COMMENTARY

End-of-life care: towards a more dignified dying process in residential care homes for the elderly

Hong Kong's older population is growing fast, amounting to 850 000 (12.4%) in the 2006 Census.[1] Of these, around 70 000 were living in residential care homes for the elderly (RCHE). Older RCHE residents tend to have multiple co-morbidities and irreversible chronic medical illnesses.[2] Many have high dependency and poor cognitive function. Residential care homes for the elderly usually send older residents to acute hospitals when they are sick, irrespective of their premorbid status, diagnoses, and prognosis. A proportion of them die in hospitals on (or soon after) admission.[3] Others will, as a rule, be placed in acute wards where they are provided with intensive treatments, instead of comfort care. This may not accord with what the patients perceive to be a 'good' or 'dignified' death. An acute ward setting is not an ideal place for an anticipated death; there are strict visiting hours, privacy is a luxury, and spiritual care is lacking. Nurses are torn between their regular duties and the special needs of the bereaved family members. When an anticipated death is not properly dealt with, deaths in a hospital may come as a shock to family members. This may result in unnecessary disputes between family members themselves, and, worse still, blame or even complaints being levelled against hospital staff.

Older RCHE residents and their family members should be given an alternative option—'dying in place'.[4,5] Dying in place means dying in RCHE (in a familiar environment and in the company of family members). The Hong Kong Chief Executive's 2009 Policy Address advocated the idea of 'ageing in place'.[6] If ageing in place is addressed, dying in place must be supported, too. Dying in place is part of end-of-life (EOL) care and may also be an integral part of a 'good' death. Unless the last journey of life is well taken care of, there will not be a good death.[7] Good death is a subjective concept that takes into account personal wishes, priorities, and an individual's autonomy. A person should have the right to choose where and how he/she dies. 'Dying in place' should be made a real option for both elderly individuals and their family members.

Western studies have identified obstacles to EOL care in RCHE.[5] Currently, there are several obstacles to EOL care in the RCHE in Hong Kong. Chinese people tend to consider death a taboo subject. This difficulty is, however, surmountable. A small local study showed that asking EOL questions skilfully was acceptable.[8] It also revealed that 28.8% of older residents actually wished to pass away in their own RCHE. A pioneer programme in the Haven of Hope Nursing Home showed that nearly 30% of all residents chose to die there.[9] Admittedly, some patients or family members may prefer intensive care in hospitals. We believe that it is imperative to educate both patients and the public about EOL care choices. The public need to understand that the curative approach emphasised by modern medicine may be unsuitable for older people with end-stage, irreversible, chronic diseases.

Patients and their families can only choose dying in place when it is a real option. This depends on the availability of a network of supportive services. Currently, most RCHE workers have yet to acquire sufficient knowledge and skills to handle patients in need of EOL care. Some may even suffer fear of, and lack of confidence about, providing EOL care in the RCHE. Many RCHE, private ones in particular, are overcrowded. There is no spare room in which an individual may pass away peacefully. The geriatric support services available to RCHE are limited, and the Government has yet to designate high-quality EOL care services as a crucial part of health care services and develop a clear policy fostering dying in RCHE.

Another common obstacle to dying in RCHE is legal in nature. This stems from the obligation to report all deaths in RCHE (except nursing homes) to the Coroner. The aim of this compulsory reporting requirement is to allow the Coroner to investigate deaths with unknown or suspicious causes. Upon notification, the deceased person's body is usually sent to a public mortuary. The Coroner will then decide, on a case-by-case basis, whether further investigation is needed to ascertain the cause of death. In many cases, where the cause of death is obvious, the Coroner will exercise his discretion to waive an autopsy. In such a case, police investigation into the death will be, at most, cursory.

We believe that if EOL care and dying in RCHE is to be made a real option, the Government needs to set up an interdepartmental working group, together with the Elderly Commission, to examine how the above-mentioned problems may be ameliorated. Not only do we need to systematically study the preferences and attitudes of our elderly population, we need to overcome the death taboo effectively. Training and education should be given to RCHE staff. The Social Welfare Department can ensure that part of the licensing requirement requires EOL practice in most, if not all, RCHE. More geriatric and EOL care

training should be given to primary care doctors who support the older residents of RCHE during their last few days.[10] Further, there may be a need to review the current mandatory reporting requirement, to decide how best to strike a balance between fostering a good death and the need to investigate deaths.

End-of-life care in RCHE is not a new concept for many western societies. Hong Kong is lagging behind on this. The Food and Health Bureau issued a consultation paper, 'Introduction of the Concept of Advance Directives in Hong Kong' on 23 December 2009, in which advanced care planning in the context of EOL care is mentioned.[11] A successful EOL programme in RCHE offers a three-way advantage: for the elderly residents it offers the choice of a good death; for the RCHE it permits them to truly fulfil their mission of caring for their residents in their last phase of life; and for the hospitals, it means scarce resources will not be wasted on futile treatments. It is hoped that policy makers can start addressing the concerns highlighted here, making ageing in place, dying in place, and a good death a reality.

James KH Luk, MB, BS, FRCP (Edin, Glasg, Irel)
Email: lukkh@ha.org.hk
Department of Medicine and Geriatrics, TWGHs Fung Yiu King Hospital, 9 Sandy Bay Road, Hong Kong
Athena Liu, PhD
Department of Law, The University of Hong Kong, Hong Kong
WC Ng, BSc(Nurs Stud), MN
Community Geriatric Assessment Team, TWGHs Fung Yiu King Hospital, 9 Sandy Bay Road, Hong Kong
Billy Lui
Faculty of Business and Economics, The University of Hong Kong, Hong Kong
Philip Beh, MB, BS, FHKAM (Pathology)
Department of Pathology, LKS Faculty of Medicine, The University of Hong Kong, Hong Kong
Felix HW Chan, MB, ChB, FRCP (Irel, Glasg)
Department of Medicine and Geriatrics, TWGHs Fung Yiu King Hospital, 9 Sandy Bay Road, Hong Kong

References

1. 2006 Population by-census. Hong Kong: Census and Statistics Department, the Government of the Hong Kong Special Administrative Region.
2. Luk JK, Pau MM, Chan FH, Yu C. Outreach geriatric private nursing home service in Hong Kong Central and Western cluster. J Hong Kong Geriatr Soc 2002;11:5-10.
3. Luk JK, Kwok T, Woo J. Geriatric screening in acute care wards—a novel method of providing care to elderly patients. Hong Kong Med J 1999;5:34-8.
4. Chan WC, Tse HS, Chan TH. What is good death: bridging the gap between research and intervention. Death, dying and bereavement—a Hong Kong experience. Chapter 9. Hong Kong: Hong Kong University Press; 2006.
5. Chan KS. Peaceful death in nursing home—a family perspective. Hong Kong Society of Palliative Medicine Newsletter 2006;3:3.
6. 2009-10 Policy address. Breaking new ground together. Government of the Hong Kong SAR website: http://www.policyaddress.gov.hk/09-10/eng/p100.html. Accessed 27 Apr 2010.
7. Smith R. A good death. An important aim for health services and for us all. BMJ 2000;320:129-30.
8. Luk JK, Chu LW, Chan FH, Sham MM, Szeto Y, Law PK. A study of the knowledge and preferences in Chinese elderly concerning advance directive. Hong Kong: Hospital Authority Convention; 2007.
9. Chu WW, Leung AC, Chan KS, Wu YM, Leung DM. A breakthrough in the end-of-life care in nursing home in Hong Kong. J Hong Kong Geriatr Soc 2002;11:38-41.
10. Hong TC, Kam TP, Chao DV. Barriers for primary care physicians in providing palliative care service in Hong Kong – qualitative study. Hong Kong Pract 2010;32:3-9.
11. Introduction of the concept of advance directives in Hong Kong. Consultation paper. The Food and Health Bureau website: http://www.fhb.gov.hk/download/press_and_publications/consultation/091223_advance_directive/ad_consultation_paper_en.pdf. Accessed 27 Apr 2010.