



# MAKING WOMEN PAY

the Hidden  
Costs of  
Fetal  
Rights

explicitly regulating adults' consent to medical treatment. Georgia is one state that does have such a law, even though Georgia is also one of the states that has authorized forcing unwanted procedures on a pregnant woman. The "Georgia Medical Consent Law of 1971" states that "nothing contained in this chapter shall be construed to abridge any right of a person 18 years of age or over to refuse to consent to medical and surgical treatment as to his own person" (Ga. Code Ann. § 31-9-7). This law played no part in the *Jefferson* case, which relied primarily on a misreading of *Roe v. Wade*. That court might have found persuasive an argument that the treatment was not "as to [Jefferson's] own person" but to that of her autonomous fetus.

No state has enacted any law that explicitly deprives competent, pregnant women of the right to choose and refuse medical treatment, but there has been a striking trend to deprive incompetent pregnant women of their rights in the area of living wills. California passed the nation's first living will law in 1976. By 1992, forty-six other states and the District of Columbia followed suit. Almost all of the thirty-seven states that specifically address pregnant women in their laws restrict women's decisions. Fully thirty-four of thirty-seven give pregnant women less authority to decide their fate than any other person signing a living will.

The purpose of a living will is to allow people to specify in advance what kinds of life-sustaining treatments they would want in the event that they are injured or develop a terminal illness and can no longer make and communicate decisions for themselves. A living will differs from a health care proxy or durable power of attorney in that the patient's own instructions govern; proxies are people designated by the patient to make decisions for them once they can no longer do so for themselves. I have focused on living will legislation because it reveals most sharply the conflict between pregnant women and the state over who gets to make life and death decisions.

Utah's law, ironically called the "Personal Choice and Living Will Act," spells out what is at stake in living will laws:

Developments in medical technology make possible many alternatives for treating medical conditions and make possible the unnatural prolongation of death. *Terminally ill persons should have the clear legal choice to be spared unwanted life-sustaining procedures, and be permitted to die with a maximum of dignity and a minimum of pain. In recognition of the dignity and privacy which all persons are entitled to expect, [the Legislature intends to] protect the right of individuals to refuse to be touched or treated in any manner without their willing consent.* (Utah Code Ann. § 75-2-1102; my emphasis)

Table 5.1. Pregnancy provisions in living will laws as of December 31, 1992

Provision	States
Women decide	Arizona, Georgia (only until viability), New Jersey
Silent on pregnancy	District of Columbia, Florida, Louisiana, Maine, New Mexico, North Carolina, Oregon, Tennessee, Vermont, West Virginia
Directive invalidated:	
If live birth is probable	Alaska, Colorado, Montana, Nebraska, Nevada, Ohio, Rhode Island
If live birth is possible; but treatment can be discontinued if it will harm or inflict pain on the woman	Kentucky, North Dakota, Pennsylvania, South Dakota
If live birth is possible	Arkansas, Illinois, Iowa, Minnesota
Automatically invalidated	Alabama, California, Connecticut, Delaware, Hawaii, Idaho, Indiana, Kansas, Maryland, Mississippi, Missouri, New Hampshire, Oklahoma, South Carolina, Texas, Utah, Virginia, Washington, Wisconsin, Wyoming
No living will law	Massachusetts, Michigan, New York

Of the forty-eight states that have living will laws, only three (6 percent) explicitly allow a woman to specify whether to carry out her instructions if she is pregnant at the time she becomes incapacitated, and in Georgia her instructions apply only before viability. Eleven states are silent on pregnancy (23 percent), leaving the question of what to do open to interpretation. The remaining thirty-four states (71 percent) all compromise or eliminate pregnant women's right to die. Of these, fifteen (31 percent of the total) require that life-sustaining procedures be continued if it is either "possible" or "probable" that the fetus could develop to the point of live birth (the statutes almost never define these terms), and nineteen (40 percent of the total) invalidate pregnant women's directives altogether, prohibiting them from having any force or effect "during the course of the pregnancy." Utah, despite its eloquence, is one of these states. Only Pennsylvania specifies that the state will pay the costs for keeping a pregnant woman alive against her wishes (20 Pa. C.S.A. § 5414) (Table 5.1).

Perhaps the most insidious thing about these statutes is that they never acknowledge the way they define pregnant women out of their guarantees. All living will laws define which people count as "qualified patients" for purposes of the law. Alabama's definition is typical: "A patient, who has

executed a declaration in accordance with this chapter and who has been diagnosed and certified in writing to be afflicted with a terminal condition by two physicians who have personally examined the patient, one of whom shall be the attending physician" (Ala. Code § 22-8A-3 [5]). Also typical is the following proviso buried in another section of the law: "The declaration of a qualified patient diagnosed as pregnant by the attending physician shall have no effect during the course of the qualified patient's pregnancy" (Ala. Code § 22-8A-4 [a]). Nowhere is this disjuncture noted, that the pregnant woman is twice referred to as a qualified patient and yet she has just been disqualified.

To give women fair notice, "qualified patients" must be defined as those who are not pregnant women. The term *incompetent* must include all pregnant women, or pregnant women with possibly viable fetuses, as determined by each state. Perhaps the most jarring example of this blind spot is in the California law's provision on patient self-determination, which was amended in 1991 to *exclude* pregnant women (Ca. Health & Safety Code § 7189.5 [c]). Because the mere presence of an embryo or fetus overrides a pregnant woman's explicit instructions, pregnant women are deprived of the rights of the terminally ill, cannot exercise personal choice, cannot have natural deaths, or die with dignity.<sup>16</sup>

James Hoefler and Brian Kamoie note that the high level of legislative activity in this area is somewhat deceptive. Most states, they argue, enact narrow measures that do not deal with the complexities of the right to die that state courts have been grappling with and encouraging legislatures to address. This narrowness of scope makes it all the more remarkable that so many states have seen fit to regulate pregnant women's exercise of the right to die (Hoefler and Kamoie 1992, 362). Many states have based their living will laws on the model law, which imposes stricter restrictions on pregnant women's decisions in each of its three versions (*Uniform Laws Annotated* 1994). Hoefler and Kamoie attribute the restrictions on pregnant women to two things—the development of anti-abortion attitudes in state legislatures and the active lobbying by anti-abortion forces. Living will laws have been passed with very little interest-group activity by potentially interested groups, such as the elderly, but Catholic and right-to-life forces have been persistent and effective in influencing most of this legislation throughout the country (Hoefler and Kamoie 1992, 364). Feminist advocates presumably were less effective, or else were engaged in other political struggles.

<sup>16</sup> See, for example, the Alaska Rights of the Terminally Ill Act, the Alabama Natural Death Act, the Delaware Death with Dignity Act, and the Utah Personal Choice and Living Will Act.

A Washington woman and her doctor filed the only known court challenge to the exclusion of pregnant women from a living will law. Joann Lynn DeNino altered the living will to reflect her wishes that it should apply if she were to become terminally ill or disabled while pregnant; Washington's law automatically invalidates pregnant women's directives. When she asked her doctor to place it in her file, he refused, saying he feared civil or criminal liability for carrying out instructions contrary to the state's Natural Death Act. The trial court found that the pregnancy exclusion unconstitutionally violated the right to privacy, but the state supreme court reversed that decision. The high court essentially dismissed the case on the grounds that there was no controversy to resolve, as DeNino was neither pregnant nor terminally ill at the time. Three justices dissented from the majority opinion, arguing that if these issues could not be addressed once a woman drafted a living will, then they never would be, because a terminally ill pregnant woman would almost certainly die before the courts could resolve her case. The dissent also argued that the majority underestimated the public importance of the issue, which put all physicians at risk if they follow a patient's altered living will, and which affects the rights of all women of childbearing age (*DeNino v. State Ex Rel. Gorton* 1984).

An analysis of right-to-die cases in the absence of living wills revealed significant gender disparities in the adjudication of cases. The researchers found that courts treated evidence of women's preferences as emotional and unreflective, and hence dismissed it, while treating evidence of men's preferences as actual decisions needing to be respected. Courts were far more likely to delegate the decision about a woman patient to family or medical personnel than to use substituted judgment to reach the woman's own decision. The judges' gender-biased reasoning in right-to-die cases did not stem from particular assumptions about pregnant women, as there is no evidence that any of the women was pregnant, but reflected widespread assumptions about women in general (Miles and August 1990).

In limiting pregnant women's health care decisions, legislatures seem to be following the lead of the medical profession. Rosalind Ladd argues that the profession shares a pervasive presumption that women in labor are not competent to give consent. She argues that the broadly worded consent forms that pregnant women are required to sign in order to be admitted to the hospital for childbirth assume that pregnant women lose their competence the minute they walk in the door. Rather than constituting informed consent, these blanket forms amount to a waiver of the right to decide anything at all after admission, and they deny the value of a woman's actual experience in reaching an informed decision about the need for pain medication or other measures that doctors typically regard

women in labor as being too emotional to make. People undergoing elective surgery or participating in medical research are also required to give their consent prior to the event, yet they can opt out if they decide to, whereas pregnant women cannot decide to defer labor and birth. "Pre-consent is in a sense," Ladd concludes, "more coercive for them than for others" (1989, 39).

The court decisions, legislation, and research all demonstrate that, compared with men, women are not treated equally as medical patients and do not have self-determination. The current medical and political trends to aggrandize the fetus, seeking to give fetuses rights of their own in opposition to pregnant women, worsen the inequality. Women are not equal to men in terms of patient rights, and they now risk inequality with their own fetuses.

### Public Opinion

What do people think about these developments? It is difficult to gauge public opinion about how perceived conflicts between pregnant women and fetuses should be resolved. There has been less public discourse about this issue than about either "fetal protection policies" in the workplace or the prosecution of pregnant women for taking drugs, as measured by high court opinions, government hearings, or news coverage and editorials. I identified only one public opinion poll that addressed pregnant women as medical decision makers. Conducted by Gallup for a health magazine, the telephone survey questioned one thousand adults on medical ethics (*Hippocrates* 1988). All such polls help to shape public opinion as well as to measure it, by the way they frame the issues and limit permissible responses, and later when the media report them as fact. Still, the survey demonstrates that many Americans hold women responsible for fetal health.

When asked, "Should a woman be held legally liable for harm done to her fetus because she refused to have a cesarean birth as recommended by her doctor?" 42 percent of respondents said yes, 41 percent said no, and 17 percent didn't know. To the follow-up question, "Should a woman be held legally liable for harm done to her fetus because she refused to let doctors operate on the fetus while it was still in the womb?" 32 percent said yes, 46 percent said no, and 22 percent didn't know. Finally, when asked whether a woman should "be held legally liable for harm done to her fetus because she chose to have surgery that was necessary to save her own life," 26 percent said yes, 63 percent said no, and 11 percent didn't know.

These responses yield two important conclusions. First, large numbers of the American public think it is appropriate to second-guess pregnant women's health care decisions and to punish them when something goes wrong. The results indicate a substantial willingness to hold women accountable for refusing treatment that doctors recommend on behalf of the fetus. Note that the question wording—"cesarean birth"—obscures the fact that a cesarean is major surgery. The question on fetal surgery met with the most uncertainty, probably because these techniques are still highly experimental and unfamiliar. Even so, one-third of those polled believe that a woman should be held liable for refusing to have this kind of surgery. Finally, one-fourth of respondents feel that women should be held liable for "choosing" surgery needed to save their own lives. This finding suggests that people commonly define motherhood as synonymous with selflessness and raises the following question: If the pregnant woman successfully discharges her maternal duty and sacrifices her life for the fetus, then who will mother it after it is born?

The second conclusion is perhaps the more politically important one. A large number of respondents said they did not know how to answer the questions: between 17 and 26 percent on every question. This significant segment of the American public is still forming its opinions, and thus can be influenced by arguments on either side, and perhaps more important, by courts' actions. If courts continue to take away women's power to make decisions, and there is no concerted protest, then people who are undecided are more likely to lean toward accepting state intervention in women's medical care.

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### Implications for the Future

Pregnant women's autonomy in the medical realm continues to be threatened by forced interventions and by developments in HIV policy in the post-1992 period. Late in 1993 a forced cesarean case once again made headlines. Tabita Bricci, a twenty-two-year-old Pentecostal Christian, refused to let doctors induce delivery or perform a cesarean when they predicted that her thirty-seven-week-old fetus would suffer brain damage or die from inadequate oxygen. The hospital contacted the Illinois state attorney's office, and Cook County Public Guardian Patrick Murphy (the county's lawyer for children) sought permission from the juvenile court to order Bricci to have the cesarean. When the juvenile court denied the order, Murphy appealed, arguing that the court must decide whether the viable fetus was "just a mass of human cells or a real life form being kept prisoner in a mother's womb" because of "primitive beliefs" (quoted in