A Cross Country Comparison of the Quality of Death and Dying, 2021

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Core Team and Funders

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Background: People Love Rankings

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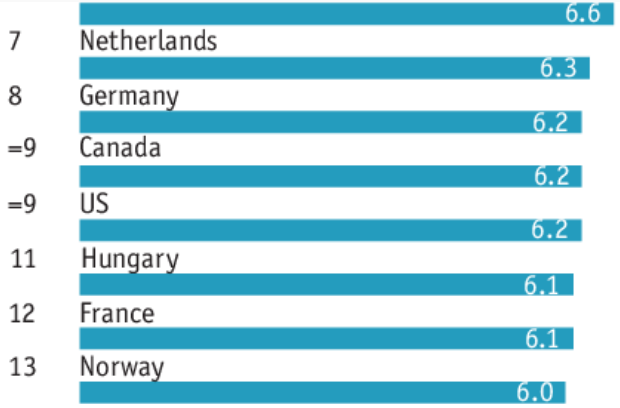
Even in Death

By **Jenny Anderson**
Senior reporter, Editor of How to be Human

Published October 6, 2015 • This article is more than 2 years old.

Britain may not be the best place to live, but it is the best place to die.



YOU ARE AT: English News ▸ India ▸ Quality Of Death Index: UK tops, India 67th, above China

Quality Of Death Index: UK tops, India 67th, above China

India has been ranked 67th of 80 countries on the 2015 Quality of Death Index, lower than South Africa (34), Brazil (42), Russia (48), Indonesia (53) and Sri Lanka (65) but above China (71).

India TV News Desk

Rankings matter…

No matter how flawed they may be!

Background: Prior Efforts to Quantify the Quality of 'Death'

- Two prior efforts (2015 and 2010) ranked countries largelyusing a Donabedian approach that focused on inputs, not outputs (i.e., a production function).
- The 2015 Quality of Death Index (QODI) evaluated 80 countries 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)
- Assumes that if these indicators are met then the EOL experience is better.
- Limitations
  - Weights arbitrarily assigned by 'experts'
  - Indicators may be only weakly correlated with outcomes that matter (e.g., community engagement)
  - Only as good as the data that is available
  - Among others
- We aimed to do better

QODDI, Overview

- Our approach for QODDI 2021
  - Aim 1: Identify core domains/sub-domains of EOL care important to patients and families based on a literature review
  - Aim 2: Quantify relative importance (i.e., preference weights) for key indicators (and levels within indicators) for these domains/sub-domains using a discrete choice experiment (DCE)
  - Aim 3: Derive preference-weighted country-level rankings by fielding the indicators survey to knowledgeable individuals in as many countries as possible

Aim 1

Aim 1: “Identifying the core domains and sub-domains to assess the ‘quality of death’: A scoping review”

Authors: Afsan Bhadelia, Leslie E. Oldfield, Jennifer L. Cruz, Ratna Singh, Eric A. Finkelstein

Aim 1: Scoping Review, Methods

The scoping review identified the core domains and subdomains that can be used to evaluate the performance of end-of-life care within and across heath systems.

Search strategy: PubMed/MEDLINE (NCBI), PsycINFO (ProQuest), and CINHAL databases were searched for peer-reviewed journal articles published prior to February,2020.

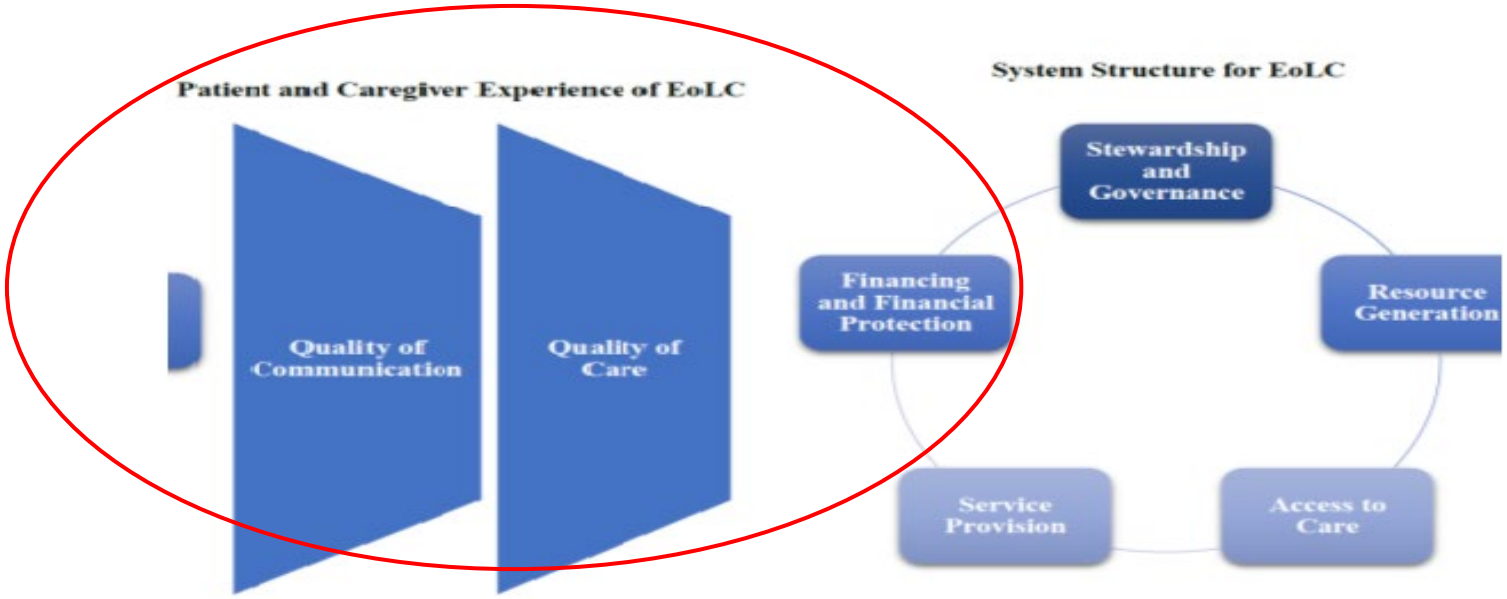
Screening criteria: A priori eligibility criteria was established. Only studies focussed on palliative care with explicit reference to the EOL period were included.

Overview of search results : Of the 2728 results, 309 eligible articles were included.

Aim 1: Scoping Review, Results

- The scoping review identified 7 domains and 33 sub-domains which capture key aspects of ‘quality of death’.
- 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 and these are outcomes

Overview of domains identified through scoping review



Aim 2

Aim 2: What contributes to a good death? A choice experiment on care indicators for patients at end of life.

Authors: Juan Marcos Gonzalez Sepulveda, Drishti Baid, F. Reed Johnson, Eric Finkelstein

Quality of Death and Dying Indicators

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	**Clear and timely information** Health care providers gave patients clear and timely information so patient could make informed decisions
2	**Treated kindly** Health care providers treated patients kindly and sympathetically
3	**Spiritual needs** Health care providers supported patients' spiritual, religious, and/or cultural needs
4	**Contact with family** Health care providers allowed patients to contact their friends and family
5	**Asked enough questions** Health care providers asked enough questions to understand patients' needs
6	**Quality of life extending treatments** Health care providers provided appropriate level & quality of life-extending treatments
7	**Managed pain and discomfort** Health care providers controlled pain and discomfort as well as the patient wanted
8	**Cope emotionally** Health care providers gave patients support to help them cope emotionally
9	**Clean and safe space** The centre was clean, safe, and comfortable.
10	**Care was well co-ordinated** Health care providers provided care that was well coordinated.
11	**Non-medical concerns** Health care providers helped with patients' non-medical concerns
12	**Preferred place of death** Health care providers made sure that patients were cared for and died at their place of choice.
13	**Costs were not a barrier** Costs were not a barrier to getting appropriate care.

Each indicator could take values from strongly disagree to strongly agree (5 levels)

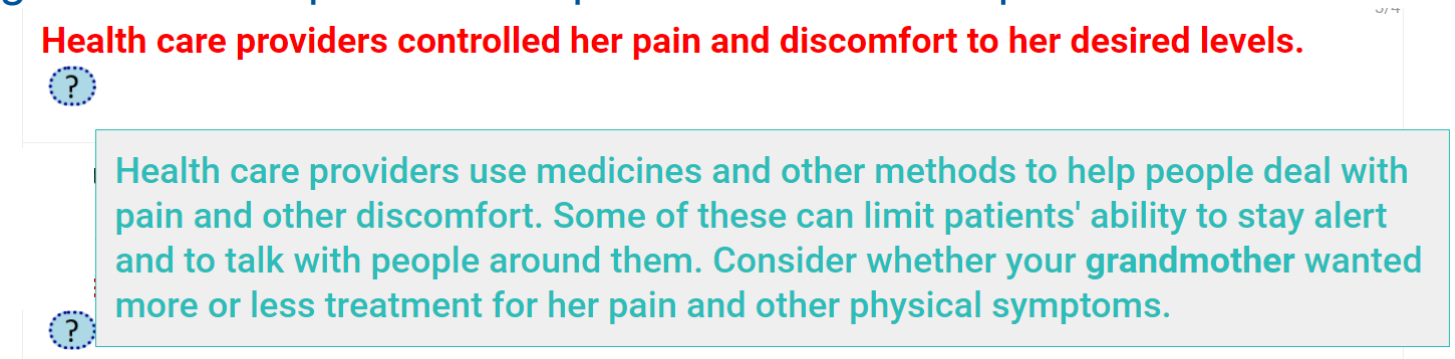
Anything obviously missing?

Aim 2, Overview

- Using the identified attributes, we created a **discrete-choice experiment (DCE)** to measure the relative importance of each attribute.
- What is a DCE?
  - A quantitative method increasingly used in healthcare to elicit preferences and tradeoffs for 'products' with multiple attributes (such as efficacy, safety, and cost)
  - Participants are typically presented with a series of hypothetical scenarios containing different levels of the attributes
  - If enough questions are asked we can quantify the relative importance of each attribute compared to the others and the value of moving from lower to higher levels within attributes
- Why use a DCE for this effort?
  - Allows for generating weights for each level of each of our 13 indicators to create an overall score that is preference-based
  - Can be administered fairly quickly and cheaply using existing web panels

Aim 2, Methods (continued)

- **Sampling Frame: We used caregivers as a proxy for patients (must have died within past two years)**
- How bad is that?
- We asked participants to rate patients' experience in the last 6 weeks of life
- In each of the DCE choice questions, respondents were asked to consider three hypothetical healthcare provider groups that were rated by other caregivers on each of the attributes using a 5-star rating system, from strongly disagree to strongly agree
    - Asked which provider group they would choose among the 3
- To limit cognitive burden, respondents evaluated only 4 attributes at a time and only 3 levels (1, 3, or 5 stars) in each of 6 DCE questions but which 4 varied across respondents
- Prior to fielding the DCE we provided respondents with an explanation of each attribute. Example:



Aim 2, Example DCE Question 1

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?	○	○	○

Continue »

Aim 2, Example 2

How about for this one?

Experience over last 6 weeks of patient's life	Provider Group D	Provider Group E	Provider Group F
Health care providers supported patients' spiritual, religious, and/or cultural needs	★★★	★	★★★★★
Health care providers mostly treated patients kindly and sympathetically	★	★★★★★	★★★
Health care providers controlled patient's pain and discomfort to patient's desired levels	★	★★★★★	★★★
Health care providers helped with patients' non-medical concerns	★★★	★★★★★	★
If these were the only options, which Provider Group (D, E or F) would you choose based on these ratings?	○	○	○

Continue »

Aim 2, DCE Example 3

One more

Experience over last 6 weeks of patient's life	Provider Group G	Provider Group H	Provider Group I
The places where health care providers treated patients were clean, safe and comfortable	★	★★★★★	★★★
Health care providers helped with patients' non-medical concerns	★	★★★★★	★★★
Health care providers made sure that patients were cared for and died at their place of choice	★★★	★	★★★★★
Costs were not a barrier to getting appropriate care	★★★	★★★★★	★
If these were the only options, which Provider Group (G, H or I) would you choose based on these ratings?	○	○	○

Continue »

Aim 2, Methods (continued)

Data analysis

- Survey and DCE design were created according to best practices

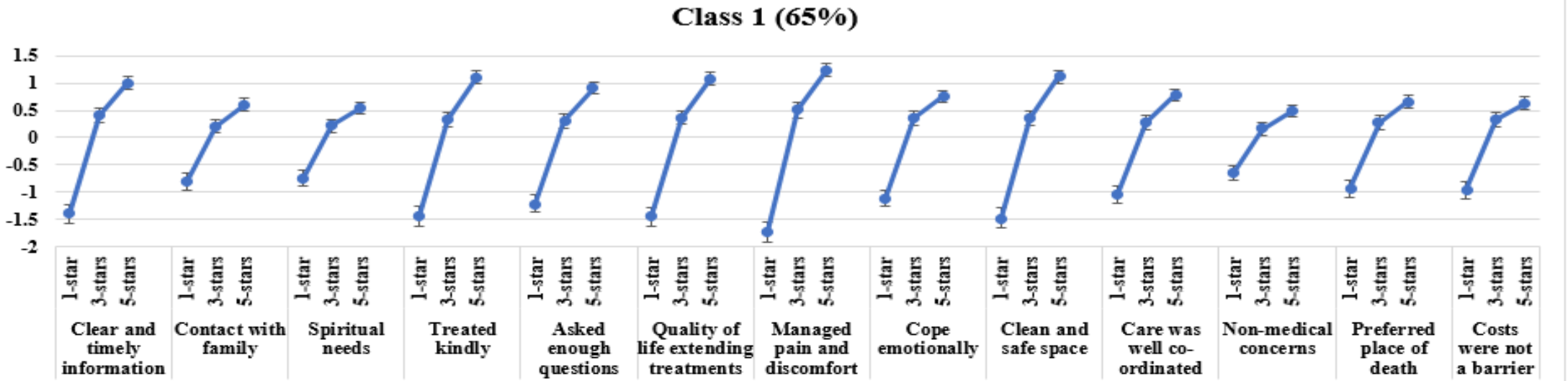
- After pilot testing, we fielded the online DCE survey to a web-panel of 1,250 caregivers of a deceased (2 years or less) family member or close friend.
    - 250 responses in each of 5 countries: India, Singapore, Kenya, UK and USA.

- Latent-class analysis was used to evaluate preference heterogeneity and determine preference weights for each attribute-level.
    - Latent class allows for identifying subgroups with different preferences but is also very good to identify those who do not take the exercise seriously (or who don’t get it)

Aim 2, Results

- A 2-class latent class model was chosen as the best fit.
- Class 1 (≈ 65% of sample) preference weights were logically ordered and highly significant
- Class 2 estimates were generally disordered with high variance, suggesting respondents either did not pay attention or did not understand the task.
- Those predicted to be in Class 2 were also more likely to fail internal validity tests
- Estimates from Class 1 were used to estimate:
  - Relative importance for each indicator
  - Preference weighted scores for every possible attribute-level combination

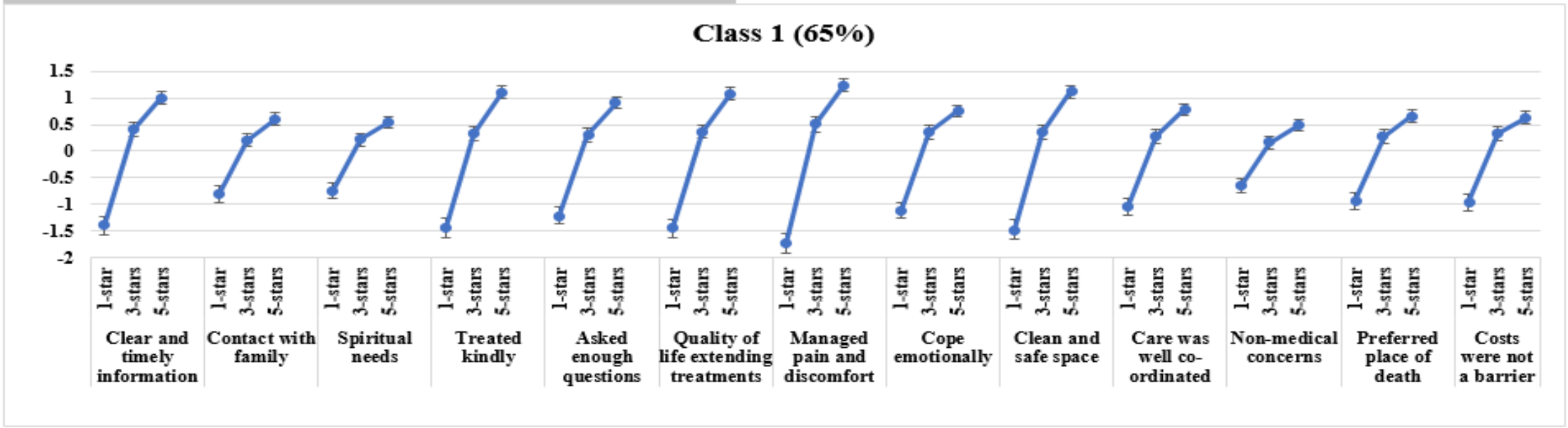
Aim 2, Results

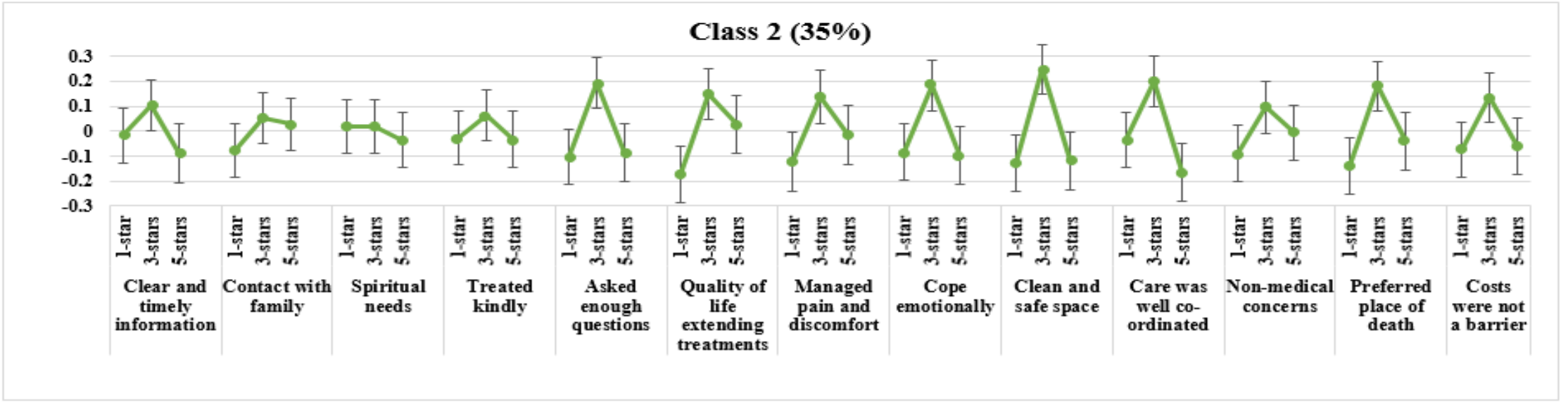


Note: All attributes were effects-coded.
95% Confidence intervals are shown.

Caregivers (in Class 1) value changes in quality ratings from 1 to 3 stars more than from 3 to 5

Aim 2, Results



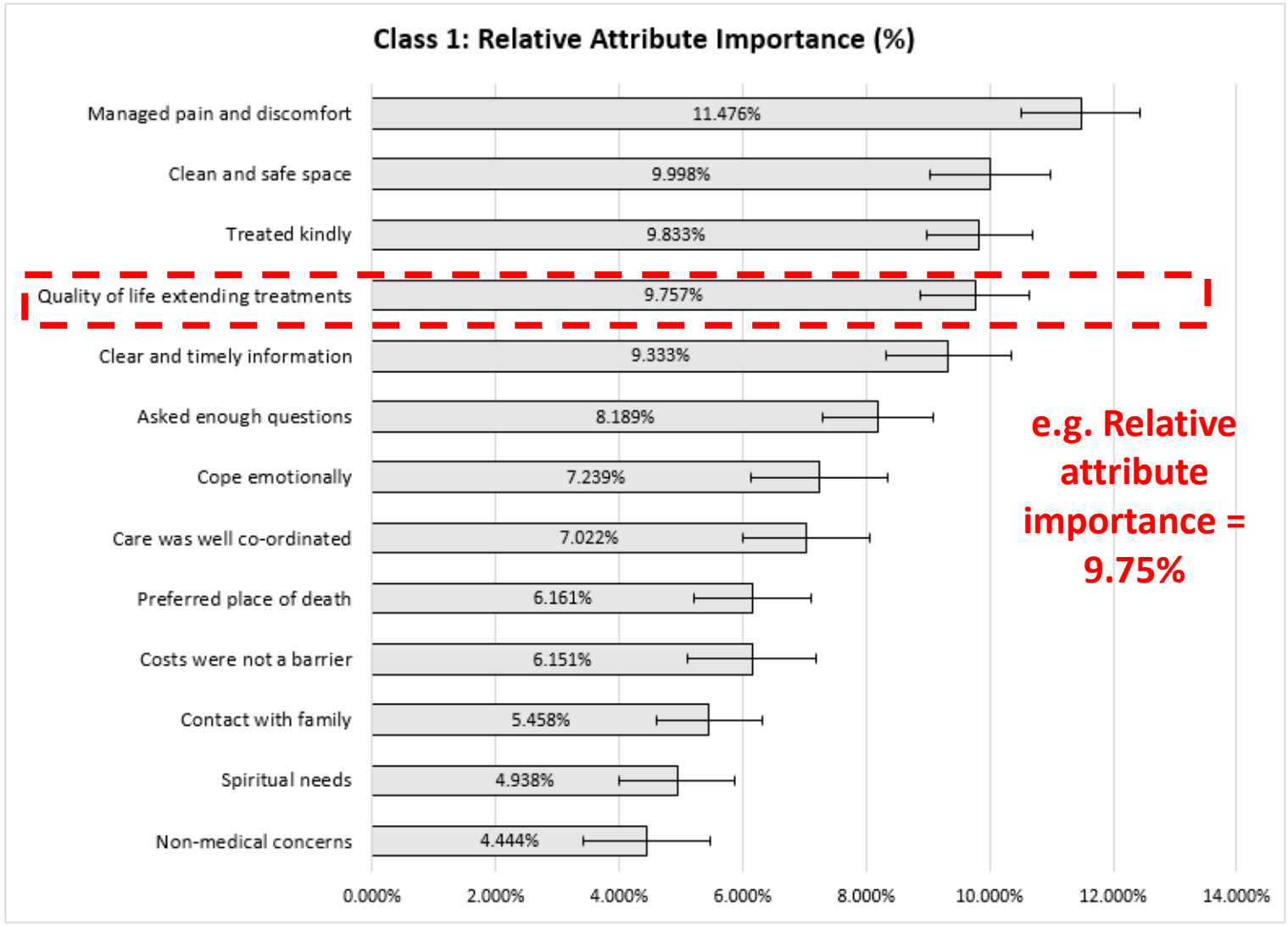


Note: All attributes were effects-coded.
95% Confidence intervals are shown.

Data from Class 2 appears problematic

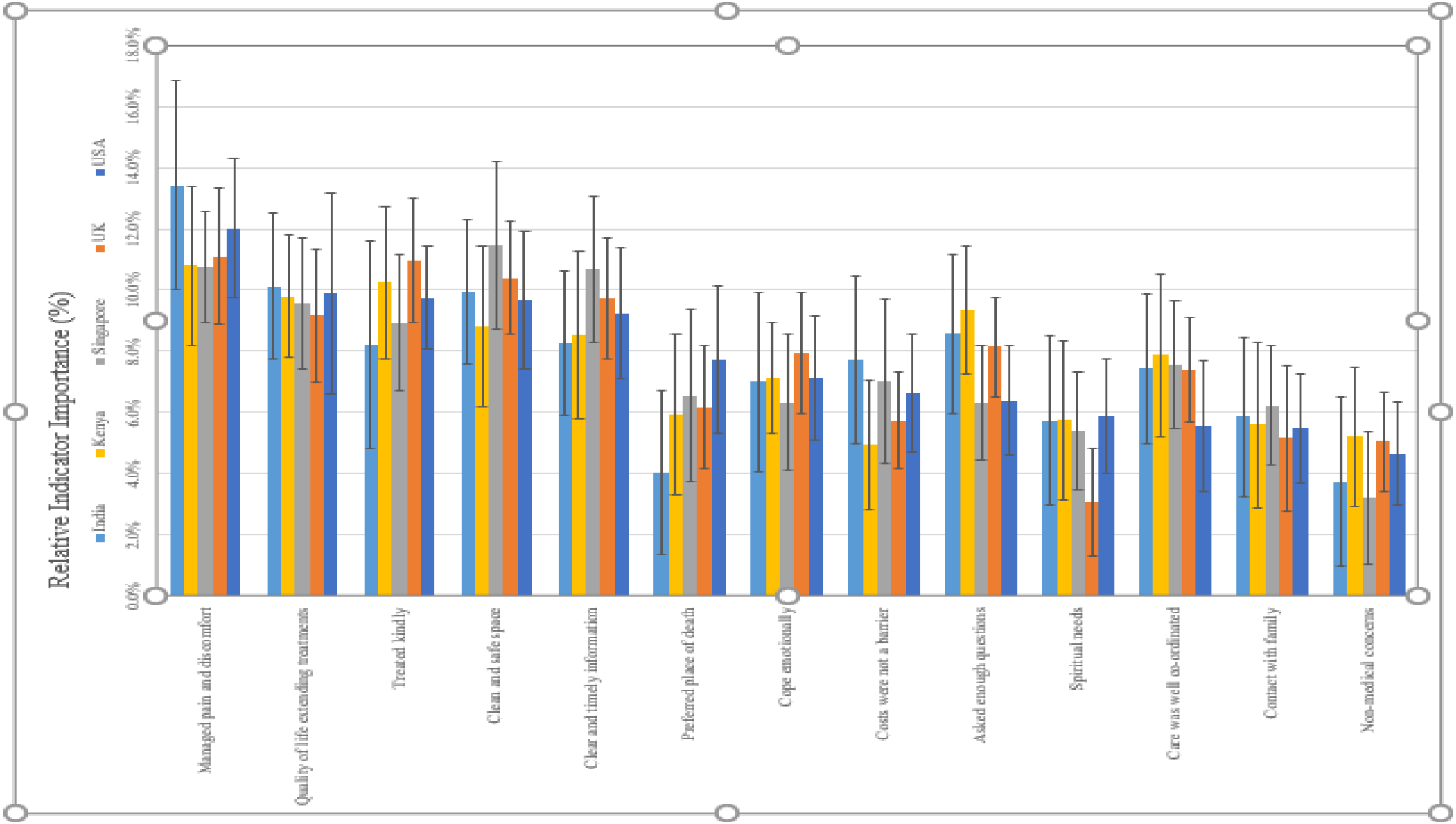
Aim 2, Results (continued)

- Attributes were not equally valued by caregivers
- Providers' ability to control patients' pain was most important, followed access to clean, safe, and comfortable facilities.
- Providers' support for spiritual needs and for non-medical concerns were of least importance.
- Valued at less than half the value of managing pain and having clean and safe spaces for care delivery
- **Any idea why?**
- **Would patients have the same rankings?**



Note: 95% Confidence intervals are shown

Aim 2, Results by Country



Note: 95% Confidence Intervals are shown.

Aim 2, Results (continued)

- Using the regression results for Class 1, we created an index where:
  - The worst possible score of 1-star on every attribute = 0
  - The best possible score of 5-stars on every attribute = 100
- Higher the overall score, better the end of life care
- The 5-level 13 attribute (weighted) survey can be administered to patients, caregivers, or any qualified respondent and scored using the above approach
- We could also apply preference weights for the 5 countries independently
- But the instrument is not without limitations
- Hold that thought

Aim 3

Aim 3: Quality of Death and Dying Index 2021: A Preference-Based Approach

Authors: Eric A. Finkelstein, Afsan Bhadelia, Cynthia Goh, Drishti Baid, Ratna Singh, Sushma Bhatnagar, Stephen R Connor

Aim 3, Methods

- **Sampling frame: 2 experts in each of 169 countries were invited to take a survey including the 13 indicator questions related to patient experiences in their country.**
- How bad is that?

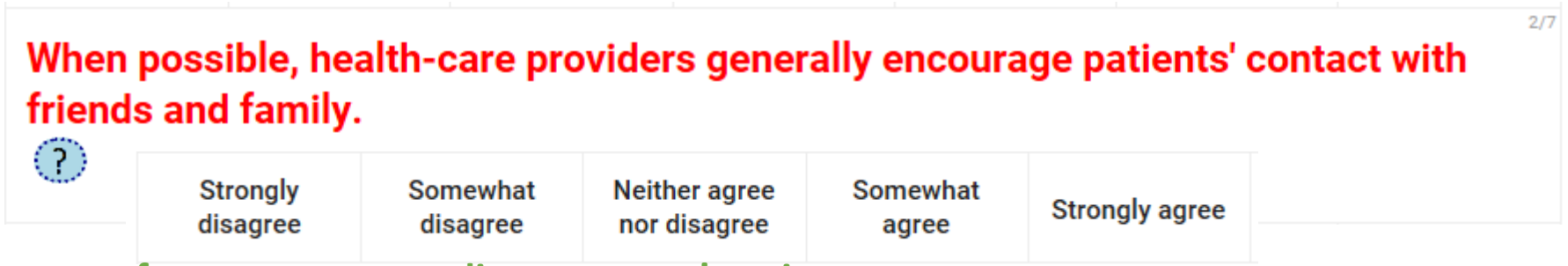
Aim 3, Methods

- **Sampling frame: 2 experts in each of 169 countries were invited to take a survey including the 13 indicator questions related to patient experiences in their country.**
- How bad is that?
- We weight country-expert scores for each indicator by relative importance weights calculated in Aim 2.

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

- Question 1:

- Question 2:



Overall score = sum of scores corresponding to expert's ratings

Aim 3, Methods (continued)

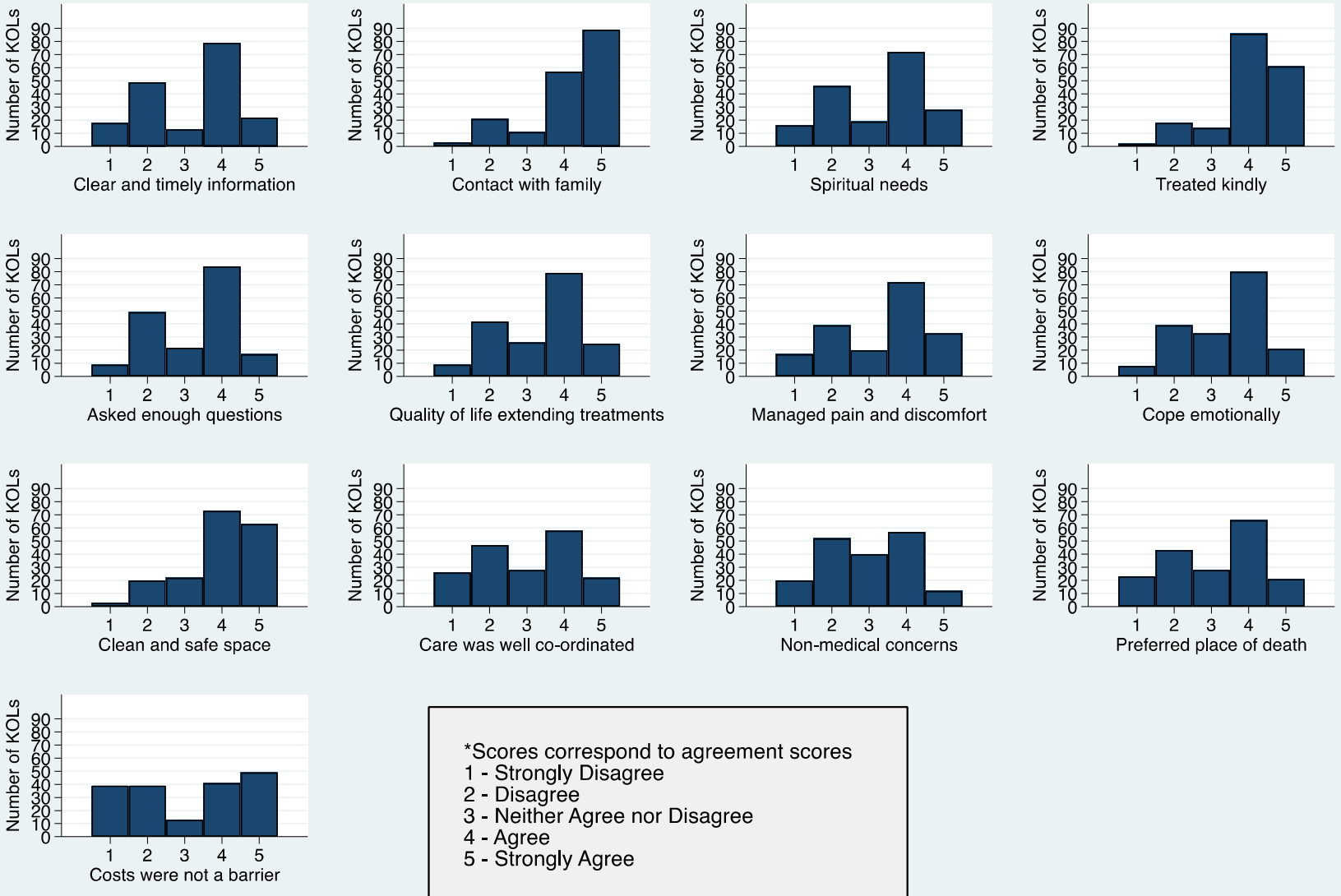
- For each country, overall scores from experts were averaged to obtain a country-level score.
- Countries were ranked and graded (A to F based on ten point decrements)
- 181 experts representing 81 countries provided responses (excluding countries with only 1 respondent)

Breakdown by region	> 2m population + at least 2 experts
East Asia & Pacific	15/20
Europe & Central Asia	26/50
Latin America & Caribbean	16/26
Middle East & North Africa	5/20
North America	2/2
South Asia	4/7
Sub-Saharan Africa	13/44
Total	81/169

Aim 3, Results (cont.)

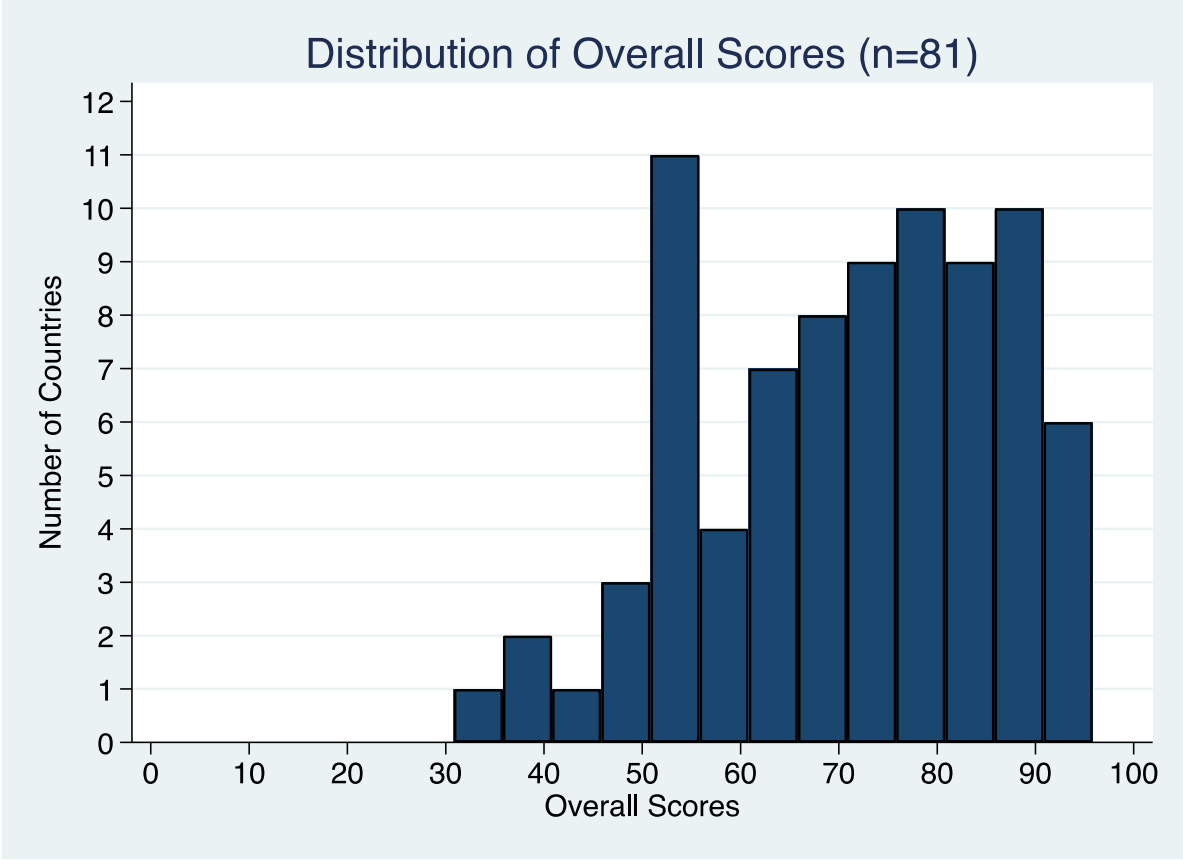
- There was variation in responses

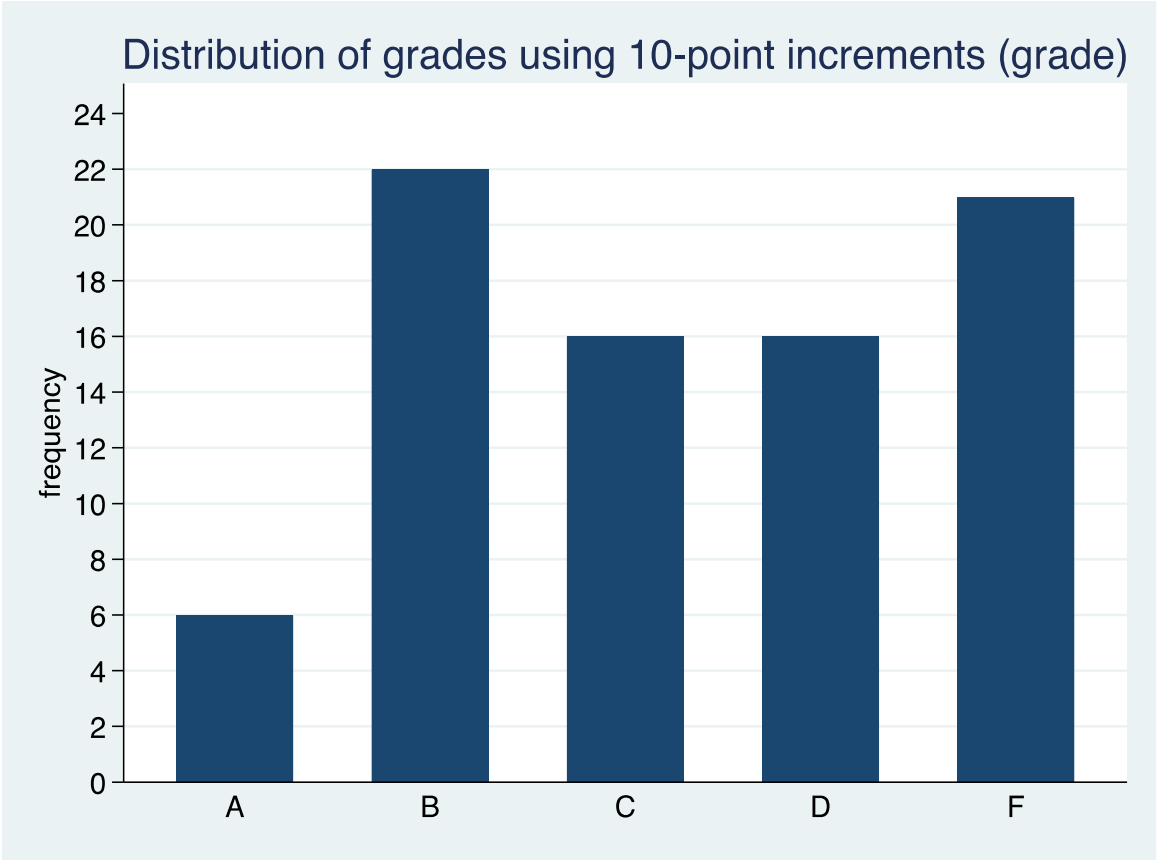
Expert level unweighted scores (1-5), n=181



Aim 3, Results (cont.)

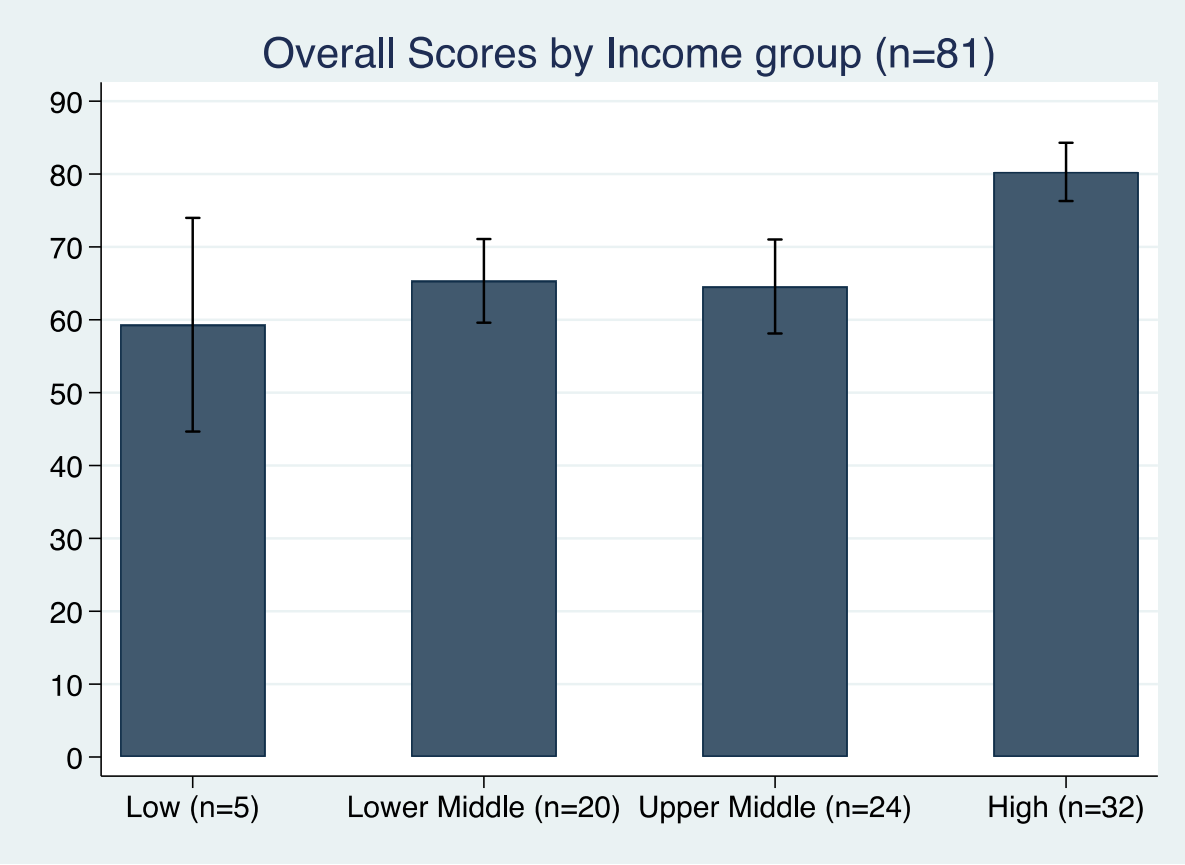
- In total, transformed scores ranged from a low of 33.3 to a high of 93.1



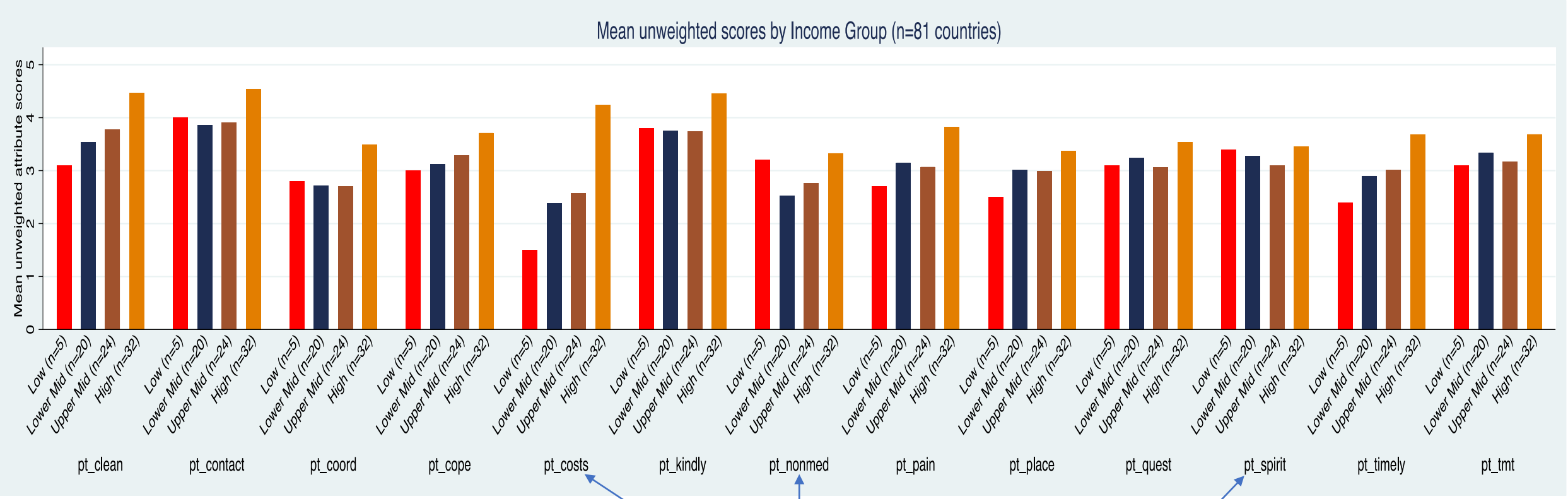


Aim 3, Results (cont.)

- If you have to die, better to die in a high income country
- Beyond that, does not seem to matter

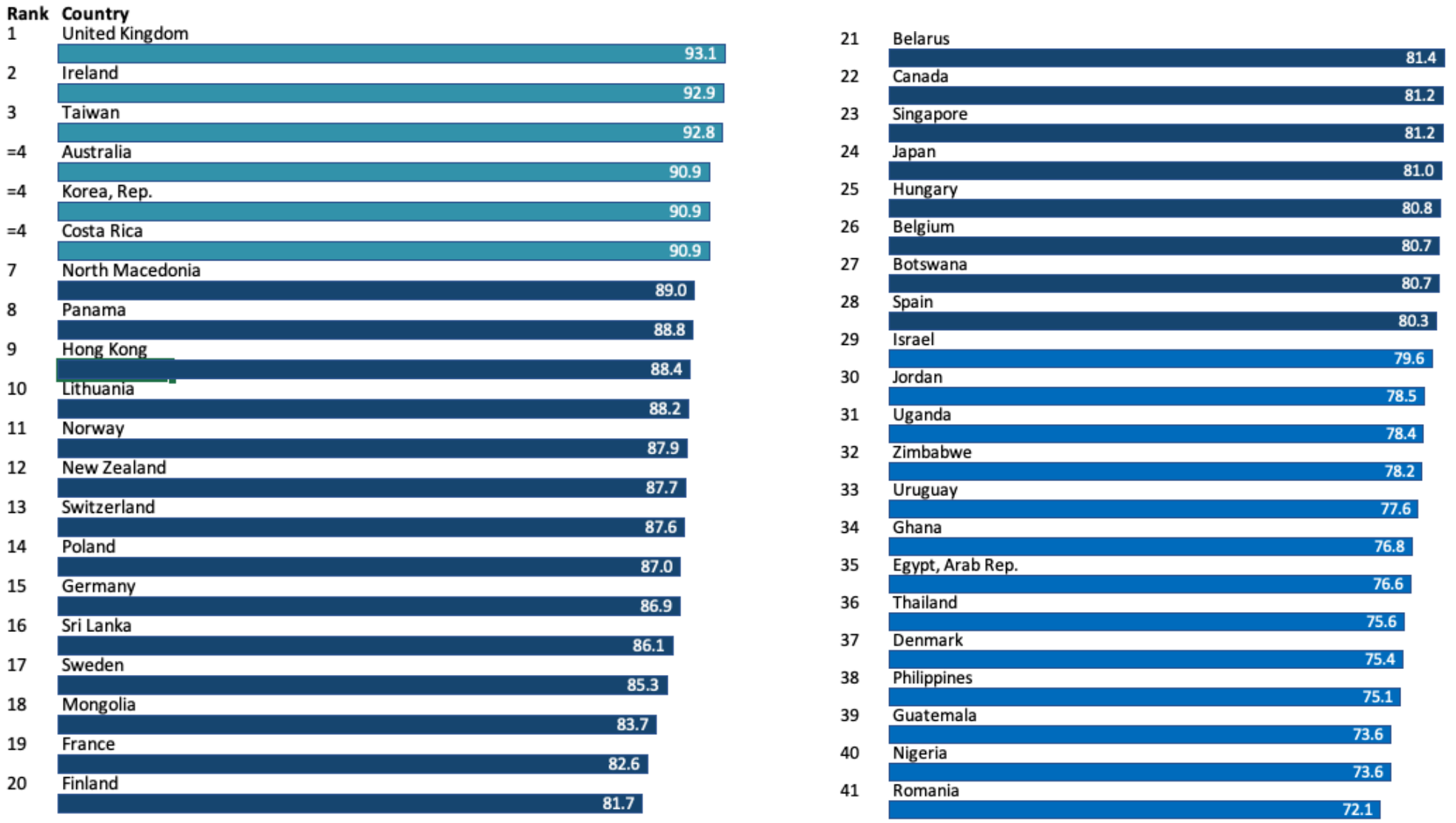


Aim 3, Results by Income (cont.)



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

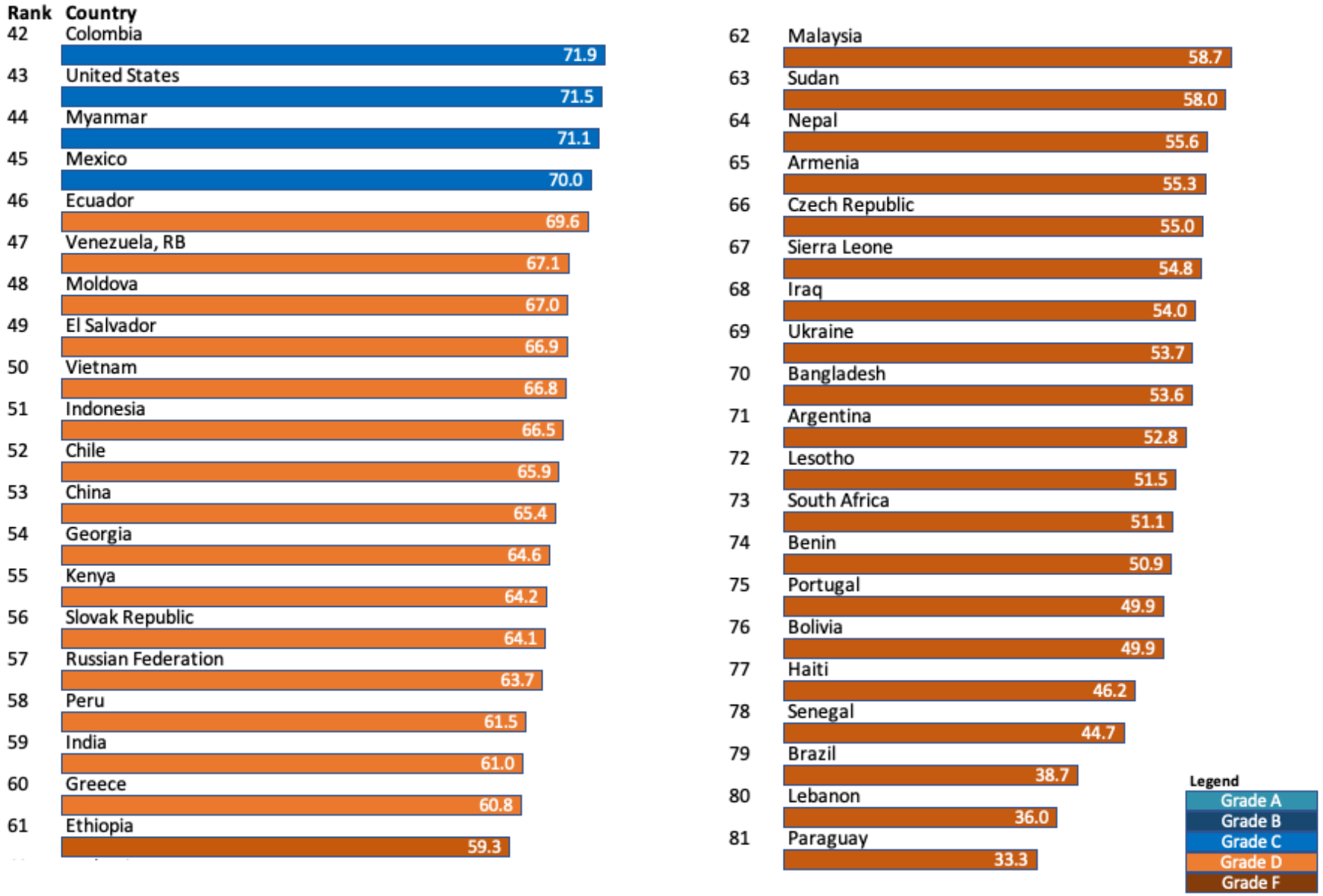
Aim 3, Results (cont.)



- High income countries tend to feature higher in the ranking

Aim 3, Results (cont.)

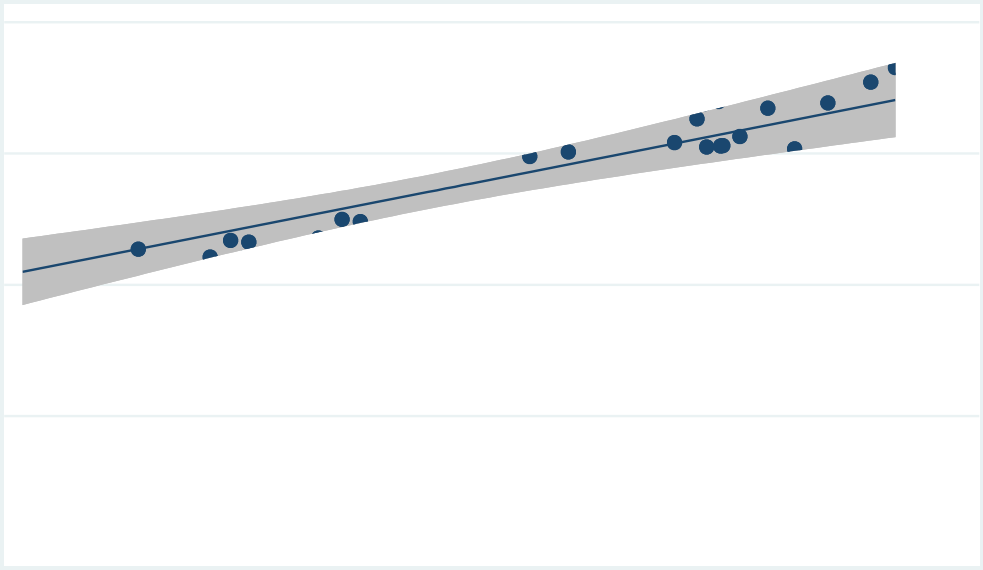
- But there are some anomalies
- Do results pass the sniff test?



Aim 3, Quality Checks

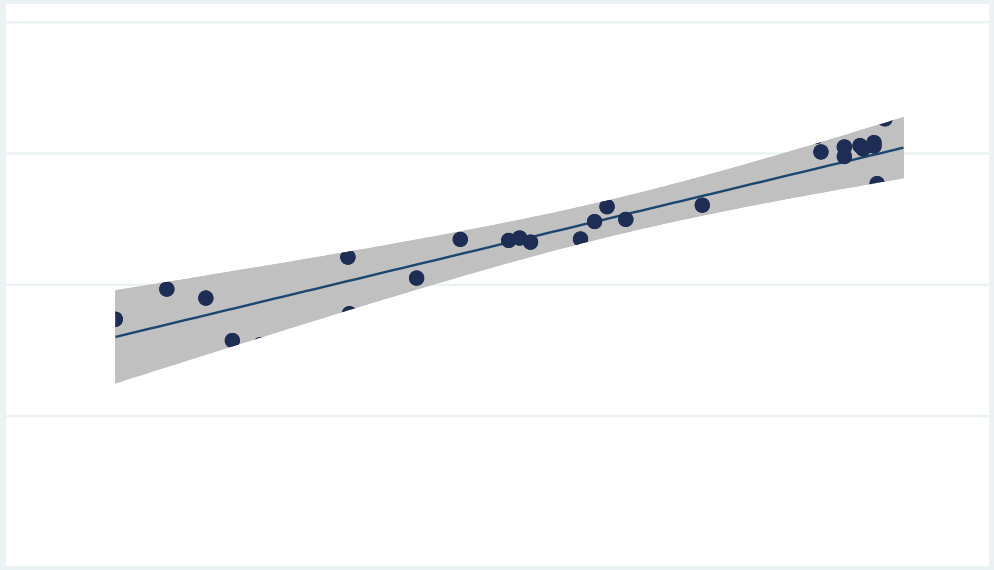
- There was a high correlation between 2021 QODDI scores and 1) 2015 QODI scores and 2) 2020 Human Development Index.

Correlation with the EIU 2015 QODI score



arsson's correlation coefficient r = 0.5755
R-squared=0.3312
n = 65

Correlation with Human Development Index (HDI) 2020

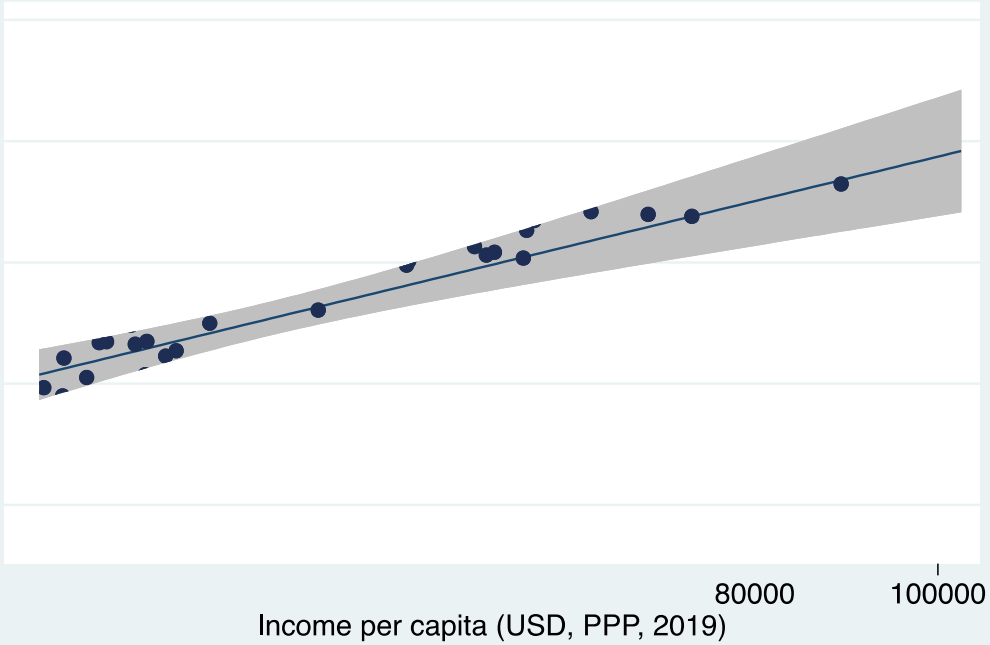


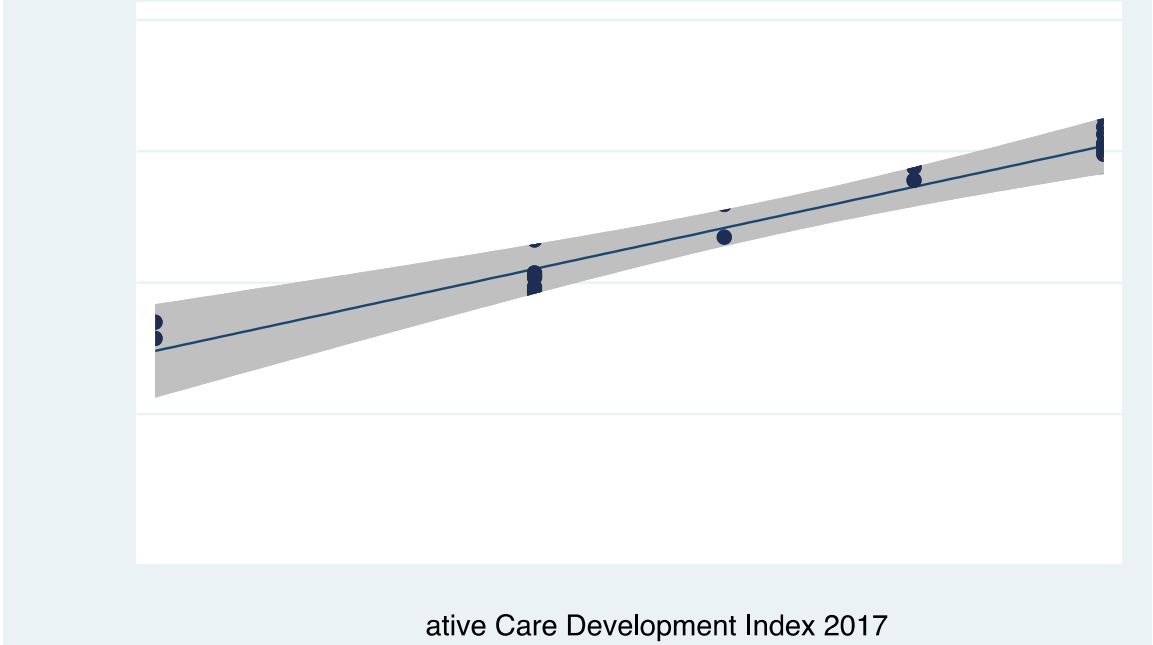
ent Index 2020

Pearson correlation coefficient r = 0.5348
Rsquare = 0.2860
n = 80

Aim 3, Results (cont.)

- And between QODDI scores and 3) 2019 GDP per-capita and 4) 2017 Palliative Care Development Index[1].





[1]Clark D, Baur N, Clelland D, et al. Mapping Levels of Palliative Care Development in 198 Countries: The Situation in 2017. *J Pain Symptom Manage*. Apr 2020;59(4):794-807.e4. doi:10.1016/j.jpainsymman.2019.11.009

2021 QODDI Summary

Strengths

- Transparent and systematic
- Adopts a patient-centered approach by paying attention to the preferences and considerations that matter most to patients and familes at EOL
- Not limited by data availability (just need to administer the survey)
- The survey and the preference weights developed through this study can be used by a single entity or an entire country to quantify EOL health system performance

Limitations

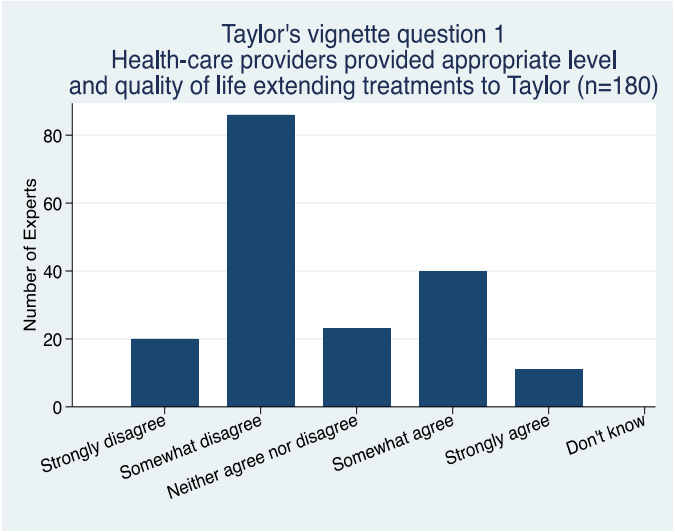
- Weights genered from caregivers due to difficulty in collecting patient data at critical EOL period
- Scores from Country Experts for same reasons
- Small sample sizes
- Not a validated PREM instrument

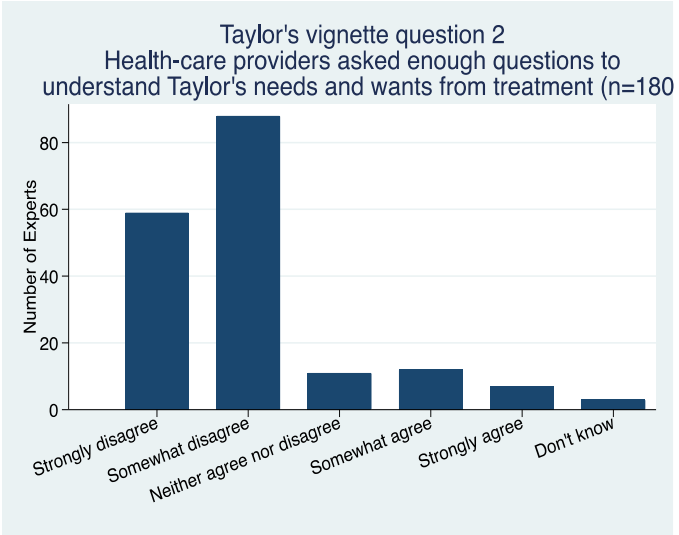
But these limitations can be overcome in future efforts

Limitations (cont).

- Results likely suffer from reporting heterogeneity
- This will be expored in a subsequent manuscript

Taylor had advanced cancer and recently died at home surrounded by friends and family. In the months prior to death, he saw many different health-care providers. All treated him with compassion, but some providers recommended he keep trying new treatments to extend his life whereas others recommended he seek palliative care and look to get his affairs in order. Feeling increasingly tired and confused he eventually gave up on treatment. In the last weeks of life his pain was well managed, but he was anxious and depressed wondering if he should have stopped treatment earlier.





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Summary

- Near universal agreement that EOL experience for many is bad
- Measuring quality at EOL is complicated due to inherent biases of patients, familes, and even doctors
- Ex ante and ex post assessments may differ
- But, we cannot improve what we don’t measure (Peter Drucker)
- Ultimately, focusing on quality from the patient perspective should improve EOL outcomes
- 2021 QODDI-2021 provides a superior (we think) approach for ranking quality of EOL care that can be improved in future iterations
- It also provides a framework that can be applied in many settings
- Current status – all 3 papers are under journal review

Discussion?

Final rankings and grades

To be made available in JPSM and on our website: www.duke-nus.edu.sg/lcpc