DEATH & DYING IN AN ASIAN CENTURY
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William Osler on Death

- Quoting Plato’s Timaeus -
  “For that which takes place according to nature is pleasant, but that which is contrary to nature is painful. And thus death, if caused by disease or produced by wounds, is painful and violent; but that sort of death that comes with old age and fulfils the debt of nature is the easiest of deaths and is accompanied with pleasure rather than with pain”.

On having professional nurses & non familiar faces on the bedside of the dying person:
“You have upturned an inalienable right in displacing those whom I have just mentioned. You are intruders and usurpers, dislocating as you do, from their tenderest and most loving duties these mothers, wives & sisters.”

Key patient & cultural concerns about death..

I am afraid…

• Personal fear: What will happen to me as I pass on?
• Fear for loved ones: What will happen to them after my time? Who will take care of them?

• CULTURAL FACTORS
• Defining the end of life…
• Acceptance of death as undeniable…
• What happens after-life.. Cultural & religious belief systems…
DEMENTIA- ISSUES IN END-OF-LIFE CARE

• Difficult to define end-stage dementia consistently
• Dementia is not viewed as a terminal illness: death attributed to physical illness
• Lack of effective health care policies specifically for dementia, as well as terminal illness as a whole.
• Choosing the right place: Hospital, Hospice or Home?
• Care-giver experiences & preferences

Unique Cultural Belief Systems

• Acceptance:
  • *Less prevalent in modern Anglo-Saxon culture but common in many cultures/religions of Asia*

• In Hindu philosophy, a person submits to the powers above (often his favorite deity) and accepts all that happens in his life as being so ordained.

• Enshrined in Tibetan Buddhism is the unshakable belief in the creator; that he will take care of one as a child, dispensing all that one richly deserves, through the good deeds (and sins) accumulated during the course of our earthly existence, in this lifetime and those that preceded it.

• Islam is akin to submission; also means hope and trust in what is to come. A believer must demonstrate humility and comply with the command to strive for god.
Unique Cultural Belief Systems

• The Afterlife
  • A belief that has been prevalent across many cultures across centuries

  • Egypt: Ba means something along the lines of soul or personality, while Ka was the part of the soul that contains the life force. While the Ka was able to live longer through the process of mummification, Ba separates from the body, dissolved completely in the kingdom of the dead and lived on as the true self.

  • Hinduism: The Rig Veda, the ancient text talks about the eternal cycle of karma-samsara. Freeing oneself from the cycle is is possible for the very few who attain Vishnu, one of the higher gods. Others experience heaven or hell depending on the balance of their good vs. bad deeds, only to inevitably reenter the cycle of birth and death.
Unique Cultural Belief Systems

• The Tibetan Book of the Dead (Bardo Thodol)

• In addition to the “wheel of life” the Buddhist understanding also includes the “wheel of rebirth”. The aim of the religion is to break the cycle of becoming and decaying.

• The central theme of the Bardo Thodol is therefore the fear of dying and our inability to overcome the projections of one’s own sub-consciousness that become very potent in the state after death

• For this reason the book accompanies the deceased (or dying) in the form of instructions, from the moment of death, through the intermediate stages of bardos, right upto the moment of rebirth. A Lama (a holy man or friend) reads aloud from it, near the deathbed.
The cycle of life and death...

- In Tibetan Buddhist teaching human existence is believed to consist of four Bardos (phases).
- The natural bardo of this life
- The painful bardo of dying
- The luminous bardo of dharmata (after death)
- The karmic bardo of becoming (rebirth)
- The Bardos are viewed as particularly powerful opportunities for liberation.
Unique Cultural Belief Systems

• The extended family/ the authority figure

• For many in traditional cultures the extended family is the fabric into which their individual lives are woven

• There is often an inherent belief in the ability of the family “to decide that which is right for the individual”. Many people who have grown up in such environments have not been burdened by “significant” decision making. Women for example often expect their father/ husband/ brother/ son to make key decisions for them.

• Very often, in medical circumstances, people rely on the doctor, nurse, priest or worse still soothsayer, to predict the right course of action.
Advance Directives of Care of Dementia - Belief System Challenges in Asia

• Acceptance: To one steeped in the mood of acceptance, who believes that “the almighty should decide the best course” the ADC may be an oxymoron

• Afterlife: To one who believes in the concept of the afterlife, ADC’s may pose unique challenges; not just decisions made now, but their repercussions thereafter

• Extended families/ Authority figures: To one who has relied on the extended family/ authority figures for key decision making, the ADC may be a bridge too far
The Caregiver in Asia

• Guilt & Shame?

• Paying back, doing one’s best for one’s parents, elders (Shaji KS on Caregiving, ASAD Colloquium, 2011)

• Cultural dissonance- Western educated/ oriented children, Eastern parents, differing values- different priorities

• ADC- An act of finality?! Loss of hope?! Acknowledgement of the inevitable?! Inauspicious?!
Unique ADC challenges in Asian cultures

- Often diagnosed late: Even in the West only about 85% of nursing home residents found to have “capacity” for simple but not complex decisions

- Patients often live in extended families; perceived disability is low (10/66 Dementia Research Group) and therefore perception of terminality is poor

- It may be (in many instances) culturally inappropriate and inauspicious to discuss “death & dying” with an elder?!
Unique ADC challenges in Asian cultures

The 3 A challenge in many settings

- Availability of trained personnel to discuss & guide implementation- doctors, psychosocial personnel, lawyers etc.

- Acceptability of such discussion process in Asian cultures: networked, extended and emotionally intertwined family structures; multiple stakeholders with differing views

- Accountability of those involved in such process- possibility of misuse for pecuniary and other advantage
How should Advance Care Directives be implemented in Asia?

• Global standards
• Local Sensitivity- medical, psychosocial & legal
• As part of all eldercare & palliative care
• Culturally relevant
• Pragmatic & applicable
• Not top down imposition but bottom up development

The Asian Challenge!
• Establish a Pan-Asian Task Force under ASAD
• A detailed report developed using qualitative methods
A final thought…

• “How can you be a truly effective doctor when you do not have at least some understanding of the truth about death, or how to care spiritually for your dying patient? How can you be a truly effective nurse if you have not begun to face your own fear of dying and have nothing to say to those who are dying when they ask you for guidance and wisdom?” Sogyal Rinpoche to Clinicians in the Tibetan Book of Living & Dying