Title

What is a good death? A choice experiment on care indicators for patients at end of life.

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References

1. Knaul, F.M., et al., *Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report.* The Lancet, 2018. **391**(10128): p. 1391-1454.
2. Dzeng, E., et al., *Moral distress amongst American physician trainees regarding futile treatments at the end of life: a qualitative study.* Journal of general internal medicine, 2016. **31**(1): p. 93-99.
3. Carter, H.E., et al., *Incidence, duration and cost of futile treatment in end-of-life hospital admissions to three Australian public-sector tertiary hospitals: a retrospective multicentre cohort study.* BMJ open, 2017. **7**(10): p. e017661.
4. Desharnais, S., et al., *Lack of concordance between physician and patient: reports on end-of-life care discussions.* Journal of palliative medicine, 2007. **10**(3): p. 728-740.
5. Chochinov, H.M., *Dying, Dignity, and New Horizons in Palliative End-of-Life Care 1.* CA: a cancer journal for clinicians, 2006. **56**(2): p. 84-103.
6. Cardona-Morrell, M., et al., *Non-beneficial treatments in hospital at the end of life: a systematic review on extent of the problem.* 2016. **28**(4): p. 456-469.
7. Davison, S.N., *End-of-life care preferences and needs: perceptions of patients with chronic kidney disease.* Clinical Journal of the American Society of Nephrology, 2010. **5**(2): p. 195-204.
8. Donabedian, A., *Evaluating the quality of medical care.* The Milbank memorial fund quarterly, 1966. **44**(3): p. 166-206.
9. Stjernswärd, J., et al., *The public health strategy for palliative care.* 2007. **33**(5): p. 486-493.

10. The Economist Intelligence Unit and Commissioned by Lien Foundation. *The quality of death. Ranking end-of-life care across the world.* 2010 [cited 2021 09 July]; Available from: http://www.lienfoundation.org/sites/default/files/qod_index_2.pdf.
11. The Economist Intelligence Unit and Commissioned by Lien Foundation, *The 2015 Quality of Death Index: Ranking palliative care across the world.* 2015. **15**.
12. Steinhauser, K.E., et al., *In search of a good death: observations of patients, families, and providers*. 2000, American College of Physicians.
13. Finkelstein, E.A., et al., *Preferences for end-of-life care among community-dwelling older adults and patients with advanced cancer: a discrete choice experiment.* Health Policy, 2015. **119**(11): p. 1482-1489.
14. Steinhauser, Karen E., et al. "Factors considered important at the end of life by patients, family, physicians, and other care providers." *Jama* 284.19 (2000): 2476-2482.
15. Lankarani-Fard, Azadeh, et al. "Feasibility of discussing end-of-life care goals with inpatients using a structured, conversational approach: the go wish card game." *Journal of pain and symptom management* 39.4 (2010): 637-643.
16. Orme, B. "Getting started with conjoint analysis: strategies for product design and pricing research second edition." Madison: Research Publishers LLC (2010).
17. Bhadelia, A., et al., *Identifying the core domains to assess heath system performance on the' quality of death': A scoping review.* Working paper.
18. Ho, Martin P., et al. "Incorporating patient-preference evidence into regulatory decision making." Surgical endoscopy 29.10 (2015): 2984-2993.
19. Bose, R.C.J.A.o.E., *On the construction of balanced incomplete block designs.* 1939. **9**(4): p. 353-399.
20. Kuhfeld, W.F. *Marketing research methods in SAS: experimental design, choice, conjoint, and graphical techniques*. in *SAS Document TS-694.<* http://support/. *sas. com/techsup/technote/ts694. pdf>. Accessed on March 2*. 2007. Citeseer.
21. Kuhfeld, W.F., R.D. Tobias, and M.J.J.o.M.R. Garratt, *Efficient experimental design with marketing research applications.* 1994. **31**(4): p. 545-557.
22. Johnson, F.R., J.C. Yang, and S.D. Reed, *The Internal Validity of Discrete Choice Experiment Data: A Testing Tool for Quantitative Assessments.* Value Health, 2019. **22**(2): p. 157-160.
23. Hauber, A.B., et al., *Statistical Methods for the Analysis of Discrete Choice Experiments: A Report of the ISPOR Conjoint Analysis Good Research Practices Task Force.* Value Health, 2016. **19**(4): p. 300-15.
24. Gonzalez, J.M., *A Guide to Measuring and Interpreting Attribute Importance.* Patient, 2019. **12**(3): p. 287-295.
25. Malhotra, C., et al., *Comparison of preferences for end-of-life care among patients with advanced cancer and their caregivers: a discrete choice experiment.* 2015. **29**(9): p. 842-850.
26. Ozdemir, S., et al., *Patient-Caregiver Treatment Preference Discordance and its Association with Caregiving Burden and Esteem.* 2021.

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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.

Objective: To quantify preference weights for key EOL care indicators.

Methods: We developed a discrete choice experiment (DCE) survey with 13 key indicators related to patients' experience in the last 6 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 5 countries: India, Singapore, Kenya, the UK and the US. Latent-class analysis was used to evaluate preference weights 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 non-medical concerns had the lowest preference weight (4.4%, 95% CI: 3.6-5.3%). Differences in preference weights across countries were not statistically significant.

Conclusions: 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.

Words: 243/250 words

Key words: End of life, palliative, terminal illness, preference weight, discrete choice experiment, relative importance

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.

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 [8]. This framework focuses on measuring structural indicators (e.g., financial resources, personnel, equipment) that are presumed to be correlated with a good EOL experience [9]. 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 [10, 11]. 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 (DNR) 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 [12]. 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 [13]. 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. [14,15]

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 non-market 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 16 April to 28 April 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 (i) be at least 21 years of age, (ii) be able to understand English, (iii) have lost a family member or close friend after a brief or extended period of illness or injury within the past two years, (iv) 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). [16] 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 end-of-life care, [17] we developed a candidate list of end-of-life 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.

[Insert Table 1]

The questions evaluated key aspects of the patient experience during the last 6 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 answer 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 (Figure 1). Finally, respondents were asked to choose one among these provider groups based on the ratings provided.

[Insert Figure 1]

Country-specific versions of the survey instrument were tested during 40 individual interviews with a convenience sample of caregivers in all participating countries, including 6 in India, 8 in Kenya, 7 in Singapore, 5 in the United Kingdom, and 14 in the United States. The interviews were conducted individually through videoconferencing and followed a semi-structured 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. [22] Respondents' choices were analyzed using latent-class logit analysis (LCA) with the number of classes determined using Bayesian Information Criterion. [23] 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 (dummy-coded) 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. [24] 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.

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.

[Insert Table 2]

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 non-medical 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 6 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 2 to 5 classes. The majority of respondents could be distinctly classified in one of 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.

[Insert Table 3]

Preference weights are presented in Figures 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.

[Insert Figure 2]

[Insert Figure 3]

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 non-medical 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 preference weights 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 6 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 in 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

Figure 4 presents preference weights from country-specific random parameters logit models. 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 down-weighting responses from individuals who exhibited large variance in their answers.

[Insert Figure 4]

Relative indicator importance from country models are presented in Figure 4 and the model estimates are available in Appendix F. Results suggest some similarities and differences across countries. Preferences for changes in ratings were highly non-linear 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 non-medical 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% versus 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% versus 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 non-medical 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, [25, 26] 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 at 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 5 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.

Disclosures and Acknowledgements

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Supplementary materials

Available online and upon request from the authors.

References

1. Knaul, F.M., et al., *Alleviating the access abyss in palliative care and pain relief—an imperative of universal health coverage: the Lancet Commission report.* The Lancet, 2018. **391**(10128): p. 1391-1454.
2. Dzeng, E., et al., *Moral distress amongst American physician trainees regarding futile treatments at the end of life: a qualitative study.* Journal of general internal medicine, 2016. **31**(1): p. 93-99.
3. Carter, H.E., et al., *Incidence, duration and cost of futile treatment in end-of-life hospital admissions to three Australian public-sector tertiary hospitals: a retrospective multicentre cohort study.* BMJ open, 2017. **7**(10): p. e017661.
4. Desharnais, S., et al., *Lack of concordance between physician and patient: reports on end-of-life care discussions.* Journal of palliative medicine, 2007. **10**(3): p. 728-740.
5. Chochinov, H.M., *Dying, Dignity, and New Horizons in Palliative End-of-Life Care 1.* CA: a cancer journal for clinicians, 2006. **56**(2): p. 84-103.
6. Cardona-Morrell, M., et al., *Non-beneficial treatments in hospital at the end of life: a systematic review on extent of the problem.* 2016. **28**(4): p. 456-469.
7. Davison, S.N., *End-of-life care preferences and needs: perceptions of patients with chronic kidney disease.* Clinical Journal of the American Society of Nephrology, 2010. **5**(2): p. 195-204.
8. Donabedian, A., *Evaluating the quality of medical care.* The Milbank memorial fund quarterly, 1966. **44**(3): p. 166-206.
9. Stjernswärd, J., et al., *The public health strategy for palliative care.* 2007. **33**(5): p. 486-493.
10. The Economist Intelligence Unit and Commissioned by Lien Foundation. *The quality of death. Ranking end-of-life care across the world.* 2010 [cited 2021 09 July]; Available from: http://www.lienfoundation.org/sites/default/files/qod_index_2.pdf.
11. The Economist Intelligence Unit and Commissioned by Lien Foundation, *The 2015 Quality of Death Index: Ranking palliative care across the world.* 2015. **15**.
12. Steinhauser, K.E., et al., *In search of a good death: observations of patients, families, and providers*. 2000, American College of Physicians.
13. Finkelstein, E.A., et al., *Preferences for end-of-life care among community-dwelling older adults and patients with advanced cancer: a discrete choice experiment.* Health Policy, 2015. **119**(11): p. 1482-1489.
14. Steinhauser, Karen E., et al. "Factors considered important at the end of life by patients, family, physicians, and other care providers." *Jama* 284.19 (2000): 2476-2482.
15. Lankarani-Fard, Azadeh, et al. "Feasibility of discussing end-of-life care goals with inpatients using a structured, conversational approach: the go wish card game." *Journal of pain and symptom management* 39.4 (2010): 637-643.
16. Orme, B. "Getting started with conjoint analysis: strategies for product design and pricing research second edition." Madison: Research Publishers LLC (2010).
17. Bhadelia, A., et al., Identifying the core domains to assess heath system performance on the' quality of death': A scoping review. Working paper.
18. Ho, Martin P., et al. "Incorporating patient-preference evidence into regulatory decision making." Surgical endoscopy 29.10 (2015): 2984-2993.
19. Bose, R.C.J.A.o.E., *On the construction of balanced incomplete block designs.* 1939. **9**(4): p. 353-399.
20. Kuhfeld, W.F. *Marketing research methods in SAS: experimental design, choice, conjoint, and graphical techniques*. in *SAS Document TS-694.*< http://support/. *sas. com/techsup/technote/ts694. pdf>. Accessed on March 2*. 2007. Citeseer.
21. Kuhfeld, W.F., R.D. Tobias, and M.J.J.o.M.R. Garratt, *Efficient experimental design with marketing research applications.* 1994. **31**(4): p. 545-557.

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23. Hauber, A.B., et al., *Statistical Methods for the Analysis of Discrete Choice Experiments: A Report of the ISPOR Conjoint Analysis Good Research Practices Task Force.* Value Health, 2016. **19**(4): p. 300-15.
24. Gonzalez, J.M., *A Guide to Measuring and Interpreting Attribute Importance.* Patient, 2019. **12**(3): p. 287-295.
25. Malhotra, C., et al., *Comparison of preferences for end-of-life care among patients with advanced cancer and their caregivers: a discrete choice experiment.* 2015. **29**(9): p. 842-850.
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