End-of-life care in Hong Kong

REVIEW ARTICLE

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INTRODUCTION

The number of people in Hong Kong over the age of 65 years amounts to 850 000, or 12.4% of the total population in the 2006 census.[1] Residents of residential care homes for the elderly (RCHE) tend to have multiple comorbidities that are irreversible and chronic. Many have poor mobility, high dependency, and poor cognitive function.[2] Good end-of-life (EOL) care is important in the management of such patients, regardless of the diagnosis (advanced dementia, chronic lung or heart diseases, end-stage renal failure, Parkinson's disease).[3] Such patients may experience distressing symptoms similar to patients dying of more commonly recognised terminal conditions.[4-7]

'GOOD DEATH'

Two important elements of a 'good death' are to have choice and control over (1) where death occurs (at home or elsewhere) and (2) who is present and shares the end.[8] Inappropriate admissions to hospital are common in Hong Kong. Almost all older patients with terminal diseases or irreversible chronic illnesses die in hospitals, as they are rarely referred to palliative care services.[9] This leads to inappropriate use of hospital services, unnecessary transportation of terminally ill elderly who will die in an unfamiliar environment with restricted visiting time, and inability of acute ward staff to dedicate time to offer a 'good death' experience to patients or assist with bereavement.[10,11]

DYING IN PLACE

The option of dying in place or dying in a familiar environment and in the company of family members should be given.[12] It usually means passing the last phase of life journey at home or in a RCHE.

In Hong Kong, the barriers of dying in place include social taboo, lack of death education, and lack of a systematic study of the preferences and attitudes of the elderly population.[13] People may fear depreciation of property value if the elderly die at home as well as the lack of necessary medical support (to care for the dying person at home). RCHE staff are not trained to handle dying patients, and they prefer residents not dying under their care. Many RCHEs, particularly private ones, are overcrowded, and there is no spare room in which a resident may pass away peacefully.

The Hong Kong government does not have a clear policy on developing high-quality EOL care services as a critical part of health care, nor on promoting dying in place, either at home or in a RCHE. The absence of a system of family practice, where doctors have fostered a long period of professional care and knowledge of their patients and home visit patients, is another barrier.

DYING AT HOME

In Hong Kong, there is no requirement to report a person dying at home to the Coroner. However, a registered practitioner must fill out a Medical Certificate of the Cause of Death (Form 18) of the Births and Deaths Registration Ordinance (Chapter 174), which is available in offices of the Registrar of Births and Deaths.[14] The practitioner must have attended the patient within 14 days immediately prior to death (except in cases entailing terminal conditions). With Form 18, the deceased's family is under a duty to register a death within 24 hours at

one of the Death Register Offices.

After death registration, a Certificate of Registration of Death (Form 12) will be issued. According to Sect 16 of the Births and Deaths Registration Ordinance, no person shall remove a dead body, unless they have obtained either Form 12, or in urgent cases, a permit from the nearest police station.[15] Any person who does not comply with this provision is liable on summary conviction to a fine of level 1 or to imprisonment for 6 months.

Although the current law does not require death at home to be reported to the Coroner, the major obstacles to dying at home include: the fear that death at home may affect the property value of the home, the lack of adequate care available at home, the lack of doctors who are willing to visit dying patients at home and provide Form 18, and the lack of sufficient ancillary medical support for the care of dying patients at home.

In Singapore, 31% of 10 399 decedents aged ≥65 years passed away at home in 2009.[16] In Taiwan, 'Rush Back Home' services are available in which terminally-ill patients are allowed to go home from a palliative care hospital to die at home. In British Columbia, Canada, a Joint Protocol for Expected/ Planned Home Deaths was formulated in 2006.[17] Its essence includes: expected home deaths are an anticipated natural event; patients and families can receive appropriate support; death pronouncement at home is not needed; the Coroner does not need to be notified; police do not need to be called; ambulance services should not be contacted; and the funeral home can be contacted directly once death has occurred as per protocol. The family is taught to wait at least one hour after the patient's breathing has stopped, and then call the funeral home directly to remove the body. The physician needs to complete a Notification of Expected Death form at the start of the programme verifying that the death will be a natural expected one and that the death is anticipated within the next few days or weeks. The physician also needs to be available to sign the Physician's Medical Certification of Death within 48 hours of death.

DYING IN RCHE

The Coroners Ordinance stipulates that all deaths in a RCHE (except a nursing home) be reported to the Coroner.[18] This compulsory reporting enables the Coroner to investigate deaths associated with unknown or suspicious causes. Failure to report can result in a fine and/or 2 weeks of imprisonment. Reporting to the Coroner also involves reporting to the police, and a police report will be made to the Coroner. The police then inform the next-of-kin to attend an interview with a forensic pathologist.

The interval between death and the interview varies from within 24 hours to several days. The Coroner then decides whether further investigation is needed to ascertain the cause of death. In many cases, where the cause of death is obvious, the Coroner exercises discretion to waive an autopsy. In 2009, there were about 40 000 deaths in Hong Kong, about 10 000 were reportable deaths and 4000 (40%) necessitated an autopsy.

In many western countries, a combined approach of a residential setting and a palliative care unit are used. As nursing homes are for dependent elderly people, EOL care is an integral part of their service. Combination of palliative care services and long-term care is available in North America and the UK. In Australia, the US, and the UK, about 15% to 20% of elderly people die in nursing homes.[19-21] In British Columbia, Canada, specialised hospice homes are set up in different districts to accept patients with terminal diseases to receive palliative treatment.

In Hong Kong, 8.5% of those aged ≥65 years live in RCHEs. The residents tend to have multiple comorbidities.[22] In 2007, 28.8% of the residents wished to pass away in a RCHE instead of a hospital.[23] 35% of older residents would prefer to die in their RCHEs.[24] In the Heaven of Hope Nursing Home, nearly 30% of all deaths occurred in the nursing home.[25]

The Hong Kong West Community Geriatric Assessment Team piloted an EOL programme for persons in a RCHE in cooperation with the Tung Wah Group of Hospitals Jockey Club Care and Attention Home since 29 September 2009. The RCHE staff received training in palliative care and a number of the nurses travelled to Taiwan to learn how EOL care was practised.

The programme set out to provide palliative care

for older residents in a RCHE who had irreversible chronic medical diseases (advanced dementia, cancer, organ failure [end-stage heart failure or renal failure], and degenerative neurological diseases). It aimed to ensure a dignified and comfortable death in a familiar environment, to reduce acute hospital admissions, and serve as a model of care in Hong Kong.

The Gold Standards Framework for the Three Illness Trajectories was used to identify suitable candidates to join the EOL programme.[26] These included the cancer trajectory, organ/system failure trajectory, and the dementia/frailty trajectory. In the programme, there were weekly EOL clinics and family conferences. The patients selected one of the 2 pathways, namely the Fung Yiu King Hospital (FYKH) Pathway and Accident and Emergency Department Pathway. In the former, the elderly was clinically admitted to FYKH for EOL care via an expedite pathway. In the latter, the elderly stayed in the RCHE with support from the RCHE staff and EOL team. At the last moment, they were transferred to the accident and emergency department by ambulance. They were not admitted to any acute ward and resuscitation was not offered. Instead, a quiet environment was provided to allow them to pass away peacefully.

A recent audit of the programme showed that the patients recruited in the pilot programme were aged 68-102 (mean, 85; standard deviation [SD], 6.9) years. Most patients were frail with poor mobility (80% were chairbound) and had a poor functional state (80% were totally dependent for activities of daily living). Their mean Barthel Index was 3.9 (SD, 5; range 1-18); 77% scored <5. They had poor cognitive function with a mean Mini-Mental State Examination score of 6.1 (SD, 8.7; range, 0-29); 63% scored <5. Most patients had multiple comorbidities; the mean number was 7.1 (SD, 3.4; range, 3-14). 60% were in the frailty/dementia trajectory, 27% in the organ failure trajectory, and 13.6% in the cancer trajectory. As in July 2011, 3 older male residents, 2 with advanced dementia and one with pancreatic cancer had passed away using the accident and emergency department pathway. Their family members were highly appreciative of the programme and wished it could be expanded to other RCHEs in Hong Kong.

CONCLUSION

There is a need for an EOL programme for older people in Hong Kong. A systematic study is needed to examine the wishes of older people regarding such care, particularly in respect to where they would prefer to end the last phase of their lives. A successful EOL programme in home or in a RCHE can be a win-win situation. The elderly could have a 'good death', whereas hospitals need not to waste resources on futile treatments. To a great extent, the quality of a health care system is reflected in the quality of EOL care provision.

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