



# Euthanasia and the Law: The Rise of Euthanasia and Relationship With Palliative Healthcare

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Euthanasia and the Law:  
The Rise of Euthanasia and Relationship with Palliative Healthcare

Amy Ann Bubnash Storer

A Thesis in the Field of Legal Studies  
for the Degree of Master of Liberal Arts in Extension Studies

Harvard University

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## Abstract

Acting as the conductor on the train of impending death, a divisive turn to the left will hasten human pain and end life; while a swerve to the right will prolong human life, but also, extend unbearable human pain and suffering. One could make sound arguments that both of these grim decisions are equally acts of compassion or malice. How do these options fluctuate when an express death wish is made, or when artificial means of life prolongation are compulsory? The only remaining option is taking no action and letting God, nature, or the universe be the resolving ruler of human fate. Dominating the American political landscape is the perpetual controversy of the point at which human life beings (i.e., abortion), but the legal and judicial systems have predominately neglected to address the other end of this vital spectrum – at what point does human life end?

What defines true autonomy and can one's autonomous choices ever fully be unfettered from external influence or subconsciously felt societal pressure? Moreover, perhaps it is simply unreasonable and implausible to expect a mortal decision be unequivocally autonomous in the most austere form. In terms of a death wish, self-rule in the *de facto* sense exists for citizens in nations practicing Active Voluntary Euthanasia (AVE) and Passive Assisted Suicide (PAS). Paradoxically, in doing so, the autonomy to subsequently change one's mind is simultaneously, eternally surrendered.

Proponents question how society can place a value on human life in the face of egregious pain and suffering. After all, without health, what is life? Essentially, when men die with dignity and grace, they have wholly exhausted human health in its earthly

form. In an era of medical advancement and a burgeoning global elderly population, the acclaimed “Right to Health” is all the rage in the modern legal landscape. Still, families confronted with end-of-life decisions are haunted by the engulfing hope that what is deemed incurable today could be scientific breakthrough tomorrow.

Whatever side of the fence one sits on, the construct of euthanasia legislation is ripe for discrimination. Those opposing euthanasia practices fear discrimination and vulnerability is bound to run rampant against the elderly, sickly and impoverished; meanwhile, proponents are concerned that discrimination against gender, age, and medical condition will obstruct citizens from rightfully governing their own health affairs. Most daunting remains the heightened ambiguity over what explicitly constitutes “unbearable suffering” and which group shall hold authority to dictate these qualifiers – the lawmaker, judicial system, physicians, families, patients, or a hybrid-combination, thereof?

Under the United States Declaration of Independence, we are assured the right of “Life, Liberty and the Pursuit of Happiness”; yet, the perspective of what is protected as an *inalienable right* has expanded in unprecedented ways. Our Founding Fathers could have never predicted where we stand today and adaptations must be made to align modern civil liberties with bioethics.

## Dedication

I dedicate this dissertation to my sister, Heidi Elizabeth Bubnash Storer, a stalwart physician working in an Intensive Care Unit in Tennessee and to all of those who have dedicated life and labor for the health, comfort, and betterment of mankind. I thank Orthopedic Surgeon Dr. James Gasho for saving me from the darkest, most excruciating years of my life, by taking the chance to perform a rare surgical procedure when no other physician would.

Foremost, to those enduring a desperate life entrapped with unbearable pain, I have felt your chronic pain and yearn for the best solution to bring you the comfort and peace you rightfully deserve. For all those who are mentally tormented; have given up on life; or feel they have become a burden on society or their families, never forget your intrinsic, human worth. More than anything, I profusely commiserate with patients and families confronted with these ghastly end-of-life decisions, and I deeply empathize with both heartbreaking positions held in the utmost precarious human conflict of our time.

## Acknowledgements

First of all, I would like to acknowledge Harvard Law School Professor Glenn Cohen for his guidance and encouragement in this project. Mr. Cohen's prominent commitment to the vital study of global Bioethics and Health Law is a rousing, awakening example for us all.

Additionally, I express my gratitude to the Harvard professors that I have had the great honor of working with on various research projects during my tenure; these once in a lifetime opportunities will forever move me: Professor Seth Harwood; Dr. Mimi Goss; and Dr. Mark Tomass. My dissertation sponsor at Johns Hopkins University, Dr. Dorteia Wolfson, and my ultimate educational lifeline, Michigan Tech University's Dr. Mary Durfee ("The Durfinator"), continue to influence me to this day.

Last but not least, I thank my parents and grandparents for teaching me that education is the key to life and believing in me throughout this eclectic journey. A true example of the American Dream, my mother (Theresa Bubnash), raised by a single mother of seven, became an Aeronautical Engineer and the eighth female airline pilot hired by Northwest Airlines. She never let anyone or anything stop her from flying.

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## I.

### Research Problem

Are human beings ultimately the masters of their own destiny? The timeless opacity of a hastened versus assisted death lingers as a prodigious conflict that has mystified ancient philosophers; left physicians with many sleepless nights; confounds modern world religious leaders; and continues to keep lawmakers in flux.

Aside from the dubious unknowns, the face of humanity is aging at an exponential rate – spurring an intensified dispute on the nodes of death and dying. For the first time in world history, the World Health Organization predicts that by 2017, citizens over the age of sixty-five will outnumber children below the age of five; additionally, they calculate: “By 2050, the proportion of the global population over 60 will double from 11 to 22 percent.”<sup>1</sup>

The New England Journal of Medicine estimates that one-third to 80% of all suicide attempts are impulsively made, typically within five minutes to an hour of the episode.<sup>2</sup> Business Insider reports that that 90% of suicide-attempt survivors later die of

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<sup>1</sup> Elaine Schmidt, “Epigenetic Clock: Changes to DNA Predict Life Expectancy,” Harvard Medical School. September 29, 2016. Accessed December 14, 2016. [https://hms.harvard.edu/news/epigeneticclock?utm\\_source=SilverpopMailing&utm\\_medium=email&utm\\_campaign=10.04.2016](https://hms.harvard.edu/news/epigeneticclock?utm_source=SilverpopMailing&utm_medium=email&utm_campaign=10.04.2016).

<sup>2</sup> Corey Adwar, “The Role of Impulsiveness is One of the Saddest Things about Suicide,” *Business Insider*, August 13, 2014. Accessed December 13, 2016.

natural causes; this data encompassed 515 people who had jumped from the Golden Gate Bridge between 1937-1971, with 94% either identified alive or having died of natural causes.<sup>3</sup> Granted, the bulk of AVE cases today involve elderly terminally ill patients, the door has now unlocked to allow children and the depressed the ability to receive state-sponsored physician assisted suicide in Belgium and the Netherlands.

In September 2016, Harvard Medical School reported that scientists are closing in on the ability to predict human lifespan expectancies directly through DNA.<sup>4</sup> Meanwhile, on December 13, 2016, scientists at King's College in London sought to test the "Pareto Principle" which claims that 80% of effects stem from approximately 20% of causes.<sup>5</sup> These scientists developed a controversial test that can identify, by the age of three, "whether children will grow up to be a burden on society, needing excessive welfare, spending time in prison, or becoming obese."<sup>6</sup> Duke University Professor Avshalom Caspi commented on the study: "Most expenses from social problems are concentrated in a small segment of the population."<sup>7</sup> Over the span of the 35-year, 1,000-participant

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<http://www.businessinsider.com/many-suicides-are-based-on-an-impulsive-decision-2014-8>.

<sup>3</sup> Adwar, "The Role of Impulsiveness," 1.

<sup>4</sup> Schmidt. "Epigenetic Clock."

<sup>5</sup> Sarah Knapton, "A Test at Age 3 Can Predict Whether Children Will Grow and Go to Jail and Lead a Troubled Life, Scientists Say," *Canadian National Post*, December 13, 2016. Accessed December 14, 2016. <http://news.nationalpost.com/news/world/a-test-at-age-3-can-predict-whether-children-will-grow-and-go-to-jail-and-lead-a-troubled-life-scientists-say>.

<sup>6</sup> Knapton, "A Test at Age 3 Can Predict," 1.

<sup>7</sup> Knapton, "A Test at Age 3 Can Predict," 1.

study, the research confirmed the Pareto Principle that 20% of the participants consumed the bulk of public services.<sup>8</sup> While some view this scientific data as socially beneficial to intervene with vulnerable children at a young age, others condemn such developments as threatening, particularly with intensification of demand and sponsorship of AVE legislation.

The World Health Organization now estimates that nearly one million citizens privately choose to end their own lives annually.<sup>9</sup> Overall, global suicide rates have climbed sixty percent within the last forty-five years, marking its highest point in world history.<sup>10</sup> Given these ostensible levels of disturbing demand, what happens when a traditionally private act is thrust into the public realm of direct governmental intervention? In an era of increasing human lifespan, who is truly capable of ascertaining the precise moment when it becomes both ethical and rational to pull the plug on human life, or to determine when an active measure must be taken to terminate “unbearable” forms of human suffering? Identifying the appropriate equilibrium of pragmatism and integrity will be essential in establishing a well-grounded solution for all euthanasia practices, policies, and regulations.

Presently, secular liberal–democratic principles are in conflict with recent legislation surrounding the practice of Active Voluntary Euthanasia (AVE). As Glenn

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<sup>8</sup> Knapton, “A Test at Age 3 Can Predict,” 1.

<sup>9</sup> “Suicide Data.” World Health Organization. 2014. Accessed December 09, 2016. [http://www.who.int/mental\\_health/prevention/suicide/suicideprevent/en/](http://www.who.int/mental_health/prevention/suicide/suicideprevent/en/).

<sup>10</sup> “Suicide Rates by Country.” World Atlas. September 19, 2016. Accessed December 09, 2016. <http://www.worldatlas.com/articles/countries-with-the-most-suicides-in-the-world.html>.

Cohen observes, the saga of the *Terry Schiavo* case illustrates just how ill-prepared the American Judicial system is to grapple with end of life circumstances: “The judicial system has repeatedly failed as a process for resolving end of life treatment disputes involving incompetent or questionably competent patients.”<sup>11</sup> Quietly rising, the ‘sleeping giant’ of global practice and demand for euthanasia has profoundly shifted legal bounds, medical norms, and societal notions of human freedom as the court systems, the law, and world leaders have been markedly slow to react. The debate is fiercely challenging international law in its capacity to concurrently promote justice, while also, protecting an exceptionally vulnerable population. Congruent to the expanding societal acceptance of AVE, the foremost concern is the theory, often expressed by disabled rights organizations that the ‘right to die’ is inconspicuously evolving into a *duty* to die.

Indeed, regardless of one’s stance on the matter, it is conceivable that elderly and sickly patients may secretly/subconsciously feel obligated to choose death in order to avoid becoming a burden on one’s family or society. However, as I will address, some researchers contend that recent statistics do not necessarily support the claim that growing acceptance of the act necessarily correspond with an uptick in PAS or AVE demand. Nevertheless, a rapidly aging global population coalesced with increased life expectancies in developed nations, specifically in Europe, present an epidemic that the World Health Organization has deemed an “urgent public health challenge.”<sup>12</sup>

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<sup>11</sup> Glenn Cohen, “Negotiating Death: ADR and End of Life Decision-Making,” *Harvard Negotiation Law Review* 9 (Spring 2004): 255.

<sup>12</sup> Elizabeth Davies and Irene Higginson, “The Solid Facts: Palliative Care,” *The World Health Organization* (2004), accessed November 24, 2013, [http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0003/98418/E82931.pdf](http://www.euro.who.int/__data/assets/pdf_file/0003/98418/E82931.pdf).

Religious and political debate aside, with changes in modern lifestyles, it is critical that scientific researchers, world leaders, medical professionals, and lawmakers join forces to evaluate the impending societal consequences and how *human vulnerability* plays a fundamental role in those facing the supreme decision to end their own lives.

Further, I argue that bolstered safeguard mechanisms to monitor the outcome of all forms of euthanasia must be rigorously and judiciously erected for society's protection, in tandem with the continued advancement of palliative health care reform. To date, several studies have indicated safeguards currently in place lack proper oversight, unveiling some troubling discrepancies. For example, a 2011 *Current Oncology* Study determined that in one Dutch jurisdiction nearly half of all euthanasia deaths went unreported, thereby, eschewing track records vital for safeguarding efforts.<sup>13</sup> With reports indicating that approximately 900 Dutch residents now annually end life, without express consent through AVE, safeguard mechanisms and protocols must be continually scrutinized in order to mitigate possible corruption.<sup>14</sup>

Citizens nearing end of life stages are confronted with chronic health illnesses, and World Health Organization representatives point to palliative care as a neglected aspect of health care policy.<sup>15</sup> Although, I evaluate achievements made in recent years to confront the demand for palliative care, particularly in the United States, these developments remain at the embryotic stage in many regions. Understanding the medical

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<sup>13</sup> J. Pereira, "Legalizing Euthanasia or Assisted Suicide: The Illusion of Safeguards and Controls," *Current Oncology* 18, no. 2 (2011): 38–45.

<sup>14</sup> Pereira, "Legalizing Euthanasia or Assisted Suicide," 1.

<sup>15</sup> Davies and Higginson, "The Solid Facts," 9.



and emotional needs of this vulnerable population warrants a reconsideration of policy towards palliative health care services as the elderly, disabled, and sickly are often unable to express their voice in the political arena. In the midst of political debates surrounding inequality and injustice, of all sub-sectors in society, the elderly and sickly will be most at risk within the next decade; yet they remain least discussed in the global political landscape. In a political climate keenly focused on the re-election cycle, politicians tend to be less concerned with appeasing elderly voters. The elderly can only hope their caregivers and loved ones will serve as their honest voice for the social issue of greatest concern to their being.

Once legislation is enacted, other avenues tend to follow suit with a wider range of citizens alleging this right. The euthanasia landscape has magnified even if quantitative data does not always conclusively support evidentiary growth; the law itself is robustly expanding and adaptations must be continually made, in both the public and private sector, to govern justly under its new breadth. Terminal illness, once considered the only last-resort option for AVE, is no longer the sole prerequisite; AVE is now open in several jurisdictions to children, the depressed, and dementia patients under a multitude of circumstances.<sup>16</sup> Indeed, the Dutch government has come a long way since it first decriminalized euthanasia in 2002; Charlotte Lozier Institute Research Associate Tim Bradley discusses 2016 developments: “Now the Dutch government is pushing to expand eligibility to include individuals who have no medical condition but nevertheless

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<sup>16</sup> Pereira, “Legalizing Euthanasia or Assisted Suicide,” 1.

feel that their life is completed.”<sup>17</sup>

Within the last decade in the United States, the map below highlights twenty-four states and the District of Columbia that have introduced euthanasia measures through legislation in 2015 (yellow).<sup>18</sup> The Charlotte Lozier Institute publication depicts two states that have passed assisted suicide measure through the court system (Montana and New Mexico) as well as three states where physician-assisted suicide laws have fully passed: Washington, Oregon and Vermont. Since this chart was drafted, California has now joined the ranks with Governor Jerry Brown signing PAS into law in 2016.

Harvard Law School Professor, Glenn Cohen, remarks on the significance of this momentous California move: “California is roughly 12% of the United States population, so now more than one in 10 Americans has access to assisted suicide.”<sup>19</sup> Mr. Cohen believes this development will coax other more legally experimental states, such as New York, to follow suit: “California is a mainstream state in a way many of the other states that have legalized the practice tend to be a little bit more, shall we say, fringe, a little more experimental.”<sup>20</sup>

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<sup>17</sup> Tim Bradley, “Proposal to Expand Euthanasia in the Netherlands,” Charlotte Lozier Institute. October 20, 2016. Accessed December 8, 2016. <https://lozierinstitute.org/proposal-to-expand-euthanasia-in-the-netherlands/>.

<sup>18</sup> “Map: Assisted Suicide Legislation in the United States,” Charlotte Lozier Institute, April 10, 2016, <https://lozierinstitute.org/map-of-assisted-suicide-legislation-in-the-united-states/>.

<sup>19</sup> Glenn Cohen and Damien Carrick, Interview: “Law Report – California: Euthanasia,” The Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics at Harvard Law School. October 27, 2015. <http://petrieflom.law.harvard.edu/resources/article/california-euthanasia>.

<sup>20</sup> Cohen and Carrick, “Law Report – California,” 1.

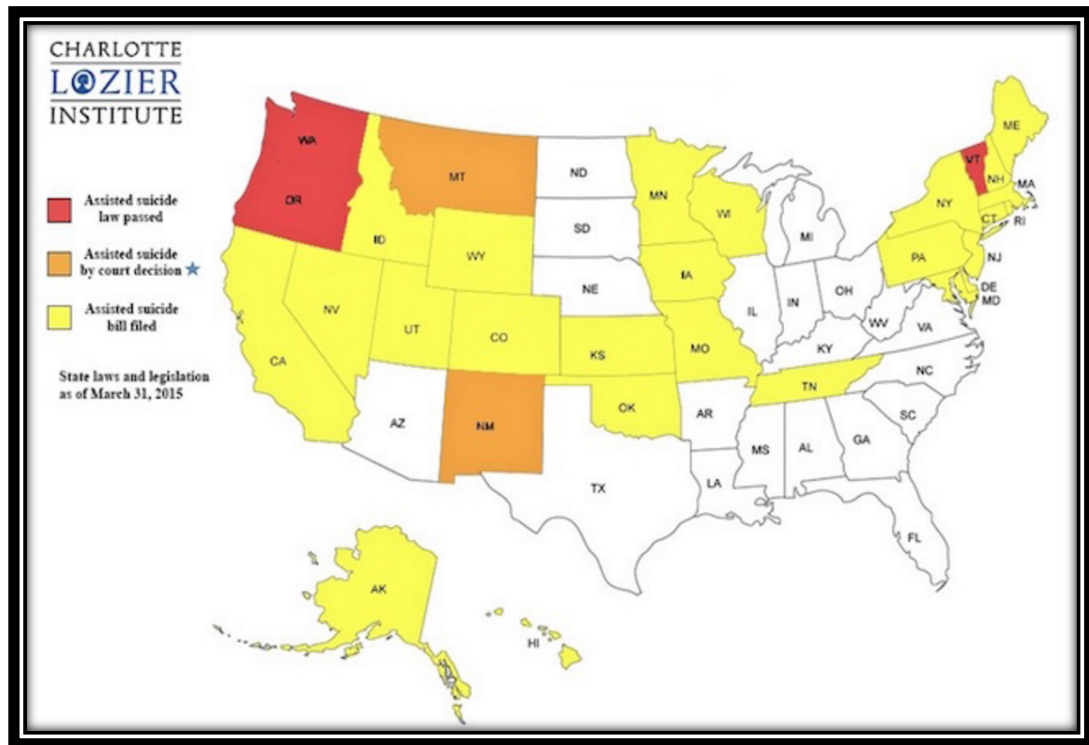


Figure 1: “State laws and legislations as of March 31, 2015” (Charlotte Lozier Institute)

Meanwhile, health law is evolving on a similar plane, yet more aggressively, as two European nations have boldly opened the pathway to break down barriers for AVE, including availability for minors and depressed patients in Belgium and the Netherlands.<sup>21</sup> As I will discuss, cultural attitudes and religious philosophies are underlying factors influencing the drive for AVE and PAS in some divergent, and other congruous ways, between the two continents.

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<sup>21</sup> “Euthanasia: The Law in Europe,” Eyewitness News. 2014. Accessed December 09, 2016. <http://ewn.co.za/2014/02/14/140214euthanasiapic>.



Figure 2: “Euthanasia laws in Europe” (Eyewitness News 2014)

Behind the legal revelations, United States Pew Research Surveys and Gallup Polls indicate an odd conundrum of a general confusion amongst U.S. respondents on the euthanasia conflict; yet, a dramatic upsurge in overall support for the passive form of the practice over time.<sup>22</sup> Meanwhile, Pew Research suggests a split in general U.S. opinion on AVE with 2013 results indicating that 49% of respondents disapproved of its use, while 47% were in support.<sup>23</sup> Gallup Poll results tend to indicate that Americans are more apt to support the morality of passive forms of euthanasia; yet questions regarding AVE tended to fare lower. Nonetheless, public perception appears to coincide with adaptations

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<sup>22</sup> Gallup, Inc., “Three in Four Americans Support Euthanasia,” Gallup.com. May 17, 2005. <http://www.gallup.com/poll/16333/three-four-americans-support-euthanasia.aspx>.

<sup>23</sup> Joseph Liu, “Views on End-of-Life Medical Treatments,” Pew Research Center's Religion & Public Life Project. November 21, 2013. <http://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/>.

in modern health law. Gallup correspondent Andrew Dugan describes key 2015 findings: “Nearly seven in 10 Americans say doctors should be legally allowed to assist terminally ill patients in committing suicide, up 10 percentage points from last year.”<sup>24</sup> Dugan also notes that, perhaps parallel to the rise in national privately committed suicides, “Support for euthanasia has risen nearly 20 points in the last two years and stands at the highest level in more than a decade.”<sup>25</sup>

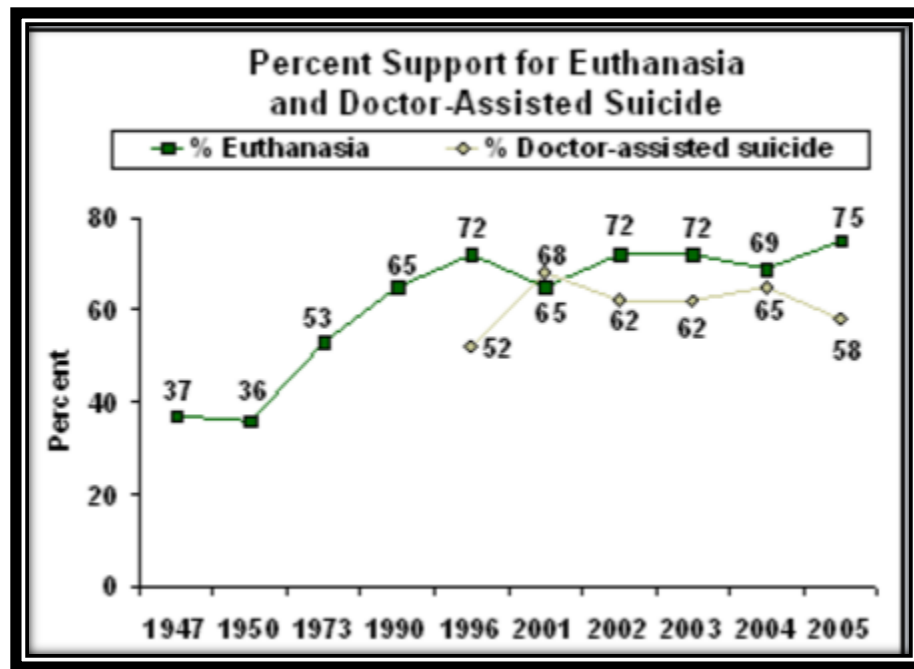


Figure 3: “Three in four Americans support euthanasia” (Gallup, Inc.)

<sup>24</sup> Andrew Dugan, “In U.S., Support Up for Doctor-Assisted Suicide.” Gallup.com. 2015. Accessed December 9, 2016. <http://www.gallup.com/poll/183425/support-doctor-assisted-suicide.aspx>.

<sup>25</sup> Dugan, “In U.S., Support Up,” 1.

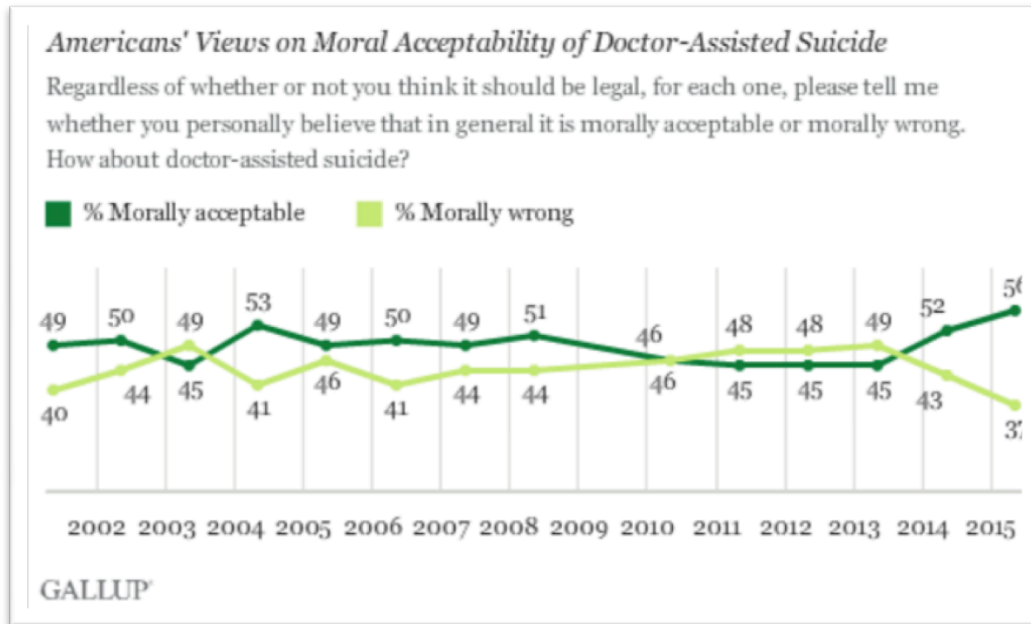


Figure 4: “In U.S., support up for doctor-assisted suicide” (Dugan 2015)

Considering the magnification of public perception, advocates for palliative health care services, like the World Health Organization, have voiced concern that palliative health programs, traditionally offered only to cancer patients, must be provided to a wider range of patients with serious illnesses and integrated more broadly into all mainstream health care systems. The shortcomings of the current system, in which families and patients in desperate situations feel trapped with few viable options, limit a patient's sense of autonomous choice. From global cases involving depressed adolescents to terminally ill patients suffering excruciating pain, the heart of the challenge is to establish balance between autonomy, justice, and compassion, in an era of expeditious medical advancement and widening laws for AVE.

Additionally, structural population changes, particularly within developed nations, are further exacerbated by increasingly smaller family demographics. Divorce, migration, unaffordable costs of health care, and increases in single lifestyles, all mount pressure on

the already flooded health care system with fewer younger family members available to care for senior members.

Another problematic issue for senior care is the jutting expense of Long-Term Care (LTC) Insurance in the United States. For example, *USA Today* Reporter Maryalene LaPonsie warns that premium rates for Pennsylvania residents have already soared by 130% in 2016 with many annual rates expected to exceed \$8,000 by the year's end.<sup>26</sup>

Larry Rosenthal, President of Rosenthal Wealth Management Group, explains that when LTC was introduced in the 1980s, it was priced inappropriately with carriers erroneously assuming citizens would abandon their policies with age.<sup>27</sup> However, as human lifespans prolonged, the opposite occurred resulting in many insurance companies fleeing the market; meanwhile, those remaining dramatically raised costs.<sup>28</sup> Moreover, the National Palliative Care Center describes another historical aspect of the health care dilemma: “Decades of fee-for-service medicine have contributed to a crisis of value: the highest per-capita spending on health care in the world, without better results.”<sup>29</sup> Pursuant to our discussion, the high costs of LTC and other health care insurance calamities continue to thrust extreme financial hardship on elderly members of society, thereby, increasing their

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<sup>26</sup> Maryalene LaPonsie, “Why No One Can Afford Long-Term Care Insurance (and What to Use Instead),” *U.S. News & World Report*, March 10, 2016. Accessed December 09, 2016. <http://money.usnews.com/money/personal-finance/articles/2016-03-10/why-no-one-can-afford-long-term-care-insurance-and-what-to-use-instead>.

<sup>27</sup> LaPonsie, “Why No One Can Afford,” 1.

<sup>28</sup> LaPonsie, “Why No One Can Afford,” 1.

<sup>29</sup> National Palliative Care Research Center, “America’s Care of Serious Illness,” 2015 State-By-State Report Card on Access to Palliative Care in Our Nation's Hospitals. 2015. Accessed November 18, 2016. <https://reportcard.capc.org/wp-content/uploads/2015/08/CAPC-Report-Card-2015.pdf>.

vulnerability in the present construct and future rollout of PAS/AVE.

Needless to say, with AVE practices gaining ground, it is imperative that our nation's leaders get creative in efforts to revamp insurance coverage availability for vulnerable members of society, while also, providing resources to communicate alternative health care options. For example, Mr. Rosenthal recommends a hybrid LTC approach with fixed premiums to mitigate calamities like the current situation in Pennsylvania: "Specialty policies, often known as life-LTC hybrids, feature fixed premiums that help consumers avoid the type of rate increases currently being experienced in Pennsylvania."<sup>30</sup> Long-term care annuities are another option that the elderly may consider for affordable care in the United States. Lowering LTC rates and establishing a more efficient, just system for nationwide health care policy/insurance coverage, and one that is geared towards our changing and aging population construct, remains an ongoing battle the United States must affront. More than ever, American shortcomings in health care will increasingly stand out with the legal road to AVE foreseeable.

My aim in this study is to awaken awareness, encourage debate, empower our citizens, and provide legal and medical professionals with an evenhanded account on how effectively operated palliative programs might influence the demand for euthanasia and recommendations on how the current structure could be enhanced. Consolidating data on the subject of palliative care will equip leaders and citizens with an in-depth picture of the crucial relationship between palliative care and euthanasia, including what this

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<sup>30</sup> LaPonsie, "Why No One Can Afford," 1.



relationship could mean for the future nation-state.

The issue of palliative health care becomes grimmer when considering warnings from the United Nations Population Fund (UNPF) that the world is unprepared for the swelling populations of elderly citizens needing care. Later, in our definitions section, I address the modern forms and accepted definitions of palliative care. Compounding the proliferating presence of euthanasia, UNPF predicts the world's population age sixty and older will exceed two billion by the year 2050.<sup>31</sup> As the UNPF chart below illustrates, the amalgamation of increased laws supporting euthanasia will soon collide with snowballing numbers of end-of-life citizens. The need for effective, equitable law with strong, supportive palliative health care systems is ominous.

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<sup>31</sup> "World Population Projected to Reach 9.6 Billion by 2050," United Nations Department of Economic and Social Affairs. Accessed December 16, 2013. <https://www.un.org/en/development/desa/news/population/un-report-world-population-projected-to-reach-9-6-billion-by-2050.html>.

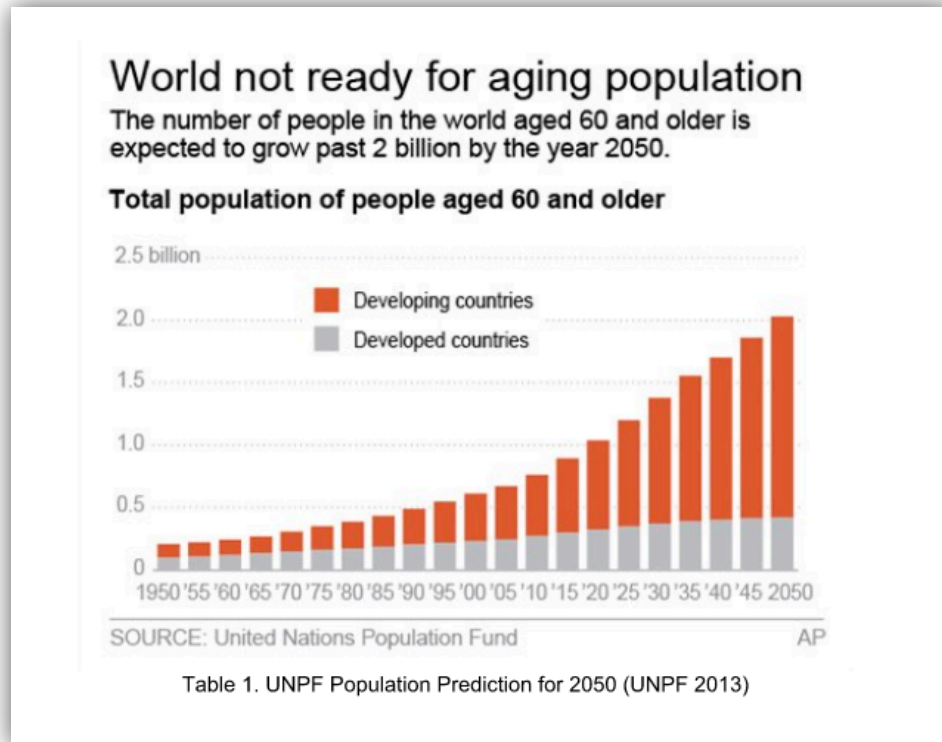


Table 1. UNPF Population Prediction for 2050 (UNPF 2013)

Figure 5: “UNPF population prediction for 2050” (UNPF 2013)

Transforming scientific evidence into pragmatic public policy is a tremendous, urgent challenge for public officials and national leaders. My intent is to deliver simplified, comprehensive scholarship on a melancholic topic that is understudied, misunderstood and profoundly underestimated. As I later address, human beings tend to avoid thinking about and discussing death, particularly Americans, which may explain why this issue has been left on the backburner. Lawmakers rarely discuss the rising AVE practice; perhaps this is also due to the morbid nature of the issue, the bleak outlook on options, and the false perception that euthanasia does not carry near-term effects. Similar to the lack of concentration on the environment, political leaders tend to focus on issues that produce immediate effects within their tenure. Bringing this tremendously important phenomenon to the foreground of political debate will reveal all that is at stake and what

AVE means not only for the nation, but also, for our world. Spurring lawmakers and politicians to act, and soon, is the first goal; establishing proper safeguards and oversight on programs already in place is of equal importance. My legal and case study research, in this regard, seeks to command a more qualitatively driven approach as a voice for two neglected sectors of society most dominant in euthanasia demand – the elderly and the depressed.

My hypothesis is that regional lack of government support for palliative health care directly correlates with the global rise in demand for euthanasia. I hypothesize that the inverse is also true: enhanced government support for palliative health care will generate lower rates of euthanasia demand in nations where robust government support for such programs and supporting laws coexist.

I will investigate recent incidents linked to euthanasia's worldwide expansion and illuminate issues often unheeded in the media and in legislative doctrine. This thesis will touch on the following three questions: (1) What accounts for the upsurge in the global demand for euthanasia? (2) What relationship, if any, is there between a nation's demand for euthanasia and its palliative health care system? (3) Should enhanced palliative care be a goal toward which governments should strive and what legal forum is necessary to achieve the best possible outcome/safeguard? The independent variable in this study is the rate of demand for euthanasia, and the dependent variable is each government's palliative health care program.

First, I define the key terms that will be used in my discussion. Next, I will provide a brief legal and historical background of both palliative health care and the practice of euthanasia. I will then review pertinent literature, examining a range of documentation and scholarly research, aimed at my hypothesis. Finally, I explain my

research methods and discuss limitations experienced during the research that will tie into concluding recommendations on how research of palliative care and the practices of euthanasia can be enhanced for the betterment and security of all world citizens.

#### A. Definition of Terms

Even within the medical profession, definitions of euthanasia and its various forms have continued to sway over time. Scholars and medical practitioners alike have expressed weariness that there remains no specific agreement on clear-cut definitions of these terms. That being said, the definitions provided in this section are meant to provide the reader with a general background on the most commonly accepted definitions as we will refer to in this study. However, for the purpose of our study, we will only be focused on the active forms of euthanasia (AVE) and (PAS).

*Active forms of (VE and PAS)* occur when the doctor would go beyond simply “pulling the plug” by actively administering a patient with a lethal injection.

*Euthanasia* is broadly defined as the “hastening of death of a patient to prevent further sufferings”.<sup>32</sup>

*Involuntary euthanasia (IE)* is the most controversial of all forms of euthanasia because it is performed without the patient's consent. In this instance, despite the patient's ability to coherently express a decision, he/she is not consulted and life is ended by an act of euthanasia.

*Medical futility* is one of the most debated terms in this field with authors

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<sup>32</sup> Dvk Chao, Ny Chan, and Wy Chan, “Euthanasia Revisited,” *Oxford Journal in Medicine, Family Practice* 19, no. 2 (2001): 128-134, accessed December 1, 2013, <http://fampra.oxfordjournals.org/content/19/2/128.full>.

attempting to define it both quantitatively and qualitatively. For example, Dvk and Chan allude to the work of 1996 research lead by Schneiderman to propose a quantitative definition of medical futility insisting that it occurs “when physicians conclude (through personal experience or reported empirical data) that in the last 100 cases, a medical treatment has been useless, they should regard that treatment as futile”.<sup>33</sup> In other words, the doctor has reason to believe that providing treatment for the patient would equate to less than a one percent chance of producing any life-enhancing benefit for the patient. In the qualitative form of the definition, a treatment would only conserve permanent unconsciousness of the patient and would not end the patient’s dependence on intensive medical care; thus rendering the treatment medically futile.<sup>34</sup>

*Non-voluntary euthanasia* is a form euthanasia performed when a patient is physically incapable or incompetent to express a decision; examples include patients in a vegetative state such as a coma or, more controversially, babies born with severe congenital abnormalities.

*Palliative Health Care*, according to the World Health Organization, consists of three general principles<sup>35</sup>:

- (1) It affirms the life of a patient, but regards dying as a normal biological process, and neither accelerates nor postpones a patient’s death.
- (2) It provides pain relief, offers bereavement support for families, and strives to enable patients to live as comfortably and actively as possible until death.

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<sup>33</sup> Dvk et al., “Euthanasia Revisited,” 128.

<sup>34</sup> Dvk et al., “Euthanasia Revisited,” 128.

<sup>35</sup> Davies and Higginson, “The Solid Facts,” 14.

(3) Palliative care combines "the physical, psychological, social, emotional and spiritual aspects of care with coordinated assessment and management of each person's needs".<sup>36</sup>

*Passive Assisted Suicide (PAS)* refers to the practice of a doctor assisting a patient in committing suicide at a patient's appeal.<sup>37</sup>

*Passive versus Active Euthanasia:* Active euthanasia occurs when the physician performs an action such as injection of a lethal drug to end the patient's life. In contrast, passive euthanasia is the omission of an act or a withdrawal of an act that was keeping a patient alive such as pulling the plug or removing a feeding tube (withholding or withdrawing treatment). However, it is important to note that passive euthanasia still holds the intention to kill. For our purposes, we will be focusing more on euthanasia in the active tense where there is "direct intentional killing of a person as part of care being offered."<sup>38</sup>

*Physician-assisted suicide*, (PAS) is often used interchangeably with euthanasia, and it essentially means that the physician provides the resources (lethal drugs, etc.) for the patient to end life.

*Voluntary Euthanasia (VE)* is the practice of a doctor ending a patient's life at the patient's request or with the patient's consent.

*The Euthanasia Act* Legalized in 2002, euthanasia and physician-assisted suicide

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<sup>36</sup> Davies and Higginson, "The Solid Facts," 14.

<sup>37</sup> Jukka Varelius, "Ending Life, Morality, and Meaning," *Springer Science & Business Media* 16 no. 3 (2012): 559-574.

<sup>38</sup> Dvk et al., "*Euthanasia Revisited*," 128.

became officially legal in the Netherlands. The law sought to provide more transparency while also putting in place legal protection for the physician given adherence to proper protocol.

*Withholding or withdrawing life-sustaining treatment* is an act in the passive form of euthanasia where the doctor ceases life-sustaining treatment for a terminally ill patient.

## II.

### Research Methods

Regardless of national stances on euthanasia practices, a detailed analysis of various case studies suggests that there is an exigent need for legislators, government decision-makers, and leaders in the medical field to strike a balance between individual autonomy and sufficient legislative safeguards, especially with regard to AVE. My research methods will include an interdisciplinary approach using primary and secondary sources from various perspectives and research in the public and private sectors, including scholarly work, legal documents, scientific and medical research, media analysis, primary source accounts, and a balance of both quantitative and qualitative data. Primary source data will be drawn from those working within the palliative care side of the house to those actually engaging in physician-assisted suicides.

Using case-study methodology, I will analyze two governments engaging in the practice physician assisted suicide, the State of Oregon and the Netherlands. Bearing in mind that both sovereignties maintain their own culture, values and thoughts on the practices of euthanasia, I aim to study the underlying complexities surrounding the commonly overlooked affiliation between euthanasia and palliative care. Specifically, I will examine the palliative health care plans promoted by each government and compare how the demand for euthanasia runs parallel to each government's promotion of palliative healthcare or alternative programs. I focus my research on how governments



can cope with the rise in demand for euthanasia while providing alternative solutions to promote fairness and equity for all citizens. Instead of common resolutions provoked by philosophical or political contention, an in-depth case study approach comprised of legal, moral, and practical justifications is necessary to bridge the gap in unanswered questions evoked within the elusive relationship between palliative care and the booming practice of euthanasia. As a result of the study, my goal is to deliver legislative and policy recommendations for national leaders and medical practitioners based on data produced by my research.

### III.

#### Background to the Problem

Without delving deep into the bowels of euthanasia's historical precedence it is, nevertheless, critical to provide a brief discussion on the background of how the social issue of euthanasia unfolded from initial philosophy to modern medicine. I first take the reader through a brief overview of euthanasia's roots including philosophical, theological and practical dimensions. With our case studies in mind, I also highlight key historical events in both the legal and judicial realms of two nations that will later be analyzed as our case studies: the state of Oregon and the Netherlands. I selected the state of Oregon as the first state in the United States to legalize the practice of PAS and chose to examine the Netherlands because it was the first nation-state to legalize AVE. Thus, both possess the most available data, precedence, and experience to research. However, qualitative and quantitative comparisons on data available from other states and nations, where applicable, will also be addressed where valuable. In this work, euthanasia in the passive form will not be the focus; rather active euthanasia via explicit request from patients for physician-assisted suicide AVE or PAS will be the primary basis of the study.

The final piece of the "Background to the Problem" chapter is the literature review, where I engage the reader with scholarly work covering the world's most predominant theories on the (1) explanation for the rise in euthanasia's demand and (2) literature probing global demand's possible connection with national palliative care programs. In essence, the first portion of the literature review covers theories that could

conceivably explain the rise in demand for euthanasia, while the second portion of the literature review addresses the theory in which my hypothesis will be aligned.

#### A. History and Overview of Euthanasia

The word “Euthanasia” finds its roots from the ancient Greek words ‘EU’ meaning ‘good’ and ‘thanos’ meaning ‘death’ combined together the word euthanasia means “good death”.<sup>39</sup> Early philosophers appear to sympathize with those suffering unbearable pain; yet most tend to draw the line at active forms of suicide. For example, Plato, in *Laws V* declares: “Suicide does what the law forbids and this means that one is doing something unjust.”<sup>40</sup> Similarly, in *Nichomachean Ethics V*, Aristotle characterizes suicide as an act of pusillanimity that is contrary to the human will of life: “But to seek death in order to escape from poverty, or the pangs of love or from pain or sorrow is not the act of courageous man, but rather of a coward.”<sup>41</sup> Even in ancient Greece, mystification and emotional confusion over the matter is abundant, particularly with regard to assisted forms of suicide. For example, in *The Women of Trachis*, Hercules beckons for his son, Hyllus, to put his pain out of its misery with a flaming torch to his flesh. Hyllus insists that he shall not be a murderer; to which Hercules responds by stating: “I ask you to be my healer, or be healer of my sufferings, sole physician of my

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<sup>39</sup> Dvk et al., “Euthanasia Revisited,” 128.

<sup>40</sup> Plato, *Laws V. The Greeks*, ed. Od Hatzopoulos (Athens: Kaktos Publishers, 1992), 80-83; line 873 c, d.

<sup>41</sup> Aristotle, *Nichomachean Ethics*, The Loeb Classical Library, vol. 5, 19 (Cambridge MA: Harvard University Press, 1982), 253-322; lines 1116a, 1138a, 11-15.

pain.”<sup>42</sup> Common themes of healer, cowardice, or murderer, are echoed themes in the bowels of ancient philosophy when the topic of assisted death arises.

In Shai Lavi’s book, *The Modern Art of Dying: A History of Euthanasia in the United States*, he discusses how the “*ars moriendi*” tradition dominated the deathbed scene during the religious awakening period at the turn of the 18<sup>th</sup> century. In Lavi’s view, the so-called “technomedical” spirit was born, engrained within the Methodist’s belief of a “holy death”; he observes that this belief would come to influence thoughts on mortality for generations, especially in the Americas.<sup>43</sup> However, with medical and scientific advancements, author Shai Lavi’s so-called “art of dying” has largely shifted away from religious doctrine, instead falling under the umbrella of modern medical governance.<sup>44</sup> Pursuant to our case studies, when evaluating the more timid acceptance of euthanasia in Oregon compared to the Dutch, figments of Lavi’s theory remain somewhat evident with religion playing a larger factor, to this day, on modern American medicine – perhaps more than one would anticipate.

As with many social movements, the Second World War reawakened the formerly suppressed discussion on euthanasia. The first practice of euthanasia began in 1939 with the Nazis’ launch of the ‘euthanasia programme’, which sought to achieve Hitler’s vision of the Aryan race. Studies estimate that over 70,000 psychiatric patients perished from

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<sup>42</sup> Sophocles, *The Women of Trachis. The Greeks*, ed. Od Hatzopoulos (Athens: Kaktos Publishers, 1992), 136-137; lines 1206-8.

<sup>43</sup> Shai J. Lavi, *The Modern Art of Dying: A History of Euthanasia in the United States* (Princeton, NJ: Princeton University Press, 2005), 6.

<sup>44</sup> Lavi, *The Modern Art of Dying*, 3.

gas or poison during the program.<sup>45</sup> Of the European nations, Germany remains fickle on legislation aimed at modern euthanasia practice, possibly a subconscious result of this tragic history. Ironically, as the post-WWII world denounced Hitler, it was Hitler's execution of this program that essentially reintroduced euthanasia's debate back into the legal sphere. Albeit, it was not until the 1970s and early 1980s, when the discussion would garner political momentum, particularly in the Netherlands.

*The Netherlands.* Becoming the first nation-state to practice euthanasia since Nazi Germany, the Royal Dutch Medical Association, in 1984, legally allowed physicians to perform assisted suicide if the request was voluntary, the patient was fully informed, no alternative treatment was available, and the patient had "unbearable suffering".<sup>46</sup> Formally, in April 2001, the Dutch signed a bill permitting euthanasia and physician-assisted suicide.

Legality became a bit more open and vague in the Netherlands in 1990, when the Royal Dutch Medical Association and the Dutch Ministry of Justice reached an agreement on the notification procedure. The decision was made to ensure doctors performing assisted suicide would be guaranteed immunity from prosecution if a threshold number of 'rules of careful practice' had been followed. Guidelines at the time were fairly mild, only requiring the physician to report the case as euthanasia to the medical examiner and undergo a basic questionnaire.<sup>47</sup> Noteworthy court decisions and media-heavy cases illustrate what many have called the 'slippery slope' argument against

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<sup>45</sup> Dvk et al., "Euthanasia Revisited," 129.

<sup>46</sup> Dvk et al., "Euthanasia Revisited," 129.

<sup>47</sup> Dvk et al., "Euthanasia Revisited," 129.

euthanasia. Three provocative cases in Dutch history are referred to as cases in point – the Chabot, Prins and Kadijk cases.

In 1991 a psychiatrist, Dr. Chabot, supplied lethal drugs to a physically healthy patient with a reoccurring history of depression. Dr. Chabot was found guilty by the Dutch Supreme Court but only because he had failed to consult with another physician for a second-opinion before performing the act. Furthermore, the court took the matter a bit further by ruling that patients with entirely non-somatic suffering would equally be eligible for assisted suicide.<sup>48</sup> Legislation dug its heels in even deeper two years later in the Prins case and the Kadijk cases which involved the killing of two disabled babies using lethal injection. As a reaction to these cases, the Dutch Medical Association tightened up guidelines a bit in 1995 by requiring “expert advice” from at least one other independent physician along with a written report documenting the account.

As early as 1999, a bill was drafted to allow doctors to perform physician-assisted suicide requests from terminally ill children as young as twelve years old and without parental consent. The killing, however, could only be performed if the physician believed it would ‘prevent serious detriment’ to the patient.<sup>49</sup> This bill eventually passed Dutch Parliament with recommendations to stretch the law even further by many members. Although illegal for patients under the age of twelve, anti-AVE activists believe the law is quietly unenforced for younger patients.

Researchers Eduard Verhagen and Pieter Sauter decided to investigate exactly

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<sup>48</sup> Dvk et al., “Euthanasia Revisited,” 130.

<sup>49</sup> Dvk et al., “Euthanasia Revisited,” 130.

how stringently the “under twelve” limit was enforced by Dutch government and medical practitioners. Substantiating their suspicions, the duo uncovered several cases of blatant infant AVE occurring despite the illegality. Then, Verhagen and Sauter teamed up with prosecutors to craft a special Protocol for action, later known as the "Groningen Protocol". However, instead of punishing the perpetrators, the Protocol’s result ended up backfiring and thrust legislation deeper in proponent’s favor by barring physicians from prosecution and allowing children under twelve to undergo AVE if four basic criteria are followed:<sup>50</sup>

1. The presence of hopeless and unbearable suffering
2. The consent of the parents to termination of life
3. Medical consultation having taken place
4. Careful execution of the termination

Criticized as sounding all too familiar and nebulous in its requirements, this updated iteration of the law took heat by many scholars and advocates condemning it as bordering on infanticide. Rather than crime and punishment, the investigation essentially extended the same law with nearly identical parameters to children under the age of twelve. Meanwhile, this result would put a damper on motivation for other independent investigators.

Aforementioned in the introduction, as of October 2016, Dutch legislation has been drafted to include elderly members of society who are immobile or otherwise simply ready for their lives to be over. This revelation has made even the most liberal

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<sup>50</sup> Edward Verhagen and Pieter Sauter, “The Groningen Protocol: Euthanasia in Severely Ill Newborns,” *New England Journal of Medicine* 353, no. 10 (2005): 959-962.

members of society slightly uneasy. *New York Times* Reporters Dan Bilefsky and Christopher Schuetze quote Dutch Health Minister Edith Schippers' address to Dutch Parliament on defense of the measure, whereby she contended the law is necessary to address the needs of:

“older people who do not have the possibility to continue life in a meaningful way, who are struggling with the loss of independence and reduced mobility, and who have a sense of loneliness, partly because of the loss of loved ones, and who are burdened by general fatigue, deterioration and loss of personal dignity.”<sup>51</sup>

In response, Populist politician, Geert Wilders, condemned the proposal stating that it would essentially allow the state to act as an “enabler” for the death of the lonely and depressed: “We cannot allow people who are needy or lonely to be talked into dying. Combating loneliness — and investing in dignity and focusing on our elderly — is always the best option.”<sup>52</sup> As it stands, Prime Minister Mark Rutte is planning to draft the law by December 2017, after consulting with national doctors and ethicists. The law plans to incorporate a vetting process of potential applicants in conjunction with a personal “death assistance provider” designated to each patient.<sup>53</sup> Bilefsky and Schuetze report the AVE death toll in 2015 as accounting for 5,516 deaths, roughly 4 percent of national Dutch deaths.<sup>54</sup>

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<sup>51</sup> Dan Bilefsky and Christopher F. Schuetze. “Dutch Law Would Allow Assisted Suicide for Healthy Older People.” *New York Times*, October 14, 2016. Accessed December 10, 2016. <http://www.nytimes.com/2016/10/14/world/europe/dutch-law-would-allow-euthanasia-for-healthy-elderly-people.html>.

<sup>52</sup> “Dutch Law Would Allow,” 1.

<sup>53</sup> “Dutch Law Would Allow,” 1.

<sup>54</sup> “Dutch Law Would Allow,” 1.



*Australia.* Although the Netherlands was the first nation to dabble with AVE, the Northern Territory of Australia was the first *territory* in the world to sanction legislation allowing a physician to end the life of a terminally ill patient in May of 1995 through the Rights of the Terminally Ill Act. The Rights of the Terminally Ill Act mirrored the scope of initial Dutch legislation requiring consent of two doctors but, additionally, a psychiatrist was required to approve the act. However, dissimilar from proposed legislation in the Netherlands, Australia was more stringent in specifically requiring patients to be legal adults with “a sound mind”, suffering from a terminal illness, and to have an unbearable amount of pain or suffering.<sup>55</sup> Australia also made clear that the practice would be more of a last resort when no other viable palliative care options could be reasonably available. Parallel to the Netherlands, physicians would be protected under the Act unless negligence or disregarding the requirements occurred.

The first Australian to die from physician-assisted suicide was Bob Dent, a severely suffering patient with carcinoma of the prostate. In 1996 Australian physician, Dr. Nitschke, operated a computer-linked machine enabling patients to inject themselves with lethal injection.<sup>56</sup> Australia’s affair with euthanasia ran dry, however, as six months after Mr. Dent’s death, the Rights of the Terminally Ill Act was overturned by the Australian Federal Senate. However, similar to current marijuana law in the United States, AVE is practically decriminalized in Australia. Trends in softer sentences reflect the nation’s position. For example, in Tasmania a nurse named Catherine Ann Pryor was

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<sup>55</sup> Dvk et al., “Euthanasia Revisited,” 130.

<sup>56</sup> Dvk et al., “Euthanasia Revisited,” 130.

convicted for both assisting in her father's death, a terminal cancer patient, and a second attempt to murder her mother, who had entered early stages of dementia.<sup>57</sup> In 2005, Pryor received a two and a half year sentence, but the judge suspended the conviction asserting his belief that the community would not want Pryor in jail.<sup>58</sup> In this case, the doctors were essentially treated with "kid gloves" because of the unusual situation where Pryor was both the daughter of the victims and the medical actor in committing AVE. Further illuminating the concern of family pressures, Pryor's two brothers were also involved in the acts and admitted to administering insulin dosages to the parents. The Australian court convicted Pryor of manslaughter and Mr. Ellis, the prosecutor, declared: "'It was planned and efforts were made to cover their tracks. Calling an ambulance does not indicate remorse."<sup>59</sup> In rebuttal, the defense made the argument that Pryor, like many who conduct assisted suicides under these circumstances, was under distress and acted for compassionate motives. Australia's *Mercury Newspaper* documented Mr. Ellis' response to defense by contending: "The distress of the mother's condition was also a personal distress to them which she sought to be relieved from."<sup>60</sup> Physicians involved in these cases tend to present evidence in court only on the grounds of receiving immunity for

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<sup>57</sup> "Assisted Suicide Case Prompts Calls for Euthanasia Law Review," ABC News. December 19, 2005. Accessed December 11, 2016. <http://www.abc.net.au/news/2005-12-20/assisted-suicide-case-prompts-calls-for-euthanasia/765010>.

<sup>58</sup> "Assisted Suicide Case," 1.

<sup>59</sup> Nick Clark, "Daughter Found Guilty of Attempted Murder," *Mercury Newspaper*, December 9, 2005. Accessed January 27, 2017. [http://www.lists.opn.org/pipermail/right-to-die\\_lists.opn.org/2005-December/001265.html](http://www.lists.opn.org/pipermail/right-to-die_lists.opn.org/2005-December/001265.html).

<sup>60</sup> Clark, "Daughter Found Guilty," 1.

their testimony; this case is a prime example as Dr. Grant (the attending physician) agreed to deliver evidence against Pryor if immunity for his testimony was upheld. However, the defense insisted Dr. Grant was a “strong and domineering man who had imparted his attitude to euthanasia on the entire family”.<sup>61</sup> In this regard, the defense felt that Ms. Pryor essentially became the scapegoat with coaxing personalities, like Dr. Grant, directly involved in the outcome. The concern over the physician-nurse relationship in the euthanasia debate is highlighted in this context as nurses are subconsciously treated as subordinates under their physicians. Thereby, the case brings to light the psychological dilemma of power and authority in the hospital and how attitudes of physicians might be powerful underlying factors.

*The United States.* Historically, the religious tradition of the Protestants and the Protestant way of thinking dominated early American thought on death and dying; author Shai Lavi believes the Methodists’ powerful influence molded initial predominant American philosophy on euthanasia.<sup>62</sup> In the *Modern Art of Dying*, Lavi discusses how the Methodists, in particular, provoked keen interest in the theology of death after arriving in America from England at the turn of the 18<sup>th</sup> century. The influence of 18<sup>th</sup>-century Methodists in America cannot be underestimated and many scholars have actually named this era the “Methodist Age” in American history. In fact, Methodism grew nearly nine times its size in a short timeframe from 1790-1830 and contained members from all sectors of society: rich, poor, northerners, southerners, slave owners

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<sup>61</sup> Clark, “Daughter Found Guilty,” 1.

<sup>62</sup> Lavi, *The Modern Art of Dying*, 5.

and abolitionists.<sup>63</sup> The Methodists' fear of dying was later substituted with a joyful, natural perception of life when the more rational and scientifically inclined religious dominations, such as the Congregationalist and Unitarians, gained power and sought to overcome "ignorance, superstition, and timid fanciful sentimentality".<sup>64</sup> As French historian Phillipe Aries described, the United States entered a period he termed "death of dying" whereby dying became a less significant, fearful experience of American life.<sup>65</sup> Eventually, as Levi explained, medical advancement would become the governing body over medicine and religious doctrine was, for the most part, cast aside.

The 1970s and 1980s brought euthanasia to the foreground of the American public eye as the media became fixated on the tragic tale of a young twenty-one year old who tragically entered into a coma. Karen Ann Quinlan's family fought to end ventilator support after prolonged continuation of her vegetative state. In the end, the court ruled in favor of withholding life support if it was truly hopeless that Karen, or any patient, could regain consciousness.

A noteworthy shift occurred in the 1980s and 1990s with gradual American acceptance of the social issue. By 1990, thirty-five states had passed Natural Death Acts recognizing the legality of a "living will" and permitting a person to specify treatment preferred if one falls into a terminal condition.<sup>66</sup> Media frenzy surrounded one of the

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<sup>63</sup> Lavi, *The Modern Art of Dying*, 16.

<sup>64</sup> Lavi, *The Modern Art of Dying*, 16.

<sup>65</sup> Lavi, *The Modern Art of Dying*, 16.

<sup>66</sup> Dvk et al., "Euthanasia Revisited," 131.

world's most famous AVE cases occurring in 1988 as Nancy Cruzan, another young woman descended into a persistent vegetative state for over four years. I discuss the importance of the *Cruzan* case for historical context; though it is not an instance of AVE that is the focus of this dissertation.

Cruzan's life was continued via artificial hydration and nutrition, a controversy in itself. Struggling with this delicate case, the Supreme Court finally ruled against discontinuation the feeding tube, stressing that the decision was made because no evidence was available ensuring that Cruzan, herself, would desire treatment to be discontinued. The precedent set by the Court provided that it would be unlawful for individual states to disregard the expressed wishes of a patient.<sup>67</sup> Moreover, the Court upheld the state's standard of proof against constitutional challenge beyond expressly blessing what the state had done.

The historical overview would be dreadfully amiss without a brief discussion about the most notorious character in the debate. Hated or loved, praised and reproached, the publicity given to Dr. Jack Kevorkian in the 1990s elevated the debate to entirely new levels in the United States. Dr. Kevorkian, a retired pathologist, began his journey by assisting an Alzheimer's patient to commit suicide in June of 1990; Kevorkian eventually admitted that he continued on to assist over 100 deaths.<sup>68</sup> Beginning his movement with PAS, Kevorkian eventually began performing direct killings with the massacre of Thomas Youk, a patient suffering amyotrophic lateral sclerosis. Kevorkian was

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<sup>67</sup> Dvk et al., "Euthanasia Revisited," 131.

<sup>68</sup> Dvk et al., "Euthanasia Revisited," 131.

eventually convicted in 1999, but only on second-degree murder charges, after documenting and broadcasting live video streaming of Youk's killing.

Oregon became a euthanasia stronghold and remains the leading state to open the door in the controversial practice. The 1994 passage of the Oregon Death and Dignity Act took place allows patients with terminally ill conditions who make an express death wish to obtain lethal medication for the purpose of ending life. However, by August 1995, an Oregon judge declared the law unconstitutional because it did not provide equal protection against suicide to terminally ill persons, thereby, rendering the act invalid, pending the Supreme Court's ruling. In October 1997, the Oregon Death and Dignity Act was upheld and resulted in fifteen deaths during a one-year period.<sup>69</sup> The Act allows terminally ill Oregon residents to end their life through by self-administration of lethal medications, prescribed by a physician with express request.

*United Kingdom.* In the United Kingdom the first known euthanasia public interest group emerged as far back as 1935 known as the “Voluntary Euthanasia Society”, or “Exit”.<sup>70</sup> The group championed legalization of euthanasia but was eventually rejected after a 1936 debate in the House of Lords. Nevertheless, this makes Great Britain the first nation to formally debate the legalization of euthanasia. In a fever pitch, citizens, politicians, and other public figures began choosing sides, stating their cases, in attempt to persuade law and society. Despite the momentary fervor, the bill's death in 1936 largely removed the topic from the public domain for several decades.

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<sup>69</sup> Dvk et al., “Euthanasia Revisited,” 132.

<sup>70</sup> Dvk et al., “Euthanasia Revisited,” 129.

Parallel to the timeframe in other nations, the trend followed in the United Kingdom with euthanasia resurfacing as a topic of political debate in the 1990s as a result of several intense national court cases. These cases were so powerful that they led the United Kingdom to take rigorous measures in attempt to secure justice for all citizens subject to the ethical medical practice debate. The United Kingdom is often heralded for its efforts in this regard, particularly in utilizing a more holistic approach in response to this multi-faceted issue.

The first British case took place in 1993 as a young man named Tony Bland suffered from a traumatic accident at Hillsborough football stadium, thrusting him in a vegetative state where artificial feeding tubes kept him alive for over three years. British courts decided that it was in the best interest of the patient and “good medical practice” to terminate the artificial feeding.<sup>71</sup>

Parallel to the Netherlands and the United States, incidents in the United Kingdom became more ominous. The standout case in UK history involves Dr. Nigel Cox who was responsible for the death of a woman suffering from severely painful rheumatoid arthritis. Cox administered a lethal injection and the Winchester Crown Court found him guilty; yet, the trend follows that the Court was relatively sympathetic towards his situation, ultimately opting not to suspend his medical license.<sup>72</sup>

Taking an investigative approach, the House of Lords expeditiously set up a Select Committee on Medical Ethics as a direct reaction to these cases. The Committee

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<sup>71</sup> Dvk et al., “Euthanasia Revisited,” 131.

<sup>72</sup> Dvk et al., “Euthanasia Revisited,” 131.

extensively researched instances of euthanasia as well as other related issues surrounding medical ethics in decisions at the end of life. Producing a February 1994 report, the Committee on Medical Ethics advised the government to move away from euthanasia's legalization. The main concern for the Committee was that although competent patients were rightfully able to refuse treatment, those who were incompetent should also have a right to be "protected from aggressive overtreatment to which the competent would object".<sup>73</sup> Other recommendations, pertinent to our study on palliative care, include the Committee's assertion that physical pain *relief* should be the main focus euthanasia policies. Similar to the World Health Organization's recommendations, the British Committee on Medical Ethics stressed the need for high quality palliative care to be more widely available for all patients in these unfortunate situations.<sup>74</sup>

Indeed, euthanasia has come a long way since the term first emerged in ancient Greece. I briefly highlighted the historical context as it paints a story, illuminating how euthanasia, as a practice, has exploded within a brief window of time in the history of the Free World, particularly over the last two decades. Concurrent with our discussion on the rise of human suicide, as a whole, the underpinning reasons for this phenomenon must be considered. The demands and pressures in modern life, medical advancements prolonging human life, and widening laws to support AVE are all factors in the adaptation of modern culture. As I describe in the proceeding section, recent developments further demonstrate just how abruptly the euthanasia practice is unfolding with evidence suggesting that the

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<sup>73</sup> Dvk et al., "Euthanasia Revisited," 131.

<sup>74</sup> Dvk et al., "Euthanasia Revisited," 131.



train will not be slowing down anytime soon.

From the foregoing, we examined the historical context of euthanasia, as a general practice, from several nations with significant history. From the bowels of Ancient Greek philosophy to the first public interest group supporting euthanasia, arising in England in 1935, the road for AVE's birth and its current construct bears noteworthy roots in international history. The historical breadth of euthanasia sets the stage for the current status of AVE in modern day.

### B. Recent Developments

Friends and the media circled the Belgium home of Nathan Verhelst for a special, extravagant, and rather emotional "Farewell Party". In the wake of 2013 Canadian consideration of euthanasia's legalization, Canadian National Post reporter Graeme Hamilton informed readers that one week after raising a rather ironic toast to "life", the 44-year-old Belgian indeed, departed — to a hospital in Brussels where he was given a lethal injection and died.<sup>75</sup> Becoming the first transsexual to be euthanized under public law, Mr. Verhelst came to his decision after a botched sex-change operation left him depressed and humiliated.

Belgium law on physician assisted suicide practice has stretched far beyond servicing the terminally ill to now include patients suffering depression or psychological

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<sup>75</sup> Graeme Hamilton, "Terminally Transsexual: Concerns Raised over Belgium Euthanized after Botched Sex Change," *Canadian National Post*, accessed December 3, 2013, <http://news.nationalpost.com/2013/11/22/terminally-transsexual-concerns-raised-over-belgian-euthanized-after-botched-sex-change/>.

distress. In fact, a year before Verhelst's death, a pair of deaf 45-year-old twin brothers, were given euthanasia after discovering they had a condition that might cause them to lose their vision.<sup>76</sup> Another case within the same year involved an anonymous 44-year old anorexic woman, who went by the alias "Ann G". Due to "unbearable mental suffering" resulting from her also being a victim of sexual abuse by a psychiatrist, she was also given the green light for AVE.<sup>77</sup>

In 2014, Belgium became first to approve legislation allowing all ages AVE access with the requirement of parental consent for minors. Additionally, the patient must "possess the capacity of discernment".<sup>78</sup> Becoming the first country in history with no age limits on the practice, Belgium killed its first minor with an incurable disease, through express consent, in September 2016.<sup>79</sup> Meanwhile, as the chart below depicts, the demand and incidence of euthanasia in Belgium has soared, particularly since 2010.<sup>80</sup> In the wake of the Canadian debate, *National Post* contributor Graeme Hamilton expresses concern that euthanasia will become the new norm, describing it as "suicide with society approval".<sup>81</sup> Hamilton reasons that Belgium's 16-member Federal Commission of

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<sup>76</sup> Hamilton, "Terminally Transsexual," 1.

<sup>77</sup> Hamilton, "Terminally Transsexual," 1.

<sup>78</sup> Tristian Hopper, "Belgium Senate Approves Highly Controversial Bill That Would Make Euthanasia Legal for Dying Children," *National Post*, December 12, 2013, accessed December 16, 2013, <http://news.nationalpost.com/2013/12/12/belgium-euthanasia/>.

<sup>79</sup> Chandrika Narayan. "First Child Dies by Euthanasia in Belgium," CNN. September 17, 2016. Accessed December 10, 2016. <http://www.cnn.com/2016/09/17/health/belgium-minor-euthanasia/>.

<sup>80</sup> Hopper, "Belgium Senate," 1.

Control and Evaluation on AVE was initially implemented to protect against corruption; yet, the irony he find is that analysis only takes place after the patient is dead. In Hamilton’s view, he finds no merit or practical use of such a policy beyond politically correct appeasement. Further, he expresses skepticism on the fact that the Commission has evaluated over 8,000 deaths since AVE legalization without leading to one prosecution.<sup>82</sup> Data gathered from a variety of publications indicates the overall trend reflecting an undeniable expansion of Belgium citizens utilizing the law, such as the European Institute of Bioethics referenced in a *BBC News* report depicted below.

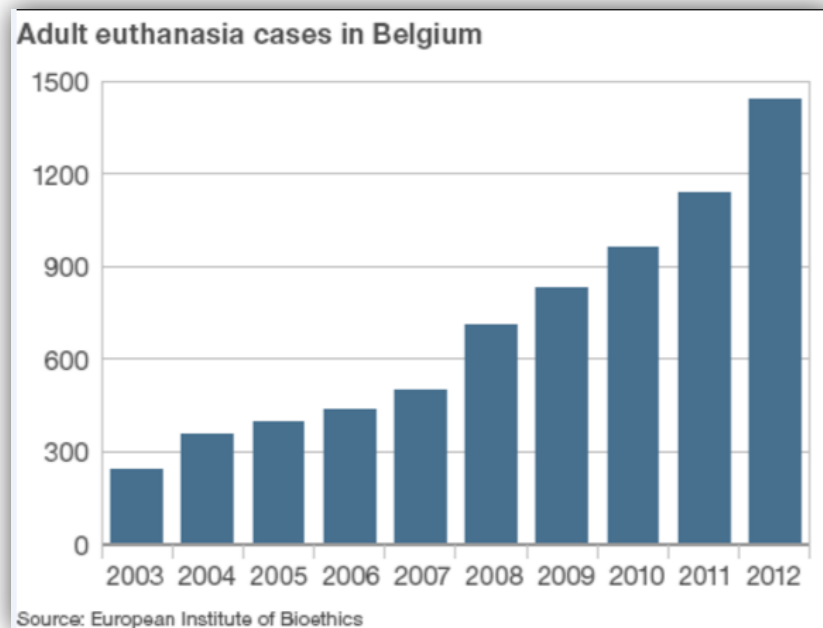


Figure 6: “Adult euthanasia cases in Belgium” (BBC News 2014)<sup>83</sup>

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<sup>81</sup> Hamilton, “Terminally Transsexual,” 1.

<sup>82</sup> Hamilton, “Suicide with the Approval,” 1.

<sup>83</sup> Linda Pressly, “Belgium Divided on Euthanasia for Children,” *BBC News*. January 08, 2014. Accessed December 14, 2016. <http://www.bbc.com/news/magazine-25651758>.

Canadian Medical Journal Association researchers Sigrid Dierickx, Luc Deliens, Joachim Cohen, and Kenneth Chambaere took a deep dive into analysis on the Belgium numbers and determined that AVE requests are on the upswing in every category since the law's inception: "The number of officially reported euthanasia cases increased each year (from 235 in 2003 to 1807 in 2013), in both sexes, across all age groups, among those with cancer and diseases other than cancer, and in all care settings."<sup>84</sup> The data further indicated that Flanders region had the most pronounced increase in rates "...from 1.9% of all deaths in 2007 to 4.6% in 2013".<sup>85</sup> The authors expressed the highest concern over the broadening statistic of non-terminally ill patients, those under the age of 80, and house requests occurring: "Our study of reported cases also corroborates the results of that survey showing increases in groups that were previously less likely to request or receive euthanasia, such as older persons and those with diseases other than cancer."<sup>86</sup> Widening types of physicians and increases in requests granted of those participating has also added to the team's conclusion that acceptance for AVE is aligning on both patient and practitioner aisles. A breakdown in these results is documented in the chart below as well as Hamilton Graeme's findings.

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<sup>84</sup> Sigrid Dierickx, Luc Deliens, Joachim Cohen, and Kenneth Chambaere, "Euthanasia in Belgium: Trends in Reported Cases between 2003 and 2013," *CMAJ* 10, no. 1503 (2016): 1-6. Accessed December 10, 2016. <http://www.cmaj.ca/content/early/2016/09/12/cmaj.160202.full.pdf.html>.

<sup>85</sup> Dierickx, Sigrid et al., "Euthanasia in Belgium," 5.

<sup>86</sup> Dierickx, Sigrid et al., "Euthanasia in Belgium," 5.

**Table 1: Characteristics of deaths in Belgium officially reported as euthanasia, relative to all deaths, 2003–2013\***

Characteristic	Year; euthanasia cases as % of all deathst										
	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Total no. of deaths	107 039	101 946	103 278	101 587	102 060	104 587	104 509	105 094	104 247	109 034	109 295
Incidence of euthanasia per 100 000	2.3	3.4	3.8	4.1	4.7	6.6	7.6	8.8	10.3	13.0	16.3
Overall	0.2	0.3	0.4	0.4	0.5	0.7	0.8	0.9	1.1	1.3	1.7
Sex											
Male	0.2	0.4	0.4	0.5	0.5	0.7	0.8	1.0	1.1	1.4	1.7
Female	0.2	0.3	0.4	0.4	0.4	0.6	0.8	0.8	1.1	1.3	1.6
Age, yr											
18–59	0.6	0.8	0.8	1.0	1.0	1.2	1.5	1.7	1.6	2.3	2.5
60–79	0.3	0.5	0.5	0.6	0.8	1.0	1.1	1.4	1.6	1.9	2.5
≥ 80	0.1	0.1	0.1	0.2	0.2	0.3	0.4	0.4	0.6	0.8	1.0
Diagnosis											
Cancer	0.7	1.1	1.2	1.3	1.5	2.0	2.3	2.6	2.9	3.7	4.3
Other than cancer	< 0.1	0.1	0.1	0.1	0.1	0.1	0.2	0.3	0.4	0.5	0.7
Place of death											
Home	0.4	0.5	0.6	0.7	1.0	1.2	1.5	1.8	2.1	2.4	3.1
Hospital	0.2	0.4	0.4	0.4	0.5	0.6	0.7	0.8	1.0	1.2	1.5
Nursing home	0.1	0.1	0.1	0.1	0.1	0.2	0.2	0.2	0.4	0.5	0.8
Other	0.1	0.3	0.4	0.4	0.3	0.7	1.2	0.7	0.7	0.9	0.6

\*Data on the number of deaths were obtained from Statistics Belgium. Data for 2002 were excluded from analysis because the euthanasia law came into force on Sept. 23, 2002,<sup>15</sup> and data for 2002 thus represent less than an entire year. A total of 24 cases were reported from Sept. 23 to Dec. 31, 2002.  
†Except where indicated otherwise.

Table 1: Euthanasia in Belgium<sup>87</sup>

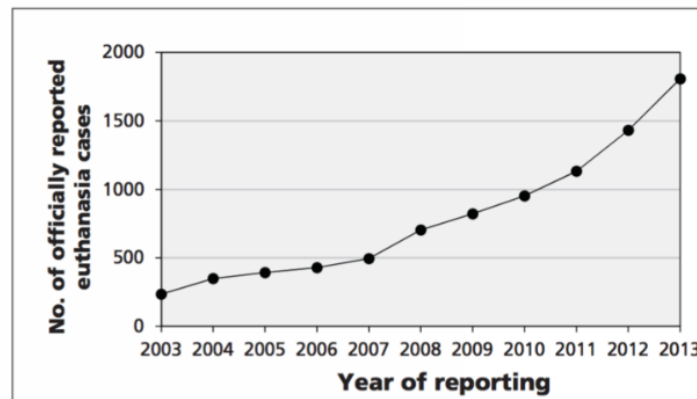


Figure 1: Number of officially reported cases of euthanasia in Belgium, 2003–2013. Data for 2002 were excluded from the analysis because the euthanasia law came into force on Sept. 23, 2002,<sup>15</sup> and data for that year thus represent less than an entire year (a total of 24 cases were reported from Sept. 23 to Dec. 31, 2002).

Figure 7: Reported cases of euthanasia in Belgium<sup>88</sup>

<sup>87</sup> Dierickx, et al., “Euthanasia in Belgium,” 5.

**LEGAL REGISTERED  
EUTHANASIAS IN BELGIUM**

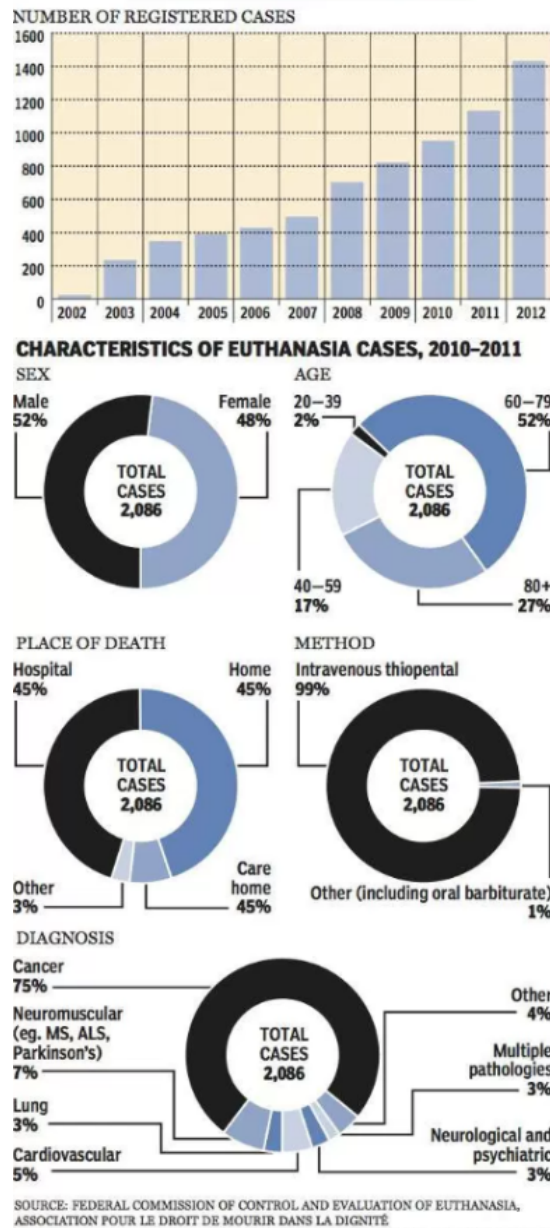


Figure 8: “Legal Registered Euthanasia in Belgium” (Hamilton 2013)

In response to the recent Canadian experience with AVE, Scott Kim and Trudo Lemmens conducted a study on psychiatric disorders, firmly contending that they should

<sup>88</sup> Dierickx, et al., “Euthanasia in Belgium,” 3.

not be eligible under AVE law. The pair argued that those with psychiatric conditions would be subject to a “premature death” due to vulnerable conditions espoused by AVE, particularly through lack of realistic decision-making capabilities.<sup>89</sup> Analyzing cases in Belgium and the Netherlands where AVE has been granted to patients with schizophrenia, eating disorders, autism, and depression, the authors express leering over the Canadian threshold of “irremediable condition” as the new national standard for AVE as established in *Carter v. Canada*. Kim and Lemmens believe this is too vague of a criterion and point to a wide range of evidence demonstrating how psychiatric patients are able to recover with the right type of treatment. The authors question Belgium’s threshold for determining patients’ decision-making capabilities: “In the case series from Belgium, 5 the psychiatrist deemed all 100 patients who requested assisted dying for psychiatric conditions (14 of whom had psychotic disorders) “capable,” which raises the question of whether a rigorous threshold for capacity was used.”<sup>90</sup> In fact, the team noted that only one case out of 10,000 reported Belgium euthanasia cases had ever failed to meet the criteria for AVE.<sup>91</sup>

As these statistics imply, a little over a decade after the Belgium law’s inception, many argue is embodied the dangerous “slippery slope.” The fear of where this expansion might take society implores underlying questions on where the line should be drawn on the limits of autonomy as other Western nations are inching closer to legalization. As it

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<sup>89</sup> Scott Y. Kim, and Trudo Lemmens, “Should Assisted Dying for Psychiatric Disorders Be Legalized in Canada?” *Canadian Medical Association Journal* 188, no. 14 (2016): E337–E339. <https://ssrn.com/abstract=2818009>

<sup>90</sup> Kim and Lemens, “Should Assisted Dying,” 6.

<sup>91</sup> Kim and Lemens, “Should Assisted Dying,” 6.

stands, Canadian officials traveled to Belgium this year in attempt to produce legislation, for the first time in Canadian history, which would sanction euthanasia in a model similar to that of Belgium's. This development has made some legal analysts question how global laws are being mirrored between nation states on the issue. Indeed, Canada's PAS law passed in June of 2016; however, it contains a more restrictive form of the practice, with additional safeguards in place than the law currently operated in Belgium. The measure was passed partly as a response to the Canadian Supreme Court decision that struck down criminalization of the practice. Taking heat from proponents who argue the law is too discriminatory for euthanasia-seekers, under Canadian law:

“A person may receive medical assistance in dying only if they meet all of the following criteria: (a) they are eligible — or, but for any applicable minimum period of residence or waiting period, would be eligible — for health services funded by a government in Canada; (b) they are at least 18 years of age and capable of making decisions with respect to their health; (c) they have a grievous and irremediable medical condition; (d) they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and (e) they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.”<sup>92</sup>

Canada is quite specific in defining what constitutes a “grievous and irremediable” medical condition, requiring the below four parameters:

- (a) “they have a serious and incurable illness, disease or disability;
- (b) they are in an advanced state of irreversible decline in capability;
- (c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and
- (d) their natural death has become reasonably foreseeable, taking into

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<sup>92</sup> “Euthanasia – End-of-Life Law and Policy in Canada.” End-of-Life Law and Policy in Canada. June 17, 2016. Accessed December 11, 2016. [http://eol.law.dal.ca/?page\\_id=238](http://eol.law.dal.ca/?page_id=238).



account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.”<sup>93</sup>

Moreover, the Canadian law is praised for its robust safeguard process that requires two independent witnesses along with the physician to acknowledge the patient’s death wish. With legalization of AVE for children now adopted for Belgium, despite concerns, Canada does not appear to have mimicked Belgium’s law; instead it drafted its own unique rendition. In the law’s short lifespan, since June 17, 2016, about 200 Canadians have died through AVE.<sup>94</sup>

However, Toronto Star reporter Colin Perkel believes these numbers are misleading and, pertinent to our discussion, Perkel expresses skepticism on Canada’s ability to acquire proper analysis with little data available on those who made requests but were refused, information on the patients’ specific medical conditions, and information on those making requests but later changing their mind. In his hunt, Perkel asserts: “Even statistics on gender, age, and where the deaths have occurred are elusive.”<sup>95</sup> More concerning is the admission of Shanaaz Gokool, CEO of *Dying with Dignity Canada*, that it is “nearly impossible to discern clearly what’s happening across the country, or how the legislation is being applied.”<sup>96</sup> Even under Canada’s careful,

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<sup>93</sup> "Euthanasia – End-of-Life Law," 1.

<sup>94</sup> Colin Perkel, “About 200 Canadians Have Had a Physician-Assisted Death since June,” *Toronto Star*, October 06, 2016. Accessed December 11, 2016. <https://www.thestar.com/news/canada/2016/10/06/about-200-canadians-have-had-physician-assisted-deaths-since-law-came-into-force.html>.

<sup>95</sup> Perkel, “About 200 Canadians,” 1.

<sup>96</sup> Perkel, “About 200 Canadians,” 1.

detailed construct of the law and protocols in place aimed at safeguard mechanisms, data analysis remains a gap. As we later discuss, this trend is exhibited, and remains a chief concern, in other practicing PAS or AVE. Ms. Gokool disclosed: “It’s very difficult to assess what is going on. No one’s doing this in a very systematic way. The numbers don’t tell us enough.”<sup>97</sup> So far, the latest data reveals that twenty-three Alberta citizens were denied AVE requests due to a mental-health diagnosis or their death deemed “not reasonably foreseeable”.<sup>98</sup> However, Andrew MacKendrick, spokesman for Canada’s Health Minister, stated that enhanced legislation aimed at requiring AVE data collection and monitoring will be introduced by June 2017. Nevertheless, the points raised by Ms. Gokool, as leader of the *Dying with Dignity* movement in Canada, are disquieting.

Meanwhile, recent developments under the Dutch construct now include mobile AVE services to visit the sick and elderly within their own homes providing the options of lethal injection or lethal liquid.<sup>99</sup> One in thirty Holland deaths were caused by AVE in 2012, upward thirteen percent from the previous year; rates overall have climbed steadily over the past six years.<sup>100</sup>

The *Wall Street Journal* compared the two dominant participators in U.S. physician assisted suicide, Oregon and Washington State, with those rates occurring in

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<sup>97</sup> Perkel, “About 200 Canadians,” 1.

<sup>98</sup> Perkel, “About 200 Canadians,” 1.

<sup>99</sup> Anna Holligan, “Dutch Offered 'Euthanasia on Wheels,” *BBC News Online Europe* (The Hague), March 2, 2012, accessed December 11, 2013, <http://www.bbc.co.uk/news/world-europe-17230102>.

<sup>100</sup> Holligan, “Dutch Offered,” 1.

Belgium.<sup>101</sup> As the chart below demonstrates, outside of a few outlier years, the pattern of spiked AVE increases continued in all three of these regions during the first three months after legalization took effect. With comparative trends this strong, further inquiry into the reasons for these increasing rates will enable governments to recognize what they mean for society and how the rapid demand could shape the face of the future nation-state. However, while media outlets tend to stress the increasing climb of incidences, it is important to question precisely what is the “right number”? Certainly, once a practice is legalized, citizens are bound to utilize the service or take advantage of the new law. At what point should these numbers become troubling and when should a nation be alarmed or concerned about their level? Tracking statistics on the practices of euthanasia and AVE are critical for monitoring the growth of the issue; yet, understanding what these numbers mean and what world leaders should do about them is an entirely larger debate.

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<sup>101</sup> Naftali Bendavid, “For Belgium’s Tormented Souls, Euthanasia-Made-Easy Beckons.” *Wall Street Journal World (New York)*, June 14, 2013, sec. Europe News. <http://online.wsj.com/news/articles/SB10001424127887323463704578495102975991248> (Accessed October 13, 2013), 1.

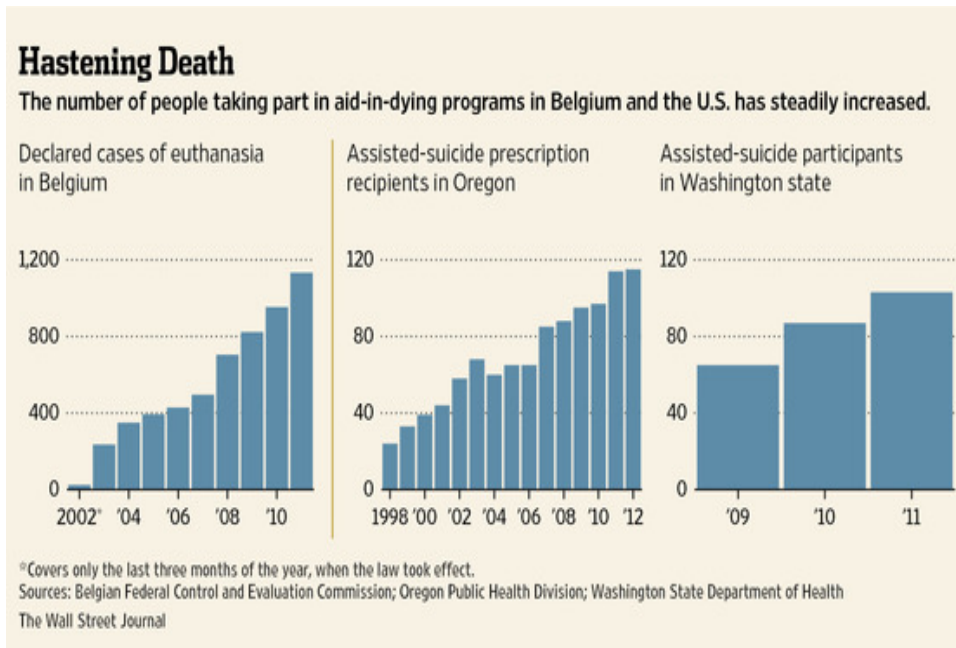


Figure 9: Belgium, Oregon and Washington state rates (Bendavid 2013)

According to opponents, AVE law creates a sub-group of society classified as “eligible” to end their lives, hence, encouraging discrimination and injustice at its most deadly state. Yet, promoting justice and protecting citizens from discrimination are two primary functions of any modern, democratic government, which shapes culture through the creation of laws, governance, and the leadership of its people. Discrimination, on the other hand, is equally alleged by AVE proponents with the view that governmental restrictions on the practice cherry-pick whom is eligible to participate, thereby, prolonging the sufferers’ physical and emotional pain. Nikki Kenward, a miraculous survivor of a terminal illness, discusses how the culture produced by a government’s acceptance of euthanasia becomes one of sudden “expectation and inevitability”.<sup>102</sup> From

<sup>102</sup> Nikki Kenward, “Anti-euthanasia Groups Oppose Attempt by Paul Lamb and Dignity in Dying to Change the Law on Assisted Suicide,” *Press Statement from Alert and Distant Voices* (Aston). Accessed April 18, 2013. <http://www.alertuk.org/docs/2013-03-18-Anti-euthanasia.pdf>.

her experience, the search for quality palliative care can incongruously be portrayed as “selfish” and there becomes little incentive to improve these industries or services.<sup>103</sup>

This thought leads us into the next section where we examine the historical backbone of palliative care and the hospice movement.

### C. History and Overview of Palliative Care

Despite increased hospice use, a study produced by the American Psychological Association (APA) states that palliative care and hospice are still largely “underutilized services.”<sup>104</sup> The World Health Organization has reverberated similar concern stating that palliative care is “by and large a neglected topic in Europe, but is one that is relevant to everyone in the Region.”<sup>105</sup> In this regard, the World Health Organization has urged lawmakers worldwide to come together in instituting policies for palliative care as part of an innovative *global* health care policy “practiced as an integral part of care rather than a special provided service.”<sup>106</sup> As I later address in our case study section, booming developments have been underway by many nations to augment palliative care systems.

Contrary to popular belief, as Thierry Berghmans and Dominique Lossignol stress in “Euthanasia: From Ethical Debate to Clinical Reality,” terminal or palliative sedation is not globally considered euthanasia by law.<sup>107</sup> To date, this remains an ethical dispute

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<sup>103</sup> Kenward, “Anti-euthanasia Groups,” 1.

<sup>104</sup> Lori L. Alexander, “Palliative Care and Pain Management at End of Life,” CME course, November 1, 2015. Accessed June 26, 2016. <http://www.netce.com/coursecontent.php?courseid=1264#chap.6>

<sup>105</sup> Davies and Higginson, “The Solid Facts,” 6.

<sup>106</sup> Davies and Higginson, “The Solid Facts,” 3.

because, in most cases, the patient will die following this operation. While many view palliative care as an alternative to euthanasia, some have actually used it as a platform to promote euthanasia by asserting that euthanasia is merely a *continuation* of palliative care, insisting that physicians must honor patients' autonomy.<sup>108</sup> This is, of course, not the mainstream view held by those operating in the palliative care practice.

In the 1960s, a breakthrough was discovered by small hospice teams working to alleviate pain for cancer patients in the hospice movement. Their research prompted the World Health Organization to publish *Cancer Pain Relief* in 1986. While receiving relatively scant recognition, these hospice teams are ultimately the founders of the palliative care movement, paving the way for the next stage of modern public health care commitment. Renowned anthropologist Margaret Mead proudly reflected: "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever does."<sup>109</sup>

The system of pain relief sought for cancer patients eventually evolved into what is now known as palliative care and has gradually extended to other patients with chronic illnesses and cancers, predominately in the elderly populations. Saint Christopher's Hospice, the first official hospice in the United States, was founded in 1974 by Balfour Mount, a Canadian physician, who also coined the term "palliative care" when he set up the first palliative program at Royal Victoria Hospital in Montreal.<sup>110</sup> This program was the first to be integrated in an academic teaching hospital.

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<sup>107</sup> Thierry Berghmans and Dominique Lissignol, "Euthanasia: From Ethical Debate to Clinical Reality," *European Respiratory Journal* 40, no. 4 (2012): 804.

<sup>108</sup> P. Peretti-Watel et al., "Opinions on Euthanasia, End of Life Care, and Doctor-Patient Communication: Telephone Survey in France," *British Medicine Journal* no. 327 (2003): 595-602, <http://www.bmj.com/content/327/7415/595>.

<sup>109</sup> Davies and Higginson, "The Solid Facts," 7.

<sup>110</sup> Alexander, "Palliative Care and Pain Management."

Palliative care is often misunderstood as purely “end of life care,” but this is only one aspect of the practice. Medical experts across specialties have fought for further integration of palliative care “throughout the continuum of care, from diagnosis to death.”<sup>111</sup> There has been increased focus on palliative health care efforts in the United States and certificates slated for palliative healthcare degrees have been authorized by the Joint Commission in 2011.<sup>112</sup> We discuss these modern developments in the analysis portion of the following section in conjunction with our case study review.

In the chart below, consolidated by the APA, we can see how the definition of palliative care has shifted over time to encompass a greater range of illnesses and specializations, both mental and physical.<sup>113</sup> For the purposes of our study, we will be focused on the World Health Organization’s 2007 general definition of palliative health care in the chart below.

Year	Source and Definition	Comments <sup>114</sup>
1990	World Health Organization (WHO): The active total care of patients whose disease is not responsive to curative treatment.	Does not apply exclusively to palliative care
1993	<i>The Oxford Textbook of Palliative Medicine</i> : The study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is the quality of life.	Lacks essential aspects, such as support provided to families, as well as specificity about timing
2004	National Consensus Project: The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies."	First definition to reflect integration of palliative care earlier into the disease continuum

<sup>111</sup> Alexander, “Palliative Care and Pain Management.”

<sup>112</sup> Alexander, “Palliative Care and Pain Management.”

<sup>113</sup> Alexander, “Palliative Care and Pain Management.”

<sup>114</sup> Alexander, “Palliative Care and Pain Management.”

Year	Source and Definition	Comments <sup>114</sup>
	Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision making, and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care.	
2007	WHO (revision): An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.	Improvement over original WHO definition, but expansion of palliative care throughout the continuum of care not explicit
2009	American Society of Clinical Oncology: Palliative cancer care is the integration into cancer care of therapies to address the multiple issues that cause suffering for patients and their families and have an impact on the quality of their lives. Palliative cancer care aims to give patients and their families the capacity to realize their full potential, when their cancer is curable as well as when the end of life is near."	Defines palliative care for patients with cancer, but definition can be applied to palliative care in all settings

Table 2. Evolving definition of palliative care (APA 2012)

Although, historically, palliative care practices were offered only to patients during the last few weeks of life as an option of last resort; however, many experts have argued that palliative care treatment should begin significantly earlier, before the pain becomes unmanageable and, pertinent to our discussion, “unbearable”. Wider demand for palliative care is also a reaction to advances in medicine, which have transformed once-deadly diseases into livable chronic conditions. Effectually, medical advancements have shifted the trajectory of illness, causing more patients to need palliative care and for longer periods of time.

Examples of others who could benefit from beginning palliative care much earlier include those suffering from heart failure, chronic obstructive pulmonary disease (COPD), end-stage renal disease, and dementia.<sup>115</sup> Health organizations such as the



World Health Organization have expressed frustration that palliative care programs offered globally are part of an “add-on” cost to the patient rather than being employed as a core element of primary health care plans.<sup>116</sup> In modern day, a greater array of patients are turning to palliative care for services as depicted in the model below which breaks down the percentages of citizens using the care with the majority of patients suffering cardiovascular disease and cancer (39% and 34%, respectively).<sup>117</sup> Congruent with worldwide disparities of healthcare, India’s *Child Family Health International* references the World Health Organization’s 2014 finding that gaps in palliative care still persist for 86% of world citizens who need palliative care but do not receive it, and tragically, 98% of which are children in low/middle income nations who need palliative care but are unable to receive it.<sup>118</sup> Highly pertinent to the topic of AVE and PAS is the persisting gap that 83% of citizens live in pain but lack basic access to pain relief.<sup>119</sup> The World Health Organization describes the benefits of palliative care in its ability to allow a greater range of healthcare professionals and volunteers to serve patients and it is also amenable to home-settings or other centers outside the hospital, thereby, alleviating the strain on congested hospitals and physicians.<sup>120</sup> However, cultural and professional barriers exist including: overbearing restrictions on pain-relief opioids, ill-equipped, poorly trained workers, and general cultural attitudes about dying.<sup>121</sup>

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<sup>115</sup> Alexander, “Palliative Care and Pain Management.”

<sup>116</sup> Davies and Higginson, “The Solid Facts,” 13.

<sup>117</sup> “End-of-Life & Palliative Care,” *Child Family Health International*. 2014. Accessed December 17, 2016. <https://www.cfhi.org/end-of-life-palliative-care-0>.

<sup>118</sup> “End-of-Life & Palliative Care,” 1.

<sup>119</sup> “End-of-Life & Palliative Care,” 1.

<sup>120</sup> “End-of-Life & Palliative Care,” 1.

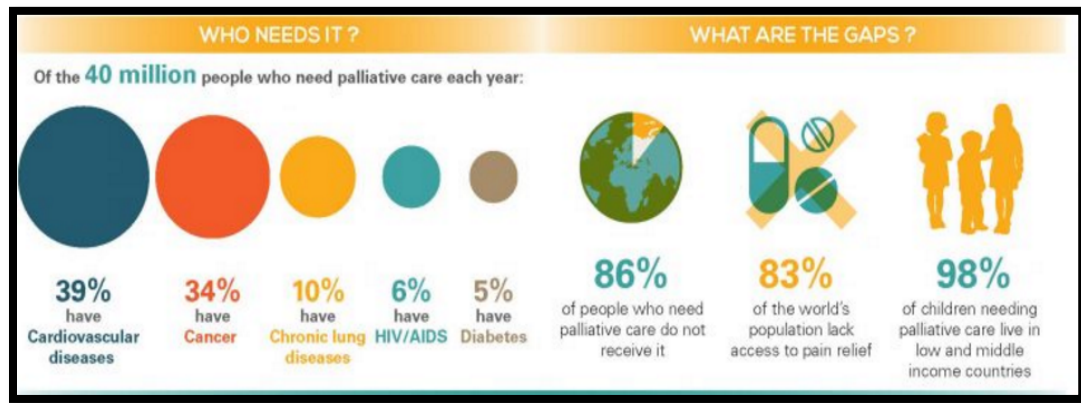


Figure 10: Improving access to palliative care (World Health Organization 2014)

Various models of palliative care practices range from hospital-based inpatient programs, outpatient clinics, joint services and inpatient programs, joint hospice and palliative care programs, hospice-based consultation services, and hospice-based palliative care delivered in the home.<sup>122</sup> Yet, there is continued debate over when palliative care should be introduced to the patient. The chart below depicts the two most prominently conflicting views on the timeframe that palliative care ought to be introduced to the patient.<sup>123</sup>

<sup>121</sup> “End-of-Life & Palliative Care,” 1.

<sup>122</sup> Alexander, “Palliative Care and Pain Management.”

<sup>123</sup> Alexander, “Palliative Care and Pain Management.”

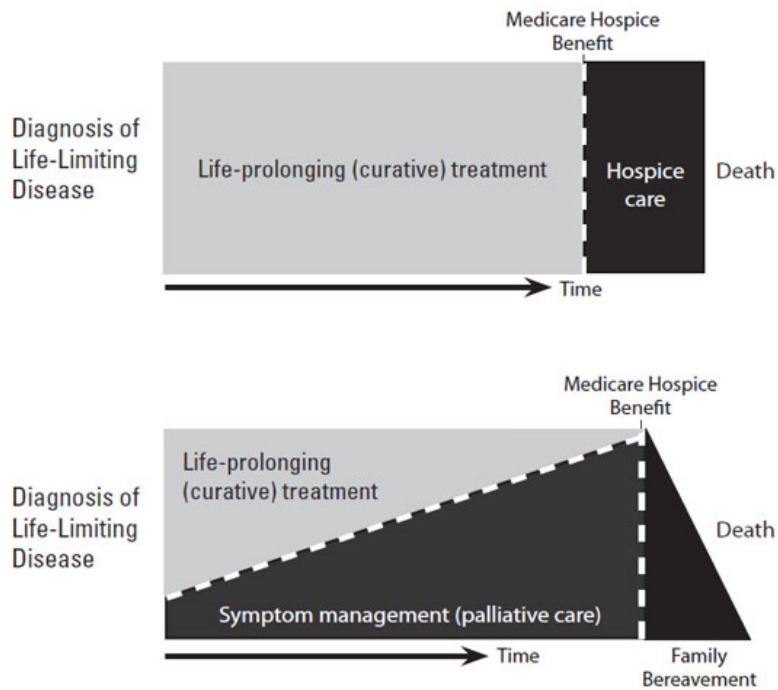


Figure 11: Conflicting views on the introduction of palliative care (APA 2013)

The bottom figure characterizes the current push by many in the field for earlier implementation of palliative care closely aligned to the prognosis date and acting as maintenance throughout treatment. However, additional discrepancies exist regarding the exact time period that encompasses one’s “end of life” stage and it largely remains an undefined phrase in the medical world.<sup>124</sup>

As the movement to enhance palliative healthcare systems in the Americas and abroad continues, the Institute of Medicine (IOM) literature exposes the need for new studies aimed at achieving more black and white definitions on medical stages of end-of-life patients. Albeit, several organizations have gained a foothold in the movement and paved the way for action, including the American Academy of Hospice and Palliative Medicine (AAHPM), the Center to Advance Palliative Care (CAPC), the Hospice and Palliative Nurses Association, the Last Acts Partnership, and the National Hospice and

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<sup>124</sup> Alexander, “Palliative Care and Pain Management.”

Palliative Care Organization (NHPCO). Together these organizations joined the National Consensus Project for Quality Palliative Care Consortium and produced clinical practice guidelines in an effort to streamline palliative care programs and enhance the continuity of care across healthcare settings.<sup>125</sup>

The National Quality Forum (NQF) expanded on this work, and recently introduced an entire national framework for palliative and hospice care.<sup>126</sup> Precisely how these guidelines will be implemented is a work in progress, but the collaborative advancements are, nevertheless, encouraging. As the World Health Organization envisioned back in 2004, other globalized efforts focusing on outreach and educational support for palliative programs have come to fruition including: the first core curriculum in hospice and palliative care brought on by the development of the Education in Palliative and End-of-Life Care (EPEC) Project and the End-of-Life Nursing Education Consortium Project.<sup>127</sup>

Rapid enhancement of American palliative health care programs indicates a refreshing trend in modern medicine parallel with euthanasia law. Lisa Schenker, of Modern Healthcare Medicine, documents the upward trajectory of hospice and booming U.S. palliative programs.<sup>128</sup> Pertinent to our hypothesis the growth is appearing to align with the growth in demand for AVE/PAS in the last decade.

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<sup>125</sup> Alexander, “Palliative Care and Pain Management.”

<sup>126</sup> Alexander, “Palliative Care and Pain Management.”

<sup>127</sup> Alexander, “Palliative Care and Pain Management.”

<sup>128</sup> Lisa Schenker, “Assisted-suicide Debate Focuses Attention on Palliative, Hospice Care,” *Modern Healthcare Magazine*. May 16, 2015. Accessed December 17, 2016. <http://www.modernhealthcare.com/article/20150516/MAGAZINE/305169982>.

### Palliative care in hospitals grows

Between 2000 and 2010, the number of hospitals with 50 beds or more with a palliative-care program grew.

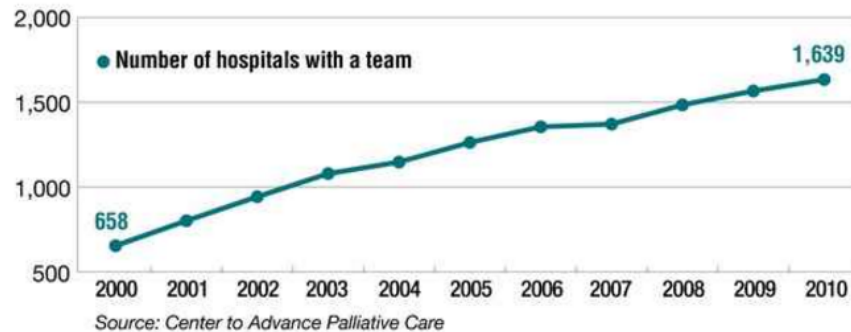


Figure 12. “Palliative care in hospitals grows” (Schenker 2015)

### Growth in U.S. hospice programs, 1974-2013

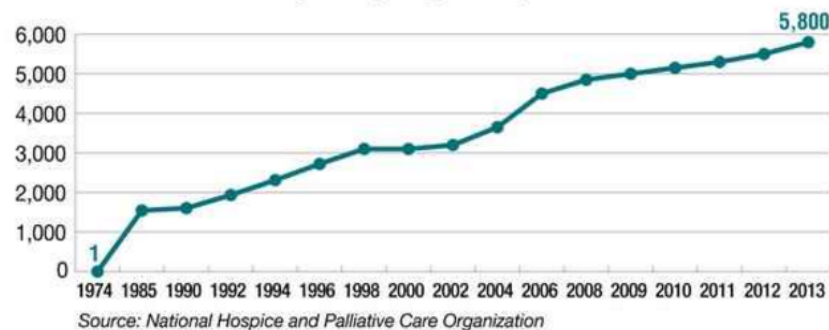


Figure 13. “Growth in U.S. hospice programs” (Schenker 2015)

As researcher Sean Morrison describes, “Palliative care services have been heavily influenced by the public–private fee-for-service reimbursement system.”<sup>129</sup> Hospice programs in the United States now account for nearly half of end-of-life adults under Medicare hospice benefits; in fact, Morrison reports that, “...over two-thirds of all hospitals and over 85% of mid to large size hospitals report a palliative care team”.<sup>130</sup> President Obama’s Patient Protection and Affordable Care Act of 2010 encompass

<sup>129</sup> Sean Morrison, “Models of Palliative Care Delivery in the United States,” *Current Opinion in Supportive and Palliative Care*. June 2013. Accessed December 1, 2016. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4651439/>.

<sup>130</sup> Morrison, “Models of Palliative Care,” 1.

certain levels of healthcare reform and expanded models of care; although President-Elect Donald Trump aims to repeal Obamacare, and these developments may be curtailed, revamped, or otherwise rearranged.

The history of palliative care and the hospice movement's roots shed light on the goals of the practice and provide insight into the ways in which the movement might contribute to the cause. Born as a method to treat cancer victims, the hospice movement is precipitously becoming reenergized, conceivably as a side effect of AVE's rise and the aforementioned changes in global population demographics. Putting history "behind us," the next section contains a brief literature review on top scholars in the euthanasia spectrum, assessing popular themes, theories and scholarship pertinent to our topic.

#### D. Literature Review

Studies that link patient demand for euthanasia to national palliative health care programs have produced a wide range of conflicting data. Similarly, research into the reasons for the rise in the global demand for euthanasia has created a troubling amount of incongruity in a multitude of fields. In this section, I will explore (1) literature encompassing the driving force behind the increase in worldwide euthanasia demand, and (2) literature relating to euthanasia's demand in relationship to state-sponsored palliative health care programs.

*Perspectives on the Driving Force behind Demand.* Aside from controversial consent issues involving family members, an examination of a patient's autonomous decision to choose life or death is vital in gaining a solid background on the demand for such practices. For this reason I will provide an overview of such theories as they relate to my study.

*Cost-Effective Nature of Euthanasia.* A sensitive yet significant argument is that the demand for euthanasia may be mounting as an implicit way for the state and medical field to cut costs. As discussed in the introduction, expanding populations and more citizens reaching end-of-life are already congesting medical facilities at exponential rates. Perceived savings could sway a patient's decision or society's support for AVE, thereby impelling demand as a whole. Sentiment expressed in amicus curiae briefs submitted to the Supreme Court echoed an analogous, grim rationale: "The cost effectiveness of hastened death is as undeniable as gravity."<sup>131</sup> The Supreme Court further predicted "if physician-assisted suicide were permitted, many might also resort to it to spare their families the substantial financial burden of end-of-life health care costs."<sup>132</sup> Politician Ralph Nader once voiced similar fears in comments about the terminally ill in Oregon, "Then along come doctors working for HMOs who are under pressure to cut costs and the deed is done."<sup>133</sup> The relationship between economics and euthanasia is rarely openly discussed, likely because the very idea would not be "politically correct" to even suggest the unfathomable that a state would discreetly take this stance given euthanasia's polemic pretext. Though, on its face, this argument seems to make logical sense when considering the soaring costs of modern intensive care, particularly in the United States.

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<sup>131</sup> Margaret Battin and Ezekiel Emanuel, "What Are the Potential Cost Savings from Legalizing Physician-Assisted Suicide?" *New England Journal of Medicine*, no. 339 (1998): 167-172, accessed December 9, 2013, <http://www.nejm.org/doi/full/10.1056/nejm199807163390306>.

<sup>132</sup> Battin and Emanuel, "What Are the Potential Cost Savings," 167.

<sup>133</sup> Ralph Nader, "Ralph Nader Condemns Assisted Suicide Law." Accessed December 17, 2013. <http://www.euthanasia.com/nader.html>.

In fact, since the inception of Obamacare, 2016 deductible rates have mushroomed by 67% since 2010; a cost nearly seven times average American worker wages.<sup>134</sup> Bear in mind, that this disturbing figure does not include inflation adjustments. Likewise, the *Altarum Institute* warns of the jolting expense to U.S. GDP with gross healthcare spending reaching 18.2% as of June 2016 – a startling increase of 13.3% since 2000.<sup>135</sup> Harvard University healthcare economist David Cutler fears that the middle class will suffer the brunt of the burden in what he classifies as the “tale of three Americas”; whereby, the rich are able to afford healthcare, the lower class is able to access public assistance, but for those in the middle/lower-middle class, “the income struggles and the healthcare struggles together are a really potent issue.”<sup>136</sup> Evidence of this unfortunate revelation can be found in healthcare research non-profit *The Kaiser Family Foundation’s* discovery that data from tens of millions of insurance claims determined “patient cost-sharing rose by 77% between 2004 and 2014, driven by a 256% jump in deductible payments”.<sup>137</sup> Indeed, the long-fought American struggle with healthcare policy reform is becoming entangled in the AVE web at an untimely moment while expanding legislation for the practice mounts. It goes without saying that this situation compounds the already complex euthanasia minefield and directly pummels vulnerability on those unable to afford care. National general acceptance and laws

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<sup>134</sup> Mike Shedlock. “Death Panel Discussion: Obamacare Costs Skyrocket; When Does It Stop?” *MishTalk*. August 29, 2016. Accessed December 12, 2016. <https://mishtalk.com/2016/08/29/death-panel-discussion/>.

<sup>135</sup> Shedlock, “Death Panel Discussion,” 1.

<sup>136</sup> Shedlock, “Death Panel Discussion,” 1.

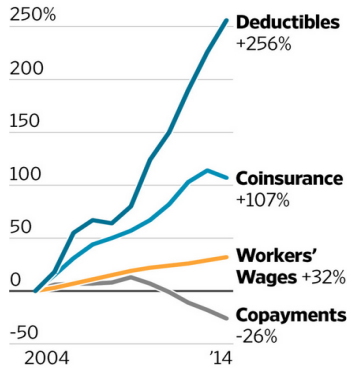
<sup>137</sup> Shedlock, “Death Panel Discussion,” 1.



supporting PAS/AVE have risen; yet, clearly, the burdens on healthcare circle in flux. We must begin to ask the hard question about what happens over time when the cost of healthcare continues to peak and, say, AVE becomes adopted by the majority or even half of states nationwide?

### Shifting Burdens

Percent change in payments by patients, by insurers and in wages from 2004-2014

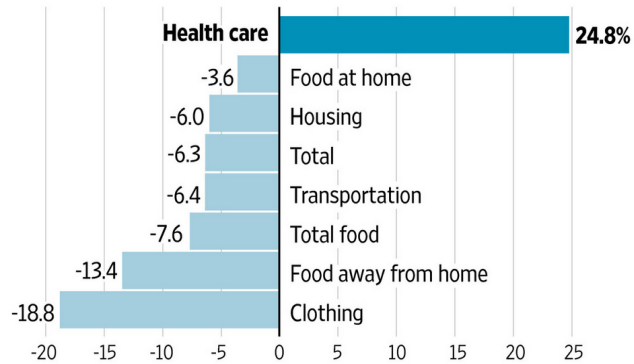


Sources: Kaiser Family Foundation analysis of Truven Health Analytics Claims; Labor Department  
THE WALL STREET JOURNAL.

### A Bigger Bite

Middle-class families' spending on health care has increased 25% since 2007. Other basic needs, such as clothing and food, have decreased.

Percent change in middle-income households' spending on basic needs (2007 to 2014)



Sources: Brookings Institution analysis of Consumer Expenditure Survey, Labor Department  
THE WALL STREET JOURNAL.

Figures 14 & 15: "Death panel discussion: Obamacare costs skyrocket"<sup>138</sup>

Mike Shedlock, investment advisor representative for SitkaPacific Capital Management, blames regulation, the insurmountable cost of prescription drugs, and the "political death panel" for the out of control costs. Instead, he contends that Medicare and insurance companies must immediately put a cap on the amount of money they are willing to pay pharmaceutical companies, per drug, to halt the madness. In doing so, Shedlock reasons that drug manufactures will be forced to keep their prices in check, while also, rightfully making the pharmaceutical companies "the death panel", as

<sup>138</sup> Shedlock, "Death Panel Discussion," 1.

opposed to the federal government, should they refuse to comply.<sup>139</sup>

In “What Are the Potential Cost Savings from Legalizing Physician-Assisted Suicide?”, scholars Ezekiel Emanuel and Margaret Battin contradict the long-held perception that physician assisted suicide would make any substantial difference in national savings. The study contained a limited amount of available data, but findings on the potential predicted savings from physician-assisted suicide were rather surprising amounting to “less than 0.1 percent of both total health care spending in the United States and an individual managed-care plan budget.”<sup>140</sup> The authors assess that only ten percent of medical care expenses account for end-of-life practices, much lower than countering claims from most analysts who estimate that the final month of life accounts for 30-40% of total medical care expenses.<sup>141</sup> Such meager amounts of predicted savings call into question the theory that economics would serve as a national driver for the practice; however, those who support the theory insist that this morbid statistic is obscured or contend that it will only swell with projected AVE/PAS attributed deaths. Claims supporting the economics theory tend to be futuristic in tone while those opposed are more centered on the present findings.

Taking a jab at the improbability of proving the economics theory, Battin and Emanuel explain that proper framework for computation must be based on four vastly

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<sup>139</sup> Shedlock, “Death Panel Discussion,” 1.

<sup>140</sup> Shedlock, “Death Panel Discussion,” 1.

<sup>141</sup> Shedlock, “Death Panel Discussion,” 1.

uncertain and largely unknowable factors<sup>142</sup>:

1. The number of patients who actually would participate if legalized
2. The amount of medical costs saved by physician-assisted suicide
3. The amount of time a patient's life might be hastened
4. The aggregate cost of medical care for patients who actually die

As these four specifications already imply, the economics-driven argument may sound compelling but proving it is another story, because calculating accurate figures may be entirely impossible. For example, there would ultimately be no way of knowing how many additional citizens would honestly choose to die if euthanasia were legalized. Likewise, a patient's date of death is unknowable, rendering it unattainable to determine the amount of life actually lost. Battin and Emanuel further admit that deficient data exists on the costs of care near the end of life, particularly in the United States. The authors decided the best course of action would be to merge existing data available from the Netherlands with the limited American data on end of life costs.<sup>143</sup> Admitting scarcity of resources, the team aimed to be as detailed as possible in analysis and sought to achieve an approximate “range of savings under reasonable conditions.”<sup>144</sup>

That said, it was estimated that if the Americans’ appetite for AVE were to mirror the Dutch, approximately 2.7 percent of the 2.3 million Americans who die annually

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<sup>142</sup> Shedlock, “Death Panel Discussion,” 1.

<sup>143</sup> Battin and Emanuel, “What Are the Potential Cost Savings,” 168.

<sup>144</sup> Battin and Emanuel, “What Are the Potential Cost Savings,” 168.

would be predicted to choose AVE if it were sanctioned nationwide.<sup>145</sup> Since exact date of death for each patient is immeasurable, the researchers instead chose to rely on predictions from physicians on population-based times of death. For example, physicians in the Netherlands estimated that 17% of requesting patients hastened life by less than one single day, and the bulk of patients (over 90%) lessened life by 4 weeks or less with the average mean approximately 3.3 weeks.<sup>146</sup> Finally, the researchers assumed the rate at the time was equivalent to estimates by Medicare that totaled average cost for the last month of life amounting to around \$10,118 per patient death. Putting it all together, Battin and Emanuel calculated that even if 2.7% of patients who die annually (62,000 Americans) chose euthanasia, thus dying approximately one month earlier; it would still only amount to \$627 Million saved which may sound sizable, but in reality, the figure equates to less than 0.07% of total U.S. health care expenditures.<sup>147</sup>

Despite research limitations, the authors' model was a commendable attempt to test the validity of the theory that the practice would save the state and healthcare systems significant amounts of money. From this lens, the argument that economics is a significant driver in demand for AVE seems fairly weak or, otherwise, inconclusive/unknowable. I bring this experiment into the literature review to show another side of a dominant theory from scholars taking an alternative route to question its legitimacy. In subsequent sections, I incorporate another important facet of the

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<sup>145</sup> Battin and Emanuel, "What Are the Potential Cost Savings," 168.

<sup>146</sup> Battin and Emanuel, "What Are the Potential Cost Savings," 168.

<sup>147</sup> Battin and Emanuel, "What Are the Potential Cost Savings," 168.

economics piece addressing the savings benefits posted by palliative healthcare and its resulting potential to meld with euthanasia practices.

*Demand for AVE Reflects Societal Image of “The Good Life”*. In a deeper philosophical realm, Trudo Lemmens, provides insight into the theory that the way in which human beings think of death is rolled up into our own individual notions of the “Good Life” and perceptual linkages between the method in which someone lives and the way they end up dying.<sup>148</sup> From this construct, Lemmens believes that someone dying from AIDS will be judged with the preconceived notion that the individual lived an “immoral” lifestyle. Connecting this idea with driving forces of PAS/AVE, Lemmens feels decisions are inevitably going to be impounded by the philosophical notion that someone either deserves life or death based on their individual lifestyle or medical condition. Obviously, one’s death in does not coincide directly with the life they have led. Adolf Hitler went out peacefully and Mahatmi Ghandi was violently killed and on any given day an innocent bystander could be tragically hit by a bus. However, although it sounds rudimentary, Lemmens makes a dangerous, grave point: “We also have to reject firmly the idea that disease, misery, and suffering, is the normal pay-off for sins committed. What happens is that people often find points of resemblance between one’s own lifestyle and one’s death.”<sup>149</sup> Slightly adding a disturbing trace of evidence to Lemmens’ theory, I later address a study by *Current Oncology*’s J. Pereira which

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<sup>148</sup> Trudo Lemmens, “Euthanasia and the Good Life,” *Perspective in Biology and Medicine* (Johns Hopkins University Press) 39, no. 1 (1995): 15-21. Accessed October 3, 2016. [https://www.law.utoronto.ca/documents/Lemmens/Euthanasia\\_goodlife.pdf](https://www.law.utoronto.ca/documents/Lemmens/Euthanasia_goodlife.pdf).

<sup>149</sup> Lemmens, “Euthanasia and the Good Life,” 15.

determined that those suffering from AIDS in the Netherlands were the only group found to be disproportionately vulnerable to AVE.

In a paradoxical twist, Lemmens describes how the conflict is intertwined with the very basis of the medical profession: “By attempting to preserve an optimal state of mental and physical health, medical research engenders a specific view of the desirable life”.<sup>150</sup> In essence, instead of arguing that euthanasia is counter-intuitive to the aim of medical profession, he asserts that the goal of medicine actually propels demand for it. Specifically, demand for death will increase for those living under the threshold of the continually-rising bar in modernizing health standards sensed as the new “Good Life”. Lemmens believes the problem is a false expectation in society for medicine’s unintended production of “...the dream of perfect control over death and dying”.<sup>151</sup> The legalization of euthanasia reinvigorates the notion of wanting the good life, according to Lemmens, and this vision is bound to be more “limited than desirable” in scope.<sup>152</sup>

Addressing the classical argument, Lemmens addresses proponents’ claim that demand for euthanasia is a result of technology spiraling out of control and being used inappropriately in healthcare operations. For example, life support systems in the United States were used to sustain life on 10,000 patients in complete and persistent vegetative state without consciousness.<sup>153</sup> He considers how doing this actually disrespects the life

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<sup>150</sup> Lemmens, “Euthanasia and the Good Life,” 16.

<sup>151</sup> Lemmens, “Euthanasia and the Good Life,” 16.

<sup>152</sup> Lemmens, “Euthanasia and the Good Life,” 17.

<sup>153</sup> Lemmens, “Euthanasia and the Good Life,” 17.

and dignity of the patient. Indeed, it seems somewhat foolish for the ultimate end of medicine to be saving life, at all costs, and without considering one's quality of life.

Highlighting an argument by D. Callahan, Trudo Lemmens brings up a similar argument in which medicine's responsibility over dying has resulted in the demand for death when the mission to save life is rendered improbable. The insatiable quest for human prolongation of life has prompted Callahan to determine that technology has prompted a new "reality" for patients where they expect every disease and ailment to have a proper cure, and if not, medicine then becomes responsible for ending life.<sup>154</sup> From this lens, Callahan asserts that the very fact that medicine has the potential to fully save life, the moral responsibility for cure falls solely on the shoulders of the physician. It follows that once the procedure does not produce healthful results, it becomes the fault of the physician in a cyclical process of unachievable expectations that cloud our judgement.<sup>155</sup>

Above all, Lemmens expresses concern that legalizing physician-assisted suicide transforms the good life into the notion that pain, suffering and periods of hopelessness are part of the natural human experience. According to Lemmens, citizens may want to end their lives once they come to the realization that they are no longer physically or mentally capable of achieving the good life, or a life above what has come to be considered ordinary level. Furthermore, it is illogical to expect all forms of suffering in society to be completely eradicated. Drawing on the historic failure of medicine to find

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<sup>154</sup> Lemmens, "Euthanasia and the Good Life," 17.

<sup>155</sup> Lemmens, "Euthanasia and the Good Life," 17.

the cure for cancer and AIDS, Lemmens reasons that our quest for medical and human perfection is leading to the detriment of mankind. Like a painter destroying his work of art when it becomes tarnished or botched, Lemmens fears the human race, under euthanasia, will hold itself to an unachievable standard – a standard that ends with death.

Divergently, other scholars, like D. Harris et al., believe that entitlement to a “good death” is an important cultural and societal principle if paired with the appropriate balance of holistic palliative care.<sup>156</sup> While the Harris team agrees with Lemmens’ assertion that it is foolhardy to envisage an end to all human suffering, they instead leverage this point to align with the idea that once palliative care has been exhausted, it becomes the role of the physician to conduct assisted death.<sup>157</sup> In their vision, palliative care and euthanasia can work cohesively as one unit to produce the “good death”. Basically, this view is a confirmation of Lemmens’ theory that once medicine fails to produce the cure, it becomes medicine’s duty to end it all.

Trudo Lemmens’ declaration on euthanasia causing the reproduction for societal demand of the “Good Life” was presented back in 1995. Eerily, his idea may already be coming to pass as Lemmens reported, in October 2016, to the *Chicago Tribune* that the new Dutch proposal called “The Completed Life” would allow anyone “tired of living”, regardless of physical or mental condition, to be killed through AVE.<sup>158</sup> Provocatively,

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<sup>156</sup> D. Harris, P. Khanna, and B. Richard, “Assisted Dying: The Ongoing Debate,” *Postgraduate Medical Journal*, 480th ser., 82, no. 970 (2006): 479-482. Accessed October 19, 2016. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2585714/pdf/479.pdf>

<sup>157</sup> Harris, , et al., “Assisted Dying,” 480.

<sup>158</sup> Arthur Caplan, Willem Lemmens, and Trudo Lemmens. “The Dangers of Euthanasia-on-demand,” *Chicago Tribune*, October 17, 2016. Accessed December 18,



included under the measure is an appointed “Counselor in Dying” assigned to each willing participant. This move has alarmed even some Dutch committee members since most elderly citizens already have the ability to choose AVE under current law: “The committee's chair even referred to the ‘counselor in dying’ concept as a ‘creepy idea.’”<sup>159</sup> Trudo Lemmens and his counterparts profess the sheer improbability that assisted dying outside of the medical context could be justly or even reasonably controlled. Pertinent to our case study, the group relay statistics which they believe already represent the inability of Belgium and the Netherlands to control medical cases of euthanasia: “In the Netherlands, more than 5,000 people are now euthanized per year. In Belgium, it has risen to 2,021 in 2015 from 347 in 2004.”<sup>160</sup> Citing cases of couples being jointly euthanized, disabled citizens taking the plunge, and the mentally disturbed given the green light, Lemmens fears his notion of euthanasia advancing through the human quest for the “Good Life” is already well underway: “Aid in suicide, facilitated by the state, is the logical consequence of a fetishizing of choice.”<sup>161</sup> In the article, the Lemmens duo and Arthur Caplan furthermore probe the very notion of a “completed life”, expressing grave skepticism that human life itself can somehow be measureable, and to what standard?<sup>162</sup>

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2016. <http://www.chicagotribune.com/news/opinion/commentary/ct-euthanasia-assisted-suicide-dutch-netherlands-perspec-1018-jm-20161017-story.html>.

<sup>159</sup> Caplan, et al. “The Dangers of Euthanasia-on-demand,” 1.

<sup>160</sup> Caplan, et al. “The Dangers of Euthanasia-on-demand,” 1.

<sup>161</sup> Caplan, et al. “The Dangers of Euthanasia-on-demand,” 1.

<sup>162</sup> Caplan, et al. “The Dangers of Euthanasia-on-demand,” 1.

*Nation State Variances in Suicide.* Demand for AVE varies between nation states in certain instances and leaves many scholars perplexed as to why this might be the case. For instance, one study found a wide discrepancy between French and Dutch euthanasia declarations, with 211 French cases and 911 Dutch cases reported in 2011.<sup>163</sup> Cultural differences may play a role in a nation's practice of euthanasia as numerous scholars have studied. The general nature of one's culture in acceptance of suicide may play a role as well as desperateness in one's socioeconomic circumstance.

Somewhat mysteriously, as the World Health Organization's 2014 data on global suicide rates indicates, there does not appear to be a hardline trend with regard to worldwide experiences of suicide rates. Though, Eastern European nations, India, and portions of Eastern Africa are most affected with 75% of all global suicides occurring in low and middle income nations.<sup>164</sup> Nevertheless, the United States, Australia and much of Europe is not far behind in the rankings and several notable nations suffering abject poverty yet experiencing markedly low levels of suicide – Mexico and Northern African countries, in particular.<sup>165</sup> Comparing this data with OECD's 2012 data, we also see that suicide rates in nations utilizing AVE are not dramatically high comparatively with other non-AVE practicing nations such as in Eastern Europe.<sup>166</sup>

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<sup>163</sup> Berghmans and Lossignol, "Euthanasia: From Ethical Debate," 804.

<sup>164</sup> "Suicide Data." World Health Organization. 2014. Accessed December 12, 2016. [http://www.who.int/mental\\_health/prevention/suicide/suicideprevent/en/](http://www.who.int/mental_health/prevention/suicide/suicideprevent/en/).

<sup>165</sup> "Suicide Data," 1.

<sup>166</sup> "Health Status – Suicide Rates – OECD Data." OECD Data. 2012. Accessed December 12, 2016. <https://data.oecd.org/healthstat/suicide-rates.htm>.

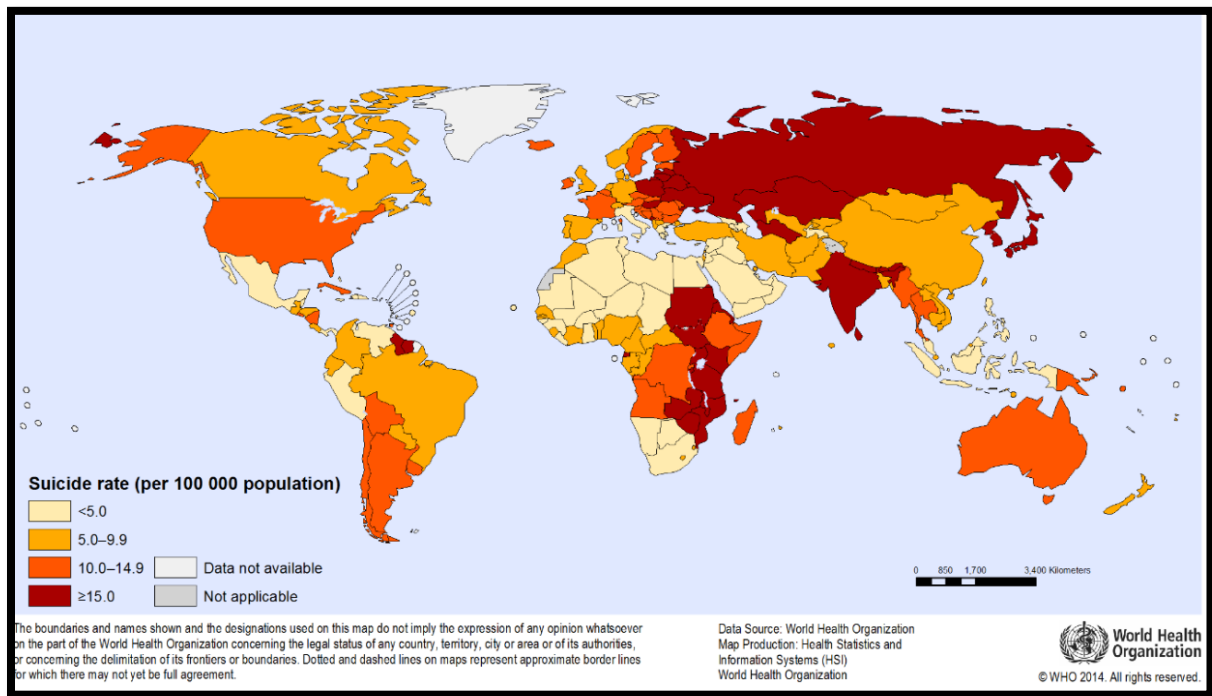


Figure 16: Suicide rates worldwide (WHO 2014)

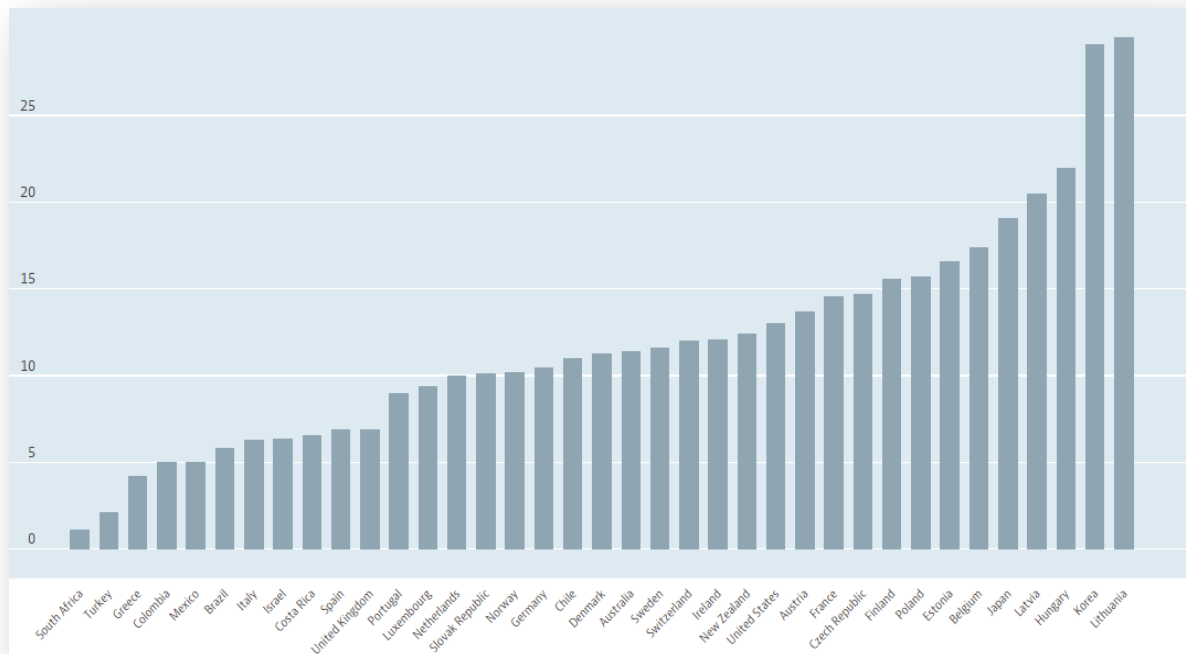


Figure 17. Suicide rates total, per 100 000 persons (OECD 2012)

Pointing to suicide data, as a whole, researchers negate the anti-AVE claim that

the practice serves as a nefarious threat to humanity through the creation of a culture that will disregard human life and succumb to committing suicide acts privately. Based on 2012 data, the global phenomenon of suicide represents 1.4% of all deaths worldwide, marking it the 15<sup>th</sup> leading cause of death and ranking as the second highest killer of all 15-29 year olds worldwide.<sup>167</sup> From this approach, a look at 2011 OECD Health Data on worldwide suicide rates paints an interesting picture for our case study with the occurrence of privately-committed suicides holding relatively steady in the United States and actually falling in the Netherlands in the years immediately following PAS/AVE legislation.<sup>168</sup> Data of this nature additionally negates the commonly purported claim that legalizing PAS/AVE will attribute to a downward spiral producing a “culture of suicide”.

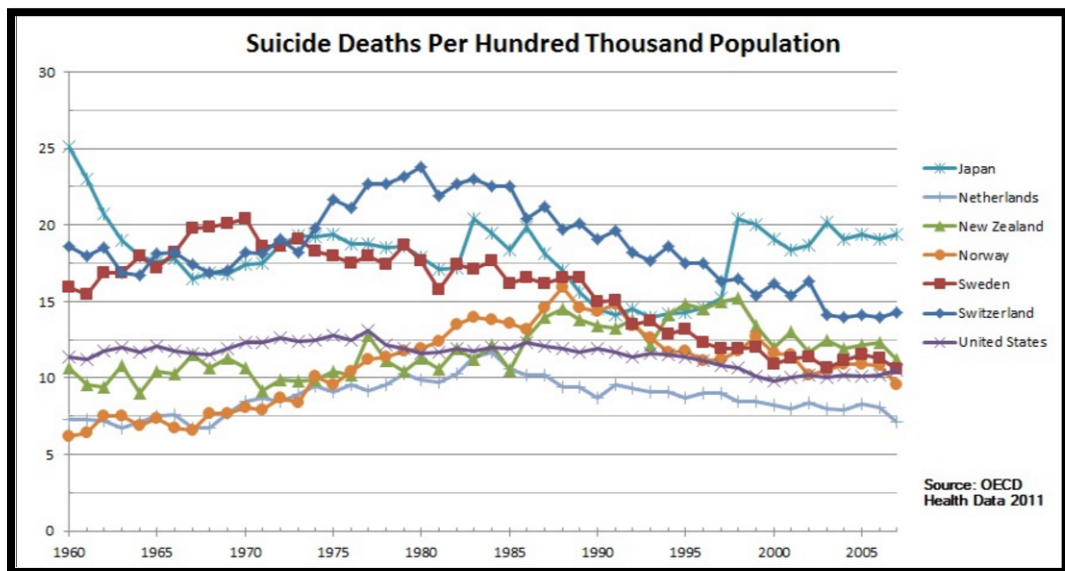


Figure 18. Global suicide rates (OECD 2011)

Some suggest underlying cultural influences may be a greater piece of the puzzle,

<sup>167</sup> “Health Status,” 1.

<sup>168</sup> “Health Status,” 1.

especially for nations who have long struggled with horrific suicide rates, like Korea and Japan. In Greece, a survey reported that only 40% of physicians and relatives would agree not to resuscitate terminally ill cancer patients in cases of cardiorespiratory arrest; however, the report also found that only 20% of Greek physicians agreed with euthanasia as a general practice.<sup>169</sup> In contrast, the same survey in Korea produced a 50% response rate of both patients and the general population morally approving of the practice; yet only 10% of physicians operating in the field of oncology reported to support euthanasia.<sup>170</sup> This presents an interesting dichotomy as the demand for the practice amongst the general population is overwhelmingly present; yet the physicians' unique beliefs and attitudes somewhat hinder the outcome when at odds with the law or with the community they serve as a whole. These studies not only reveal cultural influences, but also how differing perceptions amongst sub-groups of a population from legislators, doctors, and societal attitudes can substantially impact the rollout of the practice even after it becomes law.

Meanwhile, many nations or regions do not have standard reporting practices set in place and culture sways their general attitude towards pain and suffering. In southern Belgium, Berghmans and Lossignol reported that AVE deaths are frequently going undocumented, which is likely due to terminal sedation being used as a substitute option to euthanasia.<sup>171</sup> Inconsistencies on classifications of terms cause incongruity as the so-

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<sup>169</sup> Berghmans and Lossignol, "Euthanasia: From Ethical Debate," 805.

<sup>170</sup> Berghmans and Lossignol, "Euthanasia: From Ethical Debate," 805.

<sup>171</sup> Berghmans and Lossignol, "Euthanasia: From Ethical Debate," 805.

called “grey lines” experienced in one nation may be drawn at a much looser bound or defined in a much different manner than that of another population, state, or region.

Explaining perspectives on national differences, Berghmans and Lossingol emphasize that physicians worldwide are sometimes left in the dark on current euthanasia legal procedures especially if not confronted regularly with such situations or trained properly.<sup>172</sup> There is a shortage of physicians, particularly in less-developed countries, and physicians are extremely overworked with day-to-day operations; learning the legality and studying euthanasia as a social issue may not be on every physician’s to-do list but more in-depth education and background would be beneficial for both patients and doctors. As I discuss in the palliative section of our case studies, these developments are largely in progress for many Western hospitals.

In the view of Lossingol and Berghmans, this lack of knowledge on euthanasia and palliative care options deeply inhibits effective decision-making and can contribute to insufficient patient care.<sup>173</sup> To highlight the concern, the scholars referred to a survey about North American lung cancer specialists, revealing that physician referrals to palliative care had a negative connotation due to an underlying perception that doing so could panic or frighten patients and families.<sup>174</sup> Still, palliative care specialists would see the situation much differently in belief that palliative care is meant to relieve patient’s ailments at a much earlier stage and to be administered as a continuation of treatment

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<sup>172</sup> Berghmans and Lossingol, “Euthanasia: From Ethical Debate,” 805.

<sup>173</sup> Berghmans and Lossingol, “Euthanasia: From Ethical Debate,” 805.

<sup>174</sup> Berghmans and Lossingol, “Euthanasia: From Ethical Debate,” 805.

throughout. This disagreement returns to the two schools of thought, highlighted in the palliative care history section, on when palliative care should be introduced to the patient and what it should comprise. Unease over the lack of physician training in euthanasia and palliative care does not come without warrant. In fact, a survey collected in France recorded that only a small portion of physicians were actually trained in palliative care with a mere twelve percent of neurologists responding that they had received any type of palliative health care training at all.<sup>175</sup>

As French researchers reference in “Doctors’ Opinions on Euthanasia, End of Life Care, and Doctor-Patient Communication,” the argument that culture defines opinion on the right to die, could be explained by the heightened emphasis of general autonomy in English speaking countries than present in other developed or developing countries.<sup>176</sup> Societal and cultural outlook on the end of life, pain and death has altered over time and continues as medical advancements confront humanity with prolongation of life running into increased desire for human autonomy in all facets of life. The ways in which each culture and nation meet these challenges are bound to vary and determining the reasons for a nation’s support or condemnation of euthanasia is a bewildering task for any scholar.

This segment addressed insight into the cultural aspects of suicide and how it might impact one’s decision to undergo AVE. In addition, the connection between rising suicide rates, generally, might hold underlying insight, although not the center of our

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<sup>175</sup> Peretti-Watel et al., “Opinions on Euthanasia,” 595.

<sup>176</sup> Peretti-Watel et al., “Opinions on Euthanasia,” 595.

focus. While statistics and numerical models aid our understanding of trends, patterns, and nuances to a certain degree, a sensitive topic of this nature demands qualitative data straight from the cast, which I introduce in the following section.

#### E. Qualitative Data on Demand

Qualitative data from the sources closest at heart to this argument is scarce yet this data is valuable in gaining a full grasp on demand for euthanasia from those directly involved. The majority of surveys prompt respondents with a question that has pre-determined responses laid out; while this can be useful, acquiring more detailed, personal, and verbatim data from the respondent directly could shed light or add important details to aspects of euthanasia overlooked by the number crunching. Qualitative studies within the practice are generally limited in scope to a small sample which hinders a wider response rate; however, these studies are unique in offering the audience a glimpse of the specific mentalities the patient or doctor may have when either demanding or performing these operations. Hidden from the public eye, these personal reactions and reflections reveal important repressed emotions and opinions.

One such study took place in France as a telephone survey conducted by medical experts with the doctor-patient relationship, incorporating perspectives of over 1,500 physicians. Analyzing these attitudes, the researchers compared different medical specialties “which demand different amounts of palliative care and different amounts of empathy” in communication patients.<sup>177</sup> Throughout France random physicians were

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<sup>177</sup> Peretti-Watel et al., “Opinions on Euthanasia,” 595.



selected from three specific areas: general practitioners, oncologists, and neurologists. Under the guise of the proponent's argument that palliative care is an extension of euthanasia, and autonomy must be respected by those wishing to die, the researcher's hypothesis was turned upside down after examination of the data.

While most French doctors responded favorably towards legalization, the sentiment was far more popular amongst those who worked as general practitioners and neurologists than the oncologists; however, the Italian and American oncologists were surprisingly more supportive of euthanasia. The French oncologists were the group with the highest experience in end of life care and palliative care training, and they responded with "greater comfort and better communication with terminally ill patients."<sup>178</sup> The researchers believe these results, although limited, may contradict the cultural differences argument discussed in the previous section. Furthermore, they reason that the French physician support of euthanasia may be due to a lack of professional knowledge and experience with palliative care as demonstrated through the diverging responses from the most highly trained French oncologists in palliative care services.<sup>179</sup>

Often forgotten in the AVE discussion is fundamental role of nurses in medicine, particularly and in the practice of euthanasia. Nurses spend extensive amounts of time in intensive care units (ICU), develop bonds with patients, and are typically more intimately involved with the patients than the doctors themselves. Faced with ethical and high-pressure situations, the voice of nurses is crucial to the issue. Moreover, in the United

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<sup>178</sup> Peretti-Watel et al., "Opinions on Euthanasia," 595.

<sup>179</sup> Peretti-Watel et al., "Opinions on Euthanasia," 596.

States, Physician's Assistants have been granted extra responsibility in many hospitals to abet the shortage of doctors in the mainstream healthcare system.

In 1996 researcher David Asch documented results from an anonymous qualitative survey was sent to about 1,300 nurses in the United States operating in intensive care units.<sup>180</sup> As public debate roared over the practice in the United States, the candid responses from nurses during this time period were rather alarming. Seventeen percent reported receiving requests for euthanasia and sixteen percent had engaged in the practice.<sup>181</sup> Most disturbing, seven percent admitted to having hastened a patient's death "by only pretending to provide life-sustaining treatment that was ordered by a physician."<sup>182</sup> Asch remarked, "Eight percent reported engaging in these practices without the request or advance knowledge of physicians."<sup>183</sup> Additionally, 15 of 36 registered U.S. nurses supported a resident physician's decision to administer a lethal overdose of morphine to a 20-year old patient suffering from ovarian cancer. Disregarding the law, responses indicated that instances of assisted suicide were not always in response to actual requests for it being performed from consent or knowledge of patients, family members, or surrogates.<sup>184</sup> In comparison, at the time, 7 to 29 percent of physicians in Britain and Australia had responded that they had conducted AVE, and

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<sup>180</sup> David A. Asch, "The Role of Nurses in Euthanasia and Assisted Suicide," *New England Journal of Medicine* 334, no. 21 (1996): 1374-1378, accessed December 10, 2013, [nejm.org](http://nejm.org).

<sup>181</sup> Asch, "The Role of Nurses," 1374.

<sup>182</sup> Asch, "The Role of Nurses," 1374.

<sup>183</sup> Asch, "The Role of Nurses," 1374.

<sup>184</sup> Asch, "The Role of Nurses," 1376.

Washington State physicians had reported only fulfilling 38 of 156 requests.<sup>185</sup>

The surveys solicited nurses to write about their experiences and thoughts on the matter. Five percent responded that they had actually assisted in a suicide outside of the actual hospital; one such nurse anonymously reported<sup>186</sup>:

“My 71-year-old father was dying of cancer. He did not wish to prolong his life. Morphine in pill form “controlled” his pain. He was at home. As he lay struggling for breath, I got liquid morphine from his physician and gave him as much as he could swallow. He was frothing at the mouth. I told him if he could hear me to try to swallow and that this would stop the struggle for a life he no longer wanted.”

In these instances, the nurses acted unilaterally in creating their own personal ethical guidelines for end of life operations. As another nurse described: “I have given morphine doses much higher than prescribed, and falsified narcotic ‘waste’ to disguise it.”<sup>187</sup>

While these examples show a dark side of the medical practice, many respondents did resist engaging in these unauthorized activities; however, the reasons cited for forgoing these actions appear less honorable. The bulk of respondents who refrained from engaging in unsolicited AVE did so out of a fear of getting caught (91%), for concern the act they were engaging in could be illegal (83%), or because they could not fully

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<sup>185</sup> Asch, “The Role of Nurses,” 1374.

<sup>186</sup> Asch, “The Role of Nurses,” 1376.

<sup>187</sup> Asch, “The Role of Nurses,” 1376.

understand the patient's desires (80%).<sup>188</sup> These statistics correspond with our previous discussion about lack of proper training for palliative care and end of life practice training for medical professionals. Undoubtedly, an ethical and an educational problem exists as 83% of these 1,300 nurses working in Intensive Care Units are admitting unawareness of the laws that bind them in end of life procedures.

On the other hand, the nurses have also expressed frustration that doctors need more bedside training because they should be the primary caretakers, dealing with both patients and families sometimes 8-10 hours a day: "They should step into our shoes for about one month to get a much better idea of how much patients and their families are allowed to suffer."<sup>189</sup> Seen from this perspective, nurses expressed fear that perhaps palliative care services are underutilized due to physicians' unresponsiveness or unawareness of the level a patient is actually suffering.

In the end, David Asch is concerned that this phenomenon was not merely a few lone outliers operating inappropriately in a hospital, and he seeks to explain this sample by reflecting on the emergence of a "continuum of moral acceptability and professional practice."<sup>190</sup> Asch reasons that some nurses fell into what he dubs the "Doctrine of Double Effect", whereby nurses excused personal behavior as a reason to hasten death, end suffering, or both. The researcher neither condemns nor applauds these actions, but he notes the multi-dimensional quandary that medical professionals grapple with in a

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<sup>188</sup> Asch, "The Role of Nurses," 1376.

<sup>189</sup> Asch, "The Role of Nurses," 1377.

<sup>190</sup> Asch, "The Role of Nurses," 1377.

complex practice where professional, ethical, and personal values will inevitably collide on a human level. He portrays the attitudes from both perspectives and defines recurring themes analyzed from the nurses' written responses including an overwhelming concern about the "overuse of life-sustaining technology; responsibility for the patient's welfare; desire to relieve suffering; and desire to overcome the perceived unresponsiveness of physicians toward that suffering."<sup>191</sup>

What is clear from the results of the study is how ethical disagreement between physicians and nurses can add tension, stress and pressure in the ICU. As with many scholars, David Asch reasons that wide varieties of events described in this study illuminate the vexing inadequacy of the term "euthanasia" as well as the plethora of professional and legal policies built on its ambiguous meaning. Despite the survey results, Asch still rejects the theory that citizens should be fearful or suspicious of physicians and nurses if AVE became legal; instead he maintains that the responses indicate the nurses' compassion for human suffering. However, he does caution that these results could also signify how AVE may become "too easy of an option" and concludes that the only surefire way of limiting tragedies is for the law to prohibit assisted suicide practices entirely.<sup>192</sup>

Another qualitative study focusing on patient perspective was conducted in 2006 by U.S. National Institute of Health researchers entitled, "What People Close to Death Say About Euthanasia and Assisted Suicide: A Qualitative Study." Using a maximum

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<sup>191</sup> Asch, "The Role of Nurses," 1377.

<sup>192</sup> Asch, "The Role of Nurses," 1378.

variation sample on eighteen terminally ill patients, narrative interviews were conducted throughout the United Kingdom. Patients included those who had spent time in hospice care and the researchers used the “method of constant comparisons” to ensure all areas of perspectives were represented as they explored themes of pain, hastening of death, and dignity.<sup>193</sup> Most patients interviewed supported euthanasia, wishing for a change in UK law, and the authors assess that “control over the time and manner of death” was a reoccurring theme. As one patient described, “I, myself, want to be in control as long as I can, I don't want doctors and nurses controlling me.”<sup>194</sup>

Results showed that, contrary to popular belief, those who had witnessed others die were actually the most convinced that euthanasia should be one's right and regularly cited reasons for this decision including pain, fear of indignity, fear of becoming a burden, and cognitive impairment.<sup>195</sup> Views from the few who were opposed to changes in the law were concerns with involuntary euthanasia, abuse, or other personal religious reasons.<sup>196</sup> Data gained from these interviews contradicted a few preconceived notions the researchers held prior to the study and although it can be challenging to analyze collectively, it most certainly adds value to the field.

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<sup>193</sup> A. Chapple et al., “What People Close to Death Say about Euthanasia and Assisted Suicide: A Qualitative Study,” *Journal of Medical Ethics*, National Institute of Health 32, no. 12 (2006): 706-710, Accessed December 13, 2013. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2563356/>.

<sup>194</sup> Chapple, “What People Close to Death,” 707.

<sup>195</sup> Chapple, “What People Close to Death,” 706.

<sup>196</sup> Chapple, “What People Close to Death,” 706.

To date, AVE remains a crime in the United Kingdom; however, parallel to the decriminalizing pattern occurring in other sovereignties, the British Director of Public Prosecutions failed to convict thirty-one assisted suicide cases in court.<sup>197</sup> Prominent British Lawyer Lord Carlile most accurately described the situation as having “a hard law, with a kind face”.<sup>198</sup> That said, critics rage over the danger that the law is simply being disregarded. As with many politicized social dilemmas, opponents declare that the Director of Public Prosecutions is “Falconer’s Commission” because it is composed of nine commissioners in favor of AVE and only two who are opposed.<sup>199</sup>

A 2012 ComRes poll initiated on the eve of Lord Falconer’s push for AVE legalization, revealed a deep split in national opinion with 45% of respondents expressing concern that if AVE achieved legality, it would make citizens feel pressured to kill themselves.<sup>200</sup> Interestingly, this figure climbed 50% from the previous year regions of the South East, Midlands, and Scotland.<sup>201</sup> The poll’s breakdown in age and profession was also insightful in finding that 47% of citizens believed the law, if adopted, would not help the disabled with this figure rising to 57% for those in the 18 – 24 year old range,

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<sup>197</sup> “CARE Assisted Suicide Poll.” ComRes. January 5, 2012. Accessed December 13, 2016. <http://www.comresglobal.com/polls/care-assisted-suicide-poll/>.

<sup>198</sup> “CARE Assisted Suicide,” 1.

<sup>199</sup> “CARE Assisted Suicide,” 1.

<sup>200</sup> “CARE Assisted Suicide,” 1.

<sup>201</sup> “CARE Assisted Suicide,” 1.

and up to 55% for those working in managerial and professional jobs.<sup>202</sup> The below chart from ComRes 2014 data reflects the breakdown in unique British attitudes.

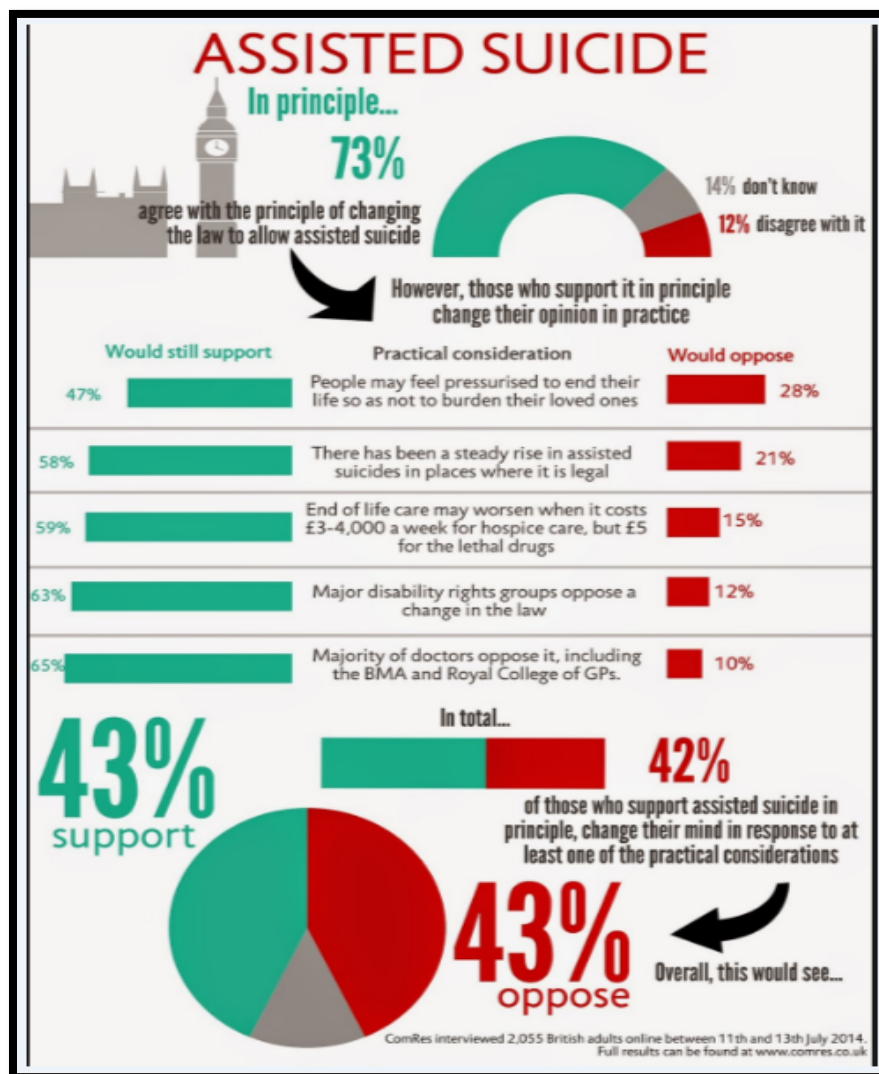


Figure 19: British Assisted suicide poll (ComRes 2014)<sup>203</sup>

<sup>202</sup> “CARE Assisted Suicide,” 1.

<sup>203</sup> “Assisted Dying & Public Opinion.” Care Not Killing – [Carenotkilling.org.uk](http://www.carenotkilling.org.uk). 2014. Accessed December 13, 2016. <http://www.carenotkilling.org.uk/public-opinion/assisted-dying-public-opinion/>.



Above all, demand for physician assisted suicide should be the chief concern of those who are in these situations and qualitative data must be conducted in such a way as to ensure their voices are heard. Terminally ill patients are, more often than not, unable to express a change of heart or true intentions as they are frighteningly trapped inside their own body with limited or no ability to communicate. Sample sizes may be limited in scope; yet simple communication and strong analysis from a team of dedicated, compassionate researchers can put a human face on this habitually dehumanized social issue. Each individual case has its own set of circumstances because every patient's experience and story is distinctive. Filing patients into a fixed box by merely assessing quantitative data will omit vital dimensions of the problem and neglect underlying demands of vulnerable patients who cannot be fully understood without dialogue. Moving into another philosophically rooted argument, the next section covers the legendary meaning to life or "meaningful existence" argument as it relates to the demand for euthanasia.

*The Meaning of Life Argument.* In *Ending Life, Morality, and Meaning*, Jakka Varelius contends that one's meaning in life, and having a "meaningful existence" is the prime factor in patients' choices about euthanasia. She argues that it is not suffering itself that causes patients to choose death, but rather, *meaningless suffering* in which the patient no longer finds significance in their suffering.<sup>204</sup> As with many theoretical and philosophical theories, the first traces of the "meaning to life" theory originated in ancient Greece. For example, in Greek mythology, the gods sentenced Sisyphus to a life of drudgery in which he was required to roll a large boulder up a mountain for the sole

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<sup>204</sup> Varelius, "Ending Life, Morality, and Meaning," 2.

purpose of watching it roll back down, repeating the process eternally.<sup>205</sup> Mental forms of torture in which one's meaning of life is relinquished illustrate the theory Varelius discusses in her understanding of demand for euthanasia. One can endure pain and suffering if one believes life still has meaning, but once that meaning is completely lost, human suffering becomes meaningless.

Correspondingly, many scholars have suggested that in order to have a meaningful existence, one must be capable of making autonomous decisions, decisions that chronically ill patients are often unable to make. Expanding on the connection between autonomy as it adds meaning to life, Tom Beauchamp and James Childress, in *The Principles of Biomedical Ethics*, discuss VE and PAS in terms of intentionality, understanding, and freedom.<sup>206</sup> Urging respect for autonomy, non-maleficence, beneficence, and justice within medical practices, the authors define an autonomous person as one who “acts freely and intentionally in accordance with her own informed view of how her life should proceed.”<sup>207</sup> Essentially, the theory holds that any autonomous action taken must align with the agent's conception of said act.

In Beauchamp and Childress's view, at the minimum, patients maintain their ability to understand only if they are equipped with relevant information about the nature and consequences of their actions. If this knowledge is withheld from patients, they would not maintain full autonomy. Thus, in Jakka Varelius' view, lack of autonomy already equates to a meaningless life and would likely lead such patients to choose, if

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<sup>205</sup> Varelius, “Ending Life, Morality, and Meaning,” 2.

<sup>206</sup> Tom L. Beauchamp and James F. Childress, *The Principles of Biomedical Ethics*, 4th ed. (Oxford: Oxford University Press, 1994), 59.

<sup>207</sup> Beauchamp and Childress, *The Principles*, 58.

able, to die through AVE.

However, in a Netherlands study led by Hilde Buiting, researchers found that since 2002 there was a significant decrease in patients requesting euthanasia because of a “loss of dignity.”<sup>208</sup> In contradiction to Varelius, they discovered that after 2002 more patients were, in fact, listing “pain” as the reason to choose death, rather than “loss of dignity.” Buiting’s team of researchers instead deduced that this change might be due to improvements made in palliative healthcare.<sup>209</sup> We will continue this thought into the next section where I will discuss the scope of these findings as they relate to palliative care’s effect on the demand for euthanasia. Still, the connection between human pain and autonomy is an acutely personal experience. On the one hand, some have argued that refusal of AVE is actually forcing suffering citizens to take measures into their own hands by seeking ways to end their lives before they reach a point where they are physically unable to do so.

The Canadian Supreme Court Case involving amyotrophic lateral sclerosis sufferer, Sue Rodriguez, brought this issue to light. In a narrow five to four ruling, the high Canadian court denied Rodriguez’s AVE plea in 1993. However, signifying just how far citizens are willing to go to end their own pain, by 1994, Rodriguez tracked down an anonymous physician to conduct the suicide.<sup>210</sup> Her chilling 1991 statement to

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<sup>208</sup> Hilde M. Buiting, Agnes van der Heide, and Bregje D. Onwuteaka-Philipsen, “No Increase in Demand for Euthanasia Following Implementation of the Euthanasia Act,” *General Medicine Journal* 15, no. 5 (2010): 1-5.

<sup>209</sup> Buiting, et al., “No Increase in Demand,” 1.

<sup>210</sup> News, CBC, “The Fight for the Right to Die.” CBCnews. June 14, 2014. Accessed December 13, 2016. <http://www.cbc.ca/news/canada/the-fight-for-the-right-to-die-1.1130837>.

the Canadian parliament floor reflects the autonomous wish many are confronted with: ““If I cannot give consent to my own death, whose body is this? Who owns my life?”<sup>211</sup> Life with chronic, excruciating pain is a living hell that those who have not suffered can never fully comprehend. I, myself, did not realize the extent of desperation until thrust into my own continuum of seemingly never-ending physical pain –a level of pain that was likely far less than the victims we have covered. Indeed, beyond physical pain, the truest form of human desperation is the direst emotion human beings can endure. Joining the ranks of nations able to practice AVE, in a narrow 5-4 Supreme Court ruling, Canada struck down the ban on physician assisted suicide on February 6, 2015 under *Carter v. Canada*.<sup>212</sup>

When the demand for AVE is less tied to the physical aspect of suffering and instead embodies mental forms of suffering, societal and legal support levels tend to drop. Nevertheless, in some cases, mental anguish has not deterred suffering citizens in their quest to ultimately find a willing, controversial medical actor. For example, the topic of Belgium AVE is personal matter for Mr. Mortier, once an AVE supporter, now vehement critic, who believes the law resulted in his mother’s unjust death: “What it created is unbearable suffering for me.”<sup>213</sup> Godelieva De Troyer was suffering depression

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<sup>211</sup> “The Fight for the Right,” 1.

<sup>212</sup> “Supreme Court of Canada Ruling,” Government of Canada, Department of Justice, Electronic Communications. October 12, 2016. Accessed January 27, 2017. <http://www.justice.gc.ca/eng/cj-jp/ad-am/scc-csc.html>.

<sup>213</sup> Graeme Hamilton. “Suicide with the Approval of Society: Belgian Activist Warns of Slippery Slope as Euthanasia Becomes Normal,” *National Post*, November 24, 2014. Accessed December 13, 2016. <http://news.nationalpost.com/news/canada/suicide-with-the-approval-of-society-belgian-activist-warns-of-slippery-slope-as-euthanasia-becomes-normal>.

after the break of a decade-long romance and she had largely broken off contact from her family. Casually, she informed Mortier that she was looking into euthanasia, but he never imagined such a request would be fulfilled as she was in perfect physical health. Upon her controversial physician-assisted death, Mortier discovered in her medical files that the request had been denied by several other doctors until finally a psychiatrist concluded her depression was “incurable”; thereby ending her life. Like many, Mortier does not find depression as an acceptable reason for his mother’s death: “It comes and it goes. Almost everyone has been depressed.”<sup>214</sup>

So, what is “pain” and how can the definition be transformed from these exceedingly personal grounds into legislation? Pain, both in physical and mental capacities, affects every human being in juxtaposed ways exclusively within our own brains. What is unbearable pain to some is bound to feel mild or nil to others in an identical set of circumstances. We all know that one person who appears to always experience their fair share of more pain than others, but despite our high judgements, we must realize that it is scientifically improbable to fully relate to someone else’s pain as we are not physically or mentally “in their shoes” nor can we ever expect to be. The qualms of mental torment may be just as grotesque, if not more, than physical forms of pain. After all, all forms of pain and suffering originate in the brain.

That stated, in other sections, I describe a variety of instances where sympathetic medical practitioners either anonymously or admittedly assisted suicide at the request of their patients or loved ones. Although nearly all instances failed to result in conviction, both societal praise and condemnation followed in the corresponding media frenzy. The

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<sup>214</sup> Hamilton, “Suicide with the Approval of Society,” 1.

theory surrounding pain and obedience circles back to the infamous 1963 “Milgram Experiment” when Yale University Psychologist Stanley Milgram shocked the world with the ominous results of his psychological experiment. As the experiment relates to our study, it is dissimilar in the fact that a figure of *authority* requested participants to willingly deliver pain to other humans. Yet, the Milgram Experiment’s merger on the themes of human obedience and personal conscience could be somewhat telling with regard to David Asch’s study of the nurses who conducted AVE at the obedience of the patients’ pleas as well as instances we have discussed of physicians who finally give in, despite illegality. Of course, compassion is another extraneous variable in our instance.

Based on the World War II Nuremberg War Criminal trials where Hitler accomplices argued that they were merely following orders, Stanley Milgram sought to examine exactly how far the average person would go in obeying instruction if it meant directly harming another human being through an electric shock generator. Results were astounding with 65% of all participants continuing to shock their victims up to the highest levels of 450 volts at the instructor’s command.<sup>215</sup> Further, every single participant in the entire study reached up to 300 volts before stopping.<sup>216</sup> Despite hearing their victim scream in agony, authority won out. “Simply Psychology” contributor Saul McLeod remarked on the study that ordinary people are highly likely to follow orders even to the extent of killing an innocent human being. McLeod reasons that obedience “is ingrained in us all from the way we are brought up”.<sup>217</sup> In the circumstance of AVE,

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<sup>215</sup> Saul McLeod, “The Milgram Experiment,” *Simply Psychology*, January 1, 2007. Accessed December 13, 2016. <http://www.simplypsychology.org/milgram.html>.

<sup>216</sup> McLeod, “The Milgram Experiment,” 1.

<sup>217</sup> McLeod, “The Milgram Experiment,” 1.

primarily the request does not coming from an authoritarian figure. However, as we discussed in David Asch's study, physicians (in authority) asked nurses, to carry out suicides, resulting in at least one documented instance of compliance. This does not include "recommendations" beyond express orders being made to nurses in these positions from family members and physicians. As the Milgram Experiment implies, perhaps the old adage "you don't know what you can get, until you ask for it" holds some underlying clout for AVE, particularly if there is nothing tangible to be lost by the actor (apart from one's moral code). It is the very reason we learn in business to ask for the raise and negotiate on the higher end of the price point because, more often than not, we are bound to come back with some level of what we bargained for or an alternative version of our initial request. Pertinent to the AVE debate, in our case study, we discuss instances of physicians receiving in some cases insurmountable pressure to kill by family members; underlying pressures include society's shifting moral code, the economics of influence, and potentially the government. The relevance of the Milgram Experiment on the powerful role of obedience to authority – even in the face of human pain and death – puts the issue of euthanasia's acceptance in a potentially disturbing light.

The ultimate human urge of desperation, driven by pain, has caused citizens under these unfortunate circumstances to go "doctor-shopping" across international borders with the intent of eventually finding someone to end their pain. Spearheaded by Harvard Law School Professor Glenn Cohen, a new wave of research intertwined with globalization and medical advancement, has spurred the phenomenon of "medical tourism". In a panel showcased by the *Harvard Crimson Gazette*, Glenn Cohen discusses his groundbreaking book, "Patients with Passports: Medical Tourism, Law, and Ethics", where he defined medical tourism as "the process of people travelling from less

developed countries to more developed countries like the United States in pursuit of higher-level medical treatment.”<sup>218</sup> In addition, Cohen describes a plethora of legal, medical, and economic issues that arise through “circumvention tourism” in which citizens, in desperate urge to find relief, travel outside their home nation to undergo an illegal procedure that is legal elsewhere. Notably, some procedures sought are less controversial than others; in particular, genital mutilation of minors has been condemned by the United Nations with estimates that 200 million girls have undergone this vile procedure.<sup>219</sup> Meanwhile, President Barack Obama declared the procedure as a sexual assault and the FBI maintains active investigations on those leaving the United States in pursuit of this self-mutilating practice, estimating that one-third are now minors.<sup>220</sup> Still, like AVE-seekers, many have been able to find someone to do the deed, and these underground doctors are known in these communities as “cutters”.<sup>221</sup> In terms of AVE, Cohen’s work broaches critical aspects on how illegality of the practice in one nation/state might coax the movement of global citizens, burdening them (and other nations) with a multitude of unforeseen hardships and complications in the process. On the grander scale, in *Patients with Passports: Medical Tourism, Law and Ethics*, Cohen considers if health, generally, is an inalienable human right. Harvard School of Public Health professor Alicia Ely Yamin quotes Cohen’s statement: “To define [health] as a

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<sup>218</sup> Katherine Scott, “Law Professor Discusses Medical Tourism. The Harvard Crimson.” *Harvard News*. November 20, 2014. Accessed December 13, 2016. <http://www.thecrimson.com/article/2014/11/20/professor-discusses-medical-tourism/>.

<sup>219</sup> “FBI Reaching Out about Female Genital Mutilation,” FBI. May 13, 2016. Accessed December 13, 2016. <https://www.fbi.gov/news/stories/fbi-reaching-out-about-female-genital-mutilation>.

<sup>220</sup> “FBI Reaching Out,” 1.

<sup>221</sup> “FBI Reaching Out,” 1.



right implies one, that it is of special moral importance; and two, that it is subject to social influence.”<sup>222</sup> I leave it to the reader to decide if PAS/AVE meets the threshold under Cohen’s paradigm of an inalienable health right.

*Effect of Palliative Care on Demand.* Palliative care centers work on controlling and minimizing pain for patients, pain that many argue accounts for patients to choose euthanasia as an escape. As the theory (and our hypothesis) predict, improved palliative care will result in less pain, which will lessen the incidence in request for physician-assisted suicides.

To pictorially summarize the argument:

Palliative care > Pain = ↓ Demand for Euthanasia

The argument is fairly straightforward and appears to make logical sense in its simplest form. Palliative care is becoming a commonly perceived citation opposing euthanasia since this type of medicine is predominately known for controlling symptoms of pain and even depression. Correspondingly, patients are thought to likely change their mind when symptoms are properly controlled. However, as the qualitative data from the National Institute of Health interviews reveal that this is not always the case because “although most patients do have a pain-free death, a few do not.”<sup>223</sup> A few respondents who had palliative care in the UK still struggled with uncontrolled pain and upheld wishes to end their lives.<sup>224</sup> The Symptom Burden, Palliative Care Need and Predictors of Physical and Psychological hospice movement and those in the profession make

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<sup>222</sup> Scott, “Law Professor Discusses Medical Tourism.”

<sup>223</sup> Chapple, “What People Close to Death,” 708.

<sup>224</sup> Chapple, “What People Close to Death,” 708.

incredible contributions to the livelihood of many, possibly the majority, of patients under their care. However, as the UK qualitative study indicates, a noteworthy minority of patients will still desire euthanasia even if they improve under palliative care.

A sub-study, conducted by Seale and Addington-Hall, interviewed family and friends of those who had died and were surprised to discover that respondents for hospice patients “were more likely than respondents for those who had not received hospice care to believe that an earlier death would have been better.”<sup>225</sup> The scholars found this was true even after “controlling for levels of distress and dependency among those who were dying.”<sup>226</sup> Other reasons may account for this result include the fact that strong hospice care could have actually enabled patients to communicate fears and decisions or those interviewed may have simply harbored predetermined beliefs prior to the interview.

Another rebuttal to the argument that palliative care could influence demand is that patient choice for physician-assisted suicide is not entirely related to physical pain – an argument supporting AVE for those with mental suffering. As the practice spreads, this may become increasingly the case and scholars struggle to pinpoint what exactly constitutes pain in the first place. With euthanasia being offered to more non-terminally ill seekers, as our initial Belgium examples revealed, measuring and defining pain in the psychological sense is problematic to affirmatively confirm or deny.

Substantiating the argument that pain may be becoming less of a factor in demand, a study conducted by Jojanneke Alphen, Gé Donker, and Richard Marquet compared incidents of euthanasia in the Netherlands five years before and after the

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<sup>225</sup> Chapple, “What People Close to Death,” 708.

<sup>226</sup> Chapple, “What People Close to Death,” 708.

Euthanasia Act (2003-2007) using data derived from standardized registration forms. Results revealed that it remained inconclusive whether or not legalizing euthanasia under strict conditions had any impact on demand for AVE as there had been no actual increase in incidents in the five years after the Act.<sup>227</sup> During the Dutch general practice (1977-2001) euthanasia gradually stabilized around 1995 after a sharp twenty year rise during the first twenty years of practice; one important shift was that citations of hopelessness and deterioration became greater factors for patients' requests with citations of pain slowly tapering off in recent years.<sup>228</sup> In fact, pain was listed by half of all patients during the first decade of Dutch general practice, but fell to only twenty-five percent in the following decade, where it held steady after the study commenced in 2007.<sup>229</sup>

Parallel to Dutch and Belgium legal expansion, the team also found depressive symptoms and dependency quickly gaining momentum as reasons for a request.<sup>230</sup> Of course, patients' depressive symptoms and fear of pain are factors that could diminish over time, or the patient could simply have a change of heart. This study concluded that pain was the leading factor in the period before implementation of the Euthanasia Act with a mean of twenty-seven percent, but it declined fairly significantly to twenty-two percent after the Act's implementation mean.<sup>231</sup> Furthermore, despite public sentiment

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<sup>227</sup> Jojanneke Evan Alphen, Ge A. Donken, and Richard L. Marquet, "Requests for Euthanasia in General Practice before and after the Euthanasia Act," *British Journal of General Practice* 60 (2010): 263-267.

<sup>228</sup> Alphen et al., "Requests for Euthanasia," 263.

<sup>229</sup> Alphen et al., "Requests for Euthanasia," 266.

<sup>230</sup> Alphen et al., "Requests for Euthanasia," 265.

<sup>231</sup> Alphen et al., "Requests for Euthanasia," 263.

and media fixation, the “loss of dignity” factor was actually reported by patients as being a less important reason after the Act, down nearly ten percent from 18% to 10% amongst Dutch patients.<sup>232</sup> This drop was especially prominent for females from seventeen percent to only six percent citing this concern after the Act’s legislation.<sup>233</sup> Overall, there was apparently no increase in demand for euthanasia after implementation of the Euthanasia Act according to this study.

Despite this evidence, the scope of the Euthanasia Act is still argued as being a driver in demand for euthanasia since it affords more protections to physicians partaking in the practice. The authors also refute the popular “slippery slope” argument by pointing to Dutch euthanasia occurrences decreasing from 2.6% of all deaths in 2001 to 1.7% in 2005 and plateauing since 2002.<sup>234</sup> Though data derived from these types of studies are regularly contested, misconstrued, or simply marginalized as subjective or otherwise inaccurate. Extraneous, underlying variables could be involved and the relatively short timeframe of this study may inhibit its scope. Be it noted, that the precise definition of “hopelessness” and “pain” are ambiguously questioned even by the researchers themselves, and the term “pain” is sometimes inter-mixed with “unbearable suffering”. These factors add a bit of confusion to the survey results and likely were to the respondents as well. As many researchers have questioned, the definitions of “pain” and “hopelessness” remain challenges for the qualitative studies on AVE.

Moreover, studies conducted examining demand for euthanasia elsewhere showed

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<sup>232</sup> Alphen et al., “Requests for Euthanasia,” 263.

<sup>233</sup> Alphen et al., “Requests for Euthanasia,” 263.

<sup>234</sup> Alphen et al., “Requests for Euthanasia,” 264.

dissimilar results and, in some cases, puzzling findings. For example, Berghmans and Lossignol discuss a study that examined demand for euthanasia after Belgium's legalization and compared their national palliative programs. They first discovered that since the law's institution in 2005, the number of euthanasia declarations increased from seventeen per month in the first year to thirty-eight per month by 2007 with statistics doubling in the last four years.<sup>235</sup> When looking at the palliative care system, the authors remarked on a much different representation: "Observations in specific palliative and supportive care units show a different picture with no systematic progression of euthanasia, showing that the number of incidents is unpredictable but will never be zero."<sup>236</sup>

What can be gained from the data in this case is the observation that sheer pain serving as a reason for one's choice to end life is not necessarily as resilient as prominently thought with most patients listing two or more motives.<sup>237</sup> In terms of our study, this could indicate that the pain relief produced through palliative care may not make much of a difference at all in one's choice for life or death. On a grander scale, with pain relief posing as a less powerful force, a population's demand for the practice may not be tied to the palliative care, or the relationship would be quite minimal if this is the case.

Then again, the researchers acknowledged that the Dutch enhancement of improved palliative care during this time, including their use of deep continuous sedation,

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<sup>235</sup> Berghmans and Lossignol, "Euthanasia: From Ethical Debate," 804.

<sup>236</sup> Berghmans and Lossignol, "Euthanasia: From Ethical Debate," 805.

<sup>237</sup> Alphen et al., "Requests for Euthanasia," 266.

could be a possible explanation for the drop in requests. Aligning with the theory that palliative care influences demand for euthanasia, the research team noted, “The use of continuous deep sedation in the Netherlands increased from 5.6% of deaths in 2001 to 7.1% in 2005.”<sup>238</sup> Used during the terminal phase of practice to help patients cope with anxiety and pain, the Dutch implemented deep continuous sedation in 2001. The research team discussed further evidence for the theory that improved palliative care could influence the practice. For example, the Dutch have worked to enhance palliative care options, spearheading the Network of Palliative Care for Terminal Patients, after “loss of dignity” as a reason for death was taking heat from the media and general public. Coincidentally, after such improvements were made, “loss of dignity” fell dramatically as a reason patients selected, markedly amongst females. Again, such a gender fluctuation may be related to different male and female perceptions or definitions of dignity.

The World Health Organization has similarly found that the Netherlands has experienced some success with palliative health programs, and determined it to be a positive advancement as Dutch patients are allowed to die within the comfort of their own home. According to the study, about 75% of patient respondents preferred to die at home with 50-75% of patients requesting home care at the end of life.<sup>239</sup> However, while several countries have followed suit in providing regional and national strategies for palliative health care programs, often these options are not even verbalized to the patient and the World Health Organization fears this could be actually minimizing the use of the system.<sup>240</sup>

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<sup>238</sup> Alphen et al., “Requests for Euthanasia,” 266.

<sup>239</sup> Davies and Higginson, “The Solid Facts,” 16.

Motives driving patients towards euthanasia are changing in the recent era. For example, the Remmelink Committee was instituted by the Dutch government in 1990 to research euthanasia in the Netherlands. Concurring with the study previously discussed, the Buiting team discovered that out of 2300 cases of euthanasia, accounting for 1.8% of all deaths in 1990, the majority of Dutch cases in 1990 involved alleviation of pain and symptoms with high dosage of opioids, representing 17.5% of all deaths.<sup>241</sup> While pain is still the most significant factor, other factors, such as depression, appear to be growing as the Euthanasia Act study previously suggested.

Ultimately, the demand for euthanasia still persists despite better-quality palliative care in the Netherlands, but this fact does not entirely dispute the relationship between the two variables, or at least their connection in opposing realms. As these examples could signify, fluxes in patient mindset or rationale in these life-or-death decisions may be also connected to palliative care advancement. In the following section, we focus more keenly on the Dutch and Oregon's implementation of palliative care and their respective practices and results under the longest held worldwide precedence.

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<sup>240</sup> Davies and Higginson, "The Solid Facts," 27.

<sup>241</sup> Dvk et al., "Euthanasia Revisited," 130.

#### IV.

#### Case Analysis

*The Oregon Experience.* For the United States, Oregon has been the trailblazer for the blueprint on euthanasia. Although federal law in the United States currently does not support physician-assisted suicide, states can come to their own decisions either through the state Supreme Courts or through legislative action. Although currently unlikely, state rights can be thwarted by federal power. For example, in 1998, House Judiciary Chairman Henry Hyde and Senator Don Nickles jointly introduced bills on the House and Senate floors aimed at revoking physicians' licenses who prescribed lethal drugs to patients for the purpose of ending their lives.<sup>242</sup> Similar to other state-sponsored laws, had the federal measure passed, doctors in Oregon would be subject to the federal conviction despite their acts being lawful under the state.

The Oregon statute went into effect in 1997, allowing doctors to prescribe (not administer) a lethal medication at a patient's request with the contingency that said patient had a prognosis of six months or less to live. Oregon requires two physicians to sign-off on the decision. In addition, safeguards under the Death with Dignity Act (DWDA) necessitate that patients must make two oral wishes to the doctor with each wish being spread out by fifteen days; a written request must also take place and be signed in front of two witnesses; and referrals to psychiatric examinations must be made should the physician suspect they are evident.

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<sup>242</sup> WGBH Educational Foundation. "The Law on Assisted Suicide." PBS Frontline. 2014. Accessed December 14, 2016. <http://www.pbs.org/wgbh/pages/frontline/kevorkian/law/>.



By 1993, it was reported that twenty-three Oregon patients were provided with lethal medications but only fifteen actually ended up following through with the deed.<sup>243</sup> Comparatively, as witnessed in Belgium and the Netherlands, since the law’s adoption the central theme is a steadily rising PAS level for the Oregon as monitored and tracked throughout numerous publications and studies depicted in the corresponding figures below.

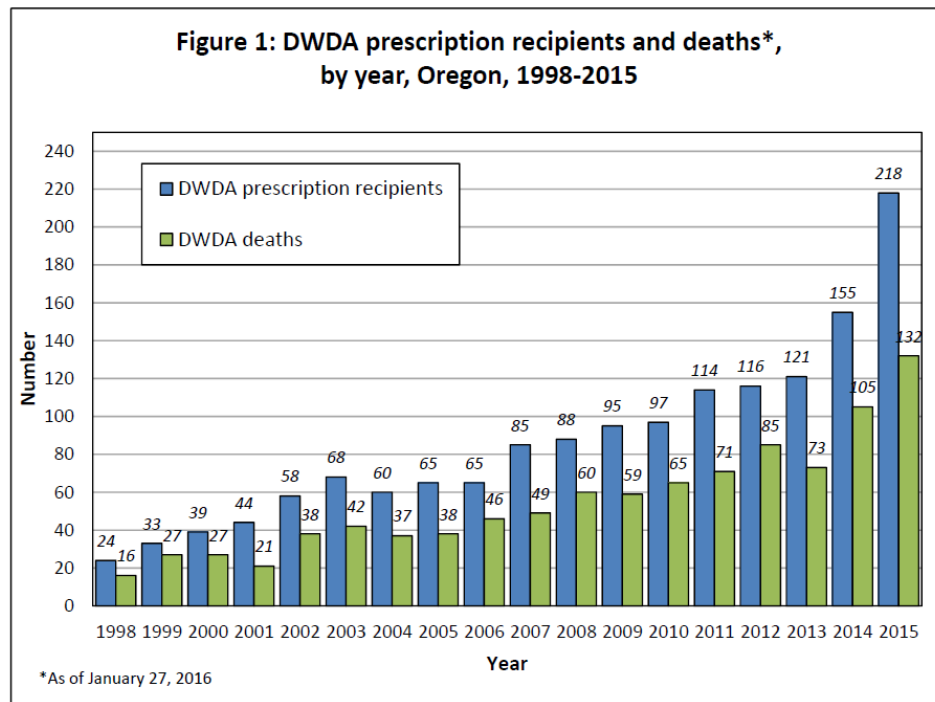


Figure 20: DWDA prescription recipients and deaths by year (2016)<sup>244</sup>

A jolt of Oregonians requesting lethal medications occurred from 2014-2015 with 155 pleas made in 2014 to a record high of 218 in 2015 – a stark jump of 24.4%.<sup>245</sup> The

<sup>243</sup> WGBH Educational Foundation. “The Law on Assisted,” 1.

<sup>244</sup> “Oregon’s Death with Dignity Act 2015 Data Summary.” Oregon Public Health Division. February 4, 2016. Accessed December 1, 2016. <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf>.

data further reflected that during 2015, "...the rate of DWDA deaths was 38.6 per 10,000 total deaths".<sup>246</sup> Previously, the report indicates that annual rates rose at an average upwards pace by 12.1% each year between the years 1998-2013.<sup>247</sup> The Oregon Health Authority documented that 1,545 death requests have occurred since the law came to pass; yet only 991 patients have actually ingested the dose.<sup>248</sup>

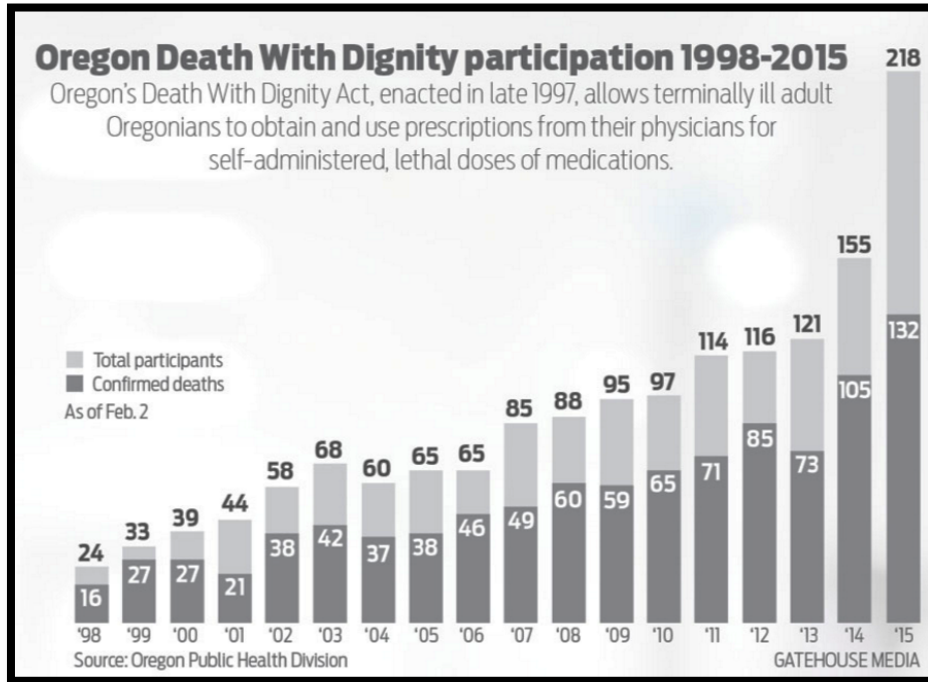


Figure 21: Oregon death with dignity participation (Cherub 2015)<sup>249</sup>

<sup>245</sup> "Oregon's Death," 2.

<sup>246</sup> "Oregon's Death," 3.

<sup>247</sup> "Oregon's Death," 3.

<sup>248</sup> "Oregon's Death," 3.

<sup>249</sup> Sandra Chereb, "Physician-Assisted Suicide Gaining Favor," *Las Vegas Review Journal*, October 25, 2015. Accessed December 14, 2016. <http://www.reviewjournal.com/news/death-las-vegas/physician-assisted-suicide-gaining-favor>.

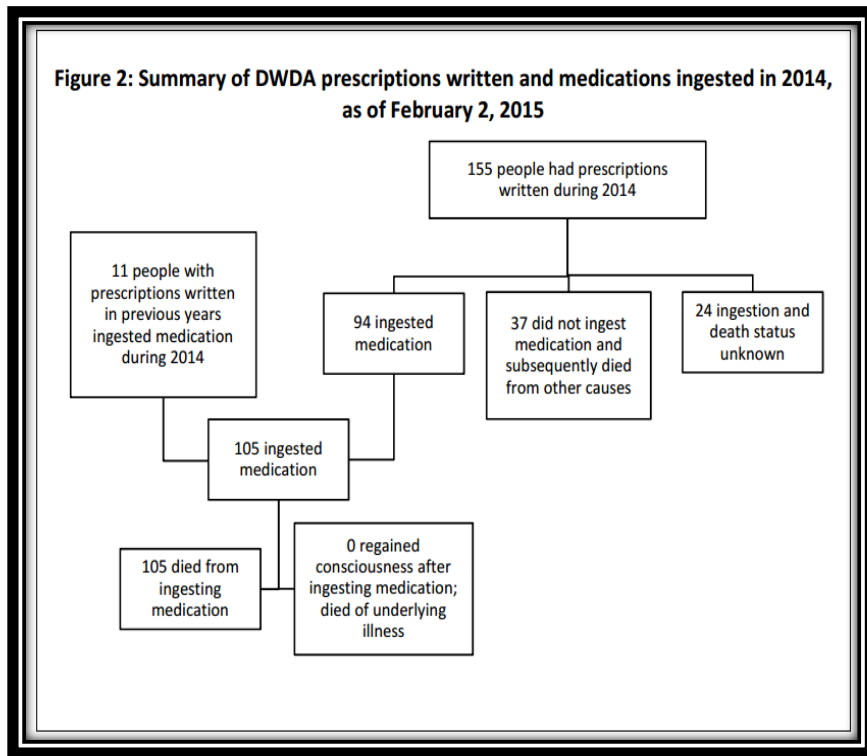


Figure 22: Summary of DWDA Prescriptions Written and Medications Ingested (Oregon Public Health Division 2015)

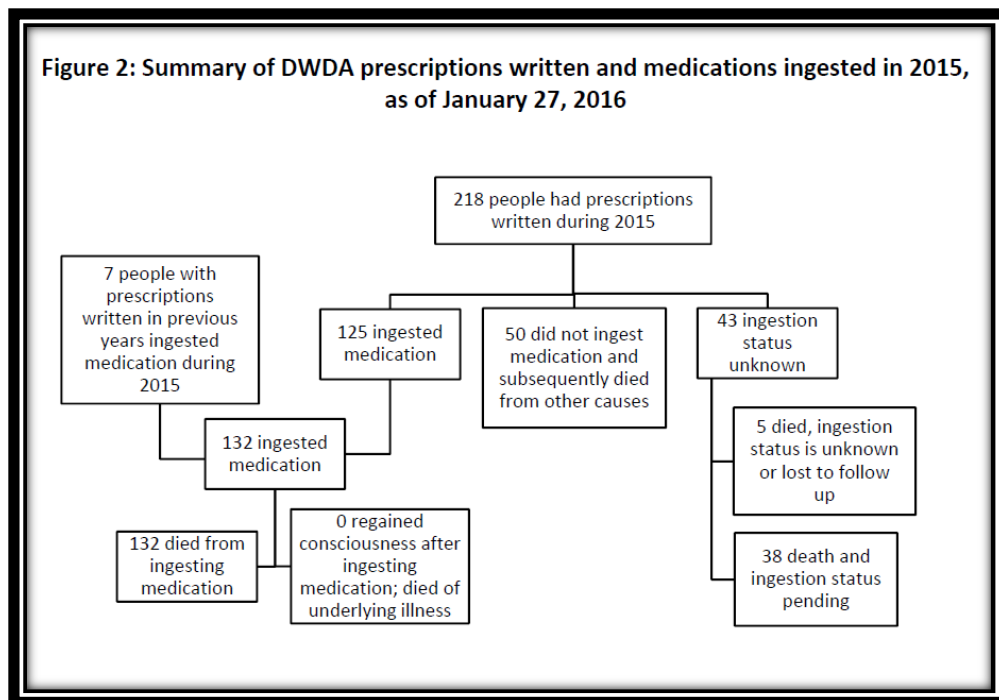


Figure 23. Oregon DWDA prescriptions (DWDA Data 2016)

Examining the 2014 DWDA data compared with Oregon's data collection in

2015, in addition to the heightened requests, there is also a considerable hike in those requesting but deciding not to ingest the lethal dose. Reminiscent of the human will to live, these instances may point out an often underestimated factor in this study. Parallel to our previous discussion in terms of general suicide attempts and subsequent survivals, the spark within us is intrinsic to the human experience and this unexpected will to live can resurface even the darkest moments in one's lifespan. In this regard, Oregon has done well in documenting PAS incidences and staying on target with protocols in place for safeguarding mechanisms; however, more qualitative research is needed in the state to officially track the reasons for the discrepancies between those who ingest the lethal doses versus those who ended up having a change of heart. This data would benefit active AVE regions, like the Netherlands, in determining how to properly counsel those who elect to end their lives.

The Oregon Public Health Division, nevertheless, is heralded for its meticulous data collection in assessing the quantitative results of patients and physicians involved with Death with Dignity Act (DWDA). Extensive guidelines for palliative care programs and medical professionals have been disseminated to hospitals statewide. Perhaps a testament to the state's education and preparedness plan on DWDA, according to the Oregon Public Health Division, since 2014, there have been zero referrals made on practitioners failing to comply with DWDA.<sup>250</sup>

Naturally opponents, like those criticizing the Belgium Commission, fervently hold that corruption is at play and voice their suspicion over the fact that no non-compliance referrals have been made in Oregon. For example, a *Current Oncology* report from 2007, raised suspicion over the fact that the Oregon law mandates PAS patients see a psychiatrist if mental concerns are witnessed; yet, not one of those dying from lethal

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<sup>250</sup> Cherub, "Physician-Assisted," 1.

dosage had ever been referred.<sup>251</sup>

Still, Oregon appears to have gone to considerable lengths to protect its people from corruption. For example, the state has refined the DWDA policy procedure in 2010 by incorporating a standardized reporting process on the follow-up questionnaire. The report states: “The new procedure accepts information about the time of death and circumstances surrounding death only when the physician or another health care provider was present at the time of death.”<sup>252</sup> Reflecting a more comfortable relationship between doctors and patients in this position, the data found twenty-seven patients were accompanied by the prescribing physician or another medical professional at the time of death compared to only fourteen patients (10.8%) in 2015.<sup>253</sup> This measure also conjures more accountability in the documentation process and provides Oregon physicians with a more in-depth, intimate journey with each patient. Doing so affords a greater opportunity of qualitative data on the last moments of life witnessed by these physicians.

Parallel to the general characteristics of the Dutch patients, the bulk of the 132 DWDA deaths in 2015 are comprised of 78% of patients aged 65 years or older with the median age at 73 years.<sup>254</sup> The Oregon Health Authority identified that, similar to years past, 2015 recipients were overwhelmingly white (93.1%) and 43.1% had achieved at least a baccalaureate degree.<sup>255</sup> However, congruent with the widening amount of non-

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<sup>251</sup> Pereira, “Legalizing Euthanasia or Assisted Suicide,” 38–45.

<sup>252</sup> “Oregon’s Death with Dignity Act 2015 Data Summary,” Oregon Public Health Division. February 4, 2016. Accessed December 1, 2016. <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf>.

<sup>253</sup> “Oregon’s Death,” 4.

<sup>254</sup> “Oregon’s Death,” 4.

cancer seekers seen in Belgium and the Netherlands, the percentage of Oregonian patients with cancer in 2015 dropped from previous years, declining to 72.0% from its post at 77.9% in 2014.<sup>256</sup> The data determined that most wished to die in the comfort of their homes (90.1%), and 92.2% of PAS patients in 2015 were also enrolled in hospice care – reflective of Oregon’s commitment to palliative programs.<sup>257</sup>

Pursuant to our discussion on healthcare insurance and vulnerability, in a somewhat refreshing statistic, the vast majority of Oregonians receiving PAS in 2015 had healthcare insurance coverage (99.2%), excluding a handful of “unknown cases”.<sup>258</sup> Oregonian patients in 2015 with private insurance (36.7%) significantly decreased than in the previous year (60.2%); yet, the share of patients with only Medicare or Medicaid coverage was significantly “... higher than in previous year (62.5% compared to 38.3%)”.<sup>259</sup> Generally on par with statistics in previous yearly reports, 2015 Oregonian PAS death requesters cited “...decreasing ability to participate in activities that made life enjoyable (96.2%), loss of autonomy (92.4%), and loss of dignity (75.4%).”<sup>260</sup>

Overall, what continues to stand out in all of the data within these three figures is a considerable amount of requestors who are granted the lethal dose but refrain from ingesting it.<sup>261</sup> Those opposing AVE point to these PAS incidences as evidence that a sizable amount of patients may not be in their right minds when making these fatal

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<sup>255</sup> “Oregon’s Death,” 4.

<sup>256</sup> “Oregon’s Death,” 4.

<sup>257</sup> “Oregon’s Death,” 4.

<sup>258</sup> “Oregon’s Death,” 4.

<sup>259</sup> “Oregon’s Death,” 4.

<sup>260</sup> “Oregon’s Death,” 4.

<sup>261</sup> “Oregon’s Death,” 3.

choices, gaining an unexpected will to live despite their condition and previous death wish. Indeed, the discrepancy between lethal dosage delivered versus those actually taking the plunge is further exaggerated in the comparison of 2007 Oregon Department of Human Services data (depicted below). This disparity exposes a certain level of confusion on the patients' truest wishes and intent.

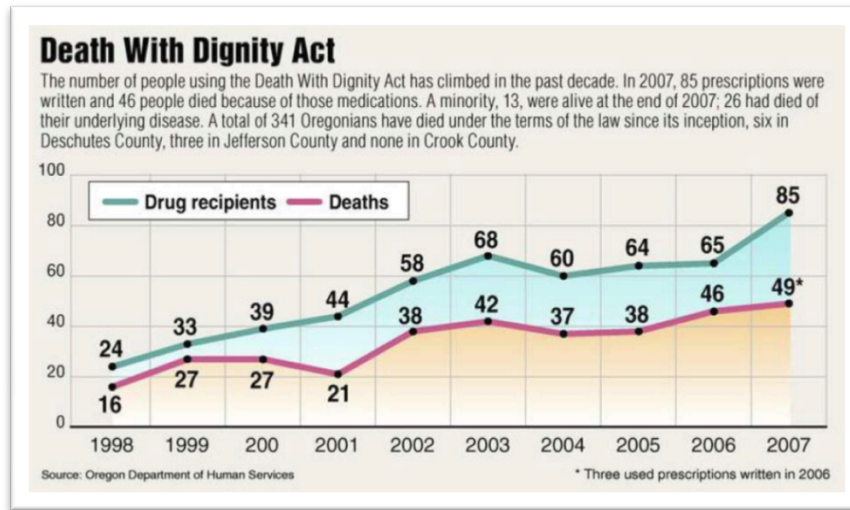


Figure 23a: DWDA Data 1998-2007 (Cliff 2008)<sup>262</sup>

Director of Health Law Institute at Hamline University, Taddeus Mason Pope insists that the Oregon experience is living proof that assisted suicide practices can be sensible and equitable. In a report to the *New York Times*, Pope advises that there has been no evidence suggesting exploitation has taken place in Oregon since the birth of Oregon Death with Dignity Act in 1997. Examining data where 1,100 lethal dosages were written and only 750 were ingested (mostly by cancer patients), Pope find no basis in the contention that corruption is at all involved in Oregon's practice: "Over 98 percent had health insurance, over 90 percent were enrolled in hospice and over 72 percent had

<sup>262</sup> Betsy Cliff, "Oregon's Death with Dignity Act," *The Bulletin*, December 18, 2008. Accessed December 2, 2016. <http://www.bendbulletin.com/news/1546154-151/oregons-death-with-dignity-act>.

gone to college.”<sup>263</sup> Pertinent to our hypothesis, proclaiming Oregonian law as the greatest success story in end-of-life practices, Thaddeus Pope deduces that despite a rise in state-wide demand, Oregon data does not demonstrate any negative impact “...on the availability of palliative care or on the physician-patient relationship”.<sup>264</sup>

With the highly politicized, dramatized debate, it is often difficult for researchers to come to grasp with the reality of the situation and to acquire data that is free from bias. While opponents of PAS and AVE condemn the Oregon policy, there are some important lessons to be learned on Oregon’s implementation and guidance of DWDA. The dedication Oregon has put into its hospice and palliative healthcare plans are other areas Oregon leaders have stressed. In fact, nearly half (45%) of all United States citizens now die under hospice care.<sup>265</sup> Healthcare Professionals for Assisted Dying also estimate that 90% of patients in Oregon who have had an assisted death were enrolled in hospice care.<sup>266</sup> The trouble spot in this data alludes to societal fear of PAS-seekers being judged or otherwise shying away from wanting to inform their families of decisions with only

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<sup>263</sup> Thaddeus Pope, “Oregon Shows That Assisted Suicide Can Work Sensibly and Fairly,” *New York Times*. October 7, 2014. Accessed November 4, 2016. <http://www.nytimes.com/roomfordebate/2014/10/06/expanding-the-right-to-die/oregon-shows-that-assisted-suicide-can-work-sensibly-and-fairly>.

<sup>264</sup> Pope, “Oregon Shows That Assisted Suicide,” 1.

<sup>265</sup> Simon Gillson, “The Assisted Dying Bill – Concierge Medical,” *Concierge Medical*, January 20, 2015. Accessed December 14, 2016. <http://www.concierge-medical.co.uk/assisted-dying-bill/>.

<sup>266</sup> Gillson, “The Assisted Dying Bill,” 1.



one in six respondents willing to talk openly about their beliefs/wants with their families and friends.<sup>267</sup>



Figure 24: “Seventeen Years of Assisted Dying” (HPAD 2016)<sup>268</sup>

As Simon Gillson points out, the emerging American appetite for euthanasia is not aligning with an apparent willingness to discuss the matter openly, contrasting our Dutch counterparts. Old religious taboos subconsciously engrained within our culture, as Shai Levi discussed in our literature review, might account for some of these discrepancies. However, not simply felt in Oregon, there exists a trend from Gallup and Pew Research data indicating that despite developments in support of euthanasia, Americans tend to resist thinking or talking about death. As simple as it sounds, if Americans continue to neglect communicating their desires in preparation for these unfortunate circumstances, it will only cause more grief for loved ones in flux. Although

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<sup>267</sup> Gillson, “The Assisted Dying Bill,” 1.

<sup>268</sup> Gillson, “The Assisted Dying Bill,” 1.

Pew Research polls determined that 34% of Americans in 2005 had put their end of life decisions in writing (up from 16% in 1990), the percentage in 2013 had only raised a meager one percentage point to 35% reporting to have documented their end of life wishes.<sup>269</sup> Yet, it should be on their mind as nearly half of those same 2013 pollsters reported having a terminally ill friend or relative (47%).<sup>270</sup> Though this figure is considerably higher amongst older age ranges, the polls, nevertheless, indicate that Americans themselves are just as unprepared and uncertain as their leaders.

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<sup>269</sup> Joseph Liu, “Views on End-of-Life Medical Treatments,” Pew Research Center’s Religion & Public Life Project. November 21, 2013. Accessed December 17, 2016. <http://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/>.

<sup>270</sup> Liu, “Views on End-of-Life Medical Treatments,” 1.

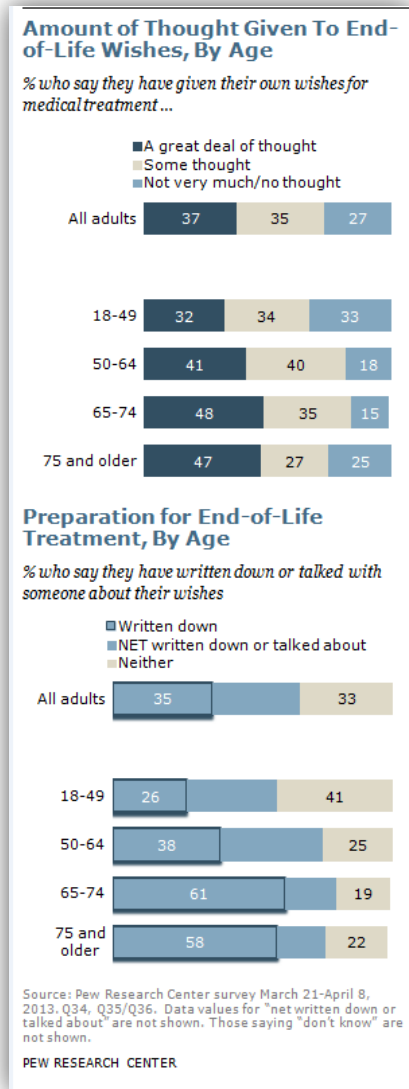


Figure 25. Amount of Thought Given to End of Life Wishes (Pew Research Center 2013)

Clearly, Oregon is not trying to hide behind the fact that more citizens are seeking out physician-assisted suicide. Yet, while opponents point to this as cause for concern, others purport that it is only logical that once a law is enacted, it is reasonable to consider that a larger share of citizens are likely to use the law/service over time. In concert with the adoption of the DWDA law, Oregon has grown its palliative healthcare reform and currently ranks as a national leader in hospice care system rankings. I next examine the governing bodies and efforts promoted by Oregon to fulfill this endeavor in the following

section.

*Palliative Care and Hospice Programs in Oregon*. Immediately after DWDA legislation passed, Oregon leaders took measures to provide guidelines and impartial task forces to ensure the goal of compassion and keep corruption at bay. Implemented in 1998 and revised four times since 2008, Oregon created the *The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals*. As part of the guidebook, a politically neutral, comprehensive task force was born. Composed of an eclectic mix of health professional organizations, agencies, and institutions, the goal of the “Task Force to Improve the Care of Terminally-Ill Oregonians” is to strive to “promote excellent care of the dying and to address the ethical and clinical issues posed by enactment of the Oregon Death with Dignity Act.”<sup>271</sup> In doing so, the state swiftly sought to ensure various Oregonian viewpoints from both sides of the conflict would be equally represented with one common, compassionate goal to promote the general wellness of the terminally ill in conjunction with DWDA’s rollout.

The missions of the task force include: “Share information, experience, and understanding; facilitate the development of professional standards; develop and coordinate educational resources; and foster relationships and networking on issues related to compassionate care of the terminally ill”.<sup>272</sup> Spearheaded by three Oregonian physicians, the Task Force members recognize that DWDA’s adoption inevitably carries a wide range of unpredictable, unprecedented scenarios that challenge the law and its bounds. Engaging in candid discussion with members of the community and

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<sup>271</sup> Patrick Dunn, Sarah Foreman, Bonnie Reagan, and Susan W. Tolle, “The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals,” March 2008. Accessed December 15, 2016. <https://www.ohsu.edu/xd/education/continuing-education/center-for-ethics/ethics-outreach/upload/Oregon-Death-with-Dignity-Act-Guidebook.pdf>.

<sup>272</sup> Dunn et al., “The Oregon Death,” 5.

confiding/sharing advice on special cases within those in the medical industry will empower both doctors and patients to be best equipped to handle situations that may arise. Stressing enhanced and candid communication, the group has sponsored a plethora of public research available on all facets of the euthanasia practice, including highly comprehensive guidelines such as “The Final Months of Life: A Guide to Oregon Resources”.

In the task force report, statements by The Oregon Board of Medical Examiners (BME) include the concern that pain management is inadequately being addressed for patients and may impact their decision-making processes. The Board’s investigation found that “... as many as one-half of patients in pain are not given sufficient pain medication to control their pain in an optimal manner.”<sup>273</sup> According to the Board of Medical Examiners, the reasons for physicians’ failure to provide appropriate pain relief medication boils down to: “concern about causing addiction; lack of knowledge about pain management techniques and pain medication pharmacology; and fear of scrutiny and discipline by regulatory agencies.”<sup>274</sup> However, the task force contends that these factors are no excuse for assuring pain is in control for patients and could adversely evoke vulnerability towards PAS choice. The BME recommends the task force encourage “physicians to become well informed in acute post-operative pain management and to hone their skills in the latest techniques for control of these acute, self- limited episodes of pain caused by surgical procedures.”<sup>275</sup> With revolutions in modern law geared towards bioethics, medicine must follow suit in adapting to training and preparedness under its modernized construct.

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<sup>273</sup> Dunn et al., “The Oregon Death,” 120.

<sup>274</sup> Dunn et al., “The Oregon Death,” 120.

<sup>275</sup> Dunn et al., “The Oregon Death,” 120.

The steadfast achievements of Oregon’s palliative health care and hospice system has been recognized by the National Palliative Care Research Center. Oregon was graded by the National Palliative Care Research Center with the top level of “A” in 2015.<sup>276</sup> Veering away from our predicted hypothesis, it appears Oregon’s augmentation of its palliative and hospice health care platform in recent years has not led to a decrease in demand and deaths by PAS. Instead, both variables in this study are on the upswing and tend to be acting harmoniously with palliative support programs improving and euthanasia patient requests still climbing. This information seems to negate the commonly accepted banter that palliative care and the practice of euthanasia are archenemies with ultimately opposing missions.

Overall, the National Palliative Care Research Center and the Center to Advance Palliative Care has graded two-thirds of all American states with an A or B in 2015, including a sizable increase in states receiving A’s – upwards from only 3% in 2008 to 17% in 2015 (“A” level states must have 80% of all hospitals containing palliative programs).<sup>277</sup> Further, for the first time since the study has been conducted, no state in 2015 stood at an “F” – defined as less than 20% of a state’s hospitals maintaining palliative programs.<sup>278</sup> Although gaps remains as the United States’ grade as a whole still lingers at a “B” (the same national rating it received in 2011) and one-third of states still

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<sup>276</sup> National Palliative Care Research Center, “America’s Care of Serious Illness,” 2015 State-By-State Report Card on Access to Palliative Care in Our Nation’s Hospitals. 2015. Accessed November 18, 2016. <https://reportcard.capc.org/wp-content/uploads/2015/08/CAPC-Report-Card-2015.pdf>.

<sup>277</sup> National Palliative Care Research Center, “America’s Care of Serious Illness,” 6.

<sup>278</sup> National Palliative Care Research Center, “America’s Care of Serious Illness,” 6.

hover at a “C” or “D” with particular concern in the southeastern United States.<sup>279</sup> Highly concerning to the future of euthanasia is the vast elderly Florida population and Florida’s grade holding stagnant at level “C” in 2015.<sup>280</sup>

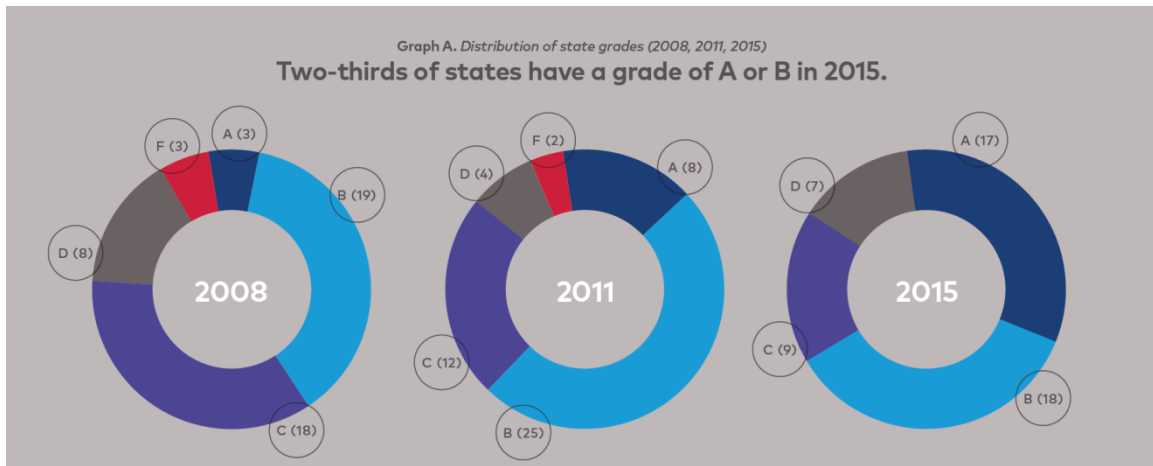


Figure 26. “Two-Thirds of States have a Grade A or B in 2015”<sup>281</sup>

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6. <sup>279</sup> National Palliative Care Research Center, “America’s Care of Serious Illness,”

11. <sup>280</sup> National Palliative Care Research Center, “America’s Care of Serious Illness,”

7. <sup>281</sup> National Palliative Care Research Center, “America’s Care of Serious Illness,”

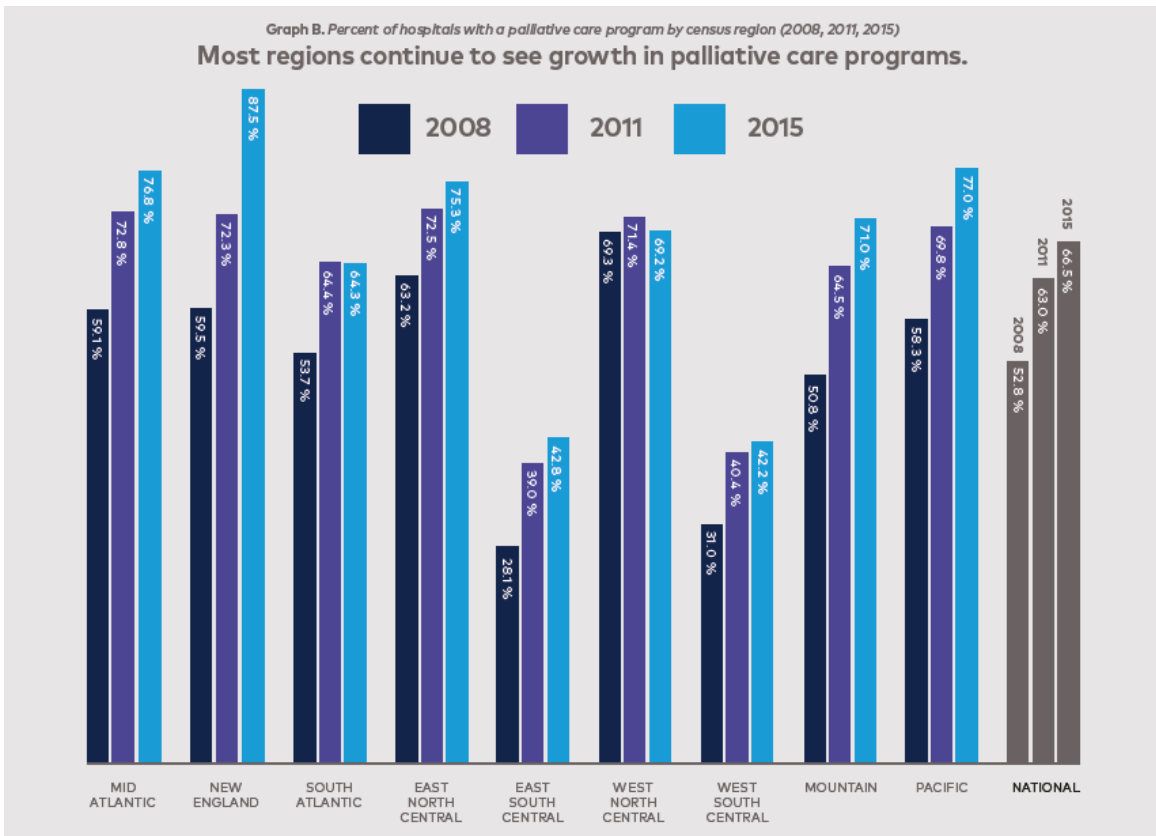


Figure 27. U.S. Regional Growth in Palliative Care (National Palliative Care Research Center 2015)<sup>282</sup>

<sup>282</sup> National Palliative Care Research Center, “America’s Care of Serious Illness,” 7.



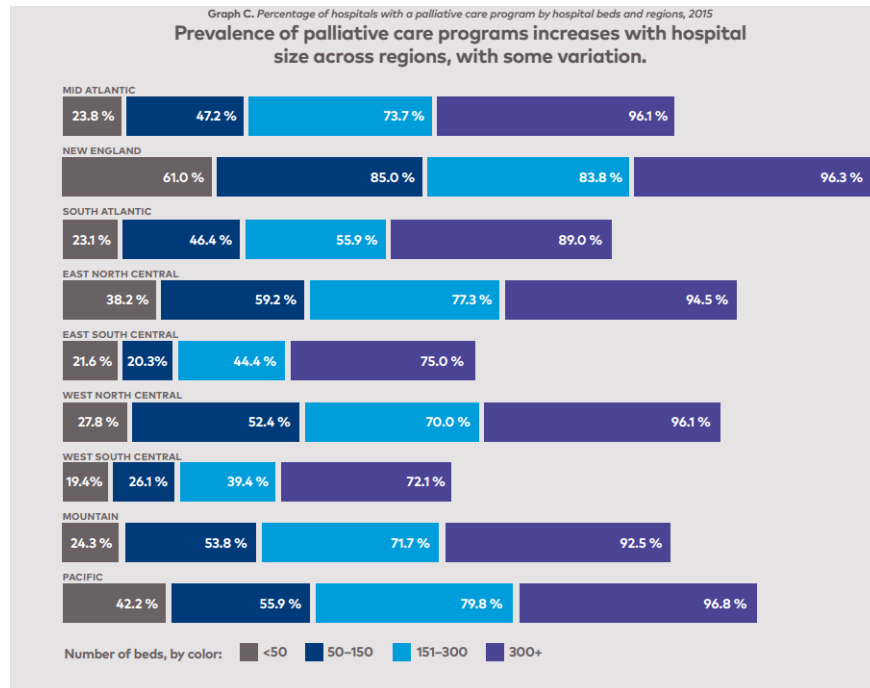


Figure 28. U.S. Prevalence of Palliative Care (National Palliative Care Research Center 2015)<sup>283</sup>

Why is this data so critical to the euthanasia debate? Extremely significant is the amount of financial and professional strain enhanced palliative care is able to remove from hospitals and health care. Per our discussion, overworked physicians and a flooded hospital system causes economic and logistical parameters that could amplify the threat of possible corruption in the future of euthanasia policy and practices.

To that effect, the investigation found an impressive amount of savings incurred directly from palliative medicine as it becomes the most booming medical specialty, “...as payers, providers and policymakers have recognized its potential to improve quality and, as a direct result of improved quality, reduce costs. Almost 90 percent of large U.S. hospitals (300 beds or more) now have a palliative care program”.<sup>284</sup> Predicting

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<sup>283</sup> National Palliative Care Research Center, “America’s Care of Serious Illness,” 13.

that palliative care could potentially save the U.S. medical industry millions, the group references a study of eight patients who had received palliative care: "...palliative care consultation was associated with a reduction in direct hospital costs of almost \$1,700 per admission for patients discharged alive and of almost \$5,000 per admission for patients who died".<sup>285</sup> In the grand scheme of medical savings this equates to "...an average 400-bed hospital containing an interdisciplinary palliative care team seeing 500 patients a year, these figures could translate into net savings of \$1.3 million a year".<sup>286</sup> Figures predicted this grandiose lead these medical researchers to crown palliative care as the producer of a "Watershed Moment" in American medicine and government.<sup>287</sup>

Leading the Pacific states, Washington and Oregon (the two most aggressively practicing states of euthanasia) were the only recipients of grade "A". Additionally, Vermont, who has also passed legislation for PAS received a top ranking. Although California has recently passed PAS legislation, the state still lags slightly behind at the "B" level in 2015. A glimpse at Oregon, Washington, and Vermont's platform in the palliative healthcare empire provides a refreshing outlook on how end of life decisions can coalesce with euthanasia policies. In examining the expanding role, ratings and statistics attributed to Oregon's holistic approach of its hospice programs, I exert great skepticism into the hypothesis that an increase in citizen demand for physician assisted suicide coincides with less governmental emphasis on palliative healthcare programs.

*AVE Going Dutch.* Although Oregon and the Netherlands enacted laws breaking

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<sup>284</sup> National Palliative Research Center, "America's Care of Serious Illness," 5.

<sup>285</sup> National Palliative Care Research Center, "America's Care of Serious Illness," 5.

<sup>286</sup> National Palliative Care Research Center, "America's Care of Serious Illness," 5.

<sup>287</sup> National Palliative Care Research Center, "America's Care of Serious Illness," 2.

barriers for euthanasia roughly around the same time, the United States has remained relatively timid in comparison to the Dutch's expansion on the issue since that time. Dutch Support and Consultation in Euthanasia (SCEN) physician, Ruben van Corvorden, explains the cultural distinctions: "Euthanasia law has its roots in the country's pragmatic instincts. We're sober-minded and Calvinistic people, we've taken the attitude that 'this is happening anyway, let's regulate it'."<sup>288</sup> In Van Corvorden's view, the measure has been taken to protect doctors from repercussions and blackmail which the United States' physicians are still susceptible to. Describing the issue as a conflict of duties, Van Coevorden is more concerned that patients will demand AVE too quickly: "We've developed this idea that death can be arranged, but there are other ways to take the pain out of dying, such as palliative sedation, where death occurs naturally."<sup>289</sup> In an interesting thought, he sees the practice of euthanasia not as juxtaposing palliative care, but actually, the ultimate form of it. Hence, his justification runs parallel to the theories implored by Mr. Thaddeus Lemmens in our literature review.

*A British Journal of General Practice* study, spearheaded by Dutch physicians Je van Alphen and RL Marquet, revealed rates of Dutch euthanasia requests fell in the years following the Euthanasia Act with research targeting the 5-year window timeframe before (1998-2002) and after (2003-2007) legalization.<sup>290</sup> The researchers noted that one reason for the steady rates may reside in the fact that euthanasia, as a whole, has been heavily discussed in the Dutch media and political landscape and, therefore, "may have been a formalization of an already existing practice rather than a turning point in

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<sup>288</sup> Gordon Darroch, "Rise in Euthanasia Requests Sparks Concern as Criteria for Help Widen," *DutchNews.nl*. July 3, 2015. Accessed December 16, 2016. <http://www.dutchnews.nl/features/2015/07/rise-in-euthanasia-requests-sparks-concern-as-criteria-for-help-widen/>.

<sup>289</sup> Darroch, "Rise in Euthanasia Requests," 1.

<sup>290</sup> Alphen et al., "Requests for Euthanasia," 263-267.

attitudes”.<sup>291</sup>

Although the group found no considerable changes in demand following the crucial years post-legalization, one important distinction was recognized from the data with a shift in female demand: “The number of requests by males decreased significantly from 3.7/10,000 to 2.6/10,000 (P = 0.008); the requests by females increased non-significantly from 2.6/10,000 to 3.1/10,000.”<sup>292</sup> The team asserts the relevance in this statistic that as it “...might imply that implementation of the Euthanasia Act helped females more than males to communicate a wish for euthanasia to their GP.”<sup>293</sup>

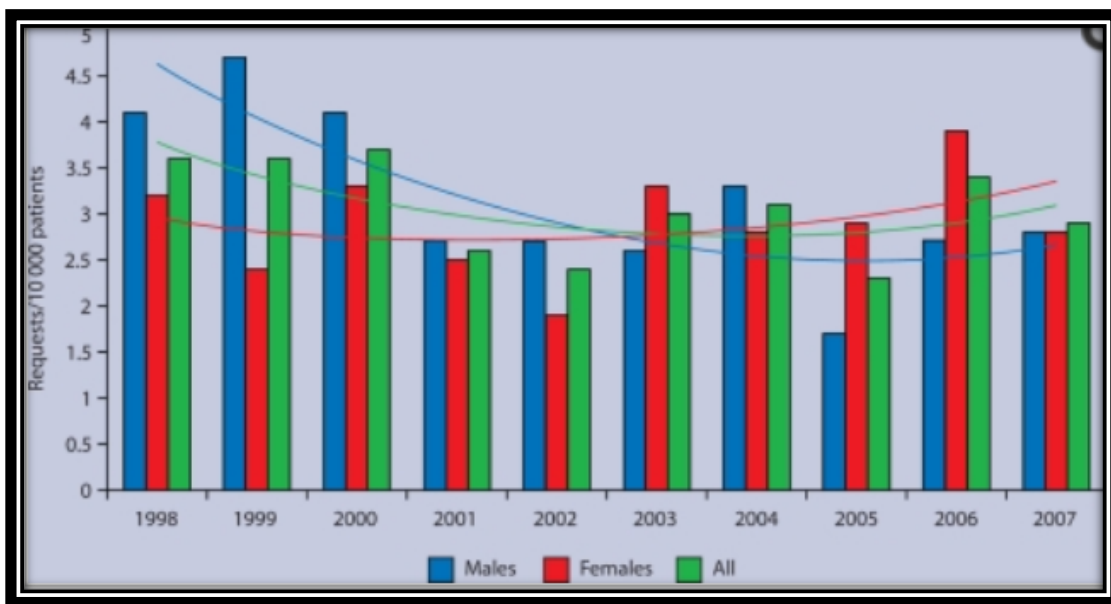


Figure 29: Requests for Euthanasia in General Practice (Alphen, et al., 2010)<sup>294</sup>

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<sup>291</sup> Alphen et al., “Requests for Euthanasia,” 256.

<sup>292</sup> Alphen et al., “Requests for Euthanasia,” 263.

<sup>293</sup> Alphen et al., “Requests for Euthanasia,” 266.

<sup>294</sup> Alphen et al., “Requests for Euthanasia,” 265.

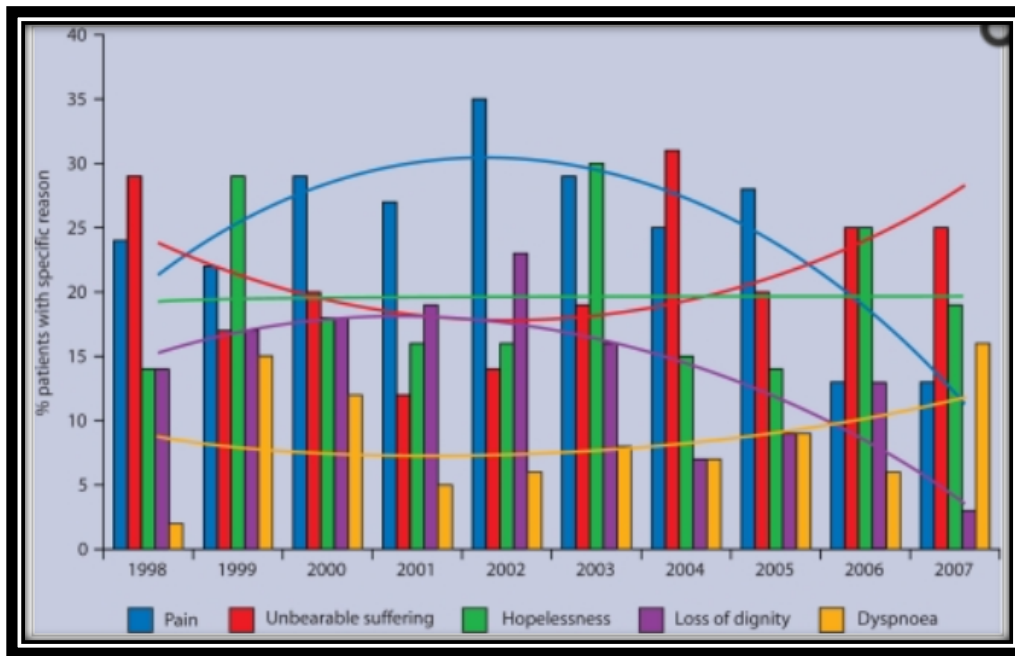


Figure 30. Percentage of Patients with Specific Concern (Alphen, etal, 2010)<sup>295</sup>

I emphasize the data from this specific year-range as it shows a direct correlation to the law’s birth and resulting Dutch demand: “The mean annual incidence of requests before implementation amounted to 3.1/10,000 and thereafter to 2.8/10,000 patients.”<sup>296</sup> Needless to say, proponents are quick to jump on these revelations to debunk the “slippery slope” mantra; adding to it the fact that underlying reasons for AVE requests have fallen under the self-reported category of “loss of dignity” while rising for “unbearable suffering”. In fact, “Loss of dignity” lowered from 18% to 10% with an interesting connotation of a striking decrease in females describing it as a reason (17% to 6%).<sup>297</sup> Comparing before and after statistics, cancer continued to top as driving force for

<sup>295</sup> Alphen et al., “Requests for Euthanasia,” 265.

<sup>296</sup> Alphen et al., “Requests for Euthanasia,” 263.

<sup>297</sup> Alphen et al., “Requests for Euthanasia,” 263.

both sexes: “82% versus 77% for men; 73% versus 75% for females”.<sup>298</sup> Overall, pain led requests during both time periods, “... increasing in the period before implementation (mean 27%), but declining in the period thereafter (mean 22%)”.<sup>299</sup>

The researchers concluded that they found no basis in contrary claims to suggest that The Euthanasia Act’s adoption led to an increase in demand for patients within five years of its implementation. Still, the media plays a central role in public perception of the practice while attempting to sway voters in unprecedented means through blatantly false reporting, even by officials in seemingly high ranking positions. For example, Dutch leaders mocked U.S. presidential candidate, Rick Santorum, for making false claims in 2012 that Dutch citizens are wearing bracelets that read “Do Not Euthanize Me” and AVE represents 10% of all deaths in the Netherlands.<sup>300</sup> Although there is some merit to the fact that additional reasons for demand are increasing with later years showing a rise in demand concurrent with the widening Dutch and Belgium law. As Wall Street Journalist Shirley Wang highlights in the below diagram, times are changing and a creeping amount of Dutch citizens are citing being “tired of living” as a reason for their fatal decision (28% in 2013).<sup>301</sup>

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<sup>298</sup> Alphen et al., “Requests for Euthanasia,” 263.

<sup>299</sup> Alphen et al., “Requests for Euthanasia,” 263.

<sup>300</sup> Darroch, “Rise in Euthanasia Requests,” 1.

<sup>301</sup> Shirley Wang, “Euthanasia Rises in Belgium's Flanders Region,” *Wall Street Journal*, August 10, 2015. Accessed December 17, 2016. <http://www.wsj.com/articles/studies-focus-attention-on-euthanasia-1439220449>.

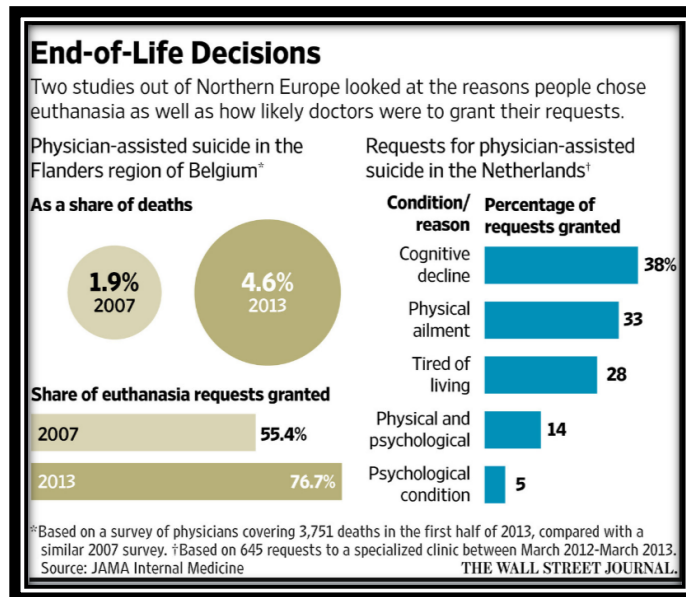


Figure 31. End of Life Decisions (Wang 2013)

Discussed in our historical section, the fetal form of the law on euthanasia has broadened since its inception to include Dutch children over the age of twelve and measures being taken in coordination with The Groningen Protocol to decriminalize certain cases, under specific guidelines, those under the age of twelve.

Observing Dutch demand statistics in the years beyond 2005, a different picture is painted with Dutch News reports generally confirming the *British Journal of Medicine* study where demand remained stagnant up until about 2007; however, a rather sharp leap occurred and continues to climb from then on as the chart below depicts in the years from 2007-2013.<sup>302</sup> Dutch News findings reported: “Initially the annual total hovered at around 1,900, but since 2006 it has increased by an average of 15% each year.”<sup>303</sup> Comparing 2013 data with assisted suicide cases in 2002, the figure has boomed nearly three times, standing at 4,829 deaths.<sup>304</sup> Dutch Journalist Gordon Darroch, notes the distinction that

<sup>302</sup> Darroch, “Rise in Euthanasia Requests,” 1.

<sup>303</sup> Darroch, “Rise in Euthanasia Requests,” 1.

on average “... around 38% of requests are carried out and 20% refused”.<sup>305</sup> When the Dutch law was first enacted 90% of patients were terminally ill cancer patients; however, in 2013, this level has reportedly dropped to only 75% of patients seeking death.<sup>306</sup>

A peculiar distinction between demand level statistics in the Netherlands and the state of Oregon is the delayed rise in Dutch demand, accelerating upwards about five years after legislation. Opponents of the law declare this trend is simply evidence of a delayed, but inevitable, slippery slope. For example, the Dutch pediatric association (NVK) is now vying for the minimum age of twelve to be cut, identifying that some terminally ill children under this age group are able to make a death request; meanwhile, Dutch News found: “Psychiatric patients, once never considered for euthanasia, are a small but growing subgroup, with 42 requests granted in 2013.”<sup>307</sup>

Despite the fact that a record number of AVE patients have taken the leap, at the time in 2013, Darroch is surprised to find that there has not been a decline in privately-committed Dutch suicide rates in general. In fact, 2013 experienced an all-time high in the Netherlands history with 1,859 Dutch citizens ending their own lives privately.<sup>308</sup> In terms of our hypothesis, this statistic reflects what I suspected to be the contrary; as nine-year Dutch euthanasia review committee panel member and ethics professor Theo Boer remarks: “Even though palliative care has improved considerably, the euthanasia rate has gone up.”<sup>309</sup>

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<sup>304</sup> Darroch, “Rise in Euthanasia Requests,” 1.

<sup>305</sup> Darroch, “Rise in Euthanasia Requests,” 1.

<sup>306</sup> Darroch, “Rise in Euthanasia Requests,” 1.

<sup>307</sup> Darroch, “Rise in Euthanasia Requests,” 1.

<sup>308</sup> Darroch, “Rise in Euthanasia Requests,” 1.

<sup>309</sup> Darroch, “Rise in Euthanasia Requests,” 1.



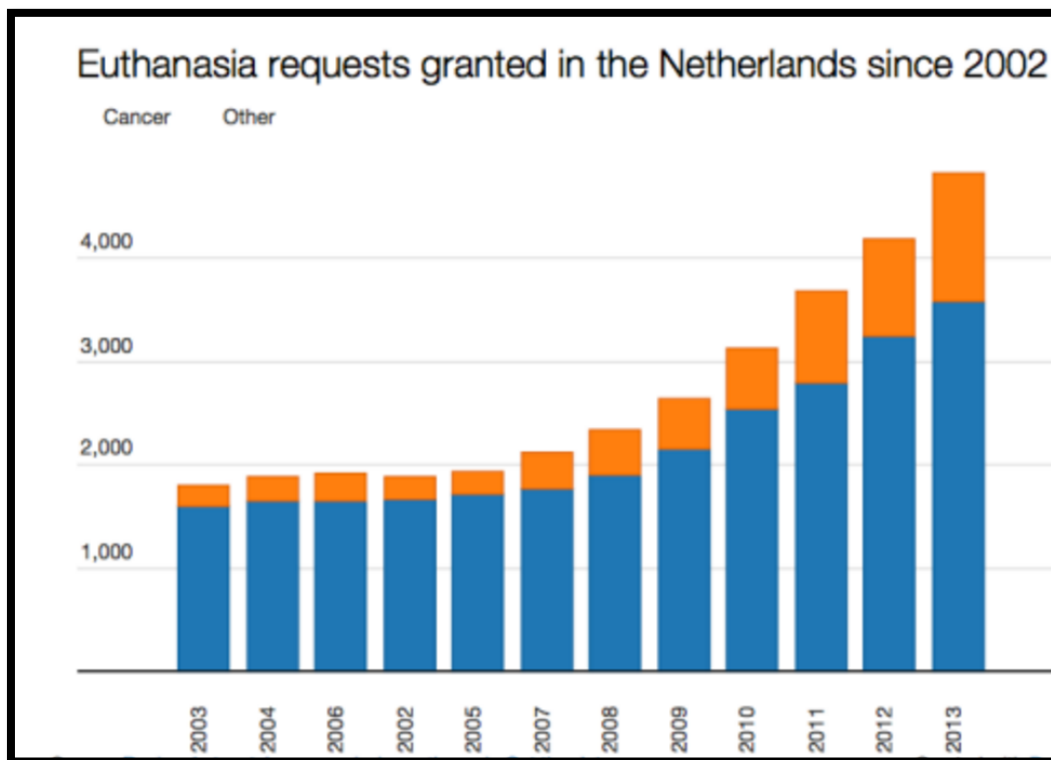


Figure 32. Requests Granted in the Netherlands since 2002 (Darroch 2013)

Digging deeper behind the numbers, Journalist Gordon Darroch obtained qualitative accounts interviewing physicians and panelists who have directly served on Dutch euthanasia review committees. Signifying how citizens have privately taken the law into their own hands under their own moral code of discretion, Dutch Physician Ruben van Coevorden recalls his first request from an Auschwitz-survivor who knew she could not beat lung cancer: "... but this was in the days before euthanasia. So I gave her some sleeping pills, enough for an overdose, and stood by her as she took them".<sup>310</sup> Van Coevorden discredits the slippery slope claim by reminding Darroch that "...only around eight cases a year out of 5,000 are taken up by the prosecution service, and none have led

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<sup>310</sup> Darroch, "Rise in Euthanasia Requests," 1.

to a conviction”.<sup>311</sup> Conversely, Theo Boer, after serving nine years on the Dutch regional euthanasia evaluation committee, argues that the definition in Dutch law on euthanasia has stretched too broadly: “We don’t have enough specific criteria in the law. It doesn’t make any mention of terminal illness, or illness at all.”<sup>312</sup> Boer believes, under Dutch law, it has gotten to a situation where bankruptcy could be grounds for “unbearable suffering” and fair game for AVE.

While abundant literature describes pressure on patients, Mr. Darroch is more concerned over the pressure the practice burdens on doctors, citing a survey put out by the Dutch Medical Association: “In a survey by KNMG, more than half (57%) of doctors who had arranged euthanasia for a patient scored the emotional strain at eight out of 10 or higher.”<sup>313</sup> Although critical for euthanasia, the tacked-on administrative burden also pummels an already overbooked general physician’s schedule. In the Netherlands, Darroch explains “...every assisted death case is investigated by one of five regional review committees, who must rule whether the doctor has acted diligently”.<sup>314</sup>

When it comes to death and divided families, lawsuits are bound to occur even if the Termination of Life on Request and Assisted Suicide Act lawfully affords their protection. Rightly so, the physicians’ actions in these cases are encumbered with greater scrutiny; yet, as the survey results display, the added emotional stress and pressure is unavoidable for any medical professional operating in this capacity. To alleviate the

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<sup>311</sup> Darroch, “Rise in Euthanasia Requests,” 1.

<sup>312</sup> Darroch, “Rise in Euthanasia Requests,” 1.

<sup>313</sup> Darroch, “Rise in Euthanasia Requests,” 1.

<sup>314</sup> Darroch, “Rise in Euthanasia Requests,” 1.

pressures and to provide a safeguard, Dutch doctors must “... be satisfied that all alternative forms of treatment have been exhausted or discounted, and seek a second opinion from an independent professional, known as a SCEN (‘support and consultation in euthanasia’) doctor”.<sup>315</sup> The Dutch Medics Federation 2013 survey breathes life into the theory that pressures on doctors, real or perceived, may be mounting with 70% reporting they felt pressure to grant euthanasia, up from 64% the previous year.<sup>316</sup>

Albeit, it is troubling to decipher where the pressure is originating and whether it was related to another underlying issue within the medical industry. Economic pressure, though hard to prove, has also been cited as a concern; in a 2012 *Current Oncology* report, J. Pierrea describes a survey finding and situation where this argument was possibly warranted: “Of physicians in the Netherlands, 15% have expressed concern that economic pressures may prompt them to consider euthanasia for some of their patients; a case has already been cited of a dying patient who was euthanized to free a hospital bed.”<sup>317</sup>

The Dutch euthanasia review committees, alone, have their fair share of paperwork to comb through in intensifying amounts. When Dutch Journalist Gordon Darroch asked former committee member Theo Boer to estimate approximately how many of the 4,000 case files involved pressure from families, Boer estimated about one in five: “Sometimes it’s the family who go to the doctor. Other times it’s the patient saying they don’t want their family to suffer. And you hear anecdotally of families saying:

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<sup>315</sup> Darroch, “Rise in Euthanasia Requests,” 1.

<sup>316</sup> Darroch, “Rise in Euthanasia Requests,” 1.

<sup>317</sup> Pereira, “Legalizing Euthanasia or Assisted Suicide,” 12.

‘Mum, there’s always euthanasia’”<sup>318</sup> Pro-AVE Dutch physician Van Coevorden substantiated Boer’s estimate in his account as a euthanasia-providing physician (SCEN). Recalling a case when a woman appeared to be dying with stomach pains, Van Coevorden went to the family house: “When I turned up at the house the family practically pinned me to the wall and said: ‘You need to give mum the jab now, she’s in agony!’”<sup>319</sup>

Through his near-decade experience, Boer described the change in the tone of the dialogue from when the law was first adopted to protect physicians to currently being interpreted, and treated, more as a patient’s right. This change is witnessed with patients becoming more assertive in, not only their right to die, but in their preference of how they wish to die, Boer reflects. Having personally signed off on hundreds of AVE cases, Boer is not opposed to the practice, but he feels the Dutch law must be tightened, and believes (parallel to my hypothesis) that if palliative care were on par with its current state back in the 1990s, legality of euthanasia may not have occurred. Though, palliative reform is at its peak in the Netherlands today and demand has nevertheless increased, Boer contends that had the chicken come before the egg, it may not have hatched.

Further, Boer fears instances of what he terms “duo-euthanasia” when one partner of a terminally ill AVE-seeker also makes a request for the fear of life without them.<sup>320</sup> Ironically, it has long been said that human beings making decisions out of fear are the

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<sup>318</sup> Darroch, “Rise in Euthanasia Requests,” 1.

<sup>319</sup> Darroch, “Rise in Euthanasia Requests,” 1.

<sup>320</sup> Darroch, “Rise in Euthanasia Requests,” 1.

most ill-fated decisions of mankind. Yet, this idea conjures the point of whether unbearable fear constitutes a form of unbearable suffering.

Viewed from another lens, Dutch Physician Van Wijlick contends that an increase in euthanasia should not be cause for alarm and only proves that the system and protocols set in place are working: “Doctors see from experience that if they follow the procedure, they won’t have difficulties, and they feel reassured.”<sup>321</sup> With all the banter on “transparency”, Van Wijlick takes a unique position in his belief that there is no real way of determining if the physician acts diligently. However, there is a silver lining in Van Wijlick’s view: “That’s its strength. The doctor is never obligated to grant euthanasia: the patient has to convince him, and he has to be convinced.”<sup>322</sup> Reverting back to the Milgram Experiment, the power of persuasion and obedience come into play.

Under murkier waters, for infants under a hopeless, excruciating prognosis, end of life decisions are incredibly traumatic for parents who must act as the voice for their infants, unable to communicate pains and wishes. All cases of Dutch euthanasia must be submitted to a formal review committee and careful considerations have been put into play as a result of court proceedings for infants. Results on twenty-two cases of infants suffering from spina bifida were documented by the *New England Journal of Medicine* in 2005 with parameters including poor quality of life, expected time the hospital, inability to communicate and life expectancy; none of the physicians were prosecuted in these cases.<sup>323</sup> While extreme suffering and poor quality of life are notable factors, many have

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<sup>321</sup> Darroch, “Rise in Euthanasia Requests,” 1.

<sup>322</sup> Darroch, “Rise in Euthanasia Requests,” 1.

bashed the criteria regarding “self-sufficiency” and “inability to communicate” as bordering on discriminative.

<b>Table 1. Considerations Used to Support the Decision to End the Life of a Newborn in 22 Cases.*</b>	
<b>Consideration</b>	<b>No. of Cases (%)</b>
Extremely poor quality of life (suffering) in terms of functional disability, pain, discomfort, poor prognosis, and hopelessness	22 (100)
Predicted lack of self-sufficiency	22 (100)
Predicted inability to communicate	18 (82)
Expected hospital dependency	17 (77)
Long life expectancy†	13 (59)

\* Data are from Verhagen et al.<sup>3</sup>

† The burden of other considerations is greater when the life expectancy is long in a patient who is suffering.

Table 3: Considerations on decisions to end life of a newborn (Vehagen et al., 2005)

As the Dutch are the world precedent-setters of AVE, most provocative is the sensitive issue of the mentally ill. A June 2016 publication by *The Economist* turns up the heat on the data and implications. Beyond the fact that overall deaths under the law have skyrocketed by 76% since 2010 (including 5,500 in 2015), the authors are more concerned about 56 cases of assisted physician suicide conducted on patients with psychiatric disorders.<sup>324</sup> *The Economist* quoted Columbia University Psychiatric Professor Paul Appelbaum on the situation. Dr. Appelbaum contends that the Dutch move ultimately “raises concerns about eliminating people from the population as an

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<sup>323</sup> Edward Verhagen and Pieter Sauter. “The Groningen Protocol: Euthanasia in Severely Ill Newborns.” *The New England Journal of Medicine* 353, no. 10 (2005): 959-962.

<sup>324</sup> “The Number of Mentally Ill Seeking Help to die is Rising. Are the Rules Being Twisted?” *The Economist*. June 15, 2016. Accessed December 17, 2016. <http://www.economist.com/news/international/21700506-between-life-and-death-number-mentally-ill-seeking-help-die-rising-are>.

alternative to providing them with the medical care and social support they need.”<sup>325</sup> Dr. Appelbaum piloted a project to study regional Dutch AVE data from 2011-2014 and determined that one-fifth were cited for psychiatric conditions although none were ever treated nor hospitalized specifically for their mental disorders.<sup>326</sup> In what he terms “Mission Creep”, Dr. Appelbaum believes that legislation which once intended “...to allow the sickest patients to truncate their final suffering is being used as a permanent end to a problem that can wax and wane”.<sup>327</sup> Appelbaum insists the system more do more to ensure Dutch citizens are genuinely sound in mind and will. Parallel to the mysterious finding reported by *Alphen et. al.*, Dr. Applebaum also identified that women, specifically with with psychiatric disorders, are “...twice as likely as men with the same disorders to approach doctors for assistance in dying”.<sup>328</sup> Downplaying Applebaum’s opinion, University of Groningen Law Professor Anne Ruth Mackor argues that nothing illegal was done in any of these cases because the 2002 law permits AVE for citizens displaying any form of “unbearable” suffering “with no prospect of improvement” which already included psychiatric cases from the get-go.<sup>329</sup> Chiming in, Dr. Mackor, Dutch panel member on the euthanasia review committee, asserts her position that doctors simply have more leeway to use their skill and discretion: “Doctors today feel more able

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<sup>325</sup> “Number of Mentally Ill,” 1.

<sup>326</sup> “Number of Mentally Ill,” 1.

<sup>327</sup> “Number of Mentally Ill,” 1.

<sup>328</sup> “Number of Mentally Ill,” 1.

<sup>329</sup> “Number of Mentally Ill,” 1.

to navigate the law’s complexities because they now have more support, as well as years of case studies and experience.”<sup>330</sup> Opponents, like Applebaum, are less trusting of physicians’ discretion and question the right of physicians to hold this high level of authority.

In an enigmatic twist, the article referenced a study of psychiatric patients in Belgium where eleven were granted the right to die but later had a change of heart. When asked why, all eleven inexplicably stated that their will to live was reborn when they realized that they were able to receive help to die.<sup>331</sup> This circumstance, however, has raised the issue of potential for unequal treatment in conditions as they pertain to differing bodily organs – after all, the brain is an organ just like the heart or any other part of the body.

Condemning the Dutch actions in allowing those with mental disorders to participate, Trudo Lemmens reminds us of an important statistic on the curability of mental illness. Named by the World Health Organization as the most commonly occurring form of mental illness, depression is dealt with by one to seven human beings in their lifespan.<sup>332</sup> Lemmens vehemently questions how the Dutch state could deem a fluctuating mental state as “incurable”: “If we connect these figures to the fact that

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<sup>330</sup> “Number of Mentally Ill,” 1.

<sup>331</sup> “Number of Mentally Ill,” 1.

<sup>332</sup> Trudo, Lemmens. “Remove Euthanasia on the Basis of Purely Psychological Suffering from the Legislation (Translation Open Letter).” TrudoLemmens. December 14, 2015. Accessed November 18, 2016. <https://trudolemmens.wordpress.com/2015/12/09/translation-of-an-open-letter-of-8-december-2015-by-belgian-psychiatrists-psychologists-philosophers-and-others-re-psychological-suffering-in-belgian-euthanasia-legislation-translation/>.



hopelessness is one of the central features of a depressive phase, it is clear that the feeling of hopelessness is in no way commensurate with the truly hopelessness of a situation.”<sup>333</sup> Moreover, Lemmens reasons that psychological forms of suffering can only be evaluated through the word of the patient. The fact that clinical depression as a form of mental suffering cannot be considered “incurable” leads Lemmens to reject the very basis of the Dutch law to allow psychologically suffering participants under the law’s current parameters.<sup>334</sup>

Previously, from the literature review, we reviewed an argument made by Trudo Lemmens that a rising demand for AVE is based on judgment of one’s condition being a deserved reflection of their lifestyle – AIDS is a targeted area he particularly calls out. Describing an investigation conducted by *Battin et al.* on cumulative data obtained from Oregon and the Netherlands, a *Current Oncology* report reviewed the team’s finding that there was no evidence that “vulnerable people, except for people with AIDS, are euthanized disproportionately more”.<sup>335</sup> Although J. Periera expresses doubt over the group’s definition of what encompasses vulnerability, seeing it as too narrowly defined in that study, the fact that those suffering from AIDS were narrowly found most vulnerable is a reflection of Lemmon’s theory. The 2007 research project was extensive in coverage on individuals to include “... elderly, female, uninsured, of low educational status, poor, physically disabled or chronically ill, younger than the age of majority, affected with

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<sup>333</sup> Lemmens, “Remove Euthanasia,” 1.

<sup>334</sup> Lemmens, “Remove Euthanasia,” 1.

<sup>335</sup> Pereira, “Legalizing Euthanasia or Assisted Suicide,” 14.

psychiatric illnesses including depression, or of a racial or ethnic minority.”<sup>336</sup> Still, Periera cites others who have viewed this data as limited in the scope of vulnerability, excluding important factors of emotional state, sense of burden, and personality type.<sup>337</sup> Critiques of studies aimed at AVE vulnerability overwhelming tend to state that mental forms of vulnerability are left off the table and therefore negate the findings. That said, I concede to the point that these are, undoubtedly, factors at play in the mindset possibly leading towards AVE or PAS decision-making processes. However, I question the critics’ lofty idea that a human’s deeply personal characteristics, such as emotional state, can reasonably and accurately be measureable, or legally captured, in terms of vulnerability. If there were an accurate method to promptly study each human brain with accuracy in this regard, these critiques would hold more clout. Nonetheless, there is substantial value in the outcomes of the Battin research team’s vulnerability study and studies more broadly aimed at vulnerability should continue on a regular basis to provide checks and balances on the practice.

On the other hand, J. Periera brings up a concerning item for both Oregon and the Netherlands in terms of evenhanded practice of the law and vulnerability of the depressed. Referencing a study of 200 terminally ill cancer patients, Pereira believes citizens in Oregon are simply denying or downplaying the reality of depression as a contributing factor: “Depressive syndromes was 59% among patients with a pervasive

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<sup>336</sup> Pereira, “Legalizing Euthanasia or Assisted Suicide,” 14.

<sup>337</sup> Pereira, “Legalizing Euthanasia or Assisted Suicide,” 14.

desire to die, but only 8% among patients without such a desire”.<sup>338</sup> Apart from Swiss law, a second physician is required for consultation on PAS/AVE measures for all European nations; however, Pereira found that the process was unevenly enforced. She notes that a Dutch consultation was disregarded in 35% of involuntary cases.<sup>339</sup> Further, adding momentum to the lapse in enforcement and slippery slope argument: “In 1998 in the Netherlands, 25% of patients requesting euthanasia received psychiatric consultation; in 2010 none.”<sup>340</sup> In a sample of eighteen Oregon patients, the *British Journal of Medicine* found that in 2007 one in six who had lethal injections were later found to be clinically depressed with three patients suffering “major depression”.<sup>341</sup> In Pereira’s interpretation, this is representative of an “illusion of safeguards”, suggesting that safeguards are highly likely to be disregarded over time.

As witnessed in Oregon, aside from an immediate five-year period of stagnation, societal demand for AVE has also risen at extensive rates for the Dutch. While some scholars fear that euthanasia practices are at odds with government support of palliative care practices, Oregon’s data and palliative growth ratings overwhelmingly signal the opposite. Let’s take a look at how the palliative healthcare trends are jiving with Dutch progression of AVE.

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<sup>338</sup> Pereira, “Legalizing Euthanasia or Assisted Suicide,” 7.

<sup>339</sup> Pereira, “Legalizing Euthanasia or Assisted Suicide,” 7.

<sup>340</sup> Pereira, “Legalizing Euthanasia or Assisted Suicide,” 7.

<sup>341</sup> Pereira, “Legalizing Euthanasia or Assisted Suicide,” 7.

*Palliative Nucleus of Dutch Medicine*: Opponents of the euthanasia practice have long argued that palliative medicine will be swept under the rug with AVE/PAS legislation. Statements where physicians and politicians have made public stances to support these claims raise the fervor. Back in 1998, for example, during a debate on the Human Rights Act, a Dutch physician boldly stated: “We don’t need palliative medicine, we practice euthanasia”.<sup>342</sup> For those trying to disconnect the two entities, there is concern that palliative care will be treated as “the enemy” of euthanasia, or vice versa.

At a the 16<sup>th</sup> Biennial Scientific Meeting of the *International Gynecological Cancer Society* this October, Andreas Obermair MD, director of the “Surgical Performance Foundation”, commented on the palliative-euthanasia linkage: “After the Dutch introduction of euthanasia in 2002 palliative care services slowed down and in response euthanasia rates soared to more than 12% of all cancer deaths.”<sup>343</sup> However, he observes the Dutch enhanced palliative care as a result of condemnation and euthanasia rates then dropped by one third.<sup>344</sup> Representative of my hypothesis, Obermair claims that the Dutch experience is a clear depiction of how a lack of palliative care can lead into a heightened pressure on patients to select euthanasia: “The pressure arises from making kinder and more humane options for the end of life care not available. It seems so much

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<sup>342</sup> Harris, et al., “Assisted Dying: The Ongoing Debate,” 480.

<sup>343</sup> Andreas, Obermair, “If Palliative Care Is Down, Euthanasia Is Up,” LinkedIn. November 10, 2016. Accessed November 28, 2016. <https://www.linkedin.com/pulse/palliative-care-down-euthanasia-up-andreas-obermair>.

<sup>344</sup> Obermair, “If Palliative Care Is Down,” 1.

‘easier’ to kill patients than to care well for them.”<sup>345</sup> Australia’s edging path towards legalization has prompted Obermair to be especially concerned about what he considers a national weakness of palliative care options, noting that the disparity is also a waste of resources and potential savings for the nation.

Mr. Obermair concedes that there have been positive experiences with the Dutch practice including the finding that family’s grief is markedly less for those who lose their loved ones through the practice: “Complicated grief was 15% in family members of patients who had euthanasia and almost the double (26%) in controls.”<sup>346</sup> Albeit, the world renown Gynaecological Oncology and Pelvic surgeon stresses the need for palliative care, not only to afford patient comfort, but also in its ability to dampen the financial burden placed on healthcare systems that are exponential within the last years of life. In a chilling hypothetical, Obermair’s greatest fear, if palliative care were abandoned, is that one day healthcare funders will simply present patients with a harrowing choice:

“We estimate that you will cause medical costs of \$1,000,000 in the next 12 months. If you agree to euthanasia, we will pay you \$100,000 cash, which you can spend on whatever you like including your child’s home loan. If you agree to donate your eyes after your death, we pay you even more.”<sup>347</sup>

Surely, the economic advantage of palliative is a double asset for the medical field and the taxpayer/government. In this regard, palliative care’s savings generator serves as a protecting agent for self-sustaining its own existence and in protecting/safeguarding the

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<sup>345</sup> Obermair, “If Palliative Care Is Down,” 1.

<sup>346</sup> Obermair, “If Palliative Care Is Down,” 1.

<sup>347</sup> Obermair, “If Palliative Care Is Down,” 1.

vulnerable in the euthanasia landscape. Despite Obermair's conviction that the Dutch experience is acting parallel with our hypothesis, many other factors are at play and a look at Dutch data on the trend in its palliative care program paints another picture, according to some researchers. Others point to the Netherland's declining GDP under the Great Recession, a burgeoning national acceptance of AVE and the upshot in elderly population in recent years, as highly contributing factors in AVE demand beyond the palliative linkage.

In fact, a September 2016 publication by *BMC Health Services Research* and *BioMed Central* indicates a sharp and steady increase in palliative healthcare services across Dutch hospitals, specifically with regard to spikes in expert teams tailored to palliative and hospice needs. In a study of seventy-four hospitals, the research team identified that 77% had palliative care teams and the nation is currently on track to have expert palliative care teams in every hospital by 2017.<sup>348</sup> Declaring that palliative care is an "integral part of regular healthcare" in the Netherlands, the study found that its strength is the construct distinguishing primary palliative care from specialist palliative care.<sup>349</sup> Contrary to popular belief, the questionnaire responses returned from these hospitals overwhelmingly reflected that palliative care is overwhelmingly a leading priority for the Dutch, despite the current demands affiliated with AVE. These results are also indicative of the Dutch government's commitment to palliative with 82% of

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<sup>348</sup> M. Boddaert, A. Brinkman-Stoppelenburg, J. Douma, and A. Van Der Heide, "Palliative Care in Dutch Hospitals: A Rapid Increase in the Number of Expert Teams, a Limited Number of Referrals," *BMC Health Services Research* 518th ser. 16, no. 1 (2016): 1-7.

<sup>349</sup> Boddaert, et al., "A Rapid Increase," 1.

hospitals tasked by the board of directors to develop palliative care programs and 85% already reporting they have a steering committee in place for palliative care.<sup>350</sup> Moreover, 73% of all hospitals have nurses who specialize in palliative care with education from the palliative healthcare field.<sup>351</sup>

Palliative Care Teams (PCTs) are sharply increasing for the Dutch with comparative data of 39% of hospitals containing them in 2013 up to 77% in a matter of two years by 2015.<sup>352</sup> The researchers attribute this swift jump to the Dutch Federation of Oncological Societies (SONCOS) mandating all hospitals develop a PCT by January 2017. Again, what we can gather from these statistics is that it does not appear that euthanasia, as a practice, is a threat to palliative medicine. Rather, it seems that the two entities are complimenting one another by eliminating a certain level of stress from patient, physician, and governance, while additionally, cutting costs.

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<sup>350</sup> Boddaert, et al., “A Rapid Increase,” 2.

<sup>351</sup> Boddaert, et al., “A Rapid Increase,” 2.

<sup>352</sup> Boddaert, et al., “A Rapid Increase,” 7.

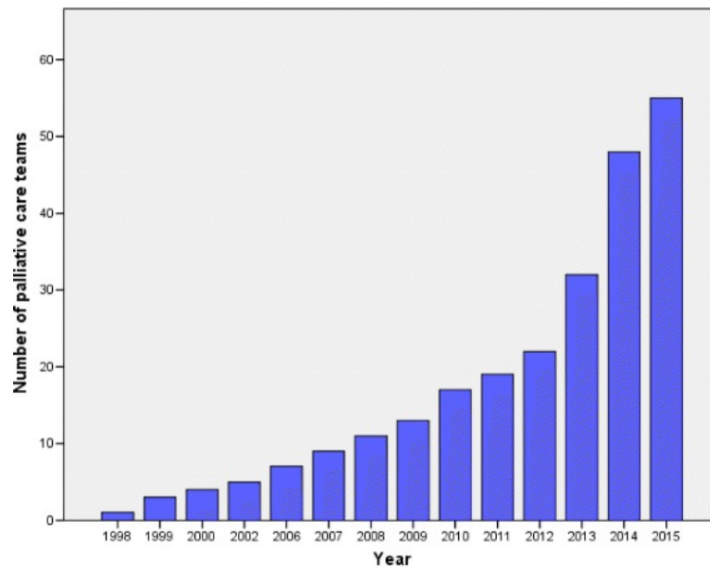


Figure 33: “Number of Palliative Care Teams” (Brinkman-Stopplenburg et al. 2016)<sup>353</sup>

Even as legislation has been introduced to expand AVE practices (i.e. “completed life”), the Dutch government is simultaneously continuing to heavily invest in palliative care reform. For example, a palliative healthcare news site reported a new Dutch initiative, titled “Palliantie: Meer dan Zorg”, is underway to invest 51 Million Euros into palliative care for the state. Beginning in 2014 and extending out to 2020, the aim of Palliantie is to “...stimulate research, helping to initiate education programmes for doctors and nurses throughout the country”.<sup>354</sup> According to Rob Bruntink, forty-eight plans were evaluated directly from members of the community on recommendations to improve palliative care with the best projects being financed by Palliantie. The program features four pillars aimed at the health of the patient and support of the community:

<sup>353</sup> Boddaert, et al., “A Rapid Increase,” 3.

<sup>354</sup> Rob Bruntink. “51 Million Euro Programme to Improve Palliative Care in Holland,” EHospice: Palliative Care News, Views, and Inspiration from Around the World. September 30, 2015. Accessed September 2, 2016. <http://www.ehospice.com/Default/tabid/10686/ArticleId/16906>.



“innovation and quality, participation of patients, awareness and culture, and organization and continuity of care”.<sup>355</sup> Bruntink notes that although euthanasia is widespread in Holland, palliative care is rather well developed with 250 hospices nationwide, consultation teams readily available and a plethora of regional organizations involved.<sup>356</sup> In fact, “World Hospice and Palliative Care Day” is a celebrated event for Dutch comrades.

Data collected from the European Association for Palliative Care, an NGO recognized by the Council of Europe provides palliative health care rankings across Europe. In the 2013 data finding, the Netherlands and Belgium were ranked in the top slot, only falling behind the United Kingdom.<sup>357</sup> It becomes doubtful where the anxiety is originating in those declaring that palliative healthcare has somehow gone to the wayside with euthanasia’s birth and boom in these nations – at least at its current state.

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<sup>355</sup> Bruntink, “51 Million Euro Programme,” 1.

<sup>356</sup> Bruntink, “51 Million Euro Programme,” 1.

<sup>357</sup> EAPC ONLUS, “Ranking of Palliative Care Development across Europe,” @EAPCONLUS. August 31, 2016. Accessed November 29, 2016. <https://eapcnet.wordpress.com/2016/08/31/ranking-of-palliative-care-development-across-europe/>.



Figure 34. Palliative Care Across Europe (EAPC 2016)

In addition, the “Quality of Death Index” headed by the Economist Intelligence Unit (EIU) ranked the Netherlands (8<sup>th</sup>), the United States (9<sup>th</sup>), and Belgium (5<sup>th</sup>) in the top ten world programs for end of life palliative care in 2015.<sup>358</sup> Vigorous factors went into the ranking system including: palliative framework, training of medical professionals, monitoring guidelines, available medications for pain relief, financial burden on patients, and community engagement. Considering Australia’s ascension into

<sup>358</sup> Janice Tai. “Republic is 12th Best on Palliative Care Index” *Straits Times*, October 7, 2015. Accessed December 19, 2016. <http://www.straitstimes.com/singapore/health/republic-is-12th-best-on-palliative-care-index>.

second place, Dr. Andreas Obermair’s previous claim that palliative care in the nation is deficient, becomes refutable. The pattern continues with the top two most aggressive nations in the world of euthanasia receiving top posts in palliative healthcare rankings.

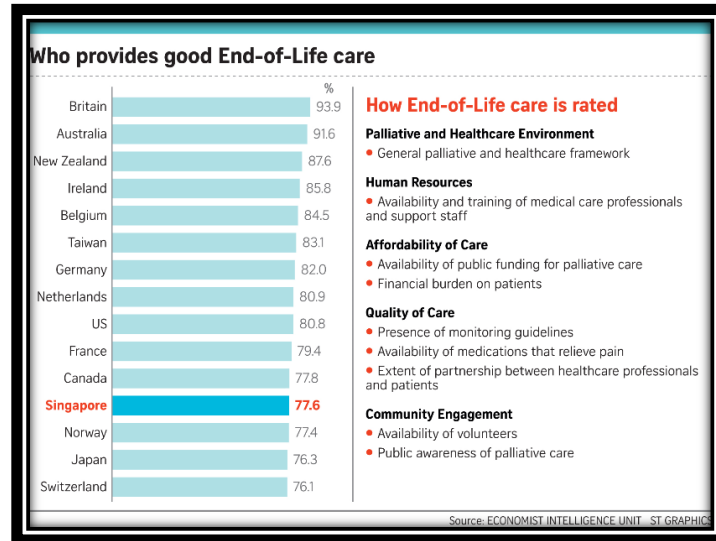


Figure 35. Palliative Care Global Rankings (Tai 2015)

I have been unable to identify any reliable sources that veer from a robust Dutch palliative health care system. Certainly improvements can always be made, as with any healthcare system, but the dedication to palliative healthcare in the Netherlands has not died with the rise of euthanasia demand; it remains alive, well and thriving. Upon review of the funding and support of Dutch palliative services by the government, medical practitioners and regional networks, I believe that statements made to the contrary tend to be more fear-based than fact-based. Rooted in fear over the idea that if palliative care gets dropped, citizens will be left with no options and insurmountable vulnerability, even high credential-toting professionals have made claims that are not fact-based. Understandably, there is much at stake. However, while certain variables and statistics are arguable, the

fact remains that palliative healthcare is and continues to be a priority for the Dutch, on all accounts – at least at surface value.

While many fear for the future of palliative care, I see no merit in the argument that increasing societal demand for PAS/AVE has produced government neglect for palliative-based healthcare programs in Oregon or the Netherlands. The reality may seem counter-intuitive, but I judge the economic and logistical benefits of palliative healthcare have unpredictably paved the way for a constructive coexistence between the practices of euthanasia and continued devotion to palliative healthcare. I full heartedly agree with the National Palliative Care Research Center’s declaration; indeed, we have arrived at a “Watershed Moment”.<sup>359</sup>

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<sup>359</sup> National Palliative Care Research Center, “America’s Care of Serious Illness,” 2.

## V.

### Concluding Remarks, Recommendations, and Research Limitations

Government discussions revolving around monetarization of human issues such as climate change, education, or even national security, tend to pose less of a societal threat. When it comes time for government to monitor “death”, the element of suspicion and anxiety reaches a fever pitch. In an elusive fashion, those in favor purport inalienable free will to elect their end without government meddling in their own health affairs. However, with legalization of AVE, the catch-22 dwells in the fact that government will automatically gain power in two forms: (1) in the need to monitor “the system”, and (2) in its capacity to allow certain citizens to choose death. So, does the solution become all or nothing? Can we effectively govern human death in a mode that truly provides liberty and justice for all?

Contrary to my prediction, the rate of demand for euthanasia ascended with steady government levels of expansion on palliative healthcare programs in Oregon and in the Netherlands. Along the route, I learned that euthanasia itself embroils an abundance of opportunities to ignite government corruption as well as societal discrimination. However, as it stands, I affirm palliative care does not currently pose any real threat to the practice of euthanasia. Inversely, and rather refreshingly, the practice of euthanasia does not appear to be threatening palliative healthcare’s promotion and growth in either of these two sovereignties.

Palliative healthcare may serve to act as an alleviator to the clogged hospital system and a facilitator for safeguarding the vulnerable. However, without the cost-savings potential of palliative healthcare, the possibility of its evaporation with the rise of euthanasia seems more tangible. Since the floodgates have broken, monitoring the euthanasia empire will remain an eternal obstacle for Government as we all wade through murky, uncharted territory in the face of ‘the good death’.

Conceivably, science is mutually a blessing and a curse by pitting humanity against itself, while shifting the moral code, with advancements that are simultaneously advantageous for humanity, but also, have produced what is artificially unsustainable. Nonetheless, in the game of life, nothing lasts forever, and this includes human life itself. In the midst of these vexing challenges, Harvard Law School Professor and leading bioethics expert, Glenn Cohen, reminds us of the overarching, common goal uniting contemporary medicine and law “that we are able to provide a thing of major concern to the aging population of America: the assurance of dying well.”<sup>360</sup>

*Recommendations.* From this study, I offer the below recommendations for future research and consideration:

1. *Revamp Ethics Review Committees.* Bioethics and health law experts, like Glenn Cohen, have articulated concern that ethics review committees surrounding the practices of PAS and AVE are stacked against a patient’s right to due process. Cohen recommends a quick-fix to mitigate end of life disputes by aligning ethics review committees with a more Alternative Dispute Resolutions (ADR) centered

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<sup>360</sup> Cohen, “Negotiating Death,” 330.

- process, including strict requirements that panelists “not be insiders.”<sup>361</sup>
2. *Alleviate Administrative Burdens on Physicians.* Administrative demands must be allotted to a new wave of clerical workers who will accompany physicians and provide documentation pertaining to euthanasia practices and healthcare documentation at large. It is time to free physicians from the shackles of paperwork and allow them to do what they have worked their lives to do – be healers, not secretaries.
  3. *Invest in Hospital Logistics.* Pursuant to the second item, more government investment into the logistical and clerical operations of hospitals and palliative healthcare centers is a must.
  4. *Increase Research Funding into Cost-benefit Analysis of Medicine.* Research on the cost-savings benefit of palliative healthcare is a gap in the medical field and reliable prediction models displaying data savings will entice lawmakers to act. Not only will this benefit the issue of euthanasia, but also, the livelihood of patients and save taxpayer dollars.
  5. *Alignment of Law with Bioethics Practices.* Lagging responses to bioethics and health law issues in the legal and judicial systems are causing confusion in society and producing ineffective results. Swifter legal and judicial action is needed to address and keep up with the steadfast demands occurring in the medical field, specifically aimed at end of life issues. I recommend task force teams stacked with our nation’s top professionals in the industry to report directly to the

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<sup>361</sup> Cohen, “Negotiating Death,” 328.

- legislative and judicial branches of government on recommendations and guidance for these issues. Additionally, state-run task forces of the same caliber must be fulfilled. Healthcare reform calamities, as we discussed with LTC insurance, must be revamped with the aging population and modern medical considerations chiefly in mind. Again, task forces comprised of medical and legal professionals must be adopted to spur bipartisan action at all levels of government where politicians continue to fail.
6. *Merge Data Cross-Nation on Euthanasia Research.* Where limitations exist, internationally collected data on the practice of euthanasia, across boundaries should be executed by one impartial body that is not tied to any specific government. This will also act as a safeguard to mitigate possible corruption and/or skewing of regional data on this delicate, provocative issue.
  7. *Emphasis on Psychological Research.* With the vulnerability of the mentally ill, increased funding is needed to research psychological conditions, particularly for clinical depression.
  8. *Care of the Mentally-Ill.* Greater support for the mentally ill must be aggressively integrated into the palliative healthcare platform. The mentally ill face the most susceptibility to homelessness, addiction, and disease; heartbreakingly, they are often neglected in the healthcare regime.
  9. *Mandatory Death Wishes Clearly Communicated.* An ugly but important quick-fix to assuage end-of-life dramatics is to mandate that all citizens declare, in writing, their last wishes should they fall under a vegetative state.

*Research Limitations.* Today's mass media is filled with alarmist, doomsday



reporting. A topic such as euthanasia can be challenging when sifting through statistics masked by political leanings. While research on the practice of euthanasia as whole is relatively robust, after extensive reviews, the World Health Organization has acknowledged a significant lapse in palliative care research and the complications with what can be offered across the European Union.<sup>362</sup> Policy-makers frequently do not have access to crucial scientific facts that could greatly impact the decision-making process. This is likely a result of minimal evidence on palliative care, but also a lack of desire or funding to support such research. At the most basic level, frustration has been voiced over the convoluted, inconsistent, and evolving definitions of terms used across the board from perplexity over what constitutes “pain” to struggles determining what point one’s “end of life” stage actually occurs. As time goes on, perplex medical advancements will require effective, steadfast responses and future policy adjustments are likely to present deeper challenges. When considering life support’s prolongation of life, some have felt that our society has gradually altered the very definition of ‘death’ itself and “relaxed standards for maintenance of life” as reflected in the Harvard Medical School report back in 1968.<sup>363</sup>

Seemingly, the bulk of research to date appears to be aimed at patients suffering from cancer, and while this is a noble endeavor, further research is compulsory for those

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<sup>362</sup> Davies and Higginson, “The Solid Facts,” 21.

<sup>363</sup> Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, “A Definition of Irreversible Coma: Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death,” *Journal of the American Medical Association* 205, no. 6 (1968): 337-340.  
<http://jama.jamanetwork.com/article.aspx?articleid=340177>

suffering from other ailments. More than ever, as stressed by Trudo Lemmens, more research is desperately needed on those suffering from psychological conditions and mental illness. Limited data on non-cancer patients impedes the study's full scope on what drives patients to consider euthanasia. Studies on the needs of families who are struggling to care for and mentally endure their loved one's dying state is another area of limited scholarship. Data is generally limited with studies tending to be conducted within small sub-groups of populations rather than studies confronting worldwide incidents. This is understandable to some degree given vast legal variances and unique situations associated with each specific nation state; nevertheless, it presents a gap in the research by only concentrating on small fragments of the global population.

Discernibly, extraneous valuables are at play in each study conducted, and the nature of the topic is rather conducive to such conditions with the vulnerability and mental state of patients. Subjectivity is a noteworthy dilemma in any study with sensitive, emotional and controversial underpinnings and I reminded myself to stay resolute. This struggle is exemplified through clashing claims regarding data and, correspondingly, varying interpretations of the same existing data gathered in the field of euthanasia's practice. Statistical representations and graphs depicting overall occurrences of physician assisted suicide are hard to come by and those available publically are commonly produced by either "right to life" or "right to death" affiliated organizations. As in any research project, what one researcher points to as evidence, another will refute as unreliable or biased. Finding common ground and achieving an evenhanded approach to the problem is challenging when wading through distorted claims and conflicting data sources.

For palliative care, there is a shortage of data pertaining to the *social* science aspect of the practice; this is particularly troubling when considering the psychological factors that are often most directly tied to one's decision-making process at the end of life. Most importantly, the scarcity of primary sources from the patients themselves is the utmost roadblock to the study, because the patients' views may be far different than that of family members, government officials, or health care professionals speaking, or speculating, on their behalf. Data from many nations on questions related to the practice of euthanasia and data directed towards national palliative health care systems is, in many cases, simply not collected. For example, the World Health Organization has specifically referenced data on place of death not being collected by several nation states.<sup>364</sup>

I finally acknowledge that as comprehensive as my research aspired to be, covering all dimensions on an issue of this magnitude was a challenge and I wished to have been able to devote more attention to underlying aspects of the phenomenon. There theories or aspects I touched upon that were not able to be fully examined, and although my goal is to provide as much relative background information as possible, the research overall was centered upon the relationship between palliative health care and euthanasia.

All in all, these limitations were setbacks that deserve further research in this historic study. As for any analytical exercise in the human world, limitations will inexorably exist but working through these obstacles by illuminating the puzzle in an even-handed manner and directing holistic, meticulous research minimizes these encountered limitations. After all, being upfront as a researcher about observed

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<sup>364</sup> Davies and Higginson, "The Solid Facts," 17.

weaknesses, lapses in judgment, research gaps, and other predispositions can add tremendous merit to the conflict by exposing areas where research has gone awry and bring awareness to embedded topics within the field that warrant further study

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