

End-of-life Issues—Preferences and Choices of a Group of Elderly Chinese Subjects Attending a Day Care Centre in Singapore

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Abstract

Introduction: This was an exploratory study that was intended to provide a descriptive analysis of the choices and preferences of a group of elderly Chinese subjects attending a day care centre in Singapore with regard to end-of-life issues. **Materials and Methods:** A semi-structured one-to-one interview was conducted to collect data from the subjects. Qualitative techniques were used to analyse the data. **Results:** Forty-three subjects were interviewed. The median age was 71 years. There were more women than men (58.1% vs. 41.9%). The predominant religion was Buddhism/Taoism. 83.7% and 76.7% of the subjects preferred to be told of the diagnosis and prognosis of a terminal illness, respectively. The person most preferred to reveal the diagnosis was the attending doctor (60.5%). About 83.7% of the subjects have never heard of the Advanced Medical Directive Act, while 37.2% agreed that making an advanced directive would be necessary. Twenty-three (53.5%) would choose the doctor, while 15 (34.9%) would choose a family member as a surrogate decision-maker. Twenty-two (51.2%) thought that euthanasia should be allowed, while 15 (34.9%) disagreed. With regard to supportive measures at the end of life, 67.4% wanted cardiopulmonary resuscitation, 62.8% wanted artificial ventilation, 55.8% wanted nasogastric feeding, 65.1% wanted intravenous hydration and 41.9% wanted renal dialysis. **Conclusion:** There is a need for closer communication between older persons and their carers with regard to end-of-life care. The attending doctor appears to have an important role in this respect.

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Key words: Advanced Medical Directive, Communication, Decision making, Living will, Supportive measures

Introduction

Doctors caring for elderly, dying and terminally ill patients are often faced with the dilemma of having to make difficult decisions especially regarding treatment where the benefit and burden is not clearly defined. Issues relating to death and dying, such as whether to disclose the diagnosis and prognosis to patients, the patient's right to self-determination, the use of futile but burdensome interventions and the legalisation of euthanasia are relevant to today's practice of medicine. These issues will become more relevant as the population in most developed and many developing countries rapidly age.

Already, steps are being taken to address some of the above problems. These include legislation and enactment of laws that allow patients to make known their preferences for end-of-life care. Legal instruments such as living wills, advanced directives and the durable power of attorney are some manifestations of these measures. The Advanced

Medical Directive Act was made law in Singapore in May 1996. In spite of this, anecdotal evidence suggests that most elderly patients seen in hospitals have not heard of the existence of this legislation, let alone executed an advanced directive. Even in the US where the Patient Self-determination Act¹ requires that all patients admitted to a healthcare institution be informed of the availability of means to make advanced directives (AD), studies there have shown that the percentage of patients who actually execute AD to be low.²⁻⁴ Though the majority of patients had wanted to discuss cardiopulmonary resuscitation and other end-of-life issues with their physicians, less than 50% of them had actually done so.^{5,6} We are therefore faced with a situation where the dying patient's choices with regard to end-of-life care is mostly unknown to the attending physician and his family members.

The desire to know and to be told the diagnosis and prognosis of one's illness is the norm in the West where

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most studies have shown that patients desire to be told the truth of their condition so that they can make timely and appropriate arrangements or preparations.^{7,8} This need becomes more urgent if one were to be diagnosed with a terminal condition. However, the need to be “informed” depends very much on the cultural background of the patient. At present there are no studies to indicate the extent of this need in the Asian context.

This study was conducted with the above issues in mind. The aim was to provide a descriptive or qualitative analysis of the choices and preferences of a group of elderly Chinese subjects who were attending a day care and rehabilitation centre in Singapore with regard to end-of-life care, such as the preferences for disclosing information, the desire for supportive measures which were deemed futile and the attitude towards euthanasia. We also sought the underlying reasons for their choices. The ultimate objective of this study was to highlight issues pertinent to end-of-life care in a group, which is often marginalised in medical decision making. We also desired to study, understand and be enlightened on the reasons for their choices and to identify, if there were any relevant issues that deserve further study in this area.

Materials and Method

This is a cross-sectional, exploratory and descriptive study in which qualitative techniques were used to collect data from the subjects. The subjects were chosen from the list of attendees of a voluntary day care and rehabilitation centre for the elderly in Singapore (in the month of June 1998).

Those who were recruited into the study were Chinese, 60 years old or above, had an ECAQ (Elderly Cognitive Assessment Questionnaire)⁹ score of more than 6 and were on the “active” list of attendees of the centre. Patients who had any one of the following were excluded from the study: less than 60 years old, an ECAQ score of 6 or less, a diagnosis of depression or being on treatment for depression, aphasia and terminal illness. Patients who showed any depressive symptoms during the interview itself such as excessive tearing, pessimism, lack of reactivity, poor eye contact, etc. were also excluded from the study.

Written consent was obtained prior to the interview survey. It was emphasised to the subjects that the interview was confidential and non-binding in nature and that it would not in any way influence the subsequent management of their illnesses.

The interviews were carried out in the months of June and July 1998. The administration of the questionnaire and interview was carried out on a one-to-one basis by 2 doctors and a trained nurse at the centre and in the spoken language of the patients. There were two parts to the interview: the

first was on the disclosure of information, where patients were asked about their desire to be told of a terminal illness and its prognosis, who should be the one revealing this information to them and whether they preferred their relatives to know of this terminal condition; and the second part which explored the choices for futile interventions to be used at the end of life, the attitudes towards AD and euthanasia. Where possible, the reasons for the choices were asked and recorded by the interviewer.

A copy of the questionnaire used in the interview can be obtained from the authors on request.

Results

Of the 61 subjects entered into the study, only 43 were interviewed. This resulted in a response rate of 70.5%. The non-responders were: 2 who refused, 9 who did not attend the day care throughout the interview period, 4 who were discharged before they could be interviewed, 2 who could not comprehend the questions and 1 who was hospitalised before being interviewed. The average ECAQ score was 8.4 while the median was 8.

The distribution of age, sex, race, marital status, religion and medical problems is shown in Table I. The median age of this cohort was 71 years; the mean age was 73 years while the age range was 60 to 89 years. There were more women than men (58.1% vs. 41.9%). The predominant religion was Buddhism/Taoism. The commonest medical problems among the subjects were stroke disease, diabetes and hypertension.

Preferences with regard to issues surrounding the disclosure of information, attitudes towards AD, choice of surrogate decision-maker and attitudes towards euthanasia are shown in Table II. It can be seen that 83.7% and 76.7% of the subjects would like to be told of the diagnosis and prognosis of a terminal illness, respectively, while the person most preferred to reveal the diagnosis was the attending doctor (60.5%). The majority (74.4%) also wanted their close family members to be told of the diagnosis, but an important number (16.3%) preferred otherwise.

About 83.7% of the subjects have never heard of the existence of the Advanced Medical Directive Act and when asked if making one would be necessary, 37.2% agreed while 39.5% disagreed. If they had to choose a surrogate decision maker to make decisions for them should they become mentally incompetent, 23 (53.5%) would choose the doctor while 15 (34.9%) would choose a family member. Of those who chose a family member, 6 chose their sons, 5 chose their daughters, 2 chose their spouses and 1 each chose their sister and nephew.

When asked if they agreed to doctors being allowed to carry out euthanasia, 22 (51.2%) answered “yes”, 15 (34.9%) answered “no” while 6 were not sure. About the same

TABLE I: THE DISTRIBUTION OF AGE, SEX, MARITAL STATUS, RELIGION AND MEDICAL CONDITIONS (n=43)

Characteristic	Number	%
Age distribution (in years)		
Mean	73.0	-
Median	71	-
Range	60-98	-
Sex distribution		
Male	18	41.9
Female	25	58.1
Marital status distribution		
Married	18	41.9
Single	5	11.6
Divorced/Separated	2	4.6
Widow(er)	18	41.9
Religious distribution		
Buddhist/Taoist	33	75.0
Christian/Catholic	8	18.2
Others	2	4.5
Medical conditions		
Stroke	34	79.1
Hypertension	26	60.5
Diabetes	16	37.2
Ischaemic heart disease	6	14.0
COLD	2	4.6
Congestive heart failure	1	2.3
Fracture of the hip	3	7.0

COLD: chronic obstructive lung disease

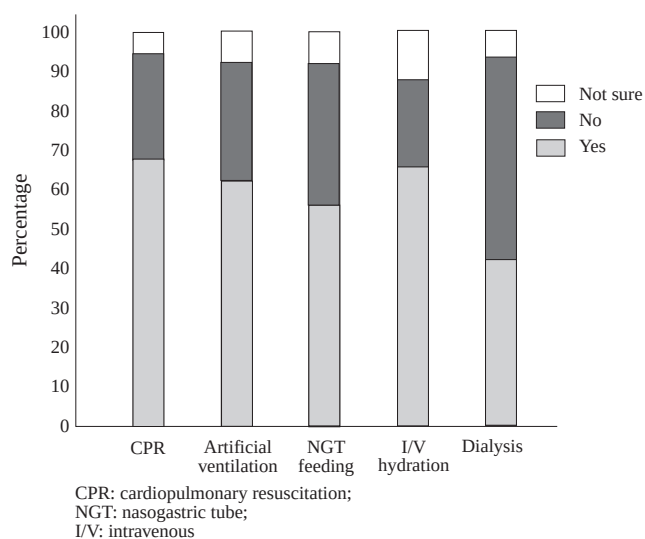


Fig. 1. Choice of interventions in the face of futility.

figures were obtained for those who would ask for euthanasia should they suffer severe pain at the end of life.

Figure 1 shows the preferences for supportive interventions which were futile. During the interviews the point of futility was strongly emphasised. The following choices were made: 67.4% wanted cardiopulmonary resuscitation, 62.8% wanted artificial ventilation, 55.8% wanted nasogastric feeding, 65.1% wanted intravenous hydration and

Table II: PREFERENCES AND ATTITUDES TOWARDS THE DISCLOSURE OF INFORMATION, AD, CHOICE OF SURROGATE DECISION-MAKER AND EUTHANASIA (n=43)

Characteristic	Number	%
Desire to be informed of diagnosis		
Yes	36	83.7
No	4	9.3
Not sure	3	7.0
Desire to be informed of prognosis		
Yes	33	76.7
No	7	16.3
Not sure	3	7.0
The person to reveal the diagnosis/prognosis		
Doctor	26	60.5
Nurse	0	0
Family member	7	16.3
Others	3	7.0
Not sure	7	16.3
Desire that family be told of prognosis/diagnosis		
Yes	32	74.4
No	7	16.3
Not sure	4	9.3
Ever heard of an advanced directive*		
Yes	7	16.3
No	36	83.7
*(None had made an AD)		
Is a living will or AMD necessary		
Yes	16	37.2
No	17	39.5
Not sure	10	23.3
Choice of surrogate decision maker		
Doctor	23	53.5
Nurse	1	2.3
Family member	15	34.9
Others	2	4.6
Not sure	2	4.6
Should doctors be allowed to carry out euthanasia		
Yes	22	51.2
No	15	34.9
Not sure	6	13.9
Would request for euthanasia		
Yes	24	55.8
No	14	32.6
Not sure	5	11.6

AD: advanced directives; AMD: advanced medical directives

41.9% wanted renal dialysis.

Table III summarises the reasons for the various preferences and choices as presented above.

Discussion

Our subjects were elderly Chinese patients who were attending a day care and rehabilitation centre. A single racial group was chosen because it was felt that the cultural background of subjects would have an influence on the

TABLE III: REASONS GIVEN FOR PATIENTS' CHOICES

Knowing the diagnosis/prognosis	So that the doctors will know that I want to be saved
To be prepared	Family will then know my wishes
So that I can make plans and preparations	Everything has to be in black and white
May still have a chance of recovery with treatment	To protect doctors from any blame
I can then search for alternative therapy	While I'm still alert and rational
It is better to know than to be guessing	Can have some peace of mind
So that I can get closer to my family	Making a living will is not necessary
I have the right to know my illnesses	My children and doctors will make the best decision for me
I can make funeral preparations and plan things to be done after my death	My children will know what to do
I can make a will	Too troublesome
There'll be peace of mind	Euthanasia/Physician-assisted suicide should be allowed
Not knowing the diagnosis/prognosis	It is more humane
No point in knowing	Because there would be no meaning in life if there was suffering
I wouldn't want to worry and have sleepless nights	The patient's request should be granted
I fear death	Dying should be easy and peaceful
I may feel sad and this will hasten death	Doctor knows better
Wanting family to know	Doctor knows when patient should die
So that they will understand	Euthanasia/Physician-assisted suicide should not be allowed
Not necessary to hide	The law is against it
They can be prepared	Nobody is allowed to kill anyone
It will be easier to cope	A doctor's job is to save and not to kill
It would be better for them to know	There still might be a chance to live
They can care for and comfort me	Should leave it up to God
They are concerned about me	Doctors will lose patients' trust
I will need financial help from them	It is cruel
They can be at peace	Means giving up hope
Not wanting family to know	Would request for euthanasia
So that they will not worry too much	To lessen suffering
So that they will not be sad	If there is so much suffering it would be better to die earlier
They will not be able to take it	I would not be able to stand the pain
Doctor as the best person to make end-of-life decisions	Since I have to die sooner or later anyway
Doctor knows best	I don't want to be a burden to my family
My family members would be too worried to decide for me	Would not request for euthanasia
The doctor will know my illness	I want to live as long as I can
Doctor is professionally qualified	Doctors would not do it
Family member as the best person to make end-of-life decisions	My mother will be heartbroken
They are the closest	I'd rather ask for pain-killers
They know the best	Killing is wrong
They are filial	Let my death be natural
Making a living will is necessary	Only God can take lives
Doctors and family will know my preferences	I will still hope to be cured
	Why should someone else help me die

answers given. Moreover, the majority of attendees at this particular centre were from this racial group. A majority of them professed to be Buddhists or Taoists. The most prevalent diagnosis was stroke disease, which indirectly suggests that most of the subjects had some disability. We, however, did not study the functional status of the subjects.

Consistent with most studies carried out in the West, the majority of our patients wanted to be told if they had a terminal condition and the prognosis of their illness. This was in order for them to make adequate preparations and to settle any unfinished business. Other reasons for wanting full disclosure included the wish to resolve uncertainties, to

get closer to the family, the belief that it was a personal right and the contingent desire to search for alternative therapy.

Therefore, the widely accepted practice in the Chinese and Oriental cultures of protecting the patient from the diagnosis of a terminal condition might be misplaced. This rather paternalistic approach would be at odds with the ultimate well-being of the patient and can cause considerable strain to the carers who have to maintain this "conspiracy of silence".¹⁰ A study by Peteet et al¹¹ found that 40% of the patients who were told of the diagnosis of cancer placed their hopes more towards remission and optimal quality of life rather than cure. The latter also found it helpful if the

information was disclosed with hope, care and honesty, with respect for their privacy and in the presence of a supportive person.

The choice of the doctor as the person to disclose information is not at all surprising. Most of the subjects thought that the doctor would know their condition best and therefore would be in the best position to reveal the diagnosis and prognosis to them. However, the practice of full disclosure depends very much on the culture and the attitudes of the community in which the physician works.¹²⁻

¹⁴ In Singapore, one suspects that most doctors would place the burden of revealing the diagnosis to the patient onto the relatives. Although most of our subjects would desire that the diagnosis be revealed to their family members, a significant number (16.3%) would choose otherwise. Hence, this practice of revealing the diagnosis through the relatives may not always be consistent with the patient's wishes and in fact may contradict the principle of maintaining strict patient confidentiality. It would also be a disservice to the patient should the family decide to seek collusion with the doctor instead of disclosing the information to the patient. It would be interesting to study the actual practice of disclosing information to the elderly patient among doctors in this part of the world. A questionnaire study by Tan et al¹⁵ of 179 doctors in private and institutional practice found that 90.4% would actually inform the patients' family about the diagnosis of cancer while 43.6% would tell the patient the diagnosis directly. Eighty per cent of the respondents would collude with the family if requested to do so and 26.4% would continue to collude with the family even if the patient insisted on knowing the truth.

About 84% of our patients have never heard of an advanced directive before, while the number who felt that it was necessary¹⁶ was about the same as those who thought otherwise.¹⁷ Interestingly, several studies have shown that those who have discussed with their physicians about their preferences or directives with regard to life-sustaining treatment are those who are more likely to decline active resuscitation and other similar measures at the end of life.^{5,6} Our group of subjects tended to want a more aggressive approach to end-of-life care (Table III). This may be the reason for a large proportion of them regarding AD as unnecessary. Studies have also shown that attitudes towards AD differ between races and cultures.¹⁶

53.5% of the subjects we interviewed preferred the doctor to make decisions for them with regard to end-of-life care should they become mentally incompetent to do so. The reasons given were that the doctor knew the patients' illness the best, that the relatives would be too worried to make decisions and that the doctor would be the "most qualified" to make such decisions. Johnston et al¹⁷ found that patients generally prefer a more active role for physicians

in both decision-making and discussion of end-of-life care than do physicians themselves. A similar study carried out in the US found that ethnicity plays a role in the choice of decision makers among a group of elderly patients.¹⁸ Asians, Blacks and Hispanics were more likely to identify an alternative decision-maker compared to Whites. Interestingly, though, studies have shown that the concordance between substitute judgements by the patient's physician or family members and the patient's actual wishes is no greater than that caused by chance.⁵

Nearly half of the patients interviewed approved of euthanasia or physician-assisted suicide and a slightly higher proportion would request for it should they experience severe suffering and pain at the end of their lives. The reasons given by those who agreed to euthanasia were that it would be more humane, life would be meaningless if there was so much suffering, patient's request should always be respected, dying would be easier and more peaceful, that the doctor knew best and the doctor knew when the patient should die. Those who thought that euthanasia should not be allowed felt that it was against the law, nobody should be allowed to kill, there still might be a chance to live on, the timing of one's death should be left to God, doctors would lose the patients' trust, this would be cruel and this would mean giving up hope. There were a few patients who felt that euthanasia should not be allowed but yet would request for it if faced with pain and suffering at the end of life. Cicirelli,¹⁹ in his study of the elderly, found that most of them would chose to maintain life even if they had a very low quality of life but a significant minority would choose to end their life by suicide, assisted suicide or euthanasia. Indeed, an opinion poll conducted in the UK showed that 82% of the public agreed that euthanasia should be allowed for patients with painful incurable disease.²⁰

Figure 1 shows that a majority of the subjects would choose cardiopulmonary resuscitation (67.4%), artificial ventilation (62.8%), nasogastric feeding (55.8%) and intravenous hydration (65.1%) even in the face of futility. This is a rather unexpected result as studies in the West have shown that most patients would refuse life-sustaining training if these were deemed futile.^{21,22} This finding appears to be at odds with the observation that an important number of the subjects desire euthanasia as an option for end-of-life care. Possible reasons for this discordance are elaborated in the discussion. A study by Heap et al²¹ found that 73% of patients did not want treatment if the chances were poor, but 30% wanted treatment no matter what the circumstances were. They also found that no patient characteristic, including age, was consistently associated with life-support preferences. Hence, the belief that the desire for intensive care treatment diminishes with age may be a misconception.

Our subjects' responses could have been influenced by their religiosity, the fear of death and dying or by their very strong will or desire to carry on living no matter what the circumstances might be. These factors have been found to influence the elderly person's wishes for life-sustaining treatment even if they are futile.^{19,23}

Finally, it is important to point out the limitations of this study. Firstly, because of the small numbers involved and the highly specific nature of this group of subjects, the findings of this study cannot be extrapolated to the elderly population of Singapore in general. Nonetheless, it gives us a glimpse of the possible attitudes, preferences and choices of a special group, which is often side-lined in medical decision-making, on end-of-life issues that are seldom addressed because they are considered taboo in the local culture. A larger study should be undertaken to validate the findings of this small study.

Other difficulties encountered in the study were in administering the interview where the meaning of the questions may have been lost during the process of translating into the local Chinese dialects of the subjects. Moreover, the subjects in our study, as in other similar studies, may not have fully comprehended the stress and trauma experienced by patients undergoing cardio-pulmonary resuscitation and other "aggressive" treatment; therefore, these treatment may not have been viewed as being overly burdensome and a cause for suffering.

The ECAQ,⁹ which was used as a tool to detect cognitive impairment in this study, is sensitive for detecting moderate and severe cognitive impairment but it lacks sensitivity in detecting the borderline and mild cases. Therefore, there is a possibility that the group with mild cognitive impairment, which inadvertently escaped detection, may not have fully understood the relatively complex issues of the questionnaire. This would have a significant impact on the results and, perhaps, may account for the discordance in some of the findings; for example, the finding that though many wanted euthanasia, yet most preferred aggressive end-of-life treatment.

The authors had originally planned to screen for depression using one of the available tools derived from the West. Unfortunately, it became evident that, in translating the questions to the local dialects, the original meaning of the former was lost. On top of that and in order for such a translation to be meaningful at all, it would have to be further validated. The addition of an extra set of questionnaire would have made the whole interview process extremely cumbersome and tiring to the elderly subjects. We therefore chose instead to identify any previous diagnosis of depression based on what was recorded in the case-notes and to detect any depressive symptoms during the interview process itself. Nonetheless, with the benefit

of hindsight, the authors realised that a more objective measure of this important condition should have been utilised as depression can influence the choices made with regard to the issues being explored in this study.

Conclusion

Finally, it is important to reiterate the message that recurs within this article, that it is incumbent upon the attending doctor to initiate discussion with the patient about his wishes with regard to end-of-life care. This should be done regardless of whether the expected decision would be consonant with that of the doctor and of whether the decision will ultimately be heeded or carried out. The elderly patient should be given a voice. The paternalistic approach of days gone by will have to make way for a more patient-centred approach, where the patient's choices and wishes are given due consideration in the decision-making process.

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