Euthanasia and Physician-Assisted Suicide: the Courage and the Right to Decide When to Die

"If I commit suicide, it will not be to destroy myself but to put myself back together again. Suicide will be for me only one means of violently reconquering myself, of brutally invading my being, of anticipating the unpredictable approaches of God. By suicide, I reintroduce my design in nature, I shall for the first time give things the shape of my will."

By Antonin Artaud

Introduction

Antonin Artaud was a poet, actor and French dramatist, who suffered from lifelong clinical depression and anal cancer. As I was reading this quote, I could imagine his pain and desire to shape a life of his will, which would be healthier and happier. The debates about euthanasia and physician assisted suicide have been in the forefront of public and political arenas for centuries, and are still being viewed today as moral and ethical issues. The guides to the art of dying were popular in the medieval time, and during that time, "people believed that death should be accepted stoically, without fear or self-pity or hope for anything more than the forgiveness of God" (Gawande, 156). As Barry Rosenfeld (2004) posed the question: "Do we have the right to decide when and how to die?" I believe that it should be the patient's right to decide.

Definition of Euthanasia from its Greek Roots

Euthanasia comes from the Greek words, Eu (good) and Thanatosis (death) and means "Good Death, "Gentle and Easy Death." Interestingly, W. Bruce Fye explained that "Greek and Roman philosophers used the term euthanasia to refer to a pleasant state of mind at the time of one's death, with no reference to the speed or timing of death per se" quoted by Rosenfeld in Assisted Interface of Social Science (p.492). Hence, euthanasia inferred a peaceful death. According to Darrel W. Amundsen (1978), Greek and Roman philosophers accepted assisted death in the face of illness during their time because physical fitness was considered "an ideal, indeed the highest good, set above beauty, wealth, and inner mobility" (p.24). Physical health was highly regarded, and even reflected in the Hippocratic Corpus: "nothing avails, not money or any other thing without health" (p.24). As a human being, one strives for good health during his or her passage on earth. But when one loses his or her autonomy and quality of life, euthanasia or physician-assisted suicide can be the escape from the unbearable pain and shame that medication cannot take away. In many instances, some patients may never recover, so having the courage and the right to decide may be the only answer for some terminally ill patients.

Possibility of Legalizing Euthanasia and Physician-Assisted Suicide

This paper will explore the possibility of legalizing euthanasia and physician-assisted suicide in the USA for all terminally ill patients with strict guidelines as in The Dutch case law and legislation enacted in 2001 for patients who choose to exercise these rights. This law allows terminally ill patients to request that their physicians to prescribe a lethal sedation. However, due to some muscular and cognitive limitations that ALS. Alzheimer's, Multiple Sclerosis and Stroke patients' exhibit, to administer the lethal dose, a family member, friend or a physician would have to do the mercy killing. I agree with the restrictions they have in the Netherlands about the non-voluntary euthanasia criteria that must be met in order to avoid prosecution. This puts the burden on a family member to prove that dying was the patient's wish before the brain succumbed to the disease. Also, defining quality of life for terminally and mentally ill patients and discussing the financial impact on taxpayers and families. Again, by examining the differences between suicide and physician-assisted suicide, patients should be allowed to have the right to choose either. We should take into account the patient's autonomy, which is allowing a patient to make his or her own medical decision, and it should be the principle premise in legalizing euthanasia and physician-assisted suicide.

Euthanasia

Lars Johan Matersvedt (2003) defines euthanasia "as the administration of a medication or other toxic substance typically but not necessarily by a physician, with the specific intent of causing the death of the individual" (p.97). According to Rosenfeld, euthanasia is different from intent to murder an individual. Likewise, in New York, a family member can initiate non-voluntary euthanasia on behalf of the patient who is comatose (Opinion E-8.081 Surrogate Decision Making, AMA policy). When a patient is on life support, end-of-life measures are legal; however, euthanasia and physician-assisted suicide should be allowed as well. The only difference is that the patient has the autonomy to make the decision in euthanasia and physician-assisted suicide.

In 1987, the first argument regarding the right to die was heard in the US Supreme Court. In the case of Cruzan v. Director, Missouri Department of Health, Nancy Cruzan, 25 years old, had been in an automobile accident in January 1983, and suffered irreversible permanent brain damage. She was on life support for 4 years until her parents became her legal guardians in 1987. In December 1990, the Cruzans' request was granted "after hearing new clear and convincing evidence about Nancy's wishes, the court again ruled in favor of the Cruzans' (2004, p.31). Nancy Cruzan died 12 days

later. This is the first case that "the U.S. Supreme Court granted *certiorari*, agreeing for the first time to hear arguments regarding the "right to die"" (p.32). Hopefully, the Supreme Court will be willing to hear more cases from terminally ill patients or their legal guardians. The hope would be for the courts to see the patient's point of view, because the disease is already killing them.

Physician-Assisted Suicide

On the other hand, when it comes to physician-assisted suicide, the patient requests a physician to administer or prescribe a lethal injection so they may die. It should be noted that, one famous retired pathologist by the name of Jack Kevorkian was convicted of second degree murder for assisting in the administration of a lethal substance to a patient. Dr. Kevorkian's action was the catalyst that put euthanasia and physician-assisted suicide into public awareness. But yet, other types of end-of-life interventions such as withdrawal of live support (mechanical ventilation), and refusal of artificial nutrition and hydration, and treatments are legal in the USA and less controversial in our society. Because the patient is on life support, our society feels that it is the last resort to let the patient expire.

End-of-life Case

In discussing end-of-life, one recent example is, Joan Rivers, a wellknown comedian and actress who was having a throat procedure on August 28, 2014 and suffered a heart attack. She was in a coma and on life support. and on September 4, 2014, her daughter, Melissa Warburg Rosenberg authorized the removal of her ventilator (Gliatto, p.54). In such cases, the patient is given a terminal sedation, which leaves the patient pain free for days and weeks, but hinders the respiratory function. Her terminal condition determined the decision to be reasonable because it was based on science. It was concluded that Joan would remain in a vegetative state. It is worth noting that these life interventions are not "subjected to the same intense public scrutiny as euthanasia and physician-assisted suicide because death results from the underlying illness or disease" (2004, p.31). These two cases below reached the Supreme Court regarding discrimination against terminally ill patients.

"In 1997, two cases (Vacco v. Quill and Washington v. Glucksberg) were heard by the U. S. Supreme Court. The premise was that terminally ill patients on life-support were permitted to hasten death. However, other terminally ill patients were prohibited to request physician-assisted suicide. So, In April 1996 the 2nd circuit Court of Appeals ruled that: "New York Law does not treat equally all

competent persons who are in the final stages of fatal illness and wish to hasten their death..." (p. 724)

Patients on life support are treated differently than terminally ill patients.

This type of discrimination was successfully argued and while the appellate court agreed that it was unlawful, the victory was short lived. The U.S.

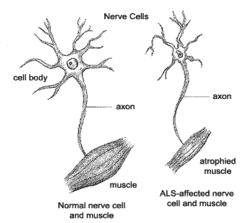
Supreme Court overturned their decision in January 1997.

It is time for all terminally ill patients to be treated equally. They should have the option to choose between euthanasia and physician-assisted suicide if they so desire and meet the established criteria.

Amyotrophic Lateral Sclerosis (ALS)

Neurological diseases and their debilitating symptoms might make a patient seek euthanasia or physician-assisted suicide. One of the neurological diseases that deprive patients of their quality of life and autonomy is Amyotrophic Lateral Sclerosis (ALS), commonly called, Lou Gehrig's disease. Discovered by French Neurologist Jean-Martin Charcot in 1869, ALS received national and international attention in 1939 when Lou Gehrig the famous baseball player was diagnosed with it. ALS is a progressive neurodegenerative illness that affects nerve cells in the brain and the spinal cord that strikes people between the age of 40 and 70. As the disease progresses, it prevents the brain's control over muscle movement

and eventually leads to paralysis. There is no cure at the moment, and only one drug on the market, Riluzole. Also, the progression is patient specific. It is reported that 5,600 people are diagnosed yearly, and the life expectancy once diagnosed is 2-5 years (Amyotrophic Lateral Sclerosis Foundation). Once the autonomy and the quality of life diminish, the patient is emotionally distorted. This might lead some patients to request the choice of euthanasia. In the case of ALS, one thing that is for sure is that paralysis is inevitable. There is only one medication for the disease and a multidisciplinary approach to managing the symptoms by utilizing occupational and physical therapists, speech therapists, nutritionists, and nurse specialists that have led to an improved quality of life and maximization of function in the person living with ALS (ALS Foundation). There are some clinical trials in experimentation but no cure on the horizon as of yet.



(Amyotrophic Lateral Sclerosis Foundation)

Stephen Hawking (ALS) Patient

"I think those who have a terminal illness and are in great pain should have the right to choose to end their lives and those who help them should be free from prosecution. We don't let animals suffer, so why humans?"

By Stephen Hawking

Hawking is a famous physicist and cosmologist who suffers from ALS. He has written numerous books, but his most well-known is *A Brief History of Time* about his discovery of black holes. Hawking has an active life. He is professor at Cambridge University, he gives numerous speeches and interviews yearly, he has had two marriages and has 3 children, and he guest appeared on two sitcoms. Despite his prestigious and successful life, he was diagnosed at the age of 21, and was given two years to live. Now 72 years old, he is still alive and active. He believes that "his active mind and sense of humor are key to his survival" (Reuters, 2013). I should mention

that only "5% of patients with this condition survive for more than a decade after being diagnosed." (BBC News, 2013). We are not sure of the contributing factors to his longevity with ALS. This is an unusual and the only known case.

While Hawking is a victim of this terminal illness, he still believes that patients should have the right to decide to end their life. As long there are "safeguards that the person concerned genuinely wants to end their life and are not being pressurized into it or have it done without their knowledge and consent as would have been the case with me" (Reuters, 2013). Hawking had pneumonia and was on life support during that hospitalization. However, his wife did not authorize the removal of the mechanical ventilator, because he did not complete the Advance Directive form prior to performing the procedure. This document allows a patient the opportunity to make provisions for healthcare decisions in the event that in the future, he or she becomes comatose or on life-support. This consent form is very important and should be discussed with patient at length. It alleviates the burden on a family member to make the decision for the patient, but if the opportunity arises, the family member must ensure that the patient's wish is fulfilled.

Discrimination Among Terminally Ill Patients

The discrimination is profound among terminally ill patients with life-support versus those with no life-support. Life-support consists of techniques used to maintain a patient alive after one or more organs failure. Interestingly, the law allows a physician to make the decision to end the life of a patient on life-support. Hawking sees denying terminally ill patients the right to decide their own demise as "a form of discrimination" (Klett, 2014).

Parkinson's Disease

Parkinson's disease is a progressive disorder of the nervous system that affects patients' movement. The neuron cells die and cause tremors, stiffness or slowing of movements. This is an incurable disease and medications only improve the symptoms. 600,000 people are diagnosed yearly, and one million live with the disease. The cost to treat PD yearly is \$25 billion (Parkinson Disease Foundation). This disease is very costly to insurance companies, especially at the end stage of the disease. I wanted to see how PD affects patients, so I had the pleasure of interviewing a Social Worker and a PD patient.

Interview with PD Social Worker

"I'm not afraid of being dead. I'm just afraid of what you might have to go through to get there."

— Pamela Bone

I interviewed the Social Worker extraordinaire, Amy Legross who had been a Social Worker for twenty years. She embarked in this incredible journey, after her best friend was left-brain dead after a motor vehicle accident. According to her physicians, she would be in a vegetative state for the rest of her life. Her parents were hoping for a miracle and waited two years before pulling the plug, and she died peacefully a few days later. A terminally ill patient on life support has the option for their family or their physician to make the decision to end their life, but not other terminally ill patients.

A year or so later, Amy was introduced by her mentor to a Neurology practice specializing in Movement Disorders, and that's when she realized that patients with Parkinson's disease and their families need psychotherapy treatment. Legross has been treating PD patients and their families for over fifteen years. She starts counseling these patients two years after they are diagnosed. Depression sets in the latter part of the disease when their quality of life starts to diminish. She assists patients in adapting to their new limitations due to the disease, and also, helps build skills and coping

mechanisms to deal with their daily activities. PD patients have a normal life span. With the uncertainty and ambiguity of the disease, anxiety is inevitable. Some patients do express their wish to die, but never pursue further, because of counseling and treatment available to alleviate their symptoms. With all these treatments available to PD patients, physicianassisted suicide may not be an option for them. Lately, Legross has noticed that more patients have their wills in order, but their final days are not discussed with family members. Legross counsels the caregivers as well, who is most often the spouse, significant other or a close relative. There are a few support organizations available to the patients and the caregivers. When a patient is near death, the caregiver expresses to Legross that she or he is afraid of the loneliness that will set in when the patient passes away, because all the support will be gone. Legross informed me that support is available to the caregiver after the patient's death.

Parkinson's disease is not curable, but patients have access to numerous medications and different types of surgical treatment. A surgical procedure called Deep Brain Stimulation (DBS) is used to treat a variety of disabling neurological symptoms such as tremor, rigidity, stiffness, walking problems, slowed movement and essential tremor. This procedure blocks the electrical signals from targeting areas in the brain. DBS is now the preferred surgical

procedure for PD patients. However, it is important for physicians and social workers to address their depression closely, so they can live a somewhat normal life. For PD patients, if their depression is managed they may not seek euthanasia or physician-assisted suicide right away. This decision cannot be made while the patient is depressed. This dialogue must be discussed early in the prognosis, before the patient loses their cognitive and communication skills. This is a big decision, and it is imperative that the physician ensures that the patient is mentally sound.

Interview with PD Patient

I had an opportunity to interview a PD patient, who was diagnosed with this disease in 1994 at the age of 36. For the purpose of this paper, I'll call her Joanne Midi. Midi developed a tremor in her left hand and stiffness in her left shoulder. It has progressed to where her whole body is stiff, which makes movement very difficult and walking has become an issue. Midi explained that she has severe depression and it has been a struggle for her to cope with the disease. She is on anti-depressant and sees a psychotherapist two to four times a month. She was just diagnosed with dysphasia a few months ago. Unfortunately, she had to move in with her parents, because

she depends on others to help her with her daily activities. PD has ruined her life, because she was diagnosed so young,. Her grand-father had PD, and now her sister is starting to exhibit some similar symptoms. Midi mentioned that physical therapy has helped her stay strong and as flexible as possible.

Alzheimer's disease Patient

"I would live my life as ever to the full and die, -before the disease mounted its last -attack, in my own home, in a chair on the lawn, with a brandy in my hand to wash down whatever modern -version of the "Brompton cocktail" some -helpful medic could supply. And with -Thomas Tallis on my iPod, I would shake hands with Death."

By Terry Pratchett

Sir Pratchett is the second most-read writer in London. He was diagnosed in 2007 with Alzheimer's disease, which is a debilitating neurological disease. He thinks that it is acceptable and reasonable for someone who suffers from a serious and debilitating disease to choose euthanasia or physician-assisted suicide. This disorder affects the memory, thinking and behavior. The progression is slow, but gets worse over time and interferes with daily tasks. Sir Prachett supports the idea of having a euthanasia tribunal comprised of an attorney with expertise in family affairs and a physician experienced in the complexities of serious long-term diseases to assist those terminally ill patients who would like a friend or family member to aid them in hastening death. He insists that they should

be at least 45 years old (The Guardian). Because of the cognitive and communication impairments associated with Alzheimer's, euthanasia has to be legalized in order to relieve family members or friends from prosecution. Sir Pratchett eloquently stated: "....because if I knew that I could die at any time I wanted, then suddenly every day would be as -precious as a million pounds. If I knew that I could die, I would live. My life, my death, my choice" (The Guardian). Many terminally ill patients with Alzheimer's desperately want to make the choice to die in control, which will make them appreciate life more. As many of them feel, they don't want to die but the disease is taking over their frail bodies and is killing them.

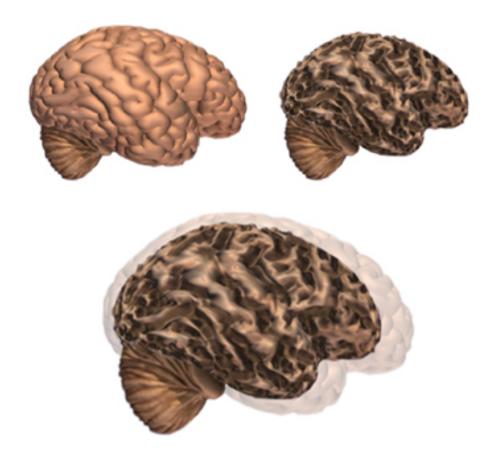
Fact on Alzheimer's disease

Most patients affected by Alzheimer's disease are 65 years old and over, but there is a small percentage that are in their 40's and 50's. Currently five million people are diagnosed in the USA. This disease has a huge burden on caregivers because of the constant supervision Alzheimer's patients require. It is reported that caregivers neglect their own health while looking after their patients (Alzheimer's Association). These hard facts must be taken into consideration; that's the only way our society will come to the conclusion that some terminally ill patients should have the right to decide to die.

Unfortunately, the survival rate for Alzheimer's and dementia is between 4-9 years for most patients, and physicians struggle to consider these two diseases as terminal illnesses, because they can't predict how long AD patients will live once diagnosed. That's the reason for the low enrollment in hospice care, because the guidelines dictate that the prognosis must be six months before death (Sachs, 2004, p.1057). Also, treating dementia patients in hospice care is a true challenge for everyone there due to the declining cognitive and communication skills. Thus, to assess their pain level a new approach is required, such as a "physical exam including observation for nonverbal indicators of pain and an openness to empirical trials of analgesics when pain is suspected" (Sachs, 2004, p.1059). Surveys reveal that the cost for hospice care for patients with Alzheimer's is higher in comparison to patient without Alzheimer's (Alzheimer's Association).

Although Alzheimer's itself does not cause pain, patients afflicted with it can also suffer from arthritis, osteoporosis and peripheral Neuropathy to name a few. Caring for patient with Alzheimer's appears to be burdensome, a caregiver who is related to the patient is more likely to die the following year due to stress (Alzheimer's foundation). A Social Worker's guidance would be a plus because he supports the caregivers in the realm of Bereavement and other areas are greatly needed. Because of the way

Medicare payment is structured, patients with dementia are sometimes transferred to hospitals for financial reasons: "the treating physicians have financial incentive to transfer the patient, because Medicare reimbursement for an admission visit for a hospitalized patient greatly exceeds that for a subsequent nursing home visit" (Mezey, 2002, p.63). Euthanasia and physician-assisted suicide with strict safeguards would help mitigate the financial loss that Medicare incurs every fiscal year. The last two months of a hospitalized terminally ill patient can cost Medicare an average of \$94,000.



(Alzheimer's Association)

AD Patient Interview

In early September, 2014, my father was diagnosed with early onset Alzheimer's disease. Although we had our suspicions, nevertheless, hearing his physician say the word was heartbreaking. For the past ten years, he felt that his memory was not as sharp as before. My dad had an appetite for reading, but lately, he could not follow the plot or forgot what he just read. To cope with his memory flaws, he decided to do crossword puzzles. For the purpose of this paper, I decided to interview my dad and will call him Philippe LaBoheme.

LaBoheme had his suspicions about his subtle episodes, but he hoped that he was wrong. He was seventy-seven years old, and did not know much about AD, besides the fact that it affected one's memory and had some cognitive and behavioral challenges. LaBoheme was prescribed two medications that will slow down the progression of AD. As there is no cure yet, LaBoheme is sure that he will not see a cure in his lifetime. He has not had any discussion with his physician about end-of-life, but has done so with his wife. He explained to her that we all have to die one day, but how we die makes a difference. "My hope is to not be a burden on my family and to die with dignity".

Research

"Stem cell research is the key to developing cures for degenerative conditions like Parkinson's and motor neuron disease from which I and many others suffer. The fact that the cells may come from embryos is not an objection, because the embryos are going to die anyway."

By Stephen Hawking

Scientists are diligently researching, and there may be light at the end of the tunnel for Alzheimer's patients. In a recent article published on September 22, 2014, on NYULMC website and in Stem Cells Reports talked about how stem cells may be able to regenerate those dead cells in Alzheimer's patients by using a technique that Dr. Stadtfeld and his team developed. Dr. Stadtfeld said, "This big boost in efficiency gives us an opportunity now to study stem cell programming mechanisms at high resolution" (NYULMC website). Matthias Stadtfeld, PhD, is an Assistant Professor of cell biology and a member of the Skirball Institute of Biomolecular Medicine and the Helen L. and Martin S. Kimmel Center for Stem Cell Biology at NYU Langone Medical Center. According to Dr. Stadtfeld's colleague Dr. Ruth Lehmann, "this is a very exciting advance. The new technology developed by the Stadtfeld lab to reprogram differentiated cells efficiently and effectively brings the prospect of stem cell technology for safe use in regenerative medicine ever so much closer" (NYULMC website). The number of patients diagnosed with Alzheimer's is increasing, and according to the graph below, in New York, 460 in 1000 patients will be diagnosed by the year 2025. However, the choice should still be available to other terminally ill patients who wish to exercise their rights. In the meantime, a patient can only hope the stem cell research for Alzheimer's patients is successful in the near future. The day they start infusing new stem cells in Alzheimer's patients, it will revolutionize the medical world and millions of patients and caregivers will be ecstatic and feeling blessed, as they will be able to reclaim their lives.

The Power of the Mind

"My diving bell becomes less oppressive, and my mind takes flight like a butterfly. There is so much to do. You can wander off in space or in time, set out for Tierra del Fuego or for King Midas's court."

By Jean-Dominique Bauby

Bauby was a 43 year-old editor-in-chief of *French Elle* who suffered a massive stroke in the brain stem that left him a paraplegic with a sharp mind. His condition was called "locked-in syndrome" LIS. He wrote his memoir while sick, and died shortly after it was published: *The Diving Bell and the Butterfly*. Unable to speak, Bauby composed each passage mentally and then dictated it, letter by letter, to a scribe who recited each letter of the alphabet until Bauby selected a letter by blinking his left once to confirm "yes". This incredible book emphasizes the power of the mind and although

Bauby was unable to move his body except his head from side to side, he was able and willing to enjoy all he was familiar with in his prior life. With no hope of recovery, he embraced this journey and was not depressed. His witty imagination was his weapon to overcome any depressed moment. In this case, Baudy may not have opted for euthanasia or physician-assisted suicide. But nevertheless, it should have been available if he had chosen to go that route.

Depression and Suicide

As noted above, depression did not play a role in Bauby's illness, but according to statistics, it seems to be present in the lives of most terminally ill patients. Just recently, we learned of the passing of Robin Williams, an actor and comedian who suffered with depression and was diagnosed with Parkinson's disease (PD), a Neurological disorder that eventually restricts a patient to a wheelchair and diminishes their quality of life. Williams was in the limelight for over 30 years, made millions of people laugh and probably could not bear the thought of being eventually restricted in a wheelchair and unable to control his movements. Sadly, he committed suicide by asphyxia. After being diagnosed with a terminal illness, patients with mental illness should be monitored closely by their therapists, physicians and family members. As Susan Schneider, Robin's wife, stated: "It is our hope in the

wake of Robin's tragic passing that others will find the strength to seek the care and support they need to treat whatever battle they are facing so they may feel less afraid" (AFP, 2014). I strongly agree with her statement; it is important to give them the support they need to make them feel at ease in accepting their new challenge. A patient should be mentally sound before making this decision to end their life, which means that the patient is "feeling comfortable about him or herself, has positive feelings about others, and has the ability to meet the demands of life (Merriam Webster). Physicians should have numerous discussions with their terminally ill patients, to ensure that their decision to end their life is genuine and not made under duress by other parties.

Financial Impact

It is great to see how modern medicine has evolved throughout the years; as a result, the life expectancy has increased drastically. Because physicians are treating the underlying diseases, it makes the process of dying harder at times. As Meyer explained in an article entitled "The Cost of Keeping the Terminally Ill Alive", the last two months of a terminally ill patient's life are very costly to Medicare, a federal government funded insurance carrier that pays the health bills for the elderly. A 60 Minutes documentary titled "The Cost of Dying" has revealed that 20 to 30% of the

medical expenses incurred during the patient's last two months have no significant impact on their health, and those claims are paid with no questions asked. In 2009 Medicare paid \$55 billion for physicians and hospital bills during the last two months of patients' lives (Meyer, 2010). Another issue, Medicare presently does not have any guidelines in place to halt physicians and hospitals from using hi-tech treatments, which have no impact on patients' prognosis. Are patients requesting these aggressive treatments or are they even given a choice? These two questions should be investigated further by experts. Perhaps we can come to the conclusion that, unless the prognosis is positive, aggressive treatments should be prohibited without patient's consent.

Again, unethical issues among professionals in the field are common. According to Joan M. Teno, MD, lead author of a study published in the Journal of the American Medical Association in February, 2014, stated "There are financial incentives to provide more care in fee-for-service care. We don't get paid to talk with patients about their goals or care or probable outcomes of care. We do pay for hospitalizations, and there are financial incentives for nursing homes to transfer patients back to acute care" (p.472). The graph below shows the astonishing amount paid out for patients in their last year of life. The Center for Medicare and Medicaid reports that more

than 25 percent of Medicare spending goes towards the five percent of beneficiaries who die each year (p. 472). Can Medicare funds sustain this type of spending for long? Will there come a time when Medicare will refuse to pay a claim for a healthy patient due to lack of funds? Respecting a patient's wish to die will not only help the patient but the families and the insurance carriers at financially.

TABLE 8 AVERAGE ANNUAL PER-PERSON PAYMENTS FOR HEALTH CARE AND LONG-TERM CARE SERVICES, MEDICARE BENEFICIARIES AGE 65 AND OLDER, WITH AND WITHOUT ALZHEIMER'S DISEASE AND OTHER DEMENTIAS AND BY PLACE OF RESIDENCE, IN 2012 DOLLARS

Payment Source	Beneficiaries with Alzheimer's Disease and Other Dementias by Place of Residence			Beneficiaries without Alzheimer's
	Overall	Community-Dwelling	Residential Facility	Disease and Other Dementias
Medicare	\$20,638	\$18,380	\$23,792	\$7,832
Medicaid	10,538	232	24,942	549
Uncompensated	284	408	112	320
HMO	1,036	1,607	236	1,510
Private insurance	2,355	2,588	2,029	1,584
Other payer	943	171	2,029	149
Out-of-pocket	9,754	3,297	18,780	2,378
Total*	45,657	26,869	71,917	14,452

^{*}Payments from sources do not equal total payments exactly due to the effect of population weighting. Payments for all beneficiaries with Alzheimer's disease and other dementias include payments for community-dwelling and facility-dwelling beneficiaries.

Created from unpublished data from the Medicare Current Beneficiary Survey for 2008. [121]

2013 Alzheimer's Disease Facts and Figures Use and Costs of Health Care, Long Term Care and Hospice

Terry Berthelot (a senior attorney with the Center for Medicare Advocacy and member of the National Council of Hospice and Palliative Care Professionals) believes that there is an over-use of services in end-of-life care. He recommends that doctors receive training on discussions about end-of-life while patients are healthy, in the hope that the patient will help them focus on quality of care instead of the next medical procedure.

Berthelot continues:

"Providers should engage in ongoing, meaningful conversations with patients when they're healthy about what matters to them when it comes to the care they receive as they near the end of life...advance directives could be the holy grail of America's end-of-life crisis...They can save our system a great deal of money because currently folks are getting all types of end-of-life care that's very, very expensive that doesn't in any way save lives. It only prolongs life at a huge cost with very, very little real benefit because of all of the misery at the end of life when somebody's dying in a hospital" (quoted in Teno, 2014).

At the end-of-life, physicians tend to request aggressive treatments, just to prolong the patients' lives for a few more days or weeks. Patient's

instructions from an advance directive form should serve as a guide to the physicians, and it will eliminate any doubt from family members.

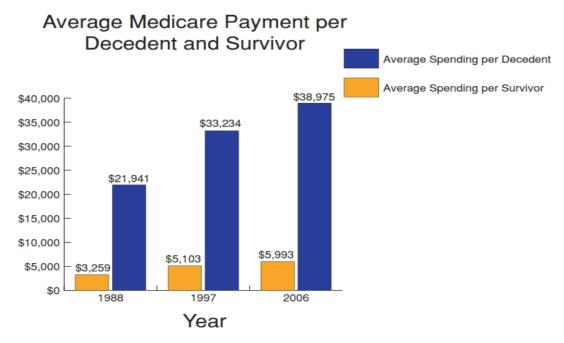
"In other words, our decision making in medicine has failed so spectacularly that we have reached the point of actively inflicting harm on patients rather than confronting the subject of morality."

By Atul Gawande

Gawande, a general surgeon admits to avoiding talking to patients about "dying". Instead, he focuses on how to help his patients at all costs, even if it means putting the patient on ventilator, dialysis and intravenous feeding. He continues to say that "in the past few decades, medical science has rendered obsolete centuries of experience, tradition, and language about our mortality and created a new difficulty for mankind: how to die" (p. 158). It is time for physicians to be honest with their patients about their prognosis, have lengthy discussions about end-of-life, and know when to say that they've tried all possibilities. To have a patient undergo experimental and painful treatment to prolong their life with marginal results is simply inhumane. Also, they must have a meaningful conversation to make the patient accept the outcome and find peace. Moreover, physicians should know and respect their patients' wishes on when and how they want to die.

Interestingly, we are animal lovers in the USA and we make these decisions for our animals with no hesitation. Do we value animals' lives far more than humans? When our pets are terminally ill, we go to the veterinarian and make the decision to euthanize them if the disease is incurable, if life expectancy is a few months and/or they are suffering. But sadly, even though we are dying, our society does not give us the right to decide when to die. Are human lives less valuable than pets?

A study in 2010 has shown that with concurrent palliative care and ongoing oncology care patients "stopped chemotherapy sooner, entered hospice care far earlier, and experienced less suffering at the end of their lives" (p. 177). Palliative care is a form of specialized care for patients with terminal illnesses. It focuses on providing relief from symptoms, pain and stress. The goal is to improve quality of life for both the patient and the family. Palliative care has a team approach; physicians and nurses collaborate with the patient's other physicians to provide extra support.



Graph 1: Data for the graph is from an article published by Riley and Lubitz, "Long Term Trends in Medicare Payments in the Last Year of Life," published by Health Services Research in April 2010.

Hospice Care Experience

I had lunch with a co-worker last week whose mother had passed away on September 16, 2014, at her home while in Hospice care. She was diagnosed with brain cancer and dementia eighteen months ago. She was impressed with the kind of care and the support system they had for her and her siblings. Although her mom declined further treatments at one point, she wished that her mom's physician had requested to initiate hospice care a few months prior. As Berthelot mentioned above, it would be great for physicians to have these discussions while their patients are healthy, and also educate the family members on what to expect for the patient and the support system that the family members will have at their disposal. The baby

boomer population is aging, so it is crucial that the end-of-life conversation become part of our healthcare discussion. Our terminally ill patients need to have the autonomy and the right to decide when to die.

Death with Dignity Act

In Oregon on October 27, 1997, The Oregon Death with Dignity Act was enacted. This law allows terminally ill patients to seek their physicians to prescribe a lethal sedation for self-administration, but it does not permit euthanasia.

"It seems to me that, as with opposition based on whether the physician is 'active,' the argument that physicians should be only 'healers' focuses too much on the physician, and not enough on the patient. When healing is no longer possible, when death is imminent and patients find their suffering unbearable, then the physician's role should shift from healing to relieving suffering in accord with the patient's wishes. Still, no physician should have to comply with a request to assist a terminally ill patient to die, just as no patient should be coerced into making such a request. It must be a choice for both patient and physician."

By Marcia Angell, MD

Dr. Angell, former editor of the Massachusetts Medical Society's *New England Journal of Medicine* and one of the Act's lead sponsors in Massachusetts, supports the legalization of physician-assisted suicide for self-administered lethal medication, which is widely accepted in 5 states in the USA. Some physicians tend to focus on treating the patient at all cost. Instead they should assess the prognosis and develop a treatment plan that is

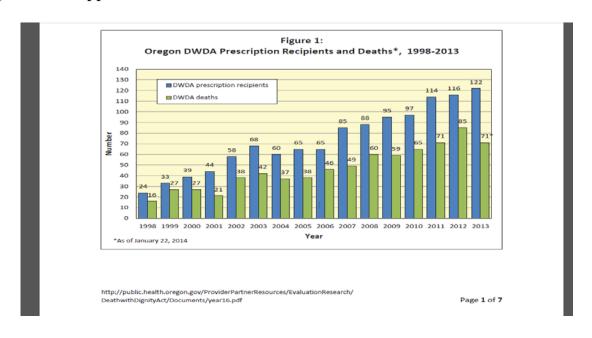
suitable and fair to the patient. Aggressive treatment should not be an option if the outcome destroys the patients' quality of life and death is eminent.

Likewise, in Oregon some protocols must be followed to obtain such a prescription: The patient must be an adult resident of Oregon; she or he must be able to communicate their decision about his or her health; the prognosis must be that the patient is expected to die in six months; one request must be in writing and two verbal requests separated by 15 days; the patient's primary physician and a consultant must confirm the diagnosis and the prognosis; the patient must be referred for counseling; other alternatives must be discussed, such as, hospice care, comfort care and pain-control options (healthoregon.org, 2014). So far these protocols have been followed.

Also, in Oregon, certain data is required to be communicated to the Oregon Health Division from the physician who prescribed the lethal medication. At time of death, the Oregon Health Division reviews all the records for compliance and interviews the physician who prescribed the drugs (healthoregon.org, 2014). In 1998, a year after its legalization, 23 patients received the lethal medication and among 15 cases "the median time from ingestion to unconsciousness was 5 minutes (range, 3 to 20 minutes), and the median time from ingestion to death was 26 minutes (range, 15

minutes to 11.5 hours). No complications, such as vomiting or seizures, were reported" (Chin, 1999 p.578).

It is true that in Oregon, the survey among these 23 patients still shows a common reason to seek physician-assisted suicide was "concern about loss of autonomy or control of bodily functions" (Chin, 1999, p.580). The outcome so far of the legalization is contrary to what was predicted by some people that, "it would be disproportionately chosen by or forced on terminally ill patients who were poor, uneducated, uninsured, or fearful of the financial consequences of their illness. In our study of physician-assisted suicide in Oregon in 1998, we found no evidence to support these fears" (Chin, 1999, p.582). It is important to note that a year after the legalization of lethal medication, there has not been a surge in requests. The graph below supports this above statement.



Feedback on Death with Dignity Act

Again, the patients who requested this type of death by lethal medication were decisive and independent throughout their lives. "The importance of controlling the manner in which they died" was essential to them (Chin, 1999, p.582). Terminally ill patients don't want to die, but the illness is killing them. However, they want to die with dignity and respect.

In 2013, there has been no significant surge in the number of patients requesting physician-assisted suicide. Only 122 prescriptions were written for lethal medications. As of January 22, 2014, only 71 deaths were reported (healthoregon.org, 2014). The reasons for requesting end-of-life in 2013 did not change from previous years. Also, only two patients in 2013 were referred for psychiatric or psychological evaluation, before the prescriptions were written. The sentiment of Coombs Lee, a nurse-turnedlawyer and chief petitioner for the Oregon Death with Dignity Act. She said, "Decisions about death should be no different than other treatment decisions" (QTD, Joyce). Patients should have the right to make their decision about when to die, as long they are mentally fit. What is a bit puzzling is a physician in New York State can make the decision to remove a mechanical ventilator, but yet, he can't prescribe a lethal sedation to end a patient's life who has a terminal illness and no quality of life.

Recent Case in Oregon

"I could request and receive a prescription from a physician for a medication that I could self-ingest to end my dying process if it becomes unbearable, it made sense to me."

By Brittany Maynard

Maynard was a 29-year-old former teacher with a rare brain cancer. She got married on September 29, 2012 and was diagnosed in January, 2013. Her physicians partially removed a tumor and gave her two to five years to live. Sadly, two months after the surgery the tumor grew back, and it was at that time she was diagnosed with Glioblastoma and was given six months to live. Glioblastomas (GBM) "are tumors that arise from astrocytes, the star-shaped cells that make up the "glue-like," or supportive tissue of the brain. These tumors are usually highly malignant (cancerous) because the cells reproduce quickly and they are supported by a large network of blood vessels" (American Brain Tumor Association). These tumors are typically found in the cerebral hemispheres of the brain, but can be located anywhere else in the brain or spinal cord. There are two types of Glioblastomas and they generally are found in people 45 and younger. Primary, or de novo, these tumors tend to form and make their presence known quickly. This is the most common form of Glioblastoma; they are very aggressive. Secondary Glioblastomas tumors have a longer, somewhat slower growth history, but still are very aggressive. They may begin as lower-grade tumors, which eventually become higher grade (American Brain Tumor Association).

Maynard searched desperately for treatment and a miracle, but sadly, she did not find one that would prolong her life with marginal side effects. She said in an interview with People magazine on October, 27, 2014: "the full-brain radiation she could opt to undergo might be brutal,.... destroying her quality of life in the hope of maybe getting a few extra months. It's not life-saving and it's torturous" (QTD in Egan, 67). Her condition had deteriorated; she was swollen from the medication prescribed to control her brain inflammation, and suffered daily with unbearable headaches. Some days she was nauseous and had seizures, which paralyzed her speech. Maynard said, "How much pain does one person can tolerate?" (Egan, 69). Maynard is right; to allow rigorous treatment to prolong her life for a few extra months would have been absurd and unfair to her and her family. On the financial side, it would have been too costly, and her quality of life would have worsened anyway. Aggressive treatment should be an option only if the outcome has merit. This means that, the patient can enjoy life again with marginal side effects, their quality of life and autonomy still untouched, so he or she is not a burden on their family. Maynard's case is a reminder that we need to advocate more for terminally ill patients that would benefit from "The Death with Dignity Act".

As she continued her search, she found an article on "The Death with Dignity Act" that they have in Oregon. After reading the article, Maynard said that "it made sense to me" to choose "to die with my family with me, to have control over my own mind, which I would stand to lose – to go with dignity is less terrifying" (Access World News). Terminally ill patients with similar conditions as Maynard should have the right to decide when to die, because they are left with no option, but simply wait to be severely impaired mentally and physically with no communication with their loved ones. These patients are in their own world and dying alone, and this is unjust and inhumane. With a sound mind, Maynard wrote on CNN.com that "she is not suicidal," if I were I would have consumed that medication long ago. I don't want to die. But I am dying. And I want to die on my own terms" (Time.com, 1). This is an uncomfortable conversation, but this case, is encouraging families to talk about their preferences in the event of a terminal illness once again. Again, some terminally ill patients want to set the tone when to die, and as Maynard summed it up, "this is far more humane" (Egan, 67).

In June, 2013, Maynard and her family moved to Oregon and selected November 1, 2014, to be the day to die. She said that, the pain is bearable now knowing that she made her decision and now is in control: "I'm choosing to suffer less, to put myself and my family through less pain. It's an enormous stress relief" (Egan, 69). We as a society, fail to realize that the terminally ill patients are under enormous stress, not only from the illness and but also from the burden they put on their family. Giving the patient the autonomy to choose when to die with strict safeguards is the right thing to do. The Death with Dignity Act has been enacted for a few years and it has not been abused. This means that this law should be passed throughout the USA, not only for the inhabitants of Vermont, Montana, Washington, New Mexico and Oregon. Due to financial reasons, some terminally ill patients can't move to one of these states to fulfill their wishes. This is discrimination at its best!

On October 24, 2014, Maynard visited the Grand Canyon as she wanted, but she had the worst seizure that day. In late October before the day set for her death, Maynard released a video stating "I still feel good enough and I still have enough joy and I still laugh with my family and friends enough that it doesn't seem like the right time right now" (Brittany Maynard website). It is obvious that Maynard is enjoying life and her family's

company, and does not want to die, but her cancer is killing her. But she continued to say that it would happen eventually, because her condition had worsened the past few days. On November 2, 2014, it was reported that Maynard died on November 1, 2014 as originally planned. In an interview Maynard gave to *People Magazine*, she said "for people to argue against this choice for sick people really seems evil to me" To inflict pain on terminally ill patients is unjust, which is what is happening in all the states that have not enacted the Death with Dignity Act.



Euthanasia and Physician-Assisted Suicide in the Netherlands

In July, 1982, Dr. Schoonheim was charged with performing euthanasia on a 95-year old patient, was eventually acquitted. This is the first time that a Dutch physician was acquitted of performing euthanasia; however, this decision was short lived, when the appellate court reversed the decision and found Dr. Schoonheim guilty. Dr. Schoonheim appealed their decision, and the Supreme Court reversed the appellate court's decision in November, 1984.

At the same time, The Royal Dutch Medical Association (1984) outlined some requirements as follows. The patient must be mentally sound and voluntarily want to die. The patient must make a few requests about dying, and the pain must be unbearable. In a case of an Alzheimer's patient, a family member would have the burden of proof that was the patient's wish before their brain succumbed to the disease. The physician must seek his or her colleague's advice. If these guidelines were followed, then no one would be prosecuted. It is important to note that a survey conducted among Dutch physicians revealed that many cases of euthanasia and physician-assisted suicide were not reported due to fear of prosecution. These fears diminished in 2001 when they both were legalized (RDM Association, 1984).

Euthanasia and physician-assisted suicide were decriminalized in the

Netherlands in the 1980s by a series of court rulings and finally legalized in April 2001. However, physicians had to adhere to some guidelines that were implemented. Conversely, it is reported that even though both were not legalized, they were exercised in the Netherlands in the 1970s. Also, nonvoluntary euthanasia is illegal in the Netherlands if the family can't prove that the patient would have requested euthanasia if she or he was competent. Euthanasia widely used is more in the Netherlands; "despite recommendations from the Royal Dutch Medical Association that physicianassisted suicide is the preferred alternative" (Onwuteaka-Philipsen et al., 2003 p.4). They would prefer that the patient's physician involvement in this process to remove the burden on the patient or family member.

Yet, the catalyst that put euthanasia and physician-assisted suicide in the forefront of public discussions in the Netherlands was the 1972 criminal case (Ms. Postma) of a physician who helped to end her mother's life at her request. She was convicted and sentenced to one week in jail and one year of probation. According to Dutch case law and legislation that was just enacted these five conditions must be present. "1) the presence of an incurable illness, 2) the terminal phase of the disease, 3) unbearable physical or mental suffering, 4) the patient's wish to die, and 5) a doctor granting the request" (Netherlandse Jurisprudentie, 1973, p. 558).

Moreover, another case of euthanasia started another public debate in 1981. Ms. Wertheim, an euthanasia activist, was tried for the murder of a 67-year old woman and convicted to a short incarceration and probation. After this case, there were new modifications to the requirements in 1982: The patient must be suffering mentally and physically, and express the desire to die, but not under duress. The physician must inform the patient of alternative options, and be sure that the patient acknowledges that he or she understands all the options. Death must be inevitable, and the patient's death must not harm others (Netherlandse Jurisprudentie, 1982, p. 223). It is clear that they don't want anyone to seek death.

Use of lethal injection on death row in the USA

Interestingly, lethal injections are used for criminals on death row and are legal. But yet, terminally ill patients are not given the platform to do so. There should be an option available to all terminally ill patients, and the ones who do not share these values and beliefs can proceed with medical treatment and pain control until death arrives naturally. The Supreme Court reinstated the death penalty in 1976, and then starting using the lethal injection in 1977. Lethal injection was first used in the USA on December 2, 1982. The lethal drug is administered intravenously, and two methods are used today, one using a three drug protocol and another using one large dose

of a barbiturate. There are protocols and strict guidelines to follow. When using the three-drug protocol, the inmate is injected with two anesthetics intended to put him to sleep, and then, the drug to paralyze his muscles and hinder his respiratory function.

Religious leaders' views

Alternatively, some religious leaders (Christian, Jewish, Muslim, Hindu, Buddhist) are strong opponents of euthanasia and physician assisted-suicide. In a letter dated July 16, 2014, to oppose the Assisted Dying Bill in the House of Lords, the religious leaders stated: "this is not the way forward for a compassionate and caring society" (Caldwell, 2014). Because of their influence in society, the battle to legalize euthanasia and physician-assisted suicide has a long way to go. But, because of strong religious beliefs about how life is sacred, in my opinion, this battle will go on for years. It is noticeable that when a patient is in pain, he or she feels closer to God and believes in eternal life, even though he or she was never a religious person.

Conclusion

"Life is pleasant. Death is peaceful. It's the transition that's troublesome."

Isaac Asimov

Despite the views of certain religious groups and other activist organizations 'actions to stand against euthanasia and physician-assisted suicide, people are getting more information about the process. I would support that state governments design laws that are more patient friendly and encourage lawyers to advocate for the patient's right and dignity. I would form a determinate task force whenever a case is irreversible with a mandate to communicate closely with relatives on any decision concerning the life and the rights of the patient. Moreover, I would establish protocols that need to be followed by the patient's, relatives, doctors and advocates before rendering a final verdict. No one wants to die, but the excruciating pain and the debilitating effects on their bodies, push some terminally ill patients to plead for death. With the recent death of Brittany Maynard, which set a precedent for patients to have the right to decide when to die, it is time to legalize euthanasia and physician-assisted suicide with strict guidelines. All terminally ill patients should be able to exercise their rights if they choose to do so. End-of-life discussion should be paramount when informing a patient that he or she has a terminal illness. The prognosis must be irreversible,

which means that death is eminent. First, psychotherapy counseling must be offered to the patient to help cope with the terminal illness and a second opinion by another physician should be obtained. Second, information on Palliative Care should be discussed at length. Third, patient must inform his physician in writing if they want to hasten death. Fourth, patient will be referred to a psychiatrist or psychologist to ensure the patient is mentally fit to make such demand. Fifth, a task force will review the request with a physician and make a decision. Sixth, if the request is granted, a prescription would be given to the patient for the self administration of the lethal sedation. In the case of a patient with muscular limitation or cognitive impairments, a family member or a friend can help administer the medication. Intravenous sedation by the patient's physician is allowed as well. Again it is important to build a health care system that assist patients in achieving what is important to them at the end of life. Most terminally ill patients want to say their good-byes and be in their loved ones company when they die. As the opening quote says it is not about death, but a way for the patient to reinvent himself in nature and "shall for the first time give things the shape of his will."

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