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

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## Abstract

**Context.**—Health systems should aim to deliver on what matters most to patients. With respect to end of life (EOL) care, knowledge on patient preferences for care is currently lacking.

**Objectives.**—To quantify preference weights for key EOL care indicators.

**Methods.**—We developed a discrete choice experiment survey with 13 key indicators related to patients' experience in the last six weeks of life. We fielded the survey to a web-panel of caregiver proxies for recently deceased care recipients. We obtained 250 responses in each of five countries: India, Singapore, Kenya, the UK and the US. Latent-class analysis was used to evaluate preference weights for each indicator within and across countries.

**Results.**—A 2-class latent-class model was the best fit. Class 1 (average class probability = 64.7%) preference weights were logically ordered and highly significant, while Class 2 estimates were generally disordered, suggesting poor data quality. Class 1 results indicated health care providers' ability to control patients' pain to desired levels was most important (11.5%, 95% CI: 10.3%–12.6%), followed by clean, safe, and comfortable facilities (10.0%, 95% CI: 9.0%–11.0%); and kind and sympathetic health care providers (9.8%, 95% CI: 8.8%–10.9%). Providers'

support for nonmedical concerns had the lowest preference weight (4.4%, 95% CI: 3.6%–5.3%). Differences in preference weights across countries were not statistically significant.

**Conclusion.**—Results reveal that not all aspects of EOL care are equally valued. Not accounting for these differences would lead to inappropriate conclusions on how best to improve EOL care.

## Keywords

End of life; palliative; terminal illness; preference weights; discrete choice experiment; relative importance

## Introduction

A common business truism is that "you can't improve what you don't measure." Yet, despite extensive work to measure the quality of curative treatments within and across countries, few efforts have focused on systematically measuring how well health systems deliver end-of-life (EOL) care. The few efforts that have been attempted largely applied a Donabedian framework.[1] This framework focuses on measuring structural indicators (e.g., financial resources, personnel, equipment) that are presumed to be correlated with a good EOL experience.[2] The underlying assumption is that meeting these indicators implies a better EOL experience.

Two prior efforts by the Economist Intelligence Unit relied on this approach to produce a Quality of Death Index, or ranking, across countries.[3,4] The rankings relied on various inputs, including whether or not a country had a national strategy for palliative care, availability of opioids and psychological supports, and many indicators on staffing ratios, clinical training opportunities, and other dimensions of access and quality of care, such as the presence of Do Not Resuscitate policies and patient satisfaction surveys. However, meeting these metrics does not necessarily translate to high quality care in the areas that most matter to patients or their family caregivers, where the latter often serve as surrogate decision-makers during the EOL period. In fact, prior efforts to quantify the quality of EOL care have largely ignored patient and caregiver preferences altogether.

High-functioning health systems should aim to deliver on what matters most to patients, which requires understanding patient preferences. For curative treatment, arguably the most important indicators of health system performance are minimizing disability and premature mortality, followed by cost and equity concerns. For dying patients and their family caregivers, there are many other considerations.[5] For example, dying at place of choice or having access to friends and family have been shown to matter more than marginal increases in life extension or even pain management.[6] Many quality indicators and patient reported outcome instruments have been developed to assess various dimensions of EOL care, however, few have attempted to quantify the *relative* importance that patients place across these dimensions.[7,8]

The goal of this study is to complement the existing literature by quantifying preference weights that represent the relative value that patients place on key EOL care indicators using a discrete choice experiment (DCE) survey. DCE is a well-established method to

assess preferences for health outcomes and other nonmarket goods. Using this approach, our results provide information on what family caregivers of EOL patients see as most important for delivering high quality EOL care and provide a framework for future efforts to take preference-based approaches to quantify health system performance at the micro (e.g., facility) or macro (e.g., region or country) level.

## Methods

### Study Setting and Participants

Recruitment took place simultaneously among web-panels in five countries from April 16 to April 28, 2021. We aimed to have variation in geographic region and income across countries but for convenience limited the study to the following English speaking countries: India, Kenya, Singapore, United Kingdom and United States. To be eligible for the survey, web panelists from these countries had to 1) be at least 21 years of age, 2) be able to understand English, 3) have lost a family member or close friend after a brief or extended period of illness or injury within the past two years, 4) have been involved in either discussions with health care providers concerning the patient's choice of treatments, helping the patient receive medical care (e.g., accompanying the patient to doctor's visits), or looking after the patient's day to day well-being. Existing panel members meeting these criteria were provided with details regarding the objective of the study, what is expected of them during the survey, privacy and confidentiality of research records, and given the option to participate.

While there is no formal power calculation for DCEs, a sample size can be approximated following Orme (2010).[9] Based on this approach, the minimum sample size for our models would be about 83 respondents per country. To ensure adequate power, the survey was administered on-line to 250 panel participants in each of the five countries. We applied soft quotas to ensure obtaining at least 10% of respondents above age 65 and at least 30% female. All activities were reviewed and approved by the National University of Singapore Institutional Review Board (protocol reference code: NUS-IRB-2020–203).

### Survey Development

Building on a recently published scoping review that identifies core domains and sub-domains of EOL care,[10] we developed a candidate list of EOL care indicators. These indicators were refined with the help of palliative-care experts. A final set of 13 indicators was used to developed a series of questions that captured quality of care delivery across relevant domains. Each indicator had five levels, ranging from strongly disagree to strongly agree (Table 1). Detailed explanations for each indicator are shown in Appendix A.

The questions evaluated key aspects of the patient experience during the last six weeks of life. Six weeks is a relatively short period of time which reduces the likelihood that respondents had to consider markedly different experiences across providers as they answered the questions.

A DCE was created to measure the importance of each indicator relative to others and of improvements within indicators. Respondents were asked to suppose they were in the

situation their loved one was in before dying and to consider what they would have preferred under such circumstances. In each DCE question, respondents had to consider a set of three hypothetical healthcare provider groups. These groups were rated by other caregivers using a 5-star system, with 1 star corresponding to strongly disagree, 3 stars to neutral and 5 stars to strongly agree (Fig. 1). Finally, respondents were asked to choose one among these provider groups based on the ratings provided.

Country-specific versions of the survey instrument were tested during 40 individual interviews with a convenience sample of caregivers in all participating countries, including six in India, eight in Kenya, seven in Singapore, five in the United Kingdom, and 14 in the United States. The interviews were conducted individually through videoconferencing and followed a semistructured think-aloud protocol. Upon completion of the interviews, country-specific surveys were finalized. The surveys included questions about the respondents' demographics, the demographics of the patient they cared for, context of the patients' death and a rating of their own experience caring for the patient, in addition to the DCE questions. A final version of the US survey is included in Appendix B.

### Statistical Analyses

Data from the DCE were evaluated based on commonly used internal-validity measures.[14] Respondents' choices were analyzed using latent-class logit analysis (LCA) with the number of classes determined using Bayesian Information Criterion.[15] We evaluated the extent to which classes were meaningful and the overall model parsimonious. Respondent covariates were included to help explain changes in the probability of class membership. Categorical variables (dummycoded) indicating the respondent country of origin (coded relative to the United States), indicators of patient/caregiver characteristics and beliefs, information on individual data quality (i.e., incorrect responses to comprehension questions, and missed validity checks), caregiver and patient characteristics, and indicators of internal validity were considered as predictors of class-membership probability. Covariates which were found to be statistically significant predictors of class membership ($P < 0.05$) were retained in the final model.

After identifying a respondent class that was highly correlated with poor data-quality signals, we calculated respondent's probability of being assigned to that class. We used the complement to this probability (1 minus the probability of assignment to class with poor data quality) as sampling weights in separate country-specific models using a random-parameters logit (n = 250 per country). This meant that respondents who were more likely to be included in the problematic class (i. e., those whose responses were more suspect) would be given a lower weight in the country-specific mean preference estimates.

Preference weights for each indicator and the corresponding 95% confidence intervals were calculated assuming profile-based normalization of the preference results for each country.[16] Weights were rescaled such that the sum of the weights across indicators totaled 100%. More details on the pretest interviews, experimental design, and analysis of the DCE data can be found in Appendix C.[11–13]

# Results

## Sample Characteristics

A total of 10,918 electronic invites were sent out to the web panelists to reach our sample of 250 respondents per country. We were unable to determine a unique response rate because many of the individuals invited to participate are likely not eligible; privacy concerns did not allow for obtaining eligibility information from non-respondents. Table 2 summarizes characteristics of caregiver respondents and their care recipients. Almost half of the sample was female (47.4%). On average, caregivers responding to the survey were 42.9 years of age (SD = 15.3). Mean age of caregivers was lower in low-income countries (India and Kenya) relative to high-income countries (Singapore, UK and US). Close to half of respondents had a bachelor's degree or higher level of education in India (49.2%) and the US (53.6%), but less than a fifth had similar levels of education in Singapore (19.2%), Kenya (18.4%) and the UK (13.6%). In every country, the vast majority of caregivers were at least somewhat involved in helping their loved one get medical care and looking after day-to-day needs, but less than a fifth was involved in talking with doctors about treatment decisions.

Almost half of care recipients (47.6%) were either close family members i.e., (parents, children, siblings, spouses or partners) or close friends of the caregiver. On average, care recipients died at the age of 62.4 years (SD = 21.3). Mean age at death was lower in India (55.5 years) and Kenya (53.4 years), relative to Singapore (66.5 years), US (65.8 years) and UK (70.8 years). COVID19-related deaths were more commonly reported in India (20.4%) and the US (18.8%), relative to other countries (less than 10% each).

More than half of care recipients received in-patient medical care. Professional nonmedical support services were received by less than a third of care recipients in each country. Palliative/hospice care was more commonly received in the UK (36.8%) and US (33.6%), relative to Singapore (26.4%), India (24.8%) and Kenya (18.4%). In Singapore, India and Kenya about a fifth of care recipients received one or more healthcare services from a domestic helper. Over two thirds of caregivers reported that the care recipients overall end of life care during the last six weeks of life was mostly good or very good in each country. However, slightly over a quarter (26.2%) of the sample reported that care recipients had trouble getting what they needed because they did not speak the same language as their doctors or nurses. Language-related communication difficulties were most commonly reported in India (39.2%) and Singapore (38.4%). Appendix D1 and D2 provides additional details on other characteristics of caregivers and their care recipients.

## DCE Results

### Preference Estimates From Latent Class Models Using Pooled Data.—Results
from the internal validity checks performed are available in Appendix E. A 2-class latent class (LC) model was selected as the best fit model, after considering LC models with two to five classes. The majority of respondents could be distinctly classified in one of the two classes; respondents had a class membership probability of at least 80% of being in one of the two classes. Estimates from the 2-class LC model are presented in Table 3.

Preference weights and relative indicator importance are presented in Figs. 2 and 3, respectively. The average probability of Class 1 membership was 64.7%. Class 1 preference weights were logically ordered and highly significant. For every indicator, preference estimates indicate caregivers value a quality-rating improvement from 1-star to 3-stars more than a quality-rating improvement from 3-stars to 5-stars.

For Class 1, preference weights indicated that providers' ability to control patients' pain to desired levels was most important (11.5%), followed closely by clean, safe, and comfortable facilities (10.0%); being able to contact close family and friends (9.8%) and access to appropriate levels and quality of life extending treatments (9.8%). Providers' support for spiritual needs (4.9%) and nonmedical concerns (4.4%) were of least importance.

The average probability of Class 2 membership was 35.3%. In contrast to Class 1, Class 2 preference estimates were disordered within every indicator and had large variance. Due to disordering and other threats to validity as noted below, we did not compute relative indicator importance for Class 2.

**Predictors of Class Membership From Latent Class Models Using Pooled Data.—**As shown in Table 2, Class 1 membership was significantly correlated with passing internal data-validity checks. Failing the second monotonicity test was the largest predictor of being in Class 2. Respondents who failed the first monotonicity test, completed the survey in less than the median survey completion time (median = 14.3 minutes), fully dominated on any one indicator, or reported finding the choice tasks "hard" or "very hard" to answer, were more likely to be classified in Class 2.

Caregiver and patient characteristics were also found to predict class membership. Respondents who reported that they preferred "to leave all healthcare decisions to the doctor" or believed that their health "depends mostly on luck" were more likely to be in Class 2, suggesting that caregivers who perceived their decision-making role to be less important for their loved one's care were more likely to be in Class 2. Younger respondents who were aged 50 years or younger, and those who reported losing a loved one less than six months ago were more likely to be in Class 2. However, respondents reporting that patients they had cared for had a "good" or "very good" overall end of life experience were more likely to be in Class 1. Factors such as young age, recentness of death and lower quality of end of life experience, which may be correlated with greater emotional distress, are more likely to be associated with Class 2.

Class membership probability also varied systematically by country. Relative to respondents in the US, those in Singapore or the UK were more likely to be in Class 1 whereas those in India were more likely to be in Class 2, this may suggest that data from India is less reliable. Respondents in Kenya were just as likely to be in Class 1 as those in the US.

**Country-Specific Preferences From Random-Parameters Logit Model.—**Fig. 4 presents the relative indicator importance from country-specific random parameters logit models. The model estimates are available in Appendix F. As DCE data from respondents in Class 2 suggested poor internal validity each respondent was weighted using probability of

belonging to Class 1. This implies downweighting responses from individuals who exhibited large variance in their answers.

Results suggest some similarities and differences across countries. Preferences for changes in ratings were highly nonlinear across indicators and countries, revealing that a quality-rating improvement from 1-star to 3-stars is valued more than a quality-rating improvement from 3-stars to 5-stars. In all countries, pain control was estimated to be the most important or second most important indicator. Quality of life-extending treatments and being treated kindly were also consistently highly valued in all countries whereas the ability to contact family and nonmedical concerns were consistently valued among the least important indicators.

Perhaps due to a lack of power, differences in indicator importance across countries were mostly not statistically significant. However, some differences in indicator importance are worth highlighting. First, relative importance of dying in the preferred patient setting was about twice as important in the US as in India (7.7% vs. 4.0%). Also, the importance that the UK assigned to spiritual needs was about half of the importance level estimated for the US, India and Kenya (3.1% vs. 5.7%–5.9%).

## Discussion

To our knowledge, this is the first international preference study aiming to quantify the relative importance of EOL care indicators within and across countries. Thus, the results provide insights into EOL care that have never been reported. Our findings suggest that not all aspects of EOL care are equally valued. Highlighting the importance of managing pain and discomfort, providers' ability to control patients' pain to desired levels was the most important indicator across the five countries. Given poor access to pain control in many countries, this finding provides a clear motivation for greater efforts to provide access to these medicines. Providing clean, safe, and comfortable facilities and being able to contact close family and friends ranked higher than access to appropriate levels and quality of life extending treatments. This finding is consistent with prior studies[25] suggesting that for dying patients, or in this case their proxy respondents, moderately extending life is not the top priority at EOL. Providers' support for spiritual needs and nonmedical concerns were of least relative importance, although it is unclear whether this is because they are not highly valued or because respondents felt these fall outside of the realm of healthcare providers.

Also consistent across countries were the views that there are diminishing returns to investments in any one of these domains suggesting that, for a fixed budget, the greatest return in EOL care is likely to come from investments that ensure some minimum level of quality for any given domain or sub-domain as opposed to trying to deliver the highest quality levels for only a subset of domains.

We found potential differences in indicator importance across countries. Further evaluation of these differences and potential correlations with other observables could identify subsets of individuals with different preferences than the average. These individuals might benefit

from a different prioritization of EOL care. Exploring this hypothesis could be an area of future research.

While we found that respondents with more recent experience with EOL care were likely to have different preferences, we do not have information to determine whether this is a result of recall effects, or simply a reflection of the dynamic nature of bereavement. Understanding that process was beyond the scope of this study.

Several limitations of our study are worth mentioning. First, while the survey instrument was designed to increase the consequentiality of the hypothetical choices made by respondents, the decisions elicited here were not obtained from real-world choices by study participants and thus may not be reflective of actual choices. This is a limitation of all DCE surveys.

We surveyed caregivers as proxies for those who were terminally ill, and within two years after the death of the care recipient. The perspective of caregivers is likely to differ from those of patients at EOL,[17,18] and surveying caregivers after they had time to reflect on the EOL experience, may generate biases in unknown directions. We also fielded the survey during the Covid-19 pandemic, which affected the death and dying experience for many people and perhaps also the bereavement experience. Future research should evaluate the importance of EOL care indicators directly from patients and caregivers during different time periods to evaluate the veracity of our results.

Our respondents were all members of an on-line panel and may be systematically different from the subset of the population who lost a close friend/family member in the countries considered. Furthermore, we invited panel members without prior confirmation of eligibility. This recruitment approach provided no assurance that everyone who was invited was qualified to complete the survey. Thus, we have limited information on systematic participation from specific respondent groups and the potential biases that may arise from this recruitment approach. The fact that few elderly are likely to join web panels may explain why respondents were only 42.9 years of age on average and relatively elderly spouses were underrepresented in our sample. We also recruited participants from only five countries. While we included countries with variation in level of development, region, and cultural background, interpretation of the preference weight as globally representative should be done with caution. Yet, while we expected (and found) some differences in preference weights across countries, results suggest that EOL care concerns may be more universal than not. Regardless, future research should aim to overcome all of the above limitations.

The goal of this study was to quantify preference weights of select EOL care indicators and of levels within indicators. Future efforts can apply these weights to comprehensively evaluate health system performance at the country, region, or facility level directly from patients/caregivers or indirectly via knowledgeable stakeholders.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Disclosures and Acknowledgments

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## Key message

This study provides information on what family caregivers of terminally-ill patients see as most important for delivering high quality EOL care and provides a framework for future efforts that aim to take a preference-based approach to quantify health system performance at the micro (e.g., facility) or macro (e.g., country) level.
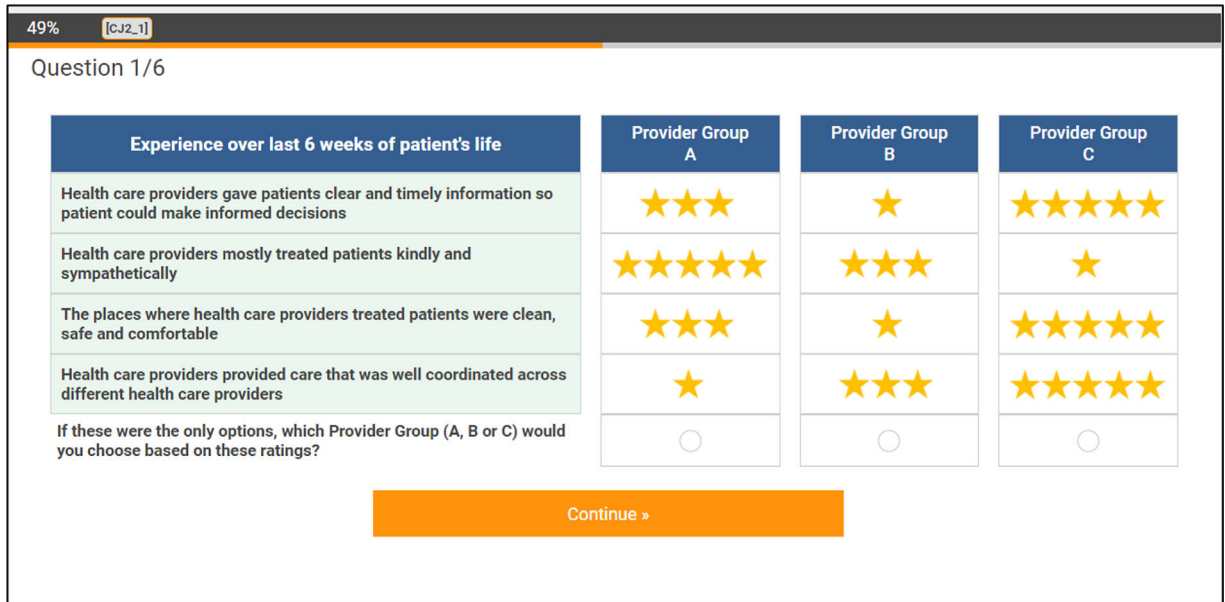
**Fig. 1.**
Example choice task as it was shown to respondents.
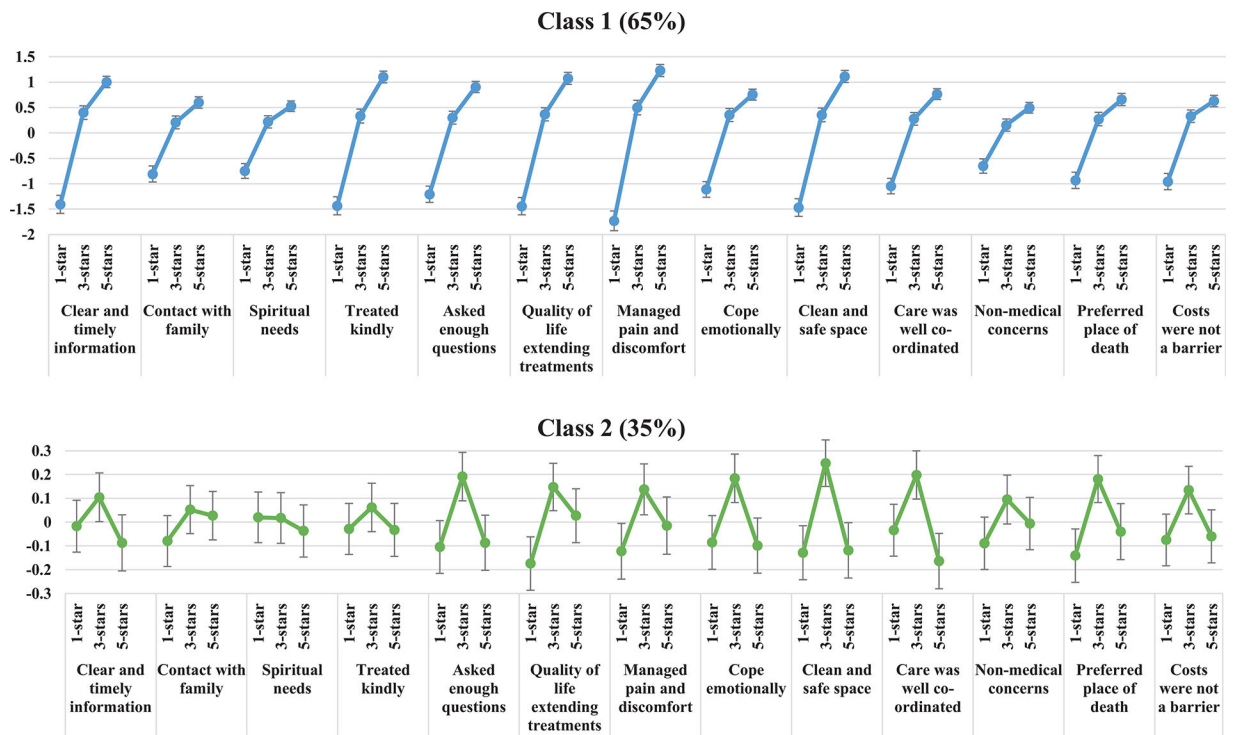
**Fig. 2.**

Preference weights estimated from 2-class latent class model.

Note: All attributes were effects-coded.

95% Confidence intervals are shown.
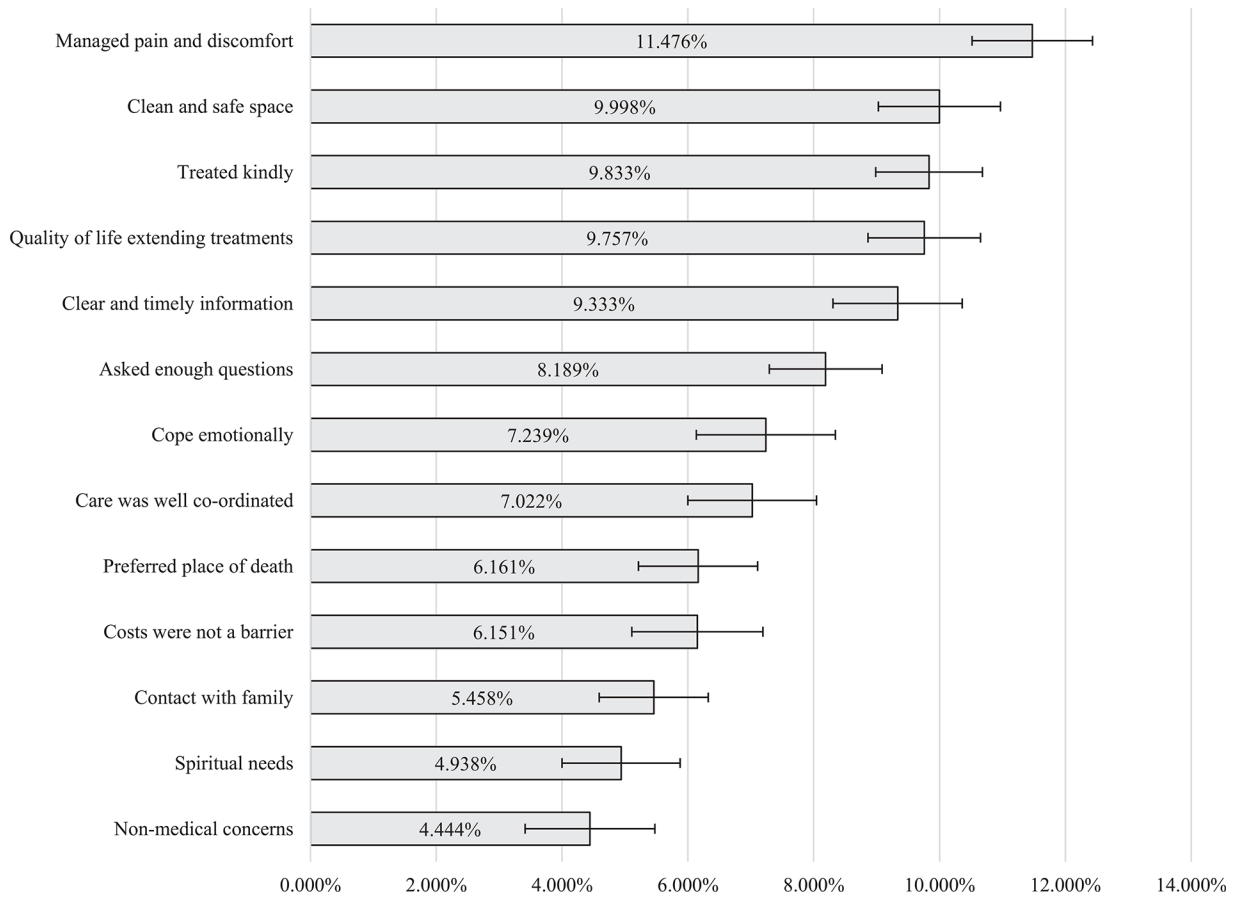
**Fig. 3.**
Relative indicator importance for Class 1 (%).
Note: 95% Confidence intervals are shown.
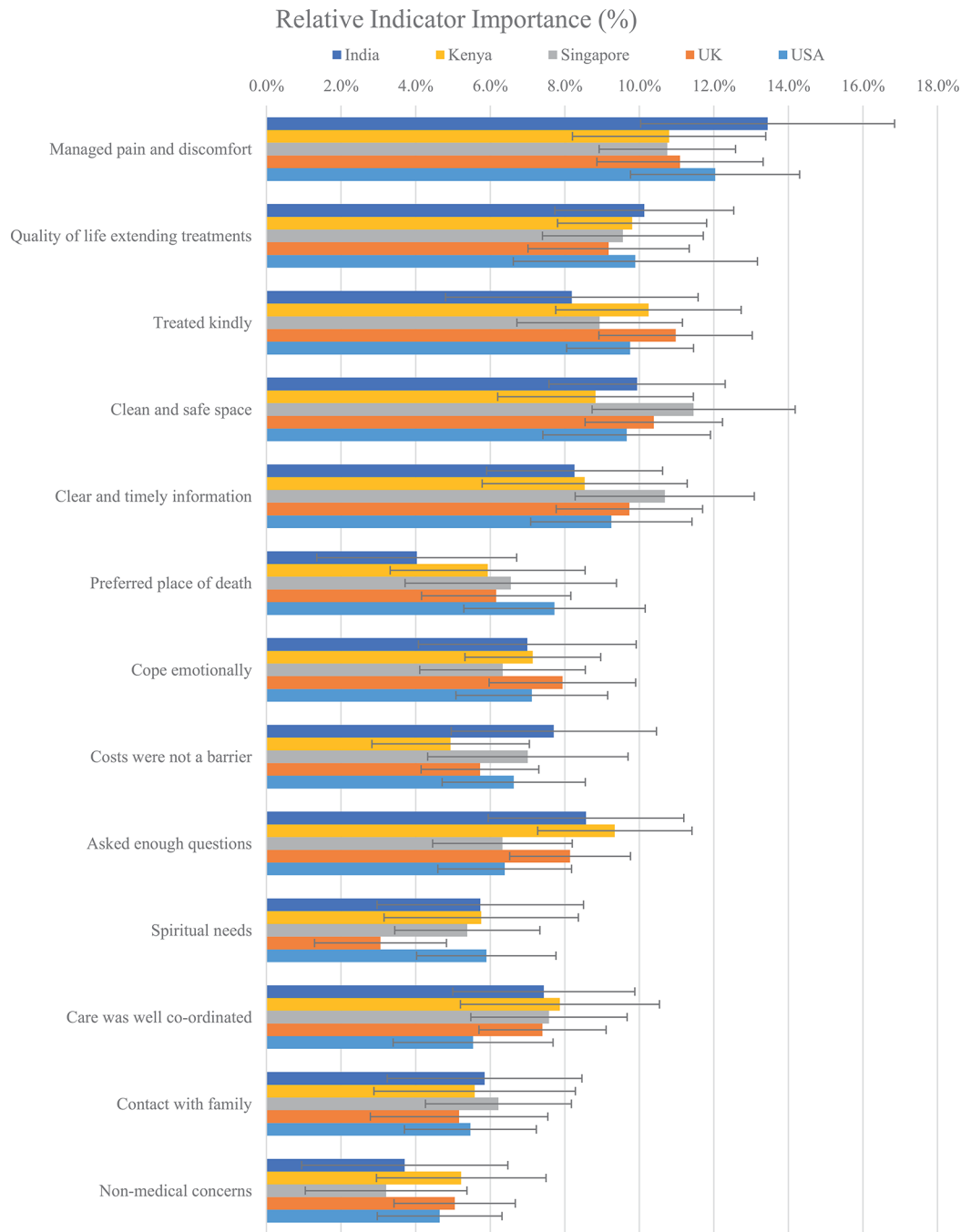
**Fig. 4.**
Country-specific relative attribute importance estimates.
Note: 95% Confidence Intervals are shown.

**Table 1**

Indicators

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

Summary of Patient and Caregiver Characteristics

**Table 2**

| A. Caregiver characteristics | Overall (n = 1250) | | India (n = 250) | | Kenya (n = 250) | | Singapore (n = 250) | | UK (n = 250) | | USA (n = 250) | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Mean (SD) / n (%) | | | | | | | | | | | |
| Age in years (Mean [SD]) | 42.85 | 15.34 | 37.49 | 15.02 | 32.85 | 9.2 | 42.59 | 11.72 | 50.74 | 15.36 | 50.58 | 15.68 |
| Female | 593 | 47% | 110 | 44% | 94 | 38% | 112 | 45% | 137 | 55% | 140 | 56% |
| Marital status | | | | | | | | | | | | |
| Single / never married | 299 | 24% | 71 | 28% | 91 | 36% | 72 | 29% | 42 | 17% | 23 | 9% |
| Married / living as a couple / civil partnership | 848 | 68% | 177 | 71% | 148 | 59% | 170 | 68% | 168 | 67% | 185 | 74% |
| Other | 103 | 8% | 2 | 1% | 11 | 4% | 8 | 3% | 40 | 16% | 42 | 17% |
| Bachelor's degree or higher level of education ** | 385 | 31% | 123 | 49% | 46 | 18% | 48 | 19% | 34 | 14% | 134 | 54% |
| Relationship to the patient | | | | | | | | | | | | |
| Spouse or partner | 62 | 5% | 12 | 5% | 3 | 1% | 9 | 4% | 15 | 6% | 23 | 9% |
| Parent | 203 | 16% | 31 | 12% | 27 | 11% | 48 | 19% | 57 | 23% | 40 | 16% |
| Grandparent | 197 | 16% | 42 | 17% | 38 | 15% | 47 | 19% | 36 | 14% | 34 | 14% |
| Sibling | 81 | 6% | 16 | 6% | 12 | 5% | 10 | 4% | 15 | 6% | 28 | 11% |
| Child | 26 | 2% | 3 | 1% | 3 | 1% | 1 | 0% | 9 | 4% | 10 | 4% |
| Close friend | 223 | 18% | 36 | 14% | 52 | 21% | 45 | 18% | 47 | 19% | 43 | 17% |
| Colleague/co-worker | 94 | 8% | 29 | 12% | 21 | 8% | 22 | 9% | 7 | 3% | 15 | 6% |
| Other (Aunt/Uncle/Other) | 364 | 29% | 81 | 32% | 94 | 38% | 68 | 27% | 64 | 26% | 57 | 23% |
| Caregiver was at least somewhat involved in… | | | | | | | | | | | | |
| Talking with doctors about treatment decisions? | 153 | 12% | 12 | 5% | 19 | 8% | 27 | 11% | 51 | 20% | 44 | 18% |
| Helping patient get medical care, such as going with them to doctor visits | 1,119 | 90% | 236 | 94% | 240 | 96% | 224 | 90% | 209 | 84% | 210 | 84% |
| Looking after patient's day-to-day needs? | 1,073 | 86% | 236 | 94% | 230 | 92% | 203 | 81% | 199 | 80% | 205 | 82% |
| Time since caregiver first learned of patient's terminal condition before patient's death | | | | | | | | | | | | |
| < 6 months | 680 | 54% | 144 | 58% | 141 | 56% | 126 | 50% | 135 | 54% | 134 | 54% |
| Between 6 months and 1 yr | 281 | 22% | 57 | 23% | 56 | 22% | 53 | 21% | 63 | 25% | 52 | 21% |
| Between 1 and 3 yrs | 289 | 23% | 49 | 20% | 53 | 21% | 71 | 28% | 52 | 21% | 64 | 26% |
| *Locus of control for health and healthcare use (% who strongly agree/agree with statements)* | | | | | | | | | | | | |
| I prefer to leave all health care decisions to the doctor. | 655 | 52% | 177 | 71% | 126 | 50% | 121 | 48% | 103 | 41% | 128 | 51% |

| | Overall (n = 1250) | | India (n = 250) | | Kenya (n = 250) | | Singapore (n = 250) | | UK (n = 250) | | USA (n = 250) | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| I am able to help doctors understand what is important to me about my health care. | 1,084 | 87% | 224 | 90% | 222 | 89% | 200 | 80% | 211 | 84% | 227 | 91% |
| My health depends mostly on luck. | 287 | 23% | 81 | 32% | 30 | 12% | 55 | 22% | 61 | 24% | 60 | 24% |
| I can do things to improve my health other than what doctors tell me to do. | 975 | 78% | 199 | 80% | 174 | 70% | 193 | 77% | 202 | 81% | 207 | 83% |
| I want as much information as possible to make decisions about my health care. | 1,118 | 89% | 226 | 90% | 235 | 94% | 210 | 84% | 218 | 87% | 229 | 92% |

**B. Patient characteristics**

| | Mean (SD) / n (%) | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Overall (n = 1250) | | India (n = 250) | | Kenya (n = 250) | | Singapore (n = 250) | | UK (n = 250) | | USA (n = 250) | |
| Patients age at death (Mean, SD) | 62.41 | 21.27 | 55.588 | 20.938 | 53.404 | 21.573 | 66.51 | 19.89 | 70.792 | 17.015 | 65.77 | 21.28 |
| *Marital status* | | | | | | | | | | | | |
| Single / never married | 168 | 13% | 39 | 16% | 36 | 14% | 43 | 17% | 25 | 10% | 25 | 10% |
| Married / living as a couple | 728 | 58% | 173 | 69% | 142 | 57% | 151 | 60% | 129 | 52% | 133 | 53% |
| Other | 354 | 28% | 38 | 15% | 72 | 29% | 56 | 22% | 96 | 38% | 92 | 37% |
| Bachelor's degree or higher level of education [**] | 523 | 42% | 170 | 68% | 92 | 37% | 81 | 32% | 82 | 33% | 98 | 39% |
| *Time since patient died* | | | | | | | | | | | | |
| < 6 months | 473 | 38% | 105 | 42% | 110 | 44% | 83 | 33% | 75 | 30% | 100 | 40% |
| Between 6 months and 1 yr | 354 | 28% | 89 | 36% | 65 | 26% | 72 | 29% | 59 | 24% | 69 | 28% |
| Between 1 and 2 yrs | 423 | 34% | 56 | 22% | 75 | 30% | 95 | 38% | 116 | 46% | 81 | 32% |
| *Care provided to patient during the last 6 weeks of life was mostly...* | | | | | | | | | | | | |
| Very good or good | 945 | 76% | 185 | 74% | 192 | 77% | 181 | 72% | 182 | 73% | 205 | 82% |
| Neither good nor poor | 166 | 13% | 37 | 15% | 33 | 13% | 46 | 18% | 37 | 15% | 13 | 5% |
| Poor or very poor | 111 | 9% | 24 | 10% | 22 | 9% | 17 | 7% | 24 | 10% | 24 | 10% |
| Don't know/not sure | 28 | 2% | 4 | 2% | 3 | 1% | 6 | 2% | 7 | 3% | 8 | 3% |
| *Professional services received by patient* | | | | | | | | | | | | |
| Nonmedical support | 335 | 27% | 75 | 30% | 62 | 25% | 62 | 25% | 68 | 27% | 68 | 27% |
| At-home medical care | 619 | 50% | 141 | 56% | 106 | 42% | 117 | 47% | 123 | 49% | 132 | 53% |
| In-patient medical care | 780 | 62% | 154 | 62% | 175 | 70% | 146 | 58% | 156 | 62% | 149 | 60% |
| Outpatient medical care | 610 | 49% | 118 | 47% | 143 | 57% | 126 | 50% | 104 | 42% | 119 | 48% |
| Palliative/hospice care | 350 | 28% | 62 | 25% | 46 | 18% | 66 | 26% | 92 | 37% | 84 | 34% |
| Traditional or herbal medicine | 168 | 13% | 47 | 19% | 35 | 14% | 38 | 15% | 14 | 6% | 34 | 14% |
| Other | 13 | 1% | 0 | 0% | 1 | 0% | 3 | 1% | 5 | 2% | 4 | 2% |

*Patien s ability to communicate during last 6 weeks of life*

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| | n | % | n | % | n | % | n | % | n | % | n | % |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Had a condition or treatments that made it difficult for them to communicate | 575 | 46% | 147 | 59% | 94 | 38% | 125 | 50% | 103 | 41% | 106 | 42% |
| Had trouble getting what they needed because they did not speak the same language as their doctors or nurses | 328 | 26% | 98 | 39% | 57 | 23% | 96 | 38% | 29 | 12% | 48 | 19% |
| Main reason for patient's death[a] | | | | | | | | | | | | |
| Cancer | 335 | 27% | 38 | 15% | 60 | 24% | 76 | 30% | 82 | 33% | 79 | 32% |
| COVID-19 | 152 | 12% | 51 | 20% | 25 | 10% | 7 | 3% | 22 | 9% | 47 | 19% |
| Heart problems | 151 | 12% | 34 | 14% | 17 | 7% | 33 | 13% | 30 | 12% | 37 | 15% |
| Kidney diseases | 69 | 6% | 23 | 9% | 9 | 4% | 7 | 9% | 7 | 3% | 7 | 3% |
| Natural causes/Old age | 68 | 5% | 15 | 6% | 9 | 4% | 23 | 9% | 12 | 5% | 9 | 4% |
| Stroke | 67 | 5% | 13 | 5% | 14 | 6% | 17 | 7% | 17 | 7% | 6 | 2% |
| Other | 408 | 33% | 76 | 30% | 116 | 46% | 71 | 28% | 80 | 32% | 65 | 26% |

** "Bachelor's degree or higher" is defined as a minimum of a three–year college degree (Singapore, India), or four-year college degree (USA), Degree level qualification or equivalent not including NVQ (UK), Higher diploma or degree (Kenya).

[a] Additional details provided in Appendix B2.

**Table 3**

Parameter Estimates From Latent Class Model With Two Classes

| Attribute | | Class 1 (65%) | | Class 2 (35%) | |
|---|---|---|---|---|---|
| | | Beta | SE | Beta | SE |
| Clear and timely information | 1-star | −1.405 | 0.09 | −0.017 | 0.056 |
| | 3-stars | 0.401 | 0.068 | 0.104 | 0.052 |
| | 5-stars | 1.004 | 0.058 | −0.087 | 0.06 |
| Contact with family | 1-star | −0.808 | 0.081 | −0.08 | 0.055 |
| | 3-stars | 0.208 | 0.065 | 0.052 | 0.052 |
| | 5-stars | 0.601 | 0.057 | 0.027 | 0.052 |
| Spiritual needs | 1-star | −0.747 | 0.075 | 0.02 | 0.054 |
| | 3-stars | 0.219 | 0.062 | 0.017 | 0.055 |
| | 5-stars | 0.528 | 0.053 | −0.037 | 0.056 |
| Treated kindly | 1-star | −1.436 | 0.091 | −0.029 | 0.055 |
| | 3-stars | 0.333 | 0.071 | 0.062 | 0.052 |
| | 5-stars | 1.103 | 0.06 | −0.033 | 0.057 |
| Asked enough questions | 1-star | −1.208 | 0.082 | −0.104 | 0.057 |
| | 3-stars | 0.302 | 0.064 | 0.191 | 0.052 |
| | 5-stars | 0.906 | 0.056 | −0.087 | 0.059 |
| Quality of life extending treatments | 1-star | −1.443 | 0.088 | −0.174 | 0.057 |
| | 3-stars | 0.367 | 0.066 | 0.148 | 0.051 |
| | 5-stars | 1.076 | 0.06 | 0.027 | 0.058 |
| Managed pain and discomfort | 1-star | −1.731 | 0.098 | −0.123 | 0.06 |
| | 3-stars | 0.501 | 0.073 | 0.137 | 0.055 |
| | 5-stars | 1.231 | 0.06 | −0.015 | 0.061 |
| Cope emotionally | 1-star | −1.112 | 0.078 | −0.085 | 0.058 |
| | 3-stars | 0.355 | 0.066 | 0.184 | 0.052 |
| | 5-stars | 0.757 | 0.055 | −0.099 | 0.059 |
| Clean and safe space | 1-star | −1.469 | 0.089 | −0.129 | 0.058 |
| | 3-stars | 0.356 | 0.068 | 0.248 | 0.05 |
| | 5-stars | 1.112 | 0.06 | −0.119 | 0.059 |

| | | Beta | SE | Beta | SE |
|---|---|---|---|---|---|
| Care was well coordinated | 1-star | −1.045 | 0.078 | −0.034 | 0.056 |
| | 3-stars | 0.278 | 0.064 | 0.198 | 0.052 |
| | 5-stars | 0.767 | 0.054 | −0.164 | 0.059 |
| Nonmedical concerns | 1-star | −0.651 | 0.073 | −0.089 | 0.056 |
| | 3-stars | 0.155 | 0.061 | 0.095 | 0.053 |
| | 5-stars | 0.496 | 0.053 | −0.006 | 0.056 |
| Preferred place of death | 1-star | −0.932 | 0.082 | −0.141 | 0.057 |
| | 3-stars | 0.273 | 0.068 | 0.181 | 0.05 |
| | 5-stars | 0.659 | 0.061 | −0.04 | 0.06 |
| Costs were not a barrier | 1-star | −0.959 | 0.082 | −0.075 | 0.055 |
| | 3-stars | 0.33 | 0.063 | 0.135 | 0.051 |
| | 5-stars | 0.629 | 0.056 | −0.06 | 0.057 |

| | Class 1 (65%) | |
|---|---|---|
| Covariates | Beta | SE |
| Country indicators (Ref: USA) | | |
| India | −0.253 | 0.126 |
| Kenya | 0.086 | 0.138 |
| Singapore | 0.257 | 0.131 |
| UK | 0.371 | 0.133 |
| *Monotonicity tests* | | |
| Failed 1st comprehension question | −0.344 | 0.096 |
| Failed 2nd comprehension question | −1.011 | 0.155 |
| *Locus of control* | | |
| I prefer to leave all health care decisions to the doctor. | −0.165 | 0.087 |
| My health depends mostly on luck. | −0.284 | 0.098 |
| Time since patient died: less than 6 months | −0.098 | 0.041 |
| Overall good EOL experience for patient | 0.298 | 0.092 |
| Communication challenges due to language | −0.154 | 0.046 |
| Respondents found choice tasks hard to answer | −0.306 | 0.105 |
| median survey completion time | −0.506 | 0.087 |
| Age > 50 yrs | 0.233 | 0.102 |
| Intercept | 0.495 | 0.157 |

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All attributes were effects-coded.

SE = Standard Error.

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