Risky Business

To the Editor: In their very fine "Risk and the Pregnant Body" (Nov-Dec 2009), Annie Lyerly and her colleagues write persuasively about the opposite ways in which health care professionals go wrong where pregnant women are concerned. Women's nonobstetrical medical needs, they report, are undertreated because the risks of intervention loom so large in professionals' thinking that they drive out considerations of the risks of *not* intervening. Conversely, though, laboring women are overtreated, because here the risks of not intervening drive out considerations of the risks of intervention.

Nor are health care professionals the only ones whose thinking is distorted in this way. Pregnancy advice books, Internet sites, friends, neighbors, and total strangers are only too eager to tell pregnant women what they must and must not do to preserve their fetus's health and well-being, regardless of the evidence of actual risk.

Lyerly et al. explain this sort of thing as a kind of magical thinking—"a way to try to tolerate an unsettling truth: that try as we might, what we love may perish." In many cases, that analysis is likely correct: if only I can eliminate all risk, I can keep my much-loved child-to-be from harm.

Yet the socially shared master narratives that guide our sense of what is supposed to happen during pregnancy (purity) and delivery (control) are deeply entangled in the master narratives about mothers and, more broadly, about women's place in society. These wider stories work on us at a visceral level beyond the reach of reason. This means that the roots of magical thinking often aren't so much about what we love as about whom some of us can police.

On January 21, not a month after "Risk and the Pregnant Body" was published, the *New York Times* reported the case of a woman in Florida (why is it always Florida?) whose doctor recommended bed rest because she was at risk for a miscarriage. When the woman protested that she had two toddlers to care for and a job, the doctor alerted the state, and a circuit court judge ordered her to bed. I doubt either the judge or the doctor was motivated by love—certainly not love of the woman or her existing children. Instead, both seemed to think she was a bad mother because she would not sacrifice herself and her family by taking drastic measures for whose efficacy there is, in any case, insufficient evidence (A. Cochrane, F. Althabe, J. Belizán, and E. Bergel, "Bed Rest During Pregnancy for Preventing Miscarriage," *Cochrane Database Systems Review*, April 18, 2005).

Lyerly and her colleagues have identified a serious problem, and they recognize that its roots are not altogether benign. I thank them for supplying us with a counterstory that, given sufficient uptake, might actually have a positive effect on how pregnant and laboring women are treated.

Hilde Lindemann
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To the Editor: Lyerly and colleagues have forcefully demonstrated many contradictions in the way we think about risk during pregnancy and childbirth. I would like to push their provocative analysis a little further on three points I think are particularly important.

First, we tend to make choices about interventions based on who we *feel* is at greater risk, and during both pregnancy and childbirth, we perceive ourselves to be acting on behalf of the fetus. In that sense, our reasoning is more consistent than it might otherwise appear. In fact, as the authors note, we usually decide that *any* risk to the fetus, no matter how small, supersedes any risk to the pregnant woman, no matter how large. This tendency to privilege the fetus extends after birth to babies and children. It is central to what I have called "total motherhood": an ethic of maternal care in which mothers and future mothers are expected to eliminate all risks to potential and developing fetuses and babies, no matter how small the threat or how steep the cost to mothers themselves (Joan B. Wolf, *Is Breast Best?* New York University Press, forthcoming). It suggests that if our preferences for intervention change according to circumstance, our overriding concern for the fetus remains constant.

Second, a great deal of evidence demonstrates that doctors, the media, and the public all have difficulty reasoning well about medical risk. Doctors frequently have only a rudimentary understanding of biostatistics. Confronted with an abundance of information,

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they often rely on reviews, synopses, or abstracts, truncations that give little information about how risk has been constructed. This research is communicated to a public poorly educated in basic math and science by journalists unschooled in both scientific methods and the meaning of risk in epidemiological discourse. Terms commonly used by scientists, such as "significant," "association," and "relative risk," are often misinterpreted by doctors, the media, and the public alike. And when risk choices provoke strong emotions, as during pregnancy, all three tend not to think about probability that harm will occur and instead focus on worst-case scenarios. The problems described in this article are deep and widespread.

Finally, I would offer a word of caution about research on pregnancy risk. The authors argue convincingly, as in the case of fish consumption, that people tend to focus on the risks of certain behaviors, such as fetal exposure to neurotoxins, and not on benefits, such as the potential for fatty acids in fish to enhance the developing brain. Yet, while counterproductive reasoning about risk is a problem, so, too, is the premise that we can (and should) engineer increasingly more perfect babies by manipulating ever more specific aspects of pregnant women's and mothers' behavior. This assumption has led to voluminous research suggesting that pregnant women and mothers have a measure of control over fetal and child outcomes that has never been scientifically demonstrated; indeed, almost all of these studies lack anything approaching the kind of evidence on which public health recommendations should be based. Nevertheless, a culture of surveillance has developed in which anxious pregnant women and mothers monitor their every action and are held accountable, in various ways, when outcomes are not optimal: if only she had eaten more—or less—fish! The authors rightly argue that life carries "an irreducible element of risk"; but the overwhelming focus on pregnant women and mothers—and not, for example, on male reproductive exposures or social problems associated with poor fetal and child development—inappropriately implies that they have a unique responsibility to overcome it.

Joan B. Wolf
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To the Editor: We applaud Lyerly and her colleagues for taking on the subject of risk in the perinatal context. Risk is a critically important yet understudied topic within bioethics. It is a central organizing feature of contemporary U.S. culture, pervading every facet of life. There are health risks, financial risks, environmental risks, social risks; there is risk analysis, risk management, and risk communication systems. The language of risk is ubiquitous. How we think about risk, who has the authority to name and classify risk, what should be done about risk and by whom, what are the consequences of our approaches to risk, whose interests are promoted by our classifications of risk—these are issues of profound moral importance.

Perhaps nowhere is this more obvious than in medicine, where pregnancy is the apex of concern. Lyerly et al. provide an insightful analysis of judgments about risk during pregnancy by examining standard advice about risk avoidance in routine contexts concerning pregnant women's daily behaviors (their diet and activities, for instance), as well as clinicians' choices to avoid intervention for women's health needs during pregnancy while embracing intervention during birth. These judgments reflect sexist assumptions about whose interests matter and lack grounding in data, even when such data is available (which, all too often, it is not). Paradoxically, these practices put both mothers and newborns at higher risk in the name of avoiding risk.

Thus, Lyerly and colleagues provide an excellent beginning and the

ON THE WEB

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Bad Vibrations
By Alice Dreger and Ellen K. Feder
The authors of a 2007 Journal of Urology *paper report why they believe a group of girls are still able to have sexual sensation after removal of parts of their clitorises: annual exams following surgery that involve a doctor stimulating their clitorises with vibrators while the girls, aged six and older, are conscious, and a parent watches. We didn't believe it, either, till we read it.*

Behind the Curtain of Personalized Medicine: The Havasupai Tribe Settlement
By Susan Gilbert
For personalized medicine to realize its potential, genetic tests must be accurate and enable prevention or treatment. Reaching these goals requires more basic genetic research on human biospecimens – blood, saliva, and leftover surgical and biopsy tissue. But there is a lack of this material for genetic research, and getting it thus far has been ethically and legally problematic.

Spin Doctors and Torture Doctors: Inconvenient Truths about Complex Systems
By Nancy Berlinger
The allegations in these reports reveal a looking-glass-land version of a legitimate health care system, in which goals such as safety and effectiveness were applied to illegitimate activities, as if torture could be considered safe as long as those being tortured did not die, and as if effective torture methods fell within the scope of quality improvement.

Also: **Michael Gusmano** tries to make sense of two conflicting reports on the financial impact of health care reform; **Karla F.C. Holloway** advocates for a valued life instead of "a grievable death"; **Erik Parens** is skeptical about the Presidential Bioethics Commission's attempt to avoid the "big" questions; and **Suzanne Schultz** shows how researchers get around the laws that prohibit paying donors for eggs.

context for a much-needed conversation about risk. We urge that the conversation continue, attending to the ways in which the discourse on perinatal risk has reached hysterical proportions and the coercive, often draconian measures that are used to control pregnant women. The sentinel case is that of Angela Carder, a young woman dying of cancer who was forced to undergo a cesarean section without her consent and against her will (*In re A.C.*, 533 A.2d 611 [D.C. 1987]). Hospital risk managers—not the clinicians involved, or the patient's family (who had reached consensus on a noninterventional plan of care)—sought declaratory relief for the operative procedure because they feared a lawsuit. More recent cases run the gamut from denial of therapy to coercive interventions. They include court-ordered, forced medical treatments and legal penalties such as involuntary confinement, arrest, and incarceration for pregnant women's potentially harmful behavior (refusing bed rest, falling down the stairs, perinatal substance use, attempted suicide). They even include a refusal to provide chemotherapy or radiation therapy for pregnant women with cancer in countries where abortion is illegal, so pregnant women cannot access lifesaving care without ending their pregnancies, and cannot end their pregnancies to access care.

Thus, from mundane matters to crises, the treatment of risk in the perinatal context raises fundamentally important and pressing moral and political issues. In a 1990 essay, anthropologist Mary Douglas wrote that cultures "develop some terms that run across the gamut of social life to moralize and politicize dangers." To moralize and politicize dangers is to identify and label what counts as a danger to the group, as well as who is to be held accountable for harm. In our secularized, scientific culture, she continues, "the dialogue about risk plays the role equivalent to taboo or sin." It is worth exploring just what these dangers are believed to be and the practices through which the moralization and politicization take place. The context of pregnancy is the perfect starting point for articulating a morality of risk.

Debra DeBruin
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To the Editor: Lyerly et al. begin their paper with a fabulous example—and we chose the word "fabulous" after much thought, to emphasize that this true story is also a fable, a perfect morality tale. One of us is a midwife who has practiced for many years, repeatedly seeing how medical care allows pregnancy to trump every other condition. Women with cardiac problems who are possibly having heart attacks get sent off to the labor and delivery floor if they show up at the hospital pregnant; women in the midst of schizophrenic crises who are cutting themselves get sent off to the labor and delivery floor if they are pregnant. And women with appendicitis have a really hard time being treated for that, if they are also pregnant. Pregnant? L&D. Obstetrician calls in other care? Dump them back on L&D.

And we agree entirely with Lyerly et al. when they say that the moral of the tale is that the fetus trumps the woman, and that's why this is happening: the obstetrician is the doctor to the fetus, and other branches of medicine are afraid to intervene. But we disagree with the contention that obstetrics has an ideology of the purity of pregnancy or a particular fear of intervention.

Medicine, as a general rule, believes itself incapable of harm, something demonstrable in obstetrics from Semmelweis onward. There have been exceptions—moments when medicine was forced to confront its own collateral damage. The two best examples are thalidomide prescribed for pregnancy nausea and routine radiation in pregnancy to determine fetal size and position. Obstetrics used radiation as much or more than most other branches of medicine (well after Hiroshima!), and the problems showed themselves. The lesson learned was that x-rays are not safe in pregnancy. Not, apparently, that radiation is unsafe, since ultrasound radiation was welcomed and used widely, even wildly, in obstetric care with virtually no preceding research on its safety. If obstetrics was extraordinarily cautious in pregnancy interventions, we would not have the routine use of ultrasound incorporated into prenatal care, much the way that electronic fetal monitoring was. But both are technologies that enable the obstetrician to get past the "maternal barrier," as the woman is often understood to be, in order to reach what they see as the true patient, the fetus.

The weakness in the argument offered by Lyerly et al. is a relatively unreflexive acceptance of medical management in general. In contrast, we argue that the idea of avoiding medical intervention might actually be rational at all times, and especially so in pregnancy. Issues of overscreening and overtreatment are finally beginning to get some attention, though in the United States they are almost always overcast with fears of "rationing." Access overshadows everything else: Why don't we all get more tests, more drugs, more procedures! It is all but funny that the two examples offered of supposed undertreatment—the case of the flu vaccine and SSRIs (routinely used to treat so very much more than severe, suicidal depression)—are both being questioned for efficacy and safety, in and out of pregnancy.

Absolutely, concern for the fetal patient continually trumps concern for the woman. But ironically, pregnancy, with its attendant lack of medical intervention, might actually protect women—up to the point of birth, when obstetrics takes a no-holds-barred approach to extracting its endangered patient from the perceived maternal threat.

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To the Editor: While risk aversion is an issue in pregnancy, we disagree with Lyerly and colleagues on the risks of antidepressants. The Food and Drug Administration's warning on paroxetine says that it causes birth defects—not that there is a risk it might. This likely holds for other SSRIs also—risks we have known about for twenty years. In addition to SSRIs doubling the risk of major congenital malformations, consistent data point to a doubling of the risk of spontaneous abortion (from 8 to 16 percent). Data also indicate increased rates of voluntary terminations; whether this stems from choices made following detection of congenital malformations or from the pervasive emotional blunting intrinsic to the action of SSRIs (which may lead to regrets when the treatment has been stopped) is unknown. The authors also downplay the evidence of neonatal withdrawal syndromes, pulmonary hypertension, premature birth, and restricted intrauterine growth (D. Healy, D. Mangin, and B. Mintzes, "The Ethics of Randomized Placebo Controlled Trials of Antidepressants with Pregnant Women," *International Journal of Risk and Safety in Medicine* 22, no. 1 [2010]: 7-16).

The authors cite rates of 13 percent for antenatal severe depression. Rates this high are for depressive symptoms, not depressive disorders. The best evidence suggests depressive disorders occur in 4 percent of women antenatally; of these, most are mild or treatable by means other than antidepressants. There are few severe depressions (melancholia), and for these, treatments such as electroconvulsive therapy or older antidepressants work. Even if the condition is left untreated, however, there is no evidence that untreated prenatal depression leads to an increase in birth defects, miscarriages, voluntary terminations, or suicide, or that it contributes significantly to postnatal depression. We agree that postnatal depression needs to be treated vigorously, but treatment is likely to be more difficult in mothers who suspect their newborn's complications stem from antidepressants. There is also no evidence that SSRIs work for severe depression. In the case of moderate depressions, an evidence-based approach to treatment would recommend against using drugs, as over 80 percent of the apparent response to drug treatment in trials stems from placebo factors.

When the authors cite the Cohen et al. paper—which claims that women who stop antidepressants are at higher risk of relapse than those who don't—they engage with another source of risk. The timing and rate of difficulties in this study suggest not relapses into depression, but withdrawal from SSRIs. Women are not being informed of the risks of birth defects and physical dependence or the consequent probability of trapping their child into treatment exposure. Should women be informed of these issues?

Perceptions of risk in these domains are increasingly shaped by marketing campaigns that target women of childbearing years. These have spawned many articles claiming untreated prenatal depression poses risks while downplaying the treatment risks. Many of these articles appear to have been ghostwritten. Furthermore, companies have retained the services of a large portion of academia, which makes it difficult to get any other view heard. As a result, other academics, ethicists included, who don't have links to the pharmaceutical industry appeal quite responsibly to the published literature and end up arguing that depression poses significant risks, and that antidepressants carry minimal risks.

The upshot, we believe, is a case study in risk perception that illustrates points opposite to those suggested by the authors. The accumulating data on antidepressants have converted notional hazards into evidence of injuries, and antidepressant use has surged—they are now among the most commonly prescribed drugs in pregnancy. Even ethicists argue for their wider use, without asking where the literature they appeal to comes from.

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To the Editor: American maternity care is in trouble. Soaring rates of medical interventions and increased policing of pregnant women in recent years have not improved poor maternal and newborn outcomes; instead, they have contributed to distressing experiences of pregnancy and childbirth for many mothers. In examining how we evaluate risks in pregnancy, and how we choose to intervene or not, Lyerly and colleagues are attending to an urgent question—but their analysis and proposed solution fall short.

The authors suggest that in the contemporary West, medical intervention is presumed to be the safest option at birth, while during pregnancy restriction of both medical interventions and many ordinary behaviors is considered the safest course. This birth-pregnancy distinction obfuscates more than it

clarifies. Applying Occam's razor suggests instead that in pregnancy or during childbirth, actions perceived as being primarily for the benefit of the fetus are presumed to be safe, and actions perceived to be primarily for maternal benefit are presumed to be unsafe until—or even after—proven otherwise. How else to explain, for instance, persistent recommendations of bed rest (assumed without evidence to offer fetal benefit in cases of impending miscarriage, preterm labor, or multiple gestation) or persistent obstetrical discomfort with water birth (an intervention intended to help the mother, without evidence of adverse impact on the newborn)? Framing the distinction in this way both forces and enables us to address the larger issues with which it is linked, including distrust of female autonomy (and, as the authors rightly note, anxieties over maternal impurity), and ever-earlier imaginations of fetal personhood.

A more serious flaw is the paper's unquestioning treatment of "evidence." The authors propose that recommendations for pregnant and birthing women should be based on evidence rather than fear or unrealistic expectations. I agree with this proposal—could anyone actually disagree?—but it is not the panacea that they imply. Recent work reveals our collective medical evidence base to be extensively corrupted by commercial and other interests, flawed by egregious practices like "ghost authorship" and by subtler distortions like publication bias or inappropriate comparator-group selection. Other biases intrude even where overt conflicts of interest are not involved: long-term follow-up studies rarely have the impact of short-term preliminary findings, and as the authors themselves note, reassuring evidence rarely gets the publicity accorded to suggestions of danger. Even quality evidence shifts constantly, is ambiguous more often than not, and is simply unavailable for many quotidian concerns of pregnancy. Not only that, but even obstetrical providers who are intelligent, well-intentioned, statistically acute, widely read and up-to-date in the current literature, and free of financial conflicts of interest may interpret available evidence differently (as recent conflicts over mammography guidelines show), and many providers—perhaps most of us—do not meet all of these criteria all of the time. Finally, exaltation of evidence makes us question what counts as evidence: Should maternal subjectivity be considered evidence? Are outcomes that can't be easily counted therefore unimportant? What questions get investigated in the first place?

A proposal to apply "evidence" to the questions that plague pregnant women and their obstetrical providers, without serious engagement with the limitations of that evidence, is itself a form of magical thinking: a ritual that exonerates us in the face of uncertainty and existential dread. The authors recognize that "responsible risk reasoning requires confronting the fundamental fact that the joy of birth carries with it a vulnerability to the possibility of traumatic loss." Reasoning may require it, but reasoning alone cannot help us—us pregnant women, us obstetricians, us midwives—with the lived experience of this vulnerability. It strikes me as important for all of us to accept and somehow to learn to live with ambiguity, uncertainty, and potential culpability, even as we clinicians and researchers also work tirelessly to both interrogate and improve the evidence base by which we must make our choices. These tasks are urgent, and they are difficult. They require an acknowledgment, not a wiping away, of the uncertainties, fears, and hopes that are as inherent to the practice of medical care as they are to the experiences of pregnancy, childbirth, and life itself.

A proposal to apply "evidence" to the questions that plague pregnant women and their obstetricians, without serious engagement with the limitations of that evidence, is itself a form of magical thinking: a ritual that exonerates us in the face of uncertainty.

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