

JCY Lee 李頌賢  
PP Chen 曾煥彬  
JKS Yeo 楊啟心  
HY So 蘇慶餘

# Hong Kong Chinese teachers' attitudes towards life-sustaining treatment in the dying patients

## 香港華人教師對垂死病人使用維生器的態度

**Objective.** To evaluate the attitudes of Hong Kong Chinese teachers towards life-sustaining treatment in the dying patients.

**Design.** Prospective structured questionnaire survey.

**Setting.** Hong Kong Institute of Education.

**Subjects and methods.** All teaching staff at the Hong Kong Institute of Education were sent the survey questionnaire. The questionnaire gathered demographic data, information on experience of 'life and death' decision-making, and views on life-sustaining treatment decisions. Respondents were also requested to respond to statements on life-sustaining treatment using a 5-point Likert Scale (1 representing strong disagreement and 5 representing strong agreement).

**Results.** A total of 436 questionnaires were sent to teaching staff at the Hong Kong Institute of Education. The response rate was 27.8%. More than half (65.8%) of the respondents were aged between 30 and 49 years. There was an equal proportion of men and women among respondents. The respondents agreed with statements supporting end-of-life decisions (mean aggregate score, 3.13; standard deviation, 1.24;  $P < 0.0001$ ), and disagreed with statements against such decisions (mean aggregate score, 2.81; standard deviation, 1.22;  $P < 0.0001$ ). If the patient is competent, half of the respondents agreed that the patient alone should make the decision, while 27.2% believed that it should be a joint decision made by the patient, the family, and the doctor. Conversely, if the patient is incompetent, 52.6% agreed that it should be a joint decision made by the family and the doctor. There was strong support for advanced directives, whereby decisions in relation to life-sustaining treatment were legally recorded in advance (mean score, 3.62;  $P = 0.0001$ ).

**Conclusion.** The teachers in this survey appear to support the practice of withdrawing and withholding life-sustaining treatment in the dying patients when medical treatment is considered futile. Although patient autonomy in decision-making was supported by the greatest number of respondents, joint decision-making by the patient, family members, and doctors was also favoured by a substantial group. There was strong support for the use of advanced directives with respect to life-sustaining treatment.

### Key words:

Euthanasia, passive;

Life support care;

Questionnaires;

Withholding treatment

### 關鍵詞：

安樂死，被動；

生命支持醫護；

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Department of Anaesthesiology, Intensive Care and Operating Services, Alice Ho Miu Ling Nethersole Hospital, 11 Chuen On Road, Tai Po, Hong Kong

JCY Lee, MB, ChB

PP Chen, FANZCA, FHKAM

(Anaesthesiology)

JKS Yeo, FANZCA, FHKAM

(Anaesthesiology)

HY So, FFICANZCA, FHKAM

(Anaesthesiology)

Dr JCY Lee is now affiliated with the Department of Anaesthesia and Intensive Care, Tuen Mun Hospital, Tuen Mun, Hong Kong

Correspondence to: Dr PP Chen

**目的：**評估香港華人教師對垂死病人使用維生器的態度。

**設計：**預期問卷調查。

**安排：**香港教育學院。

**對象和方法：**邀請香港教育學院的教員填寫問卷。問卷內容包括人口統計數據、經歷生死決擇的資料、及對使用維生器的觀點。教員還需用 Likert Scale 表達對有關維生器治療的看法：1 表示非常不讚同，5 表示非常讚同。

**結果：**共發出436張問卷予香港教育學院的教員；回覆率為27.8%。交回問卷的教員中，超過一半(65.8%)年齡在30至49歲之間，男女比例相同。對有關維生器的使用，讚同對垂死病人停止使用維生器的決定(平均集合分，3.13；標準偏差，1.24； $P < 0.0001$ )，不讚同對垂死病人停止使用維生器的決定(平均集合分，2.81；標準偏差，1.22； $P < 0.0001$ )。假如患者有能力作出決定，半數教員同意患者應自行作出決定，而27.2%相信應該由患者、家屬和醫生一起作出決定。相反，如果患者沒有能力作出決定，52.6%同意應該由家屬和醫生一起作出決定。此外，教員一般表示強烈支持使用臨終醫囑，使有關使用維生器的決定預先有法律紀錄(平均分，3.62； $P = 0.0001$ )。

**結論：**交回問卷的教員都支持當醫療無效時，應對垂死患者停止使用維生器。雖然大多數教員支持患者應自行作出決定，但仍有不少教員表示應由患者、家屬和醫生一起作出決定。結果亦顯示教員普遍支持使用臨終醫囑來決定應否使用維生器。

## Introduction

Developments in medical technology have led to a misconception in society that death can almost always be postponed. Although medical advances can be life-saving, sometimes they are only able to temporarily sustain life, rather than to restore the patient to health. This may lead to prolongation of the dying process, increasing suffering for patients and their family, as well as creating a considerable financial burden for the health care system.

The concept of withholding and withdrawing life-sustaining treatment differs from euthanasia, and is ethically acceptable and legal in situations where further medical treatment is deemed futile for the restoration of normal physiological function.<sup>1-3</sup> In contrast, euthanasia refers to a direct action with the intention to end the life of the patient.<sup>3,4</sup> Euthanasia is unlawful in most jurisdictions, including Hong Kong. The ethical distinction between withholding and withdrawing life-sustaining treatment, and euthanasia is complex, and has been fervently debated.

Numerous studies have investigated public attitudes towards life-sustaining treatment.<sup>5-7</sup> However, there remains significant disagreement over the role of the physician, patient, and the patient's family in making the decision to limit life-sustaining treatment.<sup>8</sup> One reason underlying the disagreement between surveys from different countries is that public attitudes are influenced by cultural beliefs and values, ethnicity, and religion.<sup>5</sup> Consequently, different guidelines on this issue have been promulgated, taking into account the local context.<sup>9-17</sup> Current practice with respect to limiting life-sustaining treatment in the dying patients in Hong Kong is based predominantly on western experience. Local data on public attitudes towards this issue are limited. Guidelines on life-sustaining treatment in the terminally ill patients have recently been published by the Hospital Authority in Hong Kong.<sup>2</sup> The guidelines emphasise the clinical decision-making process involved in considering the withholding and withdrawing of life-sustaining treatment, and represent one of the first major documents focusing on end-of-life issues written in Hong Kong.

Local public attitudes towards end-of-life issues such as the withholding and withdrawing of life-sustaining treatment, however, remain to be defined. End-of-life decisions, including euthanasia, are sensitive issues, especially among the more conservative Chinese people. Traditional beliefs and values often lead to matters relating to death being taboo. As a result, little attention has focused on assessing the attitudes of the local population on these issues. There has been only one recent local survey, and this reported the attitudes of the Hong Kong public and doctors specifically towards euthanasia.<sup>18</sup>

The role of the teaching profession provides teachers with considerable influence in shaping Hong Kong society. The impact of teachers' views and beliefs on many aspects of life, including attitudes towards end-of-life issues, is therefore important. Teachers comprise an educated group, likely to be relatively well-informed on the issue of withholding and withdrawal of life-support for dying patients. In addition, teachers are a diverse group, with different backgrounds and social experience, thus they could be expected to be representative of educated Chinese people in the local population. Therefore, a survey was designed to evaluate local teachers' attitudes towards life-sustaining treatment in the dying patients, and to examine factors associated with these attitudes. The study focused on the withholding or withdrawal of life-sustaining treatment only, and not on the issue of euthanasia.

## Subjects and methods

The teaching staff at the Hong Kong Institute of Education (HKIE) located in Tai Po were surveyed. The HKIE is a publicly funded, tertiary institution providing degree and non-degree undergraduate and postgraduate education and training to teachers and educators.

Two weeks prior to the commencement of the study, a notice was placed on the Institute's electronic bulletin board to publicise the purpose of the survey. Four hundred and thirty-six questionnaires were then delivered through the internal mailing system to all teaching staff at HKIE. All participants were requested to complete and return the questionnaire, either through the postal system in a stamped envelope addressed to the author, or by placing the questionnaire in a sealed box placed at the staff health clinic located at the main entrance of the Institute. The box was emptied every 2 weeks for a period of 8 weeks. At the end of the second week, a reminder to return the questionnaire was sent to all HKIE teaching staff through their Intranet e-mail addresses. In the reminder, staff were invited to request a replacement questionnaire by electronic mail if required, and advised that they may return the completed questionnaire by e-mail. All questionnaires returned within the 2-month study period were included in the analysis.

### *The measurement tool*

The questionnaire was adapted from a previously published study<sup>5</sup> and translated into Chinese by the authors. It consisted of 22 items in three parts. Part 1 gathered demographic data concerning the respondent, while Part 2 explored their personal experience with 'life and death' decision-making. Views on life-sustaining treatment decisions were examined in Part 3. Each item in Part 3 of the questionnaire consisted of a statement. The respondent was asked to respond to

the statement using a 5-point Likert Scale. A score of 1 represented strong disagreement with the statement, 2 represented moderate disagreement, 3 was neutral, 4 represented moderate agreement, and 5 represented strong agreement.

The Chinese version of the questionnaire was tested for validity and reliability. The content validity of the questionnaire was evaluated by subjecting the initial translated version to the scrutiny of three medical experts with experience in managing patients receiving life-sustaining treatment. The internal consistency of the three sub-scales was examined with reference to the Cronbach alpha obtained for a group of doctors. Reliability was also evaluated using the test-retest method, with 20 operating theatre nurses completing the questionnaire twice over a 2-week period. Pearson's correlation coefficients were determined for each part of the test.

Parts 1 and 2 of the questionnaire were essentially descriptive. For Part 3, which examined the views and attitude of the respondents, mean scores were calculated for each question. As a score of 3 was considered neutral, a mean score in either direction from 3 showed the trend either in agreement or disagreement with each statement, that is, disagreement if less than 3, and agreement if greater than 3. The non-parametric Sign test was employed to detect any significant trend in the respondents' attitudes towards each statement about life-sustaining treatment.

Univariate analysis using the Chi squared test was performed to determine whether any of the factors in Parts 1 and 2 influenced the views and attitudes of the respondent to the items in Part 3, and regression analysis to explore significant factors was planned, as appropriate. All P values less than 0.05 were considered significant. Statview for Windows, version 4.53 (Abacus Concepts Inc., California, US) was used for the one-group Sign test, and Statistical Package for the Social Sciences (Windows version 10.0; SPSS Inc., Chicago, US) was used for the remainder of the statistical analysis.

## Results

Content validity was established with all three experts agreeing with all the questions in the instrument. Evaluation of internal consistency showed the Cronbach alpha for Part 1 was 0.410, Part 2 was 0.923, and Part 3 was 0.783. Overall, the Cronbach alpha for the survey instrument was 0.829. Test-retest reliability was evaluated for Parts 2 and 3 of the questionnaire. The Pearson's correlation coefficients were 0.802 ( $P=0.103$ ) and 0.833 ( $P=0.003$ ) for Parts 2 and 3, respectively. Overall, the Pearson's correlation coefficient for the instrument was 0.926 ( $P=0.0001$ ).

A total of 121 (27.8%) questionnaires were returned at the end of the survey period but only 114 were considered valid for analysis. Seven incomplete questionnaires were excluded. The respondents' demographic profiles are shown

**Table 1. Demographic profiles of questionnaire respondents (n=114)**

| Characteristic             | Respondents No. (%) |
|----------------------------|---------------------|
| Age (years)                |                     |
| 20-29                      | 6 (5.3)             |
| 30-39                      | 21 (18.4)           |
| 40-49                      | 54 (47.4)           |
| 50-59                      | 22 (19.3)           |
| 60-69                      | 1 (0.9)             |
| Missing data               | 10 (8.8)            |
| Sex                        |                     |
| Male                       | 55 (48.2)           |
| Female                     | 59 (51.8)           |
| Religion                   |                     |
| Catholic                   | 10 (8.8)            |
| Protestant                 | 30 (26.3)           |
| Buddhist                   | 5 (4.4)             |
| None                       | 66 (57.9)           |
| Other                      | 3 (2.6)             |
| Living arrangements        |                     |
| Lives alone                | 9 (7.9)             |
| Lives with parents         | 8 (7.0)             |
| Lives with spouse          | 30 (26.3)           |
| Lives with siblings        | 1 (0.9)             |
| Lives with children        | 5 (4.4)             |
| Lives with other relatives | 1 (0.9)             |
| >1 of the above            | 60 (52.6)           |

in Table 1. More than half (65.8%) of the respondents were aged between 30 and 49 years. There were equal proportions of men and women. Fifty-eight percent of respondents did not have any specific religious affiliation. Most respondents lived with one or more family members.

Of the respondents, 21.1% had some experience with chronic illness requiring continuing medical care. Although only three (2.6%) respondents had personal experience of treatment in an intensive care unit, 51% had a family member or friend who had been treated in an intensive care unit. A total of 8% of respondents had previously been required to make an end-of-life decision for a family member or friend. No respondent had previously been required to make any end-of-life decision for themselves.

The attitudes towards end-of-life decisions in cases where treatment is ultimately futile are summarised in Table 2. Overall, the mean scores indicated the respondents' support for the withholding or withdrawal of life-sustaining treatment. The mean aggregate scores for statements supporting (items 3, 5, 6, 9, 10) and against (items 1, 2, 4, 7, 8) end-of-life decisions in dying patients were 3.13 (standard deviation [SD], 1.24;  $P<0.0001$ ) and 2.81 (SD, 1.22;  $P<0.0001$ ), respectively. Most respondents did not wish to have their own lives prolonged by life-sustaining machines if their medical condition was hopeless (item 8,  $P=0.0002$ ).

There was strong support for the use of prior directives to guide decision-making for life-sustaining treatment. Sixty-nine percent of respondents agreed that every patient should make an advance decision on whether to continue life-support treatment (item 9; mean score, 3.62;  $P=0.0001$ ) when approaching death.

**Table 2. Attitudes towards life-sustaining treatment among respondents (n=114)**

| Statements*                                                                                                                                                                                            | Mean <sup>†</sup> (SD) | P value | Attitude <sup>‡</sup> |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------|---------|-----------------------|
| 1. If life-prolonging technology exists, it should always be used. (-)                                                                                                                                 | 2.98 (1.30)            | 0.172   | Agrees                |
| 2. Doctors should generally try to keep their patients alive on machines for as long as possible, no matter how uncomfortable the machines are. (-)                                                    | 2.81 (1.11)            | 0.027   | Agrees                |
| 3. If a patient is expected to die, it is best not to prolong their lives by any means. (+)                                                                                                            | 2.61 (1.26)            | 0.011   | Disagrees             |
| 4. Under no circumstance should life-sustaining machines be stopped. (-)                                                                                                                               | 2.90 (1.22)            | 0.115   | Agrees                |
| 5. It is a doctor's duty to stop life-prolonging treatments of patients if a patient does not want them anymore. (+)                                                                                   | 3.27 (1.13)            | 0.024   | Agrees                |
| 6. When a person is in a vegetative state, medical treatments should not be used to keep them alive. (+)                                                                                               | 2.80 (1.23)            | 0.089   | Disagrees             |
| 7. If a patient is unable to breathe without a breathing machine, it would be wrong to take them off the machines (even if the condition is hopeless) because that would be killing the patient. (-)   | 2.77 (1.19)            | 0.054   | Agrees                |
| 8. Even if my condition is hopeless, I would want my life prolonged as much as possible, even if it requires life-sustaining machines to keep me alive. (-)                                            | 2.57 (1.23)            | 0.0002  | Agrees                |
| 9. Every patient should make an advance decision for himself/herself whether to continue life-support treatment (life-sustaining machines) when treatment is futile and he/she is expected to die. (+) | 3.62 (1.09)            | 0.0001  | Agrees                |
| 10. Someone (doctors, patients, or relatives) should make the decision whether to continue the life-support treatment for the patient when all the medical therapy is no longer effective. (+)         | 3.34 (1.22)            | 0.0003  | Agrees                |

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

<sup>†</sup> Tendency to disagree with the statement if the score <3 and agree if >3, 3 being neutral

<sup>‡</sup> Overall attitudes towards withholding and withdrawal of life-sustaining treatment

Half of the respondents agreed that the patient alone should make the decision regarding life-sustaining treatment if competent to do so. Another 27.2% believed that it should be a joint decision between the patient, the family, and the doctor (Table 3). If the patient was not competent to make the decision, 52.6% agreed that it should be a joint decision between the patient's family and the doctor, while 11.4% agreed that the decision-making by a family member alone was adequate.

Univariate analysis of factors in Parts 1 and 2 suggested that who the respondent lived with influenced attitudes towards decisions on end-of-life treatment. This factor significantly affected the response to item 3 ( $P=0.034$ ) and item 5 ( $P=0.049$ ). Regression analysis was not performed.

## Discussion

The study results show that teachers in this survey support the principle of withholding and withdrawal of

life-sustaining treatment when the patient's prognosis indicates probable death. In this questionnaire, the futility of treating the medical condition itself was not specified, and consequently quality of life considerations and other value judgements may have influenced some responses. This is illustrated in the respondents' disagreement with item 3 ("if a patient is expected to die, it is best not to prolong their lives by any means") which may reflect the generality of the statement with respect to a patient's condition.

A recent local survey of euthanasia reported that the general public tended to support the request for euthanasia, compared to the limitation and withdrawal of treatment.<sup>18</sup> The authors attributed this to the Hong Kong culture where efficiency is emphasised, and considered that respondents in that survey were more concerned with the consequences of the action rather than the moral or ethical implications. In our survey, questions relating to euthanasia were not included but the results showed that although the teachers supported the practice of withholding and withdrawal of treatment in a futile situation, they were not in favour of limiting life-sustaining treatment for patients in a vegetative state (item 6). The respondents recognised that a patient in a vegetative state does not face imminent death and can remain in a coma for some time, thus different principles may guide ethical care in this situation. These results suggest concern, not only with the consequences, but possibly also the moral implications of decisions made.

Unlike previous studies, age, sex, educational level, personal experience, and religious beliefs, were not shown to significantly affect respondents' attitudes to end-of-life decisions.<sup>5,18</sup> Blackhall et al<sup>5</sup> found that men, people with particular religious beliefs, Korean-Americans, and people with a low educational level were more likely to agree with the use of life-sustaining technology for people close to

**Table 3. Respondents' views on appropriate decision-makers for withholding or withdrawal of life-sustaining treatment (n=114)**

| Decision-makers                    | Respondents<br>No. (%) |
|------------------------------------|------------------------|
| Conscious and competent patient    |                        |
| Patient alone                      | 57 (50.0)              |
| Patient and family                 | 12 (10.5)              |
| Patient and doctors                | 9 (7.9)                |
| Patient, family, and doctors       | 31 (27.2)              |
| No one should make the decision    | 2 (1.8)                |
| Not sure                           | 2 (1.8)                |
| Others                             | 1 (0.9)                |
| Unconscious or incompetent patient |                        |
| Doctors                            | 5 (4.4)                |
| Patient's family alone             | 13 (11.4)              |
| Patient's family and doctors       | 60 (52.6)              |
| No one should make the decision    | 25 (21.9)              |
| Not sure                           | 8 (7.0)                |
| Others                             | 3 (2.6)                |

death, while people with personal experience of illness and withholding of medical care were less supportive. Similarly, respondents in a local survey were more likely to disagree with terminating life-sustaining treatment if religious belief was important.<sup>18</sup> On the other hand, people with personal experience of caring for terminally ill patients were more likely to disagree with life-sustaining treatment. This is likely to be related to their experience of the suffering of loved ones and the associated burden of care.

The current study appeared to suggest that who respondents live with may affect their attitudes towards decisions to prolong life in the dying patients. This might reflect the traditionally strong support and influence of the family in Chinese society. Closer examination, however, showed the results to be contradictory, since respondents living alone, as well as those living with parents or with their spouse were likely to agree with withholding and withdrawal of life-support. In retrospect, it was considered that who the respondent lived with was not truly indicative of social and family support, and that further research into this area is necessary to clarify the relationship between social and family support and attitudes to withholding and withdrawal of treatment.

There were several limitations to the current study. Firstly, the population surveyed was a small group of educated professionals and may not be representative of the attitudes of the general population at large. One therefore needs to be cautious in generalising the results to other population groups. Teachers, however, belong to an important social group that has a vital role in shaping the thoughts and values of the society. It is therefore extremely useful to examine their attitudes on this important social and medical issue.

Secondly, the response rate (27.8%) to the survey was low. Although the response rate to local surveys in the past has generally been poor—a previous survey of doctors achieved a return rate of only 25%<sup>18</sup>—the lack of interest in this issue among teachers was surprising. A possible explanation for the low response rate may be that Chinese culture generally considers the topic of death as a taboo, and not for discussion. It has previously been noted that questionnaires containing questions of a sensitive nature are less likely to be completed and returned.<sup>19</sup> A recent survey on euthanasia, however, suggested that Chinese in Hong Kong may in fact be quite willing and open when it comes to discussing death issues.<sup>18</sup> The sample population in that survey was doctors who were likely to be more comfortable with issues of life and death, and may not be reflective of the general public.

The respondents in this survey supported the concept of advanced directives, whereby prior consent or a directive is recorded legally with respect to refusing or limiting life-sustaining treatment when treatment of the individual's medical condition is futile. Advanced directives are supported

by legislative and clinical practice in countries such as the United States, Canada, Australia, and Singapore. However, this aspect of end-of-life decision-making has not been seriously deliberated in Hong Kong and there is no legislative provision for this purpose at present. As a matter of common law, however, advanced directives are acceptable to the Court of Law in Hong Kong.

The final part of the study investigated the respondents' preferences regarding decision-makers for the withdrawing and withholding of life-sustaining treatment. If the patient was conscious and competent, the majority of respondents (50%) agreed that the patient alone should make the decision. Another 45.6% favoured a joint decision between the patient and either the family or the doctor, or both. This result was similar to that found in western studies.<sup>7,11</sup> The large number of respondents who favoured an autonomous decision was surprising in the context of Chinese culture, given that the role of the family in decision-making is considered more important than in western cultures.<sup>20</sup> Possibly the family is more important among older generations of Chinese who are more strict adherents of traditions and customs. Although the importance of the family network and support remains a feature within the local Chinese community, exposure to western cultures may have influenced the attitudes of younger generations of Chinese people.

When the patient is unconscious or incompetent, 11.4% preferred the family alone to make the decision on life-sustaining treatment, while 52.6% favoured a joint doctor-family decision. A large proportion (22%) did not think that anyone should make such a decision. However, it was unclear whether their view that dying patients should have their life-sustaining treatment continued until the heart stopped was based on cultural, spiritual, or psychological reasons. This view was in contrast to the general support towards limiting life-sustaining treatment in medically futile situations. This may reflect the culture of filial piety in which it is necessary to endeavour to prolong the life of a family member for as long as possible. Some respondents may have a sense of guilt about making such a decision. In view of the strong preference for family involvement in decision-making, the findings of this study indicate that it is extremely important to discuss matters with the family before a decision about life-sustaining treatment is made. It is a good clinical practice to achieve a decision together with the family.

Although this survey on local attitudes towards life-sustaining treatment was small, it nevertheless represents an important step in promoting public discussion about life-sustaining treatment. This may have particular importance given the current limitations in health care resources. In the past, local Chinese people have been reticent about controversial and taboo issues. Perhaps now is an appropriate time for the public to deliberate issues such as the limitation of life-sustaining treatment, euthanasia, physician-assisted suicide, and advanced directives. Appropriate

legislation may be necessary in relation to some of these issues. The guidelines on life-sustaining treatment for terminally ill patients prepared by the Hospital Authority in Hong Kong is a comprehensive document intended to facilitate the decision-making process.<sup>2</sup> Favourable public response to this document suggests that the withholding and withdrawal of life-sustaining treatment are now acceptable issues for debate in Hong Kong. This is also in keeping with the general attitudes found in the current survey.

## Conclusion

The study found that Hong Kong Chinese teachers in this survey tended to support the concept of withholding and withdrawal of life-sustaining treatment in the dying patients when such treatment was futile. Although respondents viewed patient autonomy in decision-making as important, joint decision-making including family members and/or doctors was also favoured by a substantial group. Respondents were also in support of advanced directives.

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