**A Multicenter Study of the Causes and Consequences of Optimistic Expectations about Prognosis by Surrogate Decision-Makers in ICUs**

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**APPENDIX A. USING SIGNIFICANCE TESTING TO IDENTIFY POTENTIAL COFOUNDERS OF OPTMISTIC EXPECTATIONS BY SURROGATES**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Characteristic** | **Outcome Variable** | | | | | | | |
|  | **Linear Regression with Log-Transformed Outcome(a)** | | | | | | **Logistic Regression(b)** | |
|  | **Hospital LOS** | | **ICU LOS** | | **Length of Mechanical Ventilation** | | **Survivability of Hospitalization** | |
|  | **Regression Coefficient** | ***p*** | **Regression Coefficient** | ***p*** | **Regression Coefficient** | ***p*** | **Odds Ratio** | ***p*** |
|  |  |  |  |  |  |  |  |  |  |
| Patient | Age | -0.01 | 0.019\* | -0.01 | 0.021\* | -0.01 | 0.016\* | 0.98 | 0.003\* |
|  | Male (vs. female) | 0.07 | 0.730 | 0.09 | 0.637 | 0.05 | 0.789 | 0.91 | 0.702 |
|  | Race: non-Hispanic white vs. other | 0.23 | 0.337 | 0.21 | 0.363 | 0.23 | 0.339 | 0.83 | 0.502 |
|  | Race: non-Hispanic black vs. other | -0.36 | 0.303 | -0.36 | 0.288 | -0.36 | 0.313 | 1.53 | 0.287 |
|  | Enrollment APACHE II | -0.005 | 0.784 | -0.01 | 0.757 | -0.01 | 0.776 | 0.92 | 0.001\* |
|  | APACHE II score on the fifth day on mechanical ventilation | -0.06 | <0.001\* | -0.06 | <0.001\* | -0.06 | <0.001\* | 0.89 | <0.001 |
|  | Full code at enrollment | 0.30 | 0.267 | 0.28 | 0.295 | 0.28 | 0.314 | 2.38 | 0.030\* |
|  | Admitted from home | -0.12 | 0.548 | -0.14 | 0.473 | -0.12 | 0.562 | 1.17 | 0.510 |
|  | Admitted from an acute care facility | 0.03 | 0.866 | 0.07 | 0.730 | 0.03 | 0.879 | 0.99 | 0.981 |
| Surrogate | Age | 0.01 | 0.139\* | 0.01 | 0.136\* | 0.01 | 0.142\* | 0.99 | 0.388 |
|  | Male (vs. female) | 0.29 | 0.197\* | 0.32 | 0.151\* | 0.30 | 0.193\* | 1.24 | 0.427 |
|  | Race: non-Hispanic white vs. other | 0.002 | 0.992 | 0.05 | 0.841 | 0.02 | 0.941 | 0.99 | 0.968 |
|  | Race: non-Hispanic black vs. other | -0.46 | 0.212 | -0.46 | 0.196\* | -0.46 | 0.219 | 1.35 | 0.477 |
|  | Some college education or higher | -0.08 | 0.726 | -0.05 | 0.818 | -0.05 | 0.839 | 0.54 | 0.020\* |
|  | Main language is English | 0.17 | 0.621 | 0.15 | 0.669 | 0.16 | 0.657 | 1.46 | 0.406 |
|  | How well surrogate understands English | 0.07 | 0.792 | 0.05 | 0.845 | 0.06 | 0.844 | 0.97 | 0.910 |
|  | Religion: Christian vs. other | 0.28 | 0.320 | 0.25 | 0.363 | 0.31 | 0.280 | 0.82 | 0.538 |
|  | Religion: No religion vs. other | -0.53 | 0.092\* | -0.50 | 0.103\* | -0.57 | 0.070\* | 1.24 | 0.554 |
|  | Importance of religion to the surrogate | 0.05 | 0.683 | 0.04 | 0.737 | 0.04 | 0.714 | 0.78 | 0.065\* |
|  | Relationship to the patient: parent vs. other | 0.62 | 0.040\* | 0.57 | 0.053\* | 0.65 | 0.035\* | 1.41 | 0.331 |
|  | Relationship to the patient: spouse vs. other | 0.42 | 0.046\* | 0.42 | 0.042\* | 0.41 | 0.057\* | 1.30 | 0.297 |
|  | Relationship to the patient: child vs. other | -0.58 | 0.005\* | -0.57 | 0.005\* | -0.59 | 0.004\* | 0.68 | 0.145\* |
|  | Relationship to the patient: sibling vs. other | -0.35 | 0.316 | -0.33 | 0.344 | -0.32 | 0.369 | 0.98 | 0.961 |
|  | Lipkus numeracy score | 0.03 | 0.417 | 0.03 | 0.402 | 0.02 | 0.445 | 1.02 | 0.700 |
|  | STOFHLA score | -0.01 | 0.317 | -0.01 | 0.284 | -0.01 | 0.328 | 1.01 | 0.483 |
|  | Adequate level of health literacy (STOFHLA≥23) | -0.53 | 0.250 | -0.56 | 0.217 | -0.54 | 0.254 | 1.31 | 0.645 |
|  | LOTR score | 0.02 | 0.363 | 0.02 | 0.377 | 0.02 | 0.371 | 0.96 | 0.246 |
|  | High level of optimism (LOTR≥19) | 0.20 | 0.376 | 0.20 | 0.350 | 0.20 | 0.371 | 0.88 | 0.627 |
|  | PHQ9 score | -0.03 | 0.184\* | -0.03 | 0.188\* | -0.03 | 0.201 | 1.03 | 0.239 |
|  | Moderately severe or severe depression (PHQ9≥15) | 0.23 | 0.555 | 0.25 | 0.508 | 0.25 | 0.535 | 1.28 | 0.571 |
|  | GAD7 score | -0.02 | 0.269 | -0.02 | 0.274 | -0.02 | 0.238 | 1.02 | 0.397 |
|  | Severe anxiety (GAD7≥15) | -0.10 | 0.740 | -0.10 | 0.733 | -0.11 | 0.714 | 1.03 | 0.939 |
|  | Had prior conversation w patient about advance care planning | 0.07 | 0.750 | 0.03 | 0.870 | 0.04 | 0.859 | 1.38 | 0.228 |
|  | Has experience as surrogate decision-maker | 0.15 | 0.481 | 0.12 | 0.547 | 0.11 | 0.598 | 0.76 | 0.255 |
|  | Self-rating of understanding the patient’s wants | 0.02 | 0.629 | 0.02 | 0.652 | 0.02 | 0.653 | 1.09 | 0.122\* |
|  | Clinician trust score | -0.02 | 0.474 | -0.02 | 0.579 | -0.02 | 0.545 | 1.02 | 0.608 |
| Clinician | Age | 0.002 | 0.842 | 0.003 | 0.748 | 0.002 | 0.819 | 0.99 | 0.312 |
|  | Male (vs. female) | -0.02 | 0.948 | -0.03 | 0.893 | 0.004 | 0.988 | 1.02 | 0.943 |
|  | Race: non-Hispanic white vs. other | 0.07 | 0.774 | 0.05 | 0.828 | 0.05 | 0.823 | 1.29 | 0.378 |
|  | Attending vs. other | -0.04 | 0.851 | -0.01 | 0.971 | -0.01 | 0.966 | 0.70 | 0.172\* |
|  | Years in practice | 0.001 | 0.920 | 0.002 | 0.834 | 0.001 | 0.898 | 0.98 | 0.199\* |
| Cohort is (a) patient that did not survived hospitalization, n=122 (b) all patients, n=275  \*Variables with p<0.20 were subsequently considered in the stepwise regression  *Definitions of abbreviations:* ICU = intensive care unit ; LOS=Length of Stay; APACHE II = Acute Physiology and Chronic Health Evaluation II; STOFHLA = Short Test of Functional Health Literacy in Adults; LOTR = Revised Life Orientation Test; PHQ9 = Patient Health Questionnaire-9; GAD7 = Generalized Anxiety Disorder 7-item | | | | | | | | | |

**APPENDIX B. NO DIFFERENCES IN THE DEMOGRAPHIC CHARACTERISTICS OF ENROLLED VS NON-ENROLLED PATIENTS**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Characteristic** | | **Non-Enrolled**  **(N=130)** | | **Enrolled**  **(N=275)** | | ***p*** |
| **n (%)** | | **n (%)** | |
| Age |  | 58.0 | (15.5) | 58.2 | (16.5) | 0.896 |
| Gender | Female | 55 | (42.6) | 123 | (44.7) | 0.747 |
|  | Male | 74 | (57.4) | 152 | (55.3) |  |
| Ethnicity | Non-Hispanic | 75 | (86.2) | 213 | (91.0) | 0.218 |
|  | Hispanic | 12 | (13.8) | 21 | (9.0) |  |
| Race | Asian | 6 | (4.9) | 13 | (4.8) | 0.245 |
|  | Black | 19 | (15.4) | 31 | (11.4) |  |
|  | Multiethnic | 0 | (0) | 3 | (1.1) |  |
|  | Native American | 1 | (0.8) | 2 | (0.7) |  |
|  | Pacific Islander/Hawaiian | 2 | (1.6) | 0 | (0) |  |
|  | White | 95 | (77.2) | 222 | (81.9) |  |

Mean (SD) where appropriated

Comparison tests used were t-test and Fisher’s exact test

**APPENDIX C. DISCRIMINANT ACCURACY AND CALIBRATION OF PHYSICIANS’ AND SURROGATES PREDICTIONS FOR HOSPITAL SURVIVAL**

|  |  |  |
| --- | --- | --- |
| **Physician prediction of chance of hospital survival** | **Number of patients (n1)** | **Survived to hospital discharge**  **n2 (% out of n1)** |
| >95% | 6 | 5 (83.3%) |
| >90% | 12 | 11 (91.7%) |
| >80% | 44 | 37 (84.1%) |
| <20% | 38 | 5 (13.2%) |
| <10% | 23 | 1 (4.3%) |
| <5% | 17 | 0 (0%) |

We determined the calibration and discrimination of physicians’ predictions and surrogates’ predictions, measured with the Brier score and area under the ROC curve, respectively.

We determined the discriminative accuracy of physicians’ and surrogates’ prognostic estimates by calculating the area under the receiver operating characteristic curves for each group. Patient mortality during the hospitalization was the dependent variable. Physicians’ and surrogates’ survival estimates were the independent variables. We calculated the C-statistic (i.e., the area under the ROC curve), which gives the probability that a randomly selected patient who died had a higher risk score than a patient who did not die. The C-statistic score ranges from 0.5 to 1, with 1 indicating perfect accuracy. The C-statistic for physicians’ survival predictions was 0.77. The C-statistic for surrogates’ survival predictions was 0.72.

To assess the calibration of physicians’ and surrogates’ survival predictions, we calculated Brier scores for both groups. Brier scores are commonly used to assess prediction model calibration (Steyerberg et al, 2010). The Brier score ranges from 0 to a maximum value that depends on the incidence rate of the population of interest. A value of 0 indicates perfect probability prediction of the corresponding model. The maximum value of the Brier score indicates a noninformative prediction of the model. The incidence rate for patient’s survival to hospital discharge was estimated to be 56.33% in our sample, therefore the maximum (ie least informative) Brier score that can be reached was 0.25.The Brier score for physicians’ survival predictions was 0.19. The Brier score for surrogates’ survival predictions was 0.24.

1. Steyerberg et al. Assessing the performance of prediction models: a framework for some traditional and novel measures. Epidemiology. 2010 January ; 21(1): 128–138

**APPENDIX D. PROPORTION OF DEATHS PRECEEDED BY DECISION TO FORGO LIFE SUSTAINING TREATMENT**

|  |  |  |
| --- | --- | --- |
|  | **Among all patients who died in the hospital (N=122)**  **Count (%)** | **Among patients who died whose surrogate held optimistic prognostic expectations**  **(N= 45)**  **Count (%)** |
| Life support withdrawn  Life support withheld | 91 (74.6%)  16 (13.1%) | 31 (68.9%)  6 (13.3%) |

**APPENDIX E. MULTIVARIABLE ANALYSIS SHOWING NO ASSOCIATION BETWEEN OPTIMISTIC EXPECTATIONS AND ICU LENGTH OF STAY AMONG PATIENTS WHO SURVIVED**

|  |  |  |
| --- | --- | --- |
| **Outcome of Regression Model** | **Regression Coefficient of Having Optimistic Prognostic Expectations (discordance≥20%)**  **(95% CI)** | ***p*** |
| ICU LOSa  (n=133) | -0.04  (-0.30 to 0.23) | 0.779 |
| aAdjusted for the following factors: the patient’s age, APACHE II score on the fifth day on mechanical ventilation (the same day prognostic estimates were taken), and admission source (from home vs. other)  *Definition of abbreviations:* LOS=Length of Stay; ICU=intensive care unit; APACHE II= Acute Physiology and Chronic Health Evaluation II. | | |

**APPENDIX F. SENSITIVITY ANALYSES VERIFYING THE ASSOCIATION BETWEEN SURROGATES’ OPTIMISTIC EXPECTATIONS ABOUT PROGNOSIS AND DURATION OF INTENSIVE TREATMENT AT THE END OF LIFE**

**SENSITIVITY ANALYSIS 1. USING THE SURVIVAL EXPECTANCY RATIO (SER) ≥1.2 TO DEFINE OPTIMISTIC EXPECTATIONS BY SURROGATES. MULTIPLE VARIABLE ANALYSIS SHOWING ADJUSTED ASSOCIATION BETWEEN SER ≥1.2 AND HEALTHCARE UTILIZATION**

|  |  |  |  |
| --- | --- | --- | --- |
| **Outcome of regression model** | **Regression Coefficient of Having Optimistic Prognostic Expectations (SER≥1.2)**  **(95% CI)** | **Change from the Meana,b**  **(% change)** | ***p*** |
| ICU length of stay | 0.55 (0.19- 0.91)d | 10.2 days (73.6%) | 0.003 |
| Length of mechanical ventilation | 0.44 (0.06-0.81)c | 8.3 days (54.8%) | 0.023 |
| aAmong the patients who died, the mean (median) hospital length of stay is=15.3 days (8 days), the mean (median) ICU length of stay is=13.9 days (8 days), and the mean (median) length of mechanical ventilation is=15.1 days (8 days).  bThe % change from the mean is computed by exponentiating the coefficient (beta) from the regression with log-transformed outcome  cAdjusted for the following factors: the patient’s APACHE II score on the fifth day on mechanical ventilation (the same day prognostic estimates were taken), and surrogate’s relationship to the patient  dAdjusted for the following factors: the patient’s APACHE II score on the fifth day on mechanical ventilation (the same day prognostic estimates were taken), surrogate’s relationship to the patient, and surrogate’s race (non-Hispanic black vs. other)  *Definition of abbreviations*: SER=survival expectancy ratio; ICU = intensive care unit; APACHE II = Acute Physiology and Chronic Health Evaluation II. | | | |

**SENSITIVITY ANALYSIS 2. EXCLUDING PATIENTS FOR WHOM THE TREATING PHYSICIAN PREDICTED ≥ 80% CHANCE OF SURVIVAL TO HOSPITAL DISCHARGE.**

**TABLE 4. MULTIPLE VARIABLE ANALYSIS SHOWING ADJUSTED ASSOCIATION BETWEEN OPTIMISM AND HEALTHCARE UTILIZATION EXCLUDING HIGH SURVIVAL PROGNOSIS BY THE PHYSICIAN (≥80%)**

|  |  |  |  |
| --- | --- | --- | --- |
| **Outcome of regression model** | **Regression Coefficient of Having Overly Optimistic Prognostic Expectations (Discordance ≥ 20%)**  **(95% CI)** | **Change from the Meana,b**  **(% change)** | ***p*** |
| ICU length of stay | 0.60 (0.18- 1.01)d | 11.3 days (81.4%) | 0.005 |
| Length of mechanical ventilation | 0.43 (0.02-0.84)c | 8.1 days (53.5%) | 0.040 |
| aAmong the patients who died, the mean (median) hospital length of stay is=15.3 days (8 days), the mean (median) ICU length of stay is=13.9 days (8 days), and the mean (median) length of mechanical ventilation is=15.1 days (8 days).  bThe % change from the mean is computed by exponentiating the coefficient (beta) from the regression with log-transformed outcome  cAdjusted for the following factors: the patient’s APACHE II score on the fifth day on mechanical ventilation (the same day prognostic estimates were taken), and surrogate’s relationship to the patient  dAdjusted for the following factors: the patient’s APACHE II score on the fifth day on mechanical ventilation (the same day prognostic estimates were taken), surrogate’s relationship to the patient, and surrogate’s race (non-Hispanic black vs. other)  *Definition of abbreviations*: ICU = intensive care unit; APACHE II = Acute Physiology and Chronic Health Evaluation II. | | | |

**Sources of optimistic prognostic expectations by surrogates (excluding cases in which the physician estimated ≥80% chance of survival)**

In 44 cases (45%), the discordance arose from the surrogate misunderstanding the physician’s prognostic expectations. In 46 (47%) cases, the discordance arose from both surrogates misunderstanding physicians’ prognostic expectations and from surrogates holding systematically different beliefs about the patient’s prognosis compared to what they judged to be the physicians’ prognostic expectations. In 7 (7%) cases, the prognostic discordance was caused only by surrogates holding systematically different beliefs about the patient’s prognosis compared to what they judged to be the physician’s prognostic expectations. Data were missing from 1 surrogate who did not respond to the question eliciting what they thought the physician’s prognosis estimate was.