

# Attitudes to end-of-life decisions: a survey of elderly Chinese with dementia and their carers

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## ABSTRACT

**Objectives.** To explore attitudes to making end-of-life decisions (ELDs) in a group of elderly Chinese with dementia and their carers.

**Methods.** Four hypothetical case vignettes depicting different potentially life-threatening medical conditions in patients with dementia were presented. Subjects were interviewed about their treatment preferences and emotions after decision-making.

**Results.** Most subjects with dementia preferred to follow the 'natural' way. They accepted that it was their fate and felt at ease making ELDs. They had no regrets though a strong feeling of helplessness was observed. The carers had different views on different scenarios. They would consider possibility of saving life as well as the quality of life. Carers had mixed feelings after making ELDs. A sense of guilt and helplessness, as well as uncertainty about the choice, was a common finding.

**Conclusions.** Although the ability to express personal choices about ELD is impaired in people with advanced dementia, choices and feelings should be respected. The emotional burden imposed by the proxy decision carers who are forced to make should be acknowledged. Advance planning with collaborative decisions by people with dementia, their families, and health care professionals is recommended and may help to reduce the adverse emotions felt by relatives after making ELDs.

**Key words:** Caregivers; Dementia; Decision making; Life support care; Terminal care

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## INTRODUCTION

With increasing life expectancy, there has been an exponential increase in the need for dementia care. Patients with dementia suffer from progressive deterioration of their cognitive and physical functions. In the advanced stage, significant medical co-morbidity sets in and situations requiring end-of-life decisions (ELDs) are not uncommon. People with severe dementia, however, have lost the mental capacity required to make their own decisions on the choice of life-sustaining treatment. Apart from cognitive impairment, personal, carers, and cultural factors

may also affect decision-making.<sup>1-5</sup>

Unlike acute medical conditions that cause unexpected and unpredictable deaths, the need for ELD is more anticipatory for patients with dementia and their carers. Nevertheless, it is not uncommon for patients with advanced dementia to be hospitalised for treatment of medical conditions. A decision to forgo hospitalisation is not usually made until death is imminent.<sup>6</sup> In Chinese society death and related issues are seldom discussed openly. The issues surrounding arrangements for advance directives and the appointment of a proxy are practically untouched in most families. Family members of

dementia patients are frequently trapped in a dilemma when a difficult ELD is required without prior discussion with the elderly patients concerned. Health care professionals also have to face making difficult ELDs for elderly patients, frequently in the absence of any evidence of their wishes on these matters. A study conducted by Mezey et al<sup>7</sup> showed that spouses of patients with Alzheimer's disease anticipated forgoing life-sustaining treatment if those patients were comatose, but were less sure about the choices during a critical illness. Potkins et al<sup>3</sup> used treatment decisions in life-threatening situations to inquire into the impact of key variables on ELD and found that the carers were not influenced by key disease variables. The choice of ELD may be influenced by significant social and cultural factors and these factors may influence decision-making in both demented subjects and their carers. In this exploratory study, we aimed to evaluate the treatment preferences selected and the emotional responses induced by making ELDs in a group of Chinese people with dementia and their carers.

## METHODS

### Participants

Fourteen elderly people with dementia and 26 carers were interviewed at psychogeriatric clinics in New Territories East Cluster Hospitals in Hong Kong. Both people with dementias and their carers were recruited. Subjects with dementia were diagnosed as suffering from mild dementia by attending psychiatrists, using the standard criteria. They were also assessed clinically for the mental competence and emotional stability needed to participate in the research assessment. All subjects suffered from clinically mild dementia, had Mini-mental State Examination scores of over 15, and relatively intact language skills. The dementia carers were family members who accompanied demented elders to the clinic. Elderly people with dementia and their carers were not matched in pairs, as the attitude of the two groups was evaluated separately. The interviews were only conducted after the patients and their carers gave written, informed consent. The carers also completed a General Health Questionnaire (GHQ-12) to screen for possible underlying psychological distress and morbidity.<sup>8</sup>

The interviews were conducted from October 2004 to February 2005.

People with dementia were represented by the capital E and their carers by a capital R; a number was attached after the subject grouping for easier identification. For example, the first person with dementia interviewed was E1; likewise, R1 for carer number 1, etc. Of the participants with dementia, 10 (71%) were women; most (64%) were aged between 70 and 79 years; half were Christian; eight (57%) received only primary education and three (21%) had tertiary education; 11 (79%) lived with their family. Of the carers, 18 (69%) were women and half were aged 40 to 49 years; 22 (85%) had no religion; 11 (42%) received secondary education, 10 (38%) had 2 years or more primary education, and four (15%) received tertiary education. Ten (38%) carers had been caring for the patients for over 10 years, another five (19%) had been involved for over 2 years (Table).

### Assessment

Four case scenarios depicting different situations requiring ELD were developed. A focus group consisting of geriatric psychiatrists, an occupational therapist, a nurse and social workers was formed to review the applicability of the scenarios used to examine the ELD made about elderly people with dementia. The vignette technique allows participants to express their views about potentially threatening issues with reference to a non-personal story.<sup>9</sup> It was felt that this might be a more effective way of evaluating sensitive issues among Chinese people with conservative attitudes.

Four scenarios were developed. Each scenario represented a potential dilemma requiring an ELD. In scenario A, the patient was suffering from severe dementia and multiple medical complications. The decision was to choose between oral and tube feeding in order to prolong survival. In scenario B, a patient suffering from early dementia was diagnosed with advanced endometrial cancer. Scenario C described a person with moderate dementia and potentially treatable carcinoma of the prostate. In scenario D, a person with severe dementia had an easily treated acute surgical condition (acute appendicitis). Participants were requested to indicate their treatment preference for each scenario and to express

**TABLE**  
**Demographic characteristics of people with dementia and carers**

| Characteristic    | People with dementia (n=14) | Carers (n=26) |
|-------------------|-----------------------------|---------------|
| Female:male       | 10:4                        | 18:8          |
| Age (years)       |                             |               |
| 20-39             | 0                           | 2             |
| 40-59             | 0                           | 19            |
| 60-79             | 10                          | 4             |
| ≥80               | 4                           | 1             |
| Religion          |                             |               |
| Christianity      | 7                           | 3             |
| Buddhism/Taoism   | 7                           | 1             |
| Nil               | 0                           | 22            |
| Educational level |                             |               |
| <2 years          | 2                           | 1             |
| 2-6 years         | 8                           | 10            |
| 6-12 years        | 1                           | 11            |
| Tertiary          | 3                           | 4             |

the feelings generated by making their decisions. A semi-structured questionnaire was used to obtain the information required. All responses were audiotaped, with the consent of the participants, for subsequent data analyses. The study was approved by the institutional ethical review board and the objectives of the study were explained to the respondents who were also alerted to the possible emotional upset that could be brought about by touching on end-of-life issues.

### Data analysis

The semi-structured questionnaire was analysed using both quantitative and qualitative approaches. A quantitative approach was used to evaluate treatment preferences and major emotional responses after decision-making. Chi-square tests were used to compare differences between the responses to scenarios and between different subject groups. The Statistical Package for the Social Sciences Windows version 10.0 was used to carry out the quantitative data analysis. A p value of 0.05 was considered significant. For open-ended questions, all taped data were transcribed and translated by a trained assistant. The data were then ordered and the conversation coded according to the response sequence. Recurrent themes were highlighted. A colour code system was used to highlight significant statements. Expressions associated with the feelings generated in participants

by making the ELD were extracted. Major themes were identified and compared.

## RESULTS

### Treatment preferences

#### *People with dementia*

In scenario A, 10 (71%) preferred oral feeding, two (14%) preferred tube feeding and two (14%) had no comments. When further information about the potential risks of oral feeding was presented, four (40%) elderly people who had opted for oral feeding changed to more aggressive treatment. The choice of tube feeding was significantly higher in men (Pearson chi-square=5.31, df=1, p<0.05). In scenario B, eight (57%) preferred an operation; five (36%) opted for conservative treatment with medication only, and one (7%) had no comment. When further information about the potential risks of deterioration with conservative treatment was given, two (40%) who previously opted for conservative treatment changed their decision. In scenario C, seven (50%) opted for an operation; five (36%) selected drug treatment and two (14%) had no preference. When further information about the potential risks of conservative treatment was given, three (60%) who previously opted for drug treatment changed their decisions. In this scenario about prostate carcinoma, the choice of supportive treatment was significantly

higher in men (Pearson chi-square=4.00,  $df=1$ ,  $p<0.05$ ). In scenario D, nine (64%) opted for an operation; three (21%) preferred drug treatment, and the remaining two (14%) gave no clear decision. When further information about the potential risks of conservative treatment was given, two (67%) of those who previously opted for drug treatment changed their decision and chose more aggressive treatment. The subjects preferred surgery significantly more frequently than conservative treatment (Pearson chi-square=8.00,  $df=2$ ,  $p<0.05$ ).

### **Carers**

For scenario A, 20 (77%) carers preferred oral feeding and six (23%) chose tube feeding. When further information about the potential complications of oral feeding was given, 15 (75%) participants who previously opted for oral feeding changed their decisions. For scenario B, 15 (58%) preferred drug treatment, 10 (38%) chose an operation, and one (4%) made no comment. When further information about the potential risks of treatment was given, six (40%) of the participants who had opted for non-invasive treatment changed their decision. Conservative treatment was chosen significantly more frequently than an operation (Pearson chi-square=11.62,  $df=2$ ,  $p<0.01$ ). For scenario C, 15 (58%) opted for drug therapy and 11 (42%) chose an operation. When further information about the potential risks of conservative treatment was given, seven (47%) participants changed their decision. There was no significant difference between the numbers who chose hormonal therapy and those who chose an operation (Pearson chi-square,  $p>0.05$ ). In scenario D, 23 (88%) chose surgery whereas three (12%) opted for drug therapy. When further information about the potential risks of conservative treatment was given, two (67%) who previously opted for drug therapy changed their decision, while one respondent maintained his decision. An operation was chosen significantly more often than non-invasive treatment (Pearson chi-squared=15.39,  $df=1$ ,  $p<0.01$ ).

### **Comparisons between people with dementia and carers on treatment preferences**

For scenario A, significantly more carers than people with dementia opted for supportive treatment (Pearson chi-square=6.55,  $df=2$ ,  $p<0.05$ ). For scenarios B and C, there were no significant differences in the treatment preferences selected by people with dementia and

the carers (Pearson chi-square,  $p>0.05$ ). In scenario D, both groups preferred surgical treatment. There was no significant difference in treatment choice.

In both groups, age, educational levels, and duration of dementia care (for carers only) had no significant influences on treatment preferences (Pearson chi-square,  $p>0.05$ ). General Health Questionnaire was measured to screen for psychiatric morbidity in the carers. Twelve (46%) carers scored above the cut-off score, showing some evidence of mood depression. There were no significant differences in treatment preferences between carers who scored above or below the GHQ cut-off level (Pearson chi-square,  $p>0.05$ ).

For scenarios A and B, all participants with dementia considered that the illness burdened their family and 12 (86%) felt that the illness depicted in scenarios C and D was a burden. For scenario A, 21 (81%) of the carers considered that care of the afflicted elderly person was a burden. For scenario B, 24 (92%) opined that it was a burden and 23 (88%) and 22 (85%) thought that it was a burden in scenarios C and D respectively.

## **Qualitative analyses**

### **People with dementia**

#### **Central themes identified in relation to 'treatment preference'**

Four main themes could be identified, which included 'ending life', 'follow the natural way', 'save life as much as possible', and 'too old to receive any treatment'. Some participants indicated a strong intention of 'ending the life' to avoid causing a burden to the family, to shorten suffering and pass away peacefully. One had a strongly negative feeling towards life. In her view, life is meaningless without a clear mind. She considered it useless to receive invasive treatment for scenario D as the patient had in fact lost the mind already. One considered that ending life was a relief when suffering from an incurable physical disease with severe dementia. She expressed a feeling of helplessness towards life. E8 emphasised that if the pain could not be relieved in all the four scenarios, he would plan to kill himself to avoid being a burden. He considered it important to pass away peacefully without any pain. E10 opined that he did not want to become a burden to others for serious problems in scenario A but when it came

to scenario D, he would try all treatment alternatives. He indicated that being alive with incurable disease was a nightmare and death would be a relief. E4 refused to accept any kind of treatment owing to 'old age'.

E3, and E12 to E14 preferred to 'follow the natural way'. If the disease was curable, they agreed to receive treatment but would prefer no treatment if the disease was not curable. E12 wanted to follow the natural course of life and death. In all four scenarios, he considered that there was no need for extra medical interventions to prolong life. E13 emphasised the educational value, considering the care given to him would set a good example of filial piety to the next generation. E14 said that he did not mind if he were going to die soon but felt that if his children were willing to take care of him, he would like to live longer. The option to 'save life as much as possible' was expressed by two participants. E1 felt strongly that all possible treatment alternatives should be used to cure the disease in all four scenarios. E5 strongly agreed to save life by all means. He preferred non-invasive treatment but would change his mind if his condition deteriorated.

### **Central themes in relation to 'feelings after decision-making'**

After decision-making, most subjects felt relieved. The reasons included feelings that 'everyone will die eventually, it is a matter of time', 'everyone has his own destiny, having a life of many decades is more than enough', 'don't worry too much', and 'follow the natural way'. Most subjects had no feelings of regret, though a strong feeling of helplessness was observed. For some patients, 'feel relieved' meant pass away because they no longer needed to worry about anything. Some only felt regret when they were afraid that the illness might drag on after treatment, making them and their family members suffer longer.

### **Carers**

#### **Central themes on 'treatment alternatives'**

Four main themes could be identified, which included 'ending life', 'follow the natural way', 'save life as much as possible', and 'mixed preferences'. Two rationales were offered for 'ending life': to avoid suffering and the participant's inability to take care of the patient. In scenario A, R22 considered that the best solution is euthanasia so the elderly person

would suffer less. R26 thought that he was too old to take care of his wife. If his wife were suffering from the condition in scenario A, he would not choose any treatment to extend her life. Carers who considered the option 'save life as much as possible' were of the view that every alternative should be exhausted (R5, R7, and R17). R16, R18, R23, and R25 agreed to use all possible treatment alternatives. R25 said that this decision was similar to making a bet irrespective of the chance of winning. R8 opined that it was the responsibility of the children to take care of their parents. It is interesting to note that R9 opined that as euthanasia was not allowed in Hong Kong, she had no alternative but to choose supportive treatment instead.

It was noted that most carers had different views in different scenarios. Carers also took into consideration elderly people's quality of life. R1 emphasised the quality of life, consciousness, and happiness of the elderly person and supported treatment for all scenarios on the condition that these treatments would improve quality of life. R2 and R12 did not want elderly people to suffer and considered that invasive treatment should be given for the potentially curable disease in scenario D. R3 preferred only supportive treatments to make the elderly person feel more comfortable. R6 and R11 insisted on using all possible invasive treatments able to extend the life of the elderly person in all scenarios. R6 did not prefer supportive treatment when the elderly person had no chance of recovery. R13 considered the importance of the dignity and quality of life.

### **Central themes on the 'feeling after decision-making'**

Most carers had mixed feelings towards the decision-making. The following is a qualitative analysis of the carers' feeling after decision-making. A few themes were identified and were broadly categorised as 'feeling helpless and guilty', 'relieved', and 'no feeling'. A 'feeling of helplessness' arises when the carers believe they cannot help. R8, R15, R23, R24, and R25 expressed similar feelings. R2 felt guilty in all scenarios. She expressed guilty feelings because she considered that she could do more for her adopted mother. R10 had a feeling of helplessness for scenarios A, B, and C. She felt that reduction of pain so that the patient could pass away peacefully was more practical. Carers were also not sure whether the

decision made was in the best interests of the patient. They felt unsure about the decision because they did not possess the medical knowledge needed to formulate a sound decision. R1 felt helpless because she did not know whether her decision would help. R11 was afraid that she would be blamed by others if her decision was wrong. Many carers felt relieved after decision-making. R9 and R26 felt relieved because they believed that their decision would help to reduce the suffering of the patient. R16 relied on the decision of the doctor, which was considered trustworthy and in the best interests of the patient. R17, R18, and R19 felt relieved because they had tried all possible alternatives, although they were not able to alter the outcome. R20 felt relieved because his decision was in accordance with the instructions of the patient. Two carers expressed 'no special feelings' towards their decision-making. R4 felt no regrets and no guilt. R21 had no special feelings about the decision but believed the most important thing was allowing the patient to pass away peacefully.

## DISCUSSION

The progressive deterioration of cognitive and physical functions in patients with dementia mean ELDs are frequently required. The respect for personal choice and the adoption of proxy consents are related to both personal factors and societal expectations.<sup>8-12</sup> This study attempted to evaluate the highly sensitive issues raised when discussing life-and-death issues in the Chinese population. The small sample size precluded detailed statistical analyses, so the possibility of type 2 errors should be acknowledged. Moreover, the responses of matched pairs of people with dementia and their carers were not evaluated due to the small sample size. Despite these limitations, the findings offer some useful hints for future work. Most Chinese subjects with dementia wished to follow the 'natural way' when making ELDs. They accepted that it was their fate and felt at ease. There was no feeling of regret though a sense of helplessness was observed. Some said that they had lived long enough and did not regret leaving. Most subjects indicated they preferred to pass away peacefully, and, in the words of the carers, with dignity and without suffering. It is also interesting to note that after decision-making, most of the elderly people and carers felt relieved.

Most people with dementia and carers considered the conditions described in the scenarios a burden

to the family. Some people with dementia said they would forgo treatment to avoid becoming a burden. This was especially obvious for scenario A when a severely medically compromised patient with advanced dementia was presented. They said they would prefer to end their life to relieve the pain and to avoid being a burden to others. This finding was consistent with a recent study that found terminally ill men were concerned about becoming dependent and burdening loved ones during the process of active dying and death.<sup>13</sup>

On the other hand, in a study of caregiving in Hong Kong Chinese families with chronically dependent members, Mackenzie and Holroyd<sup>14</sup> found caring to be complex and burdensome. Despite continuous contact, the person with dementia may not be able to recognise their loved ones. The associated behavioural and psychological symptoms of dementia also significantly increase carers' distress. The ambivalence of the obligation to provide continuing care and the need for relief was reflected in the mixed feelings expressed after making ELD. Forbes et al<sup>15</sup> also found the strongest emotional distress was experienced by family members in their roles as decision makers. The decision was frequently made within an emotional context of overwhelming burden and underlying guilt, particularly in face of personal inadequacy and uncertainty over whether their choice was made in the best interests of the person with dementia. It is unusual for elderly Chinese people and their relatives to talk about death, even when the elderly person is seriously ill. Advance directives on ELD are highly uncommon. As dementia is associated with progressive deterioration in cognitive function, it may not be feasible for a demented subject to make personal decisions for himself/herself. When patients are no longer capable of making decisions, proxy opinions of family members are frequently sought. Apart from uncertainty about the medical basis upon which ELD should be made, the informal carers may not be certain of the patient's mental capacity to make decisions. Such uncertainty can cause anxiety and should be properly addressed. Health care professionals should be sensitive about providing carers with sufficient information on the different treatment options to facilitate their decision-making.<sup>16-18</sup>

One interesting observation is that both the elderly people and the carers gave high priority to the potential curability of the medical conditions,

while the severity of dementia did not influence decision-making. The notion of a poor prognosis and shortened survival for medical co-morbidity in patients with dementia was not readily perceived and considered.<sup>19,20</sup> This apparent lack of awareness of the nature of dementia may indirectly affect the choice of ELD. Although most subjects preferred 'the natural way' and did not report strong negative emotion towards death, the need to lead a dignified ending for life was the most important issue for both the people with dementia and the carers. With the increasing survival of people with advanced dementia, there is a pressing need to enhance community understanding of palliative care. A multi-disciplinary approach to adequate planning for ELD in people with advanced dementia is the best way to protect the interests of the patients.<sup>21-23</sup> Health care professionals also need to be prepared for and alerted to personal factors that may influence the decision-making of the patients they are caring for.<sup>24-26</sup>

In this exploratory study, elderly Chinese people with dementia reflected their quest for a peaceful, but quality end of life. The mixed emotions expressed by the carers when making ELD highlighted the distress brought on by the caring process. Although there may be differences in cultural values and priorities, the need for advance planning for palliative care for people with dementia is equally important worldwide.

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