Addressing the chasm between the philosophical and real life perspectives to ageing: making bioethics relevant to society

Jean Woo, MD

Director, CUHK Jockey Club Institute of Ageing

香港中文大學
The Chinese University of Hong Kong

香港中文大學
賽馬會老年學研究所
CUHK Jockey Club Institute of Ageing

香港賽馬會慈善信託基金
The Hong Kong Jockey Club Charities Trust
同心同步同進 RIDING HIGH TOGETHER

- CUHK Centre for Bioethics launch conference

  January 2015 in conjunction with the Hasting Center

- Themes raised: inequity in health care within a setting of resource

  - constraint

  - end of life care

- A perspective from a clinical care professional's point of view is important: Prof Raymond Tallis; Dr Derrick Au

- Should ethical principles underpin good quality care?
- What motivates health care professionals to do the right thing?

Examples of conflicting forces in the setting of resource constraint

- Duration of stay in hospitals as a performance measure – duty to superiors versus duty to patients (patients' best interest)
- No toiletting: use incontinence pads

Examples of end of life care: attempts to improve the quality of care at the end of life

- HKJCECC project:
  - building capacity among health & social care professionals
  - Community centres to provide continuing support with help of volunteers (centre-based + outreach)

The Public

- Insights from interim program review of HKJCECC project
  - Patient/public views on knowing facts, choice, no suffering
  - Media coverage well received: TV programme, newspapers, websites, etc

South China Morning Post

Nobel winner wants to die in peace at home, wife says, as she urges Hong Kong to change culture on end-of-life care

Physicist Charles Kao Kuen, who has end-stage dementia, does not wan
comes

PUBLISHED : Sunday, 1
UPDATED : Monday, 11

'Free Hong Kong doctors to help dying patients end their days at home'

Former health minister calls for legal and operational barriers to be lifted so that fewer people have to spend their last days in hospital

PUBLISHED : Monday, 11 July, 2016, 8:02am
UPDATED : Monday, 11 July, 2016, 8:02am

COMMENTS:

End-of-life care in Hong Kong severely lacking, doctors warn

With only 19 palliative care specialists in the city, priorities and training must change, they say

PUBLISHED : Wednesday, 22 June, 2016, 8:02am
UPDATED : Friday, 24 June, 2016, 4:15pm

COMMENTS: 4

Majority of Hongkongers willing to sign document setting out end-of-life treatment, survey finds

Academic says government needs to enact legislation to back up such documents

PUBLISHED : Saturday, 01 October, 2016, 5:02pm
UPDATED : Sunday, 02 October, 2016, 1:24am

COMMENT: 1

The Hardware

- Advanced Directives covering
  - Cardiac resuscitation
  - Artificial ventilation
  - Artificial nutrition and hydration
- Advanced care plan

The Doctors & medical students

- Prevalent attitude

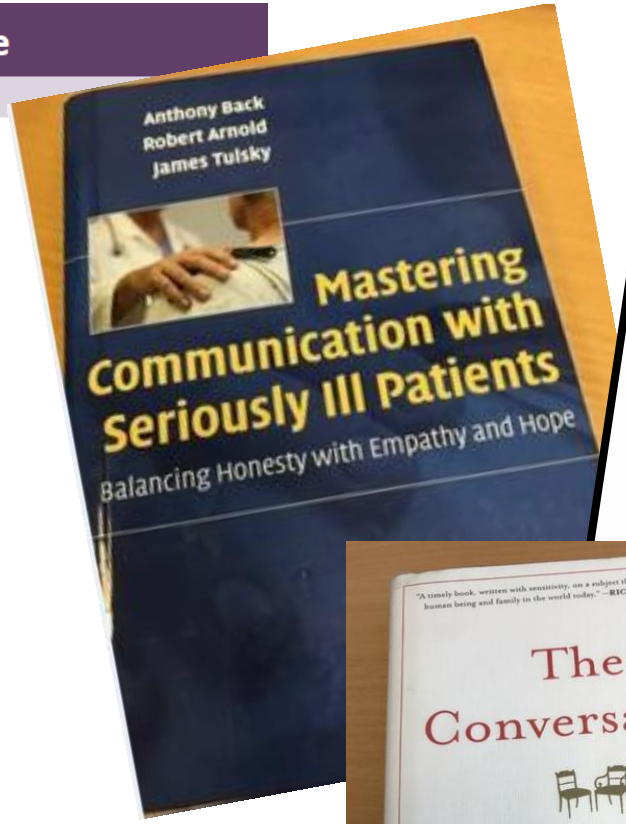
  Overriding goal to keep alive

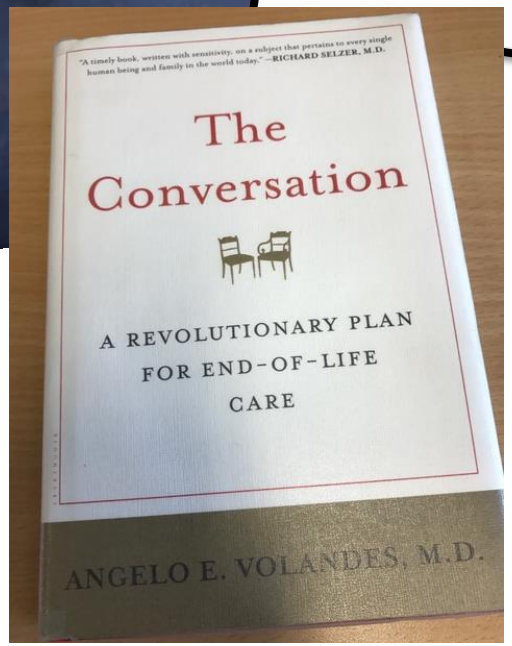
  Not achieving this goal = failure
- Reluctant to 'Label' end of life stage and initiating appropriate conversation
- Perspective of once off signing a form (as for consent form for operations) rather than initiation of a series of ongoing conversations (see serious illness conversations guides promoted by UK College of Physicians; US-National Academy of Sciences & Medicine

Serious Illness Conversation Guide

CONVERSATION FLOW

1. **Set up the conversation**
   - Introduce the idea and benefits
   - Ask permission
2. **Assess illness understanding and information preferences**
3. **Share prognosis**
   - Tailor information to patient preference
   - Allow silence, explore emotion
4. **Explore key topics**
   - Goals
   - Fears and worries
   - Sources of strength
   - Critical abilities
   - Tradeoffs
   - Family
5. **Close the conversation**
   - Summarize what you've heard
   - Make a recommendation
   - Affirm your commitment to the patient
6. **Document your conversation**





ARIADNE LABS

Clinicians

- Determining the timing of transition
- Assessing the readiness of patients and family members

Chan HYL, Lee DTF, Woo J, Huso Y. The development of palliative and end-of-life care in Hong Kong. Public Policy Research Funding Scheme (2016 – 17).

Chan HYL, Chan SSH, Ng WM, Tsang SM, Mak K, Tsang MC. Challenges in end-of-life care decision making for patients in long-term care setting: Perspectives of health professionals. 2016.

Uncertainty about disease severity

Family members had not been told of the disease trajectories and prognosis explicitly, and so sometimes it is hard for them to accept the health changes.

> "*All the things changed so quickly…The doctor had told that the surgery was very successful just 2 weeks before her readmission…The doctors should not just present all the hard facts to us…What does 20% survival rate means? We would not know which is the best option…Until today, I am still unsure if I have provided the best care to my mum.*" (a young lady whose mother died of gynecological cancer)

> "*The doctors have not explained her condition in detail, but I think it is not going well.*" *(a son whose mother had congestive heart failure)*

Ignorance about palliative & EoL care

Public awareness about palliative and end-of-life care seems poor.

A young lady reverted the DNACPR decision for her husband who had lung cancer in the last minute because she thought that the decision was made in a rush. Although the resuscitation procedures were not able to rescue his life, she thought that at least she had done something for him.

"*Probably because there are nothing they can do, they referred him [the patient] to palliative care.*" (an elderly lady whose husband had lung cancer)

"*I have never heard of that [palliative care] before. Previously I thought it was just a place for people waiting for death, but my perception changed totally after my mum was transferred to there. It is like the difference between hell and heaven…*" (a middle-aged lady whose mother died of breast cancer)

Determining the timing of transition

- Some clinicians concerned if it is premature to introduce the conversation because:
  - some patients have lived with the condition for a long period of time
  - some patients' conditions are stabilized or improved after the treatment
  - new therapies are available
  - the health care team cannot reach a consensus
  - …etc.

"It is hard to answer the Surprise Question." *(a medical doctor)*

Assessing the readiness of patients and family members

The clinicians were hesitant to introduce the conversation.

“It depends on their emotional status and whether they can accept the reality. It takes some time for observation, or else the patients and families may feel that they were being cursed or given up.”

Bad examples…

"We would not ask the patients directly about how they think about death, you would be challenged. I would ask the family members to discuss the issues among themselves and let us know their decision." (Focus group interview with clinicians)

"I can see from their faces, they are very annoyed with our silly questions. Please tolerate with us even though these questions seem silly to you, we really do not know what we should do at that moment." (a family carer)

"In my memory, I have only met the doctor once. You could never find them during the visiting hours. The doctor informed us about the DNACPR decision through phone only. At that moment, I was shocked and not knowing what to do." (a family carer)

Would management guided by facts and underpinned by ethical principles be key to culture change among doctors

- It is not an issue of running palliative care workshops for doctors, or training more PC specialists
- It is monitoring the perspective that if your job is to look after sick and dependent people, everyone should adopt this practice
- Not sufficient to just target undergraduate curriculum, since studies have shown that newly graduated doctors' attitude and behaviour are moulded by their seniors

Raising ethical literacy among health care professionals

- Autonomy, justice, benefit harm balance ……..
- Comments from philosophers:
  - Chinese culture – autonomy of group/family rather than individual
  - Moving away from principled ethics

Raising health literacy on ageing issues among philosophers

- Not commonly known facts regarding ageing issues: correct facts should guide philosophical discourse
- Tube feeding in end stage dementia
- Concept of frailty (cognitive, physical) to guide service rather than chronological age
- Pain, intolerable suffering, and assisted dying (see R. Tallis)

Conclusion

- Medical ethical principles should guide all involved in providing care to people, from frontline to policy makers
- Currently we are far from this perspective, and culture or mindset change is needed
- This requires major attention from bioethicists now
- The scenarios I have raised are happening now; not in some future date as for other hypothetical scenarios