

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

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MEDICAL ETHICS AND HUMANITIES UNIT, HKU
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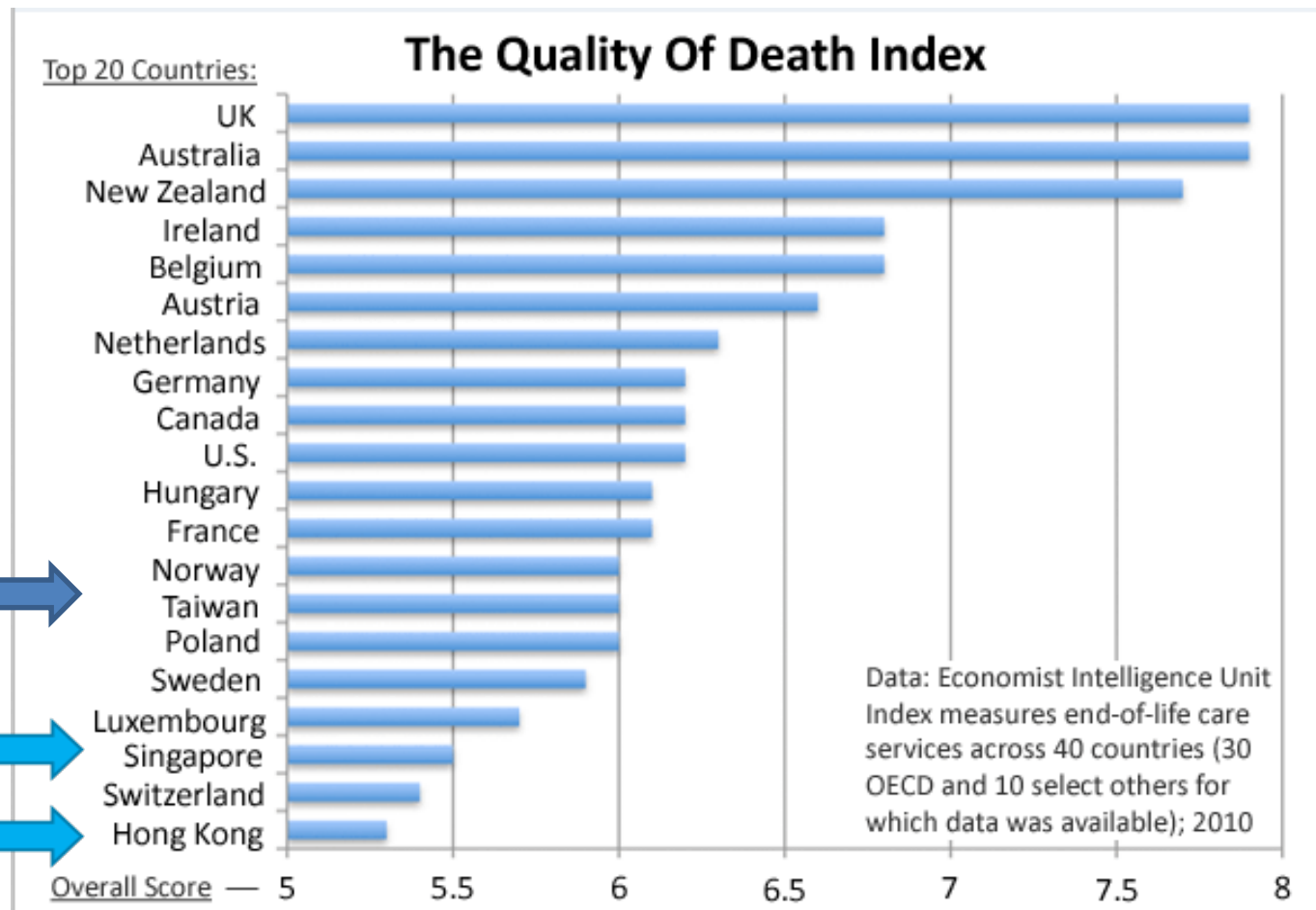
The 2015 Quality of Death Index

Ranking palliative care across the world

A report by The Economist Intelligence Unit



Commissioned by
 LIEN foundation



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

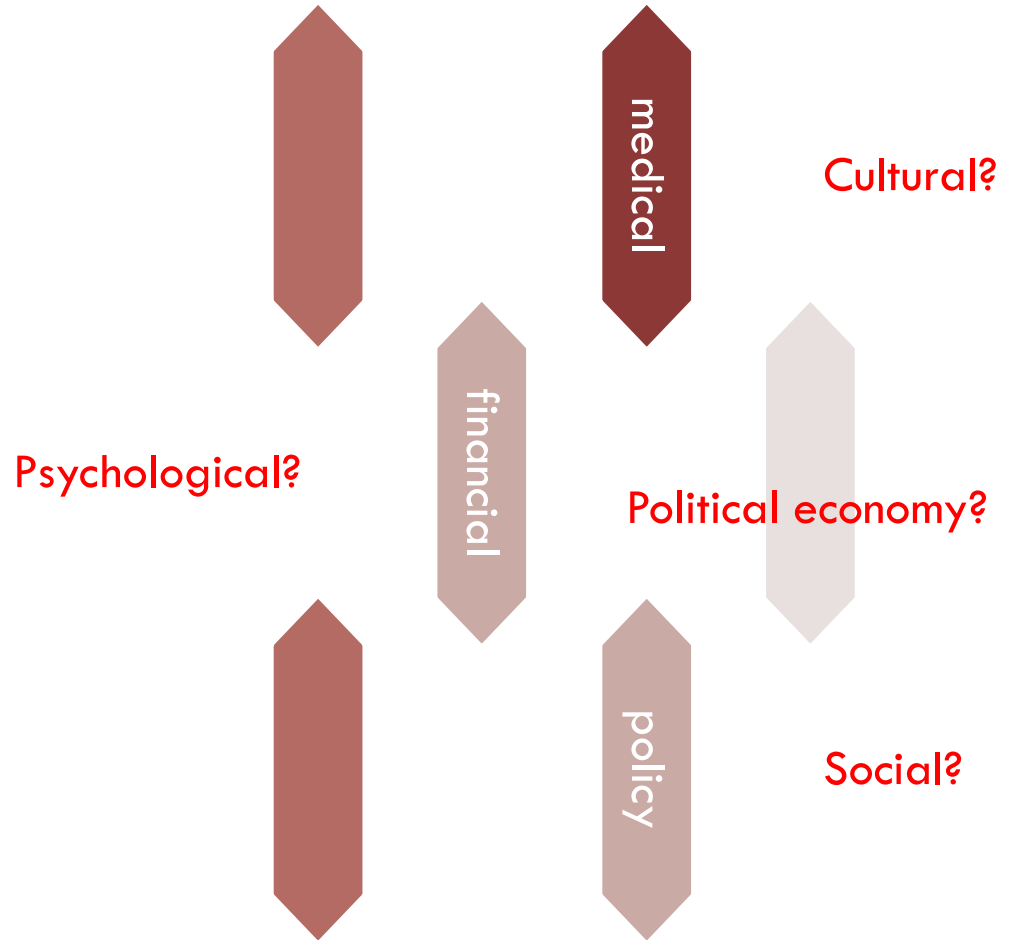
- Availability of public funding for palliative care
- Financial burden on patients

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



Comfort People

DANIEL MILLER

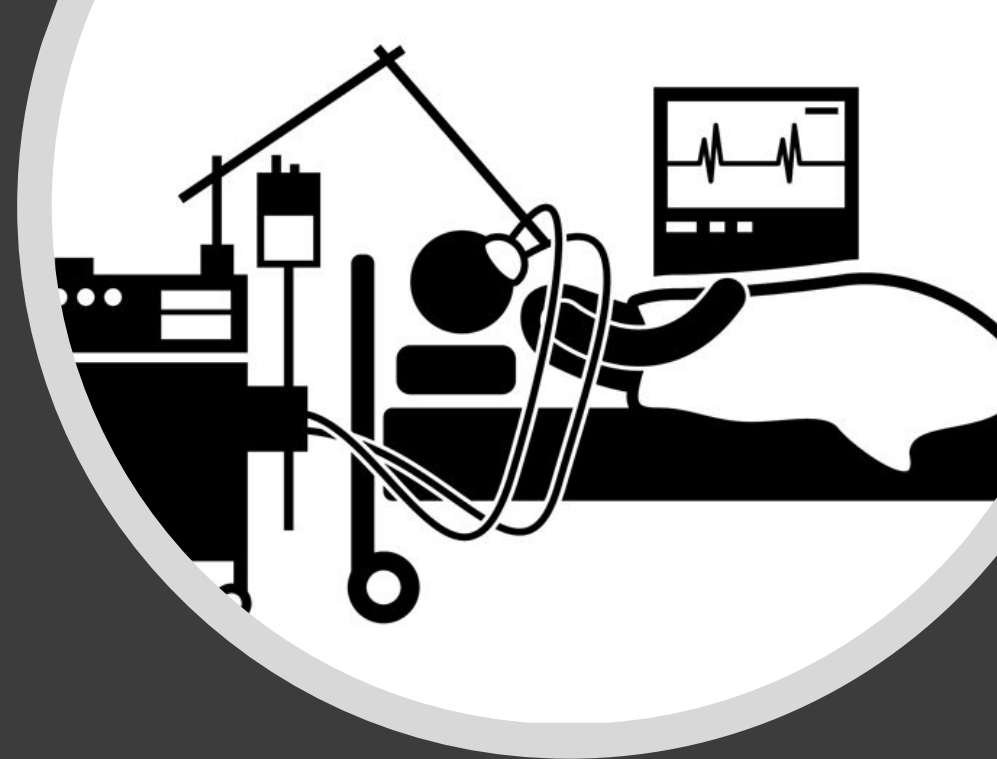


Englishness.

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



Majority of HK-ers willing to sign advanced directives

South China Morning Post 1 Oct 2016

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.



News / Hong Kong / Health & Environment

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

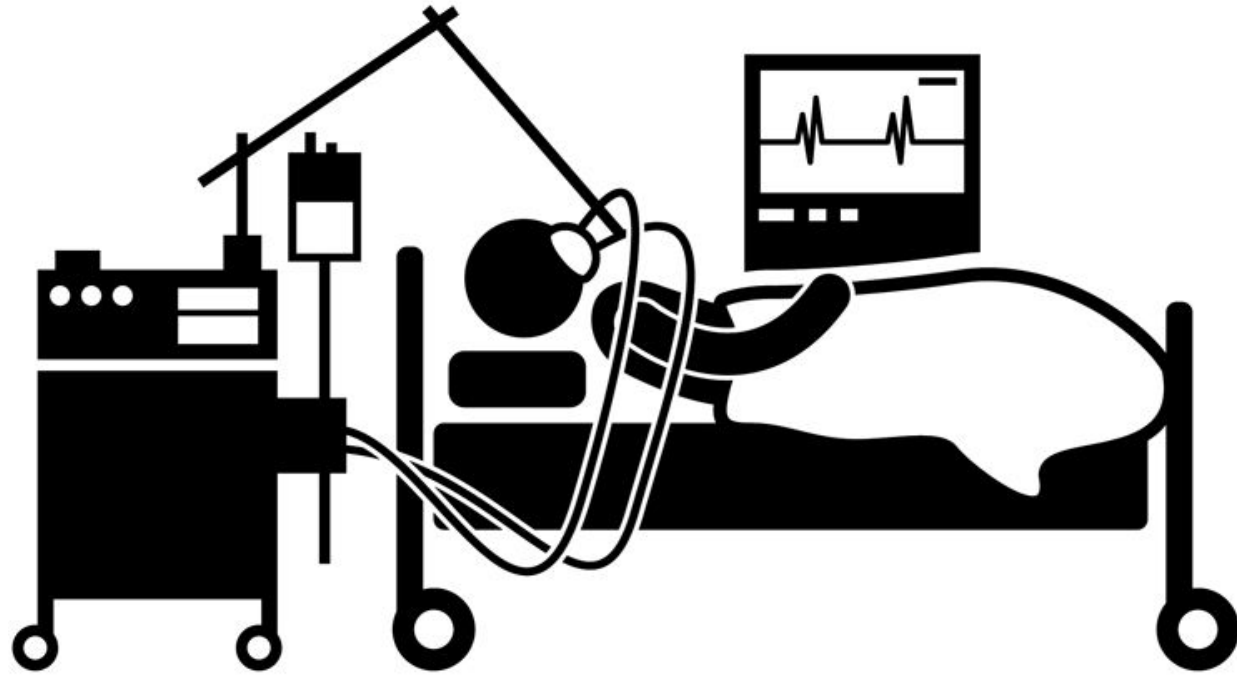
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COMMENTS:

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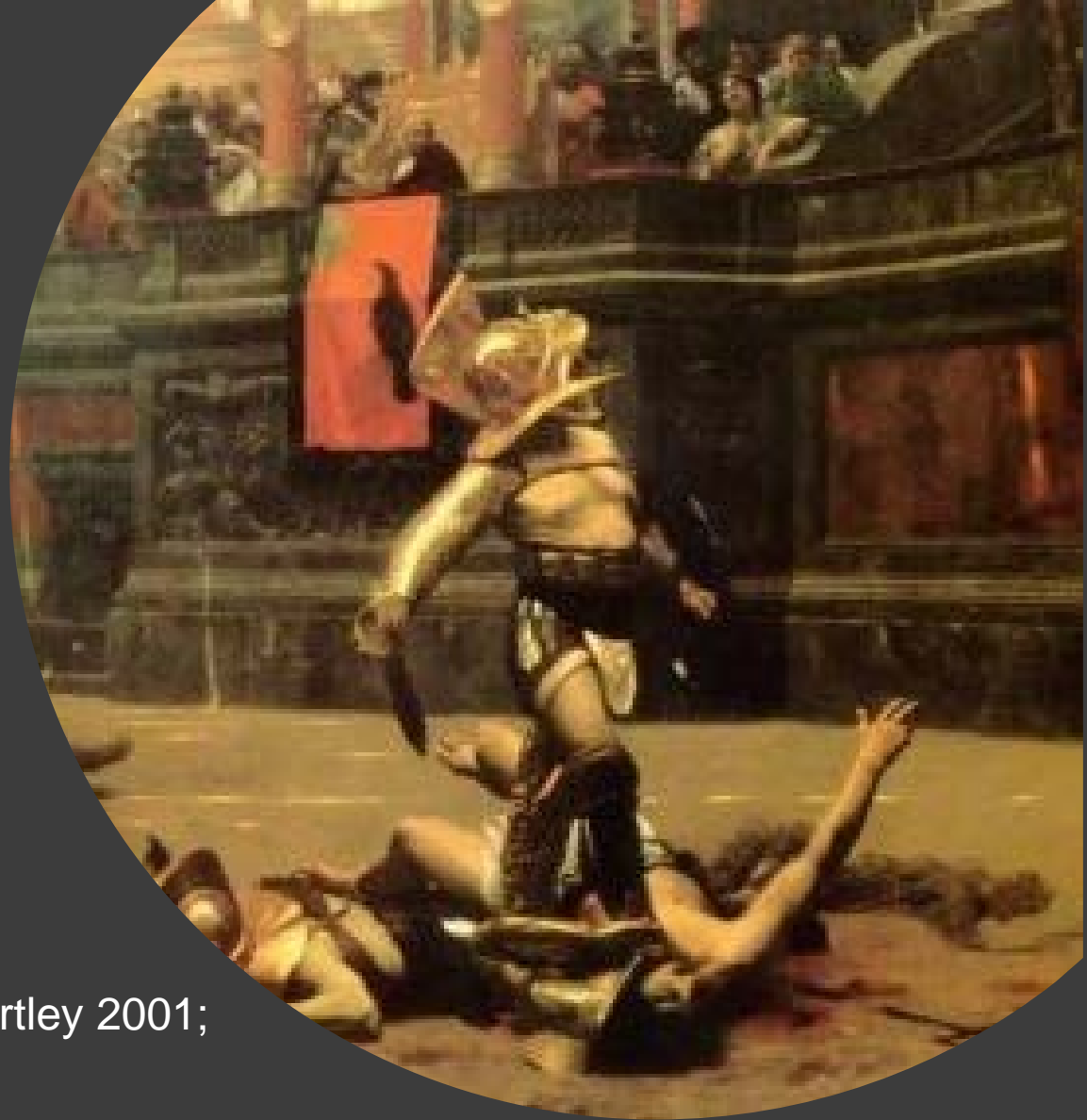




- How did traditional practice of end-of-life care emerged as a discursive centre of impoverishment in the context of colony making and decolonization (state-building)?
- What have the concept of good death changed over time and space?
- How did modern medicine (including the introduction of palliative 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?

QUESTIONS ASKED:

Good Death

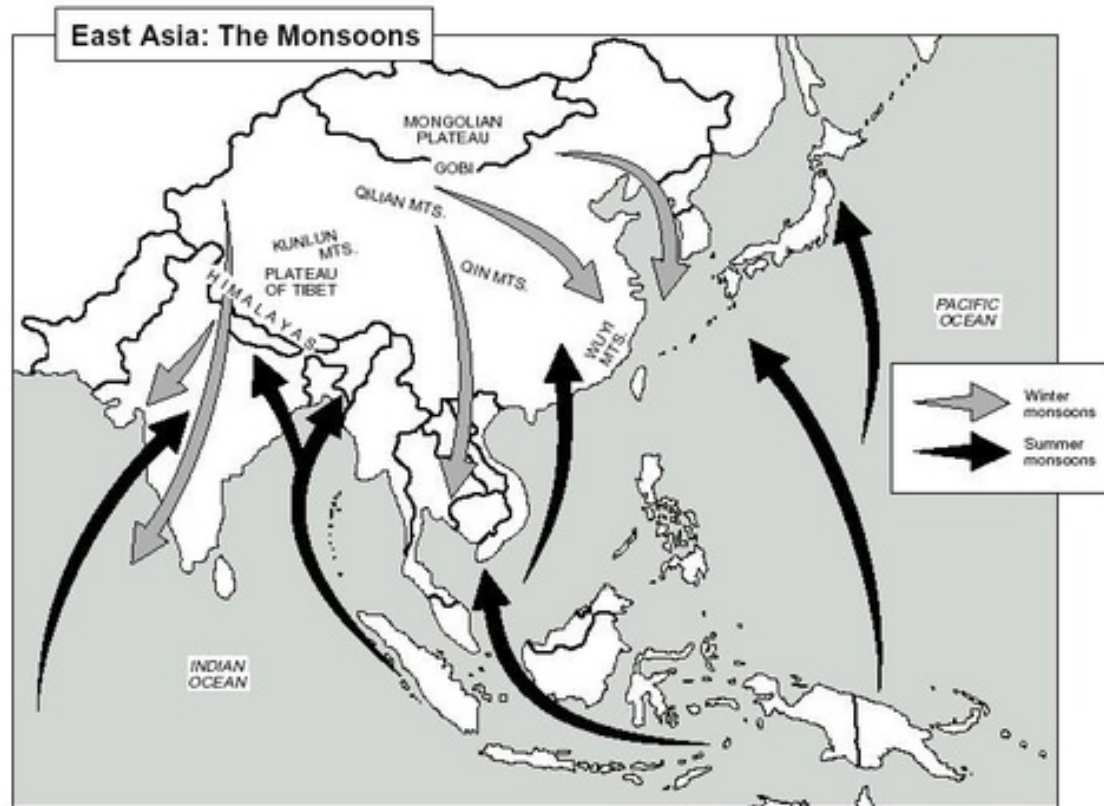


Pre-modern: Being prepared, timing, control. (Aries 1981; Bartley 2001; Howarth 2007)

Modern: physical quality; die nobly (Killehear 2000)

Hospice/ euthanasia as critiques of hospital death

How about Asia?



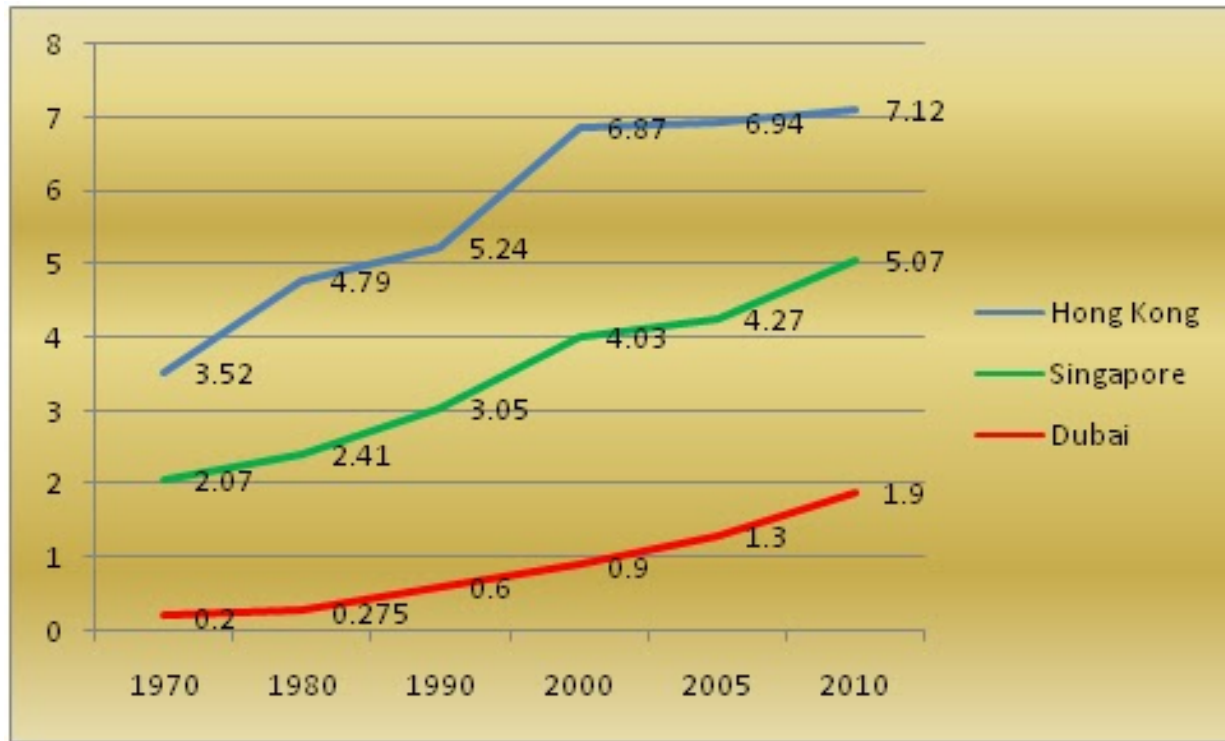
- Mobility of population: Chinese immigrants
- Cultural believes
- Practices of health related issues
- Conflicts between traditional and modern medicine
- Process of colonization and decolonization

MONSOON ASIA

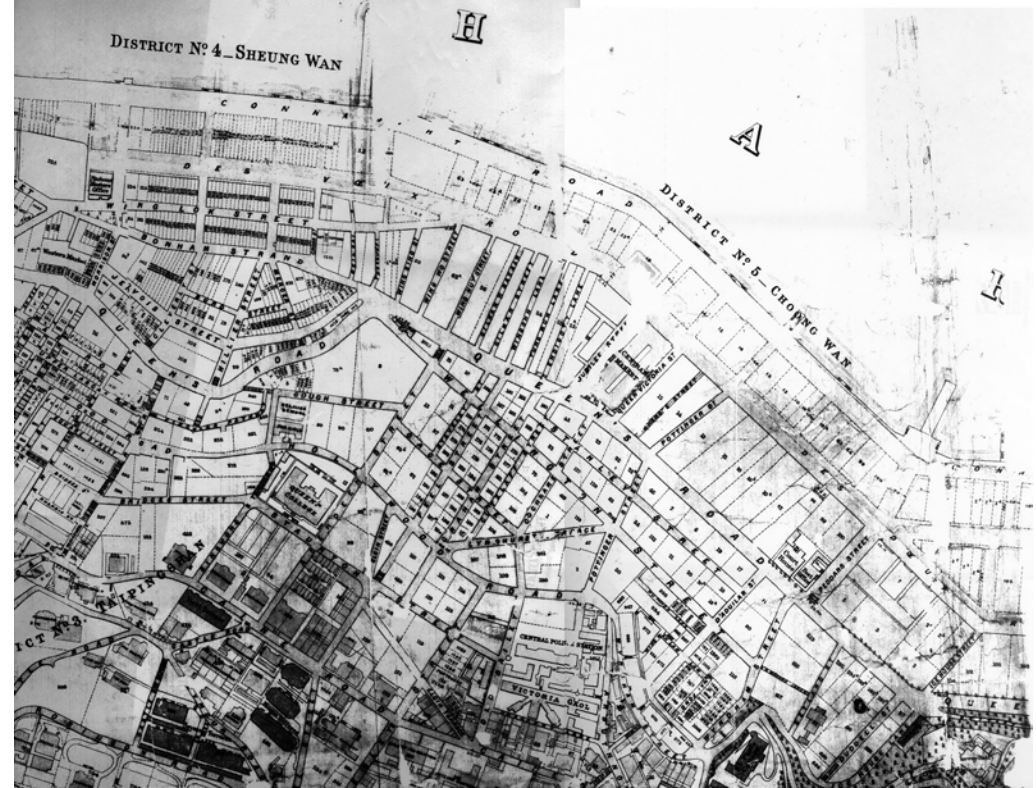
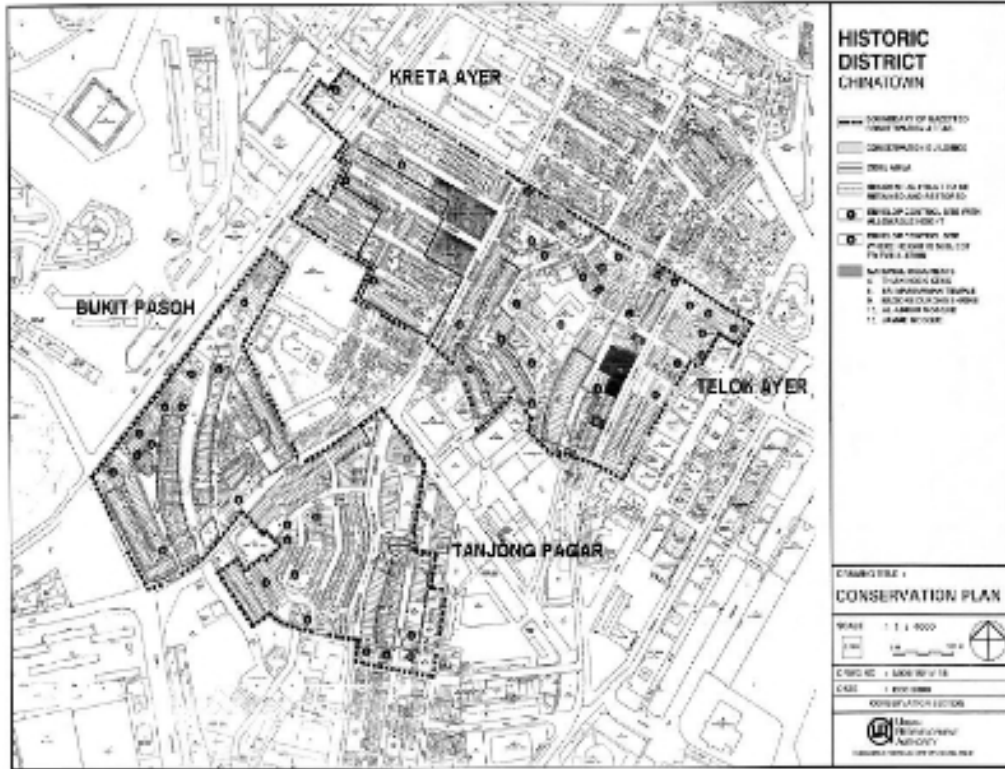


Singapore: 716 sqkm
British colonization: 1819-1942

Hong Kong: 1,104 sqkm
British colonization: 1841-1997



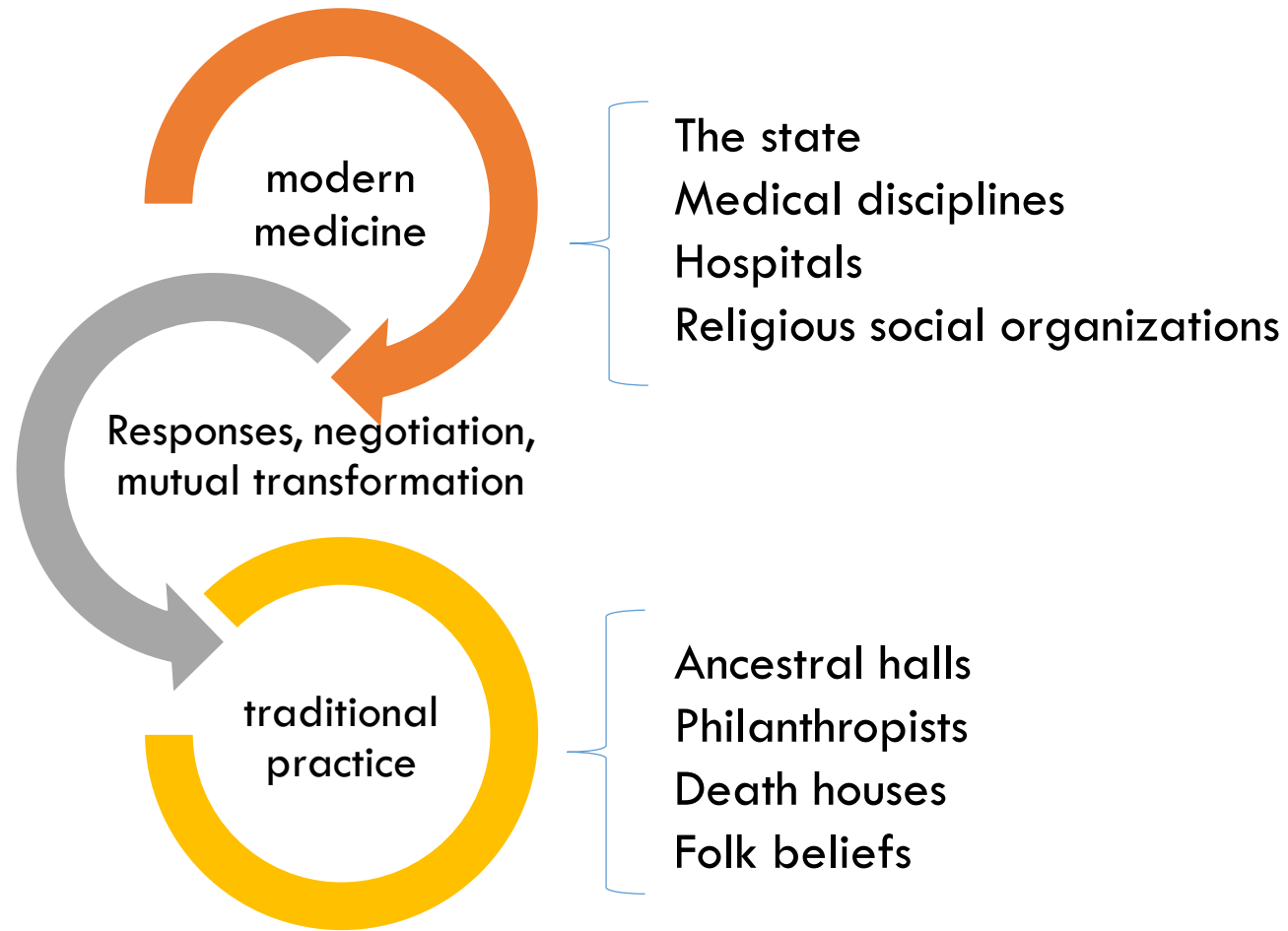
Zoning. Singapore & Hong Kong



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



DISENFRANCHISED END-OF-LIFE CARE

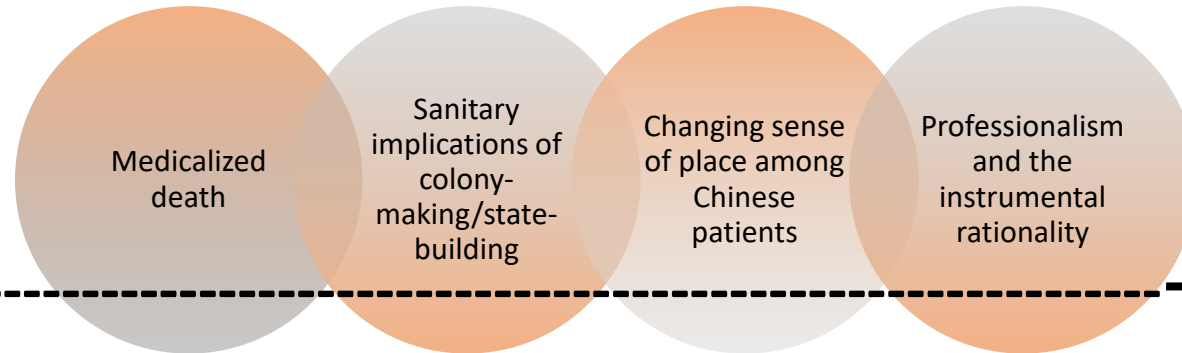


People's autonomy is stripped away.
Reluctance to decide their death location.
Attitude towards end-of-life decision becomes ambivalent.
...etc.

Proper Death -----> **Disenfranchised Death**



FOUR FACTORS



Proper Death

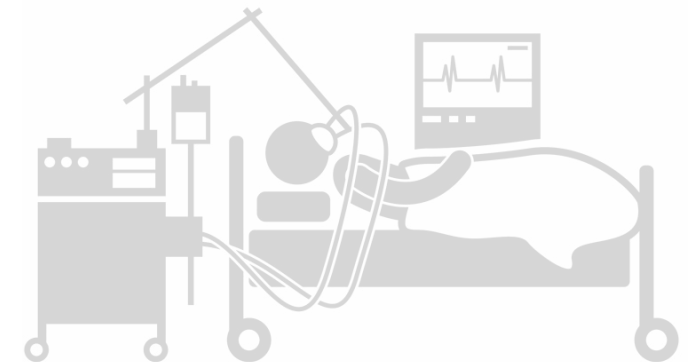
Medicalized death

Sanitary implications of colony-making/state-building

Changing sense of place among Chinese patients

Professionalism and the instrumental rationality

Disenfranchised Death



FACTORS CONTRIBUTING TO THE **DISENFRACTHISED** EOLC

Medicalized
and marketized
death

Sanitary
implications of
colony-
making/state-
building

Changing sense
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Chinese
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Professionalism
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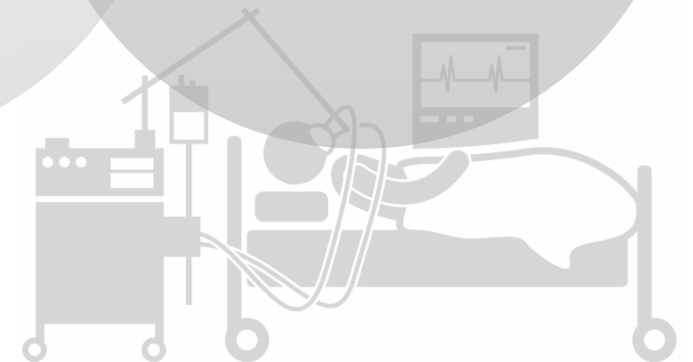
FACTORS CONTRIBUTING TO THE **DISENFRANCHISED** EOLC - I

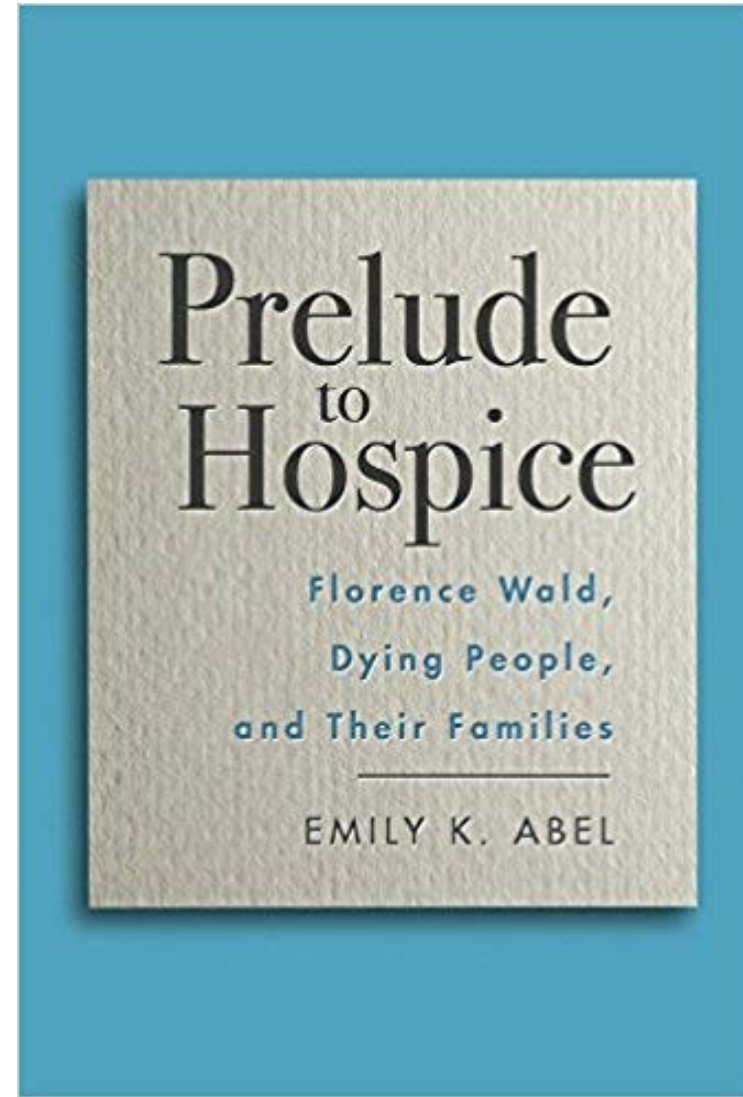
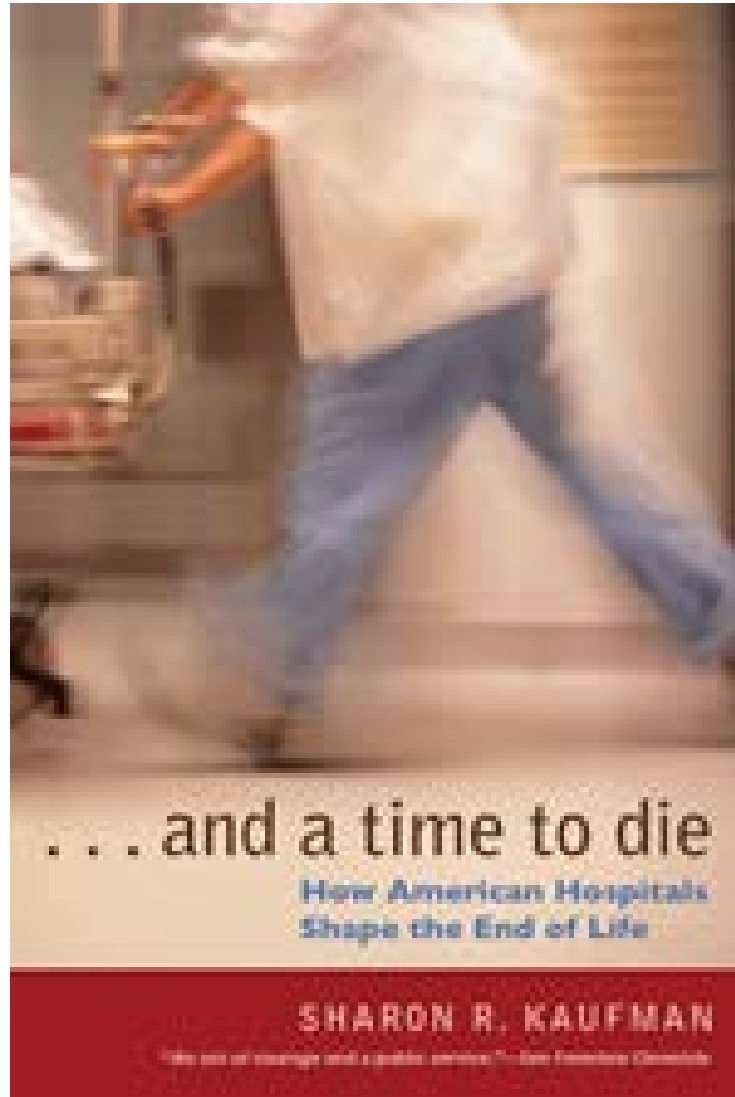
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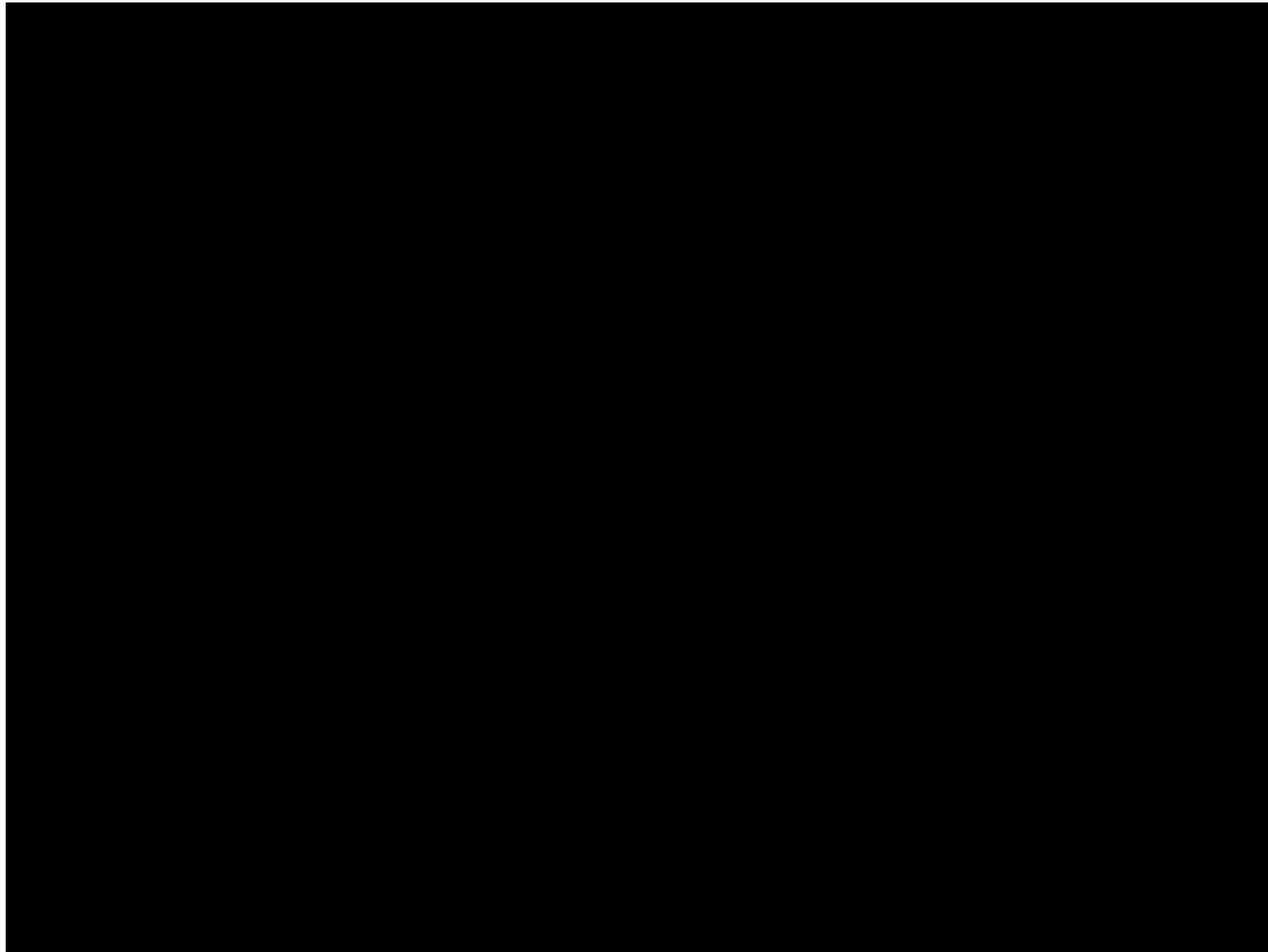






落葉歸根

- 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

| (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



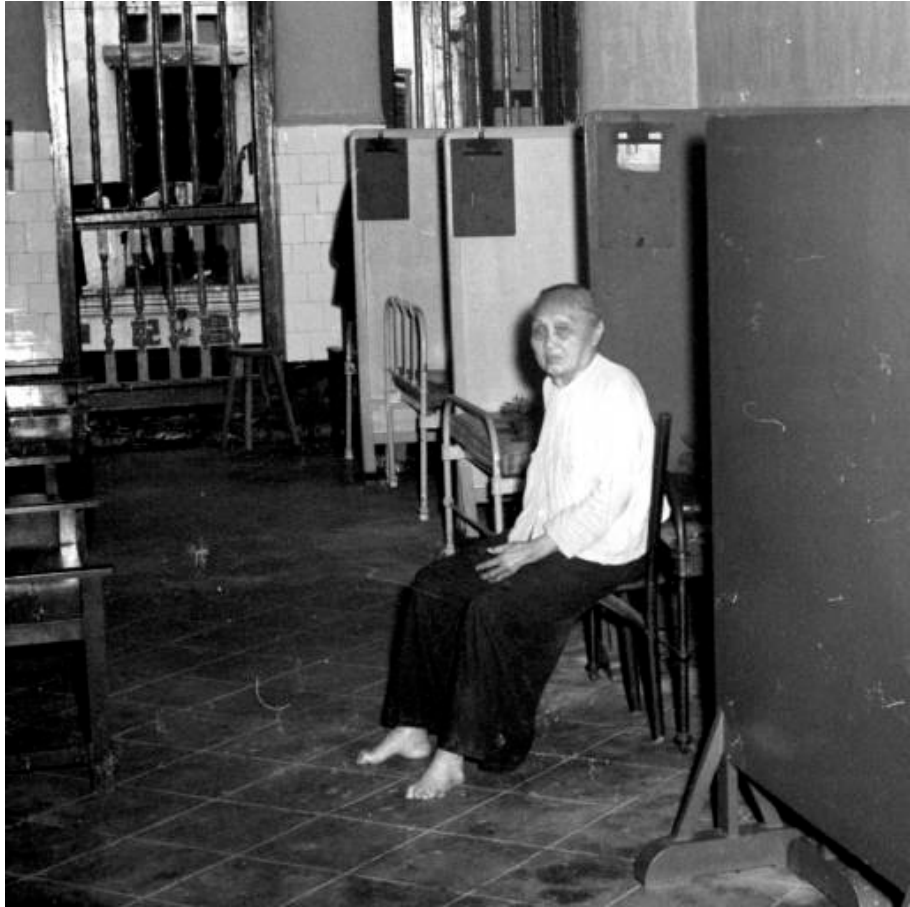
HOUSE OF GREAT DIFFICULTIES, SINGAPORE

- 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

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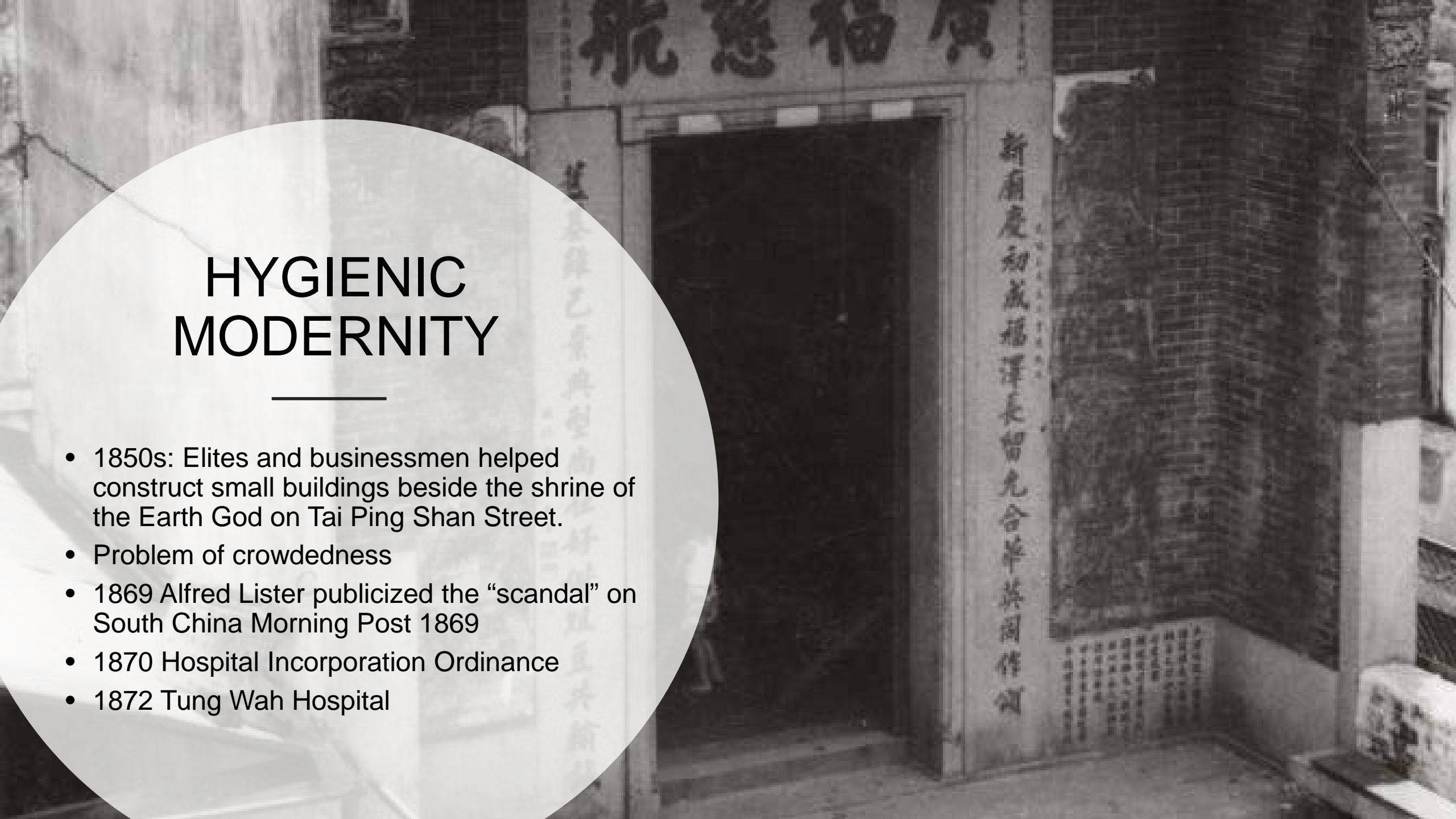
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Picture of Women Martyrs (Wong Pik-Wan)

- “This is the hottest day of Hong Kong. Your mother-in-law’s body was placed on the sideway. 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。四個仵鑿佬，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

上星期之傳染症

衛生醫官報告、上星期內本港共有傳染症五宗、華人、域、利城內有痘症一宗、九龍三宗、本港發炎症一宗云、

對海居民籌建百姓廟 (本)

對海九龍一帶居民、近發起捐建百姓廟、由各董事人稟政府、請廣華醫院總理、及中華船塢原和等均表示贊同、前日已派代表謁切、聞李司以此街坊範圍、須由他任收歛、彼亦願出面幫助、現各區華民政務司、及指定地點

大埔場與百姓廟

有華人永遠墳場之辦法、俾貧民死後、主有地安置、現此兩項在切實籌備中、一俟批准、即可切實辦理云、(早)

惟對海則尙付缺如、神黃廣田、乃建議請政府撥一地為建築永遠墳場之用、查該墳場為公開式、不論貧富、均可購地安葬、現已在積極進行中、至百姓廟、本港亦已設有、由慈善機關撥款建築、以安置死者之神主、而對海尙未有建設、對海居民曾提議此事、查現在對海居民對於此事非常注意、再提議請廣華醫院、再撥一地、俾該廟一如本港

昨晚泰山夜船往省、載有大幫生銀條、共值銀五十餘萬元、查此幫生銀、乃寄往廣州造幣廠、為鼓銀應用、由造幣廠派員一名來港押運云、

大幫生運省

共值五十餘萬元 (本報特訊)

香港新聞

舖變了廣福祠

百姓廟司祝提出異議

廟委會將下令取締

(訪生)華人習俗、於家人死後、常有神主牌之設、初一十五供奉香燈、蓋所遠也、惟貧寒之家、所租房間、儼如斗室、神主之設、實多不便、故對海有材舖、有見及此、遂在店內承接此項生意、每年由主家奉回費用數元、擬戶酸之家多稱便、以是棺材舖變了廣福祠、惟百姓廟司祝、以此項生意、應屬廟範圍、棺材舖此舉、實屬攪奪生意、故特向華民署廟宇委員會提出異議、將呈請港政府、對棺材舖此舉加以取締云、

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)

FORUM

No need to enhance Chinatown for tourists



CITY (STATE) IMAGE PRESERVING

- 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.

Once, death houses like this drew visitors; now, other customary goings-on attract.

While they may have been a never-fail attraction, restoring the death houses *in situ* is unthinkable. However, morbid curiosity is still with the tourist in the locality and he never fails to make a beeline for the spot where some dead resident lies at rest — virtually amidst the traditional trimmings, any time of the week on the paved court of Chinatown Complex.

If not a funeral wake, the site would surely be utilised for religious worship or Chinese opera performances. Surely the tourist's yen to capture the customary goings-on, regardless of what they are, on film or videotape can be depended on to cause Chinatown more publicity than any static enhancement of

CHAN KWEE

Desir Ris f

FACTORS CONTRIBUTING TO THE **DISENFRANCHISED** EOLC - III

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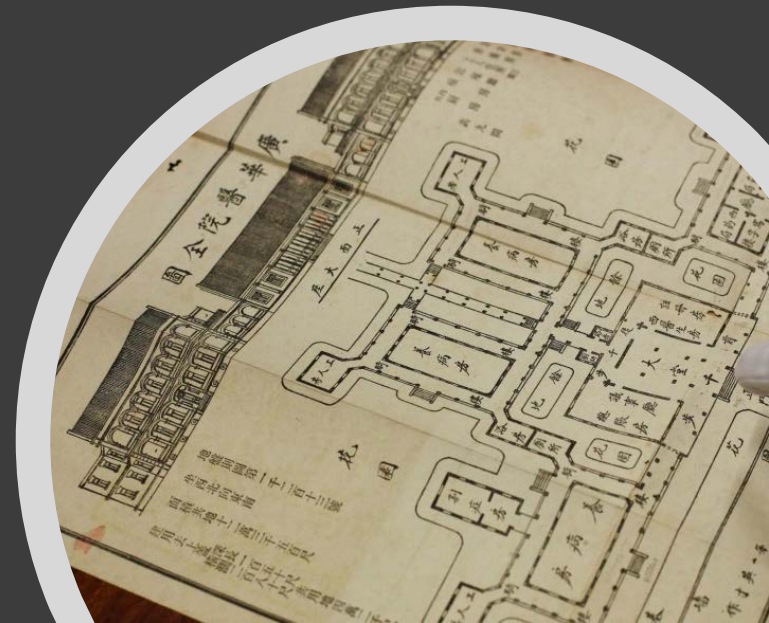
Sense of Place

- 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 btwn East-West medicine (Yang 2006)
- HKers used to hospital experience (Leung 2010)
- Hospital as nodes for medical development in Singapore (Loh 2014)



Tung Wah Dispensary
to Chinese Hospital,
San Francisco, CA

金山大埠增建東華醫院勸捐小引

別家室離鄉井子身萬里爲天涯飄泊之人其令人可憫者莫如
病病而欲歸不能欲留不得靡所依託無以爲養病之所則可憫
尤甚此本埠東華醫院之所由設也溯自創建之初於茲歷二十
稔當時熱心僑梓籌集鉅金創茲善舉使我僑美華人遇有疾病
均得入院調治醫藥兼施僑胞之受益良非淺鮮嗣以經費不敷
且房舍湫隘空氣光綫皆不足非獨衛生不合亦慮地少不能容
納不足以贖留醫者之心曾擬設法維持並增建樓宇改良病室
以期盡美盡善於年前設局募捐已集得二萬餘金終以工程浩
大不敷尙多且附近四鄰未有地基可以擴張暫從緩議至民國
九年台山余氏以事關慈善願將先人遺下局之左鄰荒地一段
貶價出售以成其美當時同人集衆磋商以三千金購得該地以
爲醫院之可以增建也然鉅欸未集仍未敢倉猝動工且相度地
基究非綽有餘裕欲爲一勞永逸之計不如再待時機僉以爲然
去臘同人等以茲事不容再緩刻日集議實行舉辦合力募捐至
今數月間已陸續捐得十餘萬金適在本埠屏慎街購得新地一
段橫七十六英尺深八十七英尺六寸局面寬敞地點適中之以
從新建築醫院一所允稱合用從此鳩工庀材吾知巍峨廣大冠
冕堂皇之醫院指顧間湧現於三藩市中矣惟預算購地建築裝
修添置器具及將來養院等費所需甚鉅仍須大衆鼎力扶助左
足以觀厥成而持永久同人等有見及此因刊發緣簿再行分任
勸捐務期多多益善共成美舉所望 各埠僑胞諸大善士見美
勇爲當仁不讓勿謂發棠復請此卽爲普渡慈航勿謂將伯頽呼

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 go to the hospital
- MPs fears 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



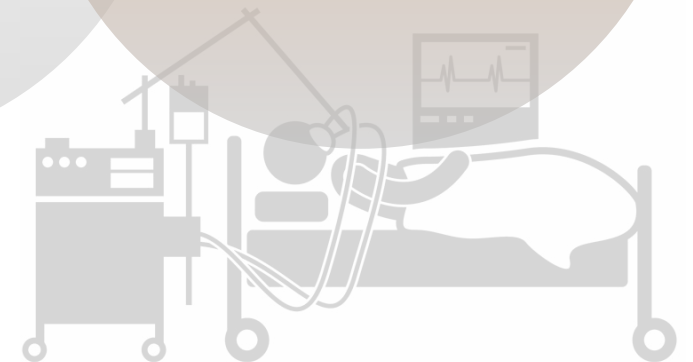
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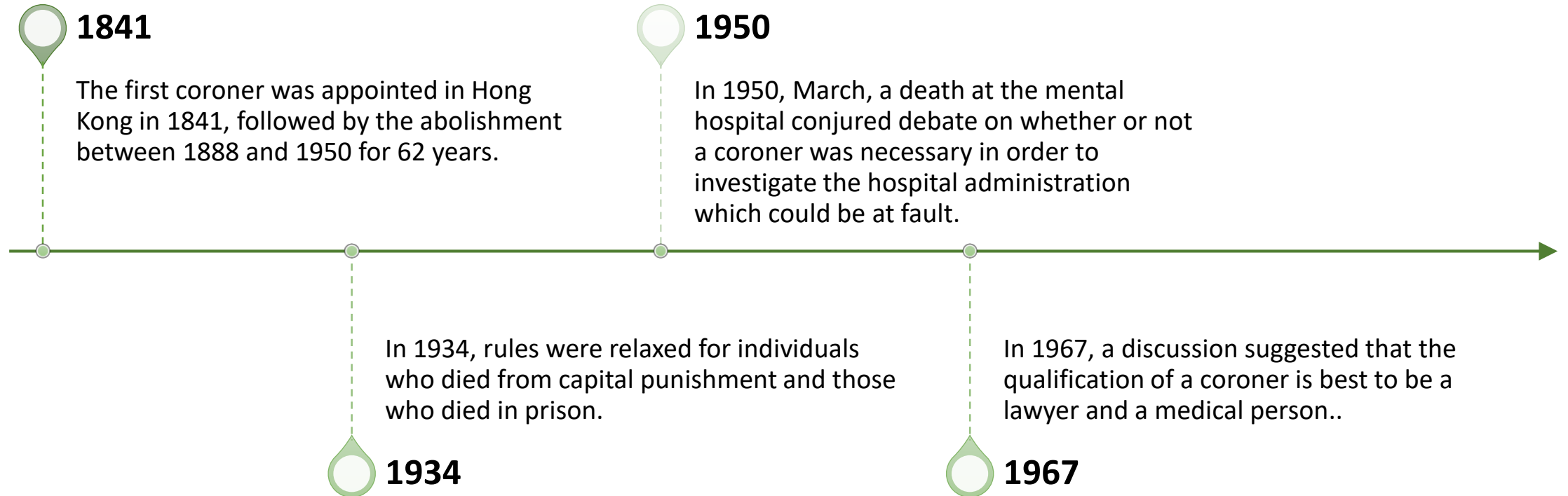


A historical black and white photograph of a harbor. In the foreground, there are several large, multi-story buildings with arched windows. In the middle ground, there are more buildings and a street with trees. In the background, a large body of water is filled with numerous ships of various sizes, including sailing ships and steamships. The sky is hazy.

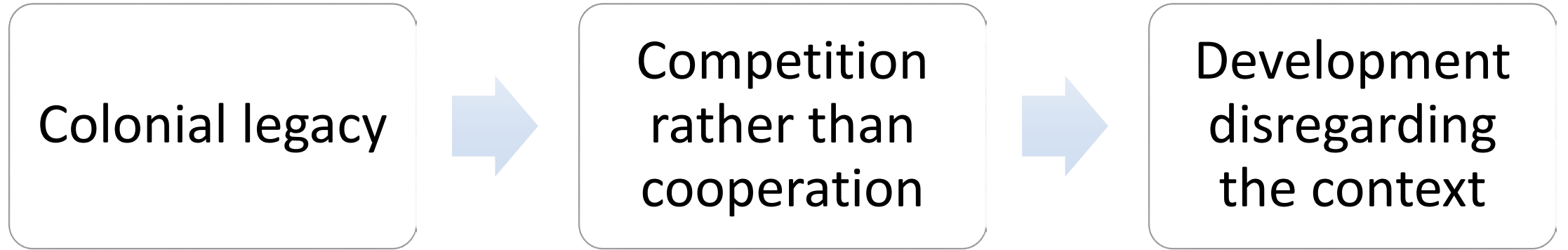
New professionals

- 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



- 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



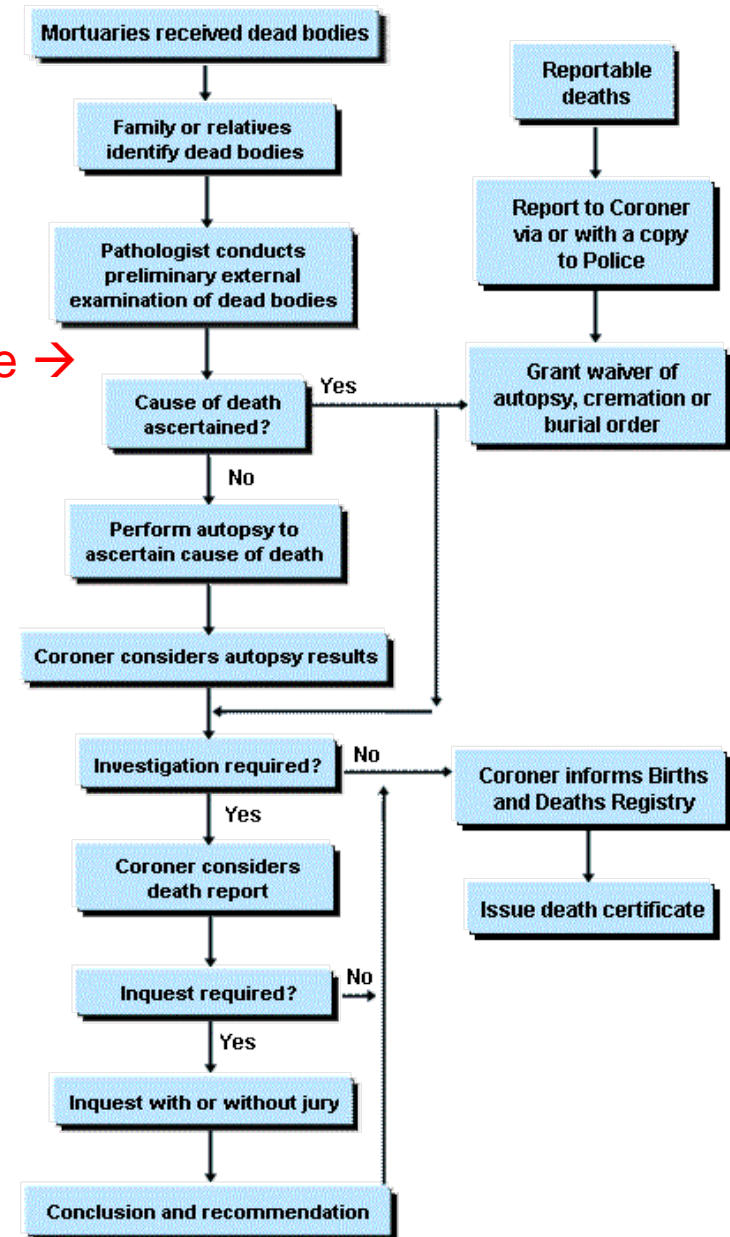
Professionals in HK and Singapore

COMPLEX LEGAL QUESTIONS AT DEATH IN HONG KONG

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

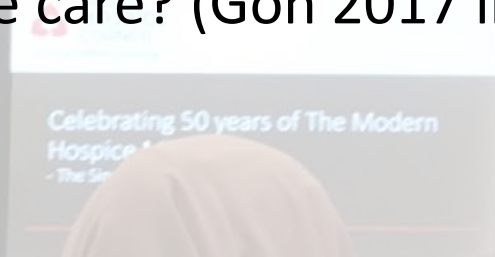
From Woody Chang, Mayer Brown JSM 2013

GP's role →



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)





- Kong, S.T. , Fanga, M-S.C. & Lou, W.V. (2017). Organizational capacities for ‘residential care homes for the elderly’ to provide culturally appropriate end-of- life care for Chinese elders and their families. *Journal of Aging Studies* **40**: 1-7.
- Understanding the EoL care service demand and provision
- Best practice using “relational personhood” framework

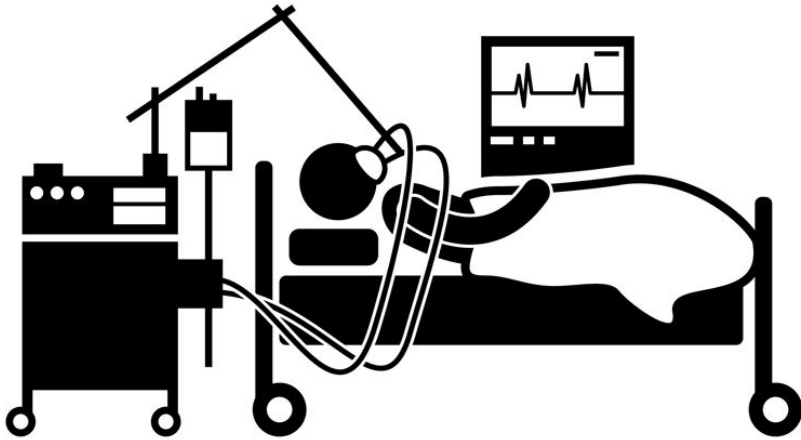
HISTORY AS EVIDENCE FOR HEALTH POLICY

- 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.

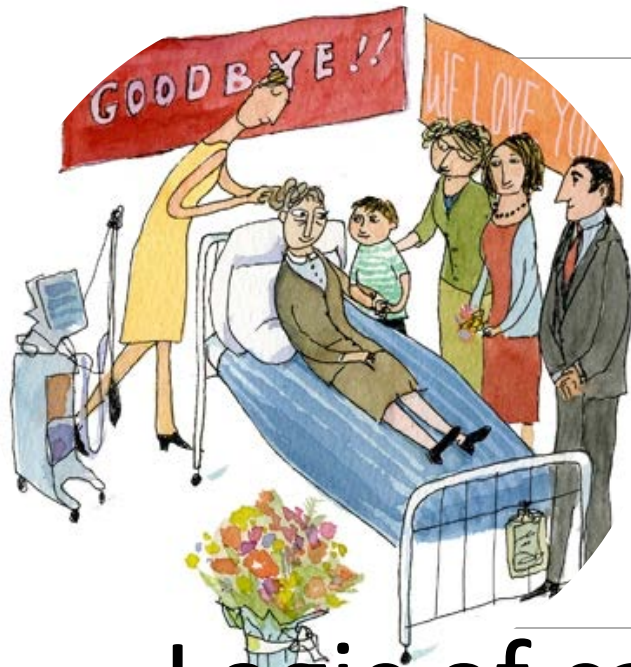
(Virginia Berridge 2010)



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



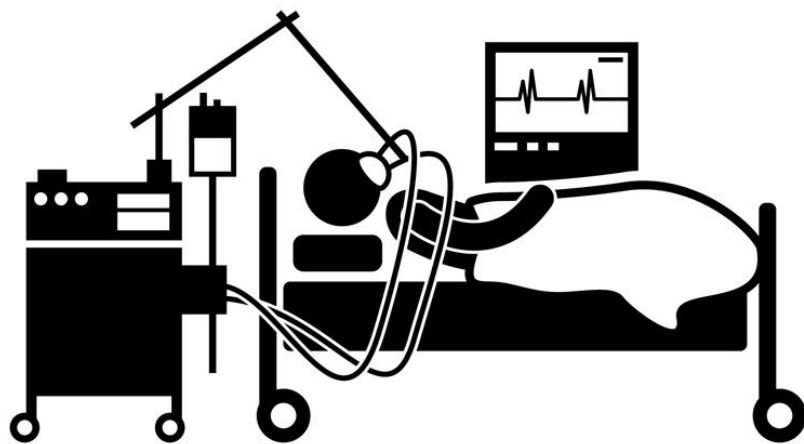
Logic of care

Annemarie Mol (2008)

Flexibility/
Adaptability

Sustainability

Catered for needs



hyjw@hku.hk