

# Advance directives and life-sustaining treatment: attitudes of Hong Kong Chinese elders with chronic disease

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**Objective** To examine the attitudes of Hong Kong Chinese elders with chronic disease with regard to advance directives and life-sustaining treatment.

**Design** Cross-sectional questionnaire survey.

**Setting** Medical unit of a regional teaching hospital in Hong Kong.

**Participants** In-patients aged 60 years or above with chronic disease.

**Main outcome measures** Demographic profiles and attitudes towards advance directives and life-sustaining treatment.

**Results** A total of 219 elderly patients completed the questionnaire. Their mean age was 73 (standard deviation, 8) years; 133 (61%) were female. The majority had neither heard about advance directives (81%), nor discussed the issue with others (73%) before participating in this study. After they were informed of the concept of advance directives, about half (49%) said they would consider using it if it is legislated in Hong Kong. The respondents generally supported the withholding or withdrawing of life-sustaining treatment in medically futile situations. In all, 55% of them believed that the patient alone should make the decision on withholding or withdrawing life-sustaining treatment, if competent to do so. If the patient became not competent, 44% believed that the individual's family alone should make such a decision.

**Conclusion** The fact that most of the respondents had never heard about advance directives or discussed the concept with others points to a lack of knowledge and to the necessity to step up public education about such issues.

## Introduction

On 23 December 2009, the Food and Health Bureau issued a consultation paper introducing the concept of advance directives in Hong Kong.<sup>1</sup> This was issued in response to the recommendations of the Law Reform Commission (LRC) August 2006 report on Substitute Decision-making and Advance Directives in Relation to Medical Treatment.<sup>2</sup> Its aim was to seek views from different sectors in society on whether the practice should be formally introduced in Hong Kong. At present, the concept of advance directives is still new in Hong Kong but common in some medically advanced countries such as Australia, Canada, the United Kingdom, and Singapore. In the United States, the Patient Self Determination Act was implemented in 1991, requiring hospitals, nursing homes, hospices, and health maintenance organisations receiving Medicare and Medicaid funding to provide information about advance directives to all patients and to inform them of their right to complete an advance directive.<sup>3</sup>

Although death and dying is an inevitable fact that everyone of us has to face, death-related issues are thought to be taboo in Chinese culture and may be considered too sensitive to discuss with Chinese elders; surrogate decision-making is therefore a common practice.<sup>4-6</sup> Local studies on this area have investigated public and professional attitudes towards life-sustaining treatment and advance directives.<sup>7-9</sup> However, there are little data on the attitudes of local elders with chronic disease in this respect. In Hong Kong, elders with chronic illness make up a large proportion of the adult primary care population. According to the General Household Survey conducted from November 2006

### Key words

Advance directives; Chronic disease; Decision making; Ethics, medical; Life support care

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## 預設醫療指示及維生治療：香港長期病患華籍長者的態度

<b>目的</b>	探討香港長期病患華籍長者對預設醫療指示及維生治療的態度。
<b>設計</b>	橫斷面問卷調查。
<b>安排</b>	香港一所分區教學醫院的內科部。
<b>參與者</b>	60歲或以上並有長期病患的病人。
<b>主要結果測量</b>	人口資料及被訪者對預設醫療指示及維生治療的態度。
<b>結果</b>	共219名長者完成問卷，他們的平均年齡73歲（標準差8歲）；其中133名（61%）為女性。大部分長者在參與此調查前未曾聽聞有關預設醫療指示（81%），亦未曾與其他人討論有關問題（73%）。經講解有關預設醫療指示的概念後，約有一半被訪者（49%）認為如果預設醫療指示合法化，便會考慮採用。如果到了醫學上無效的情況，被訪者普遍支持不予或撤除維生治療。如果病人能力許可的話，有55%的被訪者認為病人自己應決定是否不予或撤除維生治療。相反，如果病人無能力作出決定，44%的被訪者認為其家人應替病人選擇。
<b>結論</b>	本研究發現大部分長者都未曾聽聞有關預設醫療指示或未曾與其他人討論有關問題。此現象顯示在公眾教育上，有必要加強市民對預設醫療指示的認識。

to December 2007, there were 677 600 seniors aged 60 years or above with chronic disease, accounting for 59% of the total Hong Kong population with chronic disease.<sup>10</sup> Apparently, elderly patients with chronic disease are more prone to mortality and mental incompetence, so it is important to examine their wishes on end-of-life issues. This study aimed to examine the attitudes of Hong Kong Chinese elders with chronic disease with regard to advance directives and life-sustaining treatment. It is hoped that the results will contribute to the development of related policies by the government and concerned authorities, and might also facilitate development of awareness and education campaigns about advance directives.

### Methods

This cross-sectional survey was conducted in two medical admission wards of Queen Mary Hospital (QMH) after approval of data collection was granted by the Research Ethics Committees of both the Hong Kong Polytechnic University and the Hong Kong West Cluster hospitals of the Hospital Authority. The QMH is a regional acute teaching hospital affiliated to the University of Hong Kong's Faculty of Medicine. It is also a tertiary referral centre for advanced technology services, such as liver, heart and lung, and bone marrow transplants. There were 1734 admissions to

its medical admission wards between January and November 2009.

This study adopted convenience sampling to recruit Chinese elders aged 60 years or above with chronic disease, who were alert, oriented and able to communicate in Cantonese. Patients with cognitive impairment, mental illness, in an unstable condition (eg haemodynamically unstable), and those who could not understand the purpose of the survey were excluded. Each participant was given an explanation of the objectives of the study and encouraged to express their point of view freely. They were also informed that there were no right or wrong answers to the questions, because its purpose was to explore attitudes and not to promote any particular concept. This statement was clearly explained to every participant before starting the interview and during the interview when needed. All subjects were informed and assured of their right to refuse or withdraw from the study at any time, and that such a decision would have no consequences on the treatment and care they received in the hospital. Informed written consent was obtained from each participant. The following information on advance directives and life-sustaining treatment was introduced to the participants:

- A copy of the "Substitute Decision-making and Advance Directives in Relation to Medical Treatment (LRC Report)".<sup>2</sup>
- A sample of the LRC's proposed model form of advance directives.<sup>2</sup>
- An information sheet that explained various aspects of cardiopulmonary resuscitation (CPR), including its definition, risks and benefits, success rates, and prognostic indicators, the concept of vegetative state and pictures which included CPR, artificial ventilation, and intravenous fluid infusion.

The interviewer then verbally administered the questionnaire to each participant individually. On average, each interview lasted about 30 minutes. Each patient's medical history was also retrieved from the computerised electronic patient record.

The instrument consisted of four parts. The first part collected demographic data. The second was adapted from a previous study,<sup>7</sup> and explored the respondent's personal experience in 'life and death' decision-making. The third part was designed to explore each respondent's attitudes towards the use of advance directives and advance care planning. The fourth and final part, which was adapted from a previously published study<sup>11</sup> and locally validated,<sup>7</sup> examined the individual's views on life-sustaining treatment. Each respondent was asked to respond to statements about life-sustaining treatment using a 5-point Likert scale: 1 represented strongly disagree

with the statement, 2 disagree, 3 not sure, 4 agree, and 5 strongly agree.

Data were analysed using the Statistical Package for the Social Sciences (Windows version 15.0; SPSS Inc, Chicago [IL], US). Descriptive statistics were used to report the results. The Chi squared test was performed to explore the differences in the proportions of respondents who disagreed with, were not sure about, or agreed with the statements. All P values of less than 0.05 were considered significant.

The content validity of the questionnaire was evaluated by two academic lecturers, an advanced practice nurse who worked in the palliative care unit of a local hospital, and a psychologist. The content validity of the questionnaire was 100% for parts 1, 2 and 3, and 95% for part 4. Reliability was evaluated using the test-retest method for part 4, with 10 elders aged 60 years or above with chronic disease completing the questionnaire twice in 2 weeks. Overall, the Pearson correlation coefficient for part 4 was 0.97 (P<0.01).

## Results

In all, 240 eligible patients were identified between September 2009 and February 2010, nine of whom refused to participate and 12 failed to complete the interview (4 felt too tired to continue, 6 could not understand the topic, and 2 had severe hearing impairment). Thus, 219 completed the interviews. Their demographic profiles are summarised in Table 1. Their mean age was 73 (standard deviation, 8) years. Most had children and lived with a family. A relatively high proportion of them had a low education level (31% were illiterate, 39% had attended primary school) and very few of them thought they enjoyed a good health status. The total number of chronic conditions for which they received regular follow-up ranged from 1 to 11; the three most common being hypertension (70%), cardiac diseases (41%), and diabetes mellitus (33%) [Table 2].

Many of the respondents in this study had their own experience (71%) or had had family or friends (75%) admitted into hospital due to critical illness. However, few of them had experienced a situation that entailed decisions on withholding or withdrawing life-sustaining treatment for their family members (13%) or themselves (1%). Most of the elderly patients (81%) had never heard about advance directives before this survey, but after being informed of the concept, nearly half (49%) of them said they would consider using one if advance directives were to be formally legislated in Hong Kong. The reasons given for their agreement and disagreement are summarised in Table 3. Overall, 37% of the respondents had considered the issues related to advance directives, whilst 39% indicated

that they would like to discuss these issues with others, and 27% had actually done so. Among those who wanted to discuss the concept, most wanted to talk to relatives (92%) and only 9% wanted to have

TABLE 1. Respondents' demographic profiles (n=219)

Characteristic	No. (%)
<b>Sex</b>	
Male / female	86 (39) / 133 (61)
<b>Age (years)</b>	
60-69	81 (37)
70-79	89 (41)
>79	49 (22)
<b>Marital status</b>	
Married	127 (58)
Widowed	71 (32)
Divorced / separated	12 (5)
Single	9 (4)
<b>Do you have children?</b>	
Yes / no	202 (92) / 17 (8)
<b>Living arrangement</b>	
Live alone	27 (12)
Live with family	180 (82)
Live in old-age home	10 (5)
Others	2 (1)
<b>Education level</b>	
Illiterate	67 (31)
Primary school	86 (39)
Secondary school	52 (24)
Tertiary level	14 (6)
<b>Self-perceived health status</b>	
Very poor	27 (12)
Poor	87 (40)
Fair	86 (39)
Good	16 (7)
Very good	3 (1)
<b>Mobility</b>	
Independent	144 (66)
Walking with assistance	71 (32)
Wheelchair-bound	4 (2)
<b>Activity of daily living: Independent?</b>	
Yes / no	143 (65) / 76 (35)
<b>Dependent on* (n=76)</b>	
Feeding / dressing	0 / 219 (100)
Personal hygiene	9 (4) / 210 (96)
Toileting	5 (2) / 214 (98)
Cooking	60 (27) / 159 (73)
Laundry	49 (22) / 170 (78)
Shopping	57 (26) / 162 (74)

\* Multiple responses were allowed

TABLE 2. Chronic disease(s) being regularly followed up (n=219)

Disease type	No. (%)
Hypertension	153 (70)
Cardiac diseases	90 (41)
Diabetes mellitus	72 (33)
Cancer (of any type)	59 (27)
Hypercholesterolaemia	46 (21)
Arthritis (of any type)	39 (18)
Eye diseases	39 (18)
Hepatobiliary / gastro-intestinal diseases	39 (18)
Renal diseases	35 (16)
Respiratory diseases	34 (16)
Cerebrovascular accident	30 (14)
Orthopaedic diseases	22 (10)
Benign prostatic hyperplasia	18 (8)
Ear, nose, throat diseases	15 (7)
Endocrinological diseases	14 (6)
Haematologic diseases	14 (6)
Osteoporosis	9 (4)
Peripheral vascular disease	7 (3)
Other types of diseases	22 (10)
Total No. with chronic disease(s) being regularly followed up	
1-2	76 (35)
3-4	85 (39)
>4	58 (26)
Mean (standard deviation)	4 (2)
Range	1-11

discussions with a doctor. Similarly, among those who had actually discussed the concept, most (88%) had done so with relatives and none with a doctor.

The attitudes of these elderly patients towards the use of life-sustaining treatment and withholding or withdrawing treatment in medically futile situations are summarised in Table 4. The proportions of respondents answering “strongly disagree” or “disagree”, “not sure”, and “agree” or “strongly agree” differed significantly ( $P<0.01$ ) in answer to all the questions, indicating that generally they supported the withholding or withdrawing of life-sustaining treatment in medically futile situations.

In all, 55% of the elderly patients agreed that the patient alone should make the decision regarding the withholding or withdrawing of life-sustaining treatment in medically futile situations if competent to do so. Another 14% believed that it should be a joint decision between the patient, the family, and the doctor. If the patient was not competent to make the decision, most (44%) believed that the family alone should make the decision, while 31% agreed that it should be a joint decision between the family and

TABLE 3. Advance directive preferences among elderly patients (n=219)

Variable	No. (%)
Would you consider using an advance directive if their use was formally legislated in Hong Kong?	
Yes	108 (49)
No	64 (29)
Undecided	47 (21)
Rationale for agreement*	
To ensure a comfortable end of life / avoid suffering	77 (71)
To avoid causing a burden to my family	42 (39)
I hope my wishes will be respected	38 (35)
To avoid conflict between family members	15 (14)
I have experienced the death of a relative / friend	10 (9)
To avoid placing a burden on society	9 (8)
Quality of life is more important than length of life	9 (8)
Religious beliefs	4 (4)
I have witnessed others receiving resuscitation	3 (3)
I have had my own experience of receiving resuscitation	1 (1)
Rationale for disagreement*	
My relative(s) will decide for me	25 (39)
Let nature take its course	16 (25)
No need to think about that now	15 (23)
My doctor(s) will decide for me	8 (13)
My decision may change later	2 (3)
Not familiar with the concept of advance directives	2 (3)
Religious beliefs	1 (2)

\* Multiple responses were allowed

the doctor (Table 5). A large proportion of patients in our study who showed an interest in knowing more about this topic; 63% were interested in reading the pamphlet; and 48% wanted to participate in any talk on the topic if one were held in the future.

## Discussion

In contrast to the findings of other local studies,<sup>8,12</sup> participants in this study generally tended to favour refusal of life-sustaining treatment in medically futile situations. A possible reason for this is that we verbally administered the questionnaire to them one by one, explained the concept of advance directives and various terms related to life-sustaining treatment beforehand, and clarified their questions during the interview. This was because previous studies found that elders’ knowledge of life-sustaining procedures

TABLE 4. General attitudes towards the use of life-sustaining or -prolonging technology and withholding or withdrawing treatment among elderly patients (n=219)

Statements*	No. (%)			$\chi^2$
	Disagree <sup>†</sup>	Not sure	Agree <sup>‡</sup>	
1. If life-prolonging technology exists, it should always be used. (-)	178 (81)	27 (12)	14 (6)	227.7 <sup>§</sup>
2. Doctors should generally try to keep their patients alive on machines for as long as possible, no matter how uncomfortable the machines are. (-)	170 (78)	35 (16)	14 (6)	196.4 <sup>§</sup>
3. If a patient is dying, it is best not to prolong their life by any means. (+)	11 (5)	13 (6)	195 (89)	305.9 <sup>§</sup>
4. Under no circumstances should life-sustaining machines be stopped. (-)	145 (66)	42 (19)	32 (15)	107.2 <sup>§</sup>
5. It is a doctor's duty to stop life-prolonging treatments on patients if patients do not want them any more. (+)	7 (3)	22 (10)	190 (87)	282.8 <sup>§</sup>
6. When a person is in a vegetative state, medical treatments usually should not be used to keep them alive. (+)	28 (13)	45 (21)	146 (67)	111.5 <sup>§</sup>
7. If a patient is unable to breathe without a breathing machine, it would be wrong to take them off the machine (even if the condition is hopeless) because that would be killing the patient. (-)	148 (68)	35 (16)	36 (16)	115.6 <sup>§</sup>
8. Even if my condition were hopeless, I would want my life prolonged as much as possible. (-)	186 (85)	12 (5)	21 (10)	262.9 <sup>§</sup>

\* Statement supporting (+) or against (-) decision to withhold or withdraw treatment in dying patients

<sup>†</sup> Patients who chose strongly disagree or disagree were grouped together as "Disagree"

<sup>‡</sup> Patient who chose strongly agree or agree were grouped together as "Agree"

<sup>§</sup> P<0.01

TABLE 5. Elderly patients' views on appropriate decision-makers for withholding or withdrawing of life-sustaining treatment (n=219)

Decision-makers	No. (%)
Conscious and competent patient	
Patient alone	120 (55)
Doctors alone	25 (11)
Patient's family	21 (10)
Patient and his / her family	5 (2)
Patient and doctors	4 (2)
Patient's family and doctors	13 (6)
Patient, his / her family, and doctors	30 (14)
Not sure	1 (0.5)
Unconscious or incompetent patient	
Doctors alone	39 (18)
Patient's family alone	96 (44)
Patient's family and doctors	67 (31)
No one should make the decision	3 (1)
Not sure	10 (5)
Others	4 (2)

was poor, and very often they overestimated the effectiveness of CPR.<sup>8,12-15</sup> This optimistic view on the outcomes may explain why a large percentage of older patients in other studies opted for CPR. A number of studies have shown that when patients were aware of the real survival rates of CPR, they were less likely to desire this intervention.<sup>12,15-17</sup> Further, a local study showed that in-patients had significantly more knowledge and personal experience of life-sustaining treatment than old-age home residents.<sup>12</sup>

TABLE 6. In the event that you were terminally ill, which treatment would you like to receive? (n=219)

Treatment	No. (%)		
	Yes	No	Undecided
Cardiopulmonary resuscitation	19 (9)	175 (80)	25 (11)
Artificial ventilation	17 (8)	178 (81)	24 (11)
Blood products transfusion	88 (40)	106 (48)	25 (11)
Antibiotics	87 (40)	95 (43)	37 (17)
Tube feeding	39 (18)	152 (69)	28 (13)
Intravenous fluid infusion	124 (57)	76 (35)	19 (9)

In our study, all of the respondents were in-patients in acute wards, and many of them had had their own experience (71%) or had had friends or relatives (75%) admitted into hospital due to critical illness. These personal experiences of such procedures and exposure to the ward might have affected their attitudes towards end-of-life decisions in medically futile situations.

It appears that the level of patient acceptance of various kinds of life-sustaining treatment in the face of terminal illness was different in our study. A large percentage of them would refuse CPR (80%), artificial ventilation (81%), and tube feeding (69%). However, their attitudes towards the use of antibiotics and blood product transfusions were less clear; a significant percentage of the respondents would opt to receive intravenous fluid infusions (57%; Table 6). This could be explained by the fact that they might have witnessed ventilator cases in the medical admission ward and knew that CPR, artificial ventilation, and tube feeding were invasive

and painful, procedures that they might not want to endure to prolong life. However, many of them had experienced intravenous fluid infusion, use of antibiotics and blood product transfusions before (some were receiving intravenous fluid infusions during the interview), and some even thought it was a way to promote comfort. Therefore, they accepted this form of intervention more readily.

Nearly half (49%) of the elderly patients in our study expressed that now that they understood the concept, they would consider using advance directives if formally legislated in Hong Kong in the future. This was despite the fact that many of them (81%) had never heard about them before participating in this survey. The acceptance rate was similar to that of a local study in which 49% of elders accepted the concept of advance directives.<sup>8</sup>

The final part of the study investigated the elderly patients' preference regarding decision-makers for withholding or withdrawing life-sustaining treatment. Over half of our respondents (55%) believed that the patient alone should make the decision if he/she was conscious and competent. The acceptance of advance directives and favouring of self-determination by our elderly patients was surprisingly high, given the context of Chinese culture. Previous literature reported that traditional Chinese societies were strongly family-centred<sup>6,18</sup>; health care decisions were often made by the family as a group, rather than by the individual, and the principle of autonomy played a lesser role in Chinese societies. In our study, encouragingly there was a significant proportion of elderly patients who favoured self-determination and accepted the concept of advance directives, and considerable numbers were interested in more information on the topic. Their interest and response also indicate that they are capable of making decisions on the use of life-sustaining treatment.

This finding raises an important concern, namely that physicians should assess individual preferences when considering applying life-sustaining treatment to elderly patients. Advance care planning needs better promotion. In Chinese culture, death and related issues are seldom discussed openly, especially among elderly people.<sup>19-21</sup> Besides, the current application of advance care planning in Hong Kong has mainly focused on patients with advanced or terminal diseases (such as metastatic cancer), and was very uncommon for elderly persons with chronic disease. Very often, the life-sustaining decision has to be made during hospitalisation of a severely ill elderly patient, or at a moment of crisis.<sup>20</sup>

Although the current finding showed a significant proportion of elderly patients considered themselves to be the most important decision-makers on end-of-life issues if they are mentally competent,

this does not preclude a role for the family. From responses to various questions, it was inferred that the family should also play an important part in end-of-life decision-making. For example, most respondents (44%) considered that the family alone should make the end-of-life decision for them, if they become mentally incompetent. For respondents who would not consider using an advance directive even if it was formally legalised, "my family will decide for me" was the most frequently selected reason (39%). If respondents wanted to discuss issues related to advance directives with someone, most often it was their family (92%). Thus, involvement of the family in the process of advance care planning is particularly important in Chinese society.

Finally, many elderly patients in this study had not considered issues related to advance directives (63%), and had never discussed them with others (73%), even though 39% indicated that they would like to talk about these ideas with others. It is unclear why there was such strong support for the practice of withholding or withdrawing life-sustaining treatment in medically futile situations, though many patients seldom thought or talked about these issues. Perhaps end-of-life decisions are sensitive issues in traditional Chinese culture, and matters related to death are regarded as taboo. As a result, little attention was paid to them, and it was natural for the elderly and their families to avoid talking about death, especially when it was not imminent. Besides, in Hong Kong public knowledge and comprehension about life-sustaining treatment had been relatively deficient.<sup>8,12</sup> Some elderly patients may not be aware of their right to refuse treatment, which is an area of concern that deserves more research.

Our study has several limitations. First, we used a convenience sample of elderly patients with acute illness hospitalised in a single hospital. Thus, their views may not represent those of the general elderly population. Second, the questionnaire used hypothetical clinical scenarios, for which reason responses to the survey might not accurately reflect what individuals would choose in reality. Third, there was a potential bias, as only individuals who were willing to discuss death-related issues agreed to participate.

## Conclusions

Our study revealed that elderly patients with chronic disease accepted the practice of withholding or withdrawing life-sustaining treatment in medically futile situations. A significant portion of them accepted advance directives and favoured self-determination if mentally competent. This may have been related to the fact that they had been given clear information about these matters during the interview. Nevertheless, a large proportion of elderly

patients in our study had not considered the issues related to advance directives or discussed them with others. Given that the concept of advance directives and knowledge of life-sustaining treatment are not well understood in Hong Kong, more effort is needed to step up public education in this regard. These findings may help the government to formulate strategies for promoting the concept of advance directives.

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