The presenter:
Dr. Tak-kwan Kong 江德坤醫生
MBBS(HK), FRCP, FHKAM(Medicine)

- **1981 (age 25)- Intern receiving a gasping lady aged 25, in acute kidney failure at 3am**
  - Brother, "Can you let her go?"
  - Recalling she was the patient who gave me a thank you card for saving her life a month ago with acute peritoneal dialysis, "I will try my best to save her life."
- **1998 (age 42) – Consultant geriatrician i/c of a geriatric department**
  - "You have been doing so well. Why are you leaving?"
  - Resigning medical officer , "I feel sad and impotent to see so many elderly patients under my care pass away. I can only cry together with the family members mourning for the dying."
- **2005 (age 48) – Son of a dying father and host examiner of postgraduate diploma in community geriatrics**
  - Woken up near dawn by son that my father (with late stage lung cancer) was in distress and gasping, not relieved by home oxygen
  - Called 999, "Can you please take my father direct to my hospital?"
- **2017 (age 60) – Consultant reemployed after retirement**
  - Mortality meeting (1/6/2017): a 60-year-old man with metastatic prostate cancer hospitalized for suicide by burning charcoal (CO poisoning), died of multi-organ failure; senior advised case MO to revise the cause of death from acute renal failure to attempted suicide, and referred to coroner (reportable death)
  - "That would be very hurting to the family!"

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Cancer pain relief and palliative care. Report of a WHO Expert Committee.

[No authors listed]

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Review article

Common or multiple futures for end of life care around the world? Ideas from the 'waiting room of history'

Shahaduz Zaman*, Hamilton Inbadas, Alexander Whitelaw, David Clark

School of Interdisciplinary Studies, The University of Glasgow, Crichton University Campus, Dumfries, DG1 4ZL, Scotland, UK

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The author:
Dr. Shahaduz Zaman,
MBBS, PhD(Med Anthropology), MPH

- **School of Interdisciplinary Studies, University of Glasgow, UK**
- **A member of the Glasgow End of Life Studies Group**
- **East-West background:**
  – **Born and brought up in Bangladesh**
  – **PhD in Amsterdam, moved to UK in 2009**
- **Since March 2015,**
  – **a Research Fellow with the Wellcome Trust funded project Global Interventions at the End of Life, working with Professor David Clark, the Principal Investigator of the project**
  – **responsible for conducting in-depth case studies on end of life interventions in different international settings using multiple methods of enquiry.**
- **Fields of research and teaching:**
  – **medical humanities, medical anthropology, hospital ethnography**
  – **global health policy, health system research, community health intervention**
  – **end of life care**
  – **research projects involving South Asian, African, Mediterranean countries**

Global disparities in palliative care between Western and non-Western countries

- Unresolved debates on definitions and models of palliative, end of life, and hospice care
- Cultural disparities on meanings of death and dying
  - Appropriate place where death should occur
  - Religious and spiritual expectations surrounding death
  - Laws and opinions about euthanasia or assisted dying
- Inequitable access to pain control
  - High-income countries account for nearly 92% of medical morphine consumed in the world, but comprise only 17% of the total population.
  - Low and middle-income countries, representing the remaining 83% of the world's population, account for a mere 8% of total medical morphine consumption6

Cancer pain relief and palliative care. Report of a WHO Expert Committee. World Health Organ Tech Rep Ser 1990;804:1-75.

INCB, 2011. Report of the International Narcotics Control Board for 2011. Retrieved from. https://www.incb.org/incb/en/publications/annual-reports/annualreport-2011.html.

"Another event at Elsterhorst (prisoner of war camp) had a marked effect on me. The Germans dumped a young Soviet prisoner in my ward late one night. The ward was full, so I put him in my room as he was moribund and screaming and I did not want to wake the ward. I examined him. He had obvious gross bilateral crepitations and a severe pleural rub. I thought the latter was the cause of the pain and screaming. I had no morphia, just aspirin, which had no effect. I felt desperate. I knew very little Russian then and there was no one in the ward who did."

Cochrane AL, Blythe M.

One man's medicine: autobiography of Professor Archie Cochrane. London: The Memoir Club; 1989.

"I finally instinctively sat down on the bed and took him in my arms, and the screaming stopped almost at once. He died peacefully in my arms a few hours later. It was not the pleurisy that caused the screaming, but loneliness. It was a wonderful education about the care of the dying. I was ashamed of my misdiagnosis and kept the story a secret."

Cochrane AL, Blythe M.

One man's medicine: autobiography of Professor Archie Cochrane. London: The Memoir Club; 1989.

Post-colonial theory applied to end of life issues: Waiting room of history
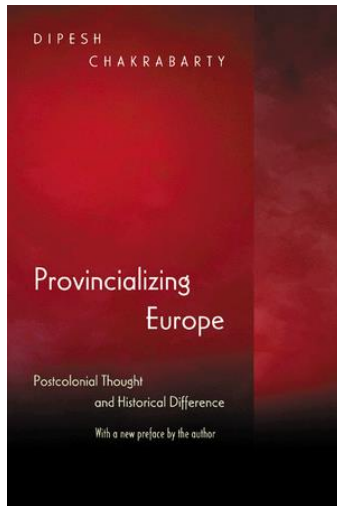
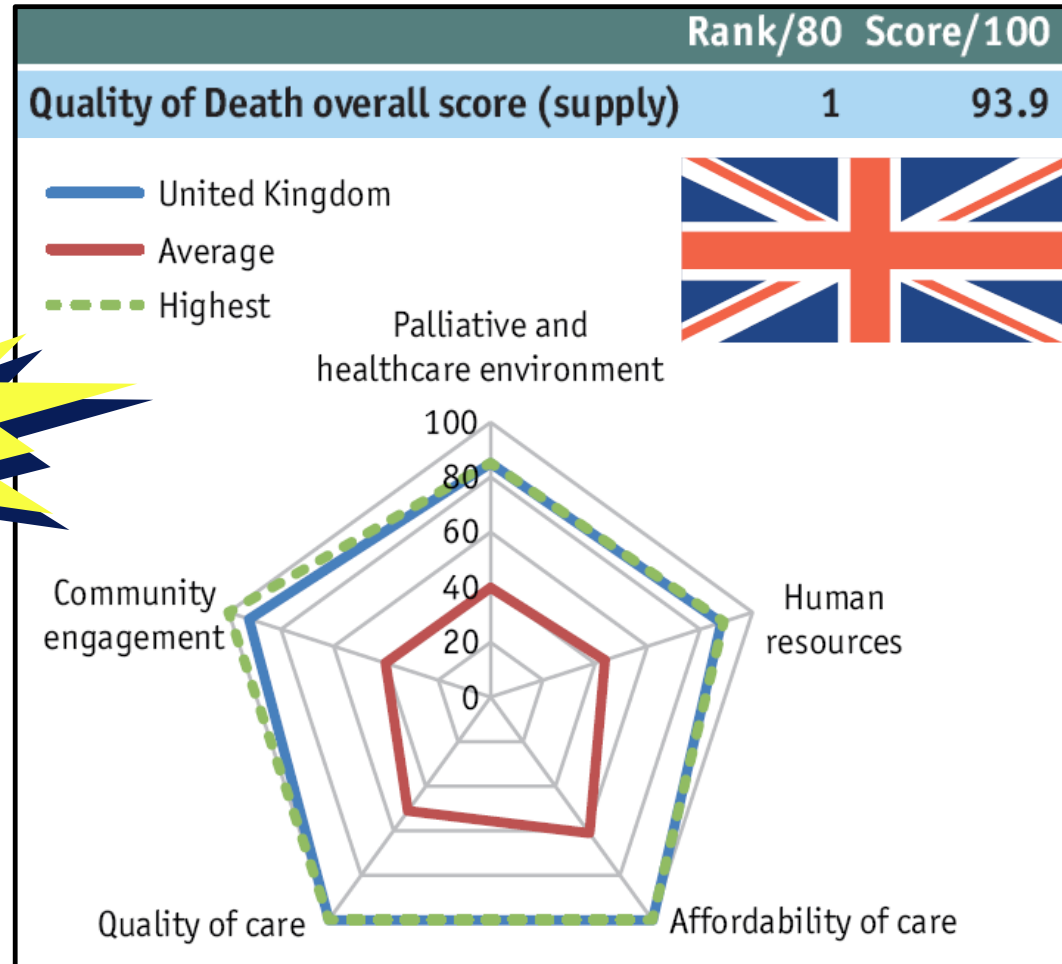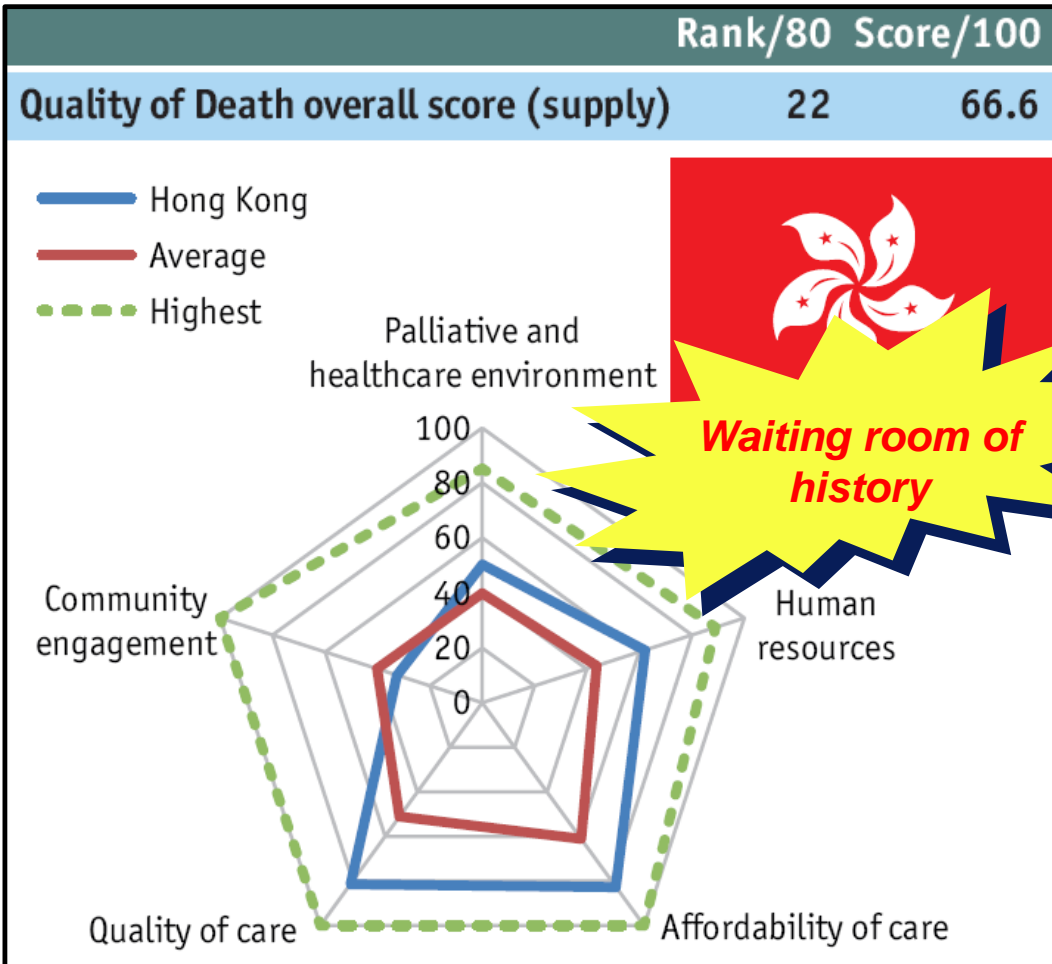**Post-colonial thinker Dipesh Chakrabarty and his book 'Provincializing Europe (2007)'**

- Chakrabarty argues how Europe is seen to be fully modern, while the rest of the world retains many pre-modern elements. In this understanding of history, the mission of the rest of the world is to try to catch up with Europe or the West.

- For Chakrabarty, Europe is not just a geographical area rather a particular mind-set associated with values which originate in the European Enlightenment. He argues that this value system judges non-European societies in terms of their incompleteness and lacking of the modernity mission. Such societies therefore remain in the waiting room of history, aspiring to the future, that of Europe.

- Zaman echoes Chakrabarty's concerns about the uncritical transfer of ideas, practices and narrative from one context to another. He argues we need to look at a history of the translation of modernity from Europe to other parts of the world through the multiple relationships that exist between them.

- Zaman advocates that we must first question some of the ideas which we take for granted in relation to end of life interventions. He suggests giving thoughts about the essence of these ideas…. whether we should transfer these ideas uncritically, or whether we should find ways to translate them to fit in a new context.

The 2015 Quality of Death Index: Ranking Palliative Care across the World.

The Economist 2015

Hong Kong panel:

	Rank/80	Score/100
Quality of Death overall score (supply)	22	66.6

- Hong Kong
- Average
- Highest

Axes: Palliative and healthcare environment, Human resources, Affordability of care, Quality of care, Community engagement

Waiting room of history

United Kingdom panel:

	Rank/80	Score/100
Quality of Death overall score (supply)	1	93.9

- United Kingdom
- Average
- Highest

Axes: Palliative and healthcare environment, Human resources, Affordability of care, Quality of care, Community engagement

The 2015 Quality of Death Index: Ranking Palliative Care across the World.

The Economist 2015

2015 Quality of Death Index—Overall scores

Rank	Country	
1	UK	93.9
2	Australia	91.6
3	New Zealand	87.6
4	Ireland	85.8
5	Belgium	84.5
6	Taiwan	83.1
7	Germany	82.0
8	Netherlands	80.9
9	US	80.8
10	France	79.4
11	Canada	77.8
12	Singapore	77.6
13	Norway	77.4
14	Japan	76.3
15	Switzerland	76.1
16	Sweden	75.4
17	Austria	74.8
18	South Korea	73.7
19	Denmark	73.5
20	Finland	73.3
21	Italy	71.1
22	Hong Kong	66.6
23	Spain	63.4
24	Portugal	60.8
25	Israel	59.9
26	Poland	58.7
27	Chile	58.6
28	Mongolia	57.7
29	Costa Rica	57.3
30	Lithuania	54.0
31	Panama	53.6
32	Argentina	52.6
33	Czech Republic	51.8
34	South Africa	48.5
35	Uganda	47.6
36	Cuba	46.6
37	Jordan	46.7
38	Malaysia	46.5
39	Uruguay	46.1
40	Ecuador	44.0
41	Hungary	42.7
42	Brazil	42.5
43	Mexico	42.3
44	Thailand	40.2
45	Venezuela	40.1
46	Puerto Rico	40.0
47	Turkey	38.2
48	Russia	37.2
49	Peru	36.0
50	Kazakhstan	34.6
51	Ghana	34.3
52	Morocco	33.8
53	Indonesia	33.6
54	Tanzania	33.4
55	Slovakia	33.2
=56	Egypt	32.9
=56	Greece	32.9
58	Vietnam	31.9
59	Zimbabwe	31.3
60	Saudi Arabia	30.8
61	Zambia	30.3
62	Bulgaria	30.1
63	Kenya	30.0
64	Romania	28.3
65	Sri Lanka	27.1
66	Malawi	27.0
67	India	26.8
68	Colombia	26.7
69	Ukraine	25.5
70	Ethiopia	25.1
71	China	23.3
72	Botswana	22.8
73	Iran	21.2
74	Guatemala	20.9
75	Dominican Republic	17.2
76	Myanmar	17.1
77	Nigeria	16.9
78	Philippines	15.3
79	Bangladesh	14.1
80	Iraq	12.6
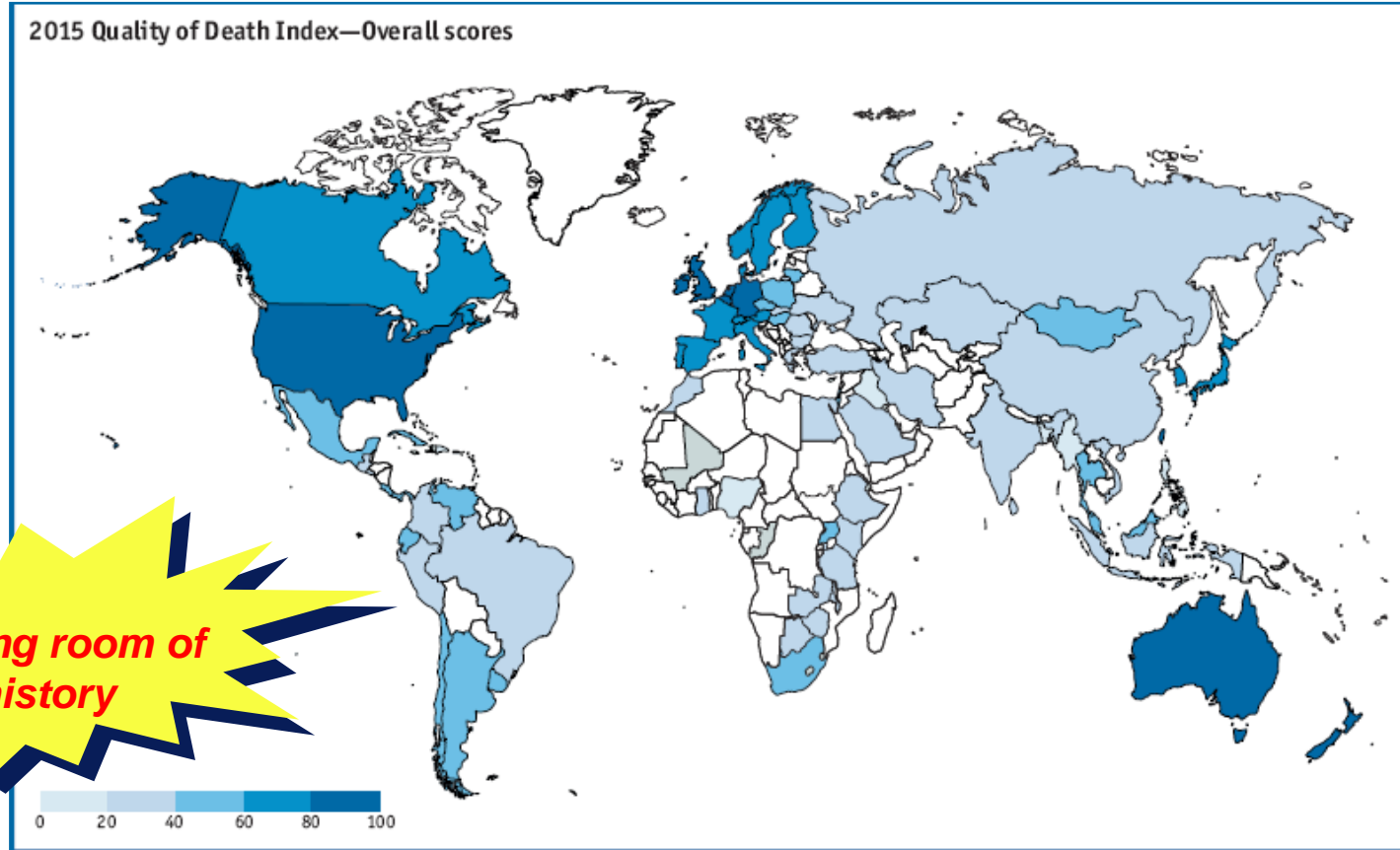
UK

HK

China

Waiting room of history

2015 Quality of Death Index—Overall scores

0   20   40   60   80   100

Can the Western model of palliative care/EOL be a common global future?
Emerging debates on palliative/EOL care within the Western world

- **Care substituting cure**
  - negative associations for 'palliative care' when it is seen as a substitute for effective prevention and cure of disease
  - concern on palliative/EOL care delivery in UK
  - the difficulties that can occur when interventions well understood and demonstrated in one context (hospice) can run into problems when applied at a system level in another (acute hospital)

- **Medicalization/ institutionalization overriding holistic care**
  - "Community engagement" given the lowest weighting among the 5 indicators in the ranking of quality of death of the Economist index
  - Development of palliative care has gone hand in hand with communities' loss of ownership of dying
  - Expectation that when someone is dying, care will be given primarily by professional carers

Sleeman KE. The Liverpool care Pathway: benefit or harm? J R Coll Phys Edin 2014; 44: 4-5.

Dyer C. Care at end of life isn't being properly managed, says ombudsman. Br Med J 2015; 350:h2724.

Abel J, Bowra J, Walter T, et al. Compassionate Community networks: supporting home dying. BMJ Support. Palliat. Care 2011;1, 129-133.

Can the Western model of palliative care/EOL be a common global future?
Emerging debates on palliative/EOL care within the Western world

- **Increasing overlap of Palliative Medicine with other specialties**
  - **oncology**
  - **geriatrics: non-cancer palliative care for patients with complex multiple problems**
  - **cardiology, neurology, paediatrics, orthopaedics, psychiatry.**
- **Debates on assisted dying and euthanasia**

Can the Western model of palliative care/EOL be a common global future?
Alternative palliative care models

- **Good death is not necessarily the Western value of dignity, autonomy, pain free (→ logistics of palliative care facilities, trained professionals, opioid availability)**
  - **E.g. Good death = death in the presence of loved ones; collective or relational self more important than autonomy**

- **Compassionate communities, making death everyone's responsibility (not solely for health for health and social services)**
  - **a health-promoting approach to end of life care through a series of actions by communities, governments, state institutions and social or medical care organisations that aim to improve health and wellbeing in the face of life-limiting illness.**
  - **Logistics: 'network development', 'development of supportive communities of volunteers' and 'creation of compassionate policies'.**

Kelleher A. Health Promoting Palliative Care. Oxford University Press, Melbourne, VIC, Australia, 1999.

Kelleher A. Compassionate Communities: end of life care as everyone's responsibility. QJ Med 2013; 106 (12), 1071-5.

Abel J, Kelleher A. BMJ Support Palliat Care 2016; 0:1-6.

Can the Western model of palliative care/EOL be a common global future?
Alternative palliative care models

- **The Neighbourhood Networks in Palliative Care (NNPC) in Kerala, India**
  - **chronic and incurable illnesses are social problems with medical components**
- **Community health promoting palliative care in Singapore**
  - **By and for the community**

Kumar, S., Palmed, D., 2007. Kerala, India: a regional community-based palliative care model. J. Pain Symptom Manag. 33 (5), 623e627.

Chan, M., Sallnow, L., Murray, S., 2014. Community initiatives foster health promoting palliative care in Singapore. Eur. J. Palliat. Care 21 (1), 27e29.

More plurality to address the common human experience of dying

- Identify common denominators of end of life care around the world
- Work from there to develop culturally and locally appropriate provision of palliative care (translation rather than transfer)
- The aim should be not to privilege one particular future for end of life care globally but to seek a suite of solutions
- In planning and developing palliative care policy it is crucial to
  - explicitly conceptualize the country specific 'value-logistic' dimensions of 'good death'
  - accepting the plurality of past and present local problems and issues relating to end of life care, as well as the plural possibilities of how they might be overcome
- More international comparative research on end of life interventions, using culturally and historically informed methods
- The future of effective, culturally appropriate and sustainable approaches will depend on the identification of 'the particular' within 'the universal' at the end of life.

The Doctor (1891) by Samuel Luke Fildes

Discussion

- **Community: Geographical boundary?**
  - **Hospital-community divide: cost, staff-mix, volunteer (professional vs lay), safety, homeliness**
  - **No geographical boundary for community: social e-network, telemedicine, ? human touch (eyes, face, not hands)**
- **Compassion:**
  - **Why not spontaneous?**
  - **"The essence of good medicine is compassion" Grimley Evans J.**
  - **Barriers in modern medicine: sensitive/ defensive, safety obsession, compassion fatigue**
  - **Medical-social divide**
  - **Legal ethics vs social ethics**
- **Common or multiple futures for end of life care?**

The discussant:
Prof. Julia Tao 陶黎寶華教授

- **She voiced out complex ethical issues (advance directives) cannot be concluded by voting**

- **She advocated engaging retired doctors in the provision of humane care to patients**