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**).

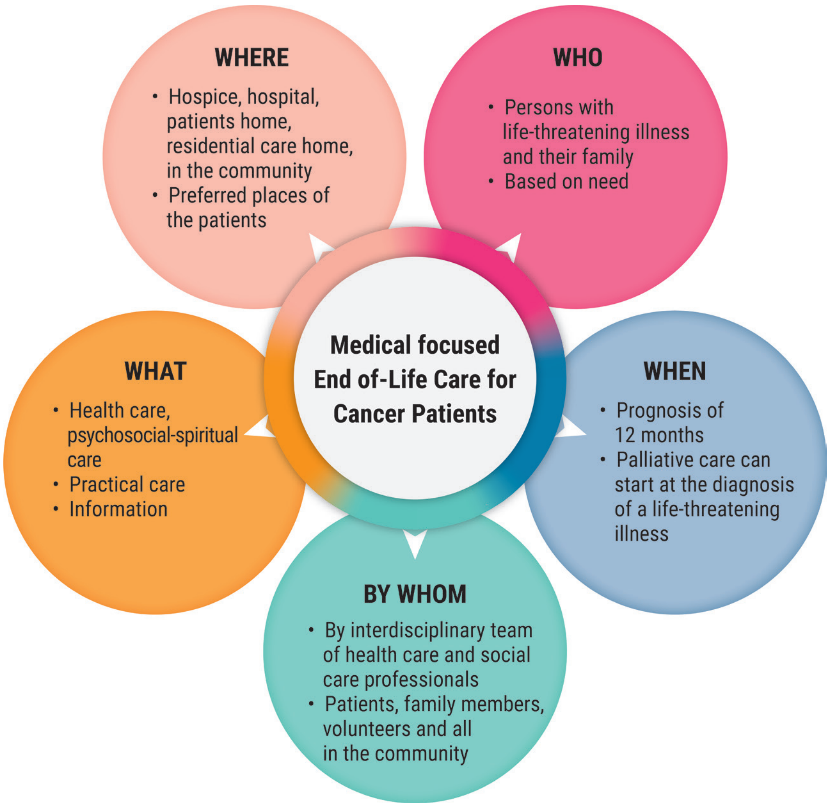

Figure 2.1 The Five Domains of EoLC

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 (NCPC) (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.

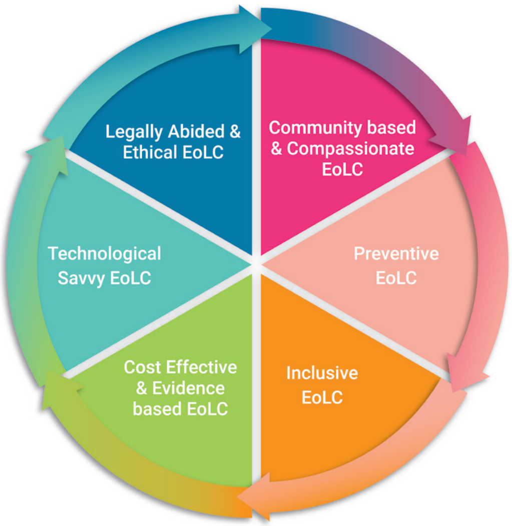

Figure 2.2 Components of Cutting-Edge EoLC

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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