A Care and Duty Ethics Perspective on Pregnancy Exceptions in Life-Supporting Technology Policy

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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Development of Life Supporting Technology: "With it, we can actually keep Kenny the tomato alive for years."

With the development of new diagnostic and life-extending technology, life expectancy has been steadily increasing since the 1960s, with the addition of approximately 10 years as of 2020 (Medina et al., 2020). Sophisticated life-extending technologies have made it possible for a patient who has sustained a traumatic incident or is battling a terminal disease to be sustained for a long period of time by artificially providing basic vital functions, particularly respiration, circulation, and nutrition, even past the point that the patient can meaningfully recover or interact with their surroundings. A patient can remain in a Persistent Vegetative State (PVS) where they are completely unaware of their environment, but still have a portion of their autonomic brain stem functions intact. After 3 to 12 months in PVS, a patient is exceedingly unlikely to regain consciousness, but their vital organ functions can be mechanically provided for many years ("Medical Aspects of the Persistent Vegetative State," 1994). Life supporting devices have led to an ethical and legal quagmire of issues relating to informed consent, resource allocation of life-supporting devices for PVS patients, high cost of long term PVS care, and new definitions of legal and ontological death.

Issues of resource allocation of scarce life-supporting devices were helped solved by the creation of brain death criteria. Although death has been classically determined by the cessation of pulse and breathing, with mechanical circulatory and ventilation equipment, another standard was needed to legally and ethically define death. The criteria of brain death were first published in a report from a committee of physicians from Harvard Medical School in 1968, which led to certain states recognizing this standard in their legislation. To provide national consistency, a President's Commission studying ethical problems in medicine analyzed the changing definitions of death being implemented by individual states, and following the publication of their results

the Uniform Determination of Death Act was created and has since been passed in all 50 states. The statutes defining death in this policy are "irreversible cessation of circulatory and respiratory functions" or "irreversible cessation of all functions of the entire brain, including the brain-stem." Establishing a brain death criteria was not only a response to the advances in critical care medicine, but also helped to create a framework for organ donation, settling legal matters including medical malpractice allegations, life insurance benefits, family estate planning, and homicide charges (Burkle et al., 2014). The brain death standard has been fiercely debated with some arguing that the standard is too conservative and that it should be framed in terms of permanence, rather than irreversibility, of the lack of function because some interventions can restore minimal biological function but not meaningful recovery, which provides false hope for family members (Parent & Turi, 2020). On the opposing side others have contended that there are logical flaws and ambiguities inherent to the concept of brain death, and that because there is some level of functioning as an organism this standard is troubling (Miller & Truog, 2011). Questions of personhood and what constitutes meaningful interaction with the environment make brain death a more complex topic than just the clinical presentation and individual views on the matter can vary widely. Disputes about what constitutes death were central to several landmark court cases that led to national standards for end-of-life decisions to withdraw care and who was authorized to make those decisions.

The end-of-life decisions made by patients and their families are emotional and complex, and laws and hospital regulations have been grappling with how to best protect the life of the patient and provide compassionate care since the 1970's. However, what compassionate care looks like can depend on many factors, such as the values of the patient, values of the doctor or hospital, patient prognosis, and the wishes of the family. As a result, disagreements relating to

end-of-life care have been polarizing, emotionally charged, and the source of several highly publicized court cases. However, end-of-life withdrawal of care decisions made with an incompetent patient on life support significantly differs from the issue of physician-assisted suicide, which is the prescription of a medication to intentionally end the life of a competent, terminally ill patient, and not considered in this discussion (Emanuel et al., 2016). It is important to understand the ethical considerations that have been codified in response to the development of life supporting technology and how we have chosen to use this technology, particularly in ethically challenging cases.

Methods

The complex legal and clinical interplay surrounding the use of life-supporting devices during pregnancy begs the question: How have duty and care ethics shaped the use of life-supporting devices during pregnancy and what are the ethical implications of policies that regulate this technology? To understand the ethical questions surrounding the expanded medical capabilities afforded by life-support devices and how they have been navigated during pregnancy, the viewpoints of the state and the clinician are considered through the frameworks of duty ethics and care ethics. Documentary research methods are used to understand the historical, legal, and clinical context surrounding Advance Directives (ADs) and the use of life-sustaining technology in pregnancy. From a legal standpoint, state legislative AD pregnancy exception policies are analyzed in context to understand the impact of the judicial decisions and state laws on clinical practice. From a clinical ethics standpoint, clinical practice guidelines from the American College of Obstetricians and Gynecologists are considered as well as other clinical guidelines, relevant court cases, and scholarly articles that discuss clinical implications of AD

pregnancy exceptions. The integration and analysis of legislation, judicial decisions, and clinical practice guidelines through the lenses of their respective ethical frameworks demonstrates the societal impact of life-sustaining technologies and the values implicit to their regulation and use.

Withdrawal or Withholding of Care Policy: "A right-to-die debate is heating up in Colorado where Kenny McCormick's feeding tube has been removed by his BFF."

Landmark court cases beginning in the 1970's have led to the creation of legal tools to establish patients' prospective treatment decisions and laws that created protocols for end-of-life withdrawal or withholding of treatment decisions and protect healthcare providers from liability. *In re Guardianship of Schiavo* (2001), was particularly salient in the media and brought fervent national attention to issues surrounding the long-term use of life-support devices as a result of the legal debates between the husband and parents of Terri Schiavo to remove Terri's feeding tube after being in PVS for many years with little to no hope for recovery. In fact the governor of Florida, Congress, and President George W. Bush all became involved by passing legislation to help Terri's parents block the removal of the feeding tube, which was later struck down by the courts (Haberman, 2014). The Schiavo case even found its way into popular culture, with episode 4 in season 9 of the animated comedy show South Park having a plot line with striking similarities to debate ignited by Schiavo, demonstrating America's increasing awareness of the right-to-die movement that started years before with the case of Karen Quinlan in 1975.

Karen Quinlan was a 21-year-old female who became comatose after the ingestion of alcohol following the ingestion of sedatives. She had slow waves on her EEG and was decorticate and deconjugate, with her eyes moving independently and not communicating with her brain. However, she would occasionally move her head, make noises, choke, and sit up suddenly with wide eyes and appear to be in pain. Under the New Jersey law at the time that

required all of the brain to be non-functioning, Quinlan was not brain dead but was in PVS. In the fall of 1975, her family made the decision to remove the ventilator since Karen would never become conscious and she had previously expressed that wish to them, which was later recognized as substituted judgment. The doctors in charge feared criminal misconduct if they complied with the family's wishes because in 1975 the American Medical Association equated withdrawing a ventilator with euthanasia and murder. Additionally, Quinlan was being treated in a catholic hospital which had strong resistance to the withdrawal of care resulting from religious beliefs and values. Because Karen had no written advance directive, the judge ruled that she must stay on the ventilator and that the right to die was not in the US Constitution. Two months later the New Jersey Supreme court reversed the decision, citing the right to privacy to allow the family of a dying family to decide what the patient would have wanted. The decision was based on *Griswold v. Connecticut*, which established the right to fundamental liberty to live one's personal life as one saw fit, and *Roe v. Wade*, which established the right to privacy. The Quinlan case granted families the right to exercise substituted judgment in healthcare decisions in the absence of written instructions (Pence, 2011).

Another significant case concerning the rights of competent dying patients was *Cruzan v. Missouri Department of Health* (1990). Nancy Cruzan was a 24-year-old female who was in a car accident in 1983, and after the impact her brain had been without oxygen for over 15 minutes before paramedics reseated her heart. She did not regain consciousness. Over 7 years her body became rigid and she could not receive adequate nutrition by mouth, so she received a feeding tube. Later, her parents requested permission to discontinue the feeding tube. The Cruzans won their case in the lower court, but the Missouri Supreme Court reversed the decision due to a lack of clear and convincing evidence because Nancy did not have an advance directive or a living

will. The ‘clear and convincing’ evidence standard is a legal term that refers to the standard of proof required, which is a greater burden of proof than the ‘preponderance of evidence’ standard commonly used in other states to justify end-of-life decisions, and less than the ‘without a reasonable doubt’ standard used in murder trials. When the case was presented to the US Supreme Court, their decision had three main components: 1. A competent patient had the right to refuse treatment, even if it led to their death. 2. Withdrawing a feeding tube was not different from withdrawing any other life-sustaining medical support and that state laws that differentiated between withdrawing ventilators and artificial nutrition were unconstitutional. 3. Regarding incompetent patients, a state could, but need not, pass a statute requiring a clear and convincing standard of evidence for implementing the non-documented wishes of a formerly competent patient. Since Missouri had a statute with that standard, the law was constitutional and the Cruzans lost their case (Pence, 2011).

The legal basis for issues of withholding or withdrawing life-sustaining care and the impetus for enacting policies concerning end-of-life decision making began with the court cases of *In re Quinlan* in 1975 and *Cruzan v. Missouri Department of Health* in 1990, however since their rulings many others with similar questions have been argued, demonstrating the complexity and situational nuances at play involved. The cases regarding Cruzan and Quinlan were the first to ask questions central in the “right-to-die” movement, which sought to establish the right of terminal and permanently unconscious patients and their proxies to refuse or remove life-sustaining treatment that only serves to prolong death. The landmark decisions further integrated the concepts of informed consent, personal liberty, and privacy with respect to medical care and have since served as vital precedents for shaping future judicial decisions concerning decision-

making authority and the use of life-sustaining devices in other difficult situations, including during pregnancy (Capron, 2019).

"I don't know if it's right to keep Kenny alive on that machine, I just don't know what he would want."

With the Quinlan case establishing states' individual rights to enact policies concerning the use of life-supporting devices, policies establishing advance directives and the durable power of attorney for health care have since been enacted, with subtle differences, in all 50 states, and have been revised and expanded over time. In 1976, California was the first state to pass legislation to allow terminally ill patients to establish a living will, called the Natural Death Act. A living will is a legal document that formalizes patients' views on life support in the event that they become incapacitated or incompetent, and can include decisions about the use of life-sustaining care and provision of artificial nutrition and hydration. The Natural Death Act was the first to allow for any form of an advance directive and was similarly adopted by 42 other states from the years of 1981 to 1990 (Jonsen, 1978). However, despite giving patients some prospective control over their medical care, living wills are inadequate at addressing every potential medical decision, only effective when a person is terminally ill or near-death, can lapse if not re-executed, and have been refused to be implemented by physicians in practice. In an attempt to address some of these shortcomings of living wills, other policies, such as the durable power of attorney for health care decisions, have been implemented. The durable power of attorney for health care decisions allow a person designated by the patient to make healthcare decisions in the event that the patient becomes unable to themselves. Durable power of attorney does not require anticipation of all treatment decisions and allows the responsible person to advocate for the wishes and best interests of the patient. From the period of 1970 to 1990, 30

states passed legislation allowing for the durable power of attorney (Sheafor, 1992). Durable power of attorney expanded abilities to establish a person's values and give them decision making power over their future course of treatment, allowing for greater personal autonomy and respect for individual choice. Importantly, states' living will and durable power of attorney policies also clarified questions of when healthcare decisions can be made on behalf of the patient and who can make them, physician liability, healthcare worker non-compliance from a moral or religious stance, whether artificial nutrition and hydration are considered life-sustaining, and the burden of proof needed for a proxy to enact a patient's wishes. The uncertainties around withholding or withdrawing care had major impacts on physicians', patients', and decision-making proxies' attitudes toward and usage of life supporting devices before they were answered through judicial decisions and legislation. With the passage of acts protecting patients' rights to autonomy at the end of their life, particularly living wills and durable power of attorney, it became codified that there is no difference between withholding and withdrawing life-support, physicians are not liable for a patient's death by legally complying with their wishes, and that withholding or withdrawing care is not considered suicide, but permitting the natural process of dying (*Advance Directives and Advance Care Planning*, 2007).

In later waves of legislation regarding the use of life-supporting devices, out-of-hospital Do Not Resuscitate orders (DNR) protocols were created to prevent unwanted resuscitations of terminally ill patients by Emergency Medical Service (EMS) who are required to do everything they can to resuscitate an unconscious patient with no pulse or breathing due to implied consent. In those situations, advance directives do not supersede the obligation to resuscitate. From the early 1990's to the end of 1999, 42 states passed protocols for Cardiopulmonary Resuscitation

(CPR) directives, signed by both patient and physician and kept near the patient to inform EMS of their wishes. Finally, the most recent addition to end-of-life decision-making legislation has been the merging of separate legal tools, including living wills and durable power of attorney for health care, into a single advance directive (AD) for health care. The creation of ADs to combine other prospective treatment decision methods was driven by a public lack of understanding and usage of existing prospective medical decision-making tools (*Advance Directives and Advance Care Planning*, 2007). In an estimate from the National Poll on Healthy Aging, only 37% of older adults have completed both a living will and a durable power of attorney for health care for reasons including not getting around to it, not knowing how, having a dislike of discussing the subject, and considering it unnecessary (Malani et al., 2021). Having both a healthcare proxy and written documentation of prospective treatment preferences is important to preserve patient autonomy because evidence has shown that legal proxies cannot accurately predict the wishes of a patient who suddenly becomes incompetent, predicting wrongly for continuing or discontinuing treatment at about the same rate (Pence, 2011; Seckler et al., 1991). The large number of patients without advance directives led to state laws and statutes establishing the default surrogate consent protocol, which is the ordered list of people who are authorized to make healthcare decisions in place of the patient. The order varies between states, but typically a spouse or child is prioritized followed by decreasingly related blood relatives. The default surrogate consent protocol was created to preserve the best wishes of the patient by ensuring they would have a close relation to advocate for their medical care. As of October 2022 all 50 states have individual policies to establish a durable power of attorney or health care proxy and 48 states have policies for creating an advance directive (*Advance Directives and Living Wills Legal Forms*, 2020).

Despite the overall shift in legislation to allow for greater patient autonomy when they are incapacitated, one gaping exception is how advance directives are applied during pregnancy. The variation in state advance directive policy is especially salient in how each state allows prospective withdraw or withholding of care treatment decisions to be applied to a patient who is pregnant. In over half of the states in the US, advance directives do not apply when a patient is pregnant, and the sentiments of these legal restrictions are quite different from those that guide clinical practice.

Care and Duty Ethics of AD Pregnancy Exceptions: "Who are we to decide that Kenny should live or die?"

In other discussions concerning pregnancy restrictions, much of the scholarly literature about the legislation use feminist legal theory as a framework of analysis, placing pregnancy restrictions within the context of subordination and devaluation of women's autonomy (Krause, 2022). Some scholarly work argues that increasing legislation enshrining fetal rights and the right-to-life movement leads to restrictions in the behavior of pregnant women and, when restrictions are taken too far, challenge their constitutional rights. Pregnancy restrictions broadly refer to restrictions applied on the basis of someone being pregnant and are found in a broad variety of issues related to regulating women's actions during pregnancy with the aim of protecting the fetus, which lead to a reduction in women's rights (Sandstad, 2008). Advance directive pregnancy exceptions are an example of a pregnancy restriction because they limit one's bodily autonomy on the basis of pregnancy. For example, in her analysis of the *Gonzalez v. Carhart* decision, which upheld federal legislation banning a procedure used during abortions, Kaplan uses a feminist legal theory framework to argue that state intervention in pregnant women's health care treatment decisions infringes on women's liberty and equality rights,

designates pregnant women as a “special class of persons” with more limited bodily autonomy and informed consent rights, and allows women’s bodies to be controlled by the state for their reproductive capabilities (Kaplan, 2010). While the feminist legal theory framework is valuable to understand how pregnancy restrictions fit into societal and historical contexts of gender inequality and discrimination, using purely a legal analysis framework for a topic of health care treatment decisions does not consider the inherent clinical perspective and does not elucidate the ethical complexities of AD pregnancy exceptions.

In contrast, from a bioethical standpoint, analysis of AD pregnancy exceptions is primarily accomplished through a variety of frameworks, including clinical ethics. Using principles like autonomy and beneficence, pregnancy exceptions are argued to be unethical because they can direct doctors to provide care against the wishes of the patient and against their best interests. Other ethical frameworks, including consequentialist ethics and deontological ethics, have also been invoked in bioethical analyses. Consequentialist ethics say that the morality of the outcome justifies the actions taken. In her analysis, Strand argues that consequentialist ethics do not support AD pregnancy exceptions because in situations where favorable moral outcomes are not predictable, like in the case of a mechanically ventilated, sick, dying, or dead pregnant body being sustained to gestate and produce a live fetus, the actions taken are not ethical if the favorable outcome does not occur. Deontological ethics argues that the action in and of itself must be ethical and not based on the outcomes. Depriving pregnant women of autonomy with AD pregnancy exceptions is not ethical, so any outcome resulting from the unethical action of providing life supporting care to a pregnant person who explicitly stated that they did not want life supporting care does not provide justification for disregarding the patient’s decision (Strand, 2021). While the bioethical perspective is important to understand

how AD pregnancy exceptions are viewed through multiple ethical frameworks, it is a primarily theoretical analysis with few tangible connections to the legal landscape of AD pregnancy exceptions and, more broadly, other pregnancy restrictions.

The analysis in this discussion uses both duty ethics and care ethics to discuss the legal and clinical implications of AD pregnancy exceptions, seeking to reconcile both the legal and ethical components to provide a more comprehensive ethical analysis of withholding life-sustaining care during pregnancy. The legal measures and judicial decisions passed have made an immense impact on how incompetent patients' health care decisions are made. To analyze the impact of legislation on clinical practices, Duty Ethics is used to understand the ethical complications that have arisen from the development of life-supporting devices. One key principle of duty ethics is that people have specific duties and one of the most important is to protect the rights of others (Fleddermann, 2004). Legal constructs governing the use of life extending technology, including Advanced Directives and Durable Power of Attorney, have been created, exemplifying the key idea in duty ethics that individuals must be respected. ADs and Durable Power of Attorney legally protect a patient's autonomy through written instructions detailing prospective medical care or designation of another person to advocate for their best interests, particularly in the event that the patient is no longer competent (Meisel, 2016). However, there are large variations across states for how ADs can be applied during pregnancy, with some states completely invalidating ADs, some providing special provisions for pregnancy, and others not making any difference for how an AD can be applied. The differences in policies and the underlying values are explored through a question fundamental to duty ethics: what are the rights of others and how can they best be protected?

Another key aspect involved in the decision of when to use life-sustaining devices are guidelines and ethics that help dictate medical treatment. Due to the inherent doctor-patient power imbalance, ethics are the cornerstone of clinical practice. Care ethics is also used to understand how legal and ethical implications that have shaped clinical practice and physician perspectives. Care ethics emphasizes the importance of relationships, stating that morals are learned from the responsibility resulting from connections with others and care felt towards them (van de Poel & Royakkers, 2011). As ethical questions often arise in clinical practice, there are four core clinical ethical principles considered in difficult cases: beneficence, nonmaleficence, autonomy, and justice. Beneficence is the obligation of the physician to act for the patient's benefit and actively promote their wellbeing. Nonmaleficence is the obligation of the physician to not harm the patient, this includes considering the risks and benefits of an action and avoiding treatments that are unnecessarily burdensome. Autonomy is the patient's fundamental right to decide what happens to their own body, which is the core idea behind informed consent, truth-telling, and confidentiality. Finally, the principle of justice is the fair, equitable, and appropriate treatment of patients (Varkey, 2021). Clinical ethical principles relate to the framework of care ethics because they are the morals that result from the unique doctor-patient relationship and they are especially salient in discussions regarding the use of life supporting devices. Through the core idea of relationships and the responsibility they incur, clinicians' perspectives are considered.

While legislation and clinical practice can seem quite separate, each one requiring different training and advanced degrees, and practiced in different places and contexts, in incapacitated decision making they have become almost inseparable. Before default surrogates and laws that establish how to resolve treatment decision disputes, the courts decided the course

of treatment for terminal patients. Legislation and clinical practice each influence the other, with certain legal decisions having clinical implications and certain clinical practice decisions having legal implications, making it vital to analyze the interplay between different ethical frameworks that drive each to better understand the complexity presented by AD pregnancy exceptions.

Ethicality of AD Pregnancy Exceptions:

The shift towards increased autonomy-preserving end-of-life and incapacitated decision-making legislation over the past 50 years demonstrates the increased understanding of the limits of life-sustaining technology and society's evolving relationship with it. Before the creation of devices that could mechanically provide for what the body needs to be kept alive, there was little ambiguity between life and death. From their perspective, states have a duty to protect the right to life of their citizens. For example, Article I § 2 in Florida's state constitution says, "All natural persons, female and male alike, are equal before the law and have inalienable rights, among which are the right to enjoy and defend life and liberty, to pursue happiness … [n]o person shall be deprived of any right because of race, religion, national origin, or physical disability," which explicitly reveals fundamental state priorities (P. F. Anderson, 2003). When life-sustaining devices and the right-to-die movement emerged, beginning with the Cruzan and Quinlan decisions, states had to evaluate how evolving technology should be used in pursuit of citizens' established rights to life, privacy, and liberty, as well as how to best protect all of those rights, particularly when they conflicted. With the direction from the courts that people's rights included having autonomy over their life and their death, states had a duty to protect those rights and preserve patients' autonomy while ensuring that their health care proxies' personal interests did not overshadow the vulnerable patient's wishes. To solve the issue of protecting rights that can come into conflict, states wrote healthcare decision laws carefully and with particular

stipulations to proactively protect citizens' rights as much as possible. The proactive protection includes clauses that require express authorization of artificial nutrition and hydration withdrawal, give healthcare providers the ability to transfer a patient to another provider due to moral disagreements, allow patients to withdraw power of attorney, and delineate strict requirements for default surrogates. From a duty ethics framework these stipulations make end-of-life care laws as ethical as possible by performing the duty of the law to protect all of the established rights of the people involved and all states have variations on proactive protections. However, one particular clause found in some states' AD legislation, pregnancy exceptions, have a greater degree of complexity and there is significant debate over who is primarily protected by pregnancy exception statutes and their inherent ethics.

AD Pregnancy Exceptions: "You say tomato, but I say Kenny!"

There is a lack of national standardization of end-of-life and incapacitated decision-making policies, which allows for states to self-determine the rights that are prioritized. Federal legislation concerning end-of-life and incapacitated decision making is sparse. The Patient Self Determination Act of 1990 is the primary federal legislation for prospective treatment decision-making, and this act empowers states to make their own policies concerning the use of life-supporting devices and requires healthcare institutions to provide patients information about their rights under the state laws (Capron, 2019; Sheafor, 1992). The Patient Self Determination Act of 1990 was created to help educate patients and give them an opportunity to express their health care decisions and preferences prior to losing decision-making capacity, which ensures that individuals' rights to self-determination are protected (Nafziger, 2022).

Despite a long-term shift of legislation towards increased preservation of personal autonomy, in some states there is still an emphasis on the right to life over the right to personal autonomy. The emphasis on the right to life is best exemplified in the state-by-state differences of whether an advance directive or a withdrawal or withhold of care decision made by a proxy applies while a person is pregnant. In 27 states life-sustaining treatment cannot be withheld or withdrawn from a person who is pregnant, with some variations, in order to protect the life of the embryo (*Guide to State Laws On Advance Directives and Pregnancy*, n.d.). Pregnancy clauses have the potential to impact a large number of pregnant people, as each year 75,000 pregnant people undergo non-obstetrical surgery, 1 in 1500 pregnant people are diagnosed with cancer, and approximately 250,000 Americans between the ages of 30 and 50 begin to show symptoms of early-onset Alzheimer's, all of which could have an impact on a person's ability to make health care decisions (Strand, 2021).

The right to bodily autonomy, self-determination, and privacy was established in the 14th Amendment, which says "[n]o State shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; nor shall any State deprive any person of life, liberty, or property, without due process of law; nor deny to any person within its jurisdiction the equal protection of the laws" (*14th Amendment to the U.S. Constitution: Civil Rights (1868) | National Archives*, n.d.). The 14th Amendment has been used in the argument of *Roe v. Wade* to deny personhood to fetuses because granting the fetus separate rights diminishes the pregnant person's rights, which are protected by the 14th Amendment. In addition the equal protection clause can be interpreted as protection against gender discrimination, of which pregnancy discrimination is a subset (Sandstad, 2008). The 14th Amendment explicitly recognizes the right to freedom and fairness for United States citizens. With freedom and fairness

being established in one of the country's most foundational and esteemed documents, it provides an immense amount of protection for those rights because the amendment is ensuring and difficult to alter. Under the consideration of the 14th amendment, pregnancy clauses in ADs are not ethical within a duty ethics framework because they abridge the right to liberty of the pregnant person and violate the equal protection clause of the amendment because they only apply to those who are pregnant. Pregnant people are not less of a person while they are pregnant, so it is not ethical for their rights to be diminished during this time. In *Roe v. Wade*, Justice Blackmun stated, "the word 'person,' as used in the Fourteenth Amendment, does not include the unborn" (Roden, 2010). With the precedent from Roe for denying fetal personhood, the 14th Amendment primarily applies to the person who is pregnant and does not extend the same provisions to the fetus, making it unethical of AD pregnancy exceptions to abridge the rights of the pregnant person in order to protect the potential of the fetus. When considering the rights guaranteed by the 14th Amendment, AD pregnancy exceptions are unethical from the perspective of duty ethics because this clause does not protect the rights to liberty and living life as one sees fit.

From a duty ethics framework, the overlap of policies that establish and protect a fetus' right to life show that these states consider it their duty to protect that right, even above the pregnant patient's autonomy. Many states that have a pregnancy clause in their advance directive laws also have implemented outright bans or limits on abortion access. After *Roe v. Wade* was overturned in *Dobbs v. Jackson Women's Health Organization* (2022), bans and legislation to stop or limit access to abortions went into effect in 21 states as of March, 2024. Of those 21 states with bans or limitations, 13 also do not allow advance directive withdrawal or withhold of care decisions to apply during pregnancy, which is shown in Figure 1 below (Times, 2022).

There are four state interests that the courts have allowed to supersede a patient's right to refuse treatment: 1) the prevention of suicide; 2) the preservation of life; 3) the protection of third parties; and 4) the preservation of the ethical integrity of the medical profession (Kaplan, 2010). The arguments of preservation of life and protection of third parties have been applied in favor of AD pregnancy exceptions and in states with AD pregnancy exceptions, the protection of life refers to the fetus's potential for life instead of the life of the decision-maker. State interests, including preservation of life and protection of third parties, that have been recognized through judicial decisions have established the legality for states to prioritize fetal potential over patient autonomy. For the states that explicitly establish and prioritize fetal personhood rights, laws protecting those rights in those states are ethical from the reasoning of duty ethics, however those laws may not be ethical from the perspective of other states that do not recognize those rights.

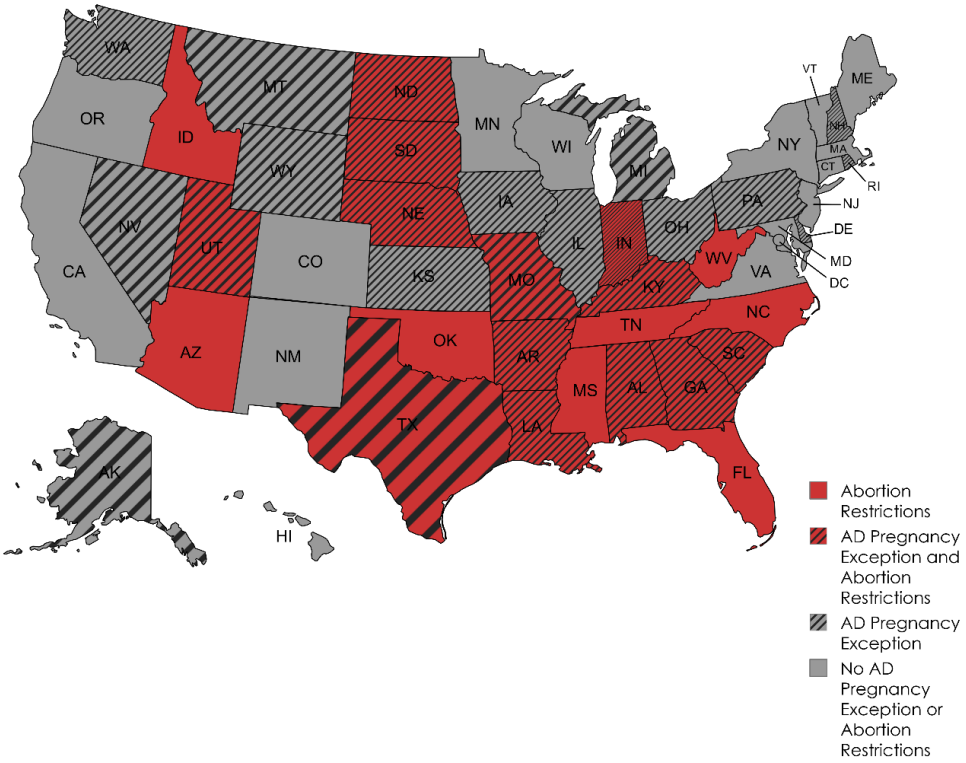

Figure 1: Map of the United States showing the overlap between states where Advance Directives do not apply to pregnant people and states with abortion bans or strict limits.

One large commonality for many of the states with AD pregnancy exceptions and abortion limits are shared socially and politically conservative beliefs. One of the most fundamental beliefs that heavily informs beliefs on abortion and autonomy during pregnancy is the right to life, which is often a large component of politically conservative ideology and certain religious beliefs. During the debate between the catholic hospital where Karen Quinlan was being treated and her family, the hospital resisted the court's decision to withdraw life-supporting care saying, "a right to death does not exist. Love for life, even a life reduced to ruin, drives one to protect life with every possible care" (Pence, 2011). The hospital's reluctance to withdraw care from Karen Quinlan was informed by religious beliefs that emphasize the sacredness of life and creation. While not every citizen in every state with an AD pregnancy exception has the same beliefs, the value placed on the right to life and the definition of personhood beginning before birth is enshrined in states with both AD pregnancy exceptions and strict abortion limits through legislation passed by democratically elected lawmakers. Overall, from the perspective of duty ethics, in states where democratically elected legislatures have established certain rights, such as the right to life and fetal personhood, laws are ethical that protect those rights.

From a clinical perspective through the lens of care ethics and the four pillars of clinical ethics, the ethicality of pregnancy clauses is not similarly resolved. The main issue with pregnancy clauses that prevent living wills or a proxy's decision from going into effect during surgery, in the event that a pregnant person enters PVS, or in an otherwise incapacitated state is that they allow clinicians to use treatments and therapies that may conflict with the wishes of the patient (Strand, 2021). The action of deliberately using treatments or therapies not explicitly

consented to by the patient is a breach of clinical ethics from the perspective of beneficence, autonomy, and justice. From the perspective of beneficence, the patient's best interests are the clinically indicated treatment decisions they determine or express when they are of a sound mind, and disregarding those preferences while they are pregnant is paternalistic and prioritizes the state of pregnancy over the interests of the patient. Also, a component of beneficence is acting in the best interest of the patient, and with the physician's patient being the person who is pregnant, beneficence requires the physician to act for their benefit, not the benefit of the fetus. The unilateral negation of ADs in the case of pregnancy assumes that life is the priority, without regard for the situational nuances of each case. There are medical or genetic abnormalities that could cause the fetus to be nonviable or in immense pain and suffering and immense risk of death to the mother, and pregnancy exceptions do not consider the context of each case when requiring care that can go against the best interests of the parent, the fetus, or both. By requiring life supporting devices be used to sustain an incapacitated pregnant person regardless of their documented wishes, AD pregnancy exceptions place restrictions on the care that clinicians can provide for the best interests of the patient, further breaching beneficence.

From the perspective of the autonomy pillar, with pregnancy negating one's AD, there is an instant loss of complete bodily autonomy and self-determination for the pregnant person because all of their legally documented choices can no longer apply. While some states have statements in their pregnancy exceptions that the exception only applies when the fetus is potentially viable, some are even more restrictive of the pregnant person's autonomy. For example, Kentucky's living will directive and health care surrogate designation says "[i]f I have been diagnosed as pregnant and that diagnosis is known to my attending physician, this directive shall have no force or effect during the course of my pregnancy" (Office of the Attorney General,

n.d.). Improvements in early diagnosis of pregnancy means that urine tests are typically positive ten days after a missed period and serum testing of an early pregnancy factor hormone can show a positive result 48 hours after fertilization (J. Anderson & Ghaffarian, 2024). Although serum tests can be positive for situations of nonviable pregnancies and abnormal placental or embryonic tissues, which requires a definitive diagnosis of pregnancy to be contingent on other positive diagnostic screenings, pregnancies can still be detected extremely early. Early pregnancy detection means that in Kentucky, and states with similar provisions, people who have been diagnosed as pregnant can lose complete bodily autonomy for up to almost 40 weeks in order to protect the life of the fetus, which is not viable for over half that length of time (Breborowicz, 2001). While autonomy is uniquely complex in the context of pregnancy, where an embryo is solely dependent on their parent for sustaining life, clinical practice guidelines continue to uphold a competent pregnant person's right to autonomy and their right to refuse recommended treatment. The College and the American Academy of Pediatrics holds that, "any fetal intervention has implications for the pregnant woman's health and necessarily her bodily integrity, and therefore cannot be performed without her explicit informed consent," and the American College of Obstetricians and Gynecologists clinical care guidelines state that, "[p]regnancy is not an exception to the principle that a decisionally capable patient has the right to refuse treatment, even treatment needed to maintain life" (Committee Opinion 664, 2016). Clinical practice guidelines that support complete autonomy, even in the case of pregnancy, illustrate that clinicians consider the pillar of autonomy paramount for competent patients and pregnancy does not invalidate that principle, making it clinically unethical to refuse a patient the right to determine what happens to their body. Even for incompetent patients the American College of Obstetricians and Gynecologists clinical care guidelines say, "[a] previously

documented or expressed refusal should be respected," which demonstrates a continued respect for patient autonomy and shows that there is not a difference between a competent and incompetent patient's authority to make decisions about their body from a physician's perspective (Committee Opinion 664, 2016). However, from a legal and judicial perspective, pregnant people's bodily autonomy has not always been as esteemed as the state's interest in protecting fetal rights, even for competent patients. For example, in *Pemberton v. Tallahassee Memorial Regional Medical Center, Inc.* the court compelled a pregnant woman to have a cesarean section contrary to her birth preferences out of concern for fetal survival, allowing the state's preservation of life interests to supersede the competent patient's right to autonomy. The ability of state interests to overrule pregnant patient's autonomy was strengthened in *Gonzalez v. Carhart*, which has implications for further allowing states to compel treatment for the benefit of the fetus, even when it could cause harm to the pregnant person and limit their right to informed consent (Kaplan, 2010). What Pemberton and Gonzalez have in common with pregnancy exceptions in AD legislation is the state's view that a pregnant person, whether they are competent or not, cannot exercise full autonomy in treatment decisions, particularly in the case of withdrawal of care decisions and other choices that have potential to harm the fetus, which violates the autonomy pillar of clinical ethics. Pregnancy exceptions are also unethical from the perspective of justice, which requires the fair, equitable, and appropriate treatment of patients. From an equity standpoint, which would require clinicians to provide unbiased and fair treatment to all of their patients, in cases where the withholding or withdrawal of life-supporting devices are requested by a patient or proxy, pregnancy exceptions require clinicians to treat pregnant patients in a different manner than they would treat other patients only on the basis of the diagnosis of pregnancy. For workplace situations there are federal protections against treating

pregnant people differently or unfavorably on the basis of pregnancy (*The Pregnancy Discrimination Act of 1978,* n.d.). However, when executing ADs, pregnancy is the primary basis for a patient's bodily autonomy to be disregarded and for them to be treated unfavorably by the clinician, which is a flagrant violation of the principle of justice. In addition, in cases where a clinician is required to keep a pregnant patient on life-sustaining care against their previously stated wishes and best interests, the pregnancy exception clause can lead to clinicians administering medically unnecessary or inappropriate treatment, which is also a violation of the justice pillar. Administering futile treatments have a negative impact on not only the patient who bears the consequences of those therapies, but also the doctor by causing moral distress and potentially compromising professional integrity (Burkle et al., 2014). The clinical ethics pillars of beneficence, autonomy, and justice were established to protect patients and create professional moral guidelines for patient-physician relationships and the care provided, and the legal imperative of pregnancy exceptions interferes with doctors' ability to provide the highest and most ethical standard of care.

A consequence that can result from pregnancy exceptions and the invalidation of a pregnant person's wish for the withholding or withdrawal of care when clinically indicated is the prolonging of suffering without the patient's consent, which violates the principle of nonmaleficence as well as autonomy. In addition to requiring the physician to not harm the patient, nonmaleficence also calls for avoiding unnecessarily burdensome treatments (Varkey, 2021). In cases where life-supporting technology is not providing clinical benefit to the patient and they have expressed a desire to not be kept alive solely dependent on life supporting devices, administering treatments that will primarily serve to prolong death for the purpose of additional fetus gestation is unnecessarily burdensome for the patient because it will not improve their

prognosis, imposes potential side effects and other resultant consequences, and is not how they wanted to be treated. Consequences of remaining on mechanical ventilation and other forms of life-supporting technology for an extended period of time include increased risk of infections, especially ones due to multidrug-resistant microbial organisms, muscle atrophy and nerve dysfunction leading to significant weakness, organ dysfunction, and skin breakdown that causes pressure ulcers (Loss et al., 2015). Long term consequences of the use of life supporting devices are physically debilitating and impose additional burdens on a body that is already struggling to maintain itself, which is what the nonmaleficence pillar exists to prevent. While mechanical ventilation and other life-supporting technologies have been miraculous and life saving for many patients, there is a large accompanying cost, and one that is not just economic, that should not be imposed on patients who do not chose to bear it. A core component of the autonomy pillar of clinical ethics is the practice of informed consent, which requires a competent patient to understand and voluntarily consent to a procedure whose benefits and risks have been fully described to them (Varkey, 2021). In pregnancy AD exceptions, procedures and treatments may be administered to patients that conflict with their or their proxy's decisions, which demonstrates a lack of informed consent. If the patient or their proxy has expressed a wish for withdrawal of life-supporting care in a state where that decision is not valid, clinicians are still required to subject their patient to treatment which was not consented to, clearly violating the principle of autonomy and making the act unethical.

Overall, there is a large discrepancy between the views and recommendations of the medical profession and the legal decisions and requirements of individual states in recognizing pregnant women's ability to refuse treatment and determine what happens to their body. The conflict between treatment required by legal and clinical regulations leads to additional legal

ramifications for physicians to consider as they determine what is medically indicated for their patient, which can lead to them violating their professional obligation of beneficence, nonmaleficence, justice, and autonomy towards their patient. The legal and clinical dimensions, which can be in synchrony or at odds depending on the context of the patient, make the ethical question of pregnancy exceptions in advance directives particularly complex. From the perspective of duty ethics, in states where the rights that protect the life of the unborn fetus are expressed, there is a duty to protect those rights. However, in all states there is also an established right to patient autonomy that must be protected, and those rights can conflict in pregnancy exceptions. The prioritization of the rights associated with pregnancy exceptions has been established as the job of the states, and there is a variability across the nation as to what each state has established, which is informed by the values and beliefs of their citizens. From the perspective of care ethics as expressed by the clinical pillars, pregnancy exceptions demonstrate a distinct violation of beneficence, nonmaleficence, justice, and autonomy by limiting the treatment decisions that can be made by a patient or their proxy as a result of their pregnancy and allowing treatments to be performed against their wishes. As the attending physician's patient is not the fetus, they have a professional ethical obligation to provide care for the benefit and best interest of the pregnant person, and pregnancy exceptions interfere with that obligation. From any view, the treatment or withdrawal of care of incompetent patients have inherent ethical complexities and questions, many of which have been settled by AD clauses, but in the case of pregnancy exception clauses only more complexities and questions have been raised.

One limitation of this analysis is the inherent personal bias of the author. Due to the ambiguity in ethical frameworks, someone with a different view of the issue could come to different conclusions and would present different supporting evidence. As the topic of AD

pregnancy exceptions has highly divisive themes, it is heavily informed by personal values and experiences, and the immense diversity of perspectives on the matter add to the discussions on the topic and illustrate that there is no one right answer. Another limitation of this analysis is that there was a generalization of states with pregnancy exceptions having politically conservative legislatures and establishing fetal personhood rights through legislation restricting access to abortion. However, there are states, including Washington and Pennsylvania, that have AD pregnancy exceptions who have also historically had politically liberal legislatures. The contradiction between liberal legislatures and conservative values inherent in AD pregnancy exceptions was beyond the scope of the discussion, but future work on the topic could examine factors involved in passing pregnancy exception clauses in states with fewer conservative beliefs and more broadly exploring the politicization of bioethics and gender equality rights in greater detail. In addition, while this analysis only focused on pregnancy exceptions, other assumptions and restrictions within ADs, particularly the assumption of a nuclear family structure to determine default surrogate consent protocols that does not account for unmarried couples and same-sex partnerships, as well as issues involving the exercise of religious freedom in treatment decisions could be further explored.

Conclusion: "The debate still rages on in America, but at least Kenny is in a more peaceful place"

In conclusion, the existence of pregnancy exceptions in ADs raise important ethical questions concerning the role of state legislation in health care decision making. At its heart, AD pregnancy exceptions are an ethical issue, meaning that there is no one right answer and analysis from different perspectives and ethical frameworks come to different conclusions, illustrating the immense complexity of the issue. From a duty ethics framework, which asserts that people have

a duty to protect the rights of others, the ethicality of pregnancy exceptions depends on what rights have been established by the state and federal governments and the states' prioritization of those rights. Thus, depending on the state, pregnancy exceptions may or may not be permissible as a method of protecting others' rights. From a care ethics perspective, the power differential innate in the doctor-patient relationship requires clinicians to be bound to the pillars of beneficence, nonmaleficence, justice, and autonomy to guide their behavior and decision making when caring for their patients. In a clinical light, AD pregnancy exceptions contradict the principles that define each pillar because these clauses do not center the patient's best interest and autonomy, and can require physicians to go against their professional obligations. Overall, the issue of determining how use of life-sustaining technology while considering the best interests of the patient, particularly in the case of pregnancy, is complex, but understanding the ethical implications of the policies that govern the use of life supporting technology is imperative to ensure that they continue to properly serve the patients they were created to protect. As medical technology continues to advance, understanding how past ethical questions were navigated can serve to guide the ethical use of future devices and medical capabilities.

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