DEMANDING OR DODGING DEATH: RECONCILING THE INCONSISTENCIES IN MEDICINE

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INTRODUCTION

Death can occur naturally, be expedited, or induced on demand. Deciding who lives and how we die is closely tied to exerting control, cultivating meaning, and discerning the value of life. Medicine offers three distinct approaches to death: (1) death is demanded; (2) death is elevated as optimal; or (3) death is a wrong and should be vigorously fought. Both abortion and physician assisted suicide offer death on demand, promising to facilitate an expedient death by offering relief from inconvenience and burden. Family members of patients with severe disabilities and complex medical conditions may be counseled that further treatment is futile, advised that death is preferable to suffering, and offered clinical options to hasten death. Yet in stark contrast, death is an injustice if it comes too soon—not only for patients fighting to stay alive, but even for the unborn and embryos that are unexpectedly destroyed.

Physician and ethicist Ezekiel J. Emanuel suggests that death is a loss because it deprives us of the things that we value, such as experiences, milestones, and time with our family.[1] In *The Atlantic*, Emanuel explained "Why I Hope to Die at 75," asserting that living too long is also a loss. Emanuel observed that aging can be associated with physical decline and illness because it reduces people's ability to work and contribute to society and the world. Ezekiel stated that people can become "feeble, ineffectual, [and] even pathetic."[2] To avoid such a fate, Ezekiel intends to die at a specific age before illness and debility occur. Emanuel acknowledges that other people may want to live despite physical and mental limitations, and that this position represents his personal choice. Despite this, Emanuel's characterization raises two issues: He assumes that our lifespan is something that we can and should control; and that a person's life loses meaning due to age, illness, or inability to contribute by performing tasks in society.

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[1] *See* Ezekiel J. Emanuel, *Why I Hope to Die at 75*, THE ATLANTIC (Oct. 2014), https://www.theatlantic.com/magazine/archive/2014/10/why-i-hope-to-die-at-75/379329/ [https://perma.cc/3XB9-FRSQ].

[2] *Id.*

Ethicist Xavier Symons and colleagues acknowledge that people with terminal illnesses experience protracted pain and suffering, but reframe how to think about physical and psychological limitations.[3] A good death is possible, according to Symons and colleagues, by recognizing the meaning and purpose of each person's life, connecting and accompanying each person in their illness, and upholding the virtues of patience and humility.[4] Symons and colleagues offer an alternative perspective by conceding that we cannot exert mastery over every lethal disease or condition, but we can honor and respect the value of each person's life during illness and when they are dying.

Emanuel and Symons represent the current contradictions surrounding death and dying in medicine: Many laws are structured to treat human life as valuable only based on certain factors, which can be reduced or erased when people are no longer vibrant, healthy, or have the potential to interact with society. In Section I, this article describes situations where patients clamor for death on demand and explores the rhetoric, law, and ethical implications of abortion and physician assisted suicide (PAS). In Section II, this article delves into patients with complex medical conditions and disabilities, where some physicians assert that allowing death by withdrawing treatment or issuing a "do not resuscitate" (DNR) is preferable to living with serious medical conditions and disabilities. This section will provide an overview of patient stories and corresponding laws relating to withdrawing futile medical treatment and withholding treatment through issuing DNR orders. On the other hand, in some instances physicians, patients, or family members portray death as a harm if it comes too soon. Section III explores one example in cardiology where physicians try to fight death by using a device to prevent cardiac arrest and explains the costs and burdens of "doing everything" in medicine. Finally, death is also a wrong if it comes too soon—even for unborn children and embryos—if parents wanted the child and view the death as a loss.

These inconsistencies reveal a deeper underlying principle: Many laws in medicine are structured to treat human life as only conditionally valuable. This article traces the problems of chipping away the value of life based on age, illness, or whether that person is wanted by others. This article suggests one avenue to alleviate fear and enhance consistency in the law is to recognize the inherent value and distinct potential of each human life.

I. DEMANDING DEATH

This section explains how two areas in medicine portray inducing death on demand as a legal right and ethically optimal to preserve autonomy, choice, and control over our body. First, this section provides an overview of how proponents of abortion describe invoking death on demand as necessary. Advocates for abortion portray the unborn as unwanted and burdensome interlopers that threaten the well-being of pregnant women. Second, this section

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[3] *See* Xavier Symons et al., *Flourishing at the End of Life*, 45 THEORETICAL MED. & BIOETHICS 401, 407 (2024).

[4] *See id.* at 408–13.

explains how supporters of PAS also frame a person's illness and reliance on others as a burden, for which the answer is opting for death by PAS.

A. Abortion: Viewing the Unborn as Unwanted Burdens

1. Abortion, Autonomy, and Free Will

In 2023, The Satanic Temple (TST) made headlines when it opened a telehealth clinic offering screening, virtual appointments, and medication abortions for patients in New Mexico.[5] TST Executive Director Erin Helian asserted that "by expanding care and access, telehealth clinics, like ours, can save lives."[6] TST offers screening and appointments free of charge to all women who are medically eligible, and women pay only the cost of medication.[7] *Cosmopolitan* praised TST's efforts as positive activism that would "expand access to urgent healthcare" by challenging restrictive state laws.[8] In 2024, TST opened a second telehealth clinic in Virginia, stating that the clinic is designed to ensure women "receive the care they need."[9]

Unlike other providers that facilitate abortion, TST offers women who obtain abortion the opportunity to perform an optional "abortion ritual."[10] This includes taking the prescriptions, looking into one's reflection, and invoking a specific Satanic affirmation. TST's website describes the Satanic tenets that abortion supports and provides directions for how to complete the ritual.[11] TST explains that these affirmations cast off "guilt, shame, and mental discomfort"

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[5] Portions of this section were adapted from Katherine Drabiak, *The Satanic Temple Asserts Medication Abortion is a Religious Right*, HARV. L..: BILL OF HEALTH (Feb. 9, 2024), https://petrieflom.law.harvard.edu/2024/02/09/the-satanic-temple-asserts-medication-abortion-is-a-religious-right/ [https://perma.cc/86A9-9FUK]; *The Satanic Temple Launches Religious Telehealth Abortion Clinic in New Mexico*, THE SATANIC TEMPLE, https://cdn.shopify.com/s/files/1/0428/0465/files/TST_Telehealth_Clinic_Press_Release_Feb_1_-_FINAL.pdf?v=1675268235 [https://perma.cc/YQD3-PGFT].

[6] Samantha Rutt, *Satanic Temple to Open 'Religious' Abortion Clinic to Promote 'Destruction Ritual' Terminations*, THE DAILY MAIL (Oct. 16, 2024), https://www.dailymail.co.uk/news/article-13964697/Satanic-temple-religious-abortion-clinic-virginia.html [https://perma.cc/PEV5-7FWT].

[7] *See* TST HEALTH, https://www.tsthealth.org/ [https://perma.cc/UF9Q-KUSU].

[8] *See* Arielle Domb, *The Satanic Abortion Clinic That's Pissed Off Pretty Much Everyone . . . and Might Beat the Bans Anyway*, COSMOPOLITAN (Nov. 14, 2023, 8:30 AM), https://www.cosmopolitan.com/lifestyle/a45613416/satanic-group-abortion-clinic-samuel-alito-mom/ [https://perma.cc/5XSB-Z2GQ].

[9] *Introducing: Right to Your Life Satanic Abortion Clinic*, THE SATANIC TEMPLE, https://thesatanictemple.com/blogs/news/introducing-right-to-your-life-satanic-abortion-clinic [https://perma.cc/N8EG-4H8N].

[10] *Satanic Abortion Ritual*, TST HEALTH, https://static1.squarespace.com/static/63b68c961da991700b94e8b7/t/63eac53263f3c063df3e1675/1676330291874/TST+Health+-+Satanic+Abortion+Ritual+Flyer-2.pdf [https://perma.cc/KCF2-8M9Y].

[11] *See id.*

by exalting personal autonomy and free will.[12] Notably, TST classifies the act of performing an abortion itself as a Satanic ritual—a rite of destruction that is *required* by the tenets of the belief system.[13]

TST is an IRS-recognized religious organization, which denies the authority of God and articulates key tenets such as bodily autonomy, the power to exercise one's free will, and scientific reason.[14] TST alleges that state restrictions on abortion interfere with their religious tenets and performing an abortion is a protected religious right.[15]

Throughout multiple states including Texas, Indiana, and Idaho, TST has filed lawsuits challenging state laws that restrict abortion.[16] TST has alleged a variety of legal claims in states that restrict abortion, including arguing that unwanted pregnancy: constitutes involuntary servitude; constitutes a "taking" by the government of a woman's property to use her uterus for other purposes; violates free exercise of religion; and violates state Religious Freedom Restoration laws.[17] Currently, TST's litigation has been unsuccessful based on procedural grounds.[18] No court has yet ruled on the merits of TST's legal arguments that abortion is a religious ritual and exercise of religious freedom.[19]

TST's involvement in activism to expand abortion may seem theatrical or odd. Yet TST's religious belief system and corresponding legal claims echo the rhetoric of abortion from amicus briefs adopted by the Supreme Court in *Roe v. Wade* and *Planned Parenthood v. Casey*, as well as arguments from a variety of legal scholars.[20]

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[12] *Id.*

[13] *See About Us*, THE SATANIC TEMPLE, https://thesatanictemple.com/pages/about-us [https://perma.cc/AG9Q-B7FW]; Joseph P. Laycock, *How the Satanic Temple Is Using 'Abortion Rituals' to Claim Religious Liberty Against the Texas 'Heartbeat Bill'*, THE CONVERSATION (Sept. 22, 2021, 8:58 AM), https://theconversation.com/how-the-satanic-temple-is-using-abortion-rituals-to-claim-religious-liberty-against-the-texas-heartbeat-bill-167755 [https://perma.cc/BC4S-SJDS].

[14] *See About Us*, *supra* note 13; Drabiak, *supra* note 5.

[15] *See* Satanic Temple, Inc. v. Tex. Health & Hum. Servs. Comm'n., 79 F.4th 512 (5th Cir. 2023); Satanic Temple, Inc. v. Rokita, No. 1:22-cv-01859-JMS-MG (S.D. Ind. Oct. 25, 2023); Satanic Temple v. Labrador*,* 716 F. Supp. 3d 989 (D. Idaho 2024).

[16] *See* cases cited *supra* note 15.

[17] *See* cases cited *supra* note 15; Drabiak, *supra* note 5.

[18] *See* cases cited *supra* note 15.

[19] *See* Hannah Wimberley, *Satan and the Law: How the Satanic Temple is Fighting Christian Hegemony in Reproductive Healthcare*, 22 HOUS. J. HEALTH L. & POL'Y 1 (2023) (explaining the argument that abortion should be viewed as exercising a religious right); *but see* Drabiak, *supra* note 5 (explaining why Religious Freedom Restoration laws do not provide a reason or defense against violating certain laws).

[20] *See, e.g.*, Jamie R. Abrams & Amanda Potts, *The Rhetoric of Abortion in Amicus Briefs*, 89 MO. L. REV. 399 (2024); Stacy A. Scaldo, *Deadly Dicta:* Roe*'s "Unwanted Motherhood,"* Carhart II*'s "Women's Regret," and the Shifting Narrative of Abortion Jurisprudence*, 6 DREXEL L. REV. 87 (2013).

2. Abortion Rhetoric

Professors Jamie Abrams and Amanda Potts systematically examined amicus briefs submitted to the Supreme Court on the issue of abortion, and the role of amici in shaping the language that both the Court and society use to describe abortion.[21] Abrams and Potts observed that amici portray women as passive, lacking agency, and vulnerable.[22] In *Roe v. Wade*, the Court referred to unwanted pregnancy as a burden that could induce psychological distress and destroy a woman's life, stating that pregnancy would "condemn" women to share their bodies.[23] Attorney Stacy Scaldo observed that the Court's characterization acts as social dicta that frames the societal debate and shapes the cultural narrative of abortion and how we classify the unborn.[24] *Roe* characterized pregnancy and motherhood as bleak and distressing, focusing on the physical limitations of pregnancy, the time intensive duties of childrearing, and the physical toll that pregnancy takes on women's bodies.[25]

Other legal scholars have observed that *Planned Parenthood v. Casey* integrated similar rhetoric, stating that controlling reproduction—which the Court concluded includes inducing fetal death on demand by abortion—is necessary for women's participation in economic and social life.[26] Legal scholar Paul Gowder suggested that women can only make certain economic choices such as investing in higher education or lucrative careers if they know abortion is available to "protect [their] choices" as an "insurance policy" and prevent their plans from being "derailed."[27] This framing suggests that the unborn are not only physically burdensome, but stand in opposition to women's central life goals. Abrams and Potts observed that amici characterize abortion as a central mechanism to preserve the equality, liberty, and freedom of women.[28]

Other legal scholars have extended this framing further, asserting that "forcing" women to gestate a fetus is cruel and unbearable.[29] Legal scholar Esra Coskun-Crabtree conceptualizes pregnancy as a contract, where women should be able to accept or reject the developing fetus. This reasoning rests on the belief that the developing fetus is "a parasite," an unwanted *thing* that drains the

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[21] *See generally* Abrams & Potts, *supra* note 20.

[22] *See id.* at 402, 443–44.

[23] *See* Scaldo, *supra* note 20, at 115–16.

[24] *See id.* at 90–95.

[25] *See* Paul Gowder, *Anti-Liberal Rights Retrenchment as a Threat to the Rule of Law*, 73 EMORY L.J. 1173, 1198–99 (2024).

[26] *See id.*; Abrams & Potts, *supra* note 20, at 434–35 (discussing gendered burdens of pregnancy and parenthood), 444–446.

[27] Gowder, *supra* note 25, at 1199; *see also* Esra Coskun-Crabtree, *Retaining a Constitutional Right to Terminate a Pregnancy by Reinterpreting Pregnancy as an Implied Contract*, 53 GOLDEN GATE U. L. REV. 79 (2023).

[28] *See* Abrams & Potts, *supra* note 20, at 462.

[29] *Id.* at 445.

woman and induces physiological harm.[30] Acceptance of this contract, according to Coskun-Crabtree, can only occur once a woman learns she is pregnant through a pregnancy test.[31] This provides women a measure of control, sovereignty, and agency in decisions over their own bodies. More than mere rhetoric, legal scholars and amici also invoke constitutional pleas, asserting that laws that restrict abortion violate the Eighth and Thirteenth Amendments, respectively because they constitute involuntary servitude and cruel and unusual punishment.[32]

Individual control, personal sovereignty, bodily integrity, the argument that unwanted pregnancy constitutes involuntary servitude, and the desire to induce fetal death are all the same arguments proffered by TST. Abrams and Potts refer to this as "rights framing," where proponents of abortion adopt terms such as "access," "freedom," and "privacy" to support the argument that abortion—intentionally causing fetal death—is necessary for women's well-being.[33] Proponents of abortion convince women and society that human sacrifice of the unborn is necessary because *we* are in control, and *we* should determine who lives and should have the authority to destroy who stands in the path of our self-prescribed goals and desires. This reasoning makes several unstated assumptions: That pregnancy and children (even if unplanned) are distressing, burdensome, and unfortunate. It also perpetuates a regrettable falsehood that unless women have the power to terminate the lives of their offspring, they cannot attain liberty and equality. This characterization is dark, callous, and not only anti-child, but anti-human.

Proponents of abortion have also integrated language to medicalize the procedure as a means to minimize or eclipse the ethical issues involved.[34] The American Medical Association, for example, characterizes abortion as a safe, modern, medical procedure, and states that decisions about abortion should remain between physicians and their patients as a matter of professional judgment.[35] Law professors Greer Donley and Jill Wieber Lens provide a

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[30] *See* Yoshihiko Araki, *Embryos, Cancers, and Parasites: Potential Applications to the Study of Reproductive Biology in View of Their Similarity as Biological Phenomena*, REPROD. MED. & BIOLOGY, Feb. 11, 2022, at 2–3 (describing the fetus as a parasite that harms the woman); *but see* Gilbert Meilaender, *The Fetus as Parasite and Mushroom: Judith Jarvis Thomson's Defense of Abortion*, 46 THE LINACRE Q. 126, 128–29 (1979) (explaining that the natural place for the fetus is the womb and rejecting the parasite argument).

[31] *See* Coskun-Crabtree, *supra* note 27, at 81, 91–93.

[32] *See id.* at 81–82 (discussing the Thirteenth Amendment and involuntary servitude); Scaldo, *supra* note 20, at 115–16 (discussing amici in *Roe v. Wade* calling state law restrictions on abortion a violation of the Eighth Amendment).

[33] Abrams & Potts, *supra* note 20, at 429, 462–63.

[34] *See id.* at 438–39.

[35] *See Opinion 4.2.7: Abortion*, AM. MED. ASS'N CODE OF MED. ETHICS, https://code-medical-ethics.ama-assn.org/ethics-opinions/abortion [https://perma.cc/92F8-5TKN]; *but see When Human Life Begins*, AM. COLL. OF PEDIATRICIANS (Mar. 2017), https://acpeds.org/position-statements/when-human-life-begins [https://perma.cc/XAJ4-YXGL] (explaining human biological research confirms that human life begins at conception because at this point in time there is a genetically distinct, living human organism that simply differs in form and stage of development).

carefully sanitized description of medical and surgical abortion procedures in stark clinical terms suggesting that in their view, abortion is only another medical procedure.[36] Abortions through medications, according to Rebouché and Ziegler, can be "safely and effectively accomplished with pills ordered over the internet" when taken early during pregnancy.[37] Donley and Lens extend this further, asserting that "the same procedures" are used both following a miscarriage to expel fetal tissue as during surgical abortions.[38] However, Donley and Lens omit the most significant distinction: For miscarriages, the physician treats the patient *after* fetal death occurred; but in abortion, the physician's primary goal is *causing* fetal death.[39] Abortion is also unlike other medical decisions, because it involves a second life, and outside the abortion context, physicians recognize a second patient during pregnancy.[40] As law professor Johnny Rex Buckles pointed out, the right to make one's own medical decisions does not equate the right to kill the unborn.[41]

3. Abortion Law and Reframing the Conversation

After the Supreme Court held in *Dobbs v. Jackson* that the Constitution does not confer a right to an abortion, states began clarifying different approaches to facilitating, regulating, or limiting abortions.[42] Multiple states codified a right to abortion in state constitution or state statute, and continue to frame abortion as an issue of reproductive freedom and privacy to make reproductive decisions.[43] As of this writing, nine states and the District of

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[36] *See* Greer Donley & Jill Wieber Lens, *Abortion, Pregnancy Loss, & Subjective Fetal Personhood*, 75 VAND. L. REV. 1649, 1685–67 (2022); *see also* Rachel Rebouché & Mary Ziegler, *Fracture: Abortion Law and Politics After* Dobbs, 76 SMU L.L. REV. 27, 70 (2023).

[37] Rebouché & Ziegler, *supra* note 36, at 70.

[38] Donley & Lens, *supra* note 36, at 1666.

[39] Even in cases involving maternal medical distress or emergency circumstances, physicians note that physicians can deliver or separate the fetus without intentionally causing fetal death. *See* AAPLOG, COMMITTEE OPINION 10: STATE RESTRICTIONS ON ABORTION: EVIDENCE BASED GUIDANCE FOR POLICYMAKERS 2–3, https://aaplog.org/CO10 (last updated Sept. 2022); *see also* Johnny Rex Buckles, *A Defense of the Unborn Person*, 28 TEX. REV. L. & POL. 629, 649–50 (2024).

[40] *See* Susan S.Mattingly, *The Maternal-Fetal Dyad: Exploring the Two-Patient Obstetric Model*, 22 HASTINGS CTR. REP. 13 (1992) (describing the maternal-fetal dyad as two distinct patients); *see also* Frank A. Chervenak & Laurence B. McCullough, *The Fetus as a Patient: An Essential Concept for the Ethics of Perinatal Medicine*, 20 AM. J. PERINATOLOGY 399 (2003) (describing the fetus as another patient); *but see* Frank Chervenak & Laurence McCullough, *The Fetus as a Patient: An Essential Ethical Concept for Maternal-Fetal Medicine*, 5 J. MATERNAL-FETAL MED. 115 (1996) (stating that the *viable* fetus is a patient, and the previable fetus is a patient only when the pregnant woman confers such status on the fetus).

[41] Buckles, *supra* note 39, at 644–47.

[42] Dobbs v. Jackson Women's Health Org., 597 U.S. 215 (2022).

[43] *See* Rebouché & Ziegler, *supra* note 36, at 29; portions of this section were adapted from Katherine Drabiak, *10 States Had Abortion Measures on the Ballot—–Where They Passed, Where They Failed, and What It All Means*, THE CONVERSATION (Nov. 8, 2024, 8:39 AM), https://theconversation.com/10-states-had-abortion-measures-on-the-ballot-where-they-passed-where-they-failed-and-what-it-all-means-243090 [https://perma.cc/8Z75-27GV].

Columbia have no gestational limits on abortion, permitting it until birth.[44] Other states moved to restrict abortion to an earlier gestational time; while some states restrict abortion once a provider can detect a heartbeat, or prohibit elective abortions.[45] These state laws articulate different legislative priorities, such as Missouri's intent to regulate the medical profession by restricting practices that may cause the medical profession to become "insensitive, even disdainful, to life."[46] Alabama frames its restrictions on abortion as a means to protect human rights, stating that the Declaration of Independence codifies the principle of natural law that recognizes all lives are equal, and all humans are entitled to a right to life.[47]

Human rights framing offers an alternative path to reenvision the unborn. Although connected and reliant on the pregnant woman—the unborn human is separate and distinct, with its own DNA, a specific blood type, predetermined sex, and individual heartbeat.[48] Replacing the negative framing of pregnancy, motherhood, and children could exalt the honor, joy, and power imbued in creating and nurturing new life. The unborn are not interlopers or aggressors but rather born into a position of reliance and vulnerability, which does not end during pregnancy but continues throughout development in infancy and childhood. Law professor Robert Byrn points out that in other instances, the more helpless and dependent one is, the more solicitous of his welfare the law tends to be.[49] Changing the law requires reframing societal thinking toward viewing intentionally inducing death of the unborn not as a freedom or liberty, but a distressing injustice that sacrifices the most vulnerable humans.

B. Physician Assisted Suicide: Medicalized Death is Better Than Being a Burden

1. Suffering and Being a Burden

In 2023, WBUR OnPoint published a story describing a variety of patients experiencing suffering from illness and disease.[50] Lenore Cornelli described

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[44] *See Abortion in the United States Dashboard*, KFF, https://www.kff.org/womens-health-policy/dashboard/abortion-in-the-u-s-dashboard/ [https://perma.cc/W2NT-2EW9].

[45] *See id.*; Drabiak, *supra* note 43; Anna Fleck, *Majority of Voting States Strengthen Abortion Rights*, STATISTA (Nov. 6, 2024), https://www.statista.com/chart/33423/projected-results-of-abortion-state-referendums/ [https://perma.cc/8TRA-4GE2].

[46] Missouri Stands for the Unborn Act, MO. REV. STAT. § 188.026 (2019).

[47] ALA. CONST. art. I, § 36.06; Alabama Human Life Protection Act, ALA. CODE § 26-23H-2 (2019).

[48] *See* Abrams & Potts, *supra* note 20, at 432; *When Human Life Begins*, *supra* note 35; *Fetal Development*, MEDLINEPLUS, https://medlineplus.gov/ency/article/002398.htm [https://perma.cc/V893-8T8X] ("The zygote contains all of the genetic information (DNA) needed to become a baby.").

[49] *See* Rebouché & Ziegler, *supra* note 36, at 49–50 (citing Robert M. Byrn, *Abortion in Perspective*, 5 DUQ. L. REV. 125, 132-135–35 (1966)).

[50] Paige Sutherland et al., *How the Medical Aid in Dying Movement Is Gaining Momentum in the U.S.*, WBUR: ONPOINT (May 31, 2023), https://www.wbur.org/onpoint/2023/05/31/how-the-

her significant other, Tom, who was diagnosed with stage four pancreatic cancer.[51] Cornelli explained that Tom was in severe pain, but did not want to take the narcotics prescribed by his physician so he could remain lucid. Instead, all Tom wanted was to "die at home in peace and on his terms."[52] However, OnPoint explained that physician-assisted suicide was not legal in Tom's state, which left Tom "no ability to access this kind of care."[53] Instead, since Tom could not obtain "medical assistance[,]" he left a note for Cornelli and shot himself.[54] OnPoint also described a woman in her seventies who feared getting dementia, so she traveled to Mexico to obtain lethal drugs used for euthanizing pets to have on hand to end her life in the future.[55] Author Katie Engelhart explained, the end of life can be a time of too many futile medical interventions that people do notnot want, which results in an overly medicalized death.[56] Moreover, even in states that allow PAS, state laws would exclude people experiencing dementia from "access[ing] [that] kind of care."[57]

These stories echo a common refrain that portray PAS as a "good death," offering a mechanism to restore patient autonomy and provide control over debilitating disease.[58] Health law professor Thaddeus Mason Pope asserted that a "medically supervised" death provides a peaceful end of life exit where patients can live or die on their own terms.[59] Legal scholar Jacob Schurman maintained that PAS provides a "proven safe, effective, and above all, meaningful" avenue for death on the patient's own terms.[60]

Offering PAS appeals to the concept of beneficence by portraying it as a mechanism to reduce patient suffering.[61] Patients may experience physical pain, psychological symptoms (anger, hopeless, desperation), or existential anguish

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medical-aid-in-dying-movement-is-gaining-momentum-in-the-u-s [https://perma.cc/A7D9-5UBR].

[51] *See id.*

[52] *Id.*

[53] *Id.*

[54] *Id.*

[55] *See id.*

[56] *See id.*

[57] *Id.*

[58] *See* Terri L. Jones, *Physician-Assisted Death: Is It Your Choice?*, DEATH WITH DIGNITY (Mar. 23, 2023), https://deathwithdignity.org/news/2023/03/3-29-23-senior-guide/ [https://perma.cc/N5AX-4A4B]; *but see* Courtney S. Campbell, *Mortal Responsibilities: Bioethics and Medical-Assisted Dying*, 92 YALE J. BIOLOGY & MED. 733, 733 (2019).).

[59] Thaddeus Mason Pope, *Medical Aid in Dying: Key Variations Among U.S. State Laws*, 14 J. HEALTH & LIFE SCIS. L. 25, 31 (2020).

[60] Jacob Schurman, *Examining the Void Between Physician-Assisted Death and the Right to Refuse Medical Treatment in Light of Changes to Oregon's Death with Dignity Act*, 23 HOUS. J. HEALTH L. & POL'Y 79, 100 (2024).

[61] Campbell, *supra* note 58; Joseph C. Masdeu et al., *Expert Care and Support, Not Physician-Hastened Death*, 93 NEUROLOGY 729, 731(2019); Lois Snyder Sulmasy & Paul S. Mueller, *Ethics and the Legalization of Physician-Assisted Suicide: An American College of Physicians Position Paper*, 167 ANN. INTERN. MED. 576 (2017). *See also* Philip A. Reed, *Against Recategorizing Physician-Assisted Suicide*, 34 PUB. AFFS. Q. 50, 57, 63 (2020).

(loneliness, loss of meaning, and concerns over death). Physicians do have a duty to address this range of pain and suffering.[62] Data from Oregon patients who sought PAS helps explain why people seek PAS.[63] The majority of patients who obtain PAS do not cite physical pain as a motivator, but explain they fear loss of autonomy, inability to participate in enjoyable activities, and they worry about losing their dignity.[64]

Physical deterioration and debility can require people to rely on others for help with their caretaking and daily needs. Proponents of PAS portray reliance on other people while experiencing suffering, pain, misery, and deterioration as an affront to one's dignity.[65] Physician Brent Kious acknowledges that people are often interdependent, and sometimes require assistance from others when they become ill.[66] However, Kious asserts that people can become a burden when there is no longer reciprocal caregiving, and can no longer provide benefits back to their caregiver.[67] Rather than trying to reassure people they are not a burden, Kious advocates affirming to people that *they are a burden* and that society should facilitate obtaining PAS if the patient chooses.[68]

2. Physician Assisted Suicide is Not Just Another Medical Treatment

OnPoint also depicts a widespread, though false binary that presents PAS as the only alternative to a slow, painful, and agonizing death. Patients cannot control the disease they have, and illness does bring unjust suffering. However, patients already have control over multiple treatment options, such as interventions to slow disease progression, manage symptoms; or alternatively forgo treatment and let natural death occur; and patients already have choices to palliate pain symptoms.[69] PAS is also not simply another "end of life option," because unlike providing treatment or allowing death to occur, and providing pain management, PAS causes the patient's death.[70] Physician Mark Komrad

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[62] *See* Sulmasy & Mueller, *supra* note 61.

[63] OR. HEALTH AUTH., OREGON DEATH WITH DIGNITY ACT: 2023 DATA SUMMARY (Mar. 20, 2024) https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year26.pdf [https://perma.cc/NU6X-796P].

[64] *Id.*; *see also* Luai Al Rabadi et al., *Trends in Medical Aid in Dying in Oregon and Washington*, 2 JAMA NETWORK OPEN, Aug. 9, 2019, at 3.

[65] Jeffrey A. Brauch, *Preserving True Human Dignity in Human Rights Law*, 50 CAP. U. L. REV. 115, 117 (2022).

[66] Brent Kious, *Burdening Others*, 52 HASTINGS CTR. REP. 15, 17 (2022).

[67] *Id.* at 19.

[68] *Id.* at 15.

[69] Joseph Masdeu et al., *Expert Care and Support, Not Physician-Hastened Death*, 93 NEUROLOGY 729, 731 (2019)

[70] Thaddeus Mason Pope, *Medical Aid in Dying Laws: More Accessible in More States*, 332 JAMA 1139 (2024); Ramona Coelho et al., *Normalizing Death as "Treatment" in Canada: Whose Suicides Do We Prevent, and Whose Do We Abet?*, 70 WORLD MED. J. 27, 28 (2022); Daniel P. Sulmasy et al., *Physician-Assisted Suicide: Why Neutrality by Organized Medicine Is Neither Neutral Nor Appropriate*, 33 J. GEN. INTERN. MED. 1394, 1396 (2018).

explains PAS does not "aid" the dying process but rather terminates the dying process by terminating the patient.[71]

For context, PAS and assisting a suicide still remains a crime in the majority of states today.[72] Though individual state laws vary, most states criminalize actions such as encouraging another person to kill themselves, offering advice about how to do so, or providing an instrument to cause the person's death.[73] This applies even in cases where the decedent was ill, close to death, or pled for assistance to cause his death.[74] The minority of states that permit PAS specify it constitutes an exception to other existing laws that criminalize assisting a suicide, or stipulate that PAS is not considered a "suicide" in state law by using euphemistic terminology for the act such as "death with dignity," "end of life option," or "aid in dying."[75]

Beneficence requires not acceding to requests for PAS, but affirming to patients who are wounded by illness, alienated, and alone that physicians will support and accompany them in their suffering. Physicians can offer compassion, sympathy, and witness to patients who are ill and dying.[76] People who are ill or dying may require expensive treatments, extensive care, and rely on others for assistance.[77] Physician and ethicist Daniel Sulmasy and colleagues assert that people need to be reminded—even if they are sick, old, or become impaired by illness—that their value does not wane based on their productivity or appearance.[78]

While *caring for people* with illness or at the end of life may be difficult and burdensome, society should not view the *person* as a burden. Law professor Jeffrey Brauch explains that this framing treats people in a utilitarian manner, where people lose value and become "undignified" if they can no longer contribute to society, or rely upon others for assistance.[79] Instead, Brauch asserts human dignity is an intrinsic value, where all people are worthy of

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[71] Mark S. Komrad et al., *Did California Dodge a "Right to Die" Bullet?*, PSYCHIATRIC TIMES (May 3, 2024), https://www.psychiatrictimes.com/view/did-california-dodge-a-right-to-die-bullet [https://perma.cc/7LKN-EFFS].

[72] Taimie Bryant, *Aid-in-Dying Nonprofits*, 57 SAN DIEGO L. REV.147, 158–62 (2020); *see also* Justine L. Newman, *Speech and Suicide_The Line of Legality*, 49 AM. J. L. & MED. 436, 441, 444 (2023) (stating even if the victim wanted to die, the law still punishes the party independent of why they participated); George C. Garbesi, *The Law of Assisted Suicide*, 3 ISSUES L. & MED. 93, 96–98, 102–05 (1987) (citing *People v. Roberts*, noting that the reason for requesting suicide assistance such as serious illness is irrelevant and stating that consent of the victim is not an effective defense); Reed, *supra* note 61, at 62 (arguing that there is no permissible homicide based on the victim's life expectancy and no exceptions if the victim is close to death).

[73] 40 AM. JUR. 2D *Homicide* § 560 (2023).

[74] *See id.*; Bryant, *supra* note 72, at 158.

[75] *See* Bryant, *supra* note 72, at 177.

[76] Daryl Pullman, *Slowing the Slide Down the Slippery Slope of Medical Assistance in Dying: Mutual Learnings for Canada and the US*, 23 AM. J. BIOETHICS 64, 68 (2023).

[77] *See* Daniel P. Sulmasy et al., *Non-Faith-Based Arguments Against Physician-Assisted Suicide and Euthanasia*, 83 LINACRE Q. 246, 249 (2016); Reed, *supra* note 61, at 56.

[78] *Id.*; Brauch, *supra* note 65.

[79] Brauch, *supra* note 65, at 137–38.

respect and bearers of dignity.[80] The intrinsic view of human dignity affirms that human dignity is innate and simply as part of being human—it is not bestowed upon people based on certain skills, nor is it a conditional value to be lost.[81]

3. Legal Requirements and Expansion

Today, there is no federal Constitutional right to PAS.[82] The Supreme Court has held that PAS is not the same as other end-of-life treatment options, and states may continue to criminalize assisting a suicide.[83] Over the past several decades, advocacy groups have developed methodical strategies to change public opinion through marketing new terminology (e.g., compassion, choice, dignity) and crafted media campaigns to revise the ordinary prevention of suicide into accepting it as normal or desirable for certain classes of people on the basis of age, disability, illness, or proximity to death.[84] Medical anthropologist Mara Buchbinder and sociologist Cindy Cain observe that advocacy groups engaged in systematic efforts across multiple states to engage in extensive marketing, along with legislative and judicial challenges to enact state laws permitting PAS.[85]

Currently, ten U.S. jurisdictions have laws that permit PAS including California, Colorado, the District of Columbia, Hawaii, Maine, New Jersey, New Mexico, Oregon, Vermont and Washington.[86] Each state contains slightly different procedural requirements, but all states specify that that patient must be over 18, have decision-making capacity, be terminally ill with six months or less to live, and able to self-ingest the lethal medication.[87]

However, advocates for PAS have been working to expand the practice through multiple avenues. Over the past few years, several states have modified their laws to increase eligible providers allowed to participate in PAS; reduce waiting periods to obtain lethal medication; and eliminate previous requirements that the patient must be a resident of the state to obtain PAS.[88]

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[80] *Id.*; *see also* Mehmet Cifti, Dignitas Infinita*'s Vital Contribution to Current Debates*, ANSCOMBE BIOETHICS CTR. (Apr. 26, 2024), https://bioethics.org.uk/media/pz1ag32p/s-vital-contribution-to-current-debates.pdf [https://perma.cc/H3TE-S25R].

[81] Brauch, *supra* note 65, at 118.

[82] Vacco v. Quill, 117 521 U.S. 793 (1997); Washington v. Glucksberg, 521 U.S. 702 (1997).

[83] *Vacco*, 521 U.S. 793; *Glucksberg*, 521 U.S. 702.

[84] *See* Lucia A. Silecchia, *Assisted Suicide, Forced Cooperation, and Coercion: Reflections on a Brewing Storm*, 98 NOTRE DAME L. REV. REFLECTION S68, S77 (2023).

[85] Mara Buchbinder & Cindy Cain, *Medical Aid in Dying: New Frontiers in Medicine, Law, and Culture*, 19 ANN. REV. L. & SOC. SCI. 195, 202–03 (2023).

[86] *Id.* at 196.

[87] Pope, *supra* note 59, at 32.

[88] Nancy Kusmaul et al., *Medical Aid in Dying: How Might U.S. Policy Prevent Suffering at the End of Life?*, J. AGING & SOC. POL'Y 1, 13 (2023) (discussing types of providers); Thaddeus Mason Pope, *Top Ten New and Needed Expansions of U.S. Medical Aid in Dying Laws*, 23 AM. J. BIOETHICS 89, 89–90 (2023) (discussing types of providers and waiting periods); Komrad, *supra* note 71 (discussing types of providers, waiting periods, and residency requirements); Leslie Francis

Legal scholars and clinicians have advocated—or even used PAS—in more expansive manners, such as (1) permitting assistance with administration for patients who cannot self-administer medication or have a disability; (2) facilitating PAS for people without decision-making capacity such as patients with dementia; (3) revising or eliminating the requirement for terminal illness; and (4) allowing PAS for mental illness.[89] Ethicist Daryl Pullman observes that requirements policymakers once referred to as safeguards designed to limit PAS are now re-defined as "barriers to access" and impediments to remove so more people can obtain PAS.[90]

Sanitizing PAS by portraying it as a "serene and painless death" distorts what it truly represents: allowing physicians to assist in systematic, medicalized deaths on demand for people who are in states of vulnerability and suffering.[91] Inducing the death of people based on illness, age, or when they require extensive caretaking is not noble, but callous and destructive.

II. DEATH IS PREFERABLE TO ILLNESS, DISABILITY, AND SUFFERING

Patients with complex medical conditions, disabilities, and chromosomal abnormalities often undergo extensive treatment measures to sustain their

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& John Francis, *Federalism and the Right to Travel: Medical Aid in Dying and Abortion*, 26 J. HEALTH CARE L. & POL'Y 49, 71–72 (2023) (discussing residency requirements).

[89] Portions of this section were adapted from Katherine Drabiak, *The Harms of Expanding Physician Assisted Suicide*, IND. HEALTH L. REV. (forthcoming 2025); *see also* Lonny Shavelson et al., *Neurologic Diseases and Medical Aid in Dying: Aid-in-Dying Laws Create an Underclass of Patients Based on Disability*, 23 AM. J. BIOETHICS 5, 9 (2023) (allowing assistance with administration of lethal drugs); Megan S. Wright, *Current Medical Aid-in-Dying Laws Discriminate Against Individuals with Disabilities*, 23 AM. J. BIOETHICS 33 (2003) (asserting that current requirements for PAS "discriminate" against certain people with disabilities or without decision-making capacity); Megan S. Wright, *Equality of Autonomy? Physician Aid in Dying and Supported Decision-Making*, 63 ARIZ. L. REV. 157, 159 (2021) (discussing using a lower standard for capacity); Pope, *supra* note 88, at 89–91 (2023) (suggesting using an advance directive to allow PAS for patients without capacity); David Orentlicher, *Aid in Dying in Canada and the United States: Are U.S. States Too Cautious?*, 23 AM. J. BIOETHICS 73 (2023) (suggesting that the legal standard to allow PAS should not be based on "suffering severe[ly] enough"); Thaddeus Mason Pope & Lisa Brodoff, *Medical Aid in Dying to Avoid Late-Stage Dementia*, 72 J. AM. GERIATRICS SOC'Y 1216 (2024) (advocating for changing the definition of "terminal illness" to include *induced terminal illness* through voluntarily stopping eating and drinking (i.e., inducing starvation and dehydration and allow more patients to obtain PAS)); Jennifer L. Gaudiani et al., *Terminal Anorexia Nervosa: Three Cases and Proposed Clinical Characteristics*, 10 J. EATING DISORDERS 1 (2022) (explaining how she unilaterally redefined a new category of illness transforming certain cases of anorexia, a psychiatric disorder, into a "terminal illness" and permitted her patients to obtain PAS); Brent M. Kious & Margaret Battin, *Physician Aid-in-Dying and Suicide Prevention in Psychiatry: AA Moral Crisis?*, 19 AM. J. BIOETHICS 29 (2019) (asserting people with mental illness also experience intolerable suffering, so they should also have "access" to PAS).

[90] Pullman, *supra* note 76, at 67.

[91] Mehmet Ciftci, *Is the Fight Against Assisted Dying a Lost Cause?*, PUB. DISCOURSE (May 21, 2024), https://www.thepublicdiscourse.com/2024/05/94964/ [https://perma.cc/5NFV-ESPS].

lives.[92] Although medicine offers the technology to keep patients alive such as using ventilators, medications, and artificial nutrition, in some instances physicians assert that further treatment is futile or inappropriate, and allowing the patient to die by withdrawing or withholding life-sustaining treatment (LST) is preferable based on the patient's quality of life. Many of these cases involve difficult gray zones, where patients, family members, and physicians have very different opinions on what quality of life is acceptable and whether it is better to allow the patient to die naturally. This section explores the significance of who has the authority to make treatment decisions for patients in these challenging cases, and how this connects to assessing the value of a person's life.

First, this section describes *T.L. v. Cook Children's Medical Center*, the principles of futility, and the differences between state laws governing withdrawing futile treatment. Next, this section explains the story of Michael Hickson and discusses why families wish to serve as medical decision-makers, especially for patients with disabilities when determining the patient's quality of life. Finally, this section describes Simon Crosier's story and state laws that govern withholding treatment by issuing DNR orders based on the physician's assessment of futility.

A. Tinslee Lewis and Futility Laws

1. T.L. v. Cook Children's Medical Center

Tinslee Lewis was born prematurely in February 2019 in Texas at 32 weeks with complex medical conditions including an Ebstein anomaly and pulmonary atresia.[93] These conditions made it difficult for her heart to function, and prevented blood from properly flowing to her lungs.[94] Shortly after birth, physicians performed multiple surgeries, but Tinslee remained connected to a ventilator, nasogastric tubes, and IVs.[95] The attending physician asserted that Tinslee's case was "hopeless" because no further surgical options existed to treat her, determined Tinslee had no likelihood of improvement in her condition, and stated there was no chance that she would leave the hospital.[96] Tinslee experienced repeated pulmonary hypertension crises, which required emergency intervention to stabilize her and sedation to maintain her status on

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[92] *See* Thaddeus Mason Pope & Kristin Kemmerling, *Legal Briefing: Stopping Nonbeneficial Life-Sustaining Treatment Without Consent*, 27 J. CLINICAL ETHICS 254, 255–60 (2016); John D. Lantos, *Tell the Parents the Truth, But Tell It Slant*, 142 PEDIATRICS 199, 200 (2018).

[93] T.L. v. Cook Child.'s Med. Ctr., 607 S.W.3d 9, 26–28 (Tex. App. 2020).

[94] Mayo Clinic Staff, *Ebstein Anomaly*, MAYO CLINIC (Feb. 25, 2025), https://www.mayoclinic.org/diseases-conditions/ebsteins-anomaly/symptoms-causes/syc-20352127 [https://perma.cc/N96C-SNFW]; Mayo Clinic Staff, *Pulmonary Atresia*, MAYO CLINIC (Mar. 26, 2024), https://www.mayoclinic.org/diseases-conditions/pulmonary-atresia/symptoms-causes/syc-20350727 [https://perma.cc/N7VU-83GL].

[95] *T.L.*, 607 S.W.3d at 27–28.

[96] *Id.*

the ventilator.[97] Tinslee's care team asserted that continuing LST was "cruel," "unnatural," and withdrawing LST was in Tinslee's best interest.[98]

Tinslee's mother, Trinity Lewis, on the other hand believed that Tinslee's case was not without hope, and did not want to withdraw LST.[99] Lewis wanted physicians to use palliative care to alleviate Tinslee's physical pain, and transition Tinslee to a long term care facility or use home health providers.[100] Despite Tinslee's complex medical conditions and potential for a shorter life, Lewis believed that Tinslee still deserved a "right to live."[101]

Physicians at Cook Children's Hospital and Lewis reached an impasse about whether continuing treatment was futile and whether physicians could withdraw LST.[102] The Texas Advance Directives Act (TADA) outlines a statutory procedure to follow when clinicians and medical decision-makers disagree about continuing or withdrawing treatment.[103] TADA states if the attending physician determines that further treatment is "medically inappropriate," and believes that withdrawing treatment is the proper course of action, then the dispute should be reviewed by the hospital ethics committee. If the hospital ethics committee agrees with the attending physician that further treatment is "medically inappropriate," then the physician can notify the medical decision-maker and withdraw LST after ten days, even over the medical decision-maker's objection.[104] In Tinslee's case, the ethics committee agreed with her attending physician, concluding that her condition may be treated, but not cured or eliminated.[105] The ethics committee determined that restoring Tinslee's health was not attainable, continuing LST offered no benefit, and it would be in Tinslee's best interest to allow her to die.[106] Following the procedure set forth in TADA, the care team notified Lewis of the decision to withdraw LST from Tinslee after ten days.[107]

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[97] *Id.*

[98] *Id.* at 28.

[99] *Id.*

[100] Sarah St. Onge, *The Media Hasn't Told You the Truth About Tinslee Lewis's Fight for Her Life*, THE FEDERALIST (Jan. 9, 2020), https://thefederalist.com/2020/01/09/the-media-hasnt-told-you-the-truth-about-tinslee-lewiss-fight-for-her-life/ [https://perma.cc/62Q3-3WWH].

[101] Nicole Chavez & Melissa Alonso, *A Texas Judge Says Hospital Can Take 11-Month-Old Girl Off Life Support Despite Her Family's Wishes*, CNN, https://www.cnn.com/2020/01/02/us/texas-infant-life-support-tinslee-lewis/index.html [https://perma.cc/E6DL-URBR] (last updated Jan. 3, 2020, 8:43 AM) (quoting Lewis and a "right to live"); *see also* Onge, *supra* note 100.

[102] *T.L.*, 607 S.W.3d at 28.

[103] *Id.*

[104] *Id.* at 22–26; *but see* Stephanie L. Tang, *When Providers and Families Cannot Agree: A New Look at Due Process for End-of-Life Care Disputes*, 61 HOUS. L. REV. 91, 102 (2023) (discussing amendments to TADA in 2023, including expanding the time to twenty-five days before withdrawing treatment and clarifying family's rights to participate in the ethics committee process).

[105] *T.L.*, 607 S.W.3d at 30.

[106] *Id.* at 31.

[107] *Id.* at 30–32.

Lewis filed an injunction to stop physicians from withdrawing LST from Tinslee.[108] Lewis asserted that TADA raised Constitutional issues, including substantive and procedural due process concerns because it deprived Tinslee of a fundamental right to life and deprived her as a parent the right to determine the course of medical treatment for her daughter.[109] The Texas Court of Appeals noted that parents are the legal medical decision-makers for their children, and transferring this authority to the state requires overcoming this presumption.[110] Parents are the appropriate medical decision-makers for their children because they have a fundamental liberty interest in the care, custody, and control of their children, which includes the right to withhold, withdraw, or consent to medical treatment.[111] In all other instances, overriding parental decision-making requires physicians obtaining a court order to demonstrate why the state must intervene as *parens patriae* to protect the child's best interests.[112] The court observed that physicians do not have independent authority to override medical decision-makers, so TADA is a mechanism to *delegate* the state's authority to physicians.[113] The court determined that Lewis demonstrated an actionable deprivation of her Constitutional rights, and a court could reasonably hold that TADA deprived Lewis of a fundamental right to make medical decisions for Tinslee, including based on potential shortcomings with due process.[114] The court determined that Lewis was entitled to injunctive relief pending a trial on the merits, which prevented physicians from withdrawing LST from Tinslee.[115]

After a protracted legal battle, the case became moot in April 2022 when Tinslee was discharged from the hospital and went home with the support of home health care.[116] In this instance, physicians believed that Tinslee's

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[108] *Id.* at 32.

[109] *Id.*; *see also* Samantha R. Johnson & Elizabeth Sivertsen, *We Have All the Time in the World: The Law and Ethics of Time-Limited Interventions in Clinical Care*, 52 J.L., MED. & ETHICS 309, 311 (2024).

[110] *T.L.*, 607 S.W.3d at 41.

[111] *Id.* at 42–45 (citing Santosky v. Kramer, 455 U.S. 745, 753 (1982) (parents have a fundamental right to control the care, custody, and management of their child); Parham v. J.R., 442 U.S. 584, 603–04 (1979) (parents have a fundamental right to give, withhold, or withdraw consent to medical treatment for their children)); *see also* Katherine Drabiak, *Resolving Physician-Parent Disputes Involving Pediatric Patients*, 20 HOUS. J. HEALTH L. & POL'Y 353, 371–376 (2021) (discussing privacy interests of parents to make medical decisions for children and why parents can make decisions that reflect not only clinical choices, but more broadly reflect the best interest of their children).

[112] *T.L.*, 607 S.W.3d at 41; see also Drabiak, *supra* note 111, at 371–72 (explaining the factors required for state intervention to override parental decision-making).

[113] *T.L.*, 607 S.W.3d at 54.

[114] *Id.* at 76, 81 (finding an actionable deprivation of Lewis's Constitutional rights and discussing due process).

[115] *Id.* at 94.

[116] Laura Miller-Smith et al., *Palliative Care: Medically Futile and Potentially Inappropriate Therapies of Questionable Benefit*, UPTODATE, https://www.uptodate.com/contents/palliative-care-medically-futile-and-potentially-inappropriate-therapies-of-questionable-benefit [https://perma.cc/23EZ-UQ7X] (last updated Sept. 13, 2023); Kaley Johnson, *'Tinslee is Home.' Toddler Discharged from Fort Worth Hospital After Lengthy*

extensive medical conditions and repeated emergent interventions created so much suffering that allowing her to die was a better course of action. However, physician Laura Miller-Smith and colleagues suggest that Tinslee's survival to discharge should raise questions about the clinical determination that continuing treatment was futile.[117] This reflected Lewis' perspective: continuing LST was not futile because it was *maintaining her life*. This same impasse has occurred in other cases–families may understand that medical interventions will not restore the patient to full health but believe that maintaining the patient's life is a "'worthy goal'" and interventions such as a ventilator are "'not only effective toward that end, but essential.'"[118]

2. Defining Futility

The Tinslee Lewis case is of one of many that raises the issue of how to define futility.[119] It also examines how to resolve disputes when medical decision-makers and physicians disagree about whether continuing to treat the patient is futile. "Physicians are not legally or ethically required to provide futile [treatment]," but the conflict arises when the physician and medical decision-makers disagree about whether providing treatment is in fact futile.[120]

Definitions for futility vary significantly.[121] Physician Keith Swetz and colleagues point out that the ordinary definition refers to interventions that are "misdirected, inappropriate, and wasteful."[122] Continuing to provide treatment beyond where it provides a benefit to the patient can not only cause the patient harm, but can prolong the dying process and induce unnecessary suffering.[123] Physicians separate futility into three separate categories: physiologic futility, quantitative futility, and qualitative futility.[124] Physiologic futility refers to whether it is even possible to achieve a specific physiologic outcome using a medical intervention.[125] Quantitative futility requires assessing the percent chance that a specific treatment will provide benefit to the patient.[126] Some experts suggest that physicians can create goals and benchmarks for patient progress and monitor the success of whether the intervention results in patient

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Legal Battle, FORT WORTH STAR-TELEGRAM https://www.star-telegram.com/news/local/fort-worth/article260358560.html (last updated Apr. 15, 2022, 8:42 AM).

[117] Miller-Smith et al. *supra* note 116.

[118] Keith M. Swetz et al., *Ten Common Questions (and Their Answers) on Medical Futility*, 89 MAYO CLINIC PROC. 943, 953 (2014) (quoting Marcia Angell, *The Case of Helga Wanglie*, 325 NEW ENG. J. MED. 511, 512 (1991) (discussing futility assessments in the Helga Wanglie case)).

[119] Pope & Kemmerling, *supra* note 92, at 255–57; *see generally* Thaddeus Mason Pope, *Procedural Due Process and Intramural Hospital Dispute Resolution Mechanisms: The Texas Advance Directives Act*, 10 ST. LOUIS U.J. HEALTH L. & POL'Y 93 (2016); Tang, *supra* note 104.

[120] Johnson & Sivertsen, *supra* note 109, at 311.

[121] Swetz et al., *supra* note 118; Miller-Smith et al., *supra* note 116.

[122] Swetz et al., *supra* note 118, at 943–44.

[123] Johnson & Sivertsen, *supra* note 109, at 312.

[124] Swetz et al., *supra* note 118, at 943–44.

[125] *Id.* at 944.

[126] *Id.*

improvement over time.[127] Finally, qualitative futility encompasses questions of how the intervention will impact the patient's quality of life, and considers factors such as patient awareness, consciousness, interacting with the environment, and suffering.[128] Critical care guidelines for physicians recommend separating discussion of physiological futility, and using the term "potentially inappropriate" treatments to encompass other categories of futility.[129]

Some physicians assert that they should define and determine whether an intervention is futile based on their judgment, expertise, and clinical context.[130] However, physicians, ethicists, and legal scholars observe that many decisions involve value judgments about what constitutes a life worth living, where the patient or decision-maker and physician may hold starkly different views.[131]

Miller-Smith and colleagues note that even a determination of physiologic futility presumes that the goal for using the intervention is to provide a physiologic benefit.[132] This may not always be the case, such as if physicians use an intervention as a way to help patients and family members see that they tried everything, which can offer psychological benefit and acceptance of the severity of the patient's condition.[133] Swetz and colleagues point out that quantitative futility may be difficult to determine because it requires imprecise prognostication, which cannot always effectively predict how each patient responds to a treatment.[134] Assessing quantitative futility also requires setting specific numeric thresholds where a treatment is likely to offer benefit, or where a patient is likely to die.[135] These thresholds involve implicit value judgments whether trying or continuing a treatment is worthwhile based on that number.

Qualitative futility raises the most value judgments. This includes determining whether there is value is prolonging a life that is short, difficult, and full of pain; or whether there is value in extending life while acknowledging inevitable impending death.[136] In some instances, treatment may never restore the patient back to optimal condition, but simply serves to maintain the patient

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[127] *See id.* at 949–51; Johnson & Sivertsen, *supra* note 109, at 311, 316–17.

[128] *See generally* Swetz et al., *supra* note 118; *see also* Johnson & Sivertsen, *supra* note 109, at 314.

[129] Johnson & Sivertsen, *supra* note 109, at 312, 314; Swetz et al., *supra* note 118, at 951.

[130] Johnson & Sivertsen, *supra* note 109, at 311.

[131] *Id.*; Miller-Smith et al., *supra* note 116; Swetz et al., *supra* note 118, at 944; *see generally* Tang, *supra* note 104; C. Scott Sergeant, Note, *Playing God: Faulty Decision-Making in Medical Futility Disputes,* 47 MITCHELL HAMLINE L.R. 396 (2021).

[132] Miller-Smith et al., *supra* note 116, at 5.

[133] *See* Lantos, *supra* note 92, at S202.

[134] Swetz et al., *supra* note 118, at 944; *see* Michael Kapottos & Stuart Youngner, *The Texas Advance Directive Law: Unfinished Business,* 15 AM. J. BIOETHICS 34, 35 (2015) (quoting Philip M. Rosoff, *Institutional Futility Policies are Inherently Unfair*, 25 HEC F. 191, 191–209 (discussing the difficulties in prognosticating patient outcomes)).

[135] Miller-Smith, *supra* note 116, at 5.

[136] *Id.* at 1; *see also* Grace Emily Stark, *Even Very Sick Children Deserve Medical Care: Why Every State Needs "Simon's Law"*, PUB. DISCOURSE (May 31, 2016), https://www.thepublicdiscourse.com/2016/05/16879/ [https://perma.cc/9JBC-B7BF].

in a stable, but disabled condition.[137] As student legal scholar Scott Sergeant points out, when physicians make determinations of qualitative futility, this entails judgment not only "whether the patient's goals are *achievable*[,] . . . but also whether those goals are *worthwhile*."[138] Some physicians may conflate the distinction between the futility of treatment (physiologic futility) and the futility of the patient's life by believing that a life that is short, marked by illness, and full of pain is not worth living.[139] Sergeant acknowledges that physicians have medical expertise, but argues that this should not include a determination of whether the patient's life is valuable enough to justify the treatment.[140]

3. State Laws Governing Futile Medical Treatment

Multiple states have enacted laws to clarify the process for determining how to proceed when there are disputes between the physician and medical decision-maker about whether continuing treatment is futile.[141] Each state law differs slightly in the terminology, such as whether the law refers to treatment that is "futile," "medically ineffective," or "medically inappropriate."[142] In the majority of states (about thirty-four), the law directs the physician to inform the patient or decision-maker of his belief that further treatment is futile, communicate his intention not to abide by the patient or decision-maker's request, and document the conflict.[143] However, the physician must continue providing treatment until the patient can be transferred to another facility.[144] In the majority of states, even if no other facility accepts the patient, the physician cannot override the decision-maker to withdraw treatment. If physicians withdraw LST without appropriate consent they could face liability.[145] A minority of states such as Texas and Virginia provide a statutory procedure whereby physicians are permitted to discontinue or withdraw treatment based on their assessment that continued treatment is "inappropriate."[146] Estimates show that physicians invoke laws such as TADA only a handful of times per

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[137] Johnson & Sivertsen, *supra* note 109, at 309; Swetz, *supra* note 118, at 953 (quoting Angell, *supra* note 118, at 512).

[138] Sergeant, *supra* note 131, at 403–04 (emphasis added).

[139] Stark, *supra* note 136.

[140] Sergeant, *supra* note 131, at 403–04.

[141] Tang, *supra* note 104, at 125, 148 app. A; *see also Bioethics, Health Law, Patent Rights: Medical Futility Statutes*, THADDEUS MASON POPE, https://www.thaddeuspope.com/medicalfutility/futilitystatutes.html [https://perma.cc/EX7Q-5SNZ].

[142] Johnson & Sivertsen, *supra* note 109, at 312.

[143] Tang, *supra* note 104, at 125.

[144] *Id.*

[145] *Id.*; *see also* Pope & Kemmerling, *supra* note 92, at 257.

[146] Texas Advance Directives Act, TEX. HEALTH & SAFETY CODE § 166.046 (2023); Virginia Healthcare Decisions Act, VA. CODE ANN. § 54.1-2990 (2018). *But see* California Healthcare Decisions Act, CAL. PROBATE CODE. § 4600-4806 (2000) (§ 4735 states that a healthcare provider may decline to comply with a healthcare decision that is medically ineffective, but unlike Texas and Virginia does not explicitly state that the healthcare provider may withdraw an intervention.).

year because most disputes can be resolved with informal conflict resolution strategies.[147]

In addition to formal laws, the vast majority (92%) of hospitals have futility policies that complement state law or provide guidance how to handle disputes involving potentially futile treatment.[148] Notably, 47% of these policies explicitly include language that reflects value-laden determinations, such as directing physicians to consider whether the patient has a "meaningful life," interacts with his environment, or whether the patient is likely to have a "meaningful recovery" when making treatment decisions.[149] Many cases involve gray zones, where different families and different physicians could weigh the same clinical evidence, but arrive at opposite conclusions of how to best proceed. Accordingly, designating who has authority to make this decision holds great meaning.

Despite legal challenges, TADA remains in effect and was amended in 2023.[150] Some experts praise laws in states such as Texas, asserting that these laws provide a clear procedure, uphold professional standards of appropriate treatment, and benefit patients because it reduces their chance of suffering through needless treatments.[151] Other experts highlight multiple problems, such as ensuring due process and a fair procedure for medical decision-makers to be heard.[152] Some legal scholars also point out that ethics committees often reinforce the physician's evaluation, which raises questions about impartiality.[153] Ethicist Tom Tomlinson, however, asserts that laws such as TADA are not centered on patient welfare, nor do they reflect the original purpose of the law.[154] State laws governing advance directives processes were initially designed to document decisions that reflect *patient* goals and wishes, not as a mechanism to protect the autonomy of *physicians'* judgments.[155]

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[147] Pope, *supra* note 119, at 102–03, 128; Pope & Kemerling, *supra* note 92, at 254; *see also* Sneha Dey, *New Texas Law Increases Notice Before Removing Patients from Life Support*, TEX. TRIB. (Aug. 30, 2023), https://www.texastribune.org/2023/08/30/texas-life-support-notice-period/ [https://perma.cc/9Z3L-47LB].

[148] Gina Piscitello et al., *Hospital Policy Variation in Addressing Decisions to Withhold and Withdraw Life-Sustaining Treatment*, 165 CHEST 950, 950 (2024).

[149] *Id.* at 955.

[150] Tang, *supra* note 104, at 102.

[151] *See* Kapottos & Youngner, *supra* note 134, at 34 (characterizing Texas's law as a fair process to resolve disputes); Tang, *supra* note 104, at 147 (asserting more states should adopt Texas's approach); Nancy S. Jecker, *Futility and Fairness: A Defense of the Texas Advance Directives Act*, 15 AM. J. BIOETHICS 43, 43 (2015) (discussing fairness, competent professional care, and benefit to the patient).

[152] Tang, *supra* note 104, at 120; Pope, *supra* note 119, at 128–29.

[153] Pope, *supra* note 119, at 133.

[154] *See generally* Tom Tomlinson, *The Texas Advance Directives Act Is Not About Professional Integrity*, 15 AM. J. BIOETHICS 46 (2015).

[155] *See generally id.* (explaining the law is not reflective of the patient's welfare and best interest and asserting the law gives authority to physicians); *see also* T.L. v. Cook Children's Med. Ctr., 607 S.W.3d 9, 90 (Tex. App. 2020) (explaining that the entire purpose of TADA was originally designed as a mechanism to ensure that physicians followed the *patient's* wishes).

TADA inverts the original purpose of protecting patient goals and preferences in the law by removing patient decision-making authority and transferring it to physicians.

B. *Michael Hickson and the Significance of Family Decision-Making*

1. Michael Hickson and Judgments About Quality of Life for People with Disabilities

In 2020, forty-six-year-old Michael Hickson was a patient at St. David's South Austin Medical Center in Texas who was receiving treatment for pneumonia, sepsis, a urinary tract infection, and suspected COVID-19.[156] Hickson also had disabilities including quadriplegia and related functional impairments that affected his motor skills; cognition; speech and language; swallowing; and bowel and bladder function.[157] Despite these impairments, Hickson's disability was static and chronic, not progressive.[158] Hickson was not born with these disabilities, but had suffered cardiac arrest and experienced anoxic brain injury several years prior.[159] Hickson was married and had a family, with *NPR* reporting that he was aware, bobbed his head, joked with his family, and interacted with his wife Melissa Hickson and children.[160]

Based on Hickson's disabilities, his wife Mrs. Hickson had filed to serve as his formal legal guardian.[161] Hickson's sister contested Mrs. Hickson's application, and both parties were in the process of determining permanent guardianship for Hickson.[162] In the interim, a court appointed Family Eldercare as the temporary legal guardian for Hickson.[163]

Initially, the appointed guardian from Family Eldercare conversed with Mrs. Hickson to ascertain Hickson's wishes, and Mrs. Hickson told the guardian that Hickson should be "full code" and continue receiving treatment.[164] Mrs. Hickson alleged that despite Hickson's disabilities, he had been treated for the same conditions previously and had stabilized after treatment.[165] Acting as

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[156] Plaintiff's Complaint, Hickson v. Family Eldercare, Case No. D-1-GN-21-001080, at 6 (Tex. Dist. Ct. Mar. 10, 2021), https://robbinsdimonte.com/wp-content/uploads/2021/03/Filed-Stamped-Complaint-Estate-of-Michael-Hickson-v.-Family-Eldercare-March-12-2021-002.pdf [https://perma.cc/BFM6-52KW] [hereinafter Hickson Plaintiff's Complaint].

[157] *Id.* at 3–4.

[158] *Id.* at 4.

[159] Joseph Shapiro, *One Man's COVID-19 Death Raises the Worst Fears of Many People with Disabilities*, NAT'L PUB. RADIO (July 31, 2020, 3:29 PM), https://www.npr.org/2020/07/31/896882268/one-mans-covid-19-death-raises-the-worst-fears-of-many-people-with-disabilities [https://perma.cc/HY4P-DGEG].

[160] *Id.*

[161] Hickson Plaintiff's Complaint, *supra* note 156, at 4.

[162] *Id.*

[163] *Id.* at 4–5.

[164] *Id.* at 7.

[165] *Id.* at 6.

guardian, Family Eldercare initially communicated with Hickson's physicians about his status and treatments.[166]

Hickson's physicians, however, recommended that he should be transitioned to comfort care.[167] Physicians asserted the best course of action would be to withdraw his nutrition and hydration, stop using medications such as antibiotics, and place a DNR order to preclude further treatment.[168] The physicians' recommendation created conflict because Mrs. Hickson believed that Hickson should continue receiving treatment. Since Hickson's disabilities after his cardiac arrest, he had been rotating between living at home, receiving care in a nursing home, and periodically requiring hospital care.[169] Mrs. Hickson recorded her conversation during the dispute with physicians, where one physician explained to Mrs. Hickson, "as of right now, his quality of life—he doesn't have much of one."[170] When Mrs. Hickson asked whether this was based on his paralysis and brain injury, the physician stated, "Correct."[171] The physician compared Hickson to other patients, noting that other patients were walking around and talking, while Hickson was unable to do this based on his disabilities.[172]

Family Eldercare provided legal consent for physicians to carry out their recommendations. Physicians stopped treating Hickson with antibiotics, removed his feeding tube, and placed a DNR order.[173] Hickson was transferred to hospice care, where a hospice nurse stated that he allegedly continued to nod to commands, was alert, and indicated that he was hungry.[174] Hickson died of pneumonia, six days after physicians withdrew his feeding tube while in hospice care.[175]

The Chief Medical Officer at St. David's South Austin Medical Center defended the physicians, asserting that it simply "wasn't medically possible" to save Hickson.[176] However, certainty of whether this is accurate is not ascertainable because physicians and his guardian decided to withdraw treatment. Moreover, the physicians' recorded statement reflects physicians may have based this decision not only on physiological factors, but that their

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[166] *Id.* at 7–8.

[167] *Id.* at 6, 9, 10.

[168] *Id.* at 9.

[169] Shapiro, *supra* note 159.

[170] *Id.*; *see also* Hickson Plaintiff's Complaint, *supra* note 156, at 9.

[171] Shapiro, *supra* note 159.

[172] Hickson Plaintiff's Complaint, *supra* note 156, at 9.

[173] *Id.*

[174] *Id.* at 11–12.

[175] Shapiro, *supra* note 159; *see also* Peter Finney, Jr., *Ethicist Alarmed Over How Treatment Decisions Were Made for Quadriplegic*, AM. MAG. (July 22, 2020), https://www.americamagazine.org/politics-society/2020/07/22/ethicist-alarmed-over-how-treatment-decisions-were-made-quadriplegic [https://perma.cc/8WEY-ANWQ].

[176] Margaret Nicklas, *The Case of Michael Hickson Highlights Legal and Ethical Issues Around Who Receives Treatment During a Pandemic*, AUSTIN CHRON. (July 24, 2020), https://www.austinchronicle.com/news/2020-07-24/the-case-of-michael-hickson-highlights-legal-and-ethical-issues-around-who-receives-treatment-during/ [https://perma.cc/XVN6-Z4PD].

recommendation also included their perception about Hickson's quality of life. Physician statements indicated they believed it was better for him to die than provide stabilizing treatment for him to continue living with physical and mental disabilities. Following Hickson's death, several disability rights organizations sent complaints to the Office for Civil Rights, requesting an investigation of whether the hospital impermissibly violated the Americans with Disabilities Act and discriminated against Hickson on the basis of his disability.[177] Mrs. Hickson emphasized that Hickson was alive, her husband, and despite his disability, he remained able to interact with her and their children.[178]

Mrs. Hickson filed a lawsuit against Family Eldercare based on its role in the process of authorizing the removal of LST and consenting to the DNR order for Hickson.[179] Mrs. Hickson alleged a variety of claims, including negligence of guardianship duties, negligence following TADA, intentional infliction of emotional distress, and wrongful death.[180] Notably, the substance of Mrs. Hickson's allegations was that physicians and the guardian did not elicit what Hickson would have wanted, but instead acted in deference to physicians' assessments about his quality of life.[181]

2. Medical Decision-Makers Make Both Clinical Choices and Protect Patient Interests

While Mrs. Hickson was not the legally appointed medical decision-maker in this case, this example does provide insight into the differences between how external parties might compare to family members engaging in medical decision-making when there is a disagreement about the value of a patient's life who has a disability, and whether death is preferable.

Ordinarily in cases that do not involve a formal guardian, medical decision-making for patients without decision-making capacity follow state surrogacy laws.[182] Most state laws establish a descending ladder of potential decision-makers in the event that the patient did not establish an advance directive or specifically designate a proxy, in cases where the patient lacks decision-making capacity.[183] State laws designate the patient's spouse as the first person who should serve as the patient's medical decision-maker; and only if the patient does not have a spouse or the spouse is not willing to act does the

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[177] Shapiro, *supra* note 159.

[178] *Id.*

[179] *See generally* Hickson Plaintiff's Complaint, *supra* note 156.

[180] *Id.* at 18–29.

[181] *See generally* Tomlinson, *supra* note 154; *see also* T.L. v. Cook Children's Med. Ctr., 607 S.W.3d 9, 80, 90 (Tex. App. 2020).

[182] Comm'n on L. & Aging*, Default Surrogate Consent Statutes*, AM. BAR ASS'N (Oct. 2022), https://www.americanbar.org/content/dam/aba/administrative/law_aging/2019-sept-default-surrogate-consent-statutes.pdf.

[183] *Id.* Portions of this section were adapted from Gregoire Calon & Katherine Drabiak, *How Clinicians Can Respond When Family Members Question a Proxy/Surrogate's Judgment and Decisional Capacity*, 19 CLINICAL ETHICS 277, 278 (2024).

law designate another decision-maker such as a different relative or external party such as a social worker to serve in this role.[184] State laws further specify whether the medical decision-maker should make a decision based on substituted judgment (what the patient would have wanted), and if this information is unknown, the surrogate should make decisions that would further the patient's best interest.[185]

Absent evidence to the contrary, spouses are generally in the best position to engage in medical decisions for adult patients.[186] Ethicists Adira Hulkower and Lauren S. Flicker note that family members are more likely to know the patient's preferences and values, which can more accurately inform decision-makers' choices.[187] Some research suggests that spouses acting as decision-makers are more likely to request continuing treatment rather than withdrawing or withholding treatment.[188] In some instances, decision-makers may opt for more aggressive treatment without certainty of outcome, or even run contrary to physician recommendations.[189] Even in cases where the decision-maker does not have specific knowledge of the patient's wishes, this person holds a degree of intimacy, connection, and duty to the patient.[190] Nursing professor Hyejin Kim and colleagues explain that the medical decision-maker's role is not simply making clinical choices, but also protecting, advocating and providing caregiving to the patient.[191] Ethicist Hilde Lindemann asserts that this affords moral authority to decision-makers to serve in this role–they are not simply making a clinical decision, but serving a much more significant function to protect the patient's welfare.[192] The medical decision-maker has moral authority to serve in this role, and the patient also has an ethical interest in having the family member serve as decision-maker because it provides an additional safeguard of the patient's interests. This reciprocal model upholds principles of relational autonomy and family privacy.[193]

The Michael Hickson case raised the possibility that some physicians may narrow the inquiry to their perception about whether the patient has a meaningful life based on the patient's *status as disabled* with life threatening medical conditions. Mrs. Hickson, however, viewed Hickson as her husband

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[184] Calon & Drabiak, *supra* note 183, at 278.

[185] *Id.*

[186] *Id.*

[187] *Id.*; *see generally* Adira Hulkower & Lauren S. Flicker, *It's All Relative*, 48 HASTINGS CTR. REP. 43 (2018).

[188] *See generally* Liat Ayalon et al., *Preferences for End-of-Life Treatment: Concordance Between Older Adults With Dementia or Mild Cognitive Impairment and Their Spouses*, 24 INTERGENERATIONAL PSYCHOGERIATRICS 1798 (2012).

[189] *See generally* Hilde Lindeman, *The Intimate Responsibility of Surrogate Decision-Making*, 48 HASTINGS CTR. REP. 41 (2018).

[190] *Id.*

[191] *See generally* Hyejin Kim et al., *Ethical Frameworks for Surrogates' End-Of-Life Planning Experiences: A Qualitative Systematic Review*, 24 NURSING ETHICS 46 (2017).

[192] *See generally* Lindeman, *supra* note 189.

[193] Calon & Drabiak, *supra* note 183, at 281.

and father to their children *as a person with a disability* who required medical care to treat his life-threatening conditions.

C. Simon Crosier and the Perception of Infants with Chromosomal Abnormalities

1. Simon Crosier and the Trisomy 18 Diagnosis

In 2010, Sheryl and Scott Crosier learned during an ultrasound that their baby had potential markers for a chromosomal abnormality.[194] Three days after their son Simon was born, physicians officially diagnosed Simon with Trisomy 18, also known as Edwards Syndrome.[195] Trisomy 18 is a chromosomal disorder where the patient has three copies of chromosome 18, which can result in low birth weight, intellectual disability, congenital heart defects, and organ abnormalities.[196] Historically, many physicians presumed that LST was not medically indicated for infants with Trisomy 18.[197] Physicians note that only 10–20% of infants with Trisomy 18 would live beyond one year; and children with this condition have neurodevelopmental impairments that affect their quality of life.[198] In this instance, the Crosiers allege that physicians began using the phrase that Simon had a disorder that is "incompatible with life."[199]

After Simon was born, physicians discussed with the Crosiers multiple complications Simon faced, including a severe heart defect.[200] Simon was treated in the neonatal intensive care unit, and the Crosiers hoped that he could grow large enough to be considered a candidate for heart surgery.[201] Sheryl Crosier pumped breastmilk and requested that the nursing staff use the milk to feed their son for growth and nutrition.[202] However, the Crosiers noticed that nursing staff started feeding Simon sugar water rather than the pumped milk.[203] Simon lived for three months and died three days before his scheduled heart

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[194] Danedri Herbert, *House Committee to Consider Simon's Law*, SENTINEL (Mar. 21, 2017), https://sentinelksmo.org/house-committee-consider-simons-law/ [https://perma.cc/YBQ2-EQ8F].

[195] *Id.*; *See also Trisomy 18*, NAT'L INSTS. OF HEALTH, https://rarediseases.info.nih.gov/diseases/6321/trisomy-18 [https://perma.cc/F6GY-RR53].

[196] *Trisomy 18*, *supra* note 195.

[197] Jennifer C. Kett, *Who is the Next "Baby Doe?" From Trisomy 21 to Trisomy 13 and 18 and Beyond*, 146 PEDIATRICS S9, S10 (2020); Agustín Silberberg et al., *Ethical Issues About the Paradigm Shift in the Treatment of Children with Trisomy 18*, 179 EUR. J. PEDIATRICS 493, 493 (2020).

[198] Kett, *supra* note 197 at S10 (citing 10% survival rate); *see also* Rachel Bovard, *States Are Right to Act Toward Preventing Alfie Evans in the US*, THE HILL (May 18, 2018, 12:00 PM), https://thehill.com/opinion/international/386907-states-are-right-to-act-toward-preventing-an-alfie-evans-in-the-us/.

[199] Herbert, *supra* note 194.

[200] Stark, *supra* note 136; *see also* Silberberg et al., *supra* note 197, at 493.

[201] Stark, *supra* note 136.

[202] Herbert, *supra* note 194.

[203] *Id.*

surgery.[204] After Simon's death, the Crosiers learned that that nurses were providing "comfort feeds" only, pursuant to a DNR order in Simon's chart.[205] Physicians issued the DNR order without the Crosiers' knowledge and without their consent.[206] After Simon's death, the Crosiers started a nonprofit organization called Simon's Law to educate the public and advocate legislative change in state law procedures governing how physicians place DNR orders for children.[207]

2. Changing Clinical Perspectives of Trisomy 18

This case highlighted the clinical perceptions about the meaning of a Trisomy 18 diagnosis, and the related issue of communicating information to parents to make informed medical decisions based on this diagnosis.[208]

Although Trisomy 18 may require multiple medical interventions at birth such as corrective surgeries, artificial nutrition, or ventilation, the condition itself is not necessarily fatal.[209] Notably, if the infant does survive one year, then the rate for ten-year survival increases to 65%.[210] Part of this entails a catch-22: physicians may not offer certain treatments, or parents may not opt for this child to have those treatments if they believe the survival rate is low, and the low rate for survival becomes a self-fulfilling prophecy.[211] In 2016, physician Adam Jacobs and colleagues surveyed attitudes and practices of neonatologists, finding that 83.3% "strongly agreed" or "agreed" that Trisomy 18 is a lethal condition, and nearly 60% stated that treating the infant would be futile.[212] Accordingly, only a small minority of the neonatologists surveyed would even offer certain corrective surgeries.[213] Critically, even where parents communicated that they wanted their infant "full code" (indicating they wanted the physician to perform all life saving measures), only 44.1% of physicians stated they would actually perform all resuscitation measures.[214] Ninety-five

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[204] Stark, *supra* note 136.

[205] *Id.*

[206] *Id.*

[207] *Simon's Law Resuscitates Parental Rights for Medically Vulnerable Children*, SIMON'S LAW, https://simonslaw.org/about-us/ [https://perma.cc/B7LY-LRMG] [hereinafter *Simon's Law*].

[208] *See generally* Adam Jacobs et al., *Trisomy 18: A Survey of Opinions, Attitudes, and Practices of Neonatologists*, 170A AM. J. MED. GENETICS 2638 (2020) (discussing physician attitudes and practices toward patients diagnosed with Trisomy 18); *but see* Silberberg et al., *supra* note 197 (discussing the shift away from categorizing Trisomy 18 as a disease incompatible with life).

[209] Bovard, *supra* note 198; *see also* Jacobs et al., *supra* note 208, at 2642 (listing potential medical interventions for infants with Trisomy 18).

[210] Kett, *supra* note 197, at S10.

[211] *Id.*

[212] Jacobs et al., *supra* note 208, at 2641.

[213] *Id.* at 2642 (citing only 12.3% of neonatologists would always/sometimes offer cardiac defect surgery and only 16.2% would offer mechanical ventilation).

[214] *Id.*

percent of physicians responded they would recommend palliative care only.[215] Physician Jennifer Kett clarifies that the appropriate question should be to determine how many children with Trisomy 18 *could* have survived if they received LST, not how many statistically *have* survived.[216]

Over the past decade, physician attitudes toward infants with Trisomy 18 have shifted.[217] Kett suggests that intellectual and physical disabilities from Trisomy 18 may not necessarily lead to an unacceptable quality of life.[218] Kett notes that despite children with Trisomy 18 experiencing neurodevelopmental impairment, they still may reach key developmental milestones.[219] In one study of parents of children with Trisomy 18, for example, the majority of parents stated that their child had a positive quality of life, and 99% of parents described their child as a "happy child."[220] For some parents, their indication of a "good quality of life" is simply being able to take the child home and spending together as a family, even if for a short time.[221] Ethicist Agustín Silberberg and colleagues observe that this contrasts with some physicians' perspectives, who might define quality of life based on the infant's chance for long- term survival.[222] Kett concludes that parents described their experience with their children differently than what was explained to them by clinicians.[223] Parents may be considering completely separate benchmarks when considering whether to continue or withdraw treatment for their child with Trisomy 18. Some physicians suggest explaining the condition and offering LST to parents to children with Trisomy 18 should no longer be viewed as offering futile treatment but an option for parents to consider.[224]

Robust information also provides important context for the related issue of providing information to parents based on a potential diagnosis of Trisomy 18 during pregnancy. Some obstetricians may suggest to patients that they obtain a "therapeutic abortion" based on a Trisomy 18 diagnosis.[225] Estimates vary, but some suggest that from 78–95% of pregnant women make the decision to abort based on this diagnosis.[226] Physician Sylvie de Kermadec posits that

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[215] *Id.* at 2638.

[216] Kett, *supra* note 197, at S10.

[217] *Id.*; *see also* Silberberg et al., *supra* note 197.

[218] Kett, *supra* note 197, at S11.

[219] *Id.*

[220] *Id.*

[221] Silberberg et al., *supra* note 197, at 494–95.

[222] *Id.*

[223] Kett, *supra* note 197, at S11.

[224] *Id.* at S10; *see also* Silberberg et al., *supra* note 197.

[225] Sylvie de Kermadec, *The 'Perinatal Hospice' and the Dignity of the Dying Infant*, ANSCOMBE BIOETHICS CTR. (June 18, 2012), https://www.bioethics.org.uk/educational-resources/guides-publications/the-perinatal-hospice-and-the-dignity-of-the-dying-infant/ [https://perma.cc/U7EV-YKDA].

[226] Julio Alejandro Peña Duque et al. *The Natural History of Pregnancies With Prenatal Diagnosis of Trisomy 18 or Trisomy 13: Retrospective Cases of A 23-Year Experience in a Brazilian Public Hospital*, 42 GENETICS & MOLECULAR BIOLOGY 286, 287 (2019) (citing 78% of pregnant women abort based on Trisomy 18 diagnosis); D.J.C. Wilkinson et al., *Perinatal Management of*

physicians may recommend abortion because they cannot imagine why parents would want to carry the child to term, and some physicians may view an infant dying after birth as a personal defeat.[227] Even for infants who die shortly after birth, de Kermadec offers a way to reframe the experience through the lens of palliative neonatology.[228] She suggests rather than viewing the infant as having a cruel existence filled with suffering, physicians could support parents in their experience of grief, emotions, and suffering toward acceptance and peace.[229] Parents can receive their infant as a person and human being, whom they accompany in the dying process if the infant does not, or cannot, survive.[230]

3. Authority to Issue a DNR Order

After the Crosiers discovered that physicians issued a DNR order for Simon without their knowledge or consent, they began working with state legislators to modify state laws governing how DNR orders are issued.[231] Multiple states such as Vermont and Maryland allow physicians to issue DNR orders without consent from the patient or medical decision-maker, although the language in each statute varies.[232] Vermont, for example, grants the physician authorization to issue a DNR order either based on the patient/decision-maker's informed consent *or on the basis of futility* "when resuscitation would not prevent the imminent death of the patient."[233] To compare, Maryland states that a DNR order (referred to as a "Medical Order for Life Sustaining Treatment") shall be consistent with the decisions of the patient, the medical decision-maker, or the patient's documented wishes, *except* where further treatment has been certified by physicians as "medically ineffective."[234] Accordingly, in several states the physician's decision to issue a DNR order without consent is legally permitted when this decision is tied to the physician's assessment of futility.

Trisomy 18: A Survey of Obstetricians in Australia, New Zealand and the UK, 34 PRENATAL DIAGNOSIS 42, 43 (2014) (citing "most respondents (70%) indicated a high rate of ≥95% of termination of pregnancy in cases with which they had been personally involved").

[227] de Kermadec, *supra* note 225.

[228] *Id.*; *see also* Brian Carter, *Pediatric Palliative Care in Infants and Neonates*, 5 CHILD. 21 (2018).

[229] de Kermadec, *supra* note 225.

[230] *Id.*; Carter, *supra* note 228.

[231] *Simon's Law*, *supra* note 207.

[232] VT. STAT. ANN. tit.18 § 9708 (2024); MD. CODE ANN., HEALTH–GEN. § 5-608.1 (c)(3) (West 2024); *see also* Robert Macauley & Susan Tolle, *POLST Signature Requirements: Responding With Compassion While Ensuring Informed Consent*, 38 AM. J. HOSPICE AND PALLIATIVE MED. 428, 428–29 (2020) (discussing whether state laws require the signature of a medical decision-maker on physician orders for life-sustaining treatment or DNR orders).

[233] *See Instructions for Physicians When Completing DNR/COLST Form*, VT DEP'T OF HEALTH, https://www.healthvermont.gov/sites/default/files/documents/pdf/DNR_COLST_Instructions_Form.April%202020.pdf [https://perma.cc/G4V7-LVMW]; VT. STAT. ANN. tit. 18 § 9708 (2024).

[234] MD. CODE ANN., HEALTH–GEN. § 5-608.1(c)(3) (West 2024).

After Simon Crosier's death, several states passed versions of "Simon's Law," which provides parents more transparency in the process of DNR orders. In Missouri, the law requires physicians to inform parents of their recommendation to issue a DNR order and requires that parents affirmatively provide consent.[235] In Utah, the law similarly states that the DNR order must be signed by parents and classifies issuing a DNR order without parental consent as a form of "unprofessional conduct" in the practice of medicine.[236] Finally, Kansas law states that parents must be informed of the physician's recommendation to issue a DNR order, and indicates that parents may "refuse consent."[237]

Some physicians endorse the approach in Kansas, where physicians may guide parents to accept the recommendation for a DNR order.[238] Physician John Lantos asserts that some parents do not want to be the final decision-maker because they tell physicians to "do everything" or "leave it in God's hands."[239] Allowing parents the option of informed dissent or declining to consent frees parents from "be[ing] explicitly made accountable," according to Lantos.[240] However, the approaches of either requiring parental consent or allowing parents to "refuse consent" are not synonymous. If an infant has Trisomy 18 or other severe medical condition and the physician believes that the condition does not offer a good quality of life, the physician may not even discuss or offer certain treatments. If the physician believes further treatment is futile, he may only suggest withholding treatment by issuing a DNR order, which has the potential to undermine truly informed decision-making by parents.

Different parents may make contrasting decisions, but these determinations are for parents—not physicians—to make. This requires that physicians fully communicate the diagnosis and prognosis to parents, so parents can weigh the factors that are meaningful to them when deciding whether to allow a natural death by withholding and withdrawing treatment or continuing treatment interventions.

III. DEATH IS A HARM

Unlike the two frameworks described above, many other areas of medicine treat death as something to forestall and prevent. Even in some cases where the patient is very ill with a poor prognosis, if death comes too soon this constitutes a failure and physicians may assert it should be fought vigorously using all available treatments. Modern medicine is replete with examples of expensive, burdensome, and invasive procedures, such as organ donation,

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[235] MO. REV. STAT. § 191.250 (3) (West 2019).

[236] UTAH CODE ANN. §§ 58-31b-502; 75-7a-103; 75a-3-106 (West 2024).

[237] KAN. STAT. ANN. § 38-150 (West 2017).

[238] Lantos, *supra* note 92.

[239] *Id.* at S200.

[240] *Id.*

chemotherapy, and cardiac interventions, that offer patients the chance at a few more months or years to live.[241]

The first part of this section explores this concept using one example of implantable cardioverter defibrillators (ICDs) for cardiac patients who are often older and very ill, explains the concept of the treatment imperative, and discusses why physicians in certain cases want to try everything to save the patient's life. However, some physicians have criticized the practice of improperly implanting ICDs, asserting that current practices are focused on fighting death but do not adequately account for the patient's quality of life or provide an accurate assessment of benefits and burdens. The orientation toward aggressive treatment and viewing death as a failure can undermine patients' ability to anticipate and plan for their death.

Viewing death as a harm also occurs at the very beginning of life, even before birth. If death comes prematurely for the unborn (including embryos), the law may classify this as a legal injury to the parents if the death is caused by actions of others. This section explains how parents view the value of the unborn, discusses associated legal claims for forms of reproductive loss, and highlights inconsistencies in legal valuation of the unborn.

A. Fighting Death Using All Available Treatment

1. ICDs and Trying to Prevent Cardiac Arrest

Every year in the United States, physicians place more than 150,000 implantable cardioverter defibrillators (ICDs) into patients.[242] ICDs are surgically implantable devices that continuously check for and detects arrythmias (irregular heartbeats) and deliver an electric shock to restore a regular heart rhythm.[243] Some patients receive an ICD following cardiac arrest,

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[241] Alejandro Diez, *Do Transplanted Organs Last a Lifetime?*, THE OHIO STATE UNIVERSITY HEALTH & DISCOVERY (Apr. 30, 2024), https://health.osu.edu/health/general-health/transplant-organs [https://perma.cc/X4TX-ADJV] (explaining that organ transplants do not last a lifetime and providing estimates for the mean length of time each type of transplant lasts or years added to a donee's life); Alfred I. Neugut& Holly G. Prigerson, *Curative, Life-Extending, and Palliative Chemotherapy: New Outcomes Need New Names*, 22 THE ONCOLOGIST 883, 884 (2017)(discussing life extending chemotherapy that will not cure the patient, but enables the patient to live a few more months to experience a few more months of "extra life worth living"); Paul S. Mueller & C. Christopher Hook, *Technological and Treatment Imperatives, Life-Sustaining Technologies, and Associated Ethical and Social Challenges*, 88 MAYO CLINIC PROC. 641, 642 (2013)(discussing physicians use of cardiac interventions, such as left ventricular assist devices, for those with severe heart failure and the possibility of death as a "destination therapy" to offer patients additional time).

[242] Daniel J. Friedman et al., *Trends and In-Hospital Outcomes Associated With Adoption of the Subcutaneous Implantable Cardioverter Defibrillator in the United States*, 1 JAMA CARDIOLOGY 900, 901 (2016).

[243] *Implantable Cardioverter-Defibrillators (ICDs)*, MAYO CLINIC (Feb. 18, 2025), https://www.mayoclinic.org/tests-procedures/implantable-cardioverter-defibrillators/about/pac-20384692 [https://perma.cc/YG95-HVK7].

but for the majority of patients (72.5%), physicians use an ICD for primary prevention.[244]

ICDs offer the benefit of lowering the risk of sudden cardiac arrest and death.[245] However, an ICD is not designed to improve the quality of life for patients with heart disease, and it will not treat other heart failure symptoms.[246] ICDs carry a variety of risks, such as infection, bleeding around the heart, collapsed lung, or potential movement of the device, which in rare cases can perforate the heart.[247]

Despite significant benefits, physicians note the limitations when suggesting placement of an ICD for patients. The potential benefits of the ICD vary depending on the patient profile, and for some patients an ICD would offer little benefit.[248] Patients who are older with multiple co-morbidities and frail are at a higher risk of death from other causes outside ventricular arrythmia, and have higher rates of procedural complications.[249] The mean age for patients receiving an ICD is 71, and in patients who are over 65, about half are enrolled in hospice or dead within five years after implantation.[250] Physicians point out that although the option of placing an ICD is available, it may not offer sufficient benefit or clinical improvements for certain patients.[251]

ICDs also carry risks that may occur over time once the device is implanted. ICDs can have procedural malfunctions, which means delivering inappropriate and painful shocks.[252] Cardiac patients who are candidates for ICD placement have higher rates of depression, anxiety, and PTSD as compared to the general population.[253] Implantation of the ICD itself may also invoke or worsen patient mood disorders.[254] Physician Erica Ghezzi and colleagues found that symptoms of anxiety and depression were more common in patients who experienced shocks from their device, and suggest that fear of experiencing

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[244] Daniel B. Kramer et al., *The Decisions, Interventions, and Goals in Implantable Cardioverter-Defibrillator Therapy (DIGNITY) Pilot Study*, 6 J. AM. HEART ASS'N 1, 4 (2017).

[245] Birju R. Rao et al., *Shared Decision-Making for Implantable Cardioverter-Defibrillators: Policy Goals, Metrics, Challenges*, 49 J.L., MED. & ETHICS 622, 623 (2021).

[246] *Id.*

[247] MAYO CLINIC, *supra* note 243.

[248] Rao et al., *supra* note 245, at 626; James M. Beattie et al., *Hardwired for Life? Implantable Defibrillator Dilemmas in Older Patients*, 131 AM. J. MED. 1143, 1143 (2018).

[249] Rao et al., *supra* note 245, at 626.

[250] Kramer et al., *supra* note 244, at 4; Beattie et al., *supra* note 248, at 1143.

[251] *See* Janet K. Shim et al., *Late-Life Cardiac Interventions and the Treatment Imperative*, 5 PLOS MED. 344, 345 (2008).

[252] Rao et al., *supra* note 245; *Implantable Cardioverter-Defibrillator*, MEDLINEPLUS (July 14, 2024), https://medlineplus.gov/ency/article/007370.htm [https://perma.cc/J2NZ-967V].

[253] Erica S. Ghezzi et al., *Burden of Mood Symptoms and Disorders in Implantable Cardioverter Defibrillator Patients: AA Systematic Review and Meta-Analysis of 39,954 Patients*, 25 EUROPACE 1, 14 (2023); Anne-Lotte C.J. van der Lingen et al., *The Link Between Cardiac Status and Depression and Anxiety in Implantable Cardioverter Defibrillator Patients: Design and First Results of the PSYCHE-ICD Study*, 167 J. PSYCHOSOMATIC RSCHS. 1, 7 (2023).

[254] van der Lingen et al., *supra* note 253, at 2.

shocks may contribute to patients' psychological burden.[255] Some physicians suggest there is a bidirectional relationship between anxiety, depression, and cardiovascular disease.[256] Depression and anxiety can worsen ventricular arrythmia, and more impairment from cardiac disease can increase rates of mood disorders.[257] The decision to place an ICD not only encompasses considering the physical risks, but also how the device affects patient mood, quality of life, and whether a longer life with this illness constitutes a benefit from the patient's perspective.[258]

2. The Treatment Imperative and Problems in Medical Decision-Making

Despite the limitations of ICDs for some patients, some experts suggest that the treatment imperative may be driving the decision-making process. Law professor Lindy Willmott and colleagues interviewed physicians to inquire why they continue to provide treatment to patients who have serious illness at the end of their life when it offers little benefit.[259] In some instances, such as those described in Section II, the patient or family may drive requests for treatment as a mechanism to feel like they tried everything, which may help with acceptance of death.[260] In other instances such as placing an ICD, it is the physician who is often driving the treatment decision. Eighty-four percent of physicians report they continue to offer treatment despite low potential benefit because they are "trained to treat" and "try everything" possible.[261] In some cases, physicians want to "cover all bases," maximize patient longevity, and acknowledge difficulty prognosticating outcomes, which can drive momentum toward offering more interventions even if they offer little potential benefit.[262]

The extent to which physicians continue to guide patients toward burdensome treatment despite minimal benefit may vary based on physician specialty and area of medicine. Cardiology, specifically, is an active discipline that offers multiple technical, invasive, and interventional procedures.[263] Cardiology has a checklist of options to offer patients, a list of potential solutions, and what one physician referred to as a "conveyor belt" or "on-ramp"

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[255] Ghezzi et al., *supra* note 253, at 2.

[256] van der Lingen et al., *supra* note 253, at 22.

[257] *Id. But see* Nanna Lindekilde et al., *Anxiety and Depression as a Risk Factors for ICD Shocks and Mortality in Patients with an Implantable Cardioverter Defibrillator—A Systematic Review*, 78 GEN. HOSP. PSYCHIATRY 97, 104 (2022).

[258] *See* Rao et al., *supra* note 245, at 623.

[259] Lindy Willmott et al., *Reasons Doctors Provide Futile Treatment at the End of Life: A Qualitative Study*, 42 J. MED. ETHICS 496, 496 (2016).

[260] *Id.* at 498.

[261] *Id.* at 498–99.

[262] Shim et al., *supra* note 251, at 344–45.

[263] Fiona Ecarnot et al., *End-of-LifeL Situations in Cardiology: A Qualitative Study of Physicians' and Nurses' Experience in a Large University Hospital*, 17 BMC PALLIATIVE CARE, no. 112, 2018, at 3.

of procedures.[264] Social scientist Janet Shim and colleagues suggest that the treatment imperative transforms what would otherwise be considered risky and aggressive procedures into routine standard care.[265] The problem, however, results when patients simply accept the recommendation for ICD placement without understanding the benefits and burdens.[266]

Research suggests that patients may not be accurately informed about risks and limitations of ICDs.[267] Physician Daniel Matlock and colleagues developed a framework explaining the potential biases and heuristics that direct patients who undergo ICD placement.[268] Physicians may frame the decision about the ICD by focusing on potential benefits, while minimizing the discussion of certain risks, such as psychosocial risks, long-term outcomes, or the risk of inappropriate shocks.[269] Some research suggests that physicians follow a default model suggesting ICD implantation, where physicians portray using an ICD as a "non-preference sensitive decision," suggesting it is necessary and required immediately.[270] Patients also report that physicians presented the ICD as the only option with minimal or no discussion of potential alternatives.[271] Research demonstrates that patients are overly optimistic about the device, overestimate its benefit, and underestimate potential harm.[272] If the information landscape is skewed toward accepting and implanting the ICD, then this can undermine patients' ability to accurately compare benefits against risks.

3. Shortcomings with Informed Consent

Biases and heuristics skew patient perception, inflate expectations for the device, and can compromise true informed consent. Informed consent pertains to both legal and ethical standards for physicians to communicate pertinent facts about the patient's condition and explain the benefits, risks, and alternatives of

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[264] *Id.* at 88 (describing medical interventions as a "conveyor belt"); *see also* Tanya Stivers & Alexandra Tate, *The Role of Health Care Communication in Treatment Outcomes*, 9 ANN. REV. LINGUISTICS 233, 242 (2023)(describing an interactional "on-ramp" in medical procedures that do not necessarily offer benefit to the patient).

[265] Shim et al., *supra* note 251, at 344.

[266] Daniel D. Matlock et al., *Evidence of Cognitive Bias in Decision Making Around Implantable-Cardioverter Defibrillators: A Qualitative Framework Analysis*, 23 J. CARDIAC FAILURE 794, 796, 798 (2017).

[267] *Id.* at 798; *see also* Alison Malecki-Ketchell et al., *Adult Patient Decision-Making Regarding Implantation of Complex Cardiac Devices: A Scoping Review*, 16 EUR. J. CARDIOVASC. NURS. 567, 572–73 (2017).

[268] Malecki-Ketchell et al., *supra* note 267, at 570.

[269] Matlock et al., *supra* note 266, at 796 (discussing framing); Shim et al., *supra* note 251, at 345 (discussing risks and negative outcomes); Malecki-Ketchell, *supra* note 267, at 570, 572 (discussing psychosocial risks, incomplete information about risks, and the risk of inappropriate shocks).

[270] Rao et al., *supra* note 245, at 623.

[271] Malecki-Ketchell, *supra* note 267, at 572–73; Rao et al., *supra* note 245, at 623.

[272] Matlock et al., *supra* note 266, at 7944; Malecki-Ketchell, *supra* note 267, at 571; Shim et al., *supra* note 251, at 345.

different treatment options.[273] Ideally, patients and physicians engage in shared decision-making, where the decision reflects the patient's specific goals, preferences, and values. This process upholds the principles of patient autonomy so the patient can make informed decisions about what happens with his body. It also furthers the principles of beneficence to ensure the decision offers more benefit than harm to each individual patient. Notably, the Centers for Medicare and Medicaid require documentation of the shared decision-making conversation within the patient's medical record as a condition for reimbursement for certain patients.[274] Still, some physicians assert that the informed consent process is insufficient because there is a disconnect in what physicians disclose compared to what patients comprehend.[275]

Several cases have addressed the issue of informed consent or alleged malpractice related to interventions in cardiology.[276] In *Melton v. Medtronic*, a patient and his wife brought a malpractice suit against his physician and device manufacturer after his ICD delivered multiple unexpected shocks.[277] The patient alleged a lack of informed consent, asserting he did not remember any discussion of risks and alternatives with his physician.[278] However, the physician countered that the patient signed both the informed consent and the device alert, which provided additional information about the device.[279] The court held that the patient did not present evidence that he would have made a different decision with different information, and offered no evidence of the physician's failure to inform him of the risks before the procedure.[280] Courts generally provide weight to the *documentation* of informed consent, despite the patient's allegation that the process did not afford them sufficient *comprehension* of the benefits, risks, and alternatives.[281] As health law professor Nadia Sawicki observes, the legal requirement for informed consent

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[273] Stivers & Tate, *supra* note 264, at 235; Rao et al., *supra* note 245, at 622–23.

[274] *See Decision Memo for Implantable Cardioverter Defibrillators*, CTRS. FOR MEDICAID & MEDICARE SERVS., (Feb. 18, 2018), https://www.cms.gov/medicare-coverage-database/view/ncacal-decision-memo.aspx?proposed=N&NCAId=288 [https://perma.cc/8AS7-HBAD]; Christopher E. Knoepke & John M. Mandrola, *Don't Be Afraid: Using an ICD Means Having Difficult Conversations*, 12 CIRCULATION: HEART FAILURE, Oct. 11, 2019.

[275] Knoepke & Mandrola, *supra* note 274, at 1.

[276] *See* Melton v. Medtronic, 698 S.E.2d 886 (S.C. Ct. App. 2010) (holding summary judgment was appropriate in favor of physician when patient alleged malpractice against a physician for placing an ICD where patient signed the informed consent form and device alert form); *see also* Snider v. La. Med. Mut. Ins. Co., 130 So. 3d 922 (La. 2013) (holding jury did not err in finding that physician did obtain informed consent in a malpractice suit for implanting a pacemaker because patient signed the informed consent form).

[277] *Melton*, 698 S.E.2d at 889.

[278] *Id.* at 893–94.

[279] *Id.* at 889–90.

[280] *Id.* at 894–96.

[281] *Id.*; *Snider*, 130 So.3d at 936; *see also* Nadia N. Sawicki, *Modernizing Informed Consent: Expanding the Boundaries of Materiality*, 2016 U. ILL. L. REV. 821, 835, 871 (2016) (explaining the distinction between physician disclosure of information and patient comprehension).

focuses on disclosure, which may not necessarily mirror patient understanding of the procedure's burdens and limitations.[282]

Engaging in a conversation about implanting an ICD involves complex tradeoffs, and should include a discussion of how the device would affect the patient's quality of life.[283] Some physicians assert that directness and honesty about device limitations—and what this means for patients potentially facing death—not only supports the ethical values behind informed consent but also upholds patient trust in their physicians.[284] In one study, only fifty-four percent of patients reported that physicians discussed the goals of treatment before implantation.[285] Some patients may want to maximize the longevity of their life and try all possible options.[286] Other patients, however, may not want a longer life if they continue to experience disease symptoms that the ICD does not address, or assess that the burdens of the ICD are not worth it. Patients may experience more shocks toward the end of their life, which may be painful and distressing.[287] Physician Daniel Kramer and colleagues found that the majority of patients (roughly seventy percent) initially reported they were satisfied with their decision to have an ICD.[288] However, patient satisfaction changed—and declined—over time.[289] Some patients report widespread dissatisfaction and misunderstanding about the limitations of the device.[290] Shim and colleagues found that some patients reported feeling confused and "demoralized" when the device failed to help them.[291]

Shim and colleagues assert that questions about death, quality of life, and limits of the ICD should be part of the informed consent process.[292] Some physicians suggest that implanting an ICD may not be consistent for patients whose goal is to experience quality versus quantity of life.[293] Matlock and colleagues explain it simply: sudden cardiac death ("dying in your sleep") is not always an adverse event for all patients.[294] Patients may also change their decision over time based on their experience with the device and their quality of life. ICDs can be deactivated, which stops them from delivering both lifesaving or inappropriate shocks if the patient decides to stop life-extending measures.[295] Deactivation does not stop the patient's heart, but it would allow

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[282] Sawicki, *supra* note 281, at 835.

[283] Matlock et al., *supra* note 266, at 794.

[284] Stivers & Tate, *supra* note 264, at 242, 246.

[285] Kramer et al., *supra* note 244, at 5.

[286] Shim et al., *supra* note 251, at 345.

[287] *See* Matlock et al., *supra* note 266, at 796–97; Kramer et al., *supra* note 244, at 6.

[288] Kramer et al., *supra* note 244, at 5.

[289] *Id.*

[290] *See* Kramer et al., *supra* note 244, at 5. *But see* Malecki-Ketchell, *supra* note 267, at 569; Shim et al., *supra* note 251, at 345.

[291] Shim et al., *supra* note 251, at 345.

[292] *Id.* at 346.

[293] Matlock et al., *supra* note 266, at 794.

[294] *Id.*

[295] Kramer et al., *supra* note 244, at 5; *see also* Beattie et al., *supra* note 248, at 1143.

natural death to occur sometime in the future. However, one study showed that fifty-three percent of patients were not even aware that device deactivation was an option.[296]

Physicians operating pursuant to the treatment imperative who want to try everything to forestall their patient's death are likely operating with benevolent intentions. Yet if patients do not understand their range of options (including forgoing the ICD or deactivating it), this creates a lost opportunity for patients to spend time, money, or resources on alternatives such as palliative care or hospice care.[297] It also reduces patients' ability to prepare financially, emotionally, and psychologically for death. For some patients, they may welcome a referral to palliative care physicians who can accompany them through severe illness and accepting natural death, which may not necessarily constitute a harm in all cases.

B. *When Death of the Unborn is a Harm*

1. *Le Page v. Center for Reproductive Medicine* and the Loss of Embryos

In 2024, the Alabama Supreme Court examined the issue of whether wrongful death lawsuits for unborn children at any stage of gestation includes embryos.[298] In this case, three couples created embryos at the Center for Reproductive Medicine, some of which resulted in the birth of children. Additional embryos remained cryogenically frozen. Three couples who created embryos for in-vitro fertilization ("IVF") at the Center for Reproductive Medicine sued the clinic after a patient who wandered into the "cryogenic nursery" where remaining frozen embryos were stored, picked some up and accidentally dropped them on the floor, "killing them."[299] Parents alleged a variety of claims, including negligence and wrongful death of an unborn child.[300]

The parents' claim rested on the meaning of "unborn child" in Alabama state law. Previous cases in Alabama held that state law permits expectant parents to allege wrongful death of unborn children at any stage of development.[301] The court noted that the state statute did not specifically exclude "extrauterine children," or embryos that had not yet been implanted.[302] Applying the plain meaning of the statute and precedent, the court held that the

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[296] Kramer et al., *supra* note 244, at 5.

[297] Swetz et al., *supra* note 118, at 945.

[298] LePage v. Ctr. for Reprod. Med., 2024 WL 656591 (Ala. 2024). Portions of this section were adapted from Katherine Drabiak, *What is a Frozen Embryo Worth? Alabama's IVF Case Reflects Bigger Questions Over Grieving and Wrongful Death Laws*, THE CONVERSATION (Mar. 7, 2024, 8:36 AM), https://theconversation.com/what-is-a-frozen-embryo-worth-alabamas-ivf-case-reflects-bigger-questions-over-grieving-and-wrongful-death-laws-224721 [https://perma.cc/9TV2-X4M3].

[299] *LePage*, 2024 WL 656591, at 1.

[300] *Id.* at 2.

[301] *Id.* at 4.

[302] *Id.*

wrongful death statute applied to all unborn children, "without exception based on developmental state, physical location, or any other ancillary characteristics."[303] As a result, the court held that the couples could pursue a claim for the wrongful death of the embryos.[304]

Some media outlets expressed panic that this holding would "hamper access to fertility treatments" and the holding "threaten[ed] patients."[305] The Alabama legislature swiftly amended state law, carving out a broad liability shield for IVF providers.[306]

Alabama, however, is not an outlier for allowing parents to bring wrongful death lawsuits to compensate for the loss of their unborn child.[307] The majority of states—forty three—allow wrongful birth lawsuits for unborn children, and fourteen of these states permit the claim for any stage of development.[308] A handful of states such as Illinois, Missouri, and Georgia also allow wrongful death lawsuits for embryos.[309] Other state laws exclude actions that occur before transferring the embryo to a woman's uterus, which would preclude wrongful death actions for destruction of embryos before implantation in those states.[310]

2. Types of Legal Claims for Death of an Unborn Child

As health law professors Dov Fox and Jill Wieber Lens point out, there is confusion and inconsistency in how the law classifies embryos, and whether they should be classified as a person, part of the woman's body, or piece of property.[311] Fox and Lens provide a framework for considering different claims related to reproductive loss: stillbirth injuries, wrongful abortion, negligence, or

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[303] *Id.*

[304] *Id.* at 8.

[305] *See* Alander Rocha, *Alabama Supreme Court Ruling Could End IVF Treatments in State*, ALA. REFLECTOR (Feb. 19, 2024, 2:43 PM), https://alabamareflector.com/2024/02/19/alabama-supreme-court-ruling-could-end-ivf-treatments-in-state/; H. Irene Su, *Alabama's Embryo Personhood Decision Threatens Patients, Medicine and Advances in IVF*, SCI. AM. (Mar. 25, 2024), https://www.scientificamerican.com/article/alabamas-embryo-personhood-decision-threatens-patients-medicine-and-advances/ [https://perma.cc/3FNH-4AGX].

[306] *See* Drabiak, *supra* note 298. *But see* Emily Cochrane, *Alabama's I.V.F. Shield Law Now Faces a Constitutional Challenge*, N.Y. TIMES (June 14, 2024), https://www.nytimes.com/2024/06/14/us/politics/alabamas-ivf-shield-law.html (describing constitutional challenges because the liability shield laws would prohibit expectant parents from filing wrongful death lawsuits for the destruction of their embryos, which parents allege is a violation of their due process and equal protection rights).

[307] *See* Paul Benjamin Linton, *In Vitro Fertilization, State Wrongful Death Statutes and State Fetal Homicide Statutes: The Reaction to* LePage v. Center for Reproductive Medicine, 39 ISSUES L. & MED. 50 (2024).

[308] *See id.* at 51–52.

[309] Jeremy Applebaum et al., *Malpractice Litigation Surrounding In Vitro Fertilization in the United States: A Legal Literature Review*, 119 FERTILITY & STERILITY 572, 577 (2023).

[310] Linton, *supra* note 307, at 52–53.

[311] Dov Fox & Jill Wieber Lens, *Valuing Reproductive Loss*, 112 GEO. L.J. 61, 64 (2023).

wrongful death.[312] Fox and Lens explain each of these injuries fall under the concept of "reproductive loss," which entails a serious loss that denies parents the opportunity to reproduce and forces childlessness on the parents, which is a profound dimension of life.[313]

During pregnancy, the law permits parents to recover for actions that caused the premature death of their unborn child.[314] This may include an injury leading to a stillbirth (after twenty-weeks gestation).[315] After fetal death, Fox and Lens explain that the mother is a human coffin.[316] As the mother endures labor, the infant's birth is simultaneously a scene of the infant's death for the parents.[317] Fox and Lens describe this process as a "special emotional harm" and "wrenching helplessness."[318] Parents may also recover for wrongful abortion, such as if a clinician provides inaccurate diagnostic information to a pregnant woman (e.g., misdiagnosing a fetal anomaly) that substantially influences her decision to abort.[319]

Fox and Lens trace the first lawsuit over the loss of embryos back to 1995, where a Rhode Island court allowed parents to recover for missing embryos based on the theory that they were "irreplaceable property."[320] A negligence lawsuit for loss of property attempts to compensate parents for the value of the loss, such as the investment of time, money, and physical hardship involved in the IVF process.[321] This would include the cost of replacement sperm, eggs, hormonal medications, embryo storage, and other fees associated with IVF.[322] However, age, health, or other factors may create circumstances that make it impossible to replace these lost sperm, eggs, or embryos.[323] Fox and Lens point out this loss is more than replacement parts, but signifies the lost chance to have a baby.[324]

During pregnancy, states may also permit negligence or wrongful death lawsuits to recover for injuries that caused injury or death to an unborn child. Negligence lawsuits permit parents seeking damages to recover for the mother's injury stemming from the loss of the unborn.[325] Health law professors like Jill Lens and Greer Donley explain that negligence claims focus on the injury to the

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[312] *Id.* at 68–70, 98–100.

[313] *Id.* at 83.

[314] *Id.* at 98.

[315] *Id.*

[316] *Id.*

[317] *Id.*

[318] *Id.* at 98–99.

[319] *Id.* at 99–100.

[320] *Id.* at 69.

[321] *See* Drabiak, *supra* note 298; Fox & Lens, *supra* note 311, at 73.

[322] *See* Fox & Lens, *supra* note 311, at 69; *see also* Dov Fox, *Reproductive Negligence*, 117 COLUMBIA L.R. 149, 175 (2017).

[323] *Id.*

[324] *Id.* at 70.

[325] *Id.* at 68; *see also* Donley & Lens, *supra* note 36, at 1684–90.

mother, noting that these claims treat the unborn as part of the woman's body and would permit her to recover damages for emotional distress.[326]

Wrongful death claims, on the other hand, recognize that the unborn child is separate and individual. Wrongful death claims are statutory and vary slightly in each state.[327] These types of claims are designed to compensate the parents for the loss of a child. This includes lost parent-child activities, positive emotions related to being a parent to this child, future experiences, and identity of being a parent to that child.[328] Lens asserts that parents who suffer from the death of a child experience a moral injury, which entails loss including grief, devastation, anger, and tragedy.[329] Parents lose potential companionship, love, and affection from the child.[330] Damages in these claims focus on this lost relationship rather than emotional distress in most states.[331]

3. Inconsistent Valuation of the Unborn

This raises the question of why the law permits abortion if a pregnant woman can decide to terminate the life of her unborn child, while simultaneously allowing negligence or wrongful death claims for actions that caused the loss of the unborn child.[332] Donley and Lens reason that both practices can exist because reproductive loss is a "subjective, personal, and relational loss."[333] Abortion, according to Donley and Lens, is permissible because the value of the unborn is not innate, biological, or fixed.[334] Rather, only the pregnant woman or the parents *bestow value* upon the unborn child.[335] Donley and Lens explain how as the pregnancy progresses as a process by which parents connect with the unborn child in increments, such as using the ultrasound to personify the baby's movements, features, or personality, naming the baby, and preparing the nursery.[336] Donley and Lens assert that the loss is subjective, and only based on the parent's valuation of the unborn child.[337]

However, many state laws expressly reject the proposition that the unborn only have subjective value. Some state laws expressly recognize the unique individual interest in the life of the unborn, and several states classify this as a

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[326] Donley & Lens, *supra* note 36, at 1684–90.

[327] *Id.* at 1685; Fox & Lens, *supra* note 311, at 68.

[328] *See* Donley & Lens, *supra* note 36, at 1686.

[329] Jill Wieber Lens, *Children, Wrongful Death, and Punitive Damages*, 100 B.U. L. REV. 437, 440–44 (2020).

[330] *Id.*

[331] *Id.*

[332] *See* Donley & Lens, *supra* note 36.

[333] *Id.* at 1656, 1676.

[334] *Id.* at 1676.

[335] *Id.* at 1678.

[336] *Id.* at 1678, 1680.

[337] *Id.* at 1691.

protectable interest in life, health, and well-being.[338] Criminal law also provides an important point of comparison for determining the valuation of fetal life. The majority of states (thirty-eight) allow criminal prosecution for fetal homicide, and the majority (twenty-nine) permit prosecution for any stage of pregnancy.[339] Notably, although criminal prosecution can vindicate the rights of the victim, the prosecutor acts on behalf of the state to ensure accountability for criminal wrongdoing, uphold fairness, and seek justice on behalf of society.[340] Most importantly in criminal law, the prosecutor seeks justice for the wrongful loss of human life, even if no other person recognizes that value of the life.

Donley and Lens reason that states created fetal homicide laws as a method to offer justice to the pregnant woman for criminal actions that caused her reproductive loss.[341] While this may be true, the fetal homicide laws also signify that a criminal wrong has occurred even if the pregnant woman does not recognize it. Fetal homicide laws recognize that death of the unborn entails death of a distinct life apart from the life of the pregnant woman, which is why the law counts fetal homicide as a separate and additional a crime.[342]

Reconciling the current inconsistencies in the law, parents may *experience* their loss of the unborn and embryos in a subjective manner, suffering immensely, or at the other end of the spectrum engaging in actions to intentionally cause fetal death through abortion. However, parents' subjective valuation of their offspring is independent from the *inherent value* of unborn children and embryos. Political science professor Robert George and ethics professor Christopher Tollefsen suggest that unborn children from the moment of conception are human beings that should be afforded moral and political rights of that status.[343] Even at the embryonic stage, each embryo is genetically unique and irreplaceable. George and Tollefsen view the issue through a human rights lens, asserting that all human beings have a right not to be intentionally killed.[344] Legal protection of this right should not be based on age, size, or stage of biological development.[345]

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[338] *See* Ala. CONST. art. I, § 36.06; The Alabama Human Life Protection Act, ALA. CODE § 26-23H-2 (2019); Missouri Stands for the Unborn Act, MO. REV. STAT. § 188.026 (2019); Linton, *supra* note 307.

[339] Donley & Lens, *supra* note 36, at 1695; *see also* Linton, *supra* note 307, at 61–63.

[340] *See What Is a DA*, NAT'L DIST. ATT'YS ASS'N, https://ndaa.org/about/what-does-a-da-do [https://perma.cc/B85B-TUMJ]; *see also* Bennett L. Gershman, *Prosecutorial Ethics and Victims' Rights: The Prosecutor's Duty of Neutrality*, 9 LEWIS & CLARK L. REV. 559 (2005) (describing the role of neutrality and duties of prosecutors, noting they represent the state).

[341] Donley & Lens, *supra* note 36, at 1695–96.

[342] *Id.*

[343] ROBERT P. GEORGE & CHRISTOPHER TOLLEFSEN, EMBRYO: A DEFENSE OF HUMAN LIFE (2008).

[344] *Id.*

[345] *Id.*

CONCLUSION

We all wish for a healthy, vibrant, and thriving life that is meaningful and free of illness. Yet genetic disorders, life threatening conditions, and disabilities can result in extensive treatments, debility, and pain. But human value is not conditional; it does not wane based on stage of life, nor is it reduced by sickness and dependence. People who have a life that is short and difficult, marked by disability and suffering, or are reliant on others are valuable because they are *human*. We do not hold the authority to confer worth or erase another human being's life, based on frailty, medical condition, or "worthiness." We cannot exert mastery over all illness or death despite miracles in medicine, but laws can facilitate and affirm the rights of patients and their medical decision-makers to make deeply personal treatment choices. Physicians hold a powerful role in communicating with patients and families in a manner that respects the potential of each human life, acknowledges when death is imminent, and supports families in the process of deciding the treatment direction based on the patient's goals and preferences. Treatment decisions do not extend to invoking the assistance of physicians to induce with death on demand, because this exceeds the bounds of medicine and contravenes the duty to care for the most vulnerable members of our society. We can understand the imminence of death but want it to occur on our own terms in a way that enables us to feel safe, valued, and honored. Finally, we can facilitate acceptance of death by affirming the innate value of each person's life and offer compassion and accompaniment for people facing illness and death.