

Life-sustaining Treatments during Terminal Illness:

Who Wants What?

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Objective: To determine patient characteristics associated with the desire for life-sustaining treatments in the event of terminal illness.

Design: In-person survey from October 1986 to June 1988.

Setting: 13 internal medicine and family practices in North Carolina.

Patients: 2,536 patients (46% of those eligible) aged 65 years and older who were continuing care patients of participating practices, enrolled in Medicare. The patients were slightly older than the 65+ general population, 61% female, and 69% white, and most had one or more chronic illnesses.

Measurements and main results: The authors asked the patients whether they would want each of six different treatments (hospitalization, intensive care, cardiopulmonary resuscitation, surgery, artificial ventilation, or tube feeding) if they were to have a terminal illness. The authors combined responses into three categories ranging from the desire for more treatment to the desire for less treatment. After adjustment for other factors, 53% of women chose less treatment compared with 43% of men; 35% of blacks vs 15% of whites and 23% of the less well educated vs 15% of the better educated expressed the desire for more treatment. High depression scores also were associated with the desire for more treatment (26% for depressed vs 18% for others).

Conclusion: Patients' choices for care in the event of terminal illness relate to an intricate set of demographic, educational, and cultural factors. These results should not be used as a shortcut to determine patient preferences for care, but may provide new insights into the basis for patients' preferences. In discussing choices for future life-sustaining care, physicians need to explore with each individual the basis for his or her choices.

Key words: terminal illness; life-sustaining treatment; living will; patient preferences.

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THERE IS a consensus in the United States that the preferences of patients should play an important role in decisions about the use of life-sustaining treatments. Many now advocate that patients, particularly older patients, be asked about their preferences regarding life-sustaining

ing treatment while they are still relatively healthy, as outpatients.^{1, 2}

A growing body of research and clinical experience shows that medical outpatients vary in their stated desires to receive life-sustaining treatment.³⁻⁶ There is less information concerning what kinds of patients state different types of preferences. Understanding patient factors associated with the desire to receive life-sustaining treatment could be useful in determining the sources of these choices, aid in their interpretation, and direct further discussion.

We examined data from a large study of older patients visiting physicians' offices to determine patient characteristics associated with preferences for life-sustaining treatment in the event of terminal illness.

METHODS

Study Practice and Patients

The Economy and Efficacy of Medicare Reimbursement of Preventive Services project was a six-year research study in the north central region of North Carolina. The purpose of the study was to determine whether a clinical screening and health promotion intervention could reduce medical care costs and improve health-related quality of life in a population of elderly patients 65 years of age and older.

Subjects were consenting patients who met eligibility criteria in participating practices. Primary care practice sites in the area were contacted and study sites were selected on the basis of specialty (e.g., internal medicine and family practices), number of active patients 65 years of age and older, and diversity of their physician and patient populations. Of 22 practice sites contacted, 13 agreed to participate — six private practices, six community health centers, and one academic hospital clinic. Four of the practices were internal medicine, five were family practices, and four were mixed specialty.

To be eligible to participate, subjects had to be continuing care patients at the participating practice site, be enrolled in both parts A and B of Medicare, be living in the community (i.e., not a resident in a group facility such as a nursing home or rest home), be approved by their physicians as having no contraindication to participation, and not be enrolled in a health maintenance organization (HMO).

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Questionnaire

In-person interviews were conducted between October 1986 and June 1988 at each subject's primary care practice site. Ten interviewers were trained in nondirective interviewing. The baseline interview, which took approximately 60 minutes to complete, consisted of structured questions with closed-ended responses.

As a secondary research question, we chose to examine patients' treatment choices in the event of terminal illness. Selected items from the questionnaire included demographic characteristics (age, gender, marital status, and race), education, health insurance coverage in addition to Medicare, the Self-Perceived Health Status scale,⁷ the Quality of Well-Being scale (QWB)⁸⁻¹⁰ (somewhat modified for a population over 65), the Perceived Quality of Life scale (PQOL),¹¹ a ten-item (0 to 30 point) shortened version of the Center for Epidemiologic Studies Depression (CES-D) scale,^{12, 13} importance of religion, possession of a living will, preference for quality rather than length of life, and a treatment preference scale.

The treatment preference scale was developed using the following series of questions:

"Now I want you to think about what things would be like if you were diagnosed as having a *terminal illness*. By this I mean if you were dying with a disease that could not get better no matter what your doctor does. Do you want to:

1. Go to the hospital?
2. Go to intensive care?
3. Have your heart revived?
4. Have surgery?
5. Be put on a breathing machine?
6. Be fed through a tube into your stomach or your veins?"

Subjects were asked to respond "yes," "no," or "don't know" to each treatment choice. To quantify the desire to receive these life-sustaining treatments, we assigned +1 for a "yes" response, -1 for a "no" response, and 0 for a response of "don't know." These values were summed for each individual's six treatment choices, resulting in a range of possible scores from -6 ("no" to all treatments) to +6 ("yes" to all treatments). This scale had a Cronbach's alpha of 0.85, indicating excellent reliability.

In addition to the treatment choices, three questions were asked about life-sustaining treatment decisions. These were: 1) "Which is more important to you, how long you live or how well you live?", 2) "A living will is a paper you sign telling how much and what kind of medical treatment you would like to receive at the

end of life. Do you have a living will?" (yes, no, don't know), and 3) "If you were unable to make the decision [regarding life-sustaining treatments] yourself, would you want your doctor to decide, your family, or other?"

Statistical Analysis

For the analyses, we divided the treatment preference scale into three categories: 1) desire for more treatment (scores +2-+6); 2) desire for moderate treatment (scores -2-+1); and 3) desire for less treatment (scores -6--3). The categories were defined to achieve a reasonable sample size among the three groups. Other categorizations yielded similar results.

Summary statistics were used to analyze all the study variables—first overall and then by the three treatment categories. Following these unadjusted analyses, we fit ordinal logistic regression models, using the three treatment choice categories as the response. The initial model included all the study variables in the previous bivariate analyses, as well as any potentially important interaction terms. These factors included age, gender, marital status, race, education, health insurance coverage (other than Medicare), Perceived Health Status scale score, presence of a living will, importance of religion, the depression scale score, the QWB score, and the PQOL score. A backward elimination technique was used to remove terms that were no longer statistically significant ($p > 0.10$). Interactions were tested first, followed by global (multiple degree-of-freedom) tests to remove groups of the least important factors. Finally, individual terms were examined and removed when their significance levels fell below an alpha of 0.10. The final model included the joint set of factors that were independently associated with the types of choices made. Finally, we used the estimates from the model to calculate adjusted proportions of the three treatment categories for subgroups of each factor.

RESULTS

Patient Characteristics

Of 5,538 patients approached for the study, 2,536 (46%) agreed to participate (Table 1). The most frequent reason given by patients for not participating was that they did not want to take part in research and that it was inconvenient to return for follow-up interviews. Because of the small numbers, we excluded the ten patients who were in racial categories other than black or white. Only 3% of the patients had Medicaid as well as Medicare, and many participants (72%) carried some type of health insurance other than Medicaid or Medicare.

The participants comprised a broad range of outpatients, from those with serious chronic illness to those who were generally healthy. Reviews of the medi-

cal records of 455 of the first participants from three of the practices showed that only 14% had no major illness, 19% had minor chronic illnesses, 50% had major chronic illnesses, and 15% had severe chronic illnesses or advanced cancers. The mean of 0.70 and broad range of scores for the QWB were typical for a population aged 65 years or older.¹⁰ Sixteen percent of the respondents were classified as depressed, as indicated by a score of 10 or more out of a possible 30 on the modified CES-D scale; the mean value for the PQOL was high

TABLE 1
Patient Characteristics

	<i>n</i>	Mean ± SD or Percentage	Range
Age	2,527	73.9 ± 5.7 years	65–99 years
Gender			
Male	980	39%	
Female	1,556	61%	
Marital status			
Married	1,431	56%	
Not married	1,104	44%	
Race			
White	1,738	69%	
Black	786	31%	
Education			
1–8 years	841	33%	
9–12 years	897	36%	
>12 years	782	31%	
Other health insurance			
Yes	1,815	72%	
No	698	28%	
Perceived health status			
Good to excellent	1,676	66%	
Poor to fair	858	34%	
Quality of Well-Being scale score	2,442	0.70 ± 0.11	0.42–1.0
Perceived Quality of Life scale score	2,479	80.2 ± 13.2	23.8–100
Depression scale* score			
Depressed range	408	16%	
Not depressed range	2,072	84%	
Religion			
Very important	2,109	84%	
Somewhat or not important	406	16%	
Living will			
Yes	395	16%	
No	2,120	84%	
Life preference			
How long you live	294	12%	
How well you live	2,135	88%	

*The Center for Epidemiological Studies Depression Scale.

TABLE 2
Study Counties and National Demographics (%)

	Study Sample	Study Counties*	United States†
Age			
65–69 years	22	34	34
70–74 years	33	26	27
75–79 years	25	19	20
80–84 years	14	12	11
85 years and older	6	9	8
Gender			
Male	39	38	41
Female	61	62	59
Race			
White	69	76	90
Black	31	23	8
Education			
0–8 years	33	46‡	29
9–12 years	36	30	49
>12 years	31	24	22

*U.S. population census, 1990.
†Current population survey, March 1988.
‡U.S. population census, 1980.

(80.2). Most (84%) participants considered religion very important in their lives.

Sixteen percent of the participants said they had living wills. About 66% chose their families to make decisions for them if they were not able, 31% chose their doctors, and only 3% chose "other." Finally, the vast majority (88%) of patients felt "living well" was more important than "living long."

Demographic characteristics of the study sample were compared with those of the population 65 years of age and older in the counties where the practices were located and in the United States (Table 2). The study sample had somewhat larger percentages of subjects who were in the middle age groups (70–84 years), were nonwhite, and were in the high or low education categories compared with the county and U.S. populations.

Treatment Preferences

While almost half (47%) of the patients said they would want to be hospitalized for a terminal illness, only 18% said they would want tube feeding (Table 3). Of the people who did not want to be hospitalized, 5% wanted intensive care, 12% wanted cardiopulmonary resuscitation (CPR), 8% wanted surgery, 7% wanted artificial ventilation, and 6% wanted tube feeding. However, people who showed these possible inconsistencies in their choices did not differ from the rest of the sample by age, gender, race, educational level, or any of the quality of life measures.

When preferences for the six treatments were combined into a single scale, 48% of the participants

TABLE 3
Patient ($n = 2,532$) Preferences Concerning Life-sustaining Treatments (%)

	Yes	No	Don't Know
Hospitalization	47	41	12
Intensive care	34	49	17
Cardiopulmonary resuscitation	27	59	14
Surgery	24	61	15
Artificial ventilation	19	68	13
Tube feeding	18	55	27

gave responses in the less-treatment category, 29% gave responses in the moderate-treatment category, and 23% gave response in the more-treatment category (Fig. 1). The range of preferences was broad: 633 people (25%) answered "no" to all six treatments choices, 169 (7%) said "yes" to all choices, and 100 (4%) answered "don't know" to all choices.

Treatment Preferences for Patient Subgroups

Patient race and education were strongly associated with treatment preferences (Table 4). Black patients were almost three times as likely as white patients (42% vs 15%) to want more treatment, while whites were 2.4 times as likely as blacks (58% vs 24%) to want less treatment. Blacks were even more likely to select more treatment when the race of the interviewer was black (54%), whereas the preferences stated by whites were not as greatly influenced by the race of the interviewer. Patients with education of more than 12 years were twice as likely as patients with one to eight years of education (64% vs 34%) to desire less treatment. However, treatment choices were similar among educational levels for blacks.

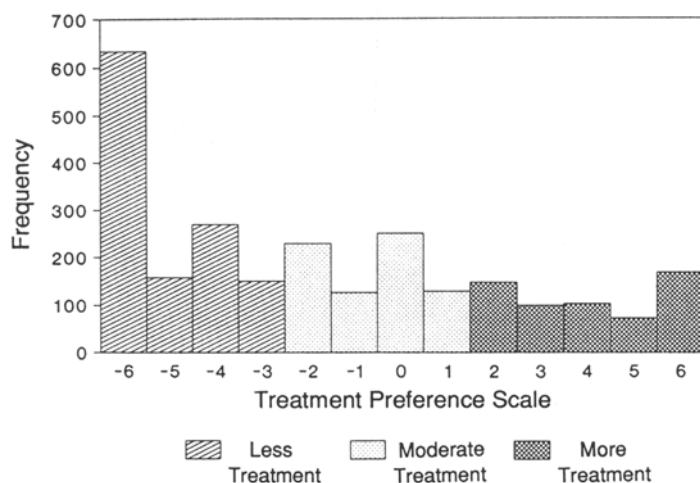


FIGURE 1. Patients' ($n = 2,536$) treatment preferences. Frequency numbers refer to actual numbers of patients with specific preference scores.

Patients desiring more treatment were more likely to rate their health as poor, to rate religion as very important in their lives, and to reply that living for a long time was more important than living well. Patients scoring in the depressed range on the depression scale also desired more treatment. This relationship held using threshold values other than 10 on the modified CES-D scale. Patients stating a desire for less treatment were more likely to have health insurance and to have a living will. There was little meaningful association between treatment choices and patient age, QWB score, or PQOL score.

We compared each of the above characteristics with the response to the question concerning the importance of living "long" or living "well." The patient characteristics associated with the desire for more treatment similarly were associated with the importance placed on living a long time.

Multivariable Associations between Patient Characteristics and Treatment Preferences

The multivariable analysis included fitting an ordinal logistic regression model to estimate the adjusted proportions of patients selecting more, moderate, or less treatment. Our final model included gender, marital status, race, interviewer's race, education, depression status, importance of religion, and presence of a living will. Female gender was independently associated with the desire for less treatment (Table 5). Race, education, and depression status each remained independently and strongly associated with stated preferences. Patients who were black, less educated, or depressed were more likely to select more treatment. Other health insurance, Self-Perceived Health Status score, QWB score, PQOL score, and the interaction effects (including an interaction term for race by education) were no longer statistically significant ($\alpha > 0.10$) after adjustment for other variables.

DISCUSSION

The study reported here is part of a larger project to examine the effects of insured preventive services upon recipients of Medicare who are attending primary care practices. Our analysis was intended to examine the inclination of this elderly population to receive life-sustaining treatments in the event of terminal illness. This population is a very relevant one for studies of preferences for life-sustaining treatments for several reasons. Such elderly outpatients have reached a time in their lives when they are still capable of expressing choices about their future care⁴ and are at risk in the subsequent decade of having life-threatening illnesses. Furthermore, recent federal legislation requires health care providers to inform Medicare recipients about their right to plan their future care through advance directives.

TABLE 4
Unadjusted Patient Characteristics by Choices of Care

	<i>n</i>	More Treatment	Moderate Treatment	Less Treatment	Chi-square
Age—mean ± SD	2,527	74.1 ± 5.9 years	74.4 ± 5.9 years	73.5 ± 5.5 years	NS
Gender					
Male	980	25%	25%	50%	14.1*
Female	1,556	22%	31%	47%	
Marital status					
Married	1,431	21%	27%	52%	25.0*
Not married	1,104	27%	31%	42%	
Race					
White	1,738	15%	27%	58%	304.0*
Black	786	42%	34%	24%	
Interviewer race = white					
Race = white	1,208	13%	25%	62%	77.9*
Race = black	342	26%	39%	35%	
Interviewer race = black					
Race = white	522	19%	31%	50%	167.1*
Race = black	439	54%	30%	16%	
Education					
1–8 years	841	34%	32%	34%	149.6*
9–12 years	897	21%	31%	48%	
>12 years	782	14%	23%	63%	
Education: 1–8 years					
Race = white	339	20%	31%	49%	65.7*
Race = black	492	43%	33%	24%	
Education: 9–12 years					
Race = white	673	16%	30%	54%	60.4*
Race = black	217	37%	36%	27%	
Education: >12 years					
Race = white	714	11%	22%	67%	73.8*
Race = black	60	47%	35%	18%	
Other insurance					
Yes	1,815	21%	27%	52%	57.6*
No	698	31%	33%	36%	
Perceived health					
Good to excellent	1,676	22%	27%	51%	24.4*
Poor to fair	858	27%	32%	41%	
Quality of Well-Being scale score—mean ± SD	2,442	0.69 ± 0.11	0.69 ± 0.12	0.71 ± 0.11	*
Perceived Quality of Life scale score—mean ± SD	2,479	80.4 ± 13.0	79.1 ± 13.7	80.8 ± 12.9	†
Depression status					
Depressed	408	30%	35%	35%	30.5*
Not depressed	2,072	22%	28%	50%	
Religion					
Very important	2,109	25%	30%	45%	50.7*
Somewhat or not important	406	14%	22%	64%	
Living will					
Yes	395	17%	23%	60%	28.5*
No	2,120	24%	30%	46%	
Life preference					
How long you live	294	46%	32%	22%	121.5*
How well you live	2,135	20%	28%	52%	

*p < 0.001.

†p < 0.05.

TABLE 5
Adjusted* Proportions for Choices of Care†

	<i>n</i>	More Treatment (%)	Moderate Treatment (%)	Less Treatment (%)	<i>p</i>
Gender					
Male	918	23	34	43	0.0001
Female	1,471	17	30	53	
Marital status					
Married	1,363	18	30	52	0.0072
Not married	1,026	22	32	46	
Race					
White	1,663	15	29	56	0.0001
Black	726	35	36	29	
Education					
1–8 years	786	23	34	43	0.0004
9–12 years	862	20	32	48	
12+ years	741	15	28	57	
Depression status					
Depressed	390	26	35	39	0.0001
Not depressed	1,999	18	31	51	
Religion					
Very important	2,009	20	32	48	0.0409
Somewhat or not important	380	16	30	54	
Living will					
Yes	382	16	29	55	0.0163
No	2,007	20	32	48	

*Adjusted for gender, marital status, race, interviewer race, the education indicator variables, depression status, religion, and living will.

†Note: The analysis is based on 2,389 observations for which there was complete information for all variables.

We found variation in the degree to which elderly outpatients stated desires for life-sustaining care if they were to become terminally ill. Women wanted life-sustaining treatments less often than did men; black patients were more inclined to choose life-sustaining treatments than were white patients; patients with less education and patients scoring higher on a depression index were more likely to state a desire for more treatment.

Several aspects of the study sample must be recognized before generalizing from the study results. While the people who entered the study composed a nonrandom sample of all elderly outpatients in the geographic area, and were slightly older and better educated than the elderly population in the study counties, other demographic characteristics were similar. The participants represented a diverse group of independently functioning elderly people from a broad range of medical and demographic situations. Although fewer than 50% of eligible patients chose to participate, given that the purpose of the study was the use of preventive care, refusals probably had little to do with preferences for life-sustaining treatment.

Several limitations of the questionnaire design also must be acknowledged. The questions were asked of subjects without prior explanations of the treatments in question; thus we cannot know how well informed the choices were. The questions were closed-ended ones,

so that the reasons for patients' choices remain to be explored through the design of studies with more open-ended questions. We nonetheless believe the choices expressed are a true reflection of the patients' wishes to receive life-sustaining treatments as evidenced by the strong correlation between the patients' scores on the treatment preference scale and their desire to live a long time. While acknowledging these limitations, we believe it is fruitful to explore the basis for the observation that certain demographic factors and measures of health status are associated with the inclination to choose life-sustaining treatments.

Women in this study population were less interested in life-sustaining treatments during terminal illness than were men. Frankl et al.¹⁴ and Danis et al.¹⁵ have observed similar findings in populations of hospitalized medical inpatients, while Wenger et al. have not.¹⁶ This is a particularly interesting finding in light of evidence that women's wishes to forgo life-sustaining treatments have often been given little legal credence.¹⁷

There are several possibilities for the racial differences in responses. One is that black individuals are less well informed about the limitations of medical technology when death is inevitable. While this explanation may account for some of the findings, the fact that highly educated black individuals were as inclined to choose life-sustaining treatment as less well-edu-

cated individuals suggests that other explanations must be considered. Apparent racial differences may reflect disparities between socioeconomic groups rather than true racial differences. We used education as an indicator of socioeconomic status and found that racial differences persisted. Some studies suggest, however, that measures of socioeconomic status or education may have different meanings for blacks and whites.^{18, 19}

Another possibility is that black individuals, who as a group have had limited access to care,²⁰⁻²³ and thus have forgone treatment without choice, are not inclined to forgo treatment when given a choice. There has been increasing concern about access to care for black Americans.²⁴ When asked about forgoing life-sustaining treatment, black individuals may be concerned about possibly being denied appropriate care. In a study of kidney dialysis patients, blacks were twice as likely as whites to want dialysis continued, even if they developed advanced Alzheimer's disease.²⁵

Finally, black individuals may differ from whites in historical experiences and cultural beliefs about the approach of death, the attachment to life, and the need to resist at the end of life. For example, suicide rates among older blacks are much lower than among whites.²⁶ In 1989, Hospice of North Carolina found that only 17% of its patients were black, while the state's population is 25% black.²⁷ Black individuals suffer more violent death earlier in life,²⁸ yet one study found that they expect and want to live longer than whites.²⁹ Black individuals also favor legalization of active euthanasia less often than do white individuals.³⁰ One may speculate that the black population in the United States is unusually familiar with and prepared to struggle against death. In our study, we found that 25% of blacks felt "how long" they lived was more important than "how well," whereas only 6% of whites shared that belief.

These results do not appear to be due to bias. The questions had been pretested on an elderly population before they were used. All interviewers were trained in the same way. Although the responses obtained by black and white interviewers differed somewhat, the association between race of respondent and treatment preference was strong for all interviewers.

The finding that patients scoring high on a standardized depression index were more likely to choose life-sustaining treatment is contrary to a common perception about depressed patients. Often when a patient refuses treatment, the physician seeks psychiatric consultation to exclude the possibility that the choice was influenced by psychiatric illness such as depression. While this practice is sometimes warranted, these data suggest that depressed patients are less likely than others to forgo life-sustaining treatments.

The independent association of education with treatment preferences and the large number of "don't know" responses raise the issue of whether many peo-

ple have adequate information and have thought enough about the situation of terminal illness to be able to respond to the hypothetical questions used in this study. We do not know whether the same responses would have been given after a longer discussion with a sensitive primary care physician. Certainly, when planning advance care directives physicians are advised to hold much more extensive discussions than are possible in the questionnaire used here.

It is noteworthy that several factors were not associated with life-sustaining treatment choices. Whereas several studies have shown an association between increasing age and increasing desire for life-sustaining treatments,^{3, 14} we found no such association. This difference may be due to the fact that our population did not include as young a sample as did these other reports. Also of note, quality of life did not influence preferences for life-sustaining treatments. Perhaps this is so because quality of life at the time of the interview is not germane to treatment wishes when one is terminally ill. We have previously found that quality of life is not associated with willingness to receive life-sustaining care, possibly because quality of life must be extremely poor before individuals desire to forgo survival.¹¹

There is a growing recognition in the United States that decisions about the use of life-sustaining treatments toward the end of life are very complex and should incorporate patients' wishes to the greatest extent possible.^{1, 31} While many physicians and ethicists would suggest that providing life-sustaining treatments to hopelessly ill patients is an unwise pursuit,³² the data presented here suggest that patients do not universally share this viewpoint. Clearly, future research would be useful to explore the basis for the varying preferences we have observed.

We do not wish to imply that the data presented here can provide a short cut to discovering patients' preferences. We are particularly concerned that this data not lead to prejudicial care for patients. One should not make assumptions about a particular patient's choices on the basis of demographic or other characteristics. In discussing choices for future life-sustaining care, physicians need to establish trust with their patients, educate them about their options, and explore with each individual the basis for his or her choices.

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Further information is available from Junius Gonzales, MD, Kathryn Magruder, PhD, MPH, or Kimberly Hoagwood, PhD, at

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