

Special Article

UNDERSTANDING THE TREATMENT PREFERENCES
OF SERIOUSLY ILL PATIENTS

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ABSTRACT

Background The questions patients are asked about their preferences with regard to life-sustaining treatment usually focus on specific interventions, but the outcomes of treatment and their likelihood affect patients' preferences.

Methods We administered a questionnaire about treatment preferences to 226 persons who were 60 years of age or older and who had a limited life expectancy due to cancer, congestive heart failure, or chronic obstructive pulmonary disease. The study participants were asked whether they would want to receive a given treatment, first when the outcome was known with certainty and then with different likelihoods of an adverse outcome. The outcome without treatment was specified as death from the underlying disease.

Results The burden of treatment (i.e., the length of the hospital stay, extent of testing, and invasiveness of interventions), the outcome, and the likelihood of the outcome all influenced treatment preferences. For a low-burden treatment with the restoration of current health, 98.7 percent of participants said they would choose to receive the treatment (rather than not receive it and die), but 11.2 percent of these participants would not choose the treatment if it had a high burden. If the outcome was survival but with severe functional impairment or cognitive impairment, 74.4 percent and 88.8 percent of these participants, respectively, would not choose treatment. The number of participants who said they would choose treatment declined as the likelihood of an adverse outcome increased, with fewer participants choosing treatment when the possible outcome was functional or cognitive impairment than when it was death. Preferences did not differ according to the primary diagnosis.

Conclusions Advance care planning should take into account patients' attitudes toward the burden of treatment, the possible outcomes, and their likelihood. The likelihood of adverse functional and cognitive outcomes of treatment requires explicit consideration. (N Engl J Med 2002;346:1061-6.)

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HONORING the treatment preferences of terminally ill patients is critical for the provision of high-quality care at the end of life.¹⁻⁴ Patients' preferences are often elicited through advance-directive documents used by hospitals. These forms ask patients whether they would want to receive or forgo specific treatments. Discussions between physicians and patients about advance care planning are also based on patients' preferences with regard to specific interventions.⁵

Several investigators have highlighted the limitations of this approach, pointing out that the desirability of an intervention depends heavily on its outcome.⁶⁻⁸ Intubation to treat a curable pneumonia is fundamentally different, for example, from intubation to treat respiratory failure in a patient with advanced lung cancer. It has therefore been suggested that the elicitation of patients' preferences be based not on specific treatments but rather on the outcomes of treatment.^{6,7}

Both qualitative data⁹ and quantitative data¹⁰⁻¹² support the importance of outcomes in patients' treatment preferences. Several studies of decisions about treatment for particular diseases^{13,14} suggest that patients weigh the burden of treatment against the possible outcomes. Studies have shown that the likelihood of death affects preferences,¹⁵⁻¹⁷ but similar data on other outcomes are lacking. We examined the effects of the burden of treatment and a variety of possible outcomes on the preferences for care expressed by older patients with serious illnesses.

METHODS**Study Participants**

We identified patients with a limited life expectancy by reviewing the charts of all persons 60 years of age or older who had received a primary diagnosis of cancer, congestive heart failure, or

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chronic obstructive pulmonary disease and who were being cared for 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 hospitals. Inpatients in three hospitals — a university teaching hospital, a community hospital, and a Veterans Affairs hospital — were also screened. Screening and enrollment were stratified according to the diagnosis in order to enroll approximately equal numbers of patients with cancer, congestive heart failure, and chronic obstructive pulmonary disease. The study protocol was approved by the human investigations committee of each of the participating hospitals. All patients provided written informed consent.

Sequential charts were screened for a limited life expectancy, which was the primary eligibility criterion. Limited life expectancy was defined according to the clinical criteria used by the Connecticut Hospice¹⁸ or those used in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment.^{19,20} An additional eligibility criterion, determined by telephone screening, was the need for assistance with at least one instrumental activity of daily living (e.g., housework or shopping),²¹ in order to improve the prognostication with respect to life expectancy.²² Patients were excluded from the study if they had cognitive impairment, as measured by the Short Portable Mental Status Questionnaire²³ and a test of executive functioning,²⁴ or if they were not full-time residents of Connecticut.

Of the 548 patients identified by chart review, 30 were not contacted because their physicians did not give permission to do so, 24 died before the telephone screening was performed, 6 could not be reached, and 19 declined the telephone screening. A total of 108 patients were excluded because they required no assistance with instrumental activities of daily living, 76 because of cognitive impairment, and 6 because they were not full-time Connecticut residents. Of the 279 patients who were eligible for participation, 2 died before enrollment and 51 declined participation. Thus, the final sample consisted of 226 patients (participation rate among eligible patients, 82 percent). Nonparticipants did not differ significantly from participants according to age, sex, or the score on the Charlson comorbidity index.²⁵ Eight percent of eligible patients with congestive heart failure declined participation, as compared with 19 percent of those with cancer and 25 percent of those with chronic obstructive pulmonary disease ($P=0.02$).

Data Collection

All participants were interviewed in their homes with the use of a questionnaire that assessed treatment preferences according to three components of any given therapy: the burden it imposed, the possible outcomes, and the likelihood of these outcomes. The interviewer described two treatment approaches, one involving a low burden and one a high burden; each approach was a composite of specific interventions. These approaches reflect clinical practice, in which specific therapies are rarely administered individually but are instead part of a larger plan of care involving an array of diagnostic tests and interventions. The low-burden approach was described as a few days to a week of hospitalization, minor tests such as radiographs and blood tests, and therapies such as intravenous antibiotics and oxygen supplementation. The high-burden approach was described as at least one month of hospitalization, many minor tests as well as more complex tests, and major interventions such as care in an intensive care unit, surgery, or mechanical ventilation.

In each of four scenarios, the low- or high-burden therapy was described as having a specific outcome, expressed in terms of the state of health resulting from treatment, and participants were asked whether they would want the therapy. For each scenario, participants were told that without the therapy they would die. Scenario 1 was low-burden therapy that restored current health. Scenario 2 was high-burden therapy that restored current health. Scenario 3 was low-burden therapy resulting in severe functional impairment, described as being bedbound and unable to get to the bathroom

independently and requiring help with all daily activities. Scenario 4 was low-burden therapy resulting in severe cognitive impairment, described as not being aware of one's surroundings and not being able to recognize family members.

For each scenario, participants were asked their preference when the outcome of treatment was certain. Then they were asked their preference as the likelihood of an undesirable outcome increased. For scenarios 1 and 2, the outcome was death instead of a return to current health. For scenarios 3 and 4, the outcomes were functional impairment and cognitive impairment, respectively, instead of a return to current health. The participants were asked about their preferences when the likelihood of an undesirable outcome was 1 percent, 10 percent, 50 percent, 90 percent, and 99 percent, with a 100 percent likelihood of death in the absence of therapy. The percentages were presented in a pie-chart format. This method, which is understandable and reliable when used with older persons,¹⁶ avoids framing effects by presenting negative and positive outcomes simultaneously.²⁶ Figure 1 shows an example of a pie chart used for scenario 1, representing a 10 percent chance of death and a 90 percent chance of a return to current health. The test-retest reliability for scenarios 1, 2, 3, and 4 was 0.93, 0.49, 0.69, and 0.77, respectively; the interrater reliability was 0.84, 0.95, 0.73, and 0.89, respectively.

Statistical Analysis

We used simple frequencies to describe the characteristics of the study population and participants' treatment preferences according to the diagnosis. For the scenarios involving dichotomous outcomes (i.e., when the outcome was certain and the participants indicated whether they would want the therapy), the chi-square test was used to determine the statistical significance of differences in preferences. The log-rank test was used to determine the statistical significance of differences in preferences as the likelihood of an adverse outcome increased across the four scenarios, with scenarios 2, 3, and 4 compared individually with scenario 1. The log-rank test was also used in a separate analysis of each scenario to determine the statistical significance of differences in preferences according to the diagnosis. All reported P values are two-sided.

RESULTS

The 226 participants had a mean (\pm SD) age of 72.8 ± 7.2 years, 43 percent were women, and 91 percent were white. Table 1 shows the characteristics of the participants according to their primary diagnosis. Figure 2 shows the influence of the burden of treatment and its outcome on preferences, when the outcome was certain. For the choice between a low-burden treatment that would restore the participant's current state of health and no treatment, resulting in death (scenario 1), 98.7 percent of participants stated that they would want the treatment. For scenario 2, in which the burden of the treatment was higher but the outcome was the same as that in scenario 1, 11.2 percent of the participants who wanted to receive the treatment in scenario 1 did not want the treatment in scenario 2. For scenarios 3 and 4, in which the burden of treatment was low but the outcome was survival with severe functional impairment (scenario 3) or cognitive impairment (scenario 4), 74.4 percent and 88.8 percent of participants, respectively, who wanted the treatment in scenario 1 no longer wanted it.

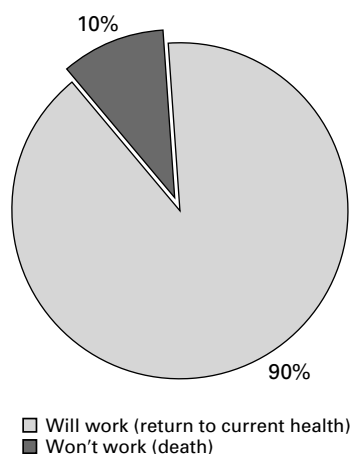


Figure 1. Example of a Pie Chart Used to Illustrate the Likelihood of a Desirable Outcome as Compared with an Undesirable Outcome.

Figure 3 shows the influence of an uncertain outcome on treatment preferences. Across all scenarios, the number of participants who wanted treatment decreased as the likelihood of an adverse outcome increased. However, the number did not decrease when the likelihood of the adverse outcome was low (i.e., ≤ 10 percent). When the adverse outcome was death, the number of participants who wanted treatment began to decrease substantially only with a likelihood of death that was 90 percent or higher. In contrast, when the adverse outcome was functional or cognitive impairment, the number of participants who wanted treatment began to decrease substantially with a likelihood of impairment that was 50 percent or higher. Preferences in scenario 2, scenario 3, and scenario 4 each differed significantly from preferences in scenario 1 ($P < 0.001$ for each comparison).

There were no significant differences in treatment preferences according to the primary diagnosis. Table 2 shows preferences according to the diagnosis when the outcome of treatment was certain. Although there was a trend toward lower proportions of patients with chronic obstructive pulmonary disease or cancer who chose high-burden therapy with a return to current health, as compared with the proportion of patients with congestive heart failure who made this choice, the trend was not statistically significant. In each of the four scenarios, the proportions of participants who chose therapy as the likelihood of an adverse outcome increased did not differ significantly according to the diagnosis.

TABLE 1. CHARACTERISTICS OF THE STUDY PARTICIPANTS ACCORDING TO THE PRIMARY DIAGNOSIS.*

CHARACTERISTIC	CANCER (N=79)	CHRONIC OBSTRUCTIVE PULMONARY DISEASE (N=81)	CONGESTIVE HEART FAILURE (N=66)
Age (yr)	71.7±6.7	72.2±7.0	74.9±7.8
Education (yr)	12.4±2.9	11.5±2.9	11.7±2.8
Female sex (%)	43	51	33
White (%)	92	93	88
Not enough money at end of month (%)	5	8	15
Married (%)	62	54	56
Living alone (%)	16	26	30
Charlson comorbidity index	0.70±0.92	0.92±1.2	2.0±1.8
Perceived health poor (%)	24	44	13
Needs help with one or more basic ADL (%)	30	47	35
Two or more hospitalizations in previous year (%)	32	49	62
ICU admission in previous year (%)	22	36	45
Intubation in previous year (%)	6	22	21
Perceived life expectancy (%)			
≤ 6 mo	4	1	0
7–12 mo	4	7	5
13–24 mo	5	10	7
> 24 mo	39	42	45
Does not know or did not answer	48	40	43

*Plus-minus values are means \pm SD.

†ADL denotes activities of daily living, and ICU intensive care unit.

DISCUSSION

This study shows that the burden of treatment, its outcomes, and the likelihood of the outcomes all influence the treatment preferences of older persons who are seriously ill. Almost all the study participants chose a low-burden therapy that would restore their current health if the alternative without treatment was death. However, for a low-burden treatment with an outcome of severe cognitive impairment, almost 90 percent of the participants stated that they would not wish to receive therapy. Clearly, treatment outcomes are a strong determinant of patients' preferences.

The proportion of participants who wanted therapy also changed, but to a lesser degree, when the outcome of treatment was the same but the burden differed. Whereas less than 2 percent of participants rejected or were undecided about low-burden therapy that would restore their current state of health, more than 10 percent rejected or were undecided about high-burden therapy that would do the same. When the burden and outcome were the same but

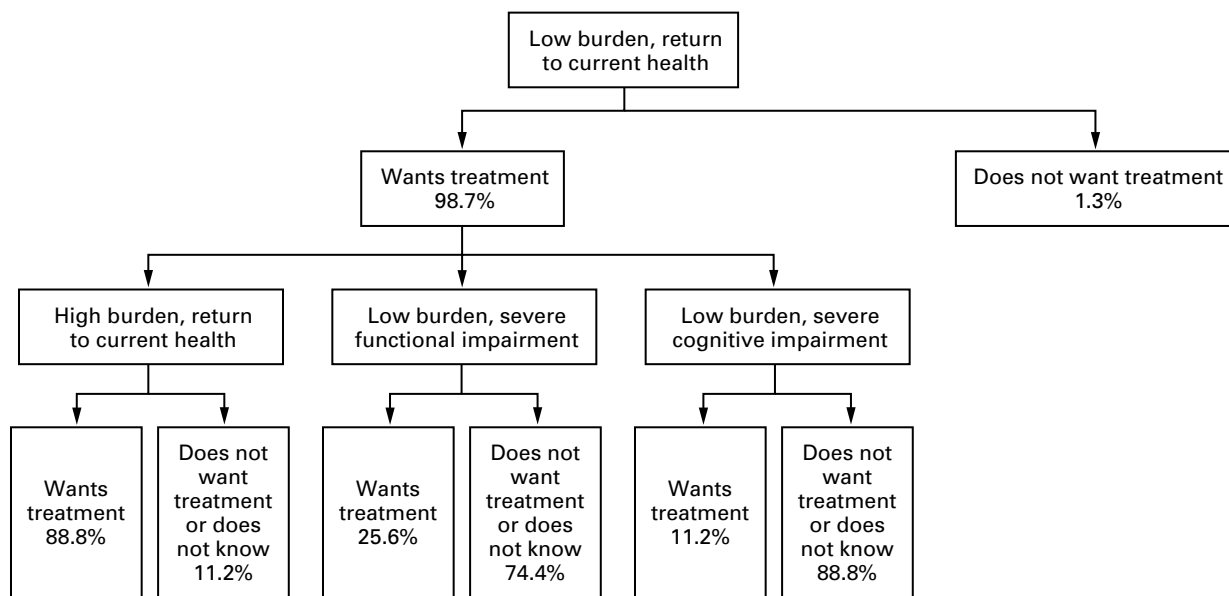


Figure 2. Treatment Preferences According to the Burden and Outcome of Treatment.

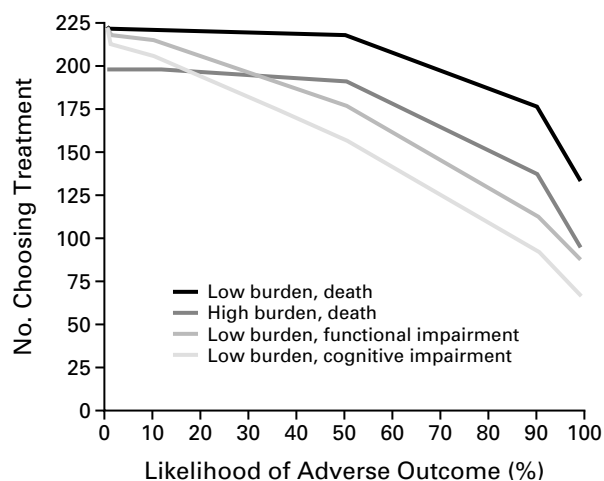


Figure 3. Treatment Preferences According to the Burden of Treatment and the Likelihood of an Adverse Outcome. $P < 0.001$ for each comparison with scenario 1 (a low-burden treatment with an adverse outcome of death).

the likelihood of the outcome differed, the percentage of patients who wished to receive the therapy decreased as the likelihood of an adverse outcome increased; these reductions were greater for an outcome of disability than for an outcome of death.

Our finding that patients are willing to undergo

therapy despite a high treatment burden or a high likelihood of an undesirable outcome appears to conflict with previous studies showing that seriously ill patients frequently receive unwanted aggressive treatment²⁷ and that they use hospice and other services because they do not want to die in the hospital.^{28,29} However, other studies have shown that patients are willing to undergo burdensome treatment with a potentially limited benefit^{15,30,31} and are reluctant to accept hospice care.³²

These contradictory findings can be reconciled in several ways, suggesting the context in which the results of our study should be interpreted. First, it has been suggested that although many patients would not wish to receive aggressive care if they knew that they were dying, uncertainty about the prognosis coupled with a “deeply held desire not to be dead” makes patients willing to undergo therapy even when they are seriously ill but not close to death.³³ Although the patients in our study had advanced stages of illness, their perceptions of their life expectancy suggest that they may not have considered themselves to be close to death. Second, although the approach we used had the advantage of explicitly considering treatment outcomes, it forced the study participants to choose between a particular treatment approach and certain death. In reality, however, the choices may not be so simple, and there may be alternative approaches, including palliative therapies,

TABLE 2. TREATMENT PREFERENCES ACCORDING TO THE PRIMARY DIAGNOSIS.*

DIAGNOSIS	NO. OF PARTICIPANTS	SCENARIO 1 —	SCENARIO 2 —	SCENARIO 3 —	SCENARIO 4 —
		LOW BURDEN, RESTORATION OF CURRENT HEALTH	HIGH BURDEN, RESTORATION OF CURRENT HEALTH	LOW BURDEN, FUNCTIONAL IMPAIRMENT	LOW BURDEN, COGNITIVE IMPAIRMENT
percent of participants choosing treatment					
Cancer	79	100	83.5	27.9	11.4
Congestive heart failure	66	98.5	93.9	21.2	7.6
Chronic obstructive pulmonary disease	81	97.5	86.4	25.9	13.6

*In each scenario, the likelihood of the outcome (restoration of current health or impairment) was 100 percent. Treatment preferences in each scenario did not differ significantly according to the diagnosis.

with other outcomes. In addition, these alternative treatment options may have benefits beyond their effects on functional or cognitive status — for example, the relief of symptoms or a reduction of the family’s burden of care³⁴ — and may therefore be considered highly desirable by some patients.

Our study has several limitations in addition to the circumscribed treatment choices offered to the study participants. First, we excluded older persons with cognitive impairment because of our concern that they would have difficulty responding to complex questions. Second, we did not ask the participants about all possible combinations of treatment burdens and outcomes, and we did not ask about all outcomes that are potentially pertinent to decision making. We do not know, for example, how the study participants would have viewed high-burden treatment that resulted in less pronounced functional or cognitive impairment than that described in scenarios 3 and 4.

The strength of our study is its demonstration of how preferences change in response to changes in the burden of treatment, its outcomes, and the likelihood of the outcomes. This finding has important implications for advance care planning. The predominant clinical approach, focusing on patients’ preferences with regard to specific interventions in the absence of an explicit consideration of the probability of different outcomes, may provide misleading information about treatment preferences. For example, the proportion of persons who say they would want to undergo cardiopulmonary resuscitation is much lower after they have been told the probability of survival than before they have been given this information, suggesting that their uninformed estimates of survival after resuscitation have been mistakenly high.^{16,17}

Our findings suggest that the functional and cognitive outcomes of a given therapy play an even greater part than mortality in patients’ preferences.

The risk of functional impairment due to serious illness and its treatment is substantial.³⁵ Without explicit consideration of functional and cognitive outcomes, patients are likely to have overly optimistic expectations of the results of treatment. Identification and correction of these misconceptions are especially important, since our study showed that many patients would not want to receive treatment if there was even a 50 percent chance of severe functional or cognitive impairment.

Taking into account patients’ attitudes toward the burden of treatment, its outcomes, and their likelihood will make the process of advance care planning more complex. However, our finding that patients’ preferences do not differ according to the diagnosis suggests that attitudes toward burden and outcome reflect fundamental aspects of treatment preferences that are consistent among patients with a variety of diseases. In addition, although several studies have demonstrated limitations in patients’ numeracy,^{36,37} our results suggest that older persons understand probabilistic thinking and incorporate it into their preferences.

The provision of care at the end of life should honor patients’ preferences. If these preferences are to be honored, they must first be understood. Our results suggest that an understanding of patients’ preferences depends on an assessment of how they view the burden of treatment in relation to its possible outcomes and their likelihood. The possibility of functional or cognitive impairment has a particularly important role in patients’ preferences and thus merits explicit consideration in advance care planning.

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