Patients’ Knowledge of Options at the End of Life
Ignorance in the Face of Death

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For the past 25 years, US citizens have sought increased control over their experience of dying. In the courts, they have ensured their rights to refuse and withdraw life-sustaining treatment, while in the legislature, they have had laws passed to promote the use of advance directives (the 1990 Patient Self-Determination Act) and to legalize physician-assisted suicide (the 1994 Oregon Death with Dignity Act).

A firm belief in informed consent has justified and legitimated these efforts to enhance patients’ control over end-of-life care. For example, the Patient Self-Determination Act aims to create “clear and convincing evidence” regarding every admitted patient’s end-of-life care choices, assuming that these anticipatory choices would be fully informed.

Similarly, the Oregon Death with Dignity Act allows terminally ill patients to request lethal prescriptions only “after being fully informed by the attending physician of...the feasible alternatives, including, but not limited to, comfort care, hospice care and pain control.”

Rarely has the US populace assumed so strongly that patients would be well informed regarding all care options be-

Context Effectiveness of legislation promoting advance directives and legalizing physician-assisted suicide depends on patients’ understanding their legal options about end-of-life care. However, outpatients’ understanding of their legal options at the end of life has not been studied.

Objectives To estimate the percentage of outpatients who are informed about 4 areas relevant to end-of-life care: refusal and withdrawal of lifesaving treatments, physician-assisted suicide, active euthanasia, and double effect; and to determine whether authoring advance directives, experiencing illness, acting as a proxy for health care decisions, and caring for an ill loved one are associated with better knowledge in end-of-life care.

Design Cross-sectional survey.

Setting and Participants One thousand consecutive English-speaking, adult patients attending 1 university-based internal medicine clinic and 3 community-based, university-affiliated, mixed internal medicine and family practice clinics in Oregon during May and June 1999.

Main Outcome Measures Percentage of correct responses in the 4 topic areas and total knowledge score, adjusted for demographic (eg, age, race, educational level, income level, marital status) and experiential (eg, health, proxy decision making, advance directives, and death of a loved one) factors.

Results Of the 1000 patients invited to participate, 728 (73%) consented and completed the questionnaire and were included in the analysis. A total of 69% of respondents answered correctly regarding refusal of treatment, 46% for withdrawal of treatment, 23% for assisted suicide, 32% for active euthanasia, and 41% for double effect. Sixty-two percent of respondents did not distinguish between assisted suicide and euthanasia. After adjustment for other covariates, better knowledge was significantly associated with white race (odds ratio [OR], 2.3; 95% confidence interval [CI], 1.3-4.2), having at least a college degree (OR, 3.0; 95% CI, 1.4-6.7), and having been a proxy for health care decisions (OR, 1.8; 95% CI, 1.2-2.6). Personal experience with illness (OR, 1.0; 95% CI, 0.6-1.5), death or illness of a loved one (OR, 1.6; 95% CI, 1.0-2.7), and authoring an advance directive (OR, 1.3; 95% CI, 0.9-2.0) were not associated with better knowledge.

Conclusions A significant proportion of outpatients at university-affiliated clinics in Oregon appear to misunderstand options in end-of-life care. Our results suggest that greater public knowledge about end-of-life care is needed, and advance care planning must be preceded by education about options in end-of-life care.

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See also Patient Page.

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fore making a health care decision, yet this assumption may not be warranted. If patients mirror the general public, then many are misinformed about terminal palliative care. A national poll conducted by the American Medical Association in 1997 found that 40% of respondents did not know it is legal to give pain medicine that could have the additional effect of hastening death (double effect), and 35% were not familiar with the terms hospice or palliative care. Furthermore, studies suggest that some patients do not distinguish between physician-assisted suicide and euthanasia. Therefore, we sought to assess outpatients’ knowledge of their legal options near the end of life. Our primary goal was to estimate the percentage of outpatients who are informed about 4 areas relevant to end-of-life care: refusal and withdrawal of life-saving treatments, physician-assisted suicide, active euthanasia, and the doctrine of double effect. Our secondary goal was to test whether authoring advance directives, experiencing personal illness, acting as a proxy for health care decisions, and caring for an ill loved one are associated with better knowledge in end-of-life care. We chose to study outpatients specifically because they represent a convenient population at risk of hospitalization who, by virtue of their access to a physician, can be educated about and encouraged to participate in advance care planning. As stated by Linda Emanuel, “[Advance care] planning with young and healthy patients may be considered analogous to screening for illness: the chance of illness is low, but the effort may be worth it.” Moreover, studies have shown that patients prefer to discuss advance directives early in the patient-physician relationship and that advance care planning can be effectively introduced in the outpatient setting.

**METHODS**

**Subjects**

During May and June of 1999, 1000 consecutive English-speaking outpatients 18 years or older who were checking in for their clinic appointment were invited independently to participate in the study. All qualified patients were offered the self-administered survey during check-in at 4 primary care sites: 1 internal medicine clinic at Oregon Health Sciences University in Portland (400 patients approached) and 3 mixed, internal medicine and family practice clinics affiliated with Oregon Health Sciences University in Beaverton, Sellwood, and Tigard (200 solicitations each). The sample size was sufficiently large to yield 95% confidence intervals (CIs) of ± 3% or less around prevalence estimates.

Throughout the study period, occasional audits of the distribution and collection process were conducted to ensure proper selection of patients and full confidentiality. The study was approved by the Oregon Health Sciences University institutional review board, which considered completion of the survey as giving informed consent.

**Survey Instrument**

The survey was developed by one of us (M.J.S.), written at a sixth-grade reading level, and then pilot tested for clarity by a group of 20 randomly selected outpatients from the internal medicine clinic at Oregon Health Sciences University. The questionnaire presented a sequence of events in an unfolding clinical vignette that traced the medical saga of “John,” a hypothetical patient (see “Survey Vignettes and Questions” box). John eventually dies of cancer but not before his case raises several issues and presents dilemmas regarding refusal of treatment, withdrawal of treatment, euthanasia, assisted suicide, and double effect. The vignettes did not use the terms assisted suicide or euthanasia to avoid the ambiguity and emotional reaction that these terms might provoke. After each portion of the vignette, subjects were posed questions in the following format: “In Oregon, does a patient who has less than six months to live have the legal right to . . . ?” Subjects could answer, “Yes in all cases,” “Yes in some cases,” “No,” or “Don’t know.”

The questionnaire inquired about the participants’ age, sex, marital status, employment status, income level, ethnicity, religion, educational level, and health status. The questionnaire also assessed experience with end-of-life dilemmas by inquiring about the following experiential factors: personal illness, authoring an advance directive, experiencing the death or grave illness of a loved one, and participating in proxy decision making. Finally, respondents rated the clarity of the questions as well as their confidence level regarding their answers on scales of 1 to 5.

**Analysis**

After calculating the percentage of correct responses to the 4 topic areas, we generated a total knowledge score for each respondent according to a point system whereby fully correct answers were awarded 1 point, partially correct answers were given a half point, incorrect answers had a point deducted, and anything else (including “Don’t know”) had no value. With this formula, knowledge scores could range from −8 to 8. A respondent was considered knowledgeable if his/her score was above the median for the survey population (4.0).

Demographic factors associated with being knowledgeable (ie, scoring above the median) were initially identified using χ² testing. The strength and independence of the associations was tested using a stepwise logistic regression procedure whereby a parsimonious set of strong independent predictors of knowledge were identified from among the set of demographic variables (eg, race, educational level, income level, and marital status). Using that model, each experiential factor (such as health, proxy decision making, authoring advance directives, and experiencing the death of a loved one) was examined separately while adjusting for the relevant sociodemographic variables using logistic regression. Results were verified using ordered logistic regression. Statistical analysis was conducted using STATA 6.0 software (Stata Corp, College Station, Tex).

**RESULTS**

**Population Characteristics**

Of the initial 1000 outpatients approached, 728 (73%) consented,
### Survey Vignettes and Questions

Subjects were instructed to read the vignettes that follow and answer the 9 questions by circling 1 of the following 4 answers: yes in all cases; yes in some cases; no, no legal right; and don’t know.

John has cancer. He has been told that he has less than 6 months to live and is terminally ill. His cancer doctor offers him a form of medical treatment, called “Chemotherapy,” that may cure him. He decides that he does not want the treatment.

1. In Oregon, does a patient like John, who has less than 6 months to live, have the legal right to refuse treatment that might cure him or save his life?

John does not get any treatment and the cancer worsens. At one point, John loses the energy to eat or drink on his own. If John continues without food or water, he will soon die. His physician offers him intravenous fluids (water through the veins) and a feeding tube (a tube that goes directly into the stomach and allows the physician to feed him). John is still able to speak for himself and make his own decisions. He decides that he does not want the intravenous fluids or the feeding tube.

2. In Oregon, does a patient like John, who has less than 6 months to live, have the legal right to refuse intravenous fluids even if it means that his death will occur sooner?

John rethinks his situation and changes his mind. He decides that he does want the intravenous fluids and the feeding tube. His doctor orders these and, for a brief time, John decides that he does not want the intravenous fluids or the feeding tube.

3. In Oregon, does a patient like John, with less than 6 months to live, have the legal right to refuse a feeding tube even if it means that his death will occur sooner?

John continues without food or water, he will soon die. His physician offers him intravenous fluids (water through the veins) and a feeding tube (a tube that goes directly into the stomach and allows the physician to feed him). John is still able to speak for himself and make his own decisions. He decides that he does not want the intravenous fluids or the feeding tube.

4. In Oregon, is it legal for a physician to turn off a ventilator when requested by a patient like John, with less than 6 months to live, even if it means the patient might die?

The ventilator is turned off, but John miraculously lives. He is not expected to live long, but he cannot bear his illness any longer. He asks his physician to help him die. He asks, “Doc, give me a shot or put something through the IV to make me die right away.”

5. In Oregon, is it legal for a physician to inject a medication that would cause a patient’s immediate death if a patient like John, with less than 6 months to live, requests it?

John’s doctor refuses to inject John with a medication that would cause him to die. John asks if his doctor would instead prescribe a medication that John could give to himself to end his life. He asks, “Can’t you prescribe something I can take to die? Don’t worry, I could take it without anyone’s help.”

6. In Oregon, is it legal for a physician to refuse to inject a medication that would cause a patient’s immediate death if a patient like John, with less than 6 months to live, requests it?

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7. In Oregon, is it legal for a physician to prescribe a medication and provide advice so that the patient can take medications that will end his life if a patient like John, with less than 6 months to live, requests it?

John’s doctor refuses his request, but promises John that she will do everything in her power to keep him comfortable. She puts John on a painkiller. John is very sleepy but appears restless and uncomfortable. She increases the dose of the painkiller to comfort him even though she knows that the painkiller at high doses can cause patients to stop breathing. Finally John looks comfortable, but suddenly he stops breathing. He dies peacefully soon thereafter.

8. In Oregon, can a physician refuse to prescribe a medication and provide advice so that a patient like John, with less than 6 months to live, can take medications that will end his life if the patient requests it?

John’s physician refuses his request, but promises John that she will do everything in her power to keep him comfortable. She puts John on a painkiller. John is very sleepy but appears restless and uncomfortable. She increases the dose of the painkiller to comfort him even though she knows that the painkiller at high doses can cause patients to stop breathing. Finally John looks comfortable, but suddenly he stops breathing. He dies peacefully soon thereafter.

9. In Oregon, is it legal for a physician to give patients like John, with less than 6 months to live, pain medications with the goal of relieving pain and suffering even if death may occur sooner as a result?

### Patients’ Knowledge of Options at the End of Life

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<th>Question</th>
<th>Answer</th>
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patients correctly understood that competent patients in Oregon can legally refuse life-saving or life-sustaining treatment in all cases (TABLE 2). Respondents had less knowledge about withdrawal of treatment, with only 46% correctly identifying that competent patients in Oregon can legally withdraw life-sustaining treatment in all cases. Only 23% of respondents correctly identified assisted suicide (defined as “prescribing a medication and providing advice so that a patient can take medications that will end his life”) as a legal option for competent terminally ill adults in Oregon in all cases. Thirty-two percent of respondents recognized that active euthanasia (portrayed as “injecting a medication that would cause a patient’s immediate death”) is illegal. Forty-one percent of respondents recognized that double effect (described as “giving pain medications with the goal of relieving pain and suffering even if death may occur as a result”) is legal in Oregon. When asked if physicians could legally refuse to satisfy a patient’s request for assistance in dying, 340 (48%) of 708 respondents believed that active euthanasia was legal and assisted suicide was illegal.

Confusion Between Assisted Suicide and Active Euthanasia

Many respondents did not distinguish between assisted suicide and active euthanasia. For example, of those who correctly believed that assisted suicide is a legal option for terminally ill competent adults in Oregon, 262 (64%) of 411 respondents believed that active euthanasia is legal as well. A comparison of responses for the assisted suicide and euthanasia questions (TABLE 3) demonstrated that many respondents gave similar answers for both questions (eg, most respondents believed that both assisted suicide and active euthanasia are legal when, in fact, only assisted suicide is). Only 127 (18%) of 705 respondents answered both questions correctly. Finally, 38 (5%) of 705 answered that euthanasia was legal and assisted suicide was illegal.

Clarity and Confidence

Despite the frequency of “Don’t know” and incorrect responses, 626 (89%) of 703 respondents indicated that the survey was clearly worded and 440 (63%) of 700 were confident in their responses. Having confidence was associated with respondents having experienced the illness or death of a loved one (P < .01) or having acted as a proxy for health care decisions (P < .01). Authoring a living will (P = .51), experiencing personal illness (P = .14), or being well educated (P = .80) was not associated with confidence.

Associations of Knowledge

Total knowledge scores were significantly higher for respondents who were white, married, aged at least 30 years, English-speaking, college-educated, and Jewish, but after multivariable adjustment, knowledge was independently associated only with white race and college education (TABLE 4).

We then examined, after adjusting for demographic variables, 4 experiential factors: personal illness, death or illness of a loved one, proxy decision making, and authoring an advance directive. Among these markers of personal life history, only the experience of proxy decision making was independently and significantly associated with accurate knowledge about options in end-of-life care (odds ratio [OR], 1.8; 95% CI, 1.2-2.6). Experience with death or illness of a loved one showed a trend toward significance (OR, 1.6; 95% CI, 1.2-2.0).
The characteristics listed are only those that significantly associated with better knowledge under bivariate analyses using \( \chi^2 \) test (significance was determined as \( P<.05 \)). The adjusted odds ratio (OR) and 95% confidence interval (CI) resulted from multivariable analyses using a model adjusting for education, income, ethnicity, religion, and marital status. Ellipses indicate that age, primary language, and religious practice were excluded from the multivariate model result from multivariable analyses using a model adjusting for education, income, ethnicity, religion, and marital status. Ellipses indicate that age, primary language, and religious practice were excluded from the multivariate model. The bold number represents those who answered both questions correctly. Pearson \( \chi^2 \) for homogeneity is 373.6 and \( P<.001 \). The total number of respondents to both questions equaled 706.

The number (percentage) of those who were knowledgeable indicates the number or percentage in each category who scored above the median score for the entire population (4.0). Total knowledge scores were calculated by giving fully correct answers 1 point, partially correct answers a half point, and incorrect answers minus 1 point. All other answers had no value, including the answer, “Don’t know.”

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health care rights. If borne out in other settings, the high prevalence of misunderstanding found among these patients underscores the need for more effective physician-directed discussion about end-of-life care.18-21

How might more effective discussion about end-of-life care occur? Our findings raise several points that should be considered in formulating a response. First, no group of patients knows enough about end-of-life care (if our goal is to inform all patients fully), not even those with better socioeconomic situations or higher educational levels. Second, having patients go through the exercise of composing or signing an advance directive appears an insufficient means of educating patients about options in end-of-life care. Third, authoring advance directives does not improve patients' comfort with end-of-life deliberations. Fourth, patients may be more likely to learn about options in end-of-life care when a loved one is in peril than when they themselves are threatened.

In light of these findings, physicians might consider discussing end-of-life issues with all patients, using a questionnaire or structured interview to identify knowledge deficits, then educating accordingly. Furthermore, besides using hypothetical situations involving the patients themselves, physicians might examine end-of-life care options with patients by exploring their prior experiences with a loved one's illness or death (87% of our study population had such experiences).

In conclusion, advance directives generally and legalized physician-assisted suicide specifically make it imperative that people properly understand options in end-of-life care. Our study suggests that the majority of patients do not understand them. Not only should physicians consider this issue as they discuss end-of-life issues with patients, but legislators and policymakers must also consider how well US residents comprehend options in end-of-life care because this level of comprehension may affect how patients interact with the health care system and how citizens vote on measures such as the Oregon Death with Dignity Act.

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REFERENCES