APPROACH TO END-OF-LIFE ISSUES IN ASIAN PATIENTS

Don C. Ng, MD
Clinical Professor of Medicine
Medical Director, General Medicine Clinic at Osher
Division of General Internal Medicine
University of California, San Francisco

Disclosure
I have not been bribed by, nor sold out to, anyone

GOALS OF THIS PRESENTATION

• By example of the Chinese population, increase awareness of the diversity of Asians
• Increase awareness of how folk beliefs can influence outlook on end-of-life issues
• Increase awareness of the need to assess the cultural context of outlook on end-of-life when approaching a family about terminal care

Asian Demographics

• ~1/3 of San Franciscans are Asian with the majority Chinese
• Asians comprise 13% of the California population, 5% of the US populace
• Now the fastest growing immigrant population
Diversity of Chinese Americans influenced by diversity of China

- Especially true for the first generation (defined among Asians as the generation born in their country of origin who immigrated to the US)
- Less applicable for second and third generations onward

RELIGIONS IN CHINA

- Buddhism
- Taosim (Daoism)
- Christianity
- Islam

SOCIOECONOMIC BACKGROUND

Poor “peasants” to multi-billionaires

EDUCATIONAL BACKGROUND

Illiterates to PhDs, attorneys, dentists, physicians
PHILOSOPHIES/BELIEFS

- Folk religion: an amalgam of Confucianism, Buddhism, and Taoism
- Ancestral worship:
  - Ancestors’ spirits live on
  - Filial piety
  - Saving face
  - The family is more important than the individual

LUCK, SUPERSTITIONS

- Certain numbers, objects, colors, behaviors bring good luck
- Likewise, there are counterparts that bring bad luck
- “Good Wind”/“Bad Wind”

ASIAN PERSPECTIVE ON A DEVELOPMENTALLY DISABLED FAMILY MEMBER

- Very scant literature on this subject
- 2nd/3rd generations onward have a more Western/American perspective
- 1st generation Asians tend to have traditional biases, depending on socioeconomic/educational background

FOLK (UNEDUCATED) VIEWS

- Result of a curse from something an ancestor committed
- Result of some bad behavior by a family member which brought bad luck to the family
- Entire family is genetically defective (or cursed), making it difficult to marry off daughters and for sons to find wives
DEALING WITH TERMINAL CARE OF A
DEVELOPMENTALLY DISABLED PATIENT IN
THE CONTEXT OF AN ASIAN FAMILY

- Parents have a hard time letting go
- Parents may feel guilt for feeling shame about
  the patient
- Siblings may be very attached, very caring

CASE

58 yo male with cerebral palsy on tube feedings,
Hx of multiple aspiration pneumonias with resultant
bronchiectasis, CKD due to nephrolithiasis and
multiple bouts of pyelonephritis, recently found to
have likely colon cancer with multiple metastasis to
the liver. How do you approach the discussion
about the diagnosis, palliative care and code
status?

APPROACH WITH AN OPEN MIND

- Can be challenging due to superstitions/beliefs
- The word “cancer”, “death” or “die” is considered
  bad luck, even a curse
- Preferable: “When his time comes”, “at the end of his
  journey through life”, “His time to go home”
- How the question is asked makes a big difference:
  make comfortable vs doing everything to prevent
death
CODE DISCUSSION

• Find out who in the family serves as the decision-maker/spokesperson
• If no parents or if they defer, ask for the sibling with the decision-making authority
• Be aware siblings may feel an obligation to provide the best care if the patient is the oldest sibling
• Stress comfort and avoidance of suffering over merely prolonging life (to LIVE vs to merely EXIST)

IMPORTANT: MAKE SURE FAMILY DOESN’T INTERPRET “DNR” TO MEAN NON-TREATMENT OF ILLNESS

IMPORTANT OF ADVANCE DIRECTIVE AND POLST

• Stress importance for the sake of the patient and also the family
• Helping clarify goals of care for patient so there is no confusion during stressful time of terminal illness
• Promotes discussion and (hopefully) consensus among family
• Allows dissident views to be discussed, and if necessary, assistance of legal help to reach agreement

ADVANCED DIRECTIVE

• Websites for bilingual forms:
  • http://www.agingwithdignity.org/translated-five-wishes.php
  • http://www.nlm.nih.gov/medlineplus/languages/advancedirectives.html
POLST

- Website for bilingual POLST forms:
  http://www.capolst.org

HOSPICE CARE
NEGATIVE PERCEPTIONS OF HOSPICE

- Giving up hope
- Parents/family failed in their duty to care for the patient
- Dying at home may bring bad luck to the family

BENEFITS OF HOSPICE

- Ensures patient will be comfortable
- Extensive services and counseling for the family provided

HOSPICE CARE, continued

- If dying at home is unacceptable, full service hospice facilities may be acceptable
- Stress comfort, being free of pain, no suffering
- Offer the parents/family the opportunity to be at the bedside at the time of death (to let the patient dies alone might be interpreted as a disgrace by some families)
CULTURAL ISSUES IN END-OF-LIFE CARE OF ASIAN PATIENTS

DIVERSITY

Asian Americans are a very diverse group encompassing many Asian countries, languages, religions, and socioeconomic ranges. From Hmong to Cambodians to Vietnamese, Koreans, Chinese, Japanese, South Asians and other Asian ethnicities, the spectrum of cultural differences require providers to show awareness when it comes to sensitive issues such as end-of-life care. The range of health literacy can range from shamanism to sophisticated Western medicine, sometimes in combination with traditional healing methods. Immigration patterns are just as diverse, from refugees to asylum seekers to immigration for education, work, and special skills. Cultural acclimatization, folk and religious beliefs, filial piety, family honor, and even superstitions play into how a family processes bad news and terminal care.

ATTITUDES ABOUT DEVELOPMENTAL DISABILITIES

There is very little literature about attitudes of Asians towards people with developmental disabilities. How enlightened a family will view a member with developmental disabilities will depend on their educational level, degree of knowledge/assimilation with Western society and medicine, and their own comfort with caring for the patient and dealing with relatives. Second generation Asians (those born in the US to immigrant parents) and generations beyond tend to have a more Western/American outlook. Folk perspectives, usually among the uneducated, about a developmentally disabled family member among the first generation Asians may include feeling it was a curse from something bad an ancestor committed, result of some bad behavior of a family member that brought bad luck, feeling their entire family is “defective” (and thus unable to marry off daughters, sons will have difficulty finding wives).

DEMOGRAPHICS OF CHINESE

I cannot speak with authority about so many Asian cultures, so I will use the Chinese culture, of which I am most familiar, as an example of how diverse even one ethnic group can be. Chinese immigrants represent the gamut of the diverse populations in various regions in China, but the majority of first generation Chinese Americans are from Northern China, Taiwan, and Guandung (aka Canton), including Hong Kong (Asians define the first generation as the those born in the country of origin and immigrating to the US to establish work and family). Mandarin is the official language of China and Taiwan, so most immigrant Chinese speak Mandarin. Immigrants from Guandung and Hong Kong speak Cantonese, but the younger immigrants will speak Mandarin as well. The socioeconomic spread ranges from poor “peasants” to multimillionaires, the education level from illiterate to graduate/professional degrees. Religious beliefs range from Christianity to Buddhism, Taoism, and folk religion, including ancestral worship. Superstition plays a role for many, with certain numbers and actions bringing good luck and fortune, and other numbers and actions bringing bad luck. The family unit is central in how children, siblings, and parents conduct themselves. Filial piety is a central theme for many first and second generation Chinese, and many other Asian groups as well.
BAD DIAGNOSES, END OF LIFE ISSUES

CANCER: TO TELL OR NOT TO TELL

Diagnosing a patient with cancer poses a difficult situation for the physician. In China and other Asian countries, the culturally accepted norm is to inform the family but not the patient. Again, superstition comes to the forefront: telling the patient brings bad luck and will accelerate their process of dying or will stamp out any glimmer of hope. Families often feel that informing the patient will cause them to “give up” or make them weak and unable to fight the cancer. However, there is some recent evidence showing that patients and families do want to know the truth (1).

A well accepted approach is the concept of "informed refusal", which is useful for not only Chinese patients, but also patients from all other parts of the world as the doctrine in many cultures worldwide is similar: the family is informed but not the patient. In the US, we are legally required to inform the patient if she or he wants to know the diagnosis. However, the patient can request that we discuss the diagnoses and treatment recommendations with the family instead. Hence the physician should ask the patient whether she/he wants to be told the diagnosis or would she/he prefer the provider to inform the family instead and to let them make the decisions regarding treatment recommendations. If the patient does want to be told, we are legally obligated to inform her/him even if the family disagrees, and you will need to explain to them this is the law.

DEATH AND DYING, AND CODE STATUS

Issues about code status and life-supporting measures are particularly delicate subjects to broach. Many Chinese are quite superstitious and consider discussion of issues about death and dying (especially the use of the word death) to be bad luck; some may feel that they have been cursed if the topic is discussed and the words are used in the discussion. However, there is evidence that Chinese are becoming less likely to adhere to these traditional beliefs (4). Using more euphemistic phrases like “passing on”, "when your time arrives", “end of the journey”, and “time to go home” are often more acceptable. Determination of code status often depends on how it is explained; asking whether the patient or the family want "everything possible to be done to sustain life" will almost always result in an affirmative answer from those who are unfamiliar with Western medicine. This is especially true if posed to the family because they would feel it is their filial duty to provide their parent with every possible intervention to keep them alive. Some may believe that Western techniques are so sophisticated that anything is possible, while others may wonder why one would ask such a ridiculous question - of course one would want to do everything possible to avoid death. Many immigrant Chinese tend to be a group of survivors - many have survived harsh conditions and persecution in their own countries, others have managed to eke out a living and successfully raise a family in America, while Chinese from Southeast Asia (as well as Asians from other war-torn countries) often have survived the horrors of war, harrowing escapes to freedom, and refugee camps en route to America; hence it is natural that they would want everything done to ensure continued survival.

In situations where the patient is incapable of making decisions, it is expected that the family members take responsibility for looking after the patient’s best interests. Family members may feel a filial obligation to do everything they can to prolong the life of and provide hope for their loved one because filial piety dictates that the children are expected to act in the best interest of the parents – failure to fulfill this obligation not only brings bad luck to the family, it brings bad luck to subsequent generations. In addition, they risk “losing face” (appearing to have failed their duty in the eyes of their community). Decision-making is group oriented, but there is often a hierarchy dictated by the culture - usually the oldest son (in some cases the oldest
daughter) is the one who bears the burden of responsibility to avoid burdening the already distraught spouse of the patient with such crucial matters. An approach to broach this subject to families is to tell them other Chinese patients in similar situations have told you that when their time comes, they just want to go peacefully and without suffering. Then proceed to ask whether that is what their loved one also desires. Another culturally syntonic approach is to reaffirm the filial duty of the family to ensure their loved one does not suffer, then question whether heroic measures, which may be painful or cause suffering (cracked ribs during CPR, intubation), should be used to forcibly prolong the patient's life beyond what would be their natural time of passing on. Emphasize that your priority is to make sure the patient is comfortable, and to avoid interventions that would prolong life at the expense of causing the patient to suffer.

When the situation is unquestionably hopeless (e.g. critically ill patient with widely metastatic cancer) but the family still wants everything done to prolong life (resuscitation), you might have to ask the hospital Ethics Committee to get involved. At that time, you might make a last ditched effort, saying that you may need to ask the Ethics Committee to review the situation because you feel continued interventions will cause the patient unnecessary pain and suffering, and your goal is to make sure their loved one is comfortable and can pass on with dignity. State that in your opinion, CPR would be inhumane (breaking ribs, electric shocks) and that is not something you would want to do if your own parent was in the same situation.

**HOSPICE**

Hospice care can be a sensitive subject, as traditional Chinese families may view it as giving up hope. Although they may know death is imminent, they feel having hope allows the terminal ill patient to live their last days with energy and the feeling that things will be better. The family may also view hospice as an admission of failure on their part to fulfill their filial duty of caring for their parent until the very end.

Hospice care can be problematic if the patient is required to die at home because traditional Chinese feel that the hospital is the appropriate place to die. Death in the home raises the superstitious belief of bad luck and specter of the dying one's ghost being unable to leave the home (many traditional Chinese believe in ghosts, as ancestral worship is part of the cultural belief system). This will then make it hard for the family to someday sell their home, and in homes where neighbors share a common wall, that would bring bad luck to the neighbor as well. Chinese view the hospital as the appropriate place to die, although a full service hospice facility may be acceptable as long as they feel the patient is well cared for.

Many Chinese patients do not want their adult children burdened with having to take care of all their bodily needs, and in fact, many are uncomfortable at the thought of having family members cleaning them when they become incontinent and immobile (2). Patients worry that their family may not be able to adequately control her/his pain and make her/him comfortable at home — and families have the same concern. When a patient is in palliative care in a hospital or full service hospice, families are concerned whether the patient is comfortable and pain-free (ie, communicating adequately with the nurses) and therefore not suffering, they wonder whether they can bring favorite Chinese foods to the patient (with guidelines regarding what is acceptable or not), they appreciate emotional support for the family from the nurses or physicians, and they often wish to be at the bedside at the time of death (3).

**APPENDIX**

**Bilingual Advanced Directive forms:**

Websites:
Bilingual POLST forms:
Website: http://www.capolst.org

3. Wong, M, Chan, SW; The Experiences of Chinese Family Members of Terminally Ill Patients – A Qualitative Study; Journal of Clinical Nursing 16 (2007): 2357-2364
4. Mjelde-Mossey, LE, Chan, CLW, Survey on Death and Dying in Hong Kong, Social Work in Health Care, 45:1 (2007); 49-65