PART I:

INTRODUCTION

CHAPTER 1

INTRODUCTION

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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.

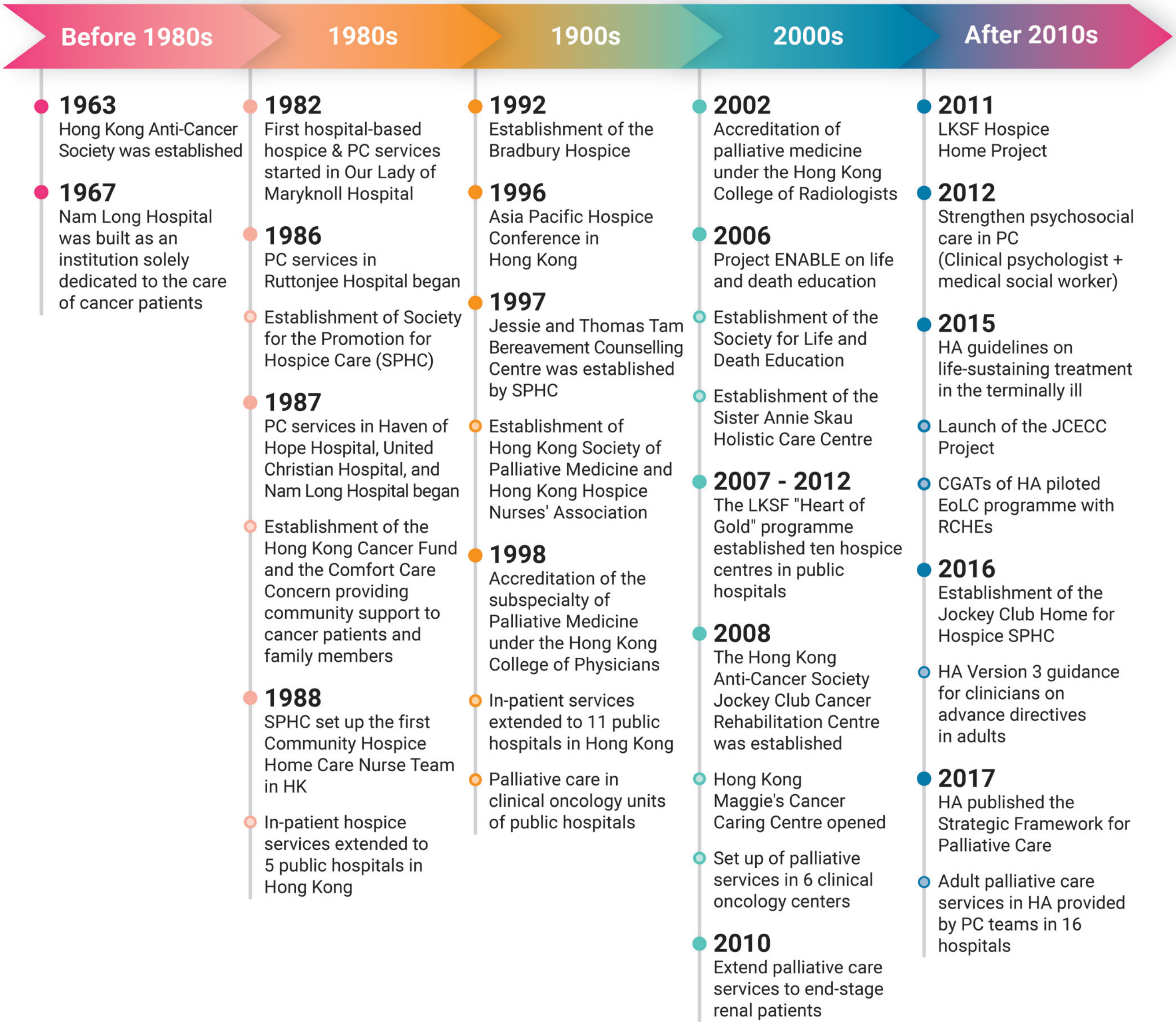
While it is important to optimise health and functionality among older adults, it is equally important to support them as they enter to the inevitable EoL phase and subsequent death. In the past three years, there have been over 46,000 deaths per year in Hong Kong, with one-third deaths attributed to 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.



Before 1980s

1963
Hong Kong Anti-Cancer Society was established

1967
Nam Long Hospital was built as an institution solely dedicated to the care of cancer patients

1980s

1982
First hospital-based hospice & PC services started in Our Lady of Maryknoll Hospital

1986
PC services in Ruttonjee Hospital began

Establishment of Society for the Promotion for Hospice Care (SPHC)

1987
PC services in Haven of Hope Hospital, United Christian Hospital, and Nam Long Hospital began

Establishment of the Hong Kong Cancer Fund and the Comfort Care Concern providing community support to cancer patients and family members

1988
SPHC set up the first Community Hospice Home Care Nurse Team in HK

In-patient hospice services extended to 5 public hospitals in Hong Kong

1900s

1992
Establishment of the Bradbury Hospice

1996
Asia Pacific Hospice Conference in Hong Kong

1997
Jessie and Thomas Tam Bereavement Counselling Centre was established by SPHC

Establishment of Hong Kong Society of Palliative Medicine and Hong Kong Hospice Nurses' Association

1998
Accreditation of the subspecialty of Palliative Medicine under the Hong Kong College of Physicians

In-patient services extended to 11 public hospitals in Hong Kong

Palliative care in clinical oncology units of public hospitals

2000s

2002
Accreditation of palliative medicine under the Hong Kong College of Radiologists

2006
Project ENABLE on life and death education

Establishment of the Society for Life and Death Education

Establishment of the Sister Annie Skau Holistic Care Centre

2007 - 2012
The LKSF "Heart of Gold" programme established ten hospice centres in public hospitals

2008
The Hong Kong Anti-Cancer Society Jockey Club Cancer Rehabilitation Centre was established

Hong Kong Maggie's Cancer Caring Centre opened

Set up of palliative services in 6 clinical oncology centers

2010
Extend palliative care services to end-stage renal patients

After 2010s

2011
LKSF Hospice Home Project

2012
Strengthen psychosocial care in PC (Clinical psychologist + medical social worker)

2015
HA guidelines on life-sustaining treatment in the terminally ill

Launch of the JCECC Project

CGATs of HA piloted EoLC programme with RCHEs

2016
Establishment of the Jockey Club Home for Hospice SPHC

HA Version 3 guidance for clinicians on advance directives in adults

2017
HA published the Strategic Framework for Palliative Care

Adult palliative care services in HA provided by PC teams in 16 hospitals

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).

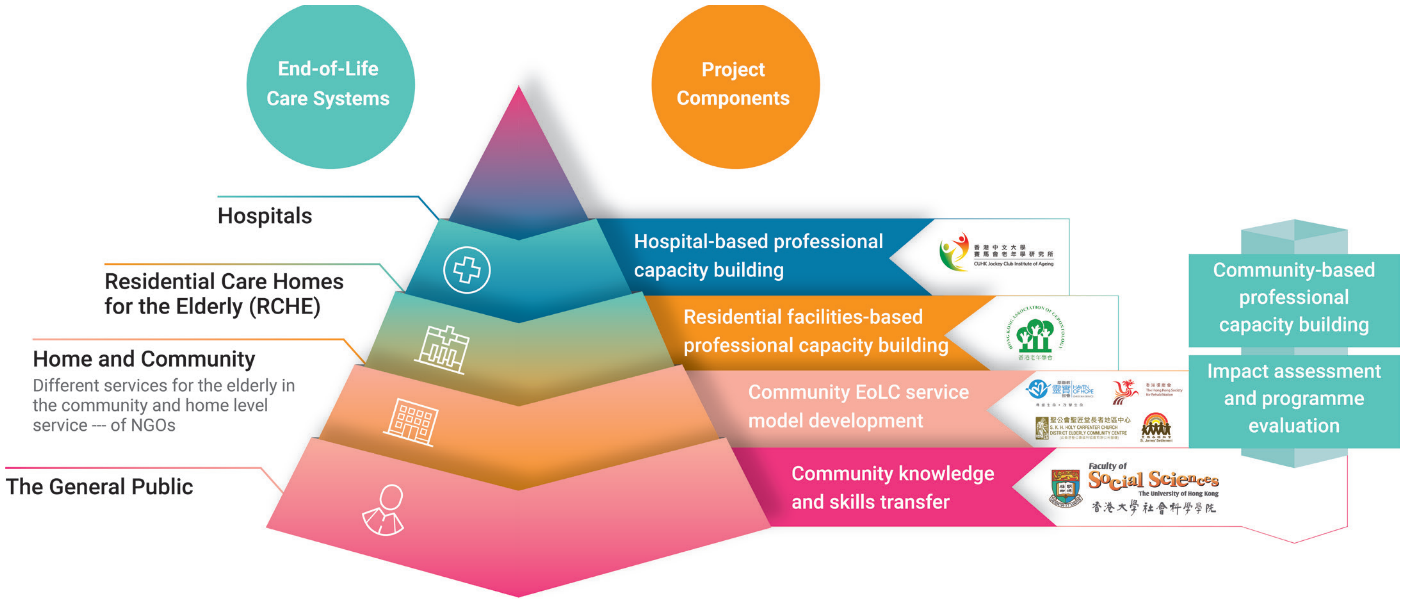


Figure 1.2 JCECC Project Components

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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