UNITED STATES PHYSICIAN AID IN DYING (PAD) STATUTES: HISTORY, OUTCOMES, AND IMPLICATIONS FOR STAKEHOLDERS

BY

DOUGLAS DAVISON

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Approved By:

Mark Hall, J.D., Advisor

John Moskop, Ph.D., Chair

Nick Colgrove, Ph.D.

Dedicated To Roy L. Comstock

Table of Contents

Abstract

Keywords: Physician Aid in Dying, Disability, Palliation, Palliative Treatment, Death with Dignity

Physician Aid in Dying (PAD) has been legalized in 11 United States Jurisdictions. The history of the practice in what would become the United States reaches back to the colonial times, through the 20th Century Supreme Court cases of *Washington v. Glucksberg* and *Vacco v. Quill* to the legalization of PAD by statute, starting with the Oregon Death with Dignity Act in 1997, to today. Advocacy organizations have been influential throughout the debate. Pro-PAD organizations have lobbied for PAD legalization and worked alongside policymakers to craft the Oregon statute and the other 10 based off the Oregon template. PAD opponents have warned against the slippery slope which they argue is the end result of the excesses of PAD.

This thesis focuses in particular on two prevalent arguments against PAD, the first stemming from palliative care organizations and the second from disability studies literature. The former addresses the theme that when a patient is provided appropriate palliative care, they often reverse their previously-expressed wish to be provided PAD. The latter, termed the “disability critique”, argues PAD expresses harmful attitudes about persons with disabilities, and could lead to economic pressure that could coerce persons with disabilities into choosing aid in dying. Lastly, the thesis details an original pilot study undertaken to determine the attitudes of North Carolina palliative care and clinical ethics consultation professionals on their attitudes towards aid in dying.

Preface

1. Project Overview

The initial inspiration for this thesis came from Carbone et al. (2019). In their essay published in the North Carolina Medical Journal, the authors advocate that North Carolina medical professionals should begin to practice Physician Aid in Dying (PAD), despite the absence of a state statute that explicitly legalizes PAD. They argue that providers can be assured they will not face legal or professional retribution for practicing PAD due to North Carolina's "unusual situation" of not having an explicit "statutory prohibition of [aid in dying]" (Carbone et al., 2019). Additionally, the authors contend that the practice is becoming more widely accepted as an appropriate treatment by medical professionals. Despite the authors advocating for PAD in a state that has not explicitly legalized this practice, the authors note "Support for AID among North Carolina physicians is unknown, as no targeted survey has been done" (Carbone et al., 2019).

Information about the views of medical professionals would be indispensable for determining the feasibility of passing a PAD statute in North Carolina, given that physician opposition could be a major hurdle to the successful passage of any such statute. After reading this essay I felt the need to decrease this dearth of information, at least to a modest degree. Thus, at its inception the objective of this thesis was to investigate attitudes on PAD among Wake Forest Baptist Medical Center (WFBMC) and Atrium Health professional's attitudes on PAD. This goal led to an IRB approved research project based on qualitative interviews of health professionals at the Medical Center who specialize in palliative care and clinical ethics.

To complement this study, I also undertook in this thesis to collect all reasonably available information about how PAD has functioned in states where it has been legalized. And, I undertook to better understand the various bases for objecting to PAD that have arisen from different professional and patient-advocacy groups.

Chapter one of this thesis begins with an exploration of the history of Physician Aid in Dying in America, from colonial times to the early 20th century. Next, the chapter discusses the history of legalization of PAD in each of the 11 United States that have done so, and it reports information about the use of PAD in those jurisdictions. The Oregon Death with Dignity Act (DWDA) of 1994 was the first its kind, and each successive statute has used it as a framework.

These statutes have a few things in common. First, all restrict eligibility for PAD prescriptions to patients who possess decision-making capacity. Second, they limit the diagnoses eligible for PAD to terminal conditions. Terminality is defined in every state as having a life expectancy of 6 months or less.

There are also ways in which the statutes vary. California stipulates that a provider can refer the patient to a mental health provider if they suspect the patient's PAD request is due to clinical depression or other mental illness. Hawai'i and Maine allow for conscientious objection for physicians who have moral disagreements with PAD. Both Maine and New Jersey stipulate that the patient must make two written requests and one oral request. In California the patient must make two requests, either written or oral, but the second must be at least 15 days from the initial one. Also unique to Maine and New Jersey is qualification that "qualified witnesses" can attest that the patient is not coerced into PAD.

Chapter two begins by discussing the United States Supreme Court case *Washington v. Glucksberg*. *Glucksberg* was a suit by the advocacy organization Compassion in Dying against state of Washington on behalf of four Washingtonian medical professionals who sought to practice PAD. Ultimately, the United States Supreme Court rejected the plaintiff's argument that PAD is supported by a right to privacy found in the fourth amendment. *Glucksberg* and the involvement of Compassion in Dying is instrumental in demonstrating the impact that advocacy organizations can have on the public discourse on PAD legalization and expansion. This Chapter discusses the histories of both pro- and anti-PAD advocacy organizations and the respective arguments employed to defend those positions. PAD defenders share the core defenses of patient autonomy and beneficence, whereas prohibitionists fear the slippery slope of involuntary euthanasia, decreased coverage, and abuse (Moskop, 2016).

The third chapter reports the data obtained from the pilot study I undertook, overseen by my advisor, Prof. Hall. In each interview I posed a series of questions, four derived from Lee et al., 2009, and three are derived from Ditommaso, Kirshenbaum & Parent, 2018, and three additional questions that I formulated. These interviews to generated qualitative data on the attitudes of WFBMC and Atrium palliative care clinician and clinical ethicists' attitudes on PAD, whether they had ever received a PAD request during their professional career, and lastly whether they have advocated for PAD in their career and would support passage of a PAD statute in North Carolina.

Five medical professionals were interviewed. Three of the professionals practiced in the hospice/palliative care specialty. The remaining two were clinical ethicists. Average time practicing medicine was 13 years, with the longest being 23 years and the shortest being eight. All physician-subjects responded that they were involved with the care of dying patients. All of the subjects had received PAD requests and the ethicist has been involved with consults.

The research led to several conclusions. First, rather than oppositional to PAD, the palliative care professionals interviewed were open to the notion that PAD is an ethical treatment can be successfully integrated into palliative practice. Second, the palliative medicine professionals were also personally open to the idea of receiving appropriate training that would enable them to provide PAD. The almost uniform acceptance of PAD by the palliative medicine subjects differed from the views of the two clinical ethics subjects. One ethicist expressed no opposition to PAD legalization and felt no qualms about consulting in a PAD case, whereas the other expressed a staunch prohibitionist opinion. Third, the research found that none of the subjects had publicly advocated for legalization or prohibition. Lastly, all but one (a clinical ethicist) would personally support legalization of PAD in North Carolina.

Chapter four concerns an objection to PAD common in the palliative care literature. This objection states that when a patient has appropriate pain management alongside spiritual and mental health care, their suffering can decrease to the point that their attitude changes to no longer desire aid in dying. This chapter begins with a description and brief historical exposition on palliative care. This is followed by a discussion of palliative care organizations' declarations on PAD. The majority endorse the palliative objection to PAD, though several would allow palliative care professionals to provide PAD (if legal) when standard palliation does not decrease suffering (Inbadas, Carrasco, & Clark, 2020). The next section of the chapter is devoted to arguments that respond to palliative care objection. The opinions of the palliative care professionals involved in the pilot study are also discussed.

The fifth and final thesis chapter concerns the disability critique of PAD. This criticism comprises a collection of arguments, all implicating PAD as a thinly veiled attempt to target harm at persons with disabilities. These include both economic concerns such as the pronouncement that PAD is coercive and could be used to deny insurance or Medicaid/Medicare coverage, to societal discrimination concerns alleging that PAD will become a slippery slope leading to back to eugenics. In contrast to disability rights critics of PAD a minority of disability scholars argue in favor of PAD. This group appeals to autonomy and freedom as supporting PAD expansion for persons with disabilities. To deny PAD to the persons with disabilities is not to treat them with respect, rather it is belittling and overly paternalistic. Regarding the risks of PAD, it is specious to expect that PAD will be entirely without risks for all those who opt for it, including the persons with disabilities. But so too is overemphasizing its risk compared to other everyday activities for which we accept risks in proportion to their benefit, such as automobile driving compared to the risk of accident.

2. Relevant Definitions and Distinctions

What has now become known as Physician Aid in Dying (PAD) has undergone several name changes. The shifting lexicon is liable to create confusion among terms and can–whether purposefully or otherwise–influence the public's perception of PAD depending on personal and societal perceptions of the different terms.[1] As such it is crucial here in this introduction to define PAD, discuss the development of previous terms, and explain how PAD differs from related concepts such as euthanasia. According to Dugdale, Lerner, & Callahan, denoting the practice as *aid in dying* distinguishes it from the practice of suicide, which (to supporters of the use of PAD) should only denote the tragic taking of one's own life that is the result of severe mental illness. While this change has admirable intention, opinions on its merit are mixed, as others believe the use of PAD demeans and stigmatizes suicide done for honorable reasons (Dugdale, Lerner, & Callahan, 2019; Yuill, 2013).[2]

The process of PAD is done via the steps of an individual requesting assistance in dying, next a prescription is written by a licensed professional, and finally the patient fills the prescription and takes the medication. Some patients begin but do not complete this process. Some change their mind and never fill the prescription or ingest the lethal medication. Still others die due to the natural progression of their terminal illness before they have the opportunity to commit the PAD process.

Euthanasia is differentiated from PAD in that, whereas with PAD, the patient administers the lethal agent that leads to death, with euthanasia the physician directly

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[1] For instance, the difference between phrases such as aid in dying, suicide, euthanasia, mercy killing, and murder.

[2] To this end, Yuill, an opponent of PAD, writes:

> Doubtless most people have a negative connotation of suicide but there are noble suicides…each suicide must be judged individually. In distancing themselves from suicide, these assisted suicide advocates are condemning all unofficial suicides, all suicides taken with- out express approval. This is despite the fact that suicide is illegal almost nowhere (India is one of the last countries where suicide remains a crime) and despite the argument often employed by pro-legalization forces (like Gloria Taylor's lawyers) that laws against assisted suicide are discriminatory because disabled people should have the right to suicide. (Yuill, 2013)

administers the lethal agent (Dugdale, Lerner, & Callahan, 2019). Euthanasia is legal alongside standard PAD in Belgium, Colombia, and Luxembourg as well as Canada, which legalized the practice in 2016. It has a "decriminalized" status in the Netherlands, meaning a physician will not be prosecuted for the act, provided they go through the mandatory steps of reporting the euthanasia to the municipal forensic pathologist, who in turn, "forwards the report to the appropriate Regional Euthanasia Review Committee" and the Committee finds the euthanasia was in accord with the current practices and was justifiable (i.e. to end a competent patient's suffering) (Dugdale, Lerner, and Callahan, 2019; Legemaate & Bolt, 2013).

Though it has now fallen out of use in the bioethical literature, another early distinction was between active and passive euthanasia. According to Rachels, the idea among those who support the distinction "…is that it is permissible, at least in some cases, to withhold treatment and allow a patient to die, but it is never permissible to take any direct action designed to kill the patient" (Rachels, 1975). No United States jurisdiction has legalized euthanasia. Nothing in this thesis should be thought of as discussing, reporting, or likewise advocating for the legalization or prohibition of euthanasia. Rather our discussion will remain solely on PAD.

3. Conclusion

The debate over the extent of medicine's proper role in end of life care is not one that can be easily resolved. This thesis does not pretend to be the final word on the subject. Rather, it offers a historical, juridical, medical, and most paramount a bioethical examination that adds to the ongoing dialectic over aid in dying. It spans the history of the right-to-death movement in America to the present day, providing contemporary data on the outcomes of relevant statutes. Of particular focus is the views of disability community members and scholars. Lastly, this thesis adds to the literature with data on views among North Carolina medical providers, which could be a valuable contribution in any future debate over PAD legalization in the state.

I. History of Physician Aid in Dying in America with Relevant Data from Each Jurisdiction

1. Introduction

This chapter will first discuss the history of aid in dying in the United States. The timeline extends from the colonial era to the legalization of the first aid in dying statute, the Oregon Death with Dignity law. It will also touch on the landmark joint Supreme Court decisions of *Washington v. Glucksberg* and *Vacco v. Quill,* whose precedent left any chance of federal legalization of PAD highly unlikely. The chapter will then move on to explain the requirements and safeguards of the state statutes allowing PAD and will elucidate how many patients in each state have selected PAD, along with key demographic information which can help determine whether certain underprivileged social groups are utilizing the practice–a potential sign of abuse. Concerns related to abuse will be discussed in greater length in chapters 4 and 5.

2. Brief History of PAD from Colonial America to the mid 20th century

English common law had outlawed any attempt to commit or assist suicide as a felony offense since the ruling of Hales v. Petit (Neelman, 1996; Washington v. Glucksberg, 1997). As such the American colonies were under such prohibition until the Revolution. The idea that suicide was a moral wrong and the state could rightfully penalize both the completed and uncompleted act was kept in American jurisprudence. Those who completed suicide were often stripped of their rights to property and burial on consecrated ground. For instance, the colony of Rhode Island declared in its official charter:

"[s]elf murder is by all agreed to be the most unnatural, and it is by this present Assembly declared, to be that, wherein he that doth it, kills himself out of a premeditated hatred against his own life or other humor: . . .his goods and chattels are the king's custom, but not his debts nor lands; but in case he be an infant, a lunatic, mad or distracted man, he forfeits nothing" (Washington v. Glucksberg, 1997).

Similarly, *Glucksberg* states the colony of Virginia would condemn those who committed the offense to a "ignominious burial" and declare eminent domain on their estate (Washington v. Glucksberg, 1997).

After the Revolution and into the nascent 19th century the use of substances to hasten death was evidently practiced, though not widespread. Battin, discussing the "synchronicity" of the deaths of Jefferson and Adams on Independence Day, 1826, points to personal correspondence both had with others indicating that the use of medicine to hasten death, while proscribed by religious authority and culture of the time, was undertaken by some physicians. Battin quotes a letter from Adams to fellow founding father Benjamin Rush, in which the former writes: "You Physicians are growing so familiar with Hemlock, and Arsenick, and Mercury Sublimate, and Laudanum, and Brandy and every Thing that used to frighten me, that I know not what you will do with us" (Battin, 2005). In an 1813 letter to Dr. Samuel Brown Jefferson wrote of the use of the Datura plant as a "suicide pill" for those looking to escape the fate of the guillotine during the French Revolution, musing that it could be used to end one's life if one were suffering from an untreatable ailment such as cancer (Battin, 2005).

The first state to criminalize a physician aiding in death was New York, which did so in 1828, followed by Washington State in 1854 (Blakey, 2021). However, concurrent to the burgeoning prohibition of PAD was the appearance of the earliest essays in the modern medical establishment that argued in favor of euthanasia in the 1870's (Pappas, 1996). According to Blakey, the tide began to change during this time, as there was interest in medicine in utilizing morphine to euthanize those in pain. Two successive bills introduced into the state legislature of Ohio, the first of which would have legalized euthanizing adult terminal patients, and the second legalizing euthanasia of both adult and pediatric patients with cognitive and physical disabilities were struck down in 1905 and 1906 (Blakey, 2017; Pope 2018). Similar bills effectively legalizing what now is referred to as PAD were rejected by the Iowa state legislature in 1906 and the Nebraska state legislature in 1937 (Pope, 2018). Due to negative association with Nazi war crimes–fairly or unfairly–aid in dying would leave the American public debate for a time after the Second World War (Pope, 2018).

3. *Washington v. Glucksberg*

The decades long interlude in social engagement with aid in dying–spurred by its perceived association with Nazism–would break before the turn of the century. In 1993 four physicians in conjunction with the organization Compassion in Dying sued the state of Washington in federal court, arguing that the right to privacy as protected by United States Constitution requires recognition of a basic right to physician-assisted suicide. The suit was formally titled *Compassion in Dying v. State of Washington*, and was decided in favor of the plaintiffs. Judge Stephen Reinhardt with the court of appeals wrote the opinion of the 7-4 majority. Within a short time, another appellate court struck down a similar law in New York in *Vacco v. Quill* (1996) (Chemerinsky, 2008). Both *Vacco* and *Compassion* were appealed to the U.S. Supreme Court, where the previous ruling of each was its unanimous decisions *Vacco v. Quill* and Washington v. Glucksberg (1997) (Chemerinsky, 2008). In those decisions the court found there was no constitutionally protected right to assisted dying.

Public debate over PAD long-preceded *Vacco* and *Glucksberg*, but the high profile of these Supreme Court decisions brought to light the leading advocacy groups both opposed to and in favor of PAD. The remainder of this chapter reviews the history of PAD legalization in the United States.

4. History of PAD Statutes

As of the composition of this thesis, 11 United States legal jurisdictions have legalized PAD (10 states and the District of Columbia). The most recent state to do so is New Mexico, through the "Elizabeth Whitefield End-of-Life Options Act", which was passed in 2019 and went into effect in June of 2021. In addition, Montana's Supreme Court has ruled that no law prohibiting PAD can be supported by the Montana constitution. Through this decision, titled *Baxter v. Montana*, terminally ill Montanans are eligible for aid in dying (Baxter v. Montana, 2009). Quill, Battin, & Pope state that these eleven jurisdictions have a population comprising around 20 percent of the American population (Quill, Battin, & Pope, 2021). All of these laws have attributes in common. First, they all require a patient to have a terminal diagnosis. Terminal diagnosis is interpreted by most of the states to mean the patient is expected to live six months or less. Diagnosis is made by a licensed physician and confirmed by at least one other physician. The patient must have decision-making capacity and be legally competent. The PAD request must be voluntary and not coerced or otherwise made under unfair duress. Second, there is also widespread support for the right of conscientious objection for providers, with the caveat that they refer the patient to a PAD-willing provider. Third, each jurisdiction has stipulations for patients' written and oral requests, though the number of requests varies, as does the mandatory sufficient wait time between each request. In addition, the majority of states have a mandatory waiting period of at least 48 hours between fulfillment of the requests and dispensing the medication for fulfillment of PAD treatment (Death with Dignity National Center, 2021).

As it is the oldest and most well documented, Oregon's Death with Dignity Act is the first to be discussed here.

5. Oregon's Death with Dignity Act

In 1994 Oregon voters passed Ballot Measure 16, colloquially called the "Death with Dignity Act" (DWDA) by a narrow margin of 51% to 49%. The act was met at its outset by a court injunction delaying the roll out for three years before its implementation in 1997. November of that same year Oregonians again voted to maintain the DWDA, defeating a ballot measure to overturn it (Oregon Health Authority, 2021).

The DWDA was the brainchild of five right-to-die pioneers, businessman Elven "Al" Sinnard, attorneys Eli Stutsman and Mark Trinchero, and healthcare professionals Dr. Peter Goodwin and Myriam Coppens (Hillyard & Dombrink, 2001; Stutsman, 2013). Goodwin especially cited his own experience witnessing the discomfort physicians had with discussing death with patients and relating the news to loved ones as a substantial impetus for his supporting PAD laws (Hillyard & Dombrink, 2001). This group of PAD advocates would go on to form "Oregon Right to Die", a political action committee (PAC), in 1993 (Stutsman, 2013). After its creation, Oregon Right to Die then filed a "citizen's initiative" with the state, putting Measure 16 on the ballot for the upcoming election (Stutsman, 2013).

Oregon's Death with Dignity Act has been in effect for 24 years. Robust data has been gathered describing the practice and the patients who opt for it. Blanke et al. (2017) found from 1998 to 2015, 1545 prescriptions for PAD were written, resulting in 991 completed deaths, amounting to 64%. A slight majority of these deaths were of men (approximately 51 percent). Median patient age was 71 years. Cancer (77%), Amyotrophic Lateral Sclerosis (8%), lung disease (4.5%), heart disease (2.6%) and HIV (0.9%) were the diseases most commonly prescribed PAD. Loss of autonomy was the most common justification, cited in 91.6 percent of cases (Blanke et al., 2017). The majority of patients were white, had insurance, and a college education. Median time to a comatose state was five minutes, and 25 minutes for death (Blanke et al., 2017).

PAD opponents point to the case of Kate Cheney as an example of abuse in the Oregon system. In 1999 Cheney was an 85 year old Portland resident. After experiencing abdominal distress which caused her to double over in pain during a visit to the hairdresser, she was diagnosed with an inoperable abdominal cancer. Kate's daughter Erika, a nurse, came to Portland to care for her. During this time Kate and Erika began to explore Kate's options with ending her life under the DWDA–though PAD opponents argue that the elderly Kate whose memory is unreliable was pressured by her daughter, who was coaching her through the medical visits and psychological evaluations in order to obtain the prescription that Erika ultimately wanted. Though the German immigrant Kate can crisply envision in her mind's eye the terrifying experience of living through the bombing of Dresden, "she struggles to describe her initial psychiatric evaluation, the one she needs to get a prescription to die” (Osler, 1999). After the pair attended initial consult with a physician at Kaiser Permanente physician, who Kate described as “dismissive”, a second physician prescribed psychological evaluation. The psychologist arrived at the elder Cheney’s home on May 31st. The psychologist’s report “found that Kate understood some things -- including that she was incurably ill and had weeks or months to live. But she didn't remember the details of her hospital stay in May or the names of her hospice nurses or her new doctor” (Osler, 1999). Though the psychologist wrote that the PAD request seemed to align with her values, they felt that Kate was not “‘explicitly pushing for this’” (Osler, 1999). Lastly, the psychologist argued Kate lacked decision-making capacity. Based on these findings, Kate was denied PAD medication.

Kate pushed for a second evaluation which was done in June. This interview was done solely with Kate, Erika was not present. In their evaluation, the psychologist described that "Mrs. Cheney was alert and oriented to person, place and generally to time." However, the psychologist noted Kate’s “‘choices may be influenced by her family's wishes and her daughter, Erika, may be somewhat coercive’” (Osler, 1999). Despite some evidence of outside influence, the psychologist wrote Kate retained “‘the capacity to weigh the differences and articulate her own values’” (Osler, 1999). During the test Kate correctly answered the name of the governor and the date of Erika's birthday, though she could not recollect her diagnosis date. After a lengthy deliberation on the conflicting results of the evaluations, Kate’s physician consulted with Dr. Robert Richardson, a clinical ethicist at Kaiser Permanente. Richardson met individually with Cheney, and “was convinced not only of her competency but also that she was acting on her own” (Osler, 1999). Kate was prescribed PAD medication on July 23. Though

Kate's condition initially improved to the point where she was comfortable and spending time with loved ones, she decided that her pain was unbearably by August, and on the 29th she ingested an applesauce and barbiturates mixture and died.

The Cheney case raises several issues which PAD prohibitionists argue demonstrate the potential for abuse inherent in the Oregon system. The first is the issue of influence. To the PAD opponent, the Cheney case is an example of an easily persuadable person who lacks decision-making capacity bent to the whims of their child. They argue Kate did not hold a genuine and consistent desire to die. Rather she was influenced by her daughter. Second, prohibitionists argue the case demonstrates a failure of safeguards. PAD supporters are quick to point to the safeguards in the system including psychological evaluations, requirements of multiple requests, and qualified witnesses. But PAD opponents argue the Cheney case strips these supposed safeguards bare and shows how truly ineffectual they are. Third, this case demonstrates an instance of healthcare "shopping" where the Cheney family searched for a provider who would give them the result they wished for.

However, PAD supporters have responded to these claims. In a letter to the editor published in the June 2006 issue of the American Journal of Psychiatry, Linda Ganzini outs herself as the psychologist who at first denied Cheney's PAD request. However, she did so not out of any concern that Cheney was being coerced. Rather, she recommended further psychological evaluation because of Cheney's "mild, potentially reversible cognitive deficits that interfered with her ability to understand her options" (Ganzini, 2006). According to Ganzini this second evaluation is necessary for determining how these cognitive deficits impacted Cheney's decision-making capacity. Ganzini quotes

Grisso and Appelbaum, who argue “A key element in attempting to maximize patient performance is delaying the final decision about their capacities…Repeat evaluations are often helpful in distinguishing between time limited and permanent impairments” (Ganzini, 2006; Grisso & Applebaum, 1998). Ganzini’s testimony at least diffuses the strength of the relevance of the influence argument to the Cheney case.

Battin argues that fully understanding the Cheney case might require more information regarding Kate’s condition. But, in Battin’s estimation, these cases often require information on the evaluators themselves. She writes:

> …but it is not obvious that what we always need is more information about the patient. After all, when two or more different clinicians give different findings, there will always be a disagreement to be explained-though in some cases, perhaps like that of Kate, explanation may involve a change in the patient's condition. Sometimes, however, what we need is not more information about the patient, but more about the physicians in question. What criteria are they using? How did they conduct their examination of Kate? And what political or ideological motives, conscious or subconscious, might be at play?
> (Battin, 2008)

Though the case of Kate Cheney has been used by PAD opponents as a case example demonstrating their claim of widespread abuse in the Oregon system, ultimately her case does not have the strength that opponents argue it does. First, Ganzini, the initial psychologist who performed the capacity analysis on Cheney was concerned her decision-making capacity might be temporarily fluid, that is present at times and decreased in others. As such she denied the initial request not because she felt Erika or others were influencing Kate, but rather to determine if Kate had a strong enough case for having decision-making capacity. Second, Battin argues that while further information about the patient is relevant to this case, so too is the information about the clinicians doing the capacity determinations. Differences in examination criteria, or particular ethical or political motives could explain the differing opinions. These arguments help counter the relevancy of linking the Cheney case to fears of widespread abuse in the Oregon statute and the other ten statutes which used it as a template.

6. Washington State

Washington State's "Chapter 70.245 RCW" also commonly called the "Death with Dignity Act" was passed by ballot initiate on November 4, 2008, and was implemented on March 5, 2009 (Washington State Department of Health, 2021). The most recent Death with Dignity Act Report, compiled by the Washington State Department of Health (WSDH) in July of 2019, details PAD statistics for the state from the legalization in 2009 to the end of the 2018 calendar year. During this timeframe there have been 1,668 Washington participants[3] in PAD. Of these participants, 1,622 successfully completed PAD (WSDH, 2019).

7. Vermont

Vermont was the first state to enact a PAD statute through its legislative body rather than by citizen ballot initiative (Tucker, 2014). Act 39, formally titled the "Patient Choice and Control at the End of Life Choices Act", was signed by Governor Peter Shumlin on May 20, 2013 (Tucker, 2014; Lewis, 2017). A report of the Vermont

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[3] A participant, as defined by the report is "someone to whom medication was dispensed…under the terms of the act." (WSDH, 2019)

Department of Health to the state legislature titled ‘Report Concerning Patient Choice at the End of Life” found 87 deaths that meet the criteria under Act 39 in the timespan of May 31, 2013, until June 30, 2019. The underlying condition which led to these patients seeking PAD is as follows:

1) 68 (78%) were due to cancer
2) 11 (13%) were due to ALS
3) 3 (3%) were due to neurodegenerative diseases
4) 5 (6%) were due to other causes

(Vermont Department of Health, 2020)

8. California

California became the fourth state to legalize PAD when the California state assembly enacted Assembly Bill 15, which was officially signed by Governor Jerry Brown on October 15, 2015 (Clodfelter & Adashi, 2016; California Legislative Information, 2015). The statute, officially titled, the ‘End of Life Option Act’ (ELOA) was implemented on June 9, 2016 (Harman & Magnus, 2017). The ELOA legalized PAD under the three following conditions: 1) patient must be expected to die in less than 6 months, 2) patient must not have a diagnosis of clinical depression, and 3) patient must have enough bodily function to be able to self-administer the medication necessary to complete PAD (Thyden, 2017). Moreover, the physician is obligated to refer the patient to a licensed mental health professional if they believe a psychological evaluation is necessary before prescribing PAD (Thyden, 2017).

The California Department of Public Health (CDPH) publishes yearly reports of the outcomes of the statute in the state, most recently being the 2020 calendar year report.

The 2020 report summarizes the findings of the previous years. In the span of time between June 9, 2016, and December 31, 2020, a reported 2,858 persons were prescribed PAD medication (CPDH, 2021). Out of the group of those prescribed a total of 1,816 (63.5%) were reported to have successfully completed PAD by their physician. The number of participants receiving palliative or hospice care was 1,587 (87.4%) (CPDH, 2021).

9. Colorado

The fifth state to legalize PAD was Colorado, which did so via a referendum in the 2016 election. Proposition 106, formally titled the "Colorado End of Life Options Act" passed with a "nearly 2-1 margin." (Kluger, 2020). The statute made it legal for "'eligible terminally ill individual with a prognosis of six months or less to request and self-administer medical aid-in-dying medication in order to voluntarily end his or her life'" (Colorado Department of Public Health and Environment, 2019; Kluger, 2020).

Mirroring California, the Colorado Department of Public Health and Environment (henceforth "CDPHE') publishes data summaries of PAD requests, prescriptions, and completions for each year since 2017. The most recent report both compiled the PAD statistics for the 2020 calendar year as well as a running total from 2017-2020. In this span of time, CDPHE reported 554 patients received prescriptions for PAD. Of those 554, 422 patients filled the prescription. CDPHE was made aware of 508 deaths related to patients who were given PAD prescriptions. The age demographics of the patients were as follows:

1) 4 patients were 18-34 (0.8%)
2) 4 patients were 35-44 (0.8%),

3) 36 patients were 45-54 (7%)
4) 96 patients were 55-64 (19%)
5) 153 patients were 65-74, (30%)
6) 130 patients were 75-84 (26%)
7) 85 patients (17%) were aged greater than 85 years old

CDPHE found that an even split between males and females seeking PAD, both at 254 (CDPHE, 2021). Lastly, CDPHE listed the data on the diagnoses for which PAD was prescribed. Dividing the patients by type of diagnosis reveals that 348 patients (62.8%) were diagnosed with malignant neoplasms (cancer), 98 patients (17.7%) were diagnosed with a progressive neurological disorder, 42 (7.6%) patients had a diagnosis of some form of cardiovascular disease, 34 were diagnosed with chronic lower respiratory diseases (6.1%). Cerebrovascular disease as well as interstitial lung disease were tied with five cases (0.9%). Four patients (0.7) suffered from kidney disease, and 18 (3.2%) were diagnosed with (other) (CDPHE, 2021).

10. District of Columbia

As it is not a state and is therefore governed by Congress, D.C.'s PAD legislation history is complex. The statute, officially D.C. Law 21-182 was titled the "Death with Dignity Act of 2016" (D.C. Health, 2021). The impetus for the law began in 2016, when D.C. councilmember Mary Che introduced a bill legalizing PAD. After its introduction the bill was sent to the D.C. Council's health committee, which reviewed it and then sent it forward to the full Council. The measure passed in two separate voting sessions, both ending with a 11-2 favorable vote. Passing by this majority ensured that the bill did not need the signature of Mayor Muriel Bowser to be implemented, nor could she veto it.

The law was immediately met by challenge from the federal government. First the U.S. House Oversight Committee endeavored to obstruct the implementation of the ordinance (Lauffer, Baker, & Seely, 2020). When that was ultimately unsuccessful, "Rep. Andy Harris (R-Maryland) led attempts to block the law through the House Appropriations Committee by refusing to approve the district's budget" (Lauffer, Baker, & Seely, 2020). Lauffer, Baker, and Seely remark that this move was done even though mayor Bowser had unequivocally stated that the law would not use federal or local taxpayer revenue for its implementation. D.C.'s PAD program was operational by 2017 (Lauffer, Baker, & Seely, 2017).

11. Hawai'i

Hawai'i is the sixth American state that legalized PAD. It did so on April 5, 2018, when the Governor, David Ige ratified bill HB2739 HD1, titled "Hawai'i Our Care Our Choice Act" (Connolly, Blanchette, & Oue, 2019; Hawai'i State Legislature, 2021). As specified by the 2020 report by the Department of Health of the State of Hawai'i, the bill requires that a patient seeking PAD be expected to die from their illness in six months or less.

Like other states described here, the Health Department of the state of Hawai'i has released reports which tabulate the number of PAD deaths and patient demographics for 2019 and 2020. In 2019 and 2020, 67 were prescribed PAD medications. Of these 50 died, with 40 successful completions of PAD and ten dying of their underlying diagnosis or other causes. For both years DDMP2 was the most common prescription, and DDMA the least prescribed (State of Hawai'i, 2020-2021).[4] The 2020 report lists a singular instance of a

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[4] According to Shavelson & Parrot, 2021 DDMP2 is the medical abbreviation or the drug cocktail of Digoxin 50 mg, Diazepam 1 gm, Morphine 15 gm, Propranolol 2 gm, and DDMA is the medical

"complication with ingesting DDMP2" (State of Hawai'i, 2021). The majority of patients suffered from cancer. There is an unknown consumption/death status for seven patients. The reports found a total of 27 Hawai'ian physicians wrote PAD prescriptions over the two-year span (State of Hawai'i, 2020-2021).

12. New Jersey

In 2019 New Jersey became the seventh state to legalize PAD when in April Governor Murphy signed bill No. 1504, officially titled the "Physician Aid in Dying for the Terminally Ill Act" (Nigro, 2021). The authority to prescribe PAD medications is relegated solely to an attending physician, defined by the 2019 Chief State Medical Examiner's report as "a physician who has primary responsibility for the care of the patient and treatment of a patient's terminal disease" (The Office of the Chief State Medical Examiner of New Jersey, 2019). New Jersey mandates that the written request be witnessed by two observers who can attest to the patient having decision-making capacity and that the request is made autonomously and uncoerced (The Office of the Chief State Medical Examiner of New Jersey, 2019). One of the observers must be neither a relative of the patient, a beneficiary of the patient's estate, affiliated with any treatment facility the patient is receiving care from, nor the patient's attending physician (The Office of the Chief State Medical Examiner of New Jersey, 2019).

Combining the 2019 and 2020 PAD Data Summary reports reveals the PAD statistics in New Jersey in the period between August 1st[5] 2019 through December 31st, 2020. These reports state 55 PAD cases were reported to the Office of the Chief State

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abbreviation for the cocktail of Digoxin 100 mg, Diazepam 1 gm, Morphine 15 gm, Amitriptyline 8 gm (Shaverson & Parrot, 2021). These medications work as either heavy sedatives or to suppress breathing.

[5] The day bill 1504 went into effect.

Medical Examiner (OCSME) (The Office of the Chief State Medical Examiner of New Jersey, 2019-2020).

13. Maine

The eighth state to pass PAD legislation was Maine. Maine's legislation was passed in 2018 and became operational on September 19, 2019 (Journal of Medical Regulation, 2019). The bill was introduced by Maine Representative Patricia Hymanson and passed by the narrow margin of 73-72 in the state House of Representatives and by 19 to 16 in the Senate. H.P. 948, or 'An Act To Enact the Maine Death with Dignity Act' was signed by Governor Janet Mills on June 12, 2019 (Death with Dignity National Center, 2021; Maine Legislature, 2019).

Similar to New Jersey, Maine mandates that a "qualified witness" observe the whole process comprises an additional safeguard. Second, to vouchsafe the rights of providers, the bill prohibits basing a complaint against a provider solely on the fact that a provider practices PAD (Journal of Medical Regulation, 2019). A complaint can, however, be based on a provider improperly administering PAD (Journal of Medical Regulation, 2019).

Maine Department of Health and Human Services compiles the state's PAD data under the "Patient-Directed Care at End of Life Annual Report." The statistics for the period between the September legalization and December 31st, 2019 report one PAD death in this period. The patient was a Maine resident diagnosed with prostate cancer. The patient completed PAD through the "self-administrat[ion]" of a combination of "digoxin, diazepam, morphine sulfate, and amitriptyline" (MDHHS, 2020). The patient's age was >65 and they had a college degree (MDHHS, 2020).

9. New Mexico

The ninth and final state to legalize PAD was New Mexico, which did so through the aforementioned "Elizabeth Whitefield End-of-Life Options Act." The statute was signed by Governor Michelle Lujan Grisham, on June 8th, 2021. The namesake and inspiration for the bill Elizabeth Whitefield, was a judge who was diagnosed with cancer and became a proponent of aid in dying for both herself and others (Attanasio, 2021). As the Elizabeth Whitefield Act is only in the nascent stages, there is no available data on PAD statistics at the time of the composition of this thesis.

14. Montana

Since Montana's judicial decision authorizing PAD is unique, this section will depart from our timeline to explicate the 2009 court case of Baxter v. Montana. Baxter was heard by the Montana Supreme Court after the appeal of a lower court's decision to the Supreme Court concerning a PAD request made by one Robert Baxter. Baxter was "retired truck driver from Billings who was terminally ill with lymphocytic leukemia with diffuse lymphadenopathy" who at the time of the appeal was undergoing chemotherapy (Baxter v. Montana, 2009). The chemotherapy was expected to be less efficacious as his treatment prolonged (Baxter v. Montana, 2009). The cancer caused the patient much physical and emotional pain. As a result, Baxter sought a PAD prescription (Baxter v. Montana, 2009).

A suit was brought by Baxter as well as the pro-PAD advocacy group "Compassion and Choices."[6] The plaintiffs argued that the application of the Montana homicide statute

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[6] See the next section for an in-depth discussion on this and other PAD advocacy and anti-legalization groups.

to physicians assisting their patients to die was unconstitutiona1, stating their case that "that patients have a right to die with dignity under the Montana Constitution Article II, Sections 4 and 10, which address individual dignity and privacy" (Baxter v. Montana, 2009). The state of Montana appealed. In an odd turn of jurisprudence, the Montana Supreme Court legalized PAD without necessarily agreeing with Baxter, finding that nothing in the Montana Constitution outlawed PAD, as well as arguing that prosecuting Montana physicians for PAD was unconstitutional (Baxter v. Montana, 2009). Thus, PAD was effectively legalized by jurisprudence, and not through a legislative act as with the other states discussed here.

According to Robinson (2010), the majority opinion of Baxter rests on the notion of patient consent being an exculpatory factor for any physician who practices PAD. The patient gave informed consent; therefore, the act does not violate the homicide statute. There is a clause in the Constitution of Montana arguing that the so called "consent defense" is constrained by a "public policy" argument, wherein the act initially justified by individuals' consent is proscribed because it violates the good of the public. Justice Leaphart–who delivered the majority opinion–argued that a physician prescribing and a patient peaceably consuming a PAD medication was not comparable to violence. (Robinson, 2010). According to Tucker (2020) the several attempts to overturn Baxter have been unsuccessful (Tucker, 2020).

Because it was not legalized via a legislative statute, there was no regulatory framework put in place for PAD statistics (Tucker, 2020). Tucker cites a YouTube video with a Montanan physician discussing PAD as evidence that PAD is practiced, though she remarks, “Even so, it seems that clinicians consider the practice to be ‘in the closet,’ despite the Baxter decision” (Tucker, 2020).

15. Conclusion

Physician Aid in Dying is now a legal option for one-fifth of the American public. The route to the current reality was begun by the pioneering work of the Oregon Right to Die PAC. Oregon’s DWDA modeled the framework which was adopted by other groups and eventually passed in the other 9 jurisdictions. Montana also legalized PAD through jurisprudential decision-making, though as a result it does not record and publish its PAD data for analysis. For the early adopting states of Oregon and Washington enough time has elapsed that we can analyze specifics about the demographics of patients. For instance, in Oregon we know that the majority of the patients who died were middle class white males with health insurance. However, the more recent data is incomplete and spotty in places, so additional investigation is needed. One fruitful area of inquiry is providers attitudes on PAD. For that purpose, it helps to supplement descriptive counts with more in-depth qualitative interviews, which this thesis introduces in later chapters. Before doing so, however, we examine in more detail the various interest groups that have supported or opposed PAD, and the reasons for their positions.

II. Pro and Anti-PAD Advocacy Organizations & Main Arguments

1. Introduction

The evolution of PAD into a legal medical option for terminal patients was influenced by advocacy organizations striving to push PAD into the public consciousness, crafting PAD statutes, publishing literature on the topic, organizing conferences where advocates met and presented information on the current legal challenges to PAD, and lobbying law-making bodies. PAD has also been contested by organizations that for various reasons desire PAD to remain prohibited, seek to rollback its legalization, and warn against its expansion, particularly for non-terminal persons with disabilities. This chapter will first present an overview of the large pro- and anti- PAD advocacy organizations, both historical and those still active. Second, the chapter will provide examples arguments pro and anti-PAD organizations employ. Lastly, the chapter will review various medical professional organization's opinions on PAD.

2. Pro PAD Advocacy Groups

a. Euthanasia Society of America & The SRD/CFD Split

On January 16, 1938, the National Society for the Legalization of Euthanasia (NSLE) was formed by Charles Francis Potter. The organization initially had 200 members in its roster (Pyle, 2015). It was soon renamed the Euthanasia Society of America (ESA). Potter had left his position as a Unitarian minister as well as his faith, and soon after founded the Humanist Society of New York (Dowbiggen, 2003). Dowbiggen describes Potter as:

> …an excellent example of the kind of person attracted to the euthanasia crusade in its early years. He was a tireless opponent of traditional religious doctrine and

> many of the inherited moral values that dominated American society and culture, as well as an advocate of eugenics, social Darwinism, and the mercy killing of severely handicapped inmates of state institutions. (Dowbiggen, 2003)

The growth of the ESA was hampered in post-war America due to two factors. The first was its defense of involuntary killing of persons with disabilities and those with mental illness, which had fallen out of favor due to the aforementioned association with Nazism (Cheyfitz, 1999; Pyle, 2015). Second was a statement issued by the AMA in 1950 condemning PAD (Pyle, 2015).

During the 1960's the group pivoted in two distinct ways. First it shifted to focus solely on "passive euthanasia", especially highlighting the right of autonomous patients to refuse life-sustaining treatment (LST). This put it in greater concert with the Catholic doctrine of allowing patients to forgo care deemed "extraordinary." Second, the ESA sidelined legislative aspirations, deferring to a strategy of focusing "on education, research, and a public dialogue to work through the ethical questions of the right to die" (Pyle, 2015). By 1974 the ESA split in two different organizations and was formally dissolved. One of the daughter organizations called itself Society for the Right to Die (SRD) and was headed by theologian and bioethics pioneer Joseph Fletcher. The SRD faction split from the ERA over the issue of active euthanasia. While the ESA was appealing to the aforementioned right to refuse LST and a patient right to passive euthanasia, Fletcher's SRD was adamantly supporting legal changes in favor of active euthanasia (Pyle, 2015).

The other daughter organization to come out of the former ERA was initially called the Euthanasia Educational Council (EEC), later re-christened Concern for Dying

(CFD) in 1978 (Pyle, 2015). According to Pyle, the CFD "focused on increasing end-of-life care and improving communication between patients, their families, and their health care providers" (Pyle, 2015). While initially cooperative, the reticence of CFD to embrace enthusiastic lobbying for active euthanasia would cause the groups to separate ties with one another by 1979 (Pyle, 2015). By the late 1980's SRD would go on to be dwarfed by the popular Hemlock Society. SRD ceased advocacy operations in 1990, with "its agenda picked up by the Hemlock Society" (Pyle, 2015).

b. Hemlock Society

The Hemlock Society was a PAD advocacy group formed in 1980 by British PAD activist Derek Humphry who was living in Santa Monica, California. Its original location was Humphry's garage. Five years previous to founding the organization, Humphry had assisted the suicide of his first wife Jean, who was diagnosed breast cancer and given a terminal prognosis. (Childress, 2012; Pyle, 2015). According to Childress (2012), the "mission" of the Society "is to help terminally ill people die peacefully, and advocate for laws backing physician-assisted suicide" (Childress, 2012). Henretta (2000) reports that at the turn of the century the Society had 80 chapters and 25,000 members. The Hemlock Society's Humphry published several books including *Let Me Die Before I Wake* (1984) and *Final Exit* (1991) (Barry, 1986; Childress, 2012). The latter is a how-to manual for patients to end their lives on their own. Humphry insists that his book's singular purpose is informing terminal patients who wish to end their lives how to do so in a manner as painlessly as possible, but critics charge it encourages suicidal but otherwise healthy persons to end their lives (Barry, 1986). After publishing these books, Humphry formally retired from the Society in 1992 (Pyle, 2015). But the Society continued to advance its goals even after the departure of its founder, as it was instrumental in the drafting, lobbying, and passing of the Oregon statute (Pyle, 2015).

According to Pyle, because the Hemlock Society advocated for both active euthanasia and PAD, it forced the SRD and CFD to take a stance on these issues in the latter organizations waning years (Pyle, 2015). The Hemlock Society would later take on controversy for its promotion of the infamous Jack Kevorkian and for the fact that Susan Adkins, a patient to whom Kevorkian administered PAD, was a Hemlock Society member (Pyle, 2015). By 2003 the group rebranded as End-of-Life choices (Childress, 2012).

c. Compassion & Choices

The largest still active pro-PAD organization is Compassion & Choices. Compassion & Choices was borne out of the 2005 merger of Compassion in Dying, one of the plaintiffs in Glucksberg, and another pro-PAD advocacy organization End-of-Life Choices, the organization that superseded the Hemlock Society (White, 2005). Compassion & Choice’s website lists its main goals as follows:

- Educate the public about the importance of documenting end-of-life values and priorities and about the full range of available options.
- Empower every individual with achievable options, authoritative information, and constructive advice for guiding their care and engaging with their providers.
- Advocate for expanded choices, secure and ready access to them and improved medical practice that puts patients first and values quality of life in treatment plans for terminal illness.

- Defend existing end-of-life options from efforts to restrict access.

(Compassion & Choices, 2021).

d. Death With Dignity National Center

The Death With Dignity National Center (hereafter the DWDNC) is a pro-PAD organization which has been involved with the PAD debate since the outset. DWDNC was formed by the 1994 merger of Oregon Death with Dignity Legal Defense and Education Center ("ODLDEC")–the advocacy organization, which was formed by Stutsman, Trinchero, Dr. Goodwin, and Coppens–with California based Death with Dignity National Center. After the merger the combined organizations opened its new headquarters in Portland, Oregon (Death with Dignity National Center, 2021). DWDNC was the main architect of the framework of the Oregon statute (Simmons, 2018; Death with Dignity National Center, 2021). DWDNC's funding comes from the Death With Dignity Political Fund, described on the DWDNC's page as "501(c)(4) nonprofit organization that acts as the political arm of the National Center" (Death with Dignity National Center, 2021). Many of the values listed on the site as those espoused by the organization are archetypal of the sorts of kinds put forward to defend PAD. Those which are quintessentially part of the PAD defense include: Dignity, Freedom and Autonomy, as well as Trust. Some unique values which are peripherally associated with PAD defense include: Financial Stability, Moral Courage, and finally, Diversity, Equity, and Inclusion (Death with Dignity National Center, 2021). Alongside being the main drafter of the Oregon statute, DWDNC was involved in the advocacy and drafting of the Washington State, Vermont, California, District of Columbia, and Maine legislations (Death with Dignity National Center, 2021).

The preceding sections trace the history of the largest pro aid in dying organizations. What would become the aid in dying advocacy movement started with the development of pro-euthanasia organizations during the early 20th century, a time when organized science embraced eugenics, class and race based sterilizations, and biological race categories/hierarchies. The original aid in dying advocacy organizations embraced this worldview until the midpoint of the century, when the widespread condemnation of Nazi war crimes and the growing civil rights movement made such policies publicly unpopular. Following the emergence of the era of informed consent and patient rights, many euthanasia organizations gave ground on their previous fervency on active euthanasia, pivoting to a strategy of safeguarding a competent patient's legal right to refuse care. This pivot was made possible by the legal cases of Quinlan, Bouvia, and Cruzan, which were instrumental in developing both the right for surrogate decision-making on behalf of a patient lacking decision-making capacity, as well as the right to refuse life sustaining treatment and the right to voluntarily stop eating and drinking (VSED). During this time two physicians took center stage for their aiding death. In 1991 Timothy Quill publicly declared he had aided the death of a terminally ill cancer patient.[7] The second such case was of that of the aforementioned retired pathologist Jack Kevorkian, who claimed to have assisted in as many as 180 deaths. Kevorkian was later was imprisoned for murder, practicing medicine without a license, and unlawfully delivering a controlled substance when he directly administered aid in dying medication to ALS patient Thomas Youk, a videotape of which aired on the CBS television program 60 minutes (Schneider, 2011). By

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[7] See Quill (1991)

the early 1990’s work was being done to craft the Oregon statue, which was enacted by 1997. Oregon statute was an influence on those which followed in the other 10 jurisdictions.

The next sections of this essay discuss the anti-PAD advocacy groups. While these groups have different justifications for opposing PAD, they often employ similar arguments such as the disability critique, slippery slope concerns, and fears over coercion and decreases in funding for patients with disabilities who opt for continued care instead of PAD.

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3. Anti-PAD Groups

a. Not Dead Yet

Not Dead Yet (NDY)is a New York State based organization comprised of persons with disabilities and their advocates who oppose PAD legalization and expansion on the grounds it will harm persons with disabilities. It was founded by Diane Coleman (Conolly, 2005). Its members view “assisted suicide and euthanasia” as “deadly forms of discrimination against old, ill and disabled people” (Not Dead Yet, 2021). NDY gained public notoriety for being instrumental in staging protests during the legal battle over the removal of Terri Schiavo’s feeding tube. Many associated with the organization argued that rather than a person in a vegetative state with a hopeless prognosis, Terri was a person with a disability who was still entitled to care (Conolly, 2005). These disability rights PAD opponents use several arguments to defend their position. First, they view any attempt to define terminality as subjective and therefore arbitrary. Second, the Oregon data pointing towards loss of autonomy and dignity as well as burdensomeness as the main justifications of PAD are seen not as complaints about the pain involved in late terminal illness but rather concerns affecting persons with disabilities. Third, they argue that living a disabled life is dignified, and that persons with disabilities “don’t need to die to have dignity” (Not Dead Yet, 2021). Other concerns relate to economic pressures such as the concern that, if PAD were legal, this could result in the denial of insurance funding or denial of care for patients with disabilities who decide to continue to live. Lastly there is concern over poorly constructed safeguards:

> The Oregon law grants civil and criminal immunity to physicians providing lethal prescriptions based on a stated claim of “good faith” belief that the person was terminal and acting voluntarily. This is the lowest culpability standard possible, even below that of “negligence,” which is the minimum standard theoretically governing other physician duties. The Oregon Health Division does not investigate the reports filed by doctors who issue lethal prescriptions
>
> (Not Dead Yet, 2021).

It appears, though, that even if the organization thought there were well placed safeguards in Oregon and the subsequent states that have legalized PAD, that still would not justify legalization in their eyes. A British Affiliate, Not Dead Yet U.K. (NDYUK) was founded in 2002 by Baroness Jane Campbell, herself a person with a disability, and a person who had “direct personal as well as professional experience of the issues” (Not Dead Yet U.K., 2021). NDYUK lists its purpose as “responding to an increasing number of well-coordinated campaigns aimed at legitimising the killing of terminally ill and persons with disabilities, which would inevitably result from the removal of legal barriers and the promotion of social acceptance of voluntary euthanasia and assisted suicide" (Not Dead Yet U.K., 2021).

b. National Right to Life Committee

While the National Right to Life Committee's (NRLC) primary notoriety is in its opposition towards abortion legalization after the Roe v. Wade decision, it is also the largest Christian organization to oppose PAD. NRLC was founded in 1968 by the National Conference of Catholic Bishops (NCCB), and currently has 3,000 local chapters in all 50 states (NRLC, 2021; Karrer, 2011). In 1967 the NCCB appointed James McHugh to an administrative role in the future organization. Though it had Catholic origins, McHugh believed the pro-life "movement was larger than one religious group" and thus strived to make the fledgling organization "as ecumenical as possible" (Karrer, 2011).

The NRLC's website lists its arguments against PAD. First, it cites that most persons who commit suicide are depressed and can be treated with mental illness (NRLC, 2021). This equating of PAD with mental health suicide is specious, as few advocates who support PAD would support it for solely mental health issues such as depression.[8] But, even when focusing solely on terminal patients, the NRLC reiterates that most aid in dying requests come from depression, and that this can be treated with adequate mental health care (NRLC, 2021). They also invoke the argument that adequate palliative care can lead to a patient retracting a PAD request (NRLC, 2021). The same argument is

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[8] There has been bioethical debate on the topic of Physician Aid in Dying prescribed for chronic depression. See Schuklenk & Vathorst (2015) for a defense of such a practice. While the open debate on this subject might seem to support NRLC's position, those who support expansion of Physician Aid in Dying support it for those who have had a diagnosis of depression for an extended time which has resisted all previous treatments.

levied for the case of patients with “uncontrollable pain.” Lastly, the site lists as objections to legalizing the practice a form of the disability objection, as well as a final slippery slope argument that PAD will lead to involuntary euthanasia (NRLC, 2021).

4. Archetypal Arguments Utilized by Anti and Pro-PAD Activists

Table 1 lists common arguments used by PAD supporters. Table 2 lists common arguments used by opponents.[9] An example found in the literature or published by an advocacy or professional group is provided.

Supporting Arguments
The Argument from Autonomy: “Under the principle of autonomy or self-determination, people are entitled to be the architects of the very end of their lives; this liberty- right includes dying in a way that is in accord with one's own values and interests-provided, of course, that the harm principle is satisfied and that this does not constitute a serious harm to others.” (Battin, 2008)
The Argument from Suffering/Mercy: “The principle of mercy is typically less clearly phrased, but plays an equally important role. It holds that pain and suffering are to be relieved to the extent possible, provided taking such action does not serve some further purpose in the treatment of disease, play a role in religious or other value-commitments of the person, or worsen the state of affairs for an individual.” (Battin, 2008)
The Argument from Consistency: To begin with a familiar type of situation, a patient who is dying of incurable cancer of the throat is in terrible pain, which can no longer be satisfactorily alleviated. He is certain to die within a few days, even if present treatment is continued, but he does not want to go on living for those

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[9] Arguments taken from Moskop (2016).

days since the pain is unbearable. So he asks the doctor for an end to it, and his family joins in the request. Suppose the doctor agrees to withhold treatment, as the conventional doctrine says he may. The justification for his doing so is that the patient is in terrible agony, and since he is going to die anyway, it would be wrong to pro- long his suffering needlessly. But now notice this. If one simply withholds treatment, it may take the patient longer to die, and so he may suffer more than he would if more direct action were taken and a lethal injection given. This fact provides strong reason for thinking that, once the initial decision not to prolong his agony has been made, active euthanasia is actually preferable to passive euthanasia, rather than the reverse… (Rachels, 1975)

Table 1.

Opposing Arguments
The Argument from Theology: “As Catholic leaders and moral teachers, we believe that life is the most basic gift of a loving God--a gift over which we have stewardship but not absolute dominion. Our tradition, declaring a moral obligation to care for our own life and health and to seek such care from others, recognizes that we are not morally obligated to use all available medical procedures in every set of circumstances. But that tradition clearly and strongly affirms that as a responsible steward of life one must never directly intend to cause one's own death, or the death of an innocent victim, by action or omission.” (United States Conference of Catholic Bishops, 1991)
The Argument from Abuse: “…the State has an interest in protecting vulnerable groups- including the poor, the elderly, and disabled persons-from abuse, neglect, and mistakes. The Court of Appeals [Ninth Circuit] dismissed the State's concern that disadvantaged persons might be pressured into physician-assisted suicide as ludicrous on its **face....** We have recognized, however, the real risk of subtle coercion and undue influence in end of life situations." (U.S. Supreme Court, joint opinion in Washington v. Glucksberg and Vacco v. Quill, 1997; Battin, 2008)

The Argument from Medical Integrity:

> "It is the policy of the AMA that: (1) Physician assisted suicide is fundamentally inconsistent with the physician's professional role…"
> (AMA Policy on Physician Assisted Suicide H-140.952, 2019)

Table 2.

5. Medical Professional Organizations And PAD

Medical professional organizations have varied attitudes about PAD legalization and expansion. The American Medical Association (AMA) proscribes its members from participating in PAD. Chapter 5 section 7 of the AMA Code of Medical ethics states "Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks" (AMA Code of Medical Ethics, 2017). It continues:

> Instead of engaging in assisted suicide, physicians must aggressively respond to the needs of patients at the end of life. Physicians:
>
> (a) Should not abandon a patient once it is determined that cure is impossible.
>
> (b) Must respect patient autonomy.
>
> (c) Must provide good communication and emotional support.
>
> (d) Must provide appropriate comfort care and adequate pain control.
>
> (AMA Code of Medical Ethics, 2017)

In 2019 the AMA's Council on Ethical and Judicial Affairs (CEJA) was asked by the AMA's House of Delegates to study the issue of PAD in order to respond to calls to modify 5.7 in order to endorse physicians participating in PAD where legalized. After a "extensive review of relevant philosophical and empirical literature" as well as "thoughtful input from numerous individuals and organizations", the CEJA ultimately recommended 5.7 not be modified (AMA CEJA, 2019). While the report recommended not to amend 5.7, it was not biased towards PAD opposition. Rather, it recognized:

> While supporters and opponents of physician-assisted suicide share a common commitment to "compassion and respect for human dignity and rights" (AMA Principles of Medical Ethics, I), they draw different moral conclusions from the underlying principle they share. Where one physician understands providing the means to hasten death to be an abrogation of the physician's fundamental role as healer that forecloses any possibility of offering care that respects dignity, another in equally good faith understands supporting a patient's request for aid in hastening a foreseen death to be an expression of care and compassion. (AMA CEJA, 2019).

Similar to the AMA, as of 2019 the American Nursing Association holds a prohibition against its members engaging in PAD. Further, it states that greater research is needed to "examin[e] the degree to which palliative care reduces the requests for euthanasia or assisted suicide (ANA, 2013; Hamric et al., 2018). The American Academy of Hospice and Palliative Medicine (AAHPM) stresses that medical treatment, especially that which utilizes "excellent palliative care" can obviate many requests for PAD. However, the policy has a corollary statement which states that "[o]n occasion, however, severe suffering persists; in such a circumstance a patient may ask his physician for assistance in ending his life by providing physician-assisted death (PAD)" (Compassion & Choices, 2021) Thus, the AAHPM maintains a "a position of 'studied neutrality' on the subject of whether PAD should be legally regulated or prohibited, believing its members should instead continue to strive to find the proper response to those patients whose suffering becomes intolerable despite the best possible palliative care" (Compassion & Choices, 2021). Similarly, the American Academy of Family Physicians (AAFP) maintains "engaged neutrality" on the subject (Compassion & Choices, 2021). In 2018 the American Academy of Neurology (AAN) adopted its resolution which:

> …decided to retire its 1998 position on "Assisted suicide, euthanasia, and the neurologist" and to leave the decision of whether to practice or not to practice LPHD[10] to the conscientious judgment of its members acting on behalf of their patients. The Ethics, Law and Humanities Committee and the AAN make no attempt to influence an individual member's conscience in consideration of participation or nonparticipation in LPHD" (Compassion & Choices, 2021).

Lastly, in 2008 the American Public Health Association (APHA) endorsed a position which "Supports allowing a mentally competent, terminally ill adult to obtain a prescription for medication that the person could self-administer to control the time, place and manner of his or her impending death, where safeguards equivalent to those in the Oregon DDA are in place" (Compassion & Choices, 2021).

6. Conclusion

Physician Aid in Dying has been part of the historical narrative of the medico-professional, legal, and bioethical tapestry of America. Its history reaches from the Founding Fathers, the Supreme Court's decision in *Washington v. Glucksberg* and *Vacco v. Quill*, to the first PAD statute in Oregon. PAD advocacy, disability rights critics of PAD, medical professional organizations, and religious organizations have all contributed to this ongoing debate. Pro-PAD organizations appeal to patient autonomy, decreasing

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[10] Lawful Physician-Hastened Death

suffering, and to consistency in offering PAD alongside currently accepted end-of-life medical treatments such as VSED and refusal of life-sustaining treatment. Anti-PAD organizations appeal to the theological argument, the potential for abuse, and the possibility professional integrity would be compromised by participating in PAD. Today millions of people live in jurisdictions where PAD is offered as a way to control one's ending. Because end of life decision-making holds such high stakes for many people, it is important to understand how history unfolded to bring us to our contemporary position in the PAD debate, and to identify that key advocacy organizations that have been integral to PAD's legalization in United States jurisdictions. Chapters 4 and 5 of this thesis will discuss in greater detail the palliative care objection and the disability critique of PAD, two forceful arguments used by PAD opponents.

III. PAD in North Carolina: Legal Status and Clinician & Clinical Ethicist Attitudes

1. Introduction

The subject of North Carolina physician and clinical ethicist attitudes on aid in dying is a heretofore under-analyzed topic in the literature. Thus, whether the majority of clinicians and ethicists in the state support prohibition or legalization of PAD is unknown (Carbone et al., 2019). Unlike states that have either legalized PAD or categorically criminalize a medical professional aiding suicide, North Carolina does not have a statute on the practice (Carbone et al., 2019, Tucker, 2019). However, the right to other end-of-life care measures is supported in North Carolina, such as withdrawal of life sustaining treatment, VSED, and palliative sedation (Carbone et al., 2019). This chapter begins by discussing the history of legal cases that established the PAD prohibition precedent in North Carolina. The remainder of the chapter will describe and discuss the independent research undertaken to identify North Carolina clinician attitudes on PAD.

2. History of PAD in North Carolina

The 1987 case of *State v. Forrest* impacts the legal status of aid in dying in North Carolina. *Forrest* concerned the death of Clyde Forrest, an 83-year-old man who was a patient at Moore Memorial Hospital in Pinehurst. Forrest had previously been suffered a heart attack and presented at the hospital with “severe heart disease, hypertension, calcification of his heart valves, a thorac [sp?] aneurism, pulmonary emboli, and a peptic ulcer” (Brooks, 1988). At the hospital Forrest was accompanied by his son, John. By the next day Clyde’s prognosis was looking bleak. Expected to expire in the near future, the physicians transferred Clyde to comfort care. Over the next few hours John expressed his resolute belief that his father was dying, despite the medical staff indicating evidence to the contrary. John became so distraught that on Christmas Eve day he smuggled a pistol into the hospital and fired four rounds into his father's head, after which he dropped the weapon and surrendered peacefully to authorities. At his trial the jury found John guilty of first degree murder, and accordingly sentenced him to life imprisonment. His appeal made its way to the Supreme Court, which upheld the ruling of the lower court (Brooks, 1988). According to Tucker (2019), the ruling in *Forrest* does not preclude PAD. This is because the actions of John Forrest constitute an instance of euthanasia, not aid in dying:

> Euthanasia can remove the patient's autonomy in his or her end-of-life decisions; even if the patient in *Forrest* had previously communicated to his son his wish for death in such a situation, the patient could not communicate at the time the son acted, foreclosing any opportunity to change his mind. This sort of concern is not found with AID, as the patient must have capacity and controls the process every step of the way (Tucker, 2019).

Tucker argues North Carolina should follow the example of Montana and legalize aid in dying through the courts. Replicating the system in Montana, where "…physicians providing care to mentally competent, terminally ill patients can provide AID, subject to the standard of care, without exposing themselves to viable criminal or disciplinary action" is, according to Tucker, the preferred model because it would "more closely resemble how all of medicine is practiced, offering benefits to patients and physicians" (Tucker, 2019).

Although the Forrest decision appears to foreclose any such move by North Carolina courts, it does not bar the legislature from legalizing PAD. Accordingly, several

North Carolina lawmakers have proposed PAD statutes. Bills in 2015 and 2017 were introduced by Democratic lawmakers in the North Carolina, but neither passed (Tucker, 2019). The possibility that similar legislation might arise in the future prompted the inquiry undertaken in this chapter, to learn more about views on PAD by North Carolina medical professionals. Knowing more about these attitudes can help to determine whether PAD legislation is feasible in North Carolina, and what concerns might either deter such legislation or need to be addressed in how such legislation is drafted and debated.

3. Methods

The purpose of this pilot study was to shed some, albeit limited, light on North Carolina medical professional's opinions on PAD. The study's format was simply to interview each of the 5 Wake Forest Baptist or Atrium clinicians and clinical ethicists who agreed to participate. The interview was hosted on Zoom, and recordings were later analyzed for content. The project was approved by the Reynolda campus IRB, under Prof. Hall's supervision. The questions were derived from Lee et al. (2009) and Ditommaso, Kirshenbaum, & Parent (2018) with author permission as well as three original questions.

The first four questions are listed in table 1:

#1	What is your medical occupation/specialty?
#2	For how long have you been practicing medicine?
#3	In your work do you care for dying patients?
#4	Have you received a request from a patient for assistance in dying, either through direct medical action, (commonly called "euthanasia") or through prescribing a medication the patient self-

	administers (commonly called physician aid in dying)?

Table 1.

In cases of an affirmative answer to question #4, I engaged in further prompting, asking at what stage of their career the clinician was, and asked them to describe the encounter and what their response was.

Questions 5-8 asked the patient to agree/disagree with the following statements, shown in Table 2:

#5	I would be prepared to prescribe and administer a fatal drug to a terminally ill patient who was suffering unbearably, were that course of action to become legal in the future.
#6	If a patient with capacity to make major medical decisions has an incurable painful illness from which they will die within 6 months, doctors should have the legal right to hasten that patient's end of life if that is what the patient desires.
#7	Physician Aid in Dying (PAD) is ethically justifiable if a suffering competent patient explicitly and repeatedly expresses a wish to be allowed to die.
#8	PAD is a valuable option within the general framework within palliative-care treatment

Table 2.

Lastly, original questions were posed, shown in table 3:

#9	In your work have you advocated for the legalization or prohibition of physician aid in dying in North Carolina?
#10	Would you support a PAD statute if it were to be introduced into the North Carolina state legislature, added as a resolution to a North Carolina election, or debated in the North Carolina Supreme Court?

Table 3.

4. Results

Five medical professionals were interviewed. Three of the professionals practiced in the hospice/palliative care subspecialty. The remaining two were clinical ethicists, one of whom also was a clinician. Average time practicing medicine was 13 years, with the longest being 23 years and the shortest being eight years. All subjects responded that they were involved with the care of dying patients, or in the case of the non-clinician ethicist, working in, as the subject described it, the "ancillary care of dying patients from time to time." All of the clinicians had received PAD requests, and the non-clinician ethicist has been involved with consults where the patient has "either hinted or have expressed a willingness for someone to help them [to die]."

Responses to questions 5-8 are listed in Table 4:

	Agree	**Disagree**
#5	2 (40%)	3 (60%)
#6	4 (80%)	1 (20 %)
#7	4 (80%)	1 (20%)
#8	4 (80)	1 (20%)

Table 4.

None of the subjects have professionally advocated for PAD prohibition or legalization in North Carolina and the passage of a PAD statute. Four subjects supported passage of a PAD statute in North Carolina (80%). One of the two ethicists was opposed (20 %).

5. Discussion

While the small sample size makes it difficult to draw conclusions, this pilot study did successfully obtain responses from both perspectives of the PAD debate. It was interesting that the oppositional view and the view embracing PAD were each expressed by clinical ethics. Also of interest, subject 3 initially answered question #5 as disagree, though immediately followed up their response by stating, "*we have not had that included in our training.*" When the researcher prompted whether the subject would agree if the proper training was integrated into palliative care training, they stated, "*I personally would be willing to do it if I had additional training, you know, on the medications that are used…the protocols, that sort of thing.*" When further probed as to whether the patient had moral disagreement to the scenario presented by 5, they answered in the negative, and further stated*, "right, so you wouldn't ask me to take your appendix out, right? You would want me to have more training. It is a procedure in my mind. So, I would want to do that first before I just jump in!"*

The data gathered from this pilot study provides evidence from at least a small group of North Carolina palliative care physicians that there is support for, or at least not opposition to, the legalization of PAD. Whether the state trend follows the national trend cited by Carbone et al., namely being "increasingly supported by the medical community", is unknown, but this pilot study provides groundwork for a further study that could uncover how broadly these views are held based on state-wide data. The study shows that clinical ethicists are consulted in cases of PAD requests. This is hardly a novel insight, but it lends credence to the idea that these groups are stakeholders in any future debate over passage of a PAD statute in North Carolina. While a large majority

(80%) supported the legalization of PAD for terminal patients with decision-making capacity, only a minority felt comfortable with providing the treatment in their practice. In their professional capacity, none of these subjects had formally advocated for change in the law. In partial response to this, of the ethicists noted a mentor had told them that they should wait to get a foothold in their professional career, and when they had sufficiently matured, they could endorse policies that are more controversial.

One of the clinical ethicists pointed out distinctions not touched on by the questions. First, regarding question 6, the subject thought it morally salient to distinguish between euthanasia and assisted dying. The subject's upholding a euthanasia/assisted dying distinction suggests that they found self-administration vs. physician administration of the PAD medication to be an ethically relevant difference. However, they were not entirely opposed to euthanasia, rather expressing that they were *"on the fence"* when it came to "*the physician actually administering that…or coming to their home to end that patient's life in some way the physician deems to be humane.*"

The same subject also found relevant distinctions in the wording of question #7, specifically over the meaning of "suffering" in the question. The question is silent as to whether the suffering is "existential" suffering, i.e., psychological, emotional, social, or spiritual suffering, or suffering only physical pain. Additionally, the question lacked any mention of terminality of the diagnosis, as opposed to the previous questions. The subject stated they were not "*wholly opposed to [PAD for existential suffering]"* but also that they "*can understand why people have reservations about [PAD for existential suffering]."* Of relevance to the ethicist was *"the extent of that suffering, how long the patient has been suffering with this, have they exhausted all potential treatment options."*

The distinction between physical and existential suffering is relevant to the debate because, like terminality, relegating PAD solely to cases of physical suffering in end of life cases, and prohibiting it in cases of existential/psychological suffering is in line with many persons', including many clinicians', intuitions regarding the acceptability of the practice, though it clashes with Blanke et al.'s data which found autonomy concerns to be the most common PAD justification in Oregon. That is not meant to say, however, that a majority believing a moral position makes it correct, nor does legality equal morality. It might be morally right to allow PAD for these cases. However, even if the distinction is not morally compelling, it is still a relevant distinction from a descriptive ethics standpoint which ought to be investigated in detail.

6. Conclusion

While there have been legislative attempts to pass PAD legislation in North Carolina, none have been successful. The opinions of North Carolina clinicians and ethicists are relevant to any future PAD statute debate in North Carolina. As such this pilot study attempted to discern what the opinions of medical professionals who interact with dying patients is regarding PAD, whether they have professionally advocated for the prohibition or legalization of PAD, and whether they would support a North Carolina PAD statute. In contrast to palliative care organizations, the data revealed that there are palliative care professionals who embrace PAD and who, if PAD were legal, would view it as an integral part of palliative care. While a large majority of the subjects expressed that PAD should be a legal option (80%), they were less comfortable with providing the treatment in their practice. Additionally, the data suggested contrasting views within clinical ethics, suggesting that there is heterogeneity of views. It also found that while all the subjects had not professionally advocated for the passage of a PAD statute or its prohibition, a majority would be in favor of its legalization.

IV. Palliative Care & PAD

1. Introduction

This chapter discusses both objections made by palliative care organizations against PAD as well as empirical data done on the attitudes of palliative care professionals on PAD. First, the chapter will provide a definition and history of palliative care. Second, it will discuss arguments against PAD legalization advanced by palliative care organizations. Third, the thesis will provide counterarguments to palliative care objections to PAD. Lastly, it will integrate the data from the pilot study presented in chapter 3, discussing attitudes the palliative care subjects had towards PAD.

2. What is Palliative Care?

The term palliation comes from the Latin word for cloak, which found its way into 15th century English where it was modified to the word "palliate", meaning a "cloak of protection", or more specifically, "to lessen the intensity of a disease" (Merriam-Webster, 2021). Palliative care now extends beyond the end-of-life setting, but it was developed out of 19th century treatments given to the sick and dying. Much of this was done by philanthropists and religious institutions, outside of organized medicine, which was at the time was working towards "endeavouring to develop its scientific base, sometimes at the expense of caring for those beyond cure" (Graham & Clark, 2007). Into this milieu entered Cicely Saunders. Saunders, a nurse by background, was by the time she joined St. Joseph's Hospice in London finishing her training in social work and medicine. Saunders felt compassion for those suffering and in terminal stages of illness. Through her observations she developed the concept of "Total Pain", which encompassed not only physical aspects of pain, but the psychosocial dimensions that heretofore had been ignored (Graham & Clark, 2007). Saunders argued that types of analgesic drugs–that were just beginning to be used clinically during this time–could hold promise to decrease pain and suffering for patients if given consistently.

This method proved fruitful and was soon replicated all over Britain. By 1987 palliative care had developed into its own sub-specialty in British medicine, soon followed by many Commonwealth Nations (Graham & Clark, 2007). Recognition of palliative care as its own medical subspeciality occurred in America in 2008 (Graham & Clark, 2007). During this time professional organizations such as the International Hospice Institute, later re-christened the International Association for Hospice and Palliative Care, as well as the European Association for Palliative Care in Milan, Italy was founded (Graham & Clark, 2007). This was followed by the founding of hospice professional organizations in Asia, Central and South America, and Africa, all in the early years of the 21st century (Graham & Clark, 2007).

3. Palliative Care & PAD

The palliative care objection to PAD has been a powerful tool in the anti-PAD playbook. It works by supposedly refuting the so called beneficence argument in favor of PAD–or the argument that the practice is justified on the grounds that it is necessary to circumvent the painful physical and psychosocial symptoms of terminal illness and in particular the harsh dying process (Moskop, 2016). In contrast to the beneficence argument, according to Moskop (2016), PAD detractors rebut:

> …although such suffering may once have been unavoidable, recent developments in palliative care now make it possible to provide effective relief for physical pain, and psychological and spiritual support can relieve the mental suffering

> associated with terminal illness. If this is the case, then access to physician aid in dying is not necessary in order to relieve suffering, and it may distract health care professionals from providing optimal palliative care for their patients (Moskop, 2016).

Palliative care opponents to PAD point to the trend of PAD requests being rescinded once the patient's pain needs are met and they are eased into the death process through the administration of palliative care (McCormack, Clifford, & Conroy, 2012; Inbadas, Carrasco, & Clark, 2020). The Position Statement on Euthanasia and Physician-Assisted Suicide published by the International Association for Hospice and Palliative Care addresses this issue as follows:

> In the discussion of these wishes [for aid in dying] with patients, it becomes clear that only very rarely is this wish a request to act. Healthcare professionals should acknowledge these wishes and requests and interpret them as the starting point of holistic care, with adequate symptom control to relieve suffering, adequate psychosocial and spiritual care, and intense communication to better understand the patient's underlying motivations and attitudes (De Lima et al., 2017).

The position statement goes on to argue that most requests for PAD have as their impetus either a fear of an expected painful death in the near future or the concern that loss of autonomy will lead to burdensome care exacerbating the demands placed on loved ones (Lima et. al., 2017)

Inbadas, Carrasco, & Clark (2020) compiled a list of 104 "declarations" of palliative care organizations on their opinions of PAD. Their research divided the declarations into 3 distinct categories:

> Declarations with the primary purpose of promoting palliative care were classified as palliative care declarations (n = 36). Those with the primary purpose of advocating for or against acceptance of euthanasia/assisted dying were classified as euthanasia/assisted dying declarations (n = 62). There were six declarations that did not fit either of the two groups but advocated around the significant end of life issues such as 'treatment of pain', 'access to morphine' and 'rights of the dying child' (Inbadas, Carrasco, & Clark, 2020).

The conclusions of the study were that each declaration could be mapped along at least one of the three of the "dimensions", which were termed "framing", "claiming", and "demanding." The framing of each declaration differed first in the way it defined both palliative treatment, as well as aid in dying/euthanasia (the latter of which was more difficult to define). Second, the framing changed based on conceptual assertions about ethical concepts such as rights and autonomy. Last, many of the palliative care documents clarified myths about palliative care and death itself (Inbadas, Carrasco, & Clark, 2020). The documents also used "claiming" to make mostly positive claims about the benefits of palliation, as well as negative statements warning of the harms of aid in dying. Several declarations that positively portrayed PAD also argued that palliative sedation to unconsciousness (PSU) was not ethically different from PAD (Inbadas, Carrasco, & Clark, 2020). The third and final dimension of the declarations was "demanding", or "those elements which seek specific actions from governments, organisations and the general public for the advancement of palliative care or euthanasia/assisted dying" (Inbadas, Carrasco, & Clark, 2020). These demands mostly took the form of asking for resources and education for palliative care in both anti- and pro-PAD declarations, as well as the pro-PAD declarations demanding overturning laws which ban PAD as well as education for professionals on how to practice PAD (Inbadas, Carrasco, & Clark, 2020).

4. Arguments Against the Palliative Care Objection

Several arguments can be marshaled to respond to the palliative care objection. In contrast to the objection, data from Oregon have found that legalization of PAD led to greater access to palliative care (Buchbinder, 2018). At the same time, referrals to palliative care did in some cases cause the patient to reverse their decision to pursue PAD (Ganzini, 2016; Ganzini & Dobscha, 2004) This finding counters the idea that PAD patients are being given sub-standard care. In fact, as discussed in Chapter 1, most of the PAD recipients in Oregon and Washington State were middle class and insured patients receiving palliative or hospice treatment. This does not support the claim that a group of patients are being unjustly shunted off to receive the sub-standard care PAD while the wealthy and influential receive preferential PAD. Rather it supports the idea that PAD can be planned in tandem with appropriate palliation and completed at the time the patient wants to die; or at least as a last resort for those whose concerns over such issues as diminished autonomy and freedom from burdensome care are critical for wellbeing.

Others have advocated that even if not used by the majority of patients prescribed, PAD legislation may provide “wellbeing and reassurance”, especially that one can control the time, manner, and symptoms of one’s death (Harris, Richard, & Khanna, 2006). Additionally, as PAD is often unrelated to present pain but rather fears of a “bad death” or burdensomeness as an illness progresses, as well as a desire to choose where one dies (e.g., at home as opposed to a hospital), a hasty referral to a palliative program is often irrelevant and unnecessary (Ganzini, 2016). These patients are better served by being prescribed PAD, preparing advance care planning, and discussing with professionals how to disclose their decision to loved ones.

The efficacy of a patient's palliative care might also be unrelated to whether they request aid in dying, as argued by al-Awamer (2015). Al-Awamer argues first that, as discussed, most PAD requests are not about pain, but autonomy. Second, the countries with legalized PAD have better equipped and higher ranked palliative care programs. Lastly, PAD requests are subjective and highly dependent on a person's attitude and personality. Two individuals can have the same diagnosis and one will opt for aggressive care (even at the chagrin of the care team) while the other will opt for PAD (al-Awamer, 2015). The arguments employed by al-Awamer support the idea that PAD can be harmonized with, and not be in opposition to appropriate palliative care.

The outcomes of the original research described in the last chapter are relevant to the palliative care objection. The sampling of the three palliative care professionals stands in contrast to the International Association for Hospice and Palliative Care and the arguments of palliative care critics of PAD discussed by Moskop (2016). Rather than feeling that appropriate palliation made PAD requests irrelevant, the palliative care professionals interviewed felt the practice was ethical and were receptive to PAD being integrated into the practice. They were also open to the idea of receiving appropriate training. This training would personally enable them to participate in the treatment, a scenario several felt comfortable with.

5. Conclusion

Rather than embracing the legalization and expansion of PAD many palliative care organizations and professionals support the argument that meeting the terminal patient's pain needs and emotional turmoil during the death process leads to most PAD requests being rescinded. However, PAD and palliative care need not be at odds with one another. Rather, PAD can be interpreted as a function of palliative care options. Such a change has happened in Canada[11]. PAD supporters believe such a change is possible for American palliative care professionals and organizations.

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[11] See Claxton-Oldfield & Beaudette (2021) which found that a majority of Canadian hospice palliative professionals embrace PAD and expressed interest in participating in this practice. A majority of subjects agreed that PAD should be an option for advance care planning. Similarly, a majority would want to be present at the procedure if their presence was requested by the patient. Two-thirds were interested in learning more about the practice (Claxton-Oldfield & Beaudette, 2021).

V. The Disability Critique

1. Introduction

Persons with Disabilities have resisted PAD legalization both in the academic literature and through legal challenge (Ouellette, 2017). The main objective of these groups and individuals is to warn against the danger of legalization/expansion of PAD to non-terminal persons with disabilities. In contrast to its disability rights detractors, there is a minority of disability ethics scholars who would like PAD legalized for persons with a disability who have decision-making capacity over other aspects of their healthcare. This chapter will discuss both arguments and relevant cases of reported abuse in the system–in particular the Canadian Foley and Gladders cases–put forth by disability scholars criticizing PAD. The chapter then moves to explicating the pro-PAD literature in disability studies.

2. The Disability Rights Case Against PAD

Criticisms of PAD by disability rights advocates have infused the PAD debate since adoption of the first PAD statutes. Scoccia (2010) delineates two major kinds of objections. The first is that people with disabilities as a group would be harmed by the social biases pervasive in wider society (Scoccia, 2010). Scoccia states that this argument is analogous to those raised against laws promoting segregation or outlawing miscegenation, as they have in common the premise that “assumes that disabled people, like racial minorities in the U.S., constitute a historically marginalized group that has suffered and continues to suffer systemic injustice.” Further, this aspect of the disability objection “claims that a [Physician Assisted Suicide] law like Oregon's reinforces a social stigma attached to disability, thereby harming all disabled people” (Scoccia, 2010). Asch

(2005) and Gill (2000) both argue that this social stigma has at its root incorrect assumptions about the lives of persons with a disability that society, including medical professionals, tend to harbor. To counter this bias, they point to studies that conclude, contra the medical establishment assumption, that people with disabilities rate their quality of lives quite highly. They further argue quality of life is often not reduced in the highest degree by the physical impairments of disability, but rather by social and economic barriers which lead to inaccessible worlds for persons with disabilities (Asch, 2005).

Scoccia argues that the second version of the disability objection is concerned with protecting individuals with disabilities who wish to utilize PAD from their own choices–choices which are deleterious to their personal dignity and wellbeing. Scoccia compares this argument to "objection[s] to legalizing prostitution that focuses on the plight of prostitutes—the physical and spiritual harms that they suffer, their exploitation and lack of freedom." This argument calls into question autonomy of persons with disabilities, as "[i]t alleges that the majority of disabled people who would opt for [Physician Assisted Suicide] if it were legal would be making a choice that is neither free nor in their best interests, so the option should be denied them for the sake of both their autonomy and their welfare." (Scoccia, 2010).

A second concern raised as part of the disability critique arsenal against PAD is that it will lead to decreased societal spending and access to social services for persons with disabilities. Supporting this idea, Not Dead Yet's webpage comments:

> For seniors and people with disabilities who depend on publicly funded health care, federal and state budget cuts pose a very large threat. Many people with

> significant disabilities, including seniors, are being cut from Medicaid programs that provide basic help to get out of bed, use the toilet and bathe. (Not Dead Yet, 2021)

This economic pressuring might influence a person with a disability to choose PAD for grossly inappropriate reasons which would have otherwise been ameliorated by measures with less finality (e.g., assistive devices, home caretakers, palliation of pain) had the person with a disability lived in a society that prioritized these measures for the people with disabilities over the–in the detractor's opinion- "quick fix" of PAD.

As stated in Chapter 1, the most common justification for PAD under the DWDA was loss of autonomy (Blanke et al., 2017). Disability critics have been quick to point out the incongruity of this justification given that the PAD statutes primarily rest on the rationale that the motivation for these patients is suffering and pain experienced in the twilight of terminal illness. Discussing the Oregon data results Asch (2005) writes:

> When these data reveal that fear of burdening others is of much greater concern to patients who seek suicide than concerns about finances or physical pain, then how can professionals and families know that the supposedly autonomous wish to end life is not a response to a patient's deep fear that she has become disliked, distasteful to, and resented by the very people from whom she seeks expertise, physical help, and emotional support? (Asch, 2005)

According to Asch, autonomy concerns have at their root the internalization by the person with a disability of this "dislike" and distaste. As opposed to the picture of PAD as solely a rational and autonomous decision made by the chronically ill person close to death, this sort of case is one of coercion, shaming, and pressuring. Thus, disability concerns are a grossly inappropriate reason to choose PAD according to Asch and others who uphold the disability critique. They counter that rather than allowing people with disabilities to end their lives due to their perception that their autonomy will dwindle as their disease progresses, we should work on fostering an accessible world so persons with disabilities can be more independent in their day to day lives. Anti-PAD disability rights scholars also point out that the societal stigma associated with requiring assistance by others to complete tasks of daily living if one's condition can lead to the person with a disability feeling shame for their needs. According to these PAD opponents, this fear of losing bodily autonomy and having to be cared for is often the reason persons with disabilities seek PAD. They suggest that rather than shame people with disabilities, the culture should embrace assistive devices associated with impairment as inconsequential as other normalized assistive devices (such as glasses). To this end, Asch writes:

> Wheelchairs do not confine; they liberate. Voice synthesizers aid communication for people who can no longer speak. Diapers or catheters are akin to eyeglasses. Using the services and skills of a personal assistant who helps them get into and out of bed, eat their meals, or travel to their next appointment is no more shameful or embarrassing than it is for a nondisabled per son to work closely with an administrative assistant or to value the expertise of a mechanic, plumber, or the magician who restores data after a computer crash.
>
> (Asch, 2005)

If this change were to occur, PAD opponents argue, the logic follows that rather than turning to PAD because they fear losing autonomy, person with disabilities would reject

PAD, feeling empowered to choose to live full and robust lives as healthy and productive persons with disabilities.

Last is the slippery slope concern. Many of the disability studies scholars are concerned that elective PAD will lead to an expansion of the class of patients who could qualify, beginning with those with terminal illnesses, expanding to non-terminal persons with disabilities, then extending to those with mental illness to finally those with cognitive disabilities who cannot choose for themselves. The valley of the slippery slope is a society whose practices bear resemblance to the Aktion T4 directive that marked the beginning of Nazi eugenic war crimes against the persons with disabilities, which were expanded to racial and sexual minorities as well as political dissidents. Such an argument was advanced by Ron Amundson, Not Dead Yet's spokesperson during a 2002 session of the Hawaiian state legislature, which at the time was debating a proposed PAD statute (Scoccia, 2010). Battin (2007) cites case law[12] and professional organizations[13] as all listing slippery slope concerns as justifications for PAD prohibition (Battin, et al., 2007). In part to evaluate the merit of this argument, Battin et al., (2007) conducted research comparing the outcomes of both the Oregon death with dignity laws and Dutch euthanasia laws. Their research uncovered "no evidence of heightened risk" for a collection of demographic groups, including "the physically disabled or chronically ill" (Battin et al., 2007). Their research did find a heightened risk of abuse for those with

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[12] See *Washington v. Glucksberg*, and *Vacco v. Quill*

[13] The AMA, Canadian Medical Association, and the British Medical Association, respectively. (Battin, et al., 2007)

AIDs in both the Oregonian and Dutch health systems, which is obviously concerning, but AIDs patients do not qualify as people with disabilities as laid out in this essay.[14]

2. Cases of Abuse in the Canadian Aid in Dying System and Responses

Harold Brasswell argues the 2016 Canadian euthanasia and aid in dying bill C-7 has caused discrimination for disabled persons. C-7 was a revision of the original 2016 bill C-14, which legalized both euthanasia and aid in dying (a combination that was termed 'medical aid in dying (MAID)')." The revisions to C14:

> …clarified procedural safeguards for individuals whose natural death is not reasonably foreseeable and [made] some amendments to the safeguards that apply in the case of individuals whose natural death is reasonably foreseeable.
>
> The bill also amends the eligibility criteria by establishing that mental illness is not an illness, disease, or disability for the purpose of determining eligibility for MAID.
>
> (Parliament of Canada, 2021)

Brasswell points to the cases of Roger Foley and Chris Gladders as prime examples of the abuse which the lax laws have created. Both were disabled individuals who languished after receiving inadequate care. In Foley's case "Over a four-day period, they gave him rotten food, denied him access to his medicine and banged his debilitated body into the walls. He had to be immediately admitted to the hospital where he now resides" (Braswell, 2021). Gladders was similarly mistreated by being abandoned to horrible conditions: bedsheets that had been unchanged for weeks, urine and feces on the floor, a staff unresponsive to his calls for help (Braswell, 2021). Foley was told he would need to

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[14] We will have more to say on the definition of disability and its application to the PAD debate further on in this section

pay thousands of dollars to provide for the necessary care to be discharged from the hospital and into home care. It was at this point that the medical team, instead of working with Foley to get appropriate discharge care, urged he pursue aid in dying. While Foley pursued a legal case against the Canadian government, Gladders case has an unfortunate end–that is if the allegations of coercion are to be believed. Gladders ended up pursuing and completing aid in dying. According to Brasswell, "[w]hile Chris's serious medical condition undeniably contributed, his brother believes that his mistreatment in the home heavily influenced his decision to die" (Braswell, 2021).

Though these cases cause a visceral reaction upon reading, they have not gone without rebuttal from aid in dying supports Canadian legal scholar and PAD/MAID supporter Jocelyn Downie testified to the Canadian Parliament's 'Special Joint Committee on Medical Assistance in Dying'. Her testimony touched on the reports of abuse. Rather than pressure to capitulate to aid in dying affecting underprivileged groups, Downie states the data has found that those groups actually suffer from *unequal access* to aid in dying. On cases such as Foley and Gladders, she argues the Parliament members ought to:

> …deliberately and explicitly make evidence-informed recommendations using rigorous standards of evidence. This means following the pyramid of reliability, which is appended to the opening statement that I sent to the clerk. It also means looking to the considerable body of peer-reviewed and court-tested evidence about MAID in Canada.
>
> (Special Joint Committee on Medical Assistance in Dying, 2021)

And likewise warns of hasty judgments based on reports of cases, as:

> There is no need or justification to make recommendations based on anecdotes or untested narratives. Where there are gaps in reliable evidence, don't fill those gaps with unreliable evidence and use that to inform your recommendations. Rather, call for and facilitate more research.
>
> (Special Joint Committee on Medical Assistance in Dying, 2021)

Pressed further as to what she meant by anecdotes, Downie stated:

> I was thinking of the narratives that you see on the Internet, the stories, and even some of the names that Professor Lemmens [Downie's anti-PAD opponent testifying at the hearing] mentioned. These are narratives that have not been tested in court, or tested in any other kind of way where we can test the evidence. Testimonies that come before you, where you hear these horror stories as you did in the Bill C-7 hearings, are not tested. The only evidence we have that meets a quality standard doesn't demonstrate these concerns. If people want to make allegations, they have to put them to the test.
>
> (Special Joint Committee on Medical Assistance in Dying, 2021)

In short, Downie is arguing that these sorts of stories are eye catching, but prone to sensationalist journalism. The relevant evidence has found that aid in dying in Canada has not led to abuse. In fact, the opposite has occurred. Patients who would prefer that aid in dying be offered as an end-of-life option have found it hard to access because of their under-privileged social situation. Furthermore, when asked if there were cases of aid in dying where the patient was not adequately informed of palliative care, Downie argued, "There is absolutely not evidence of that", and reiterated that clinicians are "legally obligated to raise…the option of palliative care" with their patients who are requesting aid in dying (Special Joint Committee on Medical Assistance in Dying, 2021). While the relevancy of the Foley and Gladders cases to current United States PAD legalization is tenuous due to the fact that outright euthanasia is not legal in any PAD jurisdiction, it does highlight the potential for abuse which could present itself elsewhere. The example of the Canadian system helps us prepared appropriate safeguards in our aid in dying statutes in order to prevent the kinds of abuse Braswell describes.

3. The Case for PAD from a Disability Theory Perspective

While the disability rights critique of PAD is forceful and has many supporters, it would be wrong to say there is absolute homogeneity amongst disability scholars on the issue. Rather, there is an undercurrent of pro-PAD departure from the mainstream that has been in the literature for years. The next sections will summarize those arguments

a. Curtailing Choice is Overly Paternalistic

According to some scholars, the notion that PAD ought to be curtailed to prevent abuse towards the people with disabilities is paternalistic towards the very class of persons it claims to protect. In summarizing this view, Silvers writes:

> Those in the disability community who oppose physician- assisted dying say anyone with a disability who disagrees with them is hopelessly naive. They characterize people with disabilities who choose to expedite their own deaths as victims without volition, bent to the preferences of the non-disabled community, too weak-willed, inept, or unlucky to arrange to be cared for with reasonable quality." (Silvers, 1997)

This view was recapitulated in Riddle (2017)[15], who argues contra the prohibitionist stance, that "respect (both generally and for the autonomy of the disabled) requires that we allow everyone to seek assistance in dying." (Riddle, 2017). Riddle employs two main arguments, the first of which is a concern over the stigma towards persons with disabilities that prohibition would create. Riddle & Silvers align in diagnosing the prohibitionist's mistake as ignoring the *individuality* of a person with a disability seeking PAD. Silvers puts it in terms of "communal duty", as opposed to a matter of "individual responsibility", viz. the freedom the patient has to have a dignified death if they have the misfortune of qualifying for PAD (Silvers, 1997).[16] Riddle employs arguments offered by Nelson (2003) to hammer the point in further. Not only does PAD opposition ignore individuality. It actively perpetuates bias against persons with disabilities, who are citizens who should be entitled to the same freedoms, including if legal the freedom to hasten their death (Riddle, 2017; Nelson, 2003). Riddle compounds this concern by raising the notion of further harm from a "bad death" that can result if persons with disabilities are denied the freedom to hasten their own death. Thus, prohibition would both:

> "[perpetuate] harmful attitudes towards the disabled while simultaneously creating a doubly disadvantaged group: not only do people with disabilities suffer from social injustices or harms associated with impairment, but they are forced to

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[15] It should be noted that in personal correspondence with the author he makes it clear that he remains "uncommitted" on the qualification of terminal illness found in many of the statutes discussed in section 1. His arguments as laid out here are harmonious with both retaining the qualification that the patient–whether disabled or not–be terminally ill as well as abolishing this qualification

[16] Assuming they have decision-making capacity, which is a qualification for all PAD statutes discussed in section one.

> endure tremendous pain at the end of life from a misguided effort to provide protection." (Riddle, 2017)

Instead of protecting people with disabilities from befalling a great harm, it treats them with disrespect. PAD opponents might concede that opening up PAD for disabled people would have some immediate benefits (respect for autonomy, greater medical decision-making options, etc.); however, they argue, prohibiting it for this group sacrifices a short term benefit for long term gains. In the long run, opponents argue, the safeguards against persons with disabilities accessing PAD prevent a slippery slope leading to involuntary killing. This type of disability rights activism is misguided. While it is afraid that people with disabilities will buckle under societal pressure and mistreatment by electing to kill themselves in mass droves, this ignores that they are autonomous individuals who can elect PAD for a myriad of reasons.[17] These persons have decision-making capacity, and legitimate justifications to end their lives. To deny them this option would be capricious and inappropriate.

b. Risk

A second argument in the literature also comes from Riddle (2017). Riddle begins by citing scholars who argue that PAD safeguards have already been violated. Chiefly among these scholars is Wolbring (1998). Riddle affirms that it would be outlandish and incorrect to state that the legalization of PAD has been a seamless process without issues. However, he writes "We can reaffirm Wolbring's concern about a broken system, while endorsing a reform of the conditions required to permit assisted suicide or euthanasia" (Riddle, 2017). To counteract the supposed high risk from permitting PAD

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[17] If PAD is expanded, it is surmisable that the Oregon data would replicate and the most common justification amongst participants with non-terminal disabilities would be autonomy.

for persons with disabilities, Riddle points out that many mundane activities such as automobile use have very high rates of risk, yet almost no one questions their overall benefit to society.

The statues evaluated in chapter 1 contain protections for persons with disabilities, which work to mitigate the risk of negligent or coercive death. An example such protections can be found in section 2 of the Oregon statue. It states, "No person shall qualify under the provisions of ORS 127.800 to 127.897 solely because of age or disability" (State of Oregon, 1994). Likewise, section 1 of the California End of Life Option Act specifies "A person shall not be considered a 'qualified individual' under the provisions of this part solely because of age or disability" (State of California, 2015). Similar protections for persons with disabilities are built into the laws of the other states. These protections have legal and procedural force.

In Riddle's evaluation, just as the high risk of these activities do not lead to persons questioning their inherent value to society, so too we should not prohibit PAD just because there is an opportunity for abuse in a nascent system that is still figuring out the most appropriate safeguards. Instead of prohibiting PAD, Riddle argues that when an instance of improper use is reported, we should probe into the failures of the system, how they can be fixed, as well as the intentions of the persons who elect PAD, and whether they are properly aligned with PAD to end suffering or whether they are being unduly induced, coerced, or pressured into PAD (Riddle, 2017).

4. Statute Data and the Disability Critique

Attempts to determine which populations of people with disabilities have been prescribed PAD under current statutes yields mixed results. On the one hand, most of the illnesses for which physicians have prescribed PAD were terminal illnesses not considered disabilities. Typically, these patients have either cancer or respiratory illnesses. On the other hand, a large percentage of PAD case have been for ALS patients, and oftentimes this is the second-highest group prescribed PAD, following cancer diagnoses. In California, approximately 10 percent of the patients prescribed PAD during the 2020 calendar year had a neurological condition, including ALS (CDPH, 2021). Similarly, 17% percent of patients who received PAD in Colorado between legalization in 2017 up to 2020 had a neurological condition. Of this group approximately 10% were diagnosed with ALS and 0.5% were diagnosed with Multiple Sclerosis (CDPHE, 2021).

Writing in a festschrift response to concerns about PAD and disability raised by the late Jerome Bickenbach, L.W. Sumner notes that the task of determining which PAD participants qualify as people with disabilities is difficult because of the continued debate over the definition, nature, and societal impact of disability (Sumner, 2018). According to Sumner, Silver's use of the ADA definition of Disability[18] is troublesome because it is too broad and would include persons who are not typically viewed as qualifying for PAD. Almost all the major diagnoses for which patients have elected PAD under Oregon's Law[19] would then be considered people with disabilities. Sumner considers a definition that would divorce impairments that were diagnosed previous to a terminal diagnosis, but this too is rejected by Sumner as Oregon does not track the life-long health history of participants of DWD participants. Therefore, "it becomes impossible to determine how

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[18] Where disability is defined as "the substantial limitation of one or more major life activities due to a physical or mental impairment, or having a history of such, or being regarded as such." (Sumner, 2018; Silvers, 1998)

[19] The majority diagnosis, cancer, and others including HIV/Aids, Respiratory Disease, and heart disease would all be considered disabilities under this definition.

many deaths under the Oregon policy involved persons with disabilities, since the annual statistical reports provide no information about preexisting functional impairments" (Sumner, 2018). Sumner ends up agreeing with Bickenbach – a disability-rights focused prohibitionist – that at least "persons with ALS, as well as those afflicted by other motor neuron diseases, qualify as disabled" (Sumner, 2018). This is a diagnosis unlike cancer or end-stage HIV/AIDS for which a person is not terminal, and also meets our preconceived notion or at least our "folk concept" of a 'person with a disability.'[20]

Even if the disability critique defender is convinced that ALS patients are an especially vulnerable disability group, ALS is also clearly a chronic disease that progresses into terminal stages more rapidly than other disabilities. Given the evidence of common diagnoses listed by state health departments, the most common explanation is that terminal patients are opting for PAD to preserve autonomy and choose the manner of their death, not that individuals with disabilities are being castigated in the shadows and influenced to end their lives due to their burdensomeness. Neither are they choosing PAD because they cannot afford care or other economic reasons, considering Blanke et al.'s finding that approximately 90% percent of Oregon DWD patients had insurance (Blanke et al., 2017). A person with a disability choosing PAD because they are denied coverage of their wheelchair or ventilator or are influenced by gross assumptions regarding their quality their life would be a tragedy. But this does not appear to be happening in PAD cases. Rather, as Riddle and Silvers point out, widening the accessibility of PAD to non-terminal disability cases allows rational patients with

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[20] This should not imply that "hidden disabilities" are any less legitimate than the physically disabled or the use of assistive devices such as a wheelchair or ventilator gives more legitimacy to the claim that one is disabled, though it is hard to imagine the law changing to the point where it would legalize PAD for all persons with disabilities.

decision-making capacity making a deeply personal decision about their healthcare. Disabled or not, they ought to be allowed to make that decision.

Thus, the disability opponents of PAD are searching for a *geist* that is non-existent. While it is incorrect to assert that persons with disabilities *never* use PAD, and that their quality of life is not a factor at times, it is also incorrect to assert that PAD expansion perpetuates harmful biases about the persons with disabilities, or that they are being coerced into the practice.

5. Conclusion

Disability scholars critical of PAD are right to remind us that only a short time has lapsed between Buck v. Bell (1927) and our modern society. However, the disability critique does a disservice to persons with disabilities in its portrayal of them as feeble and impressionable, unable to stand up for their needs against the gale-force winds of a society that would rather see them dead. In contrast, those who argue in favor of the expansion of PAD for people with disabilities, including Riddle and Silvers see people with disabilities as rational, mature, and competent. They argue that respect demands that persons with disabilities be given optimal access to healthcare on par with the able-bodied population. This includes PAD in jurisdictions where available. Further, Riddle (2017) points to the evidence that PAD expansion does not pose any greater risk than that already experienced by the average person in their daily life doing menial tasks such as driving. Future research will need to be done on the demographics of which diagnoses use PAD and philosophical debate over which diagnoses qualify as disabling. Whatever conclusions are drawn from this empirical data it is clear that objections raised by the disability critique do not ultimately succeed in their intended goal of supporting PAD prohibition.

Concluding Remarks

The legalization of Physician Aid in Dying has revolutionized end-of-life care. The practice is now option for millions of terminal patients. First implemented in Oregon in 1997 under its death with Dignity Act, PAD is now available 10 other United States jurisdictions, including the nation's Capital, Washington D.C. The history of PAD in America stems from its early prohibition in the nascent 20th century to the last two decades which have seen an increasing trend in the reversal of these laws. The development of the PAD debate was fostered by the growth of advocacy organizations, both pro- and anti-PAD. Medical professional organizations also have mixed opinions on PAD, as some outright prohibit members from participating, and others endorse PAD with appropriate safeguards such as the ones modeled in the Oregon law. Several organizations take a position of neutrality on whether their members can engage in the practice.

The attitudes of medical professionals towards PAD are relevant to the PAD debate. This is especially true in states that do not formally prohibit or condone PAD, such as North Carolina. Yet no formal study has been done inquiring into provider opinions in the state. To enhance understanding of this under-appreciated aspect of the debate, I undertook an IRB-approved pilot research project based on qualitative interviews of health professionals at the medical center who specialize in palliative care and clinical ethics. The study had five participants, three palliative care professionals and two clinical ethicists. The palliative care professionals who were interviewed supported PAD legalization, though a majority expressed that they were not comfortable with participating in the PAD treatment in their practice. The ethicists opinions were split, as one favored legalization and the other favored continued prohibition. None of the subjects had formally advocated for PAD.

These pilot findings help inform my response to arguments against PAD from the palliative care profession. This objection to PAD points out that when a terminal patient's pain needs are met, in particular addressing their physical pain and mental health suffering, the patient often rescinds their request for aid in dying. Ultimately, the argument in favor of PAD being an end-of-life option is stronger than the concern that palliative care abrogates PAD requests. In contrast to palliative care opposition, jurisdictions that have legalized PAD have higher rated palliative care compared with those jurisdictions that prohibit the treatment. Furthermore, as discussed by Al-Awamer, end-of-life care is subjective. One patient might want aggressive treatment for a terminal illness, while the other might have peace of mind and feel greater autonomy and control knowing when and how they will die. Empirical data provides further arguments against palliative care objections. Buchbinder's research demonstrates the majority of Oregon PAD participants had access to robust palliative treatment. Additionally, there is growing evidence that PAD can be a useful tool for palliative care. The pilot study data support such a claim, as the palliative care professionals interviewed were in favor of PAD legalization.

This objection argues at its most benign, a harmful perception of persons with disabilities is perpetuated by PAD legalization, at its worst PAD might in some cases coerce persons with a disabling terminal diagnosis into choosing aid in dying. In contrast to this disability critique, some disability scholars defend PAD for persons with disabilities. Their argument takes two forms. First, they argue that to forbid PAD out of a seemingly righteous concern over coercion unfairly portrays persons with disabilities as weak and naïve, unable to advocate for their own choices when faced with pressure from the broader able-bodied world. To the contrary, disability scholars argue that consistently treating people with disabilities with respect includes allowing them the freedom to make healthcare decisions, including electing for PAD. The second response challenges the idea that PAD for persons with disabilities is unnecessarily risky. It appeals to the notion that the risk of inappropriate use of PAD is no greater than the risks entailed in common, uncontroversial activities such as automobile driving. The counterarguments against the disability critique are ultimately convincing. The Cheney case demonstrates there is no perfect system without the potential for abuse, but there will always be certain risks. Allowing the disabled to access PAD, with the caveat of appropriate safeguards in place, is preferable to a well-meaning but misguided curtailing of options due to concerns over perpetuation of stigma, denial of resources and financial aid, and abuse.

In the two decades since it was first legalized in America, Physician Aid in Dying has taken a center stage in bioethical debate. As the debate continues, it is my hope that the analysis presented can help inform better understanding of the competing arguments. Furthermore, the data gathered from the research study can be expanded to a statewide analysis. This broader research project could be used to inform policymakers on the support a PAD statute has amongst North Carolina medical professionals.

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DOUGLAS B. DAVISON

Email: davidb20@wfu.edu

EDUCATION

M.A. Wake Forest University, Bioethics — Aug. 2020-Dec. 2021

Relevant Coursework:
Clinical Ethics, Clinical Ethics in Context, Bioethics Theory

B.A. Elmhurst College, Philosophy — Aug. 2017-May 2019
Double Minored in Medical Humanities and Religion

HONORS AND AWARDS

Elmhurst College Honors Scholar — Fall & Spring Semester, 2018-2019

College of Dupage Deans List — Fall & Spring Semesters, 2015-2017

Creative and Scholarly Endeavors (CASE) Fellowship-Elmhurst College — Summer 2018

PUBLICATIONS

Journal Publications

Davison, Douglas (2016) "The Reaper in the “Nursery”: A Defense of Parental – Elective Euthanasia of Severely Ill Newborns," *ESSAI*: Vol. 14.
Available at: https://dc.cod.edu/essai/vol14/iss1/16

PRESENTATIONS AND INVITED LECTURES

Paper Presentation, ““Smart pills”: The Ethics of Non-therapeutic Ritalin Use for Neuroenhancement",” Elmhurst College Philosophy Department Symposium, 2018.

Paper Presentation, “The Failings of the Social Construction of Disability: What Lives Are Worth Living?” Elmhurst College Philosophy Department Symposium, 2019.

PROFESSIONAL TRAINING

ASBH Annual Conference
American Society for Bioethics and Humanities, Attendee

PROFESSIONAL SERVICE

Event Volunteer (10 hours)
Center for Bioethics and Human Dignity's Annual Conference
Center For Bioethics and Human Dignity, Trinity University, Deerfield Illinois, 2015

- Managed clock for paper presenters.

COMMUNITY SERVICE

Brother of Lambda Chi Alpha Fraternity (150 hours)

- Volunteer for Feeding America Food Drives, Elmhurst, Illinois, 2018 & 2019
- Volunteer for Feed My Starving Children, Schaumburg, Illinois, 2018 & 2019
- Volunteer for Hoops for Hearts, 2019