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 follo swing 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.

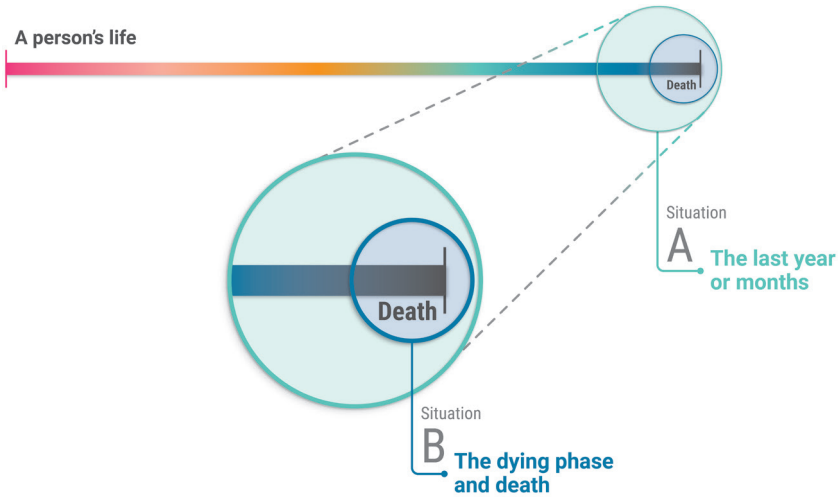

Figure 3.1 The Dual Application of the Term EoL

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, Hanvey, 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).

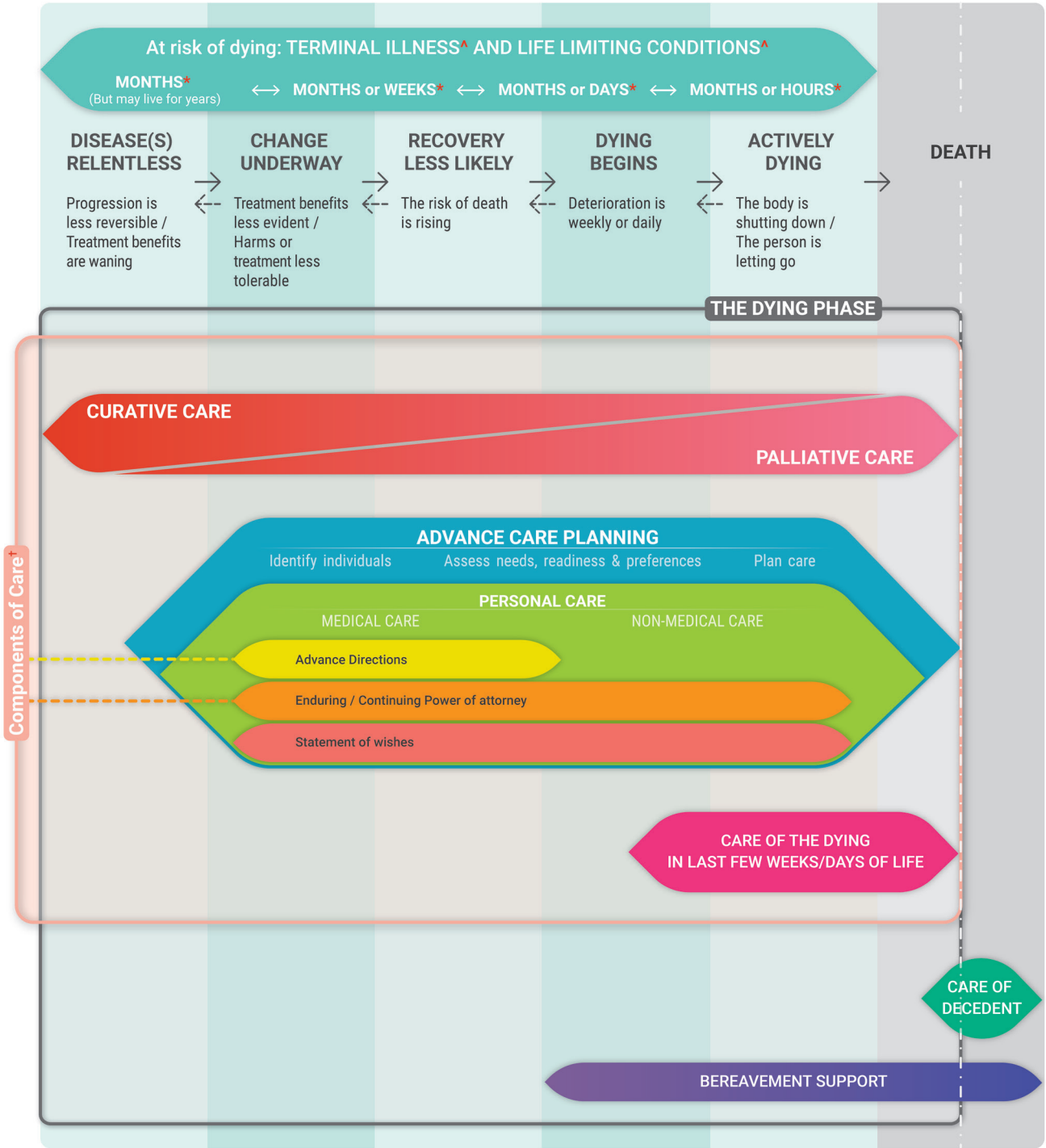

Figure 3.2 Conceptual Framework for EoL Care for Terminal Illness and Life-Limiting Conditions of Older Persons (adapted from Department of Health UK, 2013)

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.

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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