

Quality of Death and Dying

Eric Finkelstein, PhD MHA Executive Director, Lien Centre for Palliative Care Duke-NUS Medical School, Singapore





- Discussion of three related efforts to inform on the quality of death and dying worldwide
 - 1. Lancet Commission on the Value of Death
 - 2. Survival Expectations and Hope among Advanced Cancer Patients (SHAPE)
 - 3. Quality of Death and Dying Index (QODDI) 2021



Part 1: Lancet Commission on the Value of Death





THE LANCET

COMMENT | VOLUME 392, ISSUE 10155, P1291-1293, OCTOBER 13, 2018

Lancet Commission on the Value of Death

Richard Smith 🖾 🛛 for the Lancet Commission on the Value of Death

Published: October 13, 2018 DOI: https://doi.org/10.1016/S0140-6736(18)32388-2



There have been many attempts to define a good death,¹¹ and usually it's one that is pain free, with symptoms controlled, dignified, inexpensive, and in a chosen place with chosen people. But

The Lancet Commission on the Value of Death will have a global focus and concentrate on four issues: the medicalisation and possible demedicalisation of death; how people die and think of death in different countries and cultures; whether the battle with death is beggaring us financially and spiritually; and the utility of attempts to tame death, including advanced directives, assisted suicide, palliative care, the concept of a good death, and the pursuit of immortality. We welcome contributions to



- Members of the Commission universally agreed that End of Life (EOL) care is bad nearly everywhere.
- EOL patients often lack access to basic palliative care services.
- Beyond that, we had a hard time articulating and agreeing on what else was bad.
- IMHO partly due to no clear definition of 'the problem'.
- My take is that beyond basic access to palliative care, key problems include:
 - Overtreatment in developed countries
 - Undertreatment in developing countries
 - Potential for mistreatment in all countries
- But even these terms are difficult to define, and almost impossible ex ante.
- Recently our team has explored overtreatment and one key contributing factor.



Part 2: Exploring Overtreatment via Survival Expectations and Hope among Advanced Cancer Patients in Singapore (SHAPE)





Received: 1 December 2020 Revised: 27 January 2021 Accepted: 4 March 2021

DOI: 10.1002/pon.5675

ORIGINAL ARTICLE

WILEY

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

Eric A. Finkelstein^{1,2} I Drishti Baid¹ | Yin Bun Cheung^{2,3} | Maurice E. Schweitzer⁴ | Chetna Malhotra^{1,2} I Kevin Volpp⁴ | Ravindran Kanesvaran⁵ | Lai Heng Lee⁶ | Rebecca Alexandra Dent⁵ | Matthew Ng Chau Hsien⁵ | Mohamad Farid Bin Harunal Rashid⁵ | Nagavali Somasundaram⁵

Psycho-Oncology. 2021;1–9.



- Access to insurance insulates the patient from the real costs of treatment.
- Patients and families do not want to experience regret (social reasons to push treatment over palliative care).
- Health literacy and health communication may be lacking.
- But there is one other major reason for excess consumption at EOL.



Question 1:

How long do you think people diagnosed with advanced stage IV metastatic cancer live on average?

Question 2:

How long do you think people diagnosed with Advanced Stage IV metastatic cancer think they will live?

Why the disconnect?



What do advance cancer patients think about their prognosis?

Findings from Costs and Medical Care of Patients with Advanced Serious Illness in Singapore (COMPASS), a cohort study of advanced cancer patients.

- 600 advanced cancer patients and their family caregivers surveyed every three months until death.
- Recruited at outpatient clinics in 2 large public hospitals.
- Survey focuses on quality of life, quality of care, utilization, costs, and prognostic beliefs.



Perceived curability among those who know they have advanced cancer

Do you think that the current treatment you are taking for your illness will **cure you**? (n=441)



26% of patients who knew they had advanced cancer thought that their cancer was curable and another 31% are not sure

Expected survival among those who know they have advanced cancer

How long do you think you are likely to live? (n=441)



More than a quarter of patients think that they will live more than 10 years. 61% think they will live at least 3 years In less than 3 years more than half have passed away.



- Enzinger et al 2015 (JCO): In a study of 252 advanced cancer patients:
 - 87% over-estimated their survival relative to their actual death date
 - 29% over-estimated survival by > 5 years
- Weeks et al 1998 (JAMA): For 917 adults hospitalized for advanced cancer and their treating physicians:
 - 82% of patients were more optimistic about their prognosis than their physicians.
 - 85% of patients estimated that their chances for 6-month survival was 75% or greater.
 - Only 45% survived past 6 months

Many studies show that patients of all types are unrealistically optimistic about their prognoses. Why?



What is hope?

- "The thing with feathers" (Emily Dickinson)
- "Hope is as a **transient state of mind** that tends to result from a **negative circumstance** where the expectations of a positive outcome are low yet highly important to the individual." (Averill et al., 2012; Bruininks & Malle, 2005; Bury et al., 2016)

Hope vs optimism

• State of mind" vs "state of being".

Is it good when EOL patients maintain hope?

• Kind of, depends on what they are hoping for.



One circumstance where hope is almost certain to appear: diagnosis of a terminal illness, such as advanced cancer.

• Hope tends to centre around **survival outcomes** (e.g., life extension, remission, and cure)

Hope offers many benefits, but false hope has potentially negative consequences

• Including overtreatment.



Motivation

Prior studies show patients with life limiting illnesses are biased, but do not:

- attempt to identify which **biases** are prevalent.
- how biases are associated with the degree of hope.

Primary Objective

In SHAPE, we explored the degree to which hope is associated with biases and prognostic beliefs.



Measuring Hope

HERTH HOPE INDEX								
Listed below are a number of statements. Read each statement and place an [X] in the box that describes how								
much you agree	much you agree with that statement <u>right now</u> .							
		Strongly Disagree	Disagree	Agree	Agree			
1. I have a positive outlook toward life.		1	2	3	4			
2. I have short and/or long range goals.			SCOD			1		
3. I feel all alone.			SCOR	ING				
		E	ach item is scor	ed from 1 to	4			
 I can see possibilities in the midst of difficulties. 		(reverse coding for item 3 and 6)						
5. I have a faith that gives me comfort.	Total score is the sum of 12 item scores							
6. I feel scared about my future.		Range: 12 (least hope) – 48 (most hope)						
7. I can recall happy/joyful times.						1		
8. I have deep inner strength.								
9. I am able to give and receive caring/love.								
10. I have a sense of direction.								
11. I believe that each day has potential.								
12. I feel my life has value and worth.								
© 1989 Kaye Herth. 1999 items 2 & 4 reworded. Reprinted with permission of Kay Herth.								



We hypothesize that the following factors are associated with greater levels of hope:

- First diagnosis at an advanced stage (why?),
- Better reported health related quality of life, including physical and mental health and lower pain scores,
- Lower loneliness scores,
- Younger age, and
- Being able to find strength and comfort from religion.



SHAPE, Hypotheses (cont.)

Patients with higher levels of hope will be more likely to:

- Believe that their illness is curable and state a longer expected survival duration (optimism bias).
- Believe that their survival outcomes are better than those of the average patient with the same condition (illusory superiority).
- Believe that the primary intent of their treatment is curative (cognitive dissonance/selfdeception).
- Report being no less informed about how their medical condition will change over time (cognitive dissonance).

Secondary objective

• We hypothesize the accuracy incentive would reduce the extent of bias among participants in intervention arm relative to control.







Instruments

- SF12 Physical and Mental component summaries
- Loneliness: 3-item UCLA Loneliness scale

Current pain: scale of 0 (no pain) to 10 (worst pain).

Ability to find strength in religion, age, stage at first diagnosis were measured through survey questions.



- Cross-sectional survey of 200 patients.
- Inclusion criteria:
 - Stage IV solid cancer OR leukaemia/lymphoma
 - prognosis of one year or less, determined by asking the primary treating oncologist a surprise question:
 - "Do you believe that there is a high chance (greater than 50%) that this patient is unlikely to be alive in 12 months?"
- We used multivariable linear and logistic regression models to test hypotheses about the association between patient's hope, biases and survival expectations.
- We compared the mean expected survival across arms to evaluate the effect of the incentive-based intervention.



Hope and it's correlates



Patient reported hope was high:

- Mean HHI = 39.7 (SD = 7.4) out of a max. 48 points
- Thirty-two patients (16%) reported the maximum level and not a single patient scored the minimum score of 12





What does this mean?

Difference in hope scores for patients who:

- Mental well-being "same or better" than general population norm (average MCS score = 58) relative to those who report "well below" (average MCS score = 30): + 7.6 HHI points
- Experience low levels of pain (pain = 2) relative to high levels of pain (pain = 8) :
 + 3 HHI points
- Feeling lonely "hardly ever" (loneliness score = 3) relative to "often" (loneliness score = 9) : + 6.5 HHI points
- Being ten years younger: + 1.1 HHI points
- Ability to find strength/comfort from religion: + 2.2 HHI points Note: all differences are statistically significant (p < 0.05)



Survival Expectations



Expected Survival (Optimism bias)

Among those who responded

- Mean expected survival was 9.7 years (SD = 9.23 years).
- Only **17 patients (12%)** provided an estimate consistent with their physician (1 year or less).





Curability (Optimism bias)

• 40% unrealistically believed that their current treatment regimen would cure their illness and another 29% stated they did not know.





Survival relative to average (Illusory superiority)

- The majority of patients perceived their survival outcomes to be much longer (29%) or slightly longer (21%) than the average patient
- Only 4.5% perceived their own survival outcomes to be shorter than average.

Compared to other patients being treated with the <u>same</u> <u>condition</u> as you, do you expect your survival outcomes to be...?





Expected vs Actual age at death (n=111)

<u>All but 8 deceased patients overestimated their survival.</u>

On average, patients expected to live for an <u>additional 8.31 years (SD = 7.63)</u> but only survived an <u>additional 0.73 years (SD = 0.53</u>) from the time of the survey.



Note: Red points indicate minimum survival estimates. (used when patients did not provide an estimate of age at death)

Last updated Jan 2021.



Hope and Survival/Treatment Expectations



Hope and Curability

Each 1-point increase in the HHI is associated with a:

- 6% increase in the odds of believing their illness is curable
- 4 month increase in expected survival

Compared to a less hopeful patient (HHI = 24), a more hopeful patient (HHI = 36) would report their survival to be approximately <u>4 years longer</u>.



Hope and Illusory Superiority

A 1-point increase in the HHI is associated with a:

- 6% increase in the odds of believing that their survival outcomes are **better than** average.
- 5% increase in the odds of believing that the primary intent of their treatment is curative
- 11% *increase* in the odds of believing that they are **very well-informed**.



- We all suffer from known and unknown biases
- Most likely biases will lead to overtreatment
- It may be possible to reduce overtreatment by reducing these biases (and hope?) but...
 - This may make patients worse off
 - So might overtreatment but the lesser of two evils?
- Brings us back to the question of how do we measure a good death



Part 3: Quality of Death and Dying Index (QODDI) 2021





Core Team Members	
Eric Finkelstein (PI)	Professor, Duke-NUS Medical School, Singapore
Stephen Connor	Executive Director, World Hospice Palliative Care Association
Cynthia Goh	Senior Consultant, National Cancer Centre, Singapore
Afsan Bhadelia	Senior Research Associate, Harvard T.H. Chan School of Public Health, USA
Juan Marcos Gonzalez	Asst. Prof, Duke University School of Medicine, USA
Reed Johnson	Professor, Duke University School of Medicine, USA
Sushma Bhatnagar	Professor & Head of Anaesthesiology, All India Institute of Medical Sciences, India
Ratna Singh	Consultant, Duke-NUS Medical School, Singapore
Funder	
Lien Foundation	www.lienfoundation.org



Background and Motivation

- Prior QODIs were highly effective but also highly suspect in their approach.
- Our approach for QODDI 2021
 - Aim 1: Identifying core domains of EOL care
 - Aim 2: Quantifying relative importance for identified domains
 - Aim 3: Deriving preference-weighted country-level rankings
- We may be highly suspect as well, but in very different ways.
- Looking forward to your reactions.



- Two prior efforts led by Economist Intelligence Unit (EIU).
- They ranked countries using the Donabedian approach that focused on inputs, not outputs.
- They allocated:
 - 70% weight to structural indicators like:
 - Palliative and healthcare environment (20%)
 - Human resources (20%)
 - Affordability of care (20%)
 - Community engagement (10%)
 - 30% weight allocated to Quality of Care, largely measured by the presence of guidelines and standards.
- The ranking relied on various inputs, including whether or not a country had a national strategy for palliative care, and many indicators on staffing ratios, clinical training opportunities, and various dimensions of access to care.
- The EIU research team arbitrarily assigned indicator weights after consultations with internal analysts and palliative care experts.
- Limitations:
 - Assumes that if these structural indicators are met then the EOL experience is better.
 - However, meeting these metrics does not necessarily translate to high quality care delivery in the areas that most matter to patients or their family caregivers, who often serve as surrogate decision-makers during the EOL period.



Aim 1 (lead: Afsan Bhadelia, Harvard T.H. Chan School of Public Health):

• A systematic scoping review of peer reviewed literature to identify domains and sub-domains that can be used to evaluate the performance of end-of-life care within and across health systems.

Aim 2 (leads: Juan Marcos Gonzalez and F. Reed Johnson, Duke University):

- Identify a short list of quality indicators based on the scoping review from Aim 1.
- Conduct a discrete choice experiment of caregivers of EOL patients to determine importance weights across levels of key indicators.

Aim 3 (Ongoing) (leads: Eric Finkelstein, Duke-NUS Singapore and Stephen Connor, WHPCA):

- Field a Country Experts survey to as many countries as possible on scores for each indicator.
- The responses from country experts will be aggregated and combined with the DCE importance weight derived through Task 2 to determine country- specific scores, rankings and grades.

Aim 1: Identifying the core domains and sub-domains to assess health system performance on the 'quality of death and dying': A scoping review



The scoping review identifies 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, 312 eligible articles were included.



- The scoping review identified 7 domains and 33 sub-domains which capture key aspects of 'quality of death'.
- Of the identified domains, 5 relate to the system structure to provide EoLC and 2 domains relate to patient and caregiver experience.
 - These 2 domains, plus one on Financing were used to develop a survey presented to caregivers to capture quality of care delivery.

Overview of domains identified through scoping review





List of identified domains and sub-domains used for developing attributes related to patient EoL experience

Domains	Sub-domains
Quality of Care	 Safety Appropriateness (of care) Coordination and continuity of care and support across phases/stages/transitions in EoLC Health-related quality of life Life continuity Empowerment
Quality of Communication (within system and with patients/caregivers)	1. Effective interpersonal interactions and relations
Financing and Financial Protection	1. Financial distress and fragility

Aim 2: Quantify relative importance of identified attributes



Based on the information derived from the scoping review, a survey to capture quality of care delivery across the domains was developed. The survey consists of 13 attributes related to the identified domains:

Domain: Quality of Care	QODDI Attributes for Measuring Patient Experiences for EoL care
Safety	1. The places where health care providers treated patient were clean, safe and comfortable
Appropriateness (of care)	 Patient was able to be cared for and die at place of choice. Health care providers asked enough questions to understand patient's needs. Health care providers provided appropriate levels and quality of life extending treatments. Health care professionals supported patient's spiritual, religious and cultural needs.
Coordination and continuity of care and support across phases/stages/transitions in EoLC	6. Care was well coordinated across different healthcare providers.
Health-related quality of life	 Health care providers controlled pain and discomfort to patient's desired levels. Health care providers helped cope emotionally. Health care providers encouraged contact with friends and family.
Life continuity	10. Health care providers helped with patient's non-medical concern.
Empowerment	11. Health care providers delivered clear and timely information so patient could make informed decisions.



Domain: Quality of Communication	QODDI Attributes to Measure Patients' Experience at EOL
Effective interpersonal interactions and relations	12. Health care providers mostly treated patient kindly and sympathetically.
Domain: Financing and Financial Protection	
Financial distress and fragility	13. Costs were not a barrier to patient getting appropriate care.

- The resulting survey consisted of 13 attributes related to aspects of the patient experience.
- Each attribute was presented with 5 levels, ranging from strongly disagree to strongly agree.
- We debated and ultimately excluded an attributed on Hope because we struggled to define it and our cognitive interviews showed patients and caregivers had very different understandings of the role of the health system when it comes to fostering hope.
- This should be am area of future research.



- Using the identified attributes, a **discrete-choice experiment (DCE)** was created to measure the relative importance of each attribute.
- Why Discrete-Choice Experiments?
 - Stated-preference, survey research method.
 - Used for products with multiple features, termed attributes.
 - Present alternatives that consist of combinations of attributes.
 - The level of the attributes vary across alternatives.
 - Choice tasks identify trade-off relationships.
 - Subjects state preferences among hypothetical alternatives based on the levels shown.
 - If even trade-offs are shown, it is possible to quantify relative importance of each level of each attribute.
 - This is how we construct the weights.



- Building on the scoping review in Aim 1, we developed a choice-experiment survey with the 13 attributes related to patients' experience in the last 6 weeks of life.
 - We provided respondents with an explanation for each attribute. Example:

Health care providers controlled her pain and discomfort to her desired levels.

- Hea and to talk with people around them. Consider whether your grandmother wanted more or less treatment for her pain and other physical symptoms.
- In each of 10 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 5star rating system.
- To limit cognitive burden, respondents evaluated only **4 attributes** in each of 6 DCE questions but which 4 varied across respondents.
- Let us look at some examples...



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?	\bigcirc	\bigcirc	\bigcirc

Continue »



Let's try another one... which healthcare provider would you choose to care for a loved 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	$\star\star\star$	*	****
Health care providers mostly treated patients kindly and sympathetically	*	****	$\star\star\star$
Health care providers controlled patient's pain and discomfort to patient's desired levels	*	****	$\star\star\star$
Health care providers helped with patients' non-medical concerns	$\star \star \star$	****	*
If these were the only options, which Provider Group (D, E or F) would you choose based on these ratings?	\bigcirc	\bigcirc	\bigcirc

Continue »



One last example.... Which healthcare provider would you choose to care for a loved one?

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	*	$\star \star \star \star \star \star$		
Health care providers made sure that patients were cared for and died at their place of choice	$\star\star\star$	*	****	
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?	\bigcirc	\bigcirc	\bigcirc	

Continue »



Data analysis

- Survey and DCE design were created according to best practices for DCEs.
- After pilot testing, we fielded the online DCE survey to a web-panel of 1250 caregiver proxies for a recently deceased 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.



- A 2-class latent class model was chosen to evaluate respondents from 1250 caregivers.
- Class 1 (65% of the sample) membership was significantly correlated with passing internal datavalidity checks relative to Class 2 (35% of the sample).
 - Class 1 preference weights were logically ordered and highly significant
 - Class 2 estimates were generally disordered with very large variance, suggesting Class 2 respondents either did not pay attention or did not understand the task.
- Estimates from Class 1 were used to estimate:
 - Relative attribute importance
 - Preference weight for each attribute-level



Attributes were not equally valued by caregivers

- Providers' ability to control patients' pain to desired levels was most important, followed access to clean, safe, and comfortable facilities.
- Providers' support for spiritual needs and support for non-medical concerns were of least importance.



Note: 95% Confidence intervals are shown





- Results suggest that caregivers would value changes in quality ratings from 1 to 3 stars more than changes from 3 to 5 stars.
- Model estimates provide a preference-weight for 1, 3 and 5-star levels of each attribute.
- Preference weights for 2 and 4-star levels are constructed using linear interpolation.



Overall score = sum of preference weights corresponding to the quality-rating on each of 13 attributes.

Preference weights indicate that the **overall score** for:

- The worst possible score of 1-star on every attribute = -14.94
- The best possible score of 5-star on every attribute = 10.87

For ease of interpretation, preference weights were **rescaled** such that the **overall score** for:

- The worst possible score of 1-star on every attribute = 0
- The best possible score of 5-star on every attribute = 100

Higher the overall score, better end of life care

Aim 3: Generating the rankings and grades.



- At least 2 experts (determined by our Advisory Board Members) qualified to comment on EoL care delivery in each of 169 countries were invited to participate.
- Each expert is presented with 13 rating questions corresponding to each of the **13 attributes** related to patient experience. Example:

2/4

Health care providers provided appropriate levels and quality of life extending treatments.

Respondents could click ? for more information (?)

Sometimes health care providers can give patients too much treatment to try to extend their lives. Other times they provide too little treatment. Providers also sometimes give patient low-quality treatments that can cause unnecessary suffering. Consider whether your **grandmother** felt she was given too much treatment, too little treatment or low-quality treatments.



Calculating a preference-weighted country score

• We weight country-expert scores for each attribute by relative importance weights calculated in Aim 2.

Simplified example for calculating weighted score for 1 country expert with 2 attributes:

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

•	Question 1:	Health- make ir	care provi nformed de	ders generally ecisions.	y deliver clea	r and timely	/ information s	o patients can
		$\textcircled{\baselineta}$	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Overall score based on 2
	Preference	weights:	1-star	2-stars	3-stars	4-stars	5-stars	(unscaled) =
		_	-1.11	-0.38	0.36	0.56	0.76	(anocarca)
•	Question 2:	When p friends	ossible, he and family	ealth-care pro	viders gener	ally encoura	age patients' c	ontact with ² Sum of preference weights
		\cup	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	corresponding to
Preference		eights:	1-star	2-stars	3-stars	4-stars	5-stars	expert's ratings
			-0.93	-0.33	0.27	0.47	0.66	



- For each country, overall scores from experts will be averaged to obtain a country-level score.
- Countries will be ranked and graded based on country-level average overall scores
- Results due in late 2021



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





Strengths

- Transparent and systematic
- Not limited by data availability
- Adopts a patient-centered approach by paying attention to the preferences and considerations that matter most to patients and their caregivers at the EOL period.
- The survey and the preference weights developed through this study can be used by a single entity to 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

But these limitations can be overcome in future efforts



- Near universal agreement that EOL experience for many is bad.
- Both 'too much' and 'too little' medical care may be a cause.
- Hope may be part of the 'problem' but efforts to reduce costs/utilization at EOL may make people worse off.
- Measuring quality at EOL is complicated due to inherent biases of patients, familes, and even doctors and because the definition of 'quality' likely changes throughout the EOL period.
- But, we cannot improve what we don't measure.
- Ultimately, focusing on quality from the patient perspective should improve EOL outcomes.
- But a good death may actually be 'the thing with feathers'.



Questions