

Attitudes of Demented and Non-demented Chinese Elderly Subjects Towards End-of-life Decision Making

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Abstract

Objective: Due to progressive cognitive and physical deterioration, it is not uncommon for carers and medical professionals to face situations requiring proxy end-of-life decisions for patients with dementia. In this study, attitudes toward making end-of-life decisions were compared in non-demented and mildly demented Chinese subjects.

Patients and Methods: Responses to three hypothetical scenarios concerning end-of-life decisions in demented subjects with different medical comorbidities were developed. 30 cognitively intact non-demented and 26 mildly demented subjects were interviewed with a semi-structured questionnaire on attitudes towards end-of-life decisions in these scenarios.

Results: There were no significant differences between the groups in the proportion of subjects choosing supportive therapy to prolong life, and in attitudes towards more invasive treatment if their condition deteriorated. Compared with non-demented subjects, a higher proportion of the demented group “highly agreed” with having their life saved by all means in the scenario of severe dementia and medical debilitation (chi-squared = 8.47, df = 3, p = 0.04). For more treatable medical problems, the groups showed similar preference (p > 0.05). Regarding emotional reactions after making end-of-life decisions, more demented subjects had “no special feeling” and more non-demented subjects felt “relieved” towards possible poor treatment outcome after making end-of-life decisions, although the difference was not significant.

Conclusion: Despite significant cognitive impairment, mildly demented subjects express a relatively positive view towards making end-of-life decisions. Their personal choice should be explored and respected in clinical management and planning for care.

Key words: *Aged, Attitude to death, Decision making, Dementia*

Introduction

Dementia is the commonest neurodegenerative disorder of old age. Progressive deterioration in cognitive abilities affects judgment and capacity to make personal decisions. The making of end-of-life decisions (ELD) is a frequently encountered issue for both demented patients and their caregivers, as serious medical comorbidity often becomes more significant as dementia progresses. Apart from cognitive

ability, choices for ELD are also influenced by multiple psychosocial and cultural factors. Physical condition, mood disturbances, religious orientation, cultural background, and social support are all potential factors that may affect a subject's choice in relation to ELD for themselves and their relatives.¹⁻³

Advance directives provide the elderly person an opportunity to arrange her/his affairs before possible mental deterioration occurs. This is especially relevant in demented patients when the prolonged process of cognitive deterioration would affect a person's ability to make personal judgement and decisions.^{4,5} The issue has been overlooked in Hong Kong. Relatively few older people will anticipate the need to make ELD with advancing age.

In most circumstances, medical professionals and carers are involved in the proxy decision-making process. As cognitive impairment and psychological disturbances may influence decision-making and perception of life in subjects with dementia, their attitudes toward ELD should be explored. Undoubtedly, personal preferences of the decision-makers would have a direct effect on their choice

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of ELD⁶⁻⁸ for patients with dementia, patients' choices for treatment are very infrequently sought or respected.

In particular, possible changes in attitude towards life and death as dementia sets in are of interest. The present study aimed to examine the attitudes of non-demented and demented elderly towards ELD, in the hope of identifying preliminary areas of concern from cognitively intact elderly subjects concerning death and dying.

Patients and Methods

Subjects

Subjects over the age of 60 years were recruited from social centres and subvented residential homes for the elderly in the New Territories East region of Hong Kong in 2005. The cognitive status of participants was evaluated using the Cantonese version of Mini-Mental State Examination⁹ and a battery of cognitive screening assessments. Severity of dementia was evaluated using Clinical Dementia Rating (CDR)¹⁰ by trained psychiatrists. CDR is a clinical interview evaluating 6 areas of functioning, in order to generate a global score representing severity of dementia. Eligible subjects included subjects with CDR of 0 (CDR 0) and 1 (CDR 1); CDR 0 represented normal cognition and CDR 1 mild dementia. Demented subjects were assessed by the psychiatrist to be competent in communication and able to express their own views before recruitment. To avoid confounding mood problems affecting the response, all subjects were clinically non-depressed, with a Cornell Depression Scale for dementia¹¹ score less than 6. The sample of elderly subjects consisted of 30 CDR 0 and 26 CDR 1 subjects. Written informed consent was obtained before the interview. The study was approved by the institutional ethical review board concerned.

Questionnaire

A questionnaire was adapted from a recently conducted study designed to evaluate the attitude of demented patients and their caregivers after the making of proxy ELD for the demented elderly.¹² The questionnaire consisted of 2 sections. The first section recorded demographic characteristics of participants, family relationships, religious orientation (Tang et al., unpublished data) and prior experience similar to the 3 hypothetical scenarios reported below.

The second section consisted of three scenarios concerning ELD in patients with dementia and were read aloud to each participant (Appendix 1). The interviewer asked the participant to picture themselves in the scenarios and explore their preferences of treatment in each scenario. The primary considerations in developing the content of the scenarios were: first, the subject suffers from dementia but the severity of dementia varies; second, the subject also suffers from comorbid physical conditions with a high chance of deterioration (the nature and urgency of the comorbid medical condition varies in each scenario); third, ELD is anticipated; fourth, the content of the scenarios should be easily understood by the lay public of geriatric age group. Scenario 1 involved an account in

which a demented elderly subject suffered from serious medical comorbidity requiring a decision about nasogastric tube feeding. Scenario 2 concerned a newly diagnosed demented elderly subject with mid-stage colonic carcinoma, who was advised to undergo an operation with fair prognosis. In the last scenario, a man with advance stage dementia developed acute appendicitis and required an emergency operation.

In each scenario, participants were asked a set of similar questions. These included: whether or not treatment should be given; whether invasive treatment (i.e., surgery) or conservative/palliative treatment should be implemented; whether doctors should try their best to save the subject's life in any situation; and the subject's feelings towards possible poor treatment outcome after making ELD.

Data Analysis

A combination of descriptive and quantitative approach was used to analyse the data collected. Cross tabulations, were used to evaluate data and statistical significances were tested with Pearson's chi-squared test. Data analysis was done by use of the Statistical Package for the Social Sciences (SPSS), Windows Version 11.0. (SPSS Inc., Chicago, IL, USA).

Results

Elderly

There were no significant differences between the demented and non-demented elderly groups in gender, marital status, religiosity and educational levels (t test and chi-squared, $p > 0.05$). Demented subjects were significantly older than non-demented subjects (85.9 ± 5.3 years versus 79.2 ± 5.9 years; $t = 4.4$, $p < 0.001$) [Table 1]. Five subjects (9%) lived with family members, 7 (13%) lived alone or with friends and 44 (79%) lived at old age homes. There were no significant difference in the place of abode between the two subject groups.

Supportive Versus Invasive Therapy

Choices in relation to receiving or forgoing supportive therapy to prolong life in the 3 scenarios are summarised in Table 2. A higher proportion of subjects in both the non-demented and demented groups chose treatment in scenario 3 (acute surgical

Table 1. Demographic characteristics of subject groups.

	NDG (n = 30)	DG (n = 26)
Age (years [SD])*	79.2 (5.91)	85.9 (5.32)
Gender ratio (male:female)	3:27	0:26
Marital status (M:D:P:S)	5:1:21:3	1:0:23:2
Educational level	3.23 (4.15)	1.48 (2.91)
Religion (yes:no)	26:4	18:8
MMSE score*	26.97 (1.85)	16.81 (3.08)

Abbreviations: NDG = non-demented control group; DG = demented group; SD = standard deviation; M:D:P:S = married:divorced:spouse passed away:single; MMSE = Mini-Mental State Examination.

* t test, $p < 0.001$.

Table 2. Choice of supportive therapy to prolong life.

	Supportive therapy*		χ^2	Further treatment†		χ^2
	Yes (No. [%])	No (No. [%])		Yes (No. [%])	No (No. [%])	
Scenario 1						
NDG	10 (33)	20 (67)	0.48	11 (37)	19 (63)	2.48
DG	11 (42)	15 (58)		15 (58)	11 (42)	
Scenario 2						
NDG	17 (57)	13 (43)	0.006	17 (57)	13 (43)	1.2
DG	15 (58)	11 (42)		11 (42)	15 (58)	
Scenario 3						
NDG	17 (57)	13 (43)	0.44	19 (63)	11 (37)	0.004
DG	17 (65)	9 (35)		16 (62)	10 (38)	

Abbreviations: NDG = non-demented control group; DG = demented group.

* Yes, agreed on the use of supportive therapy to prolong life; no, disagreed on the use of supportive therapy.

† Yes, agreed on the use of more invasive treatment if supportive therapy fails; no, disagreed on the use of further invasive treatment if supportive therapy fails.

emergency) than in the case of serious medical complication in scenario 1. There were no significant differences between the choices of the non-demented and demented elderly (chi-squared test). Concerning the decision regarding further invasive therapy when the physical condition further deteriorated, similar proportions of the 2 subject groups chose to undergo invasive procedures or operations when indicated.

Attitude Towards 'Saving Life by All Means'

For scenario one, there was a significant difference on this aspect (Table 3). A higher proportion of demented elderly (62%) chose "highly agree" in regard to being saved using all methods, versus only 33% of the non-demented elderly. Thirty percent of normal elderly chose "highly disagree" concerning being saved, compared with only 4% in the demented group (Pearson chi-squared = 8.47, df = 3, p = 0.04). For scenarios 2 and 3, the attitude towards "saving life by all means" was not significantly different between the two groups (Pearson chi-squared). The most common response was "highly agree" in both groups.

Feelings Towards Possible Treatment Outcome after Making End-of-life Decisions

The participants were asked about their feelings if they were not cured after treatment. No significant differences were

found between the groups in attitudes towards the circumstance. For scenario one, the typical response of the demented elderly was along the lines of: "there isn't much I can do, there are no other methods" while the normal elderly usually felt "relieved" about not being treated over aggressively. Another reaction expressed by both groups was "having no special feelings". In scenarios 2 and 3, the most common statement in both groups was "no special feelings" or "there are no other methods" (Table 4).

Discussion

One of the most difficult situations encountered by health care workers is the need to undertake ELD on a patient's behalf. ELD may be required in acute medical conditions, or more commonly, in acute on chronic conditions when medical comorbidity becomes a terminal event for patients suffering from degenerative conditions. Due to progressive deterioration in cognitive function, it is expected that patients with advanced dementia will lose their ability to make personal decisions, and are unlikely to be able to participate in their own ELD. However, the attitude of mildly demented patients towards advance planning of their lives has rarely been explored. Our results indicate that their attitudes towards life are not significantly deviated from those of

Table 3. Attitude towards 'saving life by all means'.

	Highly agree (No. [%])	Agree (No. [%])	Disagree (No. [%])	Highly disagree (No. [%])	χ^2
Scenario 1					
NDG	10 (33)	4 (13)	7 (23)	9 (30)	8.47*
DG	16 (62)	5 (19)	4 (15)	1 (4)	
Scenario 2					
NDG	14 (43)	4 (13)	8 (27)	4 (13)	1.74
DG	13 (50)	59 (19)	7 (27)	1 (4)	
Scenario 3					
NDG	15 (50)	4 (13)	4 (13)	7 (23)	3.5
DG	14 (54)	7 (27)	3 (12)	2 (8)	

Abbreviations: NDG = non-demented control group; DG = demented group.

* p < 0.04.

Table 4. Feelings towards possible treatment outcome after making end-of-life decisions.

	Relieved No. (%)	Anxious No. (%)	Helpless No. (%)	No choice No. (%)	No special feeling No. (%)	Regret No. (%)	Unhappy No. (%)
Scenario 1							
NDG	7 (23)	5 (17)	2 (7)	4 (13)	9 (30)	2 (7)	1 (3)
DG	4 (15)	5 (19)	0	3 (11)	13 (50)	0	0
Scenario 2							
NDG	10 (33)	8 (27)	1 (3)	2 (7)	9 (30)	0	0
DG	4 (15)	6 (23)	0	7 (27)	9 (35)	0	0
Scenario 3							
NDG	15 (50)	3 (10)	1 (3)	2 (7)	9 (30)	0	0
DG	4 (15)	3 (12)	0	6 (23)	12 (46)	0	0

Abbreviations: *NDG* = non-demented control group; *DG* = demented group.

non-demented elderly of similar demographic background. It is encouraging to note that demented elderly (> 50%) showed positive attitudes towards the use of supportive therapy for prolonging life. One might have been assumed that demented elderly either will not endeavour to prolong their life or would not be able to make decisions due to intellectual impairment. On the contrary, they showed a similar level of preference as the non-demented elderly for further invasive treatment if supportive therapy failed. More than half of the demented elderly “agreed” that they should be treated with all methods available, compared with only one-third of the normal demented elderly; one-third of normal elderly chose the “highly disagree” response with regard to being saved aggressively. This ‘positive’ and ‘aggressive’ attitude in the demented group may reflect a genuine motivation for life. However, there is a possibility that the demented subjects were less able to appreciate the hypothetical scenarios from their personal perspectives. It was observed during the interview process that the elderly would often make choices as if they were making a choice for a friend; after being reminded to make choice as if undergoing the situation themselves, they would typically change their mind. Despite this, our results suggest that demented subjects retain a positive attitude towards life and do not readily give up their self-interest in health care.

Regarding emotional reaction after making ELD, both groups commonly expressed their feelings towards poor treatment outcome as “there are no special feelings” or “there is nothing much that one can do”. This could reflect different attitudes. Old people might have learnt to respond to certain changes in life with an accepting attitude. On the other hand, this may reflect a sense of learnt helplessness. Compared with the demented group, the non-demented group expressed additional feelings towards undesirable outcomes, such as feeling “relieved” if they knew they would not be treated too aggressively. While both groups of subjects would opt for supportive therapy to prolong life, they did not express much dissatisfaction should a poor outcome occur. This reflected a realistic expectation towards life and death, and adaptive adjustments towards adversities. The attitude toward ELD was different when faced with different clinical situations. In scenario 1, involving serious medical problems in a patient with advanced dementia, the attitude

was generally more conservative and the emotional response more pessimistic. For scenario 3, a demented patient faced with acute treatable surgical emergency, the attitude was more positive and active.

There are some limitations to our study. Most elderly participants were chosen from old age homes; in the Chinese culture, placement of parents in old age homes may (more or less) be a negative indicator for family relationships and happiness in family relationships. Conversely, those elderly living with their children might have more optimistic and active attitudes towards life. Another possible limiting factor is that the majority of participants were women. We are not sure if there are gender differences in the attitude towards making ELD. Elderly men may be more antagonistic towards invasive treatment, or value dignity more and prefer to die comfortably without intervention. Further studies with larger sample size will be able to explore this aspect. A further limitation would be related to the use of scenarios in the assessment. The use of scenarios may improve responses towards discussion on sensitive and emotional issues. The scenarios in this study have undergone pilot testing and modifications; the phrasing and expressions used simple language, to reduce potential ambiguity. However, it is still difficult to judge the extent to which subjects are able to place themselves into the situations in scenarios. This issue is especially relevant in demented subjects with compromised cognitive abilities. As the questionnaire aims to explore the attitudes and feelings of the elderly toward making ELD, it is reasonable to assume that the subjects were expressing the choice from their own emotional reactions. However, the ability to understand the nature of the scenarios and the complexity of response will reduce as dementia progresses. The same questionnaire may not be applicable to testing in subjects with moderate or severe dementia, or those with specific impairments in language. Finally, the small sample size limited the generalisability of the results.

This exploratory study presented some initial data regarding the attitude of a group of Chinese elderly in making ELD. It is hoped that this will initiate further research and discussion on the issue of care for demented elderly in the community. As the overall prognosis for demented patients to survive medical illness is poor, it would be helpful to

consider subjects' own attitudes early in the dementia process. The openness of the subjects in discussing ELD in this study is also a reminder to health care professionals that personal decisions for treatment should be duly considered and respected as much as possible.¹³⁻¹⁷

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Appendix I. Case scenarios.

Scenario 1

Mrs A was a 75-year-old housewife living with her husband. She was found to be suffering from dementia with progressive deterioration in everyday functioning. Her husband needed to accompany her all the time to avoid her getting lost. For the past two years, Mrs A's condition had deteriorated. She lost her ability to take care of herself and became incontinent. She slipped and fell about a year ago. After the operation for fixing her broken leg, she suffered from pneumonia and required nasogastric tube feeding.

Mrs A was then admitted to a care and attention home. Her general condition further deteriorated. She had contractures of limbs and was bedridden. She tried to pull out her nasogastric tube for a few times. The doctor commented that the prognosis was poor.

Scenario 2

Mrs B was a 75-year-old widow living with her son. One year ago, her children noticed that she became forgetful. Mrs B also felt that her memory was failing. For example, she would forget what she needed to do as soon as she entered the kitchen. Mrs B was diagnosed as suffering from Alzheimer's disease. She was still ambulatory and active. She attended a day care centre every day.

For the past few weeks, Mrs B was noted to pass blood in her stool. She was diagnosed to have middle phase cancer of the great intestine (colon). The doctor suggested resection of the tumour, but commented that there was no guarantee of a cure. Mrs B refused the operation, and her condition worsened.

Scenario 3

Mr C was an 80-year-old widower living with his daughter. He had experienced poor memory for a few years already. After assessment, Mr C was diagnosed to have dementia. His condition worsened with nocturnal confusion and poor self-care.

About a year before, Mr C was admitted to an old age home. He could not recognise his daughter and was rather quiet. One day, Mr C shouted in agony and was very restless. He was brought to the attention of the doctor. Acute appendicitis was diagnosed, and if an operation was not conducted shortly, his condition would deteriorate.