

SPECIAL ARTICLE

Implementing a Death with Dignity Program at a Comprehensive Cancer Center

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ABSTRACT

BACKGROUND

The majority of Death with Dignity participants in Washington State and Oregon have received a diagnosis of terminal cancer. As more states consider legislation regarding physician-assisted death, the experience of a comprehensive cancer center may be informative.

METHODS

We describe the implementation of a Death with Dignity program at Seattle Cancer Care Alliance, the site of care for the Fred Hutchinson–University of Washington Cancer Consortium, a comprehensive cancer center in Seattle that serves the Pacific Northwest. Institution-level data were compared with publicly available state-wide data from Oregon and Washington.

RESULTS

A total of 114 patients inquired about our Death with Dignity program between March 5, 2009, and December 31, 2011. Of these, 44 (38.6%) did not pursue the program, and 30 (26.3%) initiated the process but either elected not to continue or died before completion. Of the 40 participants who, after counseling and upon request, received a prescription for a lethal dose of secobarbital (35.1% of the 114 patients who inquired about the program), all died, 24 after medication ingestion (60% of those obtaining prescriptions). The participants at our center accounted for 15.7% of all participants in the Death with Dignity program in Washington (255 persons) and were typically white, male, and well educated. The most common reasons for participation were loss of autonomy (97.2%), inability to engage in enjoyable activities (88.9%), and loss of dignity (75.0%). Eleven participants lived for more than 6 months after prescription receipt. Qualitatively, patients and families were grateful to receive the lethal prescription, whether it was used or not.

CONCLUSIONS

Overall, our Death with Dignity program has been well accepted by patients and clinicians.

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IN 1997, OREGON BECAME THE FIRST STATE in the United States to pass legislation that offered a “physician-assisted” approach to dying for adults with poor short-term prognoses.¹ The Washington State legislature followed Oregon more than a decade later, passing an almost identical law, the Washington Death with Dignity Act, in November 2008.² Under the law, competent adults residing in Washington who have a life expectancy of 6 months or less because of a diagnosed medical condition may request and self-administer lethal medication prescribed by a physician (Table 1).

As of December 2011, a total of 255 patients had participated in the Washington Death with Dignity program.³ Of those participants, approximately 78% (and 81% of the 596 Oregonians) had cancer as their underlying terminal diagnosis. Although several articles have touched on the experiences of patients with cancer, family members, and physicians regarding Death with Dignity programs in the two states,⁴⁻¹⁸ none

have addressed institutional responses to the laws. Given ongoing efforts to introduce similar legislation in other states (including Hawaii, Pennsylvania, and Vermont),^{17,19-21} increasing numbers of health care institutions may be faced with the questions of whether, and how, to respond to requests for assisted dying. Because this legislation has a disproportionate effect on patients with cancer and their families, the response of a comprehensive cancer center may be particularly instructive.

Seattle Cancer Care Alliance is the outpatient site of care for patients with cancer from the Fred Hutchinson Cancer Research Center, the University of Washington, and Seattle Children’s, all in Seattle, and is the only National Cancer Institute–designated comprehensive cancer center serving the Washington, Wyoming, Alaska, Montana, and Idaho region. In response to the Washington law, Seattle Cancer Care Alliance developed a Death with Dignity program, adapted from the existing programs in Oregon. This article describes the implementation and results of our Death with Dignity program, designed to adhere to legal regulations, maintain safety, and ensure the quality of patient care.

METHODS

POLICY DEVELOPMENT

After considerable internal debate, Seattle Cancer Care Alliance instituted a Death with Dignity policy (see the Supplementary Appendix, available with the full text of this article at NEJM.org), which was written by the medical director and approved by a simple majority of Medical Executive Committee members, as is consistent with all our clinical policies. In addition, we created informational packets for patients, physicians, and patient advocates (described further below) for use during the process (available on request from the corresponding author). The policy and its implementation addressed basic aspects of the program as well as issues that were more controversial. For example, Seattle Cancer Care Alliance does not accept new patients solely for the purpose of accessing our Death with Dignity program. Instead, patients are referred to Compassion and Choices of Washington, a local affiliate of a national patient-advocacy organization that provides education and support for those pursuing physician-assisted death. Although this is not

Table 1. Essential Elements and Safeguards of the Washington State Death with Dignity Law.

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| The patient must make both an initial oral and written request |
| After the initial oral request, the patient must wait 15 days to make a second oral request |
| Before prescribing the lethal medication, the prescribing physician must: |
| Make an initial determination of the terminal nature of the disease |
| Determine the patient’s competency and the voluntary nature of the request, with referral to a state-licensed psychiatrist or psychologist, if necessary, to ensure competency and the absence of a mental health disorder causing impaired judgment |
| Confirm Washington State residency (defined as possession of a Washington State driver’s license, registration to vote, or evidence of lease or ownership of property in Washington State) |
| Assess informed consent on the basis of the patient’s awareness of the medical diagnosis, the prognosis, the risks of the medication, the result of the medication (death), and the alternatives (palliative care, hospice, and pain control) |
| Recommend that the patient notify next of kin, have someone present at ingestion, and not take the medication in a public place |
| The consulting physician confirms the diagnosis, the patient’s competency, and the voluntary nature of the request |
| At the time of prescribing, the prescribing physician must: |
| Offer the patient an opportunity to rescind the request |
| Verify that the patient is making an informed decision at the time of prescription |
| Deliver the prescription directly to the pharmacist |
| The pharmacist dispenses the medication directly to the patient or an identified agent of the patient |

part of the formal policy, we do not post information pertaining to Death with Dignity legislation or our program in public spaces, effectively requiring patients to initiate requests or their physicians to raise the topic. In addition, we require that participants sign an agreement not to take the lethal prescription in a public area or manner — a more restrictive measure than that in the law, which only recommends this to participants.

Finally, no staff or faculty members are compelled to participate in the program. To determine how many clinicians might be willing to participate, we conducted a confidential survey in March 2009, asking clinicians whether they would be willing to act as either a prescribing or a consulting clinician. The survey followed an institution-wide educational program outlining the provisions of the law and the planned program at Seattle Cancer Care Alliance. Of 200 physicians surveyed, 81 responded (40.5%, a typical response rate for a general survey with no follow-up), with 29 physicians willing to act as a prescribing or consulting physician (35.8%), 21 willing to act as a consulting physician only (25.9%), and 31 unwilling to participate or undecided about participation (38.3%). The small cadre of willing physicians was thought to be sufficient to support implementation.

IMPLEMENTATION OF THE DEATH WITH DIGNITY PROGRAM

After clinician or patient referral to the Death with Dignity program, each potential participant is assigned a patient advocate (hereafter referred to as advocate), one of three (of six) licensed social workers employed by Seattle Cancer Care Alliance. The advocate assists patients, family members, pharmacists, and physicians throughout the multistep process, while prospectively tracking compliance with required documentation submitted to the Washington Department of Health. The advocate describes the Death with Dignity process and the alternatives (specifically, palliative care and hospice, with these services offered as additions to, or in lieu of, Death with Dignity). The advocate then assesses the patient's rationale for and interest in further participation. In nearly all cases, family members are present.

If the patient elects to participate in the Death with Dignity program, the advocate conducts a preliminary chart review to confirm documenta-

tion of the terminal prognosis or, if absent, to request that the attending physician document the prognosis explicitly. The advocate then determines whether the attending physician will act as the prescribing physician. If not, the advocate identifies a prescribing physician and a consulting physician from the list of willing providers, preferentially choosing physicians who specialize in the type of cancer that the patient has. (General care of the patient is not transferred to the prescribing or consulting physician, unless the patient requests this.) The advocate then formally documents the patient's request for assistance with dying and provides the patient with written information that describes the program (including a timeline of the required requests, assessments, and waiting periods), which must be signed by the patient. The advocate also verifies that the patient is a Washington resident and completes a psychosocial assessment. At Seattle Cancer Care Alliance, social workers provide the first line of psychological evaluation for all patients, regardless of whether or not they are participating in the Death with Dignity program, using interview-based techniques and standardized assessments (e.g., the Patient Health Questionnaire 9 and the Generalized Anxiety Disorder 7 questionnaire). Although physicians retain the responsibility to evaluate patients for depression and decision-making capacity, advocates make these assessments as part of their standard practice. Advocates refer patients to the Psychiatry and Psychology Service if there is any history of, or positive screening for, a mental health disorder or impaired decision-making capacity.

The advocate then collects copies of the Physician Order for Life-Sustaining Treatment (a form that delineates the patient's preferences for interventions such as mechanical ventilation or resuscitation) and health care directives, assisting in their completion if desired; arranges for a clinician to be present at the time of medication ingestion, if requested (this is rare); provides advice regarding the securing and disposal of unused medication; provides grief support and legacy support (e.g., help in preparing letters or videos by which to be remembered) through periodic calls or visits; and requests that the family inform us when the patient ingests the medication, so that we can provide assistance in the case of complications, offer bereavement support, and aid the prescribing physician in completing

the required after-death reporting forms. Advocates participate in two in-person meetings with the patient and family on average (range, one to four); we have not assessed our use of telephone follow-up.

The patient (and family) meets sequentially with the prescribing clinician and the consulting clinician to review the medical diagnosis, prognosis, risks of medication, and alternatives (including palliative and hospice care and specialized care for pain). After the mandatory waiting period of 15 days, if all requirements are met, a written prescription is given to our retail pharmacy. The pharmacist schedules a private room to meet with the patient (and family) in order to discuss preparation of the drug for ingestion, potential side effects, and the use of antiemetic therapy (ondansetron is routinely prescribed). Because of the lack of availability of pentobarbital, we currently use secobarbital, although 16.9% and 36.1% of Death with Dignity participants in Washington and Oregon, respectively, received pentobarbital.

Checklists and medical charts are randomly audited annually by the director of supportive care and specialty clinics. We have had 100% compliance with the completion of mandated forms and processes, with the exception of one unintentional failure to observe the full waiting period early in our program.

RESULTS

CHARACTERISTICS OF PATIENTS AT SEATTLE CANCER CARE ALLIANCE

Data on patients who have participated in the Death with Dignity program at Seattle Cancer Care Alliance are presented in Table 2, along with comparable data publicly reported by Washington and Oregon for all Death with Dignity participants from March 5, 2009, through December 31, 2011, and from January 1, 1998, through December 31, 2011, respectively.^{1,2} During the former period, 114 patients inquired about our Death with Dignity program. Of those, 44 patients (38.6%) did not pursue Death with Dignity further or were deemed ineligible. We have refused participation to only 1 patient, who expressed an unwillingness to ingest the medication privately. Thirty patients (26.3%) initiated the process by making a first oral request but either elected not to pursue Death with Dignity or died before completing the process (average time from first oral request to death, 16.6 weeks [range, 2.3 to 97.1]).

Our patients seldom contact Compassion and Choices without also discussing this with their physician (Miller R, Compassion and Choices of Washington: personal communication).

Forty patients (35.1% of all those who made an initial inquiry) received prescriptions for lethal medication; all 40 have died, 24 (60.0% of those receiving prescriptions) after ingesting the medication. The 40 patients who died represent 15.7% of the 255 Washington State Death with Dignity participants. Although we do not formally track patient deaths, Death with Dignity participants account for 0.02% of annual deaths among patients at Seattle Cancer Center Alliance, on the basis of recent estimates. Most participants were white, male, and college-educated, characteristics that are consistent with the statewide Washington and Oregon data. Seattle Cancer Care Alliance participants may be more likely than overall Washington participants to be working, given the higher percentage of persons with both private and Medicare insurance in our patient population. Participants typically have known their oncologist for 8 months. At the time of the initial request, 54.2% of our Death with Dignity participants are enrolled in hospice; Seattle Cancer Care Alliance has not formally tracked hospice enrollment at the time of death. However, 80.9% of patients in Washington State and 89.7% of those in Oregon are enrolled in hospice at the time of death.

No unexpected complications have occurred; however, one patient died a day after taking the medication, with the protracted process causing distress on the part of family members and clinicians (similar cases have occurred in Washington State in general and in Oregon). We have not received any complaints from family members or caregivers regarding our process or the manner of death. Anecdotally, families describe the death as peaceful (even when death has taken longer than the average of approximately 35 minutes). In addition, both patients and families frequently express gratitude after the patient receives the prescription, regardless of whether it is ever filled or ingested, typically referencing an important sense of control in an uncertain situation. Eleven participants lived longer than the expected 6 months. Of these, nine died after ingesting the lethal prescription an average of 7.4 weeks (range, 0.1 to 18.9) beyond the 6-month cutoff.

The most common reasons given by patients

Table 2. Characteristics of Death with Dignity Participants at Seattle Cancer Care Alliance, as Compared with Participants in All of Washington State and in Oregon.*

| Characteristic | Seattle Cancer Care Alliance | Washington State | Oregon |
|--|------------------------------|------------------|----------------|
| Medication dispensed — no. | 40 | 255 | 935† |
| Died — no./total no. (%) | 40/40 (100) | 241/255 (94.5) | NA‡ |
| After ingesting medication | 24/40 (60.0) | 157/241 (65.1) | 596/935 (63.7) |
| Died at home | 20/24 (83.3) | 145/155 (93.5) | 562/596 (94.3) |
| Enrolled in hospice at time of initial request | 13/24 (54.2) | | |
| Enrolled in hospice at time of initial request or death | | 127/153 (83.0) | 522/582 (89.7) |
| Age | | | |
| 18–64 yr — no./total no. (%) | 14/40 (35.0) | 67/213 (31.5) | 187/596 (31.4) |
| 65–84 yr — no./total no. (%) | 23/40 (57.5) | 114/213 (53.5) | 409/596 (68.6) |
| ≥85 yr — no./total no. (%) | 3/40 (7.5) | 32/213 (15.0) | 71/596 (11.9) |
| Range — yr | 42–91 | 41–101 | 25–96 |
| Male sex — no./total no. (%) | 22/40 (55.0) | 111/213 (52.1) | 308/596 (51.7) |
| Non-Hispanic white — no./total no. (%) | 29/40 (72.5) | 180/189 (95.2) | 579/593 (97.6) |
| Married — no./total no. (%) | 22/40 (55.0) | 90/189 (47.6) | 271/593 (45.7) |
| High-school diploma or higher level of education — no./total no. (%) | 39/40 (97.5) | 177/188 (94.1) | 551/591 (93.2) |
| Residence east of the Cascade Mountains — no./total no. (%) | 1/40 (2.5) | 12/213 (5.6) | 43/593 (7.3) |
| Insurance status — no./total no. (%) | | | |
| Private insurance | 12/40 (30.0) | 63/182 (34.6) | 382/577 (66.2) |
| Medicare, Medicaid, or other public insurance | 13/40 (32.5) | 84/182 (46.2) | 185/577 (32.1) |
| Combination of private and public insurance | 11/40 (27.5) | 30/182 (16.5) | NA‡ |
| None | 4/40 (10.0) | 5/182 (2.7) | 10/577 (1.7) |
| Diagnosis — no./total no. (%) | | | |
| Cancer | 24/24 (100) | 166/213 (77.9) | 480/596 (80.5) |
| Neurodegenerative disease | | 22/213 (10.3) | 44/596 (7.4) |
| Respiratory disease (including COPD) | | 9/213 (4.2) | 25/596 (4.2) |
| Heart disease | | 10/213 (4.7) | 10/596 (1.7) |
| Other or unknown | | 6/213 (2.8) | 37/596 (6.2) |

* Data for Seattle Cancer Care Alliance and Washington State are complete from March 5, 2009, through February 29, 2012, for patients prescribed medication through December 31, 2011. Data for Oregon are complete from January 1, 1998, through February 29, 2012, for patients prescribed medication through December 31, 2011. Washington State does not release data for research purposes. Annual reports are released, but data from those reports are not updated in subsequent years. Therefore, data can be missing because the data were not reported on required forms, the data were reported as unknown, or forms were not available at the time of finalizing the annual report. COPD denotes chronic obstructive pulmonary disease, and NA not available.

† Oregon tracks prescriptions written, not those dispensed (as is done in Washington).

‡ The total number of deaths and data on combined public and private insurance coverage are not tracked in Oregon.

for wanting to participate in Death with Dignity were loss of autonomy (97.2%), inability to engage in enjoyable activities (88.9%), and loss of dignity (75.0%) (Table 3). Eight of 36 participants (22.2%) reported uncontrolled pain or concerns of future pain (as compared with 34.7% and 22.6% of Washington State and Oregon

participants, respectively). None of the patients who inquired about Death with Dignity and were found to have either current or previous depression or decisional incapacity elected to move forward with the process. Among patients who have pursued Death with Dignity, no participants were deemed to require mental health

Table 3. Aspects of Death with Dignity Experience for Participants Receiving Care at Seattle Cancer Care Alliance, as Compared with Participants in All of Washington State and in Oregon.*

| Variable | Seattle Cancer Care Alliance | Washington State | Oregon |
|--|------------------------------|------------------|-----------------|
| End-of-life concerns — no./total no. (%) | | | |
| Loss of autonomy | 35/36 (97.2) | 183/202 (90.6) | 538/592 (90.9) |
| Inability to engage in enjoyable activities | 32/36 (88.9) | 179/202 (88.6) | 523/592 (88.3) |
| Loss of dignity | 27/36 (75.0) | 151/202 (74.8) | 386/592 (65.2) |
| Loss of control of bodily functions | 10/36 (27.8) | 105/202 (52.0) | 318/592 (53.7) |
| Burden on family, friends, or caregivers | 8/36 (22.2) | 78/202 (38.6) | 214/592 (36.1) |
| Inadequate pain control or concern about it | 8/36 (22.2) | 70/202 (34.7) | 134/592 (22.6) |
| Financial implications of treatment | 0/36 | 8/202 (4.0) | 15/592 (2.5) |
| Patient informed family of decision — no./total no. (%) | 32/40 (80.0) | 189/202 (93.6) | 493/522 (94.4)† |
| Duration of patient–physician relationship — wk | | | |
| Median | 33 | 14 | 12 |
| Range | 4–637 | 3–1404 | 0–1905 |
| Time from ingestion of medication to death — min‡ | | | |
| Median | 35 | 45 | 25 |
| Range | 15–1680 | 5–1800 | 1–104 |
| Health care provider present at time of ingestion — no./total no. (%)§ | | | |
| Prescribing physician | | 7/157 (4.5) | 100/526 (19.0) |
| Other provider, prescribing physician not present | | 80/157 (51.0) | 231/526 (43.9) |
| No provider | | 52/157 (33.1) | 72/526 (13.7) |
| Unknown | 24/24 (100) | 18/157 (11.5) | 123/526 (23.4) |

* Data for Seattle Cancer Care Alliance and Washington State are from March 5, 2009, through February 29, 2012. Data for Oregon are from January 1, 1998, through February 29, 2012.

† In Oregon, whether the patient informed the family of the decision was recorded beginning in 2001. Since then, 21 of 522 patients (4.0%) have chosen not to inform their families, and 8 patients (1.5%) have had no family to inform. Data were missing for 1 patient in 2002, for 2 in 2005, and for 1 in 2009.

‡ Washington State presents the data in categories (1 to 90 minutes, ≥91 minutes, or unknown), with the range of times. To approximate the median, the middle of the most common category for the 3 years was selected.

§ The data shown are for 2009 through 2011 in Washington State and for 2001 through 2011 in Oregon. Information about the presence of a health care provider or volunteer, in the absence of the prescribing physician, was first collected in 2001 in Oregon. The procedure in Oregon was revised in mid-2010 to standardize reporting on the follow-up questionnaire. With the new procedure, information about the time of death and the circumstances surrounding death is recorded only when the physician or another health care provider is present at the time of death. This change resulted in a larger number of patients for whom the information was unknown, beginning in 2010.

evaluation for depression or decisional incapacity (as compared with 10 of 209 patients [4.8%] in Washington State and 40 of 596 patients [6.7%] in Oregon).

DISCUSSION

Our Death with Dignity program has been well accepted by patients, families, and staff. We attribute this to the professionalism of our advocates, the great care taken by our prescribing and consulting clinicians when interacting with pa-

tients and families, the low profile of the Death with Dignity program overall, and the willingness of the Seattle Cancer Care Alliance leadership to allow considerable debate before the program was developed. A few clinicians who were initially strongly opposed to the Death with Dignity program subsequently expressed their willingness to participate as consulting or prescribing clinicians, which further supports acceptance of the program.

The reasons for participation in our program reflect concern about autonomy, dignity, and

functional status rather than disease-related symptoms or depression, findings that are consistent with the literature.⁹ Patients, caregivers, and family members have frequently expressed gratitude after the patient obtained the prescription, regardless of whether it was ever filled or ingested, typically referencing an important sense of control in an uncertain situation. However, we continue to identify and address process and quality issues. For example, although consistent with the broader reported experience in Washington and Oregon, the eight reports of uncontrolled pain or fear of future symptoms at the time of the initial request for Death with Dignity deserve attention. Seattle Cancer Care Alliance provides specialized care for pain and palliative care services in the outpatient setting. Both services have nurse practitioners and physicians who provide care in the oncology clinic. Clinicians (social workers, nurses, and physicians) can directly refer patients to either service; however, these services have been invoked infrequently for Death with Dignity participants (perhaps because the participants typically do not have symptoms at the time of the request).⁹ Regardless, palliative care consultations will be offered as a matter of policy to all Death with Dignity participants going forward. It is our hope that this will also encourage earlier enrollment in hospice.

Opponents of Death with Dignity legislation have raised the concern that it might disproportionately affect vulnerable populations (e.g., racial or ethnic minorities and lower-income populations). The Oregon experience does not support this concern.²¹ Nor do we have evidence that our population differs from the broader Washington State population on the basis of

U.S. Census data.²² Also consistent with the literature is the finding that only a small subset of patients who are initially interested in Death with Dignity go on to pursue this option.²³ Some patients do not complete the process owing to rapidly deteriorating performance status or death, and others live longer than the estimated 6 months, findings that represent opportunities to improve both prognostication and communication. However, we have purposefully not informed prescribing and consulting physicians when Death with Dignity participants live longer than 6 months, because of the concern that such feedback may unintentionally delay prognostic conversations until clinicians are certain of the timing, thereby reinforcing the more persistent and likely problem of communicating the prognosis (too) late in the course of illness.

In conclusion, our Death with Dignity program both allows patients with cancer who wish to consider this option to do so within the context of their ongoing care and accommodates variation in clinicians' willingness to participate. The program ensures that patients (and families) are aware of all the options for high-quality end-of-life care, including palliative and hospice care, with the opportunity to have any concerns or fears addressed, while also meeting state requirements.

Disclosure forms provided by the authors are available with the full text of this article at NEJM.org.

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