

# Chapter 15

## Preferred Place of Care and Death Among the Terminally Ill: Asian Perspectives and Implications for Hong Kong

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### ABSTRACT

*The research on patients' preferred place of care and death has received increasing attention in recent decades. In palliative care, one of the main goals is to facilitate patients to stay in their preferred place of care, and to die in the place of their choice. Although 'home' is often quoted as the most preferred place of care and death among the terminally-ill in other places, local studies suggested otherwise. In Hong Kong, death is highly institutionalized with the vast majority of deaths occurring in public hospitals. Local culture, health care system and its provision and accessibility, presence of public health care policy on palliative care and care for the terminally-ill are among the factors affecting patients' preferred and actual place of care and death. This chapter is going to provide an overview of the recent studies and to discuss the topic from the Asian perspectives, and to highlight on the debates on the related policies.*

### BACKGROUND

To receive care and die in one's own preferred place is regarded as one of the indicators of "good death" for individual patient (Khan, Gomes, & Higginson, 2014). From a systematic review involving more than 100,000 people in 33 countries, most people prefer dying at home, a place where patients may feel more comfortable physically and psychologically (Gomes, Calanzani, Gysels, Hall, & Higginson, 2013).

DOI: 10.4018/978-1-5225-2633-9.ch015

A century ago, most deaths occurred at home in Chinese societies. Home death is regarded as the natural way of death in the traditional Chinese belief. “To die in one’s own bed” is regarded as the most glorious and fortunate way of death (Tang, 2000). “Falling leaf returns to the root soil described that home death is as natural as fallen leaves (Yao et al., 2007).

While Hong Kong is now highly modernized, Hong Kong is still a place where traditional Chinese culture prevails. Despite the remarkable economic growth in Hong Kong throughout all these years, the total health expenditure is only 5.5% of the GDP, lagging behind other developed economies. Nonetheless, the public services under the Hospital Authority (HA) provide a safety net in health care, which is heavily utilized by the general public. More than 90% of deaths in Hong Kong occurred in public hospitals. In 2014, there were about 46,000 registered deaths, and with the rapidly aging population, the annual deaths would rise to 69,000 by 2035 and to 92,000 by 2046 (Leung, 2016). Cancer remains the top killer in Hong Kong, accounting for almost one-third of all deaths. However, the prevalence of chronic organ failure is increasing and deaths from chronic diseases and cancer account for more than half of total deaths (Department of Health, 2015).

Western Medicine has evolved on the basis of body organs and systems. However, the needs of the dying are hardly organ-based and therefore the role of organ-specific interventions diminishes as death is near. Modern palliative care has risen against this background and has evolved with time to meet the needs of patients and their families. According to the World Health Organisation’s (WHO) definition, palliative care is no longer limited to the last days of life but is applicable in the earlier stages of the disease trajectory. Moreover, the application is no longer limited to terminal cancer patients, but also to patients with life limiting chronic diseases (Connor & Sepulveda Bermedo, 2014). Hospice care was formally established in the Hospital Authority (HA) in the 1980’s. United Kingdom is the first place to recognize Palliative Medicine as a specialty in the world, followed by Hong Kong in 1987, under the Hong Kong College of Physicians. “Palliative care” is now a commonly used term, but in the local context the term “hospice care” is sometimes used interchangeably. In Hong Kong, palliative care service in HA supports the terminal cancer patients by a comprehensive range of services including inpatient, outpatient, home care, day care and bereavement care. The recommended palliative care coverage for cancer deaths by WHO is 80%, while for Hong Kong, the percentage of cancer deaths in HA who ever received palliative care was less than 70% in the 2012-13 review (Leung, 2016). Among the cancer deaths in HA, only a proportion of them died in palliative care beds, more died in the acute settings, and very few died at home or in institutions. Palliative care for non-cancer patients, however, only began to develop in HA in 2010.

In developed countries, policies on palliative care are being established to recognize that care for the dying is about meeting the basic needs and not a luxury for the patients. Accessibility, equity and being cared for and die in patient’s preferred place are important issues to address. Such policies are often perceived as a “litmus paper” in modernized health care. In Hong Kong, although the degree of matching patients’ expressed choices and the actual place of care and death is not known, it is important for a modern society like Hong Kong to provide choices so that patients who wish to die in place are being facilitated or supported to do so (Lam, 2013; Luk, Liu, Ng, Beh, & Chan, 2011).

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