



**DukeNUS**  
Medical School



Lien Centre for  
Palliative Care

# Musings on the “Value of Death”

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## Alleviating the access abyss in palliative care and pain relief— an imperative of universal health coverage: the *Lancet* Commission report



*Felicia Marie Knaul, Paul E Farmer\*, Eric L Krakauer\*, Liliana De Lima, Afsan Bhadelia, Xiaoxiao Jiang Kwete, Héctor Arreola-Ornelas, Octavio Gómez-Dantés, Natalia M Rodriguez, George A O Alleyne, Stephen R Connor, David J Hunter, Diederik Lohman, Lukas Radbruch, María del Rocío Sáenz Madrigal, Rifat Atun†, Kathleen M Foley†, Julio Frenk†, Dean T Jamison†, M R Rajagopal†, on behalf of the Lancet Commission on Palliative Care and Pain Relief Study Group‡*

- Quantified ‘Serious Health Suffering (SHS)’ worldwide and proposed an essential medicines package for palliative care
- International collective action is necessary to ensure that all people, including poor people, have access to palliative care and pain relief for life-threatening and life-limiting health conditions and end-of-life care

## Report of the *Lancet* Commission on the Value of Death: bringing death back into life



*Libby Sallnow, Richard Smith, Sam H Ahmedzai, Afsan Bhadelia, Charlotte Chamberlain, Yali Cong, Brett Doble, Luckson Dullie, Robin Durie, Eric A Finkelstein, Sam Guglani, Melanie Hodson, Bettina S Husebø, Allan Kellehear, Celia Kitzinger, Felicia Marie Knaul, Scott A Murray, Julia Neuberger, Seamus O'Mahony, M R Rajagopal, Sarah Russell, Eriko Sase, Katherine E Sleeman, Sheldon Solomon, Ros Taylor, Mpho Tutu van Furth, Katrina Wyatt, on behalf of the Lancet Commission on the Value of Death\**

- Richard Smith: The Lancet Commission on the Value of Death will have a global focus and concentrate on four issues:
  1. The medicalisation and possible demedicalisation of death
  2. How people die and think of death in different countries and cultures
  3. Whether the battle with death is beggaring us financially and spiritually
  4. The utility of attempts to tame death, including advance decisions, assisted suicide, palliative care, the concept of a good death, and the pursuit of immortality

- Some problems the Commission aimed to address
  - Unmet need
  - High EOL costs
  - Overtreatment
  - Low quality care
- There was general agreement that many people die badly both in high- and low income countries.
- But beyond trying to reduce SHS, there was little agreement (at least by me) on what ‘problem’ the Commission was meant to address
- Terminology and lack of data confounded the task

# Unmet Need: As Google Sees It

- “Addressing unmet need is written in our DNA”
- “Defining and quantifying unmet medical need is challenging”
- “Every patient’s perspective is shaped by their experience of living with disease and each constituency’s view of unmet need is formed by their own professional expertise and opinion”

These cases show examples of unmet medical need from different stakeholder perspectives

## PATIENT PERSPECTIVE

emphasis on burden of disease of the individual, from improvement of quality of life by a new formulation to life-extending treatments



## SOCIETAL PERSPECTIVE

emphasis on (incremental) improvements in diseases with a high societal burden or treatments that help prepare for future pandemics

## HEALTHCARE SYSTEM PERSPECTIVE

emphasis on efficient resource allocation and cost-effectiveness of treatments that support and improve the overall functioning of the system

- “The concept of unmet medical need is meant to help the research and healthcare communities distinguish more pressing patient and societal health needs from the myriad of other health needs.... “
  - But it does not!
- **Recommendation: Avoid the term**

- A study from Denmark showed that the roughly 1% of people who died in a year were responsible for 10% of annual costs
- So what?
  - Healthcare costs accrue when people are sick!
  - We know that.
  - High costs may or may not be a sign of a problem
    - Example:
      - Person A spent \$100K in the last year of life (Maybe she died getting a risky surgery)
        - Sounds like a lot of \$
      - What if 100 others also spent the same \$100K and completely recovered?
        - That seems like a pretty good deal!

- The point
  - Looking at end of life costs is fundamentally flawed
  - We only know it was end of life after death
- ***Recommendation: Performance indicators related to costs should have the same lens as the treating clinician***

- Why do we care about high costs anyway?
- If individuals or families want to bankrupt themselves to try to extend their lives who are we to say they should not?
- But what if it's our money?
  - Don't offer 'a free lunch' if you are not prepared to foot the bill
  - There is an easy solution to address high public sector costs
    - Medishield used to have age caps for this very reason
  - Another solution is to restrict the 'menu' to what you see as good value for money
- ***Recommendation: Greater application of cost effectiveness analysis to limit access to what society sees as low value treatments, recognizing this is not a one size fits all approach***



# What do the following terms have in common?

- Overtreatment
  - Marginally beneficial treatment
  - Non-beneficial treatment
  - Inappropriate treatment
  - Medically futile treatment
- 
- Like “unmet need”, they are difficult to define, especially ex ante

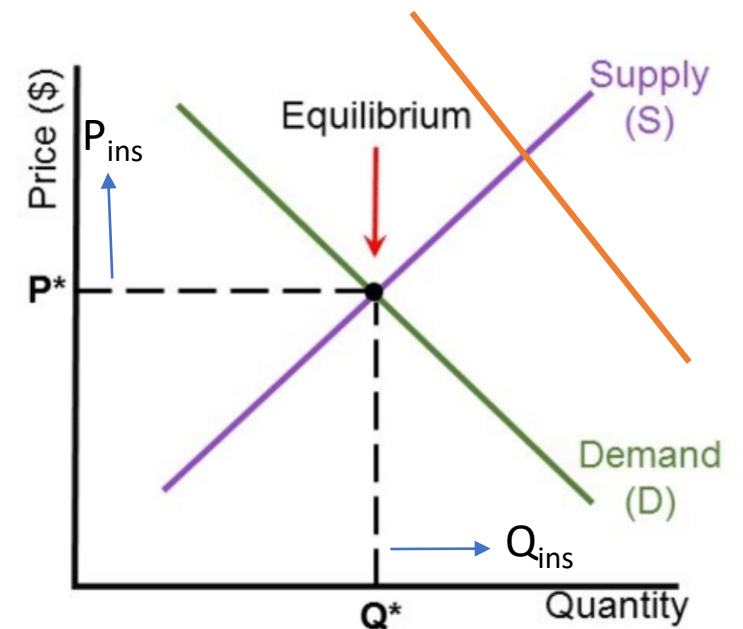
Any effort to define overtreatment ex post is fundamentally flawed

- The definition should not be outcome dependent
- Example: Chemotherapy in the last month of life
  - At the time of treatment, we don't know if it's the last month of life
- ***Recommendation: Definitions of these terms and corresponding performance indicators should have the same lens as the treating clinician***
- No doubt overtreatment exists, but that is largely by design

- Health insurance and government subsidies lower out of pocket costs and thus increase demand for medical care
- Gov. subsidies and private insurance are the largest causes of ‘overtreatment’
- But also offer substantial benefits in terms of health equity and reducing financial uncertainty
  - Can’t have one without the other
- If gov. wants to reduce overtreatment, cut the subsidies
  - Reality is public sector funding is getting more generous

***Recommendation: In addition to limiting coverage/reimbursement to high value treatments, greater use of ‘rationing’ so that subsidized treatments go to those who benefit most***

- Not everyone is a great candidate for dialysis, for example
- But this won’t solve the problem



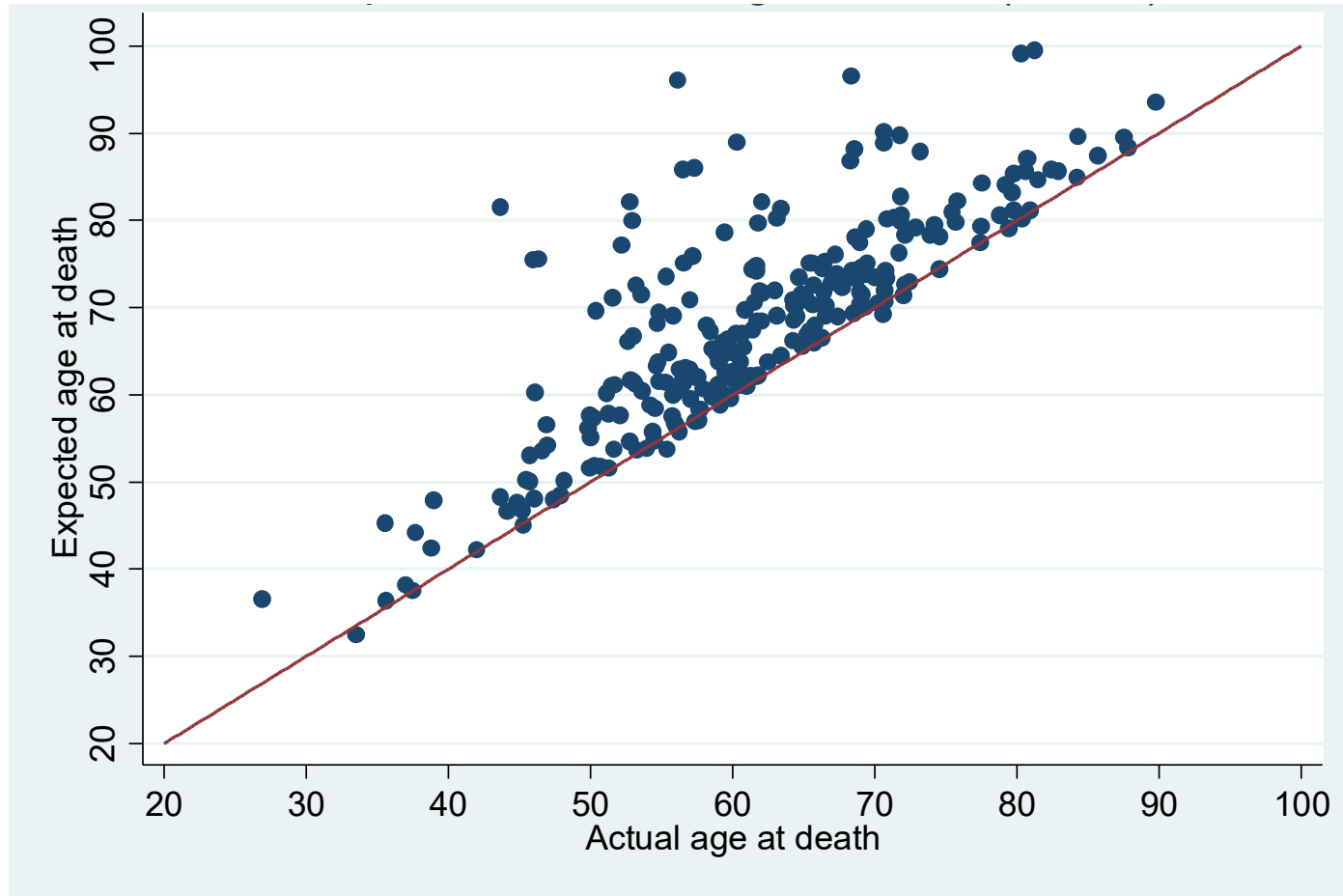
## Two Questions

- **Question 1:** How long do you think someone diagnosed with Advanced, Stage IV, metastatic cancer is likely to live?
- **Question 2:** How long do you think people diagnosed with Advanced, Stage IV, metastatic cancer believe they are likely to live?

Why the disconnect?




- Hope!
- Hope causes a series of biases that lead to over-estimating the benefits of treatment and likely greater utilization and costs

## We asked Advanced Cancer patients from our COMPASS Cohort Study in Singapore (n = 263) to Predict Age at Death



- 94% overestimated their survival
- Mean over-estimation was 6.7 years
- This finding is pervasive among advanced illness patients

# Hope, bias and survival expectations of advanced cancer patients: A cross-sectional study

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Matthew Ng Chau Hsien<sup>5</sup> | Mohamad Farid Bin Harunal Rashid<sup>5</sup> |  
Nagavali Somasundaram<sup>5</sup>

# Hope and Bias Among Advanced Cancer Patients (SHAPE Study)

- 40% stated a belief that they would be cured with treatment
- 50% believed survival would be better than average, 46% said average, and only 4% said worse
- Each 1-point increase in the Herth Hope Index was associated with a:
  - 6% increase in the odds of believing their illness is curable
  - 4 month increase in expected survival
- More hopeful patients were also more likely to state that they are very well-informed

***Recommendation: Do not assume patients (or their families) are making choices based on the information provided***

- They are often recoding the information to suit their objective
- This suggests that restricting choice may make patients **better** off
- You remove a choice that they (or their families) would ultimately come to regret

But how do we know if we are doing right by our patients?

- This requires some assessment of the quality of care delivered



**Table 1.1 Selected definitions of quality, 1980–2018** <https://www.ncbi.nlm.nih.gov/books/NBK549277/table/Ch1-t0001/?report=objectonly>

<p><b>Donabedian (1980)</b> In: <i>“Explorations in quality assessment and monitoring. The definition of quality and approaches to its assessment”</i></p>	<p>Quality of care is the kind of care which is expected to maximize an inclusive measure of patient welfare, after one has taken account of the balance of expected gains and losses that attend the process of care in all its parts. <i>[More generally, q uality in this work is “the ability to achieve desirable objectives using legitimate means”.]</i></p>
<p><b>Institute of Medicine, IOM (1990)</b> In: <i>“Medicare: A Strategy for Quality Assurance”</i></p>	<p>Quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.</p>
<p><b>Council of Europe (1997)</b> In: <i>“The development and implementation of quality improvement systems (QIS) in health care. Recommendation No. R (97) 17”</i></p>	<p>Quality of care is the degree to which the treatment dispensed increases the patient’s chances of achieving the desired results and diminishes the chances of undesirable results, having regard to the current state of knowledge.</p>
<p><b>European Commission (2010)</b> In: <i>“Quality of Health care: policy actions at EU level. Reflection paper for the European Council”</i></p>	<p>[Good quality care is] health care that is effective, safe and responds to the needs and preference of patients. <i>The Paper also notes that “Other dimensions of quality of care, such as efficiency, access and equity, are seen as being part of a wider debate and are being addressed in other fora.”</i></p>
<p><b>WHO (2018)</b> In: <i>“Handboo k for national quality policy and strategy”</i></p>	<p>Quality health services across the world should be:</p> <ul style="list-style-type: none"> <li>• Effective: providing evidence-based health care services to those who need them.</li> <li>• Safe: avoiding harm to people for whom the care is intended.</li> <li>• <u>People-centred: providing care that responds to individual preferences, needs and values.</u></li> </ul> <p>In order to realize the benefits of quality health care, health services must be timely [...], equitable [...], integrated [...], and efficient [...]</p>

- Clearly quality is multidimensional but also not so easy to define
- And more so for patients with life limiting illnesses where preferences, “needs” and values change with illness trajectory

The Economist Intelligence Unit

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

A report by The Economist Intelligence Unit



Commissioned by  

**LIEN**  
 foundation

### Overall score

Rank	Country	Overall score
1	UK	7.9
2	Australia	7.9
3	New Zealand	7.7
4	Ireland	6.8
5	Belgium	6.8
6	Austria	6.6
7	Netherlands	6.3
8	Germany	6.2
9	Canada	6.2
9	US	6.2
11	Hungary	6.1
12	France	6.1
13	Norway	6.0
14	Taiwan	6.0
15	Poland	6.0

1 Overall score

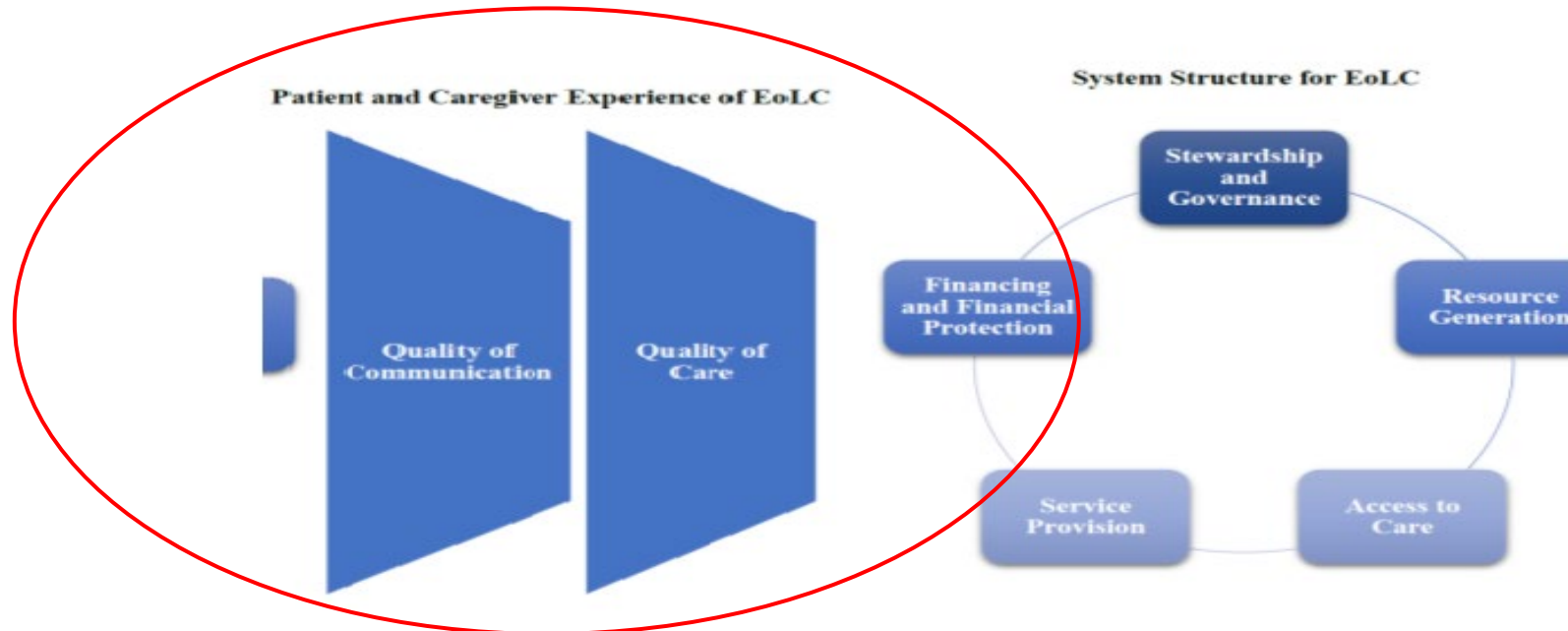


- The 2015 Quality of Death Index (QODI) evaluated quality using 20 quantitative and qualitative indicators across five categories using the following weights:
  - Palliative and healthcare environment (20% weighting; 4 indicators)
  - Human resources (20% weighting; 5 indicators)
  - Affordability of care (20% weighting; 3 indicators)
  - Quality of Care (30% weighting; 6 indicators)
  - Community engagement (10%; 2 indicators)

- Strengths
  - Considers multiple dimensions
  - Data driven (also a weakness)
- Limitations
  - Assumes that if these indicators are met then the EOL experience is better
  - But not all indicators are outcome indicators and some may be weakly correlated with outcomes that matter
  - Weights arbitrarily assigned by 'experts'
- We were asked by Lien Foundation to update the index
- We took a different tact ...

- A scoping review identified 7 domains and 33 sub-domains which capture key aspects of ‘quality of death and dying’.
- Of the identified domains, 2 relate to patient and caregiver experience and 5 relate to the system structure to provide EoLC.
- The instrument we developed focused on the domains of quality of care, quality of communication and financing/financial protection with the idea that the remaining domains are inputs to these outcomes

### Overview of domains identified through scoping review



Based on the scoping review, input from an Advisory Board, cognitive interviews, and pilot testing, we created 13 indicators to capture quality of care delivery across the 3 core domains.

**Table 1: Indicators**

No.	Indicators of patients' EOL experience over last 6 weeks of life	
1	<b>Clear and timely information</b>	8 <b>Cope emotionally</b> Health care providers gave patients support to help them cope emotionally
	Health care providers gave patients clear and timely information so patient could make informed decisions	9 <b>Clean and safe space</b> The centre was clean, safe, and comfortable.
2	<b>Treated kindly</b>	10 <b>Care was well co-ordinated</b> Health care providers provided care that was well coordinated.
	Health care providers treated patients kindly and sympathetically	11 <b>Non-medical concerns</b> Health care providers helped with patients' non-medical concerns
3	<b>Spiritual needs</b>	12 <b>Preferred place of death</b> Health care providers made sure that patients were cared for and died at their place of choice.
	Health care providers supported patients' spiritual, religious, and/or cultural needs	13 <b>Costs were not a barrier</b> Costs were not a barrier to getting appropriate care.
4	<b>Contact with family</b>	
	Health care providers allowed patients to contact their friends and family	
5	<b>Asked enough questions</b>	
	Health care providers asked enough questions to understand patients' needs	
6	<b>Quality of life extending treatments</b>	
	Health care providers provided appropriate level & quality of life-extending treatments	
7	<b>Managed pain and discomfort</b>	
	Health care providers controlled pain and discomfort as well as the patient wanted	

- Each indicator could take values from strongly disagree to strongly agree (5 levels).
- This version is a general version for 'experts' but we also developed patient and caregiver versions.

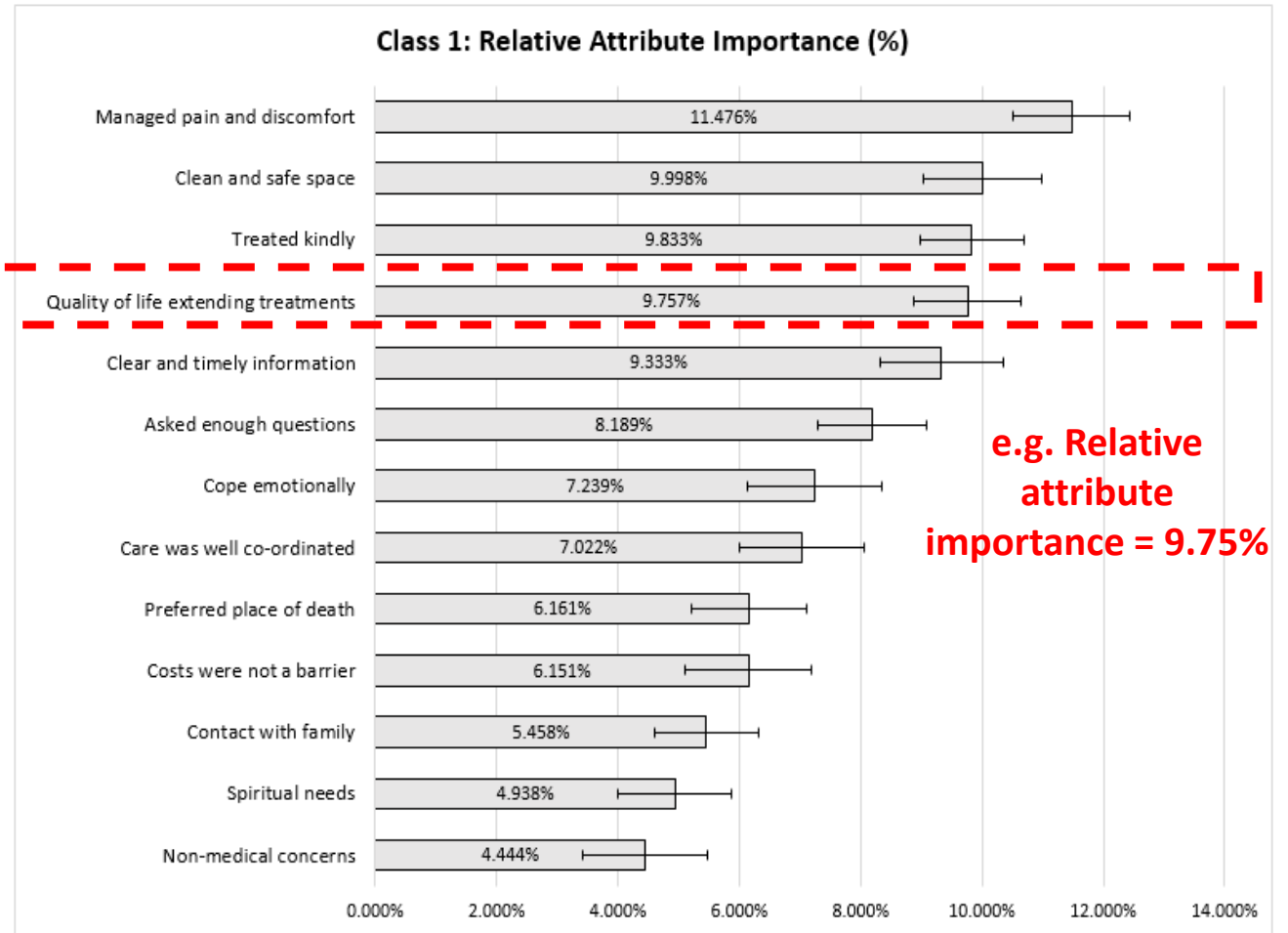
- Using the identified attributes, we fielded a **discrete-choice experiment (DCE)** to a web-panel of 1250 caregivers of EOL patients in each of 5 countries to generate relative preference weights for each attribute

## Which healthcare provider would you choose to care for a loved one?

Experience over last 6 weeks of patient's life	Provider Group A	Provider Group B	Provider Group C
Health care providers encouraged contact with patient's friends and family	★ ★ ★	★	★ ★ ★ ★ ★
Health care providers provided appropriate level & quality of life-extending treatments	★ ★ ★	★ ★ ★ ★ ★	★
The places where health care providers treated patients were clean, safe and comfortable	★ ★ ★ ★ ★	★ ★ ★	★
Health care providers made sure that patients were cared for and died at their place of choice	★ ★ ★ ★ ★	★ ★ ★	★
If these were the only options, which Provider Group (A, B or C) would you choose based on these ratings?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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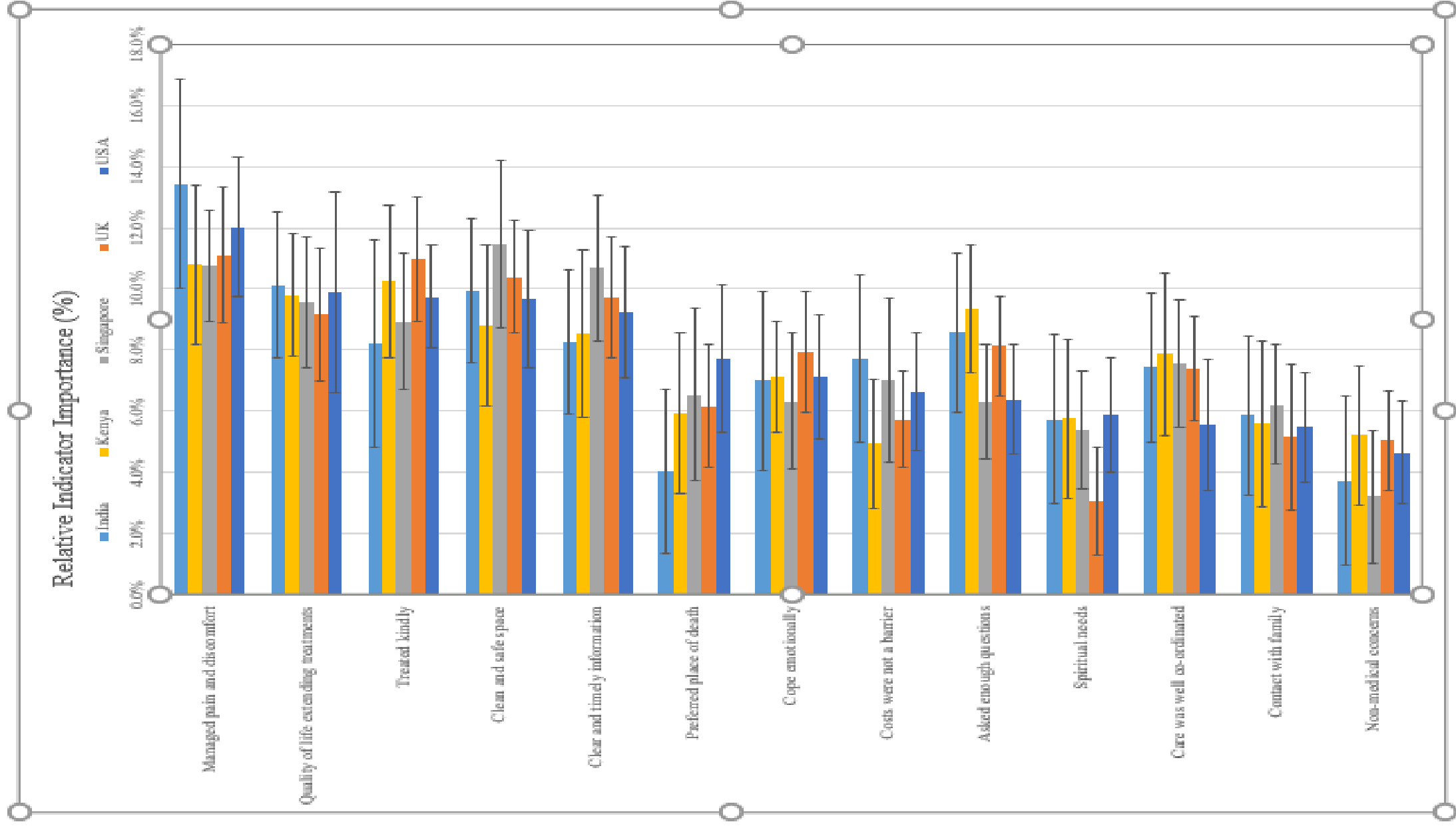
- Attributes were not equally valued by caregivers
- Managing pain was most important, followed by access to clean, safe, and comfortable facilities.
- Providers' support for spiritual needs and non-medical concerns were of least importance.
- Using the preference weights, we created a total score ranging from 0 (1-star on every attribute) to 100 (5-stars)
- Higher the overall score, better the end-of-life care.



Note: 95% Confidence intervals are shown





# Results by Country



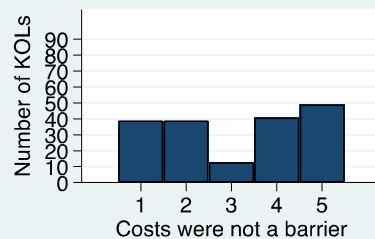
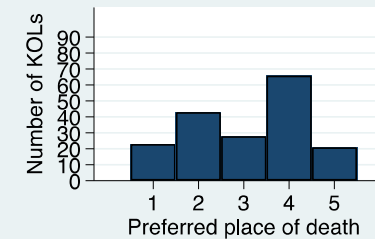
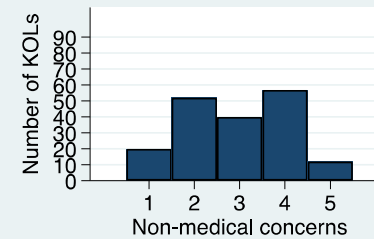
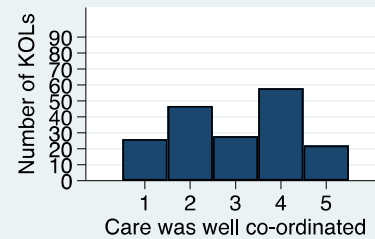
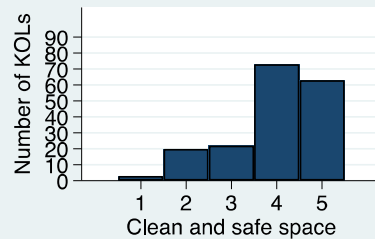
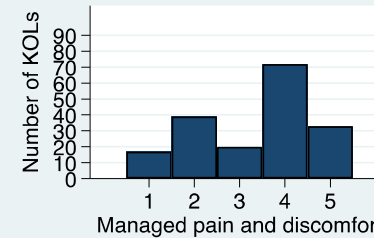
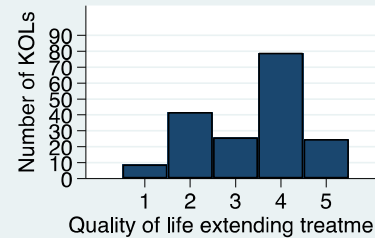
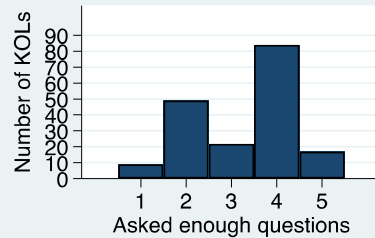
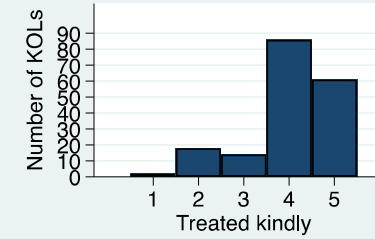
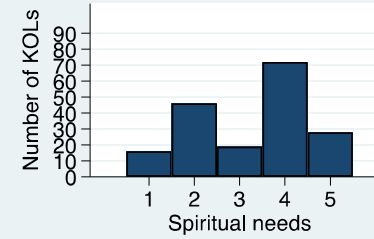
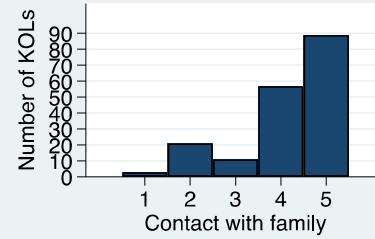
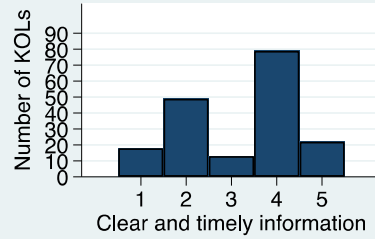
Experts around the world were invited to take the survey to rate their country.

Please tell us how much you agree or disagree with each statement **as it applies to patients in your country.**

<b>Health-care providers generally deliver clear and timely information so patients can make informed decisions.</b> <span style="float: right;">1/7</span>					
	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
<b>When possible, health-care providers generally encourage patients' contact with friends and family.</b> <span style="float: right;">2/7</span>					
	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree

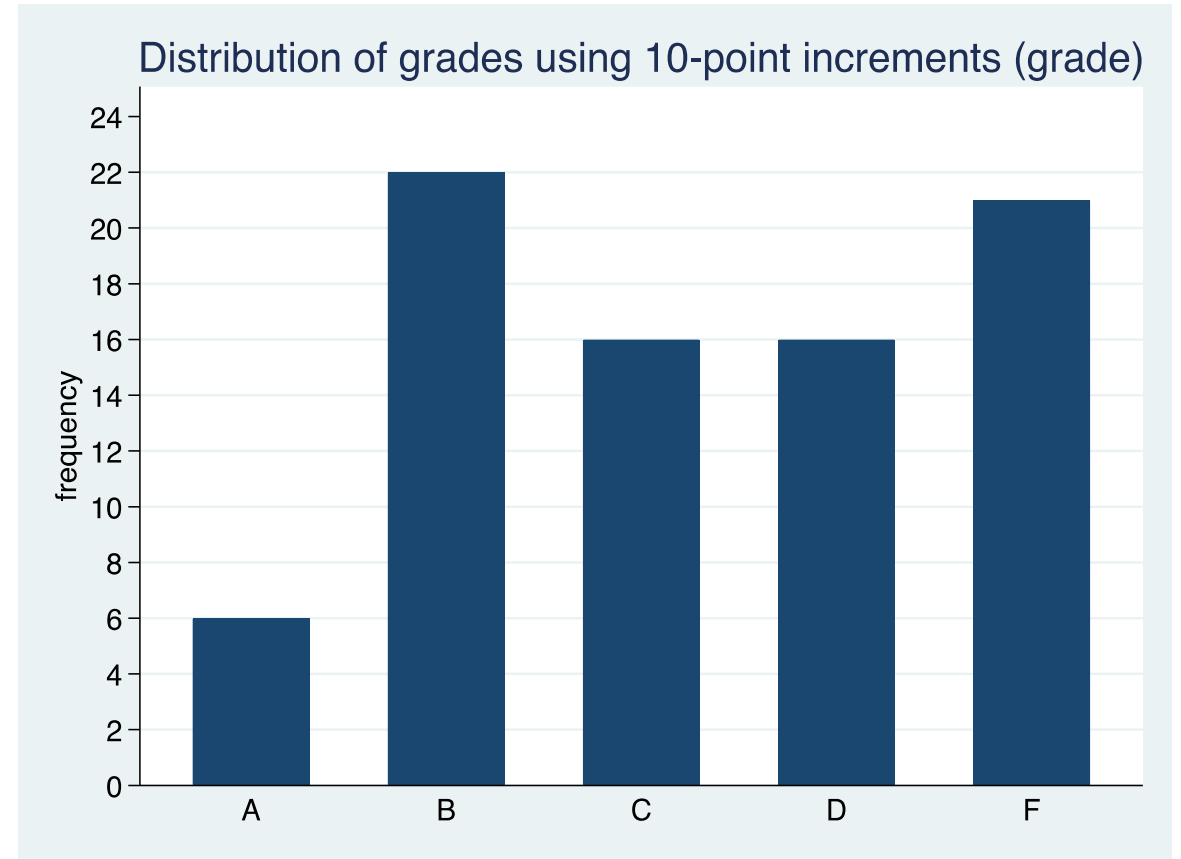
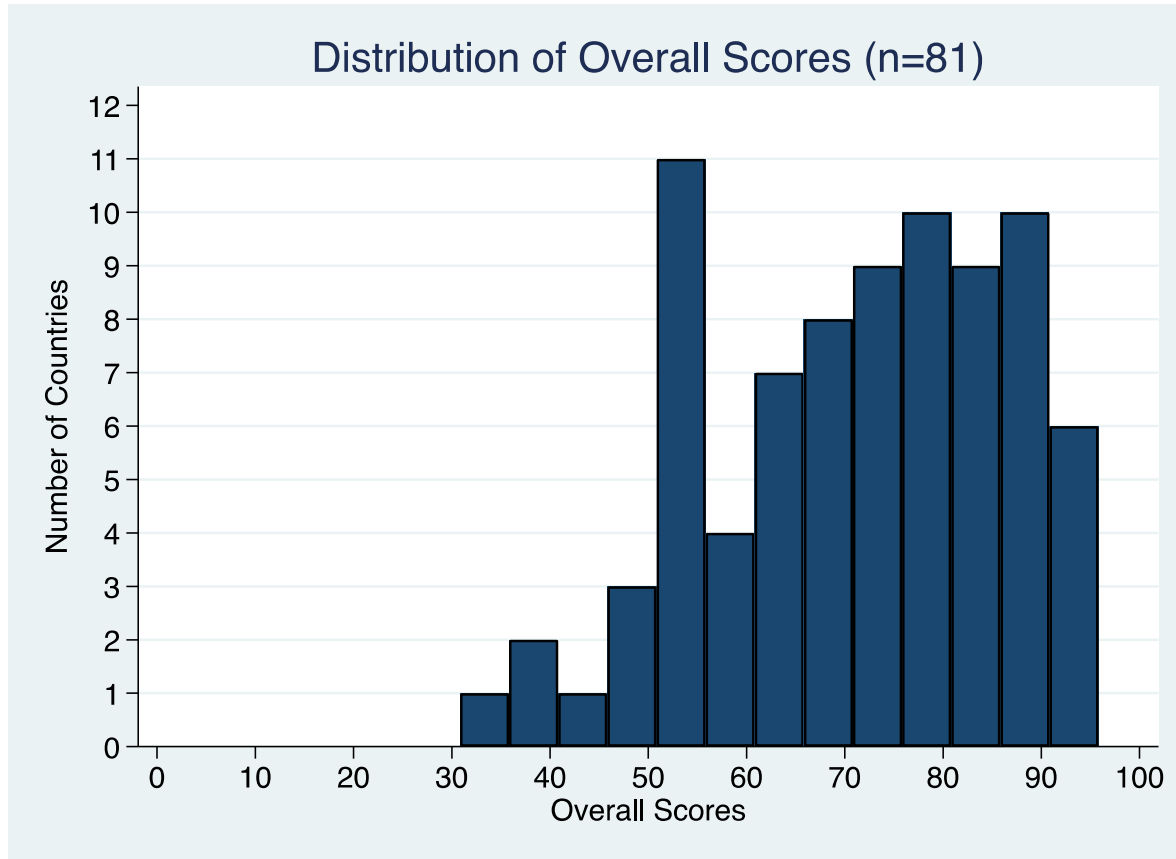
- 181 experts representing 81 countries provided responses.
- Countries were ranked and graded (A to F based on ten-point decrements) based on the total score.

## Expert level unweighted scores (1-5), n=181

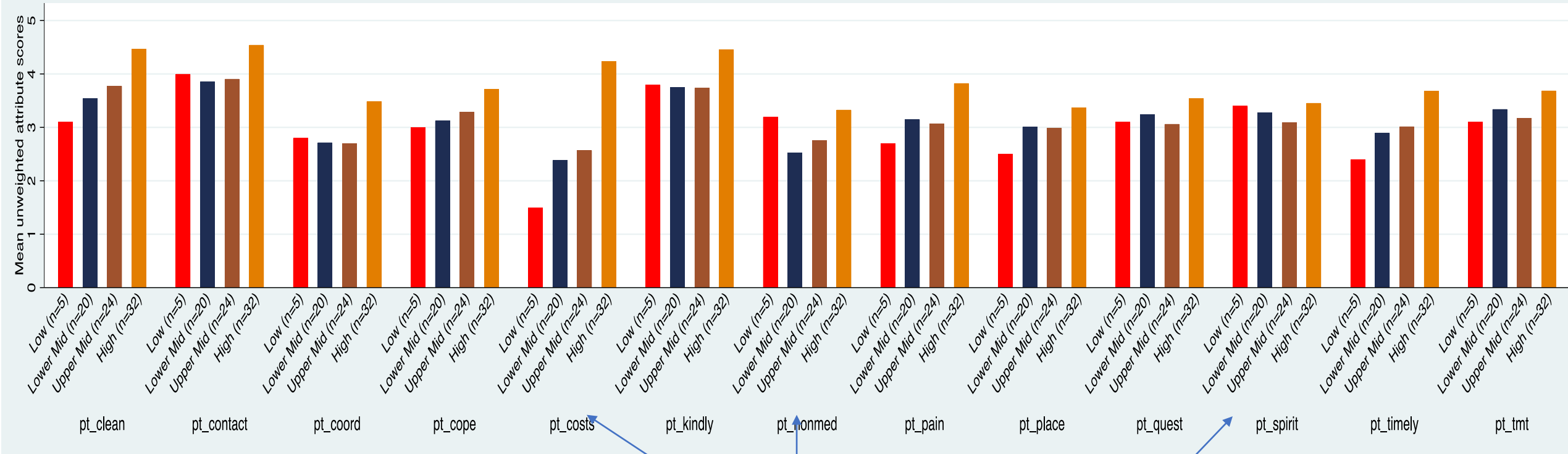


\*Scores correspond to agreement scores  
 1 - Strongly Disagree  
 2 - Disagree  
 3 - Neither Agree nor Disagree  
 4 - Agree  
 5 - Strongly Agree

- Scores ranged from a low of 33.3 to a high of 93.1

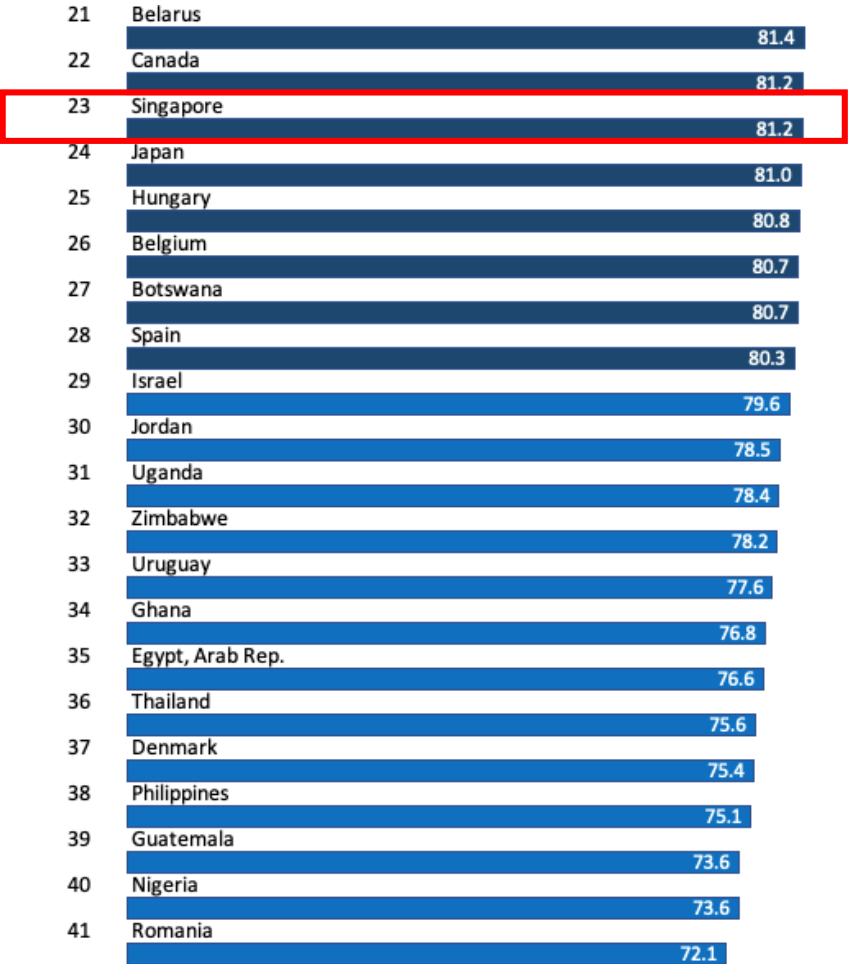
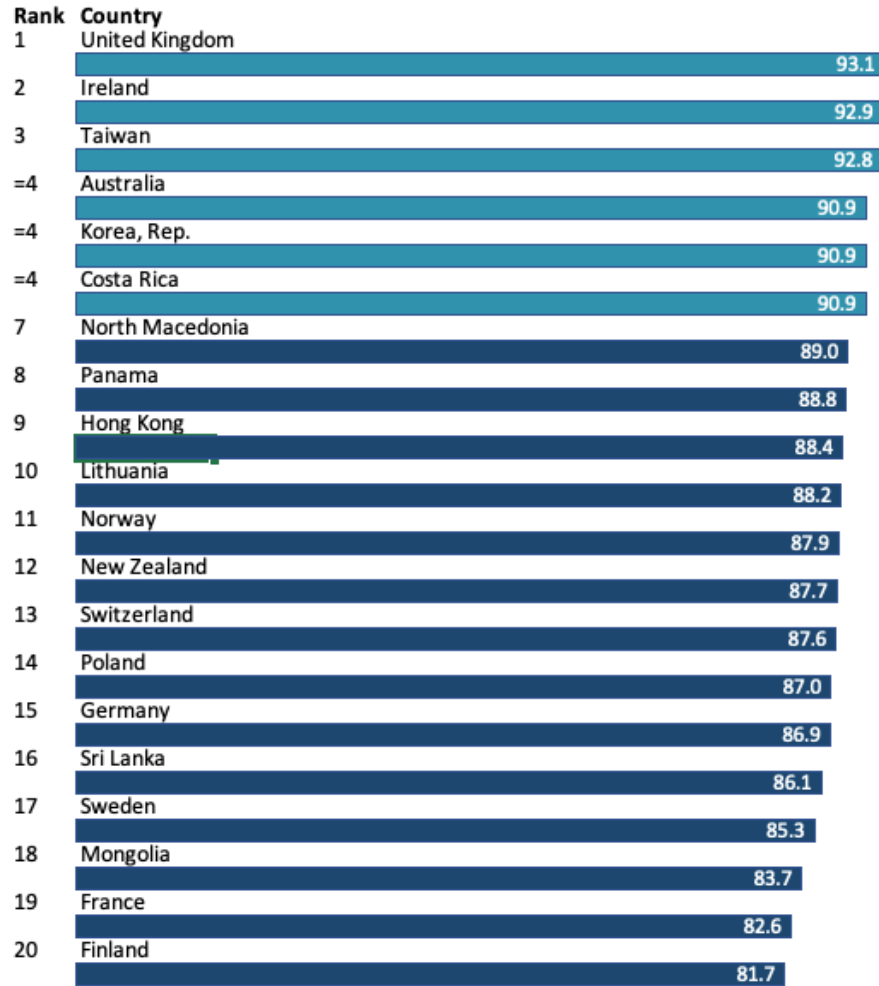


Mean unweighted scores by Income Group (n=81 countries)



- Low income countries suffer from high EOL costs (no UHC)
- But do comparatively better in non-medical concerns and spiritual needs

# Aim 3, Results (cont.)



• Where would this group have scored Singapore?

Indicators	Attendees' scores (n=43)*	95% Confidence interval	
Clean, safe, and comfortable places	4.6	4.4	4.8
Treat patients kindly and sympathetically	4.1	3.9	4.3
Provide appropriate levels and quality of life extending treatments	3.9	3.6	4.2
Control pain and discomfort to patients' desired levels	3.8	3.5	4.1
Encourage patients' contact with friends and family	3.8	3.5	4.1
Support patients' spiritual, religious, and cultural needs	3.6	3.2	3.9
Ask enough questions to understand patient needs	3.4	3	3.8
Clear and timely information	3.4	3.1	3.7
Be cared for and die at their place of choice	3.3	3	3.7
Costs generally are not a barrier	3.1	2.7	3.6
Help patients cope emotionally	3.1	2.7	3.5
Help with patients' non-medical concerns	3.1	2.7	3.5
Care is well coordinated across different health-care providers	3	2.6	3.4

- Overall score: 75 (95% CI: 71 – 79)
- Lower than KOL overall score of 81
- More important is whether it suggests areas for improvement
  - Does it?

# Quality of Death and Dying Research Outputs

Vol. 00 No. 00 xxx 2021

Journal of Pain and Symptom Management 1

## Review Article

### Identifying Core Domains to Assess the “Quality of Death”: A Scoping Review

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## Original Article

### What is a Good Death? A Choice Experiment on Care Indicators for Patients at End of Life

Juan Marcos Gonzalez Sepulveda, PhD, Drishti Baid, BSocSci,  
Department of Population Health Sciences (J.M.G.S., F.R.J.), Duke University  
Health Services and Systems Research (D.B., E.A.F.), Duke-NUS Medical  
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Journal of Pain and Symptom Management 1

## Special Article

### Cross Country Comparison of Expert Assessments of the Quality of Death and Dying 2021

Eric A. Finkelstein, PhD, Afsan Bhadelia, PhD, Cynthia Goh, MBBS, Drishti Baid, BA, Ratna Singh, MA,  
Sushma Bhatnagar, MD, and Stephen R. Connor, PhD  
Lien Centre for Palliative Care, Duke-NUS Medical School, Singapore and Duke University Global Health Institute (E.A.F.), Durham, North  
Carolina, USA; Department of Global Health and Population, Harvard T.H. Chan School of Public Health, Boston (A.B.), Massachusetts,  
USA; Department of Palliative Medicine, National Cancer Centre Singapore (C.G.), Singapore; Sol Price School of Public Policy, University of  
Southern California (D.B.), Los Angeles, California, USA; Lien Centre for Palliative Care, Duke-NUS Medical School (R.S.), Singapore;  
Institute Rotary Cancer Hospital, All India Institute of Medical Sciences (S.B.), New Delhi, India; Worldwide Hospice Palliative Care Alliance  
(S.R.C.), London, UK.

- More importantly, efforts are underway to convert our approach to a PRO tool to evaluate quality at multiple levels



- EOL experience for many is bad (even here)
- All governments would like to spend less money on EOL care
- Efforts to measure quality at EOL have been ad hoc and use metrics that, at best, are only loosely related to what matters most to patients and families at EOL

### ***Summary of recommendations***

- Apply cost-effectiveness thresholds and other rationing mechanisms as a means to define and limit “overtreatment”
- Identify (ex ante) quality metrics based on what patients truly value (or adopt ours 😊)
- Link reimbursement to these metrics (this is Accountable Care)
- Don’t assume patients or their families know what’s best
- Hope clouds judgement so some paternalism is ok

# Thank You

To learn more about QODDI and LCPC, please visit our website: [www.duke-nus.edu.sg/lcpc](http://www.duke-nus.edu.sg/lcpc)