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Interest in Physician-Assisted Suicide among Oregon Cancer Patients

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INTRODUCTION

Legalization of physician-assisted suicide (PAS) and euthanasia continues to be debated in medical, ethical, and political arenas. Even where illegal, physicians assist patients in suicide.¹ In the United States, only Oregon has legalized PAS, limiting this option to competent, terminally ill patients who request it. Since enactment of the Oregon Death with Dignity Act (ODDA) in 1997, 208 patients have died by PAS. Cancer is the most common terminal illness associated with PAS in all jurisdictions in which this option is legalized.²

When faced with a patient who requests PAS, clinicians in Oregon are advised that their obligation is to search for and treat remediable factors that may address the patient's suffering, rendering PAS an option of last resort.³ Studies among patients with advanced cancer outside of Oregon report that those who endorse on a survey that they might request PAS or prefer a hastened death are often depressed, hopeless, or psychosocially distressed. Less consistently, these studies identify poor social support, feeling unappreciated, spiritual distress, poor quality of life, declining functional status, concern with being a burden to others, and physical symptoms as factors.⁴

In studies outside of Oregon, approximately 10 percent of terminally ill cancer patients endorse a desire for death to come sooner or an interest in PAS.⁵ Yet only one in 1,000 deaths in Oregon are by PAS.⁶ Surveys of physicians and hospice professionals in Oregon paint a different picture of patients who actually receive lethal prescriptions, emphasizing the role of desire for control, independence, and avoiding institutionaliza-

tion; and existential concerns such as lack of meaning and readiness to die. Depression and poor social support were not considered important reasons for actual PAS requests.⁷ Reconciling these somewhat disparate views of why patients request PAS would facilitate the development of interventions that render PAS an option of last resort. The goals of this study were to measure:

1. The level of interest in and actions around PAS among cancer patients in Oregon,
2. How this interest changes over time,
3. The association between psychosocial and medical factors and interest in PAS, and
4. The relationship between expressing an interest in PAS on a survey and actually requesting legalized PAS from a physician.

PATIENTS AND METHODS

Cognitively intact patients with advanced cancer were recruited from the oncology clinics of the Portland Veterans Affairs Medical Center (VAMC) and the Oregon Health & Science University (OHSU) (acronyms are listed in table 1). Subject entry began in 1998 and was completed in 2001. During the study, participants who said that they were potentially interested in PAS were assessed every three months for up to two years. The patients who were considered eligible to be recruited for participation in the study included:

- Patients who had cancer, with 50 percent probability of dying within two years.
- Patients who could communicate in English.
- Patients who were negative for human immunodeficiency syndrome (HIV).
- Patients who had a Folstein Mini-Mental State Examination (MMSE) score of greater than 23.⁸
- Patients who received ongoing care at OHSU or Portland VAMC.

Each potential subject received a letter of invitation to participate from his or her primary oncologist. The study was approved by the institutional review boards at both OHSU and the Portland VAMC. After the study was described to all potential participants, subjects gave their written informed consent.

Demographic information was obtained from each participant. Pain was measured with three items from the Wisconsin Brief Pain Questionnaire, rating pain on average and at its worst in the previous two

weeks, and pain at the time of the interview, all on 0 - 10 scales.⁹ Standardized instruments were used to measure functional status (Eastern Cooperative Oncology Group — ECOG¹⁰), social support (Duke-University of North Carolina Functional Support Scale¹¹), depression (Geriatric Depression Scale — GDS¹² and Diagnostic Interview Schedule — DIS¹³), and satisfaction with advanced cancer care.¹⁴ Four

TABLE 1 Acronyms and definitions

<i>alpha</i>	Indicates the probability of rejecting the hypothesis tested, when the hypothesis tested is true.
<i>chi-square</i>	test that compares the frequency of an observation in the collected data and those that would be expected if there were no relationships between the variables
CI	confidence interval: a range of values around the mean where it is expected that the true population mean is located
df	degrees of freedom: in tests of statistical significance, refers to the number of values in the sample that cannot be mathematically calculated from knowing other values and a calculated statistic
DIS	Diagnostic Interview Schedule
ECOG	Eastern Cooperative Oncology Group
GDS	Geriatric Depression Scale
HIV	human immunodeficiency syndrome
MMSE	(Folstein) Mini-Mental State Examination
<i>n</i>	number of subjects in a group
<i>N</i>	number of subjects in the study
ODDA	Oregon Death with Dignity Act
OHSU	Oregon Health & Science University
<i>p</i>	probability value
PAS	physician-assisted suicide
SD	standard deviation: one of several indices of variability that are used to characterize the dispersion among the measures in a given population
<i>se</i>	standard error: the estimated standard deviation of a statistic
Spearman's <i>rho</i>	measure of the linear relationship between two values
two-tailed test	test of a statistical hypothesis in which the value of the statistic that is either too small or too large will lead to rejection of the hypothesis
VAMC	Veterans Affairs Medical Center

items were completed from the Beck Hopelessness Scale, which had been previously reported to be statistically different in amyotrophic lateral sclerosis patients who were interested in PAS and those who were not.¹⁵ Three items from the Zarit Burden Inventory were revised to measure patients' perception of how often their medical condition stressed or strained or caused hardship to their families or how often they felt that they were a burden to their families.¹⁶ Suffering, the importance of religion, and the degree to which health problems limited quality of life were each measured on 0 - 10 Likert scales. Each subject indicated whether she or he had ever seen a mental health professional or had ever made a suicide attempt.

Subjects indicated their overall position on legalized PAS, whether they had contacted any organizations that assist patients in obtaining legal lethal prescriptions, and whether they discussed their interest in PAS with their family, friends, or physician. They were asked whether they would ever consider requesting a lethal prescription; those who indicated they might consider or were planning to request PAS were followed every three months for up to two years, to understand variability in interest in PAS over time. Patients who indicated that they would never make such a request or were unsure were not evaluated further. At initial and follow-up appointments, participants rated their interest in requesting a lethal prescription in the previous two weeks (0 = I am very *unlikely* to request a lethal prescription, 10 = I am very *likely* to request a lethal prescription), as well as their desire for death to come sooner in the previous two weeks, also on a 0 - 10 Likert scale. At each visit, participants who rated their interest in requesting a lethal prescription as "0" were considered to have no interest, "1 - 2" minimal interest, "3 - 4" mild interest, "5" or greater a serious interest. Once referred to hospice, patients were followed monthly, as tolerated. After the patient's death, each oncologist was asked if the patient had initiated discussion about PAS and any details of the discussion.

STATISTICAL ANALYSIS

Summary statistics included proportions for categorical variables, means with standard deviations (SDs) for continuous variables, and Spearman's *rho* to examine correlations. The main dependent variable of interest, likelihood of requesting a lethal prescription in the previous two weeks, was an ordinal variable ranging from 0 to 10. We used proportional odds models¹⁷ to identify potential predictors for the likelihood of requesting PAS. The proportional odds model is commonly used for the analysis of ordinal data, and it assumes that the odds ratio of a predictor variable (for example, hopelessness) is equivalent for all logistic regressions defined by various cutpoints (for example, PAS > 4 versus PAS ≤ 4, PAS > 5 versus PAS ≤ 5). The odds ratio is referred to as the cumulative odds ratio. Predictor variables were examined in a stepwise procedure, using a forward Wald procedure with an *alpha* to enter of 0.1 and *alpha* to remove of 0.15. All tests were two-tailed, and a *p* value of < 0.05 was considered to be statistically significant.

For a subset of subjects who were followed longitudinally, we evaluated how interest in obtaining a lethal prescription (0 - 10 scale) changed over time in response to other time-varying factors (that is, an ECOG score, support scale, depression, hopelessness, family burden, religiousness, quality of life, suffering, pain, satisfaction with medical care, and hospice care). We fit a random effects model, treating each subject as a random effect,¹⁸ and estimated a change in an interest in PAS as a function of each time-varying factor. Since the residual analysis using the original PAS interest data revealed non-normality, we transformed the data using a square-root transformation and repeated the analysis. The *p* values from both analyses were almost identical, and did not change statistically significant factors. Because the interpretation of the slope estimate is more intuitive for untransformed data, we presented the results from the original data. The mixed model analysis was performed using SAS PROC MIXED procedure.¹⁹

RESULTS

PARTICIPANTS

We located 417 potential subjects from patients with advanced cancer at the Portland VAMC and at OHSU; of these, 53 patients were ineligible for the following reasons:

- The patient had a low MMSE score ($n = 26$),

- The patient did not speak English ($n = 15$)
- The patient did not have ongoing care ($n = 12$).

Among the remaining 364 potentially eligible participants, 93 (26 percent) were not approved by their oncologist or primary physician: for 69 patients, the oncologist or primary physician gave no reason for disapproval. Other reasons physicians gave for disapproval included:

- The patient had other mental or cognitive disorders,
- The patient was too sick or not aware of diagnosis,
- The oncologist or physician had not met the patient.

Of the 31 referring physicians, 10 referred 10 or more patients. Eight of these 10 physicians disapproved fewer than 10 percent of potential referrals. Two oncologists disapproved substantial numbers of referrals without explanation: one disapproved 17 of 52 patients (33 percent), and the second disapproved 51 of 132 patients (39 percent). Because these were otherwise potentially eligible patients, they are included in the non-respondent proportion.

Of the 364 remaining potentially eligible subjects, 110 declined participation (30 percent); thus, the 161 subjects who agreed to participate comprised 44 percent of the 364 potential subjects who were initially identified. Of the 161, almost three-quarters were men, 93 percent were White, and the mean age was 62 years; 60 percent were VAMC patients, with 40 percent enrolled at the OHSU site. The most frequent cancer types were lymphoma/hematologic (23 percent) and lung (22 percent). Of these 161 patients, 38 (24 percent) met criteria for major depressive disorder on the DIS, and 32 (20 percent) were probably "depressed" as measured by the GDS, because they endorsed 14 or more depressive symptoms (see table 2).

Of our 161 subjects, 31 percent indicated at initial evaluation that they might or planned to request PAS, and 9 percent said that they had had a serious interest in obtaining a lethal prescription in the previous two weeks. We followed 42 of the subjects longitudinally; of these subjects, 19 developed a serious interest in obtaining a lethal prescription at some point, eight of the 19 (42 percent) informed their oncologist of this interest, and two made an explicit request for PAS, one of whom never expressed a strong interest at any point in the study.

SUPPORT FOR PAS AND INTEREST IN PAS

Of the 161 participants, 57 percent supported or strongly supported legalization of PAS (see table 2); 47 percent stated they would never consider PAS ($n = 76$); 14 percent were unsure ($n = 23$); 34 percent might consider it in the future ($n = 55$); and 4 percent were planning to request PAS ($n = 7$). No patient had made a request for PAS to a physician at the first evaluation. Of the 161 participants, 15 (9 percent) indicated a serious interest in PAS in the previous two weeks. Of these 15 subjects, one had discussed PAS with his physician, and one had contacted a PAS advocacy organization.

Of all of the 161 participants, 57 percent had discussed their attitudes about PAS with friends or family before receiving the letter to participate in the study (see table 3); 81 percent (50 of 62) of those who either might consider PAS or who had planned to request PAS had discussed their views with friends or family, whereas only 48 percent (47 of 99) of those who would never consider PAS or who were "unsure" had discussed their views (chi -square = 17.5, $df = 1$, $p < 0.001$). Among those who might consider PAS ($n = 62$), 55 percent ($n = 34$) thought that most friends and family would be supportive, 10 percent ($n = 6$) thought that friends and family would talk them out of it, and 35 percent ($n = 22$) were unsure whether family and friends would support or oppose this decision.

FACTORS ASSOCIATED WITH INTEREST IN REQUESTING PAS

At initial evaluation, increasing interest in requesting a lethal prescription in the previous two weeks was statistically associated with greater suffering, increasing depression scores measured by GDS, increasing hopelessness, more limitations on quality of life from health problems, more pain, sense of burden to others,

and less satisfaction with medical care, but not with any demographic variables, social support, or functional status (see table 4). The correlation between desire to die and interest in PAS was 0.48 ($p < 0.001$). Five of the 15 patients with a serious interest in PAS (33 percent) met criteria for major depressive disorder on DIS; 33 of the 146 patients without a serious interest in PAS (23 percent) were also depressed ($\chi^2 = 0.839$, $df = 1$, $p = 0.36$). In the multivariate analysis, only the degree to which health problems limited quality of life remained a significant predictor of interest in PAS. There was no difference between subjects with and without a serious interest in PAS on whether they had ever seen a mental health provider (eight of the 15 with serious interest in PAS, 53 percent versus 63 of the 146 without a serious interest in PAS, 43 percent; $\chi^2 = 0.752$, $df = 1$, $p = 0.45$) or who had a previous suicide attempt (two of the 15 with a serious interest in PAS, 13 percent versus nine of the 146 participants without a serious interest in PAS, 6 percent; Fishers exact test = 0.27).

LONGITUDINAL INTEREST IN PAS

Of the 62 subjects who expressed a potential future interest in PAS (who had marked that they were planning to request a lethal prescription or might consider it in the future), 42 agreed to participate in a longitudinal evaluation to help understand how their views might change over time. Persons who declined follow-up or who died before follow-up were more depressed (seven of the 20 who declined to participate, 35 percent versus four of the 42 who agreed to participate, 10 percent; $\chi^2 = 6.03$, $df = 1$, $p = 0.01$), but did not differ in the other factors including demographic factors, interest in PAS, mean GDS, desire for death, or satisfaction with medical care, compared to those who participated in the longitudinal study. Of the 42 subjects, 29 completed three or more evaluations, 21 completed four or more evaluations, and 15 completed five or more evaluations. Among those who were followed longitudinally, 19 had a serious interest in obtaining a lethal prescription at some point, eight had a serious interest in obtaining a lethal prescription at the first evaluation, but never subsequently; and 11 had a serious interest in PAS at some point after the first evaluation. Figure 1 shows the variation over time

TABLE 2 Characteristics and views on assisted suicide of cancer patients at first evaluation ($N = 161$)

Characteristic	Mean	SD
Age in years	61.6	11.7
Years of education	13.5	2.9
Characteristic	<i>n</i>	%
Sex		
Male	118	73
Female	43	27
Race		
White	150	93
African-American	4	2
Asian-American	2	1
Hispanic	1	1
Other	4	2
Marital status		
Married/long-term partner	94	58
Single/widowed/divorced	67	42
Healthcare affiliation		
VAMC	97	60
OHSU	64	40
Functional status		
Fully active	35	22
Restricted in strenuous activities	88	55
Ambulant, but unable to work	24	15
Limited self care or bed ridden	14	9
History of suicide attempt	11	7
Ever seen by a mental health provider	71	44
Current major depressive disorder*	38	24
GDS Score ≥ 14 **	32	20
Patients' view	<i>n</i>	%
Support for legalized assisted suicide		
Strongly oppose	35	212
Oppose	13	8
Undecided	21	13
Support	39	24
Strongly support	53	33
Interest in obtaining lethal prescription in 2 weeks previous		
None (0)	117	723
Minimal (1 - 2)	24	15
Mild (3 - 4)	5	3
Serious (5 - 10)	15	9

* As determined by Diagnostic Interview Schedule.

** As determined by Geriatric Depression Scale.

in these 11 respondents. Four of the 19 (21 percent) who had ever indicated a serious interest in obtaining a lethal prescription at any point in the longitudinal part of the study requested information from a PAS advocacy organization, and eight of these 19 (42 percent) had discussed their interest with their oncologist.

For the 42 subjects who were followed longitudinally, we evaluated how interest in obtaining PAS changed over time (on a 0 - 10 scale) in response to other time-varying factors. Religiousness and hospice status were not found to influence their interest. Factors that were associated with increasing interest in obtaining a lethal prescription included:

- Declining functional status (estimate = 0.735, se = 0.247, $p = 0.004$);
- Increasing social support (estimate = -0.119, se = 0.037, $p = 0.002$);
- Increasing depression measured by GDS (estimate = 0.148, se = 0.031, $p < 0.001$);
- Increasing hopelessness (estimate = 0.377, se = 0.155, $p = 0.02$);
- Increasing sense of burden to family (estimate = 0.229, se = 0.080, $p = 0.005$);
- Degree to which poor health limited quality of life (estimate = 0.362, se = 0.075, $p < 0.001$);
- Increasing suffering (estimate = 0.398, se = 0.075, $p < 0.001$);
- Increasing pain (estimate = 0.282, se = 0.097, $p = 0.004$); and
- Decreasing satisfaction with medical care (estimate = -0.0773, se = 0.016, $p < 0.001$).

REQUESTS FOR PAS

Two subjects made an explicit request to their oncologists for a lethal prescription under the ODDA. Both had been followed longitudinally. One patient, who completed four research assessments over one year, was diagnosed with depression by DIS at each assessment; his GDS scores, which ranged from 12 to 24, indicated minimal to severe depression, and his level of hopelessness was high. He received mental health treatment in the last year of life, but he was not enrolled in hospice care before the final study evaluation. He had very little pain, rated his social support as good, with minimal burden to others, but his satisfaction with his medical care decreased from the top quartile to the 25 percent percentile at the final evaluation. At no study assessment did he indi-

cate that he had contacted a PAS advocacy organization or that he planned to request a lethal prescription. He rated his interest in obtaining a lethal prescription and desire for death as 0 at each evaluation. He rated the importance of religion very high on the first three evaluations, but low at the last, at which time he told the examiner he was "resisting his religion." He died two months after his final study assessment, during which time, as reported by his oncologist, he made two explicit requests for a lethal prescription. His physician did not prescribe a lethal medication.

The second subject was assessed six times over nine months, including twice while enrolled in hospice. He discussed his interest in PAS with his physician over time, contacted a PAS advocacy organization, and indicated that he intended to request PAS on all study assessments. He rated his interest in ob-

TABLE 3 Actions of patients around PAS at first evaluation

Characteristic	n	%
Who would be told about PAS plans* (n = 85)		
Only physician	4	5
Only one other person	15	18
Several people	26	31
Many people	23	27
Not sure	17	20
Perception of family/friends' response to patient's request for PAS* (n = 85)		
Would be supportive	41	48
Try to talk out of assisted suicide	8	9
Not sure	36	42
Contacted PAS organization (n = 161)		
Yes, contacted	11	7
Discussed assisted suicide w/ family/friends (n = 161)		
Before study contact	92	57
After study contact	4	2
Never discussed	64	40
Missing	1	1
Discussed assisted suicide with physician (n = 161)		
Yes	9	6
No	111	69
Missing**	41	25

* Only asked of 85 participants who would consider PAS or who were not sure.

** Question inadvertently deleted from 41 questionnaires.

taining a lethal prescription as serious at all but one evaluation, although his desire for death was always low. He met criteria for major depressive disorder by DIS on one of six visits (but not his final visit) and he endorsed many hopeless statements, but his GDS scores never indicated depression. His pain was moderate, his social support good, but he felt he was somewhat of a burden to his family. His satisfaction with medical care was low, ranging from the 12th to the 42nd percentile. His physician reported that he made an explicit request for PAS just before his final study assessment, and he died nine days after this assessment. His physician did not prescribe a lethal medication.

DISCUSSION

This study was conducted in Oregon after enactment of the ODDA, which legalized PAS. The main findings include:

1. Approximately one in 10 cancer patients expressed a serious interest in obtaining a lethal prescription at the initial evaluation.
2. Medical and psychosocial concerns were important in subjects' interest in PAS.

TABLE 4 Proportional odds model: predictors of interest in requesting a lethal prescription

	Univariate analysis			Multivariate analysis		
	Odds Ratio ¹	95% CI	PValue	Odds Ratio	95% CI	PValue
Age (years)	1.00	(0.97, 1.03)	.79	--	--	--
Education (years)	1.05	(0.93, 1.18)	.45	--	--	--
Functional status ²	1.26	(0.86, 1.86)	.24	--	--	--
Social support ³	0.96	(0.92, 1.00)	.06	--	--	--
Depression (DIS) ⁴	1.92	(0.90, 4.09)	.09	--	--	--
Depression (GDS) ⁵	1.08	(1.02, 1.13)	.01	--	--	--
Hopelessness ⁶	1.46	(1.14, 1.86)	.003	1.28	(0.98, 1.66)	0.07
Sense of burden ⁷	1.13	(1.02, 1.27)	.03	--	--	--
Importance of religion ⁸	0.94	(0.84, 1.04)	.19	0.90	(0.80, 1.01)	0.07
Quality of life ⁹	1.25	(1.10, 1.42)	.001	1.26	(1.10, 1.45)	0.001
Suffering ¹⁰	1.17	(1.04, 1.31)	.01	--	--	--
Satisfaction with medical care ¹¹	0.96	(0.93, 0.99)	.002	--	--	--
Pain ¹²	1.15	(1.01, 1.31)	.03	--	--	--

NOTES

1. Odds ratio associated with one unit change of the predictor variable. E.g., the odds ratio for hopelessness is 1.46 in the univariate analysis. This means that there is a 1.46-fold increase in the likelihood of requesting PAS when the hopelessness score increases by 1 (e.g., 2 to 3).

2. Eastern Cooperative Oncology Scale.

3. Duke-University of North Carolina Functional Support Scale.

4. Diagnostic Interview Schedule.

5. Geriatric Depression Scale.

6. Beck Hopelessness Scale – 4 items.

7. Three items revised from Zarit Burden Inventory.

8. 0 - 10 Likert scale.

9. 0 - 10 Likert scale.

10. 0 - 10 Likert scale.

11. FAMCARE.

12. Wisconsin Brief Pain Questionnaire.

3. Among those with interest in PAS, there was a high degree of variability in subjects' interest, when examined over time.
4. Fewer than half of the patients who were followed longitudinally who endorsed a serious interest in obtaining a lethal prescription discussed this issue with their oncologist.
5. Only two study participants who were followed over time ultimately made an explicit request for PAS, one of whom never indicated interest in PAS on any study assessment.

Although the majority of patients in the study supported legalization of PAS, only 9 percent indicated a serious interest at initial evaluation in obtaining a lethal prescription. This level of interest in pursuing PAS, and wanting to hasten death, is similar to that reported in studies in North America outside Oregon. For example, Emanuel and colleagues, in a study of 988 terminally ill patients, reported that 10.6 percent indicated they had seriously considered euthanasia or PAS for themselves.²⁰ Chochinov and colleagues, in a study of 200 terminally ill cancer in-patients, reported that 8.5 percent had a serious and pervasive interest in hastened death.²¹ Rosenfeld and colleagues developed an instrument to measure desire for hastened death among terminally ill patients — 16.3 percent of patients were found to have a high desire for death.²² Wilson and colleagues, in a study of 70 patients with advanced cancer, reported that 12 percent would have made a request for PAS or euthanasia at the time of the study interview.²³ As such, despite differences in how this construct is measured, there is increasing agreement across studies that approximately one in 10 patients with advanced cancer will, when queried, endorse a serious interest in PAS or hastened death. Despite legal availability and heightened public awareness, Oregon cancer patients do not appear to have a greater interest in pursuing PAS for themselves.

Surveys of cancer patients have found that, when examining desire for death to come sooner (including having serious thoughts about PAS or endorsing that one would request PAS if it were available), associated factors found in some, although not all studies, include depression, hopelessness, psychological distress, pain, poor social support, spiritual well-being, religiousness, quality of life, and overall symptom distress.²⁴ Although we found many of these factors associated in univariate analysis, only the degree to which health

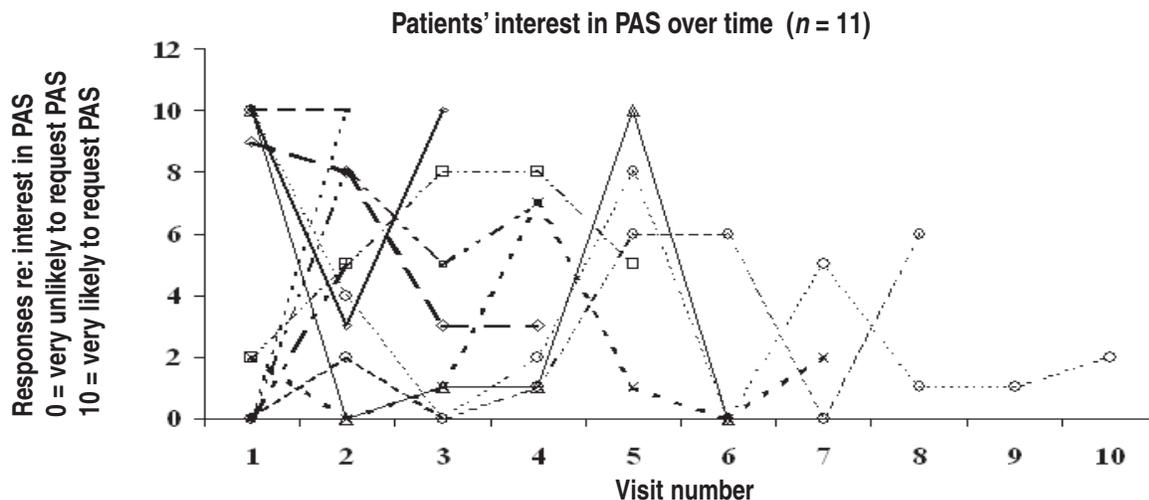


Figure 1.

This figure tracks the responses of 11 patients in the longitudinal portion of the study who expressed a serious interest in PAS at some point after the first evaluation. Each patient is represented by a unique symbol; the lines between the symbols track the patients' responses, over time, to a query about their interest in PAS. Patients were asked about their interest in obtaining a lethal prescription, in which 0 = very unlikely to request PAS, and 10 = very likely to request PAS. The patients in the longitudinal portion of the study were seen approximately every three months.

problems limited quality of life predicted interest in PAS in the multivariate analysis. Over time, depression, hopelessness, sense of burden to others, pain, the impact of health on quality of life, and suffering, proved to be important.

Our study is the first to measure satisfaction with medical care, and we found that dissatisfaction with care was associated with interest in PAS over time. Further exploring the specific sources of dissatisfaction would be key to developing interventions. Moving palliative care approaches earlier into the medical encounter may be important in addressing this level of distress. Since completion of this study, both institutions at which the study was performed have developed palliative care consultation teams. Patients in the study were evaluated for the most part before entering hospice, which we previously demonstrated was associated with patients changing their mind about PAS.²⁵ Nevertheless, 86 percent of all PAS deaths in Oregon have occurred after hospice enrollment.²⁶

We found that many patients with serious interest in PAS neither bring this up with their physician, nor, at times, with their friends and family, despite the legal availability of this option. Clinicians in Oregon have been advised not to initiate discussions about PAS, as there are concerns that patients may misinterpret inquiries, believing that the clinician is promoting assisted suicide. Clinician apprehension about this may be reflected in the large number of cases in which the oncologist withheld approval for participation in the survey. Although we do not have information about why physicians blocked referral, it is possible that clinicians are concerned that even referring patients to the study might be a detrimental communication or increase patients' interest in PAS. Notably, eight patients who had a very strong interest in PAS at first study evaluation never expressed interest in the remaining months of the survey, rebutting concerns that asking about PAS may be misinterpreted by the patient as support.

Sensitive inquiry by the physician may be needed to elicit this important information. Hesitance to bring up the issue appears to leave many patients struggling in isolation. Endorsing interest in PAS may not predict actual requests very well, but does indicate psychosocial distress. Discussion of PAS presents an opportunity to explore fears and worries regarding the future. For example, an oncologist might probe further at the transition point between care focused on life prolongation to care focused on palliation. Questions about mood or limitation of life-saving care could be followed by queries about thoughts of wanting death to come sooner. An affirmative answer should be followed by thorough exploration of the nature of these thoughts. Within psychiatry, the belief that asking about suicide plants a previously unconsidered idea in the patient's mind has been thoroughly rebutted.

We found a high degree of variability over time in interest in PAS among patients who were predisposed to consider it. Similarly, Emanuel and colleagues report that, among 988 patients who were seen at two points in time, half of those who initially considered PAS had changed their mind, whereas an equal number had begun to consider this intervention.²⁷ In our study, among 19 patients followed longitudinally who expressed a serious interest in obtaining a lethal prescription, only one patient actually made a request for PAS to his physician, despite the fact that PAS was legalized throughout this time period. A second patient, who at no point in the study expressed a serious interest in PAS, also made an explicit request to his oncologist. As such, our ongoing inquires regarding interest in PAS were neither sensitive nor specific for actual requests.

There are several shortcomings and limitations to our study. It is possible that the wording of our questions was flawed, resulting in failure to elicit actual intent to pursue PAS. However, most studies show a much higher rate of endorsement of interest in hastening death than actual requests or suicide. Our study may support that it is inappropriate to extrapolate information about patients who actually pursue PAS from information about patients who endorse interest on a survey. This may be one reason for the discrepant findings regarding characteristics of persons who request PAS and actually pursue it in Oregon. Referral biases by physicians and acceptance biases may exist among patients who ultimately participated in the study — only 44 percent of eligible patients participated — threatening generalizability. We did not ask about physical symptoms other than pain, or the adequacy of their treatment, which have been important in explaining interest in PAS. Finally, this study was performed in the only U.S. state in which PAS has been

legalized. This may limit generalizability, although our data suggests that Oregon patients are more similar than different to other cancer patients in North America who are interested in this option.

In summary, although the interest of Oregon patients in PAS may be similar to interest in terminally ill patients from other jurisdictions, Oregon patients bring this up with their physician less than half of the time. Other novel findings of our study include the role of dissatisfaction with healthcare in a patient's interest in PAS, and the variability and mutability of interest over time. Endorsing an interest in PAS on a survey appears to be a marker of psychological and symptom distress, however, it may neither be sensitive nor specific to patients who actually request PAS under legalized conditions. This information is important in interpreting data from studies that purport to apply information derived from surveys of terminally ill to those who actually pursue PAS.

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NOTES

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