Beyond Roe: Implications for End-of-Life Decision-Making During Pregnancy

Joan H. Krause

1: UNIVERSITY OF NORTH CAROLINA CHAPEL HILL, NC, USA.

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Abstract: The end of Roe v. Wade has significant implications for the autonomy of pregnant patients at the end of life. At least thirty states restrict the choice to withhold/withdraw life-sustaining treatments from pregnant patients without decisional capacity, invalidating prior advance directives and prohibiting others from choosing these options for the patient. Many restrictions are based on the *Roe* framework, applying after "viability" or similar considerations of fetal development or prospect for live birth. Scholars have also relied on the abortion framework, arguing that the restrictions impose an undue burden. The end of *Roe* will free states from having to craft limited restrictions designed to work around prior abortion jurisprudence. Similarly, advocates will no longer be able to draw support from the abortion framework, forcing them to rely instead on cases supporting rights to autonomy/bodily integrity in medical decision-making.

s the articles in this symposium demonstrate, the Supreme Court's decision to overturn fifty years of precedent protecting the right to choose an abortion has significant implications for access to health care.¹ While initial reaction has understandably focused on maintaining access to abortion, *Dobbs* has far broader implications for reproductive justice. This article addresses one such issue: the effect on pregnant patients' autonomy at the end of life, as exercised through their advance directives or surrogate decision-makers.

Advance directives allow a patient to memorialize their end-of-life treatment preferences or choose someone to act as a surrogate decisionmaker if they become incapable of doing so. Two types of directives are most significant in the pregnancy context, as they are most likely to be created by healthy individuals of reproductive age: (1) "living wills" (or health care "directives" or "declarations"), which express the patient's wishes for medical care if they become incompetent or unable to communicate;² and (2) medical or health care powers of attorney/agency, through which

Joan H. Krause, J.D., is Dan K. Moore Distinguished Professor of Law, UNC School of Law; Professor (Secondary Appointment), Social Medicine, UNC School of Medicine; and Adjunct Professor, Health Policy and Management, Gillings School of Global Public Health. the patient designates someone to make health care decisions if the patient cannot do so.³ However, pregnant patients have long been subject to special limitations on their decisions, as Sawicki and Kukura write in this symposium, which includes their end-of-life choices.

Roughly thirty states limit the ability to withhold/ withdraw life-sustaining treatment from pregnant patients without decisional capacity, invalidating their advance directives and preventing physicians and surrogates from choosing those options on the patient's behalf; moreover, many restrictions are not listed in the directive forms, but only in the underlying statutes.⁴ The abortion framework has loomed large in the debate over these restrictions. While some limits with organized religion, is the preservation of the life of the unborn. The National Conference of Catholic Bishops has publicly objected to advance directives that allow patients to decline care in case of pregnancy, arguing that they put the State "in the position of ratifying and facilitating a decision to end the life of the child ... [and] ignoring the unborn child's independent interest in life^{no} Those concerns have been codified in states such as Louisiana, whose explicit policy is "that human life is of the highest and inestimable value through natural death ... [and], any ambiguity shall be interpreted to preserve human life, including the life of an unborn childⁿ¹

A second concern is that pregnancy might not have been contemplated when the patient created

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apply throughout pregnancy, others are directly based on the *Roe v. Wade* framework, applying only when a fetus is viable or could survive to live birth.⁵ Abortion jurisprudence also has formed the basis for the most common challenge to pre-viability restrictions: if the state cannot bar a pregnant patient from seeking an abortion before viability, how can it limit the patient's own choice of medical care before that point?⁶

Dobbs throws both the statutory and analytical frameworks into question. Freed from concerns over potential interference with pre-viability rights to abortion, more states may choose to adopt limits similar to Texas, which flatly provides: "A person may not withdraw or withhold life-sustaining treatment ... from a pregnant patient."⁷ Opponents no longer can rely on *Roe's* framework to challenge these restrictions, forcing them instead to invoke cases supporting the broader right to autonomy and bodily integrity in medical decision-making.⁸ In short, *Dobbs* likely will have significant impact on the pregnancy restriction debate.

Advance Directives and Pregnancy

Despite strong precedent supporting the rights of individuals to make their own medical choices, including refusing life-sustaining care,⁹ some question whether those interests deserve the same weight when the patient is pregnant. One concern, strongly associated the directive. As one commentator notes, "the default life support situation in most people's imaginations ... may be one in which the patient is not pregnant.... If she were asked separately, then, whether she would want to be kept alive if necessary to sustain an existing pregnancy, her answer might well be different."12 The fact that many restrictions are not listed in the directives may bolster this concern: a patient who has no idea these restrictions even exist will have no reason to consider whether pregnancy might affect the instructions.¹³ While characterized as protective of patient autonomy, this argument instead suggests a deep distrust of patient choices during pregnancy, especially choices that do not treat fetal interests as paramount. Yet there is a simple solution: ask the patient if the instructions would change. Indeed, "it would seem most prudent to assume that unless [the patient] has listed exceptions ... she really did mean what she said."14

Pregnancy Restrictions

Statutes

As of 2019, thirty-eight states addressed advance directives or surrogate decisions during pregnancy, with most limiting the choice to withhold/withdraw life-sustaining care.¹⁵ While these statutes single out pregnancy as an exception to standard advance direc-

tive rules, they differ in significant ways. Some, such as the Texas provision, invalidate all advance directives during pregnancy.¹⁶ At the other end of the spectrum, a few states such as Maryland offer patients the option of listing pregnancy-specific instructions.¹⁷ Several states have no statute or case law on point, although the reasons are unclear: while some states are silent because they have repealed restrictions, others seem content to leave the issue to the courts.¹⁸

Dobbs is most relevant to statutes that take a more nuanced approach, eschewing blanket prohibitions in favor of focusing on fetal development or prospect for live birth. One of the most influential resources has been the Uniform Rights of the Terminally Ill Act, first adopted by the National Conference of Commissioners on Uniform State Laws in 1985.19 While the original Act allowed patients to specify their wishes in case of pregnancy, a 1989 revision instead provided that: "Life-sustaining treatment must not be withheld or withdrawn pursuant to a declaration from an individual known to the attending physician to be pregnant so long as it is probable that the fetus will develop to the point of live birth with continued application of life-sustaining treatment."20 A number of states follow this model by prohibiting an incapacitated pregnant patient from terminating life-sustaining care if it is probable the fetus could develop to birth.²¹ The 1985 and 1989 Uniform Acts have since been superseded by the 1993 Uniform Health-Care Decisions Act, which contains no pregnancy language at all; however, the 1989 version still forms the basis for many state laws.²² After *Dobbs*, these broad restrictions appear to be permissible.

Other statutes draw more directly from Roe, prohibiting the withholding/withdrawal of care only if the fetus is viable. Prior to repeal in 2021, Colorado law directed that after viability a directive would "be given no force or effect until the patient is no longer pregnant."²³ Delaware's restriction is broader, applying if "it is probable that the fetus *will develop to be viable* outside the uterus"24 Rejecting the amorphous concept of viability, which has never had a clear medical or legal meaning, Louisiana mandates life-support if an "obstetrician ... determines that the probable postfertilization age of the unborn child is twenty or more weeks and the pregnant woman's life can reasonably be maintained in such a way as to permit the continuing development and eventual live birth."25 Dobbs' rejection of the viability standard obviates the need for such gradations, leaving these states free to enact stricter prohibitions applying throughout pregnancy.

A final group of states combines protections for fetal health with *Roe*'s concern for the "life or health of the mother," permitting life-sustaining care to be terminated if it subjects the patient to pain and suffering.²⁶ New Hampshire's restriction does not apply if "to a reasonable degree of medical certainty ... such treatment or procedures will not maintain the principal in such a way as to permit the continuing development and live birth of the fetus or will be physically harmful to the principal or prolong severe pain which cannot be alleviated by medication."27 It is unclear whether the "life or health of the mother" requirement survives Dobbs; indeed, the dissenters sharply criticized the majority's "ominous" failure to explain "whether a State may prevent a woman from obtaining an abortion when she and her doctor have determined it is a needed medical treatment."28 If such exceptions are unnecessary, states also will be free to repeal these limitations.

Scholarly Commentary

The abortion debate has also framed the scholarly literature, offering support both to those who challenge restrictions as infringing on patient autonomy and to those who seek to protect fetal life. Before Dobbs, critics argued that pre-viability pregnancy restrictions clearly imposed an undue burden on women's pregnancy choices.²⁹ But proponents have also invoked Roe, arguing that "because the state may usually prohibit abortion after fetal viability, it also may constitutionally compel the woman pregnant with a viable fetus to undergo life-prolonging medical treatment."30 At minimum, proponents argued, the state should be able to limit decisions once the permissible time for an abortion passed,³¹ although the fact that the patient had not in fact chosen abortion was argued both in favor and against the restrictions.³² Dobbs throws this literature into disarray. With abortion no longer a protected federal right, states cannot be criticized for limiting care choices either after or before viability.

However, the literature has long recognized a second line of analysis focusing not on abortion, but on the common law right to autonomy and bodily integrity in medical decision-making. Critics of pregnancy restrictions argue that the right to control one's medical destiny includes the right to decline medical treatment, even if that treatment will end the patient's life – and pregnancy should not alter that balance.³³ This argument goes beyond the abortion framework to characterize *all* pregnancy restrictions as improper infringements on patient autonomy, not simply those applying before viability.

Clear precedent supports the right to medical decision-making. In *Cruzan v. Director, Missouri Department of Health*, the Supreme Court acknowledged - but explicitly did not hold -that the longstanding common law right to informed consent was "firmly entrenched in American tort law," as was the "logical corollary ... that the patient generally possesses the right ... to refuse treatment."³⁴ In *Washington v. Glucksberg*, the Court reiterated that "[w]e have also assumed, and strongly suggested, that the Due Process Clause protects the traditional right to refuse unwanted lifesaving medical treatment," although that protection did not extend to the right to obtain assistance in dying.³⁵

Pregnancy restrictions may well violate the principle of "[b]odily integrity, the interest in avoiding forced physical invasions, arguably [] the most fundamental of liberties."³⁶ *Cruzan* permitted states to require clear and convincing evidence of the patient's wishes to refuse treatment.³⁷ A written advance directive would appear to be the clearest possible statement, yet that is precisely what these laws restrict. However, *Glucksberg* also made clear that the Court has merely assumed the existence of these protections, stopping short of holding them to be binding legal principles.

Moreover, *Dobbs* may threaten this alternative analysis. The majority took pains to clarify that the decision applied only to abortion, but not all the Justices agreed: Justice Thomas flatly stated that "in future cases, we should reconsider all of this Court's substantive due process precedents"³⁸ In fact, the majority's crucial distinction – that only abortion involves the "critical moral question" of the destruction of "potential life" or an "unborn human being"³⁹ – is *precisely* the issue when a pregnant patient seeks to exercise the right to self-determination by refusing or terminating life support. In short, we cannot assume the law of medical self-determination will be strong enough to protect against pregnancy restrictions post-*Dobbs*.

Case Law

Even before *Dobbs*, successful challenges to pregnancy restrictions were rare. Procedural shortcomings such as lack of standing, ripeness, or a justiciable controversy have doomed most suits. In *DiNino v. State ex rel. Gorton*, for example, the Washington Supreme Court found that a request for a declaratory judgment by a woman who altered her directive to make clear that she intended her wishes to be followed during pregnancy was not ripe for review because she was "neither pregnant nor suffering from a terminal condition," and thus "present[ed] a purely hypothetical and speculative controversy."⁴⁰ Yet if challenges can only be maintained by incapacitated pregnant patients with clear written wishes to forgo life-sustaining treatment, as a practical matter few disputes will ever make it to court.

There are signs of hope in a recent federal district court opinion, Almerico v. Denney, which identified a path potentially distinct from reliance on abortion rights. While a facial challenge to the pregnancy restriction in Idaho's model directive form failed under the Due Process and Equal Protection Clauses, the court left open the possibility of an as-applied challenge.⁴¹ Later reviewing an amended complaint, the court held that the plaintiffs had standing both because two of them were pregnant when they filed suit, and because "[w]omen are injured for standing purposes when they draft a directive without a pregnancy exclusion because they face an *immediate* credible threat that their directive will be ignored and that they will receive end-of-life medical treatment to which they did not consent."42 The court held that giving a pregnant woman no choice but to "have life support forced upon her until her baby could be delivered," despite her clear directive to the contrary, would violate the right to refuse "unwanted lifesaving medical treatment."43

The effect of *Almerico* is unclear. The district court relied on pre-*Dobbs* jurisprudence to characterize the restriction as "completely den[ying]" a woman's choice regardless of fetal viability, a conclusion no longer on solid legal ground.⁴⁴ Moreover, the alternative holding — that *Cruzan* bars such forced medical treatment — may also be in doubt to the extent *Dobbs* raises significant questions about the continuing vitality of federal privacy and liberty protections. Thus, this litigation progress may prove to be short-lived.

Conclusion: The Future of Pregnancy Restrictions Post-*Dobbs*

Dobbs will force a reckoning for both existing statutes and the prevailing legal analyses of pregnancy restrictions. Clearly, statutes need no longer be written to fit within *Roe's* viability framework. Analytically, scholars can no longer rely on a federal constitutional right to abortion to argue that these restrictions place an undue burden on a pregnant patient's choices. While critics may invoke alternative arguments based on the right to autonomy and bodily integrity in medical decision-making, that precedent also may be in doubt.

On the positive side, *Dobbs* may motivate some states that strongly support abortion rights to enact explicit protections. The odds of this happening may be greatest in "newly silent" states such as Hawaii, which recently repealed its restriction because "[a] woman should have the right to predetermine her medical treatment, including treatment during her

SEEKING REPRODUCTIVE JUSTICE IN THE NEXT 50 YEARS • FALL 2023 The Journal of Law, Medicine & Ethics, 51 (2023): 538-543. © 2023 The Author(s) pregnancy, if she should lack capacity to make a health care decision for herself."⁴⁵ Maryland law provides a good model for such efforts, inviting patients to modify their instructions in case of pregnancy.⁴⁶

More likely, however, *Dobbs* will lead to an increase in the quantity and breadth of pregnancy restrictions. States such as Texas certainly have no reason to revisit prohibitions that apply throughout pregnancy, "whether the fetus is developed to 22 weeks or simply two days."⁴⁷ *Dobbs* also obviates the need for less restrictive provisions applying only after viability. Freed from *Roe*'s viability framework, there may be little to stop these states from converting their nuanced restrictions into complete prohibitions, or to prevent silent states from adding pregnancy restrictions to their anti-abortion arsenals. The end result is likely to be an increase not only in the absolute number of pregnancy provisions, but also in the most restrictive forms.

After *Dobbs*, it is clear that abortion is no longer a feasible framework under which to challenge pregnancy restrictions on end-of-life decision-making. In hindsight, perhaps it never was. While pregnancy restrictions have much in common with abortion, the analogy is imperfect: the fact that a patient "is pregnant does not convert her choice into an abortion, since her objective is not to kill the fetus, but, rather, to stop existing on life support."48 A pregnant patient who seeks to withhold/withdraw life-sustaining care seeks only to make a decision about the patient's own medical care - an independent right with even deeper common law roots. Treating pregnancy restrictions as merely a subcategory of the abortion debate conflates the critically distinct analyses of abortion and medical self-determination, a message Dobbs delivered all too clearly.

Note

The author has no conflicts to disclose.

References

- 1. Dobbs v. Jackson Women's Health Org., 142 S. Ct. 2228 (2022).
- See, e.g., N.C. Gen. Stat. § 90-321(a)(1a) (2021) (defining "declaration"), (d1) ("Advance Directive for a Natural Death ('Living Will')"). Portions of this article are adapted from J.H. Krause, "Pregnancy Advance Directives," *Cardozo Law Review* 44, no. 3 (2023): 805-871.
- 3. See, e.g., N.C. Gen. Stat. ch. 32A, art. 3 (2021) ("Health Care Powers of Attorney").
- E.S. DeMartino et al., "US State Regulation of Decisions for Pregnant Women Without Decisional Capacity," *Journal of the American Medical Association* 321, no. 16 (2019): 1629-1631, at 1630.
- 5. See Del. Code Ann. Tit. 16, § 2503(j) (2019) ("it is probable that the fetus will develop to be viable outside the uterus" with continued treatment).

- See K.A. Taylor, "Compelling Pregnancy at Death's Door," *Columbia Journal of Gender and Law* 7, no. 1 (1997): 85-165, at 110-11.
- 7. Tex. Health & Safety Code Ann. § 166.049 (2019).
- 8. See, e.g., In re A.C., 573 A.2d 1235, 1246 (D.C. App. 1990) (court erred in permitting hospital to perform C-section on dying pregnant woman without her clear permission).
- 9. See, e.g., Cruzan v. Director, Missouri Department of Health, 497 U.S. 261, 277 (1990).
- 10. National Conference of Catholic Bishops, "Statement on Uniform Rights of the Terminally Ill Act" (June 1986) at 6.
- 11. La. Rev. Stat. § 40:1151.9E (2018).
- S.F. Colb, "Excluding Pregnant Women from the Right to Terminate Life Support," Verdict, Jan. 22, 2014, available at https://verdict.justia.com/2014/01/22/excluding-pregnantwomen-right-terminate-life-support (last visited August 16, 2023).
- 13. DeMartino et al., *supra* note 4, at 1630 (69% of states with restrictions did not disclose restrictions in forms).
- 14. Colb, *supra* note 12.
- 15. See generally DeMartino et al., *supra* note 4.
- 16. Tex. Health & Safety Code Ann. § 166.049 (2019).
- Md. Code Ann. Health-Gen. § 5-603 (2018) ("If I am pregnant, my decision concerning life-sustaining procedures shall be modified as follows.").
- See Col. Rev. Stat. § 15-18-104(2) (2018); Bill Summary, SB21-193, "Protection of Pregnant People in Perinatal Period" (2021), available at <https://leg.colorado.gov/bills/sb21-193> (last visited August 16, 2023); M. Greene and L.R. Wolfe, "Pregnancy Exclusions in State Living Will and Medical Proxy Statutes," Center for Women Policy Studies, August 2012, available at <https://web.archive.org/web/20140124082041/ http://www.centerwomenpolicy.org/programs/health/statepolicy/documents/REPRO_PregnancyExclusionsinStateLivingWillandMedicalProxyStatutesMeganGreeneandLeslieR. Wolfe.pdf> (last visited August 16, 2023).
- National Conference of Commissioners on Uniform State Laws, "Rights of the Terminally Ill Act" (1985).
- Id.; National Conference of Commissioners on Uniform State Laws, "Uniform Rights of the Terminally Ill Act" (1989) §§ 6 & 7(f) (emphasis added).
- 21. See, e.g., Alaska Stat. Ann. § 13.52.055(b) (2019).
- 22. National Conference of Commissioners on Uniform State Laws, "Uniform Health-Care Decisions Act" (1993).
- 23. Colo. Rev. Stat. § 15-18-104(2) (2018), repealed by S. Bill 21-193, *supra* note 18, at § 2.
- 24. Del. Code Ann. Tit. 16, § 2503(j) (2019) (emphasis added).
- La. Rev. Stat. § 40:1151.9(E) (2018). See also *Dobbs v. Jackson Women's Health Org.*, 142 S. Ct. 2228, 2268-70 (2022) (explaining shortcomings of viability standard).
- 26. Roe v. Wade, 410 U.S. 113, 165 (1973); Taylor, supra note 6, at 120-22.
- 27. N.H. Rev. Stat. § 137-J:10(IV)(a) (2020).
- See Dobbs, 142 S. Ct. at 2328 (J. Breyer, Sotomayor, and Kagan, dissenting).
- 29. Taylor, *supra* note 6, at 110-11.
- 30. *Id.* at 118.
- B.A. Manninen, "Sustaining a Pregnant Cadaver for the Purpose of Gestating a Fetus: A Limited Defense," *Kennedy Institute of Ethics Journal* 26, no. 4 (2017): 399-430, at 409.
- 32. Compare J. Mahoney, "Death with Dignity: Is There an Exception for Pregnant Women?" *UMKC Law Review* 57, no. 2: 221-231, at 225 (need to "distinguish between a woman who is in the earlier stages of pregnancy, and who could therefore have chosen to have an abortion ... and those in the later stages for whom abortion might be prohibited under state law") with G. Gelfand, "Living Will Statutes: The First Decade," *Wisconsin Law Review* 5, no. 5 (1987): 737-822, at 780 ("mother in a terminal condition who has signed a living will would likely have wanted to child to be born (or she would have already aborted)").

- 33. See Mahoney, *supra* note 32, at 229 (situating *Roe* within a "long line of cases that affirms the right to bodily integrity which should allow persons while competent to make provisions for their medical care or allow the right to refuse medical care in the event that they become incompetent.").
- 34. 497 U.S. 261, 269-70 (1990).
- 35. 521 U.S. 702, 720 (1997).
- 36. Taylor, *supra* note 6, at 106.
- 37. Cruzan, 497 U.S. at 286-287.
- Dobbs v. Jackson Women's Health Org., 142 S. Ct. 2228, 2301-02 (Thomas, J., concurring) (2022).
- 39. *Id.* at 2236. The majority seemingly foreclosed some alternate theories by noting that an Equal Protection analysis similarly would be unavailing under precedent holding that "abortion is not a sex-based classification." *Id.* at 2245-46.
- 40. 684 P.2d 1297, 1300 (Wash. 1984).
- 41. 378 F. Supp. 3d. 920, 923 (D. Idaho 2019).

- 42. Almerico v. Denney, 532 F. Supp. 3d 993, 996-99 (D. Idaho 2021).
- 43. Id. at 1002.
- Id. at 1003. Nor does the Idaho Constitution, explicitly or implicitly, protect the right to abortion. See *Planned Parenthood Great Northwest v. State*, 522 P.3d 1132 (Idaho 2023).
- 45. Hawaii Standing Committee Report No. 2822, H.B. No. 1836 (2000), available at <https://www.capitol.hawaii.gov/session2000/commreports/HB1836_SSCR2822_.htm> (repealing restriction) (last visited August 16, 2023).
- 46. Md. Code Ann. Health-Gen. § 5-603 (2018).
- Greene and Wolfe, *supra* note 18; Tex. Health & Safety Code Ann. § 166.049 (2019).
- 48. Colb, *supra* note 12.