Who Wants What?

JOANNE MILLS GARRETT, PhD, RUSSELL P. HARRIS, MD, MPH,
JEAN K. NORBURN, PhD, DONALD L. PATRICK, PhD, MARION DANIS, MD

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


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 25% 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 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).
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,6 the Quality of Well-Being scale (QWB)7-10 (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, 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-