Pregnancy Clauses: The Ethically Unfounded Exemption to Advance Care Directives

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ABSTRACT

All people deserve the legal ability to outline their care decisions in advance and expect their decisions to govern during a pregnancy. However, until advance directives govern without pregnancy exceptions, people will not uniformly retain the ability to formulate autonomous decisions about their health care planning.

Keywords: Advanced directives, pregnancy, reproductive ethics, fetus, abortion, autonomy

INTRODUCTION

In the last few years, states have passed increasingly restrictive laws regarding abortion and reproductive health care. Recent legislation in Alabama effectively banned the procedure altogether, while more than a dozen states have passed or are currently in the process of enacting so-called "fetal heartbeat laws," which ban abortion at roughly six weeks post-conception after the detection of electrical activity in what could develop into fetal cardiac tissue.[1] While courts rarely uphold outright bans and broad sweeping legislation, they garner significant media and public attention.[2] In practice, however, often smaller legislative changes that garner the least attention have the most significant impact by steadily chipping away at healthcare rights. Few people realize the ethical impact of the poorly understood legal means by which a pregnant woman has already lost her right to make autonomous healthcare decisions over her body using an advance directive in nearly every state.

BACKGROUND

Advance directives are one of modern medicine's most powerful yet underused tools. Most clinicians and patients think of advance directives as being only for the elderly or terminally ill. This association stems from the 1991 Congressional *Patient Self-Determination Act* that requires hospitals, nursing homes, and hospice agencies receiving federal funding to inform patients of their legal right to prepare an advance directive. The 2015 announcement by the Center for Medicare and Medicaid Services (CMS) to reimburse

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for advance directives without requiring a diagnosis code recognizes that all adult patients can benefit from advance directives regardless of illness or life expectancy.[3] Providers should be aware of a small but significant exemption found in most state advance directive laws. This exemption, commonly known as the pregnancy clause, invalidates the advance directive of a pregnant woman, negating autonomy. The pregnancy clause can lead to treatment against medical standards of care and places private interests over public health.

Advance directive statutes are frequently amended, but currently, only eight states allow patients to write their pregnancy-related wishes into their advance directive and guarantee that their instructions will be followed. Eleven states automatically invalidate advance directives during pregnancy, while 18 states permit physicians to disregard a pregnant woman's (or her proxy's) wishes based on the likelihood of viability, pain, and suffering, or conscientious objector clauses. Thirteen states remain silent on whether an advance directive is binding during pregnancy or have contradictory statutes.[4] Viability has no standard definition for the purposes of the clauses and viability-based pregnancy clauses can lead to the same loss of rights as pregnancy clauses that invalidate advance directives due to pregnancy without any exceptions.

Many may wonder about the clinical relevance of pregnancy clauses. The likelihood that a woman will need to effectuate an advance care directive while pregnant is higher than many people would realize. This situation is most commonly assumed to occur in instances of a brain-dead pregnant woman, of which there are a few cases reported each year. But brain death and persistent vegetative states are just two reasons to look to an advance directive. Advance directives more commonly apply to patients with dementia, strong religious objections to medical care, or during cancer treatments, surgery, or acute injury with temporary loss of capacity. In surgery or acute lapses of capacity, a proxy may be asked to make decisions if complications arise. The number of women potentially affected by pregnancy clauses is significant. Each year, 75,000 pregnant women will undergo non-obstetrical surgery;[5] one in 1,500 pregnant women will be diagnosed with cancer; [6] and an estimated 250,000 Americans will exhibit early-onset Alzheimer's symptoms between the ages of 30 and 50.[7]

ANALYSIS

Though pregnancy clauses are a seemingly narrow focus, they can nullify an entire advance directive and restrict care not related to the fetus. By negating entire advance directives, the clauses negate proxy appointments, allowing decision-makers other than the intended proxy. Providers and proxies are left with little guidance over who can make decisions on behalf of the patient. Many states will appoint a biological family member as the surrogate decision maker if there is no designated proxy or the directive is invalid. The outdated language and assumptions about nuclear families found in these structures could significantly impact unmarried couples, same-sex partnerships, and relationships that do not meet state-defined partnership standards where the courts may appoint someone other than the woman's significant other even when she designated them as a proxy.[8] Members of religious groups whose doctrines prohibit certain medical therapies must be informed that if they become pregnant, their autonomous ability to decide about medical care through an advance directive and their right to freely practice religion can be voided entirely.

In addition to infringing on patient autonomy, pregnancy clauses also restrict how clinicians might practice medicine by mandating medically inappropriate treatments against the provider's recommendations. For example, Illinois's pregnancy clause stipulates that "if you are pregnant and your health care professional thinks you could have a live birth, your living will cannot go into effect."[9] This clause places providers in a

difficult position of sacrificing their therapeutic obligation to their patients. It may require them to use futile therapy against the patient's best interest and without regard for prolonged pain and suffering.

Pregnancy clauses are void of any consideration of the best clinical interest of the patient or the fetus and instead promote conservative rhetoric that all potential fetal life is paramount. Numerous medical and chromosomal conditions are incompatible with life or present significant potential disabilities that may be accompanied by pain and suffering. The same conditions also pose risks to the mother, including death. Accordingly, the medical profession recognizes that there are instances in which it may not be in the best medical interest of the mother or the fetus to continue the pregnancy. Yet providers are seemingly required by pregnancy clauses to violate codes of conduct and subject pregnant patients and their nonviable fetuses to treatments to which other patients would not be subjected.

Without evidence of a patient's clear and convincing intentions, states have an interest in protecting life, preventing suicide, and maintaining the ethical integrity of the medical profession that could interfere with the person's ability to refuse care.[10] The legal defense of pregnancy clauses is that the state's interest in fetal life is sufficiently important to override the mother. As established in *Planned Parenthood v. Casey* (1992), however, the state's interest only exists for fetal life post-viability.[11] Therefore, to allow the state interest to override the person's advance directive when the fetus is not yet viable violates *Casey*.

Individuals have a legal and ethical interest in maintaining bodily privacy, integrity, and freedom from unwanted touching. They have the right to appoint a proxy or use a directive to govern care in the case of incapacity. Even when contemplating brain death, organ donation, and whether to be cremated or buried, there is an expectation that personal wishes will govern. Honoring an advance directive allows providers to uphold the integrity of the medical profession by respecting the principles of autonomy and beneficence. Pregnancy clauses are inherently unethical as their creation was not to further the integrity of the medical or legal profession, nor protect a state's interest in the patient's life. In 2016, the American College of Obstetricians and Gynecologists issued a committee opinion that pregnancy is not an ethical exemption to the right of capable patients to refuse treatment.[12] The right to direct treatment while pregnant is consistent with modern medical practice, while the legislative promotion of a singular abstract interest in potential fetal life to the exclusion of all other medical and ethical considerations is not in line with the profession's values.[13]

Many pregnancy clauses are politically motivated, reflecting anti-abortion legality lobbying efforts and attempts to win over conservative voters. When Alaskan Attorney General Harold M. Brown argued the state's pregnancy clause was unconstitutional, Governor Bill Sheffield – a Democrat in a historically red state – enacted the bill anyway. Georgia's Governor Bill Kemp narrowly won his election, with some crediting his aggressive messaging against immigration and abortion.[14] With either advance directives, proxies, or even friends and relatives who know what the person (if not incapacitated) would have wanted, courts and legislatures should not have leeway to force care that a person, if conscious, would have refused.[15]

The ability to harness advance directive law to force invasive and unwanted treatment upon a pregnant patient's body continues to occur out of the fear of legal uncertainty. The lack of uniformity between states in their pregnancy clauses further adds to the confusion. Many advance directive statutes create a conditional proposition: if a provider acts in accordance with the carefully drawn circumstances of an advance directive, the provider is granted protective immunity from accusations of malpractice or wrongful death for that conduct. It is neither illegal nor unethical to remove a ventilator, for example, from a patient who has directed such a course of action in an advance directive. A pregnancy clause may remove that

immunity making the unethical act of ignoring the directive legal, but the ethical act of following it (removing a ventilator, for example) could subject the practitioner to liability.[16] Without a pregnancy clause, providers retain the ability to both follow an advance directive and to act in the best medical interest of their patient. Pregnancy clauses create confusion over the permissibility of medical acts in an attempt to coerce providers into making decisions that violate the rights of their patients and their own ethical codes of conduct.

Pregnancy clauses are a fallacy of consequentialist ethics in which the morality of the outcome justifies actions. Under consequentialist reasoning, any violation to the woman is justified if the fetus develops and results in a live birth. This reasoning is further faulty as it incorrectly assumes that mechanically ventilating an unconscious, sick, dying, or dead body will result in a live birth. Consequentialist theories should be limited to situations with predictable ends. Ethical medical providers refute consequentialism in certain contexts because it treats patients as a means to an end to produce benefit for others. In pregnancy, ignoring advance directives to achieve the chance that a fetus might survive is not justified by consequentialism.

Pregnancy clauses also fail through the lens of deontological ethics in which an action must be ethical in and of itself and not based on outcomes. The choice to respect autonomy through an advance directive should be followed uniformly absent special circumstances. Proponents of pregnancy clauses may argue that pregnancy is an appropriate exception because a woman "has chosen to lend her body to bring [a] child into the world."[17] Minnesota and Oklahoma echo this belief in their statutes, which contain an unjustified rebuttable presumption that all female patients would want life-sustaining treatment if they are pregnant.[18] Pregnancy should not abrogate the rights of a person to assign a proxy for access to an abortion or to control her medical treatment. Pregnancy exclusions are not grounded in the ethical "best interest" standards for the mother or the fetus. Instead, they are rooted in outdated expectations of female gender roles, which reaffirm a legislative assumption that a pregnancy is more morally valuable than a woman's autonomy.

CONCLUSION

All people deserve the legal ability to outline their care decisions in advance and expect their decisions to govern during a pregnancy. Providers and the government do not have to approve of a person's care decisions or values, but medical practitioners must respect a person's right to dictate their own health narratives.

With the push for more patients to execute advance directives, providers and patients must be aware that their advance directives may succumb to the authority of pregnancy clauses. Until advance directives govern without pregnancy exceptions, people will not uniformly retain the ability to formulate autonomous decisions about their health care planning. Advance directive law will continue to be hijacked by politically motivated legislators. When seeking to address inequities in healthcare laws and access, it is essential to take a closer look at not only the headline cases but also the clauses and exemptions to laws seemingly designed to benefit patients.

[1] For proposed and current abortion legislation and maps, see https://www.guttmacher.org/state-policy# and Anne Godlasky, Nicquel Terry Ellis, and Jim Sergent, "Where is Abortion Legal? Everywhere, but…" USA Today, May 15, 2019, updated April 23, 2020 https://www.usatoday.com/in-depth/news/nation/2019/05/15/abortion-law-map-interactive-roe-v-wade-heartbeat-bills-pro-life-pro-choice-alabama-ohio-georgia/3678225002/

[2] https://www.guttmacher.org/state-policy# (Many bills fail in legislatures and are not enacted.)

[3] Department of Health and Human Services Centers for Medicare & Medicaid Services; 42 CFR Part 405, 410, 411, 414, 425, and 495; "Medicare Program; Revisions to Payment Policies Under the Physician Fee Schedule and Other Revisions to Part B for CY 2016; Final Rule."

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[9] Illinois Department of Public Health website, *Statement of Illinois Law on Advance Directives and DNR Orders*, http://www.idph.state.il.us/public/books/advdir4.htm.

[10] In the Matter of Karen Quinlan, 355 A.2d 647 (1976); Cruzan v. Director, Missouri Department of Health, 497 U.S. 261 (1990); and In re Conroy 486 A.2d 1209 (1985).

[11] Planned Parenthood of Southeastern Pennsylvania v. Casey, 505 U.S. 833 (1992).

[12] The American College of Obstetricians & Gynecologists *Committee on Ethics, Committee*

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[13] Lederman, Anne D. "A Womb of My Own: A Moral Evaluation of Ohio's Treatment of Pregnant Patient's with Living Wills". *Case W. Res. L. Rev.* Vol. 45:351 (1995); 351-377.

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[15] Cruzan.

[16] Mayo, T.M. "Brain-Dead and Pregnant in Texas." *The American Journal of Bioethics*, Vol. 14, no. 8 (Nov. 2014); 15-18.

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