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Breaking bad news: a Chinese perspective

CY Tse United Christian Hospital, Hong Kong, **Alice Chong** Department of Applied Social Studies, Faculty of Humanities and Social Sciences, City University of Hong Kong, Hong Kong and **SY Fok** Division of Social Studies, City University of Hong Kong, Hong Kong

Abstract: The amount of information received by terminal cancer patients about their illness varies across different countries. Many Chinese families object to telling the truth to the patient and doctors often follow the wish of the families. However, a population study in Hong Kong has shown that the majority wanted the information. To address this difference in attitudes, the ethical principles for and against disclosure are analysed, considering the views in Chinese philosophy, sociological studies and traditional Chinese medicine. It is argued that the Chinese views on autonomy and nonmaleficence do not justify non-disclosure of the truth. It is recommended that truth telling should depend on what the patient wants to know and is prepared to know, and not on what the family wants to disclose. The standard palliative care approach to breaking bad news should be adopted, but with modifications to address the 'family determination' and 'death as taboo' issues. *Palliative Medicine* 2003; **17**: 339–343

Key words: attitude to death; cancer; Chinese; cultural characteristics; ethics; family; medical; truth disclosure

Introduction

The amount of information received by terminal cancer patients about their illness varies between countries. In the USA, the majority of doctors indicated a preference for truth telling.¹ However, the approach differs in many other countries,^{2–4} and this variation is often attributed to cultural differences.^{5,6} Some cultures perceive the disclosure as a harmful act, violating the principle of nonmaleficence.^{6,7} Many Chinese families object to telling the patient a 'bad' diagnosis or prognosis, and some experts recommend the wishes of the family are respected.⁸ Indeed, doctors in mainland China often inform the family members instead of the patient.^{9,10} Anecdotal case reports^{11,12} of Chinese patients in Western countries also highlight the strong objection of family members to the patient knowing the diagnosis or prognosis. In Hong Kong, where the majority of the population is Chinese, Fielding^{13,14} reported a diagnostic disclosure rate of 68% by doctors among 133 terminal cancer patients, but the diagnostic disclosure was often incomplete and the prognostic disclosure rate was only 38%. This was despite 92% and 86% of doctors saying that, in principle, they would disclose diagnosis and prognosis, respectively.¹⁴ However, in a population study in Hong Kong in 1996 by the same author,¹⁵ 95% of 1136 persons interviewed wanted information even if the news

was bad. Fielding concluded that there was no support for the idea that the family should be informed instead of the patient. Thus, the existing empirical evidence for the Chinese suggested a big contrast between the view of the family and the wish of the individual regarding information disclosure. The actual practice of the medical profession was also incongruent with the wish of the individual.

Autonomy and family determination

The present day preference for truth telling among most Western countries stems from the respect for autonomy,¹⁶ but the approach to autonomy varies between different cultures.^{17,18} Those against disclosure in the Chinese culture consider that there is less acceptance of autonomy in the Chinese,¹¹ with individual rights considered a recent concept among the Chinese, imported from the Western world.¹⁹ The concept of self is a relational one in Chinese culture²⁰ and family relationship emphasizes harmonious interdependence.²¹ Individuals are part of family units and autonomy requires family determination, the concept of which is summarized as 'Every agent should be able to make his or her decisions and actions harmoniously in co-operation with other relevant persons'.²¹ So, for the Chinese, important personal decisions, such as marriage or job seeking, are often made in consultation, if not in conjunction, with family members.

The issue should be discussed from two aspects. First, although autonomy is not a traditional Chinese concept, veracity is. *Cheng*, meaning sincerity or truthfulness, is a

Address for correspondence: Dr CY Tse, Hospital Chief Executive, United Christian Hospital, Hip Wo St, Kowloon, Hong Kong.
E-mail: cytse@ha.org.hk

key concept in the *Zhongyong* (Doctrine of the Mean),²² one of the 'Four Books', which are the classics of Confucian philosophy. To be 'truthful' means that when the patient asks for the truth, one should oblige unless there are strong reasons against doing so. To give false information is powerfully against the concept of *cheng*.

Secondly, although the role of the Chinese family in the decision-making process of an individual is very important, family determination can be classified into three levels.

- 1) The family takes part in decision making with the patient.
This approach adequately addresses the relational concept between self and the family. Both the patient and the family understand the bad news, and decisions about further medical treatment or personal affairs are decided together.
- 2) The patient asks the family to decide.
The patient does not want the bad news, and the right for information and decision making is delegated to the family. However, though the patient is not told the bad news, it is the result of the patient's own choice. This is also considered as exercising the patient's autonomy.¹⁷
- 3) The family decides alone despite the patient's wish to participate.
The patient wants to know the diagnosis, but the doctor colludes with family in not letting the patient know, hoping to protect the patient from potential harm.

Actually, only the third level excludes the patient and is against patient autonomy in the broad sense. This is a strongly paternalistic approach and it can not be justified solely by the concepts of harmonious dependence or relational self. Although this paternalistic approach is common in a collectivist culture, in which secrets are kept within subgroups of the family to protect the other family members from potentially painful knowledge,²³ justification of this approach depends on the principle of non-maleficence, which warrants further discussion.

Nonmaleficence and nondisclosure

The principle of nonmaleficence is often quoted as the main reason for nondisclosure.^{9,10} One can argue that the harm of disclosure is more serious in the Chinese community because talking about death is taboo for the Chinese.⁸ The reply by Confucius to a question on the meaning of death 'While you do not know life, how can you know about death',²⁴ is an often-quoted example of the long tradition of the taboo. However, 'death is taboo' does not exclude a more sensitive and implicit way of

truth disclosure.⁷ Justification of nondisclosure by the principle of nonmaleficence needs to demonstrate that disclosing the truth is a harmful act, which would cause an excessive psychosocial or spiritual burden. No systematic research studies about the harm of disclosure in the Chinese have been published in international journals, but the issue can be analysed by looking at other evidence.

Views from philosophy

A contemporary philosopher specializing in thanatology summarized the views on death in Chinese philosophy as:²⁵

- Confucian: 'willing to die to preserve virtue':
One should not be afraid of death. If a non-virtuous act is needed to preserve life, one would rather die.
- Taoist: 'life and death unified':
Life and death are natural processes. One becomes part of nature upon death, and one needs not grieve when facing death.
- Buddhist: 'belief in new life after death':
Death is part of the process of the wheel of rebirth. Death is a way to Nirvana.

Another famous contemporary Chinese philosopher succinctly summarized the traditional Chinese philosophy toward life and death by four Chinese words 'zhong sheng an si',²⁶ which means 'respecting life seriously and accepting death peacefully'.

The following direct quotations from Chinese philosophy classics help to illustrate the views.

Mencius said:

'Fish is what I want; bear's palm is also what I want. If I cannot have both, I would rather take bear's palm than fish. Life is what I want; dutifulness is also what I want. If I cannot have both, I would rather take dutifulness than life ... This is an attitude not confined to the moral man but common to all men. The moral man simply never loses it.'²⁷

Chuang Tsu said (responding to the question why he was singing and beating upon a basin when his wife died):

'If, however, we examine this question of beginnings, originally there was no birth. Not only there was no birth but originally there was no body ... This breath changed and body came into existence. This body then changed and birth occurred. Today another change has occurred, and she has reached death. It is analogous to the progression of the four seasons ... This person, my wife, is resting peacefully in the largest of abodes, but if I were to mourn her with a

lot of sobbing, I should feel that I did not understand Fate. That is why I desist.²⁸

Death in the eyes of Chinese philosophers is thus not to be feared.

Views from sociological studies

One may argue that the views expressed by philosophers may not be representative of the common people. However, recent sociological studies showed that, despite the taboo on death, the elderly in rural communities in China openly prepared for their funeral before their death.²⁹ They got ready their coffins and 'death' clothing. Some even had a 'celebration' ceremony when the preparations were completed. With such preparedness, death could not be frightening for them.

A qualitative study was done in Hong Kong by one of the authors³⁰ interviewing in-depth, 10 elderly people about their attitude towards death. None indicated a particular fear of death itself. Some even gave a detailed description of what they themselves had done in preparation for their own death. They were more willing to talk about death than was generally recognized.

Views from traditional Chinese medicine

Another useful source of material would be the traditional Chinese medicine literature. We scanned through chapters 501 to 503 of *The Collection of Past and Present Chinese Medicine Texts*,³¹ which collected the general discussion sections of important texts on Chinese medicine from before the Han Dynasty to the Qing Dynasty. Among the contents were discussions on medical ethics. The following quotes relating to truth telling or to facing death were identified, all from the Ming Dynasty (1368–1644 AD):

From *Introduction to Medicine*, by Ming Dynasty, Li Chan:

After the diagnosis, one must tell the truth to the patient.³²

From *Introduction to Medicine*, by Ming Dynasty, Li Chan:

If one uses a single word as our contract with the patient, it should be 'no deceit' ... If one does not tell the truth after diagnosis, it is deceit ...³³

From *Recovery from Illnesses* by Ming Dynasty, Gong Ting Xian:

You should identify the underlying pathology, and be bold enough to talk about life and death.³⁴

From *Miscellaneous Writings of a Doctor* by Ming Dynasty, Wang Lun:

Previous people had said: 'If you are ill, you should write the word death with your fingers on your chest. Then your worries will be gone and your heart will attain peace. This is better than medication.' This is really an excellent therapy.³⁵

There were no quotations found in this search advising a doctor to withhold bad news from a patient. The first three quotes above stress the importance of telling the truth; the second quote is clearly one against giving false information to the patient. The fourth quote is a vivid description of how to attain peace when facing death.

From the above, it would appear that in traditional Chinese culture, though death is a taboo subject, the psychosocial and spiritual burden on facing death might not have been particularly strong or necessarily any worse than in other cultures, and might not override the requirement for truth disclosure.

Fear of death as a more worldwide phenomenon

A person may rationally want the doctor to disclose bad news, but emotionally may not want to hear it. A UK study,³⁶ while demonstrating that most patients 'knew' even when not told, also showed that the majority had no wish to augment that knowledge. A study of terminally ill patients' expectations of nurses in Australia³⁷ showed that while patients wanted the nurse to tell them if their condition deteriorated, they also did not like the nurses talking to them about death and dying. It seems that this 'taboo' about death and dying is not necessarily limited to certain cultures, and could be a real dilemma for any individual in any generation. The fear of death may well have worsened in the last century, described by Callahan³⁸ as 'a gradual shift to death as a more segregated personal and psychological event, first from the community at large to the family, and then, by the late twentieth century, taken out of the hands of the families and put into those of doctors and medical institutions' or 'the tame death lost'. With the institutionalization of death, people do not view death as a natural phenomenon but as an alien and fearful event.

With this fear of death, the paternalistic approach to truth telling was prevalent in the 1960s in the USA, when 90% of doctors preferred nondisclosure.³⁹ So, this attitude is not necessarily culture specific.

The attitude dramatically changed in the USA in less than 20 years.¹ As well as the recent strong emphasis on autonomy and patient choice,¹⁶ other reasons included:

- 1) legal requirement,¹
- 2) improvement in education of doctors in communication skills,¹

- 3) better knowledge about terminally ill patients, realizing that most wanted to know,⁶ most knew even if not told³⁶ and telling did not result in further harm to the patient.⁴⁰

Actually, open communication could prevent communication barriers and the fear of death could be better addressed.⁴¹

Further research

It is quite possible that improved communication skills and better knowledge about managing terminally ill patients may alleviate the anxiety among doctors and the family members of harming the Chinese patient. However, in order to formulate a rational approach to truth telling in the Chinese, we need to know whether the psychosocial and spiritual burden of facing death is really worse among the present day Chinese or similar to other groups of people. As the influence of western culture varies among different groups of Chinese, we also need to know whether their wish for autonomy has become stronger than among their ancestors.

Empirical studies are needed to answer such questions.

Recommendation

Until more robust knowledge is available from future studies, based on results of the above analysis, we would like to make the following recommendations.

We have argued that the different view on autonomy among the Chinese does not justify nondisclosure of the truth to the patient if the patient wants to know. We have also argued that, despite the taboo on death, the psychosocial and spiritual burden on facing death may not necessarily be greater than the other cultures. Thus, we consider that, unless we have strong empirical evidence, there may be little to justify doctors colluding with Chinese families, and 'culture' should not be used as an excuse to avoid tackling collusion.

It is very important to also remember that every individual is different. Therefore, truth telling should depend on what the patient wants to know and is prepared to know, and not on what the family wants to disclose. The standard palliative care approach of breaking bad news⁴² should be basically adopted, but with modifications to address the 'family determination' and 'death as taboo' issues:

- 1) We should be very careful in using the words 'death', 'fatal illness' or 'cancer', and should accept the patient avoiding these words. However, by using a more tacit communication approach such as the use of euphemism, we may still have very effective communication with the patient on life and death issues.
- 2) We should involve the family early in the communication and decision-making processes, unless the patient objects.
- 3) We should accept the patient delegating to family members the right to understand the details of the illness and make treatment decisions, if this is the patient's choice.
- 4) If the family requests us not to approach the patient to break bad news, we should explain our communication approach to the family members and convince them.

Conclusion

While we need to be culturally sensitive in breaking bad news to terminally ill patients, we must understand the actual influence of culture on the patient's value system, attitude and belief. It is important that we do not stereotype the cultural influence after reading individual reports of extreme cases. Although further studies are required to confirm our view, it is likely that the approach to truth telling in the Chinese should not be markedly different from the palliative care approach of the western countries.

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