

# Statutory Restrictions on Advance Care Planning and Pregnancy

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**Honoring a person's wishes** at the end of life is widely recognized as profoundly important to humane, ethical care.<sup>1</sup> To that end, efforts to help individuals make their preferences about end-of-life care known have involved advance care planning, including the completion of advance directives and identification of a surrogate decision maker. Yet, in many jurisdictions in the United States, one condition invalidates a patient's wishes or efforts on the part of surrogates to honor them: pregnancy.

In this issue of *JAMA*, DeMartino and colleagues<sup>2</sup> describe state statutes governing treatment decisions for incapacitated pregnant women, as well as official state advance directive documents, as of February 2019. The authors found that 30 states restricted decisions to withdraw or withhold life support from women who are pregnant, either by invalidating their advance directives, restricting the decisions of their surrogate decision makers, or both. Of 28 states with statutory pregnancy restrictions, these restrictions were not disclosed in 68% of official advance directive forms.

The complexities of such laws were highlighted in 2014. A young woman named Marlise Muñoz, 14 weeks pregnant, collapsed on her kitchen floor because of what later was determined to be a massive pulmonary embolism.<sup>3</sup> She was pronounced brain-dead at the hospital. Her husband and family requested removal of support, believing that doing so would have been what Marlise wanted. Hospital lawyers intervened, citing the Texas law that prohibits withdrawal of support from a person who is pregnant. Her husband sued, and 2 months later, support was removed and Marlise and her undelivered fetus were finally laid to rest.

The Muñoz case turned not on the ethics nor the constitutionality of the Texas law but on a legal technicality—that the law was never meant to apply to a person who is already dead (as opposed to being alive but incapacitated, as in a persistent vegetative state). But the ethics are important, and are what make the regulations described by DeMartino et al concerning on at least 3 counts.

First, the restrictions make exception to the priority given to self-determination, bodily integrity, and freedom from unwanted medical intervention. In addition, they do so in a circumstance—the end of life—in which such priorities are considered sacrosanct and for *all people*.<sup>1</sup> Advance directives are meant to safeguard an individual's preferences and to guard against the likelihood that the priorities of others, such as the imperative to treat, conflicts of conscience,

or financial considerations, do not supersede those of the dying person.<sup>4</sup> Such directives also enable families to make decisions for loved ones that are consistent with the affected person's core beliefs.<sup>5</sup> Pregnancy restrictions marginalize a woman's interests and devalue the importance of her role as narrator of her own life.

It is the presence of the fetus—and the state's interest in its life—that prompt a challenge to ethical priorities when a pregnant woman is dying. Issues involving a fetus are always complex, yet when a person's end-of-life wishes are concerned, the calculus is clear. As legal scholars have emphasized,<sup>6</sup> restrictions on treatment decisions for incapacitated pregnant women cannot be justified *before* fetal viability, when a woman still has a legal right to terminate her pregnancy. Even in the case of 2 separate persons, constitutional and common law have recognized the rights of adults to refuse breaches of bodily integrity, even those that would save the life of another.<sup>6</sup> In medicine, explicit consent for organ donation is required,<sup>7</sup> whether the donor is alive or dead, whether the beneficiary is a stranger or a beloved child. In addition, forced intervention in the context of pregnancy is condemned by professional organizations.<sup>8</sup> It has also met with legal censure, most notably in the 1987 landmark ruling, *in re A.C.*, in which a federal appeals court vacated a lower court ruling after it had authorized a forced cesarean delivery in a young woman dying of cancer (she and her child both died). In its opinion, the court endorsed the primacy of respect for bodily integrity, offering that the lower court had “erred in subordinating [the woman's] right to bodily integrity in favor of the state's interest in potential life.”<sup>9</sup>

Second, the lack of transparency is a concern. As DeMartino et al documented,<sup>2</sup> pregnancy restrictions are largely hidden from view, ensconced in statutes but not disclosed in the majority of state advance directive forms. This stands in contrast to the emphasis on transparency otherwise characterizing the approach to advance care planning. For example, federal requirements compel all institutions participating in Medicare or Medicaid to provide written information regarding a person's legal rights to make decisions concerning medical care, to refuse treatment, and to formulate advance directives.<sup>10</sup> To the extent that state advance directive documents make no mention of the pregnancy restrictions, they manifest false assurance and also deny women the knowledge they would need to advocate for their own future interests at a time when they have the capacity to do so.

Third, the restrictions create a dilemma for physicians who may be forced to choose between breaking the law and



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abandoning their ethical duties to their patient—the woman who is pregnant—not only by violating her end-of-life wishes but potentially by inflicting harm and prolonging suffering. Only 5 of the 28 restrictive statutes indicate that life-sustaining therapies may be withdrawn if they cause undue pain that cannot be alleviated by medication.

As made vivid by the Muñoz case, restricting advance directives in pregnancy can only be accomplished by viewing women as less than persons, potentially reducing them to “fetal containers.”<sup>11</sup> To consider whether an “ethical balance”<sup>2</sup> has been struck is to ask the wrong question, to pit the interests of the woman against those of the fetus rather than considering them as an integrated unit that includes a person whose rights to bodily integrity are inviolable.

Instead, the question is how can physicians support women, especially those facing the end of life, in a political and legal context that is increasingly hostile to their interests?<sup>12</sup> Important efforts include challenging restrictive statutes, updating state advance directives to prompt pregnancy-specific wishes, and, where restrictions are in place, explicitly disclosing and addressing the contingency of pregnancy in advance care planning discussions. It is women who should decide—and their core values that should guide—whether and under what circumstances pregnancy would be a reason to delay their death, and when it would not. The detailed analysis offered by DeMartino et al, as concerning as it is, represents an important step toward ensuring that these most basic human entitlements are upheld.

#### ARTICLE INFORMATION

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