



Telling the truth to Asian patients in the hospital setting

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Abstract

Full disclosure of health information to patients is considered important in Western culture, but may be less appropriate for patients from other cultures, particularly when conveying news about a diagnosis with a poor prognosis. This issue is becoming important in New Zealand, given the rapidly increasing ethnic diversity of patients presenting to our hospitals. This paper explores culturally appropriate ways of breaking bad news to patients of different ethnicities in the hospital setting, with emphasis on identifying the locus of decision-making within families and decision-making about end-of-life care. Given that the most rapid population growth is presently occurring in the Asian community, attention is focussed on culturally sensitive ways of breaking bad news to Asian patients and their families.

Western medicine is taught and practised using a model of full disclosure.¹ This is considered important for patients to be able to make decisions about their treatment and to be informed fully prior to giving consent to treatment. However, a full disclosure model may be less appropriate for patients from other cultures.

The communication of bad news, such as a complication or a poor prognosis, is where this issue arises most often and is particularly difficult when dealing with Asian patients. Asian family members often ask health professionals for communication to be with a member of the family and not with the patient.^{2,3}

Medical interpreters are often useful in finding the correct approach and terminology, but they can complicate matters if they fail to grasp key clinical details, introduce personal bias, or communicate in a manner that the health professional does not intend. A form of “Chinese whispers” can occur, with information passing from the health professional, to interpreter, to key family member, to extended family, to the patient, and then back again.³ The potential loss of control over the content and intent of the information can make a Western-trained health professional uncomfortable.

Cross-cultural communication of health information is becoming more important because of the changes occurring in the ethnic makeup of the New Zealand population. In 2006, the European population represented 67.6% of New Zealand residents, with Māori at 14.6%, Asians at 9.2%, Pacific Islanders at 6.9%, and the rest comprising Middle Eastern, Latin American, and African at 0.9%.⁴

Auckland is the most ethnically diverse region in New Zealand, with 66.1% of the Asian population living there and comprising 18.6% and 19.0% of the total male and female populations, respectively.⁴ It has been predicted that between 2006 and 2026 the Asian population in New Zealand will increase by 95% compared with 60% for Pacific Islanders, 31% for Maori, and 7% for Europeans.⁵ The largest population

growth is therefore occurring in our Asian community, the birth rate for which is increasing 2.5 times faster than that in the European population.

There has also been a marked increase in the proportion of doctors from Asian cultures practising here, particularly in the last decade.⁶ According to the most recent census data, New Zealand's Asian population is dominated by people who identify with either Chinese (41.6%) or Indian (29.5%) ethnicity. The People's Republic of China (32%) and India (17.3%) are the commonest countries of birth of New Zealand's Asian immigrants, followed by Korea (11.9%), the Philippines (6.2%), and Malaysia (5.7%).⁷

The increasing proportion of Asian patients presenting to the New Zealand healthcare system raises a number of issues concerning language, cultural practices, and religious beliefs that clinicians should understand for the delivery of optimal patient care.

Ethnic diversification of both patients and health professional groups in this country means that the need for cultural sensitivity extends beyond the focus on Western-trained doctors and Asian patients, with wide implications for training in cultural skills and competency.

This paper examines how to tell the truth in a culturally sensitive way with particular emphasis on breaking bad news, identifying the locus of decision-making within a family, and end-of-life decision-making. The three models that are discussed in this context are *patient autonomy*, *nonmaleficence*, and *beneficence*.

Patient autonomy model

The rights of the individual are considered paramount in Western culture and are reflected in the patient autonomy model. Following this model, bad news is communicated directly and honestly to the patient, who is then able to choose whether or not to be actively involved in all aspects of decision-making about the management of his or her illness.

A minority of patients will forego their right to decide, preferring to defer to the health professional. Guidelines for breaking bad news based on the autonomy model were developed by Rabow and McPhee⁸ and later adapted by VandeKieft⁹ (ABDEE, **A**dvanced preparation, **B**uilding a therapeutic relationship, **C**ommunicating well, **D**ealing with patient and family reactions and **E**ncouraging and validating **E**motions). There is also the SPIKES approach (**S**etting up, **P**erception, **I**nvitation, **K**nowledge, **E**motions, **S**trategy and **S**ummary) which attempts to accommodate different cultural expectations of health care.¹⁰

Common features in these guidelines are truthful explanation of a diagnosis with a poor prognosis, provision of time for the patient to respond, and then offering support. The concept of patient autonomy is so powerful in Western culture that people can safeguard their right to make future decisions about their own health by arranging living wills and by providing advance directives in the event of loss of their ability to make such decisions.¹¹

Nonmaleficence model

At the opposite end of the spectrum is the nonmaleficence model, whereby the patient is not told of a poor prognosis in the belief that this will protect him or her against unnecessary physical and emotional harm. Following this model, diagnostic and prognostic information is given to the patient's immediate family members who then make treatment decisions on behalf of the patient. This practice is more common in Eastern European communities, Italy, and Africa—and several reasons have been given for this approach.

Some cultures view discussion of serious illness and death as impolite and even cruel. Others view it as provoking unnecessary anxiety, depression, and a sense of helplessness, thereby eliminating all hope.¹² In these cultures there is the concern that terminally ill people may not be able to enjoy the remainder of their lives if they are aware of their poor prognosis, and may feel as if they are “walking amongst the dead”.

Some cultures believe in the power of the spoken word to the extent that even speaking about such matters might make death become a reality², and this is common in indigenous American, Bosnian, and Chinese communities.^{13,14}

Beneficence model

Somewhere in the middle of the spectrum is the model of beneficence, where family members actively participate in the communication, share the burden of a poor prognosis with the patient, and encourage hope. The beneficence model is widely practised in a number of Eastern countries including India,^{15,16} Korea,¹⁷ Singapore,¹⁸ Thailand,¹⁹ and China.²⁰

Decisions about health care and treatment in Asian communities tend to be made jointly by family members (who are often the main caregivers) and the patient, rather than by the patient alone. In this setting the family rather than the patient is the first to be informed of the diagnosis and/or the suggested management plan. However, an overly optimistic prognosis might be given to the patient in an attempt to preserve hope.²¹

Common to all Asian cultures is a deep respect for the dignity of others, and in particular for one's parents. There are a number of words used in the Asian languages to describe this concept, none of which have adequate English equivalents. For example, the Japanese word *amae* refers to the deep embedding of an individual in their family or social group. Another such Japanese word is *omakase*, which refers to the traditional Asian practice of elderly parents leaving important life decisions to their adult children, in the knowledge that they will act in their best interests out of gratitude for their earlier nurturing and sacrifices.

Nonverbal communication appears to have a greater role in Asian cultures than in Western society, and its purpose is to preserve the dignity of others and to avoid embarrassment. Body language is known as *zhih li* in Chinese, *inshin denshi* in Japanese, and *nunchi* in Korean.

In many situations, the unspoken word can be more important than the spoken word, to the extent that an entire conversation might be understood quite clearly from body language alone.

The traditional Asian practice of nondisclosure of bad news directly to a patient was tested in Japanese law as recently as the 1980s.²² The case concerned a patient who presented to her doctor with abdominal pain and was suspected to have an adenocarcinoma of the gallbladder. Instead of disclosing this to the patient, the doctor offered a diagnosis of gallstones. The patient declined surgery in the reasonable belief that gallstones were not life-threatening, but subsequently died of gallbladder cancer. The patient's family later sued the doctor.

The suit was unsuccessful, on the grounds that "at that time most physicians did not reveal the true diagnosis of cancer to their patients". The outcome of this case highlights the deeply entrenched concept of nondisclosure in traditional Asian culture.

Navigating between the cultural poles

Determining how much information to give to patients from different ethnic groups regarding a serious diagnosis is not straightforward, and "one size does not fit all". There is a wide range of preferences, and this appears to be more so for Asians than for Europeans.² This may, in part, relate to the length of time a person has lived in his or her adopted country and its social environment.

In New Zealand, for example, a first-generation Asian person with a limited command of English may have had little exposure to Western culture and have fully retained his or her traditional Eastern cultural beliefs and preferences. In contrast, a second- or third-generation New Zealand-born Asian is likely to have developed a mixture of Eastern and Western beliefs.

Therefore, decision-making about how to deliver bad news cannot be made on ethnicity alone. Interestingly, recent evidence from China indicates that most patients want to be informed of a cancer diagnosis, although this preference reduces as the diagnosis becomes more pessimistic.^{23,24}

Determining how to best communicate bad news to Asian patients presenting in the New Zealand hospital system presents a notable challenge. To inform the patient's relatives of bad news before telling the patient is in breach of the *New Zealand Code of Health and Disability Services Consumers' Rights*.²⁵

Therefore it is necessary to offer patients a choice about whether they or nominated family members should be told bad news first, even though offering the patient this choice might not be completely in accord with their cultural expectations.

Searight and colleagues have developed a questionnaire to assess a patient's preference regarding how bad news should be conveyed.² This questionnaire asks whether or not patients want to be told directly about their medical condition and whether or not they want someone else to make decisions, but does not clarify whether or not they want a family member to be informed first.

A modified form of this questionnaire that clearly asked whether or not the patient wanted someone else informed first has been developed (Appendix 1). It was translated into Mandarin and then evaluated with a small pilot study by the

Department of Psychological Medicine, University of Auckland to determine whether it was understood, acceptable, and if it assessed what it was intended to. It was administered to an opportunistic sample of 10 Chinese people (male 3: female 7, ages 40–60 years) in the community.

Participants were asked to respond as if they had been admitted to hospital and to complete the questionnaire. Participants were then asked for verbal feedback and they all considered that the suggested use of such a questionnaire was an excellent idea and important for Asian immigrants. Participants made some suggestions to clarify the questionnaire further but indicated that not only should the name of the person to be informed first be recorded but also the relationship of this person to the patient. They commented that in Asian cultures the acknowledgement of relationships is essential in terms of family hierarchy and social networks.

The authors suggest that such a questionnaire should be completed on first presentation to hospital and be part of the patient's clinical record, providing a quick and useful reference for staff. This is in keeping with other preferences that are recorded including those relating to diet (e.g. vegetarian), treatment (e.g. transfusion and Jehovah's Witnesses) and resuscitation status.

The authors are not aware of any hospital in New Zealand where such a questionnaire has been used. It might be argued that such an approach is too formal and that a good clinician should ascertain these preferences as a matter of routine. Indeed, such a questionnaire undoubtedly needs to be tested with patients and their families in the hospital setting to determine its reliability, validity, and usefulness.

It is hoped that this type of approach, which could be readily integrated into admission questionnaires, would become a practical and useful tool to ensure that communication between patients, families, and staff in the hospital setting is culturally sensitive and appropriate.

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Appendix 1. Example of a questionnaire to determine the best way to communicate with patients and their families in relation to their medical condition, treatment options and outcomes (modified from Searight and Gafford²)

The person who is interpreting for the patient should read the following and record the answers.

Introduction

In New Zealand, patients have the right to know all about their medical condition and treatment options. Sometimes patients prefer that someone else, particularly family members, are told first about their medical condition and treatment options. We are asking you these questions so that we can know how you want to receive information. We will record your wishes on your hospital file so that everyone knows your preferences. If you change your mind at any time just tell one of the staff and they will ask you these questions again and change the information on your file.

Questions

1. Some patients prefer to know all about their medical condition and treatment options, others don't want to know or would prefer someone else who cares about them is told first. Do you want to be told, or would you prefer someone else is told first? *(please tick)*.

Tell me first *(go to Question 5)*

Tell somebody else

2. If you would prefer that we tell somebody else about your medical condition who can help make decisions about your care, who would that person be and what is your relationship to that person?

Name

Relationship to you

Contact phone number(s)

3. Would you be more comfortable if this person were spoken with alone, or would you like to be present? *(please tick)*

I want to be present

I do not want to be present

4. If you change your mind at any point and would like more information, please let me know. I will answer any questions you have. *(please tick)*

I know that I can change my mind at any time

5. Sometimes people are uncomfortable discussing their medical condition and treatment options with a doctor who is of a different race or cultural background. Is this an issue for you?

No *(go to Question 7)*

Yes

6. Can you please explain why this is an issue and how we might assist? *(Continue over page)*

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.....

7. Is there anything that would be helpful for me to know about your background/family/community/culture/faith that is relevant to how we talk with you about your medical condition and treatment options and outcome? *(Continue over page)*

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Signature of the interpreter confirming that the patient has understood the questions.

..... (Signature)

..... (Name)

..... (Contact phone number)

..... / / (Date)