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Advance directive and preference of old age home residents for community model of end-of-life care in Hong Kong

Introduction

In Hong Kong, nearly all elderly persons who have terminal illnesses receive end-of-life care and die in a hospital setting, unlike in most other countries. With ageing of the population, there is a need to review this hospital-inclined model of health care for the elderly. It is important to assess whether the government needs to develop community end-of-life care, particularly in the old age home setting. There are no local data to evaluate the preferences of old age home residents for the community model of end-of-life care. Health and social care professionals also have no means to know end-of-life care preferences of our Hong Kong elders. In this regard, the role of advance directive is very relevant.

An advance directive is a statement, usually in writing, in which mentally competent individuals indicate their health care preference in the future when they are no longer competent. Advance directive has been promoted in Hong Kong. Racial differences exist in end-of-life decisions. There is a paucity of local data on the preferences for advance directive, end-of-life care decisions, and community end-of-life care among Chinese elderly people. In Hong Kong, there was only one study on advance directive, but only a small number of elderly subjects were included. There are also no local data on the preferences for community end-of-life care among Chinese old age home residents.

This study aimed (1) to describe the knowledge and preferences of Hong Kong Chinese elders regarding advance directives and end-of-life care decisions, (2) to investigate the predictors of preference for advance directive and community end-of-life care, (3) to investigate the proportion of old age home residents who would accept community end-of-life care in the old age home, rather than the hospital, and the corresponding trade-off between attributes of care, and (4) to evaluate the potential cost-savings on the bed-day costs of hospital end-of-life care if community end-of-life care was available.

Methods

This study was conducted from July 2007 to May 2009. A total of 1600 cognitively normal subjects were recruited by face-to-face interviews from 140 old age homes in the Hong Kong West and New Territories East Clusters.

Questionnaires on preferences of advance directives, end-of-life care decisions, and community end-of-life care models were used. Hypothetical end-stage disease scenarios were used to explore the participants’ preferences for end-of-life care. Using a conjoint analysis and discrete choice experiment approach, specific questions explored acceptable trade-offs between three attributes: availability of doctors on site, attitude of care staff, and additional cost of care per month. The 2006 death case series in two clusters were retrieved for the calculation of annual bed-day costs of hospital end-of-life care and the potential cost-savings if alternative community end-of-life care was available.

Outcome measures included the proportion of elderly persons who preferred community end-of-life care in old age homes, the knowledge and preferences
on advance directives and end-of-life care decisions, the predictors of these preferences, their willingness-to-pay for additional fees for such care, and the potential cost-savings by avoiding hospital end-of-life care.

Results

Preference for advance directive and community end-of-life care
The mean subject age was 82 years; 66% were females; 94% preferred to be informed of the diagnosis if they had terminal diseases; 88% preferred treatments that could keep them comfortable; 88% agreed that it would be good to have advance directives; and 60% would ask relatives for advice in making medical decisions. Factors that favoured having advance directives in our Chinese elders included the practice of asking for relatives’ advice in making medical decisions, wishing to be informed of their terminal illness diagnoses, absence of a stroke history, and having no problems in self-care.6

Approximately one third of old age home residents would accept dying in place. Older age, religion (Catholic or non-believer of traditional Chinese religion), having a better mood (Geriatric Depression Scale) score, having no siblings, not receiving any old age allowance, and being a resident of subvented old age homes were independent predictors of preference for community end-of-life care.6

Bed-day costs for hospital end-of-life care
The annual number of deaths among old age home residents in the two clusters was 2084 in 2006. The total bed-day costs for these 2084 deaths in the two clusters for the index death episode, cumulative 3, 6, and 12 months of hospitalisation were HK$65 474 591, HK$82 543 510, HK$100 170 949, and HK$108 960 348, respectively. About 30% of these costs could be saved, as 30% of the elders accepted dying in their present old age homes. Projected for the whole of Hong Kong, the annual cost savings in hospitalisation bed-days would be HK$177 million. The savings can be used to create additional 62 149 general medical bed-days for other hospital users (at an average bed-day cost of HK$2847).

Marginal willingness-to-pay for community end-of-life care
Conjoint analyses and discrete choice experiments showed the marginal willingness-to-pay for different levels of end-of-life care services in old age homes. A good home staff attitude was the most important attribute for community end-of-life care. Elders were willing to pay an extra cost for more coverage of doctors’ time and for a better attitude from staff in the old age home. Elders who lived in subvented old age homes and not receiving any Comprehensive Social Security Allowance were more willing to pay additional fees for community end-of-life care.

Discussion

Advance directive
This was the first large-scale study on the preference for advance directives, end-of-life care decisions, and community end-of-life care among cognitively normal old age home residents in Hong Kong. Regarding the acceptability of advance directive, 88% of elders preferred to have their own advance directives. Those who would ask for relatives’ advice in making medical decisions and those wishing to be informed of their terminal illness diagnoses were more likely to prefer having advance directives. In the present study, 94% of the elders wanted to know their diagnoses and 60% would ask for relatives’ advice. In the only advance directive study in Hong Kong,7 76% of Chinese subjects were in favour of having advance directives, which was less than the 88% noted in our study.6 Nonetheless, there were key differences in both studies in terms of subject age and place of accommodation. In the former study, the subjects were from heterogeneous groups including nurses, layman adults and elderly persons living in their own homes and old age homes, and only 331 were elderly (aged ≥65 years).4

In view of the high rates of acceptance for advance directives among Hong Kong subjects,4,6 further implementation is recommended. As there is no law regarding advance directive in Hong Kong,3 public education programmes and promotion of the concept among elderly people should be initiated. There is also a need to reconsider legislation on advance directives to hasten implementation. Many countries have implemented laws on advance directives.2

Community end-of-life care
One third of elders would accept community end-of-life care and dying in their old age homes. Factors including older age, religion (Catholic or non-believer of traditional Chinese religion), having a better mood score (according to Geriatric Depression Scale), having no siblings, not receiving any old age allowance, and being a resident in subvented old age homes increased acceptance of community end-of-life care models. These factors should be considered when formulating criteria for potential participants in future community end-of-life care programmes. Appropriate health policy to promote the implementation of community end-of-life care among elderly people living in subvented old age homes are needed in Hong Kong. The use of community end-of-life care would increase if better care staff and doctors on call at night services become available. Alternative community end-of-life care programmes may lead to a large reduction in hospital end-of-life care bed-day costs. Elders can be charged a small fee not exceeding HK$400 per month. The government should provide the main funding for these programmes.

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