The Association between Treatment Preferences and Trajectories of Care at the End-of-Life

JoAnne Alissi Cosgriff, MD, MPH[1], *Margaret Pisani, MD, MPH*[1], *Elizabeth H. Bradley, PhD*[2], *John R. O'Leary, MA*[3], *and Terri R. Fried, MD*[1,4]

[1]Department of Medicine, Yale University School of Medicine, New Haven, CT, USA; [2]Department of Epidemiology and Public Health, Yale University School of Medicine, New Haven, CT, USA; [3]Program on Aging, Yale University School of Medicine, New Haven, CT, USA; [4]Clinical Epidemiology Research Center 151B, VA Connecticut Healthcare System, West Haven, CT 06516, USA.

BACKGROUND: Honoring patients' treatment preferences is a key component of high-quality end-of-life care.

OBJECTIVE: To determine the association of preferences with end-of-life care.

DESIGN: Observational cohort study.

PARTICIPANTS: 118 community-dwelling persons age ≥65 years with advanced disease who died in a study which prospectively assessed treatment preferences.

MEASUREMENTS: End-of-life care was categorized according to four pathways: (1) relief of symptoms only, (2) limited attempt to reverse acute process with rapid change to symptomatic relief, (3) more intensive attempt to reverse acute process with eventual change to symptomatic relief, and (4) highly intensive attempt to reverse acute process with no change in goal.

RESULTS: Adjusting for diagnosis, those with greater willingness to undergo intensive treatment (defined as a desire for invasive therapies despite ≥50% chance of death) were significantly more likely to receive care with an initial goal of life prolongation (pathways 2–4) [odds ratio 4.73 (95% confidence interval 1.39–16.08)] than those with lower willingness. Nonetheless, mismatches between preferences and pathways were frequent. Only 1 of 27 participants (4%) with lower willingness to undergo intensive treatment received highly intensive intervention (pathway 4); 53 of 91 participants (58%) with greater willingness to undergo intensive treatment received symptom control only (pathway 1).

CONCLUSIONS: The association between preferences and trajectories of end-of-life care suggests that preferences are used to guide treatment decision-making. In contrast to concerns that patients are receiving unwanted aggressive care, mismatches between preferences and trajectories were more frequently in the direction of patients receiving less aggressive care than they are willing to undergo.

KEY WORDS: end-of-life care; preferences; decision-making.
J Gen Intern Med 22(11):1566–71
DOI: 10.1007/s11606-007-0362-6

INTRODUCTION

Eliciting and honoring patients' treatment preferences are key components of high-quality end-of-life care;[1–3] yet, little is known about how well these preferences are met. Some investigation has relied on caregivers' reports of patients' preferences;[4–7] however, a recent review demonstrates that caregivers have a poor understanding of these preferences.[8] Studies prospectively evaluating patients' preferences and their relationship to the care patients receive have focused on the site of death[9–11] or on the receipt of specific interventions.[12–17]

Determining whether patients' preferences for end-of-life care have been met requires an examination of whether the care that they receive is consistent with their goals or, in other words, whether the treatment will provide the outcomes that patients desire. This is because patients' preferences are shaped by the probable outcomes of treatment rather than the specific intervention itself.[18,19] Moreover, a selected treatment intervention can be used with different goals regarding the outcomes of care, and patients may be willing to undergo a trial of therapy with the understanding that it be withdrawn if their prognosis worsens.[20] Although these end-of-life treatment goals have been described in terms of palliation vs life-prolongation,[7,14,15] these terms anchor two ends of what is a wide spectrum of approaches to care.[20] However, this spectrum has not been fully described or codified. The purpose of this study was to describe the end-of-life care received by a cohort of older persons with advanced illness in terms of pathways characterized by the goals and intensity of care and to determine the relationship between preferences and these pathways.

METHODS

Participants

Participants for this study were members of a longitudinal cohort of 226 community-dwelling persons aged ≥65 years

---

Supported by grant PCC-98-070-1 from VA HSR&D, R01 AG19769 from the National Institute on Aging, P30 AG21342 from the Claude D. Pepper Older Americans Independence Center at Yale, and a Paul Beeson Physician Faculty Scholars Award. Dr. Pisani is supported by K23 AG23023 from the National Institute on Aging. Dr. Fried is supported by K02 AG20113 from the National Institute on Aging. Dr. Bradley is supported by the Patrick and Catherine Weldon Donaghue Medical Research Foundation Investigator Award (Grant #02-102).
Received November 1, 2006
Revised March 30, 2007
Accepted August 29, 2007

with advanced cancer, heart failure (HF), or chronic obstructive pulmonary disease (COPD). The Human Investigations Committee of each of the hospitals participating in the study approved the study protocol, and each participant provided written informed consent. The methods and sample have been described previously.[21] Briefly, participants were community-dwelling persons aged ≥60 years who met either Connecticut Hospice[22] or SUPPORT[23] criteria for advanced disease, determined by review of sequential charts selected according to age and primary diagnosis in subspecialty outpatient practices in the greater New Haven area and in three hospitals: a university teaching hospital, a community hospital, and a VA hospital. An additional eligibility criterion was the presence of at least one disability in instrumental activities of daily living (IADLs).[24] Exclusion criteria included cognitive impairment and part-time Connecticut residence.

Of the 226 participants, 125 (55%) died during a 2-year period of follow-up and were therefore eligible for the current study. A total of seven participants (6%) were excluded from analysis because data regarding their end-of-life care was not available for the following reasons: caregiver refused review of the medical chart (2), caregiver could not be contacted to provide consent for review of the chart (2), chart could not be located (2), and site of death could not be determined (1).

Data Collection

Data were obtained from in-home interviews conducted at least every 4 months for up to 2 years and immediately following a decline in the participant's health status, as determined by a monthly telephone call. This study utilizes responses from the interview completed closest to the participant's death. Sociodemographic variables included age, race, gender, education, and marital status. Health and advance care planning variables included primary diagnosis, completion of a living will, and functional status, including activities of daily living (ADLs)[25] and IADLs.[24] Each of the ADL and IADL scales were the sum of the ability to perform seven activities, each scored 0 for independent, 1 for requiring assistance, and 2 for dependent.

Participants' preferences regarding potentially life-sustaining intervention was assessed using a scenario from a validated instrument designed to assess preferences based upon the trade-offs between treatment benefits and burdens.[26] For this study, we utilized responses to the item ascertaining participants' willingness to endure high treatment burden for a chance to avoid death (Appendix). Participants were asked whether they would be willing to undergo highly intensive treatment (described as a prolonged hospital stay with many invasive diagnostic and therapeutic procedures) if they had an exacerbation of their illness that would lead to death if untreated. They were first asked whether they would undergo therapy if it would return them to current health with certainty, and then at different likelihoods (1, 10, 50, 90, 99%) of death (vs a return to current health) despite therapy. Participants were characterized as "more willing" to undergo intensive therapy if they would choose to have treatment despite ≥50% likelihood of death and "less willing" if they would choose to have treatment only with ≤10% chance of death.

The outcome variable was the pathway of care received by participants during their final illness episode as characterized by the intensity and goals of care. A taxonomy to describe these pathways received at the end of life was created in an iterative process by three of the investigators (a geriatrician, a pulmonary and critical care physician, and a pulmonary and critical care fellow). For patients who died in a hospital or nursing home, a research nurse completed a narrative chart review of the events of the hospital or nursing home stay, summarizing the receipt and withdrawal of therapies and their timing in relationship to the patients' death. For patients who died at home, follow-up phone or in-person interviews with the primary caregiver were conducted by the research nurse. Chart reviews or interviews for 12 participants chosen to represent the full spectrum of care received were reviewed by all three investigators, who independently categorized the pathways according to intensity of care. The three met to review their categorizations, resolve differences, and finalize criteria defining the pathways. They independently categorized the pathways for an additional 10 participants, with 100% agreement. The fellow then categorized the remaining participants, with confirmatory categorization by the other investigators when she had uncertainty. Participants who died in an inpatient hospice facility did not have chart reviews. An additional three participants who died at home did not have caregiver interviews. These participants were all categorized as receiving the lowest intensity care.

Statistical Analysis

We used univariate statistics to describe the population and the prevalence of the different pathways of care. We conducted bivariate analyses to determine the relationship between patient characteristics and care pathways, utilizing the Mantle–Haenszel Chi-square test for trend for categorical variables and the Kruskal–Wallis test for functional status, which was not normally distributed.

To determine the independent association between patient preferences and care pathways, we performed logistic regression models, dichotomizing the pathways variable and including those variables which demonstrated an association with pathways in bivariate analysis at a significance of $P<0.20$. All analyses were performed using SAS, version 9.1 (SAS Institute, Cary, NC, USA).

RESULTS

Description of Participants

A description of the 118 participants is provided in Table 1. Interviews were performed a median of 76 days prior to death (interquartile range 42, 112). The majority (77%) of participants were classified as more willing to undergo intensive therapy, defined as desiring intensive therapy despite ≥50% chance of death. Preferences did not differ significantly according to the interval between the patient's final interview and their death, although there was a trend toward lower willingness to undergo intensive therapy in the time period closest to death. The proportions of participants who were more willing to undergo intensive therapy in each of the quartiles of time between final interview and death were 87, 90, 93, and 76% ($P=0.32$, Mantel–Haenzel Chi-square test for trend).

Table 1. Description of 118 Participants

Characteristic	Value
Age at death, years (SD)	73 (7)
Education, years (SD)	12 (3)
Diagnosis, *n* (%)	
Cancer	58 (49)
COPD	32 (27)
HF	28 (24)
Female gender, *n* (%)	49 (42)
White, *n* (%)	105 (90)
Married, *n* (%)	64 (54)
ADL, mean (SD)	2.11 (2.91)
IADL, mean (SD)	7.01 (3.14)
Living will, *n* (%)	72 (64)
Willing to undergo highly intensive reatment despite ≥50% chance of death, *n* (%)	91 (77)
Site of death, *n* (%)	
Hospital	37 (31)
Freestanding inpatient hospice	26 (22)
Home with hospice services	26 (22)
Home without hospice services	10 (8)
Inpatient hospice in hospital	8 (7)
Nursing home without hospice services	5 (4)
Nursing home with hospice services	3 (3)
Emergency room	3 (3)

COPD = chronic obstructive pulmonary disease, HF = heart failure, ADL = activities of daily living, IADL = instrument activities of daily living

Pathways of Care

The trajectory of care that participants received during their final episode of illness could be characterized into one of four pathways, based on the intensity and goal of care. These pathways, (1) symptom relief only (64%), (2) limited attempt to reverse acute illness process with rapid shift to goal of symptom relief only (12%), (3) more intensive attempt to reverse acute illness process with eventual shift to goal of symptom relief only (15%), and (4) highly intensive attempt to reverse acute illness process with no change in goal (9%), are further described in Table 2. Taken together, pathways 2–4 can be characterized as those with an initial goal of life prolongation, in comparison to pathway 1, which had as its goal relief of symptoms only.

Pathways According to Preferences

Preferences were significantly associated with pathway of care (Table 3). Controlling for disease diagnosis, those who were more willing to undergo intensive treatment were significantly more likely to receive care with an initial goal of life prolongation compared to those who were less willing to undergo intensive treatment {odds ratio (OR) 4.73 [95% confidence interval (CI) 1.39–16.08]}.

Disease diagnosis was also significantly associated with pathway of care. Compared to participants with cancer, participants with COPD [OR 6.44 (95% CI 2.27–18.28)] and participants with HF [OR 8.29 (95% CI 2.85–24.14)] were significantly more likely to receive care with an initial goal of life prolongation. Neither age, race, gender, functional status, site of recruitment, nor presence of a living will was associated with pathways of care (Table 4).

Table 2. Description and Prevalence of Four Pathways Describing Trajectory of End-of-life Treatment

Pathways	*n* (%)
Pathway 1—Care with a goal of symptom relief	76 (64)
Interventions (which could include hospitalization) limited to treatment of symptoms	
No treatments aimed at reversing illness	
Pathway 2—Moderately intense care with initial goal of reversing the acute illness and rapid change to goal of symptom relief	14 (12)
Interventions initially provided to reverse the acute illness, including hospital admission, IV diuretics, IV antibiotics, ICU admission, non invasive positive pressure ventilation and vasopressors	
These interventions withdrawn within 1–2 days with change in goal to relief of symptoms	
Pathway 3—Highly intense care with initial goal of reversing the illness and/or later change to goal of symptom relief	18 (15)
As in group 2, interventions initially attempted to reverse the acute illness	
In contrast to group 2, more intensive interventions, such as intubation CPR and dialysis, and/or interventions continued for a longer period of time	
Eventual withdrawal of these interventions with change in goal to relief of symptoms	
Pathway 4—Highly intense care with unchanging goal of reversing the illness	10 (9)
Interventions throughout illness in attempt to reverse the acute illness	
Interventions never withdrawn (participants died while receiving these interventions)	

Mismatches Between Preferences and Pathways

Despite the overall association between preferences and care pathways, mismatches between the two were frequent. We strictly defined a mismatch as occurring when (1) a participant was less willing to undergo intensive treatment but received a highly intensive attempt to reverse illness with no change in goal (pathway 4) or (2) a participant was more willing to undergo intensive treatment but received care with the goal of symptom relief (pathway 1). The former was considered a mismatch in the direction of receiving more care than desired and the latter a mismatch in the direction of receiving less care

Table 3. Adjusted Associations of Receipt of Care Pathway Having an Initial Goal of Life Prolongation with Participants' Preferences and with Diagnosis

	Odds ratio (95% Confidence interval)
Willingness to undergo Intensive treatment	
Lower willingness (desires invasive interventions only with ≤10% likelihood of death)	Reference
Greater willingness (desires invasive Interventions despite ≥50% likelihood of death)	4.73 (1.39, 16.08)
Disease diagnosis	
Cancer	Reference
COPD	6.44 (2.27, 18.28)
HF	8.29 (2.85, 24.14)

COPD = chronic obstructive pulmonary disease, HF = heart failure than desired. In sensitivity analysis, we relaxed the definition of a mismatch in the direction of receiving more care than desired to include participants who were less willing to undergo intensive treatment and who received a moderately intensive attempt to reverse acute illness with eventual withdrawal and shift to goal of symptom relief (pathway 3). We also made stricter our definition of willingness to undergo intensive treatment. We identified participants with even greater willingness to undergo intensive treatment by defining participants as more willing to undergo intensive treatment only if they desired intensive treatment despite ≥90%, rather than ≥50%, chance of death.

With our strict definition of a mismatch, only one of the 27 participants (4%) who were less willing to undergo intensive treatment received more than desired (Table 5). This proportion increased to 11% using the relaxed definition. With our initial definition of willingness to undergo intensive treatment, 53 of the 91 participants (58%) who were more willing to undergo intensive treatment received less care than desired. With our stricter definition of willingness, 33 of the 54 participants (30%) who were more willing to undergo intensive treatment received less care than desired.

Relationships Among Preferences, Pathways, and Diagnosis

The associations between preferences and care pathways differed across the three diagnoses (Table 5). Participants with cancer had the greatest likelihood of receiving care with the goal of symptom relief despite a greater willingness to undergo intensive therapy. Among participants with cancer, 80% of those with a greater willingness to undergo intensive therapy received care with the goal of symptom relief (pathway 1), compared with 39% among participants with COPD ($P=0.002$) and 38% among participants with HF ($P=0.001$). Participants with HF had the greatest likelihood of receiving more intensive care when they had a greater willingness to undergo intensive therapy. Among participants with HF, 58% of those with greater willingness to undergo intensive therapy received either a moderately intensive attempt to reverse acute illness with eventual shift to goal of symptom relief or a highly intensive attempt to reverse illness with no change in goal (pathways 3 and 4) compared with 11% among participants with cancer ($P<0.001$) and 26% among participants with COPD ($P=0.04$).

Table 4. Care Pathways According to Participant Characteristics

	Pathways				*P* value
	1	2	3	4	
Age at death, *n* (%)					
60–69	24 (59)	5 (12)	8 (19)	4 (10)	0.89
70–79	39 (71)	7 (13)	6 (11)	3 (5)	
80 and +	13 (59)	2 (9)	4 (18)	3 (14)	
Race, *n* (%)					
White	66 (63)	14 (13)	17 (16)	8 (8)	0.95
Other	9 (75)	0 (0)	1 (8)	2 (17)	
Gender, *n* (%)					
Male	48 (69)	6 (9)	9 (13)	6 (9)	0.38
Female	28 (58)	8 (16)	9 (18)	4 (8)	
Site of recruitment, *n* (%)					
VA	36 (72)	4 (8)	5 (10)	5 (10)	0.30
non-VA	40 (59)	10 (15)	13 (19)	5 (7)	
Functional status, mean					
ADL	2.40	1.21	1.67	2.00	0.37
IADL	7.29	6.71	6.56	6.00	0.70
Living will, *n* (%)					
Yes	48 (67)	8 (11)	11 (15)	5 (7)	0.38
No	23 (58)	6 (15)	7 (17)	4 (10)	
Diagnosis, *n* (%)*					
Cancer	49 (84)	4 (7)	4 (7)	1 (2)	<0.001
COPD	16 (50)	9 (28)	5 (16)	2 (6)	
HF	11 (39)	1 (4)	9 (32)	7 (25)	

Pathways: 1 = symptom control, 2 = limited attempt to reverse acute illness with rapid withdrawal, 3 = more intensive attempt to reverse acute illness with eventual withdrawal, 4 = highly intensive attempt to reverse illness with no withdrawal.

ADL = activities of daily living, IADL = instrument activities of daily living, VA = veterans affairs, COPD = chronic obstructive pulmonary disease, HF = heart failure

Table 5. Pathways of Care According to Patients' Preferences, Overall and Stratified by Disease Diagnosis

	Pathways, *n* (%)				*P*-value
	1	2	3	4	
All participants					
Lower willingness to undergo intensive treatment	23 (85)	1 (4)	2 (7)	1 (4)	0.03
Greater willingness to undergo intensive treatment	53 (58)	13 (14)	16 (18)	9 (10)	
Participants with cancer					
Lower willingness to undergo intensive treatment	14 (100)	0 (0)	0 (0)	0 (0)	0.09
Greater willingness to undergo intensive treatment	35 (80)	4 (9)	4 (9)	1 (2)	
Participants with COPD					
Lower willingness to undergo intensive treatment	7 (78)	1 (11)	1 (11)	0 (0)	0.09
Greater willingness to undergo intensive treatment	9 (39)	8 (35)	4 (17)	2 (9)	
Participants with CHF					
Lower willingness to undergo intensive treatment	2 (50)	0 (0)	1 (25)	1 (25)	0.76
Greater willingness to undergo intensive treatment	9 (38)	1 (4)	8 (33)	6 (25)	

Pathways: 1 = symptom control, 2 = limited attempt to reverse acute illness with rapid withdrawal, 3 = more intensive attempt to reverse acute illness with eventual withdrawal, 4 = highly intensive attempt to reverse illness with no withdrawal

ADL = activities of daily living, IADL = instrument activities of daily living, VA = veterans affairs, COPD = chronic obstructive pulmonary disease, HF = heart failure

DISCUSSION

Among a cohort of older persons with advanced illness, the pathways of care they received at the end of life, characterized according to the intensity and goals of care, were associated with their treatment preferences. Nonetheless, mismatches between preferences and pathways were frequent. Primary diagnosis was also associated with care pathways, and the pattern of mismatch between preferences and pathways differed according to diagnosis.

The association between patient preferences and trajectories of care is an encouraging sign that the medical treatment received by patients at the end of life is guided by patients' values. This finding stands in contrast to a number of studies concluding that preferences fail to determine the receipt of specific medical interventions.[12,16,17] This difference in conclusions results in part from the conceptualization of end-of-life care in terms of pathways of care. These pathways were developed with the recognition that specific interventions can be used with different goals regarding the outcomes of care and attempt to capture how well patients' care goals are met at the end of life. This difference is also in part one of interpretation, given the frequency of mismatches between preferences and care pathways. The finding that the large majority of mismatches were in the direction of patients receiving less care than desired rather than more stands in contrast to the medical literature[27,28] and lay press,[29] which has focused on the problem of patients receiving more care than they desire, but is consistent with the findings of prior studies.[12,16]

The pattern of mismatch according to disease diagnosis suggests that these mismatches may not represent a failure to honor patients' wishes but instead reflect the treatment options available to the patient. Participants with cancer were the most likely to receive care with the goal of relief of symptoms despite a willingness to undergo intensive intervention, and this care pathway was significantly more frequent among participants with cancer than among participants with COPD or HF. With cancer's predictable downward trajectory[30] and greater prognostic certainty compared to other diseases,[31] it is probable that many patients reached a point in the course of their illness where treatment options were limited regardless of the patient's preferences. Conversely, among participants who were more willing to undergo intensive intervention, participants with HF were most likely to receive more highly intensive care, which may reflect the availability of interventions even for the most advanced HF.[32]

The inability to offer a treatment plan to meet the preferences of certain patients with advanced disease who continue to desire life-prolongation suggests that honoring treatment preferences may frequently not be possible and therefore may not be a good marker of the quality of end-of-life care. The findings of this study also support the notion that advance care planning should include issues other than treatment preferences that have been shown to be important to patients, such as increasing patients' sense of control and decreasing burden on others.[33,34] Discussion of these issues can refocus the patient and family on achievable goals when treatment goals can no longer be met.

The mismatches between preferences and care pathways likely also include instances when it would have been possible to provide a care plan to meet preferences. Physicians[13,35,36] have been shown to have only poor knowledge of patients' treatment preferences. Family members, who are called upon as surrogates when patients can no longer participate in treatment decision-making, also have poor knowledge of preferences.[8] The instances of mismatches in which patients received more care than they desired emphasizes the need for patients to communicate with family members their thresholds for forgoing burdensome therapy and focusing on relief of symptoms. The finding of a lack of association between living wills and care pathways extends a long line of evidence demonstrating that living wills alone are not an effective means of advance care planning.[37]

This study has several limitations. First, by specifying a return to the patient's current state of health and assessing preferences at times when patients were well enough to participate in interviews, our preference measure simplified what is often a more complex clinical situation. It may have overestimated willingness to undergo invasive therapies when patients are failing and the best that therapy can provide is limited length of life in diminished states of health with poor quality of life. In addition, the study did not provide any clinical information to patients so that they could better understand what their own futures might hold. It is also possible that patients' preferences changed between their final interview and their last illness episode. Second, we had to make assumptions about the trajectory for the small number of patients for whom we did not have complete data. Third, although we explicitly considered patients' preferences in terms of the likelihood of survival, neither chart review nor caregiver interview included physicians' estimates of the likelihood of the patient surviving their illness episode. This is why we utilized a strict definition of mismatches between preferences and care pathways, based on the greatest discrepancy between the two. However, neither relaxing the definition of a mismatch nor changing the threshold of defining a patient's willingness to undergo intensive therapy changed the conclusions regarding the nature of the mismatches. Finally, the lack of ethnic diversity and single geographical recruitment site may limit the generalizability of the findings. The single site, however, allowed us to examine the relationship between preferences and care pathways in the presence of uniform system factors, which have been shown to be strong determinants of the care that patients receive.[38]

The association between treatment preferences and the pathways of care older persons received at the end of life is a reassuring demonstration of patient-centered end-of-life care. When mismatches between preferences and pathways occur, they are generally in the direction of patients receiving less intensive care than they desire. Rather than indicating a problem with the quality of care, these mismatches may represent the persistence of patients' willingness to continue to fight their illness even when there are no longer any effective options to prolong life.

Acknowledgments: *The authors thank Carm Joncas, RN, and Barbara Mendes, RN, for their extraordinary interviewing skills and Martha Oravetz, RN, for her meticulously conducted chart reviews. This project was supported by grant PCC-98-070-1 from VA HSR&D, R01 AG19769 from the National Institute on Aging, P30 AG21342 from the Claude D. Pepper Older Americans Independence Center at Yale, and a Paul Beeson Physician Faculty Scholars Award. Dr. Pisani is supported by K23 AG23023 from the National Institute on Aging. Dr. Fried is supported by K02 AG20113 from the National Institute on Aging. Dr. Bradley is supported by the Patrick and Catherine Weldon Donaghue Medical Research Foundation Investigator Award (Grant #02-102).*

Conflict of Interest: *None disclosed.*

Corresponding Author: *Terri R. Fried, MD; Clinical Epidemiology Research Center 151B, VA Connecticut Healthcare System, 950 Campbell Avenue, West Haven, CT 06516, USA (e-mail: terri.fried@yale.edu).*

APPENDIX

Preference Assessment Item

Think about if you were suddenly to get sick with an illness that would require you to be in the hospital for at least a month. It would either be that your [CHF, COPD, cancer] worsened, or you got sick with a different illness. In the hospital, you would need to have many minor tests, such as x-rays and blood draws, and you would require more tests, such as CT scans. You would need major therapies such as being in the intensive care unit, receiving surgery, or having a breathing machine. 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?

REFERENCES

1. **Council on Scientific Affairs AMA.** Good care of the dying patient. JAMA. 1996;275:474–8.
2. **Lynn J.** Measuring quality of care at the end of life: a statement of principles. J Am Geriatr Soc. 1997;45:526–7.
3. **Sachs GA, Ahronheim JC, Rhymes JA, Volicer L, Lynn J.** Good care of dying patients: the alternative to physician-assisted suicide and euthanasia. J Am Geriatr Soc. 1995;43:553–62.
4. **Lynn J, Teno JM, Phillips RS, et al.** Perceptions by family members of the dying experience of older and seriously ill patients. Ann Intern Med. 1997;126:97–106.
5. **Teno JM, Clarridge BR, Casey V, et al.** Family perspectives on end-of-life care at the last place of care. JAMA. 2004;291:88–93.
6. **Cohen LM, Germain MJ, Woods AL, Mirot A, Burleson JA.** The family perspective of ESRD deaths. Am J Kidney Dis. 2005;45:154–61.
7. **Teno JM, Fisher ES, Hamel MB, Coppola K, Dawson NV.** Medical care inconsistent with patients' treatment goals: association with 1-year Medicare resource use and survival. J Am Geriatr Soc. 2002;50:496–500.
8. **Shalowitz DI, Garrett-Mayer E, Wendler D.** The accuracy of surrogate decision makers: a systematic review. Arch Intern Med. 2006;166:493–7.
9. **Karlsen S, Addington-Hall J.** How do cancer patients who die at home differ from those who die elsewhere? Palliat Med. 1998;12:279–86.
10. **Gomes B, Higginson IJ.** Factors influencing death at home in terminally ill patients with cancer: systematic review. BMJ. 2006;332:515–21.
11. **Ratner E, Norlander L, McSteen K.** Death at home following a targeted advance-care planning process at home: the kitchen table discussion. J Am Geriatr Soc. 2001;49:778–81.
12. **Lee MA, Brummel-Smith K, Meyer J, Drew N, London MR.** Physician orders for life-sustaining treatment (POLST): outcomes in a PACE program. Program of all-inclusive care for the elderly. J Am Geriatr Soc. 2000;48:1219–25.
13. **Hamel MB, Teno JM, Goldman L, et al.** Patient age and decisions to withhold life-sustaining treatments from seriously ill, hospitalized adults. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. Ann Intern Med. 1999;130:116–25.
14. **Somogyi-Zalud E, Zhong Z, Hamel MB, Lynn J.** The use of life-sustaining treatments in hospitalized persons aged 80 and older. J Am Geriatr Soc. 2002;50:930–4.
15. **Rose JH, O'Toole EE, Dawson NV, et al.** Perspectives, preferences, care practices, and outcomes among older and middle-aged patients with late-stage cancer. J Clin Oncol. 2004;22:4907–17.
16. **Danis M, Southerland LI, Garrett JM, et al.** A prospective study of advance directives for life-sustaining care. N Engl J Med. 1991;324:882–8.
17. **Danis M, Mutran E, Garrett JM, et al.** A prospective study of the impact of patient preferences on life-sustaining treatment and hospital cost. Crit Care Med. 1996;24:1811–7.
18. **Rosenfeld KE, Wenger NS, Kagawa-Singer M.** End-of-life decision making: a qualitative study of elderly individuals. J Gen Intern Med. 2000;15:620–5.
19. **Fried TR, Bradley EH.** What matters to older seriously ill persons making treatment decisions? A qualitative study. J Palliat Med. 2003;6:237–44.
20. **Lo B.** Improving care near the end of life. Why is it so hard? JAMA. 1995;274:1634–6.
21. **Fried TR, Byers AL, Gallo WT, et al.** Prospective study of health status preferences and changes in preferences over time in older adults. Arch Intern Med. 2006;166:890–5.
22. **The Connecticut Hospice Inc**. Summary guidelines for initiation of advanced care. Branford, CT: John Thompson Institute; 1996.
23. **Murphy DJ, Knaus WA, Lynn J.** Study population in SUPPORT: patients (as defined by disease categories and mortality projections), surrogates, and physicians. J Clin Epidemiol. 1990;43:11S–28S.
24. **Lawton MP, Brody EM.** Assessment of older people: self-maintaining and instrumental activities of daily living. Gerontologist. 1969;9:179–86.
25. **Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW.** Studies of illness in the aged: the index of ADL: a standardized measure of biological and psychosocial function. JAMA. 1963;185:914–9.
26. **Fried TR, Bradley EH, Towle VR.** Assessment of patient preferences: Integrating treatments and outcomes. J Gerontol B Psychol Sci Soc Sci. 2002;57:S348–54.
27. **The SUPPORT Principal Investigators**. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). JAMA. 1995;274:1591–8.
28. **McCue JD.** The naturalness of dying. JAMA. 1995;273:1039–43.
29. **Brody J.** Facing up to the inevitable, in search of a good death. New York Times. 2003 Dec 30; Sect. F:F5–6.
30. **Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM.** Patterns of functional decline at the end of life. JAMA. 2003;289:2387–92.
31. **Lynn J, Harrell F, Jr., Cohn F, Wagner D, Connors AF, Jr.** Prognoses of seriously ill hospitalized patients on the days before death: implications for patient care and public policy. New Horiz. 1997;5:56–61.
32. **Hershberger RE, Nauman D, Walker TL, Dutton D, Burgess D.** Care processes and clinical outcomes of continuous outpatient support with inotropes (COSI) in patients with refractory endstage heart failure. J Card Fail. 2003;9:180–7.
33. **Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA.** Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA. 2000;284:2476–82.
34. **Singer PA, Martin DK, Kelner M.** Quality end-of-life care: patients' perspectives. JAMA. 1999;281:163–8.
35. **Covinsky KE, Fuller JD, Yaffe K, et al.** Communication and decision-making in seriously ill patients: findings of the SUPPORT project. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. J Am Geriatr Soc. 2000;48:S187–93.
36. **Haidet P, Hamel MB, Davis RB, et al.** Outcomes, preferences for resuscitation, and physician–patient communication among patients with metastatic colorectal cancer. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. Am J Med. 1998;105:222–9.
37. **Fagerlin A, Schneider CE.** Enough. The failure of the living will. Hastings Cent Rep. 2004;34:30–42.
38. **Pritchard RS, Fisher ES, Teno JM, et al.** Influence of patient preferences and local health system characteristics on the place of death. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Risks and Outcomes of Treatment. J Am Geriatr Soc. 1998;46:1242–50.