

# Patient and Physician Roles in End-of-Life Decision Making

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**This study is a cross-sectional descriptive survey of randomly selected primary care patients and physicians regarding patient, physician, and family roles in end-of-life decision making. The subjects included 329 adult outpatients and 272 practicing physicians. Physicians were more likely than patients to believe the patient alone was responsible for making end-of-life decisions. Patients were more likely than physicians to believe the physician should provide a recommendation in addition to facts to help the patient make end-of-life decisions. We conclude that patients prefer a more active role for physicians in both decision making and discussion of end-of-life care than do physicians themselves.**

**KEY WORDS:** physician-patient relationships; medical decision making; life support care; patient; physician.

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The recently published results from the SUPPORT trial demonstrated serious shortcomings in end-of-life decision making and medical care.<sup>1</sup> End-of-life decision making did not improve following the intervention, in which skilled nurses provided physicians with information about their patients' preferences for end-of-life care. Commentaries on the SUPPORT trial have noted that end-of-life decision making is a process that must occur within the context of the individual patient-physician relationship, and that nurses and computers may not help meet patients' goals.<sup>2</sup> If interventions outside the patient-physician relationship fail, characteristics of direct discussion and decisions between patients and their doctors must be improved. In this context, several questions need to be better answered. How do patients and physicians view their roles in end-of-life decision making? How should they share the decision-making process? What is the role of the family in end-of-life decision making? We performed a multicentered study of ambulatory patients and primary care physicians designed to address these questions.

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## METHODS

We conducted a cross-sectional descriptive survey of primary care patients and physicians in eight communities in the United States from January through April 1992. The study sites were those of the participants in the End-of-Life Study Group, including Tampa, Florida; Peoria and Rockford, Illinois; Wichita, Kansas; Louisville, Kentucky; Greensboro, North Carolina; Danville, Pennsylvania; and Morgantown, West Virginia. The methods were reported previously.<sup>3</sup>

### Patients

Patients were adult outpatients who had appointments in primary care offices. Exclusion criteria included active psychiatric illness, and health or emotional states that might be jeopardized by participation. Forty patients were randomly selected from appointment schedules at each site. All gave informed consent. Demographic data on patients refusing to participate were collected.

### Physicians

Physicians were primary care practitioners in general internal medicine, family medicine, and general practice. Fifty practicing primary care physicians were randomly selected from lists of primary care physicians in each community.

### Study Instrument and Data Collection

A qualitative study by our group, using structured interviews with patients and physicians regarding end-of-life decisions and discussions, preceded this study and is reported elsewhere.<sup>4</sup> We used findings from that study to formulate the questionnaires used in this study. Physician investigators or their trained research assistants administered an 83-item questionnaire face-to-face to patients. The instrument included questions about beliefs and preferences regarding decisions about end-of-life care as well as demographics, health status, and Karnofsky functional performance scores.

Practicing physicians were mailed 58-item questionnaires on beliefs and preferences regarding decisions about end-of-life care as well as demographic information.

### Statistical Analysis

We used  $\chi^2$  analysis to compare the responses of physicians and patients to identical questions.

## RESULTS

The study was completed by 329 patients and 272 practicing physicians. The response rate for patients was 76%. Nonresponding patients did not differ from responding patients in age, gender, or race (all  $p$  values  $>.20$ ). The physician response rate was 272 (69%) of 394.

The patients' ages ranged from 19 to 94 with a mean age of 50.9 years; 248 patients were white, 74 were black; 140 patients were male, 189 were female. The patients' mean Karnofsky score was 90. Twenty-six patients (8%) rated their health as excellent, 72 (22%) rated it very good, 108 (33%) rated it good, 92 (28%) rated it fair, and 25 (7.6%) rated it poor.

The physicians' ages ranged from 27 to 90 with a mean age of 44.7 years; 236 physicians were white, 4 were black; 209 physicians were male, 60 were female. One hundred thirty-four (49%) of the physicians practiced internal medicine; 123 (45%), family medicine; and 13 (5%), general practice.

### Who Should Decide?

Figure 1 shows the responses of patients and physicians to the question: "For patients who *can* communicate, who do you think has primary responsibility for making the final decision about whether or not to use life-sustaining treatments?" Although the majority of patients and physicians believed that the individual patient was responsible for making end-of-life decisions, physicians were significantly more likely to believe so. A significant minority of patients believed the physician should make decisions for competent patients. A minority of patients adhered to a family-centered model of decision making, in which the family was responsible for making decisions.

### How Should the Decision Making Be Shared by Patient and Physician?

Figure 2 shows the responses of patients and physicians to the question of how to share the decision making. Fewer physicians than patients felt it was the responsibility

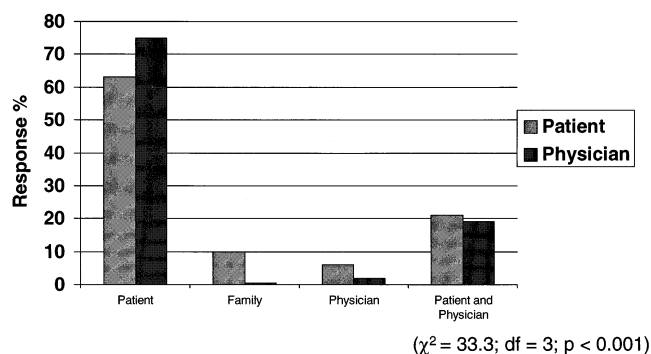
of the physician to help the patient make decisions by providing a recommendation. In contrast, patients were more likely to prefer a model of shared decision making with greater physician input.

## DISCUSSION

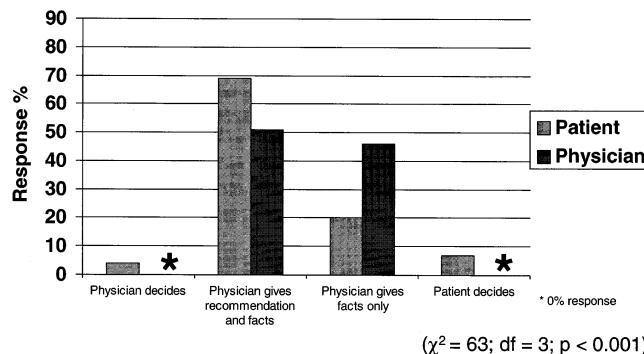
To our knowledge, this is the first multicentered study in which relatively healthy ambulatory patients and practicing primary care physicians' views on end-of-life decision making have been compared. The perspective expressed by the patients in our study is consistent with that of patients assessed in other settings. For example, Ainslie studied elderly outpatients' views on who should make treatment decisions in scenarios of current health or having a stroke.<sup>5</sup> About 64% chose "self" or "self with doctor" in these scenarios; the rest chose "doctor" or "other." Reports in which patients have shown weak desire to participate in medical decision making have generally asked patients to choose between obtaining information and medical decision making. Patients show a stronger preference for information seeking than for medical decision making.<sup>6,7</sup>

Our study has strengths and limitations. A strength is the size and diversity of the population of primary care patients and physicians we questioned. Because the patients and physicians were recruited from both academic and community settings, the responses should be generalizable to many primary care patients and physicians. However, the patients were generally healthy outpatients, so the results cannot be extrapolated to ill outpatients or inpatients. The design of our study did not allow comparison of the views of patient-physician pairs.

Our findings support the need for physician education regarding patients' perceptions of the physician's role in end-of-life decision making. Future research in this area should include analysis of end-of-life decision making preferences in patient-physician pairs to define characteristics of individual patient-physician relationships that foster convergence of both parties' perspectives. Future interventions designed to improve end-of-life care are likely to be effective if they focus on improving direct patient-physician communication and relationships.



**FIGURE 1.** Who should make decisions for a competent patient?



**FIGURE 2.** How should the patient and the physician share the decision-making process?

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The End-of-Life Study Group is based at the University of North Carolina-Chapel Hill. The members are fellows and faculty who participated in the 1990-1992 cohort of the General Internal Medicine Faculty Development Fellowship: Harold M. Adelman, MD, and Paul M. Wallach, MD, University of South Florida, Tampa; Sarah C. Johnston, MD, University of Kansas at Wichita; Rita Layson, MD, University of North Carolina-Greensboro; Robert McNutt, MD, University of Wisconsin at Milwaukee; Mark P. Pfeifer, MD, University of Louisville, Ky.; Jaan E. Sidorov, MD, Geisinger Medical Center, Danville, Pa; Arthur Evans, MD, MPH, and Miriam B. Settle, PhD, University of North Carolina-Chapel Hill.

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