Choosing Wisely: Envisioning Perinatal Hospice Notification Laws that Inform and Empower

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CHOOSING WISELY: ENVISIONING PERINATAL HOSPICE NOTIFICATION LAWS THAT INFORM AND EMPOWER

INTRODUCTION

Consider a family. This family consists of a woman, her husband, and their two young children—a five-year-old girl and a three-year-old boy. The woman and her husband are happily married, as helplessly in love with each other as they were on the day of their wedding, and they have been trying for another baby for the last few months. When the woman finds out she is pregnant with their third child, she clutches the pregnancy test in her hand in disbelief. She waits until her husband comes home to tell him the news in person. When she finally says the words, they both cry tears of joy. It is one of the happiest moments of their lives.

At the twelve-week mark, the woman and her husband visit the doctor for a blood test and ultrasound. There, the doctor informs them that their baby has a condition called Trisomy 13, or Patau Syndrome. The explanation contains a frightening, overwhelming amount of medical information, but phrases echo in the woman’s mind: “unlikely to live past the first month” and “incompatible with life.” She and her husband go home, numb with grief, and whisper questions back and forth to each other after they put their children to bed. It seems impossible: if they carry their baby to term, what will they tell their kids? Their parents? The thought of an abortion is devastating; they have already begun talking about names and nursery colors. But to continue the pregnancy means months spent fearing a day that the woman and her husband do not think their family can bear.

While this story is fictional, many individuals and families face similar circumstances. The diagnosis of life-limiting fetal conditions such as anencephaly, Patau Syndrome, and severe heart defects can place parents in a position in which the right course of action is hard to discern—if it exists at all. While some parents may have strong convictions that will

3. Frequently Asked Questions, PERINATAL HOSPICE & PALLIATIVE CARE, https://www.perinatalhospice.org/faqs (listing those conditions as some that are “appropriate for perinatal hospice”) [https://perma.cc/B28G-QVDG].
quickly determine their next steps, many need time to decide how to proceed.

Perinatal hospice refers to a cluster of medical services that some individuals choose after the diagnosis of a life-limiting fetal condition. At its core, perinatal hospice involves many kinds of support—including physical, emotional, social, and spiritual—for the pregnant person, family members, and the fetus or newborn from the time of diagnosis to bereavement. The American College of Obstetricians and Gynecologists and the American Academy of Nursing advocate for such programs, which are expanding throughout the United States and the world.

Several states have passed perinatal hospice notification laws, which differ in scope but generally require certain pregnant individuals to receive a notification about the availability of perinatal hospice services within the state. Such laws address emotionally difficult matters, and unsurprisingly, they are met with a wide range of reactions. Some find these laws to be an intrusion into a sensitive domestic and medical situation, another manifestation of the same anti-abortion sentiment that has chipped away at bodily autonomy for decades. Others believe laws like these provide essential information to pregnant individuals who may not otherwise learn about a meaningful service to help them through a painful time.

This Note will proceed in four parts. Part I will outline the historical development of perinatal hospice as a medical practice and of perinatal hospice notification laws as a legal phenomenon. Part II will identify and compare states’ approaches in crafting (or not crafting) these laws, taking special note of who receives a notification and when. Part III will consider the role of the government, the nature of informed consent, and possible legislative justifications under the police power in passing a perinatal hospice notification law, weighing the legitimacy of different interests and their logical connection (or not) to the laws passed. Finally, Part IV will conclude that two appropriate approaches exist to facilitate meaningfully informed choice in the perinatal hospice context: notifying all eligible individuals of the care they qualify for at the time of diagnosis or deliberately passing no law on the matter at all.

4. Id.
6. See infra notes 23–24 and accompanying text.
7. See infra note 21.
8. See infra Part II.
9. See, e.g., Culp-Ressler, infra note 132.
10. See, e.g., Weber, infra note 25.
11. Infra Part I.
12. Infra Part II.
13. Infra Part III.
14. Infra Part IV.
I. BACKGROUND AND HISTORY

Perinatal hospice arose out of palliative and hospice care, fields which originated abroad and first took root in the United States in 1973. Palliative and hospice care represent an effort to address “the total needs of the dying patients” as human beings, including their comfort, rather than solely making aggressive attempts to cure what are ultimately incurable ailments. By 1982, some medical literature included the subspecialty of neonatal palliative care, focusing on the needs of infants born with conditions that would allow them to live only a short time. Then, with improvements in diagnostic technology, doctors began to detect lethal abnormalities even during gestation, and the emotional timeline for parents shifted. Where they formerly experienced the sudden shock and grief of an adverse diagnosis upon the birth of their baby, they now encountered the shock and anticipation of grief before birth. The field of perinatal hospice developed in response to this new type of patient need.

Perinatal hospice refers to a type of care for fetuses with life-limiting conditions, those who carry them, and their families. As one article describes it:

The care model is a bundle of services, untethered to a hospital or medical center. Hospice nurses and social workers help families

16. See id.
18. As one article aptly states, “The suddenness of a surprise death was replaced by the suddenness of a surprise diagnosis.” Nathan J. Hoeldtke & Byron C. Calhoun, Perinatal Hospice, 185 AM. J. OBSTETRICS & GYNECOLOGY 525, 526 (2001).
19. A note about terminology: Generally, palliative care can involve continuing to receive treatments for the underlying condition in addition to symptom-relief treatments typical of hospice care. What Are Palliative Care and Hospice Care?, NAT’L INST. ON AGING, U.S. DEP’T OF HEALTH & HUMAN SERVS. (May 17, 2017), https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care [http s://perma.cc/7V8L-SHUG]. In contrast, hospice care normally means no longer attempting to treat the underlying condition, usually when there is a life expectancy of six months or less, and instead focusing exclusively on symptom relief and comfort. Id. In the specific context of perinatal care, many terms exist, including “perinatal hospice,” “perinatal palliative care,” and “perinatal palliative comfort care,” which differ in their allowance of concurrent curative treatment. See, e.g., Am. Coll. of Obstetricians & Gynecologists, Comms. on Obstetric Practice & Ethics, ACOG Committee Opinion: Perinatal Palliative Care, 134 OBSTETRICS & GYNECOLOGY e84, e84 (2019). These distinctions, while important for doctors and patients in practice, involve detail beyond the scope of this Note, which addresses the scholarship and notification laws surrounding this entire category of care more broadly. Therefore, this Note will use the term “perinatal hospice” to refer generally to all palliative care and hospice services offered to fetuses with life-limiting conditions and their families.
prepare for loss, coaching parents on what to say to siblings and co-workers. They take calls at 2 a.m. They recommend family therapists for couples whose relationships strain under grief. They teach mothers how to deliver painkillers to a dying infant, should the baby live long enough to go home.20

As perinatal hospice programs have expanded throughout the United States and abroad,21 well-respected medical groups have endorsed the practice as a valuable option for the eligible population.22 The American College of Obstetricians and Gynecologists (ACOG) describes perinatal hospice as “one of several options along a spectrum of care, which includes pregnancy termination (abortion) and full neonatal resuscitation and treatment, that should be presented to pregnant patients faced with pregnancies complicated by life-limiting fetal conditions.”23 Similarly, the American Academy of Nursing describes this care as “an essential element of childbearing choices.”24

These organizations phrase their endorsements carefully to emphasize that perinatal hospice care is not the right choice for everyone. Many pregnant persons who discover that their wanted fetus will survive only hours or days outside the womb will choose to terminate the pregnancy, and others will choose the most aggressive possible treatments to prolong the life of the fetus or newborn to the fullest extent that medical technology will allow.25 Perinatal hospice is one choice among many to which pregnant individuals should have access, not the ideal choice for all eligible patients.

Several organizations and laws explicitly frame perinatal hospice care as an alternative to abortion.26 This framing improperly situates abortion as the

22. See infra notes 23–24.
23. Am. Coll. of Obstetricians & Gynecologists, Comms. on Obstetric Practice & Ethics, supra note 19, at e84.
opposite of perinatal hospice, as if those are an eligible pregnant person’s only choices. In reality, a pregnant person can make many choices in response to a diagnosis of a life-limiting fetal condition: to proceed with the pregnancy without intervention, to proceed with the pregnancy with a high degree of intensive intervention in attempts to lengthen fetal or neonatal life even a small amount, to get an abortion, to seek individual mental health counseling in order to cope with the shock that often comes with such a diagnosis, to enroll in a perinatal hospice program, to seek more information or a second medical opinion, or to choose some combination of these options.

Given all these available choices, many people who receive a life-limiting fetal diagnosis do not get an abortion and do not enter a perinatal hospice program, whether due to lack of knowledge, lack of available services, or lack of interest in doing so. The decision is not simply one or the other, and abortion may not factor into a person’s choice at all. Though the benefits of perinatal hospice may coincide with some values broadly considered “pro-life” (in that abortion is not occurring), they also align with principles of reproductive choice (in that, when perinatal hospice is presented properly, it can expand the care options available to pregnant persons). To reduce perinatal hospice care to merely an “alternative to abortion” unduly centers abortion as the biggest concern a pregnant person may have when grappling with an adverse diagnosis. The choices pregnant individuals make are much more nuanced than that.

II. COMPARING EXISTING PERINATAL HOSPICE NOTIFICATION LAWS

As perinatal hospice programs have proliferated, several states have passed what this Note will refer to as “perinatal hospice notification laws.”

27. Frequently Asked Questions, supra note 3 (“Perinatal hospice transcends the abortion debate.”). Additionally, the traditional “pro-life vs. pro-choice” dichotomy is a false one; the “pro-life” criminalization of abortion increases incarceration, which has destructive effects on communities of color, while the “pro-choice” movement makes concerning assumptions about the ability of the poor to make truly free reproductive choices given societal constraints. Andrea Smith, Beyond Pro-Choice Versus Pro-Life: Women of Color and Reproductive Justice, 17 NWSA J. 119, 125, 128 (2005). Advocates for reproductive justice may assert fetal personhood and advocate for abortion rights simultaneously. Id. at 121. Perinatal hospice, which may appeal for different reasons both to those who support abortion rights and those who oppose them, is one example of the incomplete separation between these movements.

28. See Perinatal Hospice & Palliative Care Programs and Support, supra note 21.
These laws differ in their approaches, but in general, they require certain populations to be notified at certain times about perinatal hospice care within the state. In most states that have perinatal hospice notification laws, these laws are situated within existing abortion provisions as an informed consent disclosure. Other states classify perinatal hospice notification laws within the scope of public health laws without reference to abortion.

While respected medical organizations have consistently supported perinatal hospice as a treatment option, ACOG appears to disfavor perinatal hospice notification laws. Although it does not address these laws specifically, ACOG generally asserts that “[t]he intervention of legislative bodies into medical decision making is inappropriate, ill advised, and dangerous.” Specifically regarding informed consent, ACOG believes that the ethical requirements of informed consent extend beyond legal mandates, rendering “the ethical dimension of the meaning, basis, and application of informed consent” worthier of review than any particular legal standard. These stances suggest that ACOG would not be in favor of any law requiring healthcare providers to inform potential patients about the existence of perinatal hospice care.

A. The Three Main Categories of Perinatal Hospice Notification Laws

Existing perinatal hospice notification laws are best classified based on the event triggering notification: (1) a pregnant person, who is carrying a fetus with a life-limiting condition, attempts to get an abortion (Arizona,Arkansas, Indiana, Kansas, Maine, Oklahoma, Wisconsin).

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29. See infra Part II.A.
30. ARIZ. REV. STAT. ANN. § 36-2158.A.1 (2020); ARK. CODE ANN. § 20-16-2304 (2020); IND. CODE § 16-34-2-1.1(b) (2019); KAN. STAT. ANN. § 65-6709(a)(6) (2019); MINN. STAT. § 145.4242(c) (2019); OKLA. STAT. tit. 63, § 1-746.2.1 (2020); WIS. STAT. § 253.10(3)(c)2.em (2020).
31. IND. CODE § 16-25-4.5-6 (2019); NEB. REV. STAT. § 71-5003 (2017).
34. For persons carrying a fetus diagnosed with a “lethal fetal condition,” Arizona requires notification in person about the existence of perinatal hospice care at least twenty-four hours before an abortion may be performed. ARIZ. REV. STAT. ANN. § 36-2158.A.1 (2020). The state is also required to maintain a website containing information about perinatal hospice. Id. at § 36-2158.B.
Arkansas, Indiana, Minnesota, and Oklahoma), (2) any pregnant person, regardless of fetal condition, attempts to get an abortion (Kansas and Wisconsin), and (3) a pregnant person’s fetus is diagnosed with a life-limiting condition (Indiana and Nebraska). The first two categories consist of “abortion-triggered” notifications: the requirement to inform someone only arises once that person seeks an abortion. The third category consists of a “diagnosis-triggered” notification, in which, at or after the time a healthcare provider diagnoses a fetus with a life-limiting condition, the provider is required or permitted to provide information about perinatal hospice care. This Section will examine the three categories in detail. Figure 1 below is a chart summarizing these differences.

35. Arkansas requires persons carrying fetuses “diagnosed with a lethal fetal anomaly” to be notified about perinatal hospice care at least seventy-two hours before abortion is permitted. ARK. CODE ANN. § 20-16-2304 (2020).

36. Indiana requires a person whose fetus has been diagnosed with a “lethal fetal anomaly” to receive information about perinatal hospice care at least eighteen hours before an abortion. IND. CODE § 16-34-2-1.1(b) (2019).

37. Minnesota requires that “[a] female seeking an abortion of her unborn child diagnosed with fetal anomaly incompatible with life must be informed of available perinatal hospice services and offered this care as an alternative to abortion.” MINN. STAT. § 145.4242(c) (2019).

38. Oklahoma requires that a person carrying a fetus “diagnosed with a fetal anomaly incompatible with life” be notified about the existence of perinatal hospice care as an alternative to abortion at least seventy-two hours before receiving an abortion. OKLA. STAT. tit. 63, § 1-746.2.1 (2020). In addition, the state must maintain a website with information about perinatal hospice services available in Oklahoma. Id. at § 1-746.3.

39. Kansas requires the provision of information about perinatal hospice services in writing at least twenty-four hours before any non-emergency abortion may take place, regardless of whether the person seeking the abortion is carrying a fetus diagnosed with a life-limiting condition. KAN. STAT. ANN. § 65-6709(a)(6) (2019). The Kansas Department of Health and Environment must also maintain a website with pregnancy resources, including information about perinatal hospice services available in Kansas. Id. at § 65-6710(b).

40. Wisconsin requires every person seeking an abortion (except those whose pregnancies are a result of sexual assault or incest) to be told orally at least twenty-four hours in advance of the abortion that printed materials are available containing information about perinatal hospice. WIS. STAT. § 253.10(3)(c)2.em (2020).

41. This law is triggered by diagnosis and is mandatory: the provider who makes the diagnosis “shall” inform the pregnant patient “at the time of diagnosis.” IND. CODE § 16-25-4.5-6 (2019). In addition, a different section of this statute requires the state department to post information about perinatal hospice on its website. Id. at § 16-25-4.5-4. Indiana also has a separate perinatal hospice notification law pertaining to abortion; that law is triggered by the attempt to abort a fetus diagnosed with a life-limiting condition. See supra note 36.

42. While Indiana’s notification is mandatory and requires the pregnant person to complete a form confirming that notification has occurred, supra note 41, Nebraska’s notification is discretionary (the healthcare provider who makes a lethal fetal diagnosis “may” provide perinatal hospice information) and no signatures are required to confirm that the dispensation of information took place. NEB. REV. STAT. § 71-5003 (2017). Nebraska also requires the maintenance of a website containing information about available perinatal hospice services in the state. Id. at § 71-5004.
**Table:**

<table>
<thead>
<tr>
<th>Trigger: When does notification occur?</th>
<th>Pool of notified individuals is:</th>
<th>Which states?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pregnant person with lethal fetal condition seeks abortion (abortion-triggered)</td>
<td>Underinclusive</td>
<td>Arizona, Arkansas, Indiana, Minnesota, Oklahoma</td>
</tr>
<tr>
<td>Any pregnant person seeks abortion (abortion-triggered)</td>
<td>Both overinclusive and underinclusive</td>
<td>Kansas, Wisconsin</td>
</tr>
<tr>
<td>Pregnant person receives lethal fetal diagnosis (diagnosis-triggered)</td>
<td>Neither overinclusive nor underinclusive</td>
<td>Indiana, Nebraska</td>
</tr>
</tbody>
</table>

Figure 1. Summary of three existing notification regimes.

The first category of perinatal hospice notification laws implements a notification requirement when a person carrying a fetus diagnosed with a life-limiting condition seeks an abortion. This category notifies the most specific population. In narrowly defining the group that will be notified, the state avoids potentially overbroad meddling in pregnant persons’ medical decisions. However, this narrow trigger may also mean that the law will miss certain populations who may also benefit from learning about perinatal hospice care. Consider a woman whose wanted fetus is diagnosed with a life-limiting condition and whose personal convictions make her unwilling to consider an abortion. Under this notification scheme, she may not be informed of the full range of care options available to her, even if perinatal hospice would have been something she wanted.

The second category of perinatal hospice notification laws is broader, requiring notification to all persons seeking an abortion. For many recipients of this notification, the information will be useless because their fetuses do not have life-limiting conditions. In this way, this category of notification laws is overinclusive. At the same time, these laws are also underinclusive because they do not address the entire population eligible for perinatal hospice care. This type of law still fails to meet the needs of the woman above, who does not seek an abortion but might still benefit from information about perinatal hospice care.

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43. Government intrusion into a person’s medical decisions is a serious concern which has led to significant disapproval of unnecessary state involvement. See *Abortion Policy*, supra note 32 (“ACOG opposes unnecessary regulations that limit or delay access to care. The intervention of legislative bodies into medical decision making is inappropriate, ill advised, and dangerous.”).
Furthermore, by the time most patients enter an abortion clinic, they are certain of their decision to terminate the pregnancy. Studies indicate that over eighty-five percent of abortion-seekers are certain of their decision and that those with a high degree of certainty are unlikely to be influenced by mandatory ultrasounds or pre-abortion counseling. For this confident majority, state attempts to change their minds by providing new information at the last minute are not only unhelpful but also reveal deep biases that deny the competency of women to make the medical decisions that will best meet their needs.

Attempting to change a person’s mind during an abortion visit also has serious emotional ramifications. Consider a woman whose wanted fetus is diagnosed with a life-limiting condition. She decides, after careful thought, that carrying her fetus to term for the next several months only to watch her newborn baby die a few hours after birth is too devastating. She decides to get an abortion, and she arrives at her provider only to be targeted by materials specifically designed for people in her vulnerable position—materials singing the praises of a program that would have her do what she has already decided she cannot bear. These pamphlets leave her feeling guilty for going through with a decision that now feels framed by the state as the “wrong” choice to make. The timing of the notification requirement harms her, altering the mandatory information from an empowering piece of knowledge helpful in making a decision to a last-ditch effort to dissuade her from the choice she has already made.

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44. Diana Greene Foster, Heather Gould, Jessica Taylor & Tracy A. Weitz., Attitudes and Decision Making Among Women Seeking Abortions at One U.S. Clinic, 44 PERSP. ON SEXUAL & REPROD. HEALTH 117, 120 (2012) (“[W]omen had high precounseling confidence in their decision to terminate their pregnancy in 87% of the abortions sought . . . .”); Mary Gatter, Katrina Kimport, Diana Greene Foster, Tracy A. Weitz & Ushma D. Upadhyay, Relationship Between Ultrasound Viewing and Proceeding to Abortion, 123 OBSTETRICS & GYNECOLOGY 81, 83 (2014) (85.4% of survey respondents exhibited a high degree of certainty about their decision to have an abortion).

45. Gatter et al., supra note 44, at 84–85; Foster et al., supra note 44, at 122. More specific research is still needed on the certainty of the specific population relevant to perinatal hospice inquiries—persons choosing to abort wanted fetuses after receiving a diagnosis of a life-limiting fetal condition.

46. For a thorough examination of the biased effects of restricting abortion access based on perceived mental health effects to women, see Maya Manian, The Irrational Woman: Informed Consent and Abortion Decision-Making, 16 DUKE J. GENDER L. & POL’Y 223 (2009).

47. Part III.B.4 examines the law’s role in the protection of emotion.

48. The optimal timing of informed consent is early enough to allow the patient sufficient time to review any materials, process the information, and ask questions without undue urgency or pressure. See, e.g., Clark C. Smith & David C. Miller, Informed Consent: A Form or a Conversation?, in ASRA NEWS 38 (2019), https://www.asra.com/content/documents/asra-19-03_final_spv2.pdf [https://perma.cc/PS4K-ZUXX]; Owen A. Anderson & Mike J. Wearne, Informed Consent for Elective Surgery—What is Best Practice?, 100 J. ROYAL SOC’SY MED. 97, 97 (2007) (rather than obtaining consent the day of surgery, “it would be wiser to obtain informed consent at the time of listing in clinic” because “[t]he patient will feel under less pressure to proceed”).
The third category of perinatal hospice notification laws, notification at or after the time the provider diagnoses a life-limiting fetal condition, is the most logically connected to informed patient decision-making. Perinatal hospice care is designed to support fetuses with life-limiting conditions and their families; by notifying all whose fetuses receive such diagnoses, the state promotes a relevant medical service directly to the entire known population of potential recipients. While such a requirement will not reach every possible eligible person (because not all pregnant persons will undergo genetic testing), this notification methodology makes sense if the true goal of the law is to allow individuals to make informed decisions about their medical care. This type of notification would reach the woman in the example above who would not consider an abortion but would still benefit from perinatal hospice.

A diagnosis-based trigger has the added benefit of being untethered to abortion, which avoids the issue of state coercion under the guise of informed consent. Unlike the previous two abortion-triggered models, individuals in this paradigm receive the information before they have made any decision about how to proceed with the pregnancy. By delivering information at this time, rather than triggering notification only when the pregnant person has already chosen to abort, the law better facilitates educated decision-making. This type of law would deliver information more effectively to the woman choosing abortion in the example above, who would receive information about all her options upfront rather than having the state second-guess her decision at the eleventh hour.

However, diagnosis-triggered notification laws may still contain biases. For example, Indiana’s diagnosis-triggered law has as its only two listed purposes that “women considering abortion” know about the existence of perinatal hospice programs and that “women choosing abortion after receiving a diagnosis of a lethal fetal anomaly are making a fully informed decision.”

This abortion-centric framing is undesirable because perinatal hospice is a care model separate from abortion. Enacting a notification law for the purpose of informing “women considering abortion” about perinatal hospice care deprioritizes perinatal hospice-eligible individuals who do not seek an abortion. The very benefit of diagnosis-triggered laws is the fact that they align so well with the pool of eligible individuals; this category of

49. See generally supra note 46.
50. “Perinatal palliative comfort care is one of several options along a spectrum of care, which includes pregnancy termination (abortion) and full neonatal resuscitation and treatment, that should be presented to pregnant patients faced with pregnancies complicated by life-limiting fetal conditions.” Am. Coll. of Obstetricians & Gynecologists, Comm. on Obstetric Practice & Ethics, supra note 19, at e84.
52. See supra note 26 and accompanying text.
laws is neither overinclusive nor underinclusive. Formulating the purpose of such laws in terms of abortion, as Indiana does, cheapens this benefit by valuing the notification of only one part of the eligible pool (abortion-seekers).

Not all diagnosis-triggered notification laws have this problem. Nebraska’s diagnosis-triggered law contains no reference to abortion. The law simply states that doctors may inform eligible patients of perinatal hospice care. While this approach may seem a bit too restrained (since doctors are already permitted to inform eligible patients of perinatal hospice care), the choice to formalize this permission in a law draws greater attention to a lesser-known medical option while still leaving doctors the discretion to care for patients according to their training and good judgment. Furthermore, by refraining from discussing abortion, Nebraska’s law treats the whole pool of eligible patients as equally in need of information about a potential medical option. If the goal of a perinatal hospice notification law is to facilitate truly informed choice for as many individuals as possible, allowing doctors discretion to notify according to their expertise and treating all eligible patients as equally important both help to meet that goal.

B. Nonregulation: A Fourth Option

Most states use a model beyond the three notification methodologies listed above: they do not have a law on the subject at all. The decision not to involve the government is still a choice, and it should be analyzed as such.

Many health-related decisions are not subject to complete government regulation. For example, many surgical practices are internally regulated by the medical community and, when that fails, by tort law. Given serious concerns about the effectiveness of mandated disclosure regulations across

54. “Factors contributing to low perinatal palliative care use include availability of programs, patient access issues, and physician education and training barriers. Despite these obstacles, the benefits of these programs justify their continued development.” Am. Coll. of Obstetricians & Gynecologists, Commns. on Obstetric Practice & Ethics, supra note 19, at e87. The effects of raising awareness on actual behavior are mixed in an activism context. Julie Beck, What Good Is ‘Raising Awareness’?, ATLANTIC (Apr. 21, 2015), https://www.theatlantic.com/health/archive/2015/04/what-good-is-raising-awareness/391002/ [https://perma.cc/EC5U-457E]. However, in the context of perinatal hospice notification laws, the goal itself is awareness of options so that the person can choose most effectively what to do next, and as a result, efforts to increase awareness are a direct means to the end sought.
55. Jonathan J. Darrow, Explaining the Absence of Surgical Procedure Regulation, 27 CORNELL J. L. & PUB. POL’Y 189 (2017) (advocating for more direct regulation of surgical procedures). Darrow clarifies that while the surgeries themselves are not normally directly regulated, “indirect” regulation occurs through laws about “healthcare workers who perform surgery, the medicines and devices used during surgery, and the facilities in which surgery is performed.” Id. at 191.
a variety of fields, including the medical industry and abortion providers, one reasonable approach is for the government to step out of this matter entirely.

The choice not to mandate notification at all, allowing doctors to communicate this information to pregnant persons using their own discretion, sidesteps the problem of government manipulation or coercion more effectively than any of the other notification methods discussed. It dodges the “gender-specific paternalism” of lawmakers’ attempts to protect the largely female population of abortion-seekers from a choice the lawmakers believe will lead to regret and mental distress. It presumes that doctors and patients are competent to handle this matter without state intervention.

However, the choice to keep the state out of such matters also has negative consequences. Throughout the general surgical context, the price of nonregulation is inconsistency—in performance, terminology, and data analysis. Inconsistency is not unique to perinatal hospice, but nonregulation does affect perinatal hospice-eligible individuals. Without a requirement that every doctor notify every person whose fetus has a life-limiting condition of perinatal hospice options at the time of diagnosis, some doctors will choose not to do so, leaving some patients uninformed. Since lack of provider awareness and training on perinatal hospice is an issue in the field of obstetrics and gynecology, the absence of a notification law may prove significant. Nonregulation therefore runs the risk of being underinclusive, just like abortion-triggered notification requirements.

56. E.g., Omri Ben-Shahar & Carl E. Schneider, The Failure of Mandated Disclosure, 159 U. PA. L. REV. 647 (2011). For example, recipients of boilerplate language often do not read it, id. at 671, and even when patients receive important medical information, their comprehension and retention can be startlingly low, id. at 668.

57. See Manian, supra note 46. Manian argues that so-called “informed consent” provisions in the abortion context “deny[] women’s capacity for sound medical decision-making.” Id. at 227.

58. Notably, Nebraska’s perinatal hospice notification law is permissive rather than mandatory. NEB. REV. STAT. § 71-5003 (2017). As a result, it evades the problems of mandatory notification just as effectively as nonregulation does.

59. Manian, supra note 46, at 287.

60. Darrow highlights the difficulty of performing analysis across studies when each one takes data at different points or from different populations. Darrow, supra note 55 at 200–06.

61. Am. Coll. of Obstetricians & Gynecologists, Comms. on Obstetric Practice & Ethics, supra note 19, at e87 (“Factors contributing to low perinatal palliative care use include availability of programs, patient access issues, and physician education and training barriers. Despite these obstacles, the benefits of these programs justify their continued development.”) (emphasis added).

62. Nebraska’s diagnosis-triggered perinatal hospice notification law leaves notification up to the provider’s discretion, running the risk that a doctor will choose not to inform an eligible patient. See IND. CODE § 16-25-4.5-6 (2019). While Nebraska’s law risks being underinclusive, the very existence of the law may serve as an informing agent, potentially mitigating the
An underinclusive notification regime means that some eligible people will not be informed and will seek legal redress. In states with perinatal hospice notification laws, a statutory remedy may exist. Elsewhere, patients may need to rely on general informed consent statutes or common law standards of medical malpractice if their doctors fail to provide them with adequate information. Legal standards of informed consent vary by state, so a patient will have an easier or harder time making a case depending on location. Of course, the same is true of states with perinatal hospice notification laws. Different laws contain different remedies, and not all laws require all eligible individuals to be notified. Therefore, with respect to remedies for the underinformed, states with no perinatal hospice notification law are not necessarily any worse than those with other potentially underinclusive notification regimes.

III. THE PROPER ROLE OF THE GOVERNMENT IN REQUIRING THE PROVISION OF INFORMATION

A. The Social Construction of Informed Consent

Most states with perinatal hospice notification laws classify notification as a part of establishing informed consent to an abortion. Generally, informed consent consists of providing a patient with the material information necessary to make a particular decision. The landmark 1972
case *Canterbury v. Spence* articulates the concept of materiality well: “[a] risk is thus material when a reasonable person, in what the physician knows or should know to be the patient’s position, would be likely to attach significance to the risk or cluster of risks in deciding whether or not to forego the proposed therapy.” 69 *Canterbury* recognizes that physicians cannot read their patients’ minds and therefore assigns an objective (reasonable patient) standard to the situation. 70 This stance is understandable; it is impossible for a physician to find out what information each patient would deem necessary but does not have, since by definition the patient does not know to ask about it. However, the reasonable patient standard prompts a different question: what kinds of information is a reasonable patient likely to find “significant[] . . . in deciding whether or not to forego the proposed therapy” 71 under the *Canterbury* formulation?

The answer to this question is inherently bound up in a web of societal norms and expectations. There are, of course, some straightforward answers; *Canterbury* itself lists the “options” for different treatments and the “perils” of those treatments as a starting point. 72 Still, deciding which risks are material enough to disclose requires an assessment of social norms and the context of the individual patient. If a surgical procedure is likely to lead to minor scarring of a person’s abdomen, for example, this may be immaterial to an average person but critically important to a swimsuit model who is at risk of losing his livelihood. 73

In the fraught context of reproductive and end-of-life matters, it is difficult to determine which information is material and to whom. Americans hold an enormous range of sincere views on the personhood (or not) of fetuses, 74 the ramifications of hospice care, 75 and the morality of

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70. *Id.* at 787.
71. *Id.* at 787 (quoting Jon R. Waltz & Thomas W. Scheuneman, *Informed Consent to Therapy*, 64 NW. U. L. REV. 628, 640 (1970)).
72. *Id.* at 783.
73. Similarly, one article hypothesizes a scenario in which glaucoma treatment has a risk of changing a person’s eye color; the author notes that the materiality of this risk would likely change if the person lived in a society that discriminated based on eye color. Nadia N. Sawicki, *The Abortion Informed Consent Debate: More Light, Less Heat*, 21 CORNELL J. L. & PUB. POL’Y 1, 20 (2011).
75. For example, 15.1% of respondents in one survey asserted their belief that “accepting palliative care means giving up.” Jennifer M. Taber, Erin M. Ellis, Maija Reblin, Lee Ellington &
abortion under different circumstances or at all. The socially constructed doctrine of informed consent falters under this variety; for every argument that requiring the provision of certain information is manipulative, there is another argument that withholding it caused harm to a patient who wanted to hear it.

The risk of manipulation via information is not unique to perinatal hospice or abortion informed consent regulations. States have certain legitimate interests in preventing, encouraging, or requiring different types of behavior. To further these legitimate interests, the legislative branch creates laws and policies which either incentivize or outright demand certain actions. In order to determine whether a state law is an appropriate exercise of this power, the judiciary may look to the state’s interest in enacting the law.

B. Possible Government Interests in Enacting Perinatal Hospice Notification Laws

To investigate the legal and practical legitimacy of perinatal hospice notification laws, it can be helpful to ask why the state chose to pass the law it did. One common method of determining the legitimacy of a law is a means-end analysis. If the state cannot cite a justifiable end for which it

Rebecca A. Ferrer, Knowledge of and Beliefs About Palliative Care in a Nationally-Representative U.S. Sample, 14 PLOS ONE 1, 6 (2019), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6695129/pdf/pone.0219074.pdf [https://perma.cc/V97V-7DRS].


77. Planned Parenthood Minn., N.D., S.D. v. Rounds, 530 F.3d 724, 744 (8th Cir. 2008) (challenging required pre-abortion disclosure that a fetus is a “whole, separate, unique, living human being” as a misleading ideological message).

78. Acuna v. Turkish, 930 A.2d 416, 418–20 (N.J. 2007); Doe v. Planned Parenthood, 956 N.E.2d 564, 567 (Ill. App. Ct. 2011). Although the defendants won in both these cases, the mere existence of these suits represents the belief of certain patients that statements of fetal humanity would have been material to their decisions.

79. For example, laws requiring certain ideas to be taught in public schools also reveal serious concerns about the power of government-mandated information to manipulate behavior. See, e.g., ALA. CODE § 16-40A-2 (2020) (requiring any sex education program in Alabama to “include and emphasize” that abstinence is the only completely reliable protection against pregnancy and that “homosexuality is not a lifestyle acceptable to the general public”).


81. See Russell W. Galloway, Means-End Scrutiny in American Constitutional Law, 21 LOY. L.A. L. Rev. 449, 449 n.1 (1998) (“Means-end scrutiny is used, for example, in enforcing the requirements of substantive due process, equal protection, freedom of speech, free exercise of religion, the necessary and proper clause, the dormant commerce clause, the contract clause and the privileges and immunities clause.”).
enacted the law—for example, if its only aim is to infringe on its residents’ constitutional rights—then the law should not exist. Further, if the state asserts a justifiable end but crafts a law poorly designed to meet that end, such behavior casts doubt on the state’s true intentions and, as a result, the legitimacy of that law. This Section will outline a variety of possible ends that a perinatal hospice notification law might meet and examine how well different categories of perinatal hospice notification laws meet those ends.82

1. Protecting Life and Improving Quality of Life

In most contexts, the idea that a state has an interest in protecting life or improving quality of life is relatively uncontroversial: ideally, a state should want to do what it can to protect the lives of its residents. The police power of states “to provide for the public health, safety, and morals” legitimizes this interest.83 In the context of reproduction, a purported interest in protecting life is more controversial due to widespread disagreement about whether (or at what point) fetuses qualify as “lives” for the state to protect and to what extent, if any, fetal needs can affect the choices made by those who carry them.84

Is a state interest in protecting life or improving quality of life an appropriate reason for enacting a perinatal hospice notification law? Perinatal hospice is a medically recognized treatment program designed to help not only fetuses and newborns but also their families who may be grappling with tremendous grief, stress, and fear.85 While a perinatal hospice program may or may not extend fetal or neonatal life, it can improve the quality of parental and familial life by helping surviving family members heal from loss. Accordingly, enacting a perinatal hospice notification law could simply manifest the state’s interest in protecting life and improving quality of life.

The likelihood of this interest being the driving force behind a perinatal hospice notification law varies depending on the law’s trigger. A diagnosis-triggered notification law could be created out of an interest in improving quality of life because it would promptly and unobtrusively address all individuals whose lives may be improved by perinatal hospice care.86 An abortion-triggered notification law may still have this goal, but such laws

82. A full examination of the constitutionality of the various perinatal hospice notification laws is beyond the scope of this Note. Instead, this Section uses a means-end analysis to consider how best to craft a legitimate and beneficial perinatal hospice notification law.
84. See Strauss, supra note 74.
85. See supra Part I.
86. See supra Part II.A.
are always underinclusive (notifying only those who seek abortion, not all who receive life-limiting fetal diagnoses)\(^8^7\) and sometimes also overinclusive (notifying all those who seek an abortion regardless of whether they are eligible for perinatal hospice services).\(^8^8\) This poor overlap of the eligible and notified populations suggests that the motivation for passing an abortion-triggered notification law is something other than protecting the quality of fetal and familial life.\(^8^9\)

2. Impeding Abortion Access

A state interest in impeding abortion access is distinct from protecting life. A state may protect life and improve its residents’ quality of life without impeding abortion access (for example, by expanding access to free or low-cost mental health care).\(^9^0\) Abortion before the point of fetal viability remains a constitutional right despite widespread legislative attempts to curtail or eliminate opportunities to vindicate this right.\(^9^1\) A state does not have a legitimate interest, in and of itself, in impeding its residents’ exercise of their constitutional rights.\(^9^2\) As a result, states cannot pass a perinatal hospice notification law with the purpose of impeding abortion access. Although no existing perinatal hospice notification law explicitly asserts this impermissible goal, many such laws openly state that their purpose is to entice eligible persons toward perinatal hospice and away from abortion.\(^9^3\)

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89. One motivation to pass abortion-restrictive laws in general may come from social judgments about pregnant women, particularly ideas about their nature or the necessary consequences of choices they are presumed to have made. Reva B. Siegel, Reasoning from the Body: A Historical Perspective on Abortion Regulation and Questions of Equal Protection, 44 Stan. L. Rev. 261, 350 (1992).
90. Reva Siegel articulates a distinction between pro-life measures that affirm women’s reproductive autonomy and pro-life measures that do not, arguing that the latter should be subject to less deference. Reva B. Siegel, ProChoiceLife: Asking Who Protects Life and How—and Why It Matters in Law and Politics, 93 Ind. L.J. 207, 209 (2018).
91. See, e.g., Whole Woman’s Health v. Hellerstedt, 136 S. Ct. 2292, 2300 (2016) (quoting Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833, 878 (1992) (plurality opinion)) (“[T]here ‘exists’ an ‘undue burden’ on a woman’s right to decide to have an abortion, and consequently a provision of law is constitutionally invalid, if the ‘purpose or effect’ of the provision ‘is to place a substantial obstacle in the path of a woman seeking an abortion before the fetus attains viability.’”) (emphasis omitted).
92. See Hellerstedt, 136 S. Ct. at 2300 (impositions that “undu[ly] burden” abortion access are unconstitutional).
Outside of abortion, the state frequently mandates the provision of information to aid individuals in making decisions and to encourage certain decisions over others. Mandatory printing of nutrition facts on food and drinks, mandatory provision of gambling addiction helpline numbers in casinos, and mandatory disclosures about medical care are just a few of the countless examples of state laws wielding information to encourage residents to align their behavior with what the state thinks is best. However, legislators creating laws that regulate abortion must exercise great caution in crafting incentives. “Nudging” people’s choices about the exercise of constitutional rights, such as the free exercise of religion or freedom of speech, is unlikely to be legally permissible.

Asking whether such state incentives should exist at all is pointless; every choice incentivizes something. Even purposeful neutrality among a variety of options frames those options as equally good—a value judgment with which some will agree and others will not. As a result, “incentivization” cannot be the dividing factor between acceptable and

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95. See, e.g., Fla. Stat. § 551.118(2) (2019) (requiring a gambling helpline phone number to be provided in certain designated slot machine areas).

96. For example, Indiana has a law mandating certain disclosures to prospective general hospice patients (i.e., non-perinatal hospice patients, such as adults with terminal cancer). Ind. Code § 16-25-7-1 (2019).

97. For a thorough examination of the broad social influence of incentives in a scheme of “libertarian paternalism,” see Richard H. Thaler & Cass R. Sunstein, *Nudge: Improving Decisions About Health, Wealth, and Happiness* 5 (2008). Thaler and Sunstein’s theory focuses on small, subtle changes (for example, rearranging the placement of healthy food in a cafeteria to put it at eye level, *id.* at 1–6) rather than the somewhat intrusive efforts of certain state legislatures. Nonetheless, the idea that true neutrality is impossible applies effectively to the actions of governments, including in the contexts of perinatal hospice and abortion.

98. See, e.g., Lamont v. Postmaster Gen., 381 U.S. 301, 302, 307 (1965) (holding that a law requiring individuals who mail “communist political propaganda” to issue a written request before that mail would be delivered is an unconstitutional deterrent to free speech); Lee v. Weisman, 505 U.S. 577, 581, 586, 599 (1992) (holding that a public high school directing a rabbi to give a nonsectarian prayer at graduation is an Establishment Clause violation even though students may choose not to attend graduation).

99. Thaler & Sunstein, supra note 97, at 3 (asserting that “there is no such thing as a ‘neutral’ design”).

100. Consider a state law mandating that those who disagree about the health effects of cigarettes be given equal time and resources to defend their position in public school health classes. Cigarettes are conclusively recognized to be harmful to human health; “neutrality” in this case actually serves to unduly incentivize the more harmful choice by raising it up to equal status with the healthier one.
unacceptable state behavior. Where the line of permissibility should be drawn is a deeply subjective question.

Though there are different ways to determine the point at which permissible “nudging” crosses over into impermissible coercion or infringement upon rights, it is never a legitimate state interest to enact a law solely to infringe upon an individual’s right to an abortion (as distinct from protecting life or another purpose). As a result, if this is the purpose of a perinatal hospice notification law, such a law cannot be permissible under the state’s police power.

In determining whether impeding abortion is the purpose of a perinatal hospice notification law, the trigger for notification again provides insight. Logically, abortion-triggered laws make it much likelier that the state’s interest is in impermissibly coercing individuals not to get an abortion. If the goal is to prevent as many abortions as possible, a law which is specifically tethered to abortion or overinclusive of the abortion-seeking population makes sense. Since this goal is impermissible, perinatal hospice notification requirements that fall into this category likely lack a legitimate basis for their enactment.

3. Promoting Best Medical Practices

A state may have an interest in promoting the best available medical practices by informing the eligible population of patients about the existence of such practices. This interest would clearly fall under the protection of public health and is therefore enforceable under the police power of the state. For example, some states may enact licensing requirements for

101. Instead, courts apply the “undue burden” standard, in which “a state regulation [that] has the purpose or effect of placing a substantial obstacle in the path of a woman seeking an abortion of a nonviable fetus” is unduly burdensome and therefore constitutionally impermissible. Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833, 877 (1992) (plurality opinion). Casey allows life-promoting measures on the part of the state as long as they are not a “substantial obstacle” to an individual’s choice. Id. at 877–78. As a result, while the purpose of infringing upon abortion access is impermissible, the purpose of promoting life is permissible under Casey.

102. In many ways, this state interest fits under the umbrella of Part III.B.1, which describes an interest in preserving life or improving quality of life. This Note separates the two in order to focus on different aspects of such an interest: the “life” issue in Part III.B.1, and the issue of medical legitimacy here.
doctors and other medical professionals and laws prohibiting medical practices found to be harmful.

Is a state interest in promoting best medical practices an appropriate reason to enact a perinatal hospice notification law? Perinatal hospice is a legitimate form of medical care, and ACOG and the American Academy of Nursing both encourage medical professionals to provide information about this type of care to eligible patients. However, matters surrounding reproduction are often politically charged and singled out for cumbersome legislation, so comparing laws concerning general hospice care in the states with perinatal hospice notification laws can provide context about appropriate levels of state intervention in comparable medical practices. Regulating perinatal hospice but not general hospice would suggest that either (1) something is medically unique about perinatal hospice which justifies regulation unnecessary for other kinds of hospice, or (2) promoting best medical practices is not actually the intent of the law. Some risks of perinatal hospice have no equivalent in general hospice, but these risks primarily concern social tension and disagreements with family members, peers, and healthcare providers. Since perinatal hospice disclosures in the

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103. The Supreme Court affirmed the legitimacy of state licensing requirements for doctors in Dent v. West Virginia, 129 U.S. 114, 122 (1889):

The power of the State to provide for the general welfare of its people authorizes it to prescribe all such regulations as, in its judgment, will secure or tend to secure them against the consequences of ignorance and incapacity as well as of deception and fraud. As one means to this end . . . [states have required] an examination of parties by competent persons, or . . . a certificate to them in the form of a diploma or license from an institution established for instruction on the subjects, scientific and otherwise, with which such pursuits have to deal.

104. For example, states have banned the practice of conversion therapy for lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ) youth as a result of scientific and cultural advancements demonstrating the severe psychological damage this practice may cause. E.g., Youth Mental Health Protection Act, 405 ILL. COMP. STAT. 48/20 (2016); N.Y. EDUC. LAW § 6509-e (Consol. 2019).

105. See supra notes 23–24 and accompanying text.

106. Bonnie S. Jones, Sara Daniel & Lindsay K. Cloud, State Law Approaches to Facility Regulation of Abortion and Other Office Interventions, 108 AM. J. PUB. HEALTH 486, 491 (2018) (finding that “states had frequently singled out abortion provision [sic] for targeted regulation” and that “states had virtually never singled out other office interventions for such separate legal treatment”). Sawicki, supra note 73, at 35, suggests that the reason for additional regulation is “the inherent controversy about the sanctity of life underlying the abortion debate.” Normative judgments about women, sexuality, and childbearing are another potential cause of this heightened legislative attention. See Siegel, supra note 90, at 222–23.

107. This Note will use the term “general hospice” to refer to non-perinatal hospice: that is, hospice care for patients who are already born when they are diagnosed with a terminal condition qualifying them for hospice care.

108. In terms of overarching risks of perinatal hospice, ACOG identifies the possibilities that (1) “there may be differences of opinion between family members before and after the delivery of the infant,” and (2) “there may be differences between parents and the neonatal care providers about appropriate postnatal therapies, especially if the postnatal diagnosis and prognosis differ substantially from antenatal predictions.” Am. Coll. of Obstetricians & Gynecologists, Comms. on Obstetric Practice
states that require them do not focus on these risks,\textsuperscript{109} it is unlikely that such risks warrant different treatment of perinatal hospice and general hospice under the law.

The laws surrounding general hospice care vary by state, just as perinatal hospice notification laws do. Of the states with perinatal hospice notification laws, none have a general hospice notification law triggered in a comparable way to its perinatal counterpart.\textsuperscript{110} Abortion loses its (purported) relevance as a potential trigger for hospice of those already born, and no particular diagnosis prompts notification. Some of these states do have general hospice notification standards, but they are typically less intrusive than perinatal hospice notification laws. For example, Nebraska and Kansas law both require the maintenance of a website with information about general hospice care.\textsuperscript{111} Indiana requires disclosures to be made to prospective general hospice patients,\textsuperscript{112} while Minnesota requires...

\textsuperscript{109} See infra notes 111–113. Arizona has certification requirements for hospice institutions, but it does not require individual notification of eligible patients. See ARZ. REV. STAT. ANN. § 36-409 (2020). Arkansas codifies its general hospice provisions at ARK. CODE ANN. §§ 20-8-701–703 (2019). These provisions address the creation of a task force to recommend palliative care initiatives to the legislature, but the laws make no mention of individual notification comparable to a perinatal hospice notification law. See id. Oklahoma codifies its general hospice provisions at OKLA. STAT. tit. 63, §§ 1-860.1–862 (2020). These provisions deal with hospice licensing and do not discuss individual notification of potential patients. See id. Wisconsin codifies its general hospice provisions at WIS. STAT. §§ 50.94 (2020). These provisions also deal with hospice licensing and do not discuss individual notification of potential patients. See id.

\textsuperscript{110} Only Nebraska, Indiana, Oklahoma, Arizona, and Kansas require the state to maintain a website or online brochure with information about perinatal hospice. See supra notes 34–42 (identifying perinatal hospice laws and their requirements). None of the online resources these five states provide discuss social tension or disagreement with others as risks relevant to a decision about perinatal hospice.

\textsuperscript{111} See infra notes 111–113. Arizona has certification requirements for hospice institutions, but it does not require individual notification of eligible patients. See ARZ. REV. STAT. ANN. § 36-409 (2020). Arkansas codifies its general hospice provisions at ARK. CODE ANN. §§ 20-8-701–703 (2019). These provisions address the creation of a task force to recommend palliative care initiatives to the legislature, but the laws make no mention of individual notification comparable to a perinatal hospice notification law. See id. Oklahoma codifies its general hospice provisions at OKLA. STAT. tit. 63, §§ 1-860.1–862 (2020). These provisions deal with hospice licensing and do not discuss individual notification of potential patients. See id. Wisconsin codifies its general hospice provisions at WIS. STAT. §§ 50.94 (2020). These provisions also deal with hospice licensing and do not discuss individual notification of potential patients. See id.

\textsuperscript{112} IND. CODE § 16-25-7-2 (2019).
information and hospice referral services to be available “in all regions of the state.”\textsuperscript{113} While these requirements are significantly less demanding than the perinatal hospice notification requirements in each of these states,\textsuperscript{114} the fact that some legislation exists to regulate general hospice implies that the lawmakers of these states perceive some necessity for state intervention to promote best medical practices.\textsuperscript{115}

In trying to examine the authenticity of a state’s purported interest, the trigger for notification remains relevant. If “promoting best available medical practices” includes promoting those practices to the eligible population (which it should), then diagnosis-triggered laws are much more likely to promote best available medical practices than abortion-triggered laws. Diagnosis-triggered laws, in contrast to the underinclusive and potentially overinclusive abortion-triggered laws, aim to inform all eligible candidates and no ineligible candidates, making such laws better suited to be a manifestation of a state’s interest in promoting the best available medical practices.\textsuperscript{116}

4. Protecting Individuals from Emotional Distress

States may claim that they enacted perinatal hospice notification laws to protect pregnant individuals from the future regret of an abortion.\textsuperscript{117} Because many pregnant persons may feel that they have no other option and choose to abort when they discover that their fetus has a life-limiting condition, states may argue that notification laws are necessary to inform individuals of alternatives to abortion\textsuperscript{118} in order to protect them from eventual regret and emotional distress.

The state has a limited interest in protecting against certain kinds of emotional distress. The tort causes of action “intentional infliction of emotional harm”\textsuperscript{119} and “negligent conduct directly inflicting emotional

\textsuperscript{113} MINN. STAT. § 144A.755 (2019).
\textsuperscript{114} See supra notes 34–42.
\textsuperscript{115} It is also possible that these states’ general hospice legislation is motivated by a state interest in preserving the life and health of their occupants. See supra Part III.B.1.
\textsuperscript{116} See supra Part II.A.
\textsuperscript{117} This rationale is most relevant to abortion-triggered notification laws, but it may also apply implicitly or explicitly to diagnosis-triggered notification laws. For example, Indiana’s diagnosis-triggered notification law specifically references abortion-seekers as a target audience. See supra note 51.
\textsuperscript{118} For examples of laws and news articles categorizing perinatal hospice in this unhelpful way, see supra notes 26–27 and accompanying text.
\textsuperscript{119} “An actor who by extreme and outrageous conduct intentionally or recklessly causes severe emotional harm to another is subject to liability for that emotional harm and, if the emotional harm causes bodily harm, also for the bodily harm.” RESTATEMENT (THIRD) OF TORTS: LIAB. FOR PHYSICAL & EMOTIONAL HARM § 46 (AM. LAW INST. 2012).
harm on another\(^{120}\) both demonstrate that, at least sometimes, the state (via the judicial system) will enforce an individual’s right to be free of undue emotional distress.\(^{121}\)

While some state protection from emotional distress is legally permissible, it does not necessarily follow that a state may enact legislation to protect individuals from the possible emotional consequences of exercising their constitutional rights. For example, the right to a trial by jury is protected, yet no statute mandates the dissemination of a government-issued pamphlet about the emotional distress that a criminal defendant could experience as a result of such a trial. Intentional and negligent infliction of emotional distress both involve at least two parties\(^{122}\)—the victim and the tortfeasor—and require that the latter have engaged in some type of outrageous action which does not consist solely of the exercise of a legal right.\(^{123}\) Protecting individuals from accidentally inflicting emotional distress upon themselves by exercising their own rights in a perfectly legal way which they may later regret is not comparable.

In addition to these legal and logical flaws, enacting perinatal hospice notification laws in order to protect women\(^{124}\) from the emotional distress of an abortion they later regret treads into the region of sexist paternalism. While not as extreme a measure as banning certain types of abortions due to the state’s perception of the risk of psychological harm,\(^{125}\) such a protective motive is questionable at best given the many psychological risks of other less-regulated medical procedures.\(^{126}\) There is no reason but sexism

\(^{120}\) An actor whose negligent conduct causes serious emotional harm to another is subject to liability to the other if the conduct: (a) places the other in danger of immediate bodily harm and the emotional harm results from the danger; or (b) occurs in the course of specified categories of activities, undertakings, or relationships in which negligent conduct is especially likely to cause serious emotional harm." Restatement (Third) of Torts: Liab. for Physical & Emotional Harm § 47 (Am. Law Inst. 2012).

\(^{121}\) E.g., Childers v. Geile, 367 S.W.3d 576, 580 (Ky. 2012) (identifying a “right to be free of emotional distress”); Coca-Cola Bottling Co. v. Superior Court, 286 Cal. Rptr. 3d 855, 865 (Cal. Ct. App. 1991) (describing another case as establishing an invasion of “the right to be free of the intentional or negligent infliction of emotional distress to one’s person”).


\(^{123}\) The mere exercise of a legal right, even if the conduct is substantially certain to cause severe emotional distress, does not give rise to liability for intentional infliction of emotional harm. Restatement (Third) of Torts: Liab. for Physical & Emotional Harm § 46 cmt. e (Am. Law Inst. 2012).


\(^{125}\) For a deeper discussion of the harm and implications of outright bans on particular kinds of abortion procedures, see Manian, supra note 46, at 257–62.

\(^{126}\) See Manian, supra note 46, at 257 (“Any medical treatment decision can lead to regret in some percentage of patients. If protection from regret were sufficient to permit government regulation,
to explain why women should face more regulation than men when making high-pressure, potentially emotional medical decisions.

In an attempt to avoid perpetuating sexism, the state may reframe the emotional distress issue: pregnancy is an emotionally significant life event for many people, and the state has an interest in ensuring that individuals pregnant with fetuses diagnosed with life-limiting conditions are made explicitly aware of their care options, including perinatal hospice, in order to minimize the negative effects of grief during this time. This description is reminiscent of the state interest in preserving life and health described above. This framing is broad enough to encompass all existing perinatal hospice laws, at least theoretically, and it sidesteps the counterproductive focus on abortion. However, in avoiding those issues, two questions arise.

First, while the unexpected diagnosis of one’s fetus with a life-limiting condition no doubt holds the potential to be traumatic for many would-be parents, it seems no less traumatizing than the diagnosis of, for example, a three-year-old child with a terminal illness which qualifies for general (pediatric) hospice care. These realities are both viscerally emotionally distressing, and it is unclear why a state might choose to protect against one kind of emotional distress and not the other, as no state has pediatric hospice notification requirements for parents of young children. Unless the concern is about the emotional consequences of an abortion decision—which is invalid, as the state has no justification for protecting individuals from the emotional ramifications of exercising their constitutional rights—government could override patient decision-making for any medical procedure, eviscerating the legal and ethical norm of informed consent in healthcare.). While Manian’s discussion focuses on the ban of a particular subset of abortions in Gonzales v. Carhart, 550 U.S. 124 (2007), her logic remains relevant here.

127. See supra Part III.B.1.


129. My research indicates that no state has a law of this type. Some states address pediatric palliative care, but none address any type of mandatory or permissive notification or disclosure specific to the pediatric context. See, e.g., COLO. REV. STAT. § 25.5-5-305 (2020) (seeking federal authorization for pediatric hospice care in light of current barriers); MASS. GEN. LAWS ch. 111, § 24K (2020) (establishing a pediatric palliative care program but making no mention of notification); N.J. STAT. ANN. § 26:2H-12.75 (West 2020) (declaring the importance of pediatric hospice care generally); N.Y. PUB. HEALTH LAW § 4015 (Consol. 2020) (authorizing establishment of a pediatric hospice and palliative care program); OHIO REV. CODE ANN. § 3712.06 (LexisNexis 2019) (describing requirements of pediatric respite care programs but making no mention of notification). Ohio requires many kinds of healthcare facilities to “[e]stablish a system for identifying patients or residents who could benefit from palliative care” and “[p]rovide information on palliative care to patients and residents who could benefit from palliative care[,]” but these requirements apply to hospice for all ages, making no reference to the emotional impact of hospice for one age group over another. OHIO REV. CODE ANN. § 3701.362 (LexisNexis 2019). See also VT. STAT. ANN. tit. 18, § 1871 (2020) (outlining patient rights, including the right to be informed of palliative care options, for all ages, as well as the specific pediatric right to undergo palliative care and potentially curative treatment at the same time).
there does not appear to be a legally significant difference between choices about perinatal and pediatric hospice in terms of emotional pain.

Second, even assuming arguendo that there is something uniquely emotionally distressing about an adverse fetal diagnosis that justifies special laws, it is uncertain whether abortion-triggered notification requirements will actually prevent emotional distress in a significant enough portion of the population to merit the intrusion. Most individuals seeking an abortion are already certain of their decision. If perinatal hospice-eligible individuals are uniquely susceptible to emotional distress, state-imposed attempts to second-guess the difficult decision to get an abortion may cause more emotional distress than they prevent.

In this light, consider again the woman choosing abortion from Part II.A. After deliberating heavily and coming to a difficult decision, she reaches the clinic only to be told that there is another option the state would like her to consider. While it is possible she will feel joyful at the prospect of an additional option she had not known about before, she may also feel guilty for making what she wholeheartedly believes to be the best choice for her in the face of perceived state attempts to dissuade her from it. She may feel resentful. She may feel conflicted. She may feel any number of things, many of which may be distressing in nature. Therefore, the assumption that notifying eligible individuals of perinatal hospice care will protect them from severe emotional distress is tenuous at best—not necessarily false, but not supported by enough evidence to justify it either.

CONCLUSION

Perinatal hospice notification laws address an emotionally resonant subsection of the American population: pregnant persons and their families whose wanted fetuses are diagnosed with life-limiting conditions. There are risks of harm if such laws exist, including fears of state intrusion into an intimate and painful decision for many families, questions about the ability of the affected individual to make the best possible choice when the state expresses a preference or imposes shame, and concerns about the state’s true interest in enacting such a law. There are also risks of harm if such laws do not exist, most notably the risk of preventable distress for eligible

130. See Foster et al., supra note 44, at 120; Gatter et al., supra note 44, at 81.
131. Supra Part II.A.
individuals who would have chosen perinatal hospice if they had known it existed.

Due to the serious problems with abortion-triggered notification requirements, such laws are ill-suited to furthering any permissible government interest. Abortion-triggered notification requirements do not notify the right population: they fail to include certain eligible candidates while also sometimes notifying ineligible abortion-seekers. Furthermore, they normally require notification after an eligible individual has already come to a decision about the best course of action, thereby risking improper state interference with the exercise of a constitutional right and unnecessary emotional distress to the eligible abortion-seeker. Abortion-triggered notification requirements bring into being all the risks of a perinatal hospice notification requirement while failing to deliver the intended benefits.

Diagnosis-triggered notification requirements, in contrast, fit neatly within the state’s police power as an effort to preserve life and promote best medical practices, and they minimize the potential for emotional distress by delivering the information at the time of fetal diagnosis—before the patient has come to any decision about how to proceed. Diagnosis-triggered notification requirements track well with the goals of informed consent, providing information that many individuals will find relevant to their decision while minimizing the potential for improper state influence on the outcome. Such requirements ensure that the right population of patients receives the right information at the right time.

The choice not to enact any notification requirement and leave doctors to inform patients on their own is another logical decision. While such an approach risks a lack of information to those who need it, it also avoids all of the potential negative consequences—misogynistic restrictions on women’s decision-making, infringement upon constitutional rights, and unnecessary governmental red tape—that come from state attempts to interfere with the doctor-patient relationship.

Either a diagnosis-triggered notification law or the deliberate absence of a law will serve the needs of a state effectively, and lawmakers can debate which choice is best for their constituencies. Different localities may have different needs related to perinatal hospice care. For example, some states may not have a perinatal hospice program, making notification ineffective because eligible individuals cannot access the care they have been notified about. Such a state would not benefit from a diagnosis-triggered notification law. Additionally, as perinatal hospice becomes more familiar to patients and doctors nationwide, notification requirements may become less relevant because individuals will already be aware of existing services. Nonetheless, by crafting a notification regime that aligns with legitimate state interests, states can support the needs of their residents without compromising the
integrity of the doctor-patient relationship or an individual’s freedom to make the best available choice. Such a solution, whether through a diagnosis-triggered law or no law at all, lets the state provide access to resources, then step out of the way.

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