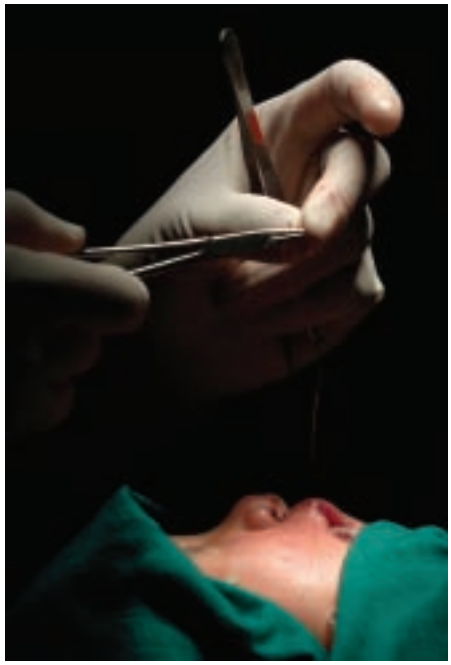
Fetal Surgery Then and Now

THERE IS TOO MUCH EMPHASIS ON THE FETUS AND NOT ENOUGH ON THE WOMAN

By Monica J. Casper

In 1981, doctors at the University of California, San Francisco (UCSF) performed the first open fetal surgery, a last-ditch, ultimately unsuccessful effort to save a dying baby. They partially removed a fetus from inside a pregnant woman's uterus, repaired a urinary obstruction, and then sealed the tiny patient back into its mother's breached womb. The team of surgeons—who had been practicing on animal models for years—created a new field of medicine, with the "unborn patient" at its center.

The primary rationale for prenatal intervention is to repair a problem and thus interrupt disease before a baby is born, when there is still a chance of "normal" development. Media coverage of early fetal surgery procedures emphasized the "miraculous" and cutting-edge aspects. The specialty was and is celebrated as the embodiment of technical progress, and pundits applauded modern medicine's ability to save even the smallest patients: those in the womb. Only infrequently did early accounts take up ethical issues; rarely did they consider whether targeting individual fetuses via boutique medicine was the best way to enhance overall infant survival and well-being.



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Fetal surgery may be able to cure problems like cleft palate before a baby is born. But is it worth the risk?

I discovered fetal surgery in 1991, as a first-year graduate student in sociology at UCSF. I was organizing files at the small, dusty office of a reproductive justice group. Inside a slender file called "Fetal Rights," I found several yellowed newspaper cuttings, including a story about fetal surgery. I felt a rush of excitement; this could be an ideal dissertation topic. To my knowledge, nobody was yet studying fetal surgery and few even knew about the nascent specialty. Not only did it appeal to my interests in medical sociology and women's health, but also, because I had located the newspaper cutting in the office of a prochoice organization, I was certain that fetal surgery intersected with reproductive politics in intriguing ways. Why fetal surgery, I wondered, and why now?

Over the next several years, I researched the history, practices, and politics of fetal surgery. I traveled to Puerto Rico and New Zealand to explore the origins of the specialty and the pioneering work of its founders; I conducted ethnography at an urban teaching hospital where fetal surgery was being advanced; I watched countless procedures being performed on pregnant women and their fetuses; I interviewed many practitioners (surgeons, obstetricians, neonatologists, radiologists, neurologists, nurses, social workers and bioethicists); I spoke to a handful of women who had undergone fetal surgery; I read popular accounts and tracked media coverage; I devoured the clinical and scientific literature. By 1996, I had produced a dissertation, completed my Ph.D., and gone off to Stanford University to study bioethics.

In 1998, my book *The Making of the Unborn Patient* was published. I argued that fetal surgery emerged along with—was constituted by and generative of—reproductive politics, especially contested notions of fetal life and the cultural ascendancy of the unborn. I drew connections between fetal surgery and other phenomena—such as ultrasound, fetal rights and federal policies—that were granting unprecedented agency and personhood to the fetus. I took surgeons to task for behaving like cowboys

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and not recognizing serious ethical issues fostered by their consequential interventions, including risks to maternal and fetal health. I exposed questionable practices of the fetal-surgery team at the institution I studied regarding the protection of human subjects. And I showcased the many ways that pregnant women were sidelined in fetal surgery, positioned as no more than heart-lung machines for the real patients, the fetuses.

I did not conclude the book with a plea to ban fetal surgery, despite its many problems and conundrums, but instead provided a detailed discussion of ways to reposition the practice so as to be favorable to women's health. In short, I suggested centering the pregnant woman and not the fetus as the real patient. After all, it is only with women's consent that fetal surgery can proceed at all, it is women's bodies that surgeons must traverse to access the fetus, and it is pregnant women who assume principal risk on behalf of their fetuses. Fetal surgery is not, I argued, "fetal surgery" at all; rather, it is more aptly maternal-fetal surgery, or just maternal surgery. I wrote, "Making a fetal surgery for women would involve social and political change on several fronts. Is such change possible? Perhaps not, in which case we should seriously question the existence of fetal surgery while also imagining new and better ways to secure healthier fetuses."

To say that my book was controversial would be an understatement. Alongside favorable reviews in the sociological literature and a handful of awards came scathing reviews in the clinical literature, suggesting that the relationship between clinical medicine and social studies of medicine is at best uncomfortable and at worst antagonistic. One surgeon, in a stunning display of paternalism, gave my book a "failing grade" in a prestigious medical journal. I heard through the grapevine that the team I studied had all but banned my book from discussion. I was, according to colleagues there, viewed with suspicion, and certainly perceived as no friend to the mission of fetal treatment.

People in the antichoice movement, too, seemed to dislike the book, and me. A few appeared on a call-in radio program to harangue me; others showed up at public lectures I gave. Fetal surgery, with its clinical and cultural imperatives to rescue the unborn, is immensely attractive to people holding so-called prolife perspectives—precisely one of the dynamics I unearthed in my research. According to a 2005 article by Vanderbilt University ethicist Mark Bliton, pregnant women for whom abortion is not an option are far more likely to pursue fetal intervention, and the endeavor is covered with a kind of divine, specifically Christian patina, from which it accrues authority and legitimacy.

I was unsurprised by negative attention from advocates for the unborn. But I was dismayed by reactions from clinicians. What had I said or done that was so objectionable? I had been critical of surgeons and their lack of ethical reflection, to be sure, but I was also deeply concerned about fetal health and well-being. Surely we were roughly on the same side. Yet I had also positioned myself as an advocate for pregnant women, arguing for their safety, care, and autonomy while challenging many aspects of the procedure itself. In the end, I realized that my book had become caught up in the very politics about which I had written. The fetus in American culture is vociferously contested, and no discussion of the unborn is untainted by these politics. *The Making of the Unborn Patient* was yet another player in the ongoing battle to determine who gets to speak for the fetus, and for pregnant women.

Since I published the book, fetal surgery has advanced considerably, as have procedures such as fetoscopy. One striking development has been the expansion of the number of centers focused on prenatal interventions. In addition to UCSF, the birthplace of fetal surgery, there now exist the Advanced Fetal Care Center of Children's Hospital in Boston, the Center for Advanced Maternal Fetal Care at Vanderbilt, the Center for Fetal Diagnosis and Treatment at Children's Hospital of Philadelphia, the Fetal Care Center of Cincinnati, the Fetal Treatment Center of Northeast Ohio, and the Texas Center for Fetal Surgery. Many other hospitals are home to maternal-fetal medicine units that, although not performing open fetal surgery, practice a range of fetal interventions, largely unregulated—except by the standard processes of hospital review boards and peer review.

New developments in prenatal diagnosis have enabled greater and more consistent detection of fetal abnormalities. As such, a proliferation of conditions and problems has been rendered amenable to various types of fetal intervention. These include heart blockages, cleft lip and palate, congenital diaphragmatic hernia, hydrocephalus, spina bifida, sacrococcygeal teratoma, and twin-to-twin transfusion syndrome. These conditions are described by surgeons as birth defects, a term unpalatable to many in the disability-rights community. Many are life-threatening, while others result in impairment, increased morbidity or reduced function.

In the early years of fetal surgery, all the fetuses treated were facing lethal illnesses.

How Fetal Surgery Works

Basic techniques of fetal surgery have changed only a bit since the 1980s. A pregnant woman is anesthetized, and an incision is made in the lower abdomen. The uterus is exposed and then opened using a special device to prevent excessive bleeding. The fetus or a fetal body part is removed from the woman's uterus, but remains connected via the umbilical cord. Surgical repair is performed on the fetus. If the fetus does not die, it is returned to the womb. The uterus and the woman's abdominal wall are sutured. This is major surgery requiring hospitalization for several days. There are substantial risks to the pregnant woman and her fetus, including death, morbidity, threatened reproductive potential, and preterm labor. Women who undergo fetal surgery must deliver their babies via Caesarean section.

Without intervention, the fetuses would surely die—and many died even with prenatal surgery. Given those odds, it made sense to some clinicians and ethicists to pursue an invasive approach. That changed in 1997, when a fetal surgery team at Vanderbilt operated on a human fetus with spina bifida, a condition in which a portion of the spinal cord, along with surrounding nerves and bones, does not fully form. Spina bifida develops relatively early in pregnancy and historically has been treated surgically after birth. Children with spina bifida rarely die, but they do require specialized medical intervention, including shunts to drain fluid from their brains. Many also suffer from learning disabilities, bladder and bowel problems, and impaired mobility.

With the advent of fetal surgery for spina bifida, the specialty moved beyond treatment of deadly conditions to those concerning disability and "quality of life." This, according to many commentators, changed the calculus of risks and benefits. Bliton, the ethicist, suggested in 2003 that "the recent development and refinement of open uterine techniques to repair a nonlethal anomaly…have produced a new set of complex ethical considerations that if not deliberately and adequately addressed risk serious impediments to further and legitimate development of maternal-fetal surgery." These issues also attend prenatal heart surgery and interventions for cleft lip and palate and for other non-fatal conditions.

Further complicating matters is lack of data on whether prenatal or postnatal surgery for certain conditions is most effective. The management of myelomeningocele (MOMS) trial was initiated in 2003 to remedy this. Through a cooperative agreement of the National Institute of Child Health and Human Development, the George Washington University Biostatistical Center, Children's Hospital of Philadelphia, UCSF and Vanderbilt, the MOMS protocol aims to answer the question whether intrauterine repair of spina bifida is more advantageous than standard postnatal repair, and to determine whether fetal interventions improve neurological function. As of 2005, however, only 69 women out of an expected 200 had enrolled in the trial, raising the specter of an unwelcome back door through which fetal surgery for spina bifida may be offered outside the trial. That is, slow progress on MOMS may lead non-participating hospitals to pursue unproven treatment and pregnant women eagerly to undergo such interventions in any setting if it means saving their babies.

Ten years ago, I argued that fetal surgery should be more thoroughly evaluated through careful clinical trials as part of a broader set of changes to make it more accountable. I am heartened to see the collaborative effort behind the MOMS trial, especially in a field that has been shaped by intense competition among its practitioners. Yet, as bioethicist Edmund G. Howe noted, "All fetal surgery is essentially experimental." I am thus also pleased that the word "maternal" has made its way into one center's name, that of my own institution. At least some consideration is emerging for the pregnant women whose consent and participation make fetal surgery possible. For example, the UCSF Web site states, "All fetal intervention is really maternal-fetal intervention, and the most important consideration in all fetal intervention is the safety of the mother and

Types of Fetal Interventions

Open fetal surgery: A hysterotomy (similar to a Cesarean section) is performed and the fetus is partially removed so that the area that needs surgery is exposed. After corrective surgery is performed, the fetus is returned and the uterus is closed.

Fetoscopic surgery: This type of surgery, which employs minimally invasive techniques, is used more often than open surgery. Surgeons can use fiber optic telescopes and specially designed instruments to enter the uterus through small surgical openings to correct congenital malformations without major incisions or removing the fetus from the womb.

The **ex utero intrapartum treatment** (**EXIT**) procedure: A special treatment used to correct fetal airway obstruction by arranging delivery in such a way that a tracheal occlusion can be removed while a baby remains on placental support. The utero-placental blood flow is kept intact and the fetus remains on a maternal 'heart-lung machine' while the airway is secured.

EXIT to **ECMO (extracorporeal membrane oxygenation)**: After the EXIT procedure an artificial heart-lung machine is used to take over the work of the lungs (and sometimes also the heart) to allow the baby to transition smoothly from the womb to avoid instability and low oxygen levels.

Intra-uterine transfusion: A procedure which provides blood to a fetus when fetal red blood cells are being destroyed. They can be given through the fetal abdomen or, more commonly, by delivering the blood into the umbilical vein.

Corticosteroids: Steroid hormones produced in the adrenal cortex that are involved in a wide range of physiologic systems such as stress response, immune response and regulation of inflammation, carbohydrate metabolism, protein catabolism, blood electrolyte levels, and behavior.

Fetoscopic-guided radiofrequency ablation: This involves using radiofrequency energy (similar to microwave heat) to destroy or remove unwanted tissues and cells such as tumors. A fetoscope is used to guide the radiofrequency ablation probe.

Other methods include **fetal cardiac intervention procedures** and the use of **vitamins** and **minerals**.

her reproductive potential. The intervention is designed to benefit the fetus who has a problem, but the mother is an innocent bystander who assumes some risk for the sake of her unborn fetus."

But pregnant women who undergo fetal surgery are not simply "innocent bystanders." They assume not minimal but rather an extraordinary degree of risk on behalf of their fetuses. It is important to note that in almost every case of fetal surgery, there is nothing wrong with the pregnant woman herself. The fetus is, still, the principal patient, the *raison d'être* of the specialty. Indeed, pregnant women are visually absent from the logos of treatment centers, which feature detached fetuses with nary a woman in sight. Yet as ethicist Mary Mahowald has suggested, "policy-makers need to acknowledge that there is actually only one patient—the pregnant woman.... Operating on a woman to correct an anomaly in her fetus may be accurately described therefore as simply that: operating on *her*."

There is some hope on the horizon. Within the centers, a tremendous amount of work has enhanced ethical consultation to ensure that pregnant women fully understand the risks and benefits both for themselves and their fetuses. Laudable efforts are made to find safer ways of intervening in the womb. Indeed, the Vanderbilt model of counseling has become the model for the MOMS trial, suggesting that there are ways to improve fetal surgery from the inside out. However, as Bliton noted to me, "The social and ethical controversies generated by maternal-fetal surgery are extremely complex. For example, scientific evaluation of the best kind of study data, like the MOMS trial, will not alleviate maternal or fetal vulnerability. This means that renewed efforts will need to be directed toward identifying and establishing legitimate processes to evaluate the ethical issues created by maternal and fetal vulnerabilities, especially at previable gestational ages, even if there are positive results from surgical trials."

I nevertheless remain skeptical of dedicating precious health-care resources to practices that may not, in fact, work any better now than they did in 1981. As David James wrote about fetal surgery in the *British Medical Journal* in 1998, "Therapeutic approaches remain limited." This is not to deny the desires and fears of individual pregnant women and their families, or sometimes favorable outcomes of prenatal intervention. It is, however, to insist also on collective or public solutions to the problems of infant suffering and death, and to recognize that many issues remain unresolved, including who is being rescued by surgery. The few patients being served by expensive fetal interventions are not the large numbers of low-income women who cannot get basic prenatal care, much less high-tech, specialized interventions. In 2002, the infant mortality rate in the United States increased; we are positioned between Croatia and Taiwan on global charts. Despite our technical prowess and vast wealth as a nation, some 28,000 babies die every year in the United States of preventable causes. Many of these deaths reflect inequities of race, ethnicity, class, geography, and access to health care.

There are better, more socially just ways to ensure the health and survival of babies. Perhaps we should start by valuing the lives of all women, regardless of race, ethnicity, socioeconomic status, age, geography, marital status, sexual orientation, health insurance coverage, immigrant status or employment—recognizing that healthy mothers create healthy babies. A truly ethical first step would be to provide universal health-care access, ensuring that pregnant women can obtain folic acid, undergo regular checkups, and, if warranted, receive fetal diagnosis and treatment. A politics of life that does not include respect for all women and their offspring—including babies outside the womb as well as inside—is not only morally fraught, it is bad public policy and sure to fail. ■

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Tino Tinoisamoa and Millie Taulau in the Infant Special Care Center at the University of California, San Diego, after the birth of their twin sons who had surgery in utero for twin-to-twin transfusion syndrome, an often-fatal condition.

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