Stability of Patient Preferences Regarding Life-Sustaining Treatments*

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Physicians often express concern about the reliability of critically ill patients' preferences regarding life-sustaining treatments. We interviewed 30 Veterans Administration intensive care unit patients to determine their preferences for resuscitation, resuscitation requiring mechanical ventilation, artificial hydration and nutrition, and hospitalization for treatment of pneumonia. Patients expressed their preferences considering their current health and then two hypothetical scenarios, stroke and dementia. Follow-up interviews occurred one month later to assess preference stability. We found a diversity of opinions about life-sustaining treatments. Despite significant changes in health status and mood (p<0.05), treatment preferences were stable over time (kappa = 0.35–0.70). Our results suggest that life-sustaining treatment preferences solicited during a serious illness are reliable and may be used in decision-making when a patient becomes unable to communicate or is mentally incapacitated. (Chest 1990; 97:159-64)

The unconditional use of medical interventions such as cardiopulmonary resuscitation and mechanical ventilation has prompted numerous discussions about the appropriate definitions and indications for life-sustaining treatments.1–5 Decisions regarding life-sustaining treatments are traditionally based on medical indications. However, patients increasingly desire consideration of their attitudes about medical therapies in health care decisions.6,7 Furthermore, patients are empowered by law to accept or refuse medical recommendations, including those regarding life-sustaining treatments.

Previous research suggests that patient preferences are one of several factors influencing physician decisions to withhold or withdraw medical therapies.8,9,10 However, physicians often question whether patients' attitudes change over time and in different clinical situations.9 Moreover, physicians are reluctant to rely on a patient's preference when expressed during a serious acute illness, due to concerns about the interference of disease and treatment (eg, pain and medication, respectively) with the patient's decision-making process.11,12

Characteristics and reliability of critically ill intensive care unit patients' treatment preferences have not been previously described, and yet may help physicians make appropriate choices regarding the implementation and continuation of life-sustaining therapies. We interviewed intensive care unit (ICU) patients to determine their preferences for life-sustaining treatments. We conducted follow-up interviews one month later to assess the changes of these preferences as health status improved.

METHODS

We interviewed Seattle Veterans Administration Medical Center patients sampled from intensive care units from October to December 1987. All interview and questionnaire content was approved by the University of Washington Human Subjects Review Committee. Informed consent was obtained from willing patients.

Subjects

Consecutive patients who had survived a medical intensive care unit or coronary care unit stay of at least 48 hours were recruited for participation. Entry criteria also included male gender, age greater than 50 years, English speaking, and ability to provide informed consent and complete the interview. Patients transferred to a surgical service were excluded from participation.

During the study period, 80 patients survived an ICU stay of at least 48 hours and were transferred out of the ICU. Forty-six of these patients did not meet the other study criteria: 25 were under 50 years of age; seven were women; seven were unable to complete the questionnaire; five were transferred to a surgical service; and two were previously interviewed. Thirty-four patients met the study criteria and were asked to participate. Thirty (88 percent) agreed.

Procedures

One member of the study team (M.A.E.) interviewed all patients either in the ICU immediately prior to transfer (n = 15) or within 24 hours following transfer to a medical ward (n = 15).

The patient interview was divided into five sections.

Mental Status: Mental status was evaluated with the Short Portable Mental Status Questionnaire (SPMSQ). The SPMSQ is a reliable and valid ten-question instrument with four-week test-retest reliability correlation coefficients for elderly subjects of greater than 0.82.12

Treatment Preference Questionnaire: Study participants completed a questionnaire in which they indicated their preferences regarding life-sustaining therapies. This questionnaire presented

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scenarios in three clinical situations: the patient's current health and two hypothetical illness conditions (stroke with resultant hemiparesis but without mental disabilities, and dementia with inability for self-care). The two hypothetical scenarios were designed to obtain preferences regarding life-sustaining therapies under two unique states of health and quality of life. (Appendix contains verbatim descriptions of the hypothetical scenarios. Copies of the questionnaire are available upon request.)

After reading each scenario, patients specified their preferences regarding several life-sustaining treatments. Patients indicated if they would want to be (1) revived if their heart stopped (resuscitation); (2) revived and then put on a "breathing machine" for an unknown period of time if this was the only way to remain conscious (resuscitation with mechanical ventilation); and (3) provided food and fluids with a nasogastric tube and an intravenous line for an unknown period of time if unable to eat and drink (artificial hydration and nutrition). After the hypothetical stroke and dementia scenarios, patients reported their desire for hospitalization for medical treatment of pneumonia. Possible answers to questions regarding the life-sustaining therapies were recorded on a four-point, visual analog scale: 1, "definitely yes;" 2, "probably yes;" 3, "probably no;" and 4, "definitely no."

Following the mechanical ventilation and artificial hydration and nutrition questions, patients selected the length of time they would be willing to continue these therapies if the necessary duration was unknown and "if stopping would lead to death." Finally, patients indicated whether they had ever discussed life-prolonging treatments with another person, and if so, the relationship to that person.

Subjective Health Status and Quality of Life Rating: Patients rated their current health status and compared their current health to their health three months ago. Current health status ratings included: 1, "excellent;" 2, "very good;" 3, "good;" 4, "fair;" and 5, "poor." Possible responses for the comparison of current to prior health were: 1, "much better;" 2, "somewhat better;" 3, "about the same;" 4, "somewhat worse;" and 5, "much worse." Quality of life was described in the questionnaire as involving "those things which make life better or worse. It may include such things as life satisfaction, health status, relationships with family and friends, physical abilities, emotional state, and ability to think or reason."

Patients reported their quality of life on a five-point, visual analog scale: 1 indicating "very poor;" 2, "poor;" 3, "fair;" 4, "good;" and 5, "very good."

Depression Screen: We administered the Center for Epidemiological Studies Depression (CES-D) scale questionnaire. The CES-D questionnaire is a reliable 20 item self-report of depressive symptoms experienced in the previous week (Cronbach alpha coefficient = .85-.91). Scores range from 0 to 60, with higher scores indicating more depressive symptoms.

Rationale: After completion of these procedures, patients explained open-endedly each of their choices regarding life-sustaining treatments in the three scenarios. All responses were recorded. Patients then selected the "most important reason" for acceptance or refusal of each life-sustaining treatment.

Objective Medical and Social Information: The following supplemental information was obtained from the patients' medical records: (1) chronic illnesses/health problems; (2) reason for current hospital admission; and (3) reason for ICU admission. The overall severity of each patient's illness was measured using the Acute Physiology and Chronic Health Evaluation II (APACHE II) system. Each APACHE II score reflects the most abnormal of 12 specified laboratory and physical examination findings during the first 24 hours of ICU stay, and any history of severe organ system insufficiency and/or of immune system compromise. APACHE II scores range from 0 to 71, with higher scores indicating greater risk of hospital mortality. In the development of APACHE II, no patient (of 5,815 patients from 13 hospitals) had a score greater than 55.

Follow-up
Follow-up interviews using the same questionnaire were conducted approximately one month (20 to 40 days) after the patient's discharge or transfer from the ICU. Of the original 30 patients, seven were lost to follow-up, two died, and one declined to be interviewed. No patients were in an ICU at the time of the follow-up interview.

Data Analysis
The original 4-point scale to assess patient life-sustaining treatment preferences was condensed into a 2-point scale (yes and no) for simplicity and clinical relevance. Friedman chi-square analysis was used to determine consistency of patient preferences regarding different life-sustaining treatments within the same scenario and regarding the same life-sustaining treatment across the three scenarios. Differences in patient self-assessed health status, CES-D scores and preferences regarding life-sustaining treatments between the ICU interview and the follow-up interview one month later were evaluated using the Wilcoxon two-tailed t-test. Kappa statistics were also used to assess the level of agreement (controlling for chance) of patient preferences between the two interviews. Unless otherwise specified, data are presented as means ± SD.

RESULTS
The age of our study participants was 64±9 years. Most patients were white (90 percent), cognitively intact (90 percent by the Short Portable Mental Status questionnaire criteria), and had at least a high school education (59 percent). Other patient characteristics are presented in Table 1.

Percentages of patients favoring each life-sustaining treatment in the three scenarios are shown in Table 2. Most patients desired resuscitation in the current health situation and hospitalization for the treatment of pneumonia in the stroke and dementia scenarios. Fewer patients wanted the other treatments. Larger

Table 1 — ICU Patient Characteristics (n=30)

<table>
<thead>
<tr>
<th>Chronic health problems</th>
<th>47%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension</td>
<td>47%</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>37%</td>
</tr>
<tr>
<td>Chronic obstructive pulmonary disease</td>
<td>27%</td>
</tr>
<tr>
<td>ICU Admission diagnosis</td>
<td></td>
</tr>
<tr>
<td>Possible myocardial infarction</td>
<td>30%</td>
</tr>
<tr>
<td>Gastrointestinal bleeding</td>
<td>23%</td>
</tr>
<tr>
<td>Cardiac dysrhythmia</td>
<td>20%</td>
</tr>
<tr>
<td>ICU Stay, days</td>
<td>3.4±1.5</td>
</tr>
<tr>
<td>ICU Health rating*</td>
<td>3.7±1.1</td>
</tr>
<tr>
<td>ICU Health compared to prior health†</td>
<td>3.5±0.9</td>
</tr>
<tr>
<td>APACHE II Score‡</td>
<td>12.3±5.5</td>
</tr>
<tr>
<td>Current quality of life (self rating)$</td>
<td>3.5±1.2</td>
</tr>
<tr>
<td>Depression index (CES-D)</td>
<td>16±10</td>
</tr>
</tbody>
</table>

*Five point scale with 3 = "good" and 4 = "fair."
†Five point scale with 3 = "about the same" and 4 = "somewhat worse."
‡APACHE II = Acute Physiology and Chronic Health Evaluation II. Mean score of 12.3 suggests an in-hospital mortality risk of 13%.
§Five point scale with 3 = "fair" and 4 = "good."
∥CES-D-Center for Epidemiological Studies Depression questionnaire.
percentages of patients favored therapies in the current health situation than in the other scenarios.

Patient acceptance of a specific life-sustaining treatment under one scenario's conditions did not ensure acceptance of other types of life-sustaining treatment under the same conditions (Friedman's chi-square, p<.01). Furthermore, patient preferences for resuscitation and the hospitalized treatment of pneumonia varied significantly across the three scenarios (Friedman's chi-square for resuscitation, p<.01; McNemar's chi-square for treatment of pneumonia, p<.005).

The most common reasons for favoring a particular life-sustaining treatment were generally similar under all three scenarios. In the current health scenario, the most common reason for wanting resuscitation was a desire for continuation of interpersonal experiences with family and friends (50 percent). “Chance for cure” was the most frequent explanation for acceptance of mechanical ventilation (38 percent) and artificial hydration and nutrition (33 percent). In all scenarios, choices to forego life-sustaining treatments were most often attributed to fear of becoming a “caretaking burden.” For example, in the current health scenario, patients reported this reasoning for refusing resuscitation (50 percent) and artificial hydration and nutrition (20 percent). Other major reasons for refusal of a life-sustaining treatment were “natural time” to die; “physical limitations;” and “no chance for cure.”

Patient preferences regarding duration of mechanical ventilation and artificial hydration and nutrition were similar in all three scenarios. In the current health scenario, many patients favored immediate discontinuation of mechanical ventilation (40 percent) and artificial hydration and nutrition (40 percent). However, patients desiring continuation of these treatments indicated a wide range of acceptable durations. For example, patients wanted mechanical ventilation for days (20 percent), weeks (23 percent) and months (7 percent), and artificial hydration and nutrition for days (13 percent), weeks (17 percent), months (13 percent) and years (3 percent). Interestingly, several patients desired indefinite continuation of mechanical ventilation (10 percent) and artificial hydration and nutrition (13 percent).

Fifty-three percent of the ICU patients had previously discussed their preferences about life-prolonging treatments with another person. However, only 10 percent of patients reported communicating their views to a physician. Forty-three percent of married patients had talked with their spouse about their preferences for life-sustaining therapies.

Patients’ health status and mood generally improved

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**Table 2 — Percentages of Patients Favoring Life-Sustaining Treatments (n = 30)**

<table>
<thead>
<tr>
<th>Treatments</th>
<th>Current Health</th>
<th>Stroke</th>
<th>Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resuscitation</td>
<td>87%</td>
<td>53%</td>
<td>37%</td>
</tr>
<tr>
<td>Resuscitation and mechanical ventilation</td>
<td>43%</td>
<td>27%</td>
<td>24%</td>
</tr>
<tr>
<td>Artificial hydration and nutrition</td>
<td>50%</td>
<td>40%</td>
<td>28%</td>
</tr>
<tr>
<td>Hospitalization for treatment of pneumonia</td>
<td>N/A</td>
<td>77%</td>
<td>67%</td>
</tr>
</tbody>
</table>

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**Table 3 — Stability of Life-Sustaining Treatment Preferences Between ICU and Follow-up Interviews (n = 20)**

<table>
<thead>
<tr>
<th>Current health</th>
<th>Percentages of Patients</th>
<th>Statistical Measure Kappa*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No Change</td>
<td>Yes—No</td>
</tr>
<tr>
<td>Resuscitation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resuscitation and mechanical ventilation</td>
<td>70%</td>
<td>10%</td>
</tr>
<tr>
<td>Artificial hydration and nutrition</td>
<td>75%</td>
<td>10%</td>
</tr>
<tr>
<td>Stroke</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resuscitation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resuscitation and mechanical ventilation</td>
<td>80%</td>
<td>15%</td>
</tr>
<tr>
<td>Artificial hydration and nutrition</td>
<td>80%</td>
<td>10%</td>
</tr>
<tr>
<td>Hospitalization for treatment of pneumonia</td>
<td>80%</td>
<td>15%</td>
</tr>
<tr>
<td>Dementia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resuscitation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resuscitation and mechanical ventilation</td>
<td>80%</td>
<td>10%</td>
</tr>
<tr>
<td>Artificial hydration and nutrition</td>
<td>85%</td>
<td>5%</td>
</tr>
<tr>
<td>Hospitalization for treatment of pneumonia</td>
<td>65%</td>
<td>25%</td>
</tr>
</tbody>
</table>

*Data are kappa statistics which indicate level of agreement controlling for chance alone. Range = −1 to 1 with 1 indicating perfect agreement.
between the two interviews. Eighty percent of patients had returned home. Ten percent were hospitalized on a general medicine service ward and 10 percent were in a nursing home. Patients' comparative health ratings (comparison of current health to health several months previously) were significantly improved (Wilcoxon 2-tailed, \( p<0.01 \)). Scores on the CES-D questionnaire showed significant improvement (Wilcoxon 2-tailed \( p<0.05 \)) with a score of 11±10 on the follow-up questionnaire.

Despite changes in health status and mood over the month after leaving the ICU, the majority of patients did not change their preferences regarding any of the life-sustaining treatments (Wilcoxon 2-tailed, \( p>0.05 \)). The changes that did occur were not systematic (Table 3). For example, in the stroke scenario, approximately 10 to 15 percent of patients who had desired a particular life-sustaining treatment while in the ICU expressed their wish to forego this treatment at the follow-up interview. Similar numbers of patients changed their minds in the opposite direction. Interestingly, the two patients who may have been depressed (CES-D score ≥20) \( ^{19} \) at the ICU interview and not at the follow-up interview did not change their preferences for life-sustaining therapies. Preferences about the duration of mechanical ventilation and artificial hydration and nutrition also did not change significantly over the time period between the two interviews (Wilcoxon two-tailed, \( p>0.05 \)). The stability of patients' preferences for all life-sustaining treatments from the initial to the follow-up interview, despite changes in health and mood, is further reflected by high kappa statistics (Table 3).

**DISCUSSION**

In this study we explored two questions: (1) what are the life-sustaining treatment preferences of critically ill ICU patients; and (2) are these preferences stable over a one-month period. In regard to the first question, ICU patients expressed a diversity of life-sustaining treatment preferences. Preferences regarding one treatment did not generalize to other treatments. Furthermore, preferences regarding a particular life-sustaining treatment often changed under the markedly different clinical conditions presented in the three scenarios. These findings suggest that patient preferences are difficult to predict. We already know that patient preferences do not appear to be strongly correlated with demographic characteristics or health status measures. \( ^{16,18} \) Thus, it is not surprising that physicians are inaccurate in predicting patient preferences. \( ^{20,21} \)

Our data support the need to discuss different life-sustaining treatments. The Office of Technology Assessment (Congressional Board of the 100th United States Congress) recommends consideration of five treatments: cardiopulmonary resuscitation, mechanical ventilation, nutritional support and hydration, dialysis for chronic renal failure, and antibiotic therapy. \( ^{22} \) This appears to be a reasonable array of treatments in terms of technologic sophistication and invasiveness. However, hospitalization is not included and may be the most important decision for terminally ill patients. An alternative approach to understanding patients' preferences might be to elicit the health and social conditions in which individuals would not want their lives prolonged.

Previous research suggests that increased familiarity with cardiopulmonary resuscitation, whether due to past experience \( ^{19} \) or education, \( ^{23} \) leads to a decreased desire for this treatment. Although a majority of this study's participants favored resuscitation, especially in the current health situation, many refused resuscitation when it was accompanied by mechanical ventilation. Education regarding the potential components of resuscitation may result in more patients' refusal of cardiopulmonary resuscitation. When obtaining information about patients' resuscitation preferences, physicians are encouraged to inform patients about the likelihood of other potentially required measures such as intubation and mechanical ventilation. As a consequence, patients may specify acceptance or refusal of select interventions used in resuscitation and these preferences can be incorporated in Do Not Resuscitate (DNR) orders.

In contrast to patients who seemed comfortable with withdrawing life-sustaining treatments, a small minority of patients did not want life-prolonging treatments withdrawn under any conditions. This minority may create an uncomfortable dilemma for physicians and society. Physicians are not obligated to administer ineffective treatments. However, some patients may view prolonged life in itself to be of sufficient "benefit" to continue treatment. For these patients, the use of any life-sustaining treatment is not considered "futile," despite no chance of recovery or discontinuation of the particular treatment without death. Although the principle of autonomy is well accepted, society may not be willing to bear the costs of life prolongation by expensive medical therapies. These questions require public debate and explicit policies.

In regard to our second study question, we found no significant differences in the life-sustaining treatment preferences, including preferences about duration of treatments expressed by ICU patients at the time of transfer from the ICU compared to those expressed by the same patients one month later when no longer in the ICU nor under the stress of an acute illness. These results suggest that patient preferences regarding life-sustaining treatments are stable over one month despite changes in health and mood. Two
studies of cancer patients' preferences obtained similar results. One study found that cancer patient preferences for treatment did not change significantly when measured before and then six months following treatment despite significant treatment toxicity.24 Another study of patients with laryngeal cancer showed stability of values regarding voice expressed before and after treatment despite changes in clinical state.25 In contrast, women's preferences about anesthesia during childbirth changed significantly during labor when compared to those expressed before and after labor.26 Our results may be more consistent with those found in the studies of cancer patient preferences because of similarities in the two populations. Our study patients, like the cancer patients, are older, have more chronic disease and are confronting choices about life-sustaining treatments and not about treatment of a symptom during a limited situation such as childbirth.

Our finding of stability in ICU patient life-sustaining treatment preferences provides support for reliance on attitudes which are expressed by competent patients in the setting of critical illness. In order to make appropriate decisions about the implementation and continuation of life-sustaining therapies, physicians should elicit ICU patient preferences. Obtaining these preferences is important even when ICU patients do not immediately require life-sustaining treatment because these patients are at increased risk for mental status changes, the need for a life-sustaining treatment while in the ICU, and the possible need for a life-sustaining treatment in the future. Although discussions regarding these therapies have sometimes been avoided due to concerns about disturbing patients, we found ICU patients very willing to indicate their opinions. However, few (10 percent) had talked with their physicians about life-sustaining treatment preferences. Other investigators report similar findings.12,18

In most cases when patients are mentally incapacitated and decisions about therapy must be made, family members are approached to supply information about "what the patient would want." Unfortunately, family members may not know specific patient preferences.27 Knowledge of previously expressed patient preferences may help surrogate decision makers to make more accurately represent patient wishes. Consideration of a patient's previously stated opinions about life-sustaining therapies may also alleviate family feelings of insecurity and guilt about choices to forego or withdraw these treatments. Our results encourage the use of previously expressed preferences when patients become unable to state their wishes. However, further research must address the questions of whether patients change their pre-ICU preferences once in the ICU and whether patients change their preferences during their ICU stay.

There are several limitations of this study. First, the number of participants is small and restricted to men over 50 years of age who were admitted, remained in the ICU for at least 48 hours, and survived the experience. Caution may be warranted in applying these results to other patient populations. The small number of participants limited the statistical power of negative results. Second, our study did not control for the amount of experience or knowledge of intensive care or life-sustaining therapies. Finally, patients were interviewed at the conclusion of their ICU stay, at a time when their condition was presumably more stable than an admission. Patient preferences regarding life-sustaining treatments on admission may have differed from those obtained at the end of their ICU stay.

In summary, an accurate knowledge of patient preferences is frequently necessary in order for physicians and surrogate decision makers to make appropriate decisions regarding the implementation or continuation of life-sustaining treatments. Our results suggest that patients are willing to discuss their preferences about life-sustaining treatments in current and hypothetical situations while in the ICU, and that their responses are likely to be stable for at least 30 days. This provides support for an approach that involves the ICU patient actively in decisions regarding the use of life-sustaining treatments.

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APPENDIX

HYPOTHETICAL SCENARIOS

Stroke

Suppose that one year ago you experienced a permanent stroke. One arm and one leg are paralyzed so that you cannot walk and have difficulty feeding yourself. You need care and assistance for 12 hours each day. You are mentally alert and able to visit with family and friends.

Dementia

Suppose that as a result of dementia (eg, Alzhei-mer's), you are very forgetful, often inattentive, unable to do two tasks in a row, and uninterested in eating. You occasionally become confused and fearful without any apparent reason. You enjoy being in the company of your family and friends, but are often excluded from their conversations. You need constant attention and assistance to do normal activities such as eating, bathing, and grooming.

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