Assessment of Patient Preferences:
Integrating Treatments and Outcomes

Terri R. Fried,1,2 Elizabeth H. Bradley,3 and Virginia R. Towle4

1Clinical Epidemiology Unit, West Haven Veterans Affairs Connecticut Healthcare System.
Departments of 2Medicine and 3Epidemiology and Public Health, and 4Program on Aging, Yale University School of Medicine, New Haven, Connecticut.

Objectives. The purpose of this study was to develop a patient-centered measure of treatment preference applicable across a range of diseases and treatment decisions.

Methods. Instrument development was based on previous research supplemented by open-ended interviews and focus groups. Psychometric properties of the instrument were determined by administration to 125 persons aged 60 or older with a limited life expectancy secondary to congestive heart failure, chronic obstructive pulmonary disease, or cancer. Test–retest and inter-rater reliability were established using intraclass correlation coefficients. Construct validity was established by examining associations of the measure with a single-item question regarding treatment goals and with age, ethnicity, and functional impairment, characteristics known to be associated with preferences. The Willingness to Accept Life-Sustaining Treatment instrument (WALT) consists of 6 scenarios in which respondents weigh treatment burden against treatment outcomes expressed in terms of the likelihood of different health states and length of life following treatment.

Results. Inter-rater reliability ranged from .73 to .95 and test–retest reliability from .49 to .93. WALT scores were significantly associated with a simpler measure of preference and with age, ethnicity, and functional impairment.

Conclusions. The WALT measures patients’ treatment preferences, assessed in the context of treatment burden and multiple aspects of treatment outcome with sound psychometric properties.

HONORING patients’ preferences for their medical care is widely accepted by clinicians and policy experts as a critical element of quality end-of-life care (Council on Scientific Affairs, American Medical Association, 1996; Lynn, 1997; Lo, Snyder, & Sox, 1999; Sachs, Ahronheim, Rhymes, Volicer, & Lynn, 1995). Furthermore, meeting patients’ preferences is central to patients’ and family members’ assessments of quality (Hanson, Danis, & Garrett, 1997; Singer, Martin, & Kelner, 1999; Steinhauser et al., 2000). However, the treatment preferences of seriously ill patients remain poorly understood. Research and clinical approaches for eliciting patients’ preferences have traditionally focused on preferences for specific treatment interventions (Danis et al., 1996), asking patients about their preferences for specific interventions according to the likelihood of survival without considering the burden of the intervention and the length of life they would have after the intervention. This approach has the advantage of being applicable to patients regardless of their underlying disease. However, it does not incorporate another potentially important aspect of preferences; namely, the burden of the intervention.

Several approaches incorporate both treatment burden and outcome. The Values History asks patients about treatment decisions in the context of their health-related values and beliefs (Doukas & McCullough, 1991). Although this approach asks patients about their attitudes toward quality versus quantity of life in general, it does not specifically ask patients to assess which outcomes they believe to be consistent with a good or poor quality of life. Furthermore, it does not consider the burden of the intervention in the context of a given outcome. Another set of measures, the Desire for Probable Benefit and the Desire for Length of Benefit Scales (Danis et al., 1996), asks patients about their preferences for specific interventions according to the likelihood of surviving the intervention and the length of life they would have after the intervention. This approach has the important advantage of incorporating another potentially important aspect of preferences, the likelihood of a given outcome. However, it includes only the outcome of survival without considering the health state in which the patient would survive. A third approach, the treatment trade-off method, also evaluates
attitudes toward treatment burden weighed against the likelihood of the outcome of survival. Its use has been limited to specific diseases and treatment choices (Brundage, Davidson, & Mackillop, 1997; Dales, O’Connor, Hebert, Sullivan, McKim, & Llewellyn-Thomas, 1999).

Taken together, the existing approaches to the assessment of patients’ treatment preferences suggest several domains important to preference: (a) treatment burden, (b) treatment outcome expressed in terms of the health state and length of life following treatment, and (c) the likelihood of the outcome. However, none systematically includes all of the three domains in an instrument that is broadly applicable across different diseases and treatment decisions. Our goal was to develop an instrument designed to assess patients’ treatment preferences across a spectrum of diseases, on the basis of an evaluation of patients’ attitudes toward treatment burden weighed against a variety of treatment outcomes and the likelihood of their occurrence.

**METHODS**

**Participants**

Participants were 125 community-living persons 60 years of age or older with a limited life expectancy secondary to cancer, congestive heart failure (CHF), or chronic obstructive pulmonary disease (COPD) according to explicit criteria. Screening for eligible patients occurred in both the outpatient and inpatient setting by reviewing the charts of consecutive patients 60 years of age or older with a primary diagnosis of cancer, CHF, or COPD. Screening among outpatients occurred in six cardiology, four oncology, and three pulmonary practices in three metropolitan areas in southern Connecticut as well as the outpatient clinics of two Veterans Affairs (VA) hospitals. We also conducted screening among inpatients with CHF. Inpatient screening took place in three hospitals: (a) a university teaching hospital, (b) a community hospital, and (c) a VA hospital. The Human Investigations Committees of these three hospitals approved the study protocol. We determined limited life expectancy by using either Connecticut Hospice criteria, which are employed clinically to select patients appropriate for hospice services because of an approximate life expectancy of 6 months or less (The Connecticut Hospice, Inc., 1996) or eligibility criteria used in the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment (Murphy, Knaus, & Lynn, 1990), which define a patient population with an aggregate 6-month mortality rate of 29–62% when used to identify patients with CHF, COPD, or certain cancers at hospital admission (Knaus et al., 1995).

Of 307 potentially eligible patients by chart review, physicians provided consent to contact 292 (95%). Of these 292, 269 patients (92%) consented to a brief telephone screen for exclusion criteria. We excluded patients if they had moderate to severe cognitive impairment (n = 41), were not a full-time resident of Connecticut (n = 1), or did not require assistance with at least one instrumental activity of daily living (IADL; n = 56). We used this final criterion to improve prognostic accuracy, as functional limitations have been demonstrated to be an independent predictor of mortality among older persons (Inouye et al., 1998). Among the 171 eligible patients, 1 died prior to participation. The participation rate among the 170 remaining patients was 74%, and nonparticipants did not differ from participants in terms of age, gender, diagnosis, or Charlson Comorbidity Index (Charlson, Pompei, Ales, & MacKenzie, 1987).

**Instrument Development**

Existing instruments suggested that 4 domains are important to patients facing treatment decisions: (a) treatment burden, (b) treatment outcome, (c) likelihood of the outcome, and (d) length of life following treatment. We conducted a series of focus groups and individual interviews with 23 patients aged 60 years and older meeting the eligibility criteria described above. These patients had a mean age of 70 years (range 60 to 84), 35% were women, and 13% were African American. These interviews, in which we asked participants to talk about how they had made treatment decisions in the past and would make decisions in the future, confirmed the importance of these four domains. They also provided patient-centered descriptions of outcomes participants viewed as desirable and undesirable and of the burdensome nature of different interventions.

We drafted items for the instrument and administered them to 10 patients meeting the same eligibility criteria, using the technique of the think-aloud strategy, whereby we used a series of probe questions to ask participants what they were thinking as they answered the questions (Fienberg, Lottus, & Tanur, 1985). We also distributed the items to eight general internists and geriatricians (four with specific expertise in end-of-life care and treatment decision making), for their written comment. We revised the items and pilot-tested them with 10 additional patients, which resulted in minor editing for further clarity and ease of administration.

**Data Collection**

A trained interviewer administered the preference instrument to participants in their home. We obtained additional descriptive variables from self-report.

**Statistical Analysis**

We used simple frequencies to describe the study population and responses to the instrument items. We examined test–retest reliability by administering the measure to 20 participants 1 week after the initial interview. We examined interobserver reliability by having 2 interviewers code the instruments simultaneously as one of the interviewers administered the instrument. We examined inter-rater reliability by having 2 interviewers administer the instrument to a single participant within 1 week of each other. We chose the 1-week time interval to insure that participants would not try to achieve consistency by remembering the answers they gave previously. We used intraclass correlation coefficients (ICC) to calculate test–retest, interobserver, and inter-rater reliability.

Because there is no gold standard of patients’ preferences against which we could test criterion validity, we performed tests of construct validity. We examined the association between responses to the measure and responses to a simpler, global measure of attitudes toward outcomes. We asked participants to rank three outcomes: (a) survival, (b) symptom relief, and (c) preservation of function (Gillick, Berkman, &
Cullen, 1999). We hypothesized that patients who ranked survival as their most valued outcome would have higher scores on the Willingness to accept Life-Sustaining Treatment (WALT) instrument than patients who ranked either symptom relief or comfort. We based additional analyses of construct validity on established associations between patient characteristics and measures of preference for specific treatment interventions and for health states. We hypothesized that younger age (Hamel et al., 1999), African American ethnicity (Garrett, Harris, Norburn, Patrick, & Danis, 1993; McKinley, Garrett, Evans, & Danis, 1996), and poorer functional status (Kind & Dolan, 1995; Sharp et al., 1999), measured using the IADL scale (Lawton & Brody, 1969), would be associated with higher WALT scores, indicating a greater willingness to undergo treatment despite an adverse outcome. Because WALT scores were non-normally distributed, we performed hypothesis-testing by using the Wilcoxon rank sum test.

**Description of Instrument**

The WALT is a quantitative assessment of participants’ willingness to undergo therapy given four characteristics of the therapy: (a) the burden imposed by the therapy, (b) the health state resulting from the therapy, (c) the likelihood of the health state, and (d) the expected life extension resulting from the therapy. The complete measure is available from the authors upon request.

**Burden of therapy.**—We operationalized the burden of therapy by creating descriptions of two treatment options, designed to represent a low-burden and a high-burden therapeutic intervention. We described the low-burden approach to participants as a few days to a week of hospitalization, minor tests such as x-rays and blood draws, and therapies such as intravenous antibiotics and oxygen. We described the high-burden approach as at least 1 month of hospitalization, many minor tests, more complex tests, and major therapies such as being in the intensive care unit, receiving surgery, or requiring mechanical ventilation. These composite descriptions incorporate the views of the participants in the focus groups and interviews toward the burdens of individual therapies and also reflect the clinical reality that individual therapies are rarely administered in isolation but rather are part of a larger overall care plan.

**Health states.**—The health states we chose were those most universally viewed as desirable and undesirable, and include (a) return to current state of health, (b) severe functional impairment (being bedbound), (c) severe cognitive impairment (not recognizing family members), and (d) death.

**Likelihood of the health state.**—We operationalized the likelihood of the health state as the probability of death or disability occurring as a result of treatment versus a return to current health. The measure uses clinically meaningful likelihoods: 99%, 90%, 50%, 10%, and 1% chance of the health state occurring. The percentages are presented in a pie chart format. This method has been demonstrated to be understandable and reliable when used with older persons (Murphy et al., 1994), and it avoids framing effects by presenting both the negative and positive outcome simultaneously (McNeil, Pauker, Sox, & Tversky, 1982).

**Life extension resulting from therapy.**—Also, we operationalized the length of life following treatment as clinically meaningful lengths of time: 1 week, 1 month, 6 months, and 1 year.

**Constructing scenarios from treatment characteristics.**—Ideally, to obtain the most complete characterization of preference, each of the four treatment characteristics would be weighed against one another. This would result in an unacceptably large number of items to ask of a seriously ill patient. Therefore, we constructed a smaller number of scenarios to understand the four characteristics in clinically relevant ways. In each of six scenarios, we asked the participants to choose whether they would want treatment, weighing either a low- or high-burden intervention against the likelihood of a given health state or length of life occurring as a result of the intervention. In each scenario, we told participants that without therapy they would die with 100% certainty. Scenario 1 was low-burden therapy/likelihood of death versus return to current health. Scenario 2 was low-burden therapy/length of life following therapy. Scenario 3 was high-burden therapy/likelihood of death versus return to current health. Scenario 4 was high-burden therapy/length of life following therapy. Scenario 5 was low-burden therapy/likelihood of functional impairment versus return to current health. Scenario 6 was low-burden therapy/likelihood of cognitive impairment versus return to current health. The complete text for Scenario 1 is provided in the Appendix.

For the purposes of performing psychometric analysis, we scored each scenario as a separate item. For Scenarios 1, 3, 5, and 6, scores can range from 1 to 7, with higher scores indicating a desire to undergo therapy despite a greater likelihood of an adverse outcome. For Scenarios 2 and 4, scores range from 1 to 5, with higher scores indicating a desire to undergo therapy despite a shorter amount of life extension.

**Results**

**Description of Sample**

The 125 participants had a mean age of 72.8 ± 6.9 years, 43% were women, and 90% were White. The high proportion of men reflects that 38% of participants were recruited from VA sites. They had a mean of 11.8 ± 2.8 years of education, 66% were married, and 20% lived alone. The primary diagnosis was cancer for 31%, COPD for 43%, and CHF for 26%. Of the participants, 31% rated their health as poor, 43% had been hospitalized 2 or more times in the previous year, and 33% had been in the intensive care unit. Only a small proportion (6%) believed they had a life expectancy of fewer than 12 months, 10% believed they had a life expectancy of 1 to 2 years, 49% believed they had a life expectancy of greater than 2 years, and 35% refused to consider their life expectancy or did not know. The majority of participants (80%) completed the WALT in 15 to 20 minutes; for the remaining participants, administration of the WALT took more than 20 minutes.
ASSESSMENT OF PATIENT PREFERENCES

Table 1. Percentage of Participants Who Would Want Treatment at Different Likelihoods of Death or Functional and/or Cognitive Impairment as an Outcome of Treatment (N = 125)

<table>
<thead>
<tr>
<th>WALT Treatment/Outcome</th>
<th>Likelihood of Outcome</th>
<th>0%</th>
<th>1%</th>
<th>10%</th>
<th>50%</th>
<th>90%</th>
<th>99%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low-burden/likelihood of death (vs. current state)</td>
<td>99.2</td>
<td>98.4</td>
<td>98.4</td>
<td>97.6</td>
<td>81.6</td>
<td>61.6</td>
<td>—</td>
<td></td>
</tr>
<tr>
<td>High-burden/likelihood of death (vs. current state)</td>
<td>89.3</td>
<td>89.3</td>
<td>89.3</td>
<td>87.7</td>
<td>68.0</td>
<td>47.5</td>
<td>—</td>
<td></td>
</tr>
<tr>
<td>Low-burden/likelihood of functional impairment (vs. current state)</td>
<td>99.2</td>
<td>97.6</td>
<td>95.2</td>
<td>80.0</td>
<td>56.0</td>
<td>44.0</td>
<td>29.6</td>
<td></td>
</tr>
<tr>
<td>Low-burden/likelihood of cognitive impairment (vs. current state)</td>
<td>98.5</td>
<td>96.8</td>
<td>92.7</td>
<td>74.8</td>
<td>47.2</td>
<td>34.2</td>
<td>11.4</td>
<td></td>
</tr>
</tbody>
</table>

Notes: Outcome without treatment was certain death. WALT = Willingness to Accept Life-Sustaining Treatment instrument.

Psychometric Properties

Internal consistency.—Tables 1 and 2 provide a description of the responses to the WALT. These responses demonstrate that responses use the full range of each of the instruments. In addition, the WALT is internally consistent; scenarios with worse outcomes or more burdensome intervention have lower levels of acceptability.

Reliability.—The test–retest and inter-rater reliability for the scenarios of the WALT are given in Table 3. The ICCs for inter-rater reliability were ≥0.7 for all scenarios, indicating adequate reliability (Aday, 1996). However, for Scenarios 3, 4, and 5, the ICCs for test–retest reliability were lower than 0.7. The interobserver reliability for the WALT was 100%.

Construct validity.—Evidence of construct validity of the WALT is provided in Table 4, which illustrates mean WALT scores according to the goal of care most highly ranked by participants. These results demonstrate that WALT scores were significantly higher (indicating a greater willingness to undergo treatment) among those who ranked survival highest compared with those who ranked comfort or activity.

Further evidence of construct validity is provided in Table 5, which demonstrates the relationship between WALT scores and characteristics known to be associated with preference.

Older age was associated with lower WALT scores for Scenarios 1 and 3, indicating that older patients more frequently than younger patients rejected low- and high-burden therapies at lower likelihoods of death versus a return to current health. Non-White ethnicity and poorer functional status, measured in terms of number of IADL impairments, were associated with higher WALT scores for Scenarios 5 and 6, indicating a greater willingness to accept low-burden therapies despite a higher likelihood of functional or cognitive impairment as a result of treatment.

DISCUSSION

The WALT instrument builds upon earlier work by incorporating all of the aspects of treatment decision-making used in these earlier instruments. It explicitly evaluates patients’ attitudes toward the burden of treatment, treatment outcomes expressed in terms of health states and length of life following treatment, and the likelihood of treatment outcomes. A major innovation of the WALT is a shift away from asking about specific treatment interventions, instead assessing more global attitudes toward treatment burden. This allows for a more thorough examination of preferences based on both the treatment burden and multiple aspects of treatment outcome. Such an approach addresses the concern that it is difficult, if not impossible, to predict all of the future specific treatment decisions an individual patient may face (Tulsky, Fischer, Rose, & Arnold, 1998). The assessment of patients’ attitudes toward treatment burden weighed against different outcomes can be applied to a wide variety of specific treatment decisions among patients with different diseases. The WALT also takes into account the complexities of treatment decision-making, particularly the uncertainty that surrounds many decisions. Despite the complexity of the instrument, participant responses are internally consistent.

Table 2. Percentage of Participants Who Would Want Treatment With Outcome of Different Degrees of Life-Extension (N = 125)

<table>
<thead>
<tr>
<th>WALT Treatment</th>
<th>Life Extension</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 week</td>
</tr>
<tr>
<td>Low-burden</td>
<td>53.6</td>
</tr>
<tr>
<td>High-burden</td>
<td>39.3</td>
</tr>
</tbody>
</table>

Notes: Outcome without treatment was certain death. WALT = Willingness to Accept Life-Sustaining Treatment instrument.

Table 3. Test–Retest and Inter-Rater Reliability for the WALT (N = 20)

<table>
<thead>
<tr>
<th>WALT Treatment Outcome</th>
<th>Test–Retest Reliability</th>
<th>Inter-Rater Reliability</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ICC</td>
<td>% Agreement Within 1 Point</td>
</tr>
<tr>
<td>Low-burden/death vs. current health</td>
<td>.93</td>
<td>75</td>
</tr>
<tr>
<td>Low-burden/length of life in current health</td>
<td>.86</td>
<td>80</td>
</tr>
<tr>
<td>High-burden/death vs. current health</td>
<td>.49</td>
<td>65</td>
</tr>
<tr>
<td>High-burden/length of life in current health</td>
<td>.61</td>
<td>60</td>
</tr>
<tr>
<td>Low-burden/functional impairment vs. current health</td>
<td>.69</td>
<td>42</td>
</tr>
<tr>
<td>Low-burden/cognitive impairment vs. current health</td>
<td>.77</td>
<td>60</td>
</tr>
</tbody>
</table>

Note: WALT = Willingness to Accept Life-Sustaining Treatment instruments; ICC = intraclass correlation coefficient.
consistent and with good evidence of reliability and construct validity.

The complexity and length of the WALT may be viewed as a limitation. However, patients’ preferences themselves are complex, and simpler instruments designed to measure preferences may not fully capture preferences. Patients’ completion of standard existing advance directive documents has recently been shown to fail to improve surrogates’ or primary physicians’ understanding of patients’ treatment preferences as examined in scenarios incorporating health states and prognosis (Coppola, Ditto, Danks, & Smucker, 2001; Ditto et al., 2001). Although briefer methods exist to elicit patients’ general treatment goals, these assessments imperfectly predict patients’ preferences when faced with specific treatment decisions (Emanuel, 1995). These results suggest that the assessment of treatment preferences need to incorporate all of the components included in the WALT. A second limitation of the WALT is the poor-to-moderate test–retest reliability of three of the scenarios. These scenarios deal with difficult situations: two include the use of high-burden therapy and one asks respondents about the outcome of functional impairment. Given the otherwise sound psychometric properties of the items, it is possible that the test–retest reliability reflects genuine uncertainty on the part of respondents. Because test–retest reliability has, with only rare exception (Brundage et al., 1997), not been performed in other preference measures, the performance of the WALT cannot be compared with other instruments. A final limitation is that the WALT, developed and tested among a population of older, seriously ill persons, may perform less well in other populations.

Table 4. Median WALT Scores With Interquartile Ranges According to Most Highly Ranked Goal of Care

<table>
<thead>
<tr>
<th>WALT Treatment/Outcome</th>
<th>Among Participants Who Ranked Survival Highest (n = 29), Median (25%, 75%)</th>
<th>Among Participants Who Ranked Comfort/ Activity Highest (n = 96), Median (25%, 75%)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Low-burden/death vs. current health</td>
<td>7.0 (7.0, 7.0)</td>
<td>7.0 (6.0, 7.0)</td>
<td>.05</td>
</tr>
<tr>
<td>2. Low-burden/length of life in current health</td>
<td>5.0 (4.0, 5.0)</td>
<td>4.0 (3.0, 5.0)</td>
<td>.08</td>
</tr>
<tr>
<td>3. High-burden/death vs. current health</td>
<td>7.0 (6.0, 7.0)</td>
<td>6.0 (5.0, 7.0)</td>
<td>.07</td>
</tr>
<tr>
<td>4. High-burden/length of life in current health</td>
<td>5.0 (3.0, 5.0)</td>
<td>3.0 (3.0, 5.0)</td>
<td>&lt;.01</td>
</tr>
<tr>
<td>5. Low-burden/functional impairment vs. current health</td>
<td>7.0 (5.0, 7.0)</td>
<td>4.5 (4.0, 6.0)</td>
<td>&lt;.01</td>
</tr>
<tr>
<td>6. Low-burden/cognitive impairment vs. current health</td>
<td>6.0 (4.0, 7.0)</td>
<td>4.0 (3.0, 6.0)</td>
<td>.01</td>
</tr>
</tbody>
</table>

Notes: Higher score indicates willingness to undergo treatment (TX) despite greater likelihood of undesirable outcome or shorter life-extension following treatment as follows: Scenarios 1 and 3: 7 = Wants TX: 99% chance of death with TX and 100% chance of death without TX; 6 = Wants TX: 90% chance of death with TX; 5 = Wants TX: 50% chance of death with TX; 4 = Wants TX: 10% chance of death with TX; 3 = Wants TX: 1% chance of death with TX; 2 = Wants TX: 0% chance of death with TX; 1 = Does not want TX: 0% chance of death with TX. Scenarios 2 and 4: 5 = Wants TX: extends life for 1 week; 4 = Wants TX: extends life for 1 month; 3 = Wants TX: extends life for 6 months; 2 = Wants TX: extends life for 1 year; 1 = Does not want TX: extends life for 1 year. Scenarios 5 and 6: 7 = Wants TX: 100% chance of functional (cognitive) impairment with TX; 6 = Wants TX: 99% chance of functional (cognitive) impairment with TX; 5 = Wants TX: 90% chance of functional (cognitive) impairment with TX; 4 = Wants TX: 50% chance of functional (cognitive) impairment with TX; 3 = Wants TX: 10% chance of functional (cognitive) impairment with TX; 2 = Wants TX: 1% chance of functional (cognitive) impairment with TX; 1 = Does not want TX: 1% chance of functional (cognitive) impairment with TX. WALT = Willingness to Accept Life-Sustaining Treatment instrument.

Table 5. Median WALT Scores With Interquartile Ranges According to Participants’ Sociodemographic and Functional Status

<table>
<thead>
<tr>
<th>Variable (n)</th>
<th>Low Burden/Death Versus Current Health, Median (25%, 75%)</th>
<th>High Burden/Death Versus Current Health, Median (25%, 75%)</th>
<th>Low Burden/Functional Impairment Versus Current Health, Median (25%, 75%)</th>
<th>Low-Burden/Cognitive Impairment Versus Current Health, Median (25%, 75%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>60–80 (108)</td>
<td>7.0 (6.0, 7.0)</td>
<td>6.0 (5.0, 7.0)</td>
<td>5.0 (4.0, 7.0)</td>
<td>4.0 (3.0, 6.0)</td>
</tr>
<tr>
<td>&gt; 80 (17)</td>
<td>6.0 (5.0, 7.0)*</td>
<td>6.0 (4.0, 7.0)*</td>
<td>4.0 (3.0, 6.0)</td>
<td>4.0 (4.0, 5.0)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-White (11)</td>
<td>7.0 (6.0, 7.0)</td>
<td>7.0 (4.0, 7.0)</td>
<td>7.0 (5.0, 7.0)</td>
<td>7.0 (4.0, 7.0)</td>
</tr>
<tr>
<td>White (112)</td>
<td>7.0 (6.0, 7.0)</td>
<td>6.0 (5.0, 7.0)</td>
<td>5.0 (4.0, 7.0)*</td>
<td>4.0 (3.0, 6.0)**</td>
</tr>
<tr>
<td>IADL Impairments</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0–4 (93)</td>
<td>7.0 (6.0, 7.0)</td>
<td>6.0 (5.0, 7.0)</td>
<td>5.0 (4.0, 6.0)</td>
<td>4.0 (3.0, 6.0)</td>
</tr>
<tr>
<td>5–7 (32)</td>
<td>7.0 (6.0, 7.5)</td>
<td>7.0 (5.0, 7.0)</td>
<td>6.0 (4.0, 7.0)</td>
<td>6.0 (4.0, 6.5)*</td>
</tr>
</tbody>
</table>

Notes: Higher scores indicate willingness to undergo treatment despite greater likelihood of adverse outcome, as follows: Scenarios 1 and 3: 7 = Wants TX: 99% chance of death with TX and 100% chance of death without TX; 6 = Wants TX: 90% chance of death with TX; 5 = Wants TX: 50% chance of death with TX; 4 = Wants TX: 10% chance of death with TX; 3 = Wants TX: 1% chance of death with TX; 2 = Wants TX: 0% chance of death with TX; 1 = Does not want TX: 0% chance of death with TX. Scenarios 2 and 4: 5 = Wants TX: extends life for 1 week; 4 = Wants TX: extends life for 1 month; 3 = Wants TX: extends life for 6 months, 2 = Wants TX: extends life for 1 year; 1 = Does not want TX: extends life for 1 year. Scenarios 5 and 6: 7 = Wants TX: 100% chance of functional (cognitive) impairment with TX; 6 = Wants TX: 99% chance of functional (cognitive) impairment with TX; 5 = Wants TX: 90% chance of functional (cognitive) impairment with TX; 4 = Wants TX: 50% chance of functional (cognitive) impairment with TX; 3 = Wants TX: 10% chance of functional (cognitive) impairment with TX; 2 = Wants TX: 1% chance of functional (cognitive) impairment with TX; 1 = Does not want TX: 1% chance of functional (cognitive) impairment with TX. WALT = Willingness to Accept Life-Sustaining Treatment instruments; IADL = instrumental activity of daily living.

*p ≤ .05; **p ≤ .01.
The psychometric properties of the WALT items suggest several ways in which the instrument may be modified and shortened for wider applicability as both a research and clinical instrument. Those scenarios with the best properties include the low-burden treatment with the outcomes of dying or cognitive impairment versus a return to current health (Scenarios 1 and 6) and the outcome of length of life (Scenario 2). The use of these three scenarios provides a brief measure able to detect differences in preferences according to patient characteristics. Such a measure can facilitate longitudinal studies identifying characteristics, such as changes in health status, which may be associated with changes in preferences over time (Sharp et al., 1999) and studies evaluating the successfullness of interventions designed to improve end-of-life care in honoring preferences (Hanson et al., 1997). As a clinical tool, the WALT can enhance physician–patient communication about treatment decision-making. Research has shown current communication about treatment to be heavily focused on preferences for specific treatment interventions, with little attention paid to uncertainty or to the health states that can result from treatment (Tulsky et al., 1998). The 3 WALT items provide a structure for a more complete discussion, by providing the physician with the specific language and examples necessary to discuss with patients how changes in the burden of treatment, the outcome of treatment, and the likelihood of the outcome result in changes in their preferences. These changes define thresholds, that is, the characteristics of a clinical situation in which a patient no longer wishes to receive therapy, either because the burden of the intervention or the likelihood of an undesirable outcome is too high. After going through these scenarios in detail to illustrate the concept of a threshold, the physician can qualitatively explore with patients where their thresholds lie.

Meeting patients’ preferences for care is an essential component of quality end-of-life care. The evaluation of whether preferences have been met requires that these preferences have been adequately assessed. The WALT provides a method for the systematic assessment of preferences based on the aspects of treatment decision-making that patients identify to be central to their preferences. On the basis of the weighing of treatment process against treatment outcomes, the WALT takes into account the complexities of clinical decision-making by incorporating the concept of uncertainty. Furthermore, it does so in a manner that patients can understand and that is applicable regardless of their underlying disease.

ACKNOWLEDGMENTS

Dr. Fried is the recipient of a VA Health Services Research and Development Career Development Award and a Paul Beeson Physician Faculty Scholar award. We thank Mary E. Tinetti, MD, for her insights into the development of the WALT and for her comments on the manuscript.

Address correspondence to Terri R. Fried, MD, Geriatrics & Extended Care, 240, VA Connecticut Health Care System, 950 Campbell Avenue, West Haven, CT 06516. E-mail: terri.fried@yale.edu

REFERENCES


Steinhauer, K. E., Clipp, E. C., McNeilly, M., Christakos, N. A., McIntyre, L. M., & Tulsky, J. A. (2000). In search of a good death: Observations of patients, families, and providers. Annals of Internal Medicine, 132, 825–832.


Received December 10, 2001
Accepted March 20, 2002
Decision Editor: Fredric D. Wolinsky, PhD

Appendix

Willingness to Accept Life-Sustaining Treatment (WALT)
Scenario 1 With Scoring System

Think about if you were suddenly to get sick with an illness that would require you to be in the hospital for a few days to a week. It would either be that you [congestive heart failure, chronic obstructive pulmonary disease, cancer] worsened, or you got sick with a different illness. In the hospital you would need to have minor tests, such as x-rays and blood draws, and therapies such as intravenous antibiotics and oxygen. Without the treatment, you would not survive. If this treatment would get you back to your current state of health, would you want to have it?

If NO: Question complete.
If YES: Now, what if the doctor told you that there was a 50/50 chance that it would work and get you back to your current state of health. If it did not work, you would not survive. Without the treatment then, you would not survive for certain. Would you want the treatment?
If NO: Now what if the doctor told you there were a 90% (99%) chance that it would work and get you back to your current state of health and a 10% (1%) chance that it would not. Without the treatment then, you would not survive for certain. Would you want the treatment?
If YES: Now, what if the doctor told you there was a 10% (1%) chance that it would work and get you back to your current state of health and a 90% (99%) chance that it would not work. Without the treatment then, you would not survive for certain. Would you want the treatment?

Scoring:
7 = Wants treatment (TX): 99% chance of death with TX and 100% chance of death without TX
6 = Wants TX: 90% chance of death with TX and 100% chance of death without TX
5 = Wants TX: 50% chance of death with TX and 100% chance of death without TX
4 = Wants TX: 10% chance of death with TX and 100% chance of death without TX
3 = Wants TX: 1% chance of death with TX and 100% chance of death without TX
2 = Wants TX: 0% chance of death with TX and 100% chance of death without TX
1 = Does not want TX: 0% chance of death with TX and 100% chance of death without TX