

REVIEW ARTICLE



Navigating the post-*Dobbs* landscape: ethical considerations from a perinatal perspective

Alaina Pyle^{1,2}✉, Shannon Y. Adams^{3,4}, DonnaMaria E. Cortezzo^{5,6,7,8}, Jessica T. Fry^{3,9,10}, Natalia Henner^{3,9,10}, Naomi Laventhal¹¹, Matthew Lin¹², Kevin Sullivan^{13,14} and C. Lydia Wraight¹⁵

© The Author(s), under exclusive licence to Springer Nature America, Inc. 2024

Restrictive abortion laws have impacts reaching far beyond the immediate sphere of reproductive health, with cascading effects on clinical and ethical aspects of neonatal care, as well as perinatal palliative care. These laws have the potential to alter how families and clinicians navigate prenatal and postnatal medical decisions after a complex fetal diagnosis is made. We present a hypothetical case to explore the nexus of abortion care and perinatal care of fetuses and infants with life-limiting conditions. We will highlight the potential impacts of limited abortion access on families anticipating the birth of these infants. We will also examine the legally and morally fraught gray zone of gestational viability where both abortion and resuscitation of live-born infants can potentially occur, per parental discretion. These scenarios are inexorably impacted by the rapidly changing legal landscape in the U.S., and highlight difficult ethical dilemmas which clinicians may increasingly need to navigate.

Journal of Perinatology; <https://doi.org/10.1038/s41372-024-01884-9>

INTRODUCTION

Restrictive abortion laws have impacts reaching far beyond the immediate sphere of reproductive health, with cascading effects on clinical and ethical aspects of neonatal care, as well as perinatal palliative care. These laws have the potential to alter how families and clinicians navigate prenatal and postnatal medical decisions after a complex fetal diagnosis is made. Since the overturning of *Roe v Wade*, the legal landscape in the U.S. has been rapidly evolving, further complicating the already intricate process of prenatal decision-making (though an expansive legal analysis is beyond the scope of this paper).

Through the discussion of a hypothetical case, we will explore the nexus of abortion care and perinatal care of fetuses and infants with life-limiting conditions. We will highlight the challenges providers face due to ambiguity in the language of new laws, the increasing risk of moral distress for care teams, as well as the potential impacts of limited abortion access on families anticipating the birth of these infants, including threats to bodily autonomy. We will also examine the legally and morally fraught gray zone of gestational viability where both abortion and resuscitation of live-born infants can occur. These prenatal and postnatal scenarios are inexorably impacted by the specific legal landscape of the practice environment, which now differs by state, and highlight difficult ethical dilemmas which clinicians increasingly need to navigate.

Case part 1

During routine fetal ultrasound, a pregnant patient at 18 0/7 weeks receives a diagnosis of fetal alobar holoprosencephaly, a severely life-limiting condition. This condition occurs when the forebrain fails to develop into two hemispheres, resulting in loss of the midline structures of the brain and face, and typically leads to stillbirth or death in the first 6 months after birth [1]. After obstetric counseling about the diagnosis and prognosis, the expectant parents do not wish to continue the pregnancy. They live in a state with a total abortion ban with few exceptions for lethal fetal anomalies or health of the pregnant individual. The obstetrician is unsure whether the fetal diagnosis meets the lethal anomaly criterion and is thus unwilling to perform the abortion. The family cannot afford to travel out of state and thus continues the pregnancy. They are referred for joint consultation with palliative care and neonatology to discuss postnatal care options.

CHALLENGES OF DEFINING LETHAL FETAL CONDITIONS

“Lethal” anomaly and “futility” exceptions within individual state abortion law have highlighted challenges in the interpretation of such terms [2]. Definitions of “lethal” can include any malformation that leads to death in-utero, or those that lead to death in the newborn period either in some, most, or all cases [3]. While some

¹Department of Pediatrics, Division of Neonatology, Connecticut Children's Medical Center, Hartford, CT, USA. ²University of Connecticut School of Medicine, Farmington, CT, USA. ³Department of Pediatrics, Northwestern University Feinberg School of Medicine, Chicago, IL, USA. ⁴Department of Pediatrics, Ann & Robert H Lurie Children's Hospital of Chicago, Chicago, IL, USA. ⁵Division of Neonatal and Pulmonary Biology, Cincinnati Children's Hospital Medical Center, Cincinnati, OH, USA. ⁶Division of Pain and Palliative Medicine, Cincinnati Children's Hospital Medical Center, Cincinnati, OH, USA. ⁷Department of Pediatrics, University of Cincinnati College of Medicine, Cincinnati, OH, USA. ⁸Department of Anesthesiology, University of Cincinnati College of Medicine, Cincinnati, OH, USA. ⁹Division of Neonatology, Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, IL, USA. ¹⁰Division of Palliative Care, Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, IL, USA. ¹¹Department of Pediatrics, Michigan Medicine—University of Michigan Medical School, Ann Arbor, MI, USA. ¹²Department of Pediatrics, Pediatric Palliative Care Team, Children's National Medical Center, Washington, DC, USA. ¹³Division of Neonatology, Nemours Children's Hospital - Delaware, Wilmington, DE, USA. ¹⁴Department of Pediatrics, Sidney Kimmel Medical College at Thomas Jefferson University, Philadelphia, PA, USA. ¹⁵University of Wisconsin School of Medicine and Public Health, Madison, WI, USA. ✉email: APyle@connecticutchildrens.org

Received: 19 September 2023 Revised: 8 December 2023 Accepted: 15 January 2024

Published online: 29 January 2024

Table 1. Examples of abortion law restrictions for fetal anomalies, as of September 2023.

Florida ^a	“two physicians certify in writing that, in reasonable medical judgment, the fetus has a fatal fetal abnormality”
Georgia ^b	““Medically futile” means that, in reasonable medical judgment, an unborn child has a profound and irremediable congenital or chromosomal anomaly that is incompatible with sustaining life after birth.”
Louisiana: “exclusive list of anomalies, diseases, disorders, and other conditions that shall deem an unborn child “medically futile” ^c	achondrogenesis; anencephaly; acardia; body stalk anomaly; campomelic dysplasia; craniorachischisis; dysencephalia splanchnocystica (Meckel-Gruber syndrome); ectopia cordis; exencephaly; gestational trophoblastic neoplasia; holoprosencephaly; hydrops fetalis; iniencephaly; perinatal hypophosphatasia; osteogenesis imperfecta (type 2); renal agenesis (bilateral); short rib polydactyly syndrome; sirenomelia; thanatophoric dysplasia; triploidy; trisomy 13; trisomy 16 (fu11); trisomy 18; trisomy 22; and “a profound and irremediable congenital or chromosomal anomaly existing in the unborn child that is incompatible with sustaining life after birth in reasonable medical judgment as certified by two physicians that are licensed to practice in the State of Louisiana”
Mississippi ^d	““Severe fetal abnormality” means a life-threatening physical condition that, in reasonable medical judgment, regardless of the provision of life-saving medical treatment, is incompatible with life outside the womb.”
Utah ^e	“If the unborn child has been diagnosed with a fetal abnormality that is incompatible with life, at the time of the diagnosis, the physician shall inform the woman, both verbally and in writing, that perinatal hospice services and perinatal palliative care are available and are an alternative to abortion.”
West Virginia ^f	“The embryo or fetus is nonviable”

^a<https://m.flsenate.gov/Statutes/390.0111>.

^bOfficial Code of Georgia Annotated 16-12-141: Restrictions on the performance of abortions; availability of records; civil cause of action; affirmative defenses.

^cLouisiana Emergency Rule: Department of Health, Office of Public Health. “Conditions that Shall Deem an Unborn Child “Medically Futile.” (LAC 48:1.401). Effective Jan 27, 2023.

^dMississippi Code § 41-41-191: 41-41-191. Gestational Age Act; legislative findings and purpose; definitions; abortion limited to fifteen weeks’ gestation; exceptions; requisite report; reporting forms; professional sanctions; civil penalties; additional enforcement; construction; severability; right to intervene if constitutionality challenged.

^e<https://le.utah.gov/xcode/Title76/Chapter7A/76-7a-S201.html>.

^f<https://code.wvlegislature.gov/16-2R-3/>.

diagnoses are consistently categorized as “lethal” by pediatric and obstetric providers, such as anencephaly, bilateral renal agenesis, and thanatophoric dwarfism, an exhaustive consensus list of “lethal” diagnoses does not exist [4]. Paradigmatically, some diagnoses historically considered lethal, such as Trisomy 13 and 18, are now recognized to have significantly more variable life expectancy with multiple studies reporting that survival is possible beyond a year in 10–20% of those infants who are liveborn [5–7]. Provision of more robust medical support and evolutions in surgical techniques have led to increased survival for some infants, demonstrating that mortality curves are not static and depend on a variety of factors.

Hypoplastic left heart syndrome is another example of a severe congenital condition with a shifting prognostic consensus [8, 9]. Despite the high rate of postnatal complications and ongoing risk of mortality, the evolution of medical and surgical care alongside decreasing morbidity and steadily increasing survival rates, has resulted in ambivalence among clinicians regarding the option of postnatal non-intervention for these patients [10, 11]. Multiple other factors impact the determination of lethality including variable disease phenotypes, prenatal care logistics, parental choices regarding degree of postnatal interventions, as well as access to pediatric subspecialty care.

The terms “lethal” and “incompatible with life” fail to capture the evolving landscape in medicine and are now thought to be broadly dismissive of entire populations, showing a lack of respect for individual viewpoints and perceptions of quality of life. As a result, the medical community - perinatal palliative care specialists in particular - are shifting to the use of more thoughtful terminology, such as life-limiting or potentially life-limiting [12]. These more inclusive terms, which are often used to support

families who wish to pursue life-prolonging intervention for infants with conditions considered to be life-limiting, contribute further to the difficulty in reintroducing the term “lethal anomaly”.

The classification of fetal diagnoses as “lethal” plays a pivotal role in states with abortion exceptions for such diagnoses, but variability and opacity in how these lists are constructed highlight some of the basis for the move away from the term “futility” as well in modern bioethics. Such lists inaccurately suggest that a high degree of diagnostic precision and accuracy for “futility” is possible. Illustrative examples of current state laws are provided in Table 1. It can be argued that for some of these conditions, interventions are not physiologically “futile” since the desired effect can be achieved (i.e., mechanical ventilation to improve oxygenation). In the ongoing absence of unanimity among medical experts on the actual definition of “lethal” or “futile,” difficulties in consistently applying this standard as part of a legal framework for abortion exemptions will remain.

A NEW DIMENSION OF MORAL DISTRESS FOR NICU AND PERINATAL HOSPICE CLINICIANS

Conscientious refusal amongst clinicians has long been a part of the conversation on abortion [13, 14]. However, as the legal landscape continues to evolve, the utilization of conscientious provision, a federally protected right to choose whether to participate in services based on moral objections or religious beliefs, may become increasingly prevalent [13, 14]. Despite the reversal of *Roe v. Wade* and subsequent laws banning or restricting abortion in their state, some obstetricians continue to provide abortion care, in order to protect their patient’s reproductive autonomy, self-determination, and maternal

personhood [2, 15]. These clinicians consider abortion provision in spite of legal restrictions to be a necessary form of professional civil disobedience, declaring that to do otherwise is to threaten the health and well-being of their patients.

Though there have not yet been cases published where the provision of perinatal palliative care has been restricted, it is possible that conscientious provision of these services may become necessary if the government attempts to limit the ethically appropriate management by neonatal-perinatal clinicians. When there is a neonatal patient with severely limited life expectancy or an expectation of significant suffering and/or morbidities based on the best medical assessment, and for whom hospice care would be an ethically appropriate choice, then a legal obligation to provide invasive medical interventions *despite* parental wishes for hospice care, is at best ethically nonobligatory, and at worst in opposition to the principle of non-maleficence [16–18]. Research has shown that high-quality bereavement services and palliative care improves parent and family experiences through compassionate counseling, therapeutic communication, and shared decision making [19, 20]. Perinatal clinicians, along with their hospitals' legal and risk management teams, need to proactively discuss their unique and shared approaches to complex cases, including the possibilities of conscientious objection and professional civil disobedience, which may decrease distress in such cases with time-sensitive decision-making [15].

Although neonatologists and palliative care clinicians do not directly provide abortion care and are not faced with restriction on their ability to provide the full spectrum of reproductive care, the entire interprofessional team might experience complex and heterogeneous distress and ambiguity in the care of infants when part of the family's journey includes unsuccessful pursuit of pregnancy termination. The context of these experiences is politically and socially charged, further heightening the emotional stakes for everyone involved. Examples of specific sources of distress for clinicians involved in the perinatal and postnatal care of families with restricted access to abortion include the challenging work of supporting parents following live birth: navigating end-of-life care or decisions about life-prolonging interventions, parental guilt about having desired an abortion, or parental requests for comfort measures only for conditions when it is not ethically appropriate. Clinicians might feel a strong sense of injustice related to patients lack of access to abortion care, or discomfort in knowing that the parents sought to terminate the pregnancy. Diverging, strongly held beliefs about abortion by members of the care team might also contribute to clinician distress. Adverse outcomes for pregnant patients, for example, attributed to delays in delivery due to ambiguity about whether the maternal condition was sufficiently life-threatening might also contribute to clinician distress.

Rates of moral distress in the neonatal ICU have always been high [21–23], due to the inherent complexities and uncertainties of perinatal care, and failures in identifying and supporting value differences between parents and providers [24, 25]. Moral distress - the tension between knowing the morally correct course of action while being unable to act upon this knowledge, is distinct from an ethical dilemma, where there is uncertainty about the correct course of action [26]. There is a scarcity of validated, evidence-based interventions to decrease burn-out and moral distress in the NICU. Availability of palliative care, psychosocial support teams, and, in some cases, healthcare ethics consultation, is critical to ensure that families, neonatal ICU staff, and trainees are all well supported.

POSTNATAL HOSPICE CARE- NOT AN ALTERNATIVE TO ABORTION

Prior to recent legislative activity, families and clinicians have taken into consideration the severity of fetal anomalies, views on

quality of life, and other personal/familial factors to determine prenatal care pathways, including abortion. Outside of the context of later-stage abortions in certain states, prognostic certainty or projected illness severity was not needed to justify the medical procedure [27]. On the other hand, provision of hospice care to a liveborn infant requires an ethical justification based on the infant's diagnosis, anticipated prognosis of less than 6 months of life, and consideration of parental views on quality of life. In addition to this nuanced ethical framework for hospice care provision, neonatologists and perinatal palliative clinicians may now increasingly face navigating care for liveborn infants whose parents sought and were unable to obtain an abortion. Many pregnant patients value the opportunity to incorporate prenatal findings into their decision-making about pregnancy continuation versus termination, but this could also be seen as supporting ableism, with concerns for potential disability strongly influencing reproductive decisions [28]. A more inclusive approach could focus on providing information from the perspectives of individuals living with disabilities, as well as from their families, to provide the full picture of life for those with medical complexity.

In situations such as the case discussed above with alobar holoprosencephaly, parents may choose to pursue comfort-focused care for their child after birth, with the support of hospice services. However, it is flawed to assume that all parents, even those who considered or unsuccessfully pursued pregnancy termination, will choose to forego life-prolonging neonatal care for infants with life-limiting conditions, or that non-intervention is appropriate in all circumstances. Instead, multiple scenarios are possible. One is that these pregnancies result in the birth of infants whose lives are supported by medical technology at parental request, whether their condition is better, worse, or exactly as was anticipated before birth. The infant might have other ongoing needs for support regardless of whether they survive with chronic medical complexity. The emotional and psychological outcomes for parents are difficult to anticipate, and the subjective valuation parents place on these outcomes will likely be highly variable and should not be assumed to be uniformly negative. Parents might struggle with guilt from having once considered a termination, or trauma due to the legal odyssey of pursuing an abortion, all while parenting a sick child. Unfortunately, some parents might not be able to access perinatal hospice care, either due to geographical or logistical limitations, with 60% of all Americans dying without any hospice care [29, 30].

A more ethically complex scenario is one in which the infant is at risk for a shortened lifespan or complex medical needs (such as in cases of myelomeningocele), but for whom hospice care is not thought to be morally justified without further prognostic certainty for a markedly poor outcome. If parents request comfort measures for an infant who might otherwise survive with a low risk of morbidity, clinicians will have to navigate nuanced conversations about ethically obligatory vs permissible choices. However, previous intentions for the outcome of a *pregnancy* are not a relevant consideration for the ethically permissible course of action for an *infant*. It is also important to note that the ethical permissibility of perinatal hospice care does not necessarily equate to moral acceptability of this option from the expectant parent's perspective, when compared to life-prolonging interventions. A spectrum of considerations, including that of undue suffering for the infant after birth, emotional suffering and trauma for the family, and health considerations for the pregnant patient might have driven the decision to pursue abortion over the choice for perinatal hospice. Lastly, those parents whose infants died with hospice care might experience trauma and loss that differs from what they may have experienced following a pregnancy termination, even if hospice care was comprehensive and compassionate.

Case part 2

The pregnant patient introduced previously, carrying a fetus with alobar holoprosencephaly, is now 22 0/7 weeks gestation. She develops preterm rupture of membranes and subsequent chorioamnionitis. This is a known risk factor for maternal sepsis, which is a leading cause of maternal death worldwide [31]. Antibiotics are started but her lab work and clinical course are concerning for ongoing infection, as well as new onset renal and hepatic dysfunction. She lives in a state which allows abortion if it is to “save the life of the mother.” The staff questions whether her condition is sufficiently dangerous to meet criteria for the state’s exception to the abortion ban, which would permit expedited delivery. They delay delivery to seek input from their legal team and clinical ethics consultation teams. While the hospital does not have a written policy covering exceptions to the abortion ban, they do have a written policy for shared decision-making regarding resuscitation at the margin of gestational viability, generally accepted as the period from 22 0/7 weeks until 24 6/7 weeks. Consistent with other hospitals around the country utilizing prognostic data from large national retrospective cohort studies, the decision to resuscitate in this period falls within the zone of parental discretion. For appropriately grown infants *without* significant congenital anomalies, after extensive counseling parents may choose initiation of intensive care or hospice care in the delivery room for periviable infants.

AUTONOMY OF THE PREGNANT INDIVIDUAL AND ETHICAL FRAMEWORKS FOR PERINATAL DECISION-MAKING

In the setting of restrictive access to abortion, it is vital for clinicians to continue to uphold a model of care which centers decision-making on the autonomy of pregnant persons. Within maternal-fetal dyads there are distinct and sometimes conflicting interests for the fetus, pregnant person, dyad, and family. Obstetric ethics describes fetal interests using the concept of “fetus as patient;” one who could benefit from the care of a physician should the pregnant individual choose to proceed [32]. This ethical framework highlights the dependent status of a fetus on the pregnant individual and avoids assigning “personhood” or independent moral and/or legal status to the fetus. It is widely recognized by ethicists and clinicians that the rights of a pregnant person to bodily autonomy outweigh the obligations of others to enforce beneficence or nonmaleficence for the fetus [2, 33]. This concept can be challenging to implement in complex cases and clinicians should provide medical information, which is then placed in the context of a family’s goals and values [34–36]. Respect for maternal autonomy relies on the foundation that the pregnant individual is best situated to evaluate the risks and benefits for the fetus and the maternal-fetal dyad, and additionally has an ultimate right to bodily autonomy and integrity [37].

Abortion bans have the potential to set a new precedent of establishing fetal personhood (this term is used here to reflect a being with independent moral and legal status), by which the state may be able to increasingly regulate the actions of the pregnant individual to protect the absolute or even relative well-being of the fetus [38]. There is a significant risk for loss of trust between clinicians (which can include obstetric or neonatal providers presenting prenatal counseling) and their patients, if there were to become a requirement to report any “less than ideal” choices during a pregnancy. This disruption to the pregnant patient’s ability to openly disclose health behaviors has the potential to drastically limit the ability to provide relevant prenatal guidance and support to those who need it [37, 39, 40]. For neonatal clinicians providing antenatal counseling in states with these potential regulatory changes, families might not feel safe answering questions or sharing concerns about health behaviors that can affect fetal development, such as substance use, which

will then adversely alter effectiveness of both prenatal counseling and postnatal management [41].

While the medicolegal precedent for “life of the mother” exceptions, resting on a foundation of maternal autonomy, has previously been well established, ethical and legal challenges are becoming evident following the *Dobbs* ruling and subsequent state laws. Multiple cases have been reported on by the lay media, as well as in newly published literature [42], where clinicians are uncertain on when they can legally intervene to save a pregnant woman’s life, as well as refusals to fill life-saving prescriptions used to treat serious medical conditions, criminal charges against women who sought medical attention for miscarriages, and cases when the health of a potentially healthy twin fetus has been compromised for the benefit of the twin that is not expected to survive [43–45]. In these circumstances, the physical health of the pregnant individual and her autonomy are placed secondary to the rights of the fetus, in contradiction to the well-established maternal autonomy standard.

In comparison, the ethical frameworks most commonly relied upon by pediatricians, such as the best interest standard (BIS) or the harm principle, cannot typically be applied in cases concerning a maternal-fetal dyad, as the fetus is not the same as a neonate, and a pregnant patient may have competing or even incompatible interests with those of the fetus. In pediatrics, the BIS directs surrogate decision-makers (typically the parents) to maximize benefits and minimize harms to the child, whereas the harm principle seeks to identify a threshold of harm below which parental discretion is permitted and above which, there will be outside (typically governmental) intervention to protect the child [46–48]. In the case described above, delivery during the periviable period is recommended due to premature rupture of membranes and progressive intrauterine infection. One could argue that it would be in the best interest of the fetus to prolong gestation in order to decrease the risk for the life-threatening complications of extreme prematurity, but maintaining a pregnancy with increasing risk to the mother also risks fetal health. It is very difficult to balance potential harms in perinatal situations marked by grave uncertainty, increasing risks of stillbirth or neonatal death, and/or possible complications for the pregnant patient. There are no easy answers here, and commonly applied pediatric principles do not typically provide reliable guidance for pregnant patients.

As was the case before the *Dobbs* decision, neonatal and perinatal palliative clinicians generally have a supportive role in obstetric decision-making. Typically, these teams provide prognostic information to obstetric clinicians who might be weighing the potential risks and benefits to the maternal-fetal dyad in proceeding with delivery vs. continuing the pregnancy, as well as provide anticipatory guidance and help to expectant parents with decision-making for post-natal infant care, or in some cases about obstetric decisions. A shifting legal landscape around maternal autonomy and fetal personhood does not fundamentally alter these responsibilities, and prognostic information provided by those who will care for the infant is independent from obstetric medical decisions about whether the *pregnant patient’s condition* warrants life-saving delivery.

ETHICAL CHALLENGES IN PERIVIALITY AND HOW IT RELATES TO ABORTION

Evolving legal restrictions on reproductive care post-*Dobbs* have the potential to impact other areas of shared decision-making, as seen in the hypothetical case presented above. Due to high rates of mortality and morbidity, the periviable period is one of the ethically protected spaces wherein parents make life-or-death decisions for their child after consultation with the medical team [49–51]. The American College of Obstetricians and Gynecologists (ACOG), the American Academy of Pediatrics (AAP), and other

societies emphasize the importance of the counseling process during this challenging period [50–54]. A multidisciplinary approach addressing considerations for the pregnant patient, fetus, and family, and providing accurate, unbiased, understandable information to families is recommended. In this collaborative approach, the parental values and goals of care, the current and anticipated medical condition of the child, and any other relevant considerations are taken into account when developing a care plan [55–57].

Post-*Dobbs*, the legality of this approach is of increasing concern. In the U.S., the best interest standard is based on medical prognosis. The determination of futility for periviable or medically complex conditions diagnosed prior to delivery, is often subjective and rarely certain, requiring real-time assessment by the medical team. For some, the existing Born Alive Infant Protection Act (initially conceived as a measure to dissuade late term abortion) and other laws being proposed, threaten to supersede physician judgement and restructure the legal limit of viability [58], by establishing personhood for any infant who breathes, has a heartbeat, or any voluntary movement at birth, and requiring the provision of standard of care to those infants. However, standard of care and appropriate treatment options are determined by available evidence, and not by the presence of personhood; a framework supported by the AAP [59]. Though clinicians understandably worry about being held criminally liable for delivery room decisions during the perivable or neonatal period, legal suits are very rare, with only 15 noted in a retrospective review of all cases 1980–2016 [60].

The birth rate for medically complex infants might continue to rise, due to state laws restricting reproductive autonomy. Clinicians might face more high stakes decisions regarding the resuscitation and care of critically ill newborns or those with known severe anomalies. Currently, 18 states have “born alive” protections which require utilizing “skills” to preserve the life of a neonate, and many others have proposed similar bills [61]. These laws could potentially require care to be provided to previable infants and those with severely life-limiting conditions, regardless of parental wishes or established standards of care [50, 62, 63]. Taken literally, bills mandating resuscitation for infants with a severely life-limiting diagnosis or at the edge of gestational viability erroneously assume that these interventions provide a real chance of long-term survival and have minimal risk to the neonate and family, which is untrue in many cases. These complex and difficult decisions should only be made by the family with the assistance of clinicians who have the knowledge and training to understand the implications of interventions and navigate goals of care [50, 63, 64].

When clinicians seek to understand the pregnant patient’s wishes in situations of uncertainty, they are correctly respecting the zone of parental decision-making [49]. This established framework indicates that if a treatment is clearly beneficial, it is obligatory to provide, and if parents wish to forego this treatment, there should be legal and ethical review. Treatments thought to be absolutely futile in a physiologic sense should be withheld in all cases. Those treatments with an extremely low likelihood of achieving the desired outcome, previously described as physiologically futile, now frequently described as “potentially non-beneficial” to avoid the emotionally charged context around the term “futile”, offer some moral space for parents to pursue them, if they are not expected to cause excessive harm. During the perivable period, medical interventions are of uncertain benefit and are thus permissible, but not obligatory. While using a prognosis-based framework to determine the zone of parental decision-making related to periviable provides clarity, there are also inherent challenges, including limits in the available data [64–68]. Ideally, a national consensus should be reached as to the limits of parental discretion at periviable that acknowledges the limitations of

using gestational age alone as an anchor for decision-making, and parents should always be given honest information to help guide discussions and discretion as to how involved they wish to be in decisions [69].

The hypothetical case above, with fetal holoprosencephaly, has the added dimension of a serious congenital anomaly. Anomalies that co-occur with extremely preterm birth generally make it difficult or impossible to provide accurate, epidemiologically derived prognostic information for expectant parents, and require reconsideration of the spectrum of choices being offered. If the infant has a condition for which perinatal hospice was offered when term birth was anticipated, this option remains an ethically permissible option in the setting of prematurity; however, preterm birth might require thoughtful revision of the birth plan. In some cases, a congenital anomaly with a good prognosis for term infants might impart a considerably worse prognosis for preterm infants and widen the zone of parental discretion. Finally, in some cases, the additive effects of a congenital condition and prematurity might significantly decrease the success of resuscitation at preterm gestational ages otherwise considered to be “viable”, moving this option towards impermissible. The impermissible-permissible-obligatory (IPO) framework provides a spectrum to help providers determine the zone of parental discretion in such contexts [69].

CONCLUSION

Restricted access to elective and medically indicated pregnancy termination has significant downstream effects on pregnant patients, infants, families, and healthcare teams as well as non-trivial impacts on postnatal care and psychosocial outcomes. Clinicians who already experience a heavy burden of moral distress are likely to face additional stressors as they face new challenges created by lack of access to pregnancy termination for fetal anomalies, and complex scenarios following live births, especially those at the margin of gestational viability. As the legal landscape continues to evolve, healthcare systems need to proactively use well established ethical frameworks to create consensus guidelines for these complex cases and build up resources across the spectrum of perinatal and neonatal care. Clinicians must familiarize themselves with current legal nuances in their state, and hospital ethics committees and legal teams should work with the medical teams, to provide clarity and support needed for the provision of medically appropriate care. Palliative care and psychosocial support services will be especially critical in mitigating the impact of limited access to the full spectrum of reproductive healthcare, so hospital systems should dedicate the necessary funding to improve the provision of these critical resources.

REFERENCES

1. Tekendo-Ngongang C, Muenke M, Kruszka P. Holoprosencephaly Overview. 2000 Dec 27 [Updated 2020 Mar 5]. In: Adam MP, Mirzaa GM, Pagon RA, et al. editors. GeneReviews® [Internet]. Seattle (WA): University of Washington, Seattle; 1993. <https://www.ncbi.nlm.nih.gov/books/NBK1530/>.
2. Grünebaum A, Moreno JD, Esq SP, Chervenak FA. Counseling for the option of termination of pregnancy for severe fetal anomalies in light of the recent Supreme Court ruling to remove the constitutional right to an abortion. *Semin Fetal Neonatal Med.* 2023;28:101441.
3. Wilkinson DJ, Thiele P, Watkins A, De Crespigny L. Fatally flawed? A review and ethical analysis of lethal congenital malformations. *BJOG.* 2012;119:1302–8.
4. Wilkinson D, de Crespigny L, Xafis V. Ethical language and decision-making for prenatally diagnosed lethal malformations. *Semin Fetal Neonatal Med.* 2014;19:306–11.
5. Nelson KE, Rosella LC, Mahant S, Guttmann A. Survival and surgical interventions for children with trisomy 13 and 18. *JAMA.* 2016;316:420–8.
6. Boghossian NS, Hansen NI, Bell EF, et al. Mortality and morbidity of VLBW infants with trisomy 13 or trisomy 18. *Pediatrics.* 2014;133:226–35.

7. Meyer RE, Liu G, Gilboa SM, et al. Survival of children with trisomy 13 and trisomy 18: a multi-state population-based study. *Am J Med Genet.* 2016;170a:825–37.
8. Yabrodi M, Mastrogiacomo C. Hypoplastic left heart syndrome: from comfort care to long-term survival. *Pediatr Res.* 2017;81:142–9.
9. Metcalf MK, Rychik J. Outcomes in hypoplastic left heart syndrome. *Pediatr Clin North Am.* 2020;67:945–62.
10. Kon AA, Prsa M, Rohlicek CV. Choices doctors would make if their infant had hypoplastic left heart syndrome: comparison of survey data from 1999 and 2007. *Pediatr Cardiol.* 2013;34:348–53.
11. Yates AR, Hoffman TM, Shepherd E, Boettner B, McBride KL. Pediatric subspecialist controversies in the treatment of congenital heart disease in trisomy 13 or 18. *J Genet Couns.* 2011;20:495–509.
12. Macauley RC. The limits of “life-limiting”. *J Pain Symptom Manag.* 2019; 57:1176–81.
13. Church Amendments, 42 U.S.C. 300a-7. (1973) chrome-extension://efaidnbnmn-nibpcjpcglcfeindmkaj/<https://www.hhs.gov/sites/default/files/ocr/civilrights/understanding/ConscienceProtect/42usc300a7.pdf>.
14. Harris L. Recognizing conscience in abortion provision. *N. Engl J Med.* 2012;367:981–3.
15. Wynia MK. Professional civil disobedience - medical-society responsibilities after Dobbs. *N. Engl J Med.* 2022;387:959–61.
16. Guimarães H, Rocha G, Bellieni C, Buonocore G. Rights of the newborn and end-of-life decisions. *J Matern Fetal Neonatal Med.* 2012;25:76–78.
17. Luce JM, Alpers A. Legal aspects of withholding and withdrawing life support from critically ill patients in the United States and providing palliative care to them. *Am J Respir Crit Care Med.* 2000;162:2029–32.
18. Benini F, Papadatou D, Bernadà M, et al. International standards for pediatric palliative care: from IMPaCCT to GO-PPaCS. *J Pain Symptom Manag.* 2022;63:e529–43.
19. Cortezzo DE, Ellis K, Schlegel A. Perinatal palliative care birth planning as advance care planning. *Front Pediatr.* 2020;8:556.
20. Wool C, Catlin A. Perinatal bereavement and palliative care offered throughout the healthcare system. *Ann Palliat Med.* 2019;8:522–29.
21. Mills M, Cortezzo DE. Moral distress in the neonatal intensive care unit: what is it, why it happens, and how we can address it. *Front Pediatr.* 2020;8:581.
22. Prentice T, Janvier A, Gillam L, Davis PG. Moral distress within neonatal and paediatric intensive care units: a systematic review. *Arch Dis Child.* 2016;101:701–8.
23. Prentice TM, Gillam L, Davis PG, Janvier A. The use and misuse of moral distress in neonatology. *Semin Fetal Neonatal Med.* 2018;23:39–43.
24. Guttmann K, Flibotte J, Seitz H, Huber M, DeMauro SB. Goals of care discussions and moral distress among neonatal intensive care unit staff. *J Pain Symptom Manag.* 2021;62:529–36.
25. Kukora SK, Boss RD. Values-based shared decision-making in the antenatal period. *Semin Fetal Neonatal Med.* 2018;23:17–24.
26. Prentice TM, Gillam L. Can the ethical best practice of shared decision-making lead to moral distress? *Bioethical Inq.* 2018;15:259–68.
27. Davis MF. The state of abortion rights in the US. *Int J Gynaecol Obstet.* 2022;159:324–9.
28. Mukherjee D, Tarsney PS, Kirschner KL. If not now, then when? Taking disability seriously in bioethics. *Hastings Cent Rep.* 2022;52:37–48.
29. Nelson KE, Wright R, Peeler A, Brockie T, Davidson PM. Sociodemographic disparities in access to hospice and palliative care: an integrative review. *Am J Hosp Palliat Care.* 2021;38:1378–90.
30. Morrison RS, Augustin R, Souvanna P, Meier DE. America’s care of serious illness: a state-by-state report card on access to palliative care in our nation’s hospitals. *J Palliat Med.* 2011;14:1094–6.
31. Society for Maternal-Fetal Medicine (SMFM), Shields AD, Plante LA, Pacheco LD, Louis JM, SMFM Publications Committee. Electronic address: pubs@smfm.org. society for maternal-fetal medicine consult series #67: maternal sepsis. *Am J Obstet Gynecol.* 2023;229:B2–19.
32. Chervenak FA, McCullough LB. Ethical dimensions of the fetus as a patient. *Best Pr Res Clin Obstet Gynaecol.* 2017;43:2–9.
33. American College of Obstetrics and Gynecology. ACOG Committee Opinion No. 390, December 2007. Ethical decision making in obstetrics and gynecology. *Obstet Gynecol.* 2007;110:1479–87.
34. Mercurio MR. Pediatric obstetrical ethics: medical decision-making by, with, and for pregnant early adolescents. *Semin Perinatol.* 2016;40:237–46.
35. Chervenak FA, McCullough LB, Brent RL. The professional responsibility model of obstetrical ethics: avoiding the perils of clashing rights. *Am J Obstet Gynecol.* 2011;205:315.e311–5.
36. Burcher P. The Ulysses contract in obstetrics: a woman’s choices before and during labour. *J Med Ethics.* 2013;39:27–30.
37. Minkoff H, Ecker J. Balancing risks: making decisions for maternal treatment without data on fetal safety. *Am J Obstet Gynecol.* 2021;224:479–83.
38. Manninen B. A critical analysis of Dobbs v. Jackson Women’s Health Organization and the consequences of fetal personhood. *Camb Q Healthc Ethics.* 2023;32:357–67.
39. Harris LH. Navigating loss of abortion services - a large academic medical center prepares for the overturn of Roe v. Wade. *N. Engl J Med.* 2022;386:2061–4.
40. Committee Opinion No. 664. Refusal of medically recommended treatment during pregnancy. *Obstet Gynecol.* 2016;127:e175–182.
41. Paltrow LM, Harris LH, Marshall MF. Beyond abortion: the consequences of overturning Roe. *Am J Bioeth.* 2022;22:3–15.
42. Nambiar A, Patel S, Santiago-Munoz P, Spong CY, Nelson DB. Maternal morbidity and fetal outcomes among pregnant women at 22 weeks’ gestation or less with complications in 2 Texas hospitals after legislation on abortion. *Am J Obstet Gynecol.* 2022;227:648–50.
43. Weinberg T and Kite A. 2022. Missouri doctors fear vague emergency exception to abortion ban puts patients at risk. Missouri Independent/Kansas Reflector. Available at: <https://kansasreflector.com/2022/07/05/missouri-doctors-fear-vague-emergency-exception-to-abortion-ban-puts-patients-at-risk/>. Accessed June 21, 2023.
44. Rath L. Arthritis Foundation. June 30, 2022. “New Barrier to Methotrexate for Arthritis Patients”. Available at: <https://www.arthritis.org/about-us/news-and-updates/new-barrier-to-methotrexate-for-arthritis-patients>. Accessed June 21, 2023.
45. McCullough, J. The Texas Tribune. April 10, 2022. “After pursuing an indictment, Starr County district attorney drops murder charge over self-induced abortion”. Available at: <https://www.texastribune.org/2022/04/10/starr-county-murder-charge/>. Accessed June 21, 2023.
46. Katz AL, Webb SA, Committee on Bioethics. Informed consent in decision-making in pediatric practice. *Pediatrics.* 2016;138:e20161485.
47. Janvier A, Leblanc I, Barrington KJ. The best-interest standard is not applied for neonatal resuscitation decisions. *Pediatrics.* 2008;121:963–9.
48. Diekema D. Parental refusals of medical treatment: the harm principle as threshold for state intervention. *Theor Med Bioeth.* 2004;25:243–64.
49. Wilkinson D. Who should decide for critically ill neonates and how? The grey zone in neonatal treatment decisions. In: McDougall R, Delany C, Gillam L, eds. *When Doctors and Parents Disagree: Ethics, Paediatrics & the Zone of Parental Discretion.* Sydney (AU): The Federation Press; 2016. June 20.
50. American College of Obstetricians and Gynecologists; Society for Maternal-Fetal Medicine. *Obstetric Care consensus No. 6: Periviable Birth.* *Obstet Gynecol.* 2017;130:e187–99.
51. Cummings J, Committee on Fetus and Newborn. Antenatal counseling regarding resuscitation and intensive care before 25 weeks of gestation. *Pediatrics.* 2015;136:588–95.
52. Lemyre B, Moore G. Counselling and management for anticipated extremely preterm birth. *Paediatr Child Health.* 2017;22:334–41.
53. Raju TNK, Mercer BM, Burchfield DJ, Joseph GF Jr. Periviable birth: executive summary of a joint workshop by the Eunice Kennedy Shriver National Institute of child health and human development, society for maternal-fetal medicine, American Academy of Pediatrics, and American College of Obstetricians and Gynecologists. *Obstet Gynecol.* 2014;123:1083–96.
54. Leuthner SR. Borderline viability: controversies in caring for the extremely premature infant. *Clin Perinatol.* 2014;41:799–14.
55. Gillam L, Wilkinson D, Xafis V, Isaacs D. Decision-making at the borderline of viability: who should decide and on what basis? *J Paediatr Child Health.* 2017;53:105–11.
56. Lantos JD. Ethical problems in decision making in the neonatal ICU. *N. Engl J Med.* 2018;379:1851–60.
57. Arzuaga BH, Lee BH. Limits of human viability in the United States: a medicolegal review. *Pediatrics.* 2011;128:1047–52.
58. Sayeed SA. Baby doe redux? The department of health and human services and the born-alive infants protection act of 2002: a cautionary note on normative neonatal practice. *Pediatrics.* 2005;116:e576–85.
59. American Academy of Pediatrics Committee on Fetus and Newborn, Bell EF. Noninitiation or withdrawal of intensive care for high-risk newborns. *Pediatrics.* 2007;119:401–3.
60. Muniraman H, Cascione M, Ramanathan R, Nguyen J. Medicolegal cases involving periviable births from a major United States legal database. *J Matern Fetal Neonatal Med.* 2018;31:2043–9.
61. Pro-Life Laws in the United States, <https://www.frc.org/prolifemaps> (2022).
62. MacDonald H, American Academy of Pediatrics Committee on Fetus and Newborn. Perinatal care at the threshold of viability. *Pediatrics.* 2002;110:1024–7.
63. Ladhani NNN, Chari RS, Dunn MS, Jones G, Shah P, Barrett JFR. No. 347-obstetric management at borderline viability. *J Obstet Gynaecol Can.* 2017;39:781–91.
64. Arnold C, Tyson JE. Outcomes following periviable birth. *Semin Perinatol.* 2014;38:2–11.

65. Dupont-Thibodeau A, Barrington KJ, Farlow B, Janvier A. End-of-life decisions for extremely low-gestational-age infants: why simple rules for complicated decisions should be avoided. *Semin Perinatol.* 2014;38:31–7.
66. Nadroo AM. Ethical dilemmas in decision making at limits of neonatal viability. *J IMA.* 2011;43:188–92.
67. Brunkhorst J, Weiner J, Lantos J. Infants of borderline viability: the ethics of delivery room care. *Semin Fetal Neonatal Med.* 2014;19:290–5.
68. Mercurio MR. The ethics of newborn resuscitation. *Semin Perinatol.* 2009;33:354–63.
69. Mercurio MR, Cummings CL. Critical decision-making in neonatology and pediatrics: the I-P-O framework. *J Perinatol.* 2021;41:173–8.

ACKNOWLEDGEMENTS

The authors would like to thank the Children's Hospital Neonatal Consortium and the Palliative Care and Ethics (PACE) Focus Group, for providing the original forum which brought together this author group.

AUTHOR CONTRIBUTIONS

AP participated in manuscript conception, design, preparation, critical editing, and development of the table. SYA, DEC, JTF, NH, ML, KS, CLW participated in manuscript conception, design, preparation, and critical editing. NL critically reviewed and edited

the manuscript, provided additional expertise on neonatal bioethics. All authors reviewed and approved the final version of the manuscript.

COMPETING INTERESTS

The authors declare no competing interests.

ADDITIONAL INFORMATION

Correspondence and requests for materials should be addressed to Alaina Pyle.

Reprints and permission information is available at <http://www.nature.com/reprints>

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Springer Nature or its licensor (e.g. a society or other partner) holds exclusive rights to this article under a publishing agreement with the author(s) or other rightsholder(s); author self-archiving of the accepted manuscript version of this article is solely governed by the terms of such publishing agreement and applicable law.