CONVERSATIONS AT LIFE'S END: REIMAGINING ADVANCE CARE PLANNING IN HONG KONG AS AN INTERVENTION

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What matters at the end of life?

- Helping terminally ill patients plan for end of life (EOL)
  - What did they find most useful in these discussions?
    - Envisioning possible outcomes
    - Renewing ties with friends and family (identifying surrogate decision-makers)
    - Establishing clarity regarding wishes
- Experience advising hospice providers
  - Growing need for services given demographic shifts
  - Emphasis from US state and federal governments on managing cost of care
  - Reducing medically futile treatments

Roadmap

- Focus on context of senior care in Hong Kong
- What is a ‘good death’?
- Moving from advance directives toward innovations in advance care planning
- End of life care pathways
- Policy gaps and finding a way forward

Demographics

- Like most developed countries as well as mainland China, Hong Kong has a significant aging population
- Approximately 13% of population is aged 65 and older (Census and Statistics Department HKSAR 2012)
  - Cancers are leading cause of death (Centre for Health Protection 2013)
  - Associated chronic health concerns
  - Decrease in traditional family structures
  - Failures in residential care and nursing assistance support systems
  - **Due to social, cultural, legal and economic factors, a majority of elderly deaths occur in public hospitals (Tse et al. 2007)**

Context of geriatric care

- Primary care
  - Structure is weak and primary care is provided mainly by GPs in the private sector (Leung et al. 2005)
- Residential care homes- Social Welfare Dept.
  - Nursing Homes
  - Care & Attention Homes
  - Homes for the Aged
  - Hostels for the Elderly
    - Regulatory and capacity issues
  - **Wait time for subvented homes generally more than two years; reduced for private homes**

Ageing in Place

- Hong Kong Government 2009-2010 Policy Address advocated ‘ageing in place’
  - Housing, social services, community integration, health services, mobility

- Resources:
  - Community Geriatric Assessment Teams
  - Community Visiting Medical Officers, Community Care Nurses, Psycho-geriatric Team services, Visiting Medical Officers

- 16 hospitals providing palliative care services
  - Need for development of palliative care services in RCHE settings

Revolving door

- High rate of accident and emergency department (AED) attendance and acute hospital readmissions of frail seniors (Reyniers et al. 2013, Yu et al. 2007, Hui et al. 2014)
  - Winter surge (Luk et al. 2013)
  - Burden on AED, congestion in acute wards
    - Lack of early transfer to step-down units
- Increased costs
  - High rate of interventions
  - Provision of medically futile care (seniors likely to be at EOL)
- Disruptive experience at a time that arguably should be peaceful and calm and devoted to quality of life

What is a “good death”?

- Larger conversation about what is a “good death”? (Yao et al. 2007, Gott et al. 2008, Ball et al. 2013)
  - Recent attention in literature to desirability of “dying at home”
  - Comfort care and palliative care
  - Focus on lowering rate of interventions and medically futile care
  - For many seniors, dying in place means dying in RCHEs
- But, patients and families may wish to feel certain they have received all possible care
- Conflicts of interest
  - Filial piety
  - Financial conflicts

Comparing site of death

- Dying at “home” (Gott et al. 2004, Temkin-Greer et al. 2013)
  - Burden on family and caregivers
  - Seniors may live strained circumstances
  - Nature of “home” may be fundamentally changed by intrusive death experience
  - Uncertainty regarding ability to provide quality care
  - But, ability to be surrounded by loved ones and possessions
  - Privacy and independence

- Dying in hospital
  - May lack intimacy, privacy and control (limited visiting hours, busy staff, crowded wards)
  - May lead to increased interventions and lack of palliative care
  - But, may be seen as providing necessary resources
  - May provide a more comfortable dying experience
  - Legal factors may lead to preference for dying in hospital

What makes a patient feel “safe”?

- Patients may have a sense of safety in hospital (Reyniers et al. 2014)
  - Access to round-the-clock care
  - Healthcare professionals
  - Technology
- However, the home may also provide a sense of safety and comfort

- Factors in a ‘good death’:
  - Reduced suffering, increased comfort
  - Time with family
  - Ability to feel a sense of resolution and control
  - Freedom from fear and worry

Where do patients die in Hong Kong?

- Hong Kong patients are prevented from dying in place
- Policy mismatch with “ageing in place”

- Death at home
  - Belief that dying at home is unlucky
  - No requirement to report to Coroner for a death at home, but registered practitioner must complete Medical Certificate of Cause of Death and have attended patient within 14 days prior to death (except in terminal conditions)
  - Family must register death within 24 hours
  - Lack of home support for palliative care

- While death at home is possible, it is inconvenient and uncommon

Dying in RCHEs

- Death in RCHE
  - Requirement to file a report with the Coroner for all deaths in RCHEs (Cap. 504)
  - Policy solutions may need to focus on improving quality and oversight of residential care homes to address legitimate concerns regarding care
- Approximately 1/3 of residents surveyed in 2007-2009 study preferred to pass away in their RCHE (Chu et al. 2011)

- Overcrowding
- Lack of trained staff
- Lack of defined procedures for EOL situations
- Palliative care still mostly provided in hospital settings

Advance care planning

- “Advance Care Planning” is a holistic description of the process of end-of-life planning
- Ongoing communication process among patients, families and health professionals regarding individual end-of-life care preferences (Teno et al. 1994)
  - Includes advance directives, but also other elements of planning
  - Advance directives focus on refusal of treatment; withdrawing or withholding treatment as distinguished from euthanasia
  - Legal and medically ethical in situations where further treatment is considered futile
  - **Can include treatments such as antibiotics, artificial nutrition and hydration, ventilator use, or more invasive measures such as resuscitation**

Advance directives

- Advance directives (AD)– variety of documents in different jurisdictions

- Living Will/Advance Directive
- Durable Power of Attorney for Healthcare (not available in Hong Kong)
- Do Not Resuscitate (DNR/DNACPR)/ Do Not Intubate (DNI)
- POLST/MOLST (new development in US)
  - Intended to complement AD, only for patients with serious illness or frailty
- Enduring Power of Attorney (Hong Kong Cap. 501, financial)

Legal status in Hong Kong

- Recent attention to advance directives by the Law Reform Commission of Hong Kong, but model form has not been granted legislative status

- Commission has rejected statutory forms because “it would be premature to legislate on advance directives when the concept is still new to the community and is one on which most people have little knowledge…”
  - **LRC has provided model form instead**
  - Two disinterested witnesses required, one a medical practitioner
  - Government to promote awareness and review in due course
- Can be argued that model form adds little to existing requirements under common law (Liu 2007)
  - 2013 consultation on DNACPR guidelines

But what does it look like in reality?

- Different patient types
  - Cancer
  - Dementia/frailty
  - Cardiac
  - COPD/ESRD/other organ failure
- How do we identify EOL or “terminal” patients and know when someone is “dying”?

Substituted decision-making

- Concerns
  - Rarely see “vegetable” scenario paired with clear EOL progression
    - ADs best suited for cancer (defined EOL progression)
    - Dementia and cardiac events, etc., may lead to loss of capacity, but lack clear EOL progression (Silveira et al. 2010)
  - Surrogate inaccuracy (Shalowitz et al. 2006, Marks and Arkes 2008, Winter et al. 2010)
  - Who decides?
    - Collective decision making culture unsuited to formal substituted decision-making
    - Patient autonomy becomes problematic when patients shift in and out of competence
    - Physician authority varies across cultures
  - Hong Kong AD form is minimal, no durable power of attorney for healthcare

Cultural context

- Chinese view of EOL:
  - Protectiveness (Pang 1999)
  - Concerns regarding truth-telling
  - Filial piety (Ng at al. 2002)
  - Family decision-making
- However, some studies have suggested that Chinese older people welcome end-of-life care discussions and are willing to indicate their own end-of-life care preferences (Hui et al. 1997, Chu & Woo 2004, Lee et al. 2006, Chan & Pang 2007)

Problems with AD documents

- POLST as reaction to problems with AD
- ADs ineffective at altering treatment outcomes (Hickman et al. 2010)
  - Patient-generated documents unhelpful in clinical settings
- DNR orders
  - More effective, but only helpful for patients in cardiac arrest
  - May be inaccurately associated with preference for less-aggressive care (Hickman et al. 2010)
- Tendency of autonomy to be fluid; doctors and family-members may override previously expressed wishes of incapacitated persons (Chan 2004, Winzelberg et al. 2005)

Value of EOL conversations

- Patients value opportunities to talk (Chan and Pang 2010)
- Functional value of conversation may be greater (establish clarity with family) than legal weight of documents
  - Decisions may be made by family consensus rather than substituted decision making
- Studies have shown a formal legal instrument would be well-received (Mok et al. 2010, Ting and Mok 2011, Lee et al. 2013)
- Many patients in RCHEs with no AD in place and already incapacitated
- Cannot use ADs but families and patients may still benefit from ACP conversations

ACP viewed as an intervention

- (1) Educate patients and their families
- (2) Introduce patients into EOL program pathways
  - Intended to avoid “revolving door” hospital admissions and futile care on a practical level, rather than the primary goal being the adoption of legal documents
  - Several pilot programs have been developed
    - Shatin Hospital and Prince of Wales Hospital
    - HK West Cluster- Fung Yiu King Hospital
- (3) Development of checklist or POLST-style documents for eligible patients?

Direct transfer programs

- Direct transfers to extended-care facilities through community geriatric care assessment teams
  - Shatin Hospital (extended care) and Prince of Wales Hospital (acute) (Hui et al. 2014)
- VMO and CGAT liaison nurse assigned to each nursing home
- Care delivered according to each patient's ACP and status
  - Group A: Clinical admission to Shatin Hospital
  - Group B: Admission to Shatin Hospital through AED of PWH
  - Group C: Admission to PWH acute wards +/- transfer to Shatin Hospital
- Patient survival and ALOS were not compromised

EOL pathways

- Other programs allow RCHE residents to elect to receive EOL care in-hospital or to stay in the RCHE before being transferred to AED for death (Luk et al. 2011)
- Candidates identified through Gold Standards framework for 3 illness trajectories (cancer, organ failure, dementia/frailty)
- AD and DNR introduced and incorporated into EMR

- Fung Yiu King Hospital Pathway
  - Patients cared for at RCHE until last days of life
  - Transfer to palliative and hospice ward of FYKH through expedited pathway until death
  - Death certificates issued by FYKH

- Queen Mary Hospital AED Pathway
  - Patients cared for at RCHE until last possible moment
  - Transfer to Queen Mary AED
  - Death certificates issued by hospital
  - Body stored at QMH mortuary and transported directly to funeral home

Policy gap

- The way people die in HK due to context of RCHEs, primary care, hospitals, and ideas about place of death means that advance directives alone cannot offer solutions

- More important is
  - 1) Having clear conversations with families who will be making group decisions about care option over a period of time during a patient's declining EOL period, and
  - 2) Offering concrete choices for EOL care

- There is a significant need for increased development and scaling up of transfer programs and other practical options to fill the gap in policy and services at end of life

Future Possibilities

- Offering meaningful options to patients to fill gaps in policy and practice
  - Need for development of Medical Assessment and Planning Units close to AEDs with dedicated geriatric teams and effective discharge planning and support
  - Scale up EOL pathway programs
  - Use ACP planning process as introduction; integrate program selection into model documents
  - Development of POLST forms and integration into ACP programs at RCHEs
  - Integration of palliative care options into RCHE settings
  - Reform of RCHEs to allow reduced death reporting obligations and make dying in place a more realistic option

Conclusions: Reimagining ACP

- The utility of advance care planning in Hong Kong is primarily as an opportunity to enrol patients in concrete intervention programs, and secondarily to establish clarity between patients, families and clinicians regarding EOL expectations and provide patients a valued opportunity to be heard.

- The next level would be to provide patients and caregivers with clinically targeted tools like the POLST to ensure patient and family wishes are carried out.

- Without real options in place, helping patients create ADs can have limited positive effect on their death experiences.

Questions?

"Don't freak out—it's just a save-the-date."