Advance directive and end-of-life care preferences among Chinese nursing home residents in Hong Kong

Leung-Wing Chu[1, 2, 3], James KH Luk[2], Elsie Hui[4], Patrick KC Chiu[2, 3], Cherry SY Chan[1], Fiona Kwan[1], Timothy Kwok[5], Diana Lee[6], Jean Woo[5].

[1] Department of Medicine, Queen Mary Hospital, The University of Hong Kong,

[2] Department of Medicine and Geriatrics, Fung Yiu King Hospital,

[3] Acute Geriatrics Unit, Grantham Hospital

[4] Department of Medicine and Geriatrics, Shatin Hospital,

[5] Department of Medicine and Therapeutics, Prince of Wales Hospital, The Chinese University of Hong Kong.

[6] The Nethersole School of Nursing, The Chinese University of Hong Kong.

Correspondence:-
Dr. Leung-Wing Chu, *MD (HK), MBBS (HK), FRCP (Edin), FRCP (Glas), FHKCP, FHKAM (Medicine)*
Division of Geriatric Medicine, Department of Medicine, Queen Mary Hospital, The University of Hong Kong,
102 Pokfulam Road, Hong Kong, Hong Kong SAR
Tel: 852 2255 3315
Fax: 852 2974 1171
Email: lwchu@hkucc.hku.hk

Abstract

Objectives: The objectives of the present study were to describe the knowledge and preferences of Hong Kong Chinese older adults regarding advance directives and end-of-life care decisions, and to investigate the predictors of preferences for advance directive and community end-of-life care in nursing homes.

Methods: This was a cross-sectional survey conducted in 140 nursing homes in Hong Kong. 1600 cognitively normal Chinese older adults were recruited. Information on demographic, social, medical diseases, preferences of end-of-life care decisions and advance directives were collected by face-to-face questionnaire interviews.

Results: The mean age of the participants was 82.4 years. 94.2% of them would prefer to be informed of the diagnosis if they had terminal diseases. 87.9% preferred to have their advance directives regarding medical treatment in the future. Approximately 35% would prefer to die in their nursing homes. The significant independent predictors for the preference of advance directive included asking for relative advice, wishing to be informed of their terminal illness diagnoses, absence of stroke and having no problems in self-care in EQ-5D. For the preference for community end-of-life care and dying in nursing homes, the independent predictors included older age, not having siblings in Hong Kong, Catholic religion, non-believer of traditional Chinese religion, not receiving any old age allowance, lower Geriatric Depression Scale score, and being residents of government-subsidized nursing homes.

Conclusions: Majority of our cognitively normal Chinese nursing home older adults prefer having an advance directive, and one-third of them would prefer to die in nursing homes.

Introduction

With aging of the China's population, there is a growing demand on nursing homes, particularly in coastal cities (1, 2). Hong Kong is a southern Chinese city with approximately 7 million population, and 12.8% of its population are older people aged 65 years and over (3), and this will rapidly reach 26.4% in the coming 30 years (4). At present, approximately 8% of Hong Kong older adults are living in nursing homes (5). Regarding nursing homes in Hong Kong, there are the two broad types. 23% of them are non-profit-making government-subsidized (subvented) nursing homes, and the remaining 77% are profit-making private nursing homes (6, 7). In general, Chinese older adults living in nursing homes are frailer than their counterparts living at their own homes (6, 8-14). To date, few studies have looked at the knowledge and preferences regarding end-of-life care preferences among Chinese living in Chinese cities such as Hong Kong. In 1997, Hui el al reported that most Chinese nursing home older adults in Hong Kong would prefer cardio-pulmonary resuscitation (CPR) and life-sustaining treatment, and only 19% of them would decline any CPR and life-sustaining treatment (15). Previous studies, mostly in North America, have shown that racial differences exist in end-of-life care decisions. For example, Chinese older adults in Canada viewed overt reference to death as taboo, because it was considered to bring bad luck, and they would not like to talk about death. Moreover, they would prefer to consult their relatives before making health care decisions, and most of them would not choose artificial life support if they were terminally ill (16).

In most Western Societies, most end-of-life care preferences can be indicated in advance in the form of advance directives (19-23). In general, an advance directive is a statement, usually in writing, in which a person indicates when mentally competent the form of health care he/she would like to have in a future time when he/she is no longer competent (17, 18). For older adults with end-stage diseases, they can write their advance directives to indicate clearly their preferences for specific end-of-life care treatments, as well as the treatment settings for these treatments. Advance directive embraces living wills and enduring power of attorney for health care. Many countries in the world have already developed legislations for advance directive. In 1991, the US Congress passed the Patient Self-Determination Act (PSDA) which specifies that all hospitals reimbursed by Medicare should have a policy on living wills and that all hospitals, nursing homes and home health agencies should advise patients of their rights to execute an advance directive (19, 20). In UK, the Mental Capacity Act was passed in 2005, which enabled a new role of lasting power of attorney (LPA) for health and welfare care decisions (i.e. a form of advance directive) (21,

22). In Australia, Queensland is the latest province to have legislation on advance directive (23). In Singapore, the doctor must comply with the advance directive made by a patient according to the Singapore Advance Medical Directive Act 1996 (24).

In Hong Kong, there is a growing interest and concern about the end-of-life care for terminally ill older adults (25-27). However, the development of advance directive in Hong Kong is very slow and there is no case law regarding the validity of an advance directive. In 2004, the Hong Kong Law Reform Commission has issued a Consultation Paper on "Substitute Decision-making and Advance Directives in relation to Medical Treatment" (28). In 2006, the final report on "Substitute Decision-making and Advance Directives in relation to Medical Treatment" was released. In this report, promotion of advance directive but not legislation was recommended (29). At present, there is only very limited published data on the preference of advance directive among Chinese older adults. In Hong Kong, Pang et al reported a survey of advance directive. As only 40 Chinese older adults were included in their study, the sample size of the elderly subgroup was too small to be representative of the older population in Hong Kong (30).

In view of the paucity of information related to end-of-life care preferences and advance directive among Chinese older adults in Hong Kong, the objectives of the present study were to describe the knowledge and preferences of Hong Kong Chinese older adults regarding advance directives and end-of-life care decisions, and to investigate the predictors of preference for advance directive and community end-of-life care in nursing homes.

Methods

Study design and participants

This was a cross-sectional study. Ethical approval of the research protocol was obtained from the Institutional Review Board of the University of Hong Kong and the Hospital Authority Hong Kong West Cluster (HKU/HA HKW IRB), as well as from the Survey and Behavioural Research Ethics Committee (SBREC) of the Chinese University of Hong Kong (CUHK). A cluster sampling method was adopted, and we sampled two out a total of seven clusters (regions) of Hong Kong - namely the Hong Kong West and New Territories East Clusters. All nursing homes in these regions were approached for permission to conduct the study, and all elderly residents in the consented homes were screened for eligibility to participate in the study. Participants were included if they were Chinese, 65 years of age or older, residents of nursing homes, and had Mini-Mental State Examination Score above the local education-adjusted cut-off score (i.e. MMSE score $\geq$ 20 if they were

educated or ≥ 18 for those without any education). Participants were excluded if they had low MMSE score below the local education-adjusted cut-off score, severe language barrier, dysphasia, severe deafness which was not improved by hearing aids, and refusal to consent. Face-to face interviews of all recruited participants were done and each interview took approximately 60 minutes. Socio-demographic data, chronic diseases, cognitive assessment by the Chinese version of the Mini-Mental State Examination (Cantonese MMSE) (31, 32), depressive mood assessment by the short version of the Chinese Geriatric Depression Scale (GDS-15) (33-36), functional status using the simplified Barthel Index (20) (37-39), Lawton Instrumental Activity of Daily Living (IADL) (40) and Chinese version of European Quality of Life – 5 Dimensions (EQ-5D) for quality of life assessment (41). Specific questions exploring their preferences related to advance directive, hospital-at-home and community end-of-life care were also asked directly. The outcome measures included the levels of knowledge and preferences of Hong Kong Chinese older adults regarding advance directives and end-of-life care decisions, and the predictors of the preferences for advance directive and community end-of-life care.

Data analyses

Descriptive analyses of the participants' characteristics and their responses to each of the questions were done first. Bivariate analyses to examine the associations of socio-demographic, chronic diseases and other factors with the preference for advance directive, using Chi-square statistics and t-test (or ANOVA) for categorical and continuous variables respectively. Subsequent multivariate analyses with logistic regression were carried out. The dependent variable was the preference for advance directive and the independent variables were factors with $p < 0.05$ in previous bivariate analyses. Similar bivariate and then logistic regression analyses were then performed for the preference for community end-of-life care and dying in present nursing homes. All p values <0.05 were regarded as statistically significant. The statistical software SPSS for Windows version 16.0 was used for all data analyses.

Results

Characteristics of participants

We recruited 1600 participants from 1 July 2007 to 16 July 2008. 140 (73.3%) out of 191 nursing homes joined the study. The former number constituted 18.1% of all nursing homes in the whole of Hong Kong in 2009 (n= 775) (42). After screening, 1674 participants were eligible, and 1600 of them (95.6%) gave written informed consents. There was no

significant difference in sex distribution, mean age and years of education between those who agreed (n=1600) and refused (n=74) to participate in the study. 66.2% of the recruited participants were females. The mean (SD) age was 82.4 (6.8) years. 38.5% lived in private nursing homes. Hypertension, back/joint pain, cataract, diabetes mellitus and itchy skin conditions were the top five most common diseases or conditions (Table 1). Most of the participants (70.6%) had good or fairly good self-rated health. Over 90% of them had been admitted into the hospital previously. Quality of life assessment was evaluated by the EQ-5D. Most of them had no problem in self-care, walking and performing usual activities (73.9, 79.9 and 83.3% respectively). Approximately 47% and 66% of them had no pain/discomfort and no anxiety/depression respectively. The mean EQ-5D Index Value was 0.79, and that of the best imaginable health state by VAS was 64.6. 46.7% and 41.9% of them were very satisfied and satisfied with their present nursing homes respectively. Only a minority of them (less than 7%) were not satisfied with their present nursing homes.

Preferences for advance directive and attitudes towards end-of-life care decisions

94.2% of the participants would prefer to be informed of the diagnosis if they had terminal diseases. 77.3% would prefer to stay in their present nursing homes till last days of life. Prior to this study, most of them had not heard of or did not understand what advance directive was. After explanation of the meaning of advance directive, 88% agreed that it would be good to have an advance directive for them regarding medical treatment decisions in the future (Table 2). When they were presented with a hypothetical terminal condition which was either a terminal illness or a persistent vegetative state / irreversible coma, that they might have in the future, 88.4% of them preferred treatments that could keep them comfortable and free from pain, even if that might shorten their life. Regarding life-sustaining treatments or devices (i.e. cardio-pulmonary resuscitation and mechanical ventilation) and artificial nutrition (i.e. tube feeding), 61.4% and 74% did not want these treatments to be started for them respectively. Regarding the choice of hospital versus community-based settings for end-of-life care, 34.7% preferred to die in their present nursing homes (Table 2).

Predictors of the preference for an advance directive

Bivariate analyses of predictors of the preference for an advance directive

There were five possible responses in the statement under the question "It is a good approach to make an advance directive to express my preference regarding medical treatment in advance" (i.e. Question 1 in table 2). Prior to the analyses, the five responses were re-categorized into three groups. We merged "totally agree' with "agree" (agree) and "totally disagree' with "disagree" (disagree), while keeping the "no comment" group. In bivariate

analyses, significant predictors of the preference for advance directive included asking for relatives' advice in medical decisions, religious beliefs (Catholics, Buddhism or no religion), having lower MMSE or GDS scores, higher BI or IADL score, being independent walkers in mobility, absence of heart failure, stroke or itchy skin conditions, having good or fairly good self-rated health, having personal experience of visiting or taking care of relatives/friends who had died previously in the hospital, wishing to be informed of their terminal illness diagnoses, having heard of advance directive previously, having no problems in mobility, self-care or usual activities in EQ-5D, being moderately anxious/depressed mood in EQ-5D, and having higher EQ-5D Index values.

Logistic regression analyses of independent predictors of the preference

We excluded the "no comment" group from the re-arranged three groups prior to subsequent logistic regression analyses of the independent predictors of the preferences for advance directive, as this group did not help in indicating the preference for or against advance directive. Forward stepwise logistic regression analyses were done in separate blocks for the socio-demographic, cognitive, mood and ADL, comorbid diseases, self-rated health, personal hospital experiences and EQ-5D assessment models, all adjusted for sex and age. Finally, significant variables in these previous models were selected and included in the final model, also adjusted for sex and age. In the final sex-and age-adjusted logistic regression model, the significant independent predictors included asking for relatives' advice, wishing to be informed of their terminal illness diagnoses, absence of stroke and having no problems in self-care in EQ-5D (Table 3).

Predictors of the preference for community end-of-life care and dying in nursing homes

Bivariate analyses of predictors

Age, type of nursing homes, religion, old age allowance, disability allowance, GDS score, Barthel Index, diseases including stroke, back/joint pain and itchy skin conditions, any painful condition, self-assessment pain score, agreeing to make an advance directive, EQ-5D on mobility, usual activities and pain/discomfort, EQ-5D Index Values and best imaginable health state by VAS of EQ-5D were significant predictors of the preference for community end-of-life care and dying in place in bivariate analyses

Logistic regression analyses of independent predictors

In the final sex-and age-adjusted logistic regression analysis model of independent predictors of the preference, older age, not having siblings in Hong Kong, Catholic religion, non-believer of traditional Chinese religion, not receiving any old age allowance, lower depressive mood score (GDS-15), and being residents of government-subsidized (subvented)

nursing homes were significant independent predictors of preference for community end-of-life care and dying in their present nursing homes (Table 4).

Discussion

Advance directive and end-of-life care decisions among Chinese older adults

In the present study, we investigated the attitudes and preferences for advance directive, end-of-life care decisions, community end-of-life care and dying in place among Chinese older adults in Hong Kong. We chose older adults living in nursing homes because of the potential feasibility of implementing community end-of-life care models in nursing homes. For older adults who have end-stage diseases in Hong Kong, most of them do not have any advance directive, and health care professionals as well as family members are uncertain about their wishes and preferences related to end-of-life care decisions. In general, all mentally competent adult persons can make their health and end-of-life care decisions by them. However, for mentally incompetent persons (MIP) including patients in coma, delirium or with advanced dementia, these end-of life care decisions can be made either by their surrogates (health care proxy) or by their advance directives (i.e. self-decisions in advance) (20, 21, 29). Hence, the acceptance and willingness of elderly persons to enact advance directives for their future end-of-life care decisions is very relevant.

Advance directive is a statement in which a person when mentally competent indicates the form of health care he/she would like to have in a future time when he/she is mentally incompetent (20, 29). Because of the requirement of mental competence in advance directive, we excluded cognitive impaired elderly residents from our study's sample, using education-adjusted MMSE cut-off scores for Hong Kong Chinese elders (31, 32). In Hong Kong, there was only one previous study on advance directive. Pang et al reported that 76.4% of their Chinese participants were in favour of having an advance directive (30), which was lower than the 88% found in our present study. However, there were key differences in terms of the age and place of accommodation between the two studies' participants. In Pang et al's study, however, only 40 participants were living in nursing homes. In contrast, all our study participants were living in nursing homes.

To our knowledge, this was the first study which investigated the acceptability of advance directive among a large group of cognitively normal Chinese older adults living in nursing homes. We found 96% of our participants had not heard of the term advance directive previously. However, after explanation of the meaning of advance directive, 88% of our participants agreed that it would be good to have an advance directive to express their preferences regarding future medical treatment and end-of-life care decisions. In view of the

high rates of acceptance of advance directive in the present study, we would conclude that most cognitively intact Chinese older adults in Hong Kong are in favour of having advance directives for themselves. Appropriate policies to facilitate the implementation of advance directives among older adults in Hong Kong will be needed. As there is no law governing advance directive in Hong Kong, public education programmes and promotion of advance directive among elderly people can be enhanced. There may be a need to re-consider legislation on advance directive, if the progress is too slow. As a matter of fact, many overseas countries now do have laws on advance directive (19-24).

Preferences for end-of-life care decisions' among Chinese elderly persons

In the present study, over 90% of our participants would prefer to know the diagnosis of terminal diseases, if they really had these illnesses. In clinical practice, the commonly encountered end-of-life care treatment decisions would include cardio-pulmonary resuscitation (CPR), do-not-hospitalize (DNH), artificial (tube) feeding or hydration, do-not-resuscitate (DNR) decisions, and the use of restraints. Hence, we used two hypothetical scenarios of cancer and non-cancer terminal conditions in the present study to explore their attitudes towards these treatments decisions. Most of our participants (over 90%) could reply clearly their preferences whether they would "agree" or "disagree" to these treatments, and only less than 10% showed no preference. Regarding the specific end-of-life care treatment decisions in the presence of terminal illnesses, 88% of the older adults in our study accepted palliative treatments that could keep them comfortable and free of pain, even though such treatments might shorten their life-spans. For life-sustaining treatments like CPR and artificial nutrition or hydration, 61% and 74% respectively of them did not want these treatments to be started, and 60% and 72% respectively wanted to discontinue these treatments. In contrast, Hui et al reported 10 years ago that only 19% of their nursing homes' participants did not want CPR and life-sustaining support. However, participants in their study were not having any end-stage terminal diseases. Also, they were not given any hypothetical terminal disease scenarios before they were asked these questions. Thus, their understandings of terminal illness and end-of-life treatments would be low (15). In another local study, Pang et al only found 17%, 18% and 21% of Chinese adults who had no background medical knowledge did not accept CPR, mechanical ventilation, and artificial tube feeding. However, for nurses in the same survey (n=145), much higher proportions of them did not want CPR, mechanical ventilation, and artificial tube feeding (i.e. 60%, 68% and 59% respectively). Obviously, nurses had more medical knowledge than layman and would make more rational decisions for different end-of-life care treatments (30). In another

local Chinese survey among non-medically trained school teachers (age 20-69 years), there was a tendency to agree more with the use of life-sustaining treatments, even when the disease condition was hopeless (43). Thus, the difference in the rates of preferences for life-sustaining treatments between this study and previous local studies could be explained by the differences in age, accommodation status and the levels of understanding regarding end-of-life care treatments among the participants in these studies. In particular, differences in the levels of understanding about life-sustaining treatments would lead to differences in their preferences. Similarly, differences in the rates of preference for life-sustaining treatments were also reported in previous Western studies. In a European study, Laakkonen et al reported 39% of their home-dwelling older adults would not want to have CPR (44). Among a group of older adults living in nursing homes in USA, O'brien et al found only 60% of them wanted CPR and 38% wanted tube feeding if they had permanent brain damage (45, 46). However, in a Canadian study of older adults who had taken care of their family members during their end-of-life periods, 92% of them did not want futile life-sustaining treatments to extend life (47). Therefore, the participants' experience and understandings of end-of-life care issues were the key influencing factor on the preference of life-sustaining treatments for end-stage diseases. Although family caregivers were often asked to make surrogate decisions when their elderly relatives had severe critical conditions or coma in Hong Kong, Kwok et al found most caregivers had poor knowledge related to life-sustaining treatments, and most of them relied on their own views but not the patients' wishes to make these end-of-life care decisions (48).

As we had provided adequate information in the hypothetical scenarios of terminal illness and explained this scenario to cognitively non-impaired older adults before they answered the questions, we believe our findings would reflect the decisions of most cognitive competent Chinese older adults for these common end-of-life care decisions. Certainly, written documentations of these end-of-life care preferences in the form of advance directives would be needed, at a time when they were still mentally competent and before they had any terminal illness. These advance directive documents would help their wishes to be respected when they might become terminally ill and mentally incompetent.

Predictors of preference for advance directive among Chinese older adults

We found the strongest predictor for having an advance directive among our Chinese older adults living in nursing homes was the wish to be informed of a terminal illness (versus those who did not have this wish), giving an odds ratio 9.2. Two other independent predictors which increased the chance of having an advance directive were having no problem in self-

care in EQ-5D and the practice of seeking advice from relatives before any medical treatment decision. Their odds ratios (OR) were 2.6 and 2.0 respectively. Furthermore, the presence of a previous stroke reduced the chance of having an advance directive by 67% (OR=0.33). However, sex, age, educational level, financial status and previous occupation were not predictors of the preference for advance directives. We noted some differences in our findings versus those from another local study, which showed young age and high education levels were in favour of having an advance directive (30). In terms of the basic characteristics between the two studies, there were clear differences. In Pang et al's study, only a limited number of potential confounding factors were investigated. The shortcomings were related to the absence of other potential confounders including the practice of asking for relatives' advice in medical care decisions, desires to be informed of their terminal illness diagnoses, self-care ability, and previous chronic diseases including stroke. These were all potentially important factors. In the present study, these factors were found to be significant predictors of preference to have an advance directive. In the Chinese culture, asking for relatives' advice is very relevant, as family members often make these decisions collectively (49). Kwak et al also reported that Asian and Hispanic patients in the US often consulted their family members before making health care decisions (16). It should be noted that our present findings echoed those reported by Douglas and Brown. They also found older adults who had previous discussions with their family members or physicians regarding end-of-life care decisions were more likely to make advance directives than those who had not (50). Ethnic difference and absence of religion, however, were found to favour the completion of an advance directive in other studies but not our present study (51, 52).

Preference for community end-of-life care model and dying at nursing homes

In Hong Kong, nearly all older adults with terminal diseases would receive end-of-life care in the hospital setting, and most of them would die at the hospital finally. In 2007, Tse et al reported a retrospective study on palliative care and cancer deaths among Hong Kong Chinese patients who received palliative care prior to death. In this study, all cancer deaths occurred exclusively in the hospital setting, and none occurred at home or nursing homes (53). In another local Chinese study, only 6 out of 1300 patients under palliative care programs died at home, while the rest all died in the hospital (54). In contrast, 53% of deaths due to chronic diseases in the US occurred in the hospital, 24% occurred at nursing homes, and the proportion of home deaths was 24% (55). In another study of Japanese-American men in the Honolulu Heart Program and Honolulu-Asia Aging Study, 53% of men died in hospitals, 23% died at home, and 18% died in nursing homes (56). For patients with dementia in the US,

67% of them died in nursing homes (57). In UK, the proportion of home deaths was 18% while that of dying at NHS hospitals was 58% in 2003 (58). In Netherlands, 25% of death occurred in nursing homes, while 31% and 28% of deaths occurred at home and hospitals respectively (59). In Japan, only 1.95% of deaths occurred in nursing homes (60, 61). In Taiwan, Liu et al reported that 20% of their Chinese cancer patients died at home (62). In mainland China, nearly 90% of oldest people died in their own homes (63). Though a small-scale end-of-life care programme and dying in place was reported in a local nursing home in 2002 (26), there was no recent major development on alternative community end-of-life care models in nursing homes. In the past, it was thought that community end-of-life care might have a poor acceptance among our Chinese older adults in Hong Kong. As demonstrated in our present study, this belief was untrue. In fact, 59% of our participants wished to receive palliative end-of-life care in the nursing home setting, and approximately 35% would accept dying at their present nursing homes. Preferably, Chinese older nursing home adults should also have their own advance directives. In a previous US study, Degenholtz et al reported that having a living will increased the chance of dying in nursing homes and decreased the chance of dying in the hospital among US nursing home residents (64).

We therefore recommend further development of community end-of-life care in the nursing home setting to respect the wishes and preferences of our elderly residents in Hong Kong nursing homes. Options should be available for them to choose between community and hospital end-of-life care programs in the future. In the implementation of these programs, appropriate selection criteria to identify the suitable participants should be developed. Those who show a preference for community end-of-life care services should be considered first. Based on our present findings, we would propose to consider using the independent predictors of the preference for community end-of-life care models as the selection criteria of future participants for community end-of-life care services. In summary, the factors which favored the preference for community end-of life care and dying at nursing homes included religion (Catholic religion; non-believer of traditional Chinese religion), being residents of subvented nursing homes, low depressive mood score (GDS-15), older age, not having any sibling in Hong Kong, and not receiving any government old age allowance.

Strength of the present study

This was the first large-scale study on advance directive and the preference for community end-of-life care among cognitively non-impaired Chinese nursing home residents in two (out of seven regions) in Hong Kong. The total populations in these two regions amounted to 1.7 millions persons, which was equivalent to one-fourth of the whole Hong

Kong population (65). In the present survey, we interviewed 1600 participants from 140 nursing homes, which was equivalent to 18.1% of all the nursing homes of whole Hong Kong. In our views, this was a high percentage. In terms of age and gender distribution, our participants were quite similar to previous local studies conducted in the nursing home setting (6, 11-13). Hence, we believe our findings could be generalized to all cognitive normal Chinese older adults living in nursing homes of Hong Kong.

Limitations of the study

There were several limitations of the present study. This was not a population-based random sample of all nursing homes' residents. Thus, our study's participants might not be representative of all nursing homes' residents in Hong Kong. However, there was a practical difficulty to do any population-based sampling in Hong Kong. Due to the legal issue related to the Privacy Ordinance of Hong Kong, it was impossible to obtain all the names and personal details of all nursing homes' residents to generate the sampling frame of all nursing homes' residents in Hong Kong. Hence, it was not possible to do a random sample study in Hong Kong. Therefore, our present cluster sampling approach was a reasonably practical alternative approach in Hong Kong. Secondly, we had excluded participants with low MMSE score. Our present results might not be generalized to those elderly residents with cognitive impairment.

Conclusions

This was the first large-scale survey on advance directive and preference of elderly people regarding advance directive, end-of-life care preferences and preference of community end-of-life care in nursing homes. Most Chinese older adults would prefer to be informed of the diagnosis if they had terminal diseases as well as palliative treatments that could keep them comfortable. 88% of them would prefer to have their own advance directives for end-of-life care decisions. Given the fact that there is no legislation on advance directive in Hong Kong, the Hong Kong SAR Government should devise an effective policy to facilitate the implementation of advance directive among older adults in Hong Kong, particularly for those living in nursing homes. Approximately one-third of older adults living in nursing homes accept dying in place. This is particularly true for those who are living in subsidized (subvented) homes. To meet the needs of our elderly population, further development of community end-of-life care models in nursing homes is recommended in our Chinese community.

Acknowledgement

Yan Szeto (Nurse Specialist) of Palliative Medicine Unit of Grantham Hospital for their helpful input in the pilot project, as well as all participating nursing homes for their kind assistance.

References:

1. National Bureau of Statistics of China. Population survey of China (one percent sample) 2006. http://www.stats.gov.cn/tjgb/rkpcgb/qgrkpcgb/t20060316_402310923.htm , accessed on April 3, 2010.

2. Chu LW, Chi I. Nursing homes in China. J Am Med Dir Assoc. 2008;9:237-43.

3. Census and Statistics Department, HKSAR. http://www.censtatd.gov.hk/press_release/press_releases_on_statistics/index.jsp?sID=1752&sSUBID=7113&subjectID=&charsetID=&displayMode=D , accessed on April 3, 2010.

4. Census and Statistics Department, HKSAR. Hong Kong population projections 2007-2036. http://www.censtatd.gov.hk/products_and_services/products/individual_statistical_tables/index.jsp , accessed on June 25, 2010.

5. Chu LW, Chi I. Long-term care and hospital care for the elderly. In: Leung GM, Bacon J, eds. Hong Kong Health Care System. Reflections, Perspectives and Visions. Hong Kong University Press. Hong Kong. 2006:223-252 & 515-517.

6. Woo J, Chau PP. Aging in Hong Kong: the institutional population. J Am Med Dir Assoc. 2009 Sep;10(7):478-85.

7. Social Welfare Department of Hong Kong SAR. http://www.swd.gov.hk/en/index/site_pubsvc/page_elderly/sub_residentia/ , accessed on July 30, 2010.

8. Chu LW, Kwok KK, Chan S, Chu M, Yip KT, Chan F, Ng M. A survey on the health and health care needs of elderly people living in the Central and Western District of the Hong Kong Island. [Report]. Central and Western District Board of Hong Kong. 1998.

9. Luk JKH, Chan FHW, Pau MML, Yu C. Outreach geriatrics service to private old age homes in Hong Kong West Cluster. J Hong Kong Geriatr Soc 2002;11:5-11.

10. Chu LW, Chi I. Long-term care and hospital care for the elderly. In: Leung GM, Bacon J, eds. Hong Kong Health Care System. Reflections, Perspectives and Visions. Hong Kong University Press. Hong Kong. 2006:223-252 & 515-517.

11. Tang M, Woo J, Hui E, Chan F, Lee J, Sham A, Chau PH. Utilization of emergency room and hospitalization by Chinese nursing home residents: a cross-sectional study. J Am Med Dir Assoc. 201011(5):325-32.

12. Chan-Yeung M, Chan FH, Cheung AH, Dai DL, Chu LW, Lam WK, Leung CC, Kam KM, Tam CM. Prevalence of tuberculous infection and active tuberculosis in old age homes in Hong Kong. J Am Geriatr Soc 2006;54:1334-1340.

13. Leung JYY, Yu TKK, Cheung YL, Ma LC, Cheung SP, Wong CP. Private nursing home residents in Hong Kong- how frail are they and their need for hospital services. J Hong Kong Geriatr Soc 2000; 10(2):65-69.

14. Chu LW, Chi I, Chiu A. Incidence and predictors of falls in the Chinese elderly. Ann Acad Med Singapore. 2005;34 (1):60-72. [Erratum Ann Acad Med Singapore. 2005;34 (7):469]

15. Hui E, Ho SC, Tsang J, Lee SH, Woo J. Attitudes towards life-sustaining treatment of older persons in Hong Kong. J Am Geriatr Soc 1997; 15: 1232-36.

16. Kwak J, Haley WE. Current research findings on end-of-life decision making among racially or ethnically diverse groups. The Gerontologist 2005;45:634-641.

17. Robertson GS. Making an advance directive. Br Med J 1995;310:236-38.

18. Chiu HFK, SW Li. Advance directive: a case for Hong Kong. J HK Geriatr Soc 2000;10:99-101

19. Brown BA. The history of advance directives: A literature review. J Gerontological Nursing 2003; 29:4-14.

20. Nolan MT, Bruder MB. Patients' attitudes toward advance directives and end-of-life treatment decisions. Nurs Outlook 1997;45: 1204-8.

21. Lush D. Advance directive and living wills. J R Coll Physicians 1993;27:274-77.

22. Website of the Department of Health, United Kingdom. http://www.dh.gov.uk/en/Publicationsandstatistics/Bulletins/theweek/Chiefexecutivebulletin/DH_4108436 accessed on 26 March 2009.

23. Department of Health and Ageing, Australian Government. http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-i-carer-toc~mental-pubs-i-carer-3~mental-pubs-i-carer-3-4 accessed on 26 March 2009.

24. Website of Ministry of Health, Singapore. http://www.moh.gov.sg/mohcorp/legislations.aspx?id=7120 accessed on 26 March 2009.

25. Liu A. Legal recognition of advance refusal needed. HKMJ 2005;11(20):133-34

26. Chu WCC, Leung ACT, Chan KS, Wu YM, Leung DMY. A breakthrough in the end-of-life care in a nursing home in Hong Kong. J Hong Kong Geriatr Soc 2002;11:38-41.

27. Chu WCC, Woo J. Attitudes of Chinese elders towards advance planning on end-of-life issues: a qualitative study in a nursing home in Hong Kong. J Hong Kong Geriatr Soc 2004;12:18-23.

28. The Law Reform Commission of Hong Kong HKSAR Government. Decision making and advance directives Sub-committee Consultation paper. Government Logistics Department, July 2004. http://www.hkreform.gov.hk/en/publications/decision.htm accessed on 26 March 2009.

29. The Law Reform Commission of Hong Kong HKSAR Government. Substitute Decision-making and Advance Directives in Relation to Medical Treatment (HKLRC Report). http://www.hkreform.gov.hk/en/publications/rdecision.htm accessed on 26 March 2009.

30. Pang M, Wong KS, Dai LK, Chan KL, Chan MF. A comparative analysis of Hong Kong general public and professional nurses' attitudes toward advance directives and the use of life-sustaining treatment in end-of-life care. Chinese Medical Ethics 2006;3:11-15.

31. Chiu HFK, Lee HC, Chung WS, Kwong PK. Reliability and Validity of the Cantonese Version of Mini-Mental State Examination – A Preliminary Study. J Hong Kong Coll Psychiatr. 1994; 4 (2): 25-28.

32. Chiu H, Lam L, Leung T, Li SW, Law WT, Chung D, Fung H, Kan PS, Lum CM, Ng J, Lau J. Prevalence of dementia in Chinese elderly in Hong Kong. Neurology 1998;50(4): 1002-1009.

33. Yesavage JA, Brink TL. Development and validation of a Geriatric Depression Screening Scale: a preliminary report. J Psychiatr Res. 1983;17:37–49.

34. Yesavage JA. The use of self-rating depression scales in the elderly. In: Poon LW, ed. Clinical Memory Assessment of Older Adults. Washington, DC: American Psychological Association; 1986:213–217.

35. Alden D, Austin C, Sturgeon R. A correlation between the Geriatric Depression Scale long and short forms. J Gerontol. 1989;4:P124–P125.

36. Lee HC, Chiu HFK, Kwok WY, Leung CM. Chinese elderly and the GDS short form: a

preliminary study. Clin Gerontol. 1993;14:37–42.

37. Mahoney FI, Barthel DW. Functional evaluation: the Barthel Index. Md State Med J. 1965;14:61–65.

38. Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index: a reliability study. Int Disabil Stud. 1988;10:61–63.

39. Royal College of Physicians of London. Standardised Assessment Scales for Elderly People. London, U.K.: Royal College of London; 1992:6–22.

40. Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. Gerontologist. 1969;9:179–186.

41. EuroQoL website: http://www.euroqol.org/ accessed on 22 March 2007.

42. Website of Social Welfare Department, Hong Kong SAR Government. http://www.swd.gov.hk/en/index/site_pubsvc/page_elderly/sub_residentia/ accessed on 11 April 2009.

43. Lee JCY, Chen PP, Yeo JKS, So HY. Hong Kong Chinese teachers' attitudes towards life-sustaining treatment in the dying patients. Hong Kong Med J. 2003; 9:186-91.

44. Laakkonen ML, Pitkala KH, Strandberg TE, Berglind S, Tilvis RS. Living will, resuscitation preferences, and attitudes towards life in an aged population. Gerontology 2004; 50:247-54.

45. O'brien LA, Grisso JA, Maislin G, LaPann K, Krotki KP, Greco PJ, Siegert EA, Evans LK. Nursing home residents' preferences for life-sustaining treatments. 1995; 274: 1774-9.

46. O'Brien LA, Siegert EA, Grisso JA, Maislin GM, LaPann K, Evans LK, Krotki KP. Tube feeding preferences among nursing home residents. J Gen Intern Med. 1997;12(6):364-71.

47. Wilson DM. End-of-life care preferences of Canadian senior citizens with caregiving experience. J Advanced Nursing. 2000;31:1416-1421.

48. Kwok T, Twinn S, Yan E. The attitudes of Chinese family caregivers of older people with dementia towards life sustaining treatments. J Advanced Nursing 2007;58:256-262.

49. Bowman KW, Hui EC. Bioethics for clinicians: 20. Chinese bioethics. CMAJ. 2000 Nov 28;163(11):1481-5.

50. Douglas R, Brown HN. Patients' attitudes toward advance directives. J Nursing Scholarship 2002;34:61-65.

51. Oh BB. Advance directives: The emerging body of research. Am J Critical Care 1999;8:514-519.

52. Rurup ML, Onwuteaka-Philipsen BD, van der Heide A, van der Wal G, Deeg DJH. Frequency and determinants of advance directives concerning end-of-life care in the Netherlands. Social Sci Med 2006;62:1552-1563.

53. Tse DM, Chan KS, Lam WM, Leu K, Lam PT. The impact of palliative care on cancer deaths in Hong Kong: a retrospective study of 494 cancer deaths. Palliat Med. 2007 Jul;21(5):425-33.

54. Liu F. Community palliative care in Hong Kong. In: Chan CLW, Chow AYM, eds.. Death, dying and bereavement: a Hong Kong Chinese experience. Hong Kong University Press. Hong Kong. 2006; 183-193.

55. Gruneir A, Mor V, Weitzen S, Truchil R, Teno J, Roy J. Where people die: A multilevel approach to understanding influences on site of death in America. Medical Care Research and Review 2007; 64:351-378.

56. Bell CL, Davis J, Harrigan RC, Somogyi-Zalud E, Tanabe MK, Masaki KH. Factors associated with place of death for elderly Japanese-American men: the Honolulu Heart Program and Honolulu-Asia Aging Study. J Am Geriatr Soc. 2009 Apr;57(4):714-8.

57. Mitchell SL, Teno JM, Miller SC, Mor V. A national study of the location of death for older persons with dementia. J Am Geriatr Soc 2005; 53:299-305.

58. Gomes B, Higginson I. Where people die (1974-2030): past trends, future projections and implications for care. Palliative Med 2008; 22:33-41.

59. van der Velden LFJ, Francke AL, Hingstman L, Willems DL. Dying from cancer or other chronic diseases in Netherlands: ten-year trends derived from death certificate data. BMC Palliative Care 2009;8:4. doi 10.1186/1472-684x-8-4.

60. Yang L, Sakamoto N, Marui E. A study of home deaths in Japan from 1951 to 2002. BMC Palliat Care. 2006 Mar 9;5:2. doi: 10.1186/1472-684X-5-2.

61. Takezako Y, Tamiya N, Kajii E. The nursing home versus the hospital as the place of dying for nursing home residents in Japan. Heth Policy 2007; 81: 280-288.

62. Liu JM, Lin WC, Chen YM, Wu HW, Yao NS, Chen LT, Whang-Peng J. The status of the do-not-resuscitate order in Chinese clinical trial patients in a cancer centre. J Med Ethics. 1999 Aug;25(4):309-14.

63. Liu G, Gu D. Factors Associated with Place of Death among Chinese Oldest-Old. Paper presented at the annual meeting of the American Sociological Association, Marriott Hotel, Loews Philadelphia Hotel, Philadelphia, PA, Aug 12, 2005. http://www.allacademic.com/meta/p22654_index.html accessed on 19 April 2009.

64. Degenholtz HB, Rhee Y, Arnold RM. Brief communication: the relationship between having a living will and dying in place. Ann Itern Med 2004;141:113-7.

65. Census and Statistics Department, Hong Kong SAR Government. http://www.bycensus2006.gov.hk/FileManager/EN/Content_981/a201e.xls accessed on 11 April 2009.

Table 1. Characteristics of Chinese older adults in nursing homes (n =1600)

Social and demographic characteristics		% (n)	Mean (SD)
Age (in years)			82.37 (6.75)
Gender	Females	66.2 (1060)	
Education level	Never attended School	47.5 (760)	
	Primary	38.9 (622)	
	Secondary	10.8 (173)	
	Tertiary	2.8 (45)	
Types of nursing homes	Private	38.5 (616)	
	Subvented (subsidized)	61.5 (984)	
Previous occupation	Housewife	16.8 (269)	
	Manual worker	58.6 (937)	
	Non-manual worker (eg. Clerical)	6.6 (105)	
	Professionals e.g. doctor, dentist, nurse, lawyer, accountant etc	2.4 (38)	
	Self-employed	11.9 (190)	
	Other occupations	3.8 (61)	
Do you have relatives (with regular contact) ?	Yes	92.2 (1475)	
Spouse	Yes	19.8 (317)	
Children	Yes	74.3 (1189)	
Would ask for relatives' advice in deciding any medical treatment ?	Yes	59.8 (956)	
	No	33.8 (540)	
	No comment	6.5 (104)	
Religion	No religious belief	34.8 (557)	
	Catholics	8.9 (143)	
	Christianity	16.0 (256)	
	Buddhism	20.5 (328)	
	Muslim	0.1 (1)	
	Traditional Chinese religious beliefs	18.4 (294)	
	Other religions	1.3 (21)	
Financial support from family members		48.2 (771)	
Old Age Allowance (OAA)		35.1 (562)	
Disability Allowance / High Disability		18.1 (289)	
Comprehensive Social Security Allowance		61.4 (982)	

Pension		4.2 (67)
Cognitive. mood and functional status		
Mini-Mental State Examination (MMSE) Score (Max.30)		23.55 (3.18)
Geriatric Depression Scale-15 (GDS-15) Score (Max.15)		3.04 (3.06)
Barthel-Index (BI)(Max.20)		18.45 (3.19)
Lawton's Instrumental Activity of Daily Living (IADL) (Max.8)		5.73 (1.40)
Mobility	Independent walker	79.8 (1276)
	Walk with supervision	10.5 (168)
	Walk with assistance	3.4 (55)
	Chairbound	5.9 (94)
	Bedbound	0.4 (7)
Chronic diseases and Health status		
	Diabetes Mellitus	21.6 (345)
	Hypertension	57.3 (917)
	Ischemic heart disease	3.9 (62)
	Heart failure	5.5 (88)
	Chronic obstructive airway disease	5.1 (81)
	Asthma	5.3 (85)
	Previous stroke	12.9 (206)
	Parkinsonism	3.2 (51)
	Previous cancer (cured)	1.8 (28)
	Active cancer under treatment	0.5 (8)
	Chronic renal failure	0.6 (9)
	Depression	1.3 (21)
	Osteoporosis	14.5 (232)
	Previous hip fracture	0.6 (10)
	Back pain and other joint pain	40.9 (654)
	Gout	8.9 (143)
	Cataract	36.1 (578)
	Urinary incontinence	2.3 (37)
	Chronic constipation	9.7 (155)
	Itchy skin condition	19.9 (318)
	Chronic Insomnia	6.4 (103)
Painful condition or disease	Yes	58.1 (929)
Self pain assessment (0-10)(none-severe)		2.49 (2.60)

Table 2. Attitudes towards advance directive and the individual directives among Chinese older adults

			% (n)
Q. 1	**Preference for advance directive**		
	It is a good approach to make an "Advance Directive" to express my preference regarding medical treatment in advance	Totally agree	50.1 (802)
		Agree	37.9 (607)
		No Comment	8.9 (143)
		Disagree	2.0 (32)
		Totally disagree	1.0 (16)
	Attitudes towards the individual directive		
Q. 2	I want treatment to keep me comfortable and free of pain, even if such care may shorten his/her life	Totally agree	62.1 (993)
		Agree	26.3 (421)
		No Comment	7.4 (119)
		Disagree	2.2 (35)
		Totally disagree	2.0 (32)
Q. 3	I do not want to start life-sustaining treatments (Including Cardiac Pulmonary Resuscitation (CPR))	Totally agree	39.8 (636)
		Agree	21.6 (345)
		No Comment	9.1 (146)
		Disagree	11.5 (184)
		Totally disagree	18.1 (289)
Q. 4	I wish to stop life-sustaining treatment if life-sustaining treatments have been started	Totally agree	36.9 (591)
		Agree	22.8 (365)
		No Comment	9.6 (153)
		Disagree	10.6 (170)
		Totally disagree	20.1 (321)
Q. 5	I do not want to start artificial nutrition and Hydration	Totally agree	50.6 (809)
		Agree	23.4 (374)
		No Comment	9.0 (144)
		Disagree	9.8 (157)
		Totally disagree	7.3 (116)
Q. 6	I wish to stop artificial nutrition and hydration if treatments have been started	Totally agree	47.4 (758)
		Agree	24.5 (392)
		No Comment	9.1 (146)
		Disagree	8.9 (142)
		Totally disagree	10.1 (162)
Q. 7	I do not want to be restrained under all Situations	Totally agree	63.0 (1008)
		Agree	12.1 (193)
		No Comment	6.9 (110)
		Disagree	12.0 (192)
		Totally disagree	6.1 (97)
Q. 8	I wish to receive treatment in the present nursing home	Totally agree	31.8 (509)
		Agree	27.3 (437)
		No Comment	10.9 (175)
		Disagree	10.3 (164)
		Totally disagree	19.7 (315)
Q. 9	I wish to die at the present nursing home	Totally agree	19.9 (319)
		Agree	14.8 (237)
		No Comment	23.1 (369)

Q. 10	I do not want an autopsy		Disagree	16.7 (267)
			Totally disagree	25.5 (408)
			Totally agree	40.9 (654)
			Agree	8.6 (137)
			No Comment	16.9 (270)
			Disagree	22.3 (356)
			Totally disagree	11.4 (183)

Table 3. Logistic regression analyses of independent predictors of preference for an advance directive. (n =1457)

Independent Predictors* (Agree Vs. Disagree)	Odds Ratio (OR)	95% CI of OR	p
Age (years)	1.011	0.965 to 1.059	0.656
Sex (Women Vs. Men)	0.618	0.306 to 1.248	0.180
Would ask relatives for advice in deciding any medical treatments (Yes Vs. No)	2.010	1.066 to 3.791	0.031
History of stroke (Yes Vs. No)	0.328	0.156 to 0.691	0.003
Wish to be informed of the diagnosis of a terminal disease (Yes Vs No)	9.186	4.088 to 20.64	<0.001
EQ-5D: Self-care			
• No problems in self-care	3.646	1.445 to 9.197	0.006
• Some problems in washing or dressing	6.111	1.888 to 19.784	0.003
• Unable to wash or dress	1.000 (reference)		

*Note: Adjusted for sex and age

Table 4. Logistic regression analyses of independent predictors of the preference for community end-of-life care and dying in present nursing homes (n=1231)

Independent Predictors* (Agree Vs. Disagree)	Odds Ratio (OR)	95% CI of OR	*p*
Age (Years)	1.031	1.012 to 1.050	0.001
Sex (Women Vs. Men)	1.071	0.824 to 1.391	0.608
Have brothers/sisters in Hong Kong (Yes Vs. No)	0.758	0.593 to 0.969	0.027
Religion			<0.001
• Catholics	1.927	1.257 to 2.955	0.003
• Christianity	0.802	0.563 to 1.141	0.219
• Buddhism	1.305	0.939 to 1.812	0.113
• Muslim & Other religion	1.586	0.543 to 4.632	0.399
• Traditional Chinese religious beliefs	0.620	0.433 to 0.887	0.009
• Nil	1.000 (Reference)		
Financial: Old Age Allowance	0.725	0.568 to 0.925	0.010
Geriatric Depression Scale-15 (GDS-15)	0.948	0.910 to 0.988	0.011
Types of nursing homes (Subvented Vs. Private)	1.567	1.219 to 2.014	<0.001

*Note: Adjusted for sex and age