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## ***Do Physicians' Own Preferences for Life-Sustaining Treatment Influence Their Perceptions of Patients' Preferences? A Second Look***

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Previous studies have documented the fallibility of attempts by surrogates and physicians to act in a substituted judgment capacity and predict end-of-life treatment decisions on behalf of patients.<sup>1-9</sup> We previously reported that physicians misperceive their patients' preferences and substitute their own preferences for those of their patients with respect to four treatments: cardiopulmonary resuscitation (CPR) in the event of cardiac arrest, ventilator for an indefinite period of time, medical nutrition and hydration for an indefinite period of time, and hospitalization in the event of pneumonia.<sup>10</sup>

This paper extends our previous observations and reports on a different and larger population of subjects, employing a more detailed procedure-oriented advance directive instrument as well as a quality-of-life questionnaire. Our hypothesis remains the same, namely, that physicians' predictions of their patients' end-of-life treatment choices are closer to the choices they would make for themselves than to the choices expressed by their patients. Since physicians are the ones who ultimately exercise control over these important decisions, any unrecognized projection of personal preferences onto their patients would raise serious concerns about physicians acting in a substituted judgment capacity. It would also emphasize the importance of patients choosing surrogate decision makers carefully and, even more important, explicating clearly their directive instructions as part of advance care planning.

### **Methods**

#### *Subjects and Setting*

The study was carried out at the University of California, San Diego (UCSD) after review and approval by the institutional review board. It was part of a larger project involving 204 patients with acquired immune deficiency syndrome (AIDS) and cancer. The project was designed to investigate the effects of advance directives on medical treatments and costs. Physicians at the UCSD Cancer Center and at a clinic devoted to the treatment of patients with AIDS were asked to identify all patients who they estimated had less than a 50% chance of surviving 5 years. Recruitment for this component of the study occurred between May 1991 and May 1993. During this period, each of 111 surviving patients was asked to identify the physician who was primarily responsible for his or her care. A total of 50 physicians were identified by the 111 patients. The identified physicians were contacted and asked to participate in the study. Eighteen patients were no longer receiving their medical treatment at UCSD but were being treated by 18 physicians in outside clinics. Of the 18 outside physicians who were contacted, 9 agreed to participate in the study. The remaining 32 physicians were on the UCSD faculty and 19 agreed to participate. A total of 28 physicians (56% of the 50 physicians identified) participated in the study. Twenty-two physicians did not participate: 8 claimed they did not know the patient who identified them well enough or did not have time; 6 could not be contacted because they had moved; 8 gave no reason. To encourage cooperation we limited each physician to the comparison study of no more than two of his or her patients; thus our study involves 35 physician-patient pairs.

The 35 patients' ages ranged from 30 to 79 years. There were 8 females and 27 males. All subjects spoke English, and included 1 Hispanic, 1 African-American, 1 Native-American, 1 Asian, and 31 Caucasians. Eleven were patients with cancer and 24 were patients with AIDS.

### *Measures*

After obtaining informed consent, the patients were offered and completed a California Durable Power of Attorney for Health Care and two advance directive instructional supplements. One instruction supplement, which we call a procedure-oriented questionnaire (POQ), was adapted from Emanuel and Emanuel.<sup>11</sup> This form provides a list of specific procedures for the patient to consider under four different clinical situations constituting severe cognitive impairment in association with prognoses of varying severity. The specific procedures were cardiopulmonary resuscitation, mechanical breathing, artificial nutrition and hydration, major surgery, kidney dialysis, chemotherapy, minor surgery, invasive diagnostic tests, blood or blood products, antibiotics, simple diagnostic tests, and pain medications even if they dull consciousness and indirectly shorten life. Respondents were asked if they would accept each treatment in four different situations: unconscious with no chance of recovery; unconscious with slight chance of recovery; permanent brain damage and inability to recognize others and terminal illness; permanent brain damage and inability to recognize others and no terminal illness. For each of the 48 unique combinations of treatments and situations there were four response options with regard to accepting treatment: Yes, No, Trial, and Don't Understand/Need More Information.

The other instruction supplement, which we call a quality-of-life questionnaire (QLQ), was developed and described in a previous publication.<sup>12</sup> This form asks patients to estimate how long they would want to live under thirteen qualitative conditions, involving varying levels of functional capacity, consciousness, pain, and burden on others. For each condition, the respondent recorded how long he or she would want to live. Responses were recorded along a visual analog scale that ranged from 0 days to 365 days. In addition, the respondent could indicate that he or she would want to live "as long as possible." Also, there was a category Don't Understand/Need More Information.

The physicians completed the same POQ and QLQ instruction supplements as their patients. In contrast to the patients, who were asked to respond with their own preferences to the clinical circumstances described, the physicians were asked to respond in two different contexts. With respect to the POQ, they were asked first to respond with their own treatment preferences given the clinical circumstances presented; then they were asked to predict what their patients' choices would be. With respect to the QLQ, the physicians were asked first to imagine themselves in the same disease condition as their patients, then choose how long they would want to be kept alive in the circumstances described; then they were asked to predict how long their patients would want to be kept alive in the circumstances described. In other words, we ascertained: (1) the patient's preferences for specific procedures or days of sustained life under certain clinical circumstances; (2) the physician's predictions of this patient's preferences; and (3) the physician's preferences for himself or herself.

To evaluate correspondence between physicians and patients, we analyzed three categories of comparison: (1) physicians' predictions of what their patients would want with patients' preferences for their own treatment (MD for Patient, Patient for Self); (2) physicians' predictions of what their patients would want with physicians' preferences for their own treatment (MD for Patient, MD for Self); (3) physicians' and patients' preferences for their own treatment (MD for Self, Patient for Self).

## Results

### *Comparison of Responses to Procedure-Oriented Questionnaire*

The procedure-oriented questionnaire (POQ) contains 12 different treatments for the patient to choose under four different clinical situations; thus it requires 48 different responses. For each treatment, we analyzed three alternative choices given to the respondent: No (would not want the treatment), Yes (would want the treatment), or Trial (would experiment with the treatment).

The most common response was that the treatment would be refused; overall, physicians were more inclined to refuse treatments than their patients. Because physicians and patients were both more inclined to refuse the described treatments, we chose to present the degree of agreement between the two groups with respect to treatment refusals. (The obverse class of treatment acceptance is not shown.) The first row of Table 1 shows the percentage of cases where there was agreement that the treatment should be refused. For a base comparison, we considered the percentage of the 48 items (averaged across 35 physician-patient pairs) where there was agreement when the physician responded for the patient while the patient responded for self. This is an important comparison because it shows the accuracy of physicians when they serve as proxies for their patients. When physicians responded for their patients and patients responded for themselves there was agreement that the treatment should be refused in 54% of the cases. The 95% confidence interval ranged from 45% to 62%. When physicians responded for themselves and on behalf of their patients, agreement rose to 68%, a value that falls outside the 95% confidence interval for the base comparison ( $p < .05$ ).

The second row in Table 1 shows the cases where perfect agreement occurs with respect to all the choices: No, Yes, Trial. In the base comparison (when physicians' responses for patients were compared with the patients' responses for themselves), there was agreement in 63% of the cases. The 95% confidence interval ranged from 55% to 71%. When physicians' predictions of their patients' choices were compared with physicians' choices for themselves agreement rose to 82%,

**Table 1.** Summary of Percent Agreement over All Items in Procedure-Oriented Questionnaire by Category

Category	MD for Patient, Patient for Self (Base Comparison)		MD for Patient, Patient for MD for Self, Self	
	(%)	95% CI	(%)	(%)
MD: No, Patient: No	54	45-62	68	60
All Perfect Agreement	63	55-71	82	66
Agreement with Trial	67	59-75	83	68

which again was outside the 95% confidence interval for the base comparison ( $p < .05$ ).

The third row presents the data comparing preferences for a trial of treatment. The trial category is, of course, subject to varying interpretation as to what this choice signifies. We elected to adopt the interpretation that choosing a treatment on a trial basis indicates that the treatment is desired –but only as long as it succeeds. We therefore analyzed the data presented in the third row as though choosing a treatment trial were equivalent to a request for the treatment. Considering the trial data separately or considering it as the same as a request for treatment, however, had nonsignificant effects on results.

These analyses used the most conservative approach, with patient-physician pairs serving as the unit of analysis. An alternative method of analyzing the data would be to consider each of the 48 responses for the 35 pairs, or 1,680 responses, independently. Such analysis does not affect the percentages but does affect the power of the statistical test. Using this less conservative analysis strategy, the differences between MD for self and MD for patient versus MD for patient and patient for self were all highly statistically significant ( $p < .001$ ). The differences between agreement rates for MD for patient and patient for self versus MD for self and patient for self were statistically significant only for the comparison of refusals (first row of Table 1) ( $p < .01$ ).

We also performed a more detailed analysis of specific items on the POQ. For these analyses, we focused on the agreement that neither the physician nor the patient wanted the procedure. Agreement was highest (73%) when the situation involved unconsciousness with no chance of recovery and lowest (35%) when the situation involved unconsciousness with small chance of recovery. Analysis of variance indicated a clear difference by situation ( $F=11.98$ ,  $df=3/95$ ,  $p < .001$ ) and by group (MD for self versus MD for patient) ( $F=9.31$ ,  $df=1/95$ ,  $p < .01$ ). However, the interaction between these two variables was nonsignificant.

There were also differences by category. Agreement overall tended to be higher for CPR, mechanical breathing, and major surgery. It tended to be significantly lower for pain medication, use of antibiotics, and blood donation.

#### *Comparison of Responses to Quality-of-Life Questionnaire*

Analyses of responses to the quality-of-life questionnaire (QLQ) focused on three selected questions: (1) How many days would the person want to live if conscious and able to recognize others and make decisions, but limited to a hospital bed and dependent on others for food, fluid, and medications? (2) How many days would the person want to live if conscious and able to recognize others but unable to speak or communicate? (3) How many days would the person want to live if conscious but in such severe constant pain that large, sedating doses of narcotics would be required?

To estimate correspondence between physicians' preferences for self and their predictions of the preferences of their patients, Pearson Product Moment correlations were calculated for each of the items. Under certain circumstances a substantial number of the participants selected the option that they would want to live "as long as possible." To permit quantitative analysis, these responses were coded as equal to two years or 730 days. Once again, correspondence was closer between physicians' predictions of their patients' choices and the physicians' preferences for self than between physicians' predictions of their patients' preferences and their patients' preferences for self. The strongest correlation was for the item concerning quality of life when the patient was in deep pain. For this item, the correlation between physicians responding for their patients and physicians responding for themselves was very high ( $r = .69$ ,  $p < .001$ ). The correlation between physicians responding for their patients and the patients responding for themselves was lower ( $r = .43$ ,  $p < .02$ ). The correlation between

physicians responding for self and patients responding for self was nonsignificant ( $r = -.11, p = .60$ ). The results for the other two items were similar. However, for the situation in which the person was unable to communicate, the correlation between physicians responding for patients and patients responding for self was higher than the correlation between physicians for patients and physicians for self. (See Table 2.)

## Discussion

These results are consistent with our previous observations suggesting that physicians' perceptions of their patients' wishes for treatment are influenced by what they would want for themselves.<sup>10</sup> A variety of studies point out obstacles to successful end-of-life treatment decision making. For example, studies show that patients view their own state of health in a better light than surrogates and physicians,<sup>13</sup> and that physicians' personal characteristics such as age, religion, and clinical experience affect their willingness to withdraw life support.<sup>14</sup> Indeed, physicians commonly misperceive what is going on in their patients' minds,<sup>15</sup> and not only may be unaware of their patients' end-of-life treatment wishes, they may even be unaware that their patients have gone to the trouble of executing advance directives in order to document their wishes.<sup>16</sup>

**Table 2.** Correlations for Three Conditions in Quality-of-Life Questionnaire

Item	MD for Patient, Patient for Self (Base Comparison)	MD for Patient, MD for Self	MD for Self, Patient for Self
Limited and Dependent	.43*	.51**	.07
Unable to Speak	.49**	.39*	.07
Severe Pain	.43*	.69**	-.11

\* $p < .05$ .

\*\* $p < .01$ .

In general, both physicians and patients in this study were more likely to refuse a treatment than to desire it. Interestingly, however, although physicians are often regarded as promoting aggressive life-prolonging treatment, the physicians were more likely than their patients to reject treatments, both for themselves and for their patients.

The results of this study should be interpreted with caution for several reasons. First, even though the results achieved statistical significance, only a relatively small number of patients and physicians were studied. Second, the study used a nested design in which each physician was responsible for up to two patients. For these analyses, therefore, we used the patient as the starting point for analysis. However, use of the physician as the starting point for analysis produces essentially the same conclusions.

Another caveat in interpreting the discrepancy between patients' wishes and physicians' predictions is that the patients may not have had the experience necessary to make accurate judgments about how they would respond to the actual employment of certain medical procedures. For example, the experience of being on a mechanical ventilator may be very abstract to patients who have never witnessed or experienced assisted breathing. Physicians, on the other hand, who are more familiar with the real world experience of artificial ventilation may be better positioned to understand the reality of it and thus may be better able to predict what their patients would do if actually confronted with this choice. Indeed, physicians and nurses who have extensive experience with serious illness are unlikely to wish aggressive end-of-life treatments for themselves.<sup>17</sup> However, there are problems with this explanation. If familiarity with serious illness were the factor that discouraged patients from seeking aggressive treatments, one would expect the preferences of patients who had experienced mechanical ventilation to be more resistant to the procedure than those who had not experienced mechanical ventilation. To the contrary, Danis et al. found that the majority of patients who survived intensive care, including mechanical ventilation, said they would do it again.<sup>18</sup> These authors did not report whether they had inquired about how much of their treatment experiences patients recalled. In fact, there may be another possible explanation for this contradictory finding, namely that although physicians and nurses are vividly aware of the aggressive treatment they employ, their heavily sedated patients (as we have often observed) have memories of these experiences that are free of pain and other discomforts. Whatever the explanation, the hypothesis that patients with treatment experience would assume the more conservative posture of experienced physicians and be less likely to want aggressive life-sustaining procedures does not seem to be consistent with observations.

We hope that the data presented here will serve as a caution to physicians claiming to make treatment choices on behalf of their patients, will stimulate more self-awareness of personal values that may be in conflict with those of their patients, and spur greater efforts to help patients achieve value clarification in their advance care planning, both for their own sake and also for the information of their surrogate decision makers.

## Notes

1. Uhlmann RF, Pearlman RA, Cain KC. Physicians' and spouses' predictions of elderly patients' resuscitation preferences. *Journal of Gerontology* 1988; 43: 115-21.
2. Hare J, Pratt C, Nelson C. Agreement between patients and their self-selected surrogates on difficult medical decisions. *Archives of Internal Medicine* 1991; 115: 92-8.
3. Ouslander JG, Tymchuk AJ, Rahbar R. Health care decisions among elderly long-term care residents and their potential proxies. *Archives of Internal Medicine* 1989; 149: 1367-72.
4. Danis M, Patrick DL, Southerland LI, Green ML. Patients' and families' preferences for medical intensive care. *JAMA* 1988; 260: 797-802.
5. Zweibel NR, Cassel CK. Treatment choices at the end of life: a comparison of decisions by older patients and their physician-selected proxies. *The Gerontologist* 1989; 29: 615-21.
6. Seckler AB, Meier RE, Mulvihill M, Cammer Paris BE. Substituted judgment: how accurate are proxy predictions? *Annals of Internal Medicine* 1991; 115: 92-8.
7. Diamond EL, Jernigan JA, Moseley RA, et al. Decision-making ability and advance directive preferences in nursing home patients and proxies. *The Gerontologist* 1989; 29: 622-6.
8. Sulmasy DP, Haller K, Terry PB. More talk, less paper: predicting the accuracy of substituted

- judgments. *American Journal of Medicine* 1994; 96: 432-8.
9. Suhl J, Simons P, Reedy T, Garrick T. Myth of substituted judgment: surrogate decision making regarding life support is unreliable. *Archives of Internal Medicine* 1994; 154: 90-6.
  10. Schneiderman LJ, Kaplan RM, Pearlman RA, Teetzel H. Do physicians' own preferences for life-sustaining treatment influence their perceptions of patients' preferences? *Journal of Clinical Ethics* 1993; 4: 28-33.
  11. Emanuel LL; Emanuel EJ. The medical directive: a new comprehensive advance care document. *JAMA* 1989; 261: 3288-93.
  12. Schneiderman LJ, Pearlman RA, Kaplan, RM, et al. Relationship of general advance directive instructions to specific life-sustaining treatment preferences in patients with serious illness. *Archives of Internal Medicine* 1992; 52: 2114-22.
  13. Tsevat J, Cook EF, Green ML, et al. Health values of the seriously ill. *Annals of Internal Medicine* 1994; 122: 514-20.
  14. Christakis NA, Aasch DA. Physician characteristics associated with decisions to withdraw life support. *American Journal of Public Health* 1995; 85: 367-72.
  15. DiMatteo MR. Health psychology research: The interpersonal challenges. In: Brannigan GG, Merrens MR, eds. *The Social Psychologists: Research Adventures*. New York: McGraw-Hill, 1995. pp. 207-20.
  16. Virmani J, Schneiderman LJ, Kaplan RM. Relationship of advance directives to physician-patient communication. *Archives of Internal Medicine* 1994; 154: 909-13.
  17. Gillick MR, Hesse K, Mazzapica N. Medical technology at the end of life. *Archives of Internal Medicine* 1993; 153: 2542-7.
  18. Danis M, Patrick DL, Southerland LI, Green ML. Patients' and families' preferences for medical intensive care. *JAMA* 1988; 260: 797-802.