by effective EoLC volunteers (Claxton-Oldfield & Banzen, 2010; Starnes & Wymer, 2000). The element “volunteer personal competences” refers to these desirable personal characteristics. Hence, a prudent screening procedure of potential volunteers must be in place to recruit volunteers with desirable attributes. According to volunteer competence theory, volunteers must then be equipped with competence in terms of knowledge and skills in EoLC before serving the community (Culp, McKee & Nestor, 2007). Thus, structured training is necessary to provide volunteers with a minimum level of competences in EoLC. Not surprisingly, a common challenge faced by many volunteer programmes is volunteer retention and sustainability. Scholars have argued that motives for volunteering are important predictors for satisfaction with volunteering experiences

and retention (Claxton-Oldfield, Claxton-Oldfield, Paulovic & Wasylkiw, 2012; Stukas, Hoye, Nicholson, Brown & Aisbett, 2016). Effective volunteer management strategies must be in place to provide continuous support to volunteers, and sustain their motivation to participate on an ongoing basis. The enactment of the four steps in the capacity building process to optimise personal competences, knowledge and skills in EoLC, as well as support the motivation of volunteers, are essential for successful and sustainable EoLC volunteering.

VOLUNTEER CAPACITY BUILDING

Guided by these building blocks, volunteer capacity building comprises four steps: promotion; recruitment and screening; training; and continuous support. This section describes how volunteer competences are built through these four steps.

Promotion. Raising public awareness on EoLC should be a prerequisite to volunteer recruitment in EoLC. Without widespread promotion of EoLC knowledge and the value of volunteers in EoLC in the community, EoLC volunteer events and training, which are mostly institutionalised, easily go unnoticed or are even misunderstood by the public. In view of these concerns, the JCECC Project had contributed to public education concerning EoLC via various means (see Chapter 14). Moreover, an online resource hub was developed under the JCECC Project to provide the public with basic knowledge on the values, contributions and roles of volunteers in EoLC (<http://foss.hku.hk/jcecc/en/volunteer-objectives/>). In the promotion stage, the core task related to personal competences is to attract potential volunteers with desirable personal qualities. Depending on the prescribed roles of volunteers in the service model, the personal features of desirable volunteers vary, and so do the promotional messages and effective channels of communication. In order to attract volunteers with desirable personal attributes, the JCECC Project partners described the qualities that they were seeking in volunteers in their promotional flyers. Partners also strategically conducted public seminars in collaboration with target groups (e.g. patient support groups, elderly centres, church groups, schools) from where they hoped to recruit volunteers.

Recruitment and screening. Interviewing and screening are pivotal steps in finding the right candidates to be volunteers, and involve finding those who can match their goals (or motives) to service objectives, screening out candidates who are at high-risk of not being able to provide appropriate volunteering services, and selecting those with appropriate personal attributes. It is thus important to find ways of identifying and encouraging potential volunteers to participate in EoLC. A short and easy-to-administrate 6-item standardised screening tool of risk factors has been developed, based on findings from the literature review (see **Table 15.2**). Completion of this assessment form has become a mandated part of the EoLC volunteer application procedure. Recruitment of volunteers who present with more than two of these risk factors are not recommended for immediate volunteer participation. NGO partners study the candidates' screening forms and arrange an interview with potentially suitable candidates. After being pilot-tested by the four partner organisations, this screening and selection procedure has been recommended for full implementation in future EoLC practice in Hong Kong.

Table 15.2 Risk-Screening Tool for EoLC Volunteers

RISK FACTORS

- » Bereavement experience in the past two years
- » Currently taking care of significant other(s) in EoL
- » Presence of depressive symptoms
- » Experiencing high stress in personal life
- » Propensity to overcommit
- » Rigidity and difficulty in considering other viewpoints

Note. For the full-assessment, please contact Dr Vivian Lou (wlou@hku.hk)

An interview guide has been developed to facilitate next-stage screening of desirable personal attributes and motives (see **Table 15.3**). Interviewers are expected to observe candidates' social- or person-skills during the interview. In particular, literature suggests that effective EoLC volunteers are often compassionate, flexible, open-minded, attentive and not overly anxious around death (Claxton-Oldfield & Banzen, 2010; Pesut, Hooper, Lehbauer & Dalhuisen, 2014; Starnes & Wymer Jr, 2000). Regarding the core task related to motivation, interviewers should identify volunteers who are high in altruistic motivation, which was suggested to be a core facilitating motive in volunteering (Claxton-Oldfield et al., 2012). Moreover, interviewers should identify potential volunteers' strengths, talents and preferences for specific tasks during the interview to facilitate future matching of volunteers with patients. They should also manage volunteers' expectations through communicating training requirements and service commitments, and explore volunteers' training needs. These have implications for both motivation as well as competence building.

Table 15.3 Volunteer Interview Guideline

	TASKS AND QUESTIONS INCLUDED
Beginning	» Welcome and explain the purpose of interview
Middle	<ul style="list-style-type: none"> » Invite the candidate to introduce oneself » Discuss motivation, values, knowledge and experiences » Explore and managing expectations
Ending	» Invite questions with clarification

Training. In this stage, the ultimate aim is to equip volunteers with core EoLC competencies, to serve EoL patients and their families. Unlike healthcare professionals providing EoLC, for whom national competence frameworks have been proposed to guide curriculum development, there is no worldwide representative competence framework specifically designed for volunteers. Most training manuals identified by the project team were developed by individual hospices or PC organisations, where training was contextualised to their settings. The most relevant to Hong Kong was the UK's End of Life Care Core Skills Education and Training Framework (Health Education England, Skills for Health & Skills for care, 2017). The Hong Kong volunteer competence framework has been built on this, by integrating it with common training topics in the existing volunteer training programme conducted by the project partners to produce a Hong Kong-specific volunteer competence building curriculum. Specifically, it aims to:

- » Cultivate appropriate attitudes in terms of identification of EoLC values;
- » Increase awareness of the roles and boundaries of volunteers in the multidisciplinary EoLC team;
- » Acquire knowledge pertinent to the multifaceted physical–psychosocial–spiritual needs of patients and families in EoLC; and
- » Facilitate the execution of appropriate skills, especially empathetic communication skills to serve families.

In order to maintain the motivation of volunteers, one of the strategies is to eliminate stressors faced by volunteers. This can be achieved by clearly defining the roles and responsibilities of volunteers, and assisting them to develop realistic expectations regarding service outcomes (Claxton-Oldfield, 2015b). Thus, the emphasis on roles and boundaries of volunteers in the core curriculum also serves the purpose of motivating volunteers.

The training curriculum consists of two parts: a centralised 16-hour JCECC Project core training, plus organisation-based training varying from 8 hours to over 30 hours. This arrangement is considered to be the best fit for different volunteer roles and responsibilities designated by the community partners (see **Table 15.4**). The JCECC Project centralised core curriculum covers eight competency domains on EoLC volunteering, delivered in four sessions (see **Table 15.5**):

1. Overarching values and knowledge in EoLC;
2. Volunteer roles and boundaries in EoLC;
3. Communication skills;
4. Psychosocial and spiritual care;
5. Symptom management, maintaining comfort and well-being of patients;
6. EoL decision-making;
7. Bereavement care; and
8. Self-care and self-reflection.

Table 15.4 A Summary of the Volunteer Collaborations in Hong Kong by the Four Community Partners

	ST JAMES' SETTLEMENT	HOPE OF HEAVEN CHRISTIAN SERVICES	S.K.H. HOLY CARPENTER COMMUNITY CENTRE	HONG KONG SOCIETY FOR REHABILITATION
Start of EoLC volunteer service	2016	2017	2004 (mainly focused on bereavement care before 2014)	2016
Local training (hours)	6 hours training + internship	6 hours training + internship	18 hours training + 20 hours internship	6 hours training + internship
Name of the service	Cheering@Home programme	Hospice Based Home Care programme	Hospice in Family Home Care Support Service programme	LET Go – Life Rainbow programme
Mission	Enjoy valuable and wonderful time at the EoL stage	Explore the meaning of life	Improve quality of life	Safeguard the dignity
Core roles of volunteers	Bring joy to patients and their families by home entertainment	Support the provision of spiritual care to patients and their families	Be a companion to patients and their family members	Emotional and social support to patients and their families
Service plan supervisors	Social workers and caregiving officer	Social workers	Social workers and nurse	Social workers and nurse
Service area	Hong Kong Island	Hong Kong Island, Kowloon, and Kowloon East	New Territories – Tuen Mun, Yuen Long and Tin Shui Wai districts	Hong Kong Island – Wan Chai & Eastern districts

Table 15.5 Topics Taught in the Centralised Core Curriculum

COMPETENCY DOMAINS	TRAINING SESSIONS			
	SESSION 1 PREPARATION	SESSION 2 PHYSICAL AND PSYCHOLOGICAL CARE	SESSION 3 SOCIAL AND SPIRITUAL CARE	SESSION 4 FAMILY CARE
Bereavement care	–	–	–	Y
Psychosocial and spiritual care	–	Y	Y	Y
Symptom management, maintaining comfort and well-being of patients	–	Y	–	–
EoL decision-making	–	Y	–	–
Overarching values and knowledge in EoLC	Y	–	–	–
Self-care and self-reflection	Y	–	–	–
Communication skills	Y	Y	Y	Y
Volunteer roles and boundaries in EoLC	Y	Y	Y	Y

The JCECC Project centralised core curriculum has three core features: balanced theory and practice; focus on volunteer roles and responsibilities; and intensive role-plays on challenging scenarios to enhance volunteers' confidence in communicating with EoL patients and their families. This is also reflected by the recurrence of competency domains of "volunteer roles and boundaries in EoLC" and "communication skills" throughout the four training sessions (see **Table 15.5**).

To determine the value of the training, a pre-post evaluation using a standardised questionnaire was conducted with 79 volunteers who completed the training. Volunteers were assessed on their sense of competence in the seven EoLC competency domains as well as personal well-being. The "self-care and self-reflection" domain was assessed using the Self-Competence Scale in Death Work (SC-DW) (Chan, Tin & Wong, 2015), and the six other domains were assessed with a multidimensional volunteer competency assessment

tool developed by the project team. The domains were rated using 10-point Likert scales. The domain on “volunteer roles and boundaries in EoLC” was not assessed. Personal well-being was assessed with the Flourish Scale (Diener et al., 2010; Tang, Duan, Wang & Liu, 2016). At post-training evaluation, participants reported significant improvements in all assessed domains of EoLC competences and personal well-being (see **Table 15.6**).

Table 15.6 *Change of Volunteers’ Perceived Competence and Life Meaning after Completing the Volunteer Core Training Course (N=79)*

ITEM	PRE MEAN (SD)	POST MEAN (SD)	PAIRED SAMPLE t-test	EFFECT SIZE d_{COHEN}
Volunteer EoLC competency				
Psychosocial and spiritual care^a	6.23 (1.87)	7.86 (1.63)	7.31***	0.93
Overarching values and knowledge^a	6.47 (2.03)	7.93 (1.12)	7.51***	0.89
Bereavement care^a	6.47 (2.05)	7.84 (1.21)	7.03***	0.82
Symptom management, maintaining comfort and well-being of patients^a	5.97 (2.16)	7.31 (1.43)	6.46***	0.73
EoL decision-making^a	7.34 (2.17)	8.49 (1.25)	5.50***	0.65
Communication skills^a	6.53 (1.87)	7.93 (2.64)	3.94***	0.61
Self-care and self-reflection^b	64.53 (7.382)	66.07 (8.6)	2.021*	0.19
Personal well-being^c	47.29 (5.38)	48.69 (5.63)	2.20**	0.25

Notes. ^a Measured on a 10-point Likert scale (1=not competent at all, 10= very competent).

^b Measured on a Self-Competence Scale in Death Work (SC-DW), with a scale score range between 16 and 80;

higher scores represent higher competences. ^c Measured on a Flourish Scale, with a scale score range between 8 and 56; higher scores represent better well-being. * $p<0.05$, ** $p<0.01$ and *** $p<0.001$.

Continuous support. Effective volunteer management through continuous support is necessary to further promote competences among volunteers, as well as retain effective volunteers. The literature suggests that motive fulfilment and continuous competence enhancement should be embedded into management strategies to guide management activities and provide continuous support (Doyle, 2002; Ferreira, Proenca & Proenca, 2015). In particular, the literature suggests that fulfilling both altruistic and egoistic motives of volunteers tend to promote satisfaction and sustained engagement (Ferreira et al., 2015; Stukas et al., 2016). Thus, expectation management strategies should be designed and applied with the aim of balancing fulfilment of volunteers’ personal motives (e.g. learning, self-enhancement and fulfilling social needs such as friendship) with their altruistic motives (including helping others).

The four partner organisations provide continuous support for volunteers so they can fulfil their role to the best of their ability, cope with the demands of the role by ensuring they do not feel isolated or exploited, and ensure that their contributions are recognised (Volunteer Scotland, 2013). Specifically, the partner organisations provide group or individual supervision to volunteers, organise regular volunteer sharing sessions to facilitate mutual support, collect opinions on further training needs, arrange booster training sessions and organise ceremonies to acknowledge volunteers' contributions. These strategies not only help to sustain volunteer motivation, but they also support continuous personal growth (i.e. personal competences) and enhancement of knowledge and skills in EoLC. Moreover, volunteers are stakeholders with whom the academic team engages in building the EoLC VCL model. The academic team participates in the volunteer sharing sessions and collects opinions from volunteers related to the training design and service coordination. Formal evaluation on volunteer retention, motivation and self-reported competence is also conducted by the academic team, six months after the volunteers complete the core training.

ORGANISATIONAL READINESS CHECKLIST

For any organisation, the EoLC VCL model could be a good choice to guide service planning and development. As a first step in establishing EoLC volunteer services, it is strongly recommended that a checklist is used to measure organisational readiness to incorporate volunteers. Sample checklist questions are provided in **Table 15.7**.

Table 15.7 Checklist Items for Organisations

ITEM	
Planning stage	<ul style="list-style-type: none"> » Programme's mission and vision » Organisation readiness » Volunteers' positioning » Expected impact of volunteers' contribution
Implementation stage	<ul style="list-style-type: none"> » Volunteer policies » Role descriptions » Recruitment procedure » Capacity building content and means » Continuous support mechanisms
Review and evaluation stage	<ul style="list-style-type: none"> » Good practice consolidation » Handling malpractice and retention » Feedback and continuous improvement

SUMMARY

EoLC volunteers in the JCECC Project are supported by theoretical and practical training and also workplace-based skills consolidation. The EoLC VCL model described in this chapter contributed significantly to EoLC volunteering in Hong Kong by:

- » Using an easy-to-administrative self-report risk-assessment tool;
- » Including a two-stage training curriculum that enhances capacity in both core competences and contextualised skills; and
- » Involving a motivation-oriented management mechanism.

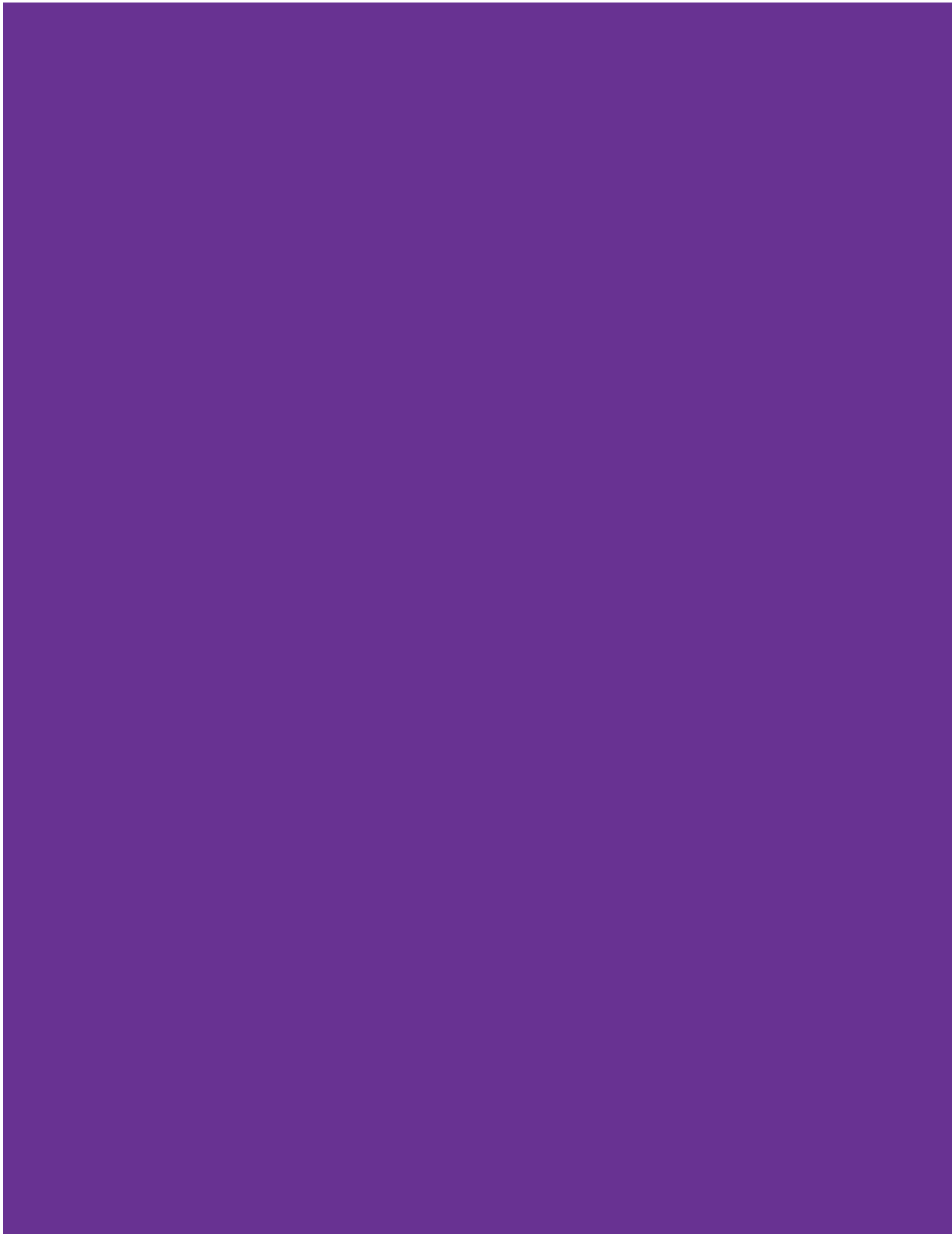
The volunteer training programme has achieved its desired synergised impacts. These impacts have been experienced not only by the JCECC Project team, but also by the JCECC Project community partners and, more significantly, by the patients and families who have received the volunteers' input with grace and courage. Without the participation and feedback of a wide range of stakeholders, the model would not have reached its current form – one that deserves wider implementation and further development. The engagement of volunteers in EoLC can improve patient and family dignity and EoL choices. As EoLC care is provided to increasing numbers of people in Hong Kong, and more volunteers embrace this worthwhile activity, the Hong Kong community will become more compassionate and “life and death friendly”, and will contribute towards celebrating life.

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PART IV:

CONCLUSION

CHAPTER 16

THE FUTURE OF COMMUNITY-BASED END-OF-LIFE CARE IN HONG KONG: SOME CONCLUDING THOUGHTS

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With the ageing population and expansion of inclusion criteria of service recipients, the growing demand for end-of-life care (EoLC) is an inconvenient truth around the world. The publication of the Strategic Service Framework for Palliative Care by the Hospital Authority (HA) (see chapter 4) indicates the readiness of the Hong Kong SAR Government in finding ways to react to this truth. This book outlines the possible response of community EoLC and describes the international and Hong Kong's local context of EoLC in the past three years. It documents the process of the experimentation of different models of community-based EoLC, delineates the parallel development of all-round competence improvement programmes and defines the evaluation mechanism. After

the first draft of this book was prepared, The Lancet published a commission report on palliative care (PC) (Knaul et al., 2018). The National Coalition for Hospice and Palliative Care also revised their clinical practice guidelines and updated to a fourth edition (National Coalition for Hospice and Palliative Care, 2018). Chan (2018), who is one of the key pioneers in PC in Hong Kong, published the paper titled *Palliative care: The need of the modern era*, which sketches the future direction of PC in Hong Kong. Integrating these recent international publications with the previous chapters in this book, this concluding chapter reviews and reflects on the concepts and practices of community EoLC in Hong Kong, with a particular focus on the future.

REFLECTIONS IN THEORETICAL ASPECTS

NOMENCLATURE IN EoLC

As stated in Chapter 2, terminologies used in EoLC are not standardised internationally and locally. Chan (2018) echoes the lack of consensus in defining EoLC internationally. He considers “care at the EoL [end-of-life] is thus an integral part of palliative care” (Chan, 2018, p. 396). He accepts variations in defining the term by different users but urges for clear definition in its usage. Chow & Chan (see chapter 2) hold a different view: instead of appreciating the diversified use of terms, there is a need for standardisation.

Variation in terms confuses the audiences and is a barrier for public education and promotion of service. In particular, the terms of PC, hospice care and EoLC need to have a clear usage with consensus. From a different angle, PC uses the content of care to define its term: the palliation of symptoms of any kinds. EoLC uses the time of care: the final stage of life when someone is facing a serious illness with a limited prognosis, usually a 12-month time frame. As for PC, it can be offered to anyone with a serious illness, irrespective of its prognosis. Moreover, it can be carried out together with curative care. Conceptually, PC and EoLC are different, although there is a degree of overlapping.

The US National Institute on Aging offers a clear differentiation between PC and hospice care in their online materials (National Institute on Aging, 2017). Specifically, hospice care is eligible for those with serious illnesses that expect limited survival time (6 months in the US). Another key differentiation is that the hospice care recipient does not receive curative treatment concurrently, while the recipient of PC does. However, hospice care is part of EoLC. With these clear definitions and differentiates, is that helpful for care recipients? Does the definition facilitate the care providers in developing a clearer division of duties or better care for the patients? Rahman, Fields, Shirsat, Suastegui-Olivares & Enguidanos (2018) shared the challenges faced by professionals in introducing PC to patients and families. How the message of PC is introduced to potential consumers affects the decision of use of service. As reflected in the qualitative data eliciting consumer perspectives, users considered the linkage of PC with EoLC as “a huge mistake” because PC is offered at different stages as soon as the patient is diagnosed with an advance illness. The study also found that many consumers equate PC with hospice care, which causes unnecessary resistance to receiving PC services.

While there are movements in clarifying the English terms related to the care for those with serious illness, the Chinese terms are more confusing. Complicated by the geographical differences of Chinese-speaking places, Mainland China, Hong Kong and Taiwan use a different Chinese translation of PC (see chapter 2). In Hong Kong, HA uses the term 紓緩治療服務 for PC. Literally, this term is “palliative treatment service”, which is associated with medical-related intervention rather than care. The need for standardisation of the term will be the first step in promoting the services.

EoLC FOR THE PREVENTION AND RELIEF OF SERIOUS HEALTH-RELATED SUFFERING

The Lancet Commission on Palliative Care coined a new concept: Serious health-related suffering (SHS). This is the suffering due to illness or injury to the level that requires medical intervention; and if not, physical, social or emotional functioning will be compromised. Although the Commission report focuses the discussion on a healthcare system that can alleviate physical and psychological suffering of patients and families, they acknowledge the significance of remediation of social and spiritual suffering. In particular, they highlight the potential impact on the delivery of PC services if patients and families have social or spiritual suffering (Knaut et al., 2018). Although quality of life has been commonly used as the outcome measure of EoLC (see chapter 5), should the new measure of the burden of SHS be included as a measurement? The objective of EoLC is the prevention and alleviation of suffering. It is sensible to adopt measures of SHS for assessment and evaluation in future work.

EoLC NEEDS EVERYONE'S EFFORT

The chapter authors of this book include administrators of funding organisations; academia in practice, policy and evaluation; researchers; hospital administrators; frontline health and social care professionals, and each party is involved in the provision of EoLC. As discussed in Chapter 3, Chung & Yeoh identified four levels of context that shape EoLC: the legal level; the organisation level; operational and socio-cultural level; and socio-cultural level. On top of the participation of health and social care professionals, legal experts, sociologists, educators and spiritual leaders all contribute to the development of EoLC. In the first three years of the project, over 1,900 professionals and frontline workers of 36 residential care homes for the elderly received intensive training onsite. Over 5,300 medical and allied health care professionals in hospital and 2,100 health and social care professionals have been trained in these three years under the project. They reported significant improvement in their competence in and attitudes towards end-of-life care. In addition, 560 volunteers have been engaged to support end-of-life care services in the community. The face-to-face public education programme on end-of-life care also reached 22,500 general public members. The multi-media channels reached another 350,000 members in the community as well.

EoLC IS SCIENCES, ARTS AND HUMANITIES

Healthcare and medical care are a core part of EoLC, and is therefore considered as a scientific care. When facing life and death issues, the care also faces an ethical dilemma when there is a blurred area between right or wrong acts. Woo (see chapter 11) found that some healthcare professionals are reluctant to initiate communication with patients with serious illness due to the unfamiliarity of the topic. The time constraints and the challenges of accurate prognosis pose further obstacles in having serious illness conversations. In responding to the need, the project team developed a case book series to demonstrate the different possible angles of consideration in decision-making and treatment plan. Using real-life ethical cases, the book series explains the clinical ethical principles behind different decision-making processes to help educate healthcare professionals.

STRENGTH-BASED AND COMPETENCE APPROACH IN EoLC

Although health and social care professionals are offering support to patients with serious illnesses, the patients and families are not necessarily passive care recipients. Chow, Chau, Yu & Mak (see chapter 8) and Lui et al. (see chapter 9) adopted a strength-based approach in enhancing the competences of family members and patients, respectively, in offering care and self-care. Chan et al. in Chapter 7 appreciated the altruistic support of volunteers in the community. EoLC is not necessarily requiring external resources; providing a platform for supporting self-reliance is an alternative. For some patients, in particular Chinese, perception as a burden to others is demoralising. Being able to take care and take charge of oneself can be therapeutic. Likewise, some family members blamed themselves for not offering adequate support to the patients while they were alive. They became regretful and struggled in the bereavement process. While serving the patients and families, EoLC worker should adopt a strength-based perspective and let the patients and families excel.

REFLECTIONS IN PRACTICE ASPECTS

COMMUNITY-BASED EoLC

Chan, Chan, Chan & Fong (see chapter 1), and Chow & Chan (see chapter 2) portray the local and international scene that demands the development of community EoLC respectively. Community EoLC provide patients and their families with more choices in the setting of care. Leung et al. (see chapter 12) illustrated that the increased competence of staff at residential care homes for the elderly (RCHE) can better support older adults who choose RCHEs as the place of EoLC and the place of death. However, Chan et al. (see chapter 7), Chow et al. (see chapter 8) and Lui et al. (see chapter 9) each shared a successful case of receiving EoLC at the patient's homes.

The National Coalition for Hospice and Palliative Care (2018) recently published the fourth edition of the *Clinical practice guidelines for quality palliative care*. One of the key revisions of the new edition is the increased emphasis on community-based resources and community-based providers, which is echoed by an international trend of expanding community-based EoLC.

PREVENTIVE EoLC

The findings of longer survival time of lung cancer patients who received early PC by Temel et al. (2010) caught the international attention of the benefits of early PC. Early PC can be started as soon as the diagnosis of a serious illness is made, irrespective of the prognosis. Early intervention is not limited to patients, but can also be applied to family members; and not only on physical care but also on social care. Chen et al. (see chapter 6) affirmed the value of Advance Care Planning (ACP) for patients and families. A five-step model of ACP was introduced. Chow et al. (see chapter 8), on the other hand, demonstrated that facilitating the communications of patients and family members when the former is healthy can reduce unfinished businesses, as well as preventing bereavement complication, even after the death of patients.

EVIDENCE-BASED EoLC

Evidence-based medicine emphasises the examination of clinical research instead of basing it only on intuition and clinical experience. It became popular in the 1990s and is gradually affecting psychosocial care. The UK Medical Research Council (MRC) (2006) published guidance of developing and evaluating the complex intervention, providing a clear framework for evaluation. Chan & Yu (see chapter 5) described the detailed process of planning and implementing the evaluation of the different projects of JCECC. The MRC published further guidance on process evaluation (Moore et al., 2015). Adding to the MRC's 2006 guidance, this updated guidance emphasised the importance of articulation of theory to explain the mechanism of intervention change required to achieve process evaluation. The context of the intervention being carried out, as well as the compliance and fidelity of the intervention, have to be taken into consideration. These are areas for future development.

REFLECTIVE EoLC AND INTEGRATED MODEL

The four non-governmental organisation (NGO) community EoLC models include the non-cancer patient capacity building model (see chapter 9), family capacity building model (see chapter 8), community capacity building model (see chapter 7) and enhanced community-based healthcare model (see chapter 6) were discussed in previous chapters of this book. They are complex interventions with several interacting care components offered by different levels of staff. They share a few common components, but they also have their unique elements, resulting in different levels of impact on the differentiated outcomes. The project has reached out to 3,800 patients and family members. Generally speaking, patients showed significant reduction in anxiety and depression. The physical symptoms of patients though expected to be deteriorating at the final stage, there were significant improvements as well. At the same time, family caregivers showed significant reduction in practical issues, family anxiety, caregiving strains and barriers in communication within family after receiving three months of services. The days of hospitalisation of the patients receiving the service were reduced in the third month of service when compare with pre-service stage. Subjective perception towards the services of the project was positive as reflected in the satisfaction survey of users and stakeholders.

The ultimate goal of the JCECC Project is to develop a comprehensive and holistic community-based EoLC model for Hong Kong: an “Integrated Community EoLC Support Teams” (ICEST) model. Through analysing and synthesising the available data of the evaluation of the four different models, a preliminary integrated model is created (see **Figure 16.1**). The model provides three core types of care – physical, psychosocial–spiritual and practical support – that have been found to be effective in the evaluation of the four NGO community models. A stepped-care model will be adopted such that interventions will be provided based on a risk-stratification tool. When the patients and their families have indicated needs in a certain care domain, as assessed by the risk-stratification tool, the model will suggest specific interventions and dosage to help guide the practice.

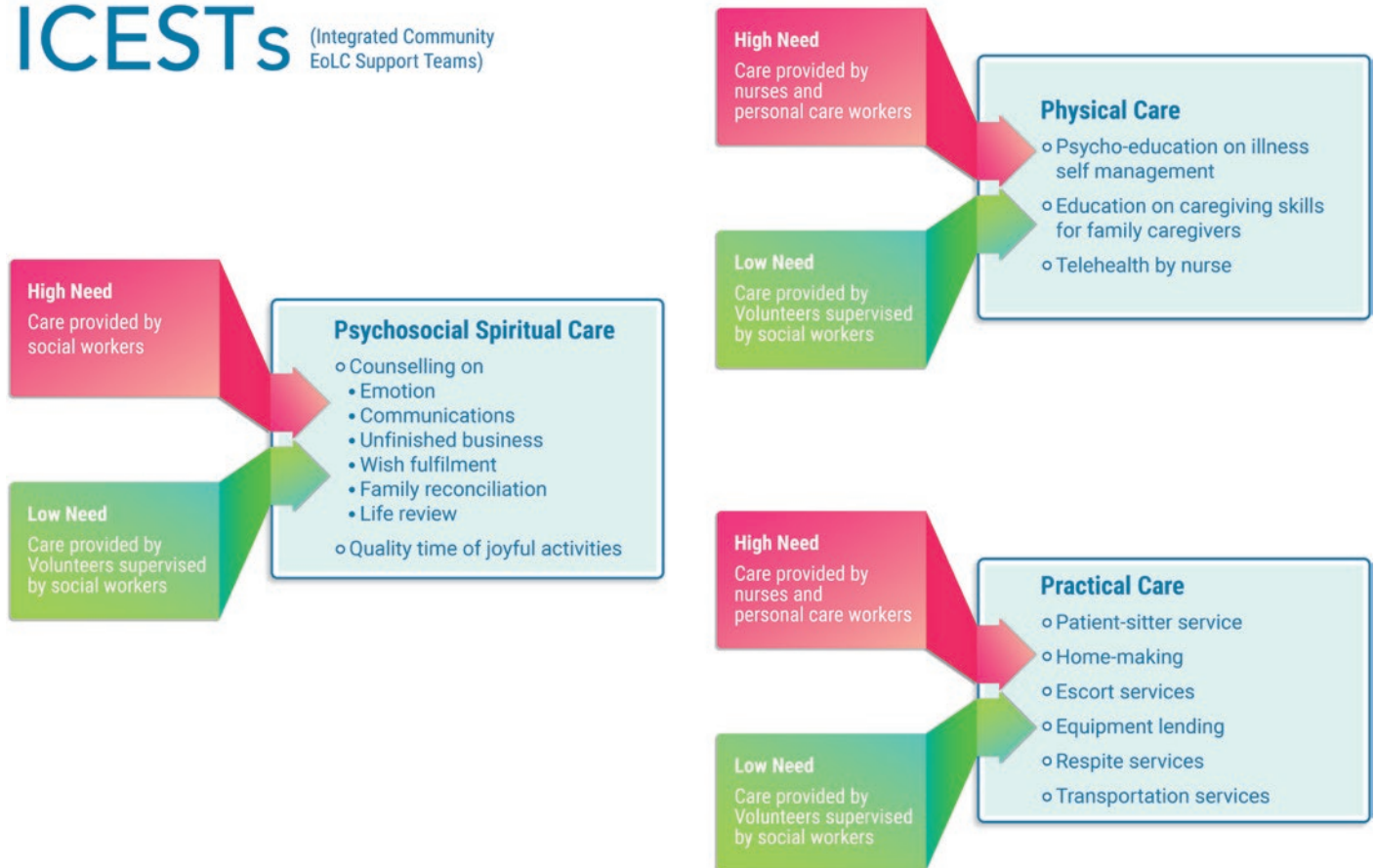


Figure 16.1 The Integrated Community EoLC Support Teams Model

As suggested by Brazil (2018), the integrated model might have a different meaning to different people. Our integrated model is not only integrating the four NGO models but it is also integration with other existing health and social care services. In line with the Strategic Service Framework for Palliative Care published by HA (HA, 2017), there is growing support of developing PC or EoLC in the community. HA is committed to enhancing medical–social collaboration to support PC in the community. Informal meetings with representatives of related bureaus and Government Departments had been carried out for exchanging ideas on the development of community-based end-of-life care in Hong Kong. Plans for collaboration with existing healthcare services provided by HA and social care services provided by the Social Welfare Department will be carried out.

CONCLUSION

The JCECC Project, which was initially a three-year project, is approaching the end of its first phase when this chapter was prepared and it has received funding from The Hong Kong Jockey Club Charities Trust for an extension of three more years until 2021. This book is like the eulogy, documenting the achievements, lessons learnt, reflections, as well as the impacts brought by the project. Hopefully the points raised in the book will offer some guidance for those who want to support people with serious illness in the community, just as legacies for the next generation and more achievements in the coming years would be recorded in the next eulogy.

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GLOSSARY

A

Accident and Emergency Department	A&E
Acquired immune deficiency syndrome	AID
Advance Care Planning	ACP
Advance Directives	AD
Advanced practice nurse	APN
All Ireland Institute of Hospice and Palliative Care	AIHPC

B

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C

Cardiopulmonary resuscitation	CPR
Care and Comfort Angels Project	PARACLETE
Comprehensive Health Enhancement Support System	CHESS
Chinese Modified Caregiver Strain Index	C-M-CSI
Chinese University of Hong Kong	CUHK
Chronic Obstructive Pulmonary Disease	COPD
Comfort Care Concern Group	CCCG
Commercial Radio Hong Kong	CRHK
Community Geriatric Assessment Team	CGAT

Community Nursing Service

CNS

Community Rehabilitation Network

CRN

Continuing Powers of Attorney

CPA

Continuous Quality Improvement

CQI

Controlled clinical trials

CCT

D

Do Not Attempt Cardiopulmonary Resuscitation

DNACPR

Do Not Resuscitate

DNR

Durable Power of Attorney

DPA

E

Edmonton Symptom Assessment Scale

ESAS

End of life

EoL

End-of-life care

EoLC

End of life care Volunteer Collaborative Leadership Model

EoLC VCL

End of life community care

EoLCC

End-stage renal failure

ESRF

Enduring Power of Attorney

EPoA

Enhanced Integrated Home Care Services

ECCHS

European Association for Palliative Care

EAPC

F

Forced expired volume in one second

FEV1

Forced vital capacity

FVC

Full-time Equivalent

FTE

G

General practitioner

GP

Glomerular Filtration Rate

GFR

H

Haven of Hope Christian Service

HOHCS

Health and Medical Research Fund

HMRF

Holistic Well-Being Scale

HWBS

Hong Kong

HK

Hong Kong Association of Gerontology

HKAG

Hong Kong Food and Health Bureau

HKFHB

Hospital Authority

HA

Hong Kong Society for Rehabilitation

HKSR

Hong Kong Society for Rehabilitation – Community Rehabilitation Network

HKSR – CRN

Hong Kong Special Administrative Region

HKSAR

Hospice and Bereavement Service Division

HBSD

Hospital Authority

HA

I	
Information technology	IT
Institute of Medicine	IOM
Integrated Care Priorities	ICP
Integrated Community EoLC Support Teams	ICEST
Integrated Home Care Services	IH
Integrated Family Service Centre	IFSC
Integrated Palliative Care Outcome Scale	IPOS
Integrative Body–Mind–Spirit	IBMS
Intensive Care Unit	ICU
Interprofessional Education Collaborative	IPEC
Inventory of Complicated Grief	ICG
J	
Jockey Club	JC
Jockey Club End-of-life Community Care	JCECC
Jockey Club Home for Hospice	JCHH
Joint Strategic Needs Assessment	JSNA

K	
Knowledge, Skills and Attitude	KSA
L	
Length of stay	LOS
Li Ka Shing Foundation	LKSF
Life sustaining treatment	LST
Long-term care institutions	LTCI
M	
McGill Quality of Life Questionnaire	MQOL
Medical Orders for Life-Sustaining Treatment	MOLST
Medical Palliative Medicine Unit	MPM
Medical Research Council	MRC
Memorial Symptom Assessment Scale	MSAS
Motor neuron disease	MND

N	
National Health Service	NHS
National Institute of Health and Care Excellence	NICE
National Institute for the Care of the Elderly	NICE
National Council for Palliative Care	NCPC
Necesidades Paliativas	NECPAL
New Territories East	NTE
New Territories West	NTW
Non-Emergency Ambulance Transfer Service	NEATS
Non-governmental organisation	NGO
Non-profit organisation	NPO
O	
Outcome Assessment and Complexity Collaborative	OACC

P

Palliative Care	PC
Palliative Care Outcomes Collaboration	PCOC
Palliative Care Outcome Scale	POS
Patient-reported outcome measures	PROMs
Physician Orders for Life-Sustaining Treatment	POLST
Plan-Do-Study-Act	PDSA
Proactive Identification Guidance	PIG

Q

Quality-Adjusted Life Year	QALY
Quality of Life	QoL

R

Radio Television Hong Kong	RTHK
Randomised controlled trial	RCT
Relief and Charity Service 6	RCS
Residential care homes for the elderly	RCHE

S

Self-Competence Scale in Death Work	SC-DW
Sister Annie Skau Holistic Care Centre	SASHCC
S.K.H. Holy Carpenter Church District Elderly Community Center	HCCDECC
Serious health-related suffering	SHS
Social Return on Investment	SROI
Social Welfare Department	SWD
Society for the Promotion of Hospice Care	SPHC
Special Administrative Region	SAR
Specialist Out-Patient Clinic	SOPC
Standard deviation	SD

T

The University of Hong Kong	HKU
Trust-Initiated Project	TIP
Tuen Mun Hospital	TMH

U

United Kingdom	UK
United States of America	USA

V

Volunteer Collaborative Leadership	VCL
Visiting Medical Officer	VMO

W

World Health Assembly	WHA
World Health Organization	WHO
Worldwide Palliative Care Alliance	WPCA

X

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Y

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Z

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賽馬會安寧頌

JCECC

Jockey Club End-of-Life Community Care Project

INITIATED AND FUNDED BY:



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