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Failure to Reform Experimental Treatment Accessibility Leads Push for Legalization of Assisted Suicide and Euthanasia in a Surprising New Group of Individuals—Children

*Caitlin Massey**

INTRODUCTION

In 1997, the Supreme Court ruled in *Washington v. Glucksberg* and *Vacco v. Quill* that physician assisted suicide was not a protected liberty interest.¹ However, the Court left the door open for states to permit physician assisted suicide through state statutes.² Currently, California, Colorado, Oregon, Vermont, Washington, and the District of Columbia, have taken advantage of the Supreme Court’s ruling and adopted Death with Dignity statutes.³ In addition, physician assisted dying was deemed legal in Montana by State Supreme Court ruling.⁴

The purpose for legalizing assisted suicide in these states is to provide terminally ill adults with an option to make their own end-of-life decisions and determine how much pain and suffering they should endure without “government and its interference, politicians and their ideology, or religious leaders and their dogma.”⁵ However, these state statutes do not provide an option to minors who are equally, if not more so, denied access to experimental treatment and similarly facing terminal illness and pain. A constitutional debate may be imminent as such demand for state legislation may be forthcoming if parents push for equal

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¹ US Legal, (Mar. 1, 2017), <https://righttodie.uslegal.com/physician-assisted-suicide/supreme-court-rulings>; *Washington v. Glucksberg*, 521 U.S. 702 (1997); *Vacco v. Quill*, 521 U.S. 793 (1997).

² *Id.*

³ Death With Dignity, *How to Access and Use Death with Dignity*, (Mar. 2, 2017), <https://www.deathwithdignity.org/learn/access/>.

⁴ *Id.*

⁵ Death With Dignity, *Death with Dignity Acts*, (Mar. 2, 2017), <https://www.deathwithdignity.org/learn/death-with-dignity-acts>.

rights in states already offering assisted suicide to adults. For terminally ill minors that are declined access to potentially life-saving experimental treatments the argument for a right to assisted suicide or euthanasia may overcome the state's compelling interest argument.

Assisted suicide for adults is increasingly gaining legal status throughout the United States. With the addition of euthanasia, these practices are no longer unfamiliar to children throughout the world.⁶ For children in the United States, once all treatment options are exercised, including experimental, parent(s) or legal caretaker(s) no longer have recourse to save their terminally ill minor's life and must resort to end-of-life care. End-of-life care for minors proves to be ineffective in preventing pain and suffering. In a recent study published by the *Archives of Pediatrics & Adolescent Medicine*, there is considerable evidence of a rise in interest for euthanasia among parents of minor children who passed away from cancer.⁷ The parent's interest in euthanasia specifically related to the child's unrelieved pain.⁸

The possibility of legalizing assisted suicide and euthanasia for minors increases as interest rises among parent(s) or legal caretaker(s). While available to adults in some states, assisted suicide is one of the only end-of-life options not equally provided to minors in the United States. As it stands today, assisted suicide and euthanasia for children is not prohibited *per se* from becoming a right via state political process. However, no state currently offering the right to assisted suicide has equally extended the right to children.⁹ Instead, these states choose to include rigorous age and competency requirements.¹⁰ Despite these requirements, critics of the right to assisted suicide fear, "[i]f the availability of physician-assisted suicide for 'terminally ill' adults continues to spread across our country, odds are that state courts will one day 'find' expansive rights to 'aid in dying' for other constituencies as well—even children."¹¹

⁶ Reuters, *Physician-assisted suicide, euthanasia: increasingly legal but still rare*, (July 19, 2016), <http://www.foxnews.com/health/2016/07/19/physician-assisted-suicide-euthanasia-increasingly-legal-but-still-rare.html>.

⁷ Dussel V, et al., *Considerations About Hastening Death Among Parents of Children Who Die of Cancer*, *Arch Pediatric Adolescent Med.*, (2010)

⁸ *Id.*

⁹ *How to Access and Use Death with Dignity*, *supra* note 3.

¹⁰ *Id.*

¹¹ William Saunders, Mary Harned, *Now That Belgium Legalized Euthanasia for Terminally Ill Kids, is the United States Next?*, (Mar. 6, 2014), http://www.lifenews.com/2014/03/06/now-that-belgium-legalized-euthanasia-for-disabled-kids-is-the-united-states-next/#_edn5 (The United States Supreme Court held there is no Federal Constitutional right to assisted suicide); *Washington v. Glucksberg*, 521 U.S. 702 (1997); *Vacco v. Quill*, 521 U.S. 793 (1997).

Future debates are likely to intensify as assisted suicide continues to gain support throughout the United States. Aligned with the prediction of Justice Gorsuch in the aftermath of *Glucksberg* and *Quill*, “A less immediate and obvious, but perhaps even more important, consequence is the fact that several justices appear to be open to considering a constitutional right to assistance in suicide for competent, terminally ill persons in an appropriate case. . . .”¹² Parent(s) or caretaker(s) of terminally ill minors denied access to potential life-saving experimental treatments might just have that appropriate case to get in front of the Supreme Court.

This comment will argue that given the increasing desire for patient autonomy, the need to ensure that terminally ill minors are provided every opportunity to fight for their lives, and a growing interest in assisted suicide and euthanasia in the United States as well as abroad, there must be a major reform to experimental treatment options. If this does not happen, the Supreme Court may have to determine whether terminally ill minors denied access to potentially life-saving treatments have a right to assisted suicide and euthanasia.

Part II of this comment discusses the correct use of common terminology involved in right to die debates. Part III explains the constitutional background for health care decision making at the end of life. This section further discusses the development of personal autonomy through key Supreme Court decisions and the conflicts between these decisions and the right to die movement.

Part IV of this comment will look at the available options to access experimental treatments currently offered to persons suffering a terminal illness and the applicability of each. Following this analysis, Part V discusses the one controversial end-of-life option not currently offered to minors within the United States—assisted suicide and euthanasia. It will also discuss how a fundamental liberty right to assisted suicide is analyzed through the due process clause; the pre-*Glucksberg* history of suicide, assisted suicide, and euthanasia; and the history and development of assisted suicide and euthanasia in the years since the Supreme Court’s controversial decision including international influences.

Lastly, Part VI will discuss the increasing need for major changes to experimental treatment access for minors to prevent a rise in the push for legalization of assisted suicide and euthanasia in the United States. This section will discuss the medical decision making authority of parent(s) or legal caretaker(s) for minors, the strong argument in favor of

¹² NEIL M. GORSUCH, THE FUTURE OF ASSISTED SUICIDE AND EUTHANASIA 17 (2009).

assisted suicide and euthanasia for minors denied access to experimental treatments, and what must be done to better provide terminally ill minors access to experimental treatment programs so that efforts can be focused on saving their lives and not on a legal battle over their right to die—a constitutional question has been avoided for many years.

Relevant Terms and Definitions

In discussing the right to die debate, often the terms suicide, euthanasia and assisted suicide are discussed together and sometimes intertwined. Therefore, it is important that there is a thorough understanding of the difference in each of these acts. Merriam Webster Dictionary defines suicide as, “the act or an instance of taking one’s own life voluntarily and intentionally.”¹³ Euthanasia and physician assisted suicide are most often used interchangeably.¹⁴ The word Euthanasia is derived from two Greek roots: ‘*eu*’ and ‘*Thanatos*,’ literally meaning ‘good death.’¹⁵ “Euthanasia involves the physician himself committing the act that leads to the premature demise of the patient.”¹⁶ Physician assisted suicide happens where the physician provides the patient the means to commit the act themselves, which is usually through a lethal prescription of sedatives.¹⁷

CONSTITUTIONAL FOUNDATION AND STATE REGULATION AUTHORITY FOR HEALTH CARE DECISIONS ABOUT DEATH AND DYING

While states have an established interest in preserving life¹⁸ and the responsibility to regulate medical standards in the best interest of society’s health and safety,¹⁹ conflicting attitudes concerning civil liberties in the realm of medicine and personal autonomy have increasingly emerged among Americans²⁰ and set forth a multitude of heated debates. Over the years, judicial analysis suggests the Supreme Court’s support of patient autonomy in health care decision making. The

¹³Merriam Webster Dictionary, (Mar. 14, 2017), <https://www.merriam-webster.com/dictionary/suicide>.

¹⁴HAIDER WARRAICH, MODERN DEATH 231 (2017).

¹⁵*Id.* at 236.

¹⁶*Id.* at 231.

¹⁷*Id.*

¹⁸*Glucksberg*, 521 U.S. 702, 729 (1997); *Quill*, 521 U.S. 793, 796 (1997).

¹⁹Kurt Altman & Christina Sandefur, *Right-To-Try Laws Fulfill The Constitution’s Promise Of Individual Liberty*, (July 14, 2015), <http://healthaffairs.org/blog/2015/07/14/right-to-try-laws-fulfill-the-constitutions-promise-of-individual-liberty>.

²⁰Emily Hogan, “*Right to Try*” Legislation and Its Implications for the FDA Drug Approval Process, 50 J. OF LAW & POLICY 171 (2016).

Court first addressing the right to refuse life-sustaining treatment in *Cruzan v. Director, Missouri Department of Health*.²¹ In this case, the parents of Nancy Cruzan sought to remove their daughter's life support, claiming this was her desire because she had commented to such effect in the past.²² Many legal scholars expected the Court to settle the question of whether the United States Constitution contained a right to die clause but instead, the court explicitly stated, "for purposes of this case, we assume that the United States Constitution would grant a competent person a Constitutionally protected right to refuse lifesaving nutrition and hydration."²³ While the Court recognized a right to refuse life support, it did not hold in favor of Nancy's parents, stating that due process did not require the state of Missouri to accept the parent's substituted judgement absent substantial proof that their views reflected those of their daughter.²⁴

Many legal scholars continue to grapple with the majority's opinion in *Cruzan*, even the Justices themselves, as made evident seven years later in *Washington v. Glucksberg*.²⁵ In *Glucksberg*, three terminally ill patients along with their physicians challenged the state of Washington's prohibition on physician assisted suicide.²⁶ The Court looked to the Due Process Clause in its analysis²⁷ referring back to *Cruzan*, "[w]e have also assumed, and strongly suggested, that the Due Process Clause protects the traditional right to refuse unwanted lifesaving medical treatment."²⁸ While there is debate regarding whether the Court is 'assuming' a constitutional right to refuse treatment or has officially found one to exist, the result has been the permission of states to establish law regarding health care decision-making with little, if any, limits by the United States Constitution.²⁹

Most law on the topic has continued to be established on a state-by-state basis.³⁰ Thus, the Court's decision in *Cruzan* did not provide much constitutional guidance in the realm of state laws which delegate "the

²¹*Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261, 283 (1990).

²²*Id.* at 284.

²³*Id.* at 262 (Stating, "[t]he choice between life and death is a deeply personal decision of obvious and overwhelming finality. We believe Missouri may legitimately seek to safeguard the personal element of this choice through the imposition of heightened evidentiary requirements").

²⁴*Id.*

²⁵BARRY FURROW, ET. AL., *HEALTH LAW: CASES, MATERIALS AND PROBLEMS*, 1550-1551, (7th ed. 2013).

²⁶*See generally Glucksberg*, 521 U.S. 702 (1997).

²⁷*Id.* at 719.

²⁸*Id.* at 720.

²⁹FURROW, *supra* note 25, at 1552.

³⁰*Id.*

conditions and extent of, and the restrictions and exceptions to, any right to forgo life-sustaining treatment.”³¹ However, the federal government has become more active in ensuring that patients are aware of their end-of-life options through the Patient Self-Determination Act (PSDA).³²

MINORS HAVE DISADVANTAGED ACCESS TO EXPERIMENTAL TREATMENTS

Assemblyman Ian Calderon, a lead author for California’s Right to Try law, states “[i]t’s inhumane to have a law on the books that allows you to end your own life, but no law on the books that allows you to fight to extend it . . . [t]hat just seems counter-intuitive.”³³ For terminally ill minors that do not have a right for either there is strong potential for debate over their right to autonomy at the end-of-life. To understand the disadvantage these minors and their parent(s) or caretaker(s) face to gain access to potentially life-saving experimental treatments, there must be an understanding of the current right to access experimental treatments in the United States, the process involved in requesting experimental treatments, as well as an understanding of the difficulties and disadvantages that terminally ill minors specifically face as opposed to terminally ill adults.

Constitutional Grounds to Access Experimental Treatment

Furrow, Greaney, Johnson, Jost, and Schwartz state, “Constitutional arguments are not limited to those who want to forgo treatment; they can be asserted by seriously ill patients who want access to treatment, too.”³⁴ In the landmark case, *United States v. Rutherford*, the Supreme Court first ruled on the matter of whether terminally ill patients had the right to access experimental treatments.³⁵ In this case, terminally ill cancer patients were denied access to the drug amygdalin (Laetrile), a

³¹*Id.* at 1553.

³²Trisha Torrey, *Do Patients Have the Right to Refuse Medical Treatment?* (Mar. 15, 2017), <https://www.verywell.com/do-patients-have-the-right-to-refuse-treatment-2614982> (Under federal law, this Act mandates nursing homes, home-health agencies, and HMOs to provide patients with information regarding advance directives, including DNRs (do not resuscitate), living wills and other discussions and documents).

³³Carrie Feibel, *Patients Demand The ‘Right To Try’ Experimental Drugs, But Costs Can Be Steep*, (Mar. 3, 2017), <http://www.npr.org/sections/health-shots/2017/03/03/517796956/patients-demand-the-right-to-try-experimental-drugs-but-costs-can-be-steep>.

³⁴FURROW, *supra* note 25, at 1551.

³⁵*United States v. Rutherford*, 442 U.S. 544, 99 S. Ct. 2470, 61 L. Ed. 2d 68 (1979); see also Johnathan J. Darrow, et al., *Practical, Legal, and Ethical Issues in Expanded Access to Investigational Drugs*, *THE N. ENG. J. OF MED.*, 283 (2015) available at <http://www.nejm.org/doi/full/10.1056/NEJMh1409465#t=article>.

discredited treatment today.³⁶ At the time, an application for clinical testing was pending before the Federal Food, Drug and Cosmetic Act (FDA).³⁷ The Court held the, “[s]afety and effectiveness standards of Federal Food, Drug, and Cosmetic Act were fully applicable to terminally ill patients” and refused to make an exception.³⁸

In 2008, the issue again arose in *Abigail Alliance v. von Eschenbach*, a case heard in the District of Columbia Circuit Court of Appeals for the United States.³⁹ Abigail suffered from squamous cell carcinoma and was denied access by the FDA and certain Congressmen to access two investigational drugs recommended to her by her oncologist.⁴⁰ Founded following Abigail’s death, the Abigail Alliance Foundation took on the legal battle, eventually filing a claim against the FDA in federal court.⁴¹ The D.C. Circuit Court held, “there is no fundamental right . . . to experimental drugs for the terminally ill,” and the Supreme Court declined to review the case.⁴² As the law stands today, there is no Constitutionally recognized fundamental right to access drugs before FDA approval.⁴³

Current Experimental Treatment Programs

There are currently three ways minors facing life threatening illnesses and with no available approved treatment may access new drugs before they become approved by the FDA and marketed nationwide.⁴⁴ These programs include participation in clinical trials and the FDA Compassionate Use (Expanded Access) programs.⁴⁵ Additionally, recent state legislation referred to as “Right to Try” laws, have been adopted in thirty-seven states and offer terminally ill patients a way to access non-FDA approved medications.⁴⁶

³⁶ *Id.*

³⁷ *Id.*

³⁸ *Id.*

³⁹ *Id.*

⁴⁰ Hogan, *supra* note 20, at 184.

⁴¹ *Id.* at 185.

⁴² *Practical, Legal, and Ethical Issues in Expanded Access to Investigational Drugs*, *supra* note 39, at 283.

⁴³ Hogan, *supra* note 20, at 186.

⁴⁴ *Id.* at 182.

⁴⁵ *Id.*

⁴⁶ GOLDWATER INSTITUTE, <http://righttotry.org/faq/> (last visited Sept. 1, 2017) (“Right To Try has been signed into law in 37 states and counting: Alabama, Arizona, Arkansas, California, Colorado, Connecticut, Florida, Georgia, Idaho, Illinois, Indiana, Iowa, Kentucky, Louisiana, Maine, Maryland, Michigan, Minnesota, Mississippi, Missouri, Montana, Nevada, New Hampshire, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, South Carolina, South Dakota, Tennessee, Texas, Utah, Virginia, West Virginia, Washington and Wyoming.”).

Unfortunately, these programs are not flawless and often patients are unsuccessful getting approval.⁴⁷ As difficult as this process is for adults, evidence points to far more difficulty in the approval and acceptance of minors into the same programs.⁴⁸ This may possibly discourage families from going down this road altogether.

FDA Clinical Trials

FDA clinical trials are necessary for drug companies to obtain FDA approval.⁴⁹ These trials are one way for terminally ill patients to access new drugs before they are approved and made available nationwide.⁵⁰ Importantly, there are various hurdles for terminally ill patients interested in selection for a clinical trial, which may prove a harrowing feat.⁵¹

First, individuals must be accepted by the drug companies to participate, which may be discouraging to the terminally ill because the participant must meet all of the criteria identified by researchers, including the current condition of their illness.⁵² Researchers look for a broad group of individuals so as to keep the group unbiased, however, this may make selection more difficult as well.⁵³ Secondly, in phases II and III of clinical trials, a percentage of participants receive placebos rather than the potential life-saving medications.⁵⁴ Lastly, fewer than three percent of terminally ill patients will gain access to the experimental treatment through a clinical trial.⁵⁵

FDA Compassionate Use Program

The Compassionate Use program, also referred to as Expanded Access, allows for the use of an experimental treatment outside of a clinical trial (i.e., one that has not been approved by FDA).⁵⁶ Under this program, “patients who are deathly ill, have no other treatment alternative, and do not qualify for clinical trials are able to gain access to

⁴⁷*Cures for all*, NATURE NEWS, 465-66 (July 28, 2016) available at https://www.nature.com/polopoly_fs/1.20331!/menu/main/topColumns/topLeftColumn/pdf/535465b.pdf

⁴⁸ *Id.*

⁴⁹ Hogan, *supra* note 20, at 182.

⁵⁰ *Id.*

⁵¹ *Id.*

⁵² *Id.*

⁵³ *Id.*

⁵⁴ *Id.*

⁵⁵ GOLDWATER INSTITUTE, *supra* note 46.

⁵⁶ U.S. Food and Drug Administration Program, *Expanded Access (Compassionate Use)*, (Mar. 4, 2017), <http://www.fda.gov/NewsEvents/PublicHealthFocus/ExpandedAccessCompassionateUse/default.htm>.

experimental drugs.”⁵⁷ However, there are a demanding amount of requirements to become a participant, as well as, tremendous risk of the unknown as the drugs are still under investigation.⁵⁸

Some requirements for participation include the patient’s licensed physician agree to participate, the probable risk to the patient is not greater than the probable risk of the disease or condition, and sufficient amount of evidence of the safety and effectiveness of the investigational product to support its use in the particular circumstance.⁵⁹ Further, the FDA must determine that by providing the patient with the investigational treatment there will be no interference with the initiation, conduct, or completion of clinical investigations to support marketing approval.⁶⁰ But most importantly, access into the program requires that the drug maker be willing to provide the treatment and the FDA approves the request.⁶¹

There are various issues with Compassionate Use. While millions of Americans are diagnosed with or die of terminal illnesses each year, roughly only one thousand people participate in the program per year and there is very little data published.⁶² Many patients run out of time before they can qualify for the exemption or complete the process.⁶³ Additionally, physicians are required to follow strict application procedures that are extremely time consuming and must continue to follow the patient for the entire treatment.⁶⁴ Further, at the end of the day, it is the drug company’s decision to provide the medication.⁶⁵

Right to Try Laws

“State Right to Try laws are an effort to bypass the federal bureaucracy by using state laws to give dying patients better access to investigational medications.”⁶⁶ Thirty-seven states have passed laws⁶⁷

⁵⁷Hopenowforals, *Sick Kids, Desperate Parents, and the Battle for Experimental Drugs*, (July 17, 2015), <http://www.hopenowforals.org/2015/07/sick-kids-desperate-parents-and-the-battle-for-experimental-drugs/>.

⁵⁸ *Id.*

⁵⁹ *Id.*

⁶⁰ *Id.*

⁶¹Sylvia Pagan Westphal, *Sick Kids, Desperate Parents, and the Battle For Experimental Drugs*, THE BOSTON GLOBE, (July 15, 2015) available at <https://www.bostonglobe.com/magazine/2015/07/15/sick-kids-desperate-parents-and-battle-for-experimental-drugs/Hle3CTwriFfTXoOvQ7TbZP/story.html>.

⁶²GOLDWATER INSTITUTE, *supra* note 46.

⁶³ *Id.*

⁶⁴ *Id.*

⁶⁵ *Id.*

⁶⁶Mark Flatten, *Dead on Arrival: Federal “Compassionate Use” Leaves Little Hope for Dying Patients*, NATIONAL INVESTIGATIVE REPORTER, GOLDWATER INSTITUTE (Feb. 24,

under this premise and are able to do so because of the broad power to regulate health and safety issues.⁶⁸ Varying by state, these laws allow patients, doctors, and drug companies to decide whether a patient has access to a drug that currently is being tested in clinical trials, however, certain requirements must be met.⁶⁹ Importantly, the FDA does not have veto power.⁷⁰

Patient are required to have a terminal illness and to have considered all available FDA approved treatment options.⁷¹ In addition, the patient's physician must agree the investigational drug is their best chance at survival.⁷² Patients must sign an informed consent form attesting to their understanding of the risks involved in using a drug that has not been approved.⁷³ The only drugs the patient will have access to are those that have been shown safe enough to continue testing after phase I clinical trials, which must remain ongoing.⁷⁴

The downfall to Right to Try laws is that the drug companies are not obligated to provide their products to requesting patients, and it is unlikely they will be willing to risk the full development and approval of the FDA to do so.⁷⁵ Further, they may charge for the cost of making and administering the treatments and insurance companies are not required to pay for the care.⁷⁶

DISADVANTAGES FACED BY TERMINALLY ILL MINORS TO ACCESS EXPERIMENTAL TREATMENTS

For terminally ill minors and their parent(s) or caretaker(s), access to experimental treatments through clinical trials, Compassionate Use, or Right to Try laws, offer unique and frustrating complexities not faced by a terminally ill adult. Pediatric patients are tragically denied time for hope due to "systemic obstacles in the world of medical research."⁷⁷ Unless and until treatment is proven effective in adults, many

2016), <http://goldwaterinstitute.org/article/dead-on-arrival-federal-compassionate-use-leaves-l>.

⁶⁷GOLDWATER INSTITUTE, *supra* note 46.

⁶⁸Flatten, *supra* note 66, at 24.

⁶⁹ *Id.*

⁷⁰ *Id.*

⁷¹ *Id.*

⁷² *Id.*

⁷³ *Id.*

⁷⁴Flatten, *supra* note 66, at 24.

⁷⁵ *Id.*

⁷⁶ *Id.*

⁷⁷David J. Bailey, *This Toddler With a Rare Disease Got a Life-Changing Treatment. Why Can't All Kids?*, STAT NEWS, (Dec. 15, 2016), <https://www.statnews.com/2016/12/15/rare-disease-children-treatment-access/>.

pharmaceutical companies find pediatric clinical trials to be more hassle than worth.⁷⁸ Unfortunately, proving drug effectiveness in adults may take decades, resulting only in obsolete treatments for minors.⁷⁹ Without enough minors with each rare disorder to build a body of scientific evidence in support or refute of effectiveness of potential treatments, minors and their families are trapped in a numbers game.⁸⁰ Only the fortunate few will get enrolled in an already limited scope of pediatric trials.⁸¹

Further, the complicated process involved in designing any clinical trial is made more difficult when adding minors to the equation.⁸² Minors do not metabolize drugs in the same way as adults. Therefore, it is difficult to predict the toxicity of a drug in a minor when simply using evidence from adult or animal trials.⁸³ This complication not only frustrates minor's access to clinical trials, but also, access through the Compassionate Use program as pharmaceutical companies have no empirical data as to the appropriate dosing measures.⁸⁴ For example, Bristol-Myers, a global biopharmaceutical company that develops cancer immunotherapy drugs,⁸⁵ offers their drug Nivolumab to adults with melanoma through Compassionate Use.⁸⁶ While the company recognizes the outcomes for pediatric patients with recurrent or metastatic tumors remain poor—because there is no data that establish the benefit/risk profile of their drug Nivolumab in pediatric tumors—they do not make it available under Compassionate Use to minors despite its potential benefits.⁸⁷ The company claims to be working with regulatory agencies to begin development of carefully conducted pediatric clinical trials,⁸⁸ however, even the most minute set-back may be detrimental for terminally ill patients.

Another complication for minors seeking access to experimental treatments is how pharmaceutical companies perceive their risk when

⁷⁸*Cures for all*, *supra* note 47.

⁷⁹ *Id.*

⁸⁰ Bailey, *supra* note 77.

⁸¹ *Id.*

⁸² *Id.*

⁸³ *Id.*

⁸⁴ *Id.*

⁸⁵ Lydia Ramsey, *Pharma Giant Bristol-Myers Squibb Just Made Another Big Bet on Cancer Immunotherapy*, BUSINESS INSIDER (Aug. 3, 2017), <http://www.businessinsider.com/bristol-myers-squibb-acquires-ifm-therapeutics-for-up-to-232-billion-2017-8>.

⁸⁶ Meg Tirrell, *When Unapproved Drugs Are The Only Hope*, CNBC, <https://www.cnbc.com/2014/08/05/a-case-for-compassionate-use-when-unapproved-drugs-are-the-only-hope.html> (last visited Sept. 1, 2017).

⁸⁷ *Id.*

⁸⁸ *Id.*

involving children.⁸⁹ These companies often fear how the death of a child will affect the publicity and approval of a new drug in development, even if wholly unrelated to the treatment itself.⁹⁰ “[F]irms worry that if a person dies or is harmed while taking a drug, it could hurt the drug’s chances of being approved.”⁹¹ This risk only grows greater when the person is a child, making it an easy choice for the company to deny drugs on the grounds that they have not been tested in children.⁹²

Importantly, efforts to put pressure on pharmaceutical companies to provide experimental treatments to terminally ill minors have gained ground in recent years. For many companies, denying a minor access to an experimental drug has unleashed an entirely new risk—the determined parent. As patients and their parent(s) or caretaker(s) have taken on the advocate role, use of social media has become a new threat to pharmaceutical companies, especially when the victim is a child of a determined and desperate parent. Drugmaker Chimerex experienced this harm when it denied Josh Hardy, a seven-year-old boy who suffered from kidney cancer and a subsequent infection due to ten intense chemotherapy treatments that depleted his immune system.⁹³ After approved treatments proved ineffective, Josh and his parents sought the potential miracle drug Brincidofovir through Compassionate Use but was denied on various occasions by Chimerex.⁹⁴ The fifty-five person company was in deep financial debt, had limited resources, and did not possess enough of the drug to provide it to every patient like Josh and still have enough of the medication to complete current clinical trials.⁹⁵ To the company’s surprise, Josh’s mother launched a campaign via Facebook describing every parent’s worst nightmare, the existence and denial of a possible cure for her child.⁹⁶ This single post ignited a debate amongst social media followers and effectively created a public relations disaster for Chimerix.⁹⁷ Although Josh did not receive Brincidofovir through Compassionate Use, he did through a quickly devised clinical trial developed so that Chimerix could benefit from the information learned from Josh and other patients like Josh.⁹⁸

⁸⁹*Cures for all*, *supra* note 47.

⁹⁰ *Id.*

⁹¹ *Id.*

⁹² *Id.*

⁹³ Flatten, *supra* note 66, at 14.

⁹⁴ *Id.*

⁹⁵ *Id.*

⁹⁶ *Id.*

⁹⁷ *Id.*

⁹⁸ *Id.*

Although Josh's case was successful and sparked a new movement to put pressure on pharmaceutical companies, not all minors are as lucky. Chloe Drury was only three months away from her 18th birthday when denied access to BioMarin's clinical trial to treat Ewing's Sarcoma.⁹⁹ Upon reaching the age of 18, she was admitted but sadly passed away two weeks after starting treatment.¹⁰⁰ Chloe's mother expressed her frustration regarding the experience, "[w]e were just sitting there watching our beautiful 17-year-old daughter get weaker and weaker, knowing there is something out there she could have had and it just seems totally wrong to me not a world that I want to live in that treats young people like that."¹⁰¹ For Nathalie Traller, a 15-year-old diagnosed with Alveolar Soft Part Sarcoma (ASPS), clinical trials and Compassionate Use seemed to completely fail her and her family, despite efforts to publicize her case.¹⁰² "The Trallers are in a position countless others have been before: they're out of options among approved drugs or those available through clinical trials. And Nathalie's running out of time."¹⁰³ Despite Nathalie meeting all the criteria for a number of clinical trials she did not meet the age requirement of 18.¹⁰⁴ As a result, and following in line with FDA guidelines, the Trallers asked Genentech, Bristol-Myers Squibb and Merck for access on a Compassionate Use basis to their experimental treatments, but were denied by all three companies.¹⁰⁵ It took many months of social media campaigns, media coverage, letters to drug companies and politicians, before the Trallers successfully convinced Genentech to provide Nathalie an exception to access their drug.¹⁰⁶ Unfortunately, months had passed and Genentech's drug was only one piece of a combination of treatments that Nathalie needed to recover.¹⁰⁷ Nathalie passed away before she had the opportunity to access any other experimental treatments, she was only 16-years-old.¹⁰⁸

⁹⁹Tirrell, *supra* note 86.

¹⁰⁰*Id.*

¹⁰¹*Bereaved Family Calls For Change in The Law After Teenage Daughter Died When She Was Denied Cancer Drugs*, (Apr. 27, 2013), <http://www.dailymail.co.uk/news/article-2315818/Debbie-Binner-Bereaved-family-calls-change-law-teenage-daughter-Chloe-Drury-died-denied-cancer-drugs.html>.

¹⁰²Tirrell, *supra* note 86; #4nathalie, <https://twitter.com/hashtag/4nathalie?src=hash> (last visited Aug. 15, 2017).

¹⁰³*Id.*

¹⁰⁴*Id.*

¹⁰⁵*Id.*

¹⁰⁶ Anna Marum, *Remembering Nathalie Traller, a Fighter to The End*, (Oct. 10, 2015), http://www.oregonlive.com/beaverton/index.ssf/2015/10/remembering_nathalie_traller.html.

¹⁰⁷*Id.*

¹⁰⁸*Id.*

While pressure on pharmaceutical companies has proven to be effective in some cases, terminally ill minors do not always have the luxury of time.¹⁰⁹ Further, such social media battles require the minor's parent(s) or legal caretaker(s) be available to launch a full out attack on the companies that deny the experimental treatments. Not to mention, "[t]he issue of who gets the drug and who doesn't" based on the publicity of their story raises inequity in the system¹¹⁰ and stems concern that the overall right to try conflict is not truly being resolved. "Patients whose stories are more appealing or who have more social media savvy may attract more attention than others with equal need."¹¹¹ In addition, rather than companies expanding access to Compassionate Use, many are focusing on ensuring their policies and guidelines for this matter are in place and that they have fully vetted patient groups and bioethicists such that they can hold firm in the event of becoming subject to any future social media campaign against them.¹¹²

Right to Try laws have attempted to act as a curative measure that may bridge the gap to experimental treatments.¹¹³ Most recently, the federal legislation "Right to Try Act" that would bolster state Right to Try laws has been introduced to the House and Senate.¹¹⁴ Critics refer to these new laws as misguided for their focus on the FDA's involvement rather than looking at the major roadblock; a lack of mandates on companies to provide the drugs.¹¹⁵ For minors with terminal illness, taking the FDA out of the equation may only cause further harm.¹¹⁶ Some believe that children, already in poor health, will fall victim to the withdrawal of the FDA's review and that those treating children should encourage FDA involvement, particularly with regards to the dosage of drugs given children.¹¹⁷ Additionally, many believe these patients already

¹⁰⁹Tirrell, *supra* note 86.

¹¹⁰*Id.*

¹¹¹*Id.*

¹¹²*Id.*

¹¹³*Id.*

¹¹⁴Marie McCullough, *For The Terminally Ill, Are 'Right-to-Try' Laws Offering a Lifeline, or False Hope?*, (Apr. 10, 2017), <http://www.philly.com/philly/health/Do-Right-to-Try-laws-offer-a-lifeline-or-false-hope-to-the-terminally-ill.html>.

¹¹⁵Tirrell, *supra* note 86.

¹¹⁶Richard L. Plotkin, *'Right to Try' is a Sham*, THE HILL (Feb. 13, 2017), <http://thehill.com/blogs/congress-blog/healthcare/319171-right-to-try-is-a-sham>.

¹¹⁷*Id.* ("[t]hese children are in poor health and those treating them typically do, and always should, welcome the review by the FDA with respect to, among other things, the dosage of the drug given to these children"); McCullough, *supra* note 120 (Where Compassionate Use offers legal protections, these constraints are removed under the Right to Try legislation for physicians, hospitals, institutional review boards (IRB), parents of minor children, and the Goldwater Institute. These parties will have the

have a route by which to get access to experimental treatments outside clinical trials, through Compassionate Use.

The need to improve access to and development of experimental treatments in minors is not new to Congress.¹¹⁸ In 2003, the Pediatric Research Equity Act (PREA) was passed by Congress in an effort to require drug companies to test experimental drugs being developed for adults in minors as well.¹¹⁹ However, various loopholes helped pharmaceutical companies from having to comply where the treatment was for the purpose of a non-pediatric condition.¹²⁰ This exempted a large number of conditions, including adult cancers that occur in different organs than pediatric cancers.¹²¹ Senator Michael Bennet of Colorado, a Democrat, sums up the inequity of new cancer treatments for children, “[o]ver the last 20 years, the Food and Drug Administration has approved roughly 190 new cancer treatments for adults but just three new treatments for children.”¹²²

On August 3, 2017, the Senate passed the Right to Try Act of 2017 that potentially expands access to experimental treatments for people with terminal illnesses.¹²³ The bill was introduced to the House on February 6, 2017,¹²⁴ where more than three dozen lawmakers have endorsed similar legislation.¹²⁵ The need to expand access to experimental treatments is clearly known to patients, physicians, lawmakers, and pharmaceutical companies. However, the disparity between adults and minors raises concern for whether future legislation will bridge this gap and ensure children are provided for equally.

THE CONSTITUTIONAL DEBATE FOR THE RIGHT TO DIE

As stated, the Supreme Court in *Glucksberg*, through due process analysis, did not determine that assisted suicide was a fundamental right

potential to be sued in state and federal court. However, producers, manufacturers, distributors, prescribers, dispensers, possessors or users, will be protected).

¹¹⁸Charles Schmidt, *Children with Cancer get More Access to Experimental Drugs: New U.S. Law Will Require Pediatric Cancer Clinic Trials*, (Aug. 11, 2017), available at <http://www.schmidtwriting.com/articles/experimental-cancer-drugs.pdf>.

¹¹⁹*Id.*

¹²⁰*Id.*

¹²¹*Id.*

¹²²Robert Pear & Sheila Kaplan, *Senate Passes F.D.A. Funding and ‘Right to Try’ Drug*, THE NEW YORK TIMES (Aug. 3, 2017), <https://www.nytimes.com/2017/08/03/us/politics/fda-senate-experimental-drugs-terminally-ill-patients.html?mcubz=0>.

¹²³*Id.*

¹²⁴H.R.878 - Right to Try Act of 2017, (Jan. 14, 2018),

<https://www.congress.gov/bill/115th-congress/house-bill/878>

¹²⁵*Id.*

in the United States.¹²⁶ However, twenty years have passed since the controversial decision and in that time major judicial decisions, state legislative action, and international legalization may drive future debates on the topic to a different conclusion. The Court has only looked at the debate as it applies to terminally ill competent persons and not terminally ill minors that lack end-of-life decision making authority.¹²⁷ Further, it has yet to be determined whether terminally ill minors denied access to experimental treatments, afforded no chance of future recovery, suffering from end stage disease symptoms, are in equal position as terminally ill adults (whom have the right in select states) to physician assisted suicide. The following discusses the Supreme Court's due process analysis in *Glucksberg*, a review of the history involved in the right to die debate, and developments in the years since the Court's decision in favor of right to die advocates.

Due Process Analysis

Under the Due Process Clause of the Fourteenth Amendment, no state shall "deprive any person of life, liberty, or property, without due process of law."¹²⁸ Established by the Court in *Griswold v. Connecticut*, "the concept of liberty protects those personal rights that are fundamental, and is not confined to the specific terms of the Bill of Rights."¹²⁹ Of these personal rights, the Court in *Glucksberg* notes, the liberty component of the Due Process Clause to include the right to marry, to have children, to direct the education and upbringing of one's children, to marital privacy, to use contraception, to bodily integrity, and to abortion.¹³⁰ It is these certain fundamental rights and liberty interests that are provided heightened protection against governmental interference.¹³¹

Importantly, the Court also explained that it must, "exercise the utmost care whenever we are asked to break new ground in this field, lest the liberty protected by the Due Process Clause be subtly transformed into the policy preferences of the Members of this Court."¹³² The careful responsibility of identifying a liberty interest, "has not been reduced to any formula."¹³³ However, the Court has consistently looked at whether

¹²⁶See *Glucksberg*, 521 U.S. 702 at 723-24.

¹²⁷*Id.* at 735.

¹²⁸U.S. CONST. amend XIV, § 1.

¹²⁹*Griswold v. Connecticut*, 381 U.S. 479, 486 (1965).

¹³⁰See *Glucksberg*, 521 U.S. 702 at 720.

¹³¹*Griswold*, 381 U.S. 479 at 488.

¹³²See *Glucksberg*, 521 U.S. 702 at 720.

¹³³*Obergefell v. Hodges*, 135 S. Ct. 2584, 2598 (2015); *Poe v. Ullman*, 367 U.S. 497, 542 (1961).

the asserted right was, “objectively deeply rooted in this Nation’s history and tradition” or “implicit in the concept of ordered liberty such that neither liberty nor justice would exist if they were scarified.”¹³⁴

With regards to history and tradition, the Court notes that “[h]istory and tradition guide and discipline this inquiry but do not set its outer boundaries.¹³⁵ That method respects our history and learns from it without allowing the past alone to rule the present.”¹³⁶ Further, the Court acknowledges that these liberty interests may change with the times, that the Nation’s founding fathers, whom wrote and ratified the Bill of Rights and Fourteenth Amendment did not account for all the freedoms “in all its dimensions.”¹³⁷ Therefore, it is up to future generations to establish these freedoms as they develop in time.¹³⁸ “When new insight reveals discord between the Constitution’s central protections and a received legal stricture, a claim to liberty must be addressed.”¹³⁹ Where the Court establishes a fundamental liberty interest, the Fourteenth Amendment “forbids the government to infringe. . . unless the infringement is narrowly tailored to serve a compelling state interest.”¹⁴⁰

The Relevant History of Suicide, Assisted Suicide, and Euthanasia for Due Process Analysis

The debate over assisted suicide and euthanasia is one that has its roots in history. And as Dr. Haider Warraich states, “is littered with unhinged characters.”¹⁴¹ Before establishing the dark background to which these characters contribute to this recent constitutional dilemma, it is prudent that a discussion on the history of suicide, euthanasia, and assisted suicide be relevant.

Federal courts have often invoked the history test when dealing with substantive due process rights.¹⁴² One of the earliest cases to use the history test for deciding substantive due process fundamental liberty interests was *Snyder v. Massachusetts*.¹⁴³ The court held the state free to regulate their courts, “in accordance with its own conception of policy and fairness, unless in so doing it offends some principle of justice so rooted in the traditions and conscience of our people as to be ranked as

¹³⁴*Glucksberg*, 521 U.S. 702 at 721-22.

¹³⁵*Obergefell*, 135 S. Ct. 2584 at 2598.

¹³⁶*Id.*

¹³⁷*Id.* at 2629.

¹³⁸*Id.*

¹³⁹*Id.*

¹⁴⁰*Glucksberg*, 521 U.S. 702 at 721-22.

¹⁴¹WARRAICH, *supra* note 14, at 230.

¹⁴²GORSUCH, *supra* note 12, at 19.

¹⁴³*Id.*; *Snyder v. Com. of Mass.*, 291 U.S. 97, 105 (1934).

fundamental.”¹⁴⁴ The history standard instilled by the Court in *Snyder* ‘is now itself deeply rooted in substantive due process jurisprudence.’¹⁴⁵ Advocates in favor hold the history test to be “a comparatively objective approach to due process adjudication” in comparison to tests which focus on the “demands of personal autonomy” and “reasoned judgement.”¹⁴⁶ However, there remains a methodological dispute over the ‘level of historical abstraction’ and ‘which history’ should be considered in such analysis.¹⁴⁷

Justice Gorsuch discusses the debate over the level of historical abstraction by analogizing and distinguishing the Court’s differing opinions in *Michael H. v. Gerald D.*¹⁴⁸ Drawing from *Michael H.* to illustrate this point, Gorsuch discussed the opposing viewpoints of Justice Scalia, joined by Chief Justice Rehnquist to that of Justices O’Connor and Kennedy regarding the relevant level of specificity substantive due process inquiries should refer.¹⁴⁹ Justice Scalia and Chief Justice Rehnquist argued that such inquiries required the “most specific level at which a relevant tradition protecting, or denying protection to the asserted right can be identified.”¹⁵⁰ Justices O’Connor and Kennedy argued that the Court, “had not always examined—and need not always rely on—the most specific level of tradition available.”¹⁵¹ Further, they argued the Court, “has legitimately examined history at a more ‘general’ level.”¹⁵²

Justice Gorsuch applied the Justice’s opposing viewpoints to distinguish the Ninth Circuit Judge Reinhardt’s opinion in *Compassion in Dying v. State of Washington* to that of the Supreme Court’s decision (and overruling) in *Washington v. Glucksberg*.¹⁵³ Similar to the opinions of Justices Scalia and Rehnquist, the majority in *Glucksberg* was, “focusing only on the narrow question whether history supports a right to assistance in suicide.”¹⁵⁴ Whereas Judge Reinhardt’s focus in *Compassion in Dying*, is more similar to the opinions of Justices

¹⁴⁴*Id.*

¹⁴⁵GORSUCH, *supra* note 12, at 20.

¹⁴⁶*Id.*

¹⁴⁷*Id.*

¹⁴⁸*Id.*; See generally *Michael H. v. Gerald D.*, 491 US 110 (1989) (Court held a possible biological father does not have a fundamental right to obtain parental rights after the presumptive father has exercised significant responsibility over the child).

¹⁴⁹*Id.*

¹⁵⁰GORSUCH, *supra* note 12, at 112.

¹⁵¹*Id.*

¹⁵²*Id.*

¹⁵³*Glucksberg*, 521 U.S. 702 at 728.

¹⁵⁴GORSUCH, *supra* note 12, at 112.

O'Connor and Kennedy, in that it focused on the legal history of suicide generally and not just that of assisted suicide.¹⁵⁵

By narrowly confining the history and tradition aspect of its analysis,¹⁵⁶ the Court in *Glucksberg*, notwithstanding the acknowledgement of changes in medical technology and an increased emphasis on the importance of end-of-life decision making, determined there was only a history of rejection when it came to physician assisted suicide.¹⁵⁷ The Court held, "The history of the law's treatment of assisted suicide in this country has been and continues to be one of the rejection of nearly all efforts to permit it."¹⁵⁸ In stark contrast, Judge Reinhardt, reviewing *en blanc* in *Compassion in Dying*, offered a more broad view of the legal history of suicide as a whole rather than that of physician assisted suicide alone.¹⁵⁹ He claimed that the inquiry at hand was "not so narrow as to be unknown to the past" nor was its "conclusion so facile."¹⁶⁰

Justice Gorsuch argues that the opinions of Justices O'Connor and Kennedy in *Michael H.* are faulty because their argument relies on unclear precedent and does not define with certainty whether a specific tradition can be disregarded in favor of more general tradition.¹⁶¹ However, looking to the Court's decision in *Glucksberg*, one may find some fault with this argument. The Court refers numerous times to the history of suicide (as opposed to the specific history of assisted suicide) to dispel arguments that society's view of suicide has changed throughout history to one which is accepting and no longer felonious.¹⁶² The Court argued that American Colonies abolishment of harsh common law sanctions for suicide were not evidence of the acceptance of suicide but rather, "the growing consensus that it was unfair to punish the suicide's family for his wrongdoing."¹⁶³ It seems from this analysis that reference to general traditions and history of suicide may be acceptable where the Court may find such reference to be valuable to their argument only. The Court argued that even though states moved away from harsh sanctions, they continued "to condemn it as a grave public wrong."¹⁶⁴ It went on to say that "suicide remained a grievous, though non-felonious,

¹⁵⁵*Id.*

¹⁵⁶*Id.*

¹⁵⁷*Glucksberg*, 521 U.S. 702 at 728.

¹⁵⁸*Id.*

¹⁵⁹GORSUCH, *supra* note 12, 20-21.

¹⁶⁰*Compassion in Dying v. State of Wash.*, 79 F.3d 790, 806 (9th Cir. 1996).

¹⁶¹GORSUCH, *supra* note 12, at 21.

¹⁶²*Glucksberg*, 521 U.S. 702 at 713-14.

¹⁶³*Id.*

¹⁶⁴*Id.*

wrong [is] confirmed by the fact that colonial and early state legislatures and courts did not retreat from prohibiting assisting suicide.”¹⁶⁵ This statement attempts to connect the specific prohibition of assisted suicide during this time in history as a justification that society still truly had a negative view of suicide in general, despite the change in American law to no longer classify suicide as a felony. While the Court claims to be focusing only on the specific aspect of assisted suicide, it seems unable to fully capture the essence to prove its point without relying on the more general history of suicide itself. Once again, the Court used the specific prohibitions on assisted suicide at the time, to justify why suicide generally was not historically viewed with acceptance. The Court seemingly used the general history of suicide and specific history of assisted suicide to prove its point.

While the analysis does not answer Justice Gorsuch’s concern over whether specific traditions may be ignored and more general preferable traditions considered when analyzing substantive due process rights, it does bring light to the fact that the Court seemingly uses the available history and traditions, whether general or specific, to get an overall understanding of whether such right existed throughout history. As Justice Gorsuch does himself in his own analysis, for purposes here, both the general history of suicide as well as the specific history of assisted suicide and euthanasia, throughout the world are considered.¹⁶⁶

HISTORY OF SUICIDE, EUTHANASIA, AND ASSISTED SUICIDE

Ancient Greek and Roman Times

It is believed that euthanasia started in ancient Greece and Rome around the fifth century B.C.¹⁶⁷ Specifically, euthanasia and physician assisted suicide was first accepted and mainstreamed by ancient Greek society.¹⁶⁸ “While the ancient Greeks valued health above all other virtues, they did not consider prolonging life at all costs to be a duty of

¹⁶⁵*Id.*

¹⁶⁶GORSUCH, *supra* note 12, at 22 (“For now, however, the question we face is: given the history test as we know it today, methodological warts and all, what can be said about assisted suicide and euthanasia from the historical record? To attempt to answer this question, we must examine as broad a historical record as possible, consulting the ancients as well as more directly relevant English, colonial, and American history examining both the specific history of assisted suicide and euthanasia and the more generally relevant history of suicide”).

¹⁶⁷*Brief History of Euthanasia*, (Dec. 20, 2016), <http://iands-euthanasia.blogspot.com/2012/05/brief-history-of-euthanasia.html>.

¹⁶⁸WARRAICH, *supra* note 14, at 232.

the physician unless it was specifically desired by the patient.”¹⁶⁹ During this time, physicians aided patients in dying whom had bladder stones and headaches through cutting their veins.¹⁷⁰ Some physicians would even provide poison to patients when asked.¹⁷¹ Other practices included the performance of abortions and mercy killings.¹⁷² While many philosophers made strong arguments against suicide during this time, including Plato and Aristotle,¹⁷³ there is strong and specific evidence regarding the actual practices that took place by physicians aiding the terminally ill.

Christianity

While the Bible does not explicitly forbid suicide it is evident that from the earliest of teachings it has been forbidden.¹⁷⁴ “Christianity has always held that human life is the property of God, a gift that we must preserve under all circumstances.”¹⁷⁵ Following the end of ancient times, the Roman emperor, Constantine the Great, converted to Christianity and brought its values to the entire Roman Empire, especially in Europe.¹⁷⁶ Philosophers had strong influence over the laws of Europe and its interpretation of Christianity at this time.¹⁷⁷ Saint Augustine¹⁷⁸ argued that intentional self-destruction generally constituted a violation of the Sixth Commandment.¹⁷⁹ It was his belief—stemming from, “thou shalt not kill,” —that “self-killing” was a simple violation of one of the ten Commandments.¹⁸⁰ He further feared that the permission of intentional

¹⁶⁹*Id.*

¹⁷⁰*Id.*

¹⁷¹*Brief History of Euthanasia, supra* note 180, at 169.

¹⁷²*Id.*

¹⁷³GORSUCH, *supra* note 12, at 22.

¹⁷⁴*Id.* at 25.

¹⁷⁵WARRAICH, *supra* note 14, at 234.

¹⁷⁶*Id.*

¹⁷⁷*Id.*

¹⁷⁸St. Augustine of Hippo, (Jan. 18, 2018), <http://www.religionfacts.com/augustine> (Saint Augustine, also known as Augustine of Hippo, was a theologian in the history of the Christian religion that had great impact on both Roman Catholicism and Protestantism. His works focused on subjects such as “grace, the Trinity, the soul, predestination, the sacraments, sexuality and free will.” These works were “an important part of the ‘baptism’ of Greek thought and its entrance into the Christian, and subsequently the European, intellectual tradition”).

¹⁷⁹GORSUCH, *supra* note 12, at 25 (“It is not without significance, that in the holy canonical books, no divine precept or permission can be discovered which allows us to bring about our own death, either to obtain immortality or to avert some evil. On the contrary, we must understand the Law of God as forbidding us to do this, where it says, ‘Thou shalt not kill’”).

¹⁸⁰Dwight G. Duncan, and Peter Lubin, *The Use and Abuse of History in Compassion In Dying*, 27 (1996).

self-destruction would lead down a slippery slope.¹⁸¹ Further building upon this notion against suicide, Saint Thomas Aquinas¹⁸² held it was “unnatural, sinful, and unconstructive to society.”¹⁸³ As a result, the teachings of Augustine and Aquinas influenced Christian law and practice,¹⁸⁴ and for almost two millennia suicide in any form was viewed as illegal and therefore punishable in Europe.¹⁸⁵

It was not until the Renaissance that Christianity’s view regarding suicide was challenged.¹⁸⁶ During this period, the question of man’s right to die became of interest to society.¹⁸⁷ Ironically, it remains of interest today. Sir Thomas More’s¹⁸⁸ prominent book *Utopia* expressed an advanced attitude toward dying in a utopian society:

They console the incurably ill by sitting and talking with them and by alleviating whatever pain they can. Should life become unbearable for these incurables the magistrates and priest do not hesitate to prescribe euthanasia. . . . When the sick have been persuaded of this, they end their lives willingly either by starvation or drugs, that dissolve their lives without any sensation of death. Still, the Utopians do not do away with anyone without his permission, nor lessen any of their duties to him.¹⁸⁹

Sir Moore’s view of euthanasia in a utopian society was even referenced by Judge Reinhardt in *Compassion in Dying* to express the changing viewpoints of the time with regards to Christian opposition to suicide in any form.¹⁹⁰ Reinhardt used the viewpoints of philosophers, poets, and clergymen to evidence that the historical Christian opinion on suicide as a wrong in all forms was not as commonplace as believed and in many cases was challenged by society even in the era of the middle

¹⁸¹GORSUCH, *supra* note 12, at 27.

¹⁸²St. Thomas Aquinas, (Jan. 18, 2018), <https://www.biography.com/people/st-thomas-aquinas-9187231>; St. Thomas Aquinas, (Jan. 18, 2018), <https://hist2615.wikispaces.com/St.+Thomas+Aquinas> (Saint Thomas Aquinas was a Philosopher and theologian that combined the theological principles of faith with the philosophical principles of reason. The rediscovery of Aristotelian works in the thirteenth century posed a potential challenge to the Church and needed to be adapted and reconciled to contemporary doctrine and thought. Aquinas made this his ‘great enterprise.’ “Rather than discounting Aristotelian thought . . . Aquinas interpreted it in a way that made it compatible with Christian faith.” The premise of this work rested on the notion that reason and religion are in harmony, and not opposition).

¹⁸³WARRAICH, *supra* note 14, at 234.

¹⁸⁴GORSUCH, *supra* note 12, at 28.

¹⁸⁵WARRAICH, *supra* note 14, at 234.

¹⁸⁶*Id.*

¹⁸⁷*Id.*

¹⁸⁸*Id.* (“Sir Thomas More was Lord Chancellor during the reign of Henry VIII and a prominent member of the Catholic Church. . .”).

¹⁸⁹*Id.*

¹⁹⁰*Compassion in Dying*, 79 F.3d 790, at 808.

ages.¹⁹¹ Reinhardt held that Sir More's view, "strongly supported the right of the terminally ill to commit suicide and also expressed approval of the practice of assisting those who wished to hasten their deaths."¹⁹²

Francis Bacon¹⁹³ in 1605 continued the debate by suggesting doctors do more to provide the dying with outward euthanasia and provide alleviation to pain and suffering.¹⁹⁴ In 1775, Philosopher David Hume¹⁹⁵ declined to share his essays "On Suicide" and "On the Immortality of the Soul" out of concern over the controversy they may enrage.¹⁹⁶ The essays were released after his death, and while they do not discuss euthanasia, a more intimate opinion on suicide and suffering can be found.¹⁹⁷ "That suicide may often be consistent with interest and with our duty to ourselves, no one can question, who allows that age, sickness, or misfortune, may render life a burden, and make it worse even than annihilation."¹⁹⁸ While Hume held general disapproval of suicide, his essays evidence a strong opposition to laws making suicide illegal.¹⁹⁹ However, not all scholars were challenging Christianity's prohibition of suicide in all forms.²⁰⁰ John Locke²⁰¹ held "since humans were created by God, self-harm would amount to infringing on the property rights of God."²⁰² Locke consistently opposed suicide in any shape or form.²⁰³

There have been clear advocates on both sides of the historical debate regarding Christianity's view of suicide. In 1995, Pope John Paul II, held "Euthanasia [to be] a grave violation of the law of God, since it is

¹⁹¹*Id.*

¹⁹²*Id.*

¹⁹³Francis Bacon, (Jan. 18, 2018), <https://www.biography.com/people/francis-bacon-9194632> ("Bacon served as attorney general and Lord Chancellor of England, resigning amid charges of corruption." Bacon was also a philosopher that "took up Aristotelian ideas, arguing for an empirical, inductive approach, known as the scientific method, which is the foundation of modern scientific inquiry").

¹⁹⁴WARRIACH, *supra* note 14, at 235 (Bacon distinguished between inward and outward euthanasia. Inward euthanasia represented a peaceful passing of the soul. Outward euthanasia represented a pain- and distress-free death of the body).

¹⁹⁵David Hume, (Jan. 18, 2018), <https://www.britannica.com/biography/David-Hume> (David Hume was a "Scottish philosopher, historian, economist, and essayist known especially for his philosophical empiricism and skepticism. Hume conceived of philosophy as the inductive, experimental science of human nature").

¹⁹⁶WARRIACH, *supra* note 14, at 235

¹⁹⁷*Id.*

¹⁹⁸*Id.*

¹⁹⁹*Id.* at 236.

²⁰⁰*Id.*

²⁰¹John Locke, (Jan. 18, 2018), <https://www.britannica.com/biography/John-Locke> (John Locke was an "English philosopher whose works lie at the foundation of modern philosophical empiricism and political liberalism. He was an inspirer of both the European Enlightenment and the Constitution of the United States").

²⁰²WARRIACH, *supra* note 14, at 236.

²⁰³*Id.*

the deliberate and morally unacceptable killing of a human person.”²⁰⁴ The Roman Catholic Church holds euthanasia to be a moral wrong.²⁰⁵ Further, the church has “always taught the absolute and unchanging value of the commandment ‘You shall not kill.’”²⁰⁶ More recently, Pope Francis has also condemned physician assisted suicide by claiming it “is part of a ‘throwaway culture’ that offers a ‘false compassion’ and treats a human person as a problem.”²⁰⁷

Importantly, while these viewpoints are evidence of Christian values that have refused to waiver in spite of changing times, this is not determinative in and of itself. The Roman Catholic Church also holds that “nothing and no one can in any way permit the killing of an innocent human being, whether a fetus or an embryo, an infant or an adult, an old person, or one suffering from an incurable disease, or a person who is dying.”²⁰⁸ While the Church recognizes the existence of life from the moment of conception this did not affect the Court’s decision in *Roe v. Wade*.²⁰⁹ While the Court was clear not to rule on whether life beings at conception or birth they did instill some input, “[i]n short, the unborn have never been recognized in the law as persons in the whole sense.”²¹⁰ The Court refused to allow Texas to adopt one theory of life as justification against the debate over abortion.²¹¹

While, the practice of Christianity has evidenced a strong history of opposition to suicide in any form, there is equally strong evidence that both practice and societal opinion on the matter is not unwavering and one-sided.²¹² For example, opposition to assisted suicide for individuals suffering the pain of terminal illness runs counterintuitive to certain other Christian values²¹³ Included among these values is the belief that all human beings require respect.²¹⁴ If we respect a person we should respect their decisions about the end of their life.²¹⁵ Therefore, Christians

²⁰⁴Pope John Paul II, *Evangelium Vitae*, 1995, available at http://w2.vatican.va/content/john-paul-ii/en/encyclicals/documents/hf_jp-ii_enc_25031995_evangelium-vitae.html.

²⁰⁵*Euthanasia and assisted dying*, Last updated Mar. 8, 2009, (Mar. 2, 2017), http://www.bbc.co.uk/religion/religions/christianity/christianethics/euthanasia_1.shtml.

²⁰⁶*Id.*

²⁰⁷*Pope Francis: Let’s be clear – assisted suicide is ‘false compassion’*, (Mar. 4, 2017), <http://www.catholicnewsagency.com/news/pope-francis-lets-be-clear-assisted-suicide-is-false-compassion-79396/>.

²⁰⁸*Euthanasia and assisted dying*, *supra* note 205.

²⁰⁹*Roe v. Wade*, 410 U.S. 113, 162 (1973).

²¹⁰*Id.*

²¹¹*Id.*

²¹²*Euthanasia and assisted dying*, *supra* note 205.

²¹³*Id.*

²¹⁴*Id.*

²¹⁵*Id.*

should accept a persons' rational decision to refuse burdensome and futile treatment and should accept their rational decision to refuse excessively burdensome treatment even if it may provide several weeks more of life.²¹⁶

English Common Law

Early Christian history is highly relevant to English common law development because of its influence on the law's initial view of suicide.²¹⁷ This statement was evident to the Court in *Glucksberg*, as their discussion begins with an analysis of the history and traditions of assisted suicide with the discussion on one of the 13th century's first legal-treatise writers, Henry de Bracton.²¹⁸ Bracton endorsed the Roman statute holding "a felon intentionally taking his life to escape punishment by the state was subject to having both his movable goods and real property confiscated."²¹⁹ However, Bracton did seek a lesser penalty for those who undertook suicide out of "weariness with life or abhorrence of pain"²²⁰ These individuals did not lose both their moveable goods and real property, but rather, as Bracton believed should only be punished with the loss of his moveable goods.²²¹ The Court contended that this idea was English common law's introduction to the principle that suicide by a sane person was a punishable felony.²²²

The Court also addresses Sir William Blackstone's²²³ later contributions to common law's development of laws against suicide as a major contribution and primary legal authority for 18th and 19th century American law.²²⁴ Blackstone referenced suicide as "self-murder"²²⁵ He went so far as to criticize "the pretended heroism, but real cowardice of the Stoic philosophers, who destroyed themselves to avoid those ills which they had not the fortitude to endure."²²⁶

²¹⁶*Id.*

²¹⁷GORSUCH, *supra* note 12, at 28.

²¹⁸*Glucksberg*, 521 U.S. 702 at 711.

²¹⁹GORSUCH, *supra* note 12, at 28.

²²⁰*Id.* at 29.

²²¹*Glucksberg*, 521 U.S. 702 at 711.

²²²*Id.*

²²³ Sir William Blackstone, (Jan.18, 2018)

<https://www.britannica.com/biography/William-Blackstone> ("Air William Blackstone was an English jurist, whose *Commentaries on the Laws of England*, 4 vol. (1765–69), is the best-known description of the doctrines of English law. The work became the basis of university legal education in England and North America").

²²⁴*Glucksberg*, 521 U.S. 702 at 711-12.

²²⁵*Id.*

²²⁶GORSUCH, *supra* note 12, at 29.

Here, the Court relied on the general history of suicide and the common law felony development against it. However, the Court's analysis pointed out that notable scholars during this period were also grappling with the issue of compassion for the terminally ill. It appeared that Bracton may have felt compassion for those suffering as well as their families. That is, individuals in weary situations and bodily pain should not be punished as those who were sane and guilty of the commission of suicide. The compassion and acceptance of suicide and possible exceptions in which society at the time, believed should exist offer some insight. The concept of an individual in pain and suffering, such as the terminally ill, was not so non-existent at this time as the Court might lead one to believe.

American Colonial Law

Following contemporary English common law, pre-Revolutionary American Colonies also penalized suicide through forfeiture acts.²²⁷ Unlike English common law, ancient pagan practices to dishonor the suicide's corpse were also followed for some time.²²⁸ While the law of forfeiture was practiced as late as 1707, often such penalty was never provided because a governor would step in to protect the family of the decedent.²²⁹

Both England and America formally abolished the harsh common law penalties on suicide.²³⁰ America began abolishing criminal penalties associated with suicide during the eighteenth century.²³¹ As previously discussed, there was much dispute in *Glucksberg* over the historical change in suicide laws at the time.²³² The Court in *Glucksberg* claimed the change to no longer make suicide a felonious crime was only a reflection of society's consensus that punishing the family for the decedent's crime was unfair.²³³ While this argument carried weight and essentially aided in overruling *Compassion in Dying*, evidence of the contrary remains relevant to potential future debates.²³⁴

The purpose of law reform comes from the desire to incorporate change in our society over time, and ensure our laws reflect the views

²²⁷*Id.*

²²⁸*Id.*

²²⁹*Id.* at 30.

²³⁰*Id.*

²³¹*Id.*

²³²*Glucksberg*, 521 U.S. 702 at 712-13.

²³³*Id.*

²³⁴GORSUCH, *supra* note 12, at 31.

and values of our citizens.²³⁵ “Law reform is the process of changing and updating laws so that they reflect the current values and needs of modern society.”²³⁶ The Court in *Glucksberg* conveniently does not discuss this simple and clear reason for the abandonment of laws punishing suicide during the eighteenth and nineteenth centuries, that is law reform and the desire to reflect society’s view on the topic of suicide at that time. Additionally, Thomas Jefferson²³⁷ recognized that not only were laws punishing suicide and attempted suicide enforced only in ‘barbarous times,’ he also recognized the growing consensus that suicide often betokened a medical problem.²³⁸ While it is impossible to know for sure what caused the change in law, it seems suspicious that the Court overlook the most obvious of reasons—law reform as a reflection of society’s values.

PROHIBITION OF ASSISTED SUICIDE IN THE UNITED STATES

Importantly, while laws penalizing suicide were abolished, laws began to develop prohibiting euthanasia and assisted suicide.²³⁹ Originally, laws against assisting in suicide drew distinction between assistants present at the decedent’s death and those that left the suicide before, only providing the suicide with the means.²⁴⁰ Those people present at the death could be tried for manslaughter or murder while those clever enough to leave prior were held innocent of any crime.²⁴¹ This was consistent with ancient common law doctrine, “assistants before the fact of any crime could not be tried until the principal criminal actor was convicted.”²⁴² As a result of the suicide’s death, there was not a way for courts to try the assistant for the crime.²⁴³ By 1861, states enacted to abolish the distinctions between accessories before and after the fact.²⁴⁴ As a result, courts determined that they could hold assistants to suicide liable for murder or manslaughter.²⁴⁵ Assisted suicide statutes

²³⁵WHAT IS LAW REFORM? (Mar. 4, 2017), <http://lawgovpol.com/what-is-law-reform/>.

²³⁶*Id.*

²³⁷Thomas Jefferson, (Jan. 18, 2018), <http://www.history.com/topics/us-presidents/thomas-jefferson> (Thomas Jefferson was an author of the Declaration of Independence and the third U.S. president).

²³⁸GORSUCH, *supra* note 12, at 31.

²³⁹*Id.* at 32.

²⁴⁰*Id.*

²⁴¹*Id.*

²⁴²*Id.*

²⁴³*Id.*

²⁴⁴GORSUCH, *supra* note 12, at 32.

²⁴⁵*Id.*

were codified as a crime in most jurisdictions.²⁴⁶ “By the time the Fourteenth Amendment was ratified in 1868, nine of the then thirty-seven states had adopted statutes making assisted suicide a crime.”²⁴⁷

While the states did develop and reform the laws for assisted suicide. It seems important that originally, there were protections for those assisting with suicide. Whether the assistant was providing the poison or the gun, the law prohibited their prosecution. This stipulation may have been a conscious effort to prevent those who did not perform the actual act from facing penalties because society believed that there were instances where such assistance may be provided out of compassion. The Court in *Glucksberg* conveniently leaves out this history from its analysis and immediately discusses assisted suicide laws as having always been the standard throughout the country’s history.²⁴⁸ The Court describes it as “the well-established common-law” that advisors assisting in the commission of suicide were guilty of murder.²⁴⁹

Current Status of Suicide, Euthanasia, and Assisted Suicide in the United States and Internationally

Aftermath of *Washington v. Glucksberg* and *Vacco v. Quill* Decisions in the United States

Due to the immediate consequence of the Supreme Court’s rulings in *Glucksberg* and *Quill*, assisted suicide is a question left to the states and the political process.²⁵⁰ Chief Justice Rehnquist stressed as much in the holding of *Glucksberg*.²⁵¹ He went on to state that “Americans are engaged in an earnest and profound debate about the morality, legality, and practicality of physician-assisted suicide. Our holding permits this debate to continue, as it should in a democratic society.”²⁵² However, *Roe v. Wade* and *Planned Parenthood v. Casey*, were also riddled in the morality, legality, and practicality of abortion laws, to which the Supreme Court determined their involvement to be essential.²⁵³ Thus, the Court’s involvement may not be precluded from future debate.

In the twenty years following *Glucksberg*, much has developed in how the United States views assisted suicide for adults. Oregon Right to Die was founded in 1993 to write and pass the Oregon Death with

²⁴⁶ *Id.* at 33.

²⁴⁷ *Id.*

²⁴⁸ *Glucksberg*, 521 U.S. 702 at 714-15.

²⁴⁹ *Id.*

²⁵⁰ GORSUCH, *supra* note 12, at 17.

²⁵¹ *Glucksberg*, 521 U.S. 702 at 735.

²⁵² *Id.*

²⁵³ See generally *Roe v. Wade*, 410 U.S. 113 (1973); *Planned Parenthood of Se. Pennsylvania v. Casey*, 505 U.S. 833 (1992).

Dignity Act.²⁵⁴ The goal was to define an effective policy and model legislation, and to defend it against legal challenges in both state and federal courts.²⁵⁵ After a successful campaign, Oregon voters approved the Death with Dignity ballot initiative that would go on to create the Oregon Death With Dignity Act (DWDA).²⁵⁶ The DWDA allowed terminally ill patients to hasten death in consultation with their physician and under strict safeguards.²⁵⁷ As a result, Oregon was the first state to officially legalize medical aid in dying.²⁵⁸ The Act has been successfully used by other states to draft similar legislation.²⁵⁹ Additionally, it has been challenged by the U.S. Attorney General Ashcroft, who attempted to block its effectiveness through the authorization of federal drug agents to prosecute doctors that prescribed life-ending medication to help terminally ill patients die.²⁶⁰ The Supreme Court ruled in favor of the DWDA, stating that Ashcroft overstepped his authority.²⁶¹ In the following years, the states of California, Colorado, Vermont, District of Columbia, and Washington have passed legislation legalizing death with dignity laws.²⁶² Further, the Montana Supreme Court has ruled in favor of physician assisted dying.²⁶³

The DWDA was approved in 1994 and only became implemented around the time of the Court's holding in *Glucksberg*.²⁶⁴ At the time, it was the only state legislation in the process of legalizing assisted suicide.²⁶⁵ This observation may bring some insight to the Court's insistence that the country's laws "have consistently condemned, and continue to prohibit, assisting suicide."²⁶⁶ In the twenty years since the Court's ruling in *Glucksberg*, not only has the nation's laws regarding suicide and assisted suicide changed in various states, but also society's opinion on the matter.

A 2013 Pew Research Center survey found that 47% of Americans approve of laws to allow the practice for the terminally ill, while 49%

²⁵⁴Death with Dignity, *History*, (Dec. 23, 2016), <https://www.deathwithdignity.org/about/history/>.

²⁵⁵*Id.*

²⁵⁶*Id.*

²⁵⁷*Id.*

²⁵⁸*Id.*

²⁵⁹*Id.*

²⁶⁰Death with Dignity, *History*, (Dec. 23, 2016), <https://www.deathwithdignity.org/about/history/>.

²⁶¹*Id.*

²⁶²*Id.*

²⁶³*Id.*

²⁶⁴*Id.*

²⁶⁵*Id.*

²⁶⁶*Glucksberg*, 521 U.S. 702 at 719-20.

disapprove.²⁶⁷ The survey acknowledge that while the majority believes there are situations in which physicians should allow patients in certain situations to die, a growing minority has emerged with the opinion that medical professionals should take every measure to save a life.²⁶⁸ Likely, this would include a growing belief that if experimental treatment were to potentially have the effect of saving a life, it should be provided to the patient.

This year, 18 states are considering adopting death with dignity statutes.²⁶⁹ While all states will likely not pass such statutes, there is evidence of the energy surrounding the death with dignity movement across the United States.

IMPACT FROM INTERNATIONAL LEGALIZATION OF ASSISTED SUICIDE AND EUTHANASIA FOR MINORS

Already gaining legal status throughout the United States for adults, assisted suicide and euthanasia is no longer unfamiliar to children throughout the world.²⁷⁰ Euthanasia or physician assisted suicide can be legally practiced in the Netherlands, Belgium, Luxembourg, Colombia, and Canada.²⁷¹ Switzerland has also legalized physician assisted suicide.²⁷²

The Netherlands

The Netherland widely and openly have practiced euthanasia for many years prior to legalizing the practice in 2002.²⁷³ Despite their history of illegal practice, when the Dutch proposed legislation in 1999, which included giving children between the ages of 12 and 16 the right to request euthanasia with doctor consent and despite parental objection,

²⁶⁷*Views on End-of-Life Medical Treatments Growing Minority of Americans Say Doctors Should Do Everything Possible to Keep Patients Alive*, PEW RES. CTR., (Nov. 13, 2013) <http://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/#physician-assisted-suicide-for-the-terminally-ill>.

²⁶⁸*Id.*

²⁶⁹*State by State Progress: A March Report*, DEATH WITH DIGNITY NAT'L (Mar. 17, 2016) <https://www.deathwithdignity.org/news/2016/03/state-progress/>.

²⁷⁰ Francesca Trianni, *Should Terminally Ill Children Have the Right to Ask for Their Own Deaths?*, (Jan. 18, 2018), <http://healthland.time.com/2014/02/15/terminally-ill-children-and-the-right-to-ask-to-die-video/>.

²⁷¹Emanuel EJ, Onwuteaka-Philipsen BD, Urwin JW, Cohen J., *Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe* (2016).

²⁷²*Id.*

²⁷³Rita L. Marker, *Euthanasia, Assisted Suicide & Health Care Decisions: Protecting Yourself & Your Family*, (Dec. 20, 2016), <http://www.patientsrightscouncil.org/site/euthanasia-assisted-suicide-health-care-decisions/>.

the law was turned down and was widely judged on an international level.²⁷⁴ The irony being that for years, Holland practiced euthanasia on disabled newborns.²⁷⁵ And as recently as 1994, the Dutch Pediatric Association issued guidelines for euthanasia on infants who were ‘mentally retarded or faced the prospect of living with chronic illness.’²⁷⁶

The Dutch amended the proposed legislation to reflect that children aged 12-15 would need among other requirements, parental consent.²⁷⁷ However, 16-17 year olds would be able to receive euthanasia with only parental involvement as to discussions, meaning no consent would be required.²⁷⁸ Additionally, adults and children need not to be terminally ill, but rather, experiencing unbearable suffering.²⁷⁹

Canada

Canada passed federal legislation legalizing medical assistance in dying on June 17, 2016.²⁸⁰ To be eligible, all criteria must be met and procedural safeguards followed.²⁸¹ Prior to the decision to legalize medical assistance in dying, an expert panel advised the provinces to extend the age requirement to include terminally ill children as young as 12.²⁸² The argument from the nine-member committee focused on the fact that there should be no ‘arbitrary age limits’ for assisted death but rather eligibility should be based on maturity and mental competence, not age.²⁸³

Belgium

Euthanasia was legalized in Belgium in 2002 for those in ‘constant and unbearable physical or mental suffering that cannot be alleviated.’²⁸⁴ Originally, minors were included in proposals but removed from the final

²⁷⁴*Id.*

²⁷⁵*Id.*

²⁷⁶*Id.*

²⁷⁷*Id.*

²⁷⁸*Id.*

²⁷⁹*Euthanasia, Assisted Suicide & Health Care Decisions: Protecting Yourself & Your Family, supra.*

²⁸⁰*End-of-Life Law and Policy in Canada*, HEALTH LAW INST. DALHOUSIE U., (Dec. 20, 2016), http://eol.law.dal.ca/?page_id=236.

²⁸¹*Id.*

²⁸²Shanon Kirky, *Terminally Ill Children as Young as 12 Should Have Euthanasia Choice, Expert Panel Urges*, (Dec. 20, 2016), <http://news.nationalpost.com/news/canada/terminally-ill-children-as-young-as-12-should-have-euthanasia-choice-expert-panel-urges>.

²⁸³*Id.*

²⁸⁴Chandrika Narayan, *First Child Dies by Euthanasia in Belgium*, CNN (Sept 17, 2016), <http://www.cnn.com/2016/09/17/health/belgium-minor-euthanasia/>.

legislation due to political opposition.²⁸⁵ However, in 2014, a bill extending the ‘right to die’ to minors under strict conditions such as the child being able to understand what euthanasia means and parental consent was passed.²⁸⁶ The change in legislation has made Belgium “the first country to lift any age restrictions associated with the procedure.”²⁸⁷

The resulting change in legislation, has spurred various opinions regarding Belgium’s dramatic and first of its kind extension of euthanasia to minors. However, supporters have placed the importance on providing children with their rights. “Advocates of child euthanasia argue that, despite the small number of euthanasia requests, these will be of immense importance, since, with this option now available, open discussions on early death will be possible, allowing the appearance of solutions to a situation that may be intolerable.”²⁸⁸

It is clear the debate is far from over, and one particularly vulnerable group of terminally ill individuals stand to turn the debate on its head altogether—children.

United Kingdom

The story of Charlie Gard, an 11-month-old suffering from a rare terminal mitochondrial disorder sparked debate across the world.²⁸⁹ Charlie’s parents desperately sought the right to allow their young son access to potentially life-saving experimental treatment offered in the United States.²⁹⁰ However, the hospital argued that the treatment was too experimental—despite the hospital having used it in the past.²⁹¹ The lawyer appointed to represent Charlie’s best interest and opposing the wishes of Charlie’s parents was long time death with dignity advocate Victoria Butler-Cole.²⁹² The case has placed Charlie Gard’s fate in the hands of the death with dignity movement.²⁹³ The Court has put the

²⁸⁵*Id.*

²⁸⁶*Id.*

²⁸⁷Ivette Feliciano, *Belgium’s euthanasia law gives terminally ill children the right to die*, PBS NEWS HOUR, (Jan. 16, 2015), <https://www.pbs.org/newshour/show/belgium-terminally-ill-children-right-die>.

²⁸⁸Filipa Martins & Silva Rui Nunes, *The Belgian case of euthanasia for children, solution or problem?* (Jan. 18, 2018), http://www.scielo.br/pdf/bioet/v23n3/en_1983-8034-bioet-23-3-0475.pdf.

²⁸⁹Gia Behnamian, *Charlie Gard Case - What it Reveals About The ‘Death With Dignity’ Movement*, FOX NEWS (July 13, 2017), <http://www.foxnews.com/opinion/2017/07/13/charlie-gard-case-what-it-reveals-about-death-with-dignity-movement.html>.

²⁹⁰*Id.*

²⁹¹*Id.*

²⁹²*Id.*

²⁹³*Id.*

burden on Charlie's parents to prove that the experimental treatment was not harmful, yet the alternative sought by opposing counsel would indefinitely result in Charlie's death.²⁹⁴ While opposing counsel was not arguing for euthanasia, they argued that Charlie be removed from his ventilator and all medical treatment be ceased so that he may die comfortably.²⁹⁵ Whether such death would be comfortable was debatable and Charlie's story was a clear example of how desperate terminally ill minors and their parent(s) or caretaker(s) become in their efforts to access experimental treatment when fighting for the right to live. Minors with the same or similar disorders as Charlie advocated for his right to access the experimental treatment and overwhelmingly people have supported Charlie and his parents right to try every life-saving measure in lieu of death.²⁹⁶ The very heart of the matter was clear—if denying minors access to experimental treatments and allowing courts to determine the death of the minor, should not the minor and/or their parents be able to determine the manner of that death. Sadly, Charlie Gard was denied access to experimental treatment and taken off life support after denying his parents more time with their son in hospice.²⁹⁷ Charlie passed away on July 28, 2017, the court further involved itself in his death by refusing his parents the right to take their son home prior to his passing.²⁹⁸

CONCLUSION

As discussed, there are various reasons why minor patients and their parent(s) or legal caretaker(s) may be unsatisfied with the current options available when dealing with a child's terminal diagnosis. The reality for minors to have the option of assisted suicide and euthanasia may not be too far off in the future. With other countries extending this right to minors, the desire of patient autonomy combined with healthcare and technology advances, coupled with the desire to prevent suffering, the movement towards legalizing assisted suicide and euthanasia may be near. Many state laws have been enacted since the Supreme Court ruling in *Glucksberg*, evidencing that the nation's history and tradition of

²⁹⁴*Id.*

²⁹⁵Behnamian, *supra* note 289.

²⁹⁶*Id.*

²⁹⁷Danny Boyle, *Charlie Gard Dies: Baby's Life-Support Withdrawn in Hospice as Parents' Denied Final Wish*, THE TELEGRAPH (July 28, 2017)

<http://www.telegraph.co.uk/news/2017/07/28/charlie-gard-dies-babyslife-support-withdrawn-hospice-parents/>.

²⁹⁸*Id.*

prohibiting assisted suicide may be changing how society views the topic in the case of terminally ill minors.

With two countries having legalized assisted suicide for minors,²⁹⁹ there are more statistics available and therefore potential opportunity for debate. This change in the law offers evidence that some feel age is only an artificial construct and not an effective way of judging whether a minor patient suffering from a terminal diagnosis should be given decision-making power to decide whether they want to live.³⁰⁰ “Children with terminal diseases like cancer mature much faster than other children.³⁰¹ They think a lot about their life and death and how they’d like their death to be. And sometimes they’re more courageous than their parents.”³⁰²

This maturity argument rings true for many adults with sick children as they struggle to make the right choices for their child while also listening to the child’s wishes. One of Canada’s panel members and ethicist, Arthur Schafer (who pushed for Canada to legalize assisted suicide for minors) argues that “the idea of an arbitrary age limit, and people suffering intolerable and waiting days, weeks or months to die because they have not reached that limit, seems morally unacceptable.”³⁰³ More plainly stated by Schafer, “at 17 years and 364 days you wouldn’t meet the criteria, but the next day you would.”

However, many still feel that minors do not always have cognitive capacity:

In the case of minors, it turns out that they don’t always have the cognitive capacity to reflect and verbalize such desires and, therefore, parents and doctors have to make decisions in accordance with the best interests of the child. In fact, the involvement of minors in the decision making process is not linear and depends on age, level of competence, nature of decisions and experience with chronic diseases. In ethical terms, this interaction between the role of parents as legal representatives and the child’s decision making capacity raises important questions about the rights of minors to self-determination on, the limits of parental

²⁹⁹Penney Lewis, *Assisted dying: What Does the Law in Different Countries Say?* BBC NEWS (Oct. 6, 2015), <http://www.bbc.com/news/world-34445715>.

³⁰⁰Elizabeth Braw, *Should a Sick Child be Allowed to Choose Death? Belgians Think So*, NEWS WEEK (Dec. 5, 2013), <http://www.newsweek.com/should-sick-child-be-allowed-choose-death-belgians-think-so-223851>

³⁰¹*Id.*

³⁰²*Id.*

³⁰³Kirky, *supra* note 282.

control and the balance between the best interests of the patient and his or her wishes.³⁰⁴

Argument from both sides make it clear there is concern for minors and their level of decision-making capacity regarding the decision to end their life. Whether the minor is an infant or 17 years of age, adds complexities to this debate, in which advocates in favor of assisted suicide and euthanasia for minors would face an uphill battle to prove. Current laws provide parent(s) or legal caretaker(s) of children with ‘wide discretionary authority in raising their children.’³⁰⁵ The Supreme Court has acknowledged that parents have great interest and responsibility in the control and upbringing of their children against that of the state.³⁰⁶ These laws are balanced by child abuse and neglect laws to ensure that the decisions made are in the child’s best interest.³⁰⁷ It is reasonable, ethical, and morally defensible when making medical decisions for a minor facing poor prognosis to limit medical therapy.³⁰⁸ For such cases, the burden of further therapy may outweigh the benefits such that parents must consider quality of life.³⁰⁹

Terminally ill minors, in the end-stages of their life, who are refused experimental treatment and suffering from immense pain make a strong case for the right to assisted suicide and euthanasia. Those against such right may prove to have no argument that such scenario would not be in the best interest of the minor. Assisted suicide statutes in the United States come with various requirements that adults must meet to be eligible.³¹⁰ Surely, these requirements would also be required of minors and could be strengthened to ensure the minor’s best interest is put first. Appropriately, terminally ill minors that are near the age of 18 and who are actively involved in their health care decisions are arguably capable of requesting assisted suicide in combination with their parents and physicians. Together they could effectively argue the choice to be in the minor’s best interest.

³⁰⁴Filpa Martins Silva & Rui Nanues, *The Belgian Case of Euthanzia for Children, solution or problem*, http://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/view/1094 ? (last visited Mar. 4, 2017).

³⁰⁵Jeffrey D. Hord, *et. al.*, *Do Parents Have the Right to Refuse Standard Treatment for Their Child With Favorable-Prognosis Cancer? Ethical and Legal Concerns Ethical and Legal Concerns*, J. OF CLINICAL ONCOLOGY (2006).

³⁰⁶*Prince v. Massachusetts*, 321 U.S. 158 (1944).

³⁰⁷Hord, *supra* note 305.

³⁰⁸*Id.*

³⁰⁹*Id.*

³¹⁰*Death with Dignity Acts*, DEATH WITH DIGNITY NAT’L (Mar. 2, 2017), <https://www.deathwithdignity.org/learn/death-with-dignity-acts/>

Further, although there are concerns regarding the cognitive ability of a minor, particularly in teenage years, as already stated the Supreme Court recognizes parents great interest and responsibility in the control and upbringing of their children against that of the state.³¹¹ This interest would infer that any statute passed to legalize assisted suicide for children would also ensure that the minors' parent(s) or legal caretaker(s) are equally involved in any decision to move forward with the act.

As changes in our history and society evolve around the issue of assisted suicide and euthanasia, Constitutional arguments for the right to assisted suicide and euthanasia for minors in the United States strengthen, especially if the minor has been denied the right to experimental treatment. A state's compelling interest argument to protect the life of vulnerable persons may be discredited where the state and federal government has provided the minor and their parent(s) or caretaker(s) no meaningful way to save the minors life. However, if changes are made to the current access programs, such that terminally ill minors are afforded a right to access any means of potentially life-saving treatment, the state's interest in protecting the minor from death (through assisted suicide or euthanasia) would outweigh the argument for a minor to have the right to access assisted suicide or euthanasia.

When a patient and their family reach the point of making the decision to apply for one of the experimental drug programs, there are likely few to no other options available. These terminally ill individuals, ". . . desire the ability to try experimental drugs to preserve their own lives in any way possible however, the FDA's intensive drug approval process and its restrictions on accessing experimental drugs suggest that the government perceives the potential deadly risks as too great, even for the terminally ill."³¹² And the difficulty minors face to access experimental drug programs is discouraging. One obvious reason for the difficulty that families face is the strenuous application process. Families looking to provide their terminally ill child with last chance experimental drug therapy should not be faced with a complicated, overwhelming, and emotional process.³¹³ Unfortunately this is the case for many families and terminally ill patients each year.³¹⁴ In addition, despite all the work these families and their doctors put in to the application process to get approved for the Compassionate Care program or access through state

³¹¹*Massachusetts*, *supra* note 306, at 158.

³¹²Hogan, *supra* note 20, at 172.

³¹³*Id.*

³¹⁴*Id.*

laws, at the end of the day it is the drug companies' choice as to whether to provide the drug.³¹⁵

The fact that the terminally ill patient is a minor exacerbates the situation and further lowers availability and willingness of drug companies to provide access due to fear of negative market effects on the company allowing a minor to try a medicine before properly vetted.³¹⁶ Clinical trials will likely decline access to the minor if already too ill to participate.³¹⁷ And often, the minor may pass away before approval.³¹⁸ Further, upon approval by the clinical program, the drug company may decline the minor access to the drugs altogether.³¹⁹ For many parent(s) or legal caretaker(s), their only option is to watch the minor slowly pass away, hopefully with the requisite care to keep from any pain and suffering. Emotionally this is draining and many parents struggle when the suffering is prolonged. The stories of Josh Hardy, Chloe Drury, and Nathalie Traller offer examples of the struggle that parents may face when desperately attempting to access healthcare for a dying minor.³²⁰

There have been various proposals to reform the FDA's requirements regarding the Compassionate Care program as well as ways to expand the state Right to Try laws. As mentioned, the most recent attempt at expanding access to experimental treatment to people with terminal illness took place on February 6, 2017,³²¹ when the Right to Try Act of 2017 was introduced to the House of Representatives.³²² However, there are many fears that the law would be ineffective and even dangerous to patients.³²³ "The reality is current state Right to Try laws have done little to widen patients' latitude to try unapproved drugs, and federal legislation would do little to strengthen state laws."³²⁴ Federal legislation creates a lax legal and regulatory environment for industry, while compromising patient safety."³²⁵ Furthermore, it is unclear whether the law will even help resolve the disparity between adults and children to access to experimental treatment.

³¹⁵*Id.*

³¹⁶*Id.*

³¹⁷*Id.*

³¹⁸Hogan, *supra* note 20, at 172.

³¹⁹*Id.*

³²⁰Flatten, *supra* note 66, at 14.

³²¹H.R. 878 - Right to Try Act of 2017, (Jan. 14, 2018), <https://www.congress.gov/bill/115th-congress/house-bill/878>

³²²*Id.*

³²³*Right to Try Legislation Risky, Ineffective*, (Mar. 10, 2017), http://www.huffingtonpost.com/entry/right-to-try-legislation-risky-ineffective_us_58c2162ee4b0a797c1d39b15.

³²⁴*Id.*

³²⁵*Id.*

Despite current attempts at resolving this issue, there are numerous other options that lawmakers may implement to be effective in resolving access to experimental treatment. One option is to balance the risk between the FDA and drug companies.³²⁶ Another proposed option is to alter clinical trial placebo use amongst terminally ill in the Compassionate Use program.³²⁷ A third option is to incentivize the programs to a level that drug companies will want to participate.³²⁸ All reform efforts are seemingly aimed at “curb[ing] the FDA’s ability to force drug companies to report adverse events, which would help remove some of the risk in participating in Compassionate Use.” A fourth and unlikely option, is for the Supreme Court to rule in favor of a fundamental right to try any potential experimental treatment in development, which would effectively overrule *Rutherford*.

Despite many efforts made by state representatives, activists, doctors, and terminally ill patients themselves, little has been effectively done to change the status quo of these programs,³²⁹ current drug approval procedures continue to inadequately serve the expediency needs of terminally ill patients.³³⁰ The absence of substantive change only further continues to build a case in favor of allowing minors access to assisted suicide and euthanasia. Without change to these programs, minors are unfairly disadvantaged when it comes to last chance experimental treatments more likely accessible to adults. Where adults are less likely to be turned down access to experimental treatment, in the case that they are, certain states allow these terminally ill adults to determine when the pain and suffering becomes too intolerable and to choose assisted suicide as an option. In contrast, when a minor is turned down access to experimental treatment, he or she will face only a future of pain and suffering, to be remedied by a large regime of pain medication. Their family left only to watch the beloved minor suffer in the last days, weeks, or months of their life.

Assisted suicide laws are evolving to reflect society’s changing attitude in regard to patient autonomy, end-of-life decision making, and the prevention of pain and suffering to those with terminal illness. Society as a whole is becoming more aware of assisted suicide and euthanasia, with references throughout the pop-culture arena drawing

³²⁶Flatten, *supra* note 66, at 17.

³²⁷*Id.* at 21.

³²⁸*Id.*

³²⁹Hogan, *supra* note 20, at 194.

³³⁰*Id.*

attention to variety of opinions on the topic.³³¹ The possibility of permitting assisted suicide for minors suffering terminal illness may not be far into the future. In recent years, various stories of terminally ill minors have received much publicity over their desire to die without suffering.³³² And already two countries have legalized the act for minors as a response to compassion for all suffering individuals no matter their age.³³³

³³¹Kelly Tatera, *The “Euthanasia” Roller Coaster: A Ride Designed for Death*, (October, 30, 2015), <http://thescienceexplorer.com/technology/euthanasia-roller-coaster-ride-designed-death> (Designed by Lithuanian engineer Julijonas Urbonas, a doctoral candidate in design interactions, the euthanasia roller coaster is an extreme ride that creates intense euphoria before starving the brain of oxygen and leading to ultimate death. Urbonas, a strong believer that death should be a choice and the process should be euphoric, entered the highly controversial euthanasia debate with the design of this roller coaster. While no commercial interest has come from any builders, it has drawn interest from one NASA engineer intrigued by the physics of the coaster as well as a volunteer test subject). See also Taylor Jarreau, *Assisted Suicide And The Movie “Me Before You”*, (Jan. 20, 2016), <https://www.theodysseyonline.com/assisted-suicide-before-you> (The movie follows an individual disabled from a motorcycle accident that prevented him from any activity. Convinced he wants to end his life through assisted suicide, he allows a young woman to try and prove his life is worth living. Overall, the movie brings to light the subject of assisted suicide and euthanasia. However, there was much controversy as to whether the movie was meant to promote the practice as normal and okay to do as a practice that death was better and nobler than living with a disability); See also Timothy Willard, *Hollywood’s Outrageous Embrace of Euthanasia*, (Jan. 18, 2018), <https://acculturated.com/hollywoods-outrageous-embrace-euthanasia/> (In an effort to “. . . promote the popular secularist message of autonomy: each person is responsible to decide for himself or herself what is morally right.” The cable network Lifetime releases the new show *Mary Kills People*, featuring a mom and ER doctor that helps save lives in the Emergency Room by day, then turns into doctor death at night by “helping” terminally ill patients “slip away on their own terms”).

³³²Jerika Bolen, *Teen With Incurable Disease, Hosts Prom Ahead of Hospice Care: ‘I’m Super Happy’*, (Mar. 4, 2017), <http://www.usmagazine.com/celebrity-news/news/teen-with-incurable-disease-hosts-prom-before-assisted-suicide-w430635>. (Jerika Bolen, a teen suffering from incurable disease wished to die, with no law providing for her to use assisted suicide or euthanasia, Jerika resorted to the removal of her ventilator to pass away); See also David Chazan, *Terminally ill child becomes first euthanized minor in Belgium*, (Sept. 17, 2016), <http://www.telegraph.co.uk/news/2016/09/17/terminally-ill-child-becomes-first-euthanised-minor-in-belgium/> (Critically ill unnamed 17 year old patient becomes first in Belgium to exercise legal assisted suicide and euthanasia law for minors). See also Diana Magnay, *Parents Plead to be Able to Help Terminally Ill Children Die*, (Nov. 28, 2013), <http://www.cnn.com/2013/11/27/world/europe/belgium-euthanasia-for-children-debate/index.html> (Ella-Louise was ten-months old when she died of Krabbe disease. Her mother described her palliative care as failing to prevent her daughter’s pain and suffering in the last days of her life. “. . . you start to get angry, because you know that there is no medication left to give her to take away that pain.” Ella’s mother wishes she could have provided her daughter with a fatal dose of medication “. . .to make the end of her daughter’s short life come more quickly”).

³³³David Chazan, *Terminally Ill Child Becomes First Euthanised Minor in Belgium*, (Sep. 17, 2016), <http://www.telegraph.co.uk/news/2016/09/17/terminally-ill-child-becomes-first-euthanised-minor-in-belgium/> (“Belgium is the only country that allows children of

Denying terminally ill minors the right to experimental treatment has devastating consequences as it is denying them the right to fight for their life. There must be effective action to resolve the barriers to entry that terminally ill minors and their parent(s) or caretaker(s) face when requesting experimental treatments. No action on this matter would be unsympathetic to the plight of these terminally ill minors. A 2014 Goldwater Institute Policy Report truly captures the importance that terminally ill patients have a right to try experimental treatment. It stated that “in a country dedicated to the idea that all people have certain ‘unalienable Rights, that among these are Life, Liberty, and the Pursuit of Happiness,’ no government official should have the power to deny a person’s last chance at all three – life, liberty, and happiness.”³³⁴ The case for assisted suicide and euthanasia for minors may be in the near future and seems to hinge on whether we believe terminally ill minors should be denied the right to fight for their life by whatever means possible.

all ages to choose euthanasia, provided parental consent is granted. The Netherlands also permits underage patients to request a doctor-assisted death, but only if they are aged 12 or over”).

³³⁴Christina Corieri, *Everyone Deserves the Right to Try: Empowering the Terminally Ill to Take Control of their Treatment*, POLICY REPORT GOLDWATER INSTITUTE 131 (Feb. 11, 2014) available at https://goldwater-media.s3.amazonaws.com/cms_page_media/2015/1/28/Right%20To%20Try.pdf.