End of Life Care
With Special Emphasis on
Asian Pacific Islander Community

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End-of-Life Discussions for Asian and Pacific Islanders: Cultural Issues

- Cultural beliefs of immigrant API’s
  - Reluctance to speak about death
  - Such talk could bring bad omens

- Religious beliefs
  - Eastern religions (Buddhism, Taoism, Confucianism) → a natural time for death – so no use planning
  - Great reverence for ancestors
  - Spirits return to place of death (hungry ghosts)
Advance Healthcare Discussions are Difficult in API Populations

- Such discussions revolve around
  - Death
  - Decision making
- Discussions of death are difficult
  - Reluctance to speak about death
  - Spiritual belief that there is a natural time
- Decision making is not autonomous
  - Involves wishes of family
  - Extended family can cause conflicts in decisions
  - The patient desires the harmony of children after death → filial piety
Family Issues

◆ Family dynamics / relationships
  ➣ Eastern philosophy: decisions are not individual, but depend on wishes and consensus of family.
  ➣ Decisions may be deferred to the wishes of children, especially sons.
  ➣ Sometimes such deference could result in conflicts.
  ➣ Family may request provider NOT disclose terminal illness and prognosis to patient.
Reasons Why Terminal Diagnosis Is Not Disclosed

- The physician may be uncomfortable with communicating “bad news”
- API families commonly ask health care providers not to disclose the diagnosis or prognosis to the patient
- Some Asian cultures believe telling someone of a cancer diagnosis is “cruel”
  - Chinese patients believe talking about death causes additional harm and becomes a self-fulfilling prophecy.
  - Reluctance to sign advance directives
- Filipino patients are very religious (Catholicism) and believe length of life is in God’s hands
Other Barriers

- Use of translators in End of Life discussions
  - Use trained medical translators
  - Translator should not be a family member
  - A family member translating may deliberately not translate the diagnosis to “protect” the family member
- Dying at home may be a problem
  - Death at home could make it hard to sell home to another API family
  - Navajo Native Americans have similar cultural beliefs: when someone dies at home, the Hogan (home) is burned
  - Work with Hospice staff on alternatives
TO IMPROVE CARE AT END OF LIFE
LEARN TO OVERCOME THE BARRIERS
Learn to Use Cultural Advantages of Involving Family in Discussions

- Discuss advance healthcare decisions with the patient
  - If the patient has dementia, the family may need to be present during the discussion
  - However, despite clinical dementia, most patients can express their wishes on how they want to be cared for
- Most patients prefer to have a peaceful natural death, without machines
- Feeding tubes are more difficult to discuss, as there is a cultural belief to not die hungry
- After the discussion
  - Inform the family of patient’s decision
  - Document in the medical record
  - Have the patient sign advance directives
- If the API elder has made a preference for no life-sustaining treatments, children will most likely agree to those wishes (filial piety)
- If the elder’s wishes are NOT known, children may choose heroic, but futile treatments out of duty to do everything for the parent
- Don’t avoid end of life healthcare decisions
It is common practice among API physicians to avoid addressing end of life discussions directly with the patient.

- The physician may have same cultural preferences of not speaking about death
- The physician may speak only to the family, so that hope is not taken away from the patient

Consider the cultural issues, but don’t avoid these difficult conversations

We can learn to deliver bad news without taking away hope
What We Can Learn From Our Patients

- Although API elders are reluctant to talk about death, most have thought about it
- They are grateful when their physician asks them for their wishes
- Once engaged in meaningful conversation, most patients want to make the decision for themselves regarding CPR and feeding tubes
- Elders are reluctant to convey their wishes to their family. Usually will ask physician to tell the children
- Physician-patient conversations about end of life issues benefit from facilitation by SW or RN
Care at End of Life

Usual Care
- Discuss Goals of Care (GOC) when patients are well
- Discuss advanced healthcare directives and review annually
- Consider prognosis as burden of illness increases
- Find resources in community to supplement care needs such as transportation, home care
- Consider case management resources
- Inform family of clinical changes

Hospice
- Make referral to Hospice provider early
- Put financial matters in order
- Funeral arrangements

Final 6 months

Time From Onset Of Illness

CONCLUDING THOUGHTS

- The cultural and ethnic characteristics of a patient may affect patient-physician end-of-life care discussions, especially when the physician is of a different culture, age and social background.

- "While medical training results in physician socialization process that provides a common knowledge base for physicians to make clinical decisions, physician attitudes and preferences are guided by social and cultural factors."---