Quality of Death

Assessing the Importance Placed on End-of-Life Treatment in the Intensive-Care Unit

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Context: The value of good end-of-life (EOL) care could be underestimated if its effects are assessed using the standard metric of quality-adjusted survival, especially if the time horizon is limited to the duration of the EOL care. This issue is particularly problematic in the intensive-care unit (ICU) where death is frequent, care is difficult, and costs are high.

Objectives: The objectives of this study were to test whether people would trade healthy life expectancy for better EOL care, to understand how much life expectancy they would trade relative to domains of good care, and to determine the association of respondent characteristics to time traded.

Design and Subjects: We used a computerized survey instrument describing hypothetical patient experiences in the ICU used to assess attitudes of a general population sample (n = 104) recruited in Pittsburgh, Pennsylvania.

Measures: We used life expectancy traded (from a baseline of 80 healthy years followed by a 1-month fatal ICU stay) for improving ICU care in 4 domains: pain and discomfort, daily surroundings, treatment decisions, and family support.

Results: Three fourths of respondents (n = 78) were prepared to shorten healthy life for better EOL care. Median time traded in individual domains ranged from 7.2 to 7.7 months overall and 9.6 to 11.4 months when restricted to those willing to trade. Median time traded for improvement in all domains was 8.3 months overall and 24.0 months by those willing to trade. In multivariable analyses, respondents who were older, nonwhite, or had children traded significantly less time, whereas those who did not perceive the ICU to be a caring environment traded more time.

Conclusions: Good EOL care is highly valued, both in terms of medical and nonmedical domains, as suggested by previous work and confirmed by our data showing respondents trading quantities of healthy life several times longer than the duration of the EOL period itself. The considerable interperson variation highlights the importance of soliciting individual preferences about EOL care.

Key Words: end-of-life care, quality of care, utility measurement

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Providing good end-of-life (EOL) care is increasingly recognized as a major healthcare goal in the United States. Achieving that goal is not straightforward. Although once considered an economic alternative to futile, high-technology services, EOL care is itself expensive and could offer no real cost savings.[1–3] Furthermore, despite the prima facie value to providing good EOL care, it is not clear how to do it or how to quantify the benefits. As the population ages and healthcare resources grow increasingly scarce, good EOL care will have to compete with other health services for available resources.

The standard approach to compare the "worth" of competing health services is cost-effectiveness analysis (CEA),[4] which typically values effectiveness of health interventions as the gain in life-years or quality-adjusted life-years (QALYs). Yet, the primary purpose of EOL care is not to increase survival, and any gains that do occur are likely to be short. This translates into even smaller gains in QALYs. For example, an EOL service affecting the last 30 days of life can provide no more than 1 quality-adjusted life month, or 0.08 QALYs, even if it is perfect in improving that final month. Thus, unless extraordinarily inexpensive, EOL care programs will be considered cost-ineffective (not "worthwhile") when measured by the standard CEA format.

This finding seems counterintuitive given society's overall commitment to EOL care[5–7] and suggests that the

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benefits of EOL care are more valuable than the QALYs gained during the EOL period itself. To explore this issue further, we conducted a time tradeoff experiment that assessed the value, or utility, people place on good EOL care. Our hypothesis was that society's valuation of EOL care, measured as the amount of perfect health traded for better EOL care, would exceed the amount of time spent in EOL care.

METHODS

Overview

Our study instrument included 1 baseline scenario (Fig. 1) and 5 alternative scenarios for EOL care. Participants were asked to 1) compare the patient in the baseline scenario with the patient in each alternative scenario; 2) decide whether either patient had a better overall quality of life; 3) decide what amount of healthy life expectancy, if any, they would be willing to trade from the "better" patient so that quality of life for both patients was equivalent; and 4) record their responses using a computerized time tradeoff assessment tool. The scenarios highlighted different aspects (domains) of EOL care, but they all occurred in the intensive-care unit (ICU). We focused on EOL care in the ICU because death in the ICU is common, not restricted to a single disease process, and used in other societal tradeoff experiments.[8–10]

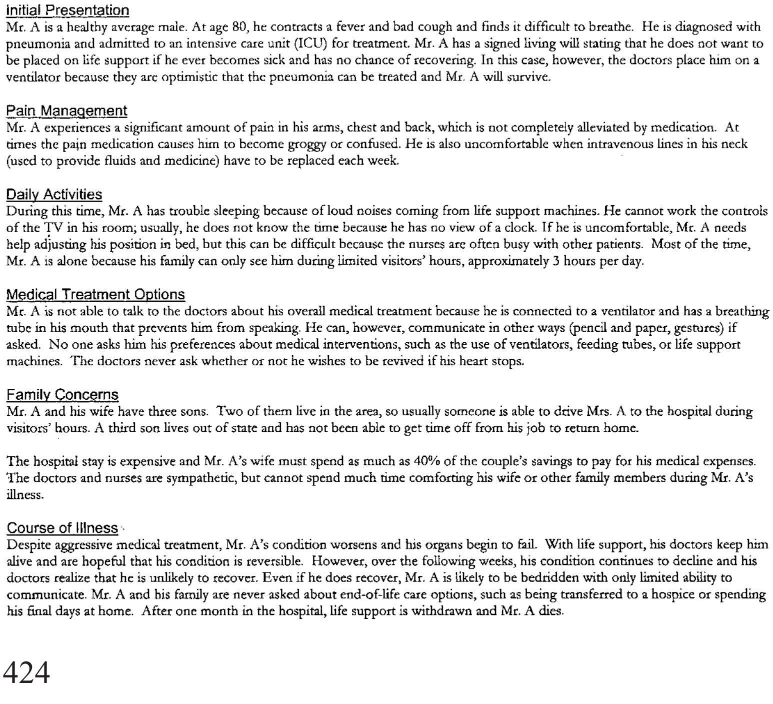
After pilot-testing the instrument, we recruited 104 community respondents to participate in the study. We chose a general population sample because the Panel on Cost Effectiveness in Health and Medicine recommends adopting the societal, or general population, perspective when valuing health states and interventions in CEA studies.[11]

Our study was approved by the University of Pittsburgh Institutional Review Board.

Development of the Study Instrument

Our study was not a traditional survey, but we followed key principles of survey design in its development.[12] To ensure appropriate construct validity, we reviewed the growing body of research on domains of good EOL care[13–17] and selected 4 examples for inclusion: 1) alleviation of pain and discomfort; 2) empowerment to control one's daily surroundings in the ICU; 3) empowerment to participate in medical treatment and care decisions; and 4) financial and emotional support for family members. To construct scenarios that were clinically valid yet understandable to the general public, we consulted with several intensivists and palliative care physicians in the ICU, including 3 of our study investigators (DCA, RMA, RSW). In writing the scenarios, we aimed for a ninth-grade audience and avoided medical jargon. We retained consistent wording across the scenarios for domains that were unchanged and summarized the differences when asking respondents to make comparisons.

We took several steps to minimize demand effects and avoid leading or biased questions. First, we wrote the scenarios in the third person and asked respondents to decide about other people's lives rather than their own lives. Again, this is consistent with adopting a societal perspective.[11] Second, the comparisons did not require respondents to choose 1 patient over another, but rather allowed them to indicate if and when quality of life was equivalent for patients portrayed in the scenarios. Third, we did not impose direction in the wording of the questions. For example, we asked respondents to



Initial Presentation
Mr. A is a healthy average male. At age 80, he contracts a fever and bad cough and finds it difficult to breathe. He is diagnosed with pneumonia and admitted to an intensive care unit (ICU) for treatment. Mr. A has a signed living will stating that he does not want to be placed on life support if he ever becomes sick and has no chance of recovering. In this case, however, the doctors place him on a ventilator because they are optimistic that the pneumonia can be treated and Mr. A will survive.

Pain Management
Mr. A experiences a significant amount of pain in his arms, chest and back, which is not completely alleviated by medication. At times the pain medication causes him to become groggy or confused. He is also uncomfortable when intravenous lines in his neck (used to provide fluids and medicine) have to be replaced each week.

Daily Activities
During this time, Mr. A has trouble sleeping because of loud noises coming from life support machines. He cannot work the controls of the TV in his room; usually, he does not know the time because he has no view of a clock. If he is uncomfortable, Mr. A needs help adjusting his position in bed, but this can be difficult because the nurses are often busy with other patients. Most of the time, Mr. A is alone because his family can only see him during limited visitors' hours, approximately 3 hours per day.

Medical Treatment Options
Mr. A is not able to talk to the doctors about his overall medical treatment because he is connected to a ventilator and has a breathing tube in his mouth that prevents him from speaking. He can, however, communicate in other ways (pencil and paper, gestures) if asked. No one asks him his preferences about medical interventions, such as the use of ventilators, feeding tubes, or life support machines. The doctors never ask whether or not he wishes to be revived if his heart stops.

Family Concerns
Mr. A and his wife have three sons. Two of them live in the area, so usually someone is able to drive Mrs. A to the hospital during visitors' hours. A third son lives out of state and has not been able to get time off from his job to return home.

The hospital stay is expensive and Mr. A's wife must spend as much as 40% of the couple's savings to pay for his medical expenses. The doctors and nurses are sympathetic, but cannot spend much time comforting his wife or other family members during Mr. A's illness.

Course of Illness
Despite aggressive medical treatment, Mr. A's condition worsens and his organs begin to fail. With life support, his doctors keep him alive and are hopeful that his condition is reversible. However, over the following weeks, his condition continues to decline and his doctors realize that he is unlikely to recover. Even if he does recover, Mr. A is likely to be bedridden with only limited ability to communicate. Mr. A and his family are never asked about end-of-life care options, such as being transferred to a hospice or spending his final days at home. After one month in the hospital, life support is withdrawn and Mr. A dies.

FIGURE 1. Scenario for baseline patient (Mr. A). The baseline patient, Mr. A, experienced the worst outcomes in all 4 domains of end-of-life care.

"adjust" rather than "decrease" or "increase" healthy life expectancy. Fourth, we intentionally asked respondents to adjust life expectancy for the patient with the better ICU experience rather than the worst experience. We wanted respondents to grapple with the more difficult task of reducing longevity of the better patient because we believed this would lead to more conservative adjustments, biasing the study against finding an effect. Fifth, we allowed respondents to adjust life expectancy for any combination of years, months, and days (including zero) so that we would not impose a bias toward larger units of time.

Pilot Testing

We built an electronic version of the scenarios and incorporated a modified time tradeoff instrument that recorded subject responses. We tested this version on a pilot sample that included both clinicians and nonclinicians (n = 26). We searched for evidence that scenarios were too complex or needed to be clarified such as selecting the worst patient as having better quality of life. We also asked the pilot subjects to comment on the ease of using the instrument and to suggest improvements. Based on the pilot test, we revised scenario descriptions and modified the instrument design.

Recruitment

To recruit a convenience sample from the community, interviewers posted signs and set up "stations" at various locations throughout the Pittsburgh, Pennsylvania, area (university student center, hospital cafeterias, wellness center, health club, parks). The signs informed interested persons of the time commitment (approximately 20 minutes) and participant payment (a $5 gift certificate to a local coffee shop, sandwich shop, or bookstore). Because virtually everyone who approached the interviewers did, in fact, participate, we did not record reasons for refusal or calculate a response rate.

Administration of Scenarios

The scenarios were self-administered by laptop computer in the presence of an interviewer, who was available to clarify instructions or provide computer assistance. Respondents were able to scroll back and forth through the patient descriptions to review any details.

The scenarios described the experiences of 6 hypothetical patients. Each patient lived for 80 years in good health before becoming ill and being admitted to the ICU, and each patient died after 30 days in the ICU. While in the ICU, however, patients received different EOL care. From our perspective, the EOL care of the baseline patient, Mr. A, was poor in all 4 domains: he experienced moderate pain, he could not alter his surroundings or environment while in the ICU, he was not consulted about his medical care preferences in the ICU, and his family was not provided with counseling or support services (Fig. 1). In contrast, the other patients (Mr's. B, C, D, E, and F) had better ICU experiences. Mr's. B through E each had better care in 1 domain (for example, Mr. B received the analgesia required to ensure no pain), whereas Mr. F had better care in all 4 domains. Of note, although we believed these changes to be improvements, we described the domains using neutral terms to avoid conveying our beliefs to the respondent.

Respondents were asked to compare the experience of Mr. A with that of each comparator patient, one at a time. Respondents first selected whether Mr. A, the comparator patient, or neither patient had a better overall quality of life, at which point a prompt appeared restating the respondent's selection and asking for confirmation. If respondents chose the comparator patient, the computer program then prompted them to "adjust" the amount of time lived in perfect health (before the ICU admission) by the comparator patient so that his overall quality of life would be equivalent to that of Mr. A. If respondents did not choose the comparator patient, the computer program automatically advanced to the next scenario and did not allow respondents to complete the time tradeoff exercise. For these respondents, the program recorded "zero" days traded. The computer program recorded responses to the scenarios in a text file.

We did not randomize the order of the scenarios, but we did offer respondents the opportunity to revise their selections in case the later scenarios affected the relative importance attached to the earlier scenarios. The original and final selections were not significantly different (range of mean differences: −0.02 months [for daily surroundings] to 1.27 months [for pain and discomfort]), so we used the final set of values in all analyses.

Administration of Respondent Questionnaire

In addition to scenario responses, the computer program elicited demographics (gender, age, race/ethnicity, education, and income), level of social support,[18] and general health status as assessed in the Short-Form 12 (SF-12).[19] It also recorded information concerning religion and prior loss of loved ones.

Statistical Analyses

For each scenario, we summarized the amount of healthy life expectancy traded to improve EOL care. Because the distributions were skewed and some respondents traded no time at all, we reported median values. We computed unadjusted medians for the entire sample as well as for those willing to trade some amount of time, and we used sign tests to determine if these values differed significantly from the duration of the ICU stay. For each scenario, we calculated medians for each domain by respondent characteristics and examined differences using Kruskal-Wallis tests.

Finally, we used 2-part regression analysis[20] for each scenario to assess time traded as a function of respondent characteristics. In part 1, we estimated logistic regression models to evaluate the probability that a respondent was willing to trade *any amount of time* for better EOL care, defining the binary outcome variable as trader versus nontrader. In part 2, we restricted our sample to only those respondents who did, in fact, trade some amount of time in part 1. We estimated multivariable linear regression models using the logarithm of the amount of time traded as the dependent variable. Parts 1 and 2 both included the same set of potential independent variables: respondent age, race, education, marital status, number of children, income, health status, religion (its overall importance, attendance at religious meetings, and participation in religious activities), and prior loss (whether a loved one died, whether the death occur in an ICU, and assessment of treatment received in the ICU). To minimize bias in the coefficient estimates,[21] we used stepwise procedures in all models and retained covariates with $P < 0.10$.

The final estimates of the 2-part models (predicting the mean amount of time traded to improve EOL care for the entire sample, given respondent characteristics) were calculated by multiplying estimates from parts 1 and 2 together and introducing a smear factor to account for the fact that we used a logarithmic transformation of time traded in the linear regressions.[22] We built the instrument in Microsoft Visual Basic (Redmond, WA), and we used SAS (version 8.0; Cary, NC) and STATA (version 7; College, Station, TX) for all analyses.

RESULTS

Respondent Characteristics

A total of 104 community respondents participated in our study (Table 1). Our sample was well matched with national statistics in terms of gender, age, and SF-12 scores for physical and mental health.[23] It was slightly more educated and reported higher income than national figures, but at the same time it overrepresented minority races/ethnicities. The majority of respondents (85 of 104, 82%) considered religion to be important and many (78 of 104, 75%) participated in religious activities. Most (86 of 104, 83%) experienced the death of a loved one. Nearly half of these deaths (40 of 86, 47%) occurred in the ICU, and almost two thirds of this group (26 of 40, 65%) described the ICU experience as caring.

Descriptive Statistics

Table 2 summarizes the amount of time traded to improve EOL care. In every scenario, some respondents (ranging from 30–50 respondents) traded no time. In a small number of these cases (maximum: 6 in scenario D), nontraders chose Mr. A as having a better quality of life. More

TABLE 1. Comparison of Characteristics Between Study Respondents and US Population*

Characteristics	Study Respondents (n = 104)	US Population
Mean age in years (SD)	34.1 (17.5)	36.6 (NA)
Male (%)	49.0%	48.9%
Race/ethnicity (%)†		
White	56.7%	82.2%
Black	24.0%	12.8%
Other race/ethnicity	11.5%	5.0%
Unknown race/ethnicity	7.7%	0.0%
High school graduate (%)†	89.4%	78.5%
Income at least $40,000 (%)†	40.4%	31.3%
Mean physical component score on SF-12	51.4	50.0
Mean mental component score on SF-12	49.8	50.0
Considered religion important (%)	81.7%	NA
Participated in religious activities or meetings (%)	75.0%	NA
Experienced the loss of loved one (%)	82.7%	NA
Loved one died in the ICU (%)	38.5%	NA
Described treatment in the ICU as "caring" (%)‡	25.0%	NA
Described treatment in the ICU as "neutral" or "not very caring" (%)‡	13.5%	NA

*US population data are derived from www.census.gov; US data for SF-12 is based on research by Ware.[20]

†Significant difference ($P<0.01$) between study respondents and the US population.

‡Table 1 uses the entire sample of 104 respondents as the denominator. However, descriptions of ICU treatment were asked only of the 38.5% who said their loved one died in the ICU.

SD = standard deviation; NA = not available; SF-12 = Short Form 12; ICU = intensive care unit.

TABLE 2. Amount of Healthy Life Expectancy Traded (in months) for a Better End-of-Life (EOL) Experience

	Total Sample (N = 104)			Respondents Willing to Trade				
Improved Domain	**Median**	**Interquartile Range**	***P* Value***	**No**	**Percent**	**Median**	**Interquartile Range**	***P* Value***
Alleviation of patient pain and discomfort	7.7	[0–12.0]	0.007	65	62.5	9.6	[7.7–48.0]	0.000
Empowerment to control daily surroundings in the intensive-care unit	7.7	[0–12.0]	0.012	64	61.5	9.6	[7.7–24.0]	0.000
Empowerment to participate in medical treatment and care decisions	7.7	[0–12.0]	0.020	63	60.6	10.7	[7.7–36.0]	0.000
Financial and emotional support for family members	7.2	[0–12.0]	0.384	54	51.9	11.4	[7.7–60.0]	0.000
All of the above	8.3	[0–60.0]	0.000	70	67.3	24.0	[8.1–104.4]	0.000

*Significance level in testing whether the median amount of time traded exceeded the duration of EOL care, that is, H_o: median = 1 vs. H_a: median > 1 using the sign test.

commonly, however, nontraders indicated that the quality of life was equivalent for the patients or decided that the comparator's was better but refused to decrease healthy life expectancy in the time tradeoff exercise. There were 26 respondents who refused to trade healthy life expectancy in any of the scenarios. This group tended to be older than the traders (mean age, 41 vs. 31 years, $P = 0.007$) but was otherwise similar in terms of gender, race/ethnicity, physical and mental health status, religion, and prior loss.

The domains included in the scenarios were not independent. Using the Spearman correlation test between the amounts of time traded, we found positive and significant associations for each pair of domains. The correlation coefficients ranged from 0.41 (alleviation of pain and family support, $P < 0.0001$) to 0.67 (daily surroundings and family support, $P < 0.0001$).

Although the duration of EOL care received in the ICU was only 1 month (30 days), the median amount of healthy life expectancy respondents were willing to trade was substantially greater than 1 month, supporting our hypothesis that the time traded in perfect health for better EOL care exceeds the duration of the EOL care itself ($P < 0.05$ for each domain except family support). In the total sample, including traders and nontraders, the median time traded to improve 1 domain ranged from 7.2 months (for family support) to 7.7 months (for pain and discomfort, daily surroundings, and treatment decisions). To improve all 4 domains, the median amount of time traded increased to 8.3 months. When restricted to those willing to trade, the median ranged from 9.6 months (for pain and discomfort and daily surroundings) to 11.4 months (for family support). For full improvement in all domains, the median response increased to 24.0 months, indicating that the amount traded was partly cumulative.

Amount of Time Traded for Domains of End-of-Life Care

Table 3 illustrates variations in the amount of time traded based on respondent demographics, religion, and prior loss. In all domains except pain and discomfort, the amount of time traded to improve EOL domains varied considerably by respondent characteristics. For the remaining individual domains, respondents 40 years of age and older traded less time to improve EOL care than younger respondents, and those with children traded less time than those without children. In 2 individual domains (treatment decision and family support), black respondents traded less time than nonblack respondents to improve EOL care. When the 4 domains were improved simultaneously, differences based on age, race, and children remained significant. In addition, respondents who were married traded less time than those who were not, and respondents who experienced the death of a loved one traded less time than those with no prior loss.

Multivariable Analysis of Respondent Characteristics Predictive of Time Traded

In part 1, respondents were more likely to be traders if they were younger, were white, were college graduates, had better mental health status, or had a loved one who died in the ICU. In part 2, which included only those willing to trade, respondents traded more time if they were younger, had no children, had worse mental health status, or described treatment received by their loved one in the ICU as "neutral" or "not very caring." (Full results are available on request.)

To examine the overall trends, we stratified the predicted estimates for the combined model by those characteristics that proved significant in either part 1 or part 2 (Table 4). Respondents who were older, nonwhite, had children, were not college graduates, or participated in religious activities traded less time across the scenarios. The effect of

TABLE 3. Differences in the Median Amount of Time Traded (in months) for Improvements in End-of-Life Care According to Characteristics of the Respondents

		Median Number of Months Traded to Improve Domain					
Respondent Characteristics*	**No.**	**Pain and Discomfort**	**Daily Surroundings**	**Treatment Decisions**	**Family Support**	**All Domains**	**Percent Who Traded (any scenario)**
Age							
Less than 40 years	71	7.7	7.7	7.7	7.7	21.6	83.1
40 years or older	33	7.2	6.7[†]	0.0[†]	0.0[†]	0.0[†]	60.6
Race/ethnicity							
White	59	7.7	7.7	7.7	7.7	7.7	81.4
Black	25	7.7	0.0	0.0	0.0	0.0	64.0
Other race/ethnicity	12	3.8	7.9	7.9	7.4	7.4	75.0
Unknown race/ethnicity	8	3.8	3.8	0.0[†]	0.0[†]	0.0[†]	75.0
Married/cohabitating							
No	74	7.7	7.7	7.7	7.2	10.8	79.7
Yes	30	7.7	7.5	0.0	0.0	7.0[†]	66.7
Had children							
No	66	7.7	7.7	7.7	7.7	21.6	83.1
Yes	38	7.4	7.2[†]	0.0[†]	0.0[†]	0.0[†]	63.2
Experienced the loss of loved one							
No	15	7.7	8.1	7.7	10.0	60.0	73.3
Yes	86	7.7	7.7	7.7	7.2	7.9	79.1
Unknown loss	3	0.0	0.0	0.0	0.0	0.0[†]	0.0
Loved one died in the ICU							
No	61	7.7	7.7	7.0	7.2	8.4	73.8
Yes	40	7.7	7.7	7.9	7.4	8.3	85.0
Not applicable	3	0.0	0.0	0.0[†]	0.0	0.0	0.0

*Additional characteristics were tested but differences were not significant: gender, social support, education, income, physical component score on the SF-12, mental component score on the SF-12, considered religion important, participated in religious activities, and described treatment in the ICU as "caring."

[†] Significant difference ($P < 0.05$) in the median amount of time traded to improve the domain based on respondent characteristics. For example, respondents who were less than 40 years of age traded more time to improve daily surroundings than those who were age 40 and older (7.7 months vs 6.7 months).

SF-12 = Short Form 12; ICU = intensive care unit.

mental health status was mixed across the domains. Respondents traded less time if their loved one did not die in the ICU or if they perceived the treatment in the ICU to be caring. Finally, respondents consistently traded more time to improve all of the domains than to improve a single domain.

DISCUSSION

Our study is the first to examine the amount of healthy life expectancy that individuals would be willing to trade for good EOL care. That most respondents were willing to trade substantial durations of healthy life for a better EOL experience supports the contention that EOL care matters[24] and suggests that traditional methods to calculate QALYs will underestimate the true societal value. Consistent with prior research, we found that good EOL care encompasses both medical and nonmedical domains.[16,17]

We also found substantial variation in preferences for EOL care based on respondent demographics and prior loss. Older respondents, blacks, and those with children traded less time for higher-quality EOL care. The fact that older respondents seem to place a higher value on longevity relative to quality of EOL care is reminiscent of results obtained by Slevin et al. in which patients with cancer expressed greater willingness to undergo grueling chemotherapy for 3 extra months of life than healthy persons, including physicians.[25] Alternatively, respondents could apply internal discount rates to future gains, which could vary or be applied to different time horizons by younger and older respondents. Regardless, this finding seems particularly relevant when families discuss care options for seriously ill loved ones who are unable to communicate their own preferences directly. In subsequent research, we plan to address this issue more directly by

TABLE 4. Predicted Number of Months Traded to Improve End-of-Life Domains (combined results for the 2-part model) Presented for Selected Respondent Characteristics

Respondent Characteristics	Pain and Discomfort	Daily Surroundings	Treatment Decisions	Family Support	All Domains
Age					
Less than 40 years	15.8	14.2	15.1	16.1	40.3
40 years or older	10.3	6.8	5.9	8.2	8.3
Race/ethnicity					
White	16.1	13.4	14.9	16.4	33.2
Black	10.4	7.7	6.2	6.8	19.9
Other race/ethnicity	10.9	12.0	10.4	12.7	34.7
Had children					
No	16.6	14.7	15.7	15.8	38.9
Yes	9.2	6.2	5.3	9.2	13.1
Education					
Less than college	12.2	9.8	11.3	12.2	33.3
College graduate	16.3	14.3	13.2	15.3	26.2
Mental component score on SF-12					
Less than 50	9.9	11.0	13.2	14.0	35.9
50 or higher	16.7	12.3	11.5	13.3	26.4
Participated in religious activities					
No	20.5	15.8	17.6	17.5	41.6
Yes	11.8	10.5	10.3	12.2	26.2
Described treatment in the ICU as "caring"					
No	16.4	25.6	14.9	14.4	35.1
Yes	15.3	9.6	13.1	13.5	24.8
Not applicable (loved one did not die in the ICU)	12.9	9.3	11.1	13.4	31.0

The predicted amount of time traded is based on coefficient estimates from the 2-part model. In part 1 (the logistic regression), the following characteristics were significantly related to being a trader: age, race, education, mental health status, participation in religious activities, and having a loved one who died in the ICU. In part 2 (the conditional linear regression), the following characteristics were significantly related to the amount of time traded: age, having children, mental health status, and description of treatment in the ICU.

SF-12 = Short Form 12; ICU = intensive care unit.

eliciting preferences for EOL care from patient populations. In the meantime, the variation in preferences only strengthens the argument that we must strive to elicit patients' own preferences for EOL care before they get sick.

Of note, exposure to the ICU setting through a loved one's death increased the value of EOL care relative to longevity, especially if the loved one's treatment was perceived to be neutral or uncaring. This raises the question of whether those with no exposure to death in the ICU undervalue the benefits of high-quality EOL care. Not surprisingly, those who rated the ICU as caring traded smaller amounts of time than those who did not. Presumably, they saw little need to give up longevity to improve quality of care already perceived as high. For ICU specialists, it should be comforting that most respondents with prior ICU exposure characterized the treatment as caring.

This study represents the first application of our instrument and, as such, was subject to a number of limitations. First, our findings were based on a small convenience sample of participants who self-selected into our study and therefore might not accurately represent societal preferences. Only persons willing to devote their time and interested in the $5 participant payment approached the interviewers, and we have no data about how similar or different they could be from individuals who did not inquire about the study. In all likelihood, this group was more willing to "play the game" than a systematic sample would have been, and we therefore need to test the robustness of our findings with larger, population-based samples.

As discussed previously, it is also important to elicit preferences for EOL care from patient populations who have more direct experience with the kinds of tradeoffs that our measurement tool asks people to make and are likely to differ from those found here. Divergence between patient preferences and general population preferences occurs in most utility-based research, often leading to the question of which preferences are more accurate. However, patient surveys should be viewed as a supplement rather than a substitute for general population surveys. The Panel on Cost Effectiveness in Health and Medicine recommends that all cost-effectiveness analyses include analyses conducted with the general public so as to facilitate comparisons of findings across studies.[11] Furthermore, because EOL care is an emotional topic, it was important to test our instrument in a less sensitized sample before approaching patients currently coping with a terminal illness.

Second, all of the patients in our scenarios were identical: 80-year-old men with identical family structures, except in terms of the quality of EOL care they received. We held the patient in the scenarios constant so as to focus on the issues that we were most interested in, but having done so raises the question of whether our findings would generalize to patients with different characteristics.

Third, using the time tradeoff to assess utilities could be confusing. For example, some respondents chose the baseline patient as having a better quality of life even though his experience was dominated in every subsequent scenario. Also, we could have asked respondents to increase life expectancy in the worst patient, but we felt this approach would overestimate the value of the domains. The time tradeoff technique best characterizes our interest in balancing length of life with quality of death, although we need to explore further respondent comprehension and framing effects.

Fourth, among the nontraders for a given scenario, we did not distinguish between respondents with computer-assigned zeroes (who chose the baseline patient or neither patient as having better quality of life) and respondents who discerned quality-of-life differences but refused to decrease longevity for the better patient. Given our current sample size, we analyzed these groups together, although their attitudes and preferences are likely to be different. The former group does not appear to value quality as a consideration, whereas the latter group recognizes differences in quality but is resistant to trading against longevity.

Fifth, we did not incorporate all EOL domains identified by previous researchers[16,17] or fully explore interdependencies among the domains. As an initial research effort to test our hypothesis, this was a deliberate decision, largely driven by the complexity of the scenarios as well as the time commitment required to complete them.

Finally, we did not incorporate uncertainty regarding the course of treatment or patient outcomes into the scenarios. Treating death as a certainty was a simplification, although ICU patients who are on ventilators for more than 1 week do, in fact, have a high 6-month mortality rate.[26,27]

Given the progress we made toward quantifying the value of EOL care, it is worthwhile considering how these findings might be incorporated into formal cost-effectiveness analyses. According to the estimates presented here, an intervention that alleviates pain and discomfort in the final month of life provides an average of 14 quality-adjusted life months of benefit, or 1.2 QALYs, whereas the standard approach to measurement would assign a maximum of 0.08 QALYs to the same intervention. Do we integrate this information by allowing utility weights for EOL services to exceed the conventional [0, 1] interval, or do we treat the use of EOL care as an upper bound and normalize values for other health states accordingly? We need to address this question if our work is going to be used to implement good EOL care and possibly inform policy and resource allocation decisions.

More generally, our results challenge the assumption that overall quality of life can be measured as the integral of momentary quality of life over time. People could, in fact, care about gestalt characteristics of life not captured by momentary utility ratings. Dying surrounded by friends and family could be extremely important to people, despite the fact that it occurs over a short period of time and will not be remembered.

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