Last Rights in Six Key Narratives:

Autonomy, Religion, and the Right to Die Movement in America

by

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ABSTRACT

The purpose of this thesis is to identify the key determinants of changes in the public's perception and the historical and legal context for the current laws that govern the Right to Die in America. At its essence, the Right to Die Movement can be summarized in six selected narratives that were performed, told, debated, or reported for the public throughout history. Each of these six stories was presented with the most effective communication technologies available to the narrators in their respective eras.

The thesis includes an original research study assessing the impact of a social media phenomenon on the Right to Die Movement. While the Brittany Maynard Farewell video may not have been solely responsible for the surge of public support for MAID, it certainly captured the sense of autonomy and individual rights Americans believe they have in 2014 and continuing at least through 2019. This belief in autonomy and individual rights influenced the American sense of who owns their bodies and who can control their deaths after they are given terminal diagnoses. The first key narrative introduced Natural Law and the Natural Rights that proceed from this universal law. The second opened up communication about death. The next three demonstrated to Americans what legal rights they had and which were withheld by tradition and law. The last narrative captured and embodied the American sense of autonomy and individual rights that a majority of Americans now feel they possess. The laws and policies that have resulted from the Right to Die Movement both define the boundaries of autonomy and construct an evolving understanding of human freedom.

DEDICATION

This thesis was a multi-generational effort in terms of its foundation, motivation, and purpose. It is first dedicated to my parents—both teachers—who both passed away many years ago. For these two human beings, education and religion were their tickets out of the poverty and backwardness into which they were born. Between them, they earned eight post-secondary degrees. Not bad for a maid and a sharecropper. I now see my parents as a bridge with many broken slats but still strong enough to allow me cross to the other side to a far better life than the ones they had to survive.

Secondly, my own family has supported me every step of the way: I dedicate this thesis to my amazing, multi-talented daughter/wife/mother, Lindsey Beagley, who cheered me on and expressed her support in a hundred different ways along with her husband, Phil Beagley, who is himself a fine example of steadfast, lifelong learning. To my son, Zachary, who also holds a degree in and loves the field of Religious Studies. To my daughter, J.J., a great mother and company manager who has a positive attitude and a "can-do" spirit. To her life partner, Trent, who wants to do it all in life—from scratch. To my four grandchildren who contributed smiles and affection which constantly linked me to the future: to Xavier and Chloe who were born during the writing of this thesis, to 6-year-old Gemma whose joyful exuberance constantly energized me, and to 14-year-old J.L. who read parts of my thesis and discussed ethics, human rights, and the subject of death as though she were a grad school colleague of mine. Our immediate family has now earned an additional eleven post-secondary degrees between us.

Most of all, I wish to dedicate this work to my wonderful husband, Dr. Gary Michael Grossman, who was my rock during the difficult parts. Whenever I wanted to give up, we went for a brisk midnight walk through the park, and I got a loving, cheerful pep talk that got me over quite a few hurdles. We are both truly grateful to Arizona State University, to the U.S. Fulbright Commission which turns university professors, students, and their families into ambassadors of peace, and to the United Nations for giving us the opportunity to conduct research while living in Rome, Italy.

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Writing this thesis was one of the most difficult yet enlightening challenges of my life. This finished work reflects the minds of many as well as the culmination of my own studies at Arizona State University. My subject, Medical Aid in Dying, not only taught me about the American institutions that restrict human freedom, but also taught me concepts that increase human liberty and broaden individual rights. I owe this insight initially to Dr. Shai Lavi whose work helped me tie together the strands of advanced medical technology and human liberty for the first time. Intellectually, I am also indebted to Dr. Raymond Whiting of Augusta University whose in-depth look at Natural Law was a foundational insight for this study. Recognition also goes to Rabbi Shmuly Yanklowitz for providing the podcast of Rabbi David Novak speaking about one Jewish view of the Right to Die. I am also indebted to Elisabeth Kübler-Ross who personally walked my husband and me through the grief surrounding the birth of our severely disabled son. Her encouraging words and perspective carried us through many years of heartache and joy.

I wish to thank and acknowledge Dr. Joel Gereboff, ever the encouraging mentor and advisor, who was always available to me with great advice and very helpful feedback throughout the researching and writing of my thesis. Our weekly Skype chats set a steady pace all the way to the finish line. I felt supported and validated the whole way through.

My heartfelt thanks goes to Brittany Maynard's widower, Dan Diaz, who generously gave of his time and ideas as I was formulating this thesis. His work on behalf of medical aid in dying is a promise made good to his lovely, courageous wife who made the concepts of human freedom and individual rights so crystal clear for a great many Americans. And to the staff of *Compassion and Choices*, especially Kim Callinan, Sean Crowley, and Sarah Brownstein, for answering my many questions over the past two years.

I also wish to thank my supporters and teachers in the School of History, Philosophy, and Religious Studies at Arizona State University: Dr. Miguel Aguilera, Lindsey Plait Jones, Roxanne Shand, Dr. Anne Feldhaus, Dr. Alexander Henn, Dr. Leah Serat, Dr. John Carlson, and Dr. Doe Daughtrey. My warmest thanks go to Dr. Heather Ross, co-chair of my committee and a faculty member in the School for the Future of Innovation and Society. Dr. Ross's campaign for a seat in

the United States House of Representatives reminds me that what we learn and discover in the world of ideas can lead to a better society, and that the university is often the incubator of democratic ideals and workable solutions for our increasingly complex world. Finally, my deep thanks go to Dr. Gaymon Bennett who taught me some life-altering ideas. Unbeknownst to the two of us until the very end of my studies, his own extended family had been a part of my own far-flung religious community since I was a child. It turns out the two of us wrestled with many of the same religious issues—yet came out in different places. Finding this out somehow made his erudite teaching and his genius insights that much more amazing and personal to me. Einstein once said, “Coincidence is God’s way of remaining anonymous.”

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INTRODUCTION AND OVERVIEW

Section 1.1 Purpose of this Thesis

The purpose of this thesis is to identify the key determinants of changes in the public's perception of Medical Aid in Dying as well as the historical and legal context for the current laws that govern the Right to Die in America. This thesis will examine the ways in which social perception about the Right to Die changed due to six key narratives which were communicated to the public through the most effective technology of their respective eras.

These narratives begin with Key Narrative #1—the Greek tragedy, *Antigone*, written by Sophocles in 441 BC. Next, Key Narrative #2—Elisabeth Kübler-Ross's *On Death and Dying* changed the way the nation regarded and spoke of death. Key Narratives #3, 4, and 5 are print and television stories describing in installments the complex ethical questions three families faced and the court battles they waged as these three young women lay in permanent vegetative states. Finally, we have Key Narrative #6—Brittany Maynard's farewell on YouTube video. She chose to die by her own hand using Oregon's Death with Dignity Act rather than let her brain cancer have the last word.

For twenty-three-hundred years, through their interactions with the concepts presented in these six key narratives, human beings have been asking the question, "Who has sovereignty over my body?" The varying answers throughout time reveal a great deal about autonomy, religion, and whether there is an actual *right* to die. The varying answers to this question have been reflected in a progression of attitudes, policies, and laws that can be traced down through history. The laws that have resulted from the concepts represented by these six key narratives have both defined the boundaries of human autonomy and have constructed our evolving understanding of human freedom.

Section 1.2 Why This Issue Now?

The Right to Die Movement is at a particularly sensitive juncture in 2019. Laws allowing medical aid in dying are being considered by twenty-four state legislatures. At the time of this writing, nine

states and the District of Columbia have already passed laws allowing medical aid in dying. Like the abortion debates which have been reawakened by the appointment of conservative judges all over America and to its highest court, the Right to Die is not only a debate about ethics and law. For many Americans, it is a debate about religion and whether the traditional view of "God's Law" and "Thou shalt not kill" is still in force in an increasingly secular country. Whether or not our country is a secular one, Americans have claimed since its founding that the constitution and the laws of the land are based on reason rather than religious revelation. *But is that true?* This thesis argues that Americans have been living with mistaken notions of constitutionally-guaranteed civil liberties while those very liberties and rights have been highly restricted—and even sometimes *increasingly* restricted—by the institutions of government, medical and scientific technology, and religion. This study looks at laws that have specified who owns the human body and who has the right to end a human life when that life is already essentially at its end. The Right to Die is a people's movement that seeks to earn perhaps the last civil right in America—the right to a death without suffering when the end of life is inevitable.

Section 1.3 Suicide as a Context for Understanding the Right to Die Movement

Although Medical Aid in Dying is decidedly not suicide in its reasons for carrying it out, in its character, or in its technical aspects, the history of suicide is the context in which the Right to Die Movement was formed and now exists. Suicide, originally called "self-killing" or "self-murder" prior to 1642, has been one means of death since humans have walked the earth.

> ...Sir Thomas Browne was the first to coin the word ''suicide'' in his Religio medici (1642). A physician and a philosopher, Browne based the word on the Latin sui (of oneself) and caedere (to kill). The new term reflected a desire to distinguish between the homicide of oneself and the killing of another.[1]

Throughout history, suicide has taken on a variety of meanings and messages. It has been considered a purely irrational act—the very definition of insanity. In other circumstances, suicide has been regarded as entirely rational and even heroic. The Japanese had great respect

[1] https://www.who.int/violence_injury_prevention/violence/global_campaign/en/chap7.pdf p. 185 Also, Minois, p. 131

for their suicidal kamikaze pilots in World War 2 because those soldiers put their country before their lives. We admire and commemorate the Jews at Masada who committed mass suicide rather than be captured by the Roman Army in 73 CE.

> Since we long ago resolved never to be servants to the Romans, nor to any other than to God Himself, Who alone is the true and just Lord of mankind, the time is now come that obliges us to make that resolution true in practice ... We were the very first that revolted, and we are the last to fight against them; and I cannot but esteem it as a favor that God has granted us, that it is still in our power to die bravely, and in a state of freedom.[2]
>
> Elazar ben Yair, leader of the Sicarii rebels

Because Jews believed dying in this way "was a favor that God has granted," we can deduce that this act was an exception to their understanding of the usual will and commandments of God. Dying by their own hands rather than being taken captive, however, is still considered a brave act and that the Jews, through suicide, had achieved a "state of freedom." Since early history, suicide—under certain circumstances—has been considered an act of autonomy, power, and liberty. This ultimately is what the Right to Die Movement is all about.

Though Judaism and Christianity have condemned suicide throughout most of their histories, other religions have different views about the taking of one's own life. A cardinal virtue of the Jains is captured in the Sanskrit word "*Ahimsa*" or non-violence. Hindus and Buddhists also honor this virtue. This concept refers to the prohibition of the killing of any living being for any reason. Though Jains wear veils over their mouths to prevent the accidental death of flies and gnats, they allow and expect the suicide of their elders at the end of their lives. The Jains consider the body a temporary vessel or housing for an immortal soul. Suicide at the end of life is achieved by a gradual lessening of food intake to achieve this final liberation from the material world. Not feeding a dying body is regarded as a rational act in service of eventual self-liberation:

> Alluding to a Jain metaphor, one may recall that a house shelters one from the elements, but it is best to leave a crumbling house to prevent injury. For someone who is merely departing from such a house, it makes little sense to keep adding bricks and mortar. At the threshold of an inevitable collapse, the Jain prizes the ability to walk away gracefully.[3]

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[2] https://www.jewishvirtuallibrary.org/elazar-ben-yair-speech-at-masada

[3] http://www.jainism.com/blog/does-jainism-really-have-ritual-suicide

Before it was outlawed, Hindu widows committed *suttee* as an heroic act of honoring their husbands. Suttee, meaning "good woman," involved a widow throwing herself on her husband's funeral pyre to accompany him into death. This practice, though horrifying to the Western mind, was sanctioned by Hindu teachings and Indian culture until it was banned in all provinces in 1829 by the British Governor-General Lord William Bentinck.[4] Westerners believe this practice exposed the value Hindus placed on the individuality and value of female lives.

This thesis is not just about whether hastening their own deaths by terminal patients is "right or wrong" and thus whether or not it should be legal. Instead, this thesis uses this movement as a lens into the history of Western thought, values, rights, and liberties. The Right to Die Movement offers an opportunity to examine American society, the way we think, what values we uphold, what rights and liberties we actually possess, and how our various religions ask us to regard our bodies and lives. The Right to Die Movement causes us to ask ourselves questions: *Who owns my body? Who has the power over when and how I die? Whose permission must I have before I choose to end my own life when it is already over?* and *Despite my own philosophy about dying, may I allow another human this end-of-life option even if I disagree with it?*

Section 1.4 Medical Technology and How We Die

We know that Americans in 2019 in all demographics overwhelmingly approve of the Right to Die. The advocacy group *Compassion and Choices* in Portland, Oregon reports that the 2018 Gallup's poll shows the following:

> Nearly three quarters agree that doctors should be able to help terminally ill patients die (72%)
> Majority support included nearly every demographic group surveyed, including men (79%), women (65%), Republicans (62%), Democrats (80%), Independents (73%), conservatives (54%), moderates (79%), liberals (89%), those who attend church nearly weekly/monthly (69%), and who attend church seldom/never (86%).[5]

Now that the Right to Die is becoming law in a growing number of states, we can ask ourselves further questions: *What are the reasons why a majority of Americans now support laws*

[4] https://www.indiatoday.in/education-today/gk-current-affairs/story/sati-pratha-facts-275586-2015-12-04

[5] https://compassionandchoices.org/resource/polling-medical-aid-dying/

that allow the Right to Die? What are the factors that created a surge of support for Medical Aid in Dying from 2014 to 2019? What is the role of religion in both resistance to and support for the Right to Die?

Top 10 Causes of Death, 1900
1. Tuberculosis 11.3%
2. Pneumonia 10.2
3. Diarrhea 8.1
4. Heart Disease 8.0
5. Liver Disease 5.2
6. Injuries 5.1
7. Stroke 4.5
8. Cancer 3.7
9. Bronchitis 2.6
10. Diphtheria 2.3

Table 1.1[6]

Top 10 Causes of Death, 2010
1. Heart Disease 29.6%
2. Malignant Neoplasms (Cancer) 23.0
3. Stroke 7.0
4. Chronic Lower Respiratory Disease 5.1
5. Accidents 4.1
6. Diabetes Mellitus 2.9
7. Pneumonia and Influenza 2.7
8. Alzheimer's Disease 2.1
9. Kidney Disease 1.5
10.Septicemia (toxins in blood) 1.331

Table 1.2[7]

Top 10 Causes of Death, 2017
1. Heart disease (23.4% of all deaths)
2. Cancer (22.5%)
3. Chronic lung diseases (5.6%)
4. Accidents (unintentional injuries; 5.2%)
5. Stroke (5.1%)
6. Alzheimer's disease (3.6%)
7. Diabetes (2.9%)
8. Influenza and pneumonia (2.1%)
9. Kidney disease (1.8%)
10. Suicide (1.6%)

Table 1.3[8]

One obvious development in the last few decades is that the United States and many other developed countries now have the medical technology and expertise to keep dying people alive for days, weeks, and even a great many years. The field of medicine now has endless tests, treatments, technologies, and machines, medicines, and means to prolong what can be very agonizing deaths. It can keep the dying in a morphine stupor until death finally arrives. When patients are in a pain-free stupor but can no longer think or communicate, we can ask whether they have already died as to what made them their unique selves. On behalf of their loved ones and themselves, this is the phase of dying many Americans wish to avoid. They wish to die with their personalities, thinking, and speech intact so that their lives are meaningful and relational until the very end.

[6] Ball, Howard. At Liberty to Die : The Battle for Death with Dignity in America, New York University Press, 2012. ProQuest Ebook Central, http://ebookcentral.Created from asulib-ebooks on 2019-04-15 16:07:53 p. 17

[7] Ibid., p. 19

[8] Ibid.

We can see from these charts that Americans in 2019 die mostly of diseases that take much longer to kill us. We now have pharmaceutical treatments, chemotherapy, transplants, genetic interventions, advanced surgeries, antibiotics, and machines like respirators, heart-lung machines, defibrillators, and pacemakers which serve to cure some people, but also both delay death and prolong the dying process.

Before 1939 when antibiotics became available, simply lying in bed because of illness or injury could cause the pneumonia that would take life quickly. Pneumonia was once called "the old man's friend" because it hastened death that was already in progress due to other causes.

Because of modern medical advances and technologies, 80% of deaths in America now take place in hospitals or care facilities rather than in homes because death has now become "medicalized." Despite the fact that most people want to die at home, the medicalization of death has moved the arena of death to places that are more convenient to medical providers:

- Studies have shown that approximately 80% of Americans would prefer to die at home, if possible.
- Despite this, 60% of Americans die in acute care hospitals, 20% in nursing homes and only 20% at home.
- A minority of dying patients use hospice care and even those patients are often referred to hospice only in the last 3-4 weeks of life.
- However, not every patient will want to die at home. Dying at home is not favored in certain cultures (due to cultural taboos) and some patients may wish not to die at home, out of concern that they might be a burden on the family.[9]

Section 1.5 What Accounts for the Growing Acceptance of the Right to Die?

Some scholars attribute the growing acceptance for the Right to Die to reasons other than the advancement of technology and how it is prolonging the act of dying. These scholars say the reason the spate of Right to Die cases has come before the courts, state legislatures, and the media in the past few decades is not because of medical advances but because of changes in *how Americans now conceptualize their rights, freedoms, and autonomy.* Shai Lavi is one of these scholars:

> To consider euthanasia* as a late twentieth-century dilemma is both historically inaccurate and conceptually misleading. Euthanasia is not a response to the

[9] https://palliative.stanford.edu/home-hospice-home-care-of-the-dying-patient/where-do-americans-die/

> advance of medical technology nor to the ability of medicine to prolong life beyond acceptable bounds…Euthanasia proposals first emerged in the late nineteenth century, long before medicine achieved the unprecedented ability to prolong human life. More important, associating euthanasia with advances in medical techniques overlooks the connections between euthanasia and deep cultural changes that made euthanasia possible. For euthanasia to emerge, no significant medical breakthrough was necessary but rather fundamental changes in the ways we wish for our lives to end; namely the decline of the art of dying and the rise of technical mastery over death…*The most significant difference between contemporary euthanasia proposals and those made more than a half a century ago is the growing emphasis on patients' rights and autonomy*.[10] (emphasis added)

This thesis argues for a combination of these two viewpoints as the reason why the Right to Die is being debated in the courts and legislatures at this time. The Right to Die movement is occurring at a moment in time when legal and moral concepts such as self-ownership, autonomy, individual rights, and civil rights have evolved to the point that they have now come into conflict with the medicalization of death. The clash of these two strands of human evolution during the last five decades has caused American citizens to question their constitutional individual rights and many believe they should have the final authority in how and when they will die when death is inevitable. Just as the medical community has been growing in technical dominance over the act of dying, Americans have been growing in their awareness of their individual rights and the freedoms they wish to have over their own bodies and lives.

Just as Dr. Elisabeth Kübler-Ross was bringing the subject of death into public conversation after it had been submerged in taboo for centuries, the medical world became proficient in prolonging death to a previously unimagined degree. With the taboo on speaking of death lifted by Kübler-Ross's work, the media began reporting on and leading the debate about whether advanced medical technology represented milestones or millstones to the American people. Americans soon became highly aware and agitated by the issues raised by this national conversation. As awareness grew, the families of the dying as well as advocacy groups began to bring the debate to the courts to push for answers and policies that would settle some of these

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[10] Lavi, Shai Joshua., and Ebrary, Inc. *The Modern Art of Dying : A History of Euthanasia in the United States*. Princeton, N.J.: Princeton University Press, 2005. p. 164

*Lavi is referring to aid in dying here.

controversies. The result was that, just as medicine was achieving technical dominance over the dying process, the American public was achieving a robust and deepening sense of their desire for increased autonomy.

What brought this about?

Several key, politically-sensationalized, media-curated events between 1976 and 2006 caused American citizens to begin to grapple with the limits and restrictions on their autonomy and rights. The very first Right to Die law was passed in Oregon in 1994 in the middle of these very public controversies. These media events centered around three medical cases which included: Karen Ann Quinlan (Persistent Vegetative State from 1975-1985), Nancy Cruzan (PVS from 1982-1990), and Terry Schiavo (PVS from 1990-2005). These three women were kept alive with medical technology for ten, eight, and fifteen years respectively as their families used the courts to decide who had the right to end their daughters' lives. These cases and the court interventions accompanying them gave the public front row seats to the powers of medicine to prolong life—even when that life was essentially a living death. These public debates and media narratives attracted attention and changed perceptions and laws around the world. The media coverage of these three particular medical cases lead to a reaction in the courts that affirmed an individual's right to refuse medical treatment and to state in writing what were and were not acceptable measures at the end of life. These stories resulted in hospital bioethics committees, statements of patients' rights, advance directives, living wills, and eventually the first Right to Die law in America.

The average human being now knew what horrors were possible for themselves and their loved ones due to the medicalization of death. But the real understanding often did not occur until people faced their own deaths or the deaths of loved ones. It was then that many Americans found out just how much power doctors and nurses actually have as evidenced by their ignoring or overriding living wills, DNRs (do not resuscitate orders), a patient's voiced preferences, and the wishes of legal proxies or family members. In the country with the most advanced, constitutionally guaranteed individual rights, doctors often still have the last word about what actually happens to a dying patient.

Then Dr. Jack Kevorkian appeared on the scene with his own solution to these controversies. The MacGyver-like device he invented called the "Thanatron"—and a later version called the "Mercitron"—allowed people who wished to die to take their own lives with this patient-controlled machine. The Thanatron, operated by the patient and not Dr. Kevorkian, delivered a dose of thiopental which induced a coma, followed by a dose of potassium chloride which stopped the heart. After he lost his medical license and could no longer obtain lethal drugs, Kevorkian's Mercitron used carbon monoxide operated by the patient.[11] Since, in all fifty states, suicide is not a crime, Kevorkian got away with his performance art. "…[B]etween 1993 and 1996, juries acquitted him in three trials…[It] is likely that the jurors considered that the patient's death occurred because a physician was attempting to alleviate suffering."[12] No judge was willing to throw him in jail because of the strong jury and public support for his actions. That is, until he stepped over the line and directly killed a person by administering a lethal injection. "Dr. Death," as he was called, videotaped his killing of a patient which *60 Minutes* aired in 1998. This nose-thumbing at the state courts finally won Kevorkian ten to twenty-five years in prison. He refused to post bail and began a hunger strike in support of his cause. He eventually served eight years. The *60 Minutes* broadcast represented one of several watershed moments in the Right to Die Movement:

> Of all the interviews he conducted for "60 Minutes," Mike Wallace often said none had a greater impact than this one.
>
> Dr. Jack Kevorkian had long been a public advocate of assisted suicide for the terminally ill. From 1990 to 1998, he claimed to have helped end the lives of some 130 willing subjects. In September of 1998, Dr. Jack Kevorkian videotaped himself injecting Thomas Youk, who suffered from Lou Gehrig's disease with a dose of lethal drugs.[13]

This thesis contends that five of the six narrative milestones—Key Narratives #2 through #6—could not have resulted in changed attitudes, policies, and laws without the operation of the first

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[11] https://www.pbs.org/wgbh/pages/frontline/kevorkian/aboutk/thanatronblurb.html

[12] Zucker, and Zucker, Marjorie B. *The Right to Die Debate: A Documentary History*. Primary Documents in American History and Contemporary Issues. Westport, Conn. ; London: Greenwood Press, 1999.p. 235

[13] https://www.cbsnews.com/news/dr-jack-kevorkians-60-minutes-interview/

key narrative (see Section 2.1). The Greek tragedy *Antigone* introduced to the Greek world and consequently to Western thought the concept of an "unwritten law" or "fundamental law" or "Natural Law." This concept was portrayed by the character of *Antigone* in the play written by Sophocles in 441 BC. The influence of Natural Law on the Right to Die Movement is important to understand:

> …[W]hen the Constitution speaks of a right to "Life and Liberty," it speaks of rights not held by the community, but by the individual. It speaks of a right that allows each of us to use that life as we see fit, so long as it does not directly bring harm to others. As a corollary to this right is the unquestioned right to self-ownership within the United States; by virtue of this right, we are free to do with our bodies those things that we believe to be morally correct as long as they do not infringe on the freedoms of others. [14]

As a result of the court battles over Quinlan, Cruzan, and Schiavo, new laws and policies were set in motion. During these controversies, religious organizations and leaders reacted to the new laws, medical practices, and public perceptions by raising their voices both for and against the Right to Die. Some of those voices will be included in this study. Despite the vigorous objections, contemporary concepts and laws protecting patient autonomy, individual rights, and the Right to Die have resulted. This study contends that judges, attorneys, the Supreme Court, and the public were responding to the innate guidance of Natural Law whether or not they were aware of it. Whereas Natural Law once meant the "unwritten, unshakeable laws" of the Greek pantheon of gods, Natural Law can also be intuited, discovered by reason and logic, and promoted by secular citizens who instinctively endorse maximum freedom, autonomy, and individual rights. Rather than only obeying laws written down by humans (positive law), those who promote Natural Law sense the universality, virtue, and rightness of laws that ought to be, but are not written down and obeyed by human beings.

The ways in which the media reported to, analyzed for, and questioned society during the court battles over Quinlan, Cruzan, and Schiavo explain how Americans came to have a firmer understanding of the capabilities and powers of the medical community as well as a new awareness of their own relationship to law and government. The values of life, liberty, and the

[14] Whiting, Raymond. *A Natural Right to Die : Twenty-three Centuries of Debate*. Contributions in Legal Studies, No. 101. Westport, Conn.; London: Greenwood Press, 2002. p. 151

pursuit of happiness have long been the foundations of the American way of life and the foundational principles of our constitution. But, absent the openness of speech about death brought about by Kübler-Ross, and the ever-present echoes of Natural Law in this country, this thesis argues that Americans might never have come to understand the human liberty which is at stake with regards to an individual's Right to Die.

Although many of these questions were similarly debated during the abortion debates in the 1960s and 70s, American values had rarely been tested and probed on the subject of voluntary death before the time of narratives 2 through 6. Americans have come a long way in their conceptions of who they are with regard to their government. The personal control over the timing and manner of one's own death after a terminal diagnosis has been made is now considered, by some Americans, to be a civil right. For those who identify with particular religions, the timing and manner of one's death has always been assumed to be a matter left to God. Taking their own life or the life of another goes against the traditions of many religions—especially Catholics, Evangelical Protestants, many Christians, Latter-day Saints, and nearly all Jews. People of these religions believed and still believe that suicide was condemned in the Bible and in the Torah. This myth is dispelled in a later section that explains what the Bible (including the Torah) actually says on the subject of suicide. Nevertheless, for centuries—since Augustine and Maimonides—a human life was believed to be both given and taken by God alone. This is still the main argument in 2019 against the Right to Die even though its scriptural roots can be questioned and legitimately returned to a more accurate interpretation.

The concept of individual rights can be both learned and understood through a study of human history and human reasoning. The perceived conflict between scriptural interpretations and human law is very present in the current debates about the Right to Die. Indeed, besides the concern over whether Right to Die laws will be abused in some manner, one of the most salient, ongoing issues in this debate is whether the time and manner of one's own death should be regarded as "God's choice alone" or as the last "civil right" for Americans.

Section 1.6 Terms and Distinctions

This study uses the terms "**Right to Die**" and "**aid in dying**" as overarching concepts. These phrases subsume the various terms used by advocates and opponents over the past few decades. As in any movement, its members have preferred various terms as problems and misunderstandings occur with the terms they or others have been using. Many of the more emotionally charged or inaccurate terms were and are still used by opponents of the **Right to Die** as a further means of defeating **Right to Die** legislation. For instance, the American Medical Association which opposes medical aid in dying insists on using the more emotionally-charged term "physician-assisted suicide" even in 2019 though members of this association know the technical differences between suicide and medical aid in dying.

The first distinction this paper makes is that the **Right to Die Movement** is not about **active** or **passive euthanasia**. In fact, the success of the **Right to Die Movement** has been attributed to the fact that the laws and procedures are written to make it clear that no one but the dying patient is in charge of their own death including the act of ingesting the lethal medicine that will end their life. Had the patient's death been a result of **active** or **passive euthanasia**, another person or doctor would be either in charge of the initiation and/or the implementation of the patient's death. **Active euthanasia** refers to actions such as giving a lethal injection or an oral dose of narcotics with the intention of causing death. **Passive euthanasia** refers to withdrawal of treatments such as respirators, pacemakers, feeding tubes, IVs with medicine or hydrating fluids, and any other interventions that are keeping a dying patient alive. The new **Medical Aid in Dying** laws allowing a terminal patient to request a hastening of their own death *never* requires another person to initiate the request or complete the action of causing the patient's death. Since suicide is legal in all fifty states, the ingesting of lethal medicine by the dying patient alone protects all those involved in each case of aid in dying.

With respect to the word "**euthanasia**," the term that comes closest to the **Right to Die** is **Voluntary Euthanasia** which means the patient has *consented* to either **active** or **passive**

euthanasia which would be performed by someone other than himself.[15] However, since that term is not very clear to most laypersons, the term will be avoided in this study unless, as in Chapter 2, the history of the **Right to Die Movement** is being discussed. The negative terms **self-murder** and **self-killing** will not be used even though these were the standard terms until the word "**suicide**" first appeared in 1642.[16]

The second distinction is that the **Right to Die Movement** is not about **suicide** as that term is commonly understood. However, it is necessary to use the concept to provide an ethical and historical context for the current **Right to Die Movement**. The word **suicide** or **physician-assisted suicide** might seem accurate, but the problems with this term are many. The word **suicide** is fraught with emotional overtones, fears, revulsion, religious and ethical prohibitions, and general distaste. People who intend to use a law permitting **aid in dying** are highly insulted when their planned action is labeled a "**suicide.**" The distinction is that people who commit **suicide** *want* to die. People who ask for **aid in dying** *do not* wish to die, but they are dying nonetheless. The issues that make people desire **aid in dying** or a **hastening of death** are the patient's wishes to avoid the indignities, dependence, physical suffering, emotional agonies, and feelings of uselessness that occur as a person is dying. These people do not wish to die in the same way that a suicidal person does. Suicidal persons may be physically healthy but are distraught or depressed and, for a variety of reasons, no longer see meaning in their lives. Instead, people who seek aid in dying are already dying and wish to avoid the suffering that often attends the process.

> The legal status and consequences of the two acts are different. In the United States, the statutes in those states with "**Death with Dignity**" or "**End of Life Options**" laws assert that such a death 'shall not, for any purpose, constitute suicide, assisted suicide, mercy killing, or homicide under the law.' Deaths under

[15] Downing, Smoker, Downing, A. B, and Smoker, Barbara. *Voluntary Euthanasia : Experts Debate the Right to Die*. Rev., Enl. and Updated ed. London: Peter Owen, 1986.

[16] Note: According to the Oxford English Dictionary, the word suicide was first used in 1651, but Alfred Alvarez reported that it appeared in Sir Thomas Brown's Religio Medici in 1642. http://www.deathreference.com/Sh-Sy/Suicide-Basics.html

these laws are not reported as suicide on death certificates, but as death from the underlying terminal condition.[17]

The term **Death with Dignity** refers particularly to the **aid in dying** law which was passed in Oregon in 1994. The reason the term "**Death with Dignity**" fell out of favor is because it implies that those who die by other means did not die "with dignity." This was certainly not the intent of the authors of the Oregon law.

In an effort to cover the history and the legal context of this issue, this thesis will use the terms **Right to Die Movement, Right to Die, Aid in Dying, Medical Aid in Dying, or MAID** interchangeably**. Medical Aid in Dying (**or **MAID)** is now the preferred term across the United States. *Compassion and Choices*, the premier advocacy non-profit is trying to make this more modern term, **Medical Aid in Dying or MAID**, the only term used in order to avoid inaccuracies and distasteful connotations.[18] In fact, nearly all state laws that are now being passed are titled **Medical Aid in Dying Law.**

Section 1.7 Why Are Right to Die Laws Left to the States?

Understanding why MAID is left to each state individually is useful in understanding the Right to Die Movement in America. In 1997, the cases of Washington v. Glucksberg and Quill v. Vacco were argued in the Federal Second and Ninth Circuit Courts of Appeal. Both courts ruled that the Right to Die was a constitutional right for all Americans. But when these cases were appealed to the highest court, the United States Supreme Court judges ruled that the Right to Die was a medical issue and not a constitutional right. "While the Constitution does not *require* the states to allow PAD [physician-assisted dying], it does allow states to decide for themselves whether to legalize it or criminalize it, setting the stage for a state-by-state political battle over proposals to allow and regulate PAD."[19]

[17] https://compassionandchoices.org/?s=Suicide Definition of Suicide

[18] https://www.compassionandchoices.org/news/compassion-choices-pres-barbara-coombs-lees-statement-canada-euthanasia-bill/

[19] https://biotech.law.lsu.edu/cases/pro_lic/vacco_glucks_brief.htm

At this writing, nine states as well as the jurisdiction of Washington, D.C. have passed Right to Die laws. Those states are: Oregon (1994, ballot initiative), Washington (2008, ballot initiative), Montana (2009, state Supreme Court decision), Vermont (2013, legislation), California (2015, legislation), Colorado (2016, ballot initiative), Washington, D.C. (2017, legislation), Hawai'i (2018, legislation), and New Jersey (2019, legislation) and Maine (2019, legislation).[20] According to *Compassion and Choices*, twenty-four additional states are considering Right to Die laws.

Because it is a model for all other states, the Death with Dignity Act (DwDA) of Oregon which was passed in 1994 and passed again and implemented in 1997 is given here:

> **To be eligible to use the Death with Dignity law, one must:**
> » Be 18 years or older
> » Have been diagnosed with a terminal illness
> » Have a prognosis of six months or less to live
> » Be capable of making their own healthcare decisions
>
> **One must also be**:
> » A resident of Oregon
> » Capable of self-administering and ingesting the aid-in-dying medication
> » Making an informed decision and voluntary request
>
> **The patient has a psychological examination, if either doctor feels the patient's judgment is impaired:**
> » The prescribing doctor informs the patient of any feasible alternatives to the medication, including care to relieve pain and keep the patient comfortable.
> » The prescribing doctor asks the patient to notify their next of kin of the prescription request. (The doctor cannot require the patient to notify anyone, however.)
> » The prescribing doctor offers the patient the opportunity to withdraw the request for aid-in-dying medication before granting the prescription.
> » To use the medication, the patient must be able to ingest it on their own. A doctor or other person who administers the aid-in-dying medication may face criminal charges.[21]

In response to the Right to Die becoming a state-level decision, citizens have formed independent advocacy groups or state chapters of *Compassion and Choices* to enact state laws that would allow the Right to Die in their own states. These groups often receive calls from ordinary citizens who have recently experienced the agonizing death of a loved one. These callers have become aware that palliative care cannot remove all the possible kinds of suffering

[20] https://www.compassionandchoices.org/about-us/our-accomplishments/

[21] https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/requirements.pdf

involved at the end of life. They may have helplessly witnessed the progressive loss of dignity and independence that their dying loved one endured. Looking into the blank abyss of a loved one's morphine stupor also motivates some of those left behind to champion the right to end a life before these agonies begin or become unbearable.

After they encounter the limitations on the rights of the dying, these citizens often question whether anyone but the patient should have the final say over their end-of-life options. These callers often become advocacy volunteers or offer to testify before a state legislative committee or to a full legislative body that is considering a Right to Die law. Patients who themselves are facing death also tell their stories on social media and to the print/television media or testify before state legislatures about their helplessness in the face of current laws against medical aid in dying.

Section 1.8 Brittany Maynard and Social Media

Because this issue is a political and ethical debate of which all Americans should be aware, this thesis will take up several questions arising from the debates in order to give a full treatment of the issues at hand. Unlike the abortion debate that does not directly affect everyone, facing and experiencing death will happen to all humans. The questions answered in this paper include several that may be of interest to the average American: *What are the key cases and historical milestones that have sparked interest in the Right to Die Movement in the general public? What do various Jewish and Christian scriptural texts say about suicide? How has social media played a part in the growing acceptance of the Right to Die?*

In response to the question about the role of social media in the Right to Die Movement, this thesis will present and discuss the results of an original, quasi-experimental study of attitudes and beliefs of 99 Arizona State University students toward Right to Die laws and how these students reacted to the personal narrative of the 29-year-old California woman named Brittany Maynard who used Oregon's *Death with Dignity Act* (DwDA) to end her own life in 2014. The study will then compare these students' beliefs and attitudes to those of a sample of 130 Amazon MTurk crowd-sourced participants using the same survey instrument.

The significance of Brittany Maynard's YouTube farewell video is that, in 2019, social media is often a source of news as well as a worldwide platform for public debate about many topics of interest and import. Sometimes a single idea can spread across the nation or the world in a matter of hours or days through social media. The series of rebellions across the Middle East in 2011 known as the "Arab Spring," was both initiated and conducted through social media. Calls for immediate action on climate change by Swedish school children have been spread despite the resistance of climate deniers and world leaders who claim the world is not facing a crisis or that nothing can or should be done to reverse it.

Along with spreading knowledge and public awareness, social media can also spread ignorance and lies. The 2016 American election interference by the Russians—something unprecedented in American history—is one example. The belief that vaccines can cause autism is another. Even though a single, extremely flawed, and completely mistaken research study in Britain showed that certain vaccines caused autism, the social media reports about the study made parents all over the world question the safety of childhood vaccinations. As certain key celebrities like Jenny McCarthy supported and promoted this idea, it spread like wildfire in the United States and beyond. McCarthy's celebrity gave the idea the status it might never have had otherwise. The fact that measles is now making a comeback represents perhaps one of the most vexing health threats in recent history because the cause of its resurgence is voluntary ignorance spurred by non-experts through social media. Despite the efforts of doctors, government, news outlets, and the Center for Disease Control, parents are still leery of childhood vaccines and a great number of them are opting not to vaccinate their children. Although various states are now mandating that children be vaccinated, it may take decades to once again remove the measles from the list of human miseries.[22]

Similarly, Brittany Maynard's YouTube video went viral and, within one month, an estimated 100 million people across the globe learned the story of Brittany Maynard either through her video or the news reports based on her video. Maynard became a celebrity in the

[22] Chiou, Lesley, and Catherine Tucker. *Fake News and Advertising on Social Media: A Study of the Anti-Vaccination Movement*, 2018.

Right to Die Movement. She was in her first year of marriage to Dan Diaz and the two had been trying to start a family. Brittany was a beautiful, articulate, very intelligent woman in the prime of her life who was diagnosed with a highly aggressive brain cancer called glioblastoma. True to her independent spirit, and despite the severity of her seizures and other symptoms, Maynard moved to Oregon from her lifelong home in California, found new housing, located and became a patient of new doctors, and gathered her loved ones around her so she could make use of the state's Death with Dignity Act. Her incredible effort to relocate her residence while she was terminally ill seemed itself a terrible injustice and caused Brittany to waste some of the valuable, dwindling time she had left. Her videotaped personal narrative on YouTube touched viewers across the world. News outlets, magazines, and academic scholars picked up her story, using it to discuss and debate the Right to Die.

Many of the staff members at *Compassion and Choices* believe Maynard's videotaped personal narrative was worth ten years of advocacy efforts.[23] They also believe her video was responsible for the surge of support after 2014 in the way Americans viewed the Right to Die. Could one viral video cause this obvious leap in the acceptance of the Right to Die? Table 1.4 shows that, in 2014, public opinion in support of the Right to Die took a large leap from majority opposition of 49% in 2013 to 56% support in 2015.

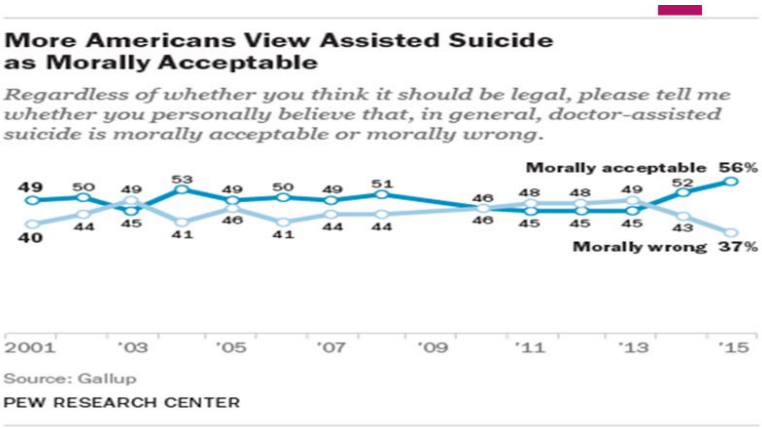

Table 1.4[24] Support/Opposition to MAID 2001 to 2015

[23] Email exchange with Sarah Brownstein, staff member of *Compassion and Choices*, June, 2019

[24] https://news.gallup.com/poll/235145/americans-strong-support-euthanasia-persists.aspx

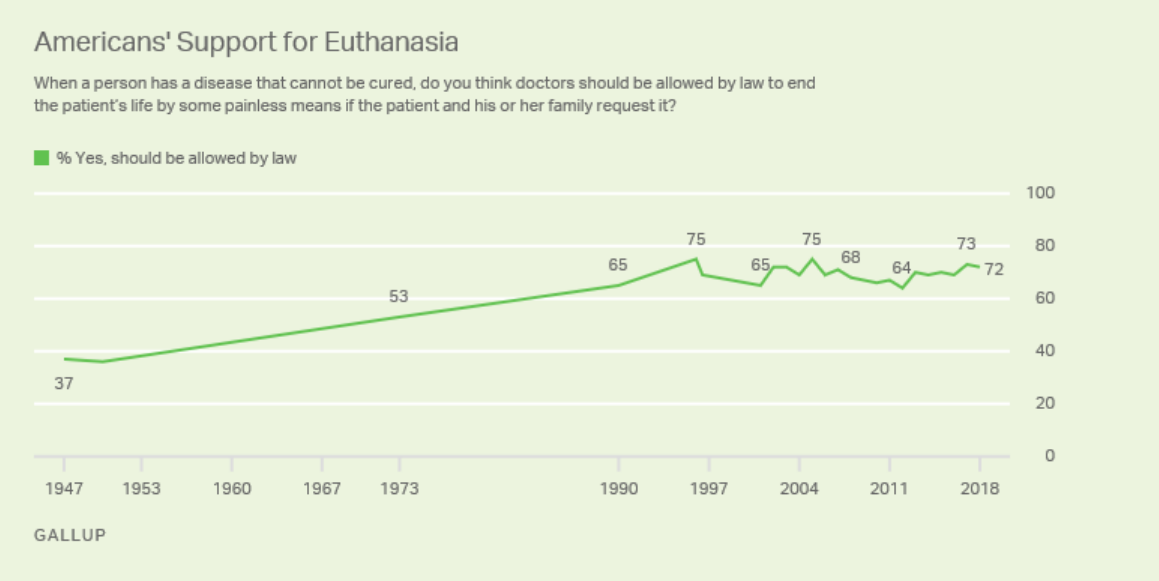

Table 1.5 [25] Support/Opposition to MAID 1947 to 2018

Table 1.5 (above) shows that support for MAID continues to 73% in 2017, then 72% in 2018. Table 1.6 (below) shows the demographic breakdown of those who support and oppose MAID. By comparing the May, 2014 support (5 months before the Maynard video went viral) and the May, 2015 support for MAID (7 months after the Maynard video went viral), it seems to indicate that the video may have contributed to the significant rise of support for MAID. Another possibility is that this data *reflects* rather than *creates* the support for MAID and the sense of autonomy and self-ownership underlying this support.

[25] Gallup Poll 2018 https://news.gallup.com/poll/183425/support-doctor-assisted-suicide.aspx

Support for Doctor-Assisted "Suicide," by Year

When a person has a disease that cannot be cured and is living in severe pain, do you think doctors should or should not be allowed by law to assist the patient to commit suicide if the patient requests it?

% Yes, should be allowed

	May 2014	May 2015	Change
	%	%	pct. pts.
18 to 34 years old	62	81	+19
35 to 54 years old	57	65	+8
55 and older	56	61	+5
Republicans	51	61	+10
Independents	64	80	+16
Democrats	59	72	+13

GALLUP

Figure 1.6 [26] Demographic breakdown of Support/Opposition in 2014 and 2015

The survey-based study in this thesis will define the various positions on the Right to Die, the attitudes and beliefs of ASU students as compared to the general population that identifies as "religious," and will conclude with an assessment of the Right to Die Movement in America as evidenced by the current trends and national polling. At the end of this thesis, the six key narratives will be presented together to show how they tell a bare-bones story of the Right to Die in America.

Section 1.9 Organization of this Thesis

Chapter 2 will briefly trace twenty-five hundred years of selected legal concepts that have influenced the Right to Die Movement. Beginning with the Greek Stoics and particularly Sophocles' tragedy ***Antigone*** (441 BC) (Narrative #1), this thesis will move to Roman Law and Catholic Canon Law and their contributions to the legal debates regarding Natural Law. The concept of Individual Rights which coalesced in the late 1600s is examined. The omnipresence of Natural Law is noted despite its falling from favor in legal history since the seventeenth and eighteenth centuries. The role of Natural Law combined with the concepts of Individual Rights is shown in the writings of John Locke. This combination of concepts can be seen in Thomas Jefferson's writings as well as serving as the conceptual framework that inspired both the French and American Revolutions. The Right of Privacy has also been a relatively recent concept (1965)

[26] https://news.gallup.com/poll/235145/americans-strong-support-euthanasia-persists.aspx

which is used in both the abortion and Right to Die debates. The particular and varying views of Christianity and Judaism on the subject of suicide are discussed as well as a survey of which religions currently support or oppose the Right to Die.

Chapter 3 offers a closer look at the fifty years between 1969 and 2019 which involves a cascade of new perceptions of death and dying as well as perceptions about the Right to Die as a civil right. Thanks to the writing and thinking of Dr. Elisabeth Kübler Ross beginning in 1969 (Narrative #2), public conversations about death and dying emerged from the taboo which society and even the medical community had placed on these discussions.

From the 1970s on, Americans witnessed the highly publicized series of three medical/legal cases of Quinlan, Cruzan, and Schiavo (Narratives #3, #4, and #5). During this time, the public also read about the suicides assisted by Dr. Jack Kevorkian. During Kevorkian's controversial acts of suicide assistance, Oregon passed the Death with Dignity Act in 1994 and, after repeal efforts, passed it again with even wider support in 1997. Finally, this paper tells the story of the *Compassion and Choices* advocacy organization and the viral video phenomenon of Brittany Maynard's 2014 Farewell YouTube narrative (Narrative #6).

Chapter 4 discusses previous polls and studies on Medical Aid in Dying. Then it describes the research design of an original study of the effect on ASU students of Brittany Maynard's YouTube video. A second study design is then presented using the same survey instrument—but testing a larger sample of participants who identify as religious.

Chapter 5 presents the data from the two survey samples categorized by specific research questions. The resulting data from each research question are analyzed. The chapter concludes with a summary of the survey findings and an overview of the six narratives that tell the story of the Right to Die Movement.

Section 1.10 A Restatement of the Purpose of this Thesis

At its essence, the Right to Die Movement can be summarized in six key narratives. Each of these stories was communicated through the most effective technologies available to these storytellers in their own eras. This thesis argues that these six key narratives not only *tell* the story of the Right to Die Movement but that they are also the *cause* of the changes in public

perception, new laws and policies, and more and more acceptance of medical aid in dying. In regards to the Brittany Maynard Farewell video, this narrative seems to both *cause* and *reflect* the rise in support for medical aid in dying since 2014. The extreme interest and sharing of the video reflects the greater support for American concepts of autonomy, self-ownership, individual rights, and constitutional freedoms.

These six key narratives caused the public to ask themselves important questions such as "*who owns my body?"; "Who has authority over how and when I die when my death is already in motion?"* and *"What are my constitutional rights and freedoms with regard to my own manner of death?"* The answers to these questions paved the way for the first Medical Aid in Dying laws in America. The stories that emerged from the Right to Die Movement have resulted in laws, policies, and concepts that have brought Americans more individual rights and liberties. They have also helped American citizens explore the boundaries of human autonomy and construct an evolving understanding of human freedom.

We begin with a look at a legal basis for the Right to Die. For this foundation, Chapter 2 presents a brief history of Natural Law, how it has been used as a guideline for laws and practices throughout Western thought, and particularly how it was used to create the unique fabric of American jurisprudence and constitutional law.

CHAPTER 2

SELECTED CONCEPTS, HISTORIES, AND RELIGIOUS VIEWS RELEVANT TO THE RIGHT TO DIE OVER THE COURSE OF WESTERN THOUGHT

Section 2.1 Key Narrative #1: *Antigone* by Sophocles; the Concept of Natural Law and Individual Rights through History

Socrates (470-399 BCE), Plato (427-347 BCE), and Aristotle (384-322 BCE) all believed the polis or the "city state" was superior to the individual. These thinkers made their arguments beginning more than a hundred years before the Stoics came on the scene. Here is Socrates' thinking as reflected in Plato's *Phaedo*:

> There is a doctrine whispered in secret that a man is a prisoner who has no right to open the door and run away; this is a great mystery which I do not quite understand. Yet I too believe that the gods are our guardians, and that we men are a possession of theirs…then, if we look at the matter thus, there may be reason in saying that a man should wait, and not take his own life until God summons him, as he is now summoning me.[27]

Aristotle similarly did not believe a man's life belonged to himself. "For Aristotle, the citizen belonged to the state; as such, any citizen who took his own life was guilty of taking that which rightly belonged to the community."[28] For the Greeks, the value of a human being was as a part of a collective rather than as an individual. The Greeks were not yet conversant with the concept of individual rights since they saw their citizens as essentially a part of a city state or "polis" and to be apart from this polis meant humiliation, exile, or death. Aristotle said, "He who is without polis is either a god or a beast." [29] Laws were made for the communal good rather than to benefit the individual.

Although Heraclitus had already introduced concepts implying a Natural Law in 478 BCE, [30] it was Sophocles who put a more developed form of this concept of justice into the mouth of the

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[27] https://ethicsofsuicide.lib.utah.edu/selections/plato/

[28] Ibid., p. 26

[29] Whiting, Raymond. *A Natural Right to Die : Twenty-three Centuries of Debate*. Contributions in Legal Studies, No. 101. Westport, Conn. ; London: Greenwood Press, 2002. p. 71

[30] Ibid., p. 72

compelling character of Antigone in his Greek tragedy of the same name. Antigone insists that her slain brother Polyneices be buried despite King Creon's command not to bury him because her brother was an enemy of the city. When King Creon asks if Antigone disobeyed his command not to bury her brother, she answers:

> Of course I did. It wasn't Zeus, not in the least,
> Who made this proclamation—not to me.
> Nor did that Justice, dwelling with the gods
> Beneath the earth, ordain such laws for men.
> *Nor did I think your edict had such force*
> *That you, a mere mortal, could override the gods,*
> *The great, unwritten, unshakable traditions.*
> *They are alive, not just today or yesterday:*
> *They live forever, from the first of time,*
> And no one knows when they first saw the light.[31]
> (emphasis added)
> *Antigone,* ll. (Robert Fagles trans.).

In her dialogue with King Creon, Antigone proposes a concept of justice that is based on the authority of an "unwritten, unshakable" law of the gods. She speaks of this law as "a form of justice that human authority has no power to set aside and that all mortal commandments must express, or ought to express, if they seek to do justice."[32] She argues that human laws that fail to express this eternal sense of justice forfeit their authority and power to command.[33]

The concept of Natural Law refers to unwritten law—often called "fundamental law" in modern parlance—that seems to pre-exist man-made law. It is an intuitive law that seems to have come "from the gods themselves" since it is fair and just and reflects the highest virtues a person or society can express.

Raymond Whiting, in his A *Natural Right to Die: Twenty-three Centuries of Debate* shows how the Stoics, beginning in 300 BCE, were the first to use Natural Law to develop the idea that a citizen had certain powers over his own life—powers which belonged to him from birth. These powers or "rights" as they would later be called included the right to die when illness, injury, harsh

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[31] https://lawandreligionforum.org/2015/10/29/the-unwritten-laws-of-greece/

[32] https://lawandreligionforum.org/2015/10/29/the-unwritten-laws-of-greece/

[33] https://lawandreligionforum.org/2015/10/29/the-unwritten-laws-of-greece/

circumstances, or old age prevented him from living a full life. Whiting provides a full definition of Natural Rights here:

> Natural Rights are said to proceed from natural law and include entitlements as are derived from inherent rights and inalienable rights. These rights are neither created by acts of positive law nor brought about by mutual agreement between contractual parties. In fact, such rights are said not to be created at all, but rather to have simply been officially recognized as existing. Thus, such rights exist independently of any government or association of people, though it may well take the cooperation of one or the other to give them practical force within society. Such rights are believed to exist as a result of a rational understanding of human beings' relationships within the natural world and with each other. [34]

Whiting says it was the Stoics who first conceptualized the philosophical basis for the Right to Die. This signaled a radical departure in Greek philosophy because it valued the individual and his own powers of reason in making decisions for himself:

> Stoics saw the human being as an entity capable of making his or her own decisions regarding matters of personal destiny…For the Stoics, the main justification for ending one's existence was directly tied to questions concerning the quality of life…If at any time persistent ill health or old age interfered with these important qualities of life, it was permissible, but in no way mandatory, for one to terminate one's existence.[35]

In his book, Whiting provides a legal basis for the Right to Die in his tracing of the history of Natural Law. He says that Natural Law has been operative all through history whether modern legal experts wish to acknowledge it or not. Whiting holds that doctors themselves have been responding to this innate, inner sense of justice for decades since it has been in their power to cause death with narcotics. When doctors provide active euthanasia through a lethal dose of morphine or other deadly narcotic, they are ending the suffering of a patient who has directly asked the doctor for death to end suffering. When a doctor causes the hastened death of their dying patient when the patient has not asked for it, he has determined that there is no valid reason to keep his patient alive and suffering when a simple medical technique can bring the ultimate, permanent relief of death. Like doctors who end the lives of their dying patients, even family members have been known to follow a sort of "unwritten law" or a deeply felt sense of

[34] Whiting, Raymond. *A Natural Right to Die : Twenty-three Centuries of Debate*. Contributions in Legal Studies, No. 101. Westport, Conn. ; London: Greenwood Press, 2002., pp. 69-70

[35] Whiting, pp. 100-101

justice in giving a lethal dose of morphine when the suffering and agonies of their loved ones have become pointless and unbearable. For both doctors and family members, this response to an innate sense of justice and compassion has been sublegal, covert, and rarely spoken of. Whiting says:

> In political reality, the United States has few options when it comes to the legal status of the "right to die," since euthanasia has been both secretly and openly practiced in the United States for at least the last twenty years, and there is no reason to believe that this state of affairs will change. The reality of this debate is that the frequency of the acts of euthanasia will only continue to increase, whether government recognizes such a right or not…the 'right to die' question is not simply a question of law, majority or moral will, but rather a cultural question that involves some of the fundamental theories of the Western world…[The] controversy is related to basic questions about the proper role of society, as well as the proper position of the individual within society.[36]

Though the Greeks, particularly the Stoics, set the stage for the concept of rights, it was the Romans who furthered the concept and provided further development of Natural Law which they began to call "universal law" as they governed their diverse tribes of conquered peoples.

Section 2.2 Natural Law, the Romans, and Early Christians

After the Greeks spent decades debating Natural Law, the Romans used Natural Law or "Universal Law" as they began to call it to govern the numerous territories and diverse peoples they had conquered. Roman law had to bind these various tribes together to form a single functioning empire. The Romans were known to select the best concepts of their conquered peoples to perfect their own system of laws—even throwing out some of their own laws when they came across better ones among their newest Roman citizens:

> …the doctrine of Natural Law has served as a criterion for the evolution of international law, and Natural Law theory has served as a yardstick against which the positive enactments of man could be measured…[It] has been one of the mediating theories for many of the significant historic events that have shaped Western Civilization.[37]

Whiting describes the Roman contributions as being in the areas of International Law and in establishing an overarching structure that could govern Roman citizens. In the hands of the

[36] Whiting, p. 1

[37] Ibid., p. 52 (Whiting quoting from Ernan McMullin's paper given at the 1978 AAAS Selected Symposium 18, Boulder, Colorado: Westview Press, 1978)

Romans, the use of law was transformed from a collection of disconnected local legal codes into a unified legal system capable of handling the growing complexities of both social and commercial life. The concept of the semi-autonomous individual who was equal to other citizens was one of the most important contributions of mixing the Stoic philosophy with Roman law.[38] Geifferet Samule outlines three historical stages in the evolution of legal rights:

> The first stage of legal rights has to do almost entirely with physical property, which was what determines an individual's sovereignty within society…The second historical stage, the inductive, was concerned with moving away from subject to property and toward the relationship between subject and subject. The third, or deductive historical stage…culminates in such claims as 'I have a right to vote' or 'I have a right to free speech.' [39]

The Romans, according to both Whiting and Susan Ford Wiltshire in her book, *Greece, Rome, and the Bill of Rights*, were instrumental in bringing about the first two stages of legal rights development but could not be said to have achieved the third historical stage. Beyond their initial conception of rights, the Roman contribution was to produce laws that had intrinsic value and should be obeyed because they produced "that which is just and good for all."[40] The Romans acknowledged that positive law often reflected its roots in prejudice and self-interest. There were many situations involving human beings that required laws that were fairer and more just. So the Romans used Natural Law and human reason to guide them in making laws about moral practices which *ought* to exist.[41] At this point, the implications for the legal basis of the Right to Die should be apparent.

As the power of the Roman Empire waned and eventually collapsed, a power vacuum was created.[42] The Church stepped into this void and used Natural Law to justify its authority and power. Natural Law and Positive Law were the basis for the ideas of a *Divine Law* and a *Civil*

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[38] Whiting, p. 78

[39] Wiltshire, Susan Ford. *Greece, Rome, and the Bill of Rights*. Vol. 1st ed, University of Oklahoma Press, 1992. p. 28

[40] Whiting, p. 79

[41] Whiting, p. 79

[42] Ibid., p. 81

Law. This was a way to codify the relationship between God and Man. "Stoicism," says Susan Ford Wiltshire "was ready for baptism."[43]

> In essence, the Church took the Greek and Roman philosophies of Natural Law and Christianized them…the body of citizens, *corpus civium*, was transformed into the body of Christ, *corpus Christi*…Neither historical situation permitted a notion of individuality apart from the group…[44]

Wiltshire says, "Both Greek philosophy and Roman law were pressed into the service of the Church in the Medieval period." One consequence was that individual rights and autonomy would be overshadowed by the authority of the church. Just as Roman citizens were emerging from the authority of the polis and the Roman Empire, the Catholic Church would present itself as the chief authority of the Roman Empire. It was the Church that would decide what constituted Divine Law and what laws and areas of human life would be left to civil authorities.

The Apostle Paul, a Jew and a Roman citizen himself, incorporated the Roman sense of the rule of law into early Christianity. Both the Jews and the Romans had ruled by law, so he was quite conversant with this method of structuring and governing a community. As people were converted to Christianity, Paul told them they were *new creatures* in Christ, a part of the *body of Christ*—under *a new order*—and *no longer belonging* to whatever community they came from.[45]

> The organic theory of society—articulated by Aristotle, made concrete in the system of Roman law, and appropriated at the beginning of the Christian era by the apostle Paul—provided a strong foundation for a Church Universal. What it did not permit was a theory of the autonomous rights of individuals…"[46]

As the Church's power came under attack, Thomas Aquinas (1224 -1274 CE) redefined Natural Law by "bringing it back into line with the teachings of Aristotle."[47] This meant that the Church recognized once again, as Aristotle had, that the authority of the state was necessary for mankind to achieve its full development. This meant the state was elevated to the top of the

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[43] Wiltshire, Susan Ford. *Greece, Rome, and the Bill of Rights*. Vol. 1st ed, University of Oklahoma Press, 1992. p. 32

[44] Ibid.,p. 30

[45] Wiltshire, p. 42

[46] Ibid., p. 41

[47] Whiting, p. 82

authoritative hierarchy. The Church began using the concept of Natural Law as a sort of "catchall category used to justify whatever principle the church deemed appropriate at any given time."[48] Despite the highest authority being the state, the Church believed that there were four kinds of laws: eternal, divine, natural, and positive. The eternal, divine, and natural laws made and enforced by the Church were equal to the positive laws made and enforced by the State. Further, Aquinas held that if a law made by civil authorities (positive law) was inconsistent with Natural Law, that "we may have a duty to disobey it."[49] In this idea of a law that may be disobeyed in favor of a higher law, we remember Antigone's defiance of King Creon's royal decree not to bury her rebel brother. She believed she had a duty to disobey his command because she was, in her mind, obeying the law of the gods—unwritten, unshakeable traditions.

Antigone was exercising her sense of Individual Rights which come from Natural Law.

It would take another five centuries to develop Natural Rights theory with the added essential understanding of a human being as an autonomous individual. As this more developed theory of Natural Rights finally coalesced in the late 18th century, "the individual emerged from the protective

shell of society as an autonomous political being."[50] The theories of Natural Law and Natural Rights together were further developed by John Locke. "It fell to John Locke to transform the theory of natural law into a theory of rights that would serve as a justification for revolution and shape the political arrangements of a continent."[51] This was a major departure from the way the Church saw human reason:

> While natural law theory of the medieval period recognized the individual, rationality was not considered to be inherent in the human animal, but was a gift from God; the test of man's rationality was not common understanding, but conformity with the Church's interpretation of divine law. The eighteenth century conception of individual rationality, freed from the constraints of community or church, departs radically from both of these conceptions…rationality was now

[48] Ibid.

[49] Ibid, p.83

[50] Whiting, p. 89

[51] Ibid., p. 109

considered to be a self-evident part of human nature.[52]

As we follow this development of individual rights and the value of the individual in relation to the Church and the State, we can appreciate what a vast leap it was for Thomas Jefferson to use these principles in creating the founding documents of the United States of America. We can see Natural Law at work in Thomas Jefferson's writings which still inspire us in 2019 and serve as the very basis of the American experiment. The American sense of individual rights and liberties had to evolve out of and overcome several different eras in which the individual existed to serve the polis, the Empire, the State, and then the Church. The Enlightenment prepared Thomas Jefferson to see a way forward and beyond what had gone before. In his writings, we can hear echoes of Sophocles, Cicero, Seneca, Aquinas, and John Locke. Jefferson used Natural Law and Natural Rights theory as the binding principle upon which to base the Declaration of Independence.[53]

> Locke's understanding of natural rights…would find its way into the second paragraph of the Declaration of Independence, 'We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain inalienable rights, that among these are Life, Liberty, and the pursuit of Happiness.'[54]

Although Natural Law has fallen out of favor since the 17th and 18th centuries, what is not disputed is that it is sometimes called upon when positive law made by man falls short of achieving a full sense of justice. Natural Law is a sense of what *ought* to be in order to achieve justice while man-made law is what the law actually *is* that is attempting to bring about justice.[55] While those in the modern legal profession would be embarrassed to call upon Zeus and Jupiter or even the Judeo-Christian god to determine a path to justice, they sometimes use the words "the unwritten law" or "universal law" or "fundamental law" to refer to Natural Law.[56]

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[52] Ibid, p. 89

[53] Ibid., p. 109

[54] Whiting., p. 89

[55] Ibid., p. 78

[56] Whiting, Chapter 6 note on p. 198

Had the decisions of both the ninth and second Circuit Courts (discussed in Section 1.7) of Appeal prevailed in the United States Supreme Court, the Right to Die would have been declared a constitutional right for every American, and it would be a federal law in 2019. Instead, the Supreme Court of the United States ruled that aid in dying was *permissible* according to the constitution but not a constitutional *right*. We can see from the preceding section that this position is highly debatable—the SCOTUS justices upheld this ruling on a five to four vote—and thus it could be reversed in the future as Americans continue to debate about whether the Right to Die is a private and autonomous action which may or may not be a civil right based on liberty, privacy, autonomy, and self-ownership.

The fact that physicians are not bound by the patient's request for aid in dying means that patients who are dying do not have the *right* to die with a physician's assistance. Pharmacists who do not agree with medical aid in dying are also not required to provide the lethal medicine. Since no doctor or pharmacist has a duty to assist the dying patient who wishes to hasten their own death, there is at present no *Right* to Die. In the states where aid in dying is legal, the most that can be said is that the law permits the dying to hasten their deaths if a willing physician and pharmacist can be found to prescribe and then provide the lethal medication. One way around this, in states where aid in dying is legal, is to appoint people other than physicians and pharmacists to assess patients and then provide the lethal medication to patients who meet the criteria. These people would already be supporters of medical aid in dying and the laws that regulate it. As such, these practitioners can be depended on to perform a *duty* to terminally ill patients who wish to hasten their deaths.

Section 2.3 Suicide According to Christianity, the Bible, Augustine, and Aquinas

Now that this thesis has put forth a legal basis for the Right to Die, this study examines the origins of the *objections* to the Right to Die. The general public may assume that, since the Right to Die involves the ending of one's own life, that this is suicide. Since it is suicide, the argument goes, both the Old and the New Testament prohibit it. This is not true. The following section gives a

more accurate account of how the act of self-killing *became* a prohibition of the Christian fathers over time—and as the needs of the Church changed.

Some writers refer to the death of Jesus Christ as a *suicide*. Since Christ was believed to be God's son as well as an earthly incarnation of the one God, it is reasoned, Christ's death was voluntary since he could most certainly have prevented his own death. Others call Christ's death on the cross a *martyrdom.* Others call it a Roman *capital punishment*—the kind that was commonly meted out to insurrectionists. Origen agreed with the writers who said that "…Jesus killed himself." [57]

> Christianity's founding event was a suicide, and the writing of Jesus' disciples glorified voluntary self-sacrifice. The example of Jesus Christ was followed by many willing martyrs, to the point that the Church fathers became concerned and debated the question of suicide for three centuries.[58]

In the first century, the Christian view of suicide was not much different from the Romans' view. Suicide was acceptable except in the cases of criminals, slaves, and soldiers.[59] "Early Christian writing contained no indication that taking one's own life was considered a sinful act, and early Christians responded pastorally rather than condemningly, to issues of self-killing."[60]

Naturally, Christians honored their early martyrs because those who voluntarily suffered often gruesome deaths rather than recanting their illegal faith were virtuous pioneers and were emulating the actions of Jesus Christ. Without these martyrs, it is doubtful that Christianity would have survived the hostile Roman Empire. In fact, martyrdom and suicide (to *avoid* being killed by

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[57] Minois,Georges. History of Suicide; Voluntary Death in Western Culture. Medicine & Culture. Baltirmore, Md; London: Johns Hopkis University Press, 1999. P. 24

[58] Ibid., 26

[59] Perlin, Seymour. *A Handbook for the Study of Suicide*. New York: Oxford University Press, 1975., p. 11

[60] Whiting, Raymond. *A Natural Right to Die: Twenty-three Centuries of Debate*. Contributions in Legal Studies, No. 101. Westport, Conn. ; London: Greenwood Press, 2002, p. 102

the Roman state) had become such a craving that it bordered on a mania.[61] Ignatius of Antioch sounds euphoric as he considered his death. He wrote this to the Christian community at Rome:

> I beseech you…suffer me to be eaten by the beasts that I may be found pure bread of Christ. Rather entice the wild beasts that they may become my tomb, and leave no trace of my body, then when I fall asleep I be not burdensome to any. Then shall I be truly a disciple of Jesus Christ, when the world shall not even see my body. Beseech Christ on my behalf that I may be found a sacrifice through these instruments.[62]

The debate over whether martyrdom is suicide will not be taken up in this thesis. This study will simply note that the definition of a martyr depends entirely on point of view. For example, a Muslim who kills a crowd of people using a vest laced with explosives is a "terrorist" to non-Muslims. This same person is called a "martyr" by the tiny minority of Muslims who support suicide bombing as a form of jihad against their enemies.

It was Augustine of Hippo who lived from 354 AD to 430 AD as the Roman Empire became Christianized who changed the lax attitude in the Christian community toward suicide:

> Augustine maintained the absolute sinfulness of every voluntary act of self-killing by analogy to the act of murder. He argued that taking one's own life was self-murder, bringing the concept closer to what we today characterize as suicide. Augustine also made the first appeal to Biblical writings in an effort to lay a foundation for the disapproval of all forms of self-killing.[63]

There are five instances of suicide (as we think of it in 2019) in the Old Testament and only one in the New Testament. In the Old Testament, also holy scripture to the Jews, the suicide of Saul, first king of Israel, occurred during a battle against the Philistines. Saul killed himself rather than fall into the hands of his enemy. The other suicides were Ahitophel who hanged himself and Zimri who burned himself to death in a fire he set to kill his enemies. The militaries of both these men had lost in battles. Samson died as he destroyed a temple, killing three thousand Philistines who had been standing on its roof. In the New Testament, the only mention of a

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[61] Perlin, Seymour. *A Handbook for the Study of Suicide*. New York: Oxford University Press, 1975. p. 9

[62] Ibid.

[63] Whiting, p. 103

suicide was when Judas hung himself after betraying Christ to the Romans. It was a simple accounting, not a judgment.[64]

Augustine (4th to 5th century) and Aquinas (13th century) pointed to the sixth commandment, “Thou shalt not kill” as being an absolute prohibition against suicide. However, the Hebrew word for “kill” in this commandment actually translates to “murder” so to say that murder includes suicide is a very loose interpretation.[65] To this day, the commandment “Thou shalt not kill” has been used by both Jews and Christians in their arguments against suicide and against medical aid in dying. This prohibition is still strongly held among believers of many faiths—including Islam.

Section 2.4 Individual or “Legal” Rights vs. Human Rights

This thesis distinguishes between the terms “Individual (Legal) Rights” and “Human Rights.” The term *Human Rights* was popularized after World War II and came about with the introduction of the *Universal Declaration of Human Rights* (See Appendix E). There were other documents promoting human rights that had gone before:

> Documents asserting individual rights, such as the Magna Carta (1215), the Petition of Right (1628), the US Constitution (1787), the French Declaration of the Rights of Man and of the Citizen (1789), and the US Bill of Rights (1791) are the written precursors to many of today’s human rights documents.[66]

The *Universal Declaration of Human Rights* is a document created by the United Nations’ Human Rights Commission and published on December 10, 1948. The chairperson of this Commission was Eleanor Roosevelt, widow of President Franklin Delano Roosevelt. This document enumerates thirty rights that all humans all over the world possess simply because they are alive. (see Appendix E) Here is part of the preamble which states the reason for the document and its intention to bring about peace in the world:

> *Whereas* recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

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[64] Perlin., p. 4

[65] https://www.jewishvirtuallibrary.org/the-ten-commandments

[66] https://www.humanrights.com/what-are-human-rights/brief-history/

> *Whereas* disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind, and the advent of a world in which human beings shall enjoy freedom of speech and belief and freedom from fear and want has been proclaimed as the highest aspiration of the common people.[67]

While this document has no legal force, it is up to humans everywhere to work toward achieving this ideal in the countries where they live. By having these universal rights written down and available, it allows human beings everywhere to know what they should expect in regard to equality, fairness, justice, and life itself. It also implies that governments and social institutions have a duty to provide these safeguards and protect the rights of their people.

In the language of the *Universal Declaration of Human Rights*, the concepts of Natural Law and Individual Rights can be heard. This document is often called the "universal Magna Carta for all mankind."[68]

Section 2.5 Some Conservative Jewish Views on the Right to Die

This section of the study relies on a very thorough and illuminating lecture by David Novak, a Canadian, who was a rabbi for 23 years and is now a full-time professor at the University of Toronto. By presenting his lecture as he gave it, we can observe a conservative Rabbi engaging in a method of Jewish reasoning about moral issues. He later takes questions from his audience which shows the diversity of thinking in the Jewish community.

Novak began his lecture with an example of a dilemma that Canadian doctors have been facing since their Canadian C-14 Medical Assistance in Dying law went into effect. This new law was passed in June of 2016. Novak gave this lecture about six months after the law was enacted. The law includes the requirement that, if a doctor, due to his own moral reasoning, cannot directly prescribe lethal medication for a terminally ill patient who wishes to hasten their own death, the doctor must refer the patient to someone who will provide lethal medication.

Novak was asked by a psychiatrist in his Canadian Jewish community to file an affidavit in conjunction with a challenge to this law which was being filed by the Christian Medical and

[67] https://www.humanrights.com/what-are-human-rights/brief-history/

[68] Ibid.

Dental Society. He said this situation represented two questions for Jews to answer: The first was, “Is it acceptable to make common cause with Christians on a matter upon which they agree?” The second question was, “What is your position on whether terminally ill patients have a Right to Die?”

In answer to the first question, Novak said there is fundamentally no difference between Jewish and Christian morality. He says Maimonides (1135/8-1204 CE) was asked if Christians could be taught the Torah. The great rabbi who was also a physician and a philosopher said, “Christians—yes, Muslims—no.” The reason is that Christians accept the Torah as the word of God whereas Muslims do not. On certain theological views—like the identity of the Messiah—Christians are mistaken (laughter from the audience) but not on the major teachings such as the Ten Commandments. Thomas Aquinas—who was very much influenced by Maimonides—agreed with this view. The view of both faiths is that the human being is created by God and therefore human life has a sanctity and an inviolability. The ethics regarding the sanctity of life are the same: “One is not allowed to kill innocent human life. Just as you don’t possess anyone else’s life, you don’t possess your own.” Novak tells the story of a rabbi who was about to be burned to death by the Romans. The rabbi was urged by his supporters to hasten his fiery death by opening his mouth. He replied, “Better that life should be taken by the one who gave it.” Novak says the sanctity of life is a “universal” teaching. This idea resonates in the Christian tradition—that human life is sacred and we may not destroy it except in self-defense. (Note: Jews also believe in the death penalty in certain cases.) A human being does not have the right to destroy himself. The God who gave life is the only one who can take it.

Novak said wistfully, “This flies in the face of much of secular thinking.” The idea of self-possession permeates our society. “But Jewish law says *if I do not have the right to destroy life myself, I may not authorize someone else to destroy it.*” Therefore, Jewish doctors should not be required to refer their dying patients to a physician who is willing to write a prescription so that his dying patient can hasten their own death. The principle is that “I cannot transfer a right that I do not have.” Further, if I have a right, it means others have a duty to *respect my right.* If I have a right not to be killed, everyone else must not impede my right to life. In Jewish law, not only do

others have a right *not to impede* you living your life, but others must *assist* you in living your life. Jews in Canada, through Novak's court affidavit, were asking not to be employed to assist someone else to do what they themselves had no right to do. The Jewish tradition indicates that a Jew is not to actively assist someone to do something the Jewish doctors considered to be wrong or which they themselves had no right to do.

David Novak wrote his dissertation on suicide. He says that two hundred years ago, the Jewish tradition clearly decided that a person who takes his own life is mentally ill. This means people who commit suicide should be treated like any other ill person and given a burial like anyone else. Novak suggests that it be a burial only rather than a service which includes a eulogy.

Then Novak bemoaned the current view of autonomy in modern society—the idea that *I am in charge of my own life—I am the master of my own fate*. He says, in some circumstances, we are right to exercise our autonomy. Jews regard voting as a sacred duty because it represents autonomy as well as our American rights. But the idea that autonomy means we can choose when and how to die is not acceptable in Jewish tradition.

Novak believes people live and survive and flourish when they are convinced that someone out there cares about them. Our desire to live is because there is someone out there who wants us to live. When we sense that no one out there wants us to live, the message is that the we have become useless, a burden to others.

This is the subliminal message that comes through the idea of autonomy—that you should exercise your autonomy and not be a burden to others. When society says someone has a *Right to Die*—it may eventually become something one *must* do. This is frightening—and something to worry about. The insurance companies would love this—they would like to be able to say, "We will cut off the insurance when the insured reaches a certain point in the process of dying." Moses said, "You should choose life—that you and your children should live." Our society has lost contact with traditions. The message that society sends is that you have a duty to remove yourself by dying when you have become a burden. "No one wants to be a burden on their children. But why not? They were a burden on us!" (laughter from the audience) Jews regard

every human life as something that is precious and something we don't want to let go of. The Right to Die is a question for which Judaism does make a tremendous difference.

Question from the audience: "What is the Jewish position on refusing surgery or medical treatment?

David Novak's answer: "There is only *a* Jewish position and not *the* Jewish position. Everyone who is religious has a different position. Jews don't march in lock step. Novak recalled an 82-year-old woman who was told she needed a pacemaker. If she didn't have it, her life chances would be considerably diminished. She wouldn't die right away, but her life could be shortened. This woman was a Holocaust survivor. She refused to have the pacemaker surgically implanted because she had been experimented on by Josef Mengele and said, "Nobody is ever going to tie me down on a surgical table and cut me open again."

Rabbi Abraham Steinburg of Jerusalem said the Jewish tradition in response to this woman's decision not to have the surgery is to prevent a person from an imminent death—and to do everything in our power to save a life. "Do not stand idly by the blood of your neighbor." Novak's argument was that the woman did not want to die, but the psychological trauma of being cut open by Josef Mengele in the camps had been so damaging to her, she had the right to refuse surgery. After all, the trauma of the surgery because of her experience in the camps could kill her. Novak said she did not have the right to kill herself, but she had the right to refuse surgery because the trauma from her past experience was so great. He used the Jewish tradition, "The heart knows its own pain."

Novak says, according to Halakhah, if you ask a rabbi for his opinion about something, you are morally obligated to follow it. But if you know a little something, you can ask the Rabbi to *consult* with you on an issue rather than to give his opinion. Then you factor in his advice with what you know from other sources and make your own decision. This is how Jewish moral reasoning is conducted. Issues are decided in the concrete, not in the abstract. You must know all the facts before you make a decision based on Jewish tradition.

Question from the audience (second half of a question): "If Judaism is going to be vibrant, it must be relevant to the times".

David Novak: "No! No! It must *not* be influenced by the times—it is God's law. The questioner brings up Brittany Maynard who faced the last few months of her life with brain cancer and who wanted to choose the time and circumstances of her inevitable death. The questioner stated that he didn't see how this was so very different from allowing a person to refrain from surgery or experiencing the "double effect" which results in death.

David Novak: "The *intention* is the thing—the difference between murder and manslaughter is all about intention." A lot of how we face life and the end of life very much depends on what you think will happen after your life is over. If you believe you will be asked by God, "How did you deal with your world and yourself?," you will be concerned with your choices at the end of your life. If you think you are facing oblivion—a good death would be to die in your sleep. But if you believe that you will face God after your life is over, you will want to be awake and aware so you can make your last confession and then say, "I return my life to God."

"If everything is permitted, there is no morality at all." I say the woman who refused surgery because of her experience in the Holocaust had "freedom of choice" rather than "autonomy." When someone asks you "What do you think I should do?" you must offer your opinion. Our moral decisions are not frequently comfortable. The decisions do not come for free. One of the mistakes of more liberal Jews and other religions is that they say, "Do what you think is right." I think people are comforted by the religious laws that do not change because they are God-given. Of course, *interpretations* change, but the *laws and traditions do not*. The choice is ultimately one's own. People can choose to follow the rabbi's or physician's advice or not. But ultimately, a decision must be made by some criteria. Otherwise, it is a leap into the void. The more you know, the more choices you know you have.

Novak ends his lecture by saying that he believes suicide is the easiest thing in the world to commit. But he says people are actually very morally conflicted about physician-assisted suicide—otherwise, why do they need physicians to be involved? Physicians are authority figures in our society. Their opinions matter. When our laws include doctors in this end-of-life choice, it indicates people are actually unsure about the morality of aid in dying. These people need the stamp of authority on the act in order to go through with it. Novak recalls a typical objection from a

doctor friend who said, “I as a physician was not trained to kill people.” Novak says it is difficult to get nurses to work in abortion clinics because they see the body parts. Physicians are perceived to have a God-like authority so their involvement in the suicide of dying patients makes it easier to accept.[69]

This study includes a number of voices on the Right to Die. The lecture given by David Novak above allows us to peer into a process by which an ethical decision is reached in the Jewish faith. Novak shows us that conservative Jews take into consideration a great many factors when arriving at a complex moral decision. With regard to aid in dying, Jews must consider with whom they can join forces—whether Christians can be trusted to collaborate in reaching a moral decision when so much of Christian history shows they have been a stumbling block for Jews or that they have discounted Jewish beliefs as they try to convert them to Christianity. Novak assures his Jewish listeners that, when a Christian follows the Torah as the word of God, it is acceptable to join in their struggles on ethical issues.

Further, Jewish laws and traditions are consulted for guidance in making ethical decisions. Asking a rabbi for his advice obligates the questioner to follow the rabbi’s decision on what a Jew should do. But if the questioner knows a little something from other sources, he or she may ask the rabbi for a consultation with the idea that the rabbi’s views will be added into the mix of opinions and interpretations that the questioner has gathered. Then it is up to the questioner to make their own decision on which path to follow.

The most important statement in Novak’s lecture in terms of this study is that conservative Judaism should not follow modern ideas but should stick with halakhah and Jewish tradition in reaching a decision. The predominant Conservative Jewish view is that, since Jewish law was given by God himself, no modern conception or situation can override that original commandment or view. This is the conservative view in general terms—that Jews must conserve the original teachings from several thousand years ago or they are not faithful Jews. Novak says

[69] https://www.valleybeitmidrash.org/learning-library/is-there-a-right-to-die-physician-assisted-suicide-in jewish-thought/

that not following tradition and law is a “leap into the void” and that all things become permissible when there is no spiritual guidance from Jewish law and tradition.

In the next section, this study looks at several views of Reform rabbis on the subject of the Right to Die. Here, we see that Reform Jews do not base their decisions only on Jewish laws and traditions but understand halakhah as a system of *values* from which Jews can devise their own answers. When looking at the views of several Reform rabbis, it is clear that, as the saying goes, in a room with 9 rabbis, there will be 10 answers. These varying views will be touched upon in the next section.

Section 2.6 Some Reform Jewish Views on the Right to Die

As Rabbi Novak stated, there is no one Jewish view on any subject—in either the Conservative or Reform traditions. Although many in Reform Judaism may agree with Novak that Jews should have nothing to do with the Right to Die, many have come to accept medical aid in dying as a compassionate way to end the suffering of a dying person.

Here is a statement by Rabbi Cohen from North Carolina on medical aid in dying:

> Patients like my congregant need to be made comfortable through their final days. Yet for some, even treatment at the most supportive hospice or palliative care unit does not alleviate their physical and psychological pain. In these dire circumstances, it is not right to force a human being to suffer against his/her will. We should instead honor one of the hallmarks of Reform Jewish thinking—individual autonomy—and grant a patient the right to end their own life.[70]

In Rabbi Cohen’s thinking, his acceptance of the Right to Die is based on the Jewish values of not allowing a neighbor or loved one to suffer, autonomy, and a desire not to coerce.

Here is a 1994 Responsa about medical aid in dying from the Responsa Committee of the Central Conference of American Rabbis:

> Our 1994 teshuvah begins with a consideration of euthanasia and assisted suicide (often referred to as “physician-assisted suicide”) as responses to terminal illness. *We reject both of those courses of action on Jewish as well as general moral grounds: to hasten the death of a person, even of a dying person and even out of compassionate motivations, is tantamount to bloodshed.* While Jewish tradition permits us, indeed requires us to administer palliative care and pain control therapy to manage and to relieve the discomfort that the patient suffers, it does not regard euthanasia or suicide as legitimate functions of medical practice. On the other hand, Jewish tradition has long distinguished

[70] https://reformjudaismmag.org/past-issues/summer2013/debatable-suicide Statement by: Rabbi Phil Cohen, rabbi of the Aguda Israel Congregation in Hendersonville, North Carolina

> between "hastening death" (which is forbidden) and "removing an impediment to death" (which is permitted).[71] (italics emphasis added)

Despite the fact that the Right to Die is objected to by many Reform Jews in their Responsa writings, some Reform Jews find values in their religion that support medical aid in dying.

In response to the comment from Rabbi Cohen above, Reform Rabbi Barry Block from Little Rock, Arkansas took strong issue with Cohen's acceptance of aid in dying. His comment began with the capitalized, word in bold, "**NO.**" He said the alternative to assisted suicide is "hard work."

> If we do not hasten death, we also have more time to explore each patient's individual emotional and spiritual needs. We can ask, "Do you feel right with the people in your life, and with God?" We can discuss Judaism's rich teachings about everlasting life, which can be as comforting as any palliative care. And when we pray together with the person who is dying and his/her loved ones, we can help our fellow human beings face eternity with faith and hope.[72]

From this exchange between two Reform Jewish rabbis, we see the process of Jewish moral reasoning in the Reform tradition. Reaching a viewpoint involves a process of sharing competing interpretations of Jewish tradition and Halakhah and hearing the alternative views offered by others. In this case, Rabbi Block further clarifies the kind of "hard work" involved in caring for those who are dying. He brings in the additional "hard work" of the Jewish congregation as they stand as witnesses and act as advocates for their dying community member:

> The meaningful alternative to euthanasia is hard work. Rabbis and caring congregants can offer their constant, supportive presence to those facing life-threatening illnesses. We can be knowledgeable about euthanasia alternatives. When we perceive suffering, we can suggest questions and concerns that families may pose to doctors. We may even advocate—with families and sometimes even directly with medical personnel—for transition to hospice care, increased pain medication, or psychiatric referral.[73]

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[71] https://www.ccarnet.org/ccar-responsa/nyp-no-5768-1/

[72] Ibid. Rabbi Barry Block

[73] https://reformjudaismmag.org/past-issues/summer2013/debatable-suicide (Rabbi Barry Block's comment)

In the end, the Reform Jew honors Jewish values found in the halakhah as well as their own experience, reason, and moral intelligence in order to reach a point of view.

Section 2.7 The Catholic View of the Right to Die

In 2014, according to the Pew Research Center Religious Landscape Study, there were 51 million adult Catholics (70,412,021 in total) and 17,000 Catholic parishes in the United States. This means about 21% of Americans identify as Catholic—a decrease from 24% in 2007.[74]

In 2015, Pope Francis delivered written remarks in anticipation of the 2015 World Day of the Sick. Here are some excerpts from and commentary about his remarks which show the reasoning and theology behind the official Catholic position on the Right to Die:

> This is the same evil tactic used to undermine all pro-life campaigns. We stop talking about a child's right to life, and start talking about "a woman's right to choose." To choose what exactly? The life and death of a child.
>
> The value of a human life is inherent, bestowed by The Creator, God, who has breathed life into us as he did into Adam and who has given us an allotment of days to praise Him and to do His will. This fact alone makes life too precious to cast aside. This is why murder in all its forms, be it abortion, war, or euthanasia, is morally repugnant.
> The value of a human life is not dependent on the individual's productivity nor the comfort or discomfort they face. Even the least productive person was formed by God and is loved by God. We have no right to discount God's creation.
>
> Likewise, suffering has no capacity to devalue life. Many saints of the Church suffered terribly, sometimes for years, before their death, yet they all understood that each day was a gift from God and they had a duty to fulfil, even if it was nothing more than prayer from their sickbed.
>
> We have no right to judge the value of that which God has created, for God's creations all have inestimable values which we, as men, cannot possibly measure. Let us stop discounting the value of all human life and let us start appreciating that which God has created and which is beautiful and beloved by Him.[75]

In these remarks, we hear echoes of Rabbi Novak's reasoning against medical aid in dying in Section 2.4 on Judaism. We recall that Novak, with support from Maimonides of the 13th century, believed that Jewish and Christian ethics are the same since they are taken from the

[74] https://www.pewresearch.org/fact-tank/2018/10/10/7-facts-about-american-catholics/

[75] https://www.catholic.org/news/hf/faith/story.php?id=58225

Torah which both faiths believe is the word of God. In both faiths, we are told that since human beings did not create life, no one may take their own or another's life. It is not theirs to take.

Although it may be comforting for a sick Catholic to hear that "The value of a human life is not dependent on the individual's productivity nor the comfort or discomfort they face," and that God values and loves them no matter how much suffering they are enduring, we can imagine how a non-Catholic or a non-believer would react to this statement. For those who do not pray, it is little comfort to be told by a Catholic pope that "if all they can do is pray from their beds," that should be reason enough to stay alive. [76]

The National Right to Life Committee, founded in 1968 and originally funded by the Catholic Church, is very active in opposing the Right to Die all over the nation. This is a statement from their website:

> National Right to Life, its fifty state affiliates, and more than 3,000 local chapters, are single-issue organizations existing to protect innocent human life from abortion, infanticide, assisted suicide, and euthanasia. In the Declaration of Independence, the Founding Fathers observed that we are endowed "with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness."[77]

Although the Catholics' single focus is on protecting all life in all circumstances, they are less keen on protecting the Liberty and the Pursuit of Happiness clauses of the Declaration of Independence. Also, they seek to deny other Americans their own opportunity to die as they wish by opposing legislation that would allow medical aid in dying.

When the Right to Life organization mounted an aggressive opposition campaign in Oregon—the least churched state in the United States—it backfired because it was clear to Oregonians that the organization was determined to undermine every citizen's autonomy and Right to Privacy in order to promote a Catholic value:

> Between the passing of the [Death with Dignity] Act and its eventual implementation in 1997, a rivalry between socially liberal groups and conservative religious organizations developed [in Oregon]. Politically liberal organizations that supported the Act drew on public hostility against the Catholic

[76] Ibid.

[77] https://www.nrlc.org/medethics/advancecareplanning/

> Church and depicted PAS as both a right that respected individual autonomy and as a more dignified way of facing death.[78]

During Oregon's 1997 campaign to repeal the 1994 Oregon Death with Dignity Act, the Catholics steered away from religious and moral arguments and focused on creating fears that aid-in-dying techniques did not always work and that medical diagnoses are sometimes wrong:

> Moreover, since Oregon had only a small percentage of Catholics in the state, most Oregon voters saw the Catholic Church's involvement against Measure 16 as an attempt by organized religion to impose its views on the public. Campaign television ads commonly attacked the Catholic Church's active role in politics. One such ad, "Faces," showed a series of adult faces while a voice told listeners: "I don't need any church playing politics with my choices, with my life" and "Measure 16 . . . ends . . . religious interference in a part of our lives that is strictly personal". Other radio ads supported by the Oregon Right to Die argued that groups campaigning against PAS felt a "divine right" to interfere with other people's lives and choices.[79]

Whereas the original citizen's initiative in 1994 passed by a very narrow margin of 51%, the second vote on Oregon's Death with Dignity Act passed by 60%. Many Oregonians believe this was a reaction to the Catholic Church's interference in politics and the resentment of the public toward legislators who allowed the Catholic Church and other opponents of the DwDA to put the measure back on the ballot three years after the citizens of Oregon had passed it.

The Catholic Church continues to oppose all attempts to end life. And it is important to understand how truly pervasive the papal prohibition against the Right to Die truly is. One out of every six patients are seen in Catholic hospitals. This restricts access to contraception, abortion, and medical aid in dying even in states where all those practices are legal:

> According to the United States Conference of Catholic Bishops (USCCB) website, there are 629 Catholic hospitals in the country, serving one out of every six patients: that's nineteen million emergency room visits and more than one hundred million outpatient visits each year. Catholic hospitals operate, like all hospitals, according to standard medical procedure, *except when that procedure falls outside the Ethical and Religious Directives for Catholic Health Care Services (ERDs), seventy-two guidelines that are approved by the USCCB.*[80]

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[78] https://www.deathwithdignity.org/news/2016/03/catholic-church-influence/

[79] Ibid.

[80] https://www.deathwithdignity.org/news/2016/03/catholic-church-influence/

This strong, seemingly unequivocal position seems contradictory to the Catholic acceptance of the "Double Effect" or "Palliative Sedation" which allows a doctor to provide pain management to a Catholic patient to the point that it hastens death as long as the physician does not *intend* to cause death:

> Catholic leaders have long been supportive of pain-management measures, up to and including high doses of morphine that slow a patient's respiration to the point of death, said Courtney Campbell, a professor of religion and culture at Oregon State University, and an expert on faith and end-of-life issues. The Catholic position on physician-assisted death contradicts its support of such pain management, known as palliative sedation, he said, "*If the religious tradition had towed the line firmly and said that death can't be hastened under any circumstances, it wouldn't have allowed palliative sedation death to occur,*" he said. [81] (emphasis added)

When asked about this seeming contradiction between the acceptance of the practice of the Double Effect and the Catholic Church's opposition to the Right to Die, Dierdre McQuade, spokeswoman for the US Conference of Catholic Bishops, said:

> The Catholic Church hasn't shifted its policies regarding end-of-life care…[T]he difference between palliative sedation and physician-assisted death is *intent*. Even in the case of increasing morphine doses, the intent is to manage pain; the intent of physician-assisted death is to extinguish a life, she said.
>
> God prohibits the taking of one's life under any circumstances, McQuade said; "It's evil."
>
> Suffering, even when death is imminent and the pain is excruciating, is a critical piece of life, McQuade said. If someone tries to bypass suffering by taking a lethal drug, that person is losing out on the chance to experience the redemption that suffering brings, she said.[82]

The National Right to Life Committee suggests that one reason the Right to Die is being advocated is because it will save costs in the Affordable Care Act. They oppose the ACA because of this. Catholics express similar concerns should any single payer health insurance system be proposed and implemented in the United States.

When the current director of *Compassion and Choices*, Kim Callinan, was asked about whether the ACA or a single payer system in the United States would be supportive of the Right

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[81] http://religiondispatches.org/death-with-dignity-combatting-religious-opposition-to-physician-assisted-suicide/

[82] http://religiondispatches.org/death-with-dignity-combatting-religious-opposition-to-physician-assisted-suicide/

to Die since it would save costs as the Right to Life Committee suggested on its website, she emailed the following reply:

> Given my experience, I don't have high hopes that the U.S. will ever move to a single payer; however, even if it did, currently, it would not help us. The assisted suicide funding restriction act (which is a federal law) makes it so that federal funds can not be used to pay for medical aid in dying. So unless that changed with a single payer, it would be worse for us. One day, I hope we can repeal the assisted suicide funding restriction act, as it makes our law inaccessible for lower income people. However, we need more political will before we can make that happen.[83]

The Catholic Church, as well as many Evangelical Protestant churches and Jewish congregations, will make it difficult in the future for those in Right to Die states to find physicians willing to prescribe the medication that will hasten death. Despite the seeming contradiction of allowing the practice of the Double Effect and Palliative Sedation, Catholics as well as many other conservative religionists will continue to oppose Right to Die legislation. The sixth commandment (the fifth commandment for Catholics) still reigns supreme in its authority despite the fact that no Biblical injunction against suicide exists and "Thou shalt not kill" may not ever have been intended by the ancients to prohibit suicide.

Section 2.8 Views of the Southern Baptists on the Right to Die

Although Catholics are the largest church in America, the Southern Baptists are the second largest. According to the Southern Baptists' official website, in 2018, there were 14,813,234 Southern Baptists and 47,456 Southern Baptist churches in the United States.[84] By way of comparison and to show how little variance exists between conservative Protestants, Jews, and Catholics, the Southern Baptists' position on the Right to Die has remained unchanged since 1992. Here is the Southern Baptist Convention's position in full:

> WHEREAS, The Bible teaches that God created all human life in His own image and declares human life to be sacred from conception until death; and
>
> WHEREAS, Southern Baptists have historically affirmed biblical teaching regarding the sanctity of human life; and
>
> WHEREAS, A growing "quality of life" ethic has led to increasing acceptance of euthanasia and assisted suicide in the United States.

[83] Email from Kim Callinan, director of *Compassion and Choices*, December 12, 2018

[84] http://www.sbc.net/BecomingSouthernBaptist/FastFacts.asp

> Therefore, Be it RESOLVED, That we the messengers to the Southern Baptist Convention, meeting in Indianapolis, Indiana, June 9-11, 1992, affirm the biblical prohibition against the taking of innocent human life by another person, or oneself, through euthanasia or assisted suicide; and
>
> Be it further RESOLVED, That in light of the fact that the end of life may be painful, we urge scientists and physicians to continue their research into more effective pain management; and
>
> Be it further RESOLVED, That we encourage hospitals, nursing care facilities, and hospices to increase their efforts to keep dying persons as comfortable as possible and call on Christians to help provide companionship and appropriate physical and spiritual ministry to persons who are dying; and
>
> Be it further RESOLVED, That we oppose efforts to designate food and water as "extraordinary treatment," and urge that nutrition and hydration continue to be viewed as compassionate and ordinary medical care and humane treatment; and
>
> Be it further RESOLVED, That we reject as appropriate any action which, of itself or by intention, causes a person's death; and
>
> Be it finally RESOLVED, That we call upon federal, state, and local governments to prosecute under the law physicians or others who practice euthanasia or assist patients to commit suicide.

The objections to aid in dying from Christian Bioethicists show a dedication to suffering and humility as paths to redemption. Overcoming the agonies of the deathbed, in their thinking, prevents a Christian from achieving a life purged of sin and error.

> As H. T. Engelhardt, Jr…notes: “The traditional Christian life has always experienced such a death as a separation from the humility and holiness of the life and death of Christ. This opposition to suicide, assisted suicide, and euthanasia is rooted in the experience of the Christian life as a life directed to humility.”[85]

Many Americans point to the fact that they would not allow their beloved pet to experience pain and suffering when the animal’s death is inevitable, but the law requires Grandma to experience death’s agonies. Gerald Kelly turns that idea on its head and says we should not liken man to a mere animal (who is not required to suffer in order to atone for past sins).

> [Medical aid in dying]…likens man to a mere animal; it makes pain the greatest evil in the world. *It ignores the fact that no one suffers save through the will of God; that through suffering a man can beautify his character, atone for his sins, take a special part in the sublime work of the Redemption, and win for himself an eternity of glory.* This does not mean, of course, that Christians deify pain and sit

[85] Cherry, Mark J. "Physician-Assisted Suicide and Voluntary Euthanasia: How Not to Die as a Christian." Christian Bioethics: Non-Ecumenical Studies in Medical Morality 24, no. 1 (2018): p.4.

> idly by while men suffer. There is also something Christlike in alleviating pain, in helping the sufferer, and in trying to conquer disease. But there is nothing either Christian or Christlike in killing the sufferer to relieve his suffering.[86] (italics emphasis added)

Christian Bioethicists are extremely disturbed at the notion that secular society is inhabited by people whose worldview is not shaped by any of the religions of the world. They consider that citizens with no religious background or beliefs are deficient in moral reasoning and so these citizens fall back on modern secular notions like "human liberty" and "autonomy" and "individual rights." These words become anathema to Christian commentators with regard to the Right to Die. They believe that these secular notions take no account that God is sovereign over all the world and everything in it—including unbelievers. By claiming "self-ownership" and "the right to privacy," Christian Bioethicists believe the secular citizen has deprived himself of the traditional worldview that he is not sovereign over his own earthly fate or his eternal fate in the hereafter.

Ironically perhaps, advocates of the Right to Die point out that these same secular concepts from Greek philosophy, Roman Law, the Enlightenment, our own Declaration of Independence, and the United States Constitution protect the rights of Christian Bioethicists to hold their own religious views despite the fact that they are at variance with the society at large. These same secular principles protect the inalienable rights of everyone—they are not given to us and they cannot be taken away from us as long as the United States and its founding documents stand. The Right to Die Movement has as one of its bedrock principles that no dying patient or no physician must ever be coerced into accepting medical aid in dying. Initiating the request for aid in dying is always in the hands of the dying person. It can never come from an external source—even from within the dying patient's own family. Further, if the patient's mind is compromised by dementia or Alzheimer's or mental illness, that patient forfeits his right to aid in dying since no one can be sure the patient understands the ramifications of their request for it.

When the Federal Ninth Circuit Court was coming to a decision about the constitutionality the State of Washington's Death with Dignity Act, it enshrined within its documents the principle

[86] Ibid., p. 5

of freedom of choice and human liberty for all. The courts made sure that those who did not support an aid in dying law never had to participate as a patient or as a doctor. However, it also noted in the court records that those citizens with religious convictions were "not free to force their views, convictions, or philosophies on other members of a democratic society." Here is the exact wording of the Federal Ninth Circuit Court as its judges were deciding whether to accept the State of Washington's own Death with Dignity Act in 1996:

> In the United States, the Federal Ninth Circuit Court argued with respect to Oregon's Death with Dignity Act that: *Those who believe strongly that death must come without physician assistance are free to follow that creed, be they doctors or patients. They are not free to force their views, their religious convictions, or their philosophies on all other members of a democratic society, and to compel those whose values differ from theirs to die painful, protracted, and agonizing deaths.* (Compassion in Dying v. State of Washington 79 F.3d 790 (9th cir 1996): 810–39 at 839)[87] (Italics emphasis added)

These "secular laws" are the very foundation of the American experiment. They protect citizens from coercion of any kind. The principles that protect one party from coercion also give freedom to the opposing party not to be coerced. This absence of coercion is the hallmark of a democratic society. Religionists who oppose aid in dying depend upon this protection as much as those who do not agree with their views.

Section 2.9 Religions that Support the Right to Die

The American Baptists differ from the Southern Baptists (see Section 2.6) as to their views on end-of-life options. They state that their mission is "to advocate within the medical community for increased emphasis on the caring goals of medicine which preserve the dignity and minimize the suffering of the individual and respect personal choice for end of life care."

Among the other religions in the United States, only the Unitarian Universalists fully support medical aid in dying. In fact, without the support of the First Unitarian Church of Portland, Oregon, there might never have been a Death with Dignity Act passed in both 1994 and 1997. The Unitarian Universalist Association, headquartered in Boston, Massachusetts, has made medical aid in dying an integral aspect of their church's ministry. Since *Compassion and Choices*'

[87] Cherry, Mark J. "Physician-Assisted Suicide and Voluntary Euthanasia: How Not to Die as a Christian." Christian Bioethics: Non-Ecumenical Studies in Medical Morality 24, no. 1 (2018): p.7

(C&C) founder, Barbara Coombs Lee, is a member of the Portland First Unitarian Church, a close tie exists between the Unitarians and C&C which advocates for a broad range of end-of-life options including medical aid in dying. The Portland Unitarians see themselves as stewards of Oregon's Death with Dignity Act.

Unitarians have an interesting and yet largely hidden history where aid in dying is concerned. In the 1960s, when few Americans were talking about medical aid in dying, the Reverend Dr. Richard Steiner, minister of the Portland Unitarian Church, was an early advocate of the practice. When he himself became terminally ill, someone helped him obtain lethal medication, and he ended his life peacefully. In 1991, Reverend Dr. Alan Deale spoke out at the Oregon State Legislature in support of Oregon's Death with Dignity Act. Dr. Deale stood alone against scores of ministers, rabbis, priests, and members of the clergy. Just the year before, a woman in the Portland Unitarian congregation, Janet Adkins, became the first person to ask Dr. Kevorkian to help her die. Adkins had early onset Alzheimer's and had no desire to live with a malfunctioning brain. Her husband and three adult sons tried to talk her out of her decision to die, but Adkins was certain of her decision:

> The Adkins family said Janet Adkins' choice did not go unchallenged. Her husband said her sons talked her into abandoning her plans for "self-deliverance" for a time to undergo experimental treatment in Seattle. When that treatment failed, though, Ronald Adkins said there was no dissuading his wife.
>
> "The thing is she was so definite about it," he said. "There was no question in her mind that this is what she wanted to do."[88]

From early on, medical aid in dying became a rallying point for Unitarians across the country. Here is the 1988 resolution from their national association:

> [From their]1988 general resolution, the Unitarian Universalist Association has considered "the right to self-determination in dying, and the release from civil or criminal penalties of those who, under proper safeguards, act to honor the right of terminally ill patients to select the time of their own deaths." This statement is inherent in one of the association's Seven Principles: respect for the worth and dignity of each individual.[89]

[88] https://www.oregonlive.com/health/1990/06/portlands_janet_adkins_suicide.html

[89] http://archive.uuworld.org/2004/05/forum.html

Barbara Coombs Lee wrote, in a statement on the Unitarian Universalist's website, that "it was in that church's chapel that we held many news conferences during heated statewide campaigns in favor of the [Death with Dignity] law in 1994 and 1997."[90] Coombs Lee joined the Portland First Unitarian Church after she saw the congregation's deep dedication to the cause for which she was already the chief advocate.

Buddhists, Hindus, and Jains believe in reincarnation. "So a person's state of mind at the time of death is important: their thoughts should be selfless and enlightened, free of anger, hate or fear. This suggests that suicide is only appropriate for people who have achieved enlightenment and that the rest of us should avoid it [suicide]."[91] For Hindus, "helping to end a painful life…is performing a good deed and fulfilling…moral obligations."[92]

The United Church of Christ "generally affirms individual freedom and responsibility, including the right to choose in regards to reproductive rights, and has a history of encouraging inclusive discussion about all aspects of death and dying."[93] In 1973, at the 9th Synod, the United Church of Christ adopted the document: *The Rights and Responsibilities of Christians Regarding Human Death*, which…"affirms the right to die and execution of living wills; supports the right to die with dignity through termination of extraordinary measures to keep a terminally ill, unconscious patient alive…" (emphasis added) However, the Synod "did not address the question of euthanasia at a conscious patient's request."[94]

Brittany Maynard's widower, Dan Diaz, spoke to the 2017 United Church of Christ's General Synod and a resolution was called to a vote: The "Resolution of Witness in Support of Legislation Authorizing Medical Aid in Dying" narrowly failed to achieve the required support of

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[90] https://www.uuworld.org/articles/choice-end

[91] https://www.deathwithdignity.org/learn/religion-spirituality/

[92] Ibid.

[93] https://www.ucc.org/news_gs_medical_aid_in_dying_fails_to_win_approval_of_synod_delegates_by_just_a_few_votes_07032017

[94] https://www.ucc.org/news_gs_medical_aid_in_dying_fails_to_win_approval_of_synod_delegates_by_just_a_few_votes_07032017

two-thirds of the 737 delegates, and was not adopted by General Synod 2017. The resolution failed by just 12 votes. This means a majority of UCC members who vote in synods support medical aid in dying—about the same number who support aid in dying among the general population of the United States.[95]

In the United States, Methodists generally accept the individual's freedom of conscience to determine the means and timing of death. Some regional conferences have endorsed the legalization of medical aid in dying. One of these is the Methodist Church on the US West Coast.

Pro-choice statements also have been made by the Episcopalians (Anglicans), Presbyterians, and Quakers who are amongst the most liberal Christian churches in the United States, allowing at least individual decision-making in cases of hastened death.[96]

Section 2.10 Right to Die Organizations in America

Ian Dowbiggen claims his 2003 book, *A Merciful End,* is the first chronicle of the long process by which Americans passed their first Right to Die law in Oregon in 1994. His access to private documents, letters, committee notes, and his personal interviews with some of the actual founders of the movement laid bare the extremely contentious history of the Right to Die Movement from the tumultuous *Euthanasia Society of America* in 1938 to the relatively calmer, more respected, and better-funded *Compassion and Choices* in 2019.[97]

The *Euthanasia Society of America* was founded in New York in 1938 as a result of public and private debates about Social Darwinism and the eugenics movement. The Eugenics Movement was an effort to improve the stock of American people by weeding out individuals who had compromised it. Paul Popenoe, a biologist, an avocado grower, and the father of Marriage and Family Counseling used the ideas of eugenics to promote this weeding out process just as he did with his avocados. The goal of Popenoe's Marriage and Family Counseling Institute in Los Angeles was to promote the marriages of healthy citizens with prized attributes and to discourage

[95] Ibid.

[96] https://www.deathwithdignity.org/learn/religion-spirituality/

[97] Dowbiggen, Chapter 5 recounts the history of the organizations

marriages between people who would weaken the gene pool of the American people. Supporters of euthanasia and the Right to Die were often also supporters of the eugenics movement. They saw the principles of Darwinism as a way to improve human life by selective breeding and selective killing.

One aspect of the eugenics movement did take hold in the United States. Beginning in 1907, coerced sterilizations became legal and were eventually federally funded in thirty-two states. This aspect of eugenics is briefly included in this study to call attention to the ease with which a majority of states passed laws that allowed the *forced* sterilization of human beings based on the biases and prejudices of the times.

> Coerced sterilization is a shameful part of America's history, and one doesn't have to go too far back to find examples of it. Used as a means of controlling "undesirable" populations – immigrants, people of color, poor people, unmarried mothers, the disabled, the mentally ill – federally-funded sterilization programs took place in 32 states throughout the 20th century. Driven by prejudiced notions of science and social control, these programs informed policies on immigration and segregation.[98]

We can imagine if unwed mothers were sterilized in 2019 as a punishment for not being married when their babies were born. In 2018, according to the Centers for Disease Control, nearly 40% of first babies are born to unwed mothers.[99]

The first sterilization law was passed in Indiana in 1907. It legalized the forced sterilization of the "feeble-minded." Other states legalized the mandatory procedure for immigrants, people of color, poor people, the disabled, and the mentally ill. Permanently halting the reproductive capacity by force using subjective criteria and the federal dollar is unthinkable to many Americans in 2019. It would be an outrage and would never become law. And yet, hastening one's own death when an agonizing death has become inevitable which strictly prohibited any form of coercion was strongly resisted until 1994. It is still resisted in most states in 2019.

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[98] http://www.pbs.org/independentlens/blog/unwanted-sterilization-and-eugenics-programs-in-the-united-states/

[99] https://www.cdc.gov/nchs/fastats/unmarried-childbearing.htm

When Hitler came to power in 1933, coerced sterilization was one of the first laws passed by his new government.

> The similarities in eugenic thinking and practice in the USA and Germany force us to re-evaluate the peculiarity of Nazi racial policies: historians of the Third Reich often draw a straight line from racial hygiene to the euthanasia programme of the Nazis and thence to the genocide of the Jews, Sinti and Roma during the Second World War.[100]

The aim of the eugenics movement was to spread its ideas across the globe. Most Jews as well as the survivors of the Holocaust were horrified that Americans would even consider any aspect of eugenics. The slippery slope toward fascism was all too real for Jews all over the world whose numbers had been reduced by half (six million) in their lifetime. Another five million "undesirables" had also perished at the hands of the Nazis.

> German experts of race hygiene who advised the Nazi government in drafting the sterilization law were well informed about the experiences with similar laws in American states, most importantly in California and Virginia, but there is little evidence to suggest they depended on American knowledge and expertise to draft their own sterilization law.[101]

After World War II, the sterilization policies of Adolf Hitler that were once touted in support of America's model programs were now used by its critics to end forced sterilizations. Hitler and the German quest to "improve" their race acted as a wake-up call to Americans as they realized what was at stake and what these laws indicated about their own American culture. Yet the sterilization policy lingered in the United States. Finally, in 1981, the State of Oregon performed the last legal sterilization in U.S. history.[102] This put an end to America's dalliance with eugenics.

Eventually, the Euthanasia Society of America found that "promoting the Right to Die was easier than promoting the Right to Kill"[103](as in mercy killings). Eventually, the ESA hoped to extend active euthanasia to vulnerable and incurable populations—the elderly, terminally ill,

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[100] Klautke, Egbert. "'The Germans Are Beating Us at Our Own Game': American Eugenics and the German Sterilization Law of 1933." History of the Human Sciences 29, no. 3 (2016): 25-43.

[101] https://embryo.asu.edu/pages/oregon-state-board-eugenics

[102] Ibid.

[103] Ibid.

disabled, developmentally disabled—in an effort to purge society of its suffering citizens. Noting the 1938 date of its founding, it is not difficult to anticipate the public's eventual reaction to the society's efforts as the atrocities of the Nazis were revealed during the decade that followed.

After World War II, Americans wanted to settle down and raise families. Churches were full. People were conservative and risk avoidant. Mercy killings and euthanasia were repulsive topics and a fear of a *slippery slope* toward authoritarian acts of euthanasia scuttled the ESA's efforts to pass Right to Die legislation in 1939 and later. The strong personalities of the early Right to Die advocates made for hostile meetings, expulsions from boards, and public accusations against one another.

For this thesis, the organizational side of the Right to Die Movement is largely left alone due to its complexity and vast number of abrupt changes over the next forty years. Also, the public lost interest after World War II and did not pay much attention to the efforts of the ESA. Within the movement itself, suspicions about hidden agendas, accusations that some founders were actually heartless "killers," and the plethora of differing values ensured that early organizational efforts to pass Right to Die legislation were unsuccessful. This supports the thesis of this study that it was the *stories* of actual Americans—specifically three young women who were in permanent vegetative states —that finally caught the public's attention. Americans empathized and identified with these young women who, in the prime of their lives, became suspended between life and death as their families and the courts fought over Right to Die issues and laws that prevented their deaths. After Elisabeth Kübler-Ross opened up the subject of death for discussion, Americans finally began talking about how medical advances had made dying a far less straightforward proposition. In fact, physicians now used advanced medical technology and appeared to have mastered death itself. Americans were well aware that physicians now had the technology that appeared to prolong dying indefinitely, but they began to question whether doctors had the authority to do so.

Important questions began to be asked, *"Who owns the human body?" "Who has the right to end a human life?" "Judges? Politicians? Congress? The President of the United States?" "Does God own my body?" "Do I own my own body?" "Do the courts own my body?"*

Starting with Karen Ann Quinlan in 1976, then Nancy Cruzan in 1983, and on to Terry Schiavo in 1990, the media told the stories of what was at stake and who was on which side of the Right to Die debate. These high-profile cases lead to a series of legal challenges. The result was the passage of significant federal and state laws that affect every American who comes under the care of a doctor or a hospital or who is facing death. Individual rights were defined. Guardianship and legal proxy rules were clarified. Patient rights were defined and informed consent prior to medical procedures became mandatory. Patients were acknowledged as having self-ownership and autonomy. The courts upheld what the patients themselves wanted—or what their guardians or legal proxies wanted for them when those patients became incapacitated. Patients could specify ahead of time what they would accept or not accept in terms of medical intervention and treatment because *they owned their own bodies.* The paternalism of medicine had now been challenged. The United States Constitution had weighed in on the side of the patient who had rights and freedoms.

American families discussed these medical cases and the new laws and policies. Liberal and conservative positions were staked out. Religious and secular positions were defined and hotly debated. The Vietnam war had just concluded, so there were generational differences of opinions already at play in families and in the media all over America. Citizens turned to their religious leaders for spiritual guidance. Religious thinkers, ministers, rabbis, and theological scholars issued written position statements and made public declarations of their support or opposition to the Right to Die Movement. The Catholic Church and the Right to Life Movement (funded initially by the Catholic Church) stood staunchly on the side of the sixth commandment. Jews, in general, believed it was a duty to follow the sixth commandment, and agreed with many Christians that “Thou shalt not kill” included aid in dying.

The Right to Die Movement—with its emphasis on patient choice, privacy, autonomy, and individual rights—came into its own toward the end of the twentieth century. Some researchers say 1980 begins the real history of the Right to Die Movement. The *Hemlock Society* was founded in 1980 by Derek Humphreys. At its founding, the *Hemlock Society* joined the *World Federation of Right to Die Societies* (WFRTDS). *Hemlock* eventually merged with *Compassion in*

Dying and became *Compassion and Choices* headed up by Barbara Coombs Lee. Like Dame Cecily Saunders who went back to school to become a physician and founded the hospice movement in Britain, Barbara Coombs Lee had been an ICU nurse and later became an attorney. Under her direction, C&C directed the ballot initiative for the Death with Dignity Act in Oregon, and Coombs Lee co-authored Oregon's Death with Dignity Act. This law passed in 1994 and was implemented in 1997 after prevailing in a series of repeal efforts. Coombs Lee is still advising C&C as its President ex Officio. Her 2019 book *Finishing Strong* is the current standard for advocates and supporters of the Right to Die.[104]

This brings us to August of 2019. At this writing, nine states and the District of Columbia have Right to Die Laws. Two of these state laws were passed during the preparation and writing of this thesis. Several more states may have passed Right to Die Laws before this thesis is finished and submitted. In 2019, 72% of Americans support the Right to Die. Among physicians in a MedScape Survey, 58% support medical aid in dying. [105]

The first key narrative in this study which captures the philosophical beginnings of the Right to Die Movement was the Greek tragedy by Sophocles, *Antigone*. In the next chapter, the other five key narratives will be presented to tell the rest of the story of the Right to Die Movement. These narratives are about: Elisabeth Kübler-Ross, Karen Ann Quinlan, Nancy Cruzan, Terri Schiavo, and Brittany Maynard. Some new questions will also be answered: *What were the key factors that brought about the changes in perceptions about autonomy, human liberties, and medical aid in dying? What brought Americans to their current majority of 72% who believe the Right to Die is moral and should be a law? What was the significance of Brittany Maynard's 2014 farewell YouTube video, a narrative that eventually reached 100 million viewers?*

[104] https://www.compassionandchoices.org/finish-strong/

[105] https://www.medscape.com/viewarticle/914231#vp_2

CHAPTER 3

50 YEARS OF THE RIGHT TO DIE MOVEMENT (1969 to 2019)

3.1 1969+ Narrative #2: Elisabeth Kübler-Ross Breaks the Death Taboo

Swiss-American psychiatrist Dr. Elisabeth Kübler-Ross and her book *On Death and Dying*, which was published in 1969, is the second key narrative of the six examined in this study. Without question, Americans had to be able to speak of death before they could develop perceptions and make laws concerning death and the practices around it. "We live in a very peculiar, death-denying society," [Kübler-Ross] told Senator Church's committee in 1972. "We isolate both the dying and the old, and it serves a purpose, I guess. They are reminders of our own mortality."[106] Doctors were and still are reticent to speak of death to their patients fearing the subject of the patient's immanent death may bring about overly emotional discussions or lessen the patients' ability to fight their diseases. To some doctors, death represents the failure of their efforts to treat or cure a disease. To others, the subject is uncomfortable because patients often need emotional support after they are told they will die soon.

Kübler-Ross began working with medical students, doctors, nurses, social workers, and other health care workers in a lab setting. She allowed herself to be observed and recorded as she modeled speaking directly and authentically to patients who were dying. By 1976, Kübler-Ross had sold a million copies of her book, and America was abuzz with a still rather superficial level of speech about dying. The five stages of dying—denial, anger, bargaining, depression, and acceptance[107]—represented a sound bite that was easy to remember and, for health care professionals, carried the illusion of control.[108] One critic in 1975 claimed that her book didn't cause people to be more "open" about death—just more "talkative" about it.[109] Americans then wrestled with the subject of death and how best to speak about it for the next few decades. To

[106] Dowbiggen, p. 117

[107] Kübler-Ross, Elisabeth. On Death and Dying. London; New York: Routledge, 1973.

[108] Bishop, Jeffrey P. Anticipatory Corpse: *Medicine, Power, and the Care of the Dying*. Notre Dame Studies in Medical Ethics. Notre Dame, Ind.: University of Notre Dame Press, 2011. p. 238

[109] Bishop, p. 238

this day, speaking about death is uncomfortable for many doctors and health care workers and doing it well is a skill that must be learned. According to Dr. Jeffrey P. Bishop, having open discussions about death also brought on a sense of "foreboding" and "disenchantment" among doctors.[110]

> …it is also clear that [Kübler-Ross] gave the five stages of dying/grief a scientific veneer, with the result that the five stages could be heard and accepted by those who would master death technologically. Kübler-Ross offered them a different mode of control, this time through discursive practices.[111]

Nevertheless, the subject of death was now open for discussion in society as well as in doctors' offices. Ever since Kübler-Ross, speaking about death openly with dying patients has been considered a part of good treatment and "a good death." The honesty is appreciated eventually by those who are dying. To ensure that this conversation happens, the federal government now pays doctors to have these discussions:

> Faced with the uncomfortable task of discussing death, doctors often avoid the topic. Only 17 percent of Medicare patients surveyed in a 2015 Kaiser Family Foundation study said they had discussed end-of-life care — though most wanted to do so. Since that study, Medicare has begun reimbursing providers for having these conversations. Yet still, just a fraction of Medicare recipients at the end of life have those talks with their doctors.[112]

Kübler-Ross's work was an essential step in addressing the serious problems faced by the dying. Her training of doctors and those in professions dealing with the dying was another milestone in the Right to Die Movement, inspired the improvement of end-of-life options, and eventually brought about the hospice movement in America.

In Britain, another reformer was hard at work. Cicely Saunders—later honored by the title *Dame* Cicely Saunders—was a nurse in the UK when she noticed that doctors often walked away from their patients who were dying. They isolated the dying in back rooms of hospitals and considered that their own efforts to treat and care for the patient were over. The result was that the dying felt abandoned, in unmanaged pain, and in acute emotional distress. Saunders went

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[110] Dowbiggen quoting Cohen, Ronald J. "Is Dying Being Worked to Death" The American Journal of Psychiatry, May, 1976

[111] Bishop, p. 238

[112] Yount, p. 46

back to school and became a social worker to assist the dying. Realizing she would not have much credibility in the medical profession as a social worker, Saunders went to medical school and became a physician. This statement is from her 2005 obituary:

> Not many physicians manage to influence the practice of medicine by developing a new approach to care which has become a recognised medical specialty and (in the UK) is taught to every medical student. An approach to care that has created a resonance around the world in both developed and developing countries, with burgeoning clinical services, academic departments, scientific journals, textbooks, symposia and all of the accoutrements of an emerging specialism. Such is the story of Cicely Saunders and palliative care.[113]

This was the beginning of the hospice movement in Britain. Very quickly, the movement came to the United States. But not until Elisabeth Kübler-Ross' *On Death and Dying* became a part of the American conversation did the hospice movement take hold in the United States:

> Although Dr. Saunders began writing and lecturing in the United States in 1963, the initial response of American society to the hospice concept was sparked by Dr. Elisabeth Kübler-Ross' On Death and Dying…The hospice philosophy confronted the euthanasia or 'good death' movement head-on by emphasizing the quality of remaining life and the ability of attending caregivers to provide comfort and care. [114]

However, the philosophy of the Hospice Movement—especially the national organization—is often insistent on palliative care as opposed to hastened deaths. But this view from the national and state-level hospice leaders seems to be changing as evidenced by the account provided by Ann Jackson below. Here is the official view of the national hospice organization. Note the inclusion of their support for "openness" and thus, one may presume, change:

> We reaffirm the hospice concept of care that neither hastens nor postpones the onset of death. In addition, we support all activity toward open discussion, public or private, about these or any other issues that concern hospice patients and families. Finally, we support all public policy changes that would ensure access to hospice care irrespective of patient age or diagnosis and patient/family socioeconomic status.[115]

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[113] Hanks, and Forbes. "Dame Cicely Saunders, OM, DBE, FRCP, FRCN." *Pain* 118, no. 3 (2005): 283-84.

[114] Campbell, Linda. "History of the Hospice Movement." *Cancer Nursing* 9, no. 6 (1986): 333-38. p. 336

[115] https://hospicecare.com/policy-and-ethics/ethical-issues/statements-on-euthanasia-and-physician-assisted-suicide/#AAHPM

The cooperation between hospice care and Right to Die advocates is slowly improving—especially in states where medical aid in dying is already allowed by law. Although the national organization opposes it, many state hospice associations take a neutral stand. Oregon's experience has proven that the state's Death with Dignity Act has increased awareness and use of hospices—and so few patients use the DwDA that there is essentially very little competition between the two movements. Oregon hospices have learned to co-exist with the DwDA and most allow the aid in dying process to occur within the hospice setting itself despite the differing goals of MAID and hospice care. "Nearly 90% of terminally ill patients who have used Oregon's distinctive Death with Dignity law to receive a medication to end their lives are enrolled in hospice care programs." [116]

Twenty years after the Death with Dignity Act was implemented, many hospice supporters have softened their oppositional stance on medical aid in dying and treat it as an additional option for dying patients. Ann Jackson, the director of the Oregon Hospice Association (OHA), had just such a change of heart about the law despite having officially opposed Oregon's Death with Dignity Act on behalf of the national organization. Her process of greater acceptance was reflected in her opinion piece for a Eugene, Oregon newspaper:

> "I had to speak on behalf of the OHA, and our position is that we had no position," Jackson says. "It no longer mattered whether medical aid in dying was right or wrong. It is the law in Oregon." We strongly believed that people had the right to choose, so I was able to talk about that very broadly."
>
> Jackson is frank about her own change of heart.
>
> "Over time, I realized I had been arrogant to believe that hospice and palliative care professionals can meet all the needs of dying persons, or that the desire to determine the manner and timing of one's own death was somehow unworthy," Jackson wrote in an April 5, 2017 opinion piece in the Eugene *Register-Guard.*[117]

While hospice staffs now often work directly with patients who desire medical aid in dying, the American Medical Association takes a different position. It has insisted right up through their 2019 conference this year that the term "physician-assisted suicide" be kept by the

[116] https://www.deathwithdignity.org/news/2017/10/we-had-to-be-part-of-the-debate-ann-jackson/

[117] https://www.deathwithdignity.org/news/2017/10/we-had-to-be-part-of-the-debate-ann-jackson/

association as a way to cast disfavor on the practice. This may change since the current MedScape survey[118] shows that 58% of physicians support medical aid in dying. And there must have been support for medical aid in dying at this year's conference in June, 2019 because the AMA now states openly that many of its members support the practice even though the association itself opposes it.

The current 2019 position of the American Medical Association is:

> Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks.
>
> Instead of engaging in assisted suicide, physicians must aggressively respond to the needs of patients at the end of life.
>
> Physicians:
> (a) Should not abandon a patient once it is determined that cure is impossible.
> (b) Must respect patient autonomy.
> (c) Must provide good communication and emotional support.
> (d) Must provide appropriate comfort care and adequate pain control.[119]

The American Medical Association continues to wrestle with the issue of medical aid in dying. One observer of the AMA's Council on Ethical and Judicial Affairs (CEJA) called the discussion among physicians over the issue of aid in dying as coming to a state of "irreducible differences of opinion." "Opponents and proponents alike appeal to fundamental tenents of the medical profession—either the injunction to 'do no harm' and to extend life or to honor patient autonomy and to diminish suffering."[120]

The opposition to medical aid in dying now comes largely from the American Medical Association. The fact that they oppose MAID and still refer to it as "physician-assisted suicide" shows the intransigence and conservative nature of the AMA. We should notice that, despite the fact that doctors themselves often hasten the death of their patients covertly and without reporting their assistance, they do not wish to officially share the initial decision-making process or the implementation of aid in dying with their patients.

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[118] https://www.medscape.com/viewarticle/914231#vp_2

[119] https://www.ama-assn.org/delivering-care/ethics/physician-assisted-suicide

[120] https://www.ama-assn.org/system/files/2019-05/a19-ceja2.pdf

Palliative care and referrals to hospice care seem to be where most of the major associations are focusing their advocacy at the current moment. Fortunately, palliative care in hospitals has experienced steady growth in the 21st century. Here are the statistics from 2013:

> Sixty-seven percent of hospitals with 50 or more total facility beds reported a palliative care program. Ninety percent of hospitals with 300 beds or more were found to have palliative care programs as compared to 56% of hospitals with fewer than 300 beds…Palliative care penetration was highest in the New England (88% of hospitals), Pacific (77% of hospitals), and mid-Atlantic (77% of hospitals) states and lowest in the west south central (43% of hospitals) and east south central (42% of hospitals) states.[121]

Whereas under the former American Nurse's Association (ANA) policy, nurses were prohibited from participating in medical aid in dying, the organization abandoned that position at this year's (2019) ANA conference. The following recommendations were accepted by the ANA:

> **"It is the shared responsibility of professional nursing organizations to speak for nurses collectively in shaping health care and to promulgate change for the improvement of health and health care"**
>
> **Therefore, the American Nurses Association supports recommendations that nurses:**
> 1. Remain objective when discussing end-of-life options with patients who are exploring medical aid in dying.
> 2. Have an ethical duty to be knowledgeable about this evolving issue.
> 3. Be aware of their personal values regarding medical aid in dying and how these values might affect the patient-nurse relationship.
> 4. Have the right to conscientiously object to being involved in the aid-in-dying process.
> 5. Never abandon or refuse to provide comfort and safety measures to the patient who has chosen medical aid in dying…Nurses who work in jurisdictions where medical aid in dying is legal have an obligation to inform their employers that they would predictively exercise a conscience-based objection so that appropriate assignments could be made.
> 6. Protect the confidentiality of the patient who chooses medical aid in dying.
> 7. Remain objective and protect the confidentiality of health care professionals who are present during the aid-in-dying process, as well as the confidentiality of those who choose not to be present.
> 8. Be involved in end-of-life policy discussions and development on local, state, and national levels, including advocating for palliative and hospice care services.
> 9. Furthermore, research is needed to better understand the phenomenon.[122]

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[121] Dumanovsky, T., Augustin, R., Rogers, M., Lettang, K., Meier, D. E., & Morrison, R. S. (2016). The Growth of Palliative Care in U.S. Hospitals: A Status Report. *Journal of palliative medicine*, *19*(1), 8–15. doi:10.1089/jpm.2015.0351

[122] 2019 Membership Assembly Consideration of ANA's Revised Position Statement: The Nurse's Role When a Patient Requests Medical Aid in Dying: Recommendations from the ANA Ethics and Human Rights Advisory Board which were passed in their 2019 conference.

Despite the opposition of the American Medical Association, here is a list of medical *associations that do support medical aid in dying*:

> American College of Legal Medicine, American Medical Student Association, American Medical Women's Association, American Nurses Association of California, American Public Health Association, GLMA: Healthcare Professionals Advancing LGBT Equality, and New York State Academy of Family Physicians.[123]

Numerous other medical and health groups have dropped their opposition to medical aid in dying and have adopted a *neutral position*:

> American Academy of Hospice and Palliative Medicine, American Pharmacists Association, Oncology Nursing Association, California Medical Association, California Hospice and Palliative Care Association, Colorado Medical Society, Maine Medical Association, Maryland State Medical Society, Massachusetts Medical Society, Medical Society of the District of Columbia, Minnesota Medical Association, Missouri Hospice & Palliative Care Association, Nevada State Medical Association, Oregon Medical Association, Vermont Medical Society, Hospice and Palliative Care Council of Vermont, and Washington State Psychological Association.[124]

From this survey of medical associations, we can see that national organizations tend to be opposed to medical aid in dying while regional, state, and local medical associations take more neutral stances or actually support medical aid in dying. It is also noteworthy that, "a 2018 survey conducted by Medscape showed that 58% of physicians support physician-aided dying, up from 46% in 2010."[125] These data show that medical aid in dying is still very much a contested practice with patients desiring control over their own deaths while doctors who are influential at the American Medical Association still wish to be the arbiters of when and how their patients will die. However, because the support among physicians for patient-controlled death is growing, the opposition to MAID from the national organizations is bound to decrease as more and more states allow MAID and the support of the public as well as physicians grows even larger.

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[123] Email communication from Sean Crowley, official spokesperson for *Compassion and Choices*, 9/17/2018

[124] Ibid.

[125] https://www.medscape.com/viewarticle/914231#vp_2

Section 3.2 1976+: Key Narrative #3 Karen Ann Quinlan: Right of Privacy; Living Wills; Advance Directives; Determination of Brain Death; Patient Bills of Rights; and Bioethics Committees

In 1975, Karen Ann Quinlan of New Jersey, then 21 years old, collapsed after drinking alcohol as well as ingesting aspirin and Valium. Paramedics revived her breathing, but she fell into a persistent vegetative state from which she never recovered.

The Quinlan case is still regarded as a watershed medical case in the Right to Die Movement. Twenty years after her death, her parents recalled what Karen was like in a 1996 Los Angeles Times article:

> Julia and Joseph Quinlan remember their daughter as a vibrant tomboy who taught her younger brother to wrestle, a young woman with a beautiful voice who dreamed of being a singer.
>
> Most Americans recall Karen Ann Quinlan as the comatose woman in a black-and-white photograph published around the world, whose life on a ventilator led to the nation's first major right-to-die case.
>
> Twenty years ago, the New Jersey Supreme Court ruled that the Quinlans had the right to take their daughter off life-support equipment. Since then, dozens of court rulings and scores of laws have backed that right.
>
> "They say we were the pioneers. I guess we were. We just did what we had to do," Joseph Quinlan, a former pharmaceutical executive, said at the family's hilltop home in rural western New Jersey.[126]

The Quinlans were devout Catholics and had consulted with their priest about removing their daughter from the ventilator that was forcing air into her lungs. He agreed that it was the right thing to do. But the hospital caring for Karen Quinlan refused to take her off the respirator which forced the Quinlans to take their case to the New Jersey courts.

The 1965 *Griswold v. Connecticut* was the first case to establish the *right to privacy*. The case ruled that state laws prohibiting physicians from discussing and providing contraceptives for a married couple were unconstitutional. The Quinlan case was the first time a state court had applied the right of privacy to a case of “letting die.”[127] The United States Supreme Court

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[126] https://www.latimes.com/archives/la-xpm-1996-04-07-mn-55744-story.html

[127] Yount, Lisa. Right to Die and Euthanasia. Rev. ed. Library in a Book. New York: Facts on File, 2007, p. 70

"extended the right to control one's body to include the right to make private decisions about the body, such as whom to marry, whether to use contraceptives, and, most famously, whether to have an abortion."[128] The right to refuse medical treatment had been accepted for nearly a century. In 1891, the United States Supreme Court ruled:

> No right is held more sacred, or is more carefully guarded, by the common law than the right of every individual to the possession and control of his own person, free from all restraint or interference from others, unless by clear and unquestionable authority of law.[129]

The law was clear about whether Karen herself had the right to refuse medical treatment. What was in question was whether her parents could make decisions on her behalf since Karen herself was incapacitated. In the Quinlan case, the judge ruled that the Quinlans could make the decision to remove the respirator on behalf of their daughter since they would know what she would prefer for herself. The judge ruled that the state had no compelling interest in keeping Karen alive since a return to normal human functioning had been medically determined to be impossible. The judge stated that the right to privacy was the issue that most concerned the court. He wrote:

> We think the State's interest…against the request of the plaintiff weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims. Ultimately there comes a point at which the individual's rights overcome the State interest.[130]

The idea of asserting an individual's right to privacy by another person was a radical departure from previous legal decisions and signified society's acceptance of the idea that an individual's desires could abrogate the interests of the state. This ruling would be referred to many times in Right to Die cases that were brought to the courts after the Quinlan case.

Karen was moved to a nursing home that was willing to remove her ventilator. She continued to breathe and lived another nine years after the ventilator was removed. Due to their Catholic beliefs, her parents never requested that her feeding tube and hydration delivery be

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[128] Yount, p. 69

[129] Yount, p. 69

[130] Yount, p. 70

removed since that was basic care rather than artificial care and thus prohibited by the Catholic Church.

The Quinlan case riveted the nation. It was the first time a large number of Americans began to wonder what they would want for themselves or for their children were they ever in a similar situation. The following year, California passed the first law that recognized the legality of a "Living Will" which allowed Californians to specify their wishes in writing *prior to being incapacitated by illness or injury.* In 2019, all states recognize the legality of Living Wills and a person's right to designate a Medical Durable Power of Attorney (a legal proxy) to make decisions should they ever become incapacitated and unable to speak for themselves.

In 2016, forty years after Karen's death, her mother recalled the legacy of her daughter's life and death. Julia and Joe Quinlan began working to open a hospice in Karen's honor even before Karen died. After her husband passed away at the hospice in 1996, Julia Quinlan is still very involved with the Karen Ann Quinlan Hospice in Newton, New Jersey:

> Q: Do you ever reflect on what all this has meant to the world, and what you, your daughter and your family have accomplished? Things like living wills and patient bills of rights did not exist before your case went public.
>
> A: I do, often. Particularly yesterday while driving home on Karen's birthday. Like I said, this has been a particularly heavy week, but I have to be thankful for who we are. When Karen (who was adopted) was placed in my arms at the chapel at St. Joseph's hospital in Scranton, this beautiful baby, Joe and I just thanked God. We were blessed. We became a family. Never ever did we envision that Karen's life would be such an important part of so many thousands, millions of people's lives. She is not aware of all this, yet her life has served a purpose and continues to serve a purpose, not just today and tomorrow. It will go on and on.[131]

Up until the Quinlan case, the issue of when a person had actually died was still controversial in medicine. Some doctors used the stopping of the heart and or breathing, others used brain death as the determinant of death. Because of the Quinlan case, a Presidential Commission in 1981 "recommended that states endorse the concept that human life ended when the brain stopped functioning."[132] This recommendation obscures the fact that brain death may be

[131] https://www.dailyrecord.com/story/news/2016/04/03/julia-quinlan-mother-karen-reflects-40-year-milestone/82524984/

[132] https://www.karenannquinlanhospice.org/about/history/

difficult to determine by one simple test. Because of the current need for organ donations, however, determining the moment of death is a crucial factor in determining when organs may be harvested. Here is the current legal determination of brain death, which relies on three main components:

> ***Coma:*** Patient should be completely unresponsive and unconscious (typically tested with painful stimuli).
> ***Absence of Brainstem Reflexes:*** Patient should be unresponsive to stimuli that otherwise would trigger an involuntary response (such as dilation of the pupils in the presence of a bright light).
> ***Apnea Test:*** The patient, when disconnected from a respirator, should not have respiratory movements and will show other measurable signs supporting the diagnosis of brain death.

If the patient is diagnosed as brain dead, he will be declared clinically and legally dead.[133] Brain death must include the brain stem as well as the higher cortical functions of the brain. If both of these aspects of the brain have no electrical activity, the patient is dead. In 2019, modern brain scans can ascertain brain death with absolute certainty.

Finally, the Karen Ann Quinlan case is responsible for establishing hospital bioethics committees. Although a hospital's legal department is charged with avoiding and solving legal disputes, a bioethics committee is charged with education about clinical ethics, assistance with developing and implementing policies such as end-of-life care, DNR policies, determination of brain death, and retrospective reviews of complicated problems reflecting the need for hospital policy and system changes.[134]

> Post-Quinlan institutional ethics committees (IECs) were initially formed to deal with adults in critical care [4] and focused frequently on do-not-attempt-resuscitation (DNAR) orders—previously known simply as DNR or do-not-resuscitate orders—the right to refuse treatment, determination of death, and organ transplant issues. Often the committees helped a hospital develop written policies and procedures concerning these issues. Subsequently, especially in large safety net hospitals like the one we work in, disputes have become more often centered on conflicts caused by a disagreement between patient or family and the clinical team about demand for treatment judged to be nonbeneficial or even harmful. This is sometimes called the "futility problem," although we think it

[133] https://healthcare.findlaw.com/patient-rights/brain-death-vs-persistent-vegetative-state-what-is-the-legal-difference.html

[134] https://journalofethics.ama-assn.org/article/hospital-ethics-committees-consultants-and-courts/2016-05

> is mostly a communications problem compounded by unrealistic expectations on the part of a patient's family.[135]

A movie titled *In the Matter of Karen Ann Quinlan* starring Brian Keith and Piper Laurie was released in 1977. This movie helped Americans understand the painful process the Quinlans endured to ensure their daughter was allowed to die the most natural death the Quinlans believed was possible.

Section 3.3 1983+: Key Narrative #4 Nancy Cruzan Case: The 1991 Patient Self-Determination Act; Advance Directives; Medical Proxy Laws; and Living Wills

On January of 1983, just after midnight, twenty-five-year-old Nancy Cruzan lost control of her vehicle in rural southwest Missouri. The Cruzan family attorney provides the details:

> The car crossed the center line, went off the side of the road, down an embankment, hit several small saplings, hit a rural mailbox, went back up the culvert on the side of the road, smashed a fence on the other side, and flipped on its top. Nancy was thrown thirty-five feet beyond where the car stopped. From the point where she left the road to the point where the car stopped was almost the length of two football fields. So, we know that she was going very fast.[136]

Hearing the noise, a neighbor came out to see what had caused it, then went back inside his house. Another family member emerged from the house to check out the situation, then went back in and told his wife to call the highway patrol. A patrol car and a firetruck arrived and found Nancy Cruzan face-down in the mud. The paramedics performed CPR, revived her breathing, and rushed her to the hospital.

When she arrived at the hospital, Joe and Joyce Cruzan would get that middle-of-the-night phone call that every parent dreads. Rushing to the hospital that night, they had no way of knowing that the seven-year ordeal they were about to experience would lead to the first United States Supreme Court case about the Right to Die.

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[135] Ibid.

[136] https://www.luc.edu/media/lucedu/law/students/publications/llj/pdfs/colby.pdf.
(Bill Colby was the attorney for the Cruzan family)

The brain can only go 4 to 6 minutes without oxygen before everything that makes a person herself is gone forever. Because Nancy had gone nearly twenty minutes without oxygen, only her brain stem continued to work:

> The brain stem, that part of our brain where our basic reflexes–breathing, sleeping, waking–are controlled, can go much longer without oxygen and survive than the upper, "thinking" part of the brain. So, Nancy's eyes would open. They would move around the room...and at times they would appear to stop and fix on an object, and then they would move again. She would grimace. She would smile from time to time. She would groan. She would react with a reflexive startle to noises in the room. Her body was almost completely frozen with contractures. Her nails bent in to the point that they would cut into her wrist and her parents would wedge her fingers back and put a pillow in to stop that from happening.

The doctors told the Cruzans that Nancy could stay alive in this persistent vegetative state for another thirty years with good nursing care. The Cruzans wanted their daughter to be at peace so they asked that her respirator be removed. The hospital refused to take this action without a court order. So the Cruzans had to find an attorney in Kansas City who would take their case pro bono. That attorney was Bill Colby whose account of the case is relied on in this study.

The series of court cases took a grueling seven years from 1983 to 1990 and caused a sensationalized and very controversial national debate. At one point, when Nancy Cruzan's feeding tube was finally removed, 25 pro-life protesters tried to storm the hospital to reattach it. Thirty-two law officers surrounded the hospital to keep order. Satellite trucks and newscasters kept the public informed of all the developments as they occurred. Finally, Nancy Cruzan died twelve days after her feeding tube was removed.

All of this public frenzy took its toll on Nancy's family—on her father especially. Joe Cruzan understood the contribution his daughter had made to the law and to medicine. "I think this is quite an accomplishment for a 25-year-old kid," her father said, "and I'm damn proud of her."[137] But the lengthy, contentious process had taken everything out of him. After it was all over, Joe hanged himself in the family carport.[138]

> In 1991, as a result of the Cruzan decision, the federal government enacted the Patient Self-Determination Act that requires hospitals, nursing facilities, hospices, home health care programs, and health maintenance organizations to inform

[137] https://journalofethics.ama-assn.org/article/departed-jan-11-1983-peace-dec-26-1990/2001-07

[138] https://www.luc.edu/media/lucedu/law/students/publications/llj/pdfs/colby.pdf

> patients about their right to make forward-looking care and treatment decisions through the use of advance directives.
>
> Following the Cruzan case, states developed both medical proxy laws, whereby individuals could designate someone to make medical decisions for them if they become incapacitated, and living wills, legal statements of end-of-life care wishes
>
> The legacy of the Cruzan case was to foster mechanisms to safeguard the interests of people who become incapacitated at the end of life. Others could avert the tragedy of the Cruzans—and free themselves of some of the fear around end-of-life.[139]

Despite the great necessity to have Living Wills and Health Care Proxies, about two thirds of Americans in 2019 do not have these documents:

> …[I]n the July issue of *Health Affairs*, researchers reviewed 150 studies published between 2011 and 2016 that looked at the proportion of adults who completed advance directives. Of nearly 800,000 people, 37 percent completed some kind of advance directive. Of those, 29 percent completed living wills, 33 percent filed health care proxies and 32 percent remained "undefined," meaning the type of advance directive wasn't specified or was combined.[140]

Section 3.4 1990+ Key Narrative #5 Terry Schiavo: Relational Factors in Right to Die Decisions; the Patient as Part of a Community and a Family; the Hijacking of Right to Die Cases by Politicians and Religionists; Schiavo as a Cautionary Tale

In St. Petersburg, Florida, on February 25, 1990, Terry Schiavo, who was 26 years old at the time, collapsed due to a chemical imbalance possibly caused by an eating disorder. She could breathe and her heart began to beat again once she had been revived. But Terri never regained full consciousness. Only a feeding tube stood between life and death for Terri Schiavo. During the fifteen years Terri was in a "persistent vegetative state," the nation witnessed the bitter struggle between Terri's husband, Michael Schiavo, and Terri's parents, Robert and Mary Schindler. It was a horror show that played out in the news and on television for several years. Calls to the California Medical Association's office that were normally about 50 per day—shot up to 1,750 a

[139] https://journalofethics.ama-assn.org/article/departed-jan-11-1983-peace-dec-26-1990/2001-07

[140] https://www.healthaffairs.org/doi/pdf/10.1377/hlthaff.2017.0175

day during this time.[141] The CMA, at that time, was one of the few places where a Living Will form could be obtained.

During the first few years, the Schindlers worked with Michael Schiavo in caring for Terri. But in early 1993, Michael Schiavo wanted to detach the feeding tube that gave Terri nourishment. The Schindlers, devout Catholics as was Terri, wanted her to continue to receive nourishment. The parents believed their daughter would have wanted to be kept alive. They held out hope that her condition would improve given enough therapy and treatment. Michael Schindler, whose wife was no longer the person he knew, wanted to end her life because he was certain Terri would never improve. He also maintained that Terri herself once told him she would never want to be kept alive by artificial means. The courts, while sympathizing with the parents, consistently agreed with the husband as a matter of law. Michael Schiavo was her designated guardian, and the Schindlers had very few rights with regard to their daughter's fate.

Thomas Shannon, a prolific writer on bioethics who often focuses on the Catholic viewpoint, pointed out that the earlier Catholic position was that a patient did not have to be kept alive except by ordinary care. He said the issue was whether "artificial nutrition and hydration were 'ordinary care' (which must be provided) or 'extraordinary care' (which can be discontinued) by considering whether their burden to a particular patient outweighed the benefits."[142]

During the media frenzy over Terri Schiavo's situation, this earlier Catholic view was replaced by a more definitive statement from Pope John Paul called, "*A Papal Allocution on Care for Patients in a Permanent' Vegetative State.*" Although an allocution is not an official policy statement such as an encyclical is, the pronouncement was a clear directive to Catholics:

> …the Pope stated in the March 2004 address that *such tubes were "not a medical act" and that their use "always represents a natural means of preserving life" and is part of "normal care." Therefore, their use is to be morally evaluated as ordinary and obligatory.* "If done knowingly and willingly," the removal of such feeding tubes is "euthanasia by omission." The person's medical condition is not relevant in making a determination about the use of feeding tubes because the

[141] Yount, Lisa. Right to Die and Euthanasia. Rev ed. Library in a Book. New York: Facts on File, 2007., p. 41

[142] Yount, p. 40

> food and water delivered through such tubes is ordinary care and provides a benefit--"nourishment to the patient and alleviation of his suffering."[143]
> (emphasis added)

Among Roman Catholic ethicists, the debate about this issue has been ongoing for many years. Gerald Kelly, a revered Jesuit moral theologian, expressed an early view that a patient in a persistent vegetative state should not be given food or oxygen:

> It seems to me that, apart from very special circumstances, *the artificial means not only need not but also should not be used, once the coma is reasonably diagnosed as terminal.* Their use creates expense and nervous strain without conferring any real benefit. [144] (emphasis added)

The Pope's 2004 allocution elicited much criticism. Thomas Shannon, the bioethicist mentioned earlier, said the allocution would cause much disruption. Further, Shannon insists that the pope's allocution was a reversal of 400 years of Catholic ethics. He asks if Catholics should not fill out advanced directives and designate a legal proxy since their own wishes and that of their proxy will be disregarded by Catholic institutions. Also, he asks about non-Catholic patients who are dying in Catholic hospitals. Are they required to follow the pope's directive too?

> The decision-making process at the end of life is difficult enough as it is. It is a time fraught with tension, pain, suffering, sorrow, guilt, and grieving. The strict implementation of a policy such as that in the Pope's allocution seems to us simply to prolong the agony by prohibiting responsible medical and moral evaluation of the patient's condition. Ironically, it would also be at odds with the long Catholic tradition of medical ethics. It also has the potential to cause enormous difficulties for Catholic health care facilities and their staffs. While we certainly support every effort to prevent euthanasia, we do not support policies that require medical staff to provide unwanted medical treatment. Such policies might even drive people toward euthanasia, by making them feel that they have lost a traditional and sympathetic ally in their final journey.[145]

Michael Schiavo and the Schindlers fought acrimonious court battles for years. Because Schiavo had remarried and had two children, the Schindlers accused him of having a selfish motive for wanting Terri dead. Emotions ran high all over the world as people read and heard

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[143] https://www.questia.com/library/journal/1G1-121448158/implications-of-the-papal-allocution-on-feeding-tubes

[144] https://www.questia.com/library/journal/1G1-121448158/implications-of-the-papal-allocution-on-feeding-tubes

[145] A Shannon, Thomas & J Walter, James. (2004). Implications of the Papal Allocution on Feeding Tubes. The Hastings Center report. 34. 18-20. 10.2307/3528689.

about the case. During that time, politicians—including congressmen, Governor Jeb Bush, President George W. Bush—used the Schiavo case to declare their own views. Religious leaders like Jerry Falwell said: “America has a *death syndrome*. The syndrome started…with the legalization of abortion–[and] now euthanasia.”[146] Pat Robertson called the removal of Terri’s feeding tube “judicial murder.” And the Franciscan monk, Brother Paul O’Donnell, who was a spiritual advisor to the Schiavos called the action a “modern-day crucifixion.”[147]

The Florida courts had given Michael Schiavo permission to detach her feeding tube in the year 2000, but Terri’s parents presented videos they claimed were proof that Terri was not in a persistent vegetative state and, in fact, had minimal consciousness because she seemed to turn toward sound and follow objects with her eyes. These videos were eventually examined by Senator Bill Frist, a transplant surgeon and the Republican Senate majority leader, who agreed that Terri was not brain dead. Terri’s later autopsy clearly showed that she had been totally blind and had no cortical activity, so Frist’s opinion was based on appearances only—on bodily movements which can be caused by the brain stem alone. But Frist’s status as a doctor gave his opinion about the videos of Terri Schiavo a force and an influence they would not have had otherwise.

Representative Thomas DeLay of Texas weighed in on the morality of the decision to remove Terri’s feeding tube. He said, "That act of barbarism can be and must be prevented.”[148]

In 2003, the Florida State Legislature passed a bill giving Governor Jeb Bush the authority to prevent the removal of the feeding tube. The Florida Supreme Court overturned this legislation as unconstitutional. Then President George W. Bush jumped into the fray in early 2005.

Dana Perino, then President Bush’s spokesperson, said this on behalf of the president:

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[146] https://www.npr.org/templates/story/story.php?storyId=10188427 (from NPR’s obituary for Falwell)

[147] http://content.time.com/time/specials/packages/article/0,28804,1864940_1864939_1864901,00.html

[148] http://cdn.theologicalstudies.net/66/66.3/66.3.8.pdf

> "The president is saddened by the latest ruling. When there is a complex case such as this, where serious questions and doubts have been raised, the president believes we ought to err on the side of life," …Asked whether the president was contemplating any further legal action, Ms. Perino said, "We know there are still efforts under way by the parents and the state of Florida to save her life, we continue to stand with those who are on the side of defending life."[149]

At one point, President Bush transferred the jurisdiction over Terri Schiavo from the state courts to the federal judiciary. However, the Florida state courts were awarded final jurisdiction and eventually prevailed. Terri's feeding tube was removed in 2005—five years after Michael Schiavo had been given permission to do so.

Despite the immense amount of attention focused on the Schiavo case, it did not result in one new law, one innovative policy, or one ethical judgement that could satisfy everyone involved. In fact, Terri Schiavo's case can be said to demonstrate how far away the United States was and still is from coming up with an accepted policy for when to remove life support—be it a respirator, a feeding tube, or other intervention. The United States is also a long way from allowing medical aid in dying across the nation. In many cases, *where* you live will determine *how* you die.

One thing the Schiavo case did teach the nation is that, when family members hold differing views on the rightness or wrongness of a medical action, it is best to avoid Congress and politicians and religionists who will hijack these cases to publicize their own views in order to appeal to their political and religious bases.

The other much more profound idea we can learn from the Schiavo case is that many people wanted to keep Terri alive because they believed she had intrinsic value as a human being. The debate about whether Terri still had "personhood" did not dissuade these people from fighting for her life. They insisted that Terri Schiavo was not a single, discreet, physical being. Her value was in relation to others.

When one faction of the family has devoted itself to the "sanctity of life" principle, their relationship to their unconscious loved one is complex and very deep. The Schiavos, despite the doctors and the science which held that recovery was impossible, believed their daughter's

[149] https://www.nysun.com/national/bush-err-on-the-side-of-life/11127/

condition might improve. They enjoyed interacting with her despite the limitations of their communion with her.

The results of the post-mortem, in retrospect, dashed the parents' hopes that their daughter had been aware of their presence as she smiled and moved her head in relation to sounds. Keeping Terri alive had meant everything to her parents. For many Right to Life advocates, keeping Terri alive was a principle worth fighting for despite the fact that the laws of the land had already adjudicated that the worth of her life was negligible.

There are now other reasons to question the definitive pronouncements that doctors make about their comatose patients:

> Contrary to standard definitions we cannot state categorically that the vegetative state is defined by a total loss of cortical function. Others studying patients diagnosed as vegetative—a term many critiques reject as demeaning—have found that between 12% and 34% of patients diagnosed as persistently vegetative are at least minimally conscious and may respond to therapy.[150]

The very fact that Terri Schiavo's case caused such a huge debate and concern in so many quarters shows that she is not a single human being whose life affects no one but herself. Her parents enjoyed interacting with her and did so frequently, Right to Life advocates fought for her, religious leaders scolded those who, in their view, "wanted to kill her", and disability rights advocates questioned why Terri's worth was based on her cognitive abilities alone. Her heart was beating, she breathed on her own, she received nourishment for her body. Was Terri Schiavo not a part of a community formed by people who cared about the sanctity of life above all else?

> In this construction, Mrs. Schiavo is a person equal to others because her parents said she was and her continuance had been mandated by their historically anchored unwavering commitment to that relationship's continuance…the concept of the quality of life might be replaced by the quality of *lives*, including family members. The result is a duty to care for the person the family member perceives as a person-in-relation.[151]

The deciding issue according to the Florida courts was whether Michael Schiavo or the Schindlers had guardianship rights over Terri. The courts gave the guardianship to her husband.

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[150] Koch, T. "The challenge of Terri Schiavo: lessons for bioethics." *Journal of medical ethics* vol. 31,7 (2005): 376-8. doi:10.1136/jme.2005.012419

[151] Ibid

It was Michael Schiavo's sense of what Terri wanted in her circumstances and what was the most respectful course of action that counted legally. Had the Schindlers been given guardianship, Terri might have received hydration and food through her feeding tube for decades more, and her parents would have their wish to keep their daughter alive as long as possible.

This key narrative is not included in this study as a means to confront the ethics of the removal of feeding tubes or respirators when an unconscious state is deemed permanent by physicians. Rather, this study includes the Schiavo case to point out the deep complexity that goes beyond the written law. All the relevant laws were in place by the time Terri became unconscious. With her husband as her guardian, it was his own notion of his wife's condition and what her desires had been that directed his arguments supporting her death.

But Terri Schiavo was a part of her family of origin—the people who raised her. She was now a part of a community of supporters—created by sympathetic media treatment or because human beings quite naturally believe in the sanctity of life. The reason Terri Schiavo's story is a key narrative in understanding the Right to Die Movement is so that this study includes an appreciation of the competing ideologies at play in any bioethics case. Extremely strong emotions and commitments are at play in the families of those who are comatose for many years. The mere fact that these humans are now perceived by society and by physicians to be as inert as a "vegetable" tells us that our culture places very little value on Terri's life or others who are in PVS. Imagining themselves in a similar circumstance, many Americans could see no reason why Terri or anyone else would want to live. Others realized they would fight tooth and nail to keep a child or themselves alive until "God called them home."

This is where the shared personhood concept enters in. By definition, Terri's life was connected to others who wished her to live and thus her life, for them, was meaningful.

How does this case apply to the Right to Die Movement? Most people imagine a great deal of pain associated with dying. Surprisingly, inadequate pain control was cited by only 25% of those who had applied for medical aid in dying during Oregon's first 18 years with the Death with Dignity Act. The most prominent fears of those who requested aid in dying were *relational fears:* 92% perceived a loss of autonomy; 89.7% were unable to participate in enjoyable activities;

78.7% cited a loss of dignity; 48.2% worried about control of bodily functions; 25.2% stated inadequate pain control had contributed to their decision; only 3.1% were concerned about treatment costs. While physical pain might be mitigated by palliative care and a holistic hospice approach to dying, more people worried about dependence on others and how others would regard them when they had become a burden. They worried about other human beings having to clean them up after bowel accidents or bouts of vomiting, and the indignity those medical issues would or did cause the dying person. This is not to discount these concerns. Rather, Americans must take into consideration that medical aid in dying has become acceptable because dying people fear that the loved ones in our lives will not accept the characteristics and inconveniences of a dying human being. We know this because our culture often has a hard time accepting those among us who are disabled or physically diminished in any way.

The disability community has much to say about this. As Oregon's Death with Dignity Act of 1994 was challenged in the following three years, a group of people with disabilities organized in opposition to the law. They called themselves *NOT DEAD YET*. The members of this organization testified before the Oregon legislature that many of the reasons people gave for applying for MAID were circumstances with which they struggled and managed to cope every day. These people with disabilities were burdens on others because they lacked certain physical capabilities. Their body parts did not work well. Their cognitive abilities were not up to snuff. Their disabilities had to do with walking, bowel and bladder functions, a lack of independence, and the ability to do all they wished to do. On a daily basis, they encountered physical and cultural barriers that stopped them from going where they wished to go:

> Disability groups believe that much of what motivates people to access physician-assisted death is not pain, but fear of disability. In Oregon, where physician-assisted death is legal, surveys of people who partook of the option showed that while only 28 percent cited pain as a reason for choosing to die, 93 percent cited loss of autonomy. Just about half cited fear of being a burden on others. Diane Coleman, founder of NOT DEAD YET, says, "This suggests that it may not be presently experienced pain that's motivating people, but imagined future disability.[152]

[152] https://www.thedailybeast.com/why-disability-advocates-say-no-to-doctor-assisted-death

Christian bioethicists like David Elliot agree that medical aid in dying laws send a negative message to society about how sick, disabled, and dying human beings are sub-human and live lives that have very little value. He says ending lives that have no perceived intrinsic value seems logical and does not pose much of an ethical dilemma for many people:

> Elliot…argues that legalizing medically assisted death degrades the lives of sick, disabled, and dying patients. Such statutes, he concludes, create a subclass of persons, whose lives are in some sense "objectively" the sort of lives that one should reasonably want to end.[153]

As Reform Jewish Rabbi Barry Block put it, "the meaningful alternative to euthanasia is hard work." (from Section 2.4)

> Rabbis and caring congregants can offer their constant, supportive presence to those facing life-threatening illnesses. We can be knowledgeable about euthanasia alternatives. When we perceive suffering, we can suggest questions and concerns that families may pose to doctors. We may even advocate—with families and sometimes even directly with medical personnel—for transition to hospice care, increased pain medication, or psychiatric referral.[154]

Perhaps people who are dying fear that their loved ones are not willing to do that hard work. In many cases, the dying are correct in their assessment. Family members who live far away or who must work long hours or have small children may not have the energy, patience, or financial resources that it takes to care for a dying loved one. So it is important to emphasize that most issues around the manner of death and the Right to Die are *relational* issues. But those relational issues are serious ones. Not wanting their loved ones to remember them in a wasted, compromised, or humiliated condition is very real. Not wanting to be a burden on family members already loaded down with debt and expenses is serious. In many cases, this is actual reality—not imagined scenarios. Not wanting to have one's family members pity, resent, or begrudge the one who is dying is still a reason—a legitimate one—to request medical aid in dying.

The rabbi's call to do the "hard work" of caring for a dying loved one is also real. Americans must ask themselves if they are willing to do the hard work of helping someone die.

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[153] Cherry, Mark J. "Physician-Assisted Suicide and Voluntary Euthanasia: How Not to Die as a Christian." Christian Bioethics: Non-Ecumenical Studies in Medical Morality 24, no. 1 (2018): 1-16.

[154] https://reformjudaismmag.org/past-issues/summer2013/debatable-suicide Rabbi Block's comments

Do the dying wish the peace of death more to give their relatives a reprieve from caregiving? Do the dying fear that they are resented because they are dying and their bodies no longer function very well? How much of their fear of disability is a societal prejudice rather than an individual fear? These are the questions asked by those who both support and oppose medical aid in dying. The answers to these questions are as individual as human beings are.

Modern society actually *does* have a negative effect on whether families are able to help a loved one achieve a "good death." Modern society actually *does* judge human beings as worthless when they can no longer compete, contribute, communicate, or care for themselves. The Right to Die Movement acknowledges all these factors. It also recognizes that modern medicine can prolong our lives beyond any sense of a meaningful existence—past the tolerance of the dying as well as the caregivers.

Americans now have a sense that their Individual Rights, their Right to Privacy, their liberties and freedoms and the wide array of personal choices that are now open to them—are individual choices every American has open to them. The purpose of the Right to Die Movement in 2019 is to ensure this wide range of choices for those who have come to the end of life. Unless pain and the indignities themselves have become too much to bear, people do not generally choose MAID if they are receiving adequate palliative care and have loved ones willingly attending to them as well as having adequate hospice support. But, for those Americans who dread the final moments of a painful disease, when the morphine makes them no longer themselves, state laws that allow a hastened death are probably the most merciful of possible choices. Just having the lethal medicine in their possession gives many dying persons the peace they need. They know they can say when "enough is enough." The Right to Die Movement wants to make this choice available to any American who wants to choose to die peacefully long before the indignities and final agonies set in. Those who are fortunate enough to have the care they need may never need or want to choose that option:

> It may be this sense of personhood as a shared rather than discrete quality that fueled the extraordinary public demonstration of support for Terri Schiavo's survival. For those protesting the withdrawal of hydration and nutrition, the act of demonstration served in itself as affirmation of Mrs. Schiavo's personhood and thus her place within the protected circle of the state's "life interest" in its citizens.

> The unprecedented political involvement of the Florida State Legislature and the US Congress in the Schiavo case is, from this perspective, wholly appropriate. Where else in a democracy do citizens turn when they believe current policy and law are inappropriate, prejudicial, and unethical? When courts cannot offer redress, the logical next step is to seek legislation that will alter the laws in a manner that permits future judicial support.[155]

In the future, society's view of medical aid in dying may become less palatable if and when society's view of people with disabilities improves. Perhaps people with disabilities, let alone the dying who have developed disabilities, will finally be seen as valuable human beings in their own right. The cautionary note of the Schiavo story is about the possibility that our society may instead devolve into an acceptance of euthanasia for those who cannot compete, contribute, communicate, or care for themselves. This would mean that society has continued to devalue people with disabilities to the point of taking away their self-ownership, autonomy, and liberties. This is the fear of many who oppose medical aid in dying. Americans must regard involuntary euthanasia of the physically or mentally disabled as an abhorrent practice that must never become normalized.

Section 3.5 2014+ Key Narrative #6 Brittany Maynard: Death with Dignity; Self-ownership; Autonomy; Right to Privacy; and Social Media

When the headaches began, Brittany Maynard was 28 years old, a newlywed who was eagerly planning to begin a family with her husband, Dan Diaz. The headaches were severe and debilitating, accompanied by nausea and seizures. At first, the doctors told her she had a Grade 2 astrocytoma—a slow-growing brain tumor that would allow her to live perhaps another three to ten years. For a woman in her twenties, she said, "that seemed as though she had been told she would die tomorrow."[156]

But when the couple went away to the wine country to celebrate New Year's Eve, the headaches put her back in the emergency room. This time, doctors told her she had a Grade 4 glioblastoma multiforme, a fast-growing tumor that was quickly spreading to other parts of her

[155] https://jme.bmj.com/content/31/7/376#xref-ref-3-1

[156] Brittany Maynard's Farewell https://www.youtube.com/watch?v=FLJ8yx7jcS4

brain. After giving her this revised prognosis, Brittany was told she had only about six months to live.

Brittany Maynard, a graduate of Berkeley, was a young woman who loved extreme adventures. Her mother, a former middle school science teacher, said Brittany "has always been bigger than life. She has a kind of wanderlust. She has always liked exciting things—adrenaline rushes. She has always been precocious and very, very bright. Anything she set her mind to—she did."[157] Brittany took care of orphans in Nepal, had traveled the world, and volunteered her time to help those who were less fortunate than she.

After enduring brain surgery and the reoccurrence of her brain tumor, Brittany knew her cancer was incurable. So she began to think about how she wanted to die. When her headaches were less severe, she carried on with her life. She traveled with her best friend to Alaska where they toured Denali National Park, visited Seward, and traveled to the Kenai Fjords. They kayaked to see the glaciers up close. Then she met her mother in Juneau to take a fabulous boat trip. She and Dan had an exquisite trip to Yellowstone Park. The couple hoped to visit the Grand Canyon—the last place on her bucket list.

Since her best friend was a physician, Brittany had been told about the suffering she would most likely endure toward the end. Almost no one ever survived a Grade 4 glioblastoma multiforme, and she knew it would be a hard death. Nevertheless, Brittany continued to hope for miracles.

At one point, while she was searching the web for a cure, she came across information about Oregon's Death with Dignity Act. She and husband Dan viewed the documentary "*How to Die in Oregon*" and researched how medical aid in dying worked. She decided this was what she wanted—to have a say in how her life ended. She and her family members made the decision to move from their home in California to Oregon so Brittany could use the Death with Dignity Act there. Amidst her illness, Brittany had to find a new home, locate new doctors, establish

[157] Brittany Maynard's Farewell https://www.youtube.com/watch?v=FLJ8yx7jcS4

residency in Oregon, and meet the criteria to use Oregon's Death with Dignity Act. She qualified and got the bottle of lethal medication several weeks before her death.

This is what Brittany wanted. It was completely consistent with how she had lived her life. She did not want to give her cancer "the last word." So her family gathered around to support her decision, interrupting their lives to be with Brittany until the end. Brittany made a 6-minute farewell YouTube video for her friends to tell them of her decision to die by her own hand. She set November 1, 2014 as the day she would die. She said if she felt like it, she might extend her time. A few weeks before that date, Dan and Brittany visited the Grand Canyon. She had completed her bucket list and was ready to die.

When *Compassion and Choices* got involved with Brittany to coach her through the process of aid in dying, they asked if they could use her farewell video in their advocacy for medical aid in dying. She agreed. In October of 2014, Brittany's YouTube video went viral. Sean Crowley, chief spokesperson of *Compassion and Choices*, estimated that her video was seen by 100 million viewers in the month after it was posted. *People Magazine* did a story on her. News channels across the nation carried her story. Academic scholars and bioethicists discussed her case. At one point, there were 169 articles on the Internet about Brittany Maynard's decision to use Oregon's Death with Dignity Act. Her name was recognizable by almost one third of Americans.

True to her original decision, Brittany died on November 1, 2014, with her loved ones at her side. She played the music she liked and said her good-byes to her husband, her best friend, her mother, and members of her family. On November 1, just hours before her death, she wrote this to her loved ones on Facebook:

> "Goodbye to all my dear friends and family that I love. Today is the day I have chosen to pass away with dignity in the face of my terminal illness, this terrible brain cancer that has taken so much from me but would have taken so much more," she wrote on Facebook. "The world is a beautiful place, travel has been my greatest teacher, my close friends and folks are the greatest givers. I even have a ring of support around my bed as I type Goodbye world. Spread good energy. Pay it forward!"[158]

[158] https://people.com/celebrity/terminally-ill-woman-brittany-maynard-has-ended-her-own-life/

Then Brittany took the medication, and soon fell asleep. A few minutes later, she died in her sleep.

Before she died, she asked her mother and her husband to work so that all Americans would have this option at the end of their lives. Having the lethal medication in her possession had made all the difference to Brittany. She knew it was within her power to end her life rather than having to go through the brutal end-stage of glioblastoma. Through the efforts of her husband, her family, and *Compassion and Choices*, in 2015 less than one year after Brittany's death, California passed the *California End of Life Option Act.* Soon, everyone in the Right to Die Movement began to notice what is now known as the "Brittany Maynard Effect."

> The right to die movement needed a young and beautiful person who wanted to exercise her choice to end her life to show that it is not just the very old who want the right to die. The right to die movement needed a young and pretty face to draw people in and get them to listen.[159]

Sean Crowley, C&C's chief spokesperson, said in an email exchange:

> The best evidence of the 'Brittany effect' is the increase in support among physicians and the rapid increase in the passage of laws authorizing medical aid in dying. It took 20 years for the first four states to authorize medical aid in dying, Oregon in 1994, Washington State in 2008, Montana in 2009 (via state Supreme Court ruling, not legislation), Vermont in 2013, but since Brittany went public with her story in 2014, six jurisdictions have authorized it in the last five years: California in 2015, Colorado in 2016, the District of Columbia in 2017, Hawaii in 2018, and New Jersey and Maine in 2019.[160]

This study suggests that Brittany Maynard was a modern-day Antigone. She knew the written law of her home state of California would not allow her to hasten her own death, and she knew her death would be brutal and unavoidable. She was drawn to the State of Oregon where the law there coincided with her inner sense of fairness and her need to have a say in how she died. Her sense of autonomy and self-ownership motivated her to seek a manner of death that was consistent with the values of the life she had lived. She had a supportive family around her. They were so supportive that they helped her re-establish herself in Oregon and even moved there with her to be by her side. This means the whole family was drawn to the state

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[159] http://www.bioethics.net/2014/11/why-the-right-to-die-movement-needed-brittany-maynard/

[160] Email from Sean Crowley, June 19, 2019

where death could occur when and how the dying patient chose. Brittany Maynard's legacy was that she followed her heart and her strong desire not to let her brain cancer dictate how she would die. Her internal process is similar in those humans who break the written law in order to follow an innately-felt, more just, more virtuous law—as Antigone did.

Brittany Maynard and her family, this thesis contends, were following Natural Law—unshakeable, unwritten (in California at that time), with the stamp of rightness about it. Her actions brought about a thoughtful regret to her fellow California residents whose law had necessitated that Brittany's family make a difficult move in the midst of the most difficult time of their lives. They too responded to the sense of liberty, fairness, virtue, and Individual Rights that characterizes Natural Law. Then the residents of California adjusted their written law to allow dying people like Brittany to stay in their homes and be able to choose how and when they would die when the end drew near. Isn't this the same mantle of virtue our doctors put on themselves when they disobey the written law that prohibits doctors from hastening their patients' deaths? None of them believe they are violating a worthy prohibition that must stand in all cases. None are ashamed of their actions despite the secrecy with which they must shroud this act. The fact that many doctors have admitted to hastening deaths through active, passive, or involuntary euthanasia suggests that doctors also sense that their actions are more fair and right and more consistent with their patient's wishes when the doctors end that suffering. Doctors respond to the authentic calls of their dying patients for a permanent end to unimaginable suffering. Wasn't this what the Quinlans were responding to? Weren't Joe and Joyce Cruzan wanting peace and rest for their daughter, Nancy? Wasn't Michael Schiavo responding to his own desire to give his wife a respectful death?

Brittany Maynard was also responding to her sense of her own Individual Rights through the guidance of Natural Law.

Section 3.6 2019 What We Can Learn from Oregon's 21 Years of DwDA* Data

** In this section, "DwDA" is used when speaking of Oregon; MAID or "medical aid in dying" is used in general or when speaking of medical aid in dying in other states.*

As of August of 2019, nine states and the jurisdiction of Washington, D.C. have legalized medical aid in dying. Twenty-four more states are in various stages of making MAID legal. According to the 2018 Gallup Poll, 72% of Americans now support the idea of medical aid in dying in their own state whether or not they would personally make use of it.[161] According to a 2017 Medscape survey, 58% of doctors support medical aid in dying.[162]

We have Oregon to thank for their careful data-tracking over the past twenty-two years since their Death with Dignity Act (DwDA) has been in operation to understand how the law is carried out in actual practice.[163] In fact, the State of Oregon has led the way in providing the widest range of options for people who are dying. The state is known as a progressive, iconoclastic state with a population of people who follow their own instincts and logic rather than traditional ways of thinking:

> Oregonians tend to be more open-minded to a wide variety of opinions. That climate is very important. Referring to the status of Oregon as a relatively secular place, [one historian] added, "Oregon has never been a strong church state." The fact that there has been no dominant religion has allowed a moral flexibility that a lot of states don't have.
>
> The state's political culture is one factor accounting for the success of the PAD advocates. Oregonians see themselves as "social progressives." They detest "religious pressure." Roman Catholics in Oregon, the largest religious group in the state, are only about 12 percent of the population. "Overall, Oregon, with a voting population of about 2 million voters, is 62 percent 'unchurched,' making it more secular than most states."[164] (Note: Oregon had a population of 3.3 million in 1997)

When Oregon passed the first DwDA in the country in 1994, all eyes were on the wording of the bill, the prohibitions of the bill, the oversight from the Oregon Department of Health, and the process for filling a doctor's prescription for the lethal medication that would end the life of a dying patient. Because Oregon's policy-makers were highly aware that the DwDA would be a model for other states, they made reporting and data-tracking an essential part of the Death with Dignity

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[161] https://news.gallup.com/poll/211928/majority-americans-remain-supportive-euthanasia.aspx

[162] https://www.medscape.com/viewarticle/914231#vp_2

[163] https://www.compassionandchoices.org/news

[164] Ball, Howard, and Ebrary, Inc. At Liberty to Die : The Battle for Death with Dignity in America. New York: New York University Press, 2012, Chapter 6

Act. Data are recorded on the death certificates by the physician of the deceased patient. The result is that, in 2019, we now have twenty-two years of data to answer the misgivings and worries of the opponents of the law.

Rather than show the very extensive chart with the data from twenty years (1997-2017) of Oregon's DwDA, this thesis will focus on the three most common objections to the law and whether those objections and concerns were warranted. After each objection, the facts and statistics that indicate how the law actually played out are then presented.

Objection #1: If we make the DwDA legal, thousands of suicidal people—including depressed teen-agers—will kill themselves because they will think suicide is now legal.

Facts: The process by which a dying person can get a prescription for the lethal medication that will end her life is a very strict one. Here are the DwDA's criteria and the process by which a dying patient may receive medical aid in dying:

To request a prescription for life-ending medication in Oregon, the patient must be:

- at least 18 years old
- an Oregon resident
- mentally capable of making and communicating health care decisions, and diagnosed with a terminal illness that will result in death within six months.

A patient who meets the requirements above will be prescribed aid-in-dying medication only if:

- The patient makes two verbal requests to their doctor, at least 15 days apart.
- The patient gives a written request to the doctor, signed in front of two qualified, adult witnesses.
- The prescribing doctor and one other doctor confirm the patient's diagnosis and prognosis.
- The prescribing doctor and one other doctor determine that the patient is capable of making medical decisions.

The patient has a psychological examination, if either doctor feels the patient's judgment is impaired:

- The prescribing doctor informs the patient of any feasible alternatives to the medication, including care to relieve pain and keep the patient comfortable.
- The prescribing doctor asks the patient to notify their next of kin of the prescription request. (The doctor cannot require the patient to notify anyone, however.)
- The prescribing doctor offers the patient the opportunity to withdraw the request for aid-in-dying medication before granting the prescription.

- To use the medication, the patient must be able to ingest it on their own. A doctor or other person who administers the aid-in-dying medication may face criminal charges.[165]

First, according to the process, a depressed patient—dying or not—is ineligible to receive a prescription for lethal medication. In fact, if a teen-ager or even a depressed, dying person requested the medication, it is up to the physician to refer the person to a psychiatrist for treatment of depression. Secondly, a very small number of people have actually gone through with the process of getting a lethal prescription from their doctor. Fewer still have ingested the medication:

> During this 20-year period, a total of 1,967 people have had prescriptions written under the DWDA, and 1,275 (70%) have died from ingesting the medications. Most (88.6%) patients died at home, and most (88.7%) were enrolled in hospice care and no referrals were made to the Oregon Medical Board for failure to comply with DWDA requirements.[166]

As we can see from these data, fewer than 2,000 residents of Oregon made use of the law in a twenty-year period. About one third of those who got the medication never used it and died of their disease or injury rather than the medication. Two thirds (70%) did use it. Many patients stated they had a sense of peace and control from having the medication in their possession. Having it meant they could say when "enough was enough."[167]

Almost all (88.6%) of the patients who had chosen medical aid in dying were able to die at home among their loved ones and familiar surroundings. It is notable that 88.7% of those who had chosen DwDA were enrolled in hospice care. This means Oregon citizens have found a way for hospice care and the DwDA to work together to provide the widest range possible of end-of-life options. This collaboration is despite the fact that many hospice organizations have not supported the DwDA on principle—preferring to provide palliative care instead of having their

[165] https://www.nolo.com/legal-encyclopedia/oregon-s-death-with-dignity-law.html

[166] E-mail communication with Sean Crowley, Chief Spokesperson for *Compassion and Choices*, March 25, 2019

[167] Dan Diaz in Brittany Maynard in her Final Farewell video on YouTube, October, 2014. https://www.youtube.com/watch?v=yPfe3rCcUeQ

patients hasten their own deaths.[168] Also, there were *no referrals* to the Oregon Medical Board for failure to comply with or abuse of the DwDA requirements. This means the process is a good one and prevents many imagined abuses of the DwDA. In fact, the process is so lengthy and complicated that some states are seeking to *streamline* it so as not to put an undue burden on the patients themselves.[169]

Objection #2: My religion prohibits euthanasia, and I have always thought euthanasia is morally wrong because it violates the "thou shalt not kill" commandment.

Facts: Religious opponents—especially the Catholic Church—are the biggest and most well-funded opposition to MAID laws all across the country.[170] But 70% (national average is 72%) of Catholics support MAID.[171] Also, the DwDA is not euthanasia:

> "Compassion & Choices advocates for Medical Aid in Dying because the dying person controls the process from beginning to the end. It is not euthanasia. *We do not support euthanasia because someone else — not the dying person — may choose and act to cause death.*"[172] (italics emphasis added)

It is important to make the distinction between medical aid in dying and euthanasia. Euthanasia is what people provide for their pets when they are suffering and no treatment is available to them. Euthanasia is what happens when we unplug a respirator or withdraw feeding tubes. These are acts initiated by the family, the doctor, or the unconscious/brain-dead patient through their advance directives. The patient is not in control of euthanasia. The patient is *entirely* in control of medical aid in dying.

People who choose medical aid in dying are not committing suicide. They want to live—and yet they are dying. They are simply hastening their own deaths which have become

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[168] Campbell, Courtney S, and Jessica C Cox. "Hospice-Assisted Death? A Study of Oregon Hospices on Death with Dignity." American Journal of Hospice and Palliative Medicine® 29, no. 3 (2012): 227-35.

[169] Conversation with Dan Diaz, widower of Brittany Maynard and Chief Lobbyist for *Compassion and Choices*, March 16, 2019

[170] Ibid.

[171] Ibid.

[172] https://www.compassionandchoices.org/news Barbara Coombs Lee testimony before Canadian Parliament

inevitable. When MAID advocacy groups lobby the state legislatures, the first thing they do is to make the distinction between euthanasia and suicide and medical aid in dying.

This study notes that, when medical aid in dying is used, the cause of death on the death certificate is not "suicide" but the underlying illness or injury that was the cause of the death. This distinction is important to those who die using medical aid in dying.

Objection #3: The DwDA represents a "slippery slope." What is to prevent people from eventually putting the physically disabled or the cognitively impaired to death?

Facts: In twenty years of the DwDA, there have been no reports of abuse to the Oregon Medical Board. But suspicions and fears remain within the disability community. Here is a statement from the disability activists on the NOT DEAD YET website that makes that concern clear:

> The political agenda of many assisted suicide organizations includes expansion of eligibility to people with incurable but not necessarily terminal conditions who feel that their suffering is unbearable, without examining the cause of the suffering or whether it can be alleviated.[173]

Since the person who is initiating the DwDA process *must* be the patient himself, medical aid in dying advocates say this fear is unwarranted. Also, a patient with dementia or Alzheimer's is not eligible to initiate the process since the required level of cognition is not present in these patients. In fact, many people wish that dementia or other cognitive impairments would not disqualify them from medical aid in dying. However, at this writing, allowing those who are cognitively impaired to request MAID is not a part of any medical aid in dying law. Even people with dementia or Alzheimer's who have advance directives which they wrote long before they were impaired cannot initiate a medical aid in dying request due to their state of mental functioning. Unless it is absolutely clear that a patient is initiating the process herself and that he or she is fully cognizant, he or she will be unable to make use of the Death with Dignity Act.

This study calls attention to the very real messages that MAID laws send to citizens with disabilities. The real objections of people with disabilities to medical aid in dying laws is that dying people perceive the loss of autonomy and dignity, inability to do enjoyable activities, and being

[173] http://notdeadyet.org/assisted-suicide-talking-points

disabled as the biggest reasons to initiate *MAID*. For people with disabilities who have spent their lives coping with this lack of dignity and autonomy and their fear of being a burden on others, we can imagine how insulting this must feel that their fellow human beings are more afraid of disability than even pain or actual death at the end of their lives. But if Oregon and the other states that pass MAID laws do all they can to prevent abuse of MAID, these concerns can be handled under "disability awareness and education" efforts rather than repealing MAID laws. After all, disabled people are usually not dying, so those who are dying have more at stake in this argument.

One final lesson we can learn from Oregon's twenty years of DwDA data is that, even though many in the hospice movement were and are opponents of the MAID laws, the hospice movement is more active in Oregon than anywhere else in the United States. Because of the DwDA in that state, more families are having the difficult conversation about end-of-life considerations than in any other state. Even though fewer than 1,300 people (in all 20 years) have actually ingested the lethal prescription in a state where approximately 35,000 people die annually, the "side effects" of having this law have been beneficial for all Oregonians. Since hospice's main mission is to provide comfort care during a dying person's final days, their palliative care option should be available to *everyone* who is dying—whether or not they choose to hasten their own death through MAID laws.

CHAPTER 4

RESEARCH METHODOLOGY

Section 4.1 Introduction

A review of the literature, polling data, and the observations of several staff members at *Compassion and Choices* suggested that the Brittany Maynard video played a part in the surge of support for MAID between May of 2014 and May of 2015.

According to table 4.1, 2013 marked the year when 49% of Americans believed medical aid in dying was morally unacceptable and 45% believed it was morally acceptable. This means that five months prior to the Brittany Maynard Farewell Video being released, Americans recorded one of the lowest levels of support for medical aid in dying. In May of 2015, seven months after the Brittany Maynard video went viral, support was at its highest level. And it has continued to grow from 56% in May of 2015 to 72% in 2018 (see Table 4.1). Clearly, a sea change in public opinion occurred after the Brittany Maynard video was released and support for MAID continued to rise over the months that followed.

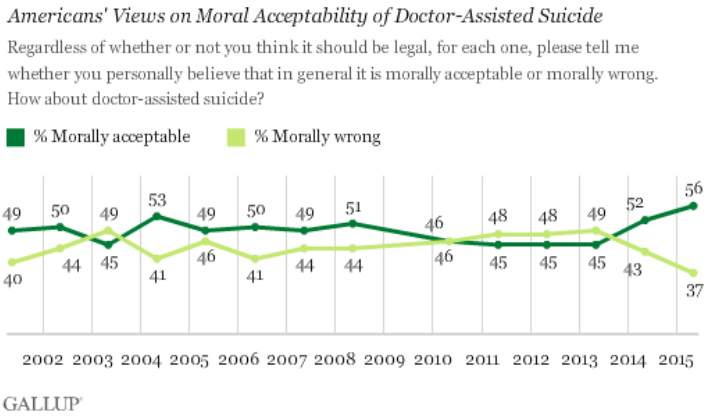

Table 4.1[174] Support for MAID 2002 to 2015

In the years 2001 to 2014, support and opposition to MAID were nearly evenly distributed. In 2010, opposition and support were equal. In 2004, 2011, 2012 and 2013, opposition to MAID was slightly greater than the support for MAID. Then, in May of 2015, we see the beginning of a surge of support for medical aid in dying. Also, during the years since 2014, according to Sean

[174] https://news.gallup.com/poll/183425/support-doctor-assisted-suicide.aspx

Crowley, six more states passed medical aid in dying laws. According to a 2018 MedScape survey, a majority of physicians—58%—now support medical aid in dying despite the fact that the American Medical Association continues to oppose MAID.

Table 4.2 shows in greater detail both the demographics and the growing support for MAID between May of 2014 (5 months before Maynard video) and May of 2015 (7 months after Maynard video). In addition to this polling data, 169 articles were written about Brittany Maynard in the five years since her video went viral. It is clear that the Maynard video either *reflected* or *helped create* this surge of support for medical aid in dying.

Support for Doctor-Assisted "Suicide," by Year

When a person has a disease that cannot be cured and is living in severe pain, do you think doctors should or should not be allowed by law to assist the patient to commit suicide if the patient requests it?

% Yes, should be allowed

	May 2014	May 2015	Change
	%	%	pct. pts.
18 to 34 years old	62	81	+19
35 to 54 years old	57	65	+8
55 and older	56	61	+5
Republicans	51	61	+10
Independents	64	80	+16
Democrats	59	72	+13

GALLUP

Table 4.2[175] Overall percentage of support for MAID in 2014 and 2015

In addition to studying the effect of the Brittany Maynard video, this thesis looked at the effect of religion on acceptance/opposition to MAID. In the survey instrument (see Appendix B), five questions were asked to determine the level of religiosity for each respondent. The answers were given on a Likert scale with 1 being Strongly Agree and 5 being Strongly Disagree. These five questions were developed by Dr. Kathryn Johnson of the ASU Psychology Department. Her specialty is testing the effect of religiosity on social attitudes and beliefs. The five questions were:

[175] https://news.gallup.com/poll/183425/support-doctor-assisted-suicide.aspx

I enjoy reading about my religion; It is important to me to spend time in thought and prayer; I have often had a strong sense of God's presence; I try hard to live all my life according to my religious beliefs; My whole approach to life is based on my religion.

In order to situate this study among others, a summary of several other studies are included in this thesis for the purpose of comparison. These other studies were chosen on the following criteria: conducted after 2013; Included US data; Tested for religiosity and/or simple acceptance/opposition to MAID; General Population rather than Medical Personnel; Reputable Study.

Section 4.2 The Economist and Ipsos MORI (June, 2015) Surveyed 15 Countries

The Economist and Ipsos MORI conducted a very large survey of approximately 2,000 adults in each of fifteen countries. From this study, we can see that the United States is on the low end of acceptance of MAID (63%) in 2015 with only Hungary (62%), Japan (54%), Poland (48%), and Russia (47%) reporting more opposition to MAID than American citizens report. All countries except Russia (47%) and Poland (48%) supported MAID by more than 50%. Belgium with 86% and France with 84% had the most supporters of MAID. [176]

Question Relevant to this Thesis:

Do you think it should be legal or not for a doctor to assist a patient aged 18 or over in ending their life, if that is the patient's wish, provided that the patient is terminally ill (where it is believed that they have 6 months or less to live) of sound mind, and expresses a clear desire to end their life?

Yes, it should be legal for a doctor to assist a patient in ending their life

No, it should not be legal for a doctor to assist a patient in ending their life

[NOTE: The rest of the respondents answered "I don't know" or "I prefer not to say"]

[176] https://www-economist-com.ezproxy1.lib.asu.edu/briefing/2015/06/27/attitudes-towards-assisted-dying

	Yes	No		Yes	No
Australia	73%	15%	Hungary	62%	17%
Belgium	86%	4%	Italy	64%	17%
Canada	77%	13%	Japan	54%	15%
Germany	75%	8%	The Netherlands	81%	8%
Spain	78%	7%	Poland	48%	29%
France	84%	5%	Russia	47%	32%
Great Britain	70%	13%	Sweden	69%	10%
			USA	**63%**	**21%**

Table 4.3 The Economist and Ipsos MORI Poll of 15 Countries[177]

Section 4.3 The 2016 Lifeway Poll Shows 38% of Evangelicals Support MAID

The Lifeway Poll reports that people with more education favor MAID more than do those with less education**:** some college (71%); graduate degree (73%); high school graduates or less (61%). It also found that younger people (18-24: 77%) support MAID more often than the older (35-44: 63%) and (55 –64: 64%). An interesting finding in the Lifeway Poll is that a greater number of Catholics (70%) favor MAID than do Christians in general (59%) and quite a lot more than Protestant Christians (53%). Evangelicals are the group that most opposes MAID (38%).[178]

Question relevant to this thesis:

"When a person is facing a painful terminal disease, it is morally acceptable to ask for a physician's aid in taking their life."

• Nonreligious (84%) are more likely to Agree than Christians (59%) and Other Religions (70%)

• Catholics (70%) are more likely to Agree than Protestant Christians (53%)

• Those with Evangelical Beliefs are less likely to Agree than those without Evangelical Beliefs (38% v. 73%)

[177] https://www-economist-com.ezproxy1.lib.asu.edu/briefing/2015/06/27/attitudes-towards-assisted-dying

[178] The 2016 Lifeway Poll https://lifewayresearch.com/2016/12/06/most-americans-say-assisted-suicide-is-morally-acceptable/

• Those who attend a religious service once a month or more are less likely to Agree than those who attend less than once a month (49% v. 76%)[179]

Section 4.4 Gallup Polls by Year

Question relevant to this thesis:

"When a person has a disease that cannot be cured…doctors should be allowed by law to end the patient's life by some painless means if the patient and his or her family request it."

2015 Gallup Social Series: Values and Beliefs: Nearly 7 in 10 (68%) agreed. This is an increase of nearly 20 points in the last two years. Support among young adults aged 18 to 34 climbed 19% to 81%

2016 Gallup Social Series: Values and Beliefs: Nearly 7 in 10 (69%) agreed.

2017 Gallup Social Series: Values and Beliefs: Nearly 3 in 4 (73%) agreed.

2018 Gallup Social Serie: Values and Beliefs: Nearly 3 in 4 (72%) agreed.

This majority support included nearly every demographic group surveyed:

Men…79% Women…65%

Republicans…62% Democrats…80% Independents…73%

Conservatives…54% Moderates…79% Liberals…89%

Conservatives who attend church nearly weekly/monthly…69%

attend church seldom/never…86%.[180]

Section 4.5 Harris Poll, November 2014

Three out of four Americans (74%) polled after Brittany Maynard utilized Oregon's Death with Dignity Act agreed that **"individuals who are terminally ill, in great pain and who have no chance for recovery, have the right choose to end their own life."**

Only 14% disagreed with this statement.

Support for this statement cut across all generations, both genders, and even political affiliation:

[179] http://lifewayresearch.com/wp-content/uploads/2016/12/Sept-2016-American-Views-Assisted-Suicide.pdf

[180] https://compassionandchoices.org/resource/polling-medical-aid-dying/

Millennials……...75%

Gen X……76%

Baby Boomers….74%

Matures……68%

High School……..75%

Some College…..74%

College Grad……72%

Post Grad…….76%

Republicans…….64%

Democrats……...78%

Independents…..78%[181]

[181] https://compassionandchoices.org/resource/polling-medical-aid-dying/

Section 4.6 Medscape Poll, January 2016

Despite the fact that the American Medical Association does not support MAID and has continued to refer to MAID as "physician-assisted suicide," the Medscape On-line survey of more than 7500 physicians from more than 25 specialties demonstrated significant increase in support for medical aid in dying from 2010. Well over half—57%—in 2017 endorse MAID.

Medscape Poll, January 2017 An on-line survey of almost 300 physicians found that 58% of doctors practicing in states without MAID laws had "been in a situation where they wished the patient could have taken advantage of such a practice." [182]

In general, the study below would be consistent with previous studies and polls if it shows religion is the variable that most connects to opposition to MAID; that younger people support MAID more than older people; that Catholics support it more than do Evangelicals and Christians or most denominations; that liberals support it more than conservatives; that Independents support it the most, followed by Democrats, and Republicans support MAID the least.

Section 4.7 Study Design

A Qualtrics Survey was created with the help of a research team that included a statistics instructor and a researcher from ASU's Department of Psychology. Two samples were used: the first was a sample of 99 Arizona State University (ASU) students who were enrolled in on-line classes in a number of university departments; the second sample of 130 participants was drawn from the general population using Amazon's Mechanical Turk (MTurk) platform. The Amazon TurkPRIME platform was also used to screen participants and to accept only those who were residents of the United States and who identified as being religious.

The same Qualtrics survey instrument was used to test attitudes and opinions about medical aid in dying in both samples. Both samples were then broken into three equal groups: One third of each sample viewed the Maynard video. One third of each sample read a verbatim script of the Maynard video (no visuals). One third of each sample acted as a control group and viewed a video about gardening that was completely unrelated to medical aid in dying.

[182] Ibid.

Section 4.8 Research Question

This survey was used to test a two-part research question: What variables are the determinants of support for medical aid in dying? How do attitudes toward medical aid in dying change when a participant is exposed to a persuasive video narrative made by an actual, terminally ill patient who is about to use Oregon's Death with Dignity Act to end her life?

Before the study began, 30 ASU students participated in a pilot study to identify glitches in the survey instrument and to refine the wording of several of the questions. Those 30 surveys were then discarded and not included in the actual study.

The Qualtrics Survey (See Appendix B) presented participants with 4 pre-PRIME questions about awareness and attitudes toward MAID. Then the participant viewed one of the three PRIMES—the control video about gardening, the Maynard video, or the Maynard video script. After viewing the PRIME, participants then answered 12 post-PRIME questions which included 5 demographic questions. A total of 188 participants from both samples left a comment about how their religion influenced their view of MAID. ASU student participants left 61 comments (out of 99) and MTurk participants left 127 comments (out of 130).

Section 4.9 Incentives for participation. ASU Sample (n=99 participants). Survey conducted: April, 2019

The 99 on-line students at ASU were incentivized to participate in the study with a drawing for a $99 Amazon Gift Card which would be given to a randomly selected student after the survey was complete. Though the survey was anonymous, each participant provided their email address at the end of the survey to be entered into the drawing. These emails were stripped from the data as soon as they were received in order to maintain anonymity.

Results: ASU participants returned approximately 150 surveys. After cleaning the data, 99 participants were left. The 51 surveys of those who did not complete the survey or had other disqualifying features were discarded. The data were recorded on Excel spreadsheets, then loaded into the SPSS program for data analysis.

Section 4.10 Incentives for participation. MTurk Sample (N=130)

It was important to the study to include participants who identified with a particular religion and who resided in the United States. In order to gather these participants, the TurkPRIME platform was used. This data collection platform charged 75 cents for each of 130 participants who met both criteria. The actual MTurk Survey-takers were each paid $1.00 for taking the 10-minute survey. The same Qualtrics Survey instrument was used for MTurk participants as was used for the ASU participants. After the results were in, the data were recorded on an Excel spreadsheet. Then the SPSS program was used to analyze the data.

Results: This study used all 130 surveys completed by MTurk workers. All 130 participants claimed to identify with a particular religion. 127 MTurk participants left comments about how their religion affected their view of MAID. The results of the MTurk survey offered a method of testing whether the Maynard video could influence participants who identified as religious—and opposed to MAID—toward a greater acceptance of MAID.

As part of the study, the research team looked at several other questions to search for any other factors that influenced attitudes toward MAID. In Chapter 5, we will analyze all major and minor research questions and present a conclusion of this study.

CHAPTER 5

DATA ANALYSIS AND CONCLUSIONS

Section 5.1 Data Analysis by Research Question

1. **How many respondents began the survey supporting MAID? How many respondents ended the survey opposing or supporting MAID after one of three PRIMES**

	ASU	MTURK
MAID PRE-PRIME		
Morally Right=	44 (44.4%)	46 (35.4%)
Neutral=	40 (40.4%)	27 (20.8%)
Morally Wrong	15 (15.2%)	57 (43.8%)
	N=99	**N=130**
MAID POST-PRIME		
Morally Right=	63 (63.6%)	50 (38.5%)
Neutral=	17 (17.2%)	20 (15.4%)
Morally Wrong=	19 (19.2%)	60 (46.2%)
	N=99	**N=130**

Table 5.1 Pre and Post-Prime Support for MAID

Section 5.2 What percentage of Participants Moved from Opposing to Supporting MAID after They saw the Maynard Video?

Among those who would be seeing/saw the Maynard video:

MAID PRE-PRIME

Morally Right=	17 (50.0%)	17 (38.6%)
Neutral=	11 (32.4%)	9 (20.4%)
Morally Wrong=	6 (17.6%)	18 (40.9%)
	N=34	**N=44**

MAID POST-PRIME

Morally Right=	23 (67.6%)	20 (45.5%)
Neutral=	4 (11.8%)	6 (13.3%)
Morally Wrong=	7 (20.6%)	18 (40.9%)
	N=34	**N=44**

Table 5.2 MAID is morally right. Pre and Post-Maynard Video

Among those who would read/read the Maynard video script:

MAID PRE-PRIME

Morally Right=	12 (40.0%)	16 (38.1%)
Neutral=	14 (46.7%)	8 (19.0%)
Morally Wrong=	4 (13.3%)	18 (42.9%)
	N=30	**N=42**

MAID POST-PRIME

Morally Right=	19 (63.3%)	16 (38.1%)
Neutral=	6 (20.0%)	7 (16.7%)
Morally Wrong=	5 (16.7%)	19 (45.2%)
	N=30	**N=42**

Table 5.3 MAID is morally right. Pre and Post-Maynard Video Script

Among those in the control groups:

MAID PRE-PRIME

Morally Right=	15 (42.9%)	13 (29.5%)
Neutral=	15 (42.9%)	10 (22.7%)
Morally Wrong=	5 (14.2%)	21 (47.7%)
	N=35	**N=44**

MAID POST-PRIME

Morally Right=	21 (60.0%)	14 (31.8%)
Neutral=	7 (20.0%)	7 (15.9%)
Morally Wrong=	7 (20.0%)	23 (52.3%)
	N=35	**N=44**

Table 5.4 MAID is morally right—Pre and Post-Control Video

Analysis: There were marked differences between the ASU and MTurk samples. As a whole, the ASU sample showed a considerable shift from pre-PRIME to post-PRIME—a nearly 20% increase in the number of participants regarding MAID as "Morally Right," although those that regarded it as "Morally Wrong" increased slightly as well. Most of the ASU participants who moved to acceptance had listed themselves initially as "neither supporting or opposing MAID". Reading the video script was responsible for moving the greatest number of participants toward acceptance of MAID (23%). After the Maynard video script, there was 17% greater acceptance and the actual Maynard video caused a 16% increase in acceptance. This is not at all what was anticipated from the literature. Having the written video script causing the biggest increase in acceptance of MAID rather than the visual video was quite an unexpected finding.

On the other hand, the MTurk sample shows very modest movement overall, increasing about 3% from pre-PRIME to post-PRIME for those regarding MAID as "Morally Right," and a similar movement for those regarding MAID as "Morally Wrong." This might indicate that people who identify as being "religious" are less likely to be influenced by a video or the video script of a dying person who is planning to do something that is against their own religion. These people might be less persuadable than people who do not identify as religious. Having a pope or a

prophet or believing the Bible or the Torah is the word of God makes these participants who identify with a particular religion less likely to rely on their own sense of morality and ethics. Either that or, as a true believer, the official pronouncements of their religion represent their own sense of morality and ethics.

Despite the views of the true believers in this study, participants who identified with particular religions very often set official prohibitions aside and supported MAID for other Americans who were suffering while dying—if not for themselves. The sense that one's own religion should dictate the laws of the land was a definite minority position. The study shows that many people understood that individual rights and autonomy means that others have the freedom to make their own decisions about MAID just as they have that same freedom to follow the dictates of their religion.

From these data, it would appear that the video had very little impact by itself. The script of the Maynard video was actually more effective in terms of increasing acceptance of MAID in the ASU sample. However, the data seem to show that the issue itself is very polarizing. What is the basis for movement toward acceptance of MAID after participants saw the gardening control video? It would appear, in those cases, that the passage of time from the beginning of the survey until the end sometimes caused a participant to have a different view of MAID at the end of the study.

The surge of acceptance for MAID in the United States is undeniable. Despite the failure of this study to show how the Maynard video itself was largely responsible for the surge of support for MAID, this does not diminish the findings of the many national polls that are tracking a growing acceptance of MAID. Medical Aid in Dying is an idea whose time has come. The passage of MAID laws in nine states as well as the District of Columbia with twenty-four additional states considering passing similar laws shows that Americans now believe in autonomy and individual rights and the liberties guaranteed by our constitution. The Right to Die might not be a constitutional right, but it most definitely can be seen as an end-of-life option for those Americans who insist that their choices in death be consistent with the choices they made during their lives. Having the full continuum of end-of-life choices available to all Americans seems to be

a value that is now accepted by a majority of Americans. Despite one's own end-of-life choices, Americans wish to see the whole range of options available to those who are dying. Medical Aid in Dying represents ultimate human freedom that Americans now accept as a national value.

Section 5.3 Among those who would be seeing/saw the Maynard video, what percentage of participants who identify as "religious" opposed MAID in the beginning and changed their position after seeing the video? (How effective was the Brittany video in changing the views of participants who identify as religious to a supportive view of MAID?)

This question calls for a zero-order Pearson's correlation coefficient between Religiosity as the independent variable against Pre-PRIME and post-PRIME in the ASU and MTURK samples. In the overall samples, the comparisons are (absolute r value; * indicates statistical significance @ p<.05):

How big a factor is "Religiosity" in how people answered, calling for a zero-order Pearson's correlation coefficient between Religiosity as the independent variable against Pre-PRIME and post-PRIME in the ASU and MTURK samples. In the overall samples, the comparisons are (absolute r value; * indicates statistical significance @ p<.05):

ASU		**MTURK**
RELIGIOSITY-----→Pre-PRIME	r= .349 *	r= .281*
RELIGIOSITY-----→Post-PRIME	r= .430 *	r= .313*

Table 5.5 Effect of Maynard Video on Respondents who Identify as Religious

Analysis: Religiosity was a significant predictor of attitudes toward MAID. The effect manifested more strongly between pre-and post-PRIME, but at the most composed about 16% (r-square) of the variance. As such, it was a significant but not the only factor differentiating attitudes toward MAID.

Section 5.4

A. What percentage of participants had never heard of the Maynard video prior to the survey?

B. What percentage of these respondents opposed MAID in the beginning and supported MAID at the end?

> **Note: This question is meant to show how familiar or unfamiliar the general public is with the Maynard video. It was estimated in the literature review that one third of Americans knew Brittany Maynard's name after her video went viral. The question also correlates familiarity with acceptance of MAID.**

What is the relationship between knowing about Brittany before the survey and how that predicts attitudes toward MAID? This question calls for a zero-order Pearson's r computation, MAID attitude as a function of "Previously familiar with Brittany." (* indicates significant at r<.05)

ASU "Previously familiar with Brittany Maynard"	MTURK-"Previously familiar with Brittany Maynard"
Yes=25 (25.3%)	38 (29.2%)
No=74 (74.7%)	92 (70.8%)
N=99	**N=130**

Table 5.6 Percentage of participants had heard of Brittany Maynard before the survey?

ASU		MTURK
r=-185*	Brittany Previous-→MAID Pre-Prime	r=-.021 (ns)
r=-.114 (ns)	Brittany Previous→MAID Post-Prime	r=-.040 (ns)

Table 5.7 Correlation between having heard of Brittany Maynard and support for MAID

Analysis: In the data-cleaning stage, seeing the Brittany video disqualified the participant since it would complicate the test of whether the video changed opinions on MAID. A minority of respondents had *heard* of Brittany but familiarity or unfamiliarity was largely immaterial to support of MAID. There was some small relationship at the beginning, but even that disappeared at the end. However, this is the entire sample, suggesting that perhaps it was different for people at the end if they read the script or saw the video. So, this is a three-variable Regression, MAID post-

PRIME as a function of “Previously familiar with Brittany” (Brittany previous), controlling for Video and Script

ASU		MTURK
R=.120 (ns)	Brittany Previous→Video→MAID Post-Prime	R=.126 (ns)
R=.114 (ns)	Brittany Previous->Script->MAID Post-Prime	R=.051 (ns)

Table 5.8 Of those who had heard of Brittany Maynard, how many supported her before and after seeing the video? After reading the Video Script?

Analysis: The data confirm there is no reason to think that prior knowledge of Brittany had any meaningful effect on MAID attitudes.

Section 5.5 What percentage of participants said they were religious, but used their own logic and sense of morality when making decisions? Of these, how many people supported MAID?

What is the relationship between moral values, religiosity, and MAID? This is a regression equation, looking at pre- and post-PRIME as the dependent variables, religiosity and values as predictors.

ASU	Religiosity-→RelvsMorals-→pre PRIME	MTURK
R=.349*		R=.312*
Betas Religiosity =-.349* RelvsMorals=-.001 (ns)		Betas Religiosity=.246* RelvsMorals=.160 (ns)

ASU		MTurk
R=.261*	Religiosity→Rel.vs.Morals→post-PRIME	R=.475*
Betas Religiosity= .475* Rel.vsMorals= .160 (ns)		Betas Religiosity= .266* Rel.vsMorals= .185*

Table 5.9 Of those who identify as Religious, how many support MAID pre and post-Prime?

Analysis: In both cases and in both samples, Religiosity is by far the stronger predictor.

Rel.vs.Morals does not contribute at all in the ASU sample and is very weak in the MTurk sample.

Section 5.6 How many people had never heard of MAID before the survey?

ASU N=99	MTURK N=130
24 (24.2%)	26 (20.0%)

Table 5.10 What percentage had never heard of MAID before the survey?

Section 5.7 What other factors were correlated with support or opposition to MAID?

A. Was higher education correlated with support of MAID?

B. Was gender correlated with support of MAID?

C. Was age—young or old—a factor in acceptance or oppos. to MAID?

Zero-order Correlations: All-→pre-Prime

ASU (N=99)		MTURK (N=130) (*significant at p<.05)
	Demographic Factors	
.031	Age	.094
.069	Education	.030
.307*	Gender	.037
	Religiosity	
.099	Rel.vs Morals	.201*
.300*	Reading About Religion	.189*
.339*	Spending Time in Prayer	.130*
.317*	God's Presence	.190*
.309*	Live Religious Beliefs	.180*

Zero-order Correlations: All-→post-PRIME

ASU (N=99)		MTURK (N=130) (*significant at p<.05)
	Demographic Factors	
.028	Age	.110
.036	Education	.023
.296*	Gender	.043
	Religiosity	
.028	Rel.vs.Moral	.253*
.401*	Reading About Religion*	.226*
.354*	Spending Time in Prayer	.257*
.412*	God's Presence	.232*
.378*	Live Religious Beliefs	.211*

Table 5.11 Which demographic variables correlate with support of MAID pre and post PRIME?

Analysis: The data, as expressed in Pearson Product-Moment correlation coefficients (r) at the zero-order, show very little impact on attitudes toward MAID in either pre- or post-PRIME as a function of demographic factors. In only one case (Gender) did the data show any demographic variable having significance at the p<.05 level of significance. Moreover, this was found only in the ASU sample, both pre- and post-PRIME. The relationship between Gender and attitudes for or against MAID in the MTURK sample had virtually no effect, at no time reaching significance, comparable to other demographic factors in the study. As such, the apparent relationship between Gender and MAID attitudes can be presumed to be an artifact of the ASU sample rather than a pattern that holds more broadly. In general terms, the data strongly show that demographic factors do not differentiate attitudes in any way regarding MAID,

By contrast, Religiosity items show a consistent (albeit moderate) impact on MAID, both pre- and post-PRIME and in both the ASU and MTURK samples. Interestingly, the zero order correlation coefficients, while always moderate in strength, get stronger from pre-PRIME to post-PRIME. This suggests religiosity in general (as opposed to any one component of the variable) is at once relevant to attitudes about MAID and becomes more influential in differentiating MAID attitudes over time. Further analyses done with using these factors in the composite variable "Religiosity" confirm the relevance of this factor, with a r value of .417. This underscores the fact that religiosity, far more than demographic factors, differentiate attitudes toward Medical Aid in Dying

Section 5.8 Qualitative/Quantitative Analysis of Comments from ASU and MTurk Participants

One thing we can clearly see from the comments at the end of the survey about MAID is how religion affects a participant's view of MAID. Of the 99 ASU participants, 61 left a comment. Of the 130 MTurk participants,127 left a comment. The comments in both samples were divided into three categories: Pro-autonomy and Pro-MAID comments; Neutral, non-committal, conflicted about MAID; Opposed to MAID due to religion or other concerns. The term "pro-autonomy" was used to include people who themselves were opposed to MAID but would allow it for others or believed every person had a right to choose for themselves.

In the ASU sample:

34 out of 61 (55.7%) were pro-autonomy and pro MAID
18 out of 61 (29.5%) were neutral, non-committal, or conflicted about MAID
9 out of 61 (14.5%) were opposed to MAID due to religion (6) or other concerns (3)

In the MTurk Sample:

53 out of 127 (41%) were pro-Autonomy and pro MAID
19 out of 127 (15%) were neutral, non-committal, conflicted on MAID
55 out of 127 (43%) were opposed to MAID due to religion (51) or other concerns (4)

Table 5.12 From comments only: How many participants were pro-Maid, neutral, and opposed to MAID? Note: See Qualitative data for more accurate sense of how many supported or opposed MAID.

Because the ASU participants were both younger and less religious, it was not surprising that 55.7% supported MAID and the autonomy their support implies. The studies and polls indicated that younger and less religious people support MAID at a higher rate. Among the MTurk participants who all identified as being religious, 41% supported MAID.

ASU participants were twice as likely as the more religious MTurk participants to take a neutral stance on MAID. ASU participants who supported MAID were nearly 4 times the number of those who were opposed to it. While, in the more religious MTurk sample, the number of those opposed to MAID (43%) was fairly close to the number who supported MAID (41%).

It should be noted that the Gallup Poll that reported that 72% of Americans supported MAID did not offer their respondents a Likert scale or a range from opposition to support as this study did. This means, in the Gallup Poll, people who were on the fence had to choose whether

they were more supportive or more on the opposing side. Offering a range of positions may be more scientific and thus support for MAID may be a bit less than what the Gallup poll reported in 2018. The dilemma is this: If a participant truly has a conflict about whether MAID is morally acceptable, forcing them to oppose or support MAID is not always a fair request. If someone feels 50% supportive and 50% opposed, can they fairly be added to either category?

ASU participants (less religious and younger) had a 14% higher level of support for MAID than the MTurk participants (more religious, all ages). The number of MTurk participants who oppose MAID was only 2 percentage points higher than those who support it. (41%)

Three representative comments from each group from both samples are presented below. Two things are noteworthy from the comments below: Among all participants who were religious, these respondents often said that they supported MAID despite their religion's opposition to it. This overriding of religion in favor of the participant's own sense of morality occurred in 16 of the 53 supportive responses (30 %) among ASU participants. Among the MTurk participants who supported MAID, 18 of the 53 supportive responses (33.9%) indicated that the respondent overrode what their religion taught about MAID.

Overall, the younger, less religious ASU participants supported MAID at a 14% higher level than the MTurk sample. After testing for age, education level, and gender, the supposition that MAID was supported less often by religious participants barely held up. In fact, it was so close that the support and opposition of the MTurk sample was only 2 percentage points apart. A more accurate statistic can be found in the results of the quantitative parts of the survey above rather than in the qualitative parts of the survey (the comments).

Three representative comments from each group: Pro MAID; Neutral; Oppose MAID. Note: These comments are less accurate than the quantitative data in this survey because the neutrals do not tell us if they supported MAID or not in the quantitative section of the survey. (For a list of all 188 paraphrased comments, see Appendix B)

ASU SAMPLE 61/99 respondents left comments:

Pro MAID or Pro Autonomy (55.7% of comments):

1. I am not religious so it doesn't shape my view on MAID. One thing we own in this life is our bodies. If someone chooses MAID, it is their choice and should be assisted.
2. I am not religious but would challenge a religious person's opposition to MAID by exploring their thoughts on autonomy. I am not religious but mostly support MAID.

3. I was raised Catholic but haven't been strongly religious. Some people might want to wait to see if there is a cure. I believe everyone has a right to choose. I believe MAID can give families and people comfort.

No religion, Neutral, Conflicted, On the fence about MAID: (These comments do not necessarily show support or opposition to MAID) (29.5% of comments)

1. My religious beliefs are on the fence. People have the right to make decisions about their own lives. However, I do believe each life is precious and should be lived to the fullest and sometimes that includes suffering.
2. My religion does not really impact how I view MAID. I support it in some situations and not in others.
3. I am not religious, so my beliefs do not influence my opinion on MAID.

Opposed to MAID due to religion (6) or other concerns (3): (14.7% of comments)

1. I am a Christian and against MAID. I am supposed to live life to the fullest and stay on earth as long as possible.
2. We believe everything happens for a reason and there is a reason you are still on this earth.
3. My religion rejects hate and supports well-being. But there is so much hatred in this world from the White House on down that I fear that MAID would be abused by people who live to hate others.

Table 5.13 Three representative comments from each of three groups (support; neutral; oppose) for the ASU sample

3 Representative Samples from MTurk sample. 127/130 respondents left comments at the end of the Qualtrics Survey on MAID

Pro MAID or Pro Autonomy (41.7% of comments):

1. Although my religion does not support MAID, I feel this is the moral thing to do. We do it for our pets and we should do it for our loved ones.
2. I believe the decision to die is personal between the person and God. I do not call it suicide and that is why I support it.
3. My religion is against MAID, but I feel we can do what we want with our bodies. We have a right to decide.

No religion, Neutral, Conflicted, On the fence about MAID: (These comments do not necessarily show support or opposition to MAID) (15% of comments)

1. I struggle with this. Catholicism expresses a strong support for life. But I struggle with personal choice and what God would consider right and wrong. I don't have any answers but can see both sides.
2. I have been told all my life "thou shalt not kill" and that God is the giver and taker of life. I can sympathize with people who are in such pain all they can think about is getting out of pain. I can see a person choosing death although I don't think I could. But who knows until you are actually in that situation?
3. My Christian beliefs have me a bit conflicted. I believe the taking of life is morally wrong but I support people having choices. I also believe in compassion, care, and mercy as values. I believe these values align with MAID.

Opposed to MAID due to religion (121) or other concerns (6) (43% of comments):

1. Christianity values all life from the womb to a natural death. Only God himself can decide when a person should die.
2. In my religion it is not up to anyone but how God intended or you will spend eternity in hell.
3. In my religion, we don't believe in the death penalty and we don't believe in MAID. Only God controls when we leave this earth. If we start assisting people in dying, we are trying to take God's role. Miracles happen every day. Doctors make mistakes. Someone might have a lot longer to live. They might get better.

Table 5.14 Three representative comments from each of three groups (support; neutral; oppose) from the MTurk sample

Section 5.9 Limitations of this Study

Study results were fairly in line with the polling and studies presented in Chapter 4. However, many of those polls did not offer a "neutral" category ("I neither support nor oppose…") thus forcing participants to choose to support or oppose MAID. Some polls offered the choice "I prefer not to answer." The result was that many of the participants who "neither supported nor opposed" MAID were allowed a "non-decision," a "no thought" option. Either that or they truly were totally conflicted about MAID and could not truthfully support or oppose it.

The subject of medical aid in dying is very polarizing and the questions may have triggered prohibitions and may represent lingering taboos about speaking of death. It may have been better if this study had not offered that "resting, no-decision" option in order to force respondents into choosing one side or the other. Perhaps an option like "I prefer not to answer" would have been better than a middle option which allowed participants not to actually have an opinion one way or the other.

It is very clear that most respondents consider MAID an act of suicide. Had there been an informative paragraph demonstrating the difference between suicide and MAID, there may have been fewer knee-jerk reactions to the subject of suicide that many people consider unquestionably wrong or immoral. However, including a paragraph such as that would have demonstrated bias toward acceptance or the appearance of a bias toward acceptance of MAID.

Another limitation of the study was that there wasn't a question asking participants whether they themselves had witnessed the death of someone close to them or the deaths of patients in their work. From the comments at the end of the survey, this single factor seemed to

influence several people toward an acceptance of MAID. Comparing those who have only imagined death to those who have actually experienced the death of a loved one or the deaths of patients in their work would have been a compelling addition to this study.

In the ASU sample, the randomizing of which participants saw the video, which read the video script, and which saw the control video had an unfortunate random outcome. Nearly all the 14 ASU participants who identified as "religious" ended up in the control group—meaning they didn't see the video or read the video script. This was the reason we conducted a second survey among religious people from the general population using the MTurk platform—so we could test the effect of the Brittany video on those who identified with a religion. Perhaps in the end, that luck of the draw strengthened the study because we were then able to observe an additional 130 responses from Americans who identified with a particular religion.

The other limitation of this study is that there was no time to send a second survey in order to compare what effect the passage of two or three weeks had on the views of participants. The study showed that some people who merely saw the control video moved toward or against MAID at the end of the questionnaire which indicated that there could be change after just a few minutes of consideration.

Section 5.10 The Right to Die Movement in Six Key Narratives: A Conclusion

Although more research would be needed to support the following conclusion, the failure of two separate studies to demonstrate the dramatic effect of the Brittany Maynard farewell video on both religious and non-religious participants seems to suggest that the video, in fact, was not solely responsible for the large surge in the acceptance of MAID between 2014 and 2015. Instead, this thesis argues that the opinions of Americans had evolved over the previous four and a half decades due to the impact of the five narratives of Kübler-Ross, Quinlan, Cruzan, Schiavo, and Maynard. Further, public opinion and awareness of one's own constitutional rights were heightened by the high-profile, well-covered legal cases Americans witnessed during those years.

Also, the *Right to Privacy* was a newly understood right as of the 1965 case of *Connecticut v. Griswold* just eleven years before. This newly understood Right to Privacy which

was decided in a case about a married couple having the right to information about contraceptives from their doctor had also recently been used in the highly publicized abortion debates and in cases involving same sex relationships. Americans were becoming aware that the State, according to the United States Constitution, did not have sovereignty over their private decisions having to do with their own bodies. This new Right to Privacy was also used to argue for the individual's right to die in the Quinlan case. Since Karen Ann Quinlan never made her wishes known about being kept alive, that private decision fell to her immediate family. This was the first time the desires of a family were allowed to override the interests of the State to keep its citizens alive.[183] Now the American values of autonomy, self-ownership, and human liberty included privacy and sovereignty over one's own body—a sovereignty that could be exercised by one's family if one was unable to speak for oneself.

In addition to the new legal precedents, the natural human instincts, "unwritten and unshakeable," that account for the phenomena of Natural Law and Natural Rights further reinforced the sense of rightness and virtue of this new Right to Privacy and the Quinlan's right over their daughter's death. As the Cruzan and Schiavo cases came along, the individual's privacy and sovereignty over their own body was reinforced again and again. Along the way, legal documents such as Living Wills and Medical Powers of Attorney (medical proxies) were created and became a part of the American understanding about the sovereignty they had over their own bodies. Conversely, this growing sense of self-ownership, autonomy, and human liberty among Americans helped to crystalize the opposition from religious groups and religious organizations such as Right to Life. Millions of dollars were spent by religious organizations to promote the idea that God owns our bodies rather than individuals. In 2004, the Pope weighed in with an allocution that food and water delivered by a feeding tube were "ordinary" rather than "extraordinary" care and became a requirement for Catholic hospitals and for Catholics who followed the Pope's dictates. Because she was Catholic, Karen Ann Quinlan lived nine more years supported by food and water delivered by a feeding tube.

[183] Yount, p. 69-70

Both the Cruzan and Schiavo cases demonstrated the strong feelings of the Right to Life organizations and the Catholic Church to keep human beings alive despite the fact that these women would never resume a life anywhere near a normal one. From 2000 to 2005, the Schiavo case showed how President George W. Bush, several Senators, the Governor of Florida (Jeb Bush), several courts, and many religious leaders publicly called for the prolonging of life for Terri Schiavo for religious reasons. It was during this time that many Americans, including Catholics, filled out their Living Wills and Medical Proxy forms to ensure that Terri's fate would not happen to them. The Schiavo case solidified the American sense of one's rights over one's own body. Well before the Schiavo case was over, Oregon had passed its Death with Dignity Act allowing medical aid in dying. Other states were considering doing the same.

By 2014, the idea that every citizen had a right to determine what happened to them at their own death was held by a majority of Americans. It was in this cultural milieu that Brittany Maynard's farewell video went viral. Her video and her reasons for wanting to die on her own terms hit a nerve in the American psyche. Her words captured what a majority of Americans now believed. And the opinions of Millennials—who are known for their sense of autonomy and individuality as well as their low level of religiosity—were now a large part of public opinion. They were, in 2014, old enough to influence public opinion and they were the age demographic who used and were influenced by social media more than anyone older than they. Based on the demographics of MAID supporters, it can be assumed that support for MAID will continue in the future.

The original study presented in this thesis questions whether the Maynard video narrative alone was responsible for the dramatic shift in public opinion toward support of medical aid in dying. Could Brittany Maynard perhaps have served as the Antigone of the Right to Die Movement? The concepts of autonomy, self-ownership, the Right to Privacy, and Natural Law had long been in the background of our evolving society. Just as Heraclitus had already laid the foundation of Natural Law which Antigone then verbalized in a dramatic presentation for a Greek audience, could Brittany Maynard's six-minute video have captured and encapsulated the American values that the Right to Die expresses and embodies? Could Brittany Maynard's brief

narrative have acted on the public in the twenty-first century as Antigone's speech to King Creon had acted on the Greek audience—and on Western Philosophy—ever since the fifth century BCE? This thesis says, "Yes!"

Despite what the laws of California actually allowed and forbade, Brittany Maynard insisted that there were "unwritten, unshakeable laws" that could be followed simply by moving to another state that had laws that seemed to be more in keeping with how she regarded her own death.

Though no one expects everyone or even a majority of the dying to use MAID, the human liberty and individual rights implied in Natural Law would include this freedom for those who desire it. Brittany Maynard, as her YouTube video viewers could plainly see in her face and in her words, embodied a human being's ultimate right to choose how and when she would die when death was already approaching. Ending her life by her own hand rather than being at the mercy of her glioblastoma was entirely in keeping with her independent spirit, her individuality, and her insistence that her death be consistent with how she had lived her life.

The Qualtrics Survey in this study clearly showed that people who identify with a particular religion often support MAID. On the other hand, religion is the main factor—and the only factor in this study—cited by participants as the reason they oppose MAID. Religion either *complicates* or *clarifies* participants' views on MAID. Religion's ancient ideas, prohibitions, and doctrinal views of who owns our bodies and our lives still ring in the hearts and minds of Americans everywhere. But, given a simple moral choice between allowing MAID for the few or forbidding it for everyone, 58.9% (excluding all neutrals) of the combined respondents in the two samples in this study found a way to support it—for other people, if not for themselves. This universal sense of what is right and what is wrong—often an insistence on liberties beyond the written laws—is Natural Law. Natural Rights which proceed logically from Natural Law are inalienable—a universal characteristic of humans all over the world that can be discovered by human logic and reason—which some people believe are gifts from a Creator God.

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APPENDIX A

IRB APPROVAL

ASU Knowledge Enterprise Development

EXEMPTION GRANTED

Joel Gereboff
SHPRS: Religious Studies Faculty
480/965-7738
Joel.Gereboff@asu.edu

Dear Joel Gereboff:

On 3/27/2019 the ASU IRB reviewed the following protocol:

Type of Review:	Initial Study
Title:	The Effectiveness of Brittany Maynard's Video Narrative on the Acceptance of Laws Permitting Medical Aid in Dying* (*MAID)
Investigator:	Joel Gereboff
IRB ID:	STUDY00009777
Funding:	None
Grant Title:	None
Grant ID:	None
Documents Reviewed:	• Video to be shown , Category: Other (to reflect anything not captured above); • University Students' Attitudes toward a State Law, Category: Recruitment Materials; • University Students' Attitudes toward a State Law, Category: Consent Form; • University Students' Attitudes toward a State Law, Category: IRB Protocol; • Qualtrics Study including Consent form and registration at the end, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions);

The IRB determined that the protocol is considered exempt pursuant to Federal Regulations 45CFR46 (2) Tests, surveys, interviews, or observation on 3/27/2019.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely,

IRB Administrator

cc: Jennifer Grossman
Kathryn Johnson
Jennifer Grossman
Gary Grossman
Heather Ross

APPENDIX B

QUALTRICS SURVEY INSTRUMENT RE MAID

Informed Consent

Screen Question:

Do you identify as:

Religious
Non-religious
Spiritual but not religious

COVER LETTER and CONSENT

RESEARCHERS: Jennifer Grossman and Dr. Joel Gereboff, Arizona State University.

REQUIREMENTS: You must be at least 18 years old to participate.

DESCRIPTION: This is a survey regarding beliefs and social attitudes. The survey takes about 20 minutes or less to complete.

RISKS: There are no known risks from taking part in this study.

BENEFITS: There are no direct benefits to you as an individual. We believe this research will help us better understand the relation between beliefs and social attitudes of people today.

COMPENSATION: You will receive $1.00 as compensation upon completion of the study. Please note that you must proceed to the end of the study, enter your MTurk ID, and provide the security code (which will be highlighted in yellow) in order to receive compensation.

CONFIDENTIALITY: The results of these research studies may be used in reports, presentations, and publications, but the researchers will not identify you in any way.

WITHDRAWAL PRIVILEGE: Participation in this research is completely voluntary. It is ok for you to say no. You may choose to withdraw from the study at any time; however, you will not receive compensation unless you proceed to the end of the study, re-enter your worker ID, and submit the security code word on the MTurk website.

CONSENT: Any questions you have concerning this research, or your participation in the study, can be answered by Jeni Grossman (jennifer.grossman@au.edu), ASU. If you have questions about your rights as a participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through the ASU Office of Research Integrity and Assurance, at 480-965 6788

Click on the "I consent" answer bar to start the survey.

Thanks for helping with this research!

- I consent. I will begin the study

CAUTION!! - Clicking the back bar on your browser will exit the survey and you will not be able to return to the survey.

Please insert your MTurk worker ID in the box below.

1. Some states are considering making Medical Aid in Dying legal. This means a patient can request medical assistance in hastening their death. This option is available when the patient is within six months of dying, fears indignities or dependence, and is suffering due to a terminal illness or condition.

   Before today, had you ever heard the term “Medical Aid in Dying”? (Also known as MAID; “Death with Dignity”; “The Right to Die”; “Physician-Assisted Dying”; “Physician-Assisted Suicide”; etc.)

   Yes
   No
   Not sure

2. In 2014, Brittany Maynard, a 29-year-old California woman chose to die by ingesting a doctor-prescribed lethal medicine rather than suffer seizures and then death from her rapidly-growing brain tumor. She made a farewell video to explain why she moved to Oregon to take advantage of the state's Death With Dignity Law. (Death with Dignity is the same as Medical Aid in Dying)
3. Before today, had you ever viewed Brittany's farewell video or heard/read a news story about Brittany Maynard?

   Yes
   No

4. Regardless of whether you think MAID should be legal, please tell me whether you personally believe that, in general, Medical Aid in Dying is morally right or morally wrong:

   Morally right
   Somewhat morally right
   Neither morally wrong nor right
   Somewhat morally wrong
   Morally wrong

5. Which of the following statements describes your method for making moral decisions:

   Nearly all my moral decisions and choices are based on my religious beliefs.
   I make my decisions and choices based on my own sense of right and wrong.
   My religious beliefs inform my moral decisions, but I also rely on my own sense of right and wrong.

6. To what extent do you agree or disagree with the following?

7.	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I enjoy reading about my religion	○	○	○	○	○
It is important to me to spend time in private thought and prayer	○	○	○	○	○
I have often had a strong sense of God's presence	○	○	○	○	○
I try hard to live all my life according to my religious beliefs	○	○	○	○	○
My whole approach to life is based on my religion	○	○	○	○	○

Brittany video

Please watch this 6-minute video, then answer the questions on the next survey.
Note that the survey will not advance until the video is finished.

[This question lets you record and manage how long a participant spends on this page. This question will not be displayed to the participant.]

8. Was this video informative?

   Yes
   No
   Not sure

Video Script: **Brittany Maynard Video Script**

Brittany: The thoughts that go through your mind when you are told you have so little time…is everything you need to say to everyone you love.

Narrator: In January, 2014, after months of suffering debilitating headaches, Brittany Maynard found out she had brain cancer. She was given a prognosis of 6 months left to live. She had recently turned 29.

Brittany: So, after getting married is when I first started experiencing the headaches and they were quite severe. And I didn't understand them because I had never had anything like that in my life. Right when I was diagnosed, my husband and I were actively trying for a family which is…heartbreaking for both of us. And then I was diagnosed this past New Year's. We went away to the wine country for a kind of New Year's Eve celebration. And, on January 1st, I was diagnosed with brain cancer and was told I was terminally ill.

Narrator: Glioblastoma multiforme is the most aggressive and lethal form of brain cancer. It grows and spreads to other parts of the brain quickly. Studies show that few patients survive beyond 3 years, regardless of the treatment course they receive.

Brittany: I was told I had a grade 2 astrocytoma and was told I had anywhere from 3 to 10 years to live. I have to tell you, when you are 29 years old being told you have that kind of time line still feels like you are being told you are going to die tomorrow. Seventy days post op, I went in for an MRI and was told I had a grade change. They were saying it looks like Grade 4 which is the worst and most aggressive form of brain cancer. It's called a glioblastoma. So that was a major shock to my system and to the system of my family because it went from being potentially years of time to being told I had like 6 months. My parents spent a couple of months—they just wanted to search for a miracle.

Brittany's Mother: In the beginning, I hoped for everything. First, I hoped that they had just the wrong x-rays, the wrong brain scans. Your brain will do really strange things when you don't want to believe something. You will come up with fairytales!

Narrator: Faced with very few options in her home state of California, Brittany and her family chose to move to Oregon so she could access its Death with Dignity law.
She met the criteria, and received a prescription for the medication that will end her life peacefully and painlessly if she chooses to ingest it.

Brittany: I don't wake up every day and look at it. I know it's there in a safe spot, and it will be there when I need it. I plan to be surrounded by my immediate family which is my husband and my mother and stepfather and my best friend who is also a physician—and probably not many more people. I will die in my bedroom upstairs in the bed I share with my husband. With my mother and husband by my side, I will pass peacefully with some music that I like in the background.

Brittany's husband, Dan: Between suffering and being allowed to decide when enough is enough—it just provides a lot of relief and comfort. Like…okay! That option is there when she decides it's time…

Brittany: I can't even tell you the amount of relief that it provides me that I don't have to die the way that has been described to me—the way the brain tumor would take me on its own.

Dan: *Death with Dignity* allows people who are in the predicament of facing a lot of suffering that they can decide when enough is enough.

Narrator: Pressed with only months to live, Brittany has prioritized spending time with the people she loves, and traveling.

Brittany's Mom: Brittany has always been bigger than life. She has a kind of wanderlust. She has always liked exciting things—adrenaline rushes. She has always been precocious and very, very bright. Anything she set her mind to—she did.

Brittany: Since becoming ill, I have traveled. My husband and I took a beautiful trip to Yellowstone. It was exquisite! Then I went with my best friend to Alaska. We went to Denali National Park and Seward and to the Kenai Fjords and kayaked up to the glaciers. Then I met my mother in Juneau and we took this spectacular boat trip. Before I pass, I'm hoping to get to the Grand Canyon because I've never been. And that's all I can do—is set little goals like that. All those things make everything worthwhile.

Brittany's mom: My hope is now that Brittany can live her life the way she wants to, that she can make the decisions that she wants to, that she can be who she is which is very autonomous, bright, well-read, well-traveled—a person who loves adventure. She's got me into this thing where

we've agreed to meet. So I'm going on a traveling adventure to this place—I'm scared to go!—Machu Picchu. A lot of climbing. She said she'll meet me there, and so, damn it—I'll go!
Brittany: I hope to enjoy however many days I have left on this beautiful earth and spend as much of it outside as I can—surrounded by those I love. I hope to pass in peace. The reason to consider life and what's of value is to make sure you're not missing out! Seize the day! What's important to you? What do you care about? What matters? Pursue that! Forget the rest!

Narrator: At present, only 7 U.S. states allow terminally ill people the right to die with dignity. A movement is underway to expand access, so that no American has to endure prolonged pain and suffering.

[This question lets you record and manage how long a participant spends on this page. This question will not be displayed to the participant.]

9. Was this script informative?

   Yes
   No
   Not sure

Control Video

Please watch this video, then take the survey.
Note that the survey will not advance until the video is finished.

[This question lets you record and manage how long a participant spends on this page. This question will not be displayed to the participant.]

10. Was this video informative?

    Yes
    No
    Not sure

Post-Prime questions:

11. Regardless of whether you yourself would end your own life if you were suffering and in your final 10. months of a terminal illness, what is your attitude toward people who wish to legally take a doctor-prescribed lethal medicine to hasten their deaths?

    Strongly support
    Somewhat support
    Neither support nor oppose
    Somewhat oppose
    Strongly oppose

12. Regardless of whether you think it should be legal, please tell me whether you personally believe that, in general, Medical Aid in Dying is morally right or morally wrong.

    Morally right
    Somewhat morally right
    Neither morally right nor wrong
    Somewhat morally wrong
    Morally wrong

13. Which describes your attitude toward laws *allowing* Medical Aid in Dying?

    Strongly support
    Somewhat support
    Neither support nor oppose
    Somewhat oppose
    Strongly oppose

14. My religion opposes Medical Aid in Dying.
    My religion strongly opposes Medical Aid in Dying
    My religion opposes Medical Aid in Dying
    I do not know if my religion opposes Medical Aid in Dying
    My religion supports Medical Aid in Dying
    My religion strongly supports Medical Aid in Dying
    I am not religious

15. Regardless of my religion's support or opposition toward Medical Aid in Dying, I believe other people should be able to legally end their lives when they are suffering and already dying.

    Strongly agree
    Somewhat agree
    Neither agree nor disagree
    Somewhat disagree
    Strongly disagree
    I am not religious

16. Some people oppose Medical Aid in Dying**.** If you do not support MAID, can you please tell me why you might oppose Medical Aid in Dying?

I oppose Medical Aid in Dying because of the following reasons:

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
Laws allowing Medical Aid in Dying are morally wrong.	○	○	○	○	○
Doctors should never be involved in ending the life of a patient.	○	○	○	○	○
Someone other than doctors should	○	○	○	○	○

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
dispense lethal medicine and supervise the legal process of Medical Aid in Dying.					
I fear that laws allowing Medical Aid in Dying can lead to abuse. People could use them to kill relatives, to kill physically or developmentally disabled people, or the medicine could kill unintended people (children, accidental ingestion, etc.)					
I fear passing MAID laws will cause a slippery slope. Once Americans accept Medical Aid in Dying, what's next? Eugenics? Killing deformed infants? Killing those who are too expensive to keep alive?, etc.					
I believe today there is plenty of pain medicine that can eliminate pain and suffering as a person is dying. Hospice care and pain medicine eliminates the need for Medical Aid in Dying.					

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
I oppose Medical Aid in Dying based on my religious beliefs.	○	○	○	○	○
OTHER	○	○	○	○	○

Qualitative piece

17. We are interested in how religious beliefs inform or shape attitudes toward Medical Aid in Dying. Please write a few sentences explaining how YOUR religious beliefs have shaped your own attitudes toward Medical Aid in Dying . . . whether supportive or in opposition.

Demographics

18. I am:

    a student
    a person with a job
    a stay-at-home parent
    unemployed
    Other

19. How old are you?

20. What is the highest level of education you have completed?

    Home Schooled
    Some High School
    High School grad
    Some college
    College grad
    Grad student
    Graduate degree/degrees

21. My religion is:

Catholicism
Mainline Protestant (e.g., Methodist)
Evangelical Christian (e.g., Bible based)
Judasim
Islam
Hinduism
Agnostic
Atheist
None
Spiritual but not religious
Other Describe_____
Latter Day Saints

22. My gender is:

    Male
    Female
    Non-binary

Please enter your MTurk worker ID number for verification purposes.

The code word to enter on MTurk is SURVEY

23. Comments before you go?_____

APPENDIX C

PARAPHRASED COMMENTS FROM ASU SAMPLE

Comments at the end of the ASU Qualtrics survey on MAID (Some of the longer comments were paraphrased but key wording was left in place)

61/99 ASU Participants left a comment at the end of the Qualtrics Survey on MAID

34/61 (55.7%) Pro-Autonomy, Pro-MAID Comments:

1. I am a Christian and neutral on MAID. I believe a terminally ill person should trust God and the doctors until the end. But I also believe everyone should make his own choice—to each his own. (Despite the claim of neutrality, this comment is in the pro-autonomy group because "everyone should make his own choice—to each his own."
2. I am Catholic which is strongly against MAID. However, I know religion does not have the right to tell others what to do.
3. I grew up Catholic and am in the medical field. I see how peaceful death could and should be.
4. I am a Christian and neutral on MAID. I believe a terminally ill person should trust God and the doctors until the end. But I also believe everyone should make his own choice—to each his own. (Despite the claim of neutrality, this comment is in the pro-autonomy group because "everyone should make his own choice—to each his own."
5. I am Catholic which is strongly against MAID. However, I know religion does not have the right to tell others what to do.
6. I grew up Catholic and am in the medical field. I see how peaceful death could and should be.
7. I am not religious so it doesn't shape my view of MAID. Those who are of sound mind and have tried everything else have the right to choose MAID.
8. I am not religious so it doesn't shape my view on MAID. One thing we own in this life is our bodies. If someone chooses MAID, it is their choice and should be assisted.
9. I was raised a liberal Christian, but I am not religious now. I think people who are suffering should be allowed to choose MAID.
10. I am not religious. Religion should not have a place in determining laws. Why should the beliefs of some religions be imposed on everyone?
11. I am not religious, but very spiritual. I believe that people control their own bodies and have a right to choose MAID if they have less than 6 months to live.
12. I am not religious but would challenge a religious person's opposition to MAID by exploring their thoughts on autonomy. I am not religious but mostly support MAID.
13. I am not religious and I think this law should be approved in every state.
14. I am not religious. Even if I were, I do not think religion should play a role in shaping our morals beliefs.
15. I am not religious. I am against suffering. If something ends suffering, it should be allowed.
16. I am not religious. I believe that a human being has the right to decide what happens to their own body. If I were suffering, I would choose to end my life on my own terms.
17. I believe everything happens for a reason, and I believe if a person is suffering at the end, they should have the right to pass on and it is a part of God's plan.
18. I can't really say what my religion says about MAID but people have a right to choose how to die.
19. I grew up Christian but consider myself a New Age spiritual person. God has a plan for everyone's life so we should not mess with this. However, I do believe in free agency for everyone. I would not use MAID myself.
20. I have spiritual beliefs, not religious. I think we all choose the next right thing for ourselves. I watched my mother die of cancer when she wanted to visit Dr. Kevorkian. I wish we all could pass peacefully and without suffering.
21. I was raised Catholic but no longer participate in organized religion. I do believe in God. I believe God gave us opportunities to choose and now it is up to us to choose.
22. I was raised Catholic but left when I was 24 because of their absurd/misogynistic/bigoted beliefs. I believe Jesus had compassion on those who were suffering and did not judge them. I think that is the most moral way to be—non-judgmental. I have the utmost compassion for those who are terminally ill and want to die with dignity.
23. I was raised Catholic but haven't been strongly religious. Some people might want to wait to see if there is a cure. I believe everyone has a right to choose. I believe MAID can give families and people comfort.
24. I'm agnostic. But if God were real, he wouldn't want one person to suffer. Each person is in charge of their own life so MAID should be available for those who wish to end a life with no quality.
25. I am not religious but I did grow up Catholic. I remember the part about do no harm and to end all suffering. MAID is a kindness because, after doing all you can to ease the suffering, you are giving the patient the power of choice.
26. Religion did not influence me, but it all depends on the situation of the person.
27. My religious beliefs do not support MAID, however seeing pain at the end of life, I believe people should be able to choose how their story ends.

28. My family and I are Catholics so we feel that suicide is wrong. That being said, if they are in extreme pain, I feel it is their choice if they are not hurting others.
29. My religion does not support MAID. However, as a neuro ICU nurse, I have seen the suffering associated with medical conditions (especially glioblastoma). If we have the means to hasten the suffering and this is what the patient wants, I believe we should be able to.
30. My religion opposes MAID but I feel individuals who have the capacity to make their own decisions should be able to decide whether they are willing to prolong the inevitable.
31. My religion opposes MAID, but I believe certain individuals should qualify to decide whether to postpone a death that is impending either way.
32. My religion teaches that all human life is valuable. But, in the end, all human life is in the control of the individual. If a person wants to die "with dignity", they should be able to.
33. My religious beliefs are very flexible but the morals and values I have learned have taught me to respect human life and human experience. MAID is a wonderful gift similar to the miracles in the Bible.
34. I was raised Catholic but have come to trust my own sense of right or wrong. Despite the great changes in the church that have brought about a more modern church, I rely on myself. Despite the fact that there is great sanctity in every life and we learn from everyone and from every death, I think it seems cruel not to provide medical aid in dying.
35. Religion: Human life is a gift. It is not to be taken for granted. Take care of ourselves. Me: People who choose MAID have exhausted all efforts: medical, spiritual, physical, and mental.
36. To be honest, I am not religious myself. I support anyone's decision to take their own life.

18/61 (29.5 %) Neutral, non-committal, conflicted on MAID

NOTE: It should be noted that many of these respondents might well be supportive of MAID. These neutral comments only stated that religion did not influence their view of MAID (9/18 or 50%) or that they were not religious (9/18 or 50%).

37. I do not have religious views.
38. I do not think my religious views have shaped my opinion on MAID.
39. I do not think my religious views go in either direction on MAID
40. I am not religious.
41. I am not religious but I know the Christian position against MAID. I think they say it is a sin to prevent people from taking the "easy way out."
42. I am not religious enough to explore what my religion things about MAID.
43. I am not religious so it doesn't shape my opinion on MAID
44. I am not religious, so my beliefs do not influence my opinion on MAID.
45. I believe when a person is terminally ill, they should not have the option to choose when they will go because it eliminates the option of God's intervention to heal the person. Even if a person must suffer, they could be a source of light to someone else or be someone to talk to. However, I have never researched this so I don't know how bad the suffering could be.
46. I have no religious beliefs.
47. I think my lack of religious education growing up has allowed me to decide for myself what is right or wrong.
48. I was taught murder was a sin and is wrong. But I am neutral on MAID because it is up to people to choose how to die. It is their choice, their life, their souls.
49. My religion does not dictate my beliefs.
50. My religion does not support MAID. All suffering, illness, and deformity is brought on by the individual therefore suffering is not from God. Since it is not of God, it is exempt from my religious beliefs.
51. My religious beliefs are on the fence. People have the right to make decisions about their own lives. However, I do believe each life is precious and should be lived to the fullest and sometimes that includes suffering.
52. My religion does not really impact how I view MAID. I support it in some situations and not in others.
53. I prefer not to answer.
54. My views on MAID are not informed by my religion because I no longer hold any religious beliefs.

9/61 (14.7%) Against MAID due to religion (6) or other concerns (3):

55. Buddhism insists you can meditate through the pain and let go of attachments.
56. I do not think my religious beliefs influence my views on MAID. However, I have concerns about the widespread use of MAID.

57. I live in California where they allow MAID. I watched my wife die of ovarian cancer and a bowel obstruction. I could never kill my wife nor did she ask me to. I might not be the right person to ask because it took me awhile to realize my wife is in a better place and no longer in pain. I am against MAID.
58. I think life is precious.
59. I would like to think my religion has nothing to do with my opinion on MAID. However, I worry about other issues with all the decisions involved in ending a life. Who is right? Who has the authority? Should this be a part of a healthcare plan? Where do doctors draw the line?
60. My religion rejects hate and supports well-being. But there is so much hatred in this world from the White House on down that I fear that MAID would be abused by people who live to hate others.
61. I am a Christian and against MAID. I am supposed to live life to the fullest and stay on earth as long as possible.
62. MAID is not God's way.
63. We believe everything happens for a reason and there is a reason you are still on this earth.
64. We die in our own time.

APPENDIX D

MTURK SURVEY RESPONDENT COMMENTS

127/130 respondents from the MTurk survey left comments

53/127 (41.7 %) Pro-Autonomy, pro-MAID Comments:

1. A lot of my religion involves human dignity and doing all we can to preserve that for ourselves and others. I support MAID because it allows a person to die a dignified death.
2. Although my religion does not support MAID, I feel this is the moral thing to do. We do it for our pets and we should.
3. God is in charge of the universe. But he also gives us free will. I sympathize with Brittany Maynard and support her right to do what she wants. I just wouldn't do it.
4. Even if my Catholic religion told me it was wrong, I would change my mind that a person stricken with a terminal illness has the right to die. These people have done nothing wrong and will go to heaven.
5. I am generally opposed to this but I can understand some people deciding this for themselves.
6. I am not a religious person and support a person's right to use MAID.
7. I don't care what my religion says, I strongly support MAID and would use it were I in the same situation.
8. I don't know where my religion stands on this but I approve of MAID regardless.
9. I am not sure how I feel. Life is precious and sacred, but God has given us free will. Only God can is capable to judge our actions and decisions.
10. Because I am older now, I feel like I think more sensibly. I approve of MAID and would use it if I were in the same situation.
11. I believe everyone has their own belief in their own religion and has their own view of living. No one has the right to tell anyone else what to do. All we can do is support them and let our voice be heard!
12. I believe God is the giver of life and we each have a purpose. Can I stop my suffering? Yes. Should I stop my suffering and hasten death? That is for each person to decide.
13. I believe God would be ok with it.
14. I believe in reincarnation so if someone wants to try again with life then I think they will just be reborn. That way they can start over and achieve the life they really want.
15. I believe it is wrong to let people suffer. I have watched many suffer and pain meds don't always help. The dying need dignity and to have a dignified death.
16. I believe the decision to die is personal between the person and God. I do not call it suicide and that is why I support it.
17. I believe in God and have witnessed miracles in my life. I also believe that if someone is suffering and of sound mind, they have the right to end their own lives on their own terms
18. I do not associate MAID with religion. I think if you get to the stage of cancer Britany had, you should be allowed to take your own life when you are ready so you don't suffer or be in pain.
19. My religion does not support MAID, but I feel it is not my place to judge others who are in this unfortunate position. I would support a law making it legal in my state (CA) even though I would not personally agree with it.
20. I don't bother with my religious support or opposition, I strongly support it.
21. I don't know what my religion allows, but God forgives those who commit suicide and forgives them. I suppose God would forgive those who use MAID. God does not want anyone to suffer. God would be very accepting of those who chose MAID.
22. I guess my religious beliefs really do not shape my attitudes toward MAID. I feel it is immoral to allow one to suffer. As long as that person is of sound mind they should be allowed to have the choice to end their suffering in a humane manner.
23. I have mixed feelings regarding MAID. However, I think all religion should permit MAID because euthanasia is a human right. Any religion that supports human achievement and dignity should allow for a peaceful death without too much debate.
24. I honestly do not know how my religion feels about MAID. But I believe it should be completely up to the person how they choose to live and end their own life.
25. I personally do not think I would use MAID. But it should be available for someone who was terminally ill. It's up to yourself and God as to what you can do.
26. I support MAID. I am Jewish and not sure about religious view toward this. There is no need for this type of suffering in life when death can bring relief.
27. I support MAID because I would never want my religious beliefs to be forced on someone else.
28. I think if you know that you are going to die, it should be up to you if you want to take your own life.
29. It's a free country so everyone should be able to decide for or against MAID.
30. I think my religion is against MAID. But in the case of Brittany Maynard, I think it is okay and there is nothing morally wrong with it.
31. I think people should be able to do what they want with their lives. It's their right as a human being.
32. I think people who follow religion strictly miss the point. Life should be compassionate. When someone is suffering and they know the end is near, I don't think it's wrong to allow the option to remove the suffering.

33. I think that God gave us free will and part of free will means to decide to avoid or end suffering. It seems the compassionate thing to do. One thing I have learned from Jesus Christ's teachings is to help someone end their suffering if it is something we can do.
34. I'm okay with it. They are suffering and the only cure is, sadly, death.
35. My religion believes MAID is morally wrong but if a person is suffering and just wants to die, they have a right to.
36. My faith is based on the teachings of Christ and the compassion of God. I don't believe that God wants us to suffer. What is the point of medicating someone to the point they are not lucid, but still having some pain and allowing them to die with dignity? I believe that God would choose the latter.
37. My religion denounces suicide but I don't consider MAID suicide. Those people are already dying. I can understand and accept that.
38. My religion doesn't say anything about MAID. I believe in God and Jesus and there is nothing in the Bible to support or go against MAID.
39. My religion teaches that MAID is wrong. But I think people in my religion are too trusting in God and not trusting enough in science. If someone wants to use medicine to avoid a miserable death, I think God would support that.
40. My religion opposes MAID but I support it because the person is already dying.
41. My religious beliefs are that everyone is shown love and concern. If anyone wants to use MAID, no one should judge them.
42. My religion is against MAID, but I feel we can do what we want with our bodies. We have a right to decide.
43. Despite my religion being against MAID, I support it. It is irrelevant to my sense of right and wrong. My religion requires me to think openly. MAID should be legalized because no one wants to live in pain.
44. Even though my religion is opposed to MAID and suicide, I don't see why people need to suffer for months. Also, church and state should be separated so it doesn't matter what religions dictate about this.
45. I choose to follow common sense and choose not to follow the non-practical aspects of Catholicism. There is more than one path to God.
46. Choosing MAID is up to the dying patient. I would not advocate for it, but the decision is between doctor and patient if the patient is of sound mind.
47. MAID is up to the patient. They should have the freedom to choose.
48. My religion supports MAID
49. Because I have an undiagnosed illness that causes me chronic pain, I still hold open hope for a diagnosis and a treatment. But if I were terminal, I would choose MAID.
50. Religion and State should be separate so religion should have no say about MAID.
51. My religion frowns on suicide, but this woman (Brittany) should be able to die with her family and friends around her.
52. My mother in law had ALS and wanted to die, but her husband was very religious and would not help her. It was such a stressful time, but I understand this whole process.
53. My religion says MAID is wrong. But I cannot pretend to know what these people are going through. I think they should have the right to make their own choices.

19/127 (15.0%) Neutral, non-committal, conflicted on MAID

54. I struggle with this. Catholicism expresses a strong support for life. But I struggle with personal choice and what God would consider right and wrong. I don't have any answers but can see both sides.
55. I believe in Jesus Christ and am a Christian Non-denomination.
56. I have very mixed feelings about this personally and morally. I worry about the slippery slope and normalizing euthanasia.
57. I feel that you should aid in dying and let it happen medically. However, I understand why some people would want to do this regardless of religious beliefs.
58. I have been told all my life "thou shalt not kill" and that God is the giver and taker of life. I can sympathize with people who are in such pain all they can think about is getting out of pain. I can see a person choosing death although I don't think I could. But who knows until you are actually in that situation?
59. I can't really support or oppose it. My religion opposes it because it is a form of suicide. But if a person is suffering a horrible death, then I think it's OK for them to choose MAID.
60. I think it's important to respect doctors. If God says it is time to go—it's time.
61. My beliefs as a Christian have shaped by attitudes towards the taking of a life. I don't think that God approves, however, I totally understand those whoare in that situation. I don't condemn that at all.
62. I'm not sure if my religious belief is in supportive or opposition. My belief is that it can be good or bad. I can see people abusing it but if a person is suffering and don't want to suffer any longer, it can be a good thing.
63. I'm neutral about this. I find it best to stay out of these things.
64. Religion has not influenced me.
65. It is difficult to decide whether to support it or not. The weird part is they are terminal—either they die from the medicine or from their disease.

66. My Catholic religion would definitely oppose this and I think I should oppose it but then there are times when I think I would rather be dead than be a vegetable so I am torn.
67. My Christian beliefs have me a bit conflicted. I believe the taking of life is morally wrong but I support people having choices. I also believe in compassion, care, and mercy as values. I believe these values align with MAID.
68. It is difficult to know how I feel because my religious beliefs are in conflict with how I feel about MAID.
69. My religious beliefs have changed over time. I am confused about MAID morally. God never puts more on us than we can take. But I can totally understand a person who knows he is going to die wanting to get it over with. I do not judge those who choose to receive help in such a way.
70. My religious beliefs make me think that MAID is morally wrong but when in deep pain, it's acceptable.
71. I am on the fence. While I believe our lives are not ours to end, I also believe needless suffering at the end of life is cruel and inhumane.
72. Prefer not to answer

55/127 (43%) Against MAID due to religion (121) or other concerns (6):

73. According to my religion, Life and Death are predestined and we human should not meddle with it in order to keep the balance of nature. MAID is not the right way to end a life. We should try to lessen the pain and suffering and pray for a person's relief and not decide a person's end.
74. Christianity values all life from the womb to a natural death. Only God himself can decide when a person should die.
75. God gave me a life. He will end it when it is time to end.
76. God is against murder. The people are killing themselves and other people are helping them.
77. Seeing suicide means a person has lost his ability to carefully weigh the benefits and burdens of continued life. Intervention to stop the suicide is ethically warranted.
78. I am opposed to MAID because suicide is wrong! My sister was in Stage 4 cancer and did not commit suicide and she is in remission and healthy now.
79. I am very religious and think MAID is morally wrong.
80. There is no reason to end your life. God has a plan for everyone. No need to hasten, no need to fight it. It will happen when it happens.
81. I believe that life is precious and that no one but God decides the day, time, and hour of death.
82. I believe that God is the only one who can decide when our time on earth is done. He has a distinct plan that should be followed. Killing is morally wrong.
83. I believe that it is not our choice when we are supposed to die. God gave us life and decides our time to go. Any type of suicide is morally wrong.
84. God gave us life and he is the one who decides when it is our time to go. Any type of suicide is breaking God's commandments and is not morally right.
85. I believe it is totally up to God to determine the time of a person's death and that anything other than that is murder no matter how legal it is.
86. Only God knows when our day to die is going to be. I feel sorry for people that are suffering but when a person should die should be left to God. The doctors should give medicine to make them more comfortable and not to kill them.
87. I worry that making MAID legal would make it ok for trivial reasons. I also know doctors take the Hippocratic oath to do no harm. A doctor should not go against what he is supposed to be doing.
88. I took care of both my parents when they died so of course I did not want to see them suffer. But assisting someone to commit suicide is a sin and we are not to kill anyone much less ourselves. Each of us has free will and when the person meets Our Father in heaven, they will have to justify their actions.
89. I took care of my husband who died a miserable death from a glioblastoma. But I don't think I could sanction an earlier end to his life. God was in charge and took him when his time was over.
90. Only God decides when someone dies.
91. I don't support this. I feel you are not going until god say you going. (sic)
92. I feel no one should take another person life or help another person die. Only god should do that. MAID is morally wrong.
93. I just believe that God has an appointed time for us all to die. Our circumstances and sufferings and illnesses shape us and have a purpose.
94. I just don't believe it is up to us to take a life. I think God wouldn't want us to either.
95. I oppose MAID because I don't think it ok to take your own life. I feel like it is telling God he made a mistake.
96. I oppose MAID. I am a born-again Christian and my beliefs prevent me from ever taking my own life no matter what the reason. Taking my own life prevents God from healing me and negates any chance of a healing miracle.
97. Suicide is a sin. MAID is a form of suicide whether you have a terminal illness or not. End of story.

98. In my religion it is not up to anyone but how God intended or you will spend eternity in hell.
99. In my religion, we don't believe in the death penalty and we don't believe in MAID. Only God controls when we leave this earth. If we start assisting people in dying, we are trying to take God's role. Miracles happen every day. Doctors make mistakes. Someone might have a lot longer to live. They might get better.
100. In my religion, I am taught that only God can give or take life. If people want to use doctors to be healed, the outcome is in God's hands. If people want to use doctors to die, the outcome is taken out of God's hands and put in the hands of the doctor. This is wrong.
101. Killing is never a means of caring. In my religious beliefs, it is important to maximize are for one how is suffering rather than minimizing suffering which might include eliminating the sufferer.
102. It is God's right to take us. I feel God does not teach this in any way. I hope I will have the ability to trust when my time comes because if I truly believe that about God I would be wrong to go against it.
103. It's wrong to take a life. It's still murder whether you take your life or someone else's life.
104. MAID is against my religion. My beliefs will not let me support MAID.
105. Life is considered precious and can only be ended by the will of God. MAID could be considered murder.
106. My belief in God shapes my attitude in that there is a plan for us all. God presents people with ailments not only to bring them home sooner but to help those who surround the patient with their faith in Him. The only suffering God wanted and was needed was when his son died on the cross, suffering so we didn't have to—whether emotionally, spiritually, or physically.
107. My beliefs are that miracles happen all the time. People can be healed all the time. People can be healed and taking one's own life is a sin.
108. My Catholicism has taught me that no one has the right to take a life, assisted or not. It also teaches that pain and suffering are part of life. In our society, we are rationalizing about making our lives easier and playing God with technology and whether or not it is moral. I believe that those who partake in such ventures will receive justice one day.
109. My God does not approve of people killing themselves or other people Killing is wrong period.
110. My religion believes that everything will happen at their own pace.
111. My religion frowns on killing others or killing yourself. There is more than enough medicine out there to numb any suffering they may feel, but I believe when it is your time, it is your time to go—not when you want to.
112. My religion stresses the importance of being open to life always If we take matters into our own hands, we may be thwarting God's plan for us, which is always for our good even if we can't see how.
113. My religion strictly forbids suicide no matter how much a person is suffering. We are supposed to believe that only God can decide when a life should end. Having said that, I think my religion takes this too literally, especially since my religion has books filled with people killing each other in war.
114. As a Catholic, we can offer up our suffering for the betterment of others. I feel very bad for Brittany but what she is doing is very selfish. She is saying, "I decide when I die, not you. Killing is wrong. For a doctor to kill a patient, it is murder even if the patient wants to die.
115. My religion does not allow me to support MAID. Every moment of life should be cherished and there is always ways to improve livelihood.
116. My religion says MAID is wrong. But I cannot pretend to know what these people are going throught. I thing they should have the right to make their own choices.
117. Only God has the right to decide when, where and how a person will die. That is scriptural.
118. I was shocked by the video. Brittany didn't try to change her diet or cut out sugars. She could have tried cannabis. I strongly urge you to try natural treatments. If they do not work, there is hospice to help.
119. No one has the right to play god.
120. People should die in a natural way even if it means suffering like Jesus did. I am not surprised that Brittany died before age 30 because we do not have clean air, clean water, and clean soil. These and the sun are all we need.
121. God has the final say. No one has the right to take away the life of another. I believe in the power of God, miracles, and healing.
122. Suicide is suicide for whatever reason. God gave you suffering for a reason. He will not give you more than you can carry. If you make your own choices rather than leaning on God, it is going to lead you further away from heaven.
123. The Bible says killing of any kind is wrong. MAID is a personal decision, but I oppose mercy killing.
124. The Christian faith says "Thou shalt not kill". The doctors did absolutely nothing to help Brittany get well so they should not have the power to rule over who gets to die.
125. There are other ways to handle pain. Assisting death should not be a part of that. Our rabbi has taught us that our bodies belong to G_D and they are not ours so we do not have the right to destroy them. MAID is suicide and can be considered murder as well. This is strictly prohibited in Judaism.
126. To kill is wrong. MAID is suicide.
127. MAID is wrong even though it may be legalized in some places.

APPENDIX E

UNIVERSAL DECLARATION OF HUMAN RIGHTS

Universal Declaration of Human Rights

Preamble

Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Whereas disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind, and the advent of a world in which human beings shall enjoy freedom of speech and belief and freedom from fear and want has been proclaimed as the highest aspiration of the common people,

Whereas it is essential, if man is not to be compelled to have recourse, as a last resort, to rebellion against tyranny and oppression, that human rights should be protected by the rule of law,

Whereas it is essential to promote the development of friendly relations between nations, Whereas the peoples of the United Nations have in the Charter reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women and have determined to promote social progress and better standards of life in larger freedom,

Whereas Member States have pledged themselves to achieve, in cooperation with the United Nations, the promotion of universal respect for and observance of human rights and fundamental freedoms,

Whereas a common understanding of these rights and freedoms is of the greatest importance for the full realization of this pledge,

Now, therefore,
The General Assembly,

Proclaims this Universal Declaration of Human Rights as a common standard of achievement for all peoples and all nations, to the end that every individual and every organ of society, keeping this Declaration constantly in mind, shall strive by teaching and education to promote respect for these rights and freedoms and by progressive measures, national and international, to secure their universal and effective recognition and observance, both among the peoples of Member States themselves and among the peoples of territories under their jurisdiction.

Article I
All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

Article 2
Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty.

Article 3
Everyone has the right to life, liberty and security of person.

Article 4
No one shall be held in slavery or servitude; slavery and the slave trade shall be prohibited in all their forms.

Article 5
No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

Article 6
Everyone has the right to recognition everywhere as a person before the law.

Article 7
All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

Article 8
Everyone has the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him by the constitution or by law.

Article 9
No one shall be subjected to arbitrary arrest, detention or exile.

Article 10
Everyone is entitled in full equality to a fair and public hearing by an independent and impartial tribunal, in the determination of his rights and obligations and of any criminal charge against him.
Article 11
1. Everyone charged with a penal offence has the right to be presumed innocent until proved guilty according to law in a public trial at which he has had all the guarantees necessary for his defence.
2. No one shall be held guilty of any penal offence on account of any act or omission which did not constitute a penal offence, under national or international law, at the time when it was committed. Nor shall a heavier penalty be imposed than the one that was applicable at the time the penal offence was committed.
Article 12
No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.
Article 13
1. Everyone has the right to freedom of movement and residence within the borders of each State.
2. Everyone has the right to leave any country, including his own, and to return to his country.
Article 14
1. Everyone has the right to seek and to enjoy in other countries asylum from persecution.
2. This right may not be invoked in the case of prosecutions genuinely arising from non-political crimes or from acts contrary to the purposes and principles of the United Nations.
Article 15
1. Everyone has the right to a nationality.
2. No one shall be arbitrarily deprived of his nationality nor denied the right to change his nationality.
Article 16
1. Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.
2. Marriage shall be entered into only with the free and full consent of the intending spouses.
3. The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.
Article 17
1. Everyone has the right to own property alone as well as in association with others.
2. No one shall be arbitrarily deprived of his property.
Article 18
Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief, and freedom, either alone or in community with others and in public or private, to manifest his religion or belief in teaching, practice, worship and observance.
Article 19
Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.
Article 20
1. Everyone has the right to freedom of peaceful assembly and association.
2. No one may be compelled to belong to an association.
Article 21
1. Everyone has the right to take part in the government of his country, directly or through freely chosen representatives.
2. Everyone has the right to equal access to public service in his country.
3. The will of the people shall be the basis of the authority of government; this will shall be expressed in periodic and genuine elections which shall be by universal and equal suffrage and shall be held by secret vote or by equivalent free voting procedures.
Article 22
Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.
Article 23
1. Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.
2. Everyone, without any discrimination, has the right to equal pay for equal work.
3. Everyone who works has the right to just and favourable remuneration ensuring for himself and his family an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection.
4. Everyone has the right to form and to join trade unions for the protection of his interests. Article 24 Everyone has the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay.
Article 25
1. Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

2. Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

Article 26

1. Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional education shall be made generally available and higher education shall be equally accessible to all on the basis of merit.

2. Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance and friendship among all nations, racial or religious groups, and shall further the activities of the United Nations for the maintenance of peace.

3. Parents have a prior right to choose the kind of education that shall be given to their children.

Article 27

1. Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.

2. Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.

Article 28

Everyone is entitled to a social and international order in which the rights and freedoms set forth in this Declaration can be fully realized.

Article 29

1. Everyone has duties to the community in which alone the free and full development of his personality is possible.

2. In the exercise of his rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society.

3. These rights and freedoms may in no case be exercised contrary to the purposes and principles of the United Nations.

Article 30

Nothing in this Declaration may be interpreted as implying for any State, group or person any right to engage in any activity or to perform any act aimed at the destruction of any of the rights and freedoms set forth herein.