

Why Oregon Patients Request Assisted Death: Family Members' Views

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BACKGROUND: Physician assisted death (PAD) was legalized through Oregon's Death with Dignity Act in 1994 and enacted in 1997.

OBJECTIVE: The objective of this paper was to learn from family members why their loved ones requested PAD.

DESIGN: This study used the cross-sectional survey.

PARTICIPANTS: Participants of this study included family members of 83 Oregon decedents who made explicit requests for legalized PAD before their deaths, including 52 decedents who received prescriptions for a lethal medication and 32 who died of PAD.

MEASUREMENTS: Family members rated the importance of 28 possible reasons their loved ones requested PAD on a 1–5 Likert scale, with higher scores representing greater importance.

RESULTS: According to family members, the most important reasons that their loved ones requested PAD, all with a median score of 4.5 or greater, were wanting to control the circumstances of death and die at home, and worries about loss of dignity and future losses of independence, quality of life, and self-care ability. No physical symptoms at the time of the request were rated higher than a median of 2 in importance. Worries about symptoms and experiences in the future were, in general, more important reasons than symptoms or experiences at the time of the request. According to family members, the least important reasons their loved ones requested PAD included depression, financial concerns, and poor social support.

CONCLUSIONS: Interventions that help patients maintain control, independence, and self-care in a home environment may be effective means of addressing serious requests for PAD.

KEY WORDS: physician-assisted suicide; palliative care.

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Oregon voters legalized physician-assisted death (PAD) through the Oregon Death with Dignity Act (ODDA) in 1994. Since enactment of the ODDA in 1997, between 16 and 46 individuals in Oregon each year have died by PAD.¹ Because PAD is rare, most information about individuals who have received prescriptions for lethal medications under the law has come through health care professionals, including physicians and hospice workers who have cared for requesting patients.^{2–5} Oregon health care professionals generally agree that patients make these requests in an attempt to maintain control and diminish dependence on others. Health professionals, however, may lack intimate knowledge of the requesting patient's reasons and values. To gain additional perspective on why terminally ill persons in Oregon pursue PAD, we surveyed family members of Oregon patients who made explicit requests and asked them why their loved ones requested PAD.

METHODS

Family members of patients who requested assisted death learned about our study through the advocacy organization, Compassion and Choices, two large medical centers in Portland, Oregon, and the Amyotrophic Lateral Sclerosis Association of Oregon. Compassion and Choices (formerly Compassion in Dying) is a non-profit organization dedicated to expanding choices at the end of life. The organization offers information, support, and attendance at the death of clients who qualify for the ODDA.^{6,7} In 2005, Compassion and Choices reported that they had given information to or assisted 180 of the 246 (73%) persons who died of PAD under Oregon's law.⁶ The two medical centers kept a centralized registry of patients who explicitly requested a lethal prescription from a physician to assure compliance with the law.

Between 2004 and 2006, these organizations sent letters about our study to family members of clients or patients who had requested PAD from a physician if their database indicated that the family member was aware of the request and that the PAD requester had died between 4 months and 3 years before the planned interview. Family members who wished to learn more about the study contacted the research team either by

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phone or by mail. Family members were eligible to participate in the study if they had contact with the decedent at least once per week in the last month of life, were able to communicate in English, and were more than 18 years of age. The study was approved by the Institutional Review Board at the Portland VAMC, and all subjects gave written informed consent to participate.

Measures

Family members verified that the patient had requested PAD from a physician or had sought out information about PAD from Compassion and Choices. They indicated whether or not the patient received a lethal prescription and died after taking it. Demographic information about patients who died after legalized PAD was obtained from the Oregon Health Division (OHD) website and compared to our sample of requesting patients to ascertain whether our PAD requesters were representative of known PAD completers.

We developed a list of 28 potential reasons why a terminally ill patient might request PAD. These reasons were identified through review of the literature, including experts' views on why patients might request PAD, qualitative and survey studies of physicians and nurses in Oregon who had cared for similar patients, other qualitative studies of patients pursuing hastened death, and the investigators' clinical experiences with patients who made these requests.^{2-4,8-10} Reasons covered domains of physical symptoms, existential and personal care concerns, and loss of autonomy. Because our previous studies and clinical experience suggested that concerns about future suffering usually were more important than suffering at the time of the request, family members were asked to separate future worries from experiences and symptoms at the time of the request on several measures. Family members were asked to rate the importance of each reason on a 1-5 scale with 1=not at all important in the decision to request a lethal prescription and 5=very important in the decision to request a lethal prescription. Family members were asked to identify the one most important reason why the loved one had requested PAD, which did not need to be among the 28 listed.

Statistical Analysis

Categorical variables are presented as frequencies and proportions. Respondent and non-respondent demographics were compared with chi-square test. Because the distribution of responses measuring reasons for the request was skewed, results were reported as medians with intraquartile ranges (IQR), and groups were compared with Mann-Whitney *U* test. All *p* values are based on two-sided tests, and alpha was set at 0.05.

RESULTS

Compassion and Choices, the referring agency for 82% of the participants, identified 180 potentially eligible family members of whom 68 (38%) participated. Most family member respondents were well educated, female spouses who had known the decedent, on average, for more than four decades and cared for the patient extensively in the months before death (Table 1). Most PAD requesters were hospice-enrolled before death and diagnosed with cancer. Sixty-three percent of family members

Table 1. Characteristics of 83 PAD Requesters and their Family Members

	Study sample
	No. %
	N=83
PAD requester	
Sex, female	36 (43.4)
Ethnicity, white	83(100)
Terminal diagnosis	
Cancer	73 (88.0)
ALS	6 (7.2)
Cardiopulmonary disease	2 (2.4)
Other	2 (2.4)
Hospice enrolled	72 (86.7)
Outcome	
Received lethal prescription	52 (62.7)
Died by PAD	32 (38.6)
PAD family member	
Sex, female	56 (67.5)
Ethnicity, white	83 (100.0)
Relation to PAD requester	
Spouse/partner	49 (59.0)
Child	24 (28.9)
Sibling	6 (7.2)
Other family	3 (3.6)
	Mean (SD)
Age (years)	61.0 (13.0)
Years known decedent	41.8 (15.7)
Educational attainment (years)	16.1 (3.5)

reported that the loved one received a lethal prescription, and more than one third died by PAD. Reasons for not receiving or filling prescriptions were as follows: Two patients changed their mind, seven could not find a willing physician, four did not meet legal criteria, 11 died during the 15-day waiting period or before they could fill the prescription, five lost decision making or swallowing ability during the process, and one refused to see a psychiatrist.

Family members reported that the most important reasons for PAD requests were: wanting control of the circumstances of death; loss of dignity; wanting to die at home and concerns about loss of independence, quality of life, ability to care for self in the future. All these had median scores of at least 4.5 on the 1-5 scale of importance (Table 2). Other important autonomy-related concerns included worries about loss of sense of self, burdening others, and not wanting to be cared for by others. No physical symptoms experienced at the time of the request were rated higher than 2 on the 1-5 scale. In most cases, future concerns about physical symptoms were rated as more important than physical symptoms present at the time of the request. Family members did not identify social support, depressed mood, and financial concerns as important reasons for a PAD request. When asked to identify the single most important reason they believed the patient pursued PAD, 22 family members chose desire for control, nine chose future or current pain, nine chose future or current poor quality of life, six chose worries about being a burden, and six chose loss of sense of self. All other reasons were cited as most important four or fewer times by family members.

We compared the reasons for pursuing PAD between those who died by PAD (*N*=32) to those who requested but did not complete PAD (*N*=51) and found that PAD completers feared

Table 2. Family Members' Views on Why Patients Requested Physician-assisted Death

Reason for request	Median score*	Intraquartile range†
Wanting to control circumstances of death	5	5,5
Fear of poor quality of life in future	5	4,5
Loss of independence in future	5	4,5
Loss of dignity	5	3,5,5
Fear of inability to care for self in future	5	3,5
Wanting to die at home	4.5	2,5
Fear of worsening pain in future	4	2,5,5
Poor quality of life	4	2,5
Worried about loss of sense of self	4	1,5
Perceived self as burden to others	3.5	1,5
Not wanting others to care for him/her	3.5	1,5
Witnessed bad deaths	3	1,5
Lack of energy in future	3	1,4
Not able to pursue pleasurable activities	2	1,5
Ready to die	2	1,5
Fear loss of bowel/bladder control in future	2	1,4
Inability to care for self	2	1,4
Loss of independence at time of request	2	1,4
Pain at time of request	2	1,4
Fear of worsening dyspnea in future	1	1,4
Life tasks complete	1	1,4
Fear of worsening confusion in future	1	1,3,5
Lack of energy	1	1,3
Dyspnea	1	1,2
Loss of bowel/bladder control	1	1,2
Perceived self as financial drain	1	1,2
Confusion	1	1,1
Depressed mood	1	1,1
Lack of social support	1	1,1

*Importance of reason in decision rated on a 1–5 scale where 1=not at all important reason for request and 5=very important reason for request.

†Intraquartile range represents the range between the 25th and 75th percentile.

future declines in quality of life more than non-completers (median score=5, IQR 5,5 for completers; median score=5, IQR 4,5 for non-completers; $p=0.03$ Mann-Whitney test). Although inability to care for oneself at the time of the request was rated as relatively unimportant to both groups, it was significantly less so among those who died by PAD (median score=1, IQR 1,3 completers; median score=3, IQR 1,5 non-completers; $p=0.01$, Mann-Whitney test).

Decedents described by family members were demographically similar (see Table 1) to the 248 who died of PAD based on mandatory reports to the OHD between 1998 and 2005 (subtracting our sample from the OHD sample). The OHD sample was 49% female ($p=NS$); 96% Caucasian ($p=NS$), and 87% hospice enrolled ($p=NS$). Although there was no difference in proportion with ALS (OHD sample, 9% with ALS, $p=NS$), our sample was more likely than the OHD sample to have cancer as a terminal diagnosis (OHD=76%, $p=0.02$). Between 1998 and 2003, OHD records indicate that 66% of individuals who received a lethal prescription died by PAD¹ compared with 61% (32/52) of patients in our study ($p=NS$).

DISCUSSION

Family members describe loved ones who pursue PAD as individuals for whom being independent and in control is

important, who anticipate the negative aspects of dying, and who believe that the impending loss of self, abilities, and quality of life will be intolerable. They fear being a burden to others, yet want to die at home. Concerns about what may be experienced in the future, including physical symptoms, were substantially more powerful reasons than what they experienced at the time of the request. Overall, the reasons reported are similar to those reported by hospice workers in Oregon who have cared for patients pursuing PAD^{2,5} and in a separate qualitative study of family members of patients who pursued assisted suicide outside the law in Washington and Oregon.⁸ This convergence of results from several studies lends strength to the validity of our findings.

Experts on suicide speculate that depression is an important reason that patients request PAD.^{11,12} Numerous surveys of terminally ill patients indicate that endorsement of interest in PAD or desire for hastened death is associated with depressed mood, even major depressive disorder.^{13–15} And there is speculation that PAD requests may be motivated by lack of access to good medical care resulting from poor finances or lack of overall social support.¹¹ Family members did not endorse the importance of any of these factors, consistent with the findings of other studies.^{2–5,16} It is true, however, that family members may lack expertise in recognizing depression or underestimate the importance of social and financial factors, especially if they felt these factors reflected poorly on their own care giving abilities.

Our data suggest that when talking with a patient requesting PAD, clinicians should focus on eliciting and addressing worries and apprehension about the future with the goal of reducing anxiety about the dying process. Some Oregon clinicians have expressed surprise at the paucity of suffering at the time of the request among these patients.¹⁷ Addressing patients' concerns with concrete interventions that help maintain control, independence and self care, all in the home environment, may be an effective way to address requests for PAD and improve quality of remaining life. Furthermore, although careful assessment and expert treatment of depressive disorders is important, the clinician should not assume the presence of depression, which might lead to ineffective, unnecessary, even harmful treatments. Similarly, while assessment of physical discomfort at the time of the request is an important component of palliative care, the clinician should not be surprised at the relative absence of physical symptoms. Offering information as to how pain and discomfort will be managed as the disease progresses with a focus on maintaining function and cognition may help assuage fears and ensure a dignified death.

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