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Public Health Law Fall 2016 – C. Coleman

AWR Paper

**Physician Assisted Suicide:
An End of Life Care Option That Should Be Available to All Dying Patients**

INTRODUCTION

Physician assisted suicide, or PAS, is now legal in six states in the U.S., and almost twenty more states are in the process of deciding if they will legalize the practice as well. The increase in acceptance may be due to sympathetic news stories such as that of Brittany Maynard, whose story was widely covered and brought mainstream attention to PAS. Brittany had terminal brain cancer and decided to move to Oregon which was the first state to legalize PAS in 1997 under the Death with Dignity Act. In 2014 she used a lethal dose of medication, prescribed by her physician, to end her own life. In her interview with CNN, Brittany said that she feared the suffering that would likely be part of her dying process, including loss of verbal, cognitive and motor functions, pain, and the pain her family would endure watching this process¹. She wanted to have the option to end her own life if the dying process became unbearable.

Brittany's story is not unique. In fact, of the patients who have chosen to end their lives in Oregon their top three reasons for requesting PAS were loss of the ability to take part in activities that make life enjoyable, loss of autonomy, and loss of dignity². States that have

¹ Brittany Maynard, *My Right to Die with Dignity*, CNN (November 2, 2014, 10:44 PM), <http://www.cnn.com/2014/10/07/opinion/maynard-assisted-suicide-cancer-dignity/>

² Oregon Public Health Division, Oregon Death with Dignity Act: 2015 Data Summary (2016)

legalized PAS, and those states considering it today, have recognized the public health interest in providing PAS as one more end of life option to attempt to preserve the dignity, voice and autonomy of dying patients and relieve suffering³. And so the debate has seemed to swing from one focused exclusively on “if” the practice should be legalized, to “how” it should be implemented to best serve the public health interest.

In all states today, terminal patients have a number of choices for end of life care. Though terminal, patients may continue to pursue active medical treatment for their disease. They may also seek palliative care, which is intended to prevent or treat the symptoms of the disease as early as possible⁴. This is also known as “comfort care” or “supportive care” and is not intended to cure the disease but to improve the quality of life for the patient. Palliative care can be used by patients whether or not they are terminal and whether or not they are still receiving active treatment for their disease. Hospice care differs in that it is generally provided to patients who are terminal and have six months or less left to live and provides all aspects of their end of life care⁵. So, palliative care can be one aspect of hospice care, but hospice care is much broader. Medicare, like Medicaid and commercial insurers, will cover 100% of hospice care if the patient has a confirmed prognosis of six months or less to live, they have accepted palliative care, and have agreed to accept hospice over Medicare-covered treatments for their disease or illness⁶.

³ Margaret Somerville, *Excerpt: Is Legalizing Euthanasia an Evolution or Revolution in Societal Values?*, 34 Quinnipiac L. Rev. 747 (2015-2016)

⁴ *Palliative Care in Cancer*, National Cancer Institute (March 16, 2010), <https://www.cancer.gov/about-cancer/advanced-cancer/care-choices/palliative-care-fact-sheet#q1>.

⁵ *What is Hospice Care?*, American Academy of Hospice and Palliative Medicine, <http://palliativedoctors.org/hospice/care> (last visited December 15, 2016)

⁶ Centers for Medicare & Medicaid Services, *Medicare Hospice Benefits* (Revised February 2016), available at <https://www.medicare.gov/Pubs/pdf/02154.pdf>

In addition to palliative and hospice care, terminal patients who desire to have control over their dying process and maintain their autonomy, dignity and voice should have the option of PAS. For some patients, just having the medication may be enough to ease their anxiety about the dying process, and they may not even consume the medication⁷. The data from Oregon supports this hypothesis. Over the 18 years of the Oregon Death with Dignity program, 1545 lethal prescriptions have been filled, but only 991 patients, about 65%, have actually been consumed by patients to bring about their death⁸. This is consistent with the 2015 Washington Death with Dignity report, which shows that in 2015, 213 patients received prescriptions but only 166, or 78%, are confirmed to have used them⁹. But it is important that when made available, PAS does not take the place of exploring and utilizing those other options. It must not be chosen by patients because their access to, or the utility of, other options was insufficient.

LEGAL PATH TO PAS ACCEPTANCE

The legal evolution in the pursuit of autonomy in end of life decisions has been hard fought. Before PAS was in the spotlight, the legal battle was focused on the right to refuse medical care intended to prolong life, which is now well established. This acceptance was the result of a series of cases that show the increasing value placed on personal autonomy, individual liberty, and freedom from medical interventions. Cases such as *Bouvia* and *Cruzan* established that the right to refuse medical treatment is fundamental^{10,11}. In *Bouvia*, the California Superior Court held that a patient has a right to refuse medical treatment, even if that treatment is

⁷ Liz Szabo, *Terminally Ill Patients Don't Use Aid-In-Dying Laws To Relieve Pain* (October 26, 2016) <http://khn.org/news/terminally-ill-patients-dont-use-aid-in-dying-laws-to-relieve-pain/>

⁸ Oregon Public Health Division, Oregon Death with Dignity Act: 2015 Data Summary (2016)

⁹ Washington State Department of Health, Washington State Department of Health 2015 Death with Dignity Act Report Executive Summary, DOH 422-109 (2016)

¹⁰ *Bouvia v. Superior Court*, 179 Cal. App. 3d 1127 (Cal. App. 2d Dist. 1986)

¹¹ *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (U.S. 1990)

furnishing hydration and nutrition, and the removal of that intervention creates a life-threatening condition¹². In *Cruzan*, Chief Justice Rehnquist, on behalf of the Supreme Court, noted that in common law the touching of another person without legal justification is battery, which is why informed consent is now generally required for medical treatment¹³. He went on to write that “[t]he logical corollary of the doctrine of informed consent is that the patient generally possesses the right not to consent, that is, to refuse treatment.”¹⁴

The right to determine the level of medical care you do or do not receive was further recognized in 1990 when Congress passed the Self-Determination Act, which went into effect on December 31, 1991¹⁵. The Act requires healthcare facilities who receive federal funding to provide information about advanced health care directives to patients upon enrollment to the facility. This includes informing patients of their right to accept or refuse medical care. Today, all 50 states and the District of Columbia have passed legislation in support of advanced directives¹⁶.

There has been a slow but positive progression in the support of patient counseling regarding their end of life options beyond advanced directives. In 2009, Section 1233 of bill HR 3200 was a proposed section of the Affordable Care Act which provided for Medicare reimbursement to physicians for providing patient counseling on end of life care including advanced directives and living wills. This section became known as establishing “death panels”, thanks to Sarah Palin, and the section was ultimately removed from the Affordable Care Act¹⁷.

¹² *Bouvia v. Superior Court*, 179 Cal. App. 3d 1127, 1137 (Cal. App. 2d Dist. 1986)

¹³ *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 269 (U.S. 1990)

¹⁴ *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 270 (U.S. 1990)

¹⁵ 101 P.L. 508, 104 Stat. 1388, 1990 Enacted H.R. 5835, 101 Enacted H.R. 5835

¹⁶ *Chronology of Assisted Dying*, Death with Dignity, <https://www.deathwithdignity.org/assisted-dying-chronology/> (last visited December 15, 2016)

¹⁷ Paula Span, *A Quiet End to the 'Death Panels' Debate*, The New York Times (November 20, 2015)

Although factually incorrect, the debate about “death panels” created negative publicity about counseling patients regarding end of life options and the provision was removed from the Act. The public thought the provision established government review panels that would decide if patients would receive continued treatment or end of life care, or essentially be euthanized, which was not true. The tide finally changed in October 2015, when the Obama administration issued a final rule that authorizes physicians to code and bill for consultations they have with patients about the end of life care options they would like¹⁸.

The case law that exists which shows the legal battle to recognize physician assisted suicide as a fundamental right has not been as smooth or successful. State laws that have banned PAS have been upheld because the courts have distinguished withholding or withdrawing medical care, which they see as grounded in the fundamental right to bodily integrity, from steps taken to actively end life. New York had a ban on PAS, and in 1997 in *Vacco v. Quill*, the Supreme Court held that the ban did not violate the Equal Protection Clause because it neither infringed upon fundamental rights nor applied only to people of a suspect classification¹⁹. At the same time, the Supreme Court decided *Washington v. Glucksberg*²⁰. In this case, physician assisted suicide was held to not be a liberty that is protected by the Due Process Clause. Washington State has since legalized PAS, but *Washington v. Glucksberg* remains interesting for our review because the Court held that the law in Washington State that banned PAS was constitutional because it was rationally-related to three important government interests. These interests remain the most passionate and coherent arguments against PAS today:

http://www.nytimes.com/2015/11/24/health/end-of-death-panels-myth-brings-new-end-of-life-challenges.html?_r=1

¹⁸ Robert Pear, *New Medicare Rule Authorizes ‘End-of-Life’ Consultations*, The New York Times (October 30, 2015) <http://www.nytimes.com/2015/10/31/us/new-medicare-rule-authorizes-end-of-life-consultations.html>

¹⁹ *Vacco v. Quill*, 521 U.S. 793 (U.S. 1997)

²⁰ *Wash. v. Glucksberg*, 521 U.S. 702 (U.S. 1997)

1. The interest in preserving human life;
2. The interest in protecting vulnerable groups from abuse and neglect, including the elderly, the poor and the disabled; and
3. The interest in guarding against legislation that may lead to involuntary euthanasia.

The interest in protecting vulnerable groups from abuse and involuntary euthanasia are the most compelling public health arguments against PAS. These arguments, in addition to a myriad of other ethical arguments, have kept some states from legalizing PAS. For those states that have legalized PAS, and those that will decide in 2016 and 2017, the central issue is how they can legalize PAS in order to preserve the dignity, voice and autonomy of terminal patients while creating enough controls to protect vulnerable groups from abuse and guard against involuntary euthanasia.

Oregon was the first state to make physician assisted suicide legal under the Oregon Death with Dignity Act which became effective in 1997²¹. It was challenged by the Oregon Attorney General, via an interpretive rule, as being an illegitimate use of prescription medications under and therefore in violation of the Controlled Substances Act (CSA)²². In 2006 the Supreme Court, in *Gonzales v. Oregon* affirmed the ruling of the Ninth Circuit which invalidated the Attorney General's rule²³.

The language of the Oregon Act is as follows:

An adult who is capable, is a resident of Oregon, and has been determined by the attending physician and consulting physician to be suffering from a terminal disease, and who has voluntarily expressed his or her wish to die, may make a

²¹ Or. Rev. Stat., § 127.800 §1.01 (2015)

²² 21 C.F.R. § 1306.04 (2005)

²³ *Gonzales v. Oregon*, 546 U.S. 243 (U.S. 2006)

written request for medication for the purpose of ending his or her life in a humane and dignified manner in accordance with ORS 127.800 to 127.897.²⁴

Under the Act a patient may submit an oral and a written request for PAS medication to a physician and the written request must be signed by two witnesses deemed appropriate by the Act. The physician must then verify that the patient is in fact terminal, having less than six months left to live, that they are an Oregon resident, and that they have made an informed decision to choose PAS. The physician must then refer the patient to a consulting physician who must verify the patient's diagnosis and prognosis and that they are making the decision of their own volition. The physician may also refer the patient for psychiatric or psychological counseling if they think it is needed. The purpose of such counseling is to ensure that the patient's judgment is not impaired by a psychological or psychiatric disorder or depression. The physician will then inform the patient that they can rescind the request at any time now, during the 15-day mandatory waiting period, or after the waiting period has ended. At the end of the waiting period the patient must again make an oral request for the medication. Right before the physician prescribes the medication they must again tell the patient that they may rescind the request. If the patient does not rescind their request then the physician may prescribe the medication, must document the provision of medication in accordance with the statute, and may sign the death certificate after the patient has consumed the medication and died.

After Oregon initially passed its PAS legislation other states introduced bills to make PAS legal but were not successful, including Michigan, Maine, California, Vermont, Arizona, Rhode Island and Washington²⁵. But after the Supreme Court ruling in *Gonzales* which saved the Oregon Death with Dignity Act, states again proposed legislation to legalize physician

²⁴ Or. Rev. Stat. § 127.805 §2.01, § 127.800 (2015)

²⁵ *Chronology of Assisted Dying*, Death with Dignity, <https://www.deathwithdignity.org/assisted-dying-chronology/> (last visited December 15, 2016)

assisted suicide but now some were met with success. In March of 2009 the Washington Death with Dignity Act went into effect²⁶, largely modeled after the Oregon act. In 2015 Vermont enabled all provisions of Act 39, Patient Choice and Control at the End of Life²⁷. In 2015, California passed the End of Life Option Act²⁸. A challenge to the California Act was denied by the Riverside County Superior Court on August 26, 2016. Most recently, on November 8, 2016, Colorado voters passed the End of Life Options Act, making Colorado the fifth state to legalize PAS²⁹. Currently these five states have enacted laws that make physician assisted suicide legal.

Though not legalized by statute, Montana has decriminalized physician assisted suicide through case law. The first step on this journey came in 1991 when Montana passed the Rights of the Terminally Ill Act³⁰. This act made it legal for a patient or their designee to declare their wishes to withhold life-sustaining medical interventions. Then in 2009, the Montana Supreme Court, in *Baxter v. Montana*, held that it is not a crime for a physician to aid a mentally competent, adult, terminal patient in dying³¹. Their rationale was that a physician was shielded from criminal liability because these patients can give proper consent, and so it is not considered homicide. They held that when the physician gives the patient medication, and the patient ingests it of their own volition, it is simply the patient giving effect to his or her life-ending decision, provided the physician does not actually assist. In an attempt to provide guidance to physicians on PAS as a result of this case law, the Montana Senate introduced the Montana

²⁶ Wash. Rev. Code §70.245 (2009)

²⁷ Vt. Stat. Ann. 18 §§ 5281-93 (2015)

²⁸ Cal Health & Saf Code Div. 1, Pt. 1.85 §443

²⁹ *Colorado*, Death with Dignity, <https://www.deathwithdignity.org/states/colorado/> (last visited December 15, 2016)

³⁰ 1991 Mt. ALS 391, 1991 Mt. Ch. 391, 1991 Mt. HB 635

³¹ *Baxter v Montana*, 224 P.3d 1211 (2009)

Compassionate Care Act in 2015, but it was withdrawn by its sponsor in March 2016, so the *Baxter* decision still governs.

In 2016 almost twenty more states, including New Jersey, are in the process of deciding if physician assisted suicide will become legal. For these states and other states in the future that may be willing to agree that PAS is a valuable option for end of life care, the question is, then, how to make PAS available to patients while protecting the public. Data reported for states where PAS is legal shows some evidence that the safeguards put in place with the statute guard against abuse, but there are concerns raised by the data, or lack of data points, that must be addressed to ensure vulnerable groups are being protected. Another concern is that PAS is not equally available to all patients, which may be due to limited physician participation with the PAS programs or access barriers created by cost of the medications. Finally, we will look at how the limitations on access to palliative and hospice care might drive people to choose PAS unnecessarily. We will look at these public health concerns in turn.

PROTECTING VULNERABLE GROUPS FROM ABUSE

States with existing legislation and states with proposed legislation legalizing PAS have included provisions to attempt to reduce potential abuse and protect vulnerable groups. For example, common provisions include:

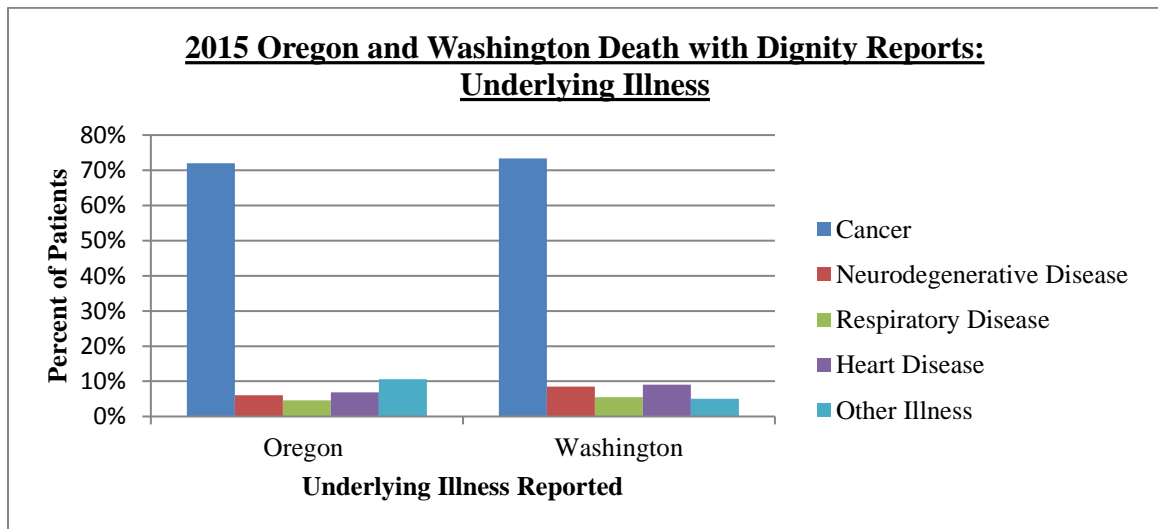
1. Requiring that the patient be diagnosed as terminal with a prognosis of less than six months to live, confirmed by two physicians;
2. Mandating a 15-day waiting period between the first request and receipt of prescription;

3. Verifying that the person is making an informed decision and doing so voluntarily;
and
4. Requiring counseling sessions if indicated to ensure patient is of sound mind.

1. REQUIRING A TERMINAL DIAGNOSIS

The underlying illnesses of those patients who opted for PAS reported in the 2015 Oregon and Washington Death with Dignity annual reports are displayed in Table 1 and appear to support the expectation that patients were in fact terminal^{32,33}. Over 70% of patients were diagnosed with cancer. The rest of the patients were diagnosed as having neurodegenerative diseases including amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig’s disease, chronic respiratory disease including COPD, heart disease and “other.”

Table 1



³² Oregon Public Health Division, Oregon Death with Dignity Act: 2015 Data Summary (2016)

³³ Washington State Department of Health, Washington State Department of Health 2015 Death with Dignity Act Report Executive Summary, DOH 422-109 (2016)

The specifically listed diseases are generally accepted to result in a terminal diagnosis at some point in the disease progression, and so the data appears to provide some reassurance that the program was only accessed by terminal patients. However, no further information is provided about what the “other” illnesses were. It would be helpful for states to conduct a more thorough analysis of the diagnosis and prognosis reported by physicians to verify that patients were reasonably characterized as having six months or less left to live, even if they in fact lived longer than six months. At a minimum, states should define the diseases that comprised the “other” category. In 2015, 14 patients in Oregon and 10 patients in Washington had a disease categorized as “other.” It would be reasonable to ask the states to provide the specific diseases for these patients considering the small number and their access to death certificates.

The fact that two physicians must confirm the diagnosis and prognosis of patients who request PAS provides a safeguard that the program cannot be accessed by non-terminal patients. An additional safeguard is that the acts only remove liability of civil and criminal prosecution and professional discipline for physicians who prescribe PAS medication in good faith in compliance with the law. Therefore, a physician who prescribes PAS medication, or a physician who confirms the terminal diagnosis or prognosis, for a patient who is not terminal could open themselves up to personal liability, which creates a deterrent to abuse.

2. 15-DAY WAITING PERIOD

The enacted acts and proposed legislation require a mandatory waiting period between the patient’s first request for PAS and when they can receive the prescription. The purpose of the waiting period is to ensure that the patient is not making a rash, emotional decision, and has time to reconsider. This is also to allow sufficient time for the confirmatory diagnosis and

prognosis, and psychiatric evaluation if needed. Further, the physician informs the patient at their first request and at the second request that they can rescind the request at any time, allowing the patient to “back out” if they are having second thoughts.

The data does not tell us how many patients rescind their request because the reports focus only on those patients who actually received a prescription. The data suggests that perhaps up to 30% of patients who receive the medication may change their mind and do not use it. It would also be helpful for states to collect survey data from physicians to attempt to quantify how many patients make a first request for medication but then do not follow through to the second request or filling the prescription.

3. VERIFYING PATIENT IS MAKING AN INFORMED DECISION, VOLUNTARILY

When a patient first requests PAS, by oral and written request, and before the physician begins any steps in the PAS process, the physician must verify that the patient is making an informed decision. In the Oregon Act “informed decision” is defined as:

[A] decision by a qualified patient, to request and obtain a prescription to end his or her life in a humane and dignified manner, that is based on an appreciation of the relevant facts and after being fully informed by the attending physician of:

- (a) His or her medical diagnosis;
- (b) His or her prognosis;
- (c) The potential risks associated with taking the medication to be prescribed;
- (d) The probable result of taking the medication to be prescribed; and
- (e) The feasible alternatives, including, but not limited to, comfort care, hospice care and pain control.³⁴

³⁴ Or. Rev. Stat., § 127.800 §1.01. Definitions (7)

This requirement appears to be a fairly low hurdle to overcome. It appears obvious that patients requesting PAS would already understand the potential risks and probable result of the medication to be prescribed. What patients may or may not know is that in Oregon in 2015 100% of the patients who ingested the medication died after ingestion. So while it may seem obvious that patients would know they will certainly die from ingesting the medication it is nevertheless important for physicians to be completely clear about the potency and effects of the medication.

Ensuring that patients receive adequate counseling by their physician on their feasible alternatives is an important step in ensuring patients are not selecting PAS as their only option. As discussed previously, PAS should be only one of the multiple options available to patients including palliative and hospice care. If the patient has Medicare the physician can be paid to have these counseling sessions, so there is incentive for the physician as well. But even more importantly, these conversations can help get to the heart of why the patient is choosing PAS. For example, about 25% of patients who have received PAS medication in Oregon cited pain as one of their end of life concerns. While the percentage may be low, it is nevertheless important for physicians to uncover this as a factor for choosing PAS. It is possible that if their pain can be more adequately managed the patient might not choose PAS.

Physicians must also ensure patients are making the decision voluntarily. This means that in the screening process they must ensure the patient is not being coerced or under undue burden that is driving them to request PAS. None of the enacted PAS acts, however, require that physicians receive any training on how to have this conversation or conduct this evaluation in a meaningful way. And yet, without such training physicians must protect, for example, the elderly, poor or disabled who might choose PAS because they were pressured to do so by

someone who had something to gain from their death, whether to receive a financial windfall or to just relieve themselves of the burden of caring for another. As an example, according to the National Council on Aging, elder abuse is estimated to happen to one out of ten elderly Americans³⁵. Ninety percent of the time the abuser is a family member and in these cases the abused have a three-fold higher risk of death. This is thought to be due to factors such as social isolation and mental incapacity.

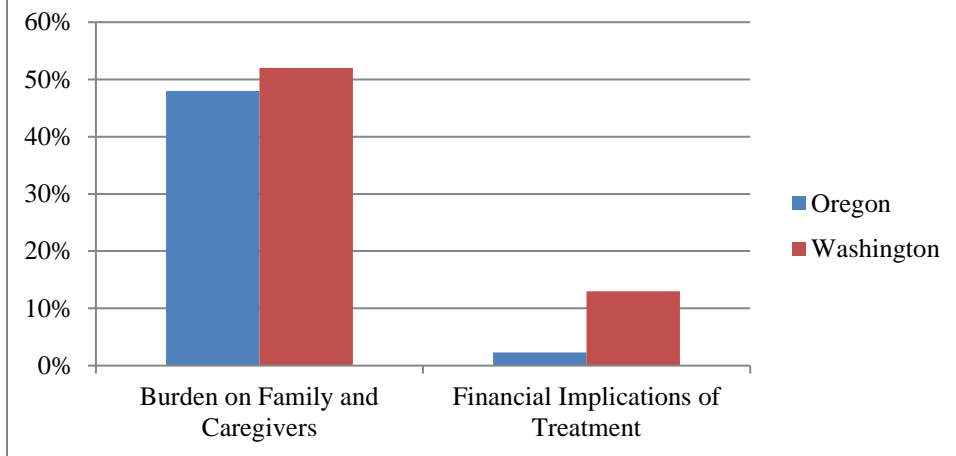
Family members may also feel pressured into committing suicide due to the financial and emotional burdens they have placed on their family. This guilt can be self-generated or may be placed on them by family and friends. In the 2015 Oregon and Washington reports patients cited concern over being a burden to family and caregivers, and financial concerns, as some of their overall end of life concerns, see Table 2 below. In this situation, there may be direct coercion but patients may also come to the decision based on their own guilt.

Table 2

³⁵ *What is Elder Abuse?* National Council on Aging, <https://www.ncoa.org/public-policy-action/elder-justice/elder-abuse-facts/> (last visited December 15, 2016)

³⁶ Table generated based on data from Year 18 Oregon Death with Dignity Report and 2015 Washington Death with Dignity Report

2015 Oregon and Washington Death with Dignity Reports: End of Life Concerns⁴¹



One provision that safeguards against undue influence is the construction of the patient request forms. When completing the Request for Medication Form³⁷ patients must verify that they are acting voluntarily in both states. The Washington form goes a little bit further than the Oregon form with the following expanded language:

I make this request voluntarily and without reservation; and I accept full moral responsibility for my actions. I further declare that I am of sound mind and not acting under duress, fraud, or undue influence³⁸.

There is also the requirement that the patient's written request be signed by two witnesses, and that those two witnesses do not have a personal interest in the patient's decision. For example, on the Oregon patient request form it is written that the witnesses must not be a relative by blood or marriage, must not have a financial interest in the patient's estate, and must not work in the facility where the patient resides³⁹. These witnesses are signing the form not only verifying the

³⁷ Or. Rev. Stat. § 127.897 §6.01, available at <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/pt-req.pdf>, Wash. Rev. Code §70.245.220 (2009) available at <http://www.doh.wa.gov/portals/1/Documents/Pubs/422-063-RequestMedicationEndMyLifeHumaneDignifiedManner.pdf>

³⁸ Wash. Rev. Code §70.245.220 (2009)

³⁹ Or. Rev. Stat. § 127.897 §6.01

patient's identity but also verifying that the patient did not sign under duress, fraud or undue influence. In addition, the Oregon and the Washington Attending Physician Compliance Forms⁴⁰ require both the attending physician and the consulting physician to verify that the patient is making the decision voluntarily.

When physicians speak openly with patients about PAS they should understand where concerns such as being a burden and financial concerns fit into their decision-making and look for signs of undue influence. It is possible that a physician can work with hospice providers or insurance payers to reduce these concerns and the associated guilt, which could also make the patient feel like they have more choices.

4. COUNSELING SESSIONS TO ENSURE PATIENT IS OF SOUND MIND

More concerning is that only 4% of patients in either Oregon or Washington were referred for psychiatric evaluation. If one of the requirements for access to PAS is the assurance that the patient does not have a psychiatric or psychological disorder or depression, this percentage seems quite low. But what is not reported by either state is the number of patients who requested the medication but were denied due to mental capacity. The number of denials could shed light on why so few patients were referred for psychiatric evaluation. Perhaps physicians are able to exclude patients who do not have the appropriate mental capacity, and therefore the need for a psychiatric evaluation was low. Survey data from physicians quantifying the number of and reason for denials is needed in order to ensure that those lacking mental capacity are denied PAS and to help explain the low number of patients referred for evaluation.

⁴⁰ Attending Physician's Compliance Form (Oregon), <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/at1form.pdf>, Attending Physician's Compliance Form (Washington) <http://www.doh.wa.gov/portals/1/Documents/Pubs/422-064-AttendingPhysicianComplianceForm.pdf>

Without reviewing such data, and knowing that the actual diagnoses of patients who choose PAS do appear to be terminal diagnosis, it would be difficult to assume that the percentage of patients who receive counseling should be higher. It is worth reviewing in greater detail.

EQUAL ACCESS TO PAS FOR ALL

The use of PAS is now, and likely will continue to be, rare. As illustration, we can look at the use of PAS in Oregon versus the use of hospice care. The 2011 NHPO report⁴¹ shows that in the US 44.6% (1.65M) of all deaths in the U.S. in 2011 occurred under hospice care. In the same year, only 71 patients in Oregon ended their life using medication prescribed under the Death with Dignity Act. The point is that even after legalization the use of physician assisted suicide is rare. But, though rare, for PAS to be an option that is presented in the best interest of public health it must not only guard against abuse but it must also be available to all eligible patients equally. Unfortunately from a policy and payer perspective this is not yet true.

Even in states where it is legal not all physicians or hospitals participate with state Death with Dignity acts. They have the choice of participating because these are voluntary programs. For example, Washington offers a draft policy⁴² for hospitals who do not want to allow PAS in their facility. If a patient requests PAS they will arrange to transport the patient to another institution and physician who can assist them. The acts are constructed to remove any civil or criminal liability or professional discipline from physicians who do prescribe PAS medications in accordance with the act in their state, not to require them to participate with the act. So for

⁴¹ NHPO facts and Figures: Hospice Care in America 2012, National Hospice and Palliative Care Organization (2012) available at http://www.nhpco.org/sites/default/files/public/Statistics_Research/2012_Facts_Figures.pdf

⁴² Washington Model Policy: Do Not Participate, Washington State Hospital Association, available at <http://www.wsha.org/our-members/projects/end-of-life-care-manual/death-with-dignity-act/> (last visited December 15, 2016)

patients who want to have access to PAS they must first live in the right state, then they must find a physician willing to provide the medication, and if they are in an institution they must ensure the institution participates with the program or instead must be moved. The fact that the programs are up to the discretion of the provider and institution creates barriers to access that limits patient choice. In order for PAS to be equally available to all patients states should consider ways to reduce barriers to access. Unfortunately it will likely not be possible to require all physicians to participate with PAS programs as they may be morally opposed to assisting someone in committing suicide.

In addition to barriers provided by state law and provider and institution lack of participation, cost may also be a barrier to access. There is a disparity when you compare the profile of the patient who uses PAS to the demographics of the United States. The data from the 2015 Oregon report reveals that the average patient who receives PAS medication is white (96.6%), married (45.3%), has a bachelor's degree or higher (45.5%) and has a median age of 71. In fact, in the 18 year history of the program in Oregon only one African American and 6 Hispanic patients have received a prescription. This use does not match the demographics of Oregon. According to the 2015 Oregon census, 87.6% of the population is white and only 30% has a bachelor's degree or higher. Some argue that this is because white, educated patients tend to want to control every aspect of their lives, and want to have control over their death as well⁴³. This is very possible, but there is also a financial barrier that may be impacting access for all patients because, as we will see below, patients generally must pay for the prescriptions out of pocket.

⁴³ Liz Szabo, *Terminally Ill Patients Don't Use Aid-In-Dying Laws To Relieve Pain* (October 26, 2016) <http://khn.org/news/terminally-ill-patients-dont-use-aid-in-dying-laws-to-relieve-pain/>

The language of the Act states that PAS is not suicide, and so it should not automatically bar insurance coverage. But at the same time, federal funds may not be used to pay for services rendered under the Act. This is because Congress passed the Assisted Suicide Funding Restriction Act of 1997⁴⁴. According to this Act federal funds may not be used to provide financial assistance for items or services offered in support of euthanasia, suicide or mercy killing. This means that Medicare, which is intended for patients 65 years of age and older, which includes the average PAS patient in Oregon, and is 100% federally-funded will not pay for PAS medication. It also means that state Medicaid support may be limited, as Medicaid is funded by both the federal and the state budgets. This is a significant barrier, as 63% of patients in Oregon and 71% of patients in Washington who received PAS medications in 2015 had only Medicare, Medicaid or another government payer to pay for their healthcare. Oregon has addressed this issue in that their state Medicaid does cover the cost of the medication but they must ensure that only state funds are used⁴⁵. Some commercial payers will cover the cost of the medication, but not many⁴⁶. But as the majority of patients in these reports are over 65 it means that to get coverage for their prescription they must have Medicare plus either Medicaid, meaning they fall below the requisite income threshold, or they have enough money to have supplemental commercial insurance. So there is a large gap in coverage for patients 65 and older who only have Medicare.

For some patients, then, in order to have access to PAS they must be able to pay for the medication out of pocket. The most commonly prescribed medications today are secobarbital

⁴⁴ 105 P.L. 12, 111 Stat. 23

⁴⁵ Frequently Asked Questions About the Death with Dignity Act, Oregon Health Authority, <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/faqs.aspx#cost> (last visited December 15, 2016)

⁴⁶ FAQs, Death with Dignity, <https://www.deathwithdignity.org/faqs/> (last visited December 15, 2016)

followed by phenobarbital alone or in combination with other medications. Secobarbital was recently in the spotlight because the price of the drug has skyrocketed thanks to price increases by manufacturer Valeant⁴⁷. In 2009 the cost of the drug was just \$200, but in 2016 it rose to over \$3,000. Patients are also at a disadvantage because of the use of barbiturates in capital punishment. For years the PAS drug of choice was pentobarbital which is much less expensive than secobarbital. But in 2015 the drug was only used by one or two patients in Washington and Oregon⁴⁸. This is because of a shortage driven by the European manufacturers who will no longer ship the product to the US because they do not agree with its use in executions⁴⁹. Washington State has come up with an interesting solution in that it permits compounding pharmacies to prepare a phenobarbital/chloral hydrate/morphine sulfate mix⁵⁰ that functions similarly to secobarbital but costs only \$450 to \$500⁵¹. Oregon has since adopted the compounding practice and California is considering it.

Ironically, government programs could likely save money by covering PAS. In 1982 Congress passed the Tax Equity and Fiscal Responsibility Act (TEFRA) which included a provision to ensure that Medicare covered Hospice care. Medicare now covers all costs of hospice care provided that the patient has Medicare Part A, is no longer seeking treatment for their disease, and has a prognosis of six months or less to live. The coverage includes physician services, 24-hour nursing, palliative care, prescription medications, lab tests and more. Hospice

⁴⁷ April Dembosky, *Drug Company Jacks Up Cost Of Aid-In-Dying Medication*, NPR (March 23, 2016) <http://www.npr.org/sections/health-shots/2016/03/23/471595323/drug-company-jacks-up-cost-of-aid-in-dying-medication>

⁴⁸ Year 18 Oregon Death with Dignity Report and 2015 Washington Death with Dignity Report

⁴⁹ Nigel Jaquiss, *Penalized By The Death Penalty*, Willamette Week (May 20, 2014) <http://www.wweek.com/portland/article-22574-penalized-by-the-death-penalty.html>

⁵⁰ FAQs, Death with Dignity, <https://www.deathwithdignity.org/faqs/> (last visited December 15, 2016)

⁵¹ JoNel Aleccia, *Death with Dignity doctors thwart drugmaker's price hike with new medication*, The Seattle Times (April 2, 2016) <http://www.seattletimes.com/seattle-news/health/death-with-dignity-doctors-thwart-steep-price-hike-for-lethal-drug/>

care is also paid for by state Medicaid and most commercial insurers. According to debt.org, 42% of terminally ill patients receive hospice care, and 83% of those patients were over 65, which means they were likely covered by Medicare⁵². The cost to the government is substantial. In 2010, for example, Medicare spent \$13 billion for hospice care, at an average cost of \$10,700 per patient⁵³. This cost goes up considerably in the last two months of life. Considering that the cost for PAS medication ranges from about \$500 to \$3,500, it makes economic sense for Medicare to cover this cost if it means they will not have to pay for continued active treatment or hospice care.

While it makes fiscal sense to cover PAS, payers must not take that rationale to the extreme. Patients must still be able to choose between active treatment, hospice and PAS. It is a scary possibility that payers could start to weigh the cost of life versus death and start to drive patients to PAS. Oregon's state-funded healthcare, the Oregon Health Plan, went through major budget cuts due to the expense of the program⁵⁴. As a result, the plan will not cover the cost of surgery, radiotherapy, or chemotherapy for patients who have less than a 5% chance of 5-year survival⁵⁵. This denial can be a tough blow for cancer patients who are not ready to stop fighting. Barbara Wagner was one such patient who made headlines around the country in 2008. An Oregon resident with a terminal lung cancer diagnosis, not only did she receive a letter from the Oregon Health Plan saying that they denied coverage of the chemotherapy suggested by her physician, in the same letter they advised her that the cost for PAS medications was covered and

⁵² Bill Fay, *Hospice and End-of-Life Options and Costs*, Debt.org, <https://www.debt.org/medical/hospice-costs/> (last visited December 15, 2016)

⁵³ *Id.*

⁵⁴ Jonathan Oberlander, *Health Reform Interrupted: The Unraveling Of The Oregon Health Plan*, Health Aff January 2007 vol. 26 no. 1 w96-w105

⁵⁵ Michael Laprarie, *Oregon Health Plan has already weighed the cost of life ...*, wizbang (August 4, 2009) <http://wizbangblog.com/content/2009/08/04/oregon-health-plan-has-already-weighed-the-cost-of-life-1.php>

would cost her only about \$50⁵⁶. She was not someone who had contemplated PAS, was not ready to stop fighting, and now felt utterly hopeless. A similar story came out of Washington this October. Stephanie Packer was denied the chemotherapy regimen suggested by her physician to treat her terminal scleroderma, and the denial letter from her insurance carrier included a suggestion that PAS medication would only cost her \$1.20⁵⁷. So we must work to enable financial coverage for PAS but must not drive patients to it in order to reduce healthcare cost.

LIMITATIONS ON PALLIATIVE AND HOSPICE CARE

As we discussed above, many patients choose PAS because of their concern that they are a burden to their caregivers and family and out of a concern over pain. Sadly, palliative care and hospice care, which specifically address issues like pain and provide support for both the patient and the caregivers, are not easily accessed by all patients.

It is possible that the construction of the hospice offering itself drives this result. Hospice is only covered when the patient is diagnosed as having six months or less to live, and only if they have chosen to forego from active treatment. By the time they are willing to stop treating the disease the patient, family, and other caregivers may have experienced a difficult and expensive path in the patient's disease progression and treatment. They may have been depleted of financial resources and may be emotionally taxed, particularly if the patient has had in-home care. It is only at this point, when the patient has given up on treatment, that the expanded

⁵⁶ Susan Donaldson James, *Death Drugs Cause Uproar in Oregon*, abc NEWS (August 6, 2008)
<http://abcnews.go.com/Health/story?id=5517492&page=1>

⁵⁷ Bradford Richardson, *Assisted-suicide law prompts insurance company to deny coverage to terminally ill California woman*, The Washington Times (October 20, 2016)
<http://www.washingtontimes.com/news/2016/oct/20/assisted-suicide-law-prompts-insurance-company-den/>

service offerings of hospice are available, aimed at both the patient and the family, including medical care, in-home nursing care, pain management, and emotional and spiritual care⁵⁸. There is an argument to be made that if the patient could simply have access to the resources provided by hospice care then perhaps the caregiver and family burden, and the pain experienced by the patient, could be avoided or reduced.

Hospice is widely used. According to the National Hospice and Palliative Care Organization's 2012 report, 44.6% of all deaths that occurred in the U.S. were under care of a hospice program⁵⁹. But, as you can see in Table 3 below, the length of time that people receive hospice care is relatively short, with about half of patients receiving care for just two weeks or less⁶⁰. The average length of hospice care was only 71.3 days⁶¹.

Table 3

⁵⁸ NHPCO Facts and Figures: Hospice Care in America, 2015 Edition, page 3.

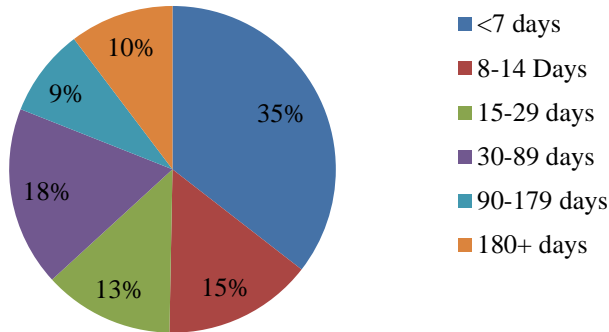
⁵⁹ NHPCO Facts and Figures: Hospice Care in America, 2012 Edition, page 4. Note that this edition is the most recent edition of this annual report to publish the proportion of U.S. deaths that occurred under hospice care.

⁶⁰ NHPCO Facts and Figures: Hospice Care in America, 2015 Edition, page 5. 35.5% of patients were under hospice for less than 7 days, 14.8% for 8-14 days.

⁶¹ *Id.*

⁶² *Id.*

Proportion of Patients by Length of Service 2014⁶²



If hospice care is fully covered as soon as patients are diagnosed as having less than six months to live, why is the actual utilization so short? It is likely because patients cannot take advantage of hospice care while still undergoing treatment. The fact that active treatment and hospice cannot overlap necessarily limits access to hospice and important resources for the family, other caregivers and patient. It would be interesting for Medicare to conduct a pilot program wherein patients are allowed to access hospice while still undergoing treatment for a disease. We would want to assess if earlier access to hospice reduces caregiver burden and improves patient care. We would also be able to assess if earlier access to hospice, even though expensive, actually reduces healthcare costs resulting from emergency room visits and hospital admissions.

Another potential and possibly more viable option that could reduce caregiver burden and address pain is to expand access to palliative care. As discussed previously, palliative is available to patients while they are still receiving treatment for their disease. Palliative care is often a team-based approach that focuses on reducing the pain, symptoms and distress associated

with a disease⁶³. Palliative care teams will also help the patient and caregivers by coordinating all of their medical care and ensuring it aligns with the patient's goals⁶⁴. This care results in less pain and anxiety for the patient and improved quality of life for the family⁶⁵.

Palliative has been shown to reduce overall healthcare expenses. A 2008 study published in the Archives of Internal Medicine reported that the eight hospitals reviewed that had palliative care saved \$1700 per admitted patient that was discharged alive and almost \$5000 per admitted patient who died⁶⁶. The study predicted that a 400-bed hospital that has a palliative care team that works with 500 patients per year could see savings of \$1.3 million per year⁶⁷. Although palliative care appears to make sense both in terms of the patient and family experience as well as the positive financial impact to the healthcare industry, access is limited. According to a 2015 report, 33% of all hospitals with 50 or more beds offer no palliative care to patients⁶⁸. This number increases to 77% for for-profit hospitals⁶⁹. It is therefore estimated that between 1 million and 1.8 million patients who could benefit from palliative care have no access to it, with access being particularly limited for patients being cared for at home or in nursing facilities and who are not eligible for hospice⁷⁰. If resources were devoted to establishing palliative care teams for hospital and community care settings that were adequately staffed to be able to meet the

⁶³ R. Sean Morrison, MD, *America's Care of Serious Illness, 2015 State-By-State Report Card on Access to Palliative Care in Our Nation's Hospitals*, Center to Advance Palliative Care (2015) p. 3.

⁶⁴ *Id.*, p. 4.

⁶⁵ *Id.*

⁶⁶ Morrison RS, Penrod JD, Cassel JB, et al. *Cost savings associated with US hospital palliative care consultation programs*, Arch Intern Med. 2008 Sep 8;168(16):1783–90.doi:10.1001/archinte.168.16.1783.

⁶⁷ *Id.*

⁶⁸ R. Sean Morrison, MD, *America's Care of Serious Illness, 2015 State-By-State Report Card on Access to Palliative Care in Our Nation's Hospitals*, Center to Advance Palliative Care (2015)

⁶⁹ *Id.*, p. 12.

⁷⁰ *Id.*, p. 12

needs of all patients, then not only could healthcare costs decrease but so too could patient pain, distress and anxiety, and caregiver burden.

Knowing that many patients may choose PAS out of concerns for caregiver burden or pain, leveraging systems already in place to reduce these issues can help ensure that patients are not just choosing PAS for a reason that could have been avoided. Expanding access to palliative care and hospice care could ensure that patients choose PAS only to preserve their voice, and the autonomy over and dignity of their death.

CONCLUSION

The dialogue around end of life decisions has evolved dramatically over the last thirty years. We've journeyed through recognizing a patient's right to refuse medical interventions, to proactively counseling patients on end of life options, to legalizing PAS in six states to now considering it in about 20 more. The balance at the heart of the public interest PAS debate is in offering this option to all while guarding against abuse. States must ensure that Death with Dignity legislation has sufficient provisions and reporting to ensure that vulnerable populations such as the poor, elderly and disabled are not at risk for being pressured into PAS as their only perceived option. At the same time, for these programs to be truly run in the best interest of all eligible patients, PAS medication must be equally available to all. That means that federal, state and private insurers should provide coverage for PAS medications. This would result in equal access for all and would likely reduce healthcare spending by shortening patient treatment, palliative care and hospice care costs. Finally, we must maximize access to palliative care and hospice to help reduce pain and caregiver burden, which may reduce these issues in becoming reasons why a patient seeks PAS. It is important that states and the nation as whole view PAS

not as an alternative to treatment, or a replacement for hospice or palliative care, but as one option in overall end of life care that should be available and equally accessible in order to preserve the dignity, voice and autonomy of dying patients.