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Attitudes and Desires Related to Euthanasia and Physician-Assisted Suicide Among Terminally Ill Patients and Their Caregivers

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WHILE NUMEROUS STUDIES address physicians' views regarding euthanasia and physician-assisted suicide (PAS), there are relatively few studies of patients' attitudes and desires. Reviews have characterized the 7 patients who were granted legalized assistance in death in Australia¹ and 43 cases of legalized PAS in Oregon.^{2,3} Studies have also examined the attitudes and practices regarding euthanasia and PAS of patients with cancer, human immunodeficiency virus (HIV) infection, and amyotrophic lateral sclerosis (ALS).⁴⁻⁹ Other studies have examined patients' suicidal ideation and "desire for death," but not euthanasia or PAS.¹⁰⁻¹³ These studies show that more than 70% of euthanasia and PAS cases involve cancer patients.^{1-3,14} They also show that, contrary to general perceptions, depression and hopelessness, rather than pain, seem to be the primary factors motivating patients' interest in euthanasia or PAS.¹⁻⁸

Additional information regarding patients' attitudes and practices related to euthanasia and PAS is needed. First, few of the patients previously interviewed regarding euthanasia and PAS were terminally ill.⁴⁻⁸ However, because the Oregon law and most proposals for legalization are restricted to the terminally ill as a safeguard, the attitudes and experiences regarding euthanasia and PAS of terminally ill patients are

Context Euthanasia and physician-assisted suicide (PAS) are highly controversial issues. While there are studies of seriously ill patients' interest in euthanasia and PAS, there are no data on the attitudes and desires of terminally ill patients regarding these issues.

Objective To determine the attitudes of terminally ill patients toward euthanasia and PAS, whether they seriously were considering euthanasia and PAS for themselves, the stability of their desires, factors associated with their desires, and the proportion of patients who die from these interventions.

Design Prospective cohort of terminally ill patients and their primary caregivers surveyed twice between March 1996 and July 1997.

Setting Outpatient settings in 5 randomly selected metropolitan statistical areas and 1 rural county.

Participants A total of 988 patients identified by their physicians to be terminally ill with any disease except for human immunodeficiency virus infection (response rate, 87.4%) and 893 patient-designated primary caregivers (response rate, 97.6%).

Main Outcome Measures Support for euthanasia or PAS in standard scenarios; patient-expressed considerations and discussions of their desire for euthanasia or PAS; hoarding of drugs for suicide; patient death by euthanasia or PAS; and patient-reported sociodemographic factors and symptoms related to these outcomes.

Results Of the 988 terminally ill patients, a total of 60.2% supported euthanasia or PAS in a hypothetical situation, but only 10.6% reported seriously considering euthanasia or PAS for themselves. Factors associated with being less likely to consider euthanasia or PAS were feeling appreciated (odds ratio [OR], 0.65; 95% confidence interval [CI], 0.52-0.82), being aged 65 years or older (OR, 0.52; 95% CI, 0.34-0.82), and being African American (OR, 0.39; 95% CI, 0.18-0.84). Factors associated with being more likely to consider euthanasia or PAS were depressive symptoms (OR, 1.25; 95% CI, 1.05-1.49), substantial caregiving needs (OR, 1.09; 95% CI, 1.01-1.17), and pain (OR, 1.26; 95% CI, 1.02-1.56). At the follow-up interview, half of the terminally ill patients who had considered euthanasia or PAS for themselves changed their minds, while an almost equal number began considering these interventions. Patients with depressive symptoms (OR, 5.29; 95% CI, 1.21-23.2) and dyspnea (OR, 1.68; 95% CI, 1.26-2.22) were more likely to change their minds to consider euthanasia or PAS. According to the caregivers of the 256 decedents, 14 patients (5.6%) had discussed asking the physician for euthanasia or PAS and 6 (2.5%) had hoarded drugs. Ultimately, of the 256 decedents, 1 (0.4%) died by euthanasia or PAS, 1 unsuccessfully attempted suicide, and 1 repeatedly requested for her life to be ended but the family and physicians refused.

Conclusions In this survey, a small proportion of terminally ill patients seriously considered euthanasia or PAS for themselves. Over a few months, half the patients changed their minds. Patients with depressive symptoms were more likely to change their minds about desiring euthanasia or PAS.

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important. Furthermore, studies of patients have been largely one-time assessments^{1-3,5-8}; yet, because euthanasia and PAS are irreversible actions, longitudinal assessments of patients' attitudes and preferences are important.^{4,9} Also, to our knowledge, no study has followed up patients until death to determine what proportion of patients actually use euthanasia or PAS. Finally, no study has determined whether families were comfortable with the deaths when patients requested and died by euthanasia or PAS.

We interviewed and followed up 988 patients, who were designated as terminally ill by their physicians, and their primary caregivers to determine their attitudes toward euthanasia and PAS, what proportion of these patients seriously considered euthanasia and PAS for themselves, how stable their desires were, what factors were associated with their desires, and what proportion of patients died from these interventions.

METHODS

The overall methodology of this study has been described in detail.¹⁵⁻¹⁷ The questionnaire is available from the authors on request.

Design and Setting

This was a prospective cohort study that surveyed and followed up patients, designated to be terminally ill by their physicians, and their primary caregivers in 6 randomly selected sites in the United States. The United States was divided into the 4 census regions. Within each region, 1 metropolitan statistical area with high managed care penetration (>20%) was randomly selected. One low managed care metropolitan statistical area was also randomly selected. Among rural counties, 1 was randomly selected. The 6 sites were: Worcester, Mass; St Louis, Mo; Tucson, Ariz; Birmingham, Ala; Brooklyn, NY; and Mesa County, Colo.

Participants

Physicians were asked to identify terminally patients, and the participating patients were then asked to identify their primary caregivers.

Physicians. No physician was paid to refer patients. Lists of physicians within each site were obtained from state boards of medical registration, state medical societies, and membership lists from the American Society of Clinical Oncology, American College of Cardiology, American Gastroenterological Association, and the American College of Chest Physicians. Within each metropolitan statistical area, physicians were randomly selected from these lists and mailed a letter requesting their participation in the study. The letter indicated that the purpose of the study was to "learn about how these patients [with significant illness] experience health care" and that interviews would be done in person. Physicians were asked to identify patients who "have a significant illness and a survival time of 6 months or less, in your opinion." They were not asked or required to use formal criteria, such as the Acute Physiology and Chronic Health Evaluation (APACHE), but rather to use their clinical judgment for 2 reasons: in clinical practice, such as referrals to hospice and eligibility for PAS in Oregon, formal criteria are not used, and the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) reported that physician determination of patients' survival was almost as accurate as formal criteria.¹⁸ A total of 383 physicians referred patients.

Patients. No patient or caregiver was paid for participation. Patients identified by physicians were mailed an explanation of the study with a postage-paid "opt-out" card. The letter indicated that purpose of the study was to understand "the attitudes of patients with a significant illness and their caregivers towards the quality of the patient's health care [and their] perspective on [their] illness experience." If the opt-out card was not returned, the patient was contacted. Patients were eligible to participate if they had any significant illness excluding HIV or acquired immunodeficiency syndrome with a survival time of less than 6 months as determined by their physician, spoke English, had no hearing difficulty, and

were competent to arrange an interview time and place and sign a consent form. Physicians referred 1472 patients, of whom 341 were ineligible. Of the ineligible patients, 194 died, 116 became mentally incompetent between referral and interview, and 31 could not speak English or had hearing limitations. Of the 1131 eligible patients, 119 refused to participate and 24 could not be located. A total of 988 patients were interviewed (response rate, 87.4%).

Caregivers. Patients were asked to identify their primary caregiver as the family member, friend, or other person who provided most of their assistance. Caregivers were ineligible if they spoke no English, had hearing limitations, or were not competent to schedule an interview and sign a consent form. Of the 988 patients, 70 reported not having caregivers and 3 caregivers did not speak English. Of the 915 eligible caregivers, 22 refused to participate. Overall, 893 caregivers were interviewed (response rate, 97.6%).

Follow-up. Two to 6 months after the initial interview (mean, 125 days), patients still alive were reinterviewed; if patients had died, the caregivers were reinterviewed. Of the 988 patients, 699 were still alive when approached for an interview but 17 were mentally incompetent and 32 could not be located or refused to participate. A total of 650 patients were reinterviewed (response rate, 95.3%). Of the 289 patients who died, 3 had not identified a caregiver, 3 caregivers were too ill to be interviewed, and 27 caregivers could not be located or refused. Overall, 256 caregivers were reinterviewed (response rate, 90.5%).

Twenty-four interviewers from National Opinion Research Center, specially trained to interview terminally ill patients, conducted all interviews in person at a site determined by the patients, usually their home. All interviews were completed between March 1996 and July 1997.

Survey Development

Survey development was guided by a conceptual framework previously outlined.¹⁹ In conjunction with the Cen-

ter for Survey Research and the National Opinion Research Center, 4 survey instruments were developed in 9 steps: (1) literature search; (2) 15 focus groups including patients, caregivers, elderly persons, hospital chaplains, and a variety of health providers; (3) 6 in-depth interviews with terminally ill patients and caregivers; (4) instrument creation; (5) cognitive pretesting; (6) behavioral pretesting; (7) reliability assessment; (8) review by an expert panel; and (9) final survey refinement. The surveys were pretested with 18 patients and 15 caregivers in Cleveland, Ohio, and Dallas, Tex.

The initial patient and caregiver surveys contained 135 and 118 questions, respectively, covering 10 domains: (1) symptoms; (2) social supports; (3) communication with health providers; (4) spiritual meaning; (5) care needs; (6) end-of-life plans; (7) economic burdens; (8) sociodemographics; (9) preferences regarding end-of-life care and euthanasia and PAS; and (10) stress of the interview.

Because the terms can be confusing and arouse emotional reactions, questions on euthanasia and PAS did not use these terms but instead relied on previously reported descriptions.^{4,20} In the initial survey, patients' attitudes toward euthanasia and PAS were assessed by means of a question used in national surveys since 1950: "When a person has a disease that cannot be cured, do you think doctors should be allowed by law to end a patient's life by some painless means if a patient and his family request it?"²¹ During the follow-up interview, patients and caregivers were asked about 2 previously published scenarios after being told to assume there were no legal restrictions.^{4,14,20,22,23} For example: "A competent patient develops terminal cancer which invades the bones resulting in excruciating pain. Current levels of morphine, nerve blocks, and other treatments are failing to completely control the pain. The patient has seen a psychiatrist and is not clinically depressed but repeatedly asks for a life-ending injection. In this case is it all right for the doctor, upon request from the pa-

tient, to administer intravenous drugs, such as potassium, to intentionally end the patient's life?"^{4,9,22} Similarly, "A competent patient has terminal cancer with a few months to live. The patient has well-controlled pain and can continue self-care but is increasingly concerned over the burden that deterioration and death will place on his/her family. The patient has seen a psychiatrist and is not clinically depressed but repeatedly asks for a life-ending injection. In this case is it all right for the doctor, upon request from the patient, to administer intravenous drugs, such as potassium, to intentionally end the patient's life?"^{4,9,22}

Regarding actions related to euthanasia and PAS, patients were asked questions, some of which had been previously used,⁴ such as "Have you ever seriously discussed taking your life or asking your doctor to end your life?" "With whom did you have that conversation?" Similarly, caregivers were asked "Did [patient's name] ever hoard drugs for the purpose of using them to end (his/her) life?" and "Did [patient's name] ever ask the doctor to inject (him/her) with medications or to prescribe medications so that (he/she) could take them to intentionally end (his/her) life?" Patients and caregivers were asked "At any point did you worry that someone might intentionally end your life prematurely?" Caregivers were asked: "Did you ever actually talk with the doctor about injecting [patient's name] with medications or to prescribe medications so that (he/she) could take them to intentionally end (his/her) life?" and "Did [patient's name] die at peace?"

Questions on symptoms were adapted from the Wisconsin brief pain inventory,²⁴ Medical Outcomes Study (MOS) Short-Form 36,²⁵ Eastern Cooperative Oncology Group (ECOG) performance measure,²⁶ and on social supports from the MOS Social Support Scale.²⁷ The MOS scale on depressive symptoms was used because it avoids questions on vegetative functions, such as disturbances of sleep and appetite, that are frequently disrupted at the end of life regardless of depression, and because it has been favorably compared with other

measures of depression and is highly predictive of major depression.²⁸ Using questions from Siegel et al,²⁹ Rice et al,³⁰ and SUPPORT,³¹ patients and caregivers were asked about care needs.^{15,16} Questions on economic burdens were adapted from previous studies.^{32,33}

Human Subjects Approval

The protocol, letters, survey instruments, and consent documents were approved by the Harvard Medical School and Dana-Farber Cancer Institute institutional review boards as well as the institutional review boards of 38 medical institutions in the 6 sites.

Data Analysis

The characteristics of patients who were reinterviewed and those who died whose caregivers were interviewed were compared using analysis of variance for age; education and income by the Cochran-Mantel-Haenszel χ^2 test; and sex, race, religious affiliation, marital status, and disease by the χ^2 test of independence for unordered categorical variables.

For multivariate regression models, statistically significant groups of factors were identified from potential explanatory variables in 5 groups: demographic characteristics, health-related symptoms, disease and health service factors, economic and caregiving burdens, and communication factors. If statistical significance was observed for the group, each explanatory variable within the group was evaluated in bivariate analyses at $\alpha=0.5$. Stepwise logistic regression was used to identify the covariates that explained the greatest variation in the outcomes, such as supporting euthanasia or PAS for a patient with unremitting pain or seriously considering euthanasia or PAS. Specific covariates of interest, such as pain, were also forced into the model.

RESULTS

Most patients had substantial symptoms at baseline, with 50.2% experiencing moderate or severe pain, 17.5% bedridden more than 50% of the day, 70.9% having shortness of breath while walk-

ing 1 block or less, 35.5% having urinary or fecal incontinence, and 16.8% having depressive symptoms (TABLE 1). Within the previous 6 months, 66.5% of the patients had been hospitalized, 36.8% had a surgical procedure, and 22.3% had a hospital stay involving a period in the intensive care unit.

Attitudes Toward Euthanasia and PAS

Fully 60.2% of terminally ill patients supported permitting euthanasia or PAS in an abstract situation.²¹ Of the patients who survived and were reinterviewed, 54.8% supported euthanasia for a terminally ill patient experiencing unremitting pain while 32.7% supported euthanasia for terminally ill patients without pain who felt they were a burden. Among caregivers of decedents, 58.7% supported euthanasia for patients in pain while 29.1% supported euthanasia or PAS for patients who believed they were a burden.

Multivariate analyses revealed that in all 3 situations, patients who reported they were more religious or who were African American were significantly less likely to support euthanasia or PAS (TABLE 2). In the multivariate analysis, patient attitudes were not related to age, education, income, length of illness, or physical activity. Importantly, patients experiencing moderate or severe pain were not more likely to support euthanasia or PAS in the pain scenario ($P = .61$). Among the 650 patients reinterviewed, patients who were Catholic (odds ratio [OR], 0.54; 95% confidence interval [CI], 0.34-0.85), who felt tranquil and serene (OR, 0.80; 95% CI, 0.66-0.96), and who received home care (OR, 0.63; 95% CI, 0.40-0.98) were less likely to support euthanasia or PAS.

In the multivariate analysis, caregivers of deceased patients who reported that caring for the patient was interfering with their personal lives were significantly more likely to support euthanasia or PAS for a patient who thought he or she was a burden (TABLE 3). Caregivers who were more religious, African American, and who reported more social supports were significantly less

likely to support euthanasia or PAS in the same situation. Caregivers' assessment of the patient's pain near the end of life was not associated with support for euthanasia or PAS for patients in pain.

Patients' Personal Preferences Regarding Euthanasia and PAS

Initially, 10.6% (100/943) of terminally ill patients had seriously thought about requesting euthanasia or PAS for themselves, and 3.1% (29/943) had discussed euthanasia or PAS for themselves. Of these, 58.6% (17/29) had talked with their family, 41.4% (12/29) with a friend, and 44.8% (13/29) with their physician or other health care pro-

vider. Compared with patients with other terminal illnesses, cancer patients were not significantly more likely to have thought about or discussed euthanasia or PAS (11.6% [59/508] cancer vs 9.5% [41/432] other terminal illness; $P = .29$). Interestingly, among patients who supported euthanasia in the abstract case, 14.3% (73) considered euthanasia or PAS for themselves while 6.8% (23) of those opposed had done so ($P < .001$).

In multivariate analysis, patients who felt more appreciated, were aged 65 years and older, and were African American were significantly less likely to have personally considered eutha-

Table 1. Sociodemographic Characteristics of Terminally Ill Patients*

Characteristic	All Terminally Ill Patients (n = 988)	Patients Who Survived (n = 699)	Patients Who Died (n = 289)	P Value†
Age, mean (range), y	66.5 (22-109)	66.1 (22-109)	67.7 (22-96)	.11
Sex				
Men	48.5	45.9	55.9]. <.001
Women	51.5	54.1	44.1	
Race				
White	78.9	77.7	80.8]. .88
African American	13.7	14.2	13.2	
Other	7.4	8.1	6.0	
Religion				
Protestant	61.8	62.9	60.2]. .41
Catholic	25.4	24.2	26.5	
Jewish	4.3	3.9	4.8	
Other	8.5	9.0	8.5	
Marital status				
Married or living with partner	59.7	59.5	62.2]. .04
Widowed	20.4	19.3	23.6	
Other	19.9	21.3	14.2	
Education				
>8th Grade	14.0	13.3	17.9]. .25
Some high school	18.9	18.3	19.1	
High school graduate	27.4	27.1	26.6	
Some college	21.8	23.7	17.5	
College graduate and higher	18.0	17.7	19.0	
Annual income				
<\$15 000	38.4	39.1	36.1]. .18
\$15 000-\$24 999	21.1	20.7	21.8	
\$25 000-\$50 000	24.9	37.7	21.8	
>\$50 000	15.6	14.5	20.4	
Diagnosis				
Cancer	51.8	44.2	67.3]. .001
Heart disease	18.0	20.9	12.0	
COPD	10.9	13.1	5.6	
Other	19.3	21.8	15.1	

*COPD indicates chronic obstructive pulmonary disease. Data are presented as percentages unless otherwise specified. Percentages may not add to 100 due to rounding.

†P value compares patients who survived with those who died. See "Data Analysis" subsection for specific tests used.

nasia or PAS (Table 2). Conversely, patients who had depressive symptoms, had more caregiving needs, and reported more pain were significantly more likely to have personally considered euthanasia or PAS.

Stability of Patients' Personal Preferences Over Time

The proportion of terminally ill patients who thought about euthanasia or

PAS for themselves remained constant from the initial interview to the follow-up interview (11.5% [71/620] initially and 10.3% [64/620] at follow-up). However, about half the patients initially interested in euthanasia or PAS and who lived changed their minds (FIGURE). Among surviving patients who initially personally considered euthanasia or PAS, 49.3% (35/71) continued to have a personal

interest while 50.7% (36/71) were no longer interested (Figure). Yet, an almost equal number of patients who had not initially personally considered euthanasia or PAS (29 patients) did so later in the course of their illness.

Terminally ill patients who had newly thought about euthanasia or PAS for themselves at the follow-up interview were significantly more likely to have depressive symptoms (OR, 5.29; 95% CI,

Table 2. Univariate and Multivariate Analyses of Patients' Support for and Personal Interest in Euthanasia and Physician-Assisted Suicide (PAS)*

Characteristic	Attitude Toward Euthanasia and PAS				Personal Interest in Euthanasia or PAS			
	No. With Characteristic†	Supported Euthanasia or PAS, %‡	Univariate OR of Support (95% CI)	Multivariate OR of Support (95% CI)§	No. With Characteristic‡	Personal Interest In Euthanasia or PAS, %	Univariate OR of Reported Interest (95% CI)	Multivariate OR With Characteristic (95% CI)
Somewhat or not religious	501	69.5			553	12.5		
Very religious	347	47.0	0.46 (0.37-0.57)	0.49 (0.39-0.61)	390	8.0	0.73 (0.55-0.98)	
White, Hispanic, and other	731	64.0			821	11.2		
African American	124	37.9	0.34 (0.23-0.51)	0.39 (0.26-0.58)	131	6.1	0.52 (0.24-1.09)	0.39 (0.18-0.84)
Age >65 y	342	64.0			384	13.8		
Age ≤65 y	509	58.0	0.77 (0.58-1.03)		564	8.3	0.57 (0.37-0.86)	0.52 (0.34-0.82)
High school or less	512	56.1			564	9.6		
Some college or above	336	67.0	1.20 (1.08-1.32)		380	12.1	1.12 (0.97-1.30)	
Income <\$25 000	441	59.6			485	11.1		
Income ≥\$25 000	300	64.0	1.20 (0.89-1.63)		334	11.7	1.06 (0.68-1.64)	
Length of illness <1 y	245	60.4			271	7.0		
Length of illness ≥1 y	600	60.0	0.98 (0.73-1.33)		669	12.1	1.83 (1.09-3.08)	
Little or no pain	424	60.4			472	7.6		
Moderate or severe pain	426	60.6	1.02 (0.90-1.15)		474	13.5	1.48 (1.22-1.80)	1.26 (1.02-1.56)
No depressive symptoms	712	60.1			789	8.7		
Depressive symptoms	141	61.0	1.00 (0.90-1.12)		159	19.5	1.43 (1.23-1.67)	1.25 (1.05-1.49)
Normal or mildly limited physical activity	702	60.5			785	9.7		
Bedridden for ≥50% of the day	152	58.6	0.92 (0.65-1.32)		165	13.9	1.51 (0.92-2.49)	
Feeling unappreciated	134	53.0			150	22.0		
Feeling appreciated	705	61.7	1.09 (0.93-1.29)		783	8.4	0.61 (0.49-0.75)	0.65 (0.52-0.82)
Few or no care needs	555	62.9			624	8.2		
Moderate or significant care needs	300	55.3	0.73 (0.55-0.97)		328	14.9	1.97 (1.30-3.00)	1.09 (1.01-1.17)

*OR indicates odds ratio; CI, confidence interval. See the "Data Analysis" section for an explanation of how factors were selected for multivariate analysis.
 †Numbers differ because not all respondents answered all questions. The number with characteristic reflects the number of respondents who gave that answer. The number of respondents is lower for questions about attitudes because those who responded "don't know" were excluded while the question about personal consideration of euthanasia or PAS required either a yes or no response.
 ‡Support in the abstract case: "When a person has a disease that cannot be cured, do you think doctors should be allowed by law to end a patient's life by some painless means if a patient and his family request it?"²⁰
 §ORs < 1.00 indicate that patients are less likely to support euthanasia or PAS and less likely to be personally interested in euthanasia or PAS. ORs are not provided for all factors.

1.21-23.2; multivariate analysis) and experience shortness of breath (OR, 1.68; 95% CI, 1.26-2.22; multivariate analysis). Terminally ill patients whose physical functioning or pain worsened were not more likely to have newly considered euthanasia or PAS for themselves (in univariate analysis: pain, $P > .24$; poor physical functioning, $P = .09$; in multivariate analysis: pain, $P = .64$; physical functioning, $P = .63$).

Patient and Caregiver Fear of Unwanted Euthanasia

Among the terminally ill patients reinterviewed, 3.5% (22/624) were worried that someone might give them euthanasia involuntarily. Similarly, 7.2% (18/249) of caregivers reported worrying that someone might commit involuntary euthanasia on the patient. Patients who worried about involuntary euthanasia were more likely to be younger than 65 years (OR, 4.85; 95%

CI, 1.76-13.3; univariate analysis) and report more unmet care needs (OR, 1.14; 95% CI, 1.02-1.28; univariate analysis). Race, religion, income, and sex were not associated with worrying about involuntary euthanasia.

Actual Requests for Euthanasia or PAS

According to the primary caregivers of decedents, 5.6% (14/249) of patients had discussed with the caregiver asking the physician for euthanasia or PAS in the last 4 weeks of their lives. Only 1.6% (4/248) were known to have actually discussed euthanasia or PAS with their physician, 2.5% (6/240) had hoarded drugs for PAS, and 0.8% (2/240) had done both (TABLE 4). Among the caregivers of decedents, 2.4% (6/250) had themselves thought of asking the physician to perform euthanasia or PAS while 1.6% (4/250) actually discussed these interventions with the physician (Table 4). In

2 cases, the patient did not discuss euthanasia or PAS with a physician or hoard drugs. In 1 case, the caregiver did not know if the patient had discussed these topics with a physician or hoarded drugs. In 1 case, the patient had discussed euthanasia or PAS with a physician. While the small numbers preclude statistically reliable comparisons, trends in the data suggest that patients who were female, had more unmet care needs, used hospice, and had living wills were more likely to discuss euthanasia or PAS with physicians or hoard drugs for PAS (TABLE 5).

Overall, 11.1% (27/244) of the caregivers reported that if the patient had asked them for assistance to end their lives by euthanasia or PAS they would help. Even among the caregivers who found euthanasia or PAS ethical for unremitting pain, only 17.9% (23/128) were willing to assist with euthanasia or PAS.

Ultimately, of the patients who actually discussed euthanasia ($n = 4$) or hoarded drugs ($n = 6$) for PAS (2 patients both discussed euthanasia and hoarded drugs), data from the caregivers on the actual circumstances of their

Table 3. Univariate and Multivariate Analyses of Caregivers' Support for Euthanasia and Physician-Assisted Suicide (PAS)*

	No.†	Supported Euthanasia or PAS, %‡	Univariate OR of Support (95% CI)	Multivariate OR of Support (95% CI)§
Somewhat or not religious	118	38.1		
Very religious	89	16.9	0.28 (0.16-0.49)	0.25 (0.14-0.45)
White, Hispanic, and other	192	31.3		
African American	25	12.0	0.30 (0.09-1.04)	0.30 (0.08-1.10)
Age <65 y	79	22.8		
Age ≥65 y	136	32.4	1.62 (0.86-3.06)	
High school diploma or less	104	25.0		
Some college or above	103	33.0	1.11 (0.87-1.41)	
Income <\$25 000	100	26.0		
Income ≥\$25 000	96	32.3	1.10 (0.98-1.24)	
Patient does not interfere with caregiver's life	131	22.9		
Patient does interfere with caregiver's life	74	37.8	1.42 (1.09-1.87)	1.49 (1.09-2.02)
Caregiver perceives patient to have moderate or severe pain at the end of life	146	28.8		
Caregiver perceives patient to have little or no pain at the end of life	66	31.8	1.05 (0.80-1.36)	
Caregiver has few or no supports	49	38.8		
Caregiver has moderate or many supports	167	26.3	0.68 (0.50-0.92)	0.63 (0.44-0.90)

*OR indicates odds ratio; CI, confidence interval.

†Not all respondents answered all questions; the number in each row reflects the number giving that answer.

‡Support in the case in which the patient has well controlled pain and can continue self-care but is increasingly concerned over the burden that deterioration and death will place on his/her family.¹⁴

§ORs <1.00 mean that patients are less likely to support euthanasia or PAS and less likely to be personally interested in euthanasia or PAS. ORs are not provided for all factors.

Figure. Disposition of Patients Interviewed About Interest in Euthanasia or Physician-Assisted Suicide (PAS)

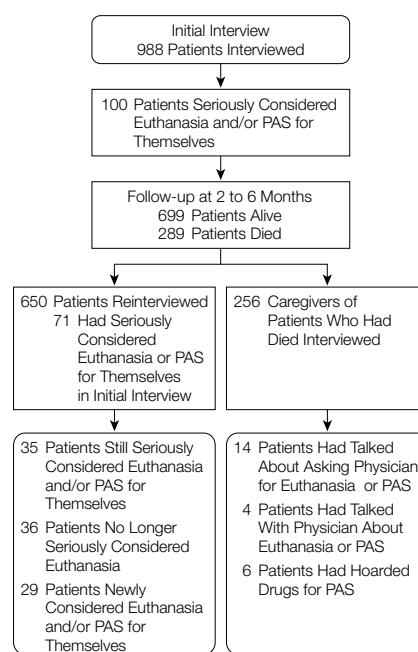


Table 4. The Practice of Euthanasia and Physician-Assisted Suicide (PAS) by Terminally Ill Patients (n = 256) as Reported by Caregivers*

Action Reported by Caregiver	Patients Who Died, No. (%)
Patient discussed euthanasia or PAS in the last 4 weeks of life	14 (5.6)
Patient asked physician for euthanasia or PAS	4 (1.6)
Patient hoarded drugs for PAS	6 (2.5)
Caregiver considered asking physician about euthanasia or PAS for the patient	6 (2.4)
Caregiver asked physician for patient's euthanasia	4 (1.6)
If patient had asked for help with euthanasia and/or PAS, caregiver would have provided help	27 (11.1)

*Denominators for percentages differ because not all caregivers were asked all questions.

death were available for all but 1. Only 2 (25%) had thought about euthanasia or PAS for themselves at the initial interview. One patient (0.4% of all 256 patients who died) died by PAS, 1 (0.4%) tried to commit suicide by carbon monoxide poisoning 2 months before death but failed, and 1 repeatedly requested that her life be ended, but her family and physician refused. All 3 had malignancies and were white and older than 70 years. In the PAS and attempted suicide cases, the patients were male. None had considered euthanasia or PAS initially. The patient who committed PAS was diagnosed with cancer within the year; he did not have limited activity, had little pain, did not have depressive symptoms, and had few care needs. He did not receive hospice care, and he had significant economic burden from his health care expenses. His caregiver demonstrated depressive symptoms. His caregiver reported that "he did not have [any] quality of life at the end. [The disease] was too much for him to bear; there was not a cure for him." The family of the patient who tried unsuccessfully to commit suicide reported poor communication with the patient. The patient reported no pain. While the patient received hospice care, the caregiver resented hospice and the fact that the patient's primary physician did not seem responsive. They were uncomfortable with the way the patient died. In the case in which the family refused to help the patient end her life, she was bedridden with moderate pain and substantial care needs, receiving both hospice and home care. The family stated that the patient was "ambivalent" about euthanasia and PAS: "[She] would not take the initia-

tive. She wanted it taken care of for her." The family did not appear to fear prosecution but stated: "[Euthanasia] was not a fair [emotional] burden for the patient to put on the family." Ultimately she died at home with her husband. The family was very comfortable with the way she died. Of those patients who personally discussed euthanasia or PAS with their physician or hoarded drugs, half (4/8) died at home or in a residential hospice, and the vast majority of their caregivers reported that the patients "died at peace."

COMMENT

This is the first study to our knowledge to assess the attitudes and experiences regarding euthanasia and PAS of patients deemed terminally ill by their physicians and to follow up the patients until death. Our data suggest 3 consistent conclusions about attitudes toward euthanasia and PAS. First, a majority of Americans support the possibility of euthanasia or PAS for patients with unremitting pain; being terminally ill or having cared for a patient who just died does not seem to affect these views.^{4,6,7,21} While a majority of those surveyed find euthanasia acceptable for terminally ill patients with unremitting pain, less than a third support it when the patient desires it because of fear of being a burden on the family.^{4,6,13,21} Finally, African Americans and religious individuals are more likely to oppose euthanasia or PAS.^{4,13,21}

Despite this support for euthanasia or PAS, these interventions play a role for relatively few dying patients. In this study, about 10% of terminally ill patients reported seriously considering euthanasia or PAS for themselves and less than 4% had discussed these interven-

tions with a physician or hoarded drugs for PAS. This is much lower than the proportion of patients who say that they can imagine circumstances in which they might consider these interventions, a hypothetical question.^{4,5,7} In this study, only 0.4% of all decedents (1/256 patients) was reported to have actually died by euthanasia or PAS. If these data are representative of the United States, extrapolated to the approximately 2.4 million persons who die each year, they would suggest that about 250 000 decedents consider euthanasia or PAS, just under 100 000 discuss these interventions or hoard drugs, but fewer than 9600 people die annually by euthanasia or PAS. The actual numbers are likely to be even lower since many people die suddenly, and 30% to 50% of the 2.4 million decedents are incompetent months or years prior to death. Patients in both groups could not request euthanasia or PAS.¹⁴ These data suggest rates of euthanasia or PAS higher than Oregon's officially reported 0.09% rate of PAS, but less than the 3.4% rate in the Netherlands.^{2,3,14,34} Ultimately, euthanasia and PAS may not be particularly pivotal interventions, since for more than 95% of deaths they do not contribute to a "good death."³⁵

This study extends to terminally ill patients the finding that most of the key determinants of interest in euthanasia and PAS relate not to physical symptoms but to psychological distress and care needs.¹⁻⁸ In this study, psychological factors—nonvegetative depressive symptoms and patients' sense of a lack of appreciation—were associated with patients' considerations and planning of euthanasia and PAS. In addition, this study found that terminally ill patients who reported substantial care needs were also more likely to consider euthanasia or PAS for themselves. Indeed, when patients had substantial care needs, caregivers were also more likely to support euthanasia and PAS. It is the first study to report that pain played a role in such considerations. This suggests a tension between attitudes and practices, between the reason people find euthanasia and PAS acceptable—predominantly pain^{4,13,21}—and the main

factor motivating interest in euthanasia or PAS—patient depression.^{4,7}

Patients' personal considerations of euthanasia or PAS appear to be quite unstable. About half the terminally ill patients interested in euthanasia or PAS changed their minds, and terminally ill patients who had not previously considered these interventions begin to do so. Indeed, none of the 3 patients who were most persistent in their desire to end their lives had considered euthanasia or PAS for themselves at the initial interview. Depressive symptoms and dyspnea³⁶ were associated with this instability. Thus, physicians who receive requests for euthanasia or PAS should recognize their volatility and not take such requests as settled views but should evaluate patients for depression and unrelieved dyspnea. This instability in patients' considerations suggests that the waiting period before a patient is given the prescription for PAS mandated in Oregon and included in many proposals for legalization is an important safeguard.

Despite caregivers' support for euthanasia and PAS, less than 20% of those who deemed euthanasia or PAS ethical would be willing to personally help their family member end their life. This may reflect anxiety about prosecution and uncertainty about committing these actions reliably. But it may also reflect the emotional burden of actually performing euthanasia or assisting with suicide. As a family whose relative had repeatedly asked for suicide assistance stated, performing euthanasia or PAS may not be a fair burden to place on the family.

Finally, a small minority of terminally ill patients and caregivers worried about involuntary euthanasia. While legalizing euthanasia or PAS might reassure some people that they will not have to endure intolerable suffering,^{37,38} it may exacerbate anxiety among others about involuntary euthanasia.⁴ In considering the pros and cons of legalization, patients' reassurance and apprehension both must be considered.³⁵

This study has several limitations. For a variety of reasons, especially physician referral bias, discussed extensively elsewhere, the population of terminally

ill patients may be biased.¹⁴⁻¹⁶ This is unlikely to be a major concern, given that the population is similar to US decedents and the SUPPORT population and had substantial symptoms. In addition, it seems highly unlikely that 6 months

prior to death physicians knew which patients desired euthanasia or PAS and screened them out, in part because patients' desire for these interventions appear inconsistent, in most cases they are not discussed with physicians, and phy-

Table 5. Patients and Caregivers Who Discussed Euthanasia or Physician-Assisted Suicide (PAS) or Hoarded Drugs for PAS*

Characteristic	Deceased Patients Who Discussed Euthanasia or PAS, Hoarded Drugs for PAS, or Caregivers Discussed Euthanasia With Physicians		P Value
	Yes, No. (%) (n = 11)	No, No. (%) (n = 245)	
Sociodemographic Characteristics			
Female	8 (73)	101 (42)	.06
White	9 (82)	190 (79)	.99
Income ≥\$25 000	6 (55)	84 (42)	.55
Age ≥65 y	5 (45)	150 (63)	.34
Diagnosis			
Cancer	6 (64)	164 (69)	.50
Symptoms			
Pain	9 (82)	187 (78)	.99
Bedridden ≥50% of the day	2 (18)	65 (27)	.73
Depressive symptoms	2 (18)	48 (20)	.99
Care Needs			
Substantial care needs	4 (36)	112 (48)	.55
Needs additional care	5 (45)	47 (20)	.06
Economic Burden			
Subjective burden	5 (45)	96 (41)	.76
Spend >10% of income on health care excluding insurance	4 (36)	39 (20)	.25
Social Support			
Caregiver lives with patient	4 (36)	61 (27)	.51
Patient feels appreciated	10 (91)	215 (90)	.99
High overall social support	9 (82)	185 (77)	.71
Health Care Services			
Hospitalized once in the last 6 months	9 (82)	183 (76)	.97
Hospitalized ≥2 times in the last 6 months	5 (45)	6 (51)	.97
Received home care	4 (36)	80 (34)	.99
Received hospice care	5 (45)	35 (15)	.02
Physician-Patient Relationship			
Relationship longer than 1 y	5 (45)	157 (66)	.02
Advanced Care Planning			
Had living will or proxy	9 (90)	139 (61)	.09
Discussed end-of-life care with physician in last 4 weeks of life	10 (91)	152 (69)	.18
Religious Beliefs and Practices			
Patient was very religious	2 (18)	97 (41)	.34
Talked with religious mentor in last 4 weeks of life	7 (64)	170 (72)	.51
Death			
Patient died at peace	10 (91)	208 (91)	.99

*Denominator may vary on specific questions because some patients and caregivers omitted some questions.

sicians are unlikely to accurately predict patients' desires.²⁰ Second, caregivers of patients who died may not have been aware of and able to report all the activities related to euthanasia and PAS of patients who died, especially discussions and the hoarding of drugs. Furthermore, despite assurances of confidentiality, caregivers might have been hesitant to honestly report cases in which patients died by euthanasia or PAS. Underreporting is an inherent limitation in all research on euthanasia and PAS and similar illegal activities.^{4-9,20-23} Yet the response rates to the initial and follow-up surveys were very high, and only 1 caregiver of a patient who discussed euthanasia or PAS could not be interviewed after the patient's death. If caregivers were hesitant to talk about the patient's death by euthanasia or PAS, they did not express it by refusing to participate. Finally, despite beginning with a relatively large cohort of 988 terminally ill patients, only a small proportion seriously considered euthanasia or PAS and died by these interventions, creating significant uncertainty in point estimates. Because few patients pursue euthanasia or PAS, the problem of small numbers affects all such studies, including those of euthanasia in the Netherlands and PAS in Oregon.^{2,3,14} Only studies of enormous size and cost, with only a single precedent in end-of-life care research, can overcome this limitation.

CONCLUSION

This study demonstrates that a significant majority of terminally ill patients and recently bereaved caregivers support euthanasia and PAS in a standard poll question and for patients with unremitting pain. Despite this strong support for euthanasia and PAS, only a small minority of terminally ill patients considered euthanasia or PAS for themselves and a very small minority of patients actually took concrete action such as requesting assistance in dying from physicians or hoarding drugs for suicide. Furthermore, patients' personal interest in euthanasia and PAS appears not to be a stable preference but may shift over time. Depressive symptoms and

other psychological factors, such as feeling appreciated, appear to be important determinants of both patients' personal interest in euthanasia and PAS and the instability of this interest. This suggests that when physicians are confronted by a patient's request for euthanasia or PAS, they should attend to the possibility of depression and other psychological stressors.

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