Negotiating end-of-life care between tradition and modern healthcare: Coastal Chinese’ perspective

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The 2015 Quality of Death Index
Ranking palliative care across the world

Top 20 Countries:
- UK
- Australia
- New Zealand
- Ireland
- Belgium
- Austria
- Netherlands
- Germany
- Canada
- U.S.
- Hungary
- France
- Norway
- Taiwan
- Poland
- Sweden
- Luxembourg
- Singapore
- Switzerland
- Hong Kong

The Quality Of Death Index

Overall Score — 5 5.5 6 6.5 7 7.5 8

Data: Economist Intelligence Unit
Index measures end-of-life care services across 40 countries (30 OECD and 10 select others for which data was available); 2010
How End-of-Life care is rated

Palliative and Healthcare Environment
- General palliative and healthcare framework

Human Resources
- Availability and training of medical care professionals and support staff

Affordability of Care
- Availability of public funding for palliative care
- Financial burden on patients

Quality of Care
- Presence of monitoring guidelines
- Availability of medications that relieve pain
- Extent of partnership between healthcare professionals and patients

Community Engagement
- Availability of volunteers
- Public awareness of palliative care

Source: ECONOMIST INTELLIGENCE UNIT   ST GRAPHIC
Englishness.

How about Chineseness?
HONG KONG(NESS?)

- Lack of choice
- Lack of dignity in death bed
- Not aware of hospice/palliative care
- Doctors do not support
- Absence of policy
Academic Roger Chung says government needs to enact legislation to back up such documents. Among the 1,067 adults aged 30 or older interviewed over the phone from April to June this year, over 60 % said they would sign the [AD] if backed up by legislation. About 74 % agreed the document was a “good approach” for people with incurable diseases.
Last wish: Hong Kong survey reveals most elderly would rather die in hospital than at home

Palliative care expert suggests that preparations should be made to allow elderly to end their life in care homes before considering death at home
QUESTIONS ASKED:

- How did traditional practice of end-of-life care emerged as a discursive centre of impoverishment in the context of colony making and decolonization (state-building)?
- What have the concept of good death changed over time and space?
- How did modern medicine (including the introduction of palliative medicine, hospice) re-shape the politics of end-of-life care?
- How can historical and ethnographic works inform policy makers regarding the best practice of end-of-life care?
Pre-modern: Being prepared, timing, control. (Aries 1981; Bartley 2001; Howarth 2007)
Modern: physical quality; die nobly (Kllehear 2000)
Hospice/ euthanasia as critiques of hospital death
How about Asia?
MONSOON ASIA

- Mobility of population: Chinese immigrants
- Cultural believes
- Practices of health related issues
- Conflicts between traditional and modern medicine
- Process of colonization and decolonization
Singapore: 716 sqkm
British colonization: 1819-1942

Hong Kong: 1,104 sqkm
British colonization: 1841-1997
Zoning. Singapore & Hong Kong
Data from mixed methods

- National archives (Singapore)
- Hong Kong Public Office Records (PRO)
- Historical newspapers, e.g. South China Morning Post, The Strait Times
- Court materials, Hansard Reports
- Medical journals
- Hospital archives (Tung Wah)
- In-death interview with key propagators of hospice
TWO PARTS STUDY: HISTORY + ETHNOGRAPHY

Modern medicine
- Responses, negotiation, mutual transformation

Traditional practice
- The state
- Medical disciplines
- Hospitals
- Religious social organizations

Ancestral halls
- Philanthropists
- Death houses
- Folk beliefs
DISENFRANCHISED END-OF-LIFE CARE

People’s autonomy is stripped away.
Reluctance to decide their death location.
Attitude towards end-of-life decision becomes ambivalent.
...etc.

Proper Death  →  Disenfranchised Death
FOUR FACTORS

Proper Death → Disenfranchised Death

- Medicalized death
- Sanitary implications of colony-making/state-building
- Changing sense of place among Chinese patients
- Professionalism and the instrumental rationality
FACTORS CONTRIBUTING TO THE DISENFRANCHISED EOLC

- Medicalized and marketized death
- Sanitary implications of colony-making/state-building
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FACTORS CONTRIBUTING TO THE DISENFRANCHISED EOLC - I

- Medicalized and marketized death
- Sanitary implications of colony-making/state-building
- Changing sense of place among Chinese patients
- Professionalism and the instrumental rationality
- Dying at home
- Surrounded by the beloved
- Preferably, (for Chinese immigrants), body will be repatriated and buried in "hometown"
- In HK and Singapore: practical arrangement
Alan Whicker’s Hong Kong and Singapore • 5’50”
Traditional death-and-dying

• Life and death not easily distinguishable: they occur in the same place
• Home or death house
• Underdeveloped medicine: CARE
• Lengthy waking time after death
• Burial sites within reach for regular visits

Credit: Harrison Forman (1955). University of Wisconsin, Milwaukee Digital Collection
I (義)

- Righteousness, human ties
- End-of-life care as moral economy
- Managed by ancestral halls, neighborhood associations or charitable organizations
- 義祠、義塚、義莊
- 3 spaces in I Ts’z
- No fear, callousness
HOUSE OF GREAT DIFFICULTIES, SINGAPORE

• A.K.A 大難館, Death House
• Sago Lane, Street of the dead.
• Mid-19th Century, initiated by ancestral halls (applied through GOV).
• Single immigrant workers: e.g. Samsui women
• Minimum rent.

photos by Henri-Cartier Bresson
大難館 House of the Great Difficulty, Singapore

Credit: Harrison Forman (1955). University of Wisconsin, Milwaukee Digital Collection
FACTORS CONTRIBUTING TO THE DISENFRANCHISED EOLC - II

- Medicalized and marketized death
- Sanitary implications of colony-making/state-building
- Changing sense of place among Chinese patients
- Professionalism and the instrumental rationality
**Picture of Women Martyrs** (Wong Pik-Wan)

- “This is the hottest day of Hong Kong. Your mother-in-law’s body was placed on the sidewalk. Fluid is oozing out from the coffin.”

- Your mother-in-law doesn’t walk. Her body is as heavy as a ship.” “Four undertakers feel itches in their ears. A worm came out from her ear.”

- “這是香港百年最熱的一天。你婆婆的屍體擱在路邊,棺材一直滴出水來。你婆婆不肯走,屍體重得像鉛。棺材擱在路邊,一點聖杯全翻。四個仵業佬,耳朵發癢,毛蟲從耳洞鑽出。” 黃碧雲
HYGIENIC MODERNITY

- 1850s: Elites and businessmen helped construct small buildings beside the shrine of the Earth God on Tai Ping Shan Street.
- Problem of crowdedness
- 1869 Alfred Lister publicized the “scandal” on South China Morning Post 1869
- 1870 Hospital Incorporation Ordinance
- 1872 Tung Wah Hospital
However, when population grew...
78 Dead rose from death houses and returned home

- 15 Oct 1958, *The Straits Times*
- Doctors answering PAP Health Officer’s question
- “Foul air” endangers health of the sick
- “Joss sticks and burning papers” as attributes to ill health
- “they were a nuisance and fire hazards”
- → City Council snap checks
- → 1961 ban of taking living individuals
- → Practice continued to 1980s (hospice movement commenced)
• This “terrible” island of Singapore, BBC, 1959.
• AGS Danaraj comment on the Straits Times (25 April 1959).
• Singaporean government’s hesitance to develop China town as tourist spot.
FACTORS CONTRIBUTING TO THE DISENFRANCHISED EOLC - III

- Medicalized and marketized death
- Sanitary implications of colony-making/state-building
- Changing sense of place among Chinese patients
- Professionalism and the instrumental rationality
Sense of Place

• Yang, Nienqun (2006)

• Space politics during the conflicts between Eastern/Western medicine

• Identity of patients through the establishment of “space”.
CHANGING SENSE OF PLACE

- Changing sense of place in the conflict between East-West medicine (Yang 2006)
- HKers used to hospital experience (Leung 2010)
- Hospital as nodes for medical development in Singapore (Loh 2014)
SNG DEATH HOUSES STOPPED TAKING THE SICK

Director of Medical Services, Dr. Ng See Hook, “We feel that the sick should be treated in our hospitals which provide all facilities available.”

“in old days, people were afraid of going to the hospitals, as the feeling was that only people about to die will go there.”

“Photographers and tourists who had always considered it is a ‘must’ to tour the houses when in Singapore are now welcome no more.”

11 Sep 1962, The Straits Times
RESIDENTS PROTESTS

• 1950s-60s: Protest against death houses
• 1960s: death house ban, practices exited to 1980s
• 1980s: hospice movement. Protests persisted.

Sunday Times Staff Reporter

THE Tiong Bahru Community Centre has dropped its plan of setting up a death house in the Tiong Bahru area because of protests from residents living near the proposed site, Mr. D. Robertson told the Sunday Times yesterday.

29 April, 1951

17 June, 1966
DIFFICULTY TO PROMOTE HOSPICE IN SINGAPORE

- Singaporeans still do not like to go to the hospital
- MPs fear hospitals may become death houses (1983)
- Lee Kwan Yew’s personal opposition
- Distrust against Christian services (Anne Merriman arrived in 1965, St Joseph’s Home 1967)
- Resident’s protest against Dover Park Hospice (1992)
- Home palliative care: good out from misfortune
FACTORS CONTRIBUTING TO THE DISENFRANCHISED EOLC - IV

Medicalized and marketized death

Sanitary implications of colony-making/state-building

Changing sense of place among Chinese patients

Professinalism and the instrumental rationality
New professionals

- Hospitals as nodes of medical modernity ← modern healthcare professionals
- Law to prevent foul play concerning unnatural death ← coroners
- Urban planning ← marginalized undertakers
CORONER’S ORDINANCE

1841
The first coroner was appointed in Hong Kong in 1841, followed by the abolishment between 1888 and 1950 for 62 years.

1934
In 1934, rules were relaxed for individuals who died from capital punishment and those who died in prison.

1950
In 1950, March, a death at the mental hospital conjured debate on whether or not a coroner was necessary in order to investigate the hospital administration which could be at fault.

1967
In 1967, a discussion suggested that the qualification of a coroner is best to be a lawyer and a medical person.
• In **1980**, the criteria for appointment of coroners were amended so that the appointee was no longer required to be a magistrate.

• **1997**, new bill passed and defined **20 reportable death** and the independence of coroners.

• **Significance**: independence and professional requirement of coroners → demands on the grounds → make-shift responses to regulations in order to work the system
Professionals in HK and Singapore

Colonial legacy → Competition rather than cooperation → Development disregarding the context
People do not know what to do if deaths occur at home or RCHE even if they prefer these options. Relevant legal requirements are complex and difficult to understand. Without sufficient help by the healthcare system, dying at home or RCHE is virtually not an option for most people.

From Woody Chang, Mayer Brown JSM 2013
Good death index = good palliative medicine index

• Hospice movement: a transnational campaign from 1980s onwards

• History of palliative care = history of hospice care = history of end-of-life care? (Goh 2017 interview)

• Understanding the EoL care service demand and provision

• Best practice using “relational personhood” framework
HISTORY AS EVIDENCE FOR HEALTH POLICY

- Historical knowledge allows us to avoid mistakes in the past, e.g. disease eradication.
- History teaches us the purpose and function of medicine vary over time and space.
- History is used in public discussion and it draws on different perspectives on health and diseases that can inform health policy planning.
- History tells us how disease onsets and developments are contingent on various factors according to different contexts.

(Virginia Berridge 2010)
IMPLICATIONS FOR POLICY

- Sources of acrimony, anxiety and debates
- Palliative medicine policy is not enough
- Infrastructure of health: e.g. GP system
- Streamlined services to respond to needs
- Effective housing policy: ownership
- Perspective education in medicine
Logic of care
Annemarie Mol (2008)
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