



Short Commentary

Medical Aid In Dying: A Layperson's Perspective

Chang S*

Director and Economist of Gulf Coast Center for Impact Studies, USA

Abstract

This is the story of the medical aid in dying movement for those who are neither familiar, nor comfortable, with the movement. They Shoot Horses, Don't They? Is a 1969 film directed by Sydney Pollack, with Jane Fonda as its star? Obviously, I am not advocating that we shoot individuals who suffer unbearable pain, mental or physical. I do advocate, however, that we try to be more humane toward dying patients by providing an option under the control of the patient who may find comfort in simply knowing that medication is available. This paper begins with a review of *Vacco v. Quill* of 1997 and the experience of the Oregon Death with Dignity Act of 1997. The paper then explores practical issues of medical aid in dying, including discussion of what terminal patients could do as well as possible preparation for the end of life by dementia patients.

Summary

This is the story of the medical aid in dying movement for those who are neither familiar, nor comfortable, with the movement.

Vacco v. Quill

The State of New York enacted a prohibition against physician-assisted suicide, making it a crime for a physician to administer lethal medication even for a consenting, mentally competent, and terminally ill patient. A number of physicians challenged the law in a suit against New York's Attorney General in the U.S. District Court (Southern District of New York). The argument put forth by the physicians was that a patient's refusal of treatment and requesting that their doctor assist them in ending their life were "the same thing." The District Court ruled in favor of the New York statute and stated that if the ban were to be repealed, it would take an act of New York's legislature.

When appealed, the U.S. Court of Appeals for the Second Circuit reversed the District Court's ruling. An example of the reasoning was that a patient attached to a life support device was allowed to demand

*Corresponding author: Chang S, Director and Economist of Gulf Coast Center for Impact Studies, USA, Tel: + 2517513944, E-mail: changsemoon@yahoo.com

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its removal while a person under identical circumstances could not demand that a doctor administer drugs to ensure the patient's death. It agreed with the plaintiffs that removal of life support devices was identical to requesting physician-assisted euthanasia. It reversed the lower court's finding. On June 26, 1997, the U.S. Supreme Court issued six different opinions in a unanimous (9-0) ruling that a New York ban on physician-assisted suicide was constitutional. This Supreme Court case is known as *Vacco v. Quill* (cited as 521U.S.793 (1997)). It was a U. S. Supreme Court landmark decision regarding the right to die movement. It prevented doctors from assisting their patients in ending life regardless of terminal illness and/or great pain.

This decision established that there was no constitutional guarantee of a "right to die." The court looked into a person's "intent" as a way of distinguishing between two acts with identical physical consequences or outcomes. For example, a person who accidentally kills a pedestrian while blinded by the sun might face punishment for vehicular manslaughter. A person who intentionally and purposefully kills another with his car might face punishment for murder. While the outcomes of these two acts give the same results, they are distinguished by the intent of the actors.

Similarly, a doctor who withdraws life support at the request of the patient intends only to respect the wishes of the patient. The doctor who honors a patient's request to end life requires more than intent to respect the patient's wishes. Put differently, the former may cause the patient to die from underlying causes, while the latter will cause the patient to die by the hands of the physician. *Vacco v. Quill* prompted Compassion & Choices to work through changes in state laws to allow Medical Aid-in-Dying. Efforts to provide choice at the end of life go back well beyond 1994, however. In 1967, a Right-to-Die bill was introduced in the Florida legislature but failed to pass. Thirteen years later, in 1980, the Hemlock Society was organized as an end-of-life care organization this later became the End-of-Life Choices. Twenty-five years later, in 2005, End-of-Life Choices merged with Compassion in dying to become today's Compassion & Choices [1]. So far eleven jurisdictions authorized medical aid in dying against numerous efforts to nullify these legislations. The 11 jurisdictions are:

1. Oregon (1994, ballot initiative)
2. Washington (2008, ballot initiative)
3. Montana (2009, state Supreme Court decision)
4. Vermont (2013, legislation)
5. California (2015, legislation)
6. Colorado (2016, ballot initiative)
7. Washington, D.C. (2017, legislation)
8. Hawai'i (2018, legislation)
9. New Jersey (2019, legislation)
10. Maine (2019, legislation)
11. New Mexico (2021, legislation)

A Glance at Oregon Experience

The Oregon Death with Dignity Act of 1997 (DWDA) authorizes medical aid in dying. The Act allows the patient with a prognosis of six months or less to live to request from his or her doctor a prescription for medication that the patient can take for a peaceful death. (This section is based on “Steps for Using the Law” on page 4 of the Introduction to Medical Aid in Dying by the Compassion and Choices.) Understandably, the Oregon law spells out numerous safeguards to make sure that the law cannot be abused. Key safeguards as well as the process are summarized below.

To be eligible for medical aid in dying under Oregon’s law, a person must be:

- At least 18 years old who is given a prognosis of six months or less to live;
- Mentally capable of making their own healthcare decisions;
- Making an informed decision that includes being given information about all other end-of-life options;
- Informed that they may choose to obtain the aid-in-dying prescription but not take it;
- Capable of self-administering and ingesting the aid-in-dying drug; and
- A resident of Oregon who is acting voluntarily.

As to the process, the law:

- Allows the patient to change his/her mind at any time and withdraw their request;
- Requires the patient to be able to ingest the medication without assistance, usually by swallowing or by using a feeding tube, without injection;
- Allows the patient to choose not to take the medication;
- Requires the patient to make three requests to their physician, two verbal requests and one written one called the “Request for Medication” form;
- Requires only the patient to make these requests;
- Requires the requests only to a physician, not office staff;
- Requires the prescribing physician to send the prescription directly to the pharmacy that is prevented from accepting a prescription directly from a patient;
- While Allows a designated family member or friend to pick up the medications, or it can be mailed to the patient.

According to Tara Haelle in her September 18, 2017 write-up in [medscape.com](https://www.medscape.com) titled “Oregon’s Death with Dignity Act: Two Decades of Data”, 1857 Oregon residents received DWDA prescriptions between 1998 and 2017. Of those residents, slightly more than half died from taking the prescribed drugs. The number of DWDA-assisted deaths represented only 19 per 10,000 of all-cause deaths, i.e., 0.19 percent of all deaths.

My Involvement

In August of 2018, an important conference was held in Boston on care for dying patients. This was the 4th International Conference on Palliative, Medicine and Hospice Nursing. Palliative care refers to medical, as well as non-medical, care provided to a patient who usually has life-threatening or terminal illness. Palliative care is not intended to provide curative treatment, but to manage, maintain, and improve the patient’s quality of life. Hospice care refers to palliative care for patients who are terminally ill and have only limited days to live. I was invited to attend the conference as one of two keynote speakers. Pancreatic cancer had taken my wife of forty-five years on December 8, 2016. This alone was not the reason I was invited to speak. In our case, we maintained two oncologists at the same time; one at the Southern Cancer Center in Mobile Alabama (where we lived), and the other at the MD Anderson Cancer Center in Houston Texas. Our idea was that we would have one with my wife’s history, if, for some reason, the other could not continue to care us. Actually, we had three, since our oncologist at MD Anderson sent us to a third oncologist for a clinical trial which was also at the MD Anderson Center. My wife had only one request to each of the three oncologists: Please let her die without pain [2].

On November 22, 2016, in Houston, we were told that the clinical trial (with the third oncologist) did not work. We did not see our assigned oncologist that day and had no opportunity to consider a prescription for pain relief. The next day we returned to Mobile and drove directly to our local oncologist, who told us that he agreed with the assessment by the clinical trial and added: “no drug would be helpful at this time”. None of these oncologists mentioned any prescription for pain control. As our last resort, and not knowing where else to turn, we met with our primary care doctor. She prescribed morphine to control the pain. In our exhaustion we did not even think to ask for any prescription. She did it solely out of her concern on our impending agony. It was the early morning hours of December 4. My wife had fever, then cold, then pain, which progressed to excruciating pain. I gave her one tablet of morphine. She begged desperately for more. I was so terrified of causing her death by overdose that I did not give her the extra tablet. She passed away on December 8. On February 16, 2019, I testified at the joint hearing of the Maryland General Assembly’s Health and Government Operations Committee and the Judiciary Committee. I was there to lobby for the passage of the End-of-Life Option Act of Maryland. Because I was the last presenter, I heard the arguments from both sides. Although each side was sincere in their presentations, there was one striking difference between the two groups of presentations. Those who supported the End-of-Life option were mostly those who had a personal and intimate experience of caring for and watching their loved ones who had passed away while struggling for breath or experiencing uncontrollable pain. Those who opposed the option stressed the general principles of the value of human life. My thought process progressed to the recall of the deaths of three more precious lives close to me.

A relative (in her 60s) of my close friend died under the hospice care of a good hospital in Richmond, Virginia. When I visited her, only a few days before she passed away, she had a severe problem with swallowing anything (medication or liquids) and was suffering with severe pain. The brother of my lady friend worked until less than two months before he died in his early 80s. Unexplained pain took him to the hospital and testing found that cancer had spread throughout his body. When I visited him, he also had great difficulty swallowing and was gaunt from weight loss.

My own brother passed away at his home in Los Angeles, California. After complaining about unbearable pain for several months, he made the decision to have a tube connected to him to control pain in exchange for no food. His death from starvation took 12 days.

Practical Issues of Medical Aid in Dying

The primary source of information in this section is the website compassion and choices. How do near-death patients actually decide to leave this world? There are four broad types of voluntary death. First is the voluntary stop in eating and drinking (VSED). The patient refuses taking food, liquids, or artificial feeding to shorten the dying process. Second is to refuse medications or procedures to treat health conditions to prolong life. The patient declines any life sustaining treatment. Third is a continuous deep sedation/palliative sedation. This approach is usually employed to reduce consciousness to relieve extreme pain and suffering, usually resulting in death.

The fourth is medical aid in dying. This is a practice in which a terminally ill adult has the option to ingest medication prescribed by their doctor to end unbearable suffering and die peacefully in their sleep. Medical aid in dying is not euthanasia. In medical aid in dying, the terminally ill patient must take the medication themselves and, therefore, remains in charge. In euthanasia, a third party administers medication. Further, medical aid in dying is not an assisted suicide. A person who seeks medical aid in dying already has a terminal prognosis of six months or less to live. In other words, a medical condition is taking the patient's life. Suicide is typically not preceded by a medical prognosis [3].

What Can Terminal Patients Do

Suppose that a terminally-ill patient is seriously interested in the medical aid in dying option. What should the patient do?

All terminally-ill patients are strongly urged to prepare;

1. A living will that specifies treatment and care you want to sustain or not sustain the patient's life, and
2. Select and name the medical power of attorney who will speak for the patient when the patient can no longer make decisions.

The patient needs to make enough copies for distribution to those individuals close to the patient. Terminally-ill patients need to consider completing an Advance Directive. Advance directives are designed to provide detailed guides that may be outlined in the will as well as the Medical Power of Attorney documents. Forms of Advance Directives vary with states and are available in Advance Directives page of the compassion and choices. An Advance Directive allows the patient to decide who the patient wants to make health care decisions if the patient is unable to do so. Importantly, the Advance Directive also allows the patient to spell out what kinds of treatments he or she does or does not want. This would include the treatments often used in a medical emergency or near the end of a person's life. These treatments include (a) life support, such as breathing with a ventilator, (b) efforts to revive a stopped heart or breathing (CPR), (c) feeding through tubes inserted into the body, and (d) medicine for pain relief. Exact steps to take in an Advance Directive vary from one state to the

next with some applying to only those states that enacted the Medical Aid in Dying laws. Information on Advance Directives of individual states is available in the "End-of-Life Choice in Your State" section of the home page of compassion and choices.

Preparing for the End of Life with Dementia

Mild memory loss problems are called "mild cognitive impairment" and is defined as having more difficulty with remembering things. Dementia is defined as the loss of memory that interferes with "activities of daily living" (ADL), such as bathing, dressing, using the toilet, preparing meals and eating. The most common type of dementia is called Alzheimer's disease or Alzheimer's Dementia. Late in dementia, persons are not able to speak or to be coherent when they try to communicate. The person may not know where they are or be unable to recognize family or friends. They may wander and get lost. They may fall. They may have hallucinations. Their sleep pattern may change. They may become suspicious and fearful of others. They may refuse to shower or to change their clothes. They may not be able to control their bladder or bowels. They may not be able to feed themselves. The key is to take care of all preparations before the patient loses the capacity to make sound decisions. Dr. Mitsuo Tomita, who works as a volunteer with me at the Asian American, Native Hawaiian, and Pacific Islander (AANHPI) leadership council of the Compassion and Choices, suggests that while you are mentally capable, you may want to include in your Advance Directive or add a separate page to it, regarding what you would not want if you developed dementia. You can specify, for example, that you do not want to be hand-fed or spoon-fed if you cannot feed yourself. Dr. Tomita gently states that "If one stops eating and drinking, one can get palliative care designed to keep you comfortable as one dies over a period of weeks mainly from dehydration [4]."

Parting Words

They Shoot Horses, Don't They? Is a 1969 film directed by Sydney Pollack, with Jane Fonda as its star? The film focuses on a group of individuals desperate to win a Depression-era dance marathon. At that time, most horses with injuries on the race course were shot, thinking that it is the most humane way of ending the horse's pain. If a horse in such a miserable shape is shot to end the misery, why should a human being be expected to suffer unbearable pain? In the movie, Jane Fonda tries to shoot herself, not from an injury from dancing, but from despair after learning that the prize money is so little and dropping out of the marathon dancing. Obviously, I am not advocating that we shoot individuals who suffer unbearable pain, mental or physical. I do advocate, however, that we try to be more humane toward dying patients by providing an option under the control of the patient who may find comfort in simply knowing that medication is available.

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